Lessons From the Practice

Two Generations—Reflections on Changes in the Treatment of a Chronic Disease

LUCY M. OSBORN, MD, *Salt Lake City*

1962—I was 16 years old when my mother became ill, although illness hardly seems the correct word. My parents and I were taking a short trip to watch Army play Michigan. I first realized something was wrong when we stopped for lunch. As we walked to the restaurant I noticed my mother was limping. Later, returning to the car, she stumbled. When I asked her about it, she shrugged her shoulders and said that her leg was not moving right, she must have slept on it wrong. She seemed nonchalant about it, as if it were not an unusual occurrence.

Two days later, she went to see our small town general practitioner. He diagnosed her as having Guillain-Barré syndrome, a name that meant nothing to us. We understood neither what it was nor what it meant. He told us that it was a reaction to a flu shot she had been given and that there was no treatment. She was ordered to stay in bed for a month.

I now know that she was frightened, but I did not recognize it then. She was outwardly calm and quite stoic. None of us knew what to do, and no one helped us find out. My father was even more frightened. Ignorant of the disease or what might happen, he had no idea what to say or how to be supportive. He left on a short hunting trip, an action he still regrets.

Confined to bed, she slowly became weaker, losing much of the use of her right hand. Her face drooped and her vision blurred. She had difficulty writing; it was hard for her to read. It must have been awful, lying there with nothing to do except to be worried and bored, but she never complained. Later, she did seem to get better, but she never fully regained the function of her right leg. She had always been an athletic, active woman, and I knew the impairment bothered her.

After a year or so, my parents decided to seek another opinion, traveling to a major university medical center to see a specialist. They were told that, indeed, she had had a reaction to the flu shot but that the name of the problem was demyelination syndrome. This name, as with the first, meant nothing to us, but the prognosis did: There was nothing that could be done; physical therapy would be useless. She just had to learn to live with her limitations. She seemed to. As time went on, to those of us who lived with her, it seemed a nuisance, not a disease.

Several years later, when my father retired from his business, my parents were denied an application for health insurance. The insurance company refused to give a reason for the denial. My parents were quite puzzled because, to their perception, they were both healthy, sturdy midwesterners. They finally concluded that it had to be related to my mother's hospital evaluation.

I was then a junior medical student at the institution where my mother had been seen. My father asked if I could check her medical record for an explanation. Unconcerned, I walked to the medical records department and requested my mother's chart. Within five minutes I was holding the folder. It seemed odd to see now-familiar phrases describing my mother: "This attractive 45-year-old woman enters the hospital for evaluation of neurologic deficits." I had never stopped to consider that someone might think my mother attractive, and I certainly had not thought of her as having "neurologic deficits." I scanned the description of the physical examination: "Horizontal nystagmus, weak extensors in the right leg, foot drop, increased deep tendon reflexes, loss of sensation in several areas, positive Romberg, positive Babinski . . . multiple, scattered neurologic deficits." There were some laboratory results. I turned to the last page. Final diagnosis: multiple sclerosis. I was incredulous. I had not thought about my mother's problems since entering medical school, but certainly in retrospect the diagnosis made sense. It obviously was not Guillain-Barré syndrome. Had that been ignorance on the part of our family physician, or had he been afraid to give an honest diagnosis? Why hadn't the neurologists told her?

I was not sure what I should say to my parents but finally decided that there was nothing to do except report what I had read. My mother's reaction was straightforward: She didn't believe it. The doctors had told her that she had "demyelination syndrome." If she had had multiple sclerosis, they would have told her. That was why she had sought their opinion.

1985—More than two decades after that trip to Michigan, my husband and I took a weekend vacation with our children. I found I could not run on the beach. I kept stumbling; I had a foot drop. Like my mother, I ignored it: I must have slept on it wrong. I did not mention it to anyone, and no one else noticed. Several months later, I finally went to see my internist. I had bothersome paresthesias, odd vibrations that roamed my body each time I looked down. After his examination, he told me that it was probably nothing but wanted me to see a neurologist the following day.

Denial is a strong emotion. I was not worried in the least, just curious about these odd, varied symptoms. I had had many others over the past several years but found a conve-

(Osborn LM: Two generations—Reflections on changes in the treatment of a chronic disease. West J Med 1990 Mar; 152:322-323)

From the Department of Pediatrics, University of Utah Medical Center, Salt Lake City.
Reprint requests to Lucy M. Osborn, MD, Department of Pediatrics, University of Utah Medical Center, 50 N Medical Dr, Salt Lake City, UT 84132.

nient explanation for each, never thinking them worthy of mention. As the neurologist examined me, I found I could not walk toe-to-heel; as I closed my eyes, I fell over; I could not feel the tuning fork, nor the pinpricks . . . multiple, scattered, neurologic deficits. Yes, I, like my mother, have multiple sclerosis. But here, our tales diverge.

After the examination, the neurologist sat down, looked at me, and said, "I could beat around the bush, or I could just tell you what's wrong. I know the best course is simply to tell you the truth. You've got multiple sclerosis." A magnetic resonance scan left no questions about the diagnosis. A spinal tap confirmed active disease.

Unlike my parents before me, I was offered not only a diagnosis but, with my husband, also given a detailed explanation of the disease. The neurologist—correctly—did not assume that we would know about multiple sclerosis, despite the fact that we are both physicians. Our stress and emotional response to the disease were not ignored. We were informed about support groups and advised to get counseling. With our psychologist we were able to discuss our fears, share our concerns, and together face a disease that at least has a name, if an unpredictable course. Ironically, my husband also went hunting, not in ignorance, as my father had, but as an escape from a frightening, puzzling situation.

The neurologist helped us again. He would call my department chairman if I wished. It was unnecessary, for we made another decision that has been a blessing: not to hide the diagnosis from either friends or colleagues. I finally told the residents I supervise and received an amazing response: "Thank goodness it's only that. You were so pale and seemed so stressed. We knew something was wrong. We were all worried you had leukemia!" The conspiracy of silence that so often in the past, and still today, surrounds the diagnosis of a chronic disease produces more fear and anxiety than knowledge of the disease possibly could.

I was not put at bedrest but encouraged to exercise. I stayed active, but the disease gradually progressed. When walking became difficult, I was again offered something not possible for my mother—treatment. After a short course of immunosuppressants, I was amazed and delighted to awaken one morning and find that I could wiggle my toes. Several days later I could flex my foot, then gradually I regained strength in my leg. A month later I discarded my cane and have not used it since. Physical therapy helped me compensate for lost muscles and strengthen weak ones.

My mother grieves that I have this disease, for she has lived with the handicaps. Yet, I can bicycle and ski. She, who is now 70, still plays golf but cannot walk without assistance. As I watch her struggle from living room to kitchen, I grieve for her, for the opportunities I have had that she did not. What would have happened had she known what afflicted her? What if she had been given a fitness program and physical therapy? How much more functional could she be today? Counseling or a support group could have helped my parents face a frightening event and a chronic disability. She was given hopelessness; I have been given hope.

It is my prayer that my mother's treatment is something of the past; it is my fear that it is not. Not all patients are blessed with the medical care I have received. Nor do many people who are chronically ill have colleagues who understand their condition, who can be supportive at work and help them to remain as functional as possible. Giving medications is the easiest part of any treatment. Thinking of the patient's life is more difficult—counseling the patient on how to approach the disease with friends, family, and colleagues, marshalling the support of psychologists, physical therapists, other specialists, referring patients to support groups—this takes time, effort, and compassion.

I don't know what my future holds, but, then, neither does anyone else. I simply have a name to attach to the uncertainty. There is one fact, however, that is assured: The quality of my life will be better than my mother's. I have had physicians who do more than give me a pill, who see me as a person, not just as a case of multiple sclerosis. They have remembered my health, not just my disease. Although it has been said a thousand times, I want to say it again. Please, treat the patient, not the disease. Though the disease may be incurable, the patient is not.

* * *

"Lessons From the Practice" presents a personal experience of practicing physicians, residents, and medical students that made a lasting impression on the author. These pieces will speak to the art of medicine and to the primary goals of medical practice—to heal and to care for others. Physicians interested in contributing to the series are encouraged to submit their "lessons" to the series' editors.

JONATHAN E. RODNICK, MD
STEPHEN J. McPHEE, MD
Series' Editors