The Maddeningly High Price of Prescription Drugs

Why are prescription drug prices such a consistent source of frustration among patient-consumers? The answer is far more complicated than it appears.

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By Susan Milligan

Bottle of pills sit on shelves at Rock Canyon Pharmacy, May 20, 2020, in Provo, Utah.(GEORGE FREY/AFP/GETTY IMAGES)

Insulin is a medical marvel, saving the lives of millions of people who would otherwise perish from diabetes. It can also be prohibitively pricey, costing up to $300 a vial for newer versions of the treatment, which diabetes patients need two to three times a month.

For patients with less common ailments, the sticker shock can be much worse. Have a small child with spinal muscular atrophy, a rare genetic disorder that weakens muscle, causes movement problems over time and can be fatal? The good news is that the Food and Drug Administration in 2019 approved a drug, Zolgensma, a one-time curative therapy. The bad news is that it costs more than $2.1 million – and may not be covered by insurance – making it the costliest drug in the world.

Prescription drug prices in America are a consistent source of frustration, anger and bafflement among patient-consumers. Why are some drugs so pricey – and why are some pills dramatically more expensive than the same medication sold overseas? Who decides what prescription drugs cost – and how can they be made affordable without stifling the innovation and research that produced the miracle treatments patients now enjoy?

Congress is grappling with that issue now, mulling provisions in the "Build Back Better" bill that are meant to reduce the burden on consumers by capping co-pays that patients are expected to cover and yearly out-of-pocket costs for certain circumstances. As it is currently written, the measure would allow Medicare to negotiate drug prices – something the government was specifically banned from doing when Medicare Part D, the prescription drug benefit for seniors, was created in 2003.

The new measure would also impose a tax penalty if drug companies increase prices more than inflation, limit insulin co-pays to $35 a month and put a $2,000 cap on out-of-pocket costs for seniors for drugs covered under Medicare.

Many Democrats cast the battle as one between helpless patients and dollar-chasing drug manufacturers. Republicans say efforts to set prices, even in a back-door way, will discourage development of the very treatments that save lives.

"The public really has a love-hate relationship with the pharmaceutical industry. They very much appreciate and value the role of the pharmaceutical industry" in coming up with life-changing and life-saving treatments, Mollyann Brodie, executive vice president of the health research group Kaiser Family Foundation, said in a webinar this week. "On the other hand, they also believe that the industry is too focused on profits and that the profits are too high."

The industry, represented by the powerful Pharmaceutical Research and Manufacturers of America (PhRMA), certainly has its boogeymen. Chief among them is Martin Shkreli, the smirking so-called "pharma bro" who raised ire in 2015 when his company, Turing Pharmaceuticals, hiked the price of a life-saving medication, Daraprim, from $13.50 to $750 per pill. (Shkreli is in prison for security fraud. Turing and its parent company agreed on Wednesday to pay $40 million to settle a case charging that they had fleeced patients).

But drug companies have also developed critical therapies and breakthrough research on ailments ranging from cancer to Alzheimer's disease. They may have saved humanity by the speedy development of vaccines (and a possible new treatment) for the COVID-19 virus.

But why do some medications cost so much? And what can be done to make therapies more affordable?

The answer is far more complicated than it appears, experts say. And the solutions are not as simple as branding manufacturers as the singular source of the problem.

"Everybody loves to find the villains," says Wayne Winegarden, director of the Center for Medical Economics and Innovation at the Pacific Research Institute. Aside from some famously bad actors (like

Shkreli), "there's not a villain here. We have a really bad health care system that incentivizes all kinds of crazy behavior," Winegarden says.

Drug prices, experts explain, are determined by a variety of players. A manufacturer sets a "launch price" – which is typically going to be higher if it's new or a breakthrough therapy. A middleman, called a Pharmacy Benefit Manager, then negotiates discounts and rebates with manufacturers for the drug, which they then provide to pharmacies, doctors and hospitals.

But the Pharmacy Benefit Managers don't necessarily pass that discount on to patients, explains Leslie Dach, chairman of the pro-health care reform group Protect Our Care. They also don't reveal how much of a discount they got, so patients don't know what the true cost is.

Insurance may well cover a particular medication, Dach explains. But since the co-pay is based on the original manufacturers' price – and not the lower, negotiated cost paid by the Pharmacy Benefit Manager – the patient ends up paying more.

"Everything about this is a black box," he says.

Pharmacies are in a bind as well, says Douglas Hoey, CEO of the National Community Pharmacists Association. The Pharmacy Benefit Managers – three of which, he says, control 80% of the market – are "incredibly powerful with health care providers." The middleman companies can direct patients to in-network pharmacies, for example, and say to pharmacies, "If you don't take our rates, we will steer this patient somewhere else."

That means that even when the original cost of a drug comes down, a patient might not see the benefit. A report by Milliman, commissioned and released this week by PhRMA, found that the net price of insulin in 2021 was, on average, 84% lower than the list price due to rebates, discounts and other payments. But experts note that a drop in the net, discounted price does not necessarily mean that patients' co-pays will be lower. The study pointed a finger at the Pharmacy Benefit Managers, saying the companies “have been found to favor products with high list prices and large rebates over lower-list price equivalents," having "unintended consequences" for patients whose co-pays are based on the original list prices.

The Pharmaceutical Care Management Association, which represents the Pharmacy Benefit Managers, turned the blame back to manufacturers, noting that the high prices start there.

"Ironically, the industry that controls the list price of prescription drugs has attempted to point the finger at those focused on reducing the cost of prescription drugs for patients and payers," the group said in a statement.

It's true that manufacturers' set the original prices, says Boston University professor Rena Conti, associate research director of biopharma and public policy at the university's Institute for Health System Innovation and Policy. But she says the answer is not to simply penalize the profitable industry.

"There are a lot of very misaligned incentives that create a lot of headaches for real people at the pharmacy counter," says Conti, who is scheduled to testify on the matter before a House committee Friday. "We are also the beneficiaries of a very robust pharmaceutical industry that is actually bringing new products to market, some of which really do transform our lives.”

"The point here is not to punish but instead to really think about how we might have the opportunity to realign incentives," she adds. For patients paying thousands of dollars or more for critical medications, that change cannot come soon enough.