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HEALTHCARE

Rules block patients from counting thousands in drug discounts toward health insurance deductible

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Julie Turner was just 17 when she needed powerful doses of radiation and chemotherapy to wipe out her stage 3 Hodgkin's Disease.

The harsh, 12 rounds of chemo and 60 radiation treatments at Ohio State University hospital in the 1970s came with two major side effects: She was sterile, and her bones became abnormally brittle, eventually requiring a twice-a-year regimen in the hospital for medication to reduce her risk for fractures.

But now, her post-retirement health insurance no longer covers those $5,000 semi-annual treatments of Prolia she needs to protect her fragile bones.

At first, after finding a pharmacy in her hometown of Springfield that would give her the shots at a much lower cost, then landing a $1,500 grant from Prolia manufacturer Amgen to help offset the cost, Turner thought she had discovered a way around her insurance company.

Unfortunately, she did not.

The former school treasurer learned that Aetna wouldn't count the $1,500 from Amgen toward her $4,000 maximum annual co-pay – even though Aetna isn't contributing a dime for the Amgen drug.

The upshot: She still has to come up with that $1,500 toward her co-pay out of her own pocket each year. It's as if the grant doesn't exist.

It turns out that Turner ran head-on into a little-known practice that pharmacy benefit managers and health insurers have come up with in recent years known as a co-pay accumulator. Simply put, the maneuver doesn't count any co-pay assistance that

patients obtain toward either their health-insurance deductible or their maximum annual out-of-pocket spending. That includes increasingly common aid from a drug manufacturer striving not to lose a prescription for an expensive drug – even though the insurance company still winds up with that patient aid.

Consolidation provides fewer choices to consumers

You might wonder: How are pharmacy benefit managers, known as PBMs, and insurance companies able to do this?

The answer: Because America's health-care system is so consolidated that consumers have few options. Without the full-fledged competition that's a basic component of capitalism driving prices down, it puts consumers in a position to take it or leave it.

Just three PBMs control nearly 80% of the U.S. market. And owners of all three – such as CVS Health, whose $69 billion union with Aetna in 2018 was the biggest health care merger in U.S. history – also offer health insurance.

The sale of expensive specialty drugs like the one Turner takes are especially monopolized. In 2020, just four specialty pharmacies – led by CVS – accounted for 75% ($132 billion) of total U.S. prescription revenue from specialty drugs dispensed by pharmacies, the nonpartisan newsletter Drug Channels found in early May.

No company outside of the "big four" has a market share of more than 3%. And each of the four is completely or partly owned by one of the country's largest PBMs – which are part of large, vertically integrated organizations themselves, the newsletter said.

The PBMs and health insurers both say that "co-pay accumulators" are necessary to alleviate the high cost of prescription drugs, especially specialized brand-name products that typically are the most expensive.

Brand-name drugs account for 10% of Americans' prescriptions but 80% of the cost –$409 billion a year, the nonprofit West Health notes. Last year, PBMs generated a third of their gross profits from specialty medications, Drug Channels says.

The increasing price of prescription drugs consistently registers as a major concern among Americans.

Two-thirds said in an April 2020 Gallup Poll that their prescription costs were going up. In November 2019, Gallup found that nearly a quarter had at least one instance in the

previous year when they didn't have enough money to pay for needed prescription drugs. And 13% said that within the previous five years, they've had a friend or family member die after not being able to pay for needed medical treatment.

Patients all across America are 'astonished' when they see their bill

If your health insurance policy doesn’t already have such a co-pay accumulator, sometimes called an "accumulator adjustment program," it likely will soon. A regulation approved by the administration of President Donald Trump authorized them for the first time starting this year.

Drug Channels estimates that within the next year, more than 80% of commercially insured beneficiaries will be in plans with these benefit designs – although not all plan sponsors will have fully implemented them.

“This is all consolidation and it’s all part of a theme,” said Ted Okon, executive director of the Community Oncology Alliance, a nonprofit based in Washington, D.C.

“The PBM-insurer complex has gotten more aggressive over time,” he said.

He said thousands of Julie Turners exist across America – people who are astonished when they receive their pharmacy bill and realize it’s not covered by insurance because of the obscure co-pay accumulator clause.

“What that does is it takes money out of the pocket of the patient and puts in the PBM/insurers’ pocket,” Okon said. “It’s going to get worse. Because of consolidation, the PBMs and insurers have gotten more brash, more aggressive, and they will in the future.”

The bottom line of PBMs, some of the biggest corporations in the U.S., actually was helped by the COVID-19 pandemic.

"Some of the leading PBMs and health-coverage companies in this market have been reporting staggering sales, with people stocking up medications to deal (with) lockdowns and movement restrictions, said Fortune Business Insights, citing quarterly increases of as much as 20% or more.

Annual revenue at UnitedHealthcare revenue jumped 20% to $357.1 billion; its PBM and care services group, Optum, reported revenue of $35.9 billion, up more than 20%, in the

fourth quarter alone. Revenue for CVS Health, which includes its PBM, Caremark, climbed 4.6% to $268.7 billion in 2020. In the first quarter of 2021, CVS recorded 10% profit growth.

The 2020 total for Cigna, which owns the PBM Express Scripts, was $160.4 billion, a 4.5% increase from 2019.

Profits for major health insurers in the first quarter of 2021, compared to net income for the same period last year, were up across the board. Anthem's bottom line increased over 9%, to $1.7 billion; Centene's jumped to $699 million from $46 million; Humana's total of $828 million represents a 75% leap; Molina 's $228 million was $50 million higher than during the first three months of 2020; UnitedHealthcare Group's figure was $4.9 billion, a rise of 43%.

At the same time, co-pay accumulator programs are making life-saving treatments increasingly inaccessible, the Hepatitis Foundation says: "Research shows that the more out-of-pocket costs a person has to pay, the more likely they are to abandon their medication."

Health insurers, PBMs say co-pay accumulators help control costs

On the other side of the argument, the trade group America's Health Insurance Plans, which represents health insurance companies, sees co-pay accumulators as a method to hold down costs.

"Branded (drug) manufacturers offer coupons to circumvent patients' cost-sharing for branded drugs and to avoid responsibility for the fundamental reason for higher patient costs – namely, the high price of the drug that is set and controlled solely by manufacturers," said a statement the trade group based in Washington, D.C., provided from Jeanette Thornton, senior vice president of product, employer, and commercial policy.

The group notes that coupons are banned from government health-care programs such as Medicare and Veterans Affairs. The Department of Health and Human Services deems them a violation of a federal anti-kickback statute because the drug manufacturer offering the coupon is directly benefiting from its use at the expense of taxpayers.

Ashley Czin, deputy vice president of policy and research for the Washington-based Pharmaceutical Research and Manufacturers of America, which represents major U.S. drug makers, said the group believes that co-pay accumulators "are operating at the detriment of patients."

"We believe the accumulator-adjustment program unfairly targets patient cost-sharing assistance," she said.

A statement from the Pharmaceutical Care Management Association, the trade association for PBMs, the middlemen in the drug supply chain, blamed drug makers for the situation.

"Co-pay accumulator programs mitigate the harmful impact that drug manufacturer copay coupons have on overall health plan costs," the association said.

"The accumulator programs are needed because drug manufacturers offer coupons to insured patients, regardless of their incomes, to induce patients to take a more expensive brand drug instead of a less costly generic or equally effective, less expensive, alternative medication," the group said in a statement.

Doctors groups oppose provision that limits prescriptions

It's that "equally effective" medication statement that especially upsets Turner. Her insurance company informed her that, although it wouldn't cover the Prolia injections that had been helping her for years, it would pay for the cheaper Fosamax, a pill taken weekly.

But about a year and a half after switching to the new medication, a bone-density scan known as DEXA (dual energy X-ray absorptiometry) by her doctor showed that her bone-mineral density had deteriorated significantly, which increased the likelihood of a debilitating break. The AARP notes that breaking a major bone increases the mortality rate for older adults.

However, her insurance company still wouldn't pay for the drug that worked.

Finally, Turner's doctor suggested contacting Prolia's manufacturer to seek financial help.

Physicians take a dim view of pharmacy benefit managers and insurance companies in effect second-guessing their medical judgment for the best treatment of their patients.

The American Medical Association approved a resolution last fall to "support federal and state legislation or regulation that would ban co-pay accumulator policies."

Doctors' groups have staunchly opposed "non-medical switching" by PBMs and health insurers – altering a patient's drug therapy for reasons other than a drug's efficacy, side effects or clinical outcome.

The Ohio State Medical Association is backing a bill that essentially would ban co-pay accumulators in the state. House Bill 135 was approved 16-0 on March 16 by the House

Health Committee. However in late May, Taylor Jach, spokeswoman for House Speaker Bob Cupp, said the measure hasn't gone to the full House because "members are continuing to work on a couple remaining issues."

Even if it gets through the House, its future in the Senate is unknown.

“Practices like co-pay accumulators can have a devastating impact,” testified the OSMA’s senior director of government relations, Monica Hueckel.

“Patients often do not even know about these policies until the (drug maker’s) coupons are no longer usable. As you can imagine, for patients with expensive medications and/or high-deductible health plans, the impact is disastrous.”

The legislation would still allow co-pay accumulators in which a generic version of a brand-name drug exists, unless the patient’s physician prescribes the more expensive brand-name drug as medically necessary.

Former state Rep. Randi Clites, a Democrat from Ravenna who is now policy director for the Ohio Bleeding Disorders Council, said that nine out of 10 insurers on the Affordable Care Act exchange in the Buckeye State now have some form of accumulator program that prevents co-pay assistance from counting toward deductibles and out-of-pocket costs.

Clites – whose son, Colton, now 19, was born with severe hemophilia – noted that the average cost of treating that condition “is easily $400,000 a year. There is no generic for his treatment, and costs between similar products are comparable. We would have never made it without assistance programs over the years.”

Bipartisan bill essentially would ban co-pay accumulators in Ohio

The proposal to virtually end the use of co-pay accumulators has bipartisan sponsorship from Republican Rep. Susan Manchester of Waynesfield in northwestern Ohio and Democratic Rep. Thomas West of Canton.

“This bill strives to protect patients who are being blindsided by unfair policies when learning they owe thousands of dollars because of unmet deductibles,” Manchester said.

Similar bans already have passed in Arizona, Illinois, Virginia and West Virginia, with legislation under consideration in Indiana, Kentucky and North Carolina, she said.

West said, "I've heard stories of patients rationing drugs or going without a dose to make their prescriptions last longer. No one should be put in this position, caught between a rock and a hard place. A constituent of mine with a rare bleeding disorder has lived this experience, along with countless others across our state."

A who's who of health advocates are backing the Ohio proposal, from Akron Children's Hospital and the National Alliance on Mental Illness to the American Academy of Pediatrics and the Susan G. Komen breast-cancer-fighting organization.

Ohioans tell how they were personally affected by co-pay accumulators

Several Ohioans testified in March about how they were personally affected by co-pay accumulators:

• Jenna Hoffman of Canton said she uses the drug Humate-P to treat her von Willebrand's Disease, a rare, severe bleeding disorder for which treatment costs $4,300 per dose. "There is no generic or cheaper version of this intravenous medication. I rely on manufacturer copay cards to help pay for my life-saving medication, but insurance company co-pay accumulator policies have made my medication difficult to afford."

• Nikki Snyder of Canfield has multiple sclerosis, as does her mother. "This new rule had been buried in the fine print of my health-insurance policy and I was not aware of the change. It is frustrating that insurers get to keep both the assistance payment and any co-pays paid directly by me while in the deductible phase – it is a double-dip that jeopardizes the health of patients. …

"My annual medication costs are over $100,000, and not being able to use any patient assistance toward my co-pay is a financial hardship to say the least."

• Robbie Huston of Cincinnati didn't know for years that she had Acromegaly, a rare hormonal disorder caused by a tumor on the pituitary gland producing excess growth hormone. Her treatment works, but it costs about $7,500 per shot.

"I was so relieved when I found out about the co-pay assistance program. It would cover my out-of-pocket expenses up to $20,000 a year," she testified. Now that the $20,000 in effect has been taken away by her health insurer, she has stopped taking her medicine regularly because of the cost.

“If I can’t get my medication, I will eventually become disabled in a very slow and painful way. Then I will have to go on public assistance. I'll lose everything."

Sharon Lamberton, a deputy vice president with PhRMA, said the organization of more than 33 biopharmaceutical companies strongly opposes the accumulators because they so often result in an unexpected bill of possibly thousands of dollars for patients – who, like Huston, may then give up taking the medication they need.

"The reason for that? It is simply because they were later informed that, while the insurer accepted the assistance when presented by patients at the pharmacy counter, it did not apply the value of the assistance toward the patient’s mandated co-payment, co-insurance, or deductible requirements. I do not believe anyone would believe that policy is in the best interest of patients."

New drugs worked; insurer says they aren't a 'medical necessity'

At the Madison Avenue Pharmacy in Springfield, which provided the Prolia shots for Julie Turner for $3,500 each, instead of the $5,000 each the local hospital was charging, patient care specialist Erin Phillips says people with all sorts of maladies are going through the same battle as Turner.

Some have rheumatoid arthritis, others psoriasis or high cholesterol that can’t be corrected by statins. All are complicated ailments that can be treated only with expensive, brand-name specialty drugs – as opposed to radically cheaper generics.

“I know what hoops people have to jump through,” she said.

In fact, Phillips has done it so often that she has the routine down by now: Call for approval if the drug the patient needs is not on the formulary set by pharmacy benefit managers for the health insurer. (A formulary is the list of drugs the insurance will cover.)

When that’s denied – and it virtually always is – file an appeal. After that’s turned down, appeal again.

Once rejected for a third time, the patient has a fighting chance: The next appeal usually receives consideration from people outside the insurance company.

Still, Phillips said, the chances of winning approval from the health insurer even at this stage is 50-50 at best.

“It can be months of work,” she said. “They can just do whatever they want, and there’s no repercussions.”

A Health Affairs blog by University of California associate professor Alice J. Chen and others noted, "For patients with rapidly progressive diseases, these delays can be life-threatening."

One of the most frustrating cases for Phillips involved a patient who battled agonizing migraines for 13 years.

“She was on every medication you can imagine,” Phillips said.

At last, she found one that worked after getting a grant from a drug maker that made it affordable. The severe headaches dropped from daily occurrences to happening just five times a month.

But the insurance company wouldn’t cover it, Phillips said, saying it did not meet the required threshold of “medical necessity.”

'A choice whether they have the best care or what they can afford'

Turner, now 63, said she, too, received no sympathy.

“I was told during one of my calls to the insurance company, insurance is changing, and we have to become better consumers,” she remembered. "I said, 'What do you think I'm doing?'"

She is bewildered that she gets no credit for using the drug company grant to help cover her cost, because “the insurance company is still getting the money.”

Indeed, a study by the AIDS Foundation last year found that "insurers profit by keeping the co-pay assistance funds. This double-dipping comes at the patient’s expense. ... only adding more financial strain for patients who may be facing hardships due to the coronavirus pandemic’s impact on jobs and family budgets."

When Turner began treatments back in the 1970s, they were almost entirely covered by the robust insurance policy of her father, a Springfield firefighter.

But the aggressive treatment was traumatic for the high schooler who started out merely wondering why she got so tired that she couldn't practice with the marching band.

"I swung from this mighty 17-year-old that could handle anything that was thrown at her to this scared little girl who wanted to crawl into my mother's arms for safety," she said.

About 25 years later, cancer would claim her mother's life a few short weeks after the illness was diagnosed.

Turner's treatment also was covered by the health plan she had as treasurer for decades at her alma mater, Clark Shawnee High School near Springfield.

She needed the help. Her spleen was removed during the initial rounds of her battle against cancer. With little ability to filter viruses or infections, she easily contracted many illnesses floating around her in ensuing years.

The intense cancer treatment – primitive by today's standards – left other lasting effects. The chemo damaged her heart. The radiation, along with making her unable to bear children and causing fragile bones, left scar tissue on her lungs.

But she says she's had a good life. She got married and she and husband, Chuck Wickline, adopted a daughter, Jodie.

"I'm so blessed to be here," Turner said.

She retired in 2016, and the couple moved to a condo in Vandalia, near Dayton. That's when she went on a "bridge" health insurance policy with Aetna through the School Employees Retirement System of Ohio to get her to Medicare in a couple of years.

Turner has become an advocate for the American Cancer Society, where she hears stories of others enduring the same struggle she has in a country overtaken by health-care consolidation.

"Unfortunately, for the patients that are going through active treatment now, they have to make a choice whether they have the best care or what they can afford," she said.

Her reward comes from moments like the one at a Relay for Life in Fayette County. After hearing Turner's story, a mother with a teen-age daughter fighting cancer came up to her with a simple message:

"You've given us hope."

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