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Unaccountable Benefit Managers:

Real Horror Stories of How PBMs Hurt Patient Care

Over 15 Years *of* Making a Difference in Cancer Care

There is no shortage of horror stories associated with the increasingly large role that Pharmacy Benefit Managers (PBMs) play in the United States' health care system. With their numerous offshoots and service lines, PBMs have managed to take on an oligopolistic presence that adversely impacts patients receiving treatments, their health care providers, and everyone else in between.

Originally created to lower prescription drug costs, it has become clear that these multibillion dollar PBM corporations have transformed into gargantuan and almost completely unaccountable arbiters of the care that cancer patients receive. As this story series demonstrates, the dangerous combination of PBM unaccountability, opacity, and lack of oversight have resulted in benefit managers that are focused on their profits and not patient care.

This paper is the second in a series from the Community Oncology Alliance (COA) that focuses on the serious, sometimes dangerous, impact PBMs are having on cancer patients today. These are real patient stories but names have been changed to protect privacy.

PBM KNOWS BETTER THAN THE DOCTOR?

A community oncology and hematology clinic in Pennsylvania was being forced to use a specific PBM specialty pharmacy for their patients' oral chemo prescriptions, despite the practice having its own in-office dispensary. They had actually applied to the PBM two years earlier for the right to dispense drugs; however, approval was still "pending."

Frank was one of the clinic's patients battling rectal cancer. His oncologist prescribed an appropriate medication and submitted it to the PBM specialty pharmacy for filling. Soon after, the PBM called the clinic and announced that approval was denied for the submitted diagnosis, however if the oncologist were to change the diagnosis to one of several other cancers, they would then approve it. The clinic responded by noting that this would be a fraudulent change, that they refused to comply with it, and would be reporting it to the State of Pennsylvania. Within ten minutes of that call, Frank's medication was approved without any changes.

Edward was another of the clinic's patients, also battling rectal cancer. He had been prescribed the same drug, with a specific dosage, to be taken twice daily, seven days a week, for five weeks. However, when the medicine arrived, the PBM specialty pharmacy had changed the dosage and instructions. This was done despite the fact that a pharmacy is forbidden to change prescription instructions without the approval of the prescribing physician. To make matters even worse, the quantities sent to Edward were incorrect, even for the adjusted regimen.

Chris was another patient at the practice battling with rectal cancer and prescribed the same medication with the same dosage. He too found that his prescription had been changed by the PBM specialty pharmacy—from seven days per week to five days per week. When the PBM specialty pharmacy called Chris to schedule shipment he refused because the instructions were different from those he'd been given at the doctor's office. At this point, the PBM specialty pharmacy called the patient's physician, who had to reinstate the original prescription.

Because of the constant, unauthorized changes to the details of prescriptions made by oncologists, this practice worries that patients' care is in danger. And these changes are not isolated to just this PBM or practice—specialty pharmacies seem to be playing it fast and loose with the oncologists' directed treatment plans. Details, such as number of dosages and their size, are crucial life-and-death matters, and PBMs and their specialty pharmacies should not be changing them.

NEARLY A MONTH OF DELAYS

James, a 73-year old husband, father and grandfather, had been battling metastatic non–small cell lung cancer (NSCLC) for a while, when his oncologist prescribed a new medication that was FDA approved for cases like James', in which the cancer was "locally advanced or metastatic."

On November 13th, James' doctor submitted a request for prior authorization to the PBM. The first sign that things were not as they should be was when the request was denied—in a way that made absolutely no sense; they were demanding the results of his blood tests for jaundice. His doctor was incensed. How could the PBM deny someone an FDA-approved medication that was indicated for their illness and prescribed by an oncologist? They resubmitted the request, and for the next three weeks, waited in vain for the determination, with the doctor occasionally calling for status, only to be disconnected or told to call back.

On December 4th, as the doctor waited on hold with James' insurance company, James' family called to say that James had died. They would never get a chance to see if the medicine would have prolonged his life.

PBMs, by giving decision-making power to administrative workers with no medical background and little to no patient contact, have created a system that often results in treatment delays and, in worst-case scenarios, the patient's untimely death. In contrast to this, when patients are permitted to purchase their medication from a physician-owned pharmacy, they are spared the crippling bureaucracy of the PBM system.

REFILLING MEDICATION TO TREAT THE DECEASED

A practice in California began receiving request after request from a particular PBM for prior authorization to initiate a refill—what was unusual was that they were for a variety of expired prescriptions. What was going on? None of the practice's patients had been prescribed these drugs recently. In fact, some were for drugs that patients had stopped taking months earlier, while others were for patients who had died.

The practice was puzzled at first, but then came to the following conclusion: "It seems they [the PBM] are just going through their files, and when a prior authorization expiration date pops up for prescriptions filled through their pharmacy at one time, they are automatically sending out prior auth requests."

An amusing anecdote on the surface, stories such as this reveal the wholesale approach taken by the PBMs, in which patients are viewed not as individuals in need of medical care, but rather as a potential market of consumers. Spread across the entire health care system with drug benefits managed by PBMs for millions of patients, this scenario also potentially means millions, if not billions, of dollars of wasted costs in cancer medications.

THE BUREAUCRACY KNOWS BETTER THAN DOCTORS' ORDERS?

George, a patient with multiple myeloma, was prescribed two specific medications that work in conjunction with each other. It was thus a great surprise when the specialty pharmacy refused to send his medication, saying that they wanted to discuss with his oncologist the drug interaction between the two medicines. His oncologist was also perplexed; it was common knowledge that these two drugs are always prescribed together, as the second medicine provides a key part of the maintenance for the first drug, a fact that was not only clinically known but actually spelled out clearly on the manufacturer's website. George had also been on the medication combination for nearly 18 months at that point without problems.

After over a month of delays, the oncologist and PBM finally got this sorted out, but George's fiasco wasn't over. The specialty pharmacy then caused further delay, as they insisted upon speaking again to the doctor, this time to ascertain how many refills were needed. The irony of this was that this particular medication cannot be refilled, so it was simply additional time wasted, while George's treatment cycle was again delayed.

PBM specialty pharmacies have a long list of complex bureaucratic protocols. While they may be designed to prevent mistakes and ensure patient safety, the result is just as often unnecessary, time-consuming delays that in fact endanger the patients they are trying to protect.

MANY PATIENTS… ONE PBM SPECIALTY PHARMACY FULL OF PROBLEMS—A PRACTICE DOCUMENTS CHRONIC DELAYS

A community oncology clinic became so fed up with the problems and delays their patients faced in dealing with a PBM specialty pharmacy that they opened a dedicated file to document each case.

Michelle, a patient at a Florida community oncology practice, had arranged for the PBM specialty pharmacy to ship her medication to one of their local branches, for easy pickup. However, when Michelle arrived at the store, she discovered that they had thrown away her prescription. She now had to request a new prescription from her doctor, get a new prior authorization from her insurance carrier, and then have the medication shipped again—all of which resulted in a two-week delay of treatment.

Diane, another patient at the clinic, had her prescription faxed to the same PBM specialty pharmacy. The pharmacy confirmed it had received the prescription. However, 50 days later, the medication had still not arrived. Clinic staff called the pharmacy, who then claimed they had never received the prescription. By the time it was all sorted out, Diane had been left two months behind in treatment.

The following month, another patient of theirs, Juan, came home to find that his medication had been delivered and left in the middle of the road. Exposed to the Florida heat and rain, the drugs were ruined and had to be reordered—subjecting him to another round of authorizations, delay of his life-saving treatment, and unnecessary cost for the health care system.

No system is perfect. But when a PBM specific pharmacy is repeatedly documented making life-threatening mistakes with no accountability, and cancer patients are forced to remain with them, unable to choose another pharmacy, it would seem that something needs to change.

NEARLY THREE WEEKS OF BROKEN PROMISES AND SHIPPING DELAYS

On January 12th, the clinic treating Liane, a cancer patient, submitted a prescription to her PBM's preferred specialty pharmacy. On January 19th, the day Liane was scheduled to begin treatment, her insurance company notified the clinic that even though they already had prior authorization, they were now requiring a new prior authorization.

Liane was understandably upset by the news; why had the insurance company not contacted them a week ago, when the prescription was first sent? This would now delay her treatment unnecessarily. Later that day, the clinic's pharmacist ascertained that the additional approval required was related to the medication's cost, which had been put under a separate review. Over the next five days, the clinic's authorization specialist, Barbara, was in constant contact with the PBM, who assured her that the medication would be going out at any moment.

A week later, Barbara discovered that this was not true, for when she finally reached a PBM supervisor, Barbara learned that authorization was still pending. She was told that it could take another seven business days or more, before a decision was made.

Barbara's call must have made a difference however, because later that day the PBM faxed over a form to the clinic, to be filled out and returned to them. The following day approval was granted, albeit for the mail order specialty pharmacy. It took another two days for the specialty pharmacy to receive the prescription, another day to process it, and then the pharmacy contacted the patient to arrange for shipping. All together it took nearly three weeks from the original prescription being submitted to the PBM for the patient to receive it.

"Approval of your medication is pending" may well join the list of phrases that savvy consumers have long-since stopped believing, such as "Your call is important to us" and "The check is in the mail." Too many patients and physicians have been promised things too many times by PBM and specialty pharmacy reps, only to find those promises unfulfilled or completely contradicted.

DATA MIGRATION OR PATIENT NEGLECT?

Cathy was one of the fortunate ones; after seven and a half years, she was among the 22% of patients diagnosed with Stage IV cancer who had made it past five years. Unfortunately, Cathy's survival was dependent upon the specialty pharmacy her PBM had mandated she use—despite the fact that her oncologist had an in-house pharmacy that she would prefer to use. The problem was that every month, Cathy had to engage in a battle with the PBM pharmacy just to obtain her oral chemo medication.

As an example, on October 12th, Cathy called the PBM specialty pharmacy to verify that they were planning to over–night the oral chemo medication to her, so she could stay on schedule. The PBM specialty pharmacy told her that her oncologist had not sent in the renewal subscription. Cathy then called the pharmacy manager at her oncologist's office, who assured her that the prescription had indeed been faxed over one week earlier.

Trying to help Cathy out, the practice pharmacy manager then called up the PBM specialty pharmacy, who placed her on hold until they eventually located the script, which indeed had arrived a week before. "Why was the medicine not shipped? " the pharmacy manager asked. "Data migration," she was told; this meant that the PBM specialty pharmacy was in the middle of reorganizing its filing system, and had failed to take proper precautions to ensure that no patient care information was lost or misplaced along the way.

Had Cathy not called up the specialty pharmacy, she would never have received her medicine in time. Furthermore, the pharmacy manager at her oncologist's office informed Cathy that while she had been talking with the PBM specialty pharmacy, another patient had called her with the exact same issue. Every month, without exception, Cathy has had difficulty getting the medicine shipped on time from the PBM specialty pharmacy. No matter what, whenever her oncologist calls it in, the PBM specialty pharmacy manages to misplace the order.

Customer satisfaction, integrity, and commitment are important qualities for any profession or field. Yet, they are even more crucial in those professions that deal directly with people's lives. As PBM specialty pharmacies deal in products that have the potential to lengthen the time another person has on Earth, there must be a different standard to which their employees are held, and clearly indifference, apathy and carelessness should have no place.

PATIENT AND CARE PROVIDERS GET THE RUNAROUND

One serious complication that often results from chemotherapy and radiation treatments is a condition called neutropenia, in which there is a significant reduction of the white blood cells that provide essential first line of defense against infections. Neutropenia can lead to sepsis, organ failure, and death; however, it need not progress this far, if properly treated in time.

Marvin, a cancer patient being treated by a community oncology clinic, had developed neutropenia, and his oncologist prescribed a medication that helps the body to produce more white blood cells. His PBM indicated that, in order for Marvin to receive this particular medication, it had to be mail ordered from a specific PBM specialty pharmacy.

The clinic where Marvin was being treated faxed the prescription over to the specialty pharmacy on February 27th. Three days later, they called to check on status, and were told that the prescription was in the 'benefits verification stage,' in which the PBM pharmacy confirms that the patient's insurance provider will indeed cover the medication's costs. The clinic asked if prior authorization was required, but the PBM specialty pharmacy representative was unable to say; she promised to call back with that information. Two days later, having heard nothing, the clinic called again, and a PBM specialty pharmacy representative told them that indeed prior authorization was required. That same day, the clinic arranged for prior authorization, called the PBM specialty pharmacy back, told them the medication had been approved, and requested that they now call the patient and arrange for delivery. The PBM specialty pharmacy representative refused, however, stating that the prescription was still 'being processed.'

Having had enough, the clinic manager asked to speak with a supervisor, who under pressure, agreed to deliver Marvin's medication on March 7th. However, the date came and went, without any medicine being delivered; nor did Marvin or his clinic receive any phone calls from the PBM or specialty pharmacy, to let them know about or explain the additional delay. When the clinic called back the next day, the PBM specialty pharmacy representative told her that the medication was out of stock, but they would arrange for delivery on March 9th.

Because of the PBM delays and runaround, Marvin's neutropenia continued to go untreated for nearly two weeks, leaving him vulnerable to any number of infections and diseases that his body was unable to fight off on its own.

Dealing with PBM bureaucracy often feels like being trapped on a merry-go-round, with no way off. Every issue is handled by a different person or entity, each with its own agenda and protocols, and there is no one person who has a bird's-eye view of the patient's situation. Nor is there any accountability or certainty that the promises made will be met.

PBM SPECIALTY PHARMACY INDIFFERENCE DELAYS MEDICATION FOR TWO MONTHS

Darla had been taking a medication to treat her thyroid cancer since June. Then, in January her insurance provider changed to a new PBM, although they assured Darla that she would be able to continue filling her prescription at her doctor's in-house pharmacy. However, when it came time for her January refill, the PBM denied the clinic authorization to fill the script, saying it had to be filled at their own specialty pharmacy.

Despite being a federal government-supported plan under Obamacare, which mandated that the PBM consent to any

"willing provider," Darla never received her January refill. By the time the PBM contacted her for benefits verification, an entire month had gone by. Another week passed, and then another, without Darla ever receiving her medication.

Six weeks later, on March 7th, the PBM called Darla to schedule delivery, but there was more to come. Now her case was passed on to the PBM clinical department, where they needed to verify the dose, diagnosis, allergies, and drug interactions, despite the fact that Darla had been on the medication already for nearly ten months.

Once everything was verified, someone at the PBM realized that the medication was being used off-label. They called up Darla's oncologist, who confirmed that the patient had received prior authorization back in June to use the drug for thyroid cancer. He also asked the PBM specialty pharmacy representative for an explanation as to why it had taken so long to get Darla her medicine, and why there had been so many lags in communication, but the PBM representative had none to offer. As the call came to an end, the physician asked if Darla could now finally get her medicine. "No," the specialty pharmacy representative said. "Now we forward to the payment verification center. Once complete, it will be forwarded to the dispensing center. Then we can ship it out."

If Darla had been allowed to purchase her meds from the in-office pharmacy at her oncologists practice, she would have had them within 48 hours at the most. With the PBM specialty pharmacy, it took closer to two months.

Even when PBM specialty pharmacies are unable to provide a patient with the necessary medicine, they still will not release that patient so he or she can purchase it where it is available. The greed is so deep that they would rather risk a patient's life than allow another pharmacy to profit in their stead.

About the Community Oncology Alliance

The Community Oncology Alliance (COA) is the only non–profit organization dedicated solely to preserving and protecting access to community cancer care, where the majority of Americans with cancer are treated. COA helps the nation's community cancer clinics navigate a challenging practice environment, improve the quality and value of cancer care, lead patient advocacy, and offer proactive solutions to policymakers. To learn more, visit www.CommunityOncology.org