

Patient's Sister, Seeking Job

MY BROTHER WAS DIAGNOSED WITH HEPATOBLASTOMA when I was 4 years old and he was just shy of 2. It wasn't until years (and several cancers) later that we learned he had Gardner syndrome. Over the last 26 years, Hans had dozens of operations and underwent many lifetime doses of radiation and chemotherapy. The disease and its treatments took a toll on his body, and he had a multivisceral transplant in 2007 that gave him a new stomach, small intestine, pancreas, and liver. Five years later, his liver showed signs of chronic rejection and he was put back on the transplant list. We waited for organs for four months. Hans was primarily in the hospital during this time. Finally, internal bleeding, the result of debilitated organs and a large abdominal wound, took his life on December 26, 2012.

Despite all Hans' suffering, he lived his life selflessly. He had an innate sense for the needs of others, and he remained dedicated to assisting others lead their lives to the fullest until his last day. He had many opportunities to positively affect his physicians, by providing a training opportunity, by reassuring them when they had to deliver bad news, or by remembering to ask about their lives outside the hospital.

As a testament to how Hans lived his life, I have written this piece. The physicians who worked with Hans were phenomenal, and they saved Hans' life many times. Many of them were incredibly dedicated, sensitive, and kind people who have become lifelong friends to our family. Nonetheless, in nearly three decades of spending so much of our time in a hospital room, Hans and I made some observations; I've compiled them and would like to share them with you now. These observations are not about specific treatment decisions: they are a reflection on the general experience of being a patient in a hospital. I humbly offer them to you hoping that Hans' spirit of assistance will shine through these words and affect you somehow.

Physicians are now trained in patient-centered care. While I applaud this movement, I am devastated that physicians were ever trained differently. The Institute of Medicine (IOM) defines patient-centered care as "Health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care."¹

This definition has a lot to do with decisions, and it emphasizes giving patients and families decision-making power and oversight. This seems misdirected to me. I come from

an intelligent family, and my brother is arguably the most intelligent among us. However, I wouldn't say any of us, my brother included, want more decision-making power. We trust the physicians' medical expertise and we rarely disagree with their medical recommendations. Besides, physicians generally believe they know what is best medically, and my family and I would say that this belief is well founded. Our family actually just seeks *understanding* of the decisions, and wishes for *sensitivity* in informing us of the decisions. I think many patient families feel this way. In other words, patient-centered care shouldn't be about changing the "what," it should be about changing the "how." This piece of writing is about changing the how.

To me, a physician is like an engineer, translator, and psychologist more than a scientist. The physician interprets what is going on in the patient's body and then makes adjustments to improve the situation. This is the engineering part of the physician's role. Then, the physician translates what has happened into terms the patient understands. Finally, the physician must be available and channel resources while the patient and his family deals with the emotional reality of the situation. Of course, this is an oversimplification, and I am acutely aware of the many more complex tasks that physicians perform. From the patient's point of view, however, these three functions are the visible ones, and the ones that are equally critical to achieve true patient-centered care. In my opinion, patient-centered care would be achieved when these functions are integrated seamlessly: patients understand what is happening, what the doctors are doing to fix it, and the patient has been sensitively handled along the way.

Related to these functions, a few more specific things that I think some physicians sometimes overlook:

1. Today is a bad day for the patient and his family. The patient is still in the hospital, which means something is wrong. Maybe today is better than yesterday, maybe the long-term outlook is good, maybe the situation is stable, maybe everyone views the patient as a miracle patient. But to the patient and his family, the situation is awful. No amount of reassurances, statistics, or pleasantries takes away the fact that you, the physician, are seeing us, the patient and patient's family, on a horrible day. We are not our best selves, and basically at any point, we can stand to get a hug and to hear, "It will be okay."

2. Along the same lines, we may be having a sensitive discussion before you come in and it may take us a

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moment to snap out of it and be ready to discuss medical realities with you. Unfortunately, physicians frequently sweep in with an entourage in an incredible hurry. I understand that physicians can't adjust their schedules for patients' emotional distresses, and I wouldn't suggest that. However, it seems like an easily implemented adjustment would be if a member of the rounding team (ideally the physician the patient and family know best) would gently knock on the door, come in and survey the room, discern the mood, and then prepare the patient and his family for an army of people coming in. If someone is visibly upset, give us a minute to compose ourselves.

3. Physicians could stand to practice volume control. A hospital room is indoors, so indoor voices are appropriate. Sick people are not deaf; they're just focusing their body's energy on recovery rather than listening for your voice. If the patient is out of it (for example, Hans was frequently hard to rouse because of pain medications), it is my experience that a louder voice will not help wake him. The downside of a booming voice is that it alarms a sleeping patient when he wakes up to someone yelling his name. When you're tempted to yell for the patient, ask yourself if there are family members who are more aware and already awake who could talk with you and answer your questions. Then, if you absolutely need to wake the patient, a gentle shake of the shoulder accompanied by a soft repeat of their name will probably do the trick. Basically, imagine you're waking your infant child. Would you scream, "Timothy! Timothy!" at the top of your lungs as you walk up to his crib? I think not.

4. The first time you meet a new family member, please introduce yourself. There's no harm in introducing yourself again, even if you think you already have. We meet a lot of you and you meet a lot of us. Introductions are important because it is highly impersonal, and somewhat alarming, to speak to a nameless physician about operating on my brother or bringing him back from death. Think of it this way: When I thank God for you in my prayers tonight, I want to refer to you by name.

5. Other patients matter to us. When there's a code down the hall, when another patient is crying out, our first thought is always, I'm so grateful that is not Hans, but I am scared it will be. There's an element of "We're in this together" among patients in a hospital ward. We don't need to know the details, but we like to know that everyone is getting the best care. If this happens in our presence, reassure us that the medical professionals will do everything in their power for them. And for heaven's sake, do *not* talk about the medical details of the case in the hall. We hear those things, and

all we think is, "Wow, that is a code blue gone wrong to you, but someone's grandmother just died." It's scary for us and also inappropriate.

6. Patients want to do normal things. They want to eat out on dates, attend birthday parties, and play board games. No matter how unrealistic it is to ever do these things again, they still want to. Saying "It's great you're even able to stand today" doesn't make patients want to do these normal things less, and it stings when you say that, as if the sadness is self-inflicted. When the patient wants to express normal, healthy desires, let him, and just say, "I hope that for you as well. We'll see what we can do. That's a great long-term goal." The best physicians are honest with their patients whenever possible, celebrate the small things with them along the way, and allow them to have dreams in the long-term. These approaches are not inconsistent.

7. Finally, family members want jobs. We feel a complete lack of control over the medical situation and we want you to tell us what we can do to help. *Please* tell us what we can do to help. That doesn't mean giving us decision-making power. It means giving us actionable, feasible tasks to put on our to-do list. I cherish the physicians who allowed me to take notes and then asked me to look back at them later to verify facts (eg, "Brigitte, what size was the Foley the last time Hans was hospitalized?). I wanted nothing more than to be allowed to silence the alarm on Hans' machine, change his bed, help him walk, find the physician a pen, literally anything I can do to make the situation just slightly less painful for everyone involved. Don't give me authority; just make me your minion. If you don't have something for me to do, find something. No task is too small. "Would you mind helping us out by starting to keep track of the number of times a night your brother wakes up and asks for pain medication?" Yes, I would love to.

Physicians are incredibly gifted in the *science* of practicing medicine. In my family's observation, training physicians more extensively in the *art* of practicing medicine could be beneficial for all. In the meantime, I am grateful for the many physicians who kept my brother with us for many meaningful memories. Thank you.

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1. Institute of Medicine Crossing the Quality Chasm: A New Health System for the 21st Century. http://books.nap.edu/openbook.php?record_id=10027. Accessed January 27, 2013.