Health Coverage Denied?
Appeal. *You might win!*

“The American healthcare system just isn't really set up for ordinary individuals to fix these kinds of things when they go wrong. Whether it is the insurance company trying to save a penny or it’s an incorrect code, patients often end up getting caught in the middle, and really fearing for their health or their financial security. “ - ***Miranda Yaver.***

What happens when your child can't breathe? You rush her to the emergency room, do exactly what doctors tell you, and weeks later, your insurance company tells you the visit wasn't medically necessary?

Welcome to **Code WACK,** where we break down how our healthcare system really works, what it means for you, and how we can make it better for everyone. I'm your host, **Brenda Gazzar.**

(intro music)

Today, we're talking about one of the most frustrating experiences in American healthcare when your insurance company says no. According to **Miranda Yaver, an assistant professor of health policy and management at the University of Pittsburgh,** insurance denials aren't rare. They're a routine part of navigating our healthcare system.

But what surprised her most wasn't how often people are denied. It was how many people simply give up.

Her new book, ***Coverage Denied: How Health Insurers Drive Inequality in the United States,*** explores what happens when patients find themselves trapped between doctors recommending treatment and insurance companies refusing to pay for it.

The stories she covered are heartbreaking, sometimes infuriating, and surprisingly hopeful. One story especially stayed with her. It involved a then four-year-old girl named Emma.

Yaver: Emma was the daughter of a couple of parents who I interviewed and she was young. She was having difficulty breathing, which of course is very scary if that's your little one. And what ended up happening was she had such bad tonsillitis that her tonsils were actually protruding and closing in on her airway, and making it really difficult for her to breathe, because she just was gasping for air all night long. They did what any concerned parent would do. They took her to the emergency department. They gave her a steroid. She was already on the schedule to get the tonsillectomy, but it was in a few days and so basically they were able to get her breathing better and send her home and then she had the tonsillectomy and was doing fine.

For Emma's parents, it should have been the end of a frightening ordeal. Their daughter was breathing again. The surgery was successful. Life could return to normal. Instead, a new crisis arrived in the mailbox.

Yaver: But then they got this huge $8,000 or so dollar bill in the mail, arguing that this emergency department visit was not medically necessary after all. And this was a lower middle class to lower income family that was really devastated and worried that they could potentially lose their home. They didn't have anything in the way of savings. And it was only because the father knew to pull any string he could, including complaining about this on social media, that they were able to get their insurance company to listen.

Think about that for a moment. A child who couldn't breathe. Parents who rushed her to the ER. Doctors who treated an airway emergency. Yet somehow an insurance company concluded it wasn't medically necessary. How does that happen? The answer wasn't what Miranda expected.

One of the really shocking things that happens all too often is that there can be billing code errors. And so there are some denials that I look at in my book that are truly the insurance company deciding whether accurately or inaccurately that something is not medically necessary. Sometimes the insurer will say, 'Oh, this is experimental or investigational and we're not gonna cover that.' But sometimes these medical necessity decisions are because the wrong code was entered. And in this case, *the hospital actually screwed up and they had basically coded the whole ordeal as a sore throat.*

A sore throat. Not respiratory distress. Not a child gasping for air. Just a sore throat. One billing code. One clerical mistake. An $8,000 bill.

Yaver: And obviously there is a world of difference between having a sore throat that's uncomfortable and literally gasping for air and struggling to breathe, but that wasn't

reflected in the coding. And it sounds like a very simple thing to clarify and say, ‘no, that shouldn't have been the code that was used.’ But as my book exposes, and I'm sure you and I and the listeners here have experienced all too often, the American healthcare system just isn't really set up for ordinary individuals to fix these kinds of things when they go wrong. And so whether it is the insurance company trying to save a penny or whether it's an incorrect code, patients often end up getting caught in the middle and really fearing for their health or their financial security.

Eventually, the family convinced the insurance company to reverse the denial. But that victory came at a cost. Hours on the phone, stress, fear, and the very real possibility that the next emergency could produce another crushing bill.

Yaver: It was one of those things where, you know, getting stuck on hold at a time when they were supposed to be working, playing phone tag, all of the kinds of things that we've probably all experienced at one time or another but, you know, when it's trying to fix a $200 bill, it's a lot less stressful than an $8,000 one. And this was someone whose family's only income was them working at an airline.

They had four kids and it was, it was a real absolute terror. And, and the family talked about how much care they themselves delayed because even as they were able to get the insurance company to reverse this decision, you know, there was a lot of fear of what if the next thing gets denied? What if we end up staring in the face of these bills yet again? We just don't have the financial wiggle room.

As Miranda dug deeper, she discovered story after story of patients who did everything right. Only to find themselves fighting their insurance company instead of focusing on getting well. One of those patients knew insurance companies well, and even she couldn't get the care her doctor said she needed.

Yaver: So the story with which I open chapter two is someone who, unlike Emma's family, did not come from a lower income background. They had a lot of health literacy with which to navigate this, and they were still really struggling. So this individual, who I call Jessica, actually works in insurance sales, not health insurance, but works in insurance sales, understands how insurance works, and is college educated in New Orleans.

Jessica also had a serious medical condition, a severe immune deficiency, the kind of illness that made everyday viruses far more dangerous, especially during the COVID-19 pandemic.

Yaver: Her doctor recommended that she get something called subcutaneous immunoglobulin therapy, or SCIG, which could help her fend off all the kinds of viruses to which we can be exposed, influenza, strep, all those kinds of things that we do not want to get, but our bodies are usually more resilient to fending off. But this medication is very expensive. Something around the $10,000 range and her insurance company's reason for denying it was that even though she was having repeated infections, they weren't life-threatening yet.

Not life-threatening … yet. Miranda says that reasoning struck her as profoundly backward.

Yaver: It really felt like telling a diabetic, "You can get treatment once you've gone into diabetic ketoacidosis." Like, exactly how much on death's door do we really need to be here?

The appeal process stretched on for a year. Meanwhile, Jessica kept getting sick. Eventually, Jessica did receive the treatment, but not because the normal appeals process finally worked.

Yaver: Ultimately, it actually was not an appeal process, but rather a call to her U.S. Senator that got the insurance company to reverse course. And again, it's one of those things where, great, she gets the treatment, but how many people have the wherewithal to manage a year delay? How many people think to call up their senator?

That's the question Miranda kept coming back to. Not whether one determined patient could eventually win, but how many people never even get that chance? For some patients, there isn't even a year to spare. One woman Miranda interviewed was fighting for something even more urgent. A bone marrow transplant.

Yaver: The other patient I was thinking of, Samantha, was fighting for a life-saving transplant and was literally calling her insurance company from her hospital bed because her insurance company would cover repeated ICU admissions, but wouldn't cover the actual treatment that she required.

The woman suffered from a rare inflammatory disease. Her doctors agreed a bone marrow transplant offered her the best chance of survival. But because the treatment was considered experimental for her condition, the insurer refused to cover it.

Yaver: When her treating physicians and a broad team with which they were consulting reviewed her records and decided ‘this is the way to go. This is what is going to help her to survive and thrive,’ I think that, you know, the evidence seemed to be robust in her favor and then the internal appeal doesn't go her way. The external appeal is a mixed bag because they say that the transplant would benefit her and is medically necessary. But

because it was still deemed to be experimental, that gave the insurer cover to continue to deny it.

Think about that. Independent reviewers agreed the treatment was medically necessary. Yet the insurance company wasn't required to pay for it. She kept ending up in intensive care.

Yaver: Basically she kept striking out, going through the insurance processes, and then was able to get into a clinical trial actually but she's doing well now.

A lot of Americans experience coverage delays and denials. About one in five claims in Affordable Care Act marketplace plans are denied. 36% of the people in my nationwide survey experienced denials.

The good news is that if you appeal denials, you will often win. The challenge that my book works to expose is that those appeals are so onerous for both patients as well as their physicians, that ultimately healthcare isn't so much rationed by an initial denial. Your care isn't kept out of reach because your insurance company decided that they didn't want to cover it right out of the gate. But rather this care is kept out of reach more because of these administrative barriers. The red tape that just makes it so much more challenging to overcome these initial barriers.

An hour on hold during your workday, gathering medical records while you're recovering from surgery, trying to understand insurance jargon while worrying about how you're going to pay your rent. Miranda says that's often where people give up.

Yaver: There were two really, really common reasons why people didn't appeal. One of them was that they didn't understand that they could. And the other was that they didn't understand that there was a value in appealing.

Insurance companies are required to tell patients they have appeal rights. But according to Miranda, that doesn't mean people actually understand those rights.

Yaver: You have to be told why you're denied and that there's an appeal process. But a lot of health insurance materials are written at a very complex level.

Then there's another misconception. Many patients assume the insurance company always wins, but Miranda's research found something very different.

Yaver: About half of appeals are successful. So if you are denied, you should absolutely appeal. But I asked everyone in my survey, how often do you think people win insurance appeals? And most people thought it was under 20%. And it makes sense. You know, you think, "Oh my gosh, I'm just one person. How could I possibly go up against this corporate giant?" But a lot of people who do end up winning.

Emma's family eventually got that $8,000 bill overturned. Jessica eventually got the medication her doctor had prescribed. The young woman fighting for a bone marrow transplant ultimately found her way into a clinical trial and is doing well today. Those are hopeful endings. But as Miranda points out throughout Coverage Denied, they also have something in common. Each required extraordinary persistence. A father who took to social media. A patient who contacted a US senator. A woman who kept calling her insurance company who was fortunate enough to find her way into a clinical trial.

For every story that ends this way, how many others never do? How many people decide they simply don't have the time, the energy, or the resources to keep fighting? Those are the patients Miranda worries about the most, and they're the reason she wrote Coverage Denied.

Next time on Code Wack, we'll continue our conversation with Miranda Yavar and explore what policymakers, insurers and patients can do to reduce unnecessary denials and what reforms could make the system work better for everyone.

I'm Brenda Gazzar. Thanks for listening and stay healthy.