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Danger, Delay, Denial:

Pharmacy Benefit Manager Horror Stories — Part IV

The cautionary tale of the Pharmacy Benefit Manager (PBM) system is a lesson not yet learned. The United States' health care system continues to be strangled by the dark presence of these ever-growing corporate middlemen, siphoning off billions of dollars in profits while leaving behind pain, suffering, anxiety, and despair for the millions of cancer patients.

This is the fourth paper in a series from the Community Oncology Alliance (COA) that focuses on the very real and negative impact PBMs continue to have on cancer patients today. This impact threatens to grow even stronger under recent proposals put forth by the Centers for Medicare & Medicaid Services and in President Trump's Blueprint. Rather than heed warnings about abusive PBMs and limit their influence, the current administration has proposed to do the exact opposite and increase the role PBMs play in our health care.

Today, while PBMs are contracted to handle Medicare Part D, which includes self-administered medications such as pills, they are not involved in Medicare Part B, which covers all doctor- administered drugs, such as infused chemotherapy. The government is now proposing a slew of changes, including that some, or all, of Part B medications be shifted to fall into Part D. It has also dictated that insurance middlemen, some of which own PBMs, can require step therapy for Part B medications in Medicare Advantage.

These proposals have been put forth to lower drug prices. Unfortunately, they ignore the vast evidence that the incompetence and greed of middlemen has not only failed to reduce drug prices but has ironically caused them to increase thanks to the network of shadowy rebates and discounts siphoned off by these middlemen. And, as these horror stories clearly demonstrate, this has all been done at the expense of cancer patients.

The following PBM horror stories have been provided to COA by community oncology practices. While patient names have been changed to protect privacy, the terrifying stories and details are unfortunately very real.

BUREAUCRATIC MADNESS AND A GAME OF TELEPHONE

Donald, an electrical engineer, husband and father of two college students, had been diagnosed with colorectal cancer and was scheduled for radiation treatments. His doctor prescribed an oral chemotherapy to be taken alongside the radiation and faxed the prescription off to Donald's PBM-mandated specialty pharmacy. Three days later, the pharmacy contacted Doreen at the clinic treating Donald, to clarify his prescription. Doreen handled the matter without delay, and then, four days later, called to ask when the medicine had shipped… only to discover that due to 'issues' it had not yet gone out.

The pharmacy transferred Doreen to the Medicare department, and after a lengthy wait, a representative came on, to whom Doreen explained that Donald was in fact not a Medicare patient. After another lengthy wait, the silence was broken only by the occasional interjection of "One moment," the representative explained that regardless of the patient's coverage, this particular medication ordered for him needed to be 'released' from the Medicare Part B department.

The representative informed Doreen that the next step was for her to call Donald and ask him to call them – the pharmacy – to schedule delivery, as the pharmacy was not able to make outbound calls. However, she said, another option was for Doreen to bring Donald in on a third-party call and then wait on the line while the pharmacy verified the entire shipping process with him.

A very frustrated Doreen hung up and called Donald to explain the situation. By now it was Friday afternoon, and Donald was scheduled to begin radiation treatments on Monday, accompanied by the oral medication. It was looking more and more unlikely that Donald would have his medication in time. Adding to the absurdity of the situation was the fact that Doreen had plenty of the medication Donald needed – right there in the in-house pharmacy, and could easily have filled Donald's prescription herself, had the PBM allowed her to do so.

Countless times, bureaucratic PBM delays mean that patients must postpone treatment – or begin, but without the right combination of medicine – that will give them their best chance at battling this devastating disease. Yet, even when the situation has become a matter of life and death, patients have no recourse other than to wait it out, as the bureaucratic machinery of the PBM is not programmed to make any kind of exception.

SHAMELESS BLAME GAME WHILE THE PATIENT SUFFERS

James, a third-grade teacher in his early 40s, has lived with leukemia for many years, keeping it in remission with a daily oral medication. In November, his insurance provider notified James' doctor that a new prior authorization was required to continue receiving his medication. There was no time to lose; James had just finished his last bottle and needed an immediate refill. The authorization was immediately obtained, and the clinic forwarded it on to the PBM-mandated specialty pharmacy.

Four weeks went by, yet no medication arrived. Brenda, a clinic worker, contacted the specialty pharmacy, and a voice on the other end stated that a new prior authorization was needed. Confused, Brenda again faxed the approval letter to the pharmacy, while continuing to wait on hold. After a considerable wait, the pharmacy worker came back on the line and told Brenda that this letter was already in the patient's file, but that a new prior authorization was needed.

What on earth for? Brenda wondered to herself, as she hung up the phone. They were in February, so perhaps it was because the previous prior authorization had been sent in 2017? Yet, according to the insurance company, the old prior authorization was still in effect. She called the specialty pharmacy back, and this time a different representative answered. He looked up James' case and stated that all was well; in fact, the medication should arrive in just a few days.

Brenda hung up and called James to let him know he should expect his medication any day now. Answering the phone, James told Brenda that for the past four weeks, going without medication, he'd been frantically calling the pharmacy on a regular basis, trying to order it. They had told him each time that they'd been unable to contact Brenda, despite many attempts, and that his being without medication was due to the clinic's negligence.

Meanwhile, during those same four weeks, while James' blood counts were reaching horrific levels, Brenda was able to fill five prescriptions of the same drug for other patients, whose PBM allowed them to receive their medications in-house.

Dealing with PBM bureaucracy can be frustrating to say the least. Getting the runaround… being told one thing by a representative, only to have that information contradicted the next moment by someone else… having the person on the other end of the phone lie to you… these are the things patients and clinic workers meet time and again. And, as if lying about the status of a drug's delivery wasn't bad enough, to add insult to that situation by implying the delay is the fault of the very people treating the patient, is unconscionable.

TROLLING FOR BUSINESS

The pharmacist of an in-house clinic at a community oncology practice was going over patient files one day when the phone rang.

The caller politely introduced herself as an employee of a well-known PBM specialty pharmacy, and then abandoned all niceties as she proceeded to ask why the pharmacist was filling a prescription for a patient that by all rights belonged to them. The in-house pharmacist pulled up the file for the patient in question, who was battling advanced stage ovarian cancer. Not seeing any conflict of interest, he requested further details.

In clipped tones, the caller explained that his filling of this script was "outside of the manufacturer's contract, and illegal." Unfazed, the pharmacist responded by saying that there was no law preventing them from filling it. At this point, realizing that her strong-arm tactics were getting her nowhere with the pharmacist, she changed tactics; perhaps the doctor would be an easier target. "Did the patient's physician intentionally send the script to you?" she asked, to which the pharmacist replied, "Of course he did. Our pharmacy is located inside of the practice."

With no wiggle room left, the caller said that she would be informing the patient of all this, and abruptly ended the call. The pharmacist was left to marvel at the audacity of trying to intimidate him into handing over a patient – and the corporation that clearly couldn't care less about what was best for her.

When that corporation's income is derived from 'trolling' the system to collect more profit-generating patients receiving treatment for life-threatening ailments, we realize things have gone way too far. At some point, something must be done to rectify the perverse profit-motives and incentives behind the corporate PBM approach patient care.

CAN'T BE BOTHERED TO GET THE PRESCRIPTION RIGHT

Annabelle, a retired cosmetician and widow, had been diagnosed with Philadelphia chromosome-positive + chronic myeloid leukemia. Her community oncologist tried her out on 180mg of a particular medication, and Annabelle's response was highly positive. Her blood work showed immediate improvement, and she showed no significant side effects.

The doctor wrote out a prescription for the medication, which according to Annabelle's PBM had to come from their mandated mail order specialty pharmacy. As the medicine does not come in pills of 180 mg, the prescription clearly stated: one 100 mg tablet and one 80 mg tablet. Nevertheless, over the following months, each time Annabelle had her prescription renewed, she was given either 100 mg or 80 mg – never both. This meant that she was not only taking the wrong dosage, but also her dosage was changing each month, according to the whim of the pharmacy and whoever happened to be filling her prescription.

Annabelle did not do well with the incorrect dosing; her laboratory results showed dangerous levels in her blood work, again.

Despite the clinic's repeated attempts to get the PBM to deliver the right medication, the PBM specialty pharmacy refused to take the necessary measures to ensure that Annabelle received the proper dosage. When the doctor tried to have the script filled in the in-house pharmacy at his clinic, it was denied. Meanwhile, Annabelle continues to be improperly dosed, impacting her opportunity for remission.

This story exemplifies the constant dangers patients are in at the hands of incompetent, faceless PBM pharmacy workers. Removed several times from the patients they are meant to serve, their inattention to crucial detail is not what we should expect from a company in the business of caring for patient lives.

PBMs STANDING IN THE WAY OF TIMELY STANDARD OF CARE TREATMENT

Rhonda, a 55-year-old wife, mother, grandmother, nurse, world traveler and self-described Disney expert had been diagnosed with Her2-negative breast cancer. She was receiving treatment at a local community oncology center. Her physician prescribed treatment and attempted to fill it on the same day at the in-house pharmacy; however, the co-pay was too high for Rhonda's limited means.

The clinic's financial assistance coordinator went to bat and, six days later, had secured a co-pay card from the drug manufacturer. Two days later, however, when the practice tried to fill Rhonda's script, her PBM rejected the use of the co-pay card at the practice pharmacy. Instead, the PBM required the script to go out to its own specialty pharmacy. Not wanting to delay her treatment, the practice quickly faxed the prescription over.

Another six days passed before the specialty pharmacy notified the clinic that the prescription must first go through the specialty pharmacy connected with the patient's PBM, regardless of who would ultimately fill it. The clinic staff filled in all the additional forms and handled all new bureaucratic measures, and then proceeded to wait. Three days later, a clinic RN called the specialty pharmacy to ask for an update. The representative who answered told her that all was well, and that no prior authorization would be needed. She then placed her on hold. Ten minutes later, the representative returned, only to say that actually prior authorization was needed. With the greatest of patience, the nurse filled out all the new forms and faxed all relevant records necessary for the prior authorization, over to the specialty pharmacy.

Later that day, the pharmacy contacted the RN to inform her that the prescription had been denied, based on the patient's Her-2 positive status. The RN again sent the patient's records to the pharmacy, highlighting the fact that she was, and had always been, since she was first diagnosed Her-2 negative. Two days later, the medicine finally arrived.

All-together, Rhonda's therapy was delayed 19 days, which, had she been permitted to fill her prescription in-house, would never have happened. In total, the clinic staff spent five hours dealing with red tape.

Worst of all, Rhonda never had the opportunity to take the first pill. The night before the medication arrived at her home, she was hospitalized for complications of her metastatic disease. After a lengthy hospital stay she was discharged home to hospice.

While the physicians caring for Rhonda were busy trying to "march to the beat of the PBM's drum", this sweet, young, vibrant woman's window of opportunity closed. How many other scenarios involving pointless deterioration, hospitalization, and death from PBM incompetence are there? When reflecting on the life and care of the patients, PBMs should not be part of the conversation.

WOULD IT KILL YOU TO WAIT?

In 2012, a 45-year-old salesman named Bill was diagnosed with colorectal cancer. Bill had a good job working for a large office supply manufacturer based in the Midwest, a loving wife and two small children, and he decided to fight with everything he had. Following surgery, Bill was treated with IV chemotherapy, but with negligible results. The cancer progressed over the next year, and his doctor changed to a different IV chemotherapy. This time his response was very good, and for the next four years things were fairly quiet.

In 2017, tests showed that Bill's cancer was back, and this time he was treated with yet a third kind of IV chemotherapy. His response seemed good at first, but by the following year, the cancer had progressed to Stage IV and metastasized to his liver. At this point, Bill's oncologist ordered an oral medication specially prescribed for relapsed or metastatic colon and rectal cancers.

Bill's physician at the community oncology practice sent the prescription over to the in-house pharmacy to fill. Unfortunately, according to Bill's new insurance plan, his prescription could only be filled by a PBM-mandated pharmacy. Despite the facts that Bill's Stage IV cancer was aggressive, that his doctor wanted to get him started on the medication that very same day, and that the medication was sitting on the shelf of the in-house pharmacy, Bill had to wait. Even the option sometimes given to have a 'one-time fill' that would let him get started while waiting for the PBM pharmacy to mail him his medication was denied. Thus, with the drug's prohibitive list price (over $10,000/month), Bill had no option but to wait.

The doctor sent his prescription on to the new pharmacy, along with Bill's contact details, so that they could arrange for delivery. Meanwhile, Bill went to his clinic and received detailed in-person counseling on how to take the drug, since it was a somewhat complicated regimen. There were specific directions on how to take the medication, what side effects to expect, and how to ensure the proper dosing. The latter could be confusing, since the drug is taken in multiple tablets twice daily on days 1-5 and 8-12 of a 28-day cycle.

After seven full days of waiting to start his therapy regimen, Bill finally received his medication in the mail. Opening the box, he began to read the label, and found to his great surprise, that it stated: "take once a day." Picking up the phone, Bill checked in with his oncologist to report the change in instructions. The clinic pharmacist confirmed that the instructions were wrong, and reached out to the PBM pharmacy, which promised to contact Bill about clearing up the matter.

Bill received a call from the PBM-mandated pharmacy representative, who apologized for having sent the wrong prescription with the wrong amount of medication. They assured Bill he would receive an additional supply of medication. First, however, they asked Bill to please return the medication he had been sent, so it could be properly labeled. Now Bill, with Stage IV metastatic cancer and his treatment already having been delayed a week, was being asked that rather than take his life-saving medicine, he ship it back to the warehouse for proper labeling and reshipping.

This was not the last time the PBM pharmacy impacted and delayed Bill's care. Later, when it came time to refill his medication, Bill's treatment was again delayed. The PBM pharmacy, it seemed, decided that before filling his prescription, it had to first clarify the dosage. It then claimed to have had difficulties in contacting Bill's community oncology clinic, despite having been provided with all the correct contact details. Ultimately, Bill had to call his local clinic and ask for the in-house pharmacist to call the PBM to confirm dosage, before they would ship it out. And while he waited, his cancer was allowed to progress, unchecked.

One of the most dangerous parts of PBM-mandated pharmacies is the distance between the pharmacy and patient. In this, we are speaking not only of geographical distance, but also of when patients are forced to wait for medicine to be shipped, rather than walk across a hallway to purchase it. More to the point, however, is the situation in which the patient becomes a name or number on a call sheet, rather than an actual human being facing a life-threatening illness; rather than a patient for whom there is care and endearment. That distance is at the core of many PBM mistakes and apathy.

About the Community Oncology Alliance

The majority of Americans battling cancer receive treatment in the community oncology setting. Keeping patients close to their homes, families, and support networks lessens the impact of this devastating disease. Community oncology practices do this while delivering high-quality, cutting-edge cancer care at a fraction of the cost of the hospital setting.

The Community Oncology Alliance (COA) advocates for community oncology and on policy issues that affect patient care. Our members include patients in active treatment, cancer survivors, caregivers, family members, medical and oncology professionals, and members of the general community. For more than 15 years our members have advocated for smart public policy that ensures the community cancer care system remains healthy and able to provide all patients with access to local, quality, affordable cancer care. Learn more at www.CommunityOncology.org