Can I Speak to My Dad's Doctor?

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"CAN I SPEAK to my dad's doctor?"

This was a question I often asked while visiting my father during his recent hospitalization. At the time of his admission, my father was 83 years old, with a long-standing history of diabetes and cardiovascular disease and a recent diagnosis of vascular dementia. He was admitted after fainting at home. During his hospital stay, he developed delirium, began to have refractory complex partial seizures, and exhibited signs of worsening dementia.

My father has a PhD and DSc in biochemistry. He had been a basic science researcher and worked until the age of 80. He published over 150 papers and edited 5 books in his 50-year academic career, the last 40 of which were spent at Massachusetts General Hospital. Now, for the first time in his life, he could no longer advocate for himself. Although a general pediatrician by training, I served as my father's medical caretaker, trying to understand and manage his medical issues while my mother attended to everything else.

My father was admitted to a hospital to which neither of us had any professional affiliation. During Dad's 8-week stay, I visited him daily. My visits would range from a few minutes to 12 hours. During each visit, I hoped to see and talk with my father's doctors. At first I would try to time my visits with rounds, but this strategy was not sustainable, as my own work schedule rarely permitted it. Thus, after a couple of days, I started asking my father's nurse whether I could speak to his doctors, either in person or by telephone. The nurse would page the physician (usually the intern, and occasionally the attending physician), and I would wait. Sometimes I would wait a few minutes. Usually I would wait an hour or two. Sometimes no one came in or called.

When I did speak with the doctor, our conversations were brief, usually lasting 2 or 3 minutes. During these encounters, I did not feel rushed. Often, I felt the doctors had answered my questions and updated me appropriately. However, after the doctor left, I would think of questions I wished I had asked. Why are his blood sugars fluctuating so much? Are you sure he is on the correct antiseizure medication? For how long will the neurologists titrate his antiseizure medication? What else is being done to assess his lethargy? Will his seizures stop? Will he be okay?

There were some instances, however, when I did not have to request to speak with a doctor. The first night in the hospital, Dad was in acute delirium, one moment thinking that he was home, the next in the hospital. I was with him until midnight. The nurse then told me that since he had one-on-one supervision, I should go home and not worry. Feeling grateful to hear these reassuring instructions, I went home thinking that my father would be safe. The doctor called me in the early morning, per protocol, to inform me that my father had fallen while trying to go to the bathroom in the middle of the night. Apparently, as a result of staffing constraints, Dad was not supervised throughout the night. The doctor also informed me that my father had a pelvis x-ray performed, which was normal. The second incident occurred a few days later, when the prior weekend's covering physician called my mother to set up a meeting with us. At the meeting, the doctor explained that Dad's recurrent seizures, which had landed him in the stepdown unit, was likely a result of the doctor mistakenly discontinuing his antiepileptic medication.

During the third week of my father's hospitalization, the communication between my father's doctors and me changed dramatically. That week, Dad's doctor—who had just started on service a couple of days before—hastily scheduled a family meeting on a Friday afternoon. The last-minute scheduling meant that I could not attend in person. I thus called in, unclear about the meeting's purpose. The doctor conveyed that my father's vascular dementia was progressing rapidly, and that because he was now medically stable, he should be transferred to a rehabilitation facility as soon as possible.

After speaking with a dementia expert—a geriatric psychiatrist who had seen my father for the first time just 4 days before his hospitalization, yet who always responded

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to my urgent e-mails and telephone calls—my mother and I began to question the prognosis along with the assessment and management of his seizures and dementia. We approached my father's attending physician to discuss these issues. The doctor abruptly dismissed us and our concerns, stating that he stood firm regarding his prognosis and discharge plan. He also refused to convene the multidisciplinary team meeting we requested. At my wife's suggestion (my wife is a pediatric hospitalist, and much more knowledgeable than I am about hospital resources), I contacted the hospital patient advocate and voiced our concerns regarding the physician's communication and care management plan. Much to my surprise, this led to a meeting the next day, Christmas Eve, headed by the hospital's chief of quality and safety and attended by other hospital brass, including the vice president of marketing and strategic planning, the director of risk management, a patient relations representative, and 2 social workers. A friend of mine who had gone through a similar hospital experience after his father's cardiac surgery dubbed this meeting "the one where you get business cards." I received 4 such cards. After the meeting, in which we received multiple apologies, the communication from the doctors improved. Initially I received daily calls from each of the various doctors involved in my father's care. After a few days, this hypervigilant communication waned.

Dad's hospitalization made me reflect on my own interactions with patients and their families. As a resident, I would typically zip in and out of patients' rooms before rounds to examine them, often when they were sleeping. During the rest of my clinical shift, I would attend to the daily activities of writing orders and notes, attending lectures, and speaking with consultants. I would also do other things such as check e-mail, update my fantasy football team, and catch up with my fellow residents and the nurses. Truthfully, these tasks were much more of a priority for me than making sure that my patients and their families fully understood our management plans or probing further about the hidden fears and questions they may have had but were afraid to share or ask. Now, as an academic general pediatrician, I spend very little time in the inpatient setting, primarily in the newborn nursery. But I still find myself zipping in and out of rooms, congratulating new mothers and performing quick physical examinations of their newborns. Most of my daily tasks as a resident have now been replaced with my regular day job of writing grants and papers, and completing my clinical notes and medical student evaluations.

One weekend, toward the end of Dad's hospitalization, I happened to be attending in the nursery. Typically I would try and work as quickly as possible to get home for my oldest daughter's basketball game, catch a nap with my younger daughter, and watch the Patriots. This time, however, I found myself lingering in the mothers' rooms. Most mothers had few questions; nonetheless, I would try to expound on my answers as much as possible. I suspect that I benefited from this as much as, if not more than, the mothers did. One mother, however, was having breast-feeding difficulties and was getting frustrated. I spent a longer time than usual reviewing breast-feeding techniques and feeding cues, along with providing reassurance to her and her husband. Another newborn had a heart murmur that sounded a little louder than expected. We decided to consult cardiology and pursue further assessment. The baby's echocardiogram revealed a ventricular septal cardiac defect. Typically I would wait for the cardiologist to come in to explain the diagnosis to the family. But not that day. Instead, I quickly reviewed in my head how I was going to explain the heart defect, thought about potential questions that the mother would have, and imagined how I would feel if I were receiving this diagnosis about my newborn daughter. I took a deep breath, walked into the mother's room, and sat down to talk.

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