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Cancer Care

Delay, Waste, and Cancer Treatment Obstacles:

The Real-Life Patient Impact of Pharmacy Benefit Managers

There is growing awareness of the problems and pitfalls with Pharmacy Benefit Managers (PBMs) in the United States health care system. Contracted by insurance carriers to negotiate on their behalf with pharmaceutical companies, these ‘middle men’ corporations have quietly become an unavoidable part of our nation’s health care system. Controlling at least 80 percent of drug benefits for over 260 million Americans, PBMs have the power to negotiate drug costs, what drugs will be included on plan formularies, and how those drugs are dispensed. Oftentimes, patients are required to receive drugs through PBM-owned specialty pharmacies.

However, while the role PBMs play in the U.S. health care system is complex and under scrutiny by policymakers and the public, with much of the debate focusing on economics, little discussion takes place of the impact PBMs have on patients.

This paper is the first in a series that will focus 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.

AN AVOIDABLE DEATH?

Derek, a young husband, was diagnosed with advanced melanoma with brain metastases. Prognosis was grim, yet a ray of light appeared in the form of a new drug prescribed by his doctor. Proven to have the potential of significantly extending life, the drug offered Derek and his wife real hope. Located in his doctor’s office was the clinic’s pharmacy, where this potentially life-prolonging medication was simply waiting on the pharmacy shelf— but not for Derek. Derek’s PBM mandated that Derek purchase his meds from one of their own mail-order specialty pharmacies. The clinic immediately faxed to the PBM all the necessary information for receiving prior authorization, and for the next ten days, Derek and his wife waited to hear that the prescription had been approved. Upon receiving the go-ahead, they then faxed the prescription to the PBM’s specialty pharmacy, and sat back to wait again.

One week later, the drug still had not appeared; instead, the couple was notified that they first had to remit the drug’s

\$1,000 co-pay, an amount they were unable to afford. Derek’s wife now began arranging co-pay assistance, but she had to deal with the matter on her own at this point, because Derek had been admitted to the ICU. Several days later, she received approval for co-pay assistance, and forwarded the information to the PBM’s pharmacy, which then FedExed the drug to Derek. The medication finally arrived— only there was no one to take them. By this time, Derek could no longer swallow pills, and sadly, shortly after, he died.

The most common and devastating issue that cancer patients face with PBMs is the fact that they must wait, for weeks or even months, to obtain medication that they could have received within 24 hours, had they been permitted to get it at the point of care from their oncologist. Beyond the stress and aggravation incurred, delays in receiving medication often translate into delayed treatment and worsening of the patient’s condition, and in the most tragic of cases, possibly contributing to the patient’s death.

TREATMENT DELAYED DUE TO PHARMACY RESTRICTIONS

Bill was prescribed an oral medication that works to prevent his cancer cells from replicating, thus reducing the growth and spread of the disease. His oncologist faxed the prescription to the specialty pharmacy indicated by Bill's PBM. Unfortunately, this particular pharmacy does not carry the medication prescribed, and so they forwarded the script to another specialty pharmacy that does carry it. However, that pharmacy does not accept Bill's insurance.

So, the prescription was forwarded again to yet another specialty pharmacy, which is the preferred pharmacy of Bill's insurance company. However, they don't carry the medication either. By this time, ten days have passed since the medication was first prescribed. Bill's physician, attempting to expedite things, now sends the prescription to a fourth specialty pharmacy that does carry the meds, and personally calls the insurance provider to explain the situation and ask for immediate approval. Five days later, and more than two weeks since the initial prescription was made, Bill receives his medication.

Agreements between insurance carriers and PBMs, which may be part of the same corporation, grant them full authority to determine where patients may or may not purchase their medication. This is carried out regardless of the detrimental effect it often has on patient health and wellbeing. In such a system, one must wonder whether the objective of curing patients from terminal disease has been usurped by that of achieving financial gain.

MEDICATION DELAYED 6 WEEKS DUE TO PBM SPECIALTY PHARMACY INDIFFERENCE

Carol was battling metastatic colon cancer. Unable to receive the same chemotherapy Carol had been treated with initially, her oncologist prescribed a medication to help stop the cancer from spreading any further. Her physician sent all documentation necessary to the specialty pharmacy mandated by Carol's PBM.

One week later, when Carol's oncologist phoned the PBM-mandated pharmacy to check on status of the prescription, again, they were told that nothing had been done— they refused to process the prescription without knowing Carol's current weight. Rather than calling Carol or the doctor to ascertain the necessary information, they had simply done nothing.

Another week went by, and the doctor called in again to check on the prescription. This time she was told that there was a form the doctor needed to fill out, in order to request Prior Authorization from the PBM. The doctor couldn't understand

why they hadn't simply sent the form to her— or told her about it a week ago, when she had called. Eventually the doctor received the form, filled it out and submitted it, as Carol continued to wait and her cancer continued its lethal advance. Ultimately Carol received the medication— a full six weeks after it was initially prescribed, the most terrible irony being that had she been allowed to receive the pills at the site of care, she would have had them within a day.

Another serious issue patients and doctors face with PBMs and specialty pharmacies is their passive attitude towards patient care. Time and again, patients and doctors wait for medication that will never arrive. One small detail missing in the documentation is enough to delay its delivery, and the specialty pharmacy staff, who do not see themselves as partners to patient care, also do not see it as their responsibility to take any action to hasten the process.

LIFE-SAVING TREATMENT POSTPONED

Barbara, who was battling brain cancer, was prescribed two drugs: one a form of chemotherapy and the other an antiemetic that would alleviate the symptoms of nausea caused by the chemo. Both were to be taken in conjunction with the radiation treatments scheduled to begin six days later.

At Barbara's clinic, well aware of the urgency of the situation, the nurse on call faxed Barbara's prescriptions over to her PBM-mandated specialty pharmacy, and at the same time, applied for prior authorization from Barbara's PBM. Five days later the nurse called over to the pharmacy, asking for an update, since neither she nor Barbara had heard anything. The pharmacy worker informed the nurse that the prescriptions had indeed arrived and they were now about to enter them into their system to see if prior authorization was necessary.

The nurse was nonplussed— why had the prescriptions not been entered five days earlier, when they were sent and received by fax? And what if the nurse had not called to follow up; how much longer would it have taken? Most importantly, how is it that the PBM-mandated pharmacy staff, who are dispensing medication aimed to keep people alive, do not see it as their duty to provide customers with the very best and fastest service possible? Barbara's radiation treatments, scheduled to begin the next day and already delayed nearly a week, now had to be postponed until the medication could be received.

Multiple cases are reported in which doctors must reach out to PBM-mandated specialty pharmacies to enquire about the status of medication— only to find that while the pharmacy has received the patient's prescription, it's been just sitting on someone's desk, untouched, with no concern for the person on the other end, who is being treated for a life-threatening condition.

PATIENT DENIED MEDS DUE TO TECHNICAL GLITCH

Carl, battling prostate cancer, was prescribed an oral chemotherapy drug to help control his disease. Under his insurance plan, however, the co-pay costs for the medication came to over \$4,000 per order. Carl simply could not afford to pay such an exorbitant amount. Fortunately, the pharmaceutical company that manufactures the drug has a co-pay program of its own, for eligible patients, making the drug affordable. Furthermore, the in-house pharmacy at the clinic where Carl receives his treatment benefits from this arrangement, and is able to acquire these and other cancer drugs for the low patient co-pay of \$20.

The clinic phoned Carl's PBM on his behalf, explained the situation and asked them to accept the pharmaceutical company's co-pay as a 'secondary insurance.' Their request was promptly denied, as the PBM explained that their system did not have the capability to add in a secondary insurance. When asked if they could then simply authorize the clinic to fill the prescription instead, as they had it right there, this was also refused. Unwilling to believe that his patient was not going to receive this medication because it could not be entered into the PBM's computer system, Carl's physician made repeated calls to the PBM, speaking to one supervisor after another. Ultimately, he was forced to admit defeat, and Carl was denied a treatment that might have extended his life.

Patients who receive medication at their treating physician's in-house pharmacy benefit from the fullest in personal care and attention, and have access to a team that will strongly advocate on their behalf. Patients who are forced to deal with PBMs and specialty pharmacies, on the other hand, are often relegated to numbers and statistics, and if their case requires special attention or extra effort, their needs are likely to go unmet.

BUSY SIGNALS AND PBM SPECIALTY PHARMACY PROTOCOLS DELAY DRUG DELIVERY

PBM specialty pharmacies require patients to schedule delivery of their medications by phone, which seems, on the surface, a simple enough task. John, who was undergoing chemo for bone cancer, tried for an entire week to get through to his specialty pharmacy and schedule the next delivery of his medication, but no matter what time of day he called, the line was always busy. Finally, one day before he was supposed to start a new chemo cycle, and with no medication left, John called the clinic in frustration, and asked if they could intervene in some way.

Calling the specialty pharmacy, John's clinic was able to speak with a representative. "You are lucky you got through!" she

was told by the rep. "Our lines are so busy, we cannot make outbound calls because all of our lines are used up." Their luck ran out fairly quickly however; as the clinic staff member was not on John's list of 'approved' contacts at the pharmacy, she was unable to speak on John's behalf and schedule delivery of the medication. And with the lines tied up throughout the day, the specialty pharmacy rep was unable to call John to verify. The clinic staff hung up, and had to call John back to tell him his only recourse was to continue trying to call in and hope that he will eventually reach someone— before it becomes too late to matter.

Another reason for delays in receiving medication from a PBM specialty pharmacy is the difficulty in adhering to their complex bureaucratic protocols. Pharmacies insist on speaking to the sick patient firsthand, hearing them name the drug, and confirming their shipping details before they will send the medication. However, patients often miss these calls, which are most often automated, and which stop after three missed attempts. In many cases, even when the patient answers the phone, they cannot confirm the name of the drug, causing another cycle of delay to begin.

SPECIALTY PHARMACY TRIES TO STEAL A PATIENT

For two days, a PBM specialty pharmacy had been calling and faxing a doctor's clinic, which offers a pharmacy to provide integrated care to the patients it treats. The specialty pharmacy was claiming that one of the clinic's patients, William, had requested that his lung cancer medication be transferred to their pharmacy, and was demanding the clinic's immediate compliance in the matter.

Surprised by the news, the physician contacted William to enquire about his decision, only to discover that this was the first time William had heard of the matter. "Please do not transfer it anywhere else!" William asked. "I want to get it filled through the dispensary. I did not ask for this. I love being able to get this right away and with no hassles. I was on an oral chemo before and it was filled by a specialty pharmacy and I always was getting it late, missed a few days of medication sometimes and had numerous phone calls from them. They never seemed to know what was going on with my medication."

At first it may seem surprising to hear of a specialty pharmacy resorting to lies in order to steal business from an in-house dispensary. On deeper examination, however, it would seem just the next step in a long line of unethical behaviors resulting from the industrialization of the pharmacy system and the dehumanization of patients seeking medical care.

PATIENT AND CARE PROVIDERS GET THE RUNAROUND

Diana, a patient with metastatic breast cancer living in Ventura County, California, needed to refill her oral medication. On a Thursday, the clinic staff called in to the PBM specialty pharmacy to refill it on her behalf. The specialty pharmacy representative promised to expedite the process and overnight the medication, at no additional cost.

On Monday morning, the staff member walked into her office to find several faxes, e-mails and voicemails from Diana's family, friends and assisted living staff. Apparently, they had received a phone call from the specialty pharmacy on late Friday afternoon, saying that the drug was out of stock in their pharmacy, and suggesting that she call around to local pharmacies to try and find some. Over the weekend, Diana's family and friends called every pharmacy in the county, before starting on those in Los Angeles and Santa Barbara, all with no success.

Hearing the news, the clinic staff immediately contacted the drug manufacturer, who gave her the name of another specialty pharmacy to try. She faxed over the prescription, and then followed up over the next few days, each time being told that the script was being processed. Near the end of the week, the new specialty pharmacy called her to say that they were unable to fill the prescription for at least another month, as it had already been filled by the initial specialty pharmacy—the one that had said they were out of stock. The staff member now called back the first specialty pharmacy, asking that they reverse their claim; however, they reported

that the medication had already been shipped out via UPS. Tracking it down, the staff member discovered that indeed the medication was on the truck, ready for delivery.

The cost in hours wasted per patient, per medicine, multiplied by the millions of people living with cancer today in the US, is astronomical. This is in addition to the high toll that the resultant stress takes on patients and their caregivers, as they race through bureaucratic hoops and set off on what often prove to be wild goose chases.

THOUSANDS OF DOLLARS IN WASTED MEDICINE

Laura was prescribed a regimen of drugs to treat her multiple myeloma. She was supposed to take it for three weeks, and then take a break for a week. After two weeks on the medication, Laura began exhibiting symptoms of toxicity, so her oncologist lowered her dosage. However, her specialty pharmacy had already sent her another bottle of the medication in its initial, stronger dosage, to be used the following month. Unable to be returned, the \$12,000 worth of medication had to be taken into the clinic and destroyed.

Numerous instances are reported in which patients' therapies have changed, but the specialty pharmacy continues to send the medicine anyway. For expensive anti-cancer drugs and therapies each wasted delivery can be worth tens of thousands of dollars. Each time, the medicine must be brought in and destroyed—a shameless waste of money, time and medicine.

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