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“Good” Patients and “Difficult” Patients — Rethinking Our Definitions

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Four weeks after his quadruple bypass and valve repair, 3 weeks after the bladder infection, pharyngeal trauma, heart failure, nightly agitated confusion, and pacemaker and feeding-tube insertions, and 2 weeks after his return home, I was helping my 75-year-old father off the toilet when his blood pressure dropped out from under him. As did his legs.

I held him up. I shouted for my mother. As any doctor would, I kept a hand on my father's pulse, which was regular: no pauses, no accelerations or decelerations.

My mother was 71 years old and, fortunately, quite fit. She had been making dinner and said she dropped the salad bowl when I yelled for her. She took the stairs two at a time. Something about my tone, she said.

Together, we lowered my father to the bathroom floor. I told her to keep him talking and to call me if he stopped, and then I dialed 911.

In the emergency department, after some fluids, my father felt better. My mother held his hand. We compared this new hospital with the last one where we'd spent so many weeks but which had been diverting ambulances elsewhere that evening. The doctor came in and reported no ECG changes and no significant labo-

ratory abnormalities, except that the INR was above the target range. The doctor guessed the trouble was a bit of dehydration. He would watch for a while, just to be safe.

My mother waited with my father. The rest of us filed in and out, not wanting to crowd the tiny room. Then my father's blood pressure dropped again. I told the nurse and stayed out of the way. She silenced the alarm, upped the fluids, and rechecked the blood pressure. It was better. But less than half an hour later, we listened as the machine scanned for a reading, dropping from triple to double digits before it found its mark. The numbers flashed, but the silenced alarm remained quiet. I pressed the call button, and when the nurse arrived I asked her to call for the doctor. When no one came, I went to the nursing station and made my case to the assembled doctors and nurses. They were polite, but their unspoken message was that they were working hard, my father wasn't their only patient, and they had appropriately prioritized their tasks. I wondered how many times I had made similar assumptions and offered similar assurances to patients or families.

After weeks of illness and caregiving, it can be a relief to be

a daughter and leave the doctoring to others. But I had been holding a thought just beyond consciousness, and not just because I hoped to remain in my assigned role as patient's offspring. At least as important, I didn't want to be the sort of family member that medical teams complain about. Now that I'd apparently taken on that persona, there was no longer any point in suppressing the thought. Although the differential diagnosis for hypotension is long, my father's heart was working well, I had adhered to the carefully calculated regimen that we'd received for his tube feeds and free water intake, and he did not have new medications or signs of infection. Those facts and his overly thin blood put internal bleeding like a neon sign at the top of the differential.

I rested my hand on my father's arm to get his attention and said, “Dad, how much would you mind if I did a rectal?”

We doctors do many things that are otherwise unacceptable. We are trained not only in how to do such things but in how to do them almost without noticing, almost without caring, at least in the ways we might care in different circumstances or settings. A rectal exam on one's father, of course, is exactly the

same as other rectal exams — and also completely different. Luckily for me, my father was a doctor too. When I asked my crazy question, he smiled.

"Kid," he replied, "do what you have to do."

I found gloves and lube. I had him roll onto his side. And afterward, I took my bloody gloved finger out into the hallway to prove my point.

I realize that walking to the nurses' station holding aloft one's bloody, gloved hand is not an optimal tactic from a professionalism standpoint — but it worked. A nurse followed me back into my father's room, saw my panicked mother holding a bedpan overflowing with blood and clots, and called for help. Within seconds, the room filled, and minutes later, when the ICU team showed up, I stood back, a daughter again.

In retrospect, what is most interesting is how much more comfortable I felt performing an intimate procedure on my father than demanding the attention of the professionals assigned to care for him. Abiding by the unspoken rules of medical etiquette, I had quieted my internal alarms for more than 2 hours. Instead, I had considered how doctors and nurses feel about and treat so-called pushy or "difficult" families, and as a result, I had prioritized wanting us to be seen as a "good patient" and "good family" over being a good doctor-daughter.

Although many physicians

would have made different choices than I did, the impetus for my decisions lay in a trait of our medical culture. When we call patients and families "good," or at least spare them the "difficult" label, we are noting and rewarding acquiescence. Too often, this "good" means you agree with me and you don't bother me and you let me be in charge of what happens and when. Such a definition runs counter to what we know about truly good care as a collaborative process. From the history that so often generates the diagnosis to the treatment that is the basis of care or cure, active participation of patients and families is essential to optimal outcomes.

There will always be patients and families who are considered high maintenance, challenging, or both by health care providers. Among them are a few with evident mental illness, but most are simply trying their best to understand and manage their own or their loved ones' illness. That we sometimes feel besieged or irritated by these advocates speaks to opportunities for improvement in both medical culture and the health care system. Culturally, we could benefit from a lens shift toward seeing more-vocal patients and families as actively engaged in their health care, presenting new, potentially important information, and expressing unmet care needs. At the systems level, we need to both count (using

specially designated sections of the medical record) and reward (through diagnostic and billing codes) the time that providers spend talking to patients and families.

I'll never know whether such changes would have altered my behavior or that of the medical staff on the night of my father's massive intestinal bleed, and fortunately we all acted in time. I do know that 8 years later, the most vivid image I have of that night is not my father wobbling in the bathroom surrounded by cold, hard tile and angular metal structures, or a mustard yellow bedpan filling with bright red blood. The image is this, a worst-case might-have-been scenario had I not been there, had I not had medical training, had I not spoken up: my parents, sleepy because it was by then late at night, snuggled up together at the top of the gurney, my mother resting her head against my father's chest, their eyes closed, their faces relaxed. His systolic blood pressure, usually 130, dropping to 80 and then 70. The monitors turned off or ignored. The lights dim. A short nap and they'd feel better. A little rest and maybe it would be time to go home.

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