

Patient empowerment means knowledge, power — and responsibility

by Brenda Denzler

Back in the day, it wasn't uncommon for physicians not to tell their patients of a cancer diagnosis. They would make vague statements about the cause of symptoms and initiate whatever treatment was available—all without the patient's input. Those days are gone.

The choices about whether to screen or not to screen for breast cancer and prostate cancer, whether to watch and wait or whether to act if cancer or proto-cancer is discovered... These are being left in the hands of patients more and more often as the medical industry embraces (in form, if not always in fact) a "patient-centered" model—the apparently breathtaking, innovative idea that patients ought to be at the center of all health services.

The very idea that "patient-centered" is a concept that had to be formulated and then articulated and promoted is a little odd to me. I mean, what was the focus of health care if not the patients? Near as I can figure, it was that old, doctor-knows-best, paternalistic approach combined with excitement about medical innovations. As advances came in the science of medicine, there was increasing fascination with all the new "stuff" that could help doctors do their doctoring: new lab tests, new forms of imaging, new ways of doing surgery, new drugs, whole new kinds of treatments like immunotherapy.... The importance of the people upon whom all these new things were being used tended to recede into the background, I guess.

The corrective to this eclipse of the patient began at the turn of the millennium with a report from the Institute of Medicine wherein the term "patient-centered" was first used. It quickly became a pithy buzzword calling for returning medicine's focus to quality patient care, which was defined in terms of improving outcomes in the aggregate, i.e., fewer hospital-acquired infections, falls, or returns to the hospital within 30 days after 100,000 people had been dismissed from one. But as the idea took hold, it sprouted corollaries, such as the concept of "patients' rights," which focused

the conversation a little less on populations and a little more on the individuals who made up that population.

There have been countless efforts to specify what a patient's rights should be. Some of these standards emphasize the right of the patient to understand their medical situation, to ask questions and receive coherent answers using non-technical language, and to give or withhold consent for treatment.

This is where we are when it comes to screening mammography, PSA tests, and decisions about how to handle very early-stage cancers. It's our choice, as patients. It's our right to ask for more information, expect it to be presented understandably and without a lot of jargon, and to choose our path. We are still in the early years of making this level of patient choice a reality, but it's coming closer all the time for all kinds of health issues—not just breast and prostate cancer.

Some go even further with the idea of "patient-centered" and "patient rights." They emphasize patient empowerment: the right of the patient to frankly share power with their doctors, not just in terms of giving or withholding informed consent for an action the doctor has chosen, but in terms of working alongside the doctor to consider options and make choices about actions well before the point where the need for formal consent is ever reached. This level of patient-centered care is still mostly a dream, but there are stunning examples of it all around us, and it is sure to be more widely adopted—if not frankly expected—in the coming decades.

The thing is, with increasing rights come increasing responsibilities. If we are going to lay claim to a right to this level of medical self-determination, we have the responsibility to do so from a position of sound knowledge, accurate and sufficient understanding, and the strength and ability to live at peace with the outcomes. If you don't find this just a bit daunting, then you aren't paying close enough attention.

Some lists of patient rights do mention patient responsibilities. In general, I find them

tepid statements, at best, of what patients need to do: Show up for appointments and be on time, they advise. Bring a short, coherent list of your complaints, when they started, and whether anything makes them better or worse. Ask questions if you don't understand something. Take medications as prescribed. Provide up-to-date insurance information. Inform us of medication changes or supplements you are taking. Tell us if your contact info has changed....

To me, this is the chump change of patient responsibility. It's the rock-bottom minimum that all patients should be doing anyway. The kind of patient responsibility I'm envisioning is far more than this. It is, in fact, taking control of your medical life.

How do we do it? How do we become more responsible for our own health? I think there are at least five things that should happen:

Live the best lifestyle you can to keep yourself healthy or manage conditions with which you were born. If you choose to engage in unhealthy habits, learn what the potential consequences are, how likely they are, and what the cumulative effects of multiple less-than-healthy choices may be. Prepare yourself to deal with those outcomes, if they occur. No whining.

Set up and maintain a health history file on yourself. This means records of medical issues, visits to medical providers, tests run, diagnoses, treatments, and outcomes. Get paper or digital copies of all test results, including imaging, for your files. Make an "executive summary" of the contents of the record so that when you share it with a health provider, he or she can quickly see the most relevant info.

Educate yourself! Use reputable websites to learn about your symptoms and diagnoses. If you feel like splashing around on the less reputable health sites, go ahead. In the end, though, weigh and balance all of the info you are getting very carefully. Develop a basic grasp of statistics so that you can read all this info and kinda-sorta understand it in a broad, general sense—like the difference between absolute risk and relative risk, for instance.

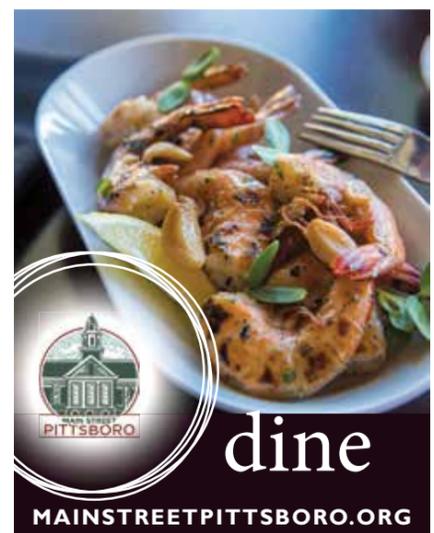
Then bring it all home to focus on a single

person: you. Your doctor is, usually, the person with the best info and perspective on your health issues. Take them and the questions generated by your self-education to him for a more individualized perspective on your situation. By this time, you are the expert on what is happening in your body. You have some decent, basic medical knowledge about your symptoms based upon your studies. But your doctor has the benefit of a background of in-depth study and a career full of experience. Work together, as true partners, to decide what needs to happen next.

Follow through! Repeat steps 3 and 4 until the issue has been resolved.

This, to me, is an empowered patient: The patient is in the driver's seat; she is the one in control throughout. The doctor is right beside her as the indispensable navigator, without whom she might never be able to reach her health destination. This is patient-centered medicine, at its best.

Brenda Denzler was diagnosed with inflammatory breast cancer in 2009. She became a cancer survivor on the very day she was diagnosed.



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