

# Healthcare Delivery: Lost in Red Tape?

By Sue Romanick, MD

The story of one physician's journey to coordinate care for a child is a worrisome example of the ways in which the healthcare system is configured for potential failure.



What happens when a patient gets caught in limbo due to reimbursement issues, a lack of treating physicians or simply because his or her medical condition can't be explained? These are situations that occur more frequently than many realize, causing significant frustration for both the physicians seeking to treat and the patient who is left without answers. Despite good intentions by all, many of the patients may never get the help they need for many reasons, all of which lie in the workings of a healthcare system that fails to focus on the patient, but instead results in a rationing of healthcare. One such example of this is a patient who has caused me to see this issue very clearly.

### **The Patient: Undiagnosed**

Mr. B is a very unusual gentleman. This was apparent from the beginning. First, he managed to steal my heart within minutes of meeting him. Second, he had baffled his physicians with his medical condition for more than two years. Finally, he broke through the usual barrier to get into my clinic. I don't usually accept his type of patient, so to speak. Why? Mr. B is only 10 years old.

Also unusual was his letter of introduction that had preceded his visit to my office. His eye doctor was, in fact, begging that I urgently evaluate him. Apparently, Mr. B had been dropped from his other doctor's practice due to "lack of clear diagnosis." At first glimpse, this would probably make some sense. Who would argue with their doctor who says: "If I don't know what your diagnosis is, then I can't treat you." But, the fact is that his team of providers had already delivered comprehensive treatment over a two-year period. This had included not only dramatic in-hospital care but also multiple high-risk medications with costs totaling more than \$15,000 per year. Moreover, over time, some of these medications had caused Mr. B to balloon to such a weight that they gave him the appearance of being severely "cushingoid" (medical jargon for collateral damage in the form of excessive weight gain or an unsightly redistribution of fat). Medically, this can mean severe obesity. To a youngster, this meant loss of self-esteem and being at risk for bullying and harassment. At least, that would be the usual part. But as I said, Mr. B was quite unusual. Which brings us to his physical examination.

When I asked Mr. B to cover his right eye and tell me how many of my fingers he could see on my left hand, his head began to roll around on his neck in a most disconcerting, unusual way. What he was desperately trying to do was to adjust the angle of his left eyeball to see around

a very large patch of complete blindness, a hole of sorts, which he called his "purple patch." But, of course, wherever he gazed, the purple patch followed. Like a curse, he couldn't escape it. Over time, Mr. B had grown accustomed to using what was left of his peripheral vision to be able to make out shapes. I knew that he no longer had the eye pain that had originally signaled his eye problem. Yet even I could feel his current pain as he struggled to see with his left eye.

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He could have played on my heartstrings and I would have dutifully melted. But, as I said, Mr. B was unusual. When I murmured that I would like to look into his eyes with my ophthalmoscope, he replied with booming confidence punctuated by a winning smile: "I know the drill!" It was as if each of his words seemed to be patting me on the shoulder to reassure me: "It's OK, Doctor, you're going to be fine." (It was I who was going to be fine?) It was precisely at that moment that I made a commitment to help Mr. B, no matter what. So, the journey started, and I found myself drawn into the jungle of primary care providers, specialists and the potential dangers of insurance and malpractice companies.

### **The Journey: Who Is Responsible?**

The first step was to understand the problem. There was, however, a rather important detail. Time was already running out. I knew that, without continuing his medication, Mr. B could lose the sight in his right eye as well. So, I needed to get going on this.

Back to the problem: code word "obscure." As a rheumatologist and specialist in adult internal medicine, I am used to conditions that defy placement in neat little categories. The autoimmune conditions can lurk in the shadows, spring forth at will, pop up in different places at different times, and pick on the sick and vulnerable. Stated

differently, try placing a neat label on a moving target. Professionally, we use terms such as “undifferentiated connective tissue disorder” or “mixed connective tissue disease” or “undifferentiated spondyloarthritis,” to name a few of my favorites. It’s really quite simple: By the time you have uttered these terms, the patient has adopted either glassy eyes or a rather forlorn look on his or her face. Translated from the medical lingo, these terms mean: “Your condition doesn’t fall into any neat category and could change for the better or change for the worse,” sounding like the cryptic answers uttered to poor Alice in the story of *Alice in Wonderland*. Yet, the medical truth could be explained using a pictorial analogy. There is a popular illustration that originated in India depicting blind men each touching a different part of the same elephant and only that specific part. The lesson here is that if each man is asked to describe what an elephant is, then the descriptions may differ dramatically. That also is true for autoimmune conditions.

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For example, having certain eye problems could be the first sign of an autoimmune condition. Over time, this condition could spread, say, to the joints or the spine, or it could cause rash or affect the hair. The list goes on and on. The fact that Mr. B had only eye involvement, in my estimation, didn’t exclude a widespread (“systemic”) condition. In fact, this young gentleman’s blood tests showed evidence of inflammation in the blood (an elevated sedimentation rate), as well as evidence of an increased level of a substance produced by the liver in response to significant inflammation in the body (an elevated c-reactive protein). These tests showed that more than the eyes were involved. I am sorry to say that this made the distinction

between which doctors ought to be claiming responsibility for Mr. B’s treatment plan a little blurry, pardon the pun. And, yes, the actual diagnosis was obscure. But do we treat words on paper, or do we treat a process that may cause a patient to go blind if we stand by and do nothing?

The way I see it, my job as a rheumatologist is to outsmart the condition. Yet, what do you do when the enemy lurks within your own defense system? Picture a widespread network with surveillance units infiltrating normal day-to-day operations. If a rogue unit breaks away and causes problems, you want to go after it. But if you can’t isolate it from the rest of the system, you could have a problem. Simply put: Damage your immune system and you could have a big problem.

Initially, I felt an extreme sense of frustration that Mr. B had been dropped from one of the main branches of his medical team. This branch was in charge of choosing, administering and following Mr. B’s strong medications. Believing initially that a mistake had been made, I contacted my medical colleagues involved. To my shock, I was able to verify that, indeed, a letter of rejection had been sent to Mr. B’s family. The explanation given to me was simple: The diagnosis was obscure, limited to the eyes, and should be treated by the eye doctor. But there was a ringer here. The condition fell out of the realm of conditions usually treated by eye doctors because of the need to have familiarity with the other organ systems in the body that the medications can adversely affect. Also, as many autoimmune conditions can pop up in different organ systems at different times in the future, I felt it was important to keep a close eye on the patient.

As much as I wanted to mount my white horse and ride into the arena, swoop up Mr. B and save him (which is, of course, the feeling that propelled me toward a medical career in the first place), I simply couldn’t. Being a board-certified adult rheumatologist, I am not “approved” to treat children. I am not a pediatric rheumatologist. Yet I found myself in action in 2009, as part of a lobbying effort on Capitol Hill, meeting with lawmakers and their staff to speak up for patients with arthritis and autoimmune disorders. One of the main talking points was the severe shortage of pediatric rheumatologists nationwide, making access to medical care difficult for children with autoimmune disorders. Sadly, there simply aren’t enough pediatric rheumatologists to go around. Mr. B’s family did some research. They would have to transfer his care out of state. However, that was not an option with the family’s financial situation.



I returned to the notion of patient selection. The hallowed halls of my deep memories shuddered. A few years ago, I urgently called a specialist colleague to ask for help with a patient who I feared was in imminent danger of a full stroke. To my shock, the receptionist at the other clinic announced that they could not make an appointment because of the patient's insurance. Curious, I pressed on with questioning. The insurance was a so-called capitated insurance, sometimes referred to as an insurance in which doctors lose money if they see patients too often. My patient at that time was out of luck. That clinic's weekly quota of patients having that specific insurance had been already met! Well, exactly *what* was the quota they had set? Answer: only two patients per week.

On another occasion, I needed to refer a delightful grandmotherly type for urgent knee surgery. My staff dutifully got on the phone and started to scratch off names on a long list of orthopedic surgeons. It was my first introduction to physicians refusing to see Medicare patients. I calculated in my own mind how many years I had left until I, myself, might need surgery. In the event getting myself an appointment at a ripe old age would be an issue, I began to plan ways I could get more mileage out of my own tires. But Mr. B was not in such a fortunate position to come up with his own treatment plan.

It appears that, in the current healthcare climate, a kind of patient selection bias is at play among providers, allowing some children to start or continue treatment, while forcing others to leave medical treatment facilities. I held a copy of the rejection letter in my hand that had been sent

to Mr. B's family. I also knew that his parents had discussed this letter in front of him. I worried not only about Mr. B's health and eyesight, but also about the blow that had been dealt to his self-esteem. Indeed, it was a mature young man who had announced to me: "I know the drill." He knew more than the drill, which I found to be very, very sad.

Very coincidentally, in May, I was invited to a meeting as "the" token adult rheumatologist in the presence of pediatric rheumatologists and ophthalmologists representing at least four countries. The point of the meeting was to try to come up with a consensus regarding the treatment of children with autoimmune eye disease, the kind of disease that can rob children of their eyesight. The issues were not simply whether certain medications work effectively, but which type of doctor should be calling the shots about treatment. A hotly debated issue was whether the eye specialists or the rheumatologists (the "aches, pains and immune specialists") should take responsibility for prescribing and monitoring higher-risk medications for these young patients with eye disease. The eye doctors have the training to use fancy equipment to identify diseases in the eyes and are trained to perform a highly skilled examination. On the other hand, the (pediatric) rheumatologists understand the complexities of the high-risk medications and are experienced in prescribing and monitoring them, as well as looking for signs of disease popping up in other parts of the body. Rheumatologists might see patients with skin, joint, eye, heart, liver, muscle, kidney and brain diseases. To my disappointment, in a room filled with members from both ranks, even from different countries, it appeared impossible to reach a clear consensus as to who is responsible for what.

### **The Solution: Coordinating Forces**

But where did that leave Mr. B (or myself, for that matter)? Without being officially trained as a specific children's rheumatologist, how could I erect a MASH unit on the battleground? Mr. B's eye doctor was also passionate about saving him and his eyesight. It had been at her urging that Mr. B found his way into my clinic in the first place. Ah, yes, a familiar request: "Dr. So-and-So just called, asking if you can't just squeeze in this patient on short notice... please?" So, the story continued, after hours, even from home, as I began identifying members for our new team and began making contacts.

If you want to coordinate forces, you need good communication. Walkie-talkies may have been fine on old battlefields, but they are insufficient for this modern-day

healthcare team. Being new at this, I had to learn from scratch. My initial ground rules were simple: Identify team members. Establish communication.

The infrastructure of communication has included letters, phone calls, faxes, emails and in-person meetings, while we have been strengthening, albeit it slowly, our sense of teamwork. Goal-setting has included trying to minimize medication where possible to minimize side effects. Mr. B's family was asked to find a new pediatrician with whom they could "bond" and who was willing to review lab tests from a pediatric perspective and regularly

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evaluate Mr. B in person. The eye specialist agreed to follow the potentially elusive eye changes every few weeks and keep us all informed. I agreed to assume the prescribing and monitoring of three high-risk medications, as long as there was a clear "all-way" instead of "two-way" flow of information between all team members, including immediate summaries of each clinic visit to alert us of any need to deal with flares of the condition. Meanwhile, I had extensive discussions with Mr. B's previous medical team that had managed him over the previous two years to understand the rationale, dosing and effects to date of the multiple high-risk medications. Mr. B's parents were given instruction on how to maintain open communication with the other team members and, to date, have proved very compliant in bringing Mr. B to all appointments. This is not an easy feat. I live in a different city than he does. And, oh yes, to preserve medical confidentiality, I suggested Mr. B take this name as a kind of nickname. In return, I made him the team captain.

### **The Worrisome Realities**

A lot of issues have been raised in Mr. B's situation that haven't been fully explored. Certainly, this case illustrates some of the worrisome realities in this current atmosphere of healthcare. Lack of accessibility to healthcare is not simply a case of having or not having health insurance.

Interpretation of the concept of "uncertainty" of a particular diagnosis may lead to decreased accessibility of care not necessarily for the protection of the patient, but for the protection of the doctor who is afraid of being sued for malpractice. In other cases, there are simply not enough doctors to go around. Of course, poor reimbursement for medical services might be the actual behind-the-scenes stumbling block behind poor accessibility to healthcare. The bottom line is that the delivery of healthcare appears to be rationed.

Unusual steps were taken, the majority outside of regular clinic hours, to allow Mr. B to continue medical treatment. Certainly, it takes time to set up a type of team that may never have been set up before. Most providers these days have less time as they are forced to learn new ways for documenting visits and to leave a paper or electronic trail in a patient's medical chart. Meanwhile, reimbursement for services is shrinking. Pressures of being audited by insurance companies looking to recoup money paid out for services already delivered further pollute the ideal, altruistic environment.

On a personal level, it is uncomfortable to disagree with one's colleagues in terms of diagnosis or diagnostic terminology. It can be even more uncomfortable to disagree with their delivery of healthcare. Given the debate I witnessed at the meeting addressing pediatric autoimmune eye disease, plenty of controversy remains as to which doctor should take responsibility for what. Yet, when the vision of a young boy hangs in the balance, do we allow ourselves to get lost in red tape? Do we rush to protect ourselves and perhaps our own free time, while keeping our own eyes on the proverbial bottom line? Or, are we willing to make a commitment and follow it through without any thought for reimbursement? These decisions are becoming increasingly difficult. It depends on your view. That is, if you can see clearly. ■

**SUE ROMANICK, MD**, is board-certified, as well as recertified in both general internal medicine and rheumatology. She was involved with immunology research on cell clones at the German Cancer Research Institute in Heidelberg, Germany, and has worked in immunology and plasmapheresis at the University of California, San Francisco. Dr. Romanick is a public speaker and has spoken for the Arthritis Foundation, University of Washington and Overlake Hospital in Bellevue, Wash. She also has participated in lobbying efforts on Capitol Hill to support arthritis patients, both young and old, at the request of the American College of Rheumatology. She runs her own private practice clinic in Bellevue, Wash.