

From the Bedside: A Family Physician Experiences Health Care from the Patient Side

Michael Ismail, MD

Perm J 2017;21:16-166

E-pub: 04/21/2017

<https://doi.org/10.7812/TPP/16-166>

During the past 18 months, I have had the opportunity to witness our care from the patient side. Although certainly not the way I would have chosen to test out the quality of the care we deliver, it has definitely given me insight into the importance of why we do what we do.

In early May of 2015, I was on a trip to Disneyland with my children and some good friends from Maryland. On the last few days of the trip, I began experiencing sudden-onset tingling on the left side of my entire body while brushing my teeth before bed, lasting for about 30 seconds. During the next few days, after traveling home, it progressed from once daily to twice an hour. Often, it would be set off by touching part of my body to something else, like putting my left arm on an armrest, and it would seemingly spread from there. Not wanting to make too big a deal of things, I found it difficult to look at the symptoms objectively and, while we were working in urgent care, found it useful to run my symptoms by a trusted colleague, who consulted by phone with neurology. I was happy that the neurologist on call that night was a friend who listened carefully to my symptoms and quickly narrowed it down to a demyelinating disease or a tumor. He recommended an MRI, which he ordered, and I was able to schedule for Friday of that

week. Within 2 days (Thursday), however, the episodes had increased in frequency to every 15 minutes and I found them too distracting to do my work. I called my office manager, cancelled my day, and walked over to the emergency room in the next building. An MRI was ordered for that day. An hour or so after it was completed (at the end of the day), the emergency room physician, looking pale, walked in the room with a telephone. It was my neurologist, who was at his son's Back to School Night but wanted to discuss the findings. There was a 4-cm right-sided parietal lobe tumor causing focal partial seizures. I could go home with antiseizure medication, but he wanted to see me in his office the next day for a lumbar puncture (to rule out infectious causes).

Getting a terminal diagnosis from a colleague and friend seemed less difficult to me than imagining getting this news from a stranger. Heartfelt concern goes a long way in softening the blow. However, it seemed to be much more difficult for my colleagues in the emergency room and for the neurologist involved.

During the next few weeks, I got some additional opinions at a nearby university hospital. Not wanting to offend my colleagues by going to other physicians, I felt I had to explain my choice to seek an opinion from someone more distanced

from me personally. Of course, the discomfort was completely one-sided. No one was ever offended, but welcomed the fresh set of eyes on the case.

As my first visit with the neurosurgeon at the Redwood City Kaiser Permanente Medical Center approached, it was very helpful that my boss came to me to reassure me that he had known my surgeon for many years and that he is an excellent physician and a surgeon with superior judgment. I try to remember that now, when I speak to patients. If I have personal knowledge about a physician's outstanding qualities, I will convey that to my patient, to help them feel confident and less anxious about the upcoming visit.

After the biopsy confirmed Grade IV glioblastoma, my surgeon recommended resection (with a 6% to 7% chance of significant neurologic function loss) followed by chemo and radiation, and a vaccine clinical trial. The neurosurgeon at a nearby university hospital was recommending chemo and radiation only (believing the tumor not to be resectable). The opposing opinions were making it difficult for me to come to a decision. By the time I met with the vaccine trial lead investigator, I was thoroughly confused. The problem with being a physician and receiving treatment is that other physicians often assume that you already know what you want. This, however, was way outside my wheelhouse. The investigator met with me to go over the trial criteria and what I could expect, and we signed the consent forms. Several days later, however, I still hadn't made a firm decision. I spoke with my specialists again, but still didn't feel sure. Then I received a call from the clinical trial investigator.

"Let me speak to you as a colleague and a friend," he began. "When I look at your

Two Journal Entries

As patients, we all want yes or no; black or white. Is my tumor back? Should I undergo surgery? Will this chemotherapy extend my life? Those of us who work in the medical field know patients want answers that frequently we cannot give. But we can always give hope and the reassurance that we will be on their side to fight beside them. Uncertainty isn't all bad: It leaves room for hope.

I think I would be a much better doctor if I remember that what I can offer, even if not a cure or a straight yes or no answer, is to treat each patient with dignity and respect. To say to them, "Let me speak to you as a friend." To offer them solid, evidence-based treatment. To never, ever, let myself forget to extend the most powerful medicine I have: Hope.

MRI, I don't see a nonresectable tumor. I know what our team can do. You have to leave room for hope. If you don't do the surgery, we know what will happen. Eventually, you will have the neurologic loss that you fear. If you do the surgery, that could still happen, but there is a chance for meaningful extension of life." His words made it easier for me to come to the decision I already knew was right: to have the surgery. I try to remember that now when I speak to patients. Sometimes they aren't looking for only statistics. Sometimes they need heartfelt advice from someone they trust.

Choosing to move forward with the surgery seemed to me like the more hopeful path, the one that offered the most possibility for "long-term" survival with a terminal diagnosis.

Ultimately, surgery is a leap of faith in the skills of another human, and in my case, the surgeon would be working very close to the parts of my brain controlling my left hand and the left side of my face.

For those of us who spend our days in medicine, accepting help from others can feel unsettling. I found it difficult to let go of my work responsibilities and accept the meals, rides, cards, and gifts that friends, coworkers, and patients generously showered on me.

I am often reminded that we stand on the shoulders of giants. If it weren't for the thousands of physicians and patients treating and being treated for this terrible disease before me, I wouldn't have had even this short time (almost 18 months) with my family, friends, and colleagues.

After six months away from work, it was nice to finally return to the office,

albeit part-time. Often when we feel overwhelmed with the amount of work we have to do, one of my colleagues says: "It is a blessing to have meaningful work, and the strength to do it." ❖

How to Cite this Article

Ismail M. From the bedside: A family physician experiences health care from the patient side. *Perm J* 2017;21:16-166. DOI: <https://doi.org/10.7812/TPP/16-166>.

Editor's Note

Before his passing in January 2017, Dr Ismail submitted this manuscript for consideration. The Sidebar: Two Journal Entries is taken from Dr Ismail's written journals, which his wife shared. Dr Ismail was writing a blog during his illness, which is available at: <https://mikeismailupdate.wordpress.com>.

Hope

He is the best physician who is the best inspirer of hope.

— Samuel Taylor Coleridge, 1772-1834, English poet, literary critic, and philosopher