

How Patient-Provider Engagement Can Transform Patient Safety

How would the world change if, suddenly, clinicians had a highly motivated partner in carrying out each care plan? I propose that a new level of safety will be possible if we shift to a shared care plan model, with patients and families aware of the plan and engaged in its execution.

I look at healthcare through the lens of a former patient: in 2007 great medicine saved me from Stage IV renal cell carcinoma. But I view it through another lens, too: as a high-tech business person who's watched industries evolve for years, it grips me that this miraculous industry has made so little progress on cost or safety—despite immense efforts by really smart people.

To me, that's a sign we've overlooked something. I assert we're making a fundamental error when we expect clinicians to know and do everything, and we pay a heavy price (literally and figuratively) for this mistake. We should share the load: enlist patients and families in making healthcare better.

The Plausible Promise of Participatory Medicine*

The Society for Participatory Medicine defines this new model as “a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners” (www.ParticipatoryMedicine.org). The Society arose in 2009 out of the “e-patient” concept developed by Tom Ferguson, MD (1944-2006). I joined the movement in 2008 after hearing about it from my physician, Dr. Danny Sands. In this column I write on my own, not on behalf of the Society.

A cornerstone of Ferguson's view is that in today's Internet-enabled world, what's possible in healthcare is radically different from 1990:

- Patients today have access to information that used to be accessible only to clinicians and researchers. That doesn't make them clinicians, but it does show why it's possible for ordinary patients to bring value to the table.
- Today patients can band together in smart communities, sharing experiences and research findings in ways that are inherently patient-centered. (Hospitals work at understanding what patients want; patients know what they want.) This doesn't mean every gathering of patients is inherently smart; it does show how it's possible for patients to aggregate knowledge.
- While patients have access to increased power, clinicians are gripped in a pincer: inexorable pressure to see more patients, while enduring an information explosion. Increasingly, it's impossible for clinicians to keep up. I vetted this point with my oncologist, and he said, “Right—unless you're a sub-sub-specialist like me.”

Ferguson saw this as an opportunity for empowered, engaged, equipped, enabled “e-patients” to help. At his death, he was compiling his observations into a white paper, which his team completed: “e-Patients: How they can help us heal healthcare.” The paper is available for download at the Society's blog, <http://e-patients.net>.

Ferguson talked about patients being engaged in their care. He didn't talk about patient safety per se

(though he did cite *To Err Is Human* [IOM, 2000]), but I'd like to extend his thinking to quality and safety, using five principles of participatory medicine.

1. Let patients help.

Start by acknowledging—patients and providers alike—that we're in this together. We're acculturated to expect miracles of brilliant, noble clinicians, and I'm proof it can happen; nothing short of luck or heroic skill could have saved me. But it makes no sense to expect one-sided heroism every time. Why not share the load?

2. Invite the ultimate stakeholder to engage.

I often see well-meaning people plan policy meetings believing they've invited all stakeholders, but they forget patients. Who has more at stake than the patient and family?

When my hospital (Beth Israel Deaconess Medical Center in Boston) remade their ICU, they engaged patients in spades. Today not only is the experience far better; at admission, families are given a pamphlet titled “Welcome to the care team.” Imagine that!

But note—on their first pass at redesign, they thought *about* patients and didn't engage them. When they showed the result to their patient advisors it was an instant flop; on round 2 they engaged patients from the start, and won.

3. Empower, engage, enable, educate.

Are you empowering your “customers” to help you, in every way they can—to contribute as much as they're willing? I mean empower literally—increasing

*This was the title of a blog post by Ferguson's colleague Susannah Fox, associate director of the Pew Internet and American Life Project. Available at <http://e-patients.net/archives/2008/05/the-plausible-promise-of-participatory-medicine.html>

their power, their ability. Are you letting them understand as much of the care plan as they have an appetite for?

I learned a ton about my treatment (high dosage interleukin-2) from my online patient community. Do you worry when your patients talk to others on the Internet, or do you teach them how to find the best quality resources?

My oncologist says there's no question my tumors were squashed by the medication. But he says he's not sure I could have *endured* my treatments if I hadn't educated myself and been committed to seeing it through.

Yes, my oncologist believes I helped save myself by being an empowered, engaged, educated patient. Shouldn't you make this available to your patients, if they want it?

4. To catch mistakes, enlist a second set of eyes.

My early career was in typesetting. We

knew better than to proofread our own work; it takes a second set of eyes. So why in healthcare do we expect superhuman perfection, especially when hospital staff members are under increasing pressure to do more work?

Inviting families to help monitor the plan may require culture change because some people expect providers to be perfect. But *their unrealistic expectations are part of the problem*, and like care itself, the solution must be participatory.

Besides, you might be surprised how many of us are eager to help. When a family member is sick, a big part of the scariness is feeling there's nothing we can do. Let us help.

5. Put the compliance shoe on the other foot.

Here's another participatory thought: compliance problems aren't just for patients anymore. Doctors and policy bemoan patient compliance, but study

after study shows that surgeons resist checklists (belligerently, I've heard) and hospital staff resist handwashing.

We're in denial if we complain about patient compliance alone. Can we use a participatory approach to share not only the workload, but admission of human shortcomings?

Could the Shared Care Plan Have Helped Duane Smith?

I have a vision of a shared care plan, a treatment plan that's completely visible to the patient and family: medications (the Five Rights), surgery, physical therapy, discharge plans—everything—right there on a computer screen or paper printout, for the family to follow along.

Perhaps if that had been a reality, Duane Smith would still have his fingers and toes.

Atul Gawande speaks of Duane, victim of a severe car crash, who was rescued dramatically by brilliant medicine

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(2010). He was put back together and discharged in good shape. A miracle, except for one thing: his spleen was removed, and at discharge they forgot to give him the vaccines every splenectomy patient needs, to fight off three bacteria the spleen normally handles.

Two years later, an ordinary strep infection swept through Duane's body. Again he was saved by medicine, but it cost him all his fingers and toes.

What if Duane's family had googled his initial treatments or had seen a shared care plan? Could they have asked, "Shouldn't Duane be getting vaccines?"

What are the obstacles to letting families help? Can we transform the obstacles?

Share the Load

Without a doubt, I was saved by great professionals. My cancer was found and diagnosed before I had any real symptoms; superb and heroic surgery

removed the organ laparoscopically; a potent immunological treatment knocked the cancer to kingdom come, as far as anyone can tell.

Yet there were errors in my care. My tissue samples have been lost (I'll never sequence my tumor's genome), my urine specimen on a pivotal post-surgical date was lost, various providers in their silos were unaware of other conditions that were relevant to my care. Healthcare, as great as it is, is imperfect.

I call on you to envision a world where patients and providers work together, for the benefit of all. It's called participatory medicine, and I already do everything in my power to help my providers and myself achieve its principles. A shared care plan can be a potent part of that new future. **IPSQH**

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