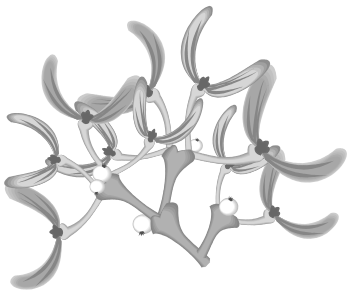
Commentaries



Hanging the Crepe

"Hanging the crepe" is an old phrase, referring to the no-fail ploy of foretelling a bad outcome to patient, family and friends. If the prediction comes true, the doctor was prescient, and if not true, a savior. I recall, many years ago, a resident who was working under my supervision, and with whom I was particularly close, telling me that he couldn't believe that I had just told a patient and family that I was optimistic the patient would make a good recovery from a stroke. I don't recall why I told them that, and while I think the patient did, in fact, recover nicely, I do recall that I worried quite a bit for a few days. The resident may have been correct. I think I'm generally pretty cautious, and usually pessimistic, but I do share my optimism as well but don't routinely hang the crepe. Of course my practice is entirely out-patient now, and what and how we tell our patients with incurable, progressive disorders is a crucial part of our jobs.

Recently I evaluated a patient, a recently retired physician, who was extremely active physically. "I came to see you for a second opinion. Another neurologist told me that I had Parkinson's disease, had to give up skiing now and would be in a wheelchair in ten years." This is hanging the crepe big time.

I was stunned. First of all, I was able to give someone that rare bit of good news that comes out of my office, "No, you don't have Parkinson's disease (PD)," or something worse. This was essential tremor, a condition occasionally misinterpreted as PD. This misdiagnosis is not all that rare and certainly can be forgiven, because the distinction may be quite challenging early on, but the bad prognosis could not be. I tried to put myself in the shoes of my colleague. Why would he say something like that? I asked the doctor if our colleague had really said that, not that he heard something not actually said, but dredged up from his inner fear. "He clearly said that. I asked about the skiing because it is so important to me. And I asked about the wheelchair in ten years. That's really why I'm here. I didn't think I had PD. My athletic abilities are just the same as they've always been. And why should I stop skiing if I'm going to be in a wheelchair in ten years?"

When and how to give a prognosis is a tricky thing and one size certainly does not fit all. I have the unfortunate responsibility, like many doctors, of telling people things they'd rather not hear. How we do so is important, even though what we say, or better still, what we think we say, and what they hear, may be so divergent. This is a running theme through our careers and I wonder how much we change with our increased experience both in life and our professions.

Telling someone with PD not to ski actually makes little sense. Simply having the diagnosis doesn't alter anything. We should be advising people on their capabilities and not their diagnoses, unless those diagnoses have hidden risks. Lifting weights with a dissecting aneurysm in any artery is a bad idea. But simply knowing you have PD, which is certainly associated with impaired balance, doesn't suddenly make your balance worse. If you could ski safely yesterday, you can ski safely today. The issue really is whether the patient can properly assess his skills and the resultant risks, not whether he has PD. This is simply common sense, and the physician hearing the admonition to desist from skiing simply couldn't understand it. Why not ski?

More bothersome to me was the statement, at least as heard by my patient, that he'd be in a wheelchair in 10 years. It is not so much that the statement isn't true, and it isn't, is the fact that almost all neurodegenerative diseases are fairly variable so that while there is data on disease progression in general, it never applies specifically to one individual. As with everything biological, there is a great deal of variability. The progression of neurodegenerative disorders is analogous to aging. We don't know when they begin. When did we become old? Is slowing down due to Parkinson's disease, arthritis or getting old? Sometimes it makes itself known in a flash, with injuries. The processes are usually so insidious that no clear onset can be distinguished, And they progress like aging. Some people age gracefully, and look 10 years younger than they are while some look 10 years older.

I always tell patients that their disorder is progressive but that the progression is measured over months to years, so there will be time to see disabilities developing. Nothing happens overnight. In addition, the progression varies enormously from person to person, so that one person may have minimal disability even after 10 years while another will be in a wheelchair in five years and that only time will tell. In the meanwhile exercise is critical in reducing disability, whichever track the patient is on. Thus, at our first meeting I can give the bad news, but also hold out hope. There must always be some hope.

– Joseph H. Friedman, MD

Disclosure of Financial Interests

Joseph Friedman, MD, and spouse/significant other. Consultant: Acadia Pharmacy, Ovation, Transoral; Grant Research Support: Cephalon, Teva, Novartis, Boehringer-Ingelheim, Sepracor, Glaxo; Speakers' Bureau: Astra Zeneca, Teva, Novartis, Boehringer-Ingelheim, GlaxoAcadia, Sepracor, Glaxo Smith Kline, Neurogen, and EMD Serono.

Conflicts: In addition to the potential conflicts posed by my ties to industry that are listed, during the years 2001-2009 I was a paid consultant for: Eli Lilly, Bristol Myers Squibb, Janssen, Ovation, Pfizer, makers of each of the atypicals in use or being tested.