

■ health systems

Spending Time on the Other Side of the Doctor-Patient Relationship

By Cheryle Sullivan, MD

For 16 years I have been a family physician, the last six with Kaiser Permanente (KP) in Colorado. Most of my first decade in medicine was spent as a solo family physician. Although I thought of myself as a physician who was very sensitive to patients' feelings and needs, I have learned many lessons during the last seven months as the result of spending time as a patient.

My Accident

February 19, 2002, was the last day of a relaxing five-day weekend spent at a friend's mountain cabin. On my way home, I decided to stop for a few runs at the Winter Park ski area, where there were four to six inches of fresh powder. I had planned to ski for many decades and had only taken up the sport since moving to Colorado. I am at best an intermediate skier, so my routine was to take it slow and easy, avoiding trees and moguls. Despite this, I had what I thought was a minor fall, slipping and falling backwards. My helmeted head struck hard against the icy ground under the new powder. I thought I had simply "rung my bell." The next day, I developed vertical diplopia then—over the next two days—cognitive problems, agitation, and significant insomnia. Thus started my journey into the world of a patient in the KP system—and the lessons began.

Transportation and Appointment Challenges

I was told during the first visit with my cognitive therapist at an outpatient neuro-trauma rehabilitation unit, "If you are used to being in control, get over it." Never has this been more relevant for me than in the area of transportation. Since having my driving privileges revoked, I have had to rely on others for transportation. Where I live, there is a nonprofit organization called *Special Transit*, which provides transportation for those unable to drive. This service has been a lifesaver for me. The difficulty is that the service is limited, only available three days a week between my home in Longmont and Boulder, a neighboring town and the location of several of my medical providers and the outpatient neuro-trauma rehabilitation center. No transportation is available to Denver, where I had appointments for imaging and with several other specialists. The system is set up so that you cannot call more than a week in advance for your transportation request—problematic since transportation is provided only on a first-come, first-served basis. This does not accommodate last-minute appointments, changes in appointment time or day, or appointments using the Advanced Access (Same Day Access) model, being introduced in the KP Colorado Region.

Pick up time for assisted transport

services is up to one hour or more before and usually within 30 minutes after a scheduled appointment. This timing creates a problem because the provider may run late so you have to allow extra time, as they will only wait five minutes for you after your scheduled pickup time. Therefore, a 20-minute appointment might use up to three hours of a day. Even with the buffers built in, on occasion you are dropped off late for your appointment.

Because I am used to being early for appointments, initially getting picked up late with subsequent late arrival to an appointment caused me significant agitation. Fortunately, the majority of my late arrivals were to see my rehabilitation specialist. She and her staff understood the transportation system and were quick to let me know that everything was fine: it was not a problem that I was late. I know some providers within our KP system might have required me to reschedule the appointment, magnifying all the associated logistic problems and adding to my stress. If I had been asked to reschedule appointments when late through no fault of my own, I would have felt as though my care providers and their staff had little regard or understanding for my feelings and needs. I have learned that we need to treat all of our patients as we would want our valued family members or friends treated.



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The Importance of a Good Social History

“Married, divorced, widowed, single?” As we learn more about providing culturally competent care, it will be important for us to develop inclusive history-taking skills. This practice would let the patients know that we provide a safe and comfortable environment for them to have open discussions with us. For example, when routinely asked this routine marital status question, I never felt comfortable relating my lesbian status. This discomfort had major implications, since I did not feel comfortable sharing additional social information and essentially did not disclose details of my home life. It is of great importance that I did not have a discussion about my lack of a local support network with any of my clinicians. I did not reveal that I had changing symptoms, including significant fatigue and short-term memory problems that resulted in missing most of my meals in the first week or more. I did not reveal that I lived alone and could not drive. I did not disclose that, at the time, I was in a fog mentally and unaware of potential personal safety issues. As I look back now, I think the information about my lack of support at home was potentially very important, and yet I did not feel comfortable in relaying the information.

What I have learned is that a better social history option could include: “Are you married, partnered, divorced, widowed, or single?” or “Do you have a spouse/partner?” or “Who lives in your home?” Another option is “What kind of support system do you have?” This would gather information about family, friends, and church in a supportive and nonjudgmental fashion.

Minimizing and Invalidating

I cringe when I reflect on how, before my brain injury, I responded as a physician to patients’ concerns about difficulties with memory. So often we tell the patient that we have experienced the same problem, such as not remembering what we intended to do, or forgetting where we put something, or not being able to remember a word we needed in a sentence. But we really don’t know what it is like! The occasional forgetfulness we all experience is in no way comparable in frequency or severity to that experienced by the brain-injured. Understandably, I never experienced this from those who work on a regular basis with the brain-injured. In the future, I will try to be more empathetic and will agree with the patient that these difficulties are frustrating and bothersome, instead of invalidating or minimizing the patient’s concerns by saying that I have the same problem and I know exactly how s/he feels.

“Any Other Questions?”

Physicians often shudder a little when we ask this question at the end of the visit. Because, at times, we may not have enough time with patient encounters during our busy days, we may ask this question insincerely. Body language may send a major message to the patient if, after asking this question, clinicians appear rushed, making it obvious they do not have the time to address the patient’s additional concerns. As a brain-injured patient with

memory, attention, and information-processing problems, I had difficulty understanding what had been presented and was not able to process the information adequately or even to remember it well enough to ask needed clarifying questions. At times, I was able only to grasp portions of what was said and was not able to handle the amount of material discussed throughout a visit. I would often bring questions to my appointment but forget to ask them or would not think of obvious questions until hours later.

I have learned that when dealing with patients with cognitive problems, it is helpful to have them repeat back the pertinent information in their own words or have them bring along someone to help them understand the information. It has been easy for me to relate to the clinicians who are comfortable and familiar with the care of brain-injured patients because these people write down the pertinent information for me to take home. This courtesy is always appreciated.

Getting Lost in the System

As a family physician, I believe in the concept of each patient having a primary care physician. However, since following my ski injury, I entered the system through the emergency department and then had most of my follow-up visits with specialists. I basically bypassed the primary care system. Being a physician probably did not help either,

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because, I suspect, people thought I knew more than I did about what was going on with my injury. It is also difficult to admit you are having cognitive problems when you are accustomed to your role as a physician and manager. I floundered in our system, seeing one specialist after another. I did not understand what was happening to me or what the expected course and longer-term plans were. In my confused and forgetful state, I was trying to decide what I should do next. Thankfully, my story was relayed to our case managers of brain injury patients, who contacted me through our local senior care coordinator. It felt as if I had been provided a life raft. I have learned that, as clinicians, we need to advocate for our patients and

be sure that someone is managing their care and providing support when things are too complicated and confusing for the patient.

Closing Comments

By the end of November, I had had my 100th medically related appointment since my traumatic brain injury more than nine months ago. Despite some pitfalls, the quality of my care has been excellent. I chose to stay within the KP system whenever possible, to take advantage of the excellent physicians and other providers, and to experience the benefits of the EMR (Electronic Medical Record). All my Permanente providers have up-to-the minute access to my medical records, allowing more efficient and accurate

medical care. Most of my learning from my experience has had more to do with quality of service and has increased my understanding of how a physician can take the patient's care experience to another level. I remember being told early in my medical training that if doctors had to be patients and had to experience what we put our patients through, we would be much better doctors. Most brain injury patients say they are not the same afterwards. I hope this result is true for me because I want to be a better physician than I was. When I am ready to return to my patient care duties, I will remember these and other lessons I have learned while I was on the other side of the doctor-patient relationship. ❖

The Problem

Doctors see patients because of disease.

Patients see doctors because of anxiety.

Therein lies the problem between the two.

— *The Doctor, His Patient, and the Illness*, Michael Bolint, MD