Playing Doctor: A Palliative Care Conversation

I’m learning to approach chronic illness conversations in new ways. I’ve read Atul Gawande’s “Being Mortal” and watched the hour with him on PBS’s Frontline. And I’m now one of the two medical directors of a hospice, no longer chief of a division of anesthesiology.

Medical conversations as I learned them almost 50 years ago went like this:

Patient: I don’t feel well. These are the problems I am experiencing.

Doctor: Based on your symptoms and on the additional signs of disease that I see on your physical examination, I made a list of diseases that you might have. I ordered tests and studies to narrow the selection. Based on your symptoms, the signs I find, and the results of your tests and studies, I believe that you have disease X.

The course of disease X is usually such-and-such, and the treatment is usually something or other. If the disease is life-threatening or disabling, a discussion of treatment usually involved some form of trading time now for possible time later. That is, if we do this big surgical procedure or give you these toxic drugs now, making your life miserable for while, there is a chance that your life later will be longer, and may even be free of the effects of the disease.

Seldom did we lack something to offer, and we were not schooled in helping people hear what would happen if we did nothing heroic, but simply made them comfortable. We learned to compare treatments at length, but we seldom considered providing no treatment, only comfort.

I think we functioned with the implicit assumption that patients came to us to achieve the longest life possible, and we focused our discussions there. We did not learn to ask what patients wanted, except so far as they were able to choose one treatment over another.

This was certainly my own experience with prostate cancer in 2000. After a panicky month in the medical library, I could quote statistics comparing radical prostatectomy with external beam radiation, brachytherapy (seeds), cryotherapy, and proton beam therapy. I knew how much erectile dysfunction, incontinence, recurrence, and death was associated with each. But I had no real idea what would happen if I did nothing. Nor could I find any reliable information. So I never for a moment considered doing nothing – my only question was which of several somethings I would choose, by whom, and how quickly. I chose to burn away an important body part with radiation because I was so afraid of dying from a disease it contained, and I accepted the losses that came with that decision.

Each of my doctors represented something to “do” to cure me. Nobody represented caring for me no matter what, and for sure nobody seemed to be saying, we’ll take care of you even if you don’t choose our particular therapy.

Prostate cancer probably isn’t a very good place to focus in this discussion. With treatment, life is long and generally comfortable. Without treatment, life is long and generally comfortable. There are exceptions in each group, but no preponderance that would sway choices.

The issue becomes more sharply focused with more rapidly progressive cancers, where there is a choice between doing little on one hand, versus choosing a series of temporarily painful or disabling therapies on the other. Although it may seem that patients are always asked which therapy they choose in order to play for future time, a more realistic discussion, at least in later stages of disease, recognizes the tradeoff between present time and possible future time.

This is where a palliative medicine perspective fits in. Palliative medicine does not ask what might cure the disease, or what might yield some imaginary better future. Palliative medicine looks at what’s important both now and in the future, and how patients might make choices consistent with their priorities.

A typical palliative medicine conversation involves more listening than telling, and might boil down to three questions:

1. What’s your understanding of your disease?
2. What’s important to do in your life?
3. What’s the best way to get these things done?

We ask about understanding because patients make decisions based on what they think is happening, and sometimes important pieces of medical communication simply haven’t occurred, or haven’t been understood.

We ask what’s important because that’s the only way to make decisions that support patient priorities. The flip side of that question is “What do you fear?” As much as possible, people shape their lives to achieve the ends they want and avoid the things they fear. Realistic discussion of both goals and fears is important.

We explore how a patient can attain priorities and minimize feared experiences because this is where the hard choice-making occurs. Sacrifices and tradeoffs are inevitable. Trying to live a long time with a chronic disease may require an unpleasant interval of disagreeable lifestyle choices and harsh therapies with no guarantee of longevity. Trying to stay completely comfortable with neither lifestyle change or medical intrusion may result in a shorter life, though most of it may be more satisfying.