When Co-Pay Assistance Backfires on Patients

Nineteen states limit copay accumulator programs, and patient advocacy groups have won a favorable court ruling against the programs.

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In early 2019, Jennifer Hepworth and her husband were stunned by a large bill they unexpectedly received for their daughter's prescription cystic fibrosis medication. Their payment had risen to $3,500 from the usual $30 for a month's supply.

That must be a mistake, she told the pharmacy. But it wasn't. It turned out that the health insurance plan through her husband's job had a new program in which it stopped applying any financial assistance they received from drugmakers to the family's annual deductible.

Insurers or employers can tap into funds provided to patients by drugmakers through co-pay assistance programs, which were designed by the companies to help patients afford increasingly expensive medications. But, because those payments are no longer counted toward the deductible, patients must pay an amount out-of-pocket, too, often for the same drugs. Those deductibles or other out-of-pocket costs can easily run into thousands of dollars.

Here's what that meant for Hepworth, who lives in Utah. Before the change, the drugmaker's co-pay assistance would almost immediately meet her family's deductible for the year, because both Hepworth and her daughter need expensive medications. As a result, the family was responsible for co-pays of only 20% of their medical costs instead of the 100% required by their plan until they met their deductible. By the middle of the year, the family would have reached the plan's out-of-pocket maximum of nearly $10,000 and would no longer owe any co-pays.

Hepworth ended up paying the $3,500 to the pharmacy, equivalent to the family's annual deductible, because she didn't want to stop giving her daughter a treatment that could extend her life. "We were struggling and everything went on credit cards."

Why did the insurer do this?

Employers or the health insurance plans they hire are saving 10% to 15% of the cost of prescription plan claims by using these co-pay accumulator programs, said Edward Kaplan, a senior vice president at Segal, a benefits consulting firm. Even so, Kaplan doesn't recommend

that his clients, who include public and private employers, take advantage of the program because of the increasing pushback from lawmakers and advocacy groups. However, the majority of insured people are in plans governed by these types of programs, according to Avalere, a consulting firm.

Nineteen states now limit co-pay accumulator programs for some insurance plans. And patient advocacy groups have won a favorable court ruling against the programs. States' limits on the practice, however, do not apply to larger, self-insured job-based plans, through which many Americans have coverage.

Bipartisan legislation has been introduced in both chambers of Congress that would require financial assistance to count toward deductibles and other out-of-pocket costs. Called the Help Ensure Lower Patient Co-pays Act, it would govern plans that are exempt from state rules.

Change is unlikely to come soon.

Insurers and employers have long complained that co-pay assistance programs are mainly a marketing ploy by the drug industry that encourages patients to stay on costly drugs when lower-cost alternatives might be available. Insurers say capturing more of that money themselves can help slow the rising price of premiums.

In a recent letter to regulators, the Blue Cross Blue Shield Association called the practice "a vital tool in keeping health insurance affordable."

Patient advocacy groups, including the HIV+Hepatitis Policy Institute and two diabetes groups, disagreed and took a case against co-pay accumulator programs to U.S. District Court last fall.

And "we won," said Carl Schmid, executive director of the institute. The groups argued the practice can cause some patients to skip their medications because of the unexpected costs they must now shoulder.

Some critics say it's a form of double dipping because even though the patient hasn't personally paid out-of-pocket, "that payment was made, and it was made on your behalf. I think that should get counted," said Rachel Klein, deputy executive director with the AIDS Institute, an advocacy group.

The court decision, Schmid said, essentially overturns a 2021 provision in Centers for Medicare & Medicaid Services rules that allowed insurers to expand the practice to cover almost any drug. Previous rules from 2020 would now be in effect, said Schmid, and those rules say co-pay assistance should count toward the deductible for all drugs for which there is no medically appropriate generic alternative available.

Even so, billing changes for many insured patients may take a while.

While the Biden administration dropped an appeal of the court decision, it has filed motions noting

“it does not intend to take any enforcement action against issuers or plans” until regulators draw up new rules, said Ellen Montz, deputy administrator and director of the Center for Consumer Information and Insurance Oversight at CMS, in a written statement to KFF Health News.

A version of these programs being used by insurers, sometimes called a “maximizer,” works a bit differently.

Under a maximizer program, insurers partner with outside firms such as PrudentRX and SaveOnSP. The programs declare certain drugs or classes of drugs “nonessential,” thus allowing them to circumvent some Affordable Care Act rules that limit patient cost sharing. That lets the insurer collect the maximum amount from a drugmaker’s assistance program, even if that is more than the patient would owe through deductibles or out-of-pocket maximums had the drugs remained essential benefits. These partner companies also work with large pharmacy benefit managers that oversee prescription services for employers.

Those maximizer payments do not count toward a patient’s deductible. Many insurers don’t charge patients an additional co-pay for the drugs deemed nonessential as a way of enticing them to sign up for the programs. If patients choose not to enroll, they could face a co-payment far higher than usual because of the “nonessential” designation.

“This is a loophole in the ACA that they are exploiting,” said Schmid of the HIV+Hepatitis Policy Institute, referring to the Affordable Care Act. Johnson & Johnson filed a lawsuit in federal court in New Jersey in 2022 against such a maximizer program, saying it coerced patients into participating because if they didn’t they faced higher co-pays. The drugmaker warned it might reduce the amount of overall assistance available to patients because of the increasingly common practice.

Now, though, a provision in the proposed 2025 federal rules governing health insurers says plans must consider any covered drug an “essential benefit.” If finalized, the provision would hamper insurers’ ability to collect the maximum amount of drugmaker assistance.

Employers are watching for the outcome of the lawsuit and the proposed federal rules and don’t yet have clarity on how rulings or regulations will affect their programs, said James Gelfand, president and chief executive of the ERISA Industry Committee, which advocates for large, self-insured employers.

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