

SYMPTOMS OF CONSCIOUSNESS

Truth Be Damned

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Though the pharmacy was closed Sundays, everyone in the neighborhood knew that my father was available if needed. One Sunday evening, a particularly demanding customer phoned to get her prescription-strength cough syrup refilled *now*. On our 15-minute drive to his store, my father muttered that the woman was an inconsiderate hypochondriac who could have easily waited until tomorrow. He railed at the indifferent universe and the general failings of mankind, yet when he arrived at the darkened store, he greeted the waiting woman as though a bosom buddy. Moments later, still wearing his public posture, he handed her the cough syrup, patted her hand, and wished her a speedy recovery. As soon as she had left, he explained that cough syrup was mostly placebo and resumed his rant against humanity.

“Instead of getting all worked up, why did not you just tell you her that you were sick and could not make it tonight?” 9-year-old me asked.

He pointed to the sign on the front door: “*In case of emergency*,” followed by our home phone number. “A promise is a promise.” On the drive home, he was initially silent, then, at a stop light, said softly, yet firmly, as though explaining himself to himself, “Personal feelings do not count. You never lie for convenience.” He squeezed my thigh and looked me square in the eye. “Agreed?” We shook hands and waited for the light to change.

Shortly after beginning my neurology practice, I consulted on Eleanor, a 35-year-old bookkeeper with a 2-week history of mild numbness in her feet, an intermittent sense of unsteadiness, fleeting double vision, and a tingling sensation in her arms and legs whenever she flexed her neck (Lhermitte’s sign). Family history revealed a sister and an aunt with multiple sclerosis (MS). Despite a normal neurological exam, her symptoms and family history raised the suspicion of early MS—a frightful diagnosis made worse by the lack of any specific treatment being available at that time.

I was debating what to say when Eleanor reached across the table, grabbed my hand and said, “My sister is in a wheelchair. Please tell me that I do not have MS. If I did, I would kill myself.”

“Do not get ahead of yourself; it could be a nonspecific inflammatory response such as you occasionally see following a viral infection.”

Prior to the introduction of CAT scans and MRIs, we relied exclusively on the history, physical exam, and a spinal fluid examination. The lumbar puncture results were in the borderline range—a few white cells and very mild nonspecific protein elevation. Absent the suspicion of MS, they could mean nothing. But with her history, I remained concerned.

“It is MS, isn’t it?” Eleanor began the follow-up visit. “I can see it in your face.” Her eyes were red; she stared down at her damp handkerchief and said, “Can’t do it, just can’t do it.”

“There is no clear-cut evidence for MS,” I blurted out. “I still favor nonspecific inflammation,” which was technically correct, but not what I was thinking. Before I could explain, she rushed across the desk and gave me a huge hug. “Thank God.” She sat down again and said, “I can live with that.”

Too late. Not what I had planned on telling her. I wanted to retract what I would have said without making a retraction. I gave a slight nod and scheduled a follow-up visit. Fortunately, her symptoms fully resolved within a few weeks, and I decided not to bring up my suspicion.

Over the next 4 years, the same scenario played itself out a half-dozen times. Eleanor would have a brief flurry of subjective complaints. Between attacks, she remained an avid tennis player and rock climber. By now, it seemed likely that she had an uncommon form of so-called benign MS; her long-term prognosis improved with each passing year without detectable neurological deficit.¹ I continued to reassure her, skirting frank discussions, instead sticking with oblique references to hard-to-pin-down inflammation. “Sometimes we never find a definitive cause,” which was semantically true in that, at that time, we had no idea what caused MS.

Then, without any specific further episode, she showed up in the office and requested a second opinion. Through her tears, she told me that her sister had gotten dramatically worse, was unable to take care of herself, and was now in an assisted living facility. Part of Eleanor’s salary as a bookkeeper would be going toward her sister’s bills. “You’ve always been reassuring, but I need to be sure that I will not end up like my sister.” I arranged for her to see another neurologist at the University. I wanted to explain to him why I had waffled in my discussions with her but said nothing.

A few days later, I received an excoriating phone call from my colleague; “How could you have not told her?”

“Did you find something on exam?” I asked.

“No, her exam’s normal, just as you described it, but so what? She has MS and I told her so in no uncertain terms. Frankly, I think she was relieved to finally have an answer. As for you....”

The next day, a medical supply house phoned. Eleanor had walked into the store demanding that I authorize her request for an electric wheelchair. “She tells me that she has Multiple Sclerosis. Is that right?” I approved the purchase.

A week later, while passing the neurology clinic waiting room, I came across Eleanor in her new wheelchair. After an awkward silence, she said, “Down deep I always knew, but recognized how uncomfortable you were telling me the truth. I guess we were both humoring each other.”

The receptionist called her name. Eleanor secured the wheelchair, and before walking into the examining area, said to me, “No hard feelings. I know that you did all that you could.”

After a couple of heart attacks and persistent chest pain unresponsive to medical management, my father reluctantly agreed to coronary bypass surgery. According to the Stanford surgeon, all the major involved vessels had been successfully grafted. “We could not get one minor marginal artery, but I do not see the point in telling him. It supplies a small area of the heart and is unlikely to cause symptoms. He should do fine.”

But my father did not do fine. His chest pain did resolve, but he was moody, had difficulty sleeping, and became uncharacteristically depressed (a common but usually transient sequelae of open-heart surgery that was not widely recognized in the early 1970s). Obsessed with the thought that something had gone wrong with the surgery, he consulted his long-time internist. “He’s one of the few doctors who always tells the truth,” my father said before the visit.

The internist confirmed that the surgery had gone smoothly and that his vague symptoms should resolve. Being thorough, he did tell my father that one of his smaller arteries had not been bypassed, but that it was unlikely that the artery was causing his symptoms. My father heard only that a diseased artery had been left unrepaired, and that the surgeon had lied to him. He went home and gave up.

After a nearly house-bound year, my father cleaned his desk, balanced his checkbook, cancelled his pharmacy license, and, on our daily evening call, told me that he loved me. At dawn the following day, my mother found my father dead in his easy chair, hands folded in his lap, wearing his favorite robe. My mother glanced at the open medicine cabinet cram full of pills but said nothing. I closed the cabinet door. “Too much information. Besides, what good would it do to know?”

Moments later, his internist phoned to offer condolences and an apology for not having been able to help him following his surgery. “Why did you mention the inoperable artery?” I wanted to ask him, but instead said, “thanks for being so honest with him. That’s what my father admired most about you.”

Note

1. Hawkins SA, McDonnell GV. Benign multiple sclerosis? Clinical course, long term follow up, and assessment of prognostic factors. *Journal of Neurology, Neurosurgery, and Psychiatry* 1999;**67**:148–2; available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1736487/pdf/v067p00148.pdf>.