

Shingles Does It

After a doctor-professor with a bad case of shingles arrives in the ER, he discovers what it's like to be a patient in pain during this age of aggressive medicine.

BY JACK COULEHAN

FOR YEARS I'VE HEARD FRIENDS DESCRIBE EXPERIENCES of being caught in a web of excessive and unnecessary medical testing. Their doctors ordered test Z to investigate a seemingly incidental finding on test Y, which, in turn, came about because of a borderline abnormality on test X. I often wondered why test X was done in the first place. As a primary care physician, I would have treated them for the likely diagnosis and done diagnostic tests—especially a series of diagnostic tests—only if they didn't respond as expected.

By the time my friends told me these stories, their original symptoms had disappeared (with or without specific diagnosis and treatment), or they'd sunk under the weight of a new symptom or anxiety about the lack of an explanation for their problem. Many of the tales also included delays in receiving their test results, frequent referrals to specialists, and poor coordination among health professionals. Naturally, I'd express sympathy or outrage, whichever the speaker seemed to expect, but internally I'd pat myself on the back. I felt fortunate that there was absolutely no way I'd ever be stuck in such a scenario. After all, I'm not only an experienced physician, but also an advocate—in fact, a teacher—of standard-of-care practice. When I get sick, I told myself, they'll have to do it by the book.

That was before last Easter.

The Weird Pain

FOR A VERY CHILLY SIX A.M. EASTER SUNRISE SERVICE, my wife and I had stumbled to the local beach. But the cold wind didn't bother me. All I could think of was the weird pain in my left eye. A strange prickly sensation and occasional needle-like stabs in my eye and forehead had begun the previous evening. Of course, I attributed these to tension and fatigue, as I always do. But suddenly the eye pain escalated to a breathtaking degree. As the priest gave his sermon, I tried to figure out what was wrong. Vision, normal. Eye movement, normal. Left side of forehead, prickly, burning. Rash? None that I noticed.

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“How does my face look?” I whispered to my wife.

“Huh?” She was half asleep, but looked closer. “A little red, I guess.”

“There’s something wrong,” I whispered. “I think it’s shingles.”

I must have diagnosed shingles more than a hundred times during the past twenty-five years. This had to be it. My symptoms were confined to the distribution of a single nerve, the ophthalmic branch of the left facial nerve. The strange unpleasant feelings must be stemming from nerve irritation. Shortly, I was sure, I’d develop a characteristic rash in the same area; an itchy, crusting rash similar to chickenpox, which is caused by the same varicella-zoster virus. After chickenpox heals, the virus doesn’t depart the body; rather, it lies dormant for decades in one or more nerve ganglia until something—stress, trauma, immune deficiency, or simply aging—weakens the body’s defenses and allows the virus to spring to life for an encore performance. The good news is that the encore, shingles, usually remains localized to the skin affected by a single nerve—in this case, the upper left side of my face. The bad news is that shingles can be extremely painful, take several weeks to heal, and, worst of all, result in permanent neuralgia or nerve pain.

By the end of the Easter service, I had a treatment plan firmly in mind: an antiviral drug to fight the culprit, a steroid to decrease inflammation, and a very strong pain reliever. Given that it was Sunday morning, and a holiday as well, instead of calling my internist or one of his partners, I decided to visit our hospital emergency room to confirm the diagnosis and get my prescriptions. My wife drove. I sat in the car with my eyes closed, wondering how it was possible for me to have turned into one of those elderly people who suffer from shingles.

A Tiny Doubt

THE PHYSICIAN ON DUTY WAS A YOUNG FACULTY COLLEAGUE who immediately agreed with the diagnosis. Parasthesias (the prickly, tingling sensation), unilateral nerve distribution, sudden onset, normal eye exam, mild skin redness. Yes, she said, it’s the earliest stage of shingles. She checked my eye with a slit lamp and determined that the cornea wasn’t involved. Good news, because if varicella-zoster virus attacks the cornea, it can cause permanent scarring and vision loss. She asked me to rate my pain on a numerical scale of 1–10. Even though it was the worst pain I’d ever experienced, I said “8 out of 10” so as not to sound melodramatic. She brought me a shot of morphine. And she suggested the same treatment plan I’d come up with at the beach during the sunrise service.

“Before you go,” my colleague mused, “just for completeness’ sake, maybe we should have an ophthalmologist and a neurologist take a look at you. What about it, just in case?”

“I don’t know...I don’t think so...well, OK...maybe it’s a good idea.”

A tiny doubt crept into my mind. Could we be missing something? Might it be a tumor behind my eye? Or a weird form of glaucoma? I wondered whether she was

being extra careful because I was a fellow physician. But, if so, why? Surely my medical training minimized the risk of my not following up if a problem occurred.

We waited an hour for the on-call neurology resident to show up, and then a second hour for his boss. Meanwhile, the ophthalmologist appeared and gave my cornea and everything underneath it a clean bill of health. He said I had classic shingles and went home. Things didn't go so well, however, with the attending neurologist, who noticed very mild drooping of my left eyelid, a finding soberly agreed to by his resident but invisible to my wife and, when I looked in the mirror, me. The neurologist recommended an immediate MRI of my head, just to make sure there was no mass. But why would a brain mass cause symptoms from that particular nerve? It made no sense. But in my morphine-induced drowsiness I was more concerned about freezing—the ER was frigid—than clear thinking. OK, I thought, it might interesting to have an MRI scan—a life experience I'd thus far avoided. Meanwhile, my wife dredged up a blanket for me, and an hour or so later we walked to the machine.

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After the scan, we waited another ninety minutes. My wife said, “If it were just shingles, they wouldn't keep you this long.” Another twenty minutes. “There's something you aren't telling me,” she complained. By this time the prospects of Sunday brunch were shot, and my eye had exploded again. The neurology resident finally appeared to tell us that my MRI showed a possible abnormality in the cavernous sinus, a large pocket of vein at the base of the cerebral cortex. It was a questionable finding. In other words, it didn't look quite normal, but, at the same time, it didn't have the specific features of a definite abnormality.

OK, Let's Do It

BUT WHEN THE ATTENDING NEUROLOGIST RETURNED from his lunch, he seemed absolutely delighted that I might have a blood clot in the sinus—a finding, he said, consistent with the redness around my eye. “Did you have any recent dental work?” he asked, searching for an infection as a possible cause of venous blockage. (I hadn't.) I was gripped by molasses-like passivity. The reasonable part of my mind cried, “This is crazy! Get me out of here!” But a twiggy little nugget deep in my brain asked, “What if there is something serious wrong?”

Surely, if it were simply a case of shingles, our hospital's high-powered radiologist and neurologist wouldn't raise these questions. Maybe I've developed this blood clot as a result of undiagnosed cancer. I mentally reviewed a number of my own patients over the years who'd developed unexpected blood clots in their legs

as a first indication of cancer. Maybe the same is true for the cavernous sinus. By this time, I was desperate for more morphine.

“What we need to do,” the neurologist explained, “is get a CT scan with contrast. This’ll clearly define the vascular structures in your brain, so we’ll get a good look at the cavernous sinus.” OK, I thought, do it, do it, let’s get it over with, realizing for the first time that my stomach was crying out for food. My wife scavenged some coffee and granola bars from machines in the almost empty waiting room. Easter Sunday appeared to be a dead day in the ER, except for me and my shingles. I was keeping them busy.

Unfortunately, there was at least one other patient being evaluated by CT scan. While I waited there in the CT suite, an attendant suddenly rushed in and rolled my wheelchair back to the little ER cubicle that had become my home base. He wouldn’t tell me why, but I learned that another ER patient had just had a cardiac arrest while in the midst of a CT study with contrast dye. An additional ninety minutes passed before the patient in arrest was either stabilized or declared dead—I didn’t want to ask which. During this time, my wife and I ate more granola bars; we called our children and grandchildren to wish them a happy Easter. It looked like we’d miss supper, too.

In the end, my head CT was completely normal, as was the second MRI they subsequently conned me into having. In fact, when the official reading of the original MRI appeared a day or so later, it was also called normal, with not even a mention of an incidental abnormality. But who knows whether the radiologist’s interpretation of MRI number 1 was biased by his seeing MRI number 2 at the same time.

Our part of New York State was drifting toward a very cold, dark evening by the time the medical brain trust was ready to send me home. During the intervening hours, my eye had swollen shut. From beneath the morphine, I could feel what was definitely a mass of electric worms crawl continuously over my left forehead and the area around my eye. And, marvelous to say, a faint but definite rash had appeared on my creepy-crawly skin: the characteristic early phase of shingles. Naturally, the original emergency physician had gone off duty, signing me out to a colleague who said he would go along with whatever the neurologist decided.

When that person finally appeared, his principal neurological concern was that I get a prescription for gabapentin, explaining that it is the best drug for nerve pain. He seemed oblivious to the fact that I was, right then, suffering from overall severe pain, as almost everyone with shingles does. Rather, he was interested in treating the chronic neuralgia that might develop later, because neuralgia is more specifically a neurological problem. He was also obtuse enough to remind me

about the dangers of using narcotics to relieve pain. Either the man was a profound masochist, or he had never in his life experienced real pain. I found it difficult to refrain from strangling him. Why had he come here to torture me? Didn't he have anything better to do on a Sunday?

"Listen up," I said. "Give me a prescription for Vicodin or Percocet." So I wound up that evening with prescriptions for valacyclovir, prednisone, and Percocet—the exact three-part regimen of a strong antiviral drug to fight the shingles, a steroid to decrease inflammation, and a really strong painkiller that I'd come up with on the beach and the emergency physician had ordered twelve hours earlier.

Reviewing The Great ER Caper

IN A FEW WEEKS I RECEIVED A STATEMENT that my insurance company had paid the hospital a humongous \$9,000 ER bill. By that time the worst was over. The swelling had gone, the rash had dried, and my severe pain was largely resolved. Unfortunately, the weird experience of chronic neuralgia had only just begun. More than a year later, the neuralgia shows no signs of disappearing. It's definitely unpleasant, but, to my way of thinking, not a sufficiently good reason to ingest hundreds of doses of a neurological medication like gabapentin that the neurologist suggested.

And by the time I learned the total of that ER bill, I'd also come to grips with my feelings about the Great ER Caper. At first I felt angry and embarrassed about spending a whole day at the hospital, subjecting myself to multiple expensive and unnecessary tests and playing along with the culture of medical overkill that I've spend decades teaching students to avoid. How stupid! Why didn't I just phone my internist, or the person taking calls for him? When I didn't do that, and went to the ER instead, why didn't I just answer the first physician, "No, that's not necessary," when she suggested referring me to a couple of specialists? Having undergone the neurology consult, why didn't I say, "Let's wait and take another look next week," when the neurologist proposed urgent imaging studies to check a borderline physical finding (the supposedly drooping eyelid) that wasn't visible to others? Even after submitting to the first MRI, why didn't I question the unexpected finding, as it suggested a rare condition that was inconsistent with the common illness that my other symptoms and signs indicated?

I don't have a good answer to any of these questions. It's easier to understand, however, why I—the patient—was faced with them: my doctors recommended

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services that were simply not indicated at the time. Unnecessary testing, inappropriate consultation, and uncoordinated care are rampant in ERs, as they are throughout our health care system. Did my status as a local doctor and professor make me more likely to receive excessive VIP treatment? Perhaps. But I also know

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full well that overtesting and inappropriate care are pretty much equal-opportunity experiences in our country. In today’s medical culture, we almost always consider that more is better. Each new machine creates pressure to expand the ways it can be used. In most health care settings, the doctor has far greater incentive than disincentive to order excessive services—that is, those that aren’t indicated by practice guidelines or evidence-based medicine.

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How can we make stories like mine less common? The only way is an approach to health care reform that encourages well-coordinated, standard-of-care practice and one that simultaneously discourages the irrational shotgun approach to medicine.

One thing’s for sure: I’ve lost the smugness and condescension I often felt when listening to others’ stories about being trapped by the system and manipulated into excessively complex and specialized medical situations. Unlike most of my patients, I actually *knew* what my diagnosis was and what to do about it, but I learned how difficult it is to remain objective when you’re feeling very sick. Maybe I should have been more assertive. Instead, I wound up as a poster boy for excessive medicine. I understand now how all those people could have been so gullible, so easily manipulated by the system. Now that I’m one of them, that is.