



It's time to flip the script on patient engagement

By Dave deBronkart | August 28, 2018

This summer in Florence, Italy, 129 dragon boat clubs gathered for the 2018 Dragon Boat Festival. The event was sponsored by the International Breast Cancer Paddlers' Commission, which promotes recreational dragon boat paddling as part of a healthy lifestyle for people diagnosed with breast cancer. I witnessed one such meet a few years ago and was inspired to be surrounded by so many people working together.

We don't think twice anymore about women with breast cancer participating in marathons, 5Ks, or multiday bike rides, but it used to be that patients were encouraged to stay passive after mastectomy and not "stress their systems."

Sports medicine specialist Don McKenzie challenged that thinking 20 years ago, publishing the first paper about a dragon boat club for breast cancer survivors, which he called "an approach to promoting health and raising breast cancer awareness that ... encourages women to lead full and active lives."

McKenzie's 1998 paper is a great read: The sense of being onto something new is palpable as he recounts how women were starting to take active steps for their health, with the wide range of benefits that accrued.

We now take it as a given that being engaged, proactive and rowing together works better than being passive. But there's a subtler lesson in the rise of the dragon boats that still needs learning: Sometimes current opinion is wrong. Sometimes, we need to rethink our assumptions.

And so it is with patient engagement. In my travels to speak at health conferences and corporate retreats as a cancer survivor and patient advocate, I've heard many conceptions of what patient engagement is, and I've come to believe that too often, we're still getting it wrong.

To many, "engaging patients" means getting them to do what someone else says they should. Often this is driven by one quality metric or another that rewards providers for patient behaviors that aren't under the doctor's control.

The resulting ritual of tug-the-donkey is frustrating to everyone. Patients feel they aren't being heard and their definition of health isn't being accommodated; physicians feel burned out when they don't have the latitude to care for patients the way they want.

Just as McKenzie wrote of the benefits a new therapy "driven by women with the disease," can we now rethink the clinical relationship so that it's driven by the people in the room – the patient-clinician pair?

Cherished relationships, mutual respect

I cherish my relationship with my clinicians. I know that every one of them – from the PCP and oncologist I see often to the dermatologist I see rarely to the inpatient nurses who tended me when I was in treatment for cancer – made life choices that led them to be with me in that setting. Each completed advanced schooling, passed licensing exams, and has for years brought themselves into the breach where people in trouble come for help, all the while accumulating clinical experience.

Many have spoken of their dream of using their minds and hearts to help people in trouble. I have been that person in trouble, and I want their dream to be fulfilled. So it bothers me when I hear of physician burnout, 400 U.S. physician suicides a year, physicians saying they wouldn't advise their children to enter the field.

And it especially bothers me when the EHR gets in the way. The function it performs – collecting data for population health and continuity of care – is vital for patient collaboration, but so often usability and workflow interfere with getting the work done, disrupting that clinical bond.

What if we tried a different approach, aiming for a different kind of relationship and a different role for the computer – as a third partner whose job is to help the primary pair accomplish their job of getting care done? What if we pledged to keep the clinical relationship absolutely sacred, and did what we could to make those moments the biggest priorities of the day – setting aside EHRs, even, to truly understand from patients what they value as healthy and well?

A participatory bond, with computer assist

The Society for Participatory Medicine, which I helped found, talks about patients engaging with clinicians, about patients as active partners. We talk a lot about EHRs and technology (especially OpenNotes, which provides patient access to visit notes) because we know that for patients to be partners, they need "everyone on the same page."

Recently I've begun doing shared keynotes with my primary care physician, Danny Sands, M.D., who advocates for changing how we use computers in the moment of care. Specifically, Sands advises practitioners to:

- get acquainted with the patient record before the visit begins, the better to ...
- establish a "golden minute" of tech-free interaction at the beginning of the visit.
- maintain eye contact and keep hands off the keyboard when the patient is discussing a sensitive topic.
- build an "equilateral triangle of trust" between provider, patient and EHR, where the medical record becomes a document shared equally between patient and provider.

On that last point in particular, Sands and I agree completely that it's an unrealistic burden to give the clinician sole responsibility for all the data related to a patient's case and thus to all the brain work. He welcomes my engagement during our visits, and I've come to feel not only welcome, but capable of participating.

Setting aside the one-sided tug

I'm heartened whenever I hear of caregivers asking not, "What's the matter with you?" but, "What matters to you?" When care plans are developed in that context, everything shifts from obedience to teamwork toward a shared goal.

You could say it's time to rethink engagement from tugs to hugs – from providers tugging at patients, trying

to drag them forward so the provider can get paid, to working together on things we care about. When a goal is something the patient has helped choose – like stepping into that dragon boat or, in my personal case, being able to walk my daughter down the aisle – then the compliance fight dissolves, and the work of healthcare becomes improving the patient’s ability to achieve what they’ve chosen.

This is empowerment, full-on, and it’s my vision of participatory medicine: patients and clinicians on the same page. We need to bring about a renaissance of human-centered care that will help both patients and burned-out doctors, with the computer acting as a trusted assistant, in pursuit of that sacred relationship.

Dave deBronkart, also known as “e-Patient Dave,” is a frequent writer and speaker on patient experience.

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