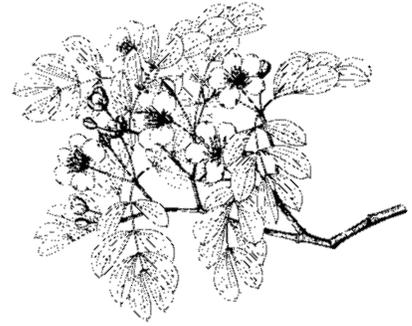




Commentaries

Three A's or Four; or, What Do Patients Want In a Doctor?



In thinking about the best way to tell Parkinson's disease (PD) patients their diagnosis, I became interested in the methodological problems a research study would encounter. I then started to think about the issue of the doctor-patient relationship in PD, which may, of course, extend to many medical encounters. The more I pondered, the more convinced I became that this complicated topic had no simple answer. Different patients and different cultures produce different needs and different desires.

The standard line we're taught in medical school, with somewhat pejorative undertones, is that patients care about the "three As: availability, affability and ability," in that order. I learned from some research articles studying the patient doctor relationship that there is a fourth A, autonomy. Patients, at least in the primary care area, want to be included in decision-making. An Israeli study of in- and outpatients on a medical service at a university center reported that patients didn't care at all about whether their doctor was a medical school faculty member or did research. They didn't even care about continuity of care, a surprising finding, of course, at a center full of resident clinics where doctor turnover is guaranteed. Three of their four major concerns were that their doctor should be competent, humanistic and available. However, the area in which they most fully agreed with each other was in the need for patient "autonomy."

In the area of medical decision-making patients are often not included. The doctor may think, after all, that they came to the doctor to be diagnosed and treated, and who knows best?

There is a literature on "shared decision-making (SDM)," evidently a buzz phrase in health-care delivery. It has been studied, to a limited extent, but different studies have reported different effects. First of all, it is unclear to me how one does a blinded trial of SDM vs not-SDM, but some studies reported controlled, blinded

trials. Few indicated that SDM produced better patient satisfaction with the doctor, or benefit in terms of compliance with treatment recommendations. Support for SDM is, therefore, more theoretical than real.

As I considered how to study this topic in my own area, PD and movement disorders, the more I became convinced that although data on autonomy and shared decision-making may be useful, the real key to being a humanistic doctor is recognizing the needs of the individual patient. And I haven't thought of any reasons why this wouldn't extrapolate to all areas of medicine. It is difficult for me to believe that patients have a uniform opinion other than that they'd like to be treated with respect and kindness, with the three A's mentioned above as well.

I suspect that every medical discipline differs in its approaches to autonomy, as do these disciplines' patients. Patients with psychiatric problems, for example, are less inclined to get second opinions, although my experience indicates that they change doctors relatively frequently. I am not sure there is room for autonomy in much of psychiatry. Oncology patients often get second opinions and are used to hearing what the options are, as do patients being referred for procedures. I think patients are often quite autonomous in these settings, like making a decision on buying a car.

A colleague asked a group of people with PD what they would have liked to have heard on their initial visit to their neurologist versus what they did hear. Of course we must keep in mind that what they recall having heard and what they were told are often different (and the same goes for the doctors). Nevertheless patients often recalled that they were given short lectures on the disease process, the options for treatment, prognosis, etc, but what they really wanted to hear (reported much later on) was that the doctor and the patient were in this together, forever. They wanted emotional support, not autonomy.

This was a surprise to me. The study has not been published and has not been replicated. The results may represent a cultural bias of Oregon, where the PD study was performed. Soon after I learned about this study, an old friend of mine was talking about the ordeal he and his wife were going through with their neurologist in the midwest, who had cared for the wife because of her dementia. At an early meeting he told her that there wasn't much he could do for her but he'd always be her doctor. Yet three years later he could not see her again. Her dementia had progressed rapidly and he was under institutional pressure to stop seeing patients with advanced dementia. My friend, her husband, who needed at least as much emotional care as she did, felt desperately betrayed. Demented as she was, she too felt betrayed and abandoned.

I have given this a fair amount of thought and have considered telling new patients that I'd always be there for them, but it sounds too ominous, too much like a death-bed promise and somewhat paternalistic as well. I have never said this to a patient. I do try to say, or at least convey, the fundamental bond we will have, that since we don't yet have a cure for PD that I'd be happy being on their treatment team until there's a cure or one of us dies. I hope that putting it this way conveys the message that I won't abandon the patient, while at the same time, placing us on the same level, acknowledging that not only are we together on the same team but also that we are *both* mortal.

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