



You Tell Me

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BEFORE I MET KC and her mother many years ago, I had cared for many patients with complex chronic illness. I felt confident in my ability to provide compassionate, patient-centered care. My approach was based on a fundamental belief that parents knew their children best. Most had opinions about how problems should be managed, and I typically went along with what they proposed. My role was to hear families' ideas, check anything that seemed unfamiliar, and recommend against options that might cause harm. I was successful in my relationships with families because I was willing to follow their lead.

KC has severe neuromuscular disease. She uses a wheelchair and does not speak. Her mother is sharply attuned to even the smallest changes in her energy, breathing, and demeanor. She is tireless and meticulous in managing KC's care and fiercely protective of her well-being.

The first time Mrs C and I needed to make a treatment decision together, I followed my usual steps. I gave her some information, offered some options, and asked her what she would like to do. She looked at me for a moment, stone-faced, and said flatly, *You tell me*.

I was lost at first. In my view, Mrs C was the expert in all things KC, and she knew best what would work for their family. Why did she want me to decide? I tried some different angles to draw out her preferences, but I could not get Mrs C to take a stand. Eventually, I made an explicit recommendation, which she accepted. We had a plan, but when the encounter ended, I was not sure I had been helpful.

During similar visits over several years, I gradually came to accept that my "patient-centered," patient-driven approach was not going to work for KC's mom. I needed to adjust. Over time our communication evolved into a dance that we have now practiced dozens of times: When confronted with a new problem, I lead with a solution. Mrs C follows with questions and additional details. On some days, she accepts my proposal outright. On others, she shoots me down and offers her own recommendation. I consider, approve, and we confirm. The dance ends.

We share the decision-making, but it is my job to make the first move—and to take responsibility for the final decision.

In my teaching, I have often used KC as an example of the need to adapt to individual families' preferences for communication. I have accepted the need to stretch beyond my own preferred style. Intellectually, I understand what Mrs C needs me to do. On an emotional level, I have always found it puzzling.

Ten years after my initial encounter with KC, I found myself at my mother's bedside in the adult ICU. She had been diagnosed with idiopathic pulmonary fibrosis a few weeks earlier, and her condition had deteriorated quickly. She was hospitalized before my family had a chance to digest what was happening.

The palliative care team had been involved since shortly after admission. As the only member of my family with medical training, it fell to me, for better or worse, to do most of the talking with the team.

After a few days of antibiotics and steroids, my mom remained on high ventilator settings and pressor support. On the morning, she developed a pneumothorax; the team asked my family what we wanted to do. We could put in a chest tube—or opt for palliative extubation.

Considering the severity and natural history of my mother's illness, it seemed unclear that she would ever return to her prehospital baseline. Even if it were possible, that baseline had been miserable—a state of constant air hunger, anxiety, and pain. Placing a chest tube seemed traumatic and futile. As I explained my thinking to the palliative care team, the lead physician's response was supportive and respectful: "That seems very reasonable to me."

As a physician, this validation of my clinical reasoning brought a brief moment of satisfaction. As a daughter, making a "reasonable" decision was not enough. I wanted to know what was right. Ultimately, I did not want to be fully responsible for the decision in front of me. "Please," I wanted to say to the doctor, "Please. *You tell me*."

Since my mother's death, my physician self knows that I helped make the right decision. My daughter self, at times, continues to question. I wished then and still do that the doctor could have been more definitive. I wish he had made a recommendation for me to react to, rather than the other way around.

Being "patient-centered," I realize, goes beyond incorporating patients' perspectives and social con-

texts into plans of care—beyond asking parents what they think would be best for their children. True patient-centeredness includes understanding and trying to honor families' preferences for balancing our respective roles in planning care. Working with Mrs C, I now feel less puzzled. I understand more deeply, in our dance of shared decision-making, why Mrs C needs me to lead.