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Cancer Care

Bureaucracy, Deadly Delays, and Apathy:

Pharmacy Benefit Manager Horror Stories — Part III

The dire consequences of having Pharmacy Benefit Managers (PBMs) within the United States' health care system continue to be seen, especially by the millions of cancer patients across the nation who must interact with them to access life-saving drugs.

Initially established as a way for insurance companies to outsource the management of drug benefits, PBMs have slowly morphed from simply handling prescription transactions to managing pharmacy benefit plans, negotiating with drug manufactures for discounts, and determining which drugs a patient will receive and from whom they will receive them. It's even reached the point where PBMs have become so bold as to usurp physicians' treatment decisions without consulting or notifying them of their actions.

This paper is the third in a series from the Community Oncology Alliance (COA) that focuses on the severe impact PBMs are having on cancer patients today. The stories are all real and provided by community oncology practices; only the patient names have been changed, to protect their privacy.

The vast number of horror stories from PBM abuses that are being reported by COA and others, shows the devastating result these institutions are having on patient care. From medication never sent or never received and mistaken dosages, to insurmountable red tape erected between the patient and their treatment, the problems are numerous and lead to one incontrovertible conclusion: action must be taken to stop PBM abuses.

PBM-PHARMACY ERROR NEARLY KILLS PATIENT

Carla, a colorectal cancer patient, was prescribed a common oral medication that has been on the market for nearly 20 years. Carla's PBM mandated that she fill the prescription at a large, well-known specialty pharmacy. Each time, the pharmacy had the medicine auto-shipped to Carla, with no patient contact or instructions.

Carla's oncologist prescribed the medication to be taken in rounds with the following specific instructions: 'two weeks on, one week off'. The PBM mail-order pharmacy, unfortunately, neglected to include the 'one week off' part of the instructions on the label. After her third refill, Carla ended up in a hospital's intensive care unit, fighting for her life.

Carla's experience was the straw that finally broke the camel's back, and the practice established its own oncology pharmacy with a pharmacist-managed program. However, many of their patients are still required to purchase their drugs from PBM-mandated, mail-order specialty pharmacies.

PBM pharmacies have been repeatedly documented making life-threatening mistakes; yet patients are forced to remain with them, unable to receive their medication at their physician-managed pharmacy, where they would receive the close, personalized care and monitoring that would easily prevent such potentially fatal occurrences from happening.

A PBM BUREAUCRACY FAILS TO HELP PATIENTS

Dylan had been on a specific medication for several years to manage his chronic cancer. Each time, he would simply fax the refill script to his pharmacy and the prescription would be filled with no glitches. Dylan's new insurance policy, however, required him to now fill his prescriptions at a specific PBM specialty pharmacy.

As usual, the clinic treating him faxed his refill prescription over to the new pharmacy in mid-May and Dylan waited for his medication to arrive. He waited and waited. In fact, over

the next few weeks, Dylan's wife began calling the pharmacy on a daily basis, asking them when the medication would arrive. Each time, she was told there was some issue delaying delivery, but that it would be resolved in just a day or two, not to worry. Every few days, she would call back to say it had still not arrived, only to have the same conversation with a different person.

Finally, after over a month of waiting, Dylan's wife asked his oncology clinic to intervene and one call from them determined the actual problem. Apparently, the prior authorization for the medication had expired, something no one at the specialty pharmacy had bothered to inform Dylan, and no one his wife had spoken to had bothered to check what the real issue was holding up delivery. The clinic handled the situation, arranging for authorization and for the medicine to finally be shipped.

Patients and practices often find their efforts to be futile in trying to overcome the massive bureaucracy morass they face with PBM-mandated specialty pharmacies. This creates a costly burden on the physician offices throughout the country, who must now take up the task of contacting pharmacies, resubmitting medication approval, locating missing prescriptions, questioning holdups, and more. But what of the thousands of patients out there with no one in their corner, who are forced to fight these battles on their own?

ONE-SIZE FITS ALL IS NO WAY TO TREAT A CANCER PATIENT

About a year ago, Darlene was diagnosed with multiple myeloma and prescribed a particular medication. Single and living alone, Darlene decided she would continue to work full-time while being treated for the disease.

The first hurdle Darlene met was getting her 21-day supply of medication filled by the mail-order pharmacy mandated by the PBM. The pharmacy called her while she was in a meeting at work and insisted that she listen to the mandatory recital of the "Patient Understanding." They promised it would take no longer than five minutes, yet forty-five minutes later, having been transferred to four different representatives as part of the process, Darlene finally hung up the phone.

While confused and upset, Darlene also felt relieved that the PBM ordeal was over, and all she had to do now was to wait for the medication to arrive. She could not have been

more wrong. Although Darlene had made it very clear that she arrives home every day from work at 4:30pm, two days later Darlene arrived home to find a note on her door that UPS had tried to deliver her medicine at 2pm. She spent the rest of the day trying to locate the medicine.

After a great deal of effort, Darlene managed to schedule future deliveries of her medication for Saturdays before 1pm. Darlene is hard of hearing, so that Saturday, she sat in her front room from 8am to 1pm, afraid to even go to the bathroom lest she miss the knock on the door. At 2pm, she opened her front door and found a note from the UPS driver that he had attempted to make the delivery but found no one at home. Again, she had to chase down the package and finally ended up retrieving her drugs from a drop center twenty-five miles away from home.

As time went on, Darlene's situation only worsened, becoming more and more time-consuming for this elderly woman who was already contending with a fatal cancer. Each time she attempted to speak to a PBM representative to resolve the issue, she was passed to a new person who refused to listen to what Darlene had to say, but rather droned on repetitively that Darlene must "follow procedures" or she would not receive her medication.

Not every cancer patient has a vast network of family and friends who are there to assist them in their time of need. Often the elderly, or those living alone without close friends nearby, are forced to handle everything by themselves. While a physician-managed pharmacy would be able to adjust to such a patient's needs and assist them in easily accessing their medication, PBM mail-order pharmacies are not set up to handle the requirements of individuals. Patients must comply with their procedures and regulations, regardless of the personal cost.

POTENTIALLY FATAL DELAY IN DELIVERY

Bertrand was diagnosed with renal cell carcinoma and prescribed a specific oral medication by his doctor. The oncology clinic sent out his prescription to the PBM-mandated specialty pharmacy on February 4th. Four days later, the clinic called the pharmacy to follow up, and was told that the pharmacy was waiting for additional information from Bertrand. Ten days later, they called again to see where things stood, and were told that while the pharmacy had tried to call the patient and schedule delivery, they had been unsuccessful in reaching him. The

patient's clinic asked why the pharmacy had not tried to call the patient's doctor; were they not aware that Bertrand was suffering from renal cell carcinoma, and that it was quickly progressing without medication?

Another eleven days passed — nearly one month from the initial prescription — and Bertrand informed the clinic that the medication had still not arrived. The clinic once again called the pharmacy and were told that the pharmacy had closed the patient's account there, having been unable to reach him and verify his information in order to schedule shipment. The clinic then called Bertrand and asked him to contact the pharmacy in order to re-open his account and immediately schedule delivery.

Nearly forty days since being prescribed the medication, Bertrand had still not received it. The oncology clinic ultimately filed a formal complaint with the insurance company and is waiting for a resolution. Meanwhile, Bertrand continued to wait, though his cancer did not; in fact, between Stage I and Stage IV of renal cell carcinoma, five-year survival rates go from 90% down to 10%.

Time and again, patients wait for medication from PBMs that will never arrive — because of a small detail missing in the documentation, or a situation that requires the specialty pharmacy worker to take some proactive measure. These workers, with their passive attitude towards patient care, unfortunately, do not see themselves as partners to the process, nor do they see it as their responsibility to shorten the time needed to deliver patients' medication.

COMPLETE INDIFFERENCE TO A SITUATION'S URGENCY

Lorraine, a multiple myeloma patient, was being denied by her insurance company the medication prescribed by her doctor. A worker at the clinic where she was being treated called Lorraine's PBM to sort the matter out. She got through to a company representative and began reviewing the situation until, at some point, the call was disconnected. Upon calling back, the worker had to start all over from the beginning with a different customer service representative.

A few days later, she called the PBM a third time, reaching yet another representative, who seemed unable to understand the situation. The clinic worker asked to speak to a supervisor, yet she turned out to be even more abysmal than the prior three representatives, both in terms of her attitude and her inability to understand the

situation. The supervisor transferred the matter over to someone in appeals.

Now, the clinic worker found herself speaking to a fifth employee of the PBM who became even more aggressive, and questioned the worker's role in the doctor's office and her right to be making the call. When the worker began to conference the doctor in, so he could participate in the phone call, the PBM representative hung up on them.

As a last resort, the worker tried reaching someone in the PBM investor relations department, and had the call transferred over to the executive escalation team. She began by emphasizing the urgency of the matter; the longer it took to get Lorraine her medication, the worse her prognosis. She added that their office would be contacting both Medicare and the Insurance Commissioner's office in Maryland, to complain about the unprofessional handling of the matter with a patient's life on the line. Within twenty-four hours, there was a case worker assigned to Lorraine's case, yet no knowledge yet of how long it would be before — or even if — Lorraine would receive authorization for the lifesaving treatment she needed.

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. Patients must wait for weeks or even months, to obtain medication that they could have received within twenty-four hours, had they been permitted to get it at the point of care from their oncologist. These delays often translate into delayed treatment and worsening of the patient's condition, and in the most tragic of cases, possibly contribute to the patient's death.

BUREAUCRACY LEAVES A PATIENT IN LIMBO

Janine, a 22-year-old woman with Hodgkin's lymphoma, was prescribed a specific medication for fertility preservation. Her clinic's representative contacted the PBM specialty pharmacy to determine if prior authorization was required for the drug, and what Janine's co-pay would be.

The PBM pharmacy representative rudely responded that Janine's doctor needed to follow the proper procedures: send in the prescription and wait the necessary two days before obtaining the benefits information. The clinic representative explained that they only wanted the benefit information in order to make a treatment decision; that without knowing the co-pay they didn't know if Janine

could afford the medication, and therefore didn't know whether or not to prescribe it.

The response was that the PBM specialty pharmacy could in no way help in this, nor could they refer them anywhere for more information. As a result, the clinic's hands were tied; they had no idea if the insurance company would authorize the medication, and if not, if Janine would be able to afford them on her own.

PBM specialty pharmacies have a long list of complex bureaucratic protocols, but shouldn't they be able to help patients and practices make cost saving decisions? Unfortunately, PBM bureaucratic protocols are often harmful to the very patients they are meant to help.

ONE DANGEROUS MISTAKE AVERTED... HOW MANY AREN'T?

Maria was a colon cancer patient prescribed several rounds of chemotherapy. For her first round of treatment, all went smoothly; she was permitted to fill the drug prescription right there at her clinic's physician-run pharmacy. However, for the second round of treatment, her insurance company mandated that she use one of the large, well-known PBM specialty pharmacies.

The problems began when the specialty pharmacy delivered Maria's medicine late, which delayed the beginning of her second treatment round. The following month, things worsened. Maria had suffered profound side effects from the medication, causing her oncologist to lower the dose for her third round of treatment. When Maria called the pharmacy, however, they said they had no record of the new prescription on file — though it had been sent and received.

Confusingly, shortly after the call, the PBM pharmacy called Maria back and said the medicine was about to be shipped. Upon her inquiry, the pharmacy informed her of the dosage; it was the same dosage and instructions as the previous two rounds, which had caused the intolerable side effects. Maria proceeded to spend the next several hours on the phone with the pharmacy to correct the situation. In addition, her physician's office called and spent time clarifying the matter with them. Had Maria been any less vigilant, her health could have been severely compromised by such sloppy drug administration.

With PBM specialty pharmacies being run completely separately from the point of care and physicians, patients must be extremely vigilant at all times to ensure they receive the correct medication. For cancer patients who are already dealing with a life-threatening disease and a range of debilitating side effects of the toxic medications they are on, this additional burden can be very costly — and for some, simply not feasible.

TOTAL INDIFFERENCE TO PATIENT'S PROGNOSIS

James was a patient in his late 50s, suffering from advanced renal cell carcinoma. On May 18th, his oncologist prescribed a particular medication, and they began a two-week wait for his insurance company to approve usage. Upon receiving approval, the doctor's office sent the prescription over to James' PBM-mandated pharmacy, with a request that it be handled ASAP, as the patient's situation was dire.

One week after making the urgent request and having heard nothing, the practice followed up to ascertain the status of his prescription. A few days later, a response came back from the pharmacy that they had attempted to contact James twice, but had not succeeded to reach him. They asked the doctor's office to have the patient call the pharmacy himself. The office asked the pharmacy if and when they had been planning to contact them, to notify them that there was an issue with delivering James' medication. The pharmacy responded that their policy is to try phoning the patient three times, and then they either contact the prescribing doctor's office or simply mail the prescription back to the patient.

While the PBM bureaucracy failed to try to remedy the situation, James' cancer continued to spread, untreated, leaving him no closer to receiving his medication than he had been three weeks earlier. As for the PBM pharmacy, they seemed completely unconcerned, despite the fact that the five-year survival rate for advanced renal cell carcinoma goes from 53% down to 8%, if it passes from Stage III to Stage IV.

Time and again, doctors reach out to PBM-mandated specialty pharmacies to enquire about the status of medication— only to discover that the process is stuck, and no one at the pharmacy feels any sense of urgency, despite the fact that the patient in question is being treated for a life-threatening condition in which time is of the absolute essence.

THE HORROR IS NOT LIMITED TO CANCER DRUGS

Carl was prescribed regular injections of anticoagulant medication. The initial prescription was sent off to the local branch of a major pharmacy and filled without issue. Three weeks later, however, when Carl tried to refill his medication, the pharmacy charged him a \$700 co-pay. They explained that they could not offer refills; they must go through his PBM-mandated specialty pharmacy. Now there was an emergent situation because Carl needed those syringes immediately.

Carl paid the high price to obtain four syringes, which was all he could afford, while his doctor contacted the insurance company, who said that if the local pharmacy would call them, they could offer an override. The doctor called the pharmacy with the terrific news, only to hear them refuse the request, outright. “We don’t have time for this,” they said. “If the customer wants an override, he needs to make the call himself.”

Several hours later, Carl received a call from the local pharmacy, saying that they had spoken with his insurance company, and that the mail-order pharmacy will need

a new prescription. No word about the override — they hadn’t even bothered to enquire about it while on the phone with the insurance company. Three hours later, the mail-order pharmacy sent Carl’s doctor a request... only it was for a refill on medication used to prevent side effects caused by chemo and radiation — not for the anticoagulant meds that Carl actually needed.

At this point, Carl was twenty-four hours away from being out of medication. Adding to the absurd irony of the situation, Carl’s doctor actually had an in-house pharmacy that stocked the necessary medicine. However, while the pharmacy was once part of the network of Carl’s insurance company, in 2011 their contract had been cancelled, as they presented competition to the PBM’s specialty pharmacy.

Even when PBM specialty pharmacies are unable to provide a patient with the necessary medicine, and even when the situation is urgent to the point of life and death, 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