Nine years ago I was dying of kidney cancer, I survived, and now I’m pre-diabetic, so I know from experience that healthcare is different in a crisis or chronic condition. What I had to do for each was completely different except for one thing: in both cases I did everything in my power to understand my situation, learn, and take empowered, effective action.
It turns out that in each case what I did was called being an engaged, empowered patient – an e-patient. The term was coined by “Doc Tom” Ferguson MD, who died ten years ago. He was a visionary who saw that technology was opening a new world in which “empowered, engaged, equipped, enabled” e-patients would start sharing the balance of power, authority, and capability with their medical professionals. The Society for Participatory Medicine was formed in 2009 by his followers.

The culture of medicine changes slowly; most clinicians and scientists have never heard of e-patients. (Try asking one.) But whether or not anyone knows it’s happening, the change is underway. Medical authority is starting to view patients as active contributors, not passive recipients.

What a remarkable and diverse set of places to see such recognition of patients not just as sick people who need help, but as actual partners.

But hardly anyone has heard of it. Ironically, in medicine word travels slower than usual. One famous paper documented that on average it takes 17 years for half of physicians to adopt new knowledge [2].

Reality is what it is, whether we know it or not.

One thing I learned during cancer is that it’s not useful to wish a situation does not exist, and it’s not useful to pretend it doesn’t. To the contrary, the better informed you are about reality, the more able you are to produce results that matter to you.

Here’s where patient power is a game-changer: if my health is about what’s important to me, instead of what I’m told I have to do, it takes on a whole new feeling. It’s up to me to take action or not; sometimes I ignore a stomachache, sometimes I ignore a stomachache, sometimes I ignore a stomachache, sometimes I go to the doctor. After all, who’s the person with the problem in the first place?

Consider This:

In 2012 the Institute of Medicine (IOM) published a 382 page report [1] that said medicine needs to be “anchored on patient needs and perspectives.” That’s pretty much the opposite of telling patients to comply with doctor’s orders!

The same report called for “patient/clinician partnerships” with “engaged, empowered patients.”

That same year the National Library of Medicine began capturing some patient blogs in its History of Medicine Division, saying “blogs authored by doctors and patients illuminate health care thought and practice in the 21st century.”

In 2014 the editors of the BMJ (formerly called the British Medical Journal) announced its Patient Partnership (http://www bmj com/campaign/patient-partnership), inviting patients to become peer reviewers of articles about their disease – yes, to review articles written by scientists – and encouraging patient voices in the design of the research!

The BMJ also named a patient editor, Rosamund Snow – a person with type 1 diabetes.

In 2015 the Mayo Clinic invited a patient to be Visiting Professor in Internal Medicine, calling for “a union of forces between providers and the patients who entrust us with their care,” since, “patient engagement and empowerment is a natural extension of Dr. Will Mayo’s vision of a medicine as a cooperative science.”
IT ALL LOOKS DIFFERENT WHEN YOU’RE THE ONE WITH THE PROBLEM

An activated, empowered patient comes to the doctor looking for a “summit,” in a sense – a gathering of stakeholders. If that’s not how the visit comes across, the patient – the ultimate stakeholder, the one with the most at stake – can end up feeling not trusted. As in any relationship, that can lead to the patient no longer trusting the provider: a downward spiral of distrust, truth-hiding, nodding when you don’t mean it, which all too often ends in labels such as “non-compliant,” and sometimes the patient being “fired” – or vice versa.

The sad thing is that no provider got trained with that in mind, nor does any patient want that. So where’s the breakdown?

One answer is available from other industries, where for decades it’s been understood that the ultimate definition of quality always ends up coming from the person with the need – the customer (in this case the patient). In healthcare, that idea makes some people crazy. For example, I’ve heard comments along the lines of, “Medicine is really hard to learn – do you have any idea what I had to go through to get this license?” or “How can someone with no medical training at all know anything worth knowing?” Can you see the quandary? Having been saved from certain death by great clinicians, I have the deepest respect for that training. However, leading thinkers are emphasizing patient/clinician partnership and recognizing the value of understanding patient needs and perspectives.

That’s why patient autonomy and empowerment are really challenging, until both partners figure out the new “dance steps.” Consider IT (information technology): highly trained security professionals know the best measures to minimize viruses and data breaches would be tight, because network and software restrictions would limit our ability to interact with other systems. But that expert protection would not work well in the “patient’s” life; it would dramatically limit the way we share and use data, which is why we have the computer in the first place.

So today we have technologies that make interacting with information easier, from saved passwords and shared bookmarks, to social networks, to targeted advertisements based on our likes and preferences. The expert advice is folded into methods that work in the “patient’s” life. This happens to be exactly the approach used by the great endocrinologist Dr. Victor Montori at the Mayo Clinic, who espouses “minimally disruptive medicine” (https://minimallydisruptivemedicine.org/), which is essentially “health care that fits” in your life through the use of “effective care programs designed and implemented in a manner that respects the capacity of patients and caregivers and minimizes the burden of treatment the care imposes on their lives.”
The DOC is exactly where the IOM (which was renamed in 2015 to “National Academy of Medicine”) wants patients to be, as an anchor to healthcare, and an empowered part of the healthcare team focused on successful patient outcomes.

Our healthcare systems have every ability to help patients get to the goals that they want. They need simply ask. And ask. And ask again, until the outcomes meet the expectations of the entire healthcare team, with the patient at its center.

REFERENCES


IT’S ABOUT PARTNERSHIP, NOT DOMINANCE

None of this diminishes the value of the trained clinician’s mind and experience. To the contrary, any shift in the balance comes entirely from elevating the patient’s potential. It’s the opposite of the old-fashioned cultural assumption that only highly trained people can know anything useful, which can lead well-trained critical thinkers to disregard the perspective of the person who has the problem. It can also lead patients to put an unrealistic burden on clinicians, if they expect every doctor to know everything important. (Did you know thousands of new medical articles are published every day? Who can keep up?)

Patients can help us raise our levels of consciousness about complex health problems. They can help us understand living with these problems better, and realize what can be done to solve them. The answer doesn’t have to always come from the clinic. Sometimes, it may come from the community.

NOBODY’S MORE “E-PATIENT” THAN A HEALTHY PWD

Since I first heard of e-patients it’s been clear to me that the archetypical engaged patient is the person with diabetes. If they are not actively involved, they can’t possibly do well with the disease. And the diabetes online community (DOC) is a great example of an engaged patient community.