Medical Coding Creates Barriers to Care for Transgender Patients

Many trans patients have trouble getting their insurers to cover gender-affirming care.

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Last year, Tim Chevalier received the first of many coverage denials from his insurance company for the hair removal procedure he needed as part of a phalloplasty, the creation of a penis.

Electrolysis is a common procedure among transgender people like Chevalier, a software developer in Oakland, California. In some cases, it's used to remove unwanted hair from the face or body. But it's also required for a phalloplasty or a vaginoplasty, the creation of a vagina, because all hair must be removed from the tissue that will be relocated during surgery.

Chevalier's insurer, Anthem Blue Cross, told him he needed what's known as a prior authorization for the procedure. Even after Chevalier received the authorization, he said, his reimbursement claims kept getting denied. According to Chevalier, Anthem said the procedure was considered cosmetic.

Many trans patients have trouble getting their insurers to cover gender-affirming care. One reason is transphobia within the U.S. health care system, but another involves how medical diagnoses and procedures are coded for insurance companies. Nationwide, health care providers use a list of diagnostic codes provided by the International Classification of Diseases, Tenth Revision, or ICD-10. And many of those, advocates for transgender people say, haven't caught up to the needs of patients. Such diagnostic codes provide the basis for determining which procedures, such as electrolysis or surgery, insurance will cover.

"It's widely regarded that the codes are very limited in ICD-10," said Dr. Johanna Olson-Kennedy, medical director of the Center for Transyouth Health and Development at Children's Hospital Los Angeles.

She advocates for a move to the 11th edition of the coding system, which was endorsed by the World Health Organization in 2019 and began to be adopted around the globe in February. Today, more than 34 countries use ICD-11.

The new edition has replaced outdated terms like "transsexualism" and "gender identity disorder" with "gender incongruence," which is no longer classified as a mental health condition, but as a

sexual health one. This is crucial in reducing the stigmatization of trans people in health care, said Olson-Kennedy.

A move away from the mental health classification may also mean more coverage of gender-affirming care by insurance companies, which sometimes question mental health claims more rigorously than those for physical illnesses. WHO officials have said they hope that adding gender incongruence to a sexual health chapter will "help increase access to care for health interventions" and "destigmatize the condition," according to the WHO website.

However, history suggests that ICD-11 likely won't be implemented in the U.S. for years. The WHO first endorsed ICD-10 in 1990, but the U.S. didn't implement it for 25 years.

Meanwhile, patients who identify as transgender and their doctors are spending hours trying to get coverage — or using crowdfunding to cover big out-of-pocket bills. Chevalier estimated he has received 78 hours of electrolysis at $140 per hour, costing $10,920.

Anthem spokesperson Michael Bowman wrote in an email that "there has been no medical denials or denial of coverage" because Anthem "preapproved coverage for these services."

However, even after the preapproval was given, Anthem responded to Chevalier's claims by stating the electrolysis would not be reimbursed because the procedure is considered cosmetic, rather than medically necessary. This is regardless of Chevalier's diagnosis of gender dysphoria — the psychological distress felt when someone's biological sex and gender identity don't match — which many doctors consider a medically legitimate reason for hair removal.

Bowman wrote that "once this issue was identified, Anthem implemented an internal process which included a manual override in the billing system."

Still, Chevalier filed a complaint with the California Department of Managed Health Care, and the state declared Anthem Blue Cross out of compliance. Additionally, after KHN started asking Anthem questions about Chevalier's bills, two claims that had not been addressed since April were resolved in July. So far, Anthem has reimbursed Chevalier around $8,000.

Some procedures that trans patients receive can also be excluded from coverage because insurance companies consider them "sex-specific." For example, a transgender man's gynecological visit may not be covered because his insurance plan covers those visits only for people enrolled as women.

"There is always this question of: What gender should you tell the insurance company?" said Dr. Nick Gorton, an emergency medicine physician in Davis, California. Gorton, who is trans, recommends his patients with insurance plans that exclude trans care calculate the out-of-pocket costs that would be required for certain procedures based on whether the patient lists themselves as male or female on their insurance paperwork. For example, Gorton said, the question for a trans man becomes "what's more expensive — paying for testosterone or paying for a Pap smear?" — since insurance likely won't cover both.

For years, some physicians helped trans patients get coverage by finding other medical reasons for their trans-related care. Gorton said that if, for instance, a transgender man wanted a hysterectomy but his insurance didn't cover gender-affirming care, Gorton would enter the ICD-10 code for pelvic pain, as opposed to gender dysphoria, into the patient's billing record. Pelvic pain is a legitimate reason for the surgery and is commonly accepted by insurance providers, Gorton said. But some insurance companies pushed back, and he had to find other ways to help his patients.

In 2005, California passed a first-of-its-kind law that prohibits discrimination by health insurance on the basis of gender or gender identity. Now, 24 states and Washington, D.C., forbid private insurance from excluding transgender-related health care benefits.

Consequently, Gorton no longer needs to use different codes for patients seeking gender-affirming care at his practice in California. But physicians in other states are still struggling.

When Dr. Eric Meininger, an internist and pediatrician at Indiana University Health's Gender Health Program, treats a trans kid seeking hormone therapy, he commonly uses the ICD-10 code for "medication management" as the primary reason for the patient's visit. That's because Indiana has no law providing insurance protections for LGBTQ+ people, and when gender dysphoria is listed as the primary reason, insurance companies have denied coverage.

"It's frustrating," Meininger said. In a patient's billing record, he sometimes provides multiple diagnoses, including gender dysphoria, to increase the likelihood that a procedure will be covered. "It's not hard usually to come up with five or seven or eight diagnoses for someone because there's lots of vague ones out there."

Implementing ICD-11 won't fix all the coding problems, as insurance companies may still refuse to cover procedures related to gender incongruence even though it is listed as a sexual health condition. It also won't change the fact that many states still allow insurance to exclude gender-affirming care. But in terms of reducing stigma, it's a step forward, Olson-Kennedy said.

One reason the U.S. took so long to switch to ICD-10 is that the American Medical Association strongly opposed the move. It argued the new system would put an incredible burden on doctors. Physicians would have to "contend with 68,000 diagnosis codes — a five-fold increase from the approximately 13,000 diagnosis codes in use today," the AMA wrote in a 2014 letter. Implementing software to update providers' coding systems would also be costly, dealing a financial blow to small medical practices, the association argued.

Unlike past coding systems, ICD-11 is fully electronic, with no physical manual of codes, and can be incorporated into a medical facility's current coding system without requiring a new rollout, said Christian Lindmeier, a WHO spokesperson.

Whether these changes will make the adoption of the new edition easier in the U.S. is yet to be seen. For now, many trans patients in need of gender-affirming care must pay their bills out-of-pocket, fight their insurance company for coverage, or rely on the generosity of others.

“Even though I did get reimbursed eventually, the reimbursements were delayed, and it burned up a lot of my time,” Chevalier said. “Most people would have just given up.”

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