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## FROM THE EDITOR

### Transgender Medicine in the Path to Progress and Human Rights

Medical professionals can play key roles in ensuring the health, well-being, and equality of marginalized populations, including lesbian, gay, bisexual, and transgender (LGBT) people. Among those who identify as LGBT, medicine may play a particularly important role for transgender patients seeking help from clinicians to affirm their gender identities through medical intervention. Gender-affirming medical therapies may involve, for example, the use of hormones or surgeries. For the foreseeable future, therefore, medicine will likely play vital roles in the ongoing journey toward social and political progress for transgender people.

There is an urgent need for increased attention to transgender health disparities and the social factors that contribute to them. One literature review found that up to one-third of transgender-identified survey respondents reported making at least one suicide attempt over their lifetime [1], and in one of the surveys included in the literature review, 45 percent of transgender youth reported having seriously considered suicide [2]. HIV prevalence is also high for transgender women: one meta-analysis estimated that approximately 28 percent of transgender women as a whole—and 56 percent of African American transgender women—have HIV [3]. Transgender patients also report problems related to stigma in accessing health care, including denial of services and unwillingness of health care professionals to accept them as patients [4].

This issue of *AMA Journal of Ethics*® offers a variety of perspectives on the ways that clinicians, students, and health care leaders can work to eliminate disparities in transgender health. The hope is that this issue can be used and disseminated as a toolkit for clinicians seeking to untangle the conditions of marginalization and vulnerability that disproportionately affect transgender patients in order to improve transgender care and health outcomes.

Perhaps the most powerful tool for improving care and outcomes in medicine is the capacity to build collective knowledge through accumulation of high-quality evidence. However, evidence-based health care resources and best practices for transgender patients are scarce. In this issue, Madeline B. Deutsch, Asa Radix, and Sari Reisner discuss the gaps in [evidence-based guidelines](#) for gender-affirming care and the cultural and social barriers that have perpetuated them. They also call for transgender health research that is gender-affirming, patient-centered, and inclusive with the aim of both improving individual patients' health outcomes and developing quality and outcome

measures to support better health care delivery. And Khadija Mitu draws on her empirical research with transgender people, highlighting the challenges surrounding clinical [reproductive planning for transgender patients](#) pursuing gender-affirming therapies.

Best practices in transgender health are also discussed by Ryan K. Sallans and by Kristen L. Eckstrand, Henry Ng, and Jennifer Potter. Sallans uses his own experiences as a transgender patient and an advocate for transgender rights to encourage clinicians to [cultivate basic values](#) of respect, humility, and a willingness to learn in caring for transgender patients. Eckstrand, Ng, and Potter examine strategies for providing competent, [patient-centered care for gender-nonconforming people](#)—those who might not self-identify as either female or male—and emphasize the clinical and ethical importance of recognizing that gender diversity exists on a spectrum.

Although there is a pressing need to develop best practices and collect high-quality data on transgender health outcomes, Tia Powell, Sophia Shapiro, and Ed Stein argue that one realm in which we should rely less on scientific claims is in crafting legal foundations for [transgender rights](#). Rather than rooting arguments for transgender equality in empirical claims about the “innateness” or “immutability” of transgender identity that have shaky scientific support, they propose a human rights approach, centered on values such as respect, dignity, and equality.

Several authors in this issue take up the question of which models of medicine should be used for transgender care. Jamie Lindemann Nelson’s article shows how [feminism](#) can be a resource for creating a model for transgender medicine that moves beyond clinical management of gender transition, which, in its inclusion of mental health counseling, pathologizes gender diversity. Timothy F. Murphy reflects on the role of psychiatrists and mental health counselors as [“gatekeepers”](#) for gender-affirming therapies and explores the potential benefits of recommended counseling for transgender patients seeking gender-affirming hormone therapy or surgery and the importance of informed consent as part of that process. In contrast to the “gatekeeping” model, Timothy Cavanaugh, Ruben Hopwood, and Cei Lambert argue for an [informed consent model](#) for access to gender-affirming therapy wherein mental health counseling could be replaced by detailed plans for care and conversations between patient and physicians about the risks and benefits of intended therapies.

The success of any model of medicine will depend in part on available resources, but what should physicians do when resources for competent transgender care are limited in a given region? Cary S. Crall and Rachel K. Jackson consider circumstances that might prompt physicians to venture outside their scope of practice to provide care such as hormone therapy to [transgender patients in resource-deprived areas](#). Elizabeth Dietz and Jessica Halem similarly assess the responsibilities that primary care physicians have

to ensure competent and inclusive [referrals for transgender patients](#) when specialist options are scarce. In the podcast, Aron Janssen discusses how [lack of family support and stigmatization](#) in health care settings harm transgender youths and offers guidance on how clinician education may help ameliorate such harms.

The cultural, political, and social barriers to health care for transgender patients are numerous, and transgender patients still endure the pangs of stigma. And yet, despite the complex challenges highlighted in this issue, medical professionals can do much to alleviate transgender health disparities. Although progress is rarely unencumbered, as Jamie Lindemann Nelson has said, the medical profession “bumps along” with the rest of us down the path toward social and political progress for gender and sexual orientation minorities [5]. This issue aspires to aid clinicians in collective efforts to promote human rights and social progress for transgender people.

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### Cameron R. Waldman

MS-2

Albany Medical College

Albany, New York

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## ETHICS CASE

### How Should Physicians Refer When Referral Options Are Limited for Transgender Patients?

Commentary by Elizabeth Dietz and Jessica Halem, MBA

#### Abstract

Transgender people encounter many barriers to health care, and recommendations about where their treatment would best be offered can promote or thwart good care. This case examines the care setting from the perspective of a patient whose experiences with specialists have been negative. We argue that an ethos of harm reduction and informed consent, with a strong emphasis on continuity of care within a primary care setting, should guide questions about how to refer transgender patients to caregivers and to good care settings.

#### Case

As a fourth-year medical student, Jasmine volunteers at a women's health clinic affiliated with her medical school. During her shifts at the clinic, Jasmine helps conduct initial patient interviews and physical exams and works with attending physicians—one of whom is Dr. Fan—to create care plans for her patients. On this afternoon, Jasmine sat down with a 29-year-old patient named Brianna.

Brianna told Jasmine that she had experienced recent episodes of nausea, which Brianna thought might be related to her hormone therapy. Brianna, who identifies as female but was birth-assigned male, began feminizing hormones five years ago. Brianna's hormone regimen is currently being managed by Dr. Maize, a specialist not affiliated with the clinic but known to the community.

"I've never had these symptoms before," Brianna said. Jasmine asked Brianna if she had told Dr. Maize about these recent symptoms. Brianna replied, "To be honest, I don't like spending much time at her office. I just try to show up for my check-ups, get my prescriptions, and leave." Brianna explained that, while at her appointments with Dr. Maize, she often catches the inconsiderate lingering stares of her staff. And on multiple occasions, Dr. Maize has said impolite things to her. During one visit, for example, Dr. Maize said to her, "Now that you've been doing well on hormones for a while, feminizing facial surgery could really help you complete 'the full look,'" which hurt Brianna and convinced her that Dr. Maize wasn't adept at making transgender patients feel comfortable.

At the conclusion of Brianna's patient interview, Jasmine went to Dr. Fan, explained Brianna's discomfort with Dr. Maize, and asked if there were another specialist to whom they might refer Brianna for hormone therapy.

"I've heard similar complaints about Dr. Maize from other trans patients," Dr. Fan said, "but she's the only gender-transitioning hormone specialist in the area." Dr. Fan explained that there were specialists in a big city nearby who had better reputations for trans-friendliness, but they tended to be younger and less experienced with hormone therapy for gender transitions than Dr. Maize. "Since Brianna has her own share of pre-existing health complications, from a strictly medical point of view, Dr. Maize could be the most qualified to care for her—but given Brianna's discomfort with her . . . I'm not so sure."

"So, what should we recommend to Brianna as her best referral option?" Jasmine asked Dr. Fan.

### **Commentary**

While some strides have been made in social acceptance and legal equality for transgender people, there is still a need to address [stigma](#) and inequities in transgender health care [1, 2]. Access to gender transition-related care (e.g., gender-affirming surgery, hormones, and culturally competent mental health services) is a pressing and often unmet need for many transgender people, but it comprises only one component of their health care. Transgender patients' other health care needs are, in many respects, identical to those of cisgender (nontransgender) people. This case highlights the question of best referral practices for transgender patients, particularly when medically qualified specialists lack the knowledge or interpersonal skill needed to care well for transgender patients. In reflecting on Brianna's case, we will emphasize the importance of ensuring that transgender people stay within the care of professionals they trust for all their health care needs, with the goal of preventing harm and promoting continuity of care.

### **Harm Reduction**

There is little empirical research on the outcomes of gender transition-related medical interventions [3]. This lack of data suggests a need for future study and a challenge to clinicians. In the absence of longitudinal evidence, [clinical practice guidelines](#), such as the standards of care issued by the World Professional Association for Transgender Health (WPATH), call for harm-reduction approaches in confronting the pressing need to treat this patient population [4]. For example, in the case of patients whom the physician knows to have acquired hormones through the black market, Internet, or other means, this approach requires physicians to manage the patient's hormone regimen [4, 5] and provide a limited prescription for hormones (until a clinician who can prescribe long-term hormones is found) rather than refusing to prescribe [4], because it is likely that denial of

care will result in “continued independent treatment and possible harm” [6]. Efforts to reduce harm are intuitively necessary in cases of potential denial of care, but recent research has also started to focus on the need to reduce [emotional harm](#) to patients, in part because “emotional harms can erode trust, leave patients feeling violated and damage patient-provider relationships” [7]. Both physical and emotional harms should be considered in harm reduction efforts.

The principle of harm reduction is applicable in this case on both physical and emotional grounds and should guide whether and to whom Brianna is referred. The specialist, Dr. Maize, and her staff are experienced by Brianna to be “inconsiderate” and not “adept at making transgender patients feel comfortable,” which, in turn, has resulted in Brianna minimizing and avoiding interactions with Dr. Maize and her staff. In the case, the patient-physician relationship can be understood to be causing two kinds of harm: emotional, since Brianna is uncomfortable and feeling pressure to seek unwanted medical intervention; and potentially physical, because she is reluctant to see Dr. Maize about her recent episodes of nausea. The scenario described above, in which transgender patients avoid medical care due to negative experiences, is neither hypothetical nor isolated [8]. In a survey of transgender people residing in Massachusetts, it was found that discrimination was associated with 24 percent of transgender patients postponing routine or preventative care and 11 percent postponing care that later resulted in emergency treatment [9]. Based on the model of harm reduction described above, Brianna should not be referred back to Dr. Maize, in order to avoid emotional harm, in particular.

### **Models of Transgender Care**

Changes to referral practices are at the heart of a significant evolution in the medical treatment of transgender people. The most recent edition of the WPATH guidelines suggests—but no longer requires—that patients provide one or more letters of referral from a “qualified mental health professional [or] ... a health professional who is appropriately trained in behavioral health and competent in the assessment of gender dysphoria” prior to the provision of hormones [10]. The referring practitioner shares ethical responsibility for the provision of hormones with the prescribing physician, and the pre-letter-writing consultations are designed to confirm that the patient is both committed to transitioning (and therefore unlikely to regret the decision to initiate hormone therapy) and able to consent to the treatment [4]. In recent years, however, many centers that specialize in transgender medical care have moved to what is termed the “[informed consent model](#)” for initiation of hormone therapy [11, 12]. In this model, no referral letters are needed for hormone therapy, and pre-prescribing consultations are designed to ensure that the patient is fully aware of the “risks, benefits, alternatives, unknowns, limitations, [and] risks of no treatment” [13]. Although informed consent to endocrine treatment is not an issue for Brianna, the model of care that the informed consent pathway presents is helpful for thinking about where she is likely to receive the

best endocrine care. In contrast to the referral model, in the informed consent model, care is patient-initiated and fits within the primary care model of overseeing all aspects of care.

Through this lens, Dr. Maize's comment that "feminizing facial surgery could really help you complete 'the full look'" raises a red flag. Historically, the relationship between gender-nonconforming people and the medical establishment was fraught with mistrust and frustration, with psychiatrists serving as gatekeepers to desired care [14, 15]. Physicians believed that their patients lied to them in order to receive transitional treatment, while patients saw their physicians as paternalistic impediments, unwilling to offer medically necessary treatment or to acknowledge variations in gender identity from patient to patient [16]. An uneasy, and, for the most part, tacit, deal was struck. Patients would repeat a similar story to their doctors: they had been "trapped in the wrong body"; they had "always felt that way"; post transition they promised to be model heterosexual women (there are few recorded medical historical accounts of transgender men) [16]. In turn, physicians would work to provide "complete" transition, which combined available surgical techniques with hormone therapy and training in feminine behavior, one physician referring to it in a 1973 paper as a "charm school" for his transgender patients [17]. In the mid-twentieth century, the stakes were high because physicians had virtually complete authority to deny or grant access to patients seeking medical assistance with their gender transitions. For patients seeking medical interventions, the idea that there was such a thing as a "complete transition" or the "full look" was a convenient and necessary shorthand to legitimize transitional treatment. However, Dr. Maize's suggestion that Brianna undergo surgery to complete "the full look" suggests that she is still operating within this older, [paternalistic model](#). Contemporary transitional care should be guided by the patient's sense of self, rather than the clinician's interpretation of gendered norms.

As our cultural [understanding of gender](#) has evolved to accommodate many different experiences of masculinity and femininity, clinical guidelines no longer require a binary expression of gender identity as a requirement for accessing care [18]. As a result, the idea that one's look must be "complete" is outdated and problematic. Because of the diversity of gender expressions and physical bodies among transgender people, there is not a standard set of surgical or endocrinal interventions that constitute an ideal or "complete" gender transition. Rather, informed consent to ensure a transitioning patient's self-determination should guide the course of medical assistance, when desired.

In considering whether and where to refer Brianna for hormone therapy, Dr. Fan and Jasmine could turn to the informed consent framework. It emphasizes patient knowledge—of transgender issues and of medical risks and benefits of potential treatments that clinicians can provide. By removing psychiatric gatekeeping

requirements, it also promotes continuity of care. Jasmine and Dr. Fan should prioritize referring Brianna to a physician that she trusts, ideally one already familiar with (or willing to be educated in) transgender medical care. Such a clinician can still, if needed, refer out to an endocrinologist in the event that Brianna's symptoms of nausea are found to be caused by her hormone therapy, while still maintaining responsibility for her hormone management.

### **A Common Problem in Transgender Health Care**

Presuppositions about gender-transitioning hormones, as well as gender identity, constitute a potential blind spot for physicians in their care of transgender patients. Transgender and gender-nonconforming people report that one of the most frustrating aspects of being in a clinic for health care needs unrelated to gender transition is the myth of constant comorbidity. This is colloquially known as “trans broken arm syndrome” [19], the causal misattribution of unrelated medical problems to aspects of gender transition or transgender identity. The consequences of this phenomenon range from a misallocation of time resources—spending too much time taking the patient's history of transition-related intervention and failing to address the condition they came in for—to erroneous attempts to change the course or regimen of hormonal treatment [20]. While it is entirely possible that Brianna's symptoms are related to her feminizing hormones, the assumption that Brianna's hormone therapy is the cause of a symptom like nausea might be a red herring. Clinicians should exercise extreme caution before recommending that the patient stop hormone therapy on account of possible side effects, which can include unwanted physical changes, as well as emotional harms. Like any other medically necessary treatment for chronic or life threatening conditions, hormones should be actively monitored and maintained in a treatment plan, unless the patient wishes to stop taking them. More clinicians are needed who are well informed about transgender health issues as well as able to provide gender affirming care.

### **Transgender Patients' Access to Health Care: Common Barriers and Overcoming Them**

Transgender people report encountering serious barrier and biases in health care [7]. Although large LGBT health centers do exist and disseminate educational materials beyond their specific patient populations [5, 21, 22], they are generally located in major cities and therefore too far for many people to travel for regular care. Surgeons who are experienced in gender-affirming procedures are also relatively few [23], and, as a result, patients might have no choice but to travel great distances for expensive procedures. This hardship has real financial impact on transgender patients and can remove them from their communities for postsurgery support. Additionally, health insurers have historically declined coverage of gender transition-related expenses, which required that procedures, such as mastectomy or hormone therapy, be paid for out of pocket unless physicians could find another way to bill for them that is unrelated to gender-affirming care [24]. Even though insurance plans are beginning to cover transition-related expenses, many transgender Americans remain uninsured and underinsured [8].

*Expanding access.* Despite these barriers to access, hormones as well as nonmedical gender-affirmation support can be provided within a patient's community and managed by a physician with whom the patient is most comfortable, even in a primary care setting. In fact, any physician, using tools and guidelines to help them gain competency, can manage hormone treatments for transgender patients. For example, the University of California, San Francisco's Center of Excellence for Transgender Health [5], the Fenway Institute at Fenway Health in Boston [21], and the Callen-Lorde Community Health Center in New York City [22] publish guidelines and instruction for clinicians. The UCSF guidelines state that "prescribing gender-affirming hormones is well within the scope of a range of medical providers, including primary care physicians" [13], and that "it is of similar difficulty to the monitoring of other similarly complex lab-monitored conditions managed by primary care providers" [25]. The Fenway approach (like the others) is "a philosophy of accessible, patient-centered care that views gender affirmation as routine part of primary care service delivery, not a psychological or psychiatric condition in need of treatment" [26]. This position doesn't mean that endocrinologists should not be involved in the provision of hormones, particularly in their roles as consultants. Rather, these guidelines allow clinicians more flexibility in weighing their own comfort and ability to provide effective care when deciding whether and how they will manage a transgender patient's care, instead of their particular specialty training overriding that decision.

A primary care-centered approach to the provision of hormones facilitates continuity of care. This continuity of care, wherein gender affirmation is a "routine part of primary care" [26], in turn can help to ameliorate "trans broken arm syndrome." Primary care physicians generally know their patients better than specialists and are familiar with many different aspects of their patients' health and well-being. They may prescribe hormones for transgender patients and are well-suited to monitoring them in the context of their overall health and well-being [5]. Primary care physicians who manage their patients' hormone therapy are better equipped to understand the therapy's effects—including what symptoms are unrelated to hormone therapy—than those who do not. Jasmine and Dr. Fan should help Brianna find a primary care physician who could both monitor her ongoing hormone therapy and serve as her regular physician.

### **Conclusion**

In weighing referral options for transgender patients, clinicians should consider not only the experience potential specialists have in working with transgender people, but also their willingness and ability to develop care plans that reflect the wants and needs of the individual patient. These referral and care management decisions should be made to minimize physical and emotional harm, taking into account the cultural competence of the clinicians who might provide gender-affirming care, the importance of continuity of care, and the fact that, in many circumstances, it is not only acceptable but also, perhaps,

preferable that a primary care physician undertake hormone management. Ultimately, transgender patients need clinicians whom they feel safe and comfortable seeing regularly for all of their health care needs. The majority of medical care related to transgender health can be administered by any physician willing to research best practices and create a care plan that centers on an individual patient's health care needs and priorities.

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**Elizabeth Dietz** is a project manager and research assistant at the Hastings Center in Garrison, New York. Her research focuses on queer and feminist issues in bioethics.

**Jessica Halem, MBA**, is the program manager for the LGBT Office in the Office for Diversity Inclusion and Community Partnership at Harvard Medical School in Boston. Previously, Jessica was the executive director of the Lesbian Community Cancer Project in Chicago, where she created a cultural competency curriculum in LGBTQ health and trained health care professionals throughout Illinois.

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## ETHICS CASE

### Should Mental Health Screening and Psychotherapy Be Required Prior to Body Modification for Gender Expression?

Commentary by Timothy F. Murphy, PhD

#### Abstract

Some people want to modify their bodies through hormonal and surgical treatments in order to resolve gender dysphoria, the distress they experience when their bodies do not align with their gender identity. The World Professional Association for Transgender Health (WPATH) offers guidelines to clinicians regarding treatment of people wanting to modify their bodies for this reason. Prior to these modifications, WPATH advises that mental health screening is needed and that psychotherapy is recommended though not a requirement. In fact, these advisories allow clinicians some freedom in applying the standards to specific cases. Although some variation from the WPATH *Standards of Care* can be clinically acceptable, informed consent remains an essential component of clinical encounters involving body modifications.

#### Case

Among her patients, Dr. Leonard, a family medicine practitioner, has developed a reputation as a physician especially welcoming to lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients. Over the years, Dr. Leonard has noticed—with much happiness—that her LGBTQ patients are coming out at younger ages and embracing identities that span an increasingly diverse spectrum of gender and sexuality—an indication, she thinks, that important social and cultural progress has been made.

Today, Dr. Leonard's nineteen-year-old patient, Tyler, is coming to see her. Tyler was female-sex assigned at birth; however, four years ago, Tyler came out to friends and family as a transgender male. In recent visits, Tyler has begun discussing with Dr. Leonard the possibility of pursuing medical assistance with gender transitioning, including gender-transitioning hormone therapy and gender reassignment surgery, which might involve "top" surgery—breast removal, in this case—or "lower" (also called gender affirmation, gender confirmation, or genital reassignment) surgery, a procedure to change genitalia. On his last visit, Dr. Leonard sent Tyler home with some readings relevant to the next steps of his transition to try to help him decide whether and when—if ever—to pursue gender transitioning with medical interventions.

“Dr. Leonard, I read what you gave me about the next steps of possible treatments, and I wanted to ask you about something,” Tyler said during his appointment. “While I do want to begin transitioning with top surgery, I read that I’ll have to get clearance from a mental health counselor first. But I don’t think my transition should require mental health counseling or approval.”

Dr. Leonard conceded that current guidelines from the World Professional Association for Transgender Health do recommend that patients receive at least an assessment and one documented referral for gender-transitioning surgery from a mental health professional before undergoing a procedure. She suggested to Tyler that he might view mental health counseling as a way to learn about and prepare for the potentially long lasting and irreversible effects of surgical body modification.

Tyler was still resistant. “Dr. Leonard, I don’t think I should have to prove to someone that I am who I am. Who else has to do that?” Tyler added that he had seen counselors in the past—for instance, to help him cope with his parents’ divorce. When it came to gender identity, however, he explained, “It’s the one thing about me I struggle with least. I’m really being pressed to do the counseling to make others comfortable with my decision, so it bothers me that this is pitched as being ‘for my own good.’”

Dr. Leonard had never been prompted to question the process of mental health assessment and counseling for transgender patients in the past. And while her medical judgment still sided with the idea that patients probably benefit from mental health counseling for gender-transitioning HRT or surgery, she also sympathized with Tyler. Dr. Leonard wondered if, in some cases, it could be harmful to ask a patient for identity affirmation through such institutionalized, formal channels. She wondered what to do next.

### **Commentary**

Many people look to hormonal and surgical interventions to bring their bodies into alignment with idealized images they have of themselves as men and women. Men do this, for example, by having chin implants, breast tissue reduction, liposuction, and other body-shaping interventions. Women do this, for example, by having breast augmentation, breast lift, liposuction, and tummy-tucks, among other body-shaping interventions. Some men and women also reshape their genitals; men remove or restore foreskins, and women reduce or enlarge labia, for example. They do so, again, to conform their bodies to idealized gendered images they have of themselves.

Despite having female- or male-typical bodies, some people experience a male or female gender identity, respectively. Some of these people regret—if not suffer from—the ways in which their bodies do not conform to their gender identity, and some consequently look to clinical interventions to achieve an idealized body appearance,

insofar as possible. The American Psychiatric Association (APA) advises physicians to treat the “dysphoria” (the distress) of people, rather than trying to treat the cross-sex identity itself [1]. Body modification through clinical interventions can help reduce the distress of wanting—but not having—physical traits that align with one’s gender identity. In what follows, I will respond to the case above by focusing on which requirements, if any, should be observed in the clinical provision of hormonal and surgical treatments that modify people’s bodies in the name of gender expression.

### **Should Mental Health Screening and Psychotherapy be Necessary before Body Modifications?**

In this case, Tyler seeks body modifications to express a male identity, but he disputes any requirement that he get “clearance” from a mental health professional as a condition of access to those modifications. The World Professional Association for Transgender Health (WPATH) [2] does maintain that a mental health assessment “is needed” [3] for people wanting to modify their bodies for reasons of gender expression. That group also recommends—but does not require—psychotherapy as a prerequisite for body modifications [2]. (In some jurisdictions, evaluation by a health care professional is necessary to change one’s sex identity, as recorded by the state [4].)

But what rationale is behind WPATH’s recommendations? One possible reason, as articulated by Dr. Leonard in the case, is that body modifications are “irreversible,” involving as they do excision of genitalia, construction of genitalia, and hormone treatment to shape secondary sex characteristics. WPATH itself uses the language of irreversibility in describing some interventions [5] and the outcome of some physical changes [6]. In the face of this irreversibility, and the scale of the changes involved, is it not just prudent to ensure insofar as possible that Tyler is committed to the interventions he is asking for? And would psychological assessment and counseling not help offer some assurance that the interventions, their consequences, and their potential risks and benefits have been carefully considered?

Tyler doesn’t see it this way, however. He is confident of his decision and skeptical about clinicians serving as gatekeepers to body modification. A skeptic might press Tyler’s point even further: Aren’t the required assessment and recommended counseling for gender-affirming body modification paternalistic? If so, whose views are supposed to be endorsed by such [paternalism](#), anyway? Why should a clinical authority have to “sign off” on an adult’s proposed body changes, except perhaps because society retains some interest in policing those changes, perhaps to secure the comfort found by some in a neat and tidy gender binary world of only *hes* and *shes*? After all, a skeptic might say, equivalent assessment and counseling are not required for men and women who wish to alter their bodies to conform to the gender norms of their given sex, even though many of those modifications are equally irreversible. There seems to be a troubling double standard at play here.

Against this skepticism, psychological assessment and therapy can be defended as important in clarifying the motives for body modification and the nature of its effects. Dr. Leonard might draw upon some of the following ideas to engage Tyler and show the benefit of assessment and therapy, despite apparent overtones of paternalism. These processes can, for example, clarify what is most important to Tyler: entering into a particular gender role, modifying relationships, having specific body traits, or something else. These processes can also help identify capacities and traits that could facilitate someone's success in a gender transition. Counseling can also help explore some of the foreseeable physical and psychological effects of gender role change, residual effects of stigma attached to gender transition, and the implications of gender transition for family dynamics and workplace status, among other things. In short, psychological assessment and counseling can be instruments of success in gender transition rather than impediments to the exercise of choice. Still, a skeptic might respond that assessment and counseling [are not equally valuable or necessary](#) to all people. If so, these processes should be optional, not obligatory.

This skeptic might even challenge the idea that body modifications are irreversible. In a sense, hormone treatment is reversible at will because someone can simply stop it at any time for any reason. Not all hormones' effects would vanish, but some would diminish over time. As for surgical interventions, breast restoration might also be possible to a degree, although it would probably involve significant additional interventions, procedures, or prosthetics. Options for penis reconstruction and even transplantation are becoming more promising for people looking to restore that body part [7]. Analogously, any constructed penis or scrotum could also be removed, and certain labial and vaginal reshaping can be carried out. These examples suggest that surgical body modifications are not irreversible in an absolute sense, even if a complete return to the *status quo ante* cannot be guaranteed. Even so, that degree of reversibility might be acceptable to some people who come to regret decisions to modify their bodies. In any case, no amount of prior assessment and counseling ahead of body modifications for gender expression will protect all people from all regrets over body modifications.

In the face of this skepticism about WPATH's required assessment and highly recommended counseling, it is worth noting that WPATH itself says that its standards are flexible:

Clinical departures from the *SOC* [standards of care] may come about because of a patient's unique anatomic, social, or psychological situation; an experienced health professional's evolving method of handling a common situation; a research protocol; lack of resources in various parts of the world; or the need for specific harm-reduction strategies. These departures should be recognized as

such, explained to the patient, and documented through informed consent for quality patient care and legal protection [8].

As a matter of professional ethics, then, a clinician might accommodate some people who want to bypass certain steps—such as psychotherapy—in the process of body modification, but important cautions apply to ensure the psychological and moral integrity of those decisions.

### **Informed Consent for Gender-Affirming Body Modifications**

As a matter of moral integrity in clinical encounters [informed consent](#) must be obtained for body modifications for gender expression, as it must be for any clinical intervention. Physicians must take steps to ensure that their patients understand the nature of the interventions (i.e., exactly what will be done), their consequences (i.e., foreseeable effects), the risks and benefits of the interventions (including their reversibility or not), and alternatives to the hormonal or surgical interventions (such as means of gender expression involving modifications of behavior, roles, and ways of relating to others).

It may be that future generations of transgender people will come to decisions about body modifications with more information and perhaps less uncertainty than people at present. WPATH offers a variety of recommendations for the care of gender-nonconforming children and adults, and some of these will be exposed to health care professionals early on in their lives; that exposure may help them consolidate their interests in modifying their bodies while still relatively young. For example, clinicians now routinely treat certain minors to [suppress the onset of puberty](#) and, later in adolescence, to initiate treatments to shape the body in desired ways [9-11]. In some instances, clinicians have even surgically modified the bodies of minors, although most professional groups recommend delay until a child reaches the age of 18 [12]. When caring for people with this kind of medical history, clinicians might depart from WPATH's recommended standards of care, depending on an individual patient's needs for mental health assessment and psychotherapy. Even so, someone's prior history of mental health assessment and psychotherapy offers little justification for any waiver of informed consent when it comes to body modifications for gender expression.

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**Timothy F. Murphy, PhD**, is professor of philosophy in the biomedical sciences at the University of Illinois College of Medicine in Chicago. He has analyzed the ethics of fertility preservation for transgender people, access to fertility treatments by transgender people, and ethical issues faced by transgender medical students. He has also written on the ethics of genetic modifications to human descendants.

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## ETHICS CASE

### Should Psychiatrists Prescribe Gender-Affirming Hormone Therapy to Transgender Adolescents?

Commentary by Cary S. Crall, MD, and Rachel K. Jackson

#### Abstract

Gender-affirming hormone therapy is a safe and effective way to improve quality of life and mental health outcomes for transgender adolescents. Access to this treatment is limited, with the most vulnerable transgender people experiencing the greatest gaps in care. Because some psychiatrists help transgender patients receive needed medical interventions, we analyze the ethical values they must balance when deciding whether to provide hormone therapy to patients who seek it.

#### Case

In the medium-sized city where he practices psychiatry, Dr. Lao has developed expertise in treating and counseling transgender adolescents. This afternoon, Dr. Lao is scheduled to meet with Jessie, a 15-year-old high school student with autism spectrum disorder. Jessie has been Dr. Lao's patient since elementary school. Within the last two years, Jessie, who was birth-assigned male, began opening up to her family and Dr. Lao about her identity as a transgender female.

In the waiting room, Jessie's parents pulled Dr. Lao aside. "Is it true that you will soon start administering hormone therapy yourself?" Jessie's father asked Dr. Lao. "Because it would be great if we didn't have to find another physician when Jessie starts hormone treatment. Jessie said she would much rather have you perform the treatments."

It was true that Dr. Lao was considering becoming trained to administer hormone therapy. Many of Dr. Lao's transgender patients and families have complained about the lack of physicians in their rural community who are trained in hormone therapy administration. Dr. Lao thought he might play a role in reducing this resource disparity for his patients by becoming trained himself.

Their previous session ended just as Jessie began to describe some of her anxieties to Dr. Lao about transitioning from male to female. Jessie worried about what her classmates might think about her transition, and, while her immediate family was very supportive, Jessie worried about the opinions of members of her extended family, who tended to be less progressive on issues of gender and sexuality.

In their session today, Dr. Lao wanted to follow up with Jessie about these concerns. “Jessie, when we last met, you mentioned concerns regarding how your classmates and family members might react to your transition—would you like to keep discussing that?” With that question, Dr. Lao noticed that Jessie seemed somewhat withdrawn and uncharacteristically uncomfortable in front of him. “No,” she replied, “I thought it over, and I’m not as worried anymore about what they’ll think.” Dr. Lao tried a couple more times in their discussion—with little success—to veer the conversation back to Jessie’s formerly expressed worries about her transition. At the end of their session, Jessie said to Dr. Lao before leaving his office, “I’m feeling very ready to begin hormones—and it would make me so happy if you were the one managing my treatments, Dr. Lao.”

As Dr. Lao waved goodbye to Jessie and her family, he couldn’t help but wonder if Jessie’s refusal to discuss her anxieties about her transition were related to her wish to pursue hormone therapy under his care. Could it be that Jessie feared Dr. Lao would be hesitant to treat her or might delay the process if Jessie disclosed her anxieties about transitioning with him? Dr. Lao wondered: If he developed expertise in hormone therapy, would his patients then perceive him as a kind of gatekeeper in the process of their transition? Will his role in offering hormone therapy sacrifice important elements in his therapeutic relationships with his patients like Jessie?

### **Commentary**

Initiating and managing care for transgender patients can often be daunting, even for a caring, motivated physician like Dr. Lao. Transgender people who seek gender-affirming medical care are a small, geographically diffuse community with specialized medical needs requiring coordinated communication among multiple medical specialists. They experience rampant social discrimination, often leading to unemployment and unequal access to health insurance [1] as well as high rates of mental illness [2], further complicating their ability to obtain adequate care. Additionally, many transgender people are hesitant to engage with clinicians and medical office staff due to a personal history of mistreatment by the medical community. In a 2009 survey, 70 percent of transgender or gender-nonconforming respondents reported experiencing at least one type of discrimination in health care settings, with 26.7 percent of the total reporting that they were refused care due to their gender identity and 7.8 percent of the total reporting that clinicians were physically rough while providing care [3]. Given this precedent, their hesitance is understandable.

These challenges have led to a system in which transgender care is centralized in specialized, cross-disciplinary health clinics located in major cities, leaving the most vulnerable transgender patients—those from racial or ethnic minority communities, of low socioeconomic status, or young or elderly people living in rural communities—largely without quality care. What is the nature and scope of an individual psychiatrist’s obligation to provide gender-affirming medical treatment to patients seeking hormone

therapy, especially when providing such care can extend beyond his or her normal scope of practice?

As is the case with many medical interventions, Dr. Lao's decision to provide hormone therapy is clinically and ethically complex. Careful analysis guided by the principles of patient autonomy, beneficence, nonmaleficence, and justice provides an overall framework to guide psychiatrists, particularly those in rural communities, on how they should proceed.

### **Ethical Principles Favoring Hormone Therapy Administration**

The principles of patient autonomy and beneficence support the need for psychiatrists to prescribe hormone therapy for [gender-transitioning adolescents](#).

*Patient autonomy.* The patient autonomy argument for providing HRT is straightforward—physicians should honor transgender patients' right to express their gender identity by providing desired medical interventions in line with the established [standard of care](#) [4, 5]. Historically, clinicians serving as gatekeepers to hormones led to an outcry from members of the transgender community that such a practice violates their basic human right to gender expression [6]. In turn, physician gatekeeping policies and practices limiting access to hormone therapy for those who desire it has led to a robust, unregulated black market for hormones outside the purview of pharmacist or FDA regulatory monitoring of hormone product safety and quality. Gatekeeping can exacerbate disparities in access to safe and reliable hormone treatment, particularly among transgender youth [7]. Thus, honoring patient autonomy by providing access to hormone therapy serves the dual purpose of acknowledging transgender persons' right to self-determination regarding gender expression and expressing regard for the principle of nonmaleficence by limiting potential negative health consequences of unsafe products from unregulated sources. While ethical issues of consent and autonomy specific to initiating hormone therapy in minors are complex, they have been effectively analyzed elsewhere [8, 9].

*Beneficence.* The principle of beneficence—the obligation to do good for the patient—additionally supports Dr. Lao's providing hormone therapy. The best available evidence, along with decades of clinical experience, indicates that effective hormone therapy has a positive effect on psychological and quality of life outcomes in transgender people [10]. Jessie's anxiety and depression plants her firmly within the mainstream for young transgender people who live with varying degrees of social, legal, and medical affirmation of their gender identity. In a recent study featuring a diverse, multicity cohort of 298 young transgender women, Reisner et al. found that 41.5 percent had at least one mental health or substance dependence diagnosis and 35.4 percent reached criteria for a lifetime major depressive episode [2]. Although only 7.4 percent of participants reported current suicidality in Jessie's age group (i.e., ages 16-19), that number was 23.7 percent for those just ten years older [2]. This finding suggests that the patient sitting in front of

Dr. Lao is at a critical period of development, at high risk of developing mental health problems and suicidal ideation if effective interventions are not put in place.

The causal pathway to higher rates of mental illness in transgender youth is illuminated by a recent study, which found that socially transitioned transgender children who are supported in their gender identity have developmentally normal levels of depression and only minimal elevations in anxiety compared to other children their age [11]. This finding suggests that psychopathology within this group is a product of poor social acceptance rather than an intrinsic part of transgender identity. [Pubertal suppression](#) and hormone therapy are the chief tools physicians have at their disposal for minimizing a transgender patient's risk of suffering adverse mental health outcomes.

Opportunities to provide benefit to the patient extend well beyond psychological care as Jessie, at age 16, is undergoing physical development that requires timely medical intervention to maximize medical affirmation of her gender identity. Depending on Jessie's current height, timely estrogen administration might aid in closure of the growth plates, possibly allowing for her to remain closer to the median height for girls her age. Additionally, each passing day of androgen-predominant puberty leads to further facial masculinization, deepening vocal range, and male pattern hair growth that will require costly—and variably effective—medical and behavioral interventions if Jessie chooses to pursue them in order to pass as her affirmed gender.

Tragically, passing can be a matter of safety and survival for young transgender women. In one large survey of transgender people, 53 percent reported being victims of harassment in public accommodations [12], and, in 2015, 67 percent of victims of hate crime homicides reported by the National Coalition of Anti-Violence Programs were perpetrated against transgender and gender-nonconforming people [13]. Passing can also affect transgender people's ability to find romantic partners, housing, and employment, with 63 percent of transgender survey respondents reporting acts of serious discrimination in one or more of these domains [12]. Although these are largely social and legislative problems, timely hormone therapy is crucial for transgender patients' quality of life and physical safety, given the current risks of violence and [discrimination](#) they face. In the absence of other physicians willing to provide hormone treatment, Dr. Lao's obligation to intervene based on the principle of beneficence is imperative to Jessie's well-being.

### **Ethical Principles that Do Not Support Psychiatric Administration of Hormone Therapy**

Ethical analysis based on the principles of nonmaleficence and justice suggests that Dr. Lao should think twice before providing hormone therapy for gender-transitioning adolescents.

*Nonmaleficence.* Although there are strong arguments in favor of Dr. Lao being trained to provide gender-affirming medical care, specifically hormone therapy, the ethical principles of nonmaleficence and justice weigh on the other side of the balance. Nonmaleficence—to do no harm—is a complicated standard to uphold in this case. Much has been made of potential iatrogenic harms of estrogen-based hormone therapy in late adolescence—including increased risk of deep vein thrombosis, prolactinomas (brain tumors that cause excess prolactin release by the pituitary gland), and loss of fertility for those who do not undergo cryopreservation prior to hormone initiation [14, 15]. While these medical complications can be severe, recent studies have found the incidence of adverse effects of hormone therapy to be low overall [16], and the potential harms of any treatment must be weighed with the potential gains in mind.

Dr. Lao must be prepared to monitor and treat all side effects of the medications he prescribes, whether through his own efforts or expert consultation. Unfortunately, he is unlikely to have been taught basic hormone therapy administration or pubertal suppression while completing his psychiatry residency training. Although current Accreditation Council for Graduate Medical Education (ACGME) core competencies require psychiatric residency programs to teach “fundamental principles of the epidemiology, etiologies, diagnosis, treatment, and prevention of all major psychiatric disorders in the current standard diagnostic statistical manual” [17], management of gender dysphoria—the conflict between birth-assigned and self-identified gender—including hormone therapy, is seldom taught [18]. While psychiatrists have long prescribed estrogen for indications ranging from postnatal unipolar depression to premenstrual dysphoric disorder, there is little precedent for psychiatric practitioners providing hormones for gender dysphoria [19]. Because Dr. Lao is practicing in a rural setting without access to transgender-affirming medical specialists for consultation, he must consider the potential harm to Jessie of initiating hormone therapy and then being required to stop if complications arise that he does not have the expertise to manage.

Additionally, because Dr. Lao is Jessie’s psychiatrist, he must consider the potential harm to his therapeutic alliance with her if he chooses to prescribe hormone therapy. On the one hand, the standard of care for prescribing hormone therapy, especially in adolescents, calls for invasive physical exams, including of breast and genital tissue—a practice that could generate negative [transference reactions](#) from Dr. Lao or Jessie and be detrimental to the therapeutic relationship. On the other hand, as Jessie’s mental health clinician, Dr. Lao has an obligation to help Jessie process her gender dysphoria, regardless of whether she chooses to continue medical assistance with her transition. If Dr. Lao is invested in managing Jessie’s hormone therapy, will he be able to integrate the physical dimensions of her care into their therapeutic relationship without causing harm?

*Justice.* Finally, the principle of distributive justice—the fair distribution of scarce resources and the balancing of competing needs—calls into question the ethical and

clinical wisdom of Dr. Lao taking on the responsibility of prescribing hormone therapy. While providing hormone therapy would serve to bring this resource to a population in which there is a relative scarcity of access, Dr. Lao's position as a psychiatrist who sees adolescents in a rural area makes his time another scarce resource to consider. A 2010 study in the *Journal of Pediatrics* reported that primary care pediatricians rated child and adolescent psychiatrists as the least accessible subspecialists for [patients requiring a referral](#), with the worst access reported in rural communities [20]. Long wait times for patients with high-acuity chief complaints, ranging from first-episode psychosis to posttraumatic stress disorder (PTSD) from chronic abuse, would potentially increase if a clinician unfamiliar with a relatively rare condition took time to learn its management. Is there truly a clinical and ethical imperative for Dr. Lao to take on learning to serve outside his current scope of practice when the need for him to serve within its limits is already so great?

### **Conclusion**

Physicians who choose to provide quality care for a stigmatized patient population within a system that generally ignores its unique medical needs do so at the fringes of their clinical comfort zone. In the absence of a functional system of consistent and equitable care delivery for all patients, the onus of competent care often falls on conscientious individual clinicians who are passionate about [caring for the underserved](#). As the sole clinician offering Jessie crucial gender affirmation, we argue that it is Dr. Lao's responsibility to ensure Jessie receives all medically indicated interventions she desires, including hormone therapy. To do this, it is his clinical and ethical responsibility to perform due diligence by helping Jessie receive gender-affirming medical treatment, including hormone therapy, from an experienced clinician. If geographic and cultural factors, such as transphobia, limit the availability of adequate transgender care, it becomes Dr. Lao's responsibility to become trained in and to initiate hormone therapy with the patient as long as the benefits of providing hormone therapy outweigh the potential risks. Although each psychiatrist must make his or her own decision about whether to help patients receive desired hormone therapy, a few basic principles should serve as a guide:

1. When transgender patients present seeking gender-affirming medical interventions, psychiatrists are responsible for ensuring these patients receive access to all medically indicated care. Due to the clinical complexities of gender-affirming medical treatment for adolescents, due diligence in locating an experienced and skilled clinician must be exercised.
2. ACGME-accredited psychiatry residency training programs should teach management of pubertal suppression and gender-affirming hormone therapy as part of their standard curricula. Some of this training might take the form of grand rounds, case discussions, and simulated patients if residents do not come into contact with transgender people with regularity at their available training sites.

3. When assessing the urgency of hormone therapy initiation for adolescents, special attention should be paid to developmental window periods in physiologic puberty.
4. Psychiatrists should give special consideration to the therapeutic alliance when considering initiating hormone therapy. Co-management with other professionals is the preferred method of treatment. In most cases, due to the possibility of negative transference reactions, psychiatrists should not perform sensitive physical exams on patients with whom they have an established therapeutic alliance.

With these principles in mind, it is our hope that psychiatrists will work to reverse a legacy of exclusionary gatekeeping policies towards transgender patients seeking gender-affirming medical treatment by becoming champions in the effort to expand access to care.

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**Cary S. Crall, MD**, is a first-year resident in the Massachusetts General Hospital/McLean Adult Psychiatry Residency Program in Boston. He received his MD from Harvard Medical School. His research interests include LGBTQ mental health, child and adolescent psychiatry, and medical education.

**Rachel K. Jackson** is a fourth-year medical student at the University of Washington in Seattle. She received her BS from Portland State University and plans to pursue residency training in family medicine. Rachel's professional interests include primary care for LGBTQ adults and adolescents, mental health, suicide prevention, addiction, transgender care, sexual health, and wilderness medicine.

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## THE CODE SAYS

### The AMA Code of Medical Ethics' Opinions Related to Discrimination and Disparities in Health Care

Danielle Hahn Chaet, MSB

It is recognized that members of the transgender community suffer from [disparities in health care](#) [1]. Although lack of access to appropriate care (due to lack of clinicians knowledgeable about transgender patients' specific needs and vulnerabilities) is the biggest barrier, other barriers include financial and socioeconomic obstacles, physicians' lack of awareness or education about physicians' roles in transgender health care, and discrimination [1]. The *Code of Medical Ethics* is far from silent on matters of [discrimination](#) and disparities in health care.

#### Ensuring Basic Rights

Opinion 11.1.1, "Defining Basic Health Care" [2], does just that. The opinion recognizes [health care as a fundamental human good](#), and acknowledges that "physicians regularly confront the effects of lack of access to adequate care and have a corresponding responsibility to contribute their expertise to societal decisions about what health care services should be included in a minimum package of care for all." Opinion 8.5, "Disparities in Health Care," recognizes that physicians' attitudes can exacerbate variations in patients' access to health care services or the quality of health care patients receive.

Stereotypes, prejudice, or bias based on gender expectations and other arbitrary evaluations of any individual can manifest in a variety of subtle ways. Differences in treatment that are not directly related to differences in individual patients' clinical needs or preferences constitute inappropriate variations in health care. Such variations may contribute to health outcomes that are considerably worse in members of some populations than those of members of majority populations [3].

The opinion calls on physicians to examine their own practices to ensure that [stereotypes](#) and [biases](#) against patients' traits (including gender identity) do not affect their clinical judgment or affective demeanor toward patients.

#### Physicians' Choices and their Limits

Opinion 1.1.2, "Prospective Patients" [4], explains that while physicians may choose their patients in nonemergency settings, they may not discriminate against a patient on the

basis of gender identity, sexual orientation, or other nonclinical characteristics. Opinion 1.1.7, "Physician Exercise of Conscience" [5], explains that while there is some leniency regarding practices that contradict physicians' "well-considered, deeply held beliefs that are central to their self-identities," this latitude is not unlimited. Physicians still must "respect basic civil liberties and not discriminate against individuals in deciding whether to enter into a professional relationship with a new patient" and "take care that their actions do not discriminate against or unduly burden individual patients or populations of patients and do not adversely affect patient or public trust." This sentiment is echoed in discussions of reproductive medicine. Opinion 4.2.1, "Assisted Reproductive Technology" [6], is particularly relevant; it notes that physicians who offer these services should "not discriminate against patients ... on the basis of race, socioeconomic status, or sexual orientation or gender identity."

### **Protecting Patients**

Physicians' obligations are not limited to an injunction against discrimination on the basis of gender identity or other nonclinical criteria. They also have responsibilities to protect their transgender patients as they would any other patient. Examples of opinions in the Code that address common patient protections include Opinion 3.2.2, "Confidentiality Post Mortem" [7], which states that "patients are entitled to the same respect for the confidentiality of their personal information after death as they were in life," and Opinion 4.1.3, "Third-Party Access to Genetic Information" [8], which explains that "patients who undergo genetic testing have a right to have their information kept in confidence." Importantly, Opinion 8.10, "Preventing, Identifying and Treating Violence and Abuse" [9], is pertinent for physicians who care for lesbian, gay, bisexual, and transgender (LGBT) patients, who are among the most likely targets of hate crimes [10]. Violence is widely regarded as a public health issue [11], and violent hate crimes certainly fall under that rubric. A critical part of the American Medical Association mission is dedication to the betterment of public health [12]. This opinion comprehensively outlines what physicians should do to recognize signs of abuse and protect a patient's well-being.

All opinions referenced in this article can be found [here](#).

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**Danielle Hahn Chaet, MSB**, is a research associate for the American Medical Association Council on Ethical and Judicial Affairs in Chicago. Her work involves researching, developing, and disseminating ethics policy and analyzing current issues and opinions in bioethics. She earned a master of science degree in bioethics, with a focus on clinical policy and clinical ethics consultation, from the joint program of Union Graduate College and the Icahn School of Medicine at Mount Sinai.

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[Transgender Rights as Human Rights](#), November 2016

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## STATE OF THE ART AND SCIENCE

### What's in a Guideline? Developing Collaborative and Sound Research Designs that Substantiate Best Practice Recommendations for Transgender Health Care

Madeline B. Deutsch, MD, MPH, Asa Radix, MD, MPH, and Sari Reisner, ScD

#### Abstract

Transgender medicine presents a particular challenge for the development of evidence-based guidelines, due to limitations in the available body of evidence as well as the exclusion of gender identity data from most public health surveillance activities. The guidelines that have been published are often based on expert opinion, small studies, and data gathered outside the US. The existence of guidelines, however, helps legitimate the need for gender-affirming medical and surgical interventions. Research conducted on transgender populations should be grounded in gender-affirming methodologies and focus on key areas such as health outcomes after gender-affirming interventions.

#### Introduction

The past three decades have seen exponential growth in the range and depth of evidence-based guidelines in a broad range of medical disciplines [1]. The term “[evidence-based medicine](#)” first appeared in a brief article published in 1992 in the *Journal of the American Medical Association (JAMA)* by the Evidence-Based Medicine Working Group [2]. The article built on prior efforts to describe the development of guidelines that are accurate, accountable (to patients, science, and society), predictable (i.e., provide specific detail and figures), defensible (i.e., transparent about how they were developed and consensus was reached), and usable (in a range of real-world settings). These five key considerations in the development of evidence-based guidelines were summarized in an essay published in *JAMA* in 1990 [3].

Guidelines (also referred to as “best practices” or “standards of care”) are generally developed through a consensus process involving a panel of experts (i.e., a multidisciplinary group of clinicians and methodological experts as well as representatives of populations likely to be affected) who evaluate available quantitative evidence gathered in a systematic manner, ideally filtered through a clinical lens, that is, with an eye to its applicability in clinical practice [4]. A number of approaches to achieving expert consensus have been described [5]. Numerous criteria also have been developed to assess the strength of individual recommendations based on the quality of underlying evidence and its applicability to the current question at hand [6]. Relatedly,

the question of “what is a guideline?” has been explored, with some suggesting that there exists a threshold of evidential quality and relevance below which only “good practice recommendations”—rather than guidelines—can be made [7]. The purpose of evidence-based guidelines is ultimately to improve health outcomes by both supporting clinical care of individual patients and informing the development of specific [quality and outcome measures](#) for patient care that permit meaningful surveillance of a particular practice, specialty, or health care delivery system.

The existence of guidelines in the field of transgender medicine both legitimizes the need for gender-affirming medical and surgical interventions and informs medical practitioners and policymakers on how to best meet these needs. Transgender medicine presents a particular challenge for the development of evidence-based guidelines. First and foremost, data on health outcomes in transgender medicine are currently limited to retrospective studies, case series, and individual case reports due to the lack of funding opportunities for research in this field as well as institutional stigmatization of the transgender community [8, 9]. In addition, the lack of uniform data collection by gender identity renders much of the population effectively invisible in health outcome surveillance efforts [10, 11]. Furthermore, academic transgender medicine programs are in their infancy [12], with the exception of several well-established centers in Europe and a few nascent programs in the United States, and there is a general lack of research and clinical fellowship training programs. This has resulted in little opportunity for the body of scientific evidence and academic infrastructure in the field to achieve the level needed to support the development of evidence-based guidelines.

### **Current Guidelines for Transgender Medicine**

The primary set of reference guidelines in the field of transgender medicine has been the World Professional Association for Transgender Health (WPATH) *Standards of Care (SOC)* [13]. Currently in its seventh version (*SOC v7*), the *SOC* debuted in 1979 as a set of recommendations for the diagnosis of what the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* now refers to as gender dysphoria (distress experienced by transgender people when their gender identity has not been affirmed through social, medical, and/or surgical transition), previously referred to as “[gender identity disorder](#)” or “transsexualism” [14], and for the assessment of a person’s readiness and eligibility to access a variety of medical and surgical interventions for gender affirmation, such as hormone therapy or genital surgery [15]. Over the years, this document has evolved substantially, yet it remains largely based on lower-quality evidence (i.e., observational studies) and expert opinion, and with a scope that remains limited primarily to describing best practices for the diagnosis of gender dysphoria and assessing readiness and appropriateness for interventions. *SOC v7* lacks any rating of the quality of the available evidence or strength of the recommendations or description of how expert contributors are selected to participate in the process of developing the guidelines.

Despite their limitations, the *SOC* has played an essential role in advancing transgender health by legitimizing transgender identities and serving as a reference point for policymakers and health insurance payers seeking guidance on how to respond to transgender health needs. In the US, expanded access to gender-affirming medical and surgical interventions by patients using Medicare [16] and insurance plans covered by the Patient Protection and Affordable Care Act [17] has been driven by the very existence of the *SOC*. Recent changes to the *DSM-5* [18], the removal of gender dysphoria as a mental health condition in France [19], and the current consideration by the World Health Organization (WHO) to eliminate gender dysphoria from its list of mental health conditions, have all also been influenced by the *SOC* [20]. Taking a harm-reduction approach and in refutation of those who argue for a minimum threshold setting the boundary between a guideline (or standard of care) and a weaker good practice recommendation [6], the absence of high-quality evidence should not serve as an immutable barrier to developing meaningful consensus guidelines in a field where societal stigmas have served as the principal underlying reason for the lack of quality evidence.

In addition to the WPATH *SOC*, a number of other guidelines, protocols, and best practice recommendations have been published in the peer-reviewed literature as well as in the public domain; others are behind proprietary paywalls [21, 22]. These guidelines range from rudimentary online documents intended for internal use at a specific organization to a comprehensive set of recommendations with background information and citations. One particularly rigorous and complete set of guidelines are the recently revised University of California, San Francisco (UCSF) *Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People*, second edition [23]. These guidelines consist of nearly 200 pages of fully referenced expert consensus recommendations, developed using an intentional consensus building round-robin approach, peer reviewers for each topic, community input, and a grading scheme adapted from the [GRADE system](#), a globally recognized approach to evaluating evidence based on the quality of available studies and providing a rating for the strength of recommendations [24]. Through this rigorous process, the UCSF guidelines meet the criterion of evidence-based.

In addition to following a process that insured that the UCSF guidelines would be evidence-based as well as accurate, accountable, predictable, and defensible, the authors of the UCSF guidelines also took steps to ensure that the guidelines would be usable in real-world clinical settings. The list of topics for inclusion and revision in the UCSF guidelines were developed in part based on several years of user feedback, which included specific questions for clarification or regarding omission of specific topics. The panel of individual contributors comprised experts from a broad range of disciplines, degrees, and practice settings, including academic medical centers, safety-net and

homeless clinics, and large managed care health systems. Input was also sought from community members and nonclinical academics for broader validity checking.

### **Creating Stronger Practice Guidelines for Transgender Health**

*Current limitations.* There are several key areas where data needed to inform high-quality guidelines are lacking. Unanswered questions remain regarding the long-term outcomes of hormonal and surgical interventions as well as the comparative safety and efficacy of different approaches to hormone therapy [9]. Most research on the long-term effects of hormones has been conducted in Europe, where hormonal regimens differ from those in the US and other regions [22, 25]. Additionally, these studies were conducted among fairly homogenous populations that lack the racial, ethnic, and socioeconomic diversity found in the US. Thus these findings might not provide the best evidence on which to base guidelines for a demographically heterogeneous country like the US where different hormonal regimens are used.

There are also few studies investigating potential drug-drug interactions between the formulations of estrogens commonly used in some medically assisted gender transition and other drugs like those used for the treatment or pre-exposure prophylaxis of HIV infection or hepatitis C [26]. Although some studies, mostly small and cross-sectional in design, have suggested that mental health is improved by gender-affirming care [27, 28], larger longitudinal studies on mental health and quality-of-life outcomes are needed to inform policies that would support making gender-affirming care more available and accessible and to develop best practices for the delivery of such care [29].

Evaluating health outcomes for hormonal therapies is further complicated by methodological issues such as inconsistent (or lack of) comparison groups, uncontrolled confounding factors, small sample size, difficulty accessing the population [30] and high rates of loss to follow-up (more likely among those facing homelessness or housing instability), short follow-up period, and the need to evaluate a wider range of health outcomes (e.g., physical and mental health, social functioning, and quality of life). Randomized controlled trials (RCT), particularly if they are double-blinded and conducted at multiple centers to enroll large numbers of participants, are considered the strongest study design (i.e., the highest [level of scientific evidence](#)) to evaluate the causal effects of interventions on health outcomes. However, individual RCTs might not always be feasible or ethically acceptable [31], including in transgender medicine and clinical research. For example, randomizing transgender people to receive or not receive hormone therapy would violate the principle of equipoise, the idea that there is true scientific uncertainty about whether an intervention will benefit a patient-participant, since evidence suggests that hormone therapy is helpful at alleviating gender dysphoria [27, 28]. Nevertheless, there are additional research questions that can be investigated using RCTs. In particular, research can be designed and clinical trials implemented to compare different delivery modes and schedules for hormone treatment.

*Improving research on transgender health.* Transgender medicine would benefit from well-designed and rigorous [observational comparative studies](#), which use more patients' data and longer follow-up periods than RCTs in addition to being less costly to conduct [32]. To conduct this research—and to guide provision of competent transgender clinical care—will require validated, standardized, gender-affirming clinical tools for a range of measures, including a history of hormonal or surgical care or accessing gender-affirming care outside of professional settings, which will simultaneously guide provision of trans-competent clinical care [12]. As these research recommendations suggest, patient-centeredness is a critical component of transgender health research. This means working “with,” not “on,” transgender communities in the design, methods, conduct, and dissemination of studies to inform evidence-based clinical care [33]. Meaningful transgender community engagement will ensure that the research is ethical and acceptable to transgender people and will also ensure study feasibility by fostering trust and synergy between researchers and local communities. Another concern is that individual-level randomization of transgender women in HIV prevention studies to either intervention groups or control groups could likely separate women who are socially connected and mutually supporting, with the result that the study would fail to harness existing community networks and structures that could facilitate intervention uptake (should the intervention prove to be beneficial) or bolster intervention effects.

Routine collection of gender identity data for research purposes will facilitate the conduct of high-quality observational research [33] as well as inform policymakers on the true size and nature of the transgender population, facilitating appropriate research funding allocation. More specifically, it would enable the pooling of transgender patient data from across clinics, community health centers, hospitals, and practices to create large multisite longitudinal cohorts. The use of such cohorts in transgender research would support the development of specific quality and outcome measures for transgender patient care, which in turn could support the development of evidence-based guidelines to improve the quality of clinical practice and training in transgender medicine.

Lastly, the National Institutes of Health and other research funding agencies should begin to recognize transgender status as an independent predictor of health disparities, permitting access to funding streams specifically focused on disadvantaged or minority groups and their specific vulnerabilities.

## **Conclusion**

The expanded visibility of and the medical community's awareness of the health care needs of transgender people has developed more quickly than has the development of evidence-based guidelines and standards for treatment of this population. A pipeline of new research, driven by a workforce of investigators with specific training in transgender

health, is needed to support the health care of this increasingly visible community. Any guidelines that are produced should be grounded in the same high-quality standards that are expected in other fields of health sciences, using available data and extrapolation of data from other fields. Specific research on outcomes related to gender-affirming care and the impact of such care on the natural history and management of HIV or hepatitis is of the utmost importance. Clinical tools and research methods should be transgender-affirming, patient-centered, and engage community participation. Above all, gender identity data must be collected uniformly and consistently in order to inform funding mechanisms and increase the availability of resources and support for research and other scholarly activity aimed at improving the health of transgender people.

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**Madeline B. Deutsch, MD, MPH**, is an associate professor of clinical family and community medicine at the University of California, San Francisco, where she is also director of transgender care. Her research interests include the use of electronic medical records and telemedicine in transgender clinical care, HIV pre-exposure prophylaxis for transgender populations, and developing capacity-building activities and resources for individuals and institutions seeking to improve transgender care quality.

**Asa Radix, MD, MPH**, is the director of research and education at the Callen-Lorde Community Health Center and a clinical assistant professor of medicine at New York

University in New York City, with research interests in LGBT disparities and HIV prevention.

**Sari Reisner, ScD**, is an assistant professor of pediatrics at Harvard Medical School, an associate scientific researcher at Boston Children's Hospital, and an assistant professor of epidemiology at the T.H. Chan School of Public Health at Harvard University in Boston. He is also an affiliated research scientist at the Fenway Institute. Dr. Reisner's research focuses on sexual and gender minority health with a specialization in local, national, and global transgender health.

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## POLICY FORUM

### **Affirmative and Responsible Health Care for People with Nonconforming Gender Identities and Expressions**

Kristen L. Eckstrand, MD, PhD, Henry Ng, MD, MPH, and Jennifer Potter, MD

#### **ABSTRACT**

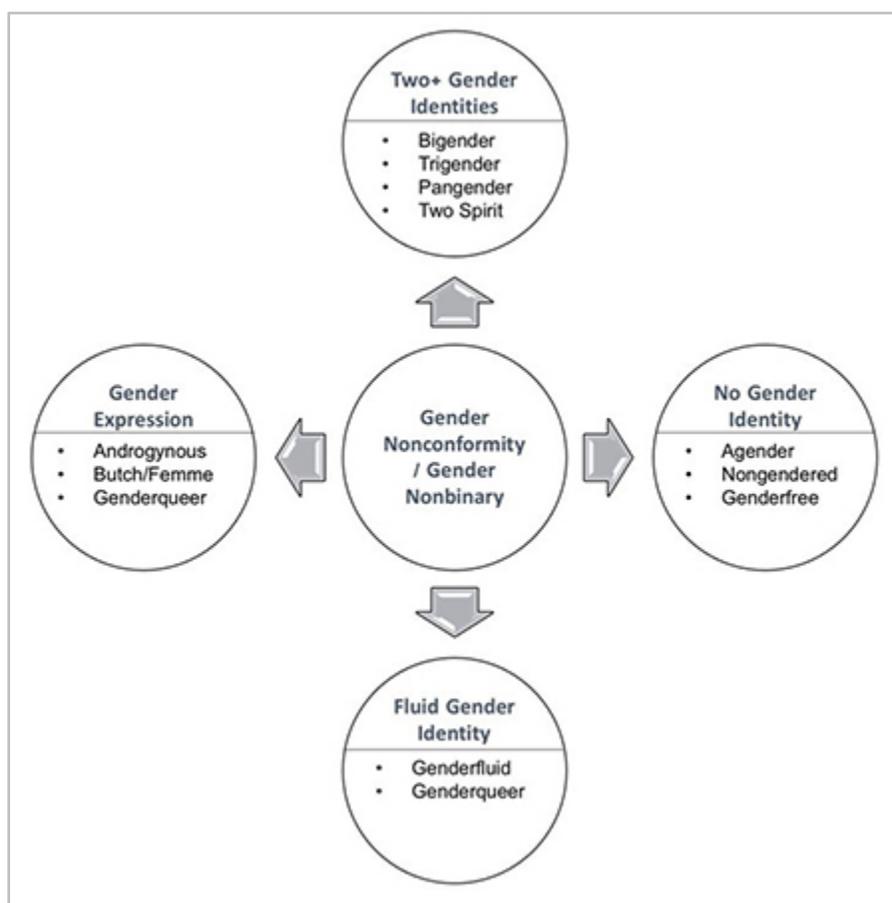
Although recent changes in health care delivery have improved routine and gender-affirming care for transgender people, common approaches to care are still often based on a binary (i.e., male/female) gender framework that can make patients with gender-nonconforming (GNC) identities and expressions feel marginalized. Binary representation perpetuates invisibility, discrimination, and victimization—and subsequent poorer health—among GNC patients. In response, clinicians and health care systems should extend their efforts to provide gender-affirming and responsible care to GNC people. This article reviews terminology related to gender, the limited research—and necessary directions for future research—on GNC communities, and provides strategies for health care professionals and systems to ensure provision of gender-affirming and responsible care to GNC patients.

#### **Introduction**

Recent years have seen rapid changes in health care delivery for patients identifying as transgender. These shifts include increasing clinicians' ability to provide patient-centered, gender-affirming care for transgender people and structural and organizational improvements to ensure that provision of care occurs in an affirming environment [1-6]. For example, health care organizations are increasingly including "gender identity or expression" in patient nondiscrimination policies and mandatory cultural competence training inclusive of principles of gender-affirming care [1]. In addition, federal health insurance plans are now more likely to cover gender-affirming care [1, 2], and several health care associations have recently released statements on requirements for caring for transgender and gender-nonconforming people [3-5]. Although these advances are a significant step forward, they implicitly rely on binary definitions of sex and gender. Such thinking forces those who self-identify as gender nonconforming into a binary mold (e.g., if someone isn't male, they must be "male-to-female") and perpetuates medical systems' lack of patient-centered and competent care for gender-nonconforming (GNC) people who do not identify with one of these binary labels. Given this reality, there remains a pressing need to better understand and optimize health care for GNC people.

## Understanding Gender Nonconformity

*What is gender nonconformity?* Gender nonconformity can refer to a gender identity—one’s personal and subjective sense of gender—that is neither male nor female. It can also refer to a gender expression characterized by mannerisms and behaviors that are not conventionally associated with an assigned gender. People with nonconforming gender identities can identify with more than one gender (e.g., bigender), no gender (e.g., agender), or feel that their gender fluctuates or is undefinable by traditional terms (e.g., genderfluid). Nonconforming expressions can incorporate or exclude aspects of masculinity or femininity that differ from societal norms based on assigned gender (see figure 1). Gender nonconformity is independent of sexual orientation, and a particular sexual orientation cannot be inferred based on gender nonconformity. Notably, the taxonomy presented above is still grounded in Western and postcolonial attempts to categorize gender; even the concepts “bigender” or “third gender” reinforce gender binaries, othering (the tendency to marginalize) gender variance instead of accepting it in modern language and culture. In contrast, some South Asian countries recognize *Hijra* (people assigned male at birth who have a feminine gender expression) as a gender [7].



**Figure 1.** Common terminology for nonconforming gender identities and expressions.

*Victimization of gender-nonconforming youth and adults.* Research on gender nonconformity is scarce, with most studies using person- or observer-reported nonconforming behaviors (e.g., gender roles taken by children during imaginative play or appearance in adolescents and adults) to measure gender expression [8-14]. What is apparent from the available research, however, are the disproportionate levels of [discrimination](#) and victimization against GNC people, including those who also identify as transgender and/or lesbian, gay, bisexual, or queer (LGBQ). Children and adolescents with GNC expressions experience more bullying, victimization, and childhood abuse than their gender-conforming peers [12, 15, 16]. Harmful experiences persist into adulthood, with 19 percent of lesbian, gay, and bisexual adults in one study experiencing chronic daily discrimination based on gender nonconformity [11]. Furthermore, in a survey of transgender and gender-nonconforming adults, 31 percent of genderqueer adults reported experiences of police harassment, 20 percent worked in underground economy settings [17]—possibly due to a combination of job discrimination, poorer educational attainment secondary to bullying, and limited job opportunities—and 19 percent lost jobs due to “anti-transgender bias” [18]. In the same survey, 83 percent and 16 percent of genderqueer adults reported harassment and sexual assault, respectively, prior to age 18 [17]. With regard to health care, GNC adults often delay necessary care for fear of bias, present themselves as male or female when accessing care to avoid discrimination, and can self-medicate rather than engage with the health care system [17].

*Gender-nonconforming people's health care needs.* GNC people's high rates of victimization, coupled with limited social and cultural structural support, set the stage for [health disparities](#). Childhood GNC is associated with poor adult mental health [14]. In particular, youth and adults who were GNC children have greater risk of lifetime depressive symptoms and higher prevalence of posttraumatic stress disorder (PTSD) than their gender-conforming peers [8, 9, 12, 13]. Consistent with minority stress theory, which links minority affiliation to poorer health through stress and discrimination [19], victimization mediates the development of depression and PTSD among GNC people [13, 20]. Although higher proportions of youth who were GNC children have nonheterosexual sexual orientations compared with gender-conforming youth, the majority identify as heterosexual [12], and mental health conditions described above remain associated with gender nonconformity independently of sexual orientation [12, 21]. This finding suggests that the discrimination and victimization of people who are gender nonconforming can lead to poorer mental health outcomes, irrespective of sexual orientation. It is also worth noting that, among GNC adolescents, natal males have a lower average body mass index (BMI) and natal females have a higher average BMI compared with gender-conforming adolescents after controlling for sexual orientation [10]. Although the clinical significance of these findings requires further evaluation because reported average BMIs were within the healthy range, childhood harassment for gender nonconformity is associated with body shame [22] and lower levels of physical activity [10, 23].

The above research highlights early and persistent health challenges experienced by GNC people. However, striking gaps remain in our knowledge of GNC people's utilization of health care services and physical health outcomes, longitudinal models of GNC people's health and the impact of gender-affirming services on their health, protective and supportive factors, and how each of these interacts with additional aspects of identity (e.g., race, culture, sex). Also lacking is an understanding of which [gender-affirming services](#)—social, psychological, medical, or legal—are desired by GNC people. Many people may prefer a nonconforming expression achieved through means other than medical support (e.g., clothing, hairstyle), but how should health care professionals respond when less reversible gender-affirming treatments (e.g., cross-gender hormones, surgeries) are requested? For example, how might a professional care for Morgan, a genderqueer, female-assigned person if the patient wants to masculinize their appearance through testosterone or chest reduction surgery? How might the clinician's feelings towards treatment change if one of Morgan's previous caregivers already initiated testosterone therapy? Or if Morgan is sixteen instead of thirty-six? Many clinicians already struggle to provide care to people who want to transition genders on a binary spectrum despite the availability of [evidence-based guidelines](#) [24, 25]. However, in view of demonstrable health benefits of gender-affirming health care interactions and accessible transition options among transgender populations [26-28], we posit that GNC people are likely to derive similar benefits. Therefore, we and others [6] urge clinicians to extend similarly tailored care to this group.

### **Advancing Gender-Affirming and Patient-Centered Care**

*Understanding gender-affirming health care practices.* Clinicians should understand how to validate and support GNC patients by providing gender-affirming care. Although resources for doing so previously were limited—including the omission of GNC people from commonly used gender transition guidelines, such as the World Professional Association on Transgender Health (WPATH) *Standards of Care* prior to its most recent version [24]—evidence-based guidelines and widely used clinician sources of medical information now address gender-affirming care for GNC people [24, 25, 29, 30]. More recently, several national regulatory and health professions education organizations have recommended strategies to promote equitable care for people who identify as GNC [31, 32], which can be categorized by recognized medical competencies (see table 1).

**Table 1.** Strategies for providing care to GNC patients across Accreditation Council for Graduate Medical Education (ACGME) domains of competence

Knowledge for Practice
<p>Define and understand the differences between gender identity and gender expression, including the nonbinary diversity within each.</p> <p>Discuss options for social, medical, and surgical gender affirmation and the roles of different health professionals in each type.</p>
Patient Care
<p>Respect and affirm identities using a patient-centered approach.</p> <p>Discuss gender histories and developments with patients across the lifespan.</p> <p>Tailor the medical history and physical exam based on patient experiences and needs, including gender identity and expression.</p> <p>Screen patients for childhood and current trauma, depression, anxiety, substance use, body image, and disordered eating.</p> <p>Discuss protective factors and sources of resilience.</p>
Systems-Based Practice
<p>Provide a medical home for GNC patients, including ensuring a welcoming and affirming climate and training all staff members.</p> <p>Work as part of an interprofessional team in order to provide patient-centered care.</p> <p>Be knowledgeable about, and include social support and community resources in, care plans.</p> <p>Include GNC people in community- and patient-engaged care delivery.</p>
Practice-Based Learning and Improvement
<p>Be aware of your own biases toward GNC identities and expressions and implement strategies to mitigate biases.</p> <p>Discuss and use existing guidelines for transitioning with patients and develop openness to nonbinary medical transitions.</p>
Interpersonal and Communication Skills
<p>Work with patients to ensure minimization of stigmatizing forces within health care systems (i.e., by knowing how to document gender nonconformity in electronic health records and ensuring safety in waiting rooms and other public areas).</p>
Professionalism
<p>Assume shared responsibility for reducing stigma and health disparities experienced by GNC people across their lifespans.</p>

A foundational concept is to understand and value the [diversity](#) embedded within the term “gender” and the panoply of ways people may choose to describe and express their gender. With this core understanding of gender in mind, clinicians can focus on optimizing interactions with individual patients. For example, GNC people might use gender-neutral pronouns (e.g., they/them/theirs); clinicians’ nonjudgmental use of this language assists with establishing rapport and cultivating respectful relationships. Discussing with patients their gender histories and evolution can aid clinicians’ understanding of how they can personally express respect for and affirm patients’ gender. Clinicians should elicit their patients’ experiences of trauma and stress and screen for associated conditions including depression, anxiety, substance use, body image, and disordered eating. Conversations with patients should address how the patient’s gender identity influences these conditions and how gender-affirming care may be part of a comprehensive care plan to improve health. Moreover, in discussing these matters, clinicians should see their patients as individuals who have coped with hardship and identify sources of patients’ resilience. These conversations, particularly concerning histories of trauma and patients’ personal relationship with their body, inform how physical exams can be tailored to minimize stress (e.g., use their preferred language for gendered body parts, position patients for procedures in ways least likely to trigger traumatic memories) [33]. For example, during a Pap test, patients may prefer a position without footrests or insert a speculum themselves to retain autonomy. Importantly, clinicians can try more mindfully to notice that they have biases or make judgments that impede the formation of strong patient-clinician relationships. Becoming aware of such biases and developing strategies to mitigate reactions so that they do not adversely influence a patient’s care are critical components of gender-affirming and responsible care.

*Personalized care.* It is incumbent upon health professionals to continue striving to meet the needs of individual patients, even when evidence of the effectiveness of interventions is lacking. A key focus for future research should be the health impact of gender-affirming care for GNC people. Although evidence supports the benefits of gender-affirming transitions for *transgender* adults [26-28], no studies have yet evaluated the impact of—or how to tailor—medical or surgical gender-affirming care among GNC people. However, because many GNC people seeking gender-affirming care present as male or female and anecdotal evidence suggests that gender-affirming models can promote better care for these individuals, it’s reasonable to expect that the health benefits of these models might be similar to those demonstrated for transgender people. In the absence of evidence, the core principles underlying the WPATH Standards of Care should be applied when initiating medical and/or surgical care for GNC people (see table 2).

**Table 2.** Core principles underlying the World Professional Association for Transgender Health (WPATH) *Standards of Care* [24]

<p>"Exhibit respect for patients with nonconforming gender identities (do not pathologize differences in gender identity or expression)" [34].</p> <p>"Provide care (or refer to knowledgeable colleagues) that affirms patients' gender identities and reduces the distress of gender dysphoria, when present" [34].</p> <p>"Become knowledgeable about the health care needs of transsexual, transgender, and gender nonconforming people, including the benefits and risks of treatment options for gender dysphoria" [34].</p> <p>"Match the treatment approach to the specific needs of patients, particularly their goals for gender expression and need for relief from gender dysphoria" [34].</p> <p>"Facilitate access to appropriate care" [34].</p> <p>"Seek patients' informed consent before providing treatment; offer continuity of care" [34].</p> <p>"Be prepared to support and advocate for patients within their families and communities (schools, workplaces, and other settings)" [34].</p>
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Each patient's unique [treatment goals](#) must be ascertained when initiating medical therapy for GNC patients. For example, recall that Morgan, who was birth assigned female and self-identifies as genderqueer might not wish to have a penis or be a man. But such a patient might wish to achieve cessation of menses and consider mastectomy in order to avoid ongoing chest binding, which can be confining and uncomfortable. Eliciting these goals of care from the patient and, in the process, discussing specific body regions that cause distress without focusing on binary gender transitions should determine the specific recommendations that a clinician can make (which, in the case of the above genderqueer patient, could include achieving menstrual control via continuous combined oral contraceptives, depot medroxyprogesterone acetate injection, or placement of a progestin-eluting IUD as well as referral to a surgeon to discuss the option of mastectomy). Participation in shared decision making requires the clinician to review all the available treatment options—including specific risks, benefits, and desired and undesired side effects—and address patient concerns associated with each modality.

*Overcoming systems-level challenges.* GNC people should have access to a gender-affirming medical home where all components of care can be discussed nonjudgmentally in an environment that minimizes stigma and discrimination. Yet delivery of quality care to GNC patients may be challenged by systemic barriers both inside and outside health care facilities. Many state laws do not include gender identity in nondiscrimination policies [35, 36]. Similar to patients who are underinsured or uninsured, GNC patients who lack insurance coverage for gender-affirming care may be prohibited from obtaining

necessary care. Strategies for enhancing the institutional climate have been extensively discussed [1, 28, 29]. Clinicians can take the lead in implementing many of these strategies, including ensuring that all front-desk and clinical staff participate in creating a welcoming and affirming environment, coordinating optimal care through interprofessional teams, referring patients to social and community services as part of personalized care plans, and involving GNC patients in systems-level decisions impacting their care by including them on community advisory boards.

## Conclusion

People with GNC identities and expressions face significant discrimination and victimization that contribute to the development of poorer mental, physical, and behavioral health. Although GNC expression and maltreatment are apparent at a young age, the latter can be mitigated by family, peers, and others with the capacity to protect and promote well-being, including health care professionals. By adopting a patient-centered approach to care, utilizing available resources to affirm patients' genders, advancing research to better address the health and health care of GNC people, advocating for patients within and outside the health care system, increasing access to gender-affirming services, and engaging GNC patients on health care advisory boards, clinicians can continue working to ensure delivery of gender-affirming and responsible care to GNC patients.

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**Kristen L. Eckstrand, MD, PhD**, is a psychiatry resident at the University of Pittsburgh Medical Center and the founding chair of the Association of American Medical Colleges Advisory Committee on Sexual Orientation, Gender Identity, and Sex Development.

**Henry Ng, MD, MPH**, is an associate professor of medicine and pediatrics and the assistant dean for admissions at Case Western Reserve University School of Medicine in Cleveland, Ohio, where he is also clinical director of the PRIDE Clinic at MetroHealth Medical Center.

**Jennifer Potter, MD**, is an associate professor of medicine at Harvard Medical School in Boston, where she is also director of women's health research at the Fenway Institute.

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### **Related in the *AMA Journal of Ethics***

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## POLICY FORUM

### Transgender Reproductive Choice and Fertility Preservation

Khadija Mitu, PhD

#### Abstract

Increasing numbers of young transgender people are now using medical technologies to achieve a physical gender transition. However, the procedures of physical gender transition might cause temporary or permanent sterility. Thus many transgender people are now using fertility preservation technologies. Nonetheless, they can experience dilemmas in making reproductive and family-building decisions and face challenges in gaining access to and utilizing fertility preservation services. Based on qualitative research conducted with transgender men and women who used reproductive technologies for preserving their fertility before or during their physical transition, this paper contributes to the discourse of reproductive choice by the inclusion of transgender people's experience.

#### Introduction

Studies of human reproduction, reproductive health, and reproductive practices have focused on cissexism (a belief that transsexuals' identified genders are inferior to, or less authentic than, those of cissexuals). Transgender reproduction is almost invisible in transgender studies as well as in studies of reproduction, which mainly have focused on whether transgender people should be offered [assisted reproduction](#) services and/or [fertility preservation technologies](#) before starting medical aspects of a transition [1-4]. The National Center for Transgender Equality published a report on unmet needs of transgender peoples' sexual and reproductive health care. The report indicates that transgender people face multiple barriers to access sexual and reproductive health care [5]. According to the report, many transgender people do not seek or receive adequate reproductive health care because of personal discomfort they feel as well as the structural barriers they face [5]. Yet studies of transgender reproduction that explore these issues are rare [6-8]. This paper seeks to begin to fill this gap in the literature on reproductive health. It examines challenges that transgender people face in preserving their fertility and argues that transgender reproductive issues should not be restricted to the discussion of fertility preservation but also should be included as crucial agenda items in [reproductive health reform](#) and in the transgender rights movement.

#### Fertility Preservation Options for Transgender People

Surgical removal of reproductive organs (as a part of transgender physical transition process) inevitably results in infertility [1, 6, 9, 10]. It's important to note that some medically assisted, nonsurgical physical transitioning also has deleterious effects on fertility, and it is uncertain to what extent those effects can be reversed [1, 9, 10]. In research I conducted, almost 40 percent of the transgender respondents who decided to undertake a physical transition used fertility preservation technologies (K.M., unpublished data, 2016).

Fertility preservation options that are already technically feasible or will soon be available to transgender people are: (a) sperm cryopreservation (particularly for transsexual patients identifying as lesbian and having female partners after transition), (b) oocyte cryopreservation, (c) embryo cryopreservation, and (d) ovarian tissue or full ovary cryopreservation (banking), which is still considered experimental [9]. At this time, there are no standard methods available to prepubertal or pubertal adolescents to preserve sperms or eggs.

**Table 1.** Fertility preservation methods for transgender people [11, 12]

Transmen (assigned female at birth)	Transwomen (assigned male at birth)
Postpubertal options	Postpubertal options
Oocyte cryopreservation	Sperm cryopreservation
Embryo cryopreservation (with partner's or donor's gamete)	Embryo cryopreservation (with partner's or donor's gamete)
Prepubertal options	Prepubertal options
Ovary/ovarian tissue cryopreservation (experimental)	Testicular tissue cryopreservation (experimental)

### Challenges in Preserving Fertility

Male-to-female (MTF) and female-to-male (FTM) transitions have very different implications for reproductive potential. Moreover, reproductive decision making plays out differently based on the particular transitioning process the patient chooses.

*FTM transitions.* In seeking to preserve their fertility, transgender people who are birth-assigned female face greater challenges for fertility preservation than those who are birth-assigned male because of the greater difficulty in harvesting and freezing eggs than sperm. Harvesting and freezing eggs requires hormone treatment to stimulate egg growth and ovulation and an invasive procedure to harvest the eggs, which can take one or more menstrual cycles to complete. In addition to these practical hurdles, hormone treatment can incur emotional costs for FTMs: the hormones they must take for egg harvesting are female hormones—which might lead to increased distress for transgender men seeking gender affirmation services. For FTMs, menstrual cycles may be experienced as painful reminders of unwelcome womanhood. This is especially true

for patients who have been on testosterone treatment for several years and who will likely require more menstrual cycles to achieve successful egg harvesting.

For FTM transitions, one's uterus poses an additional complication. For those wanting a so-called "complete" (including surgical procedures to remove female reproductive organs) FTM transition, a full hysterectomy is required. Yet having a baby with one's frozen eggs but no uterus poses challenges. If the FTM has a uterus, using it for pregnancy may be anathema to either the FTM and/or his partner. In a study I conducted, FTM interviewees, who might be physically capable of carrying a pregnancy because they still had a uterus, expressed reluctance to do so presumably because of their association of pregnancy with a female identity (K.M., unpublished data, 2016). FTMs who do not have a uterus or who have one but do not want to use it must find another surrogate. If the FTM's partner is a woman she can serve as a surrogate, although pregnancy or carrying a pregnancy to term is not certain. If the FTM's partner is not a woman or is unable to carry a pregnancy to term, another gestational surrogate must be found.

*MTF transitions.* MTFs experience fewer challenges in preserving fertility. The process of harvesting sperm is quick and easy and does not require as much planning. The act of ejaculating may not pose the same kinds of challenges for gender identity that menstruation does. In a study I conducted (K.M., unpublished data, 2016), none of the informants expressed any discomfort with the process of harvesting their sperm. One can speculate that cultural determinants can play a role, since male ejaculation is generally highly prized culturally and menstruation is generally shunned. Interestingly, MTFs did not demonstrate a strong desire to become pregnant, possibly because conception with a transplanted uterus is an incipient technology and not widely known.

However, hormone treatment for MTF transition is less reversible than hormone treatment for FTM transition. FTMs who take testosterone can remain fertile for many years after beginning [hormone treatment](#), whereas MTFs who take estrogen can face irreversible fertility loss within three months [8].

One challenge that both FTMs and MTFs face is access to information on fertility-preserving technologies. The World Professional Association for Transgender Health included a "reproductive health" section in its most recent version of the *Standard of Care* [10], and the Ethics Committee of the American Society for Reproductive Medicine recently published an opinion paper focusing on transgender reproduction [12]. These documents make clear that clinicians need to provide information to their transgender patients about the effect of the medical gender transition process on fertility preservation options. Certainly, these steps by major health care organizations convey a positive message to the transgender population and indicate the success of the transgender movement in the United States, which has achieved significant visibility in

the public sphere. Yet the challenges for transgender people begin even before they consider specific fertility preservation options.

### **Challenges in Choosing and Accessing Fertility Preservation Technologies**

Transgender people face dilemmas in making reproductive decisions and may face challenges in gaining access to fertility preservation services.

*Reproductive dilemmas.* The phase of life at which people come out as transgender and begin to transition can affect their reproductive choices. When people begin living what they experience as their “true gender” at a later stage of their life, they might have had children already and not plan on further biological reproduction [6]. However, in such cases, transgender people might experience divorce, be compelled to leave their family, or lose custody of their children [6]. Transgender people who begin transitioning early in life, however, can be faced with having to make untimely decisions regarding their fertility. Studies report that increasing numbers of transgender people undergoing procedures that can adversely affect their fecundity are at a life stage when they are not yet ready to think about reproduction or family building [7, 9, 11, 13]. For example, they might not be partnered or might lack financial stability. Some might not be sure if they want children at all. Faced with this dilemma, some young transgender people decide to have children before going through any hormone treatments or surgeries while others go ahead with physical parts of a transition, some of which are fertility impairing.

*Challenges in access.* The cost of fertility preservation services can be prohibitive. Transgender people can find the cost of fertility preservation services to be particularly burdensome because of the additional expenses associated with transitioning. For young transgender people, the cost burden can be compounded by their low income, along with their receiving little or no financial support from friends and family. Costs are especially significant for egg freezing [6], resulting in a potential barrier to transmen. Moreover, under the Patient Protection and Affordable Care Act, the extent of coverage required for expenses related to physical transitioning remains unclear [14].

Another challenge to accessing fertility preservation and assisted reproduction technologies is unique to transgender people: the social (and sometimes institutional and legal) stigma and [discrimination](#) against gender and sexual minorities. For example, if clinicians believe that transpeople are unfit for parenting and should not be allowed to reproduce, this might prevent transpatients’ access to relevant information about fertility preservation.

### **Challenges beyond Fertility Preservation**

Fertility preservation is only a tiny segment of reproductive health. Transgender people have yet to receive adequate health care services for contraception, conception, abortion, and childbirth-related health problems [6]. Transmen in particular can experience

complications that have not been properly addressed in the transhealth literature. For example, post-transition transmen who decide to give birth to a child face various challenges in accessing health care [8]. They also face tremendous social stigma in the transgender community as well as in the broader society. And transgender people face many challenges if they decide to adopt and foster children [8].

Transgender people can also face challenges if they seek to legally change their gender. In the United States, many states require certification of a physical transition in order to legally change one's gender [6]. Even when some transgender people do not want to undergo hormone therapy and/or sex reassignment surgery (SRS), state laws can create pressure to do so. Because of these policies, some transgender people are often left without a choice other than to sacrifice their reproductive abilities, since choosing SRS would strip them of their potential to have biological children.

### **Conclusion**

This paper has argued that transgender people face many challenges related to reproductive decisions and fertility preservation. These challenges exist on every level—in deciding whether to pursue fertility preservation, accessing fertility preservation technologies, and implementing the technologies—and can differ depending on phase of life and birth-assigned gender. The discussion on transgender reproduction and parenting should not be reduced to the discourse of fertility preservation or assisted reproductive technologies (ARTs), however. Rather, social stigma and structural and legal barriers should be eliminated for all procreating and family-making options for the transgender population. Barriers should also be eliminated for multidisciplinary collaborative efforts to address transgender reproductive issues.

Much of the discourse in the transgender movement has centered on the acceptance of the transgender identity and the social and medically assisted parts of the transition process. But with transgender people's long-term life plans in view, which are likely to include parenting, stronger advocacy is required both to educate this population regarding options for reproduction and to change laws, insurance policies, and, above all, social and clinical norms to facilitate transgender people's reproductive choices.

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**Khadija Mitu, PhD**, is an associate professor of anthropology at the University of Chittagong in Bangladesh. She earned her PhD from Rensselaer Polytechnic Institute,

where her research focused on the development and practices of fertility preservation technologies. Her current research interests include reproductive technologies, cryopolitics, transgender health, and gender studies.

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## POLICY FORUM

### Transgender Rights as Human Rights

Tia Powell, MD, Sophia Shapiro, MD, and Ed Stein, JD, PhD

#### Abstract

Arguments to support transgender rights often rely on “born that way” arguments, which assert that gender identity is innate, immutable, and unassociated with choice. These arguments are vulnerable to attack on several grounds, including on the basis of emerging scientific data. Stronger support for transgender rights arises from human rights arguments.

#### Introduction

In March 2016, North Carolina enacted legislation requiring public school students to use the school bathroom consistent with their birth gender [1]. The state law aimed to supersede a Charlotte, North Carolina, ordinance permitting students to use gender-segregated facilities aligned with their expressed gender, irrespective of the gender assigned them at birth [2]. These dueling laws garnered considerable controversy, yet they form only one small chapter in the story of rights for transgender people today.

Proponents of the North Carolina “bathroom bill” claim that such laws prevent violence against women, arguing that “predatory” men, under the auspices of trans-friendly bathroom policies, will enter women’s bathrooms and harm girls and women [3, 4]. However, transpeople and supporters deny there is increased harm to other women from transwomen and note that there is instead a high level of violence against transmen and transwomen [5], even compared to the high level of violence against other members of the lesbian, gay, bisexual, and transgender (LGBT) community [6]. While rates of homicide generally have dropped across the US over the last decade [7], the same is not true of homicide rates for transwomen, and in particular for transwomen of color, who account for a percentage of homicides far out of proportion to their numbers in the transgender population [8].

The need to uphold transgender rights has never been more pressing or more important than today. Although laws regarding choice in bathroom facilities are symbolically important in establishing that transpeople deserve respect, transpeople suffer active [discrimination](#) in arguably more important domains, including employment, housing, and access to general and specialized health care [9]. Compelling arguments and concerted action to support transgender rights are crucial. But which arguments

offer the strongest and most broadly applicable support for transgender people in the current political climate?

### **Arguments for Recognition and Expanded Protection of Transpersons' Rights**

Many in the LGBT community rely on arguments that we refer to collectively as “born that way” arguments, namely, arguments for LGBT rights based on the idea that sexual orientation and gender identity are innate, immutable, or unassociated with choice. Two of the authors (TP and ES) have previously addressed the difficulties of using “born that way” arguments in relation to sexual orientation [10, 11]. We now extend that critique to arguments for transgender rights. We argue that “born that way” arguments rely on both shaky science and imperfect logic, and thus fail to provide a solid basis for transgender rights. We find more solid ground in arguments based on [human rights](#).

### **Interpretations and Critiques of “Born that Way” Arguments**

In *The Mismeasure of Desire*, one of us (ES) has addressed three interpretations of the “born that way” argument, and we briefly summarize those arguments in the context of gender identity.

*Innate.* We find several problems with the claim that gender identity is innate. First, the claim is essentially unprovable. Gender identity, as with any aspect of human identity, develops over time. An infant cannot be said to experience a fully formed identity of any kind—that sort of self-awareness requires advanced cognitive development, including a nuanced concept of gender that develops over years. Similarly, we are skeptical of the claim that gender identity—one’s perceived sense of belonging to a particular gender, independent of gender assigned at birth—is genetically determined. There is limited biological research supporting such a claim and no semblance of a scientific consensus on it. Gender identity and expression are complex, incorporating ideas of the self along with a vast array of behaviors, thoughts, and feelings. Contemporary biological evidence does not support the notion that gender identity results solely from a single gene or even from the presence of a specific number of X and Y chromosomes. Rather, gender identity emerges from multiple interactions among genes, the environment, and other factors, including personal feelings of authentic gender expression [12].

*Immutable.* Another interpretation of “born that way” connotes immutability. This concept is problematic because possibilities for change are not necessarily related to whether a factor is present at birth. Even factors that are primarily determined by genes can change over the life course: hair color and texture are genetically determined, but hair can be present or absent at birth, change color over time, revert from curly to straight or vice versa, and develop different patterns of baldness as a person ages. In contrast, immunity to a disease like measles is not inherited, but vaccination or disease exposure can result in a permanent change in one’s immunological profile. These

arguments undermine the link between a trait's being present at birth and its inalterability.

However, there are additional compelling reasons to avoid relying on immutability as a foundation for transgender rights. Although the scientific study of gender identity has yet to answer many important questions, it does suggest that gender identity is not immutable in everyone. Specifically, gender identity can change in prepubescent children. Indeed, the majority of younger children who experience gender dysphoria do not go on to become transgender adults [12, 13]. Given the evidence of the fluidity of gender identity over time in many children with gender uncertainty, arguments that assume immutability seem particularly unconvincing. True, transgender adults generally do persist in their gender identity [14]. Nonetheless, [gender as a concept](#) is understood as more fluid and less rigid today than in the past. Research indicates that various aspects of sexuality, including both gender identity and sexual orientation, are more fluid than previously understood, especially in youth [15].

Rather than adhering to a rigid male/female binary, many scholars and activists describe gender as existing on a spectrum. Ideas about which attributes are socially appropriate for either male or female gender—or both or neither—have rapidly evolved over the last century. One hundred years ago, in some places, a woman could be arrested for wearing pants in public. Thirty years ago, women encountered more extreme barriers and fewer legal protections than they do today in many occupations, including soldier, pilot, or orthopedic surgeon, to name a few. Even today, men who stay home as full-time parents face questions about their “manliness.” Preserving transgender rights supports the ability of all people to align their gender expressions with a comfortable location for them on the gender spectrum. Insistence on the immutability of gender identity ignores its fluidity during development and the need to adapt to continually evolving standards of gendered behavior.

*Not chosen.* A third interpretation of “born that way” indicates lack of choice, and this aspect of LGBT identity is often referenced both regarding sexual orientation and gender identity. Transgender people do not typically describe their gender identity as a matter of choice. As one blogger wrote, “nobody really wants to be a trans woman, i.e. nobody wakes up and goes whoa, maybe my life would be better if I transitioned, alienating most of my friends and my family, I wonder what’ll happen at work, I’d love to spend all my money on hormones and surgeries” [16]. More typically, transpersons describe a growing realization of their gender identity over time. They might experience distress from social or other pressures to conform to a binary birth-assigned gender that does not match their authentic experience of gender identity. While gender identity is not subject to conscious choice, the overt expression of gender identity includes many choices, including dress, hair, naming, and all the other options that indicate one gender or another—including which public bathroom to use. Those opposed to transgender

rights wish to deny transgender people (and everyone else) these choices. Opponents do not express concern about transpersons' inner sense of identity but about outwardly expressed choices. To defend transgender rights is to defend the right to choose how one expresses gender and gender identity. Choice, far from being unimportant, is a critical aspect of transgender rights. In sum, "born that way" arguments on behalf of transgender rights are easily undermined on the basis of reasoning and scientific evidence.

### **Transgender Rights as Human Rights**

We argue, in contrast, that transgender rights stem from human rights, i.e., those fundamental rights belonging to every person. Persons with either cisgender (in which assigned and experienced gender are the same) or transgender identities deserve to live and flourish in their communities—with freedom to learn, work, love, and play—and build lives connected with others at home, in the work place, and in public settings without fear for their safety and survival. These deeply personal decisions are and should be the prerogative of the individual and deserve the law's protection. The United States protects religious freedom in the First Amendment, and religion is quintessentially a choice. We owe the same respect to all members of our communities. We don't yet know if gender identity emerges from genes, hormones, environmental factors or, most likely, an intricate combination of all these factors and more. It is unlikely that people with a transgender identity simply choose their gender identity, any more than cisgender people do. However, it is crucial that associated choices about the expression of gender—affecting vital aspects of identity in school, the workplace, and the community—are supported by our laws and policies. Supporters of transgender rights should avoid arguments that are logically flawed and that fail to acknowledge current scientific evidence about gender identity. Our best arguments must rely on the concept of inalienable human rights, including the rights to live safely, freely, and without fear of discrimination.

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**Tia Powell, MD**, is a psychiatrist, bioethicist, and professor of clinical epidemiology and clinical psychiatry at Albert Einstein College of Medicine in New York City, where she is

also director of the Montefiore Einstein Center for Bioethics. She is a fellow of the American Psychiatric Society, the New York Academy of Medicine, and the Hastings Center. Her work focuses on ethical aspects of dementia, public health disasters, and sexual orientation and gender identity.

**Sophia Shapiro, MD**, is a resident in emergency medicine at NYC Health + Hospitals/Bellevue. She received her MD from Albert Einstein College of Medicine in 2016. Her research interests are in LGBT health and implicit bias.

**Ed Stein, JD, PhD**, is professor of law at the Benjamin N. Cardozo School of Law at Yeshiva University in New York City, where he is the founding director of the Gertrud Mainzer Program in Family Law, Policy and Bioethics. His publications include *The Mismeasure of Desire: The Science, Theory and Ethics of Sexual Orientation* (Oxford University Press, 1999) and *Without Good Reason: The Rationality Debate in Philosophy and Cognitive Science* (Oxford University Press, 1996). His scholarship focuses on legal and philosophical topics related to families, sexual orientation, gender, reproduction, cognition, and science.

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## MEDICINE AND SOCIETY

### Understanding Transgender and Medically Assisted Gender Transition: Feminism as a Critical Resource

Jamie Lindemann Nelson, PhD

#### Abstract

Feminism has fought the trivialization of women's experiences, championed women's security, and insisted on respect for women's choices. In so doing, feminism has developed important perspectives on the complicated connections between what gender means as it plays itself in people's lives, and the inequalities of power and authority that structure much of human experience. Here, I put a few of these perspectives into contact with an issue where the interactions of gender and power are squarely in play: medicine's role in assisting gender transitioning generally and, specifically, the enduring controversy between medicine and many transgender people about the pathologization of transgender and the role of clinicians as gatekeepers to gender-transition interventions.

#### Introduction

It's an interesting time to be alive if your sense of yourself is out of alignment with parts of your body that traditionally have been taken to determine your gender. "Transgender" has in recent years become a (generally) viable, commodious, diverse social identity, one that has achieved some semblance of legal parity with other fundamental parts of people's identities. We can see people like ourselves in positions of responsibility in government, industry, academia, health care, in the police and military, and the arts. We see more realistic depictions of transgender lives in the media, conveyed without scorn.

Yet if scorn is no longer routine in the media, it is still painfully, and for some of us, fatally present in day-to-day interactions; if laws at the national level and in some states and localities are moving us toward recognition as full and equal citizens, there are many people who still fear and disdain us. We've become targets for politicians seeking to ban access to public accommodations in an effort to curry favor with the fearful by blocking further social uptake of how we make sense of ourselves and of gender [1].

This is not to say that transgender people are the only group who has sought to revise what gender means—or who have experienced backlashes for these efforts. Reimagining what gender is, and what it means in our own and other's lives, has been an

increasingly important feature of social life throughout the last century. Women in particular have challenged limitations on their lives that traditionally had been seen as part and parcel of the ["natural facts" of gender](#). Feminist thinkers and activists have done substantial work in responding to these challenges and in articulating the values and concepts—for example, that the agency of women must be fully respected, that their physical integrity must be honored, that the importance of their needs and desires are not lessened by their biology—that they embody. The upshot for both women and men has been slow but steady movement toward the possibility of living in ways that are more equitable, less hemmed in by rigid gender roles, and more reflective of these values.

### **Medicine and What Gender Means**

Medicine has played both progressive and regressive roles in this general process and has had a distinctive involvement in the lives of transgender people that extends at least back into the early decades of the twentieth century. Medical engagement gained momentum as the century wore on and academic centers and specialty societies dedicated to transgender-specific care began to appear. Authoritative standards of care governing access to endocrinological and surgical responses to ["gender identity disorder"](#) were first promulgated in 1979, and have been in continual evolution since [2]. However, while medicine was trying to help some people liberate themselves from the alienating experiences and expectations attached to their birth-assigned gender, it also tried to isolate the challenge such efforts posed to ordinary understandings of gender. That is, if your gender identity did not match your anatomy, you were understood to have a mental illness resistant to psychiatric intervention, but amenable to physical intervention. Surgery, for example, was often depicted in a *faute de mieux* fashion—as facilitating not a real "change of sex" but merely a harm-reducing simulacrum that preserved a familiar and safe gender binary. That is, society could rest easy with medicine pathologizing gender "deviance" and proposing a clinical strategy for explaining and containing it: nobody's genitals were going under the knife unless they had the right kind of illness, and besides, nothing that happened in an operating room on any single patient could really challenge gender's "fundamental truths"—e.g., that there are two and only two, that everyone has one or the other, and which one you are is determined by some deep and immutable fact.

Very little of this has any direct connection to medical knowledge or practice: a person could be, for instance, a highly skilled surgeon, endocrinologist, or psychiatrist without believing that transpeople suffer from a disease or a disorder, or that gender is fundamentally bivalent and unalterable. The "fundamental truths" are much more matters of ideology than science, and feminists and transgender people themselves have been busy replacing them with conceptions better equipped to consider adequately the complexities of gender.

Medicine no longer needs to make transgender unthreatening by portraying it as a disease whose therapies must preserve the gender binary. Yet giving up a disease model may seem to leave medicine in a quandary. The kinds of [psychiatrically mediated gatekeeping](#) to medical help required by various iterations of the World Professional Association for Transgender Health standards of care—for example, a mental health assessment and a referral from a mental health practitioner for gender-affirming interventions—make most sense if transgender is a sort of illness. If transgender is not an illness, it might be wondered, what business has medicine with it at all? Perhaps surgical and hormonal interventions should be seen as merely a sort of extreme cosmetic intervention—involving the destruction of healthy organs and the removal of reproductive abilities—legitimated solely by consumers' (informed) choice. Yet seeing transgender interventions in this way seems hardly more likely to reflect most transgender people's experience of themselves than would the mental illness story. Achieving a recognizable gender identity that reflects one's sense of self is not merely one choice among others aiming at more social or professional success. A habitable gender identity is not important because it is chosen; it is chosen because it is important. Understanding transgender interventions as elective cosmetic surgery could also threaten the insurance coverage that does exist for transgender-directed medical interventions and make any expansion of that coverage less likely, as it would not be seen as medically necessary.

Yet if neither "medically indicated" pathology nor elective cosmetic surgery are good ways of understanding what is going on in medically assisted gender transitioning, how can it be best understood? Here, some prominent strands in feminist thinking about gender can be helpful.

The relationship between transgender and important currents of thought within feminism is complex; over the years, feminists and feminisms have served as allies as well as critics of transgender people. Feminists agree, however, on the enormous social importance of how people are gendered and, in particular, about how damaging practices associated with gender typically are for women and girls. Disagreements among feminists concerning transgender often pivot on whether transgender and, particularly, medically assisted forms of gender crossing, reinforce or erode damaging features of gender [3].

In my view, transgender can do either, and it has done both; it has both challenged and reinforced norms and practices associated with gender that have hampered people's lives. Part of the way forward is to tap the potential of *transgender* to make of *gender* a more humane set of social relations, as well as subjective experiences. A big question for medicine is how to understand and respond to transgender in ways that will promote these conceptual, social, and cultural goals.

## Gender, Authority, and Analogies

*Gender differences are not simply natural "givens."* There is a lingering temptation to think that gender differences are straightforwardly natural facts and that social organizations have to accommodate those facts in one way or another. Some have even thought that transgender must abet this temptation: something presocial *must* be happening to explain why transpeople so strongly resist assimilation to the gender socialization to which most so readily succumb.

Yet, as many feminists and other theorists have argued, this temptation too readily accepts the idea that "natural facts" can be clearly and distinctly separated from the social contexts in which they occur [4]. What those facts mean to us, how they are taken up into our lives, reflect and reinforce the ways in which respect, authority, and access to goods are distributed in human societies; they cannot by themselves justify those distributions.

What might accepting a broadly feminist—which is at least to say a highly social and critically inclined—account of the nature of gender mean for clinicians involved with transgender patients? Feminism would provide reason to resist the notion that there is something artificial, not natural, and therefore second-best in the ways transgender people live out their gender identities. This realization might help clinicians recall that how we [express our genders](#) is important to many of us, not just to transgender people. Most people engage in practices—how they walk, talk, or wear clothing, for example—designed to make their gender identities plain to others; virtually all of us are addressed by gender-distinctive standards of behavior and of aspiration, not all of which seem unwelcome. In this sense, gender's subjective and social dimensions are not so different for trans- and nontranspeople. What the existence of transpeople can do is to testify that gender-related expectations can be assessed, resisted, and reworked, as well as affirmed.

Transpeople, then, face a certain set of problems as they live out their lives in ways that simultaneously challenge and converge with what tends to be important for most people. Medicine has resources to help some of them better resolve those problems and achieve goals—personal peace, social acceptance—that are in many respects quite commonplace. Understanding transgender also might relieve some of the social anxieties that may have prompted clinicians to continue to insist on psychiatric endorsement of transpeople's self-understanding [5]. Furthermore, it might well improve the experience of transgender people in all their dealings with [health care](#)—dealings that go far beyond what occurs in a gender identity clinic. Perhaps most importantly of all, it might speed the spread through social life of supportive and welcoming attitudes to transgender people. There is reason to believe that such attitudes can go a long way toward causing the rate of trans suicide, particularly among trans youth, to plummet [6].

*The authority of women over their bodies and their lives must be honored.* This is a key tenet of feminism, but why should we think it has special relevance for transgender people? There are, after all, transmen as well as transwomen, and transpeople who seek to live insofar as possible beyond the gender binary, resisting identification as either women or men. But in general, medicine's engagement with gender crossing involves people who have either been socially configured as women, or who understand themselves to be women, despite their anatomy. Like everyone else, these people have a presumptive authority over the fundamental terms of how they are understood by others. Yet, as is the case with many forms of authority, women face particular resistance to its recognition. This resistance can hamper gender identity expression for transmen and transwomen both. If medicine is to align itself with defensible values as it aids gender crossing, it needs to do so in a way that fully endorses both the worthiness of women's choices and the choiceworthiness of women's lives. Psychiatric assessment as a required hurdle to gender-affirming hormone therapy or surgery tends to undermine that endorsement. Counseling—including peer counseling—should be readily available and can be an important part of achieving fully informed consent, but [psychotherapy should not be mandatory](#) for access to hormone treatment or surgical procedures.

Being a woman, or a man, or a nonbinary person are worthy ways of living, not pathological impulses; those who seek medical assistance to help them live so are not on that basis alone ill or confused, and there is every reason to avoid giving the impression that they are. It then might seem that the feminist perspectives discussed here support an elective cosmetic surgery model.

But feminism, in its insistence that women's experiences need to be acknowledged as central features of human experience, might remind us that we are not limited to merely two options in thinking about the relationship between medicine and transgender.

*Birth giving as a model.* Motherhood is a social role that many people deeply want to occupy. Moreover, many of them want to achieve that role in a way that crucially involves their bodies. Medical assistance in the project is often welcome and sometimes needed to avert poor, or even tragic, outcomes. Yet it is not strictly necessary for becoming a mother. There are analogies here with transgender: while many transgender people see medical interventions as essential for social acceptance and personal integrity, others do not. Many different transition strategies are used by transpeople. Consider further how giving birth to a child can transform one's life. The process is arduous and not without dangers; the outcomes may well bring as much heartbreak as joy. Yet women aren't required to undergo any form of screening or therapy as a condition of getting medical help with pregnancy and delivery.

Pregnancy is not a disease. Nor is the decision to begin or add to a family likely to be of only instrumental significance; often, it emerges from a person's sense of what matters

deeply to her. Here too, analogies with gender crossing seem clear. As medical assistance with pregnancy and with birth giving are altogether appropriate, and insurable, it would seem that policies withholding insurance coverage for medical assistance with transgender would need to be able to cite significant disanalogies between the two to escape the charge that refusal of coverage is arbitrary.

There have always been ideologies of gender expressed in medicine's dealings with transgender people—messages sent and received in ways that do not require them to be explicitly endorsed by any particular caregiver. It seems to me, however, that now medicine should openly ally itself with ways of making sense of gender that affirm the value of transgender people's experiences and choices, in preference to conveying a hodgepodge of confused attitudes that may disrespect transgender people and slow the bend of history's arc toward justice [7].

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**Jamie Lindemann Nelson, PhD**, is a professor of philosophy at Michigan State University in East Lansing, Michigan. She is also a fellow of the Hastings Center and co-editor of *IJFAB: International Journal of Feminist Approaches to Bioethics*. Her work on philosophical and bioethical issues sparked by gender and transgender has appeared in the *Hastings Center Report*, *Journal of Bioethical Inquiry*, and *GLQ: A Journal of Lesbian and Gay Studies* among other places.

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## MEDICAL NARRATIVE

### Lessons from a Transgender Patient for Health Care Professionals

Ryan K. Sallans, MA

#### Abstract

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 within health care settings. Professionals who show sensitivity to the topic and express care about health record documentation can increase a transgender patient's trust. There are many opportunities to increase transgender health literacy, including consultation, conferences, webinars, books, and articles focused on transgender health care. It's critical for professionals to listen closely to individual patients' stated needs. This article shares one transgender patient's encounters and experiences within health care settings and offers lessons on how health care professionals can be more inclusive, respectful, and responsive to the needs of transgender patients.

#### Major Life Transitions

In the spring of 2005, I prepared for two major life transitions. The first was finishing graduate school and leaving academia to enter the workforce. The second was coming out as a transgender man—a person assigned female at birth but who identifies as male. My professional and personal lives quickly collided when I embarked on the critical medically assisted parts of my transition and found that many health care professionals were not trained to care for transgender patients. To compensate for clinicians' gaps in knowledge, I began to specialize in transgender health education.

#### Lessons Learned

After doing this work for over a decade, I share several important lessons about what I've learned as a patient and educator, with the goal of trying to cultivate health professionals' and students' understanding of how to be a helpful and responsive clinician for transgender patients.

*Lesson 1: Understanding transgender health means understanding risks faced by transgender people.* Coming out as transgender to health care professionals carries substantial risk for emotional and physical harms. A 2011 survey of

nearly 6,500 transgender respondents found that 19 percent of transgender patients were denied access or treatment due to their identity in a clinician's office, 28 percent were harassed or disrespected, 2 percent were physically assaulted in hospital settings, and 50 percent reported having to teach their clinicians about the care they needed [1]. The risk for suicide and substance abuse is also disproportionately high among transgender people [2], with 41 percent reporting having attempted suicide at least once in their lifetime [1]. Although these numbers are unrelated to coming out as transgender to clinicians, they could possibly be reduced by training health professions students and professionals about the health needs of transgender people and how their vulnerabilities can be exacerbated (including in health care settings) by social determinants, such as pervasive social and cultural discrimination.

*Lesson 2: A health care professional's humility can be a source of relief to an anxious patient.* The first health care professional I came out to was my therapist of six years. I began treatment with her because of an [eating disorder](#), and over the years I had grown up and changed before her eyes. However, coming out to her as transgender made me anxious. I predicted she would invalidate my identity and link it to my eating disorder. I feared she would stop seeing me as a patient and refuse to write the letter I needed to begin hormone therapy and undergo chest surgery (removal of breasts). Although clinicians can conduct mental health assessments of patients before medically assisted transition therapies, many request a mental health assessment and referral letter from a mental health practitioner before moving forward with treatment in accordance with current practice guidelines [3]. Many people in the transgender community feel that this requirement puts mental health practitioners in the position of [gatekeepers](#) [4] to their physical transition, causing further distress.

When I came out, though, her response was one that any health care professional can learn from and use: "I have never worked with someone who is transgender, but I am willing to learn." I felt relief upon hearing her nonjudgmental tone and sensing her humility and openness. I knew then that she would not reject me or my identity. I could rely on her to listen, learn, and be a source of support.

*Lesson 3: Transgender patients are not all alike and need different things from health care.* Each transgender patient has a different story and different needs—including general health care that are unrelated to their transition status. In regards to 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 transitions [5]. [Transgender](#)

[identities](#) and needs exist on a spectrum, and attempting to classify, generalize, or routinize them is not always helpful.

After I overcame my fear of coming out to my therapist, I was ready to find health care professionals to help me pursue the medically assisted parts of my transition. This meant finding a surgeon who could complete chest surgery and a clinician who could prescribe and monitor hormone therapy. (For transgender men, the hormone prescribed is testosterone, regardless of their anatomy. For transgender women, the hormone prescribed is estrogen, and if testes are retained, anti-androgens.) Each person's transition journey and timeline will be different. I chose to have chest surgery first because I did not want my body to begin to masculinize on hormone therapy and still have breasts. I also had the financial resources through a loan to move forward with surgery, but for many patients, even those with health insurance, lack of sufficient insurance coverage, lack of specific coverage for gender-affirming care, or the high cost of such care can prevent them from accessing the care and therapies they need [6].

*Lesson 4: There is not a single right way to transition and not a single way to order events that need to happen for patients making transitions.* I found a chest surgeon through an online support group for transgender men. During my consultation, the surgeon sat down in front of me and asked, "Are you currently living as a man?" I responded, "No." He then said, "Are you currently on hormones?" I also responded, "No," while handing him the letter from my therapist. He glanced over it and said, "Okay, I just want you to know that once I remove your breasts, I cannot put them back on." In this situation, I did not present to the surgeon with the narrative he was expecting. My story differed from those he had heard from other trans male patients because I was not living as a man [7]. I was not on testosterone. I was pre-transition. For me, the chest surgery (an early step in my transition) and where I went from that point had yet to be determined. Each patient will have different reactions to the approach and language used by their clinicians. While some patients might have been offended by my surgeon's comment about taking my breasts off, I felt relief because I knew he was confirming me as a patient, even if I didn't strictly follow the clinical perception of a transition timeline at that time, namely, that patients must be living as the gender to which they would like to transition or that patients are pursuing hormonal therapy to promote their transition.

*Lesson 5: Patients should not be required to conform to health care professionals' conceptions of what men and women are, have, or don't have.* A week after my chest surgery, I was sitting in front of a family practitioner. My chest was bound in ace wrap bandages with drains pinned to my button-up shirt. I was seeing her for an initial consultation before beginning another important part of my transition for

which I needed medical assistance, hormone therapy. During our conversation she asked if I was going to have a phalloplasty, a surgery that uses skin grafts to create a full-size penis. I told her that I was not, since I didn't feel it was a necessary part of my transition or self-definition.

Two weeks later, I received a call from her office saying she was canceling my appointment to begin hormone therapy and that I needed to see her for a second consultation. As I sat in her office again, she told me she felt I had doubts about my transition. In her exact words: "I've never met a trans man who didn't want a penis." I spent an hour convincing her that she was committing what's referred to in the psychology literature as "the phallus fallacy" [8]—one product of gender binary thinking—that is, acceptance of the oversimplification that everyone is either and only male or female, which prompts some to believe that men are men because they have penises. That is, I had to convince her that, despite her belief in the clinical significance of my lack of penis envy, I was ready to move forward with hormone therapy without a penis. Finally, a week later, I received my first testosterone injection, but I no longer trusted her to meet my health care needs. Subsequently, I sought care elsewhere, somewhere I didn't have to work so hard to get what I needed.

*Lesson 6: When personal pronoun usage mistakes happen (and they will), apologize sincerely, and move on.* When working with transgender patients, it is only a matter of time before a wrong name or pronoun slips out. Mistakes happen; we are human. What divides a forgivable error from offensive disregard is how the mistake is handled. A colleague of mine offered an example of how to handle "misgendering," or what could be perceived as misgendering. During a busy day at his clinic, he was seeing a transgender woman who had recently undergone a vaginoplasty procedure (the creation of a vaginal canal using inverted penile tissue or a colon graft). She had scheduled the appointment to have him examine her stitches and check for signs of infection. Running late, he popped his head into the exam room where she was waiting with a friend, and said, "Hey guys, I apologize for running behind. I'll be in shortly." As he closed the door, a moment of panic rushed over him; he realized he had just used the term "guys" with two transgender women. Instead of ignoring it or silently hoping they wouldn't be offended he opened the door again and said, "Sorry ... ladies, I'll be in shortly." Both of the women laughed and showed their appreciation that he had noticed and revised his message.

*Lesson 7: Challenge uses of demeaning references ("he/she," "it," or other slang) to transgender patients.* Over the years, I've found there are many people in health care who do not understand or support transgender identities. For these reasons, transgender people are often gossiped about in health care settings.

This gossip can include asking inappropriate questions about a transgender patient's identity, joking or commenting about a patient's body or appearance, and using [slang](#) or the wrong pronoun or name when referring to a patient.

It is critical that health care professionals demonstrate leadership on this issue by expressing respect for transgender patients' vulnerabilities and standing up for patients when this kind of unprofessional and aggressive behavior is taking place in care settings [9]. By informing perpetrators of inappropriate and offensive speech, and by making clear that their actions are insensitive and sources of potential harm to patients, health care professionals can help establish safer and more nurturing environments for all patients [10], including transgender patients.

*Lesson 8: Being transgender might not be relevant to a particular clinical encounter, but references to a patient's gender identity in a health record can be relevant to all subsequent clinical encounters that patient has.* Ten years after I started my transition I scheduled an appointment with a spinal specialist. I did not mark that I was transgender on the patient intake form, but I did indicate that I had undergone a mastectomy and hysterectomy. As the physician assistant went through my intake form, he confusedly asked, "Oh, you've had a mastectomy and hysterectomy?" I responded by saying, "Yes, I am trans." He replied, "Oh ... well ... bless your heart."

I felt uncomfortable and unsure how to interpret this "blessing." We continued the exam, and nothing else about my being transgender was mentioned. After receiving the medical report that I had requested, however, my discomfort with this office turned into rage. Throughout the report I was referred to not as "Ryan," "he," or "male," but instead as a "pleasant 35-year-old transgender individual." To make matters worse, there were multiple places in the report where I was referred to as "she." I don't know whether this episode of misgendering documentation was intentional, but it certainly had, and can still have, consequences for me.

*Lesson 9: Take care not to "out" patients who aren't "out" to everyone: ask patients about which information to document in their health records and preserve confidentiality.* The health record documentation episode was and is important, not only because it was and is an instance of misgendering, but because the content of this encounter in my health record was then sent to my referring health care professionals and thus can be accessed by other health care professionals. That part of my health record effectively "outs" me as transgender, including to health care professionals with whom I might not have chosen to share that information about myself.

It is not uncommon for transgender patients to avoid sharing information about their identity and medical history with health care professionals because of past [negative experiences within health care settings](#). Professionals who show sensitivity to transgender patients' risks and needs and demonstrate awareness about what is appropriate to document in a health record can increase a patient's trust. When patients trust you as a health care professional enough to 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.

*Lesson 10: Transgender health literacy requires ongoing education and training.* Like any area of medicine, in transgender health, standards of care [3] and [best practice guidelines](#) are continually being updated. As a professional who works with transgender patients, I find it is important to stay up-to-date on current research and literature pertaining to transgender identities. With new research, policies, and guidelines, past recommendations can get outdated and become unnecessary. For example, when I began training in transgender health care, it was recommended that transgender men undergo a hysterectomy within two to five years after beginning hormone therapy to avoid increased cancer risk [11]. More recent research, however, reveals that hormone therapy does not increase cancer risk or mortality [12], so it's no longer recommended that patients on hormone therapy undergo a hysterectomy unless medically necessary [3].

There are many opportunities to increase transgender health literacy among clinicians, including consultation [13], conferences [14], webinars [15], books, and articles focused on transgender health care. It's also critical for health care professionals to listen closely to individual patients' stated needs and to further support growth of knowledge about and experience in working with 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 addressing their personal limitations through respectful conversations create safer environments that will hopefully deepen patients' trust and lead to better care.

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**Ryan K. Sallans, MA**, is the lead subject matter expert consultant for Affiliate Risk Management Services, Inc., in New York, where he develops e-learning courses for health care professionals seeking CME in LGBTQ health care. He is also a public speaker, diversity trainer, publisher, and author of the book, *Second Son: Transitioning Toward My Destiny, Love and Life* (Scout Publishing, 2012).

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## SECOND THOUGHTS

### Informed Consent in the Medical Care of Transgender and Gender-Nonconforming Patients

Timothy Cavanaugh, MD, Ruben Hopwood, MDiv, PhD, and Cei Lambert, MFA

#### Abstract

Informed consent as a model of care has evolved as an alternative to the standard model of care recommended by the World Professional Association for Transgender Health's *Standards of Care*, version 7, which emphasizes the importance of mental health professionals' role in diagnosing gender dysphoria and in assessing the appropriateness and readiness for gender-affirming medical treatments. By contrast, the informed consent model for gender-affirming treatment seeks to acknowledge and better support the patient's right to, and capability for, personal autonomy in choosing care options without the required involvement of a mental health professional. Clinicians' use of the informed consent model would enable them both to attain a richer understanding of transgender and gender-nonconforming patients and to deliver better patient care in general.

#### Introduction

Informed consent is a concept that is familiar to clinicians. On a practical, day-to-day basis, [informed consent](#) is often implied rather than explicitly ensured, and whether explicit or implied, informed consent is the ethical and legal basis for most patient care decisions. It requires that clinicians or someone administering treatment, such as a pharmacist, effectively communicate anticipated benefits and potential risks of a treatment, as well as the reasonable alternatives to that treatment. It relies on the patient's capacity for understanding and weighing these options. Integral to the practice of informed consent is the principle of respect for patient autonomy—that is, respect for a person's right of self-determination—and the belief that clinicians will work to facilitate patients' decisions about the course of their own lives and care.

In the field of transgender health, the "informed consent model" of care has evolved as an alternative to the "standard model of care" as recommended in the *Standards of Care*, version 7, established by the World Professional Association for Transgender Health (WPATH) [1]. This article presents a brief overview and comparison of these two approaches and advocates for an informed consent approach to care as more patient-centered and respectful of the patient's sense of agency.

### **WPATH *Standards of Care***

WPATH is an international multidisciplinary organization that seeks to further the understanding of transgender health and to promote quality, evidence-based care for transgender and gender-nonconforming persons. Since the 1970s, WPATH has advocated on behalf of transgender persons and worked to ensure the competency of mental health and medical professionals. Toward these ends, it developed the *Standards of Care (SOC)*, first published in 1979. The original *Standards of Care* admonished psychiatrists and psychologists to determine the persistence of the patient's dysphoria "independent of the patient's verbal claim" and referred to a patient's verbal reports as "possibly unreliable or invalid sources of information" [2]. While the *SOC* allows for some flexibility in interpretation and application of these standards, until recently, the *SOC* prescribed a standard period of three to six months of psychotherapy and/or a period of "real-life experience," i.e., living full-time in one's identified gender, prior to any medical intervention. (Real-life experience, for reasons most obvious to the patient, can be impractical, undesirable and even dangerous. Additionally, the term "real-life" can be insulting to the patient's sense of self and lived experience.) Psychotherapy was deemed necessary to manage what's now called "gender dysphoria," or the "discomfort or distress that is caused by a discrepancy between a person's gender identity and that person's sex assigned at birth (and the associated gender role and/or primary and secondary sex characteristics)" [3], as well as to explore gender-related concerns. Based on the *SOC*, patients were required to obtain referral letters from mental health professionals documenting their eligibility and readiness for medical treatment; one letter was required prior to initiating hormone therapy and chest surgery and two letters were required prior to any genital surgery [4]. In a sense, transgender persons were required to prove the authenticity of their gender identity to clinicians before gaining access to gender-affirming care.

The seventh and most recent version of the *Standards of Care*, published in 2012, represents a significant change in approach and recognizes the informed consent model, but still retains a strong emphasis on the need for [mental health evaluation](#) before accessing gender-affirming treatments. Psychotherapy is "highly recommended" though not required [5]; it is used to explore the personal meaning and psychic impact of gender dysphoria. However, referral letters are still needed for interventions; the section titled "Criteria for Hormone Therapy" states that "a referral is required from the mental health professional who performed the assessment" [6]. The purpose of the mental health assessment is to assess "gender identity and gender dysphoria, ... the impact of stigma attached to gender nonconformity on mental health, and the availability of support" [7]. While the *SOC* acknowledge that the clinician prescribing hormones can assess mental health issues if "also qualified in this area" and experienced in transgender health [6], the presumption is that this is best accomplished by a mental health professional. Surgical interventions still require one or two referral letters from mental health professionals,

and a 12-month period of “living in a gender role that is congruent with ... [the person’s] gender identity” is still a criterion for genital surgeries [8]. Because the *SOC* place what some regard as an undue burden on persons seeking gender-affirming hormone or surgical treatment, the guidelines have sometimes been viewed as paternalistic and as supporting a form of [gatekeeping](#) that actually limits access to gender-affirming care [9, 10].

These standards are based in the concept of nonmaleficence—first, do no harm—and are meant to ensure that gender-affirming medical treatments are not undertaken recklessly. But the *SOC* bespeak a professional discomfort with, and a degree of uncertainty concerning, treatment for gender dysphoria, as well as a cultural unease with issues of [gender identity diversity](#). We are only just beginning to see transgender health addressed in medical schools and mainstream medical circles, and few clinicians have experience with evaluating and treating transgender patients [11, 12]. Within the context of a pervasive and continued cultural discomfort with gender variant identities, it is perhaps understandable that clinicians might focus on and even overestimate the potential for harm of gender-affirming treatments and the possibility that some patients might experience future regret. Historically, scientific data on which to base treatment guidelines and discussions of risks and benefits has been sparse, but the accumulated experience of clinicians treating transgender patients and the results of the growing number of studies that have become available suggest that hormone therapy and surgery are relatively safe and have the potential to improve the psychological state and psychosocial functioning of transgender patients [13-15].

### **Informed Consent Model of Gender-Affirming Care**

The informed consent model for gender-affirming treatment, proposed in a number of transgender health guidelines and by practicing clinicians [16-19] seeks to better acknowledge and support patients’ right of, and their capability for, personal autonomy in choosing care options without the requirement of external evaluations or therapy by mental health professionals. Through a discussion of risks and benefits of possible treatment options with the patient—a discussion that considers the current state of scientific knowledge as well as the cultural and social context of treatment decisions and that respects the patient’s capacity for self-knowledge—clinicians work to assist patients in making decisions. This approach recognizes that patients are the only ones who are best positioned, in the context of their lived experience, to assess and judge beneficence (i.e., the potential improvement in their welfare that might be achieved), and it also affords prescribing clinicians a better and fuller sense of how a particular patient balances principles of nonmaleficence and beneficence. Ultimately, clinicians’ use of the informed consent model can lead to the possibility of a richer understanding of the patient and the potential for better patient care overall. However, the model does not remove the expectation that the clinician will inquire about and understand the possible impact of gender dysphoria on the patient’s emotional state and psychosocial

functioning; in fact, it assumes that this will factor into the discussion of risks and benefits but allows the patients themselves to weigh these potential impacts. On the other hand, the *SOC*'s continued reliance on mental health professionals to determine eligibility and readiness for treatment perpetuates a message that neither the patient nor the prescribing clinician is capable of a nuanced discussion of gender variance and its management.

It should be emphasized that informed consent is not "hormones on demand," which would give no scope to the prescribing clinician's expertise and judgment. Rather, it facilitates the patient's and clinician's collaborative determination of the best available treatment. Clinicians do, and should, have these kinds of conversations with their patients all the time, and do not generally require the input of a mental health practitioner to help them in this decision-making process. Nor does the informed consent model preclude mental health intervention and treatment when it is deemed beneficial to the patient or in the relatively uncommon situation when a patient's psychological status is such that capacity for informed consent might be impaired. Indeed, patients can benefit from mental health support as they navigate the physical, mental, and psychosocial changes of gender affirmation processes. But the informed consent model separates supportive mental health treatment from gender-evaluating assessments.

Distrust of mental health professionals within transgender communities has arisen in response to the requirement for a referral from a mental health professional prior to accessing medical care. This requirement can easily be experienced as a hoop that patients need to jump through. As such, it might compel patients to tell a mental health professional only what they feel the clinician needs to hear in order to "get the letter." Some patients might feel tempted to tell a stereotypical narrative of gender identity development and dysphoria in which their authentic gender is described in binary terms, as either male or female, even if this narrative would not truly represent their authentic gender identity development, dysphoria, or understanding of their gender affirmation needs. When the mental health professional is no longer placed in the position of being a gatekeeper to medical treatment, the therapeutic relationship can evolve in a more trusting and open manner, be focused on emergent needs and not treatment eligibility, and have a clearer benefit as perceived by the patient.

As a result of the historic practice of close scrutiny of transgender patients seeking medical care and the discomfort of clinicians and society with gender identity diversity, patients might nonetheless still present a stereotypical narrative in a discussion of informed consent with a prescribing clinician and seek to say the "right words" necessary to ensure a prescription for hormones or another desired intervention. The informed consent model renders this subterfuge unnecessary. That is, when an informed consent process expresses respect for the patient's capacity for self-knowledge, without

requiring outside proof of this capacity or making implied demands for a stereotypical gender identity development narrative, a more accurate understanding of patients' individual gender identities along a gender spectrum—and an appreciation of their particular journey to self-realization—can result. We argue that a fuller, more trusting and respectful discussion with the clinician would enable a more complete assessment of a patient's goals for treatment and realization of the *Standards of Care's* goal of individualized treatment.

There remains active controversy within transgender and gender-nonconforming communities over the medicalization of gender identity [20]. A more responsive informed consent model of care gives patients permission to accept or decline possibly stigmatizing diagnoses as well as potential treatments that are available to them, while ensuring gender-affirming care is accessible in an environment that expresses respect for patient autonomy.

### **Examination of Challenges to the Informed Consent Model of Gender-Affirming Care**

Challenges to the informed consent model of gender-affirming care do exist. As mentioned earlier, prior to undergoing irreversible changes of genital surgery, the *Standards of Care* require referral letters from two mental health professionals as well as 12 months of experience living in the gender role congruent with the gender identity the patient is affirming [1]. There is no scientific evidence of the benefit of these requirements; they are based on expert consensus [1, 21, 22]. It is possible—as has occurred with gender-affirming hormone therapy, for example—that this consensus opinion will be challenged or changed in future revisions of the *SOC* as increasing numbers of professionals gain experience with, and more patients seek and undergo, genital surgery. There is a need for further research that evaluates the long-term outcomes of specific gender-affirming surgical treatments and the impact of these treatments on patient satisfaction and changes in mental health and psychosocial functioning before these requirements are reconsidered.

While most treatment in the past has been focused on adults, there has also been an increase in awareness and treatment of children and [youth with gender dysphoria](#). Mental health support is critical to the care of gender-nonconforming youth, and many of these children might have engaged in mental health care even before seeking gender-affirming treatment [23]. Mental health professionals' growing experience with and understanding of gender identity has allowed them to better facilitate the exploration of adolescent patients' gender concerns and management of the psychological consequences of gender dysphoria, although here again there is a risk that the mental health practitioner will be viewed as a gatekeeper. Certainly developmental considerations necessitate more involvement of mental health professionals in care determination for adolescents, but these considerations do not eliminate the possibility of an informed consent model of care appropriate to the patients' age and

understanding. The medical management of gender dysphoria has become increasingly accepted as safe and beneficial to adolescents who present with persistent gender identities that are not congruent with their birth-assigned sex [24, 25]. Medically, an informed consent model allows for the tailoring and timing of puberty blockers and hormone therapy that accounts for the adolescent's physical, cognitive, and psychosocial development. It should be noted that adolescents cannot legally consent to treatment but should be able to *assent* to treatment with a developmentally appropriate understanding of consequences. Informed consent for treatment of adolescents thus can pose significant ethical and legal challenges when one or both parents are unwilling to consent to treatment.

More health insurance carriers are providing coverage of transgender-related health care services [26], and hormone therapy and gender-affirming surgical procedures may be increasingly available to those who want and need these interventions. These are positive and encouraging developments in transgender care availability and access. However, each insurance company determines its own criteria for which services will be provided and for approving coverage of these services. There are no federal guidelines for which services are required or for what constitutes proof of medical necessity for services at this time. In the experience of the authors in a large urban medical facility, the services covered and criteria for accessing them are currently not uniform; they may be based on the current WPATH *Standards of Care*, or insurance carriers may impose more stringent criteria or use a standard of care that predates the seventh version of the *SOC*. Unsurprisingly, criteria for accessing care can vary significantly across carriers. Some may mandate mental health assessment and treatment for several months in order to receive even hormone therapy if it is covered. In our experience, often requirements are misinterpreted by both patients and the insurer's staff. What's important for clinicians and patients is to recognize that, at times, these insurance requirements can undermine the use of the informed consent model of care.

### **Conclusion**

Many transgender patients lack access to clinicians experienced in transgender care and will, out of necessity, seek care from local clinicians. Clinicians who are inexperienced and unfamiliar with the treatment of transgender persons may not feel competent to assess for gender dysphoria and may rely on a more standard approach to care and the input of mental health professionals. But even here, the informed consent model allows the clinician and patient to create a plan of care that is affirming and respectful of the patient and compels clinicians to enhance their own understanding and proficiency.

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**Timothy Cavanaugh, MD**, is a family practitioner and the medical director for the Transgender Health Program at Fenway Health in Boston.

**Ruben Hopwood, MDiv, PhD**, is the coordinator for the Transgender Health Program at Fenway Health in Boston.

**Cei Lambert, MFA**, is the transgender patient advocate at Fenway Health in Boston.

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## CORRESPONDENCE

### Response to “Ethical and Clinical Dilemmas in Using Psychotropic Medications During Pregnancy”

Jennifer Piel, JD, MD, Suzanne B. Murray, MD, and Carmen Antonela Croicu, MD

*This correspondence responds to Andrea L. Kalfoglou’s [“Ethical and Clinical Dilemmas in Using Psychotropic Medications During Pregnancy,”](#) which appeared in the June 2016 issue, 18(6), of the AMA Journal of Ethics.*

Andrea L. Kalfoglou recently wrote in the *AMA Journal of Ethics* about the use of psychotropic medication during pregnancy. We applaud her description of some of the clinical and ethical challenges in treating pregnant women with mental illness. Her article focuses in particular on the challenges of treating depression during pregnancy. In addition to depression, however, women present for psychiatric care for a variety of mental health conditions during pregnancy. One particularly challenging scenario is the management of pregnant women with acute psychosis.

There is limited research on the effects of psychotic illness itself on pregnancy outcomes and risks to the child. Clinical experience dictates concern for serious adverse outcomes associated with not treating or discontinuing antipsychotic medication in pregnant women with severe psychotic illness. Untreated psychosis is associated with decreased compliance with health care, poor self-care, increased risk of suicide, and higher rates of drug use [1]. Additional risks of untreated maternal psychosis to the child include premature birth, low birth weight, and fetal demise [1].

The literature on fetal exposure to antipsychotic medication is similarly limited. Most studies have found no significant increase in major congenital malformations with antipsychotic medications [2, 3]. However, the US Food and Drug Administration issued a warning regarding the potential risk of abnormal muscle tone and withdrawal symptoms to newborns with exposure to antipsychotics during the third trimester [4]. The long-term risks of fetal exposure to antipsychotics remain largely unknown.

In our experience, it is not uncommon for a pregnant woman with psychosis to refuse antipsychotic medication—either due to lack of capacity for medical decision making as a result of her mental illness or in consideration of the potential risks of the medication. In some cases, involuntary civil commitment is appropriate. Although jurisdictions vary in their involuntary civil commitment criteria, most jurisdictions require that the woman, because of her mental illness, be an acute risk of harming herself or others or unable to

care for herself [5]. Jurisdictions also vary as to the legal criteria for involuntary administration of antipsychotic medication to patients who refuse or lack capacity to consent [5].

With the limited information available on the potential risks of psychotropic medication during pregnancy, clinical management requires an individualized approach, taking into consideration the scientific, legal, and ethical parameters associated with this complex scenario. Ethical dilemmas arise when two obligations conflict. From an ethical perspective, here are some of the relevant considerations.

*Autonomy.* The autonomy of a pregnant woman with psychosis must be considered in light of the woman's understanding of what is known about the risks and benefits of medication—to herself and her fetus—during pregnancy as well as the risks associated with untreated psychosis. With limited (and sometimes conflicting) information about such risks, it can be difficult for a woman to exercise her autonomy, even when she has capacity to consider the known information. In other cases, the woman's symptoms, such as delusional denial of pregnancy or grossly disorganized thinking, can render the woman incapable of making reasoned medical decisions. In such cases in which respect for autonomy conflicts with the imperative to avoid harm, physicians may seek consultation from other stakeholders, such as the patient's loved ones, to better understand the patient's beliefs and choices prior to her worsening psychosis.

*Beneficence.* The concept of beneficence is challenged in this setting, as the physician may have multiple loyalties to the woman, the fetus, and possibly others (including other patients when on an inpatient unit). Benefits of medicating a hospitalized woman against her wishes during the time of her pregnancy could come at the cost of her not seeking care in the future, if it damages her trust in clinicians. Alternately, treatment may restore a woman's decision-making capacity and result in more rapid return of her freedom from involuntary hospitalization.

*Nonmaleficence.* The concept of nonmaleficence is similarly relevant here. However, it can be difficult to determine whose interests prevail. Take, for example, a psychiatrist who gives a pregnant patient an antipsychotic medication on a short-term basis to reduce her paranoia about the obstetrics ward in order to facilitate her transfer to the obstetrics unit for delivery. Absent the medication, the woman would have risked having her baby in a less appropriate (and, possibly, risky environment). Can short-term breaches of the patient's interest justify the anticipated longer term benefits? Arguably, yes.

*Justice.* In a time of limited mental health resources, the concept of justice must be taken into consideration alongside respect for patient autonomy. Suppose that a pregnant woman with psychosis is involuntarily committed due to her inability to care for herself. If this woman refuses antipsychotic medication, one option would be to continue her

hospitalization without forcing her to take medication. However, in this scenario, her condition is unlikely to improve. She is taking resources (hospitalization) that could be used for another patient should her condition improve to the point when she could be safely discharged.

In sum, there is no “one size fits all” approach to treating women with psychosis during pregnancy, particularly when a woman refuses treatment. Some of the ethical considerations are raised here. Consistent with Dr. Kalfoglou’s recommendations, physicians should aim to understand the scientific, legal, and ethical principles involved in providing clinical care in these complex cases.

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**Jennifer Piel, JD, MD**, is an assistant professor and an associate residency director in the Department of Psychiatry and Behavioral Sciences at the University of Washington in Seattle. She is also a staff psychiatrist at the VA Puget Sound Health Care System. An adult and forensic psychiatrist, Dr. Piel has served as an expert consultant on a variety of cases involving medical-legal issues, and her scholarly work focuses on topics in law and medicine.

**Suzanne B. Murray, MD**, is an associate professor at the University of Washington Department of Psychiatry and Behavioral Sciences at the University of Washington in Seattle, where she completed her residency and geriatric fellowship in 2002. She directed the University of Washington Medical Center Consult Liaison service from 2006-

2015 and continues to work clinically on the consult service while serving as the medical center's residency program director.

**Carmen Antonela Croicu, MD**, is an assistant professor in the Department of Psychiatry and Behavioral Sciences at the University of Washington in Seattle. She performs her clinical work at Harborview Medical Center, where she has worked on the inpatient and consult services.

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## ABOUT THE CONTRIBUTORS

### Theme Issue Editor

Cameron R. Waldman is a second-year medical student at Albany Medical College in Albany, New York. Prior to entering medical school, Cameron graduated with a BA in philosophy and worked as a research assistant at the Hastings Center, an institute for bioethics and public policy.

### Contributors

Timothy Cavanaugh, MD, is a family practitioner and the medical director for the Transgender Health Program at Fenway Health in Boston.

Danielle Hahn Chaet, MSB, is a research associate for the American Medical Association Council on Ethical and Judicial Affairs in Chicago. Her work involves researching, developing, and disseminating ethics policy and analyzing current issues and opinions in bioethics. She earned a master of science degree in bioethics, with a focus on clinical policy and clinical ethics consultation, from the joint program of Union Graduate College and the Icahn School of Medicine at Mount Sinai.

Cary S. Crall, MD, is a first-year resident in the Massachusetts General Hospital/McLean Adult Psychiatry Residency Program in Boston. He received his MD from Harvard Medical School. His research interests include LGBTQ mental health, child and adolescent psychiatry, and medical education.

Carmen Antonela Croicu, MD, is an assistant professor in the Department of Psychiatry and Behavioral Sciences at the University of Washington in Seattle. She performs her clinical work at Harborview Medical Center, where she has worked on the inpatient and consult services.

Madeline B. Deutsch, MD, MPH, is an associate professor of clinical family and community medicine at the University of California, San Francisco, where she is also director of transgender care. Her research interests include the use of electronic medical records and telemedicine in transgender clinical care, HIV pre-exposure prophylaxis for transgender populations, and developing capacity-building activities and resources for individuals and institutions seeking to improve transgender care quality.

Elizabeth Dietz is a project manager and research assistant at the Hastings Center in Garrison, New York. Her research focuses on queer and feminist issues in bioethics.

Kristen L. Eckstrand, MD, PhD, is a psychiatry resident at the University of Pittsburgh Medical Center and the founding chair of the Association of American Medical Colleges Advisory Committee on Sexual Orientation, Gender Identity, and Sex Development.

Jessica Halem, MBA, is the program manager for the LGBT Office in the Office for Diversity Inclusion and Community Partnership at Harvard Medical School in Boston. Previously, Jessica was the executive director of the Lesbian Community Cancer Project in Chicago where she created a cultural competency curriculum in LGBTQ health and trained health care professionals throughout Illinois.

Ruben Hopwood, MDiv, PhD, is the coordinator for the Transgender Health Program at Fenway Health in Boston.

Rachel K. Jackson is a fourth-year medical student at the University of Washington in Seattle. She received her BS from Portland State University and plans to pursue residency training in family medicine. Rachel's professional interests include the primary care of LGBTQ adults and adolescents, mental health, suicide prevention, addiction, transgender care, sexual health, and wilderness medicine.

Cei Lambert, MFA, is the transgender patient advocate at Fenway Health in Boston.

Jamie Lindemann Nelson, PhD, is a professor of philosophy at Michigan State University in East Lansing, Michigan. She is also a fellow of the Hastings Center and co-editor of *IJFAB: International Journal of Feminist Approaches to Bioethics*. Her work on philosophical and bioethical issues sparked by gender and transgender has appeared in *The Hastings Center Report*, *Journal of Bioethical Inquiry*, and *GLQ: A Journal of Lesbian and Gay Studies*, among other places.

Khadija Mitu, PhD, is an associate professor of anthropology at the University of Chittagong in Bangladesh. She earned her PhD from Rensselaer Polytechnic Institute, where her research focused on the development and practices of fertility preservation technologies. Her current research interests include reproductive technologies, cryopolitics, transgender health, and gender studies.

Timothy F. Murphy, PhD, is professor of philosophy in the biomedical sciences at the University of Illinois College of Medicine in Chicago. He has analyzed the ethics of fertility preservation for transgender people, access to fertility treatments by transgender people, and ethical issues faced by transgender medical students. He has also written on the ethics of genetic modifications to human descendants.

Suzanne B. Murray, MD, is an associate professor at the University of Washington Department of Psychiatry and Behavioral Sciences at the University of Washington in Seattle, where she completed her residency and geriatric fellowship in 2002. She directed the University of Washington Medical Center Consult Liaison service from 2006-2015 and continues to work clinically on the consult service while serving as the medical center's residency program director.

Henry Ng, MD, MPH, is an associate professor of medicine and pediatrics and the assistant dean for admissions at Case Western Reserve University School of Medicine in Cleveland, Ohio, where he is also clinical director of the PRIDE Clinic at MetroHealth Medical Center.

Jennifer Piel, JD, MD, is an assistant professor and an associate residency director in the Department of Psychiatry and Behavioral Sciences at the University of Washington in Seattle. She is also a staff psychiatrist at the VA Puget Sound Health Care System. An adult and forensic psychiatrist, Dr. Piel has served as an expert consultant on a variety of cases involving medical-legal issues, and her scholarly work focuses on topics in law and medicine.

Jennifer Potter, MD, is an associate professor of medicine at Harvard Medical School in Boston, where she is also director of women's health research at the Fenway Institute.

Tia Powell, MD, is a psychiatrist, bioethicist, and professor of clinical epidemiology and clinical psychiatry at Albert Einstein College of Medicine in New York City, where she is also director of the Montefiore Einstein Center for Bioethics. She is a fellow of the American Psychiatric Society, the New York Academy of Medicine, and the Hastings Center. Her work focuses on ethical aspects of dementia, public health disasters, and sexual orientation and gender identity.

Asa Radix, MD, MPH, is the director of research and education at the Callen-Lorde Community Health Center and a clinical assistant professor of medicine at New York University in New York City, with research interests focus on LGBT disparities and HIV prevention.

Sari Reisner, ScD, is an assistant professor of pediatrics at Harvard Medical School, an associate scientific researcher at Boston Children's Hospital, and an assistant professor of epidemiology at the T.H. Chan School of Public Health at Harvard University in Boston. He is also an affiliated research scientist at the Fenway Institute. Dr. Reisner's research focuses on sexual and gender minority health with a specialization in local, national, and global transgender health.

Ryan K. Sallans, MA, is the lead subject matter expert consultant for Affiliate Risk Management Services, Inc., in New York City, where he develops e-learning courses for health care professionals seeking CME in LGBTQ health care. He is also a public speaker, diversity trainer, publisher, and author of the book *Second Son: Transitioning Toward My Destiny, Love and Life* (TitleTown Publishing, 2012).

Sophia Shapiro, MD, is a resident in emergency medicine at NYC Health + Hospitals/Bellevue. She received her MD from Albert Einstein College of Medicine in 2016. Her research interests are in LGBT health and implicit bias.

Ed Stein, JD, PhD, is professor of law at the Benjamin N. Cardozo School of Law at Yeshiva University in New York City, where he is the founding director of the Gertrud Mainzer Program in Family Law, Policy and Bioethics. His publications include *The Mismeasure of Desire: The Science, Theory and Ethics of Sexual Orientation* (Oxford University Press, 1999), and *Without Good Reason: The Rationality Debate in Philosophy and Cognitive Science* (Oxford University Press, 1996). His scholarship focuses on legal and philosophical topics related to families, sexual orientation, gender, reproduction, cognition, and science.