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Democracy Dies in Darkness

Opinion When treating transgender youth, how informed is informed consent?

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In the debate over transgender medicine for youths, two radically opposing views take up most of the airtime. People who support the currently dominant gender-affirming model of care for children see kind practitioners trying to do their best for vulnerable patients who often have severe mental health issues due to living in a transphobic society.

Those who oppose this model see overconfident practitioners experimenting on these same vulnerable patients, many of whom might not be capable of giving truly informed consent for treatments such as puberty blockers, cross-sex hormones and surgeries, which can have lifelong consequences.

Both views will find vindication in a new report from the think tank Environmental Progress, which contains a leaked cache of internal discussions from within WPATH, the World Professional Association for Transgender Health, a group that brings together clinicians from various specialties involved in treating gender-dysphoric patients. These discussions reveal both caring people trying hard to do things right and a medical culture that appears to be operating without adequate guardrails against things going wrong.

One exchange is at once the most reassuring and the most worrying for those who are trying to sort out the competing narratives: In a workshop discussing transition and the challenge of obtaining minors' informed consent for gender-affirming procedures, participants come across as deeply thoughtful folks doing their best to grapple with complexities. But some also seem to acknowledge that their patients cannot actually give fully informed consent. Many haven't completed puberty — or high school biology. And even the brightest 16-year-old cannot yet understand the full implications of treatments that can mean, in some cases, a lifetime of infertility and medical maintenance.

This is not a novel problem in medicine. As therapist Dianne Berg points out in that discussion, if children have diabetes, they are given insulin even if they haven't learned how the pancreas works. If they have depression, they might be given drugs that could increase their risk of suicide or permanently alter their developing brains to help them toward happier futures. And if a kid has a pediatric cancer, doctors don't wait for her to be old enough to give fully informed consent to amputation or infertility — because without treatment, she might never reach that age.

Youth gender medicine is increasingly treating puberty as though it were a life-threatening condition like cancer or diabetes, and natal sex organs as though they were potentially dangerous growths. This is, of course, entirely appropriate if they *are* threatening, and letting nature take its course will end in suicide or a lifetime of emotional agony. Of course, with that kind of diagnosis you want to be very sure — and unlike doctors treating cancer or diabetes, who can rely on blood tests and imaging, gender-medicine doctors ultimately have only the patient's feelings to go by.

In the popular discourse, and apparently at some gender clinics, it's often taken for granted that that's enough — that we know transgender medical interventions are saving lives, because trans people are at higher risk for suicide. And for adults, who are entitled to decide what to do with their bodies, it is. Yet for children, it's more complicated, because this risk, while real, does not approach the magnitude of cancer or diabetes, and might persist even after treatment. In a large-scale Dutch study, trans patients were found to have almost four times the suicide risk of the general population. The researchers saw 49 suicides among more than 8,000 patients, many of which occurred during or after transition. A nationwide study of suicide rates among trans people in Denmark similarly found 12 suicides in a population of 3,759.

It would be ideal if doctors could drive that rate to zero — perhaps by identifying future trans adults, blocking their puberty and eventually treating them with hormones and possibly surgery so that their adult appearance would more closely resemble their gender identity. Unfortunately, though, we don't yet know to what extent these treatments actually improve mental health or prevent suicide. The data on their long-term efficacy is more limited than it should be, even for adults. The evidence regarding youth interventions is even less clear.

Several European health authorities have reviewed the available studies and rated the evidence for using puberty blockers and cross-sex hormones in dysphoric youth as "very low certainty," "deficient" and "limited by methodological weaknesses." A recent systematic evidence review by German researchers concludes that the current body of evidence is "based on very few studies with small samples and problematic methodology and quality. Adequate and meaningful long-term studies are equally lacking."

In other words, though WPATH says these interventions are "not experimental," youth gender medicine is still, well, effectively experimental. Now, this is true, as well, of many pediatric oncology treatments, because when a child's life is in danger, doctors pull out all the stops. About 60 percent of juvenile cancer patients are enrolled in a clinical trial, according to CureSearch, a funder of children's cancer research. But gender medicine does not yet approach the same level of rigor as an FDA-supervised clinical trial.

This puts clinicians in a difficult position, and this is what we see in the WPATH files: well-intentioned doctors and therapists groping through the considerable gaps in current medical knowledge. Yet one can also see this work being made more difficult because, as an editorial in the journal Acta Paediatrica recently put it: "The discourse surrounding the use of puberty blockers in gender dysphoria is often framed as a political human rights issue rather than as a medical issue."

In a discussion of detransitioning, one writer calls the whole idea "problematic" because "it frames being cisgender as the default, and reinforces transness as a pathology." (As though it were inherently bigoted for someone to prefer, where possible, the option that doesn't require drugs or surgery.) Others rather blithely suggest we should reframe detransition as "learning" or part of a "gender journey" rather than a "mistake."

Many other conversations in the WPATH files, of course, portray sensitive, intelligent caregivers doing their best — beset by many uncertainties, yet ultimately in little doubt that they're doing the right thing for most of their patients. I'm glad such people are trying to help some of our vulnerable people alleviate terrible distress. But I also came away wishing they seemed willing to entertain a few more doubts.