State-Mandated Ethics Oversight Is Inappropriate for Gender-Affirming Care

Currents in Contemporary Bioethics

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Abstract: A proposed state administrative rule would have required medical ethicists to approve certain aspects of gender-affirming care. The authors argue the proposed rule lacked appropriate justification compared to other instances of state-mandated ethics oversight and would undermine trust, raise practical challenges, and send harmful messages to society, patients, and providers.

In January 2024, Ohio proposed draft rules for public comment that would require any health facility providing gender-affirming care (GAC) to have a medical ethicist review the facility's written care plan, informed consent process, and any detransition plan for gender-related services.[1] The proposed rules were subsequently revised to remove the medical ethicist requirement.[2] We are medical ethicists — more commonly referred to as clinical ethicists — with experience working directly with GAC teams and gender diverse patients. Since 2021, more than half of states have passed legislation to limit or ban GAC for minors.[3] A handful of states are seeing efforts to restrict GAC for adults, as well.[4] Because of the ongoing proliferation of restrictions on GAC, much of which involves legislation modeled on that of other states,[5] we worry that similar rules could be proposed elsewhere in the future. Although clinical ethicists often add value to patient care, state-mandated ethics oversight of GAC is detrimental for several reasons.

As an initial matter, it is important to distinguish state-mandated ethics oversight in the GAC context from other instances of such oversight. States sometimes require ethics oversight when patient vulnerability is deemed to necessitate special protection or when resolution to a conflict involving particularly high stakes is needed. For example, some states require ethics committee involvement for consenting to care for unrepresented patients.[6] This requirement is justified by the risks of undertreatment, overtreatment, and care delays experienced by unrepresented patients, who have no one to speak for them or their values. In contrast, GAC involves adult patients with decision-making capacity or parents giving fully informed consent. In pediatric care, the ethical and legal presumption is that parents know what is best for their children.[7] As another example, Texas empowers ethics committees to review when a physician seeks to discontinue life-sustaining treatment over the wishes of a patient's surrogate or advance directive.[8] The state's goal is to prevent unjust paternalism and inappropriate quality-of-life assessments in the setting of conflict when there are life-or-death stakes. With GAC, the potential for physician overreach and imposition of values is mediated by the shared decision-making process, as GAC moves forward only when the

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About This Column

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clinician and an adult patient or the clinician, parents, and an adolescent patient agree on next steps in care. Moreover, providing GAC does not entail the same magnitude of stakes; even the risk of regret with gender-affirming surgeries is notably low.[9]

Another important consideration is that inappropriate state-mandated oversight promotes the damaging misconception that clinical ethicists are the "ethics police," which sows distrust and undermines the collaborative alliance required for ethicists and other stakeholders to work together successfully.[10] Ethicists often provide consultative support when a patient or family needs help with values-based decision-making or when a healthcare team is struggling to determine an ethically preferred plan of care. As clinical ethicists providing dedicated support to GAC teams, we have helped develop ethically sound care protocols in addition to providing recommendations when a patient, family, or clinician requests a consult. In this model, the ethicist's role is not to affirm or veto individual treatment decisions, but to provide input as part of a multidisciplinary care team with specialized knowledge of GAC interventions and relevant standards of care. To successfully provide this support, trust is essential. In the gender care context specifically, a state mandate has the potential to create the perception, if not the reality, that ethicists are another gatekeeper to GAC. By inserting ethicists into a larger regime of gender care restrictions, the state co-opts a supportive resource and transmutes it into an adverse one.

Since 2021, more than half of states have passed legislation to limit or ban GAC for minors. A handful of states are seeing efforts to restrict GAC for adults, as well. Because of the ongoing proliferation of restrictions on GAC, much of which involves legislation modeled on that of other states, we worry that similar rules could be proposed elsewhere in the future.

We view ethics support in GAC as a valuable and underutilized resource for patients, parents, and clinicians who may seek support in navigating complex value choices or psychosocial barriers in GAC,[11] similar to ethics support provided in settings like transplant and surgical care.[12] However, the requirement that every health facility providing GAC involve an ethicist neglects the reality that not all facilities will have trained ethicists available with relevant expertise and bandwidth to join GAC teams. The requirement thus has the potential to lead to people without appropriate qualifications interfering in the care of gender diverse patients. For example, these rules create space for individuals with anti-transgender bias to disrupt care in ways that seek to undermine established standards of care.[13] Such a requirement may also exacerbate inequities and pose barriers to care if GAC teams cannot recruit someone with appropriate qualifications to serve as an ethicist at their facility.

Finally, these kinds of rules send the wrong messages to society, patients, and providers. They signal to society that GAC requires ethics review or oversight beyond that provided in other kinds of care. Every medical specialty faces unique ethical uncertainties and dilemmas, and we regularly consult on cases across myriad specialties. Transgender and gender diverse people already face immense stigma and discrimination. Rules requiring special ethics oversight have the potential to exacerbate these challenges. Such a requirement also conveys to patients and families that the state is watching them closely and doubts clinicians can responsibly handle their care. This scrutiny may contribute to a chilling effect on healthcare professionals' willingness to provide GAC, leaving transgender patients with diminished access to essential services.

We present this perspective with the positionality of cisgender clinical ethicists with professional experience supporting GAC teams, and we encourage policymakers, clinicians, and fellow clinical ethicists to properly center the perspectives of gender diverse patients when evaluating access to GAC. We are heartened that state-mandated ethics oversight for GAC was removed from Ohio's proposed rules. The mandate lacked justification and should never have been proposed in the first place. The state has a role to play in promoting the well-being of its citizens. State-mandated ethics oversight in this context goes beyond the scope of that responsibility and risks undermining important values and exacerbating inequities. Physicians and other healthcare professionals should remain vigilant of future laws or rules modeled on those originally proposed. If such rules are passed, the medical, legal, and clinical ethics communities will need to consider ways to minimize the harms that are likely to result.

Disclosures

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rather provider operations. However, to alleviate confusion and because of assurances from healthcare leaders that providers already appropriately engage medical ethics professionals in this type of care, the … requirement has been removed." "Memo: Response to Public Comment to Gender-Related Care Rules," Ohio Department of Health, February 7, 2024, https://odh.ohio.gov/wps/wcm/connect/gov/9b217d95-bcc9-483f-8771-f4786bb93b56/Combined+to+Post.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=ROOTWORKSPACE.Z18_M1HGGIK0N0JO00QO9DDDM3000-9b217d95-bcc9-483f-8771-f4786bb93b56-oS58U7u (last visited October 21, 2024).

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