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Invisibility of “Gender Dysphoria”

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Abstract

Tension between naming *gender dysphoria* to render an important kind of suffering among transgender people more visible and avoiding pathologizing experiences of transgender people in a gender-binary world can be keenly felt among patients seeking gender-affirming services. This article suggests why clinical “verification” of a patient’s need for gender-affirming care is likely less important than clinicians’ expressions of empathy and respect for patients’ autonomy. This article also suggests that fostering transgender patients’ sense of agency should be prioritized.

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What’s Wrong With Verification?

The consequences of extended, untreated *gender dysphoria*, as it’s called in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, are observable in higher rates of suicide and mental illness among transgender patients; gender-affirming care reduces these patients’ suicide risk significantly.^{1,2} Harder to observe and measure is the pain and suffering of transgender people struggling to access gender-affirming care. Such suffering stems from a **biomedical epistemology** that privileges objective and measurable data over subjective experience. This privileging of measurement becomes more problematic the further a patient’s subjective experience of gender departs from societal norms. When subjective experiences are not shared, a patient’s words are harder to understand and believe.³ As such, it makes sense that physicians turn to empirically verifiable test results. In the case of gender dysphoria, however, such an endeavor is, we argue, unethical because it requires a patient’s participation in their oppression in order to be seen as eligible for services.

Transgender patients seeking care suffer for 2 important reasons: first, because their symptoms cannot be measured or visualized using technology; and second, because their experiences of gender are outside the norm and counter to the hegemonic **binary notion of gender**. It is the combination of these factors that makes accessing gender-affirming care particularly challenging. We argue that the medical establishment must

do more to validate the lived pain of transgender patients and ensure equitable access to gender-affirming care by removing barriers and additional gatekeeping and verification measures that make access to care more difficult. In this article, we will first approach the problem from a traditional bioethics lens, arguing that medicine should take more seriously the autonomy of transgender patients and that it unnecessarily privileges the principle of nonmaleficence by presuming that we must protect transgender patients from the consequences of their own decisions. Next, we will present an urban bioethics framework and argue that a stronger focus on agency and social justice should further motivate medicine to take seriously the experiences of transgender patients and remove **unnecessary gatekeeping measures** that make it more difficult to access gender-affirming care.

Expressing Empathy and Respect for Autonomy

Autonomy, one of the highest pillars of traditional bioethics, refers to the rights of competent adults to determine what happens to their own body. Rights are never unfettered, however, and the right to autonomy doesn't mean that patients alone dictate their medical care; in practice, patient-clinician relationships should be partnerships.

Transgender patients attempting to access gender-affirming care, however, more often find their encounters with clinicians to be adversarial ones, wherein their experiences of suffering are met with burdensome verification measures. For example, clinicians generally use an informed consent model for adults with decision-making capacity—as long as the intervention is within standard of care for the patient, the patient should be informed of the risks and benefits and can freely choose the intervention. Informed consent is seen as the clearest way to protect autonomy. However, in the case of hormone therapy for transgender care, even though professional societies are beginning to recommend an **informed consent model**, many physicians deem themselves unable to assess whether the transgender patients they treat are competent to make decisions about their own bodies.⁴ These physicians might suspect that gender dysphoria is itself a sign of other mental illnesses and that a patient might regret a decision to initiate care.

Thus, in an attempt to privilege nonmaleficence over autonomy, physicians require other clinicians, typically mental health professionals, to verify the assessment by asking for letters that lend medical credence to the patient's wishes. In a national survey, one-third of transgender people reported having a negative experience with physicians, including having to educate them about transgender care and "being refused treatment."⁵ This level of due diligence disproportionately affects transgender people, especially given data suggesting that regret after gender-affirming care is "exceedingly rare."⁶ Requesting additional verification measures when such measures are overly burdensome or stigmatizing is problematic, particularly when the rationale is not fully evidence based. Transgender patients' experience of having their subjectivity reframed as a potential mental health problem is dehumanizing.⁷ Privileging nonmaleficence thus results in a shrinking of transgender patients' right to autonomy.

The health care experiences of patients seeking gender-affirming care can be contrasted to those of other patients seeking care primarily for conditions the subjective experience of which can be considered within the range of "normal" for cisgender people. Treatment for erectile dysfunction is illustrative. The American Academy of Family Physicians suggests that a history and physical are sufficient to diagnose erectile dysfunction and that a few simple tests can also be performed to rule out organic

causes.⁸ Rarely is there an extensive vetting process to establish the truth of this form of suffering. The autonomy of the patients who suffer from it is respected, and the condition is treated with well-studied pharmaceuticals. Transgender patients' pain and suffering, on the other hand, is often subjected to double and triple verification before these patients can access gender-affirming care. When patients are outside the cisgender or heterosexual norm, their experiences may not be believed, and extra measures are taken to "protect" them from the harm of a wrong diagnosis or intervention they might later regret. However, when patients are squarely within the norm, even when their suffering cannot be objectively verified, physicians nonetheless take their self-reports at face value.

It could be argued that, because helping some transgender patients motivate authentic expression of their gender identity requires invasive surgical interventions with permanent consequences and potential for harmful complications, gatekeeping is warranted. On this view, it does make sense to institute system-wide protections to ensure that the clinical intervention is warranted and will be, on the whole, more beneficial than harmful. However, it is imperative that gatekeeping measures are narrowly tailored to the circumstances and data and that they minimally curtail autonomy. For example, in recent years, we have come to understand the dire consequences of overprescription of opioids without sufficient tracking and strong history taking.⁹ As a result, the medical field has instituted several gatekeeping measures in an effort to balance the benefit of pain relief with the potential harm of substance use disorder. However, most of these gatekeeping measures involve burdens to physicians, pharmacists, and systems (such as tracking physician prescription habits, maintaining databases, and requiring physicians to receive special permission to prescribe opioids), not to patients themselves.¹⁰ Even our most urgent efforts to address overprescription do not involve verifying that patients' pain is real. Again, when patients' subjective experience is within the norm, gatekeeping efforts to verify their claims of suffering do not emerge. The further away a patient's experience is from the norm, however, the greater is individual and systemic disbelief in that experience, a trend best demonstrated by studies that show that Black patients' pain is taken less seriously than White patients' pain.¹¹

We argue that gatekeeping for gender-affirming care is out of proportion to the potential consequences that could result from removing barriers precisely because transgender patients' experiences of pain and suffering are treated as less creditable, whereas being able to freely access gender-affirming care reduces risks of harms, such as life-long suffering and suicide.¹² In fact, autonomy and beneficence can both be adequately protected using an informed consent model for gender-affirming care, as was eloquently argued in another article in this journal.¹³ Supplemental gatekeeping measures that burden transgender patients and treat their experiences as inherently not creditable only serve to reify hegemonic cisgender and heterosexual norms.⁵

Agency and Social Justice

We now turn our attention to urban bioethics, a subset of bioethics that enhances the traditional ethical principles, to more thoroughly consider equity and social context in relation to gender-affirming care. In this framework, the concept of autonomy is broadened to include agency (the ability to execute one's right to self-determination), and justice is broadened to include society as well as individuals.¹⁴

Already, we have seen that a stronger reliance on informed consent and moving away from gatekeeping measures can both be protective of autonomy and promote beneficence. Considering agency makes the case for patient autonomy even stronger. Agency refers not only to a patient's ability to execute an autonomous choice, but also to the actual range of actions that are plausible for a particular patient within their social context. Clinician discrimination, happenstance of geography, and differential access to the resources required to overcome gatekeeping barriers all represent impediments to transgender patients' agency. For example, national surveys indicate that transgender patients have difficulty accessing health care for a multitude of reasons, including denial of coverage for certain services, experience of discrimination or harassment, and fear of being mistreated, all of which are compounded by employment and socioeconomic barriers.⁵

Whether transgender patients can fulfill gatekeeping demands will vary depending on their context. When it is not strictly necessary, asking a patient for verification of their suffering in the form of referrals to or letters from other clinicians becomes burdensome, especially if that patient has insufficient insurance coverage or scheduling or transportation problems, for example. The need to reduce patient burden is all the more reason why an informed consent model should be employed when caring for transgender patients: it would allow clinicians to better understand a patient's wishes in context rather than relying on verification of suffering from other sources deemed more credible, enabling transgender patients to exercise their own agency.

When we consider the need for gender-affirming care of transgender patients, especially those at the intersection of other marginalized identities, we must center social justice. For example, transgender patients who are also Black and poor are more likely to be homeless, without strong social support, without health insurance, and exposed to more violence.¹⁵ While it might not be difficult for some transgender patients to obtain letters from therapists or meet other gatekeeping requirements, it is certainly difficult for others, especially Black transgender patients, who may be unable to access mental health care or who fear violence, not unreasonably, if their identity is exposed. Requiring proof of suffering to affirm identity is both a product of and a contributor to racism and cissexism. A commitment to social justice requires that we do not institute system-wide gatekeeping measures that disproportionately burden the already vulnerable among us.

The default assumption that being cisgender and heterosexual are the norm is the reason for the unduly burdensome gatekeeping to which transgender patients are subject. When a patient's chief complaint is not objectively verifiable in the ways that medicine teaches, it is even more important that we teach future physicians to be comfortable with immeasurable truths and to cultivate understanding and empathy at the intersection of marginalized identities. We call for critical reevaluation of our evidentiary expectations and a foregrounding of the subjective experience of the least visible and most marginalized among us—a move away from a purely positivist epistemology to a worldview that recognizes that subjective truths can also be valid, embodied truths that only patients themselves can know.

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