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The paradigm of patient must evolve: Why a false sense of limited capacity can subvert all attempts at patient involvement

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Abstract

This essay reviews the role of paradigms in molding the thoughts of a scientific field and looks rigorously at what two key terms mean – empowered and engaged – and how their interaction points to a new way forward, requiring a re-examination of our “paradigm of patient.” Five years ago, the Institute of Medicine’s *Best Care at Lower Cost* declared that patient-clinician partnerships are a cornerstone of a learning health system, a declaration that’s foundational to the era of involvement. How can we engineer that era correctly if our conception of “patient” is out of date? And how can we validate whether our model works? In the past eight years, the author has spoken at or participated in over 500 events in sixteen countries, and although declaring himself “just a patient,” he has observed persistent cultural patterns that make one thing clear: there is a need to change our understanding of the role of the patient in achieving best possible care.

Keywords

Patient engagement, patient empowerment, patient experience, scientific revolution, Patient Activation Measure, Arnstein’s Ladder of Citizen Participation

*If language be not in accordance with the truth of things,
affairs cannot be carried on to success.*

– Confucius, *Analects*. Chapter 3, paragraph 5¹

Ah, the truth of things. When it changes – when science advances – our language must change, or affairs cannot be carried on to success. And boy would *that* be a problem in healthcare. But after 560 events in sixteen countries I’ve observed some persistent cultural patterns that make this clear: we must change our understanding of the role of the patient in achieving healthcare’s potential.

In this essay, I will review the role of paradigms in molding the thoughts of a scientific field, then look rigorously at what two key terms mean – empowered and engaged – and how their interaction points to a new way forward, requiring a re-examination of our “paradigm of patient.”

Our need for certainty and to know who has it

I was trained in science, whose motto might be “Know your facts!” So, I was shocked when I discovered the 2012 book *The Half-life of Facts*² by complexity scientist Samuel Arbesman. Subtitled *Why Everything You Know Has an Expiration Date*, it details how “know your facts” is as slippery a god as you’ll ever try to grab. (It’s entertaining, provocative, and very much based in reality, not abstractions.)

In healthcare, lives are at stake, so there’s special peril if our facts are wrong (patient or doctor). Yet in his extraordinary 2006 manifesto *e-Patients: How they can help heal health care*,³ Tom Ferguson MD spelled out three constant perils of information freshness every clinician and patient should know:

- **Publication overload:** when Ferguson wrote in 2006, 800 journal articles were published every day; today it’s over 2000.
- **The lethal lag time:** between the birth of new knowledge and its arrival on physician desks, there’s a lag of 2-5 years.
- **Death by googling: Not.** Back then people thought “Stay off the internet – there’s crap out there.” But in 2001 Eysenbach reported that in three years of seeking he’d found *zero* cases of death by googling.³

Why *do* we think we know things? Are we sure we have the latest? Did you already know those three perils? If not, then you yourself are a victim of information overload and lag time. And Ferguson didn’t even touch on the 17-year dissemination problem, nor the statements by editors of major journals about how weak a lot of the literature is.⁴

Now consider that among the things we do know, the *meanings* of some words are changing under our feet – a Confucian catastrophe.

Case in point: “patient.” Five years ago, the IOM’s *Best Care at Lower Cost*⁵ declared that patient-clinician partnerships are a cornerstone of a learning health system,

a declaration that's foundational to the era of involvement. How can we engineer that era correctly if our conception of "patient" is out of date? And how can we validate whether our model works?

For me, healthcare achieved its potential.

In January 2007, I received an incidental finding that brought me a patient experience I'll never forget: I was dying. A routine shoulder x-ray revealed a spot in my lung that proved to be Stage IV renal cell carcinoma, with metastases from skull to thigh. Kidney cancer is slow growing, silent and deadly – I had no obvious symptoms, just creeping fatigue and a little weight loss – but the best available data said the median survival for someone like me was 24 weeks. *That* will get your attention.

I got absolutely terrific clinical care, at Beth Israel Deaconess Medical Center – one of the best care teams in the world for my disease. The staff on that semi-ICU were truly wonderful in how they *took care of me*, including my personal needs and concerns. Since I was under dire threat and needed every ounce of strength, their caring felt like I had nourishing trainers in my corner, restoring me for each next round of treatment.

Did their caring help my recovery? Some would say "There's no evidence for that." Too often I've heard

people say that when they're actively implying "so it must not be true." But reality is what it is whether we know it or not, and we've already established that the literature's not as hot as we all were taught. And if language be not in accord with the truth of things ...

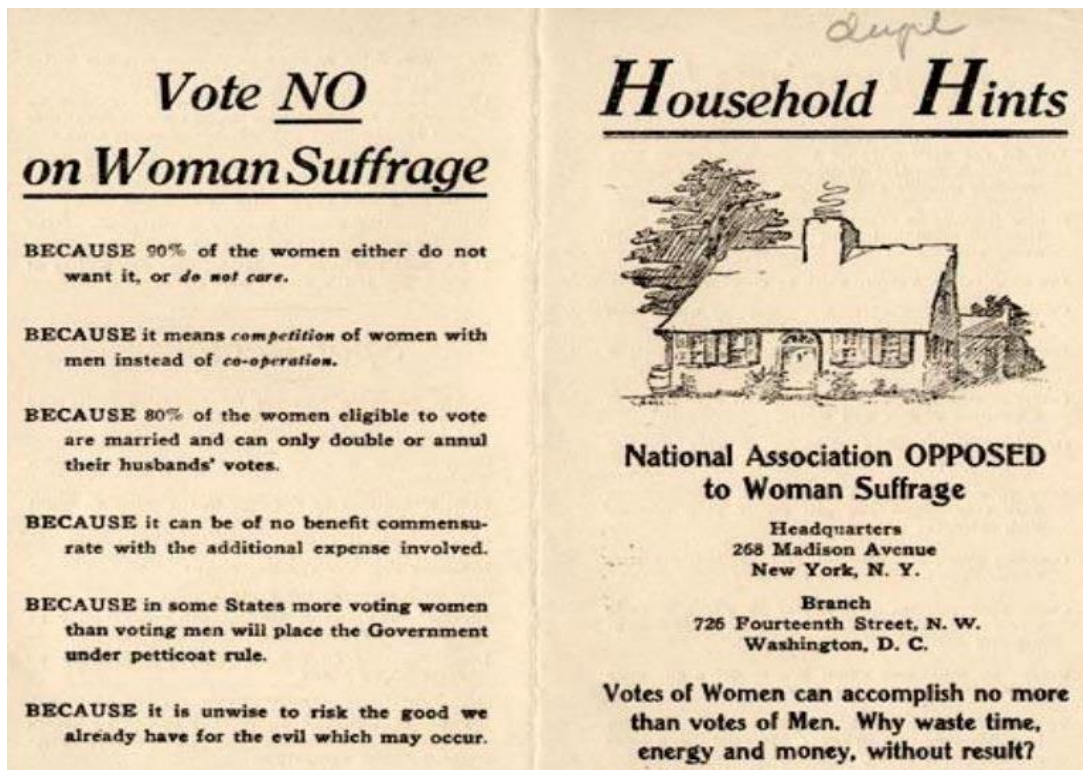
By the way, my reality is that I got a treatment that usually has no effect, but for me it did, and to this day nobody knows why. Not all valuable truth has been explained yet.

And an important part of my case is that I got valuable information from online e-patients (empowered, engaged, equipped, enabled) who have no medical credentials at all. Who says they helped? My oncologist, who let me quote him in the BMJ.⁶

New realities demand new meanings

When I talk about what e-patients are contributing to care, some people say, "That's okay for you, but my patients aren't like that." That's a terrible reason to limit potential; the same was said in 1912 when the National Association OPPOSED to Woman Suffrage (yes, they capitalized it) said most women weren't asking for the vote (Figure 1). Fifty-five years later similar thinking led the Boston Marathon's organizer to try to eject Kathryn Switzer, saying "Get the hell out of my race."

Figure 1. An example from Woman's Suffrage



In both cases current reality was based on past beliefs, which were self-fulfilling, and the men in charge lacked the vision to see what would be possible if constraints were removed. In athletics, girls' achievement was severely limited because they had no access to school sports. That became illegal in 1972 with the passage of the Title IX law, and lo and behold, girls can run! My daughter runs Boston, the US women's soccer team won the World Cup in 1999, and in 2017, Switzer ran Boston again – fifty years later.

If that race organizer couldn't imagine her running at 20, I'd love to know his thoughts as she ran it again at 70. His expectations were fact-based but wrong – his facts were the result of an old model, and when the environment changed, their potential had changed.

So must it be for our paradigm of patient. We must ensure that past beliefs about patients don't perpetuate limited capacities, or patient involvement will repeatedly fail - and they'll say it was the patients' fault.

Competence has dimensions and there's no single score. Plan accordingly.

Patients and providers alike can be great at some things and rotten in others; it's an error to overgeneralize. For accurate expectations, we must assess and plan accordingly.

Even the hospital that saved my life had shortfalls. My wife was allowed to stay overnight (we're grateful!), but her bone-sore body was abused by the creaky vinyl recliner. (At least they apologized.) And although I had a private room for each stay, some bathrooms were stupid: the door wouldn't close if you brought in your IV!

The building was a relic of an old paradigm: it went up when the paradigm of care was "Save their life – nothing else matters." Today we know better and we can do better; in fact, today patient experience affects reimbursement.

New models for a new paradigm

Thomas Kuhn's landmark 1962 book *The Structure of Scientific Revolutions*⁷ is widely considered one of the most influential books of the 20th century, yet most people in healthcare (especially health policy) have barely heard of it. That's ironic for a field where the paradigm says only professionals know what needs to be known!

Kuhn offered, loosely, that a paradigm is an agreement about how things work, from which all sorts of laws and concepts flow. Kuhn also showed that although science strives to be rational, progress is not: at various times a field finds that its assumptions can't explain what people have started to see. These observers encounter what Kuhn

calls "anomalies," leading the field to enter the stage he called Crisis.

The only way out of Crisis stage is Revolution – a complete rethinking by the field of how things work. The best-known example is the Copernican revolution in astronomy, but others include chemistry's periodic table and, in physics, quantum mechanics and relativity. In each case, for the field to move forward, fundamental beliefs had to change.

So it is today with patients in healthcare. Many doctors say, "Stay off the internet – there's crap out there." In that paradigm, if an engaged patient brings useful information it's an anomaly: it cannot be explained by current beliefs. *It makes no sense.*

Happily, we've begun to realize there are formal models – some from outside medicine – that explain what we're seeing and point the way forward. They flesh out the meaning of the two big e-patient "e's": engaged and empowered.

Models of engagement

I use two models: The Patient Activation Measure (PAM)⁸ and Arnstein's Ladder of Citizen Participation.⁹ The PAM is from healthcare and was created by Professor Judy Hibbard at the University of Oregon. Arnstein's Ladder is, amazingly, from the department of Housing & Urban Development in the 1960s.

The PAM (Figure 2) is a simple scale based on a short interview that grades a patient's "activation" – their sense of whether they can manage their own care. A decade of research has validated that activation is developmental (in stages), prescribes how to interact differently with patients based on their current level (to move them up), and has validated that PAM score tracks with outcomes and costs.

Arnstein's Ladder (Figure 3) models the transition of power between government and the governed, as citizens become better able to understand the work of their "caretaker." The comparison with patient participation in their own health, and their increasing involvement in hospital management, is fascinating. Consider a common trajectory of PFACs (patient-family advisory councils):

- At first the "citizens" are invited in for milk and cookies, figuratively, and the "caretakers" talk about what they're doing. (In Arnstein's model this is "Informing," which she defined as the lowest type of tokenism!)
- At some point the caretakers start asking, "What do you *think* (about what we're doing)?"
- At some point, real dialog starts, with patients (citizens) having increasing participation and power in the work.

Figure 2. Patient Activation Measure – Four Levels

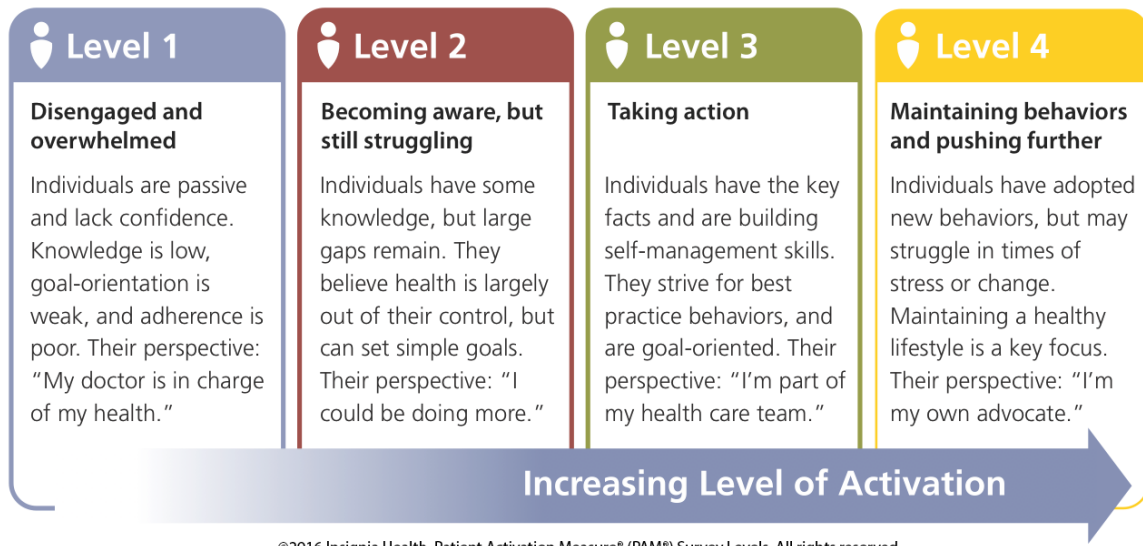
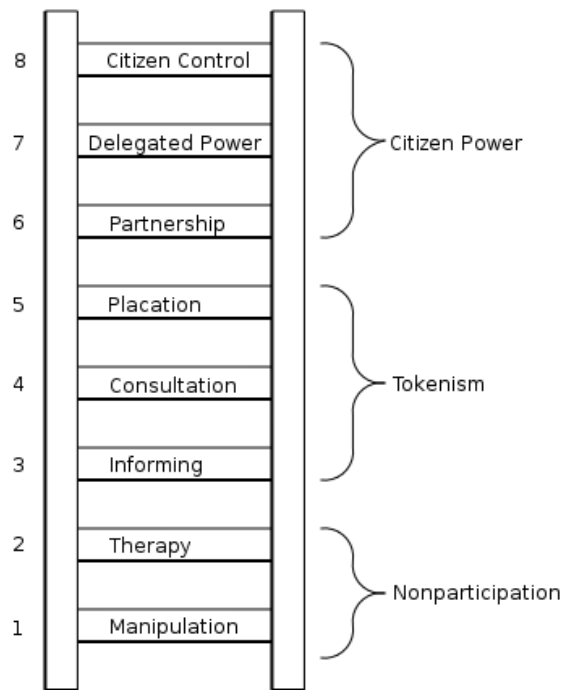


Figure 3. Arnstein's Ladder of Citizen Participation



When audiences absorb this comparison they commonly say, "But the citizens [patients] in our community have no idea what we do, and wouldn't know how to help if we asked." That matches the self-fulfilling cognitions that kept patient/citizens in the dark, kept women from voting, and kept girls from running marathons.

The remedy in all cases is to empower them – to *increase their capacity*. It turns weak partners into potent ones.

Empowerment is defined as increasing capacity.

What is empowerment? At the lowest level of both Hibbard's and Arnstein's models the citizen/patient has

no power – no ability to produce a result. At the top level of each, they do. The difference is their level of power, and the transition is called empowerment.

Here's the definition used by the World Bank since 2002 when they go into a developing nation, where the citizens have no ability to grow an economy, run a government, etc.:

*Empowerment is increasing [someone's] capacity to make choices, and to convert those choices into effective actions and outcomes.*¹⁰

Tellingly, I first heard this definition from a patient, Fulvio Capitanio, at the World Parkinson's Congress in 2013. An intriguing benefit of attending all those conferences is discovery of ideas that *you don't find in the usual journals*.

One more aspect revealed by that story is that what patients (or citizens) value is not always aligned with what their caretakers expected. This hints at an even newer idea: what will be revealed when we evolve to where patients are defining what care itself is?

The path forward

This journal is full of thoughts on the new world we can achieve if patient involvement comes to full flower. But I know first-hand that to many clinicians and policy makers, *it makes no sense* to think of patients as contributors of valuable insight. And as surely as pre-Copernicans and pre-Newtonians were impotent to explain observations and predict new ones, our efforts to optimize for the patient-involved world will fall short if we don't update our paradigm of patient.

In *Scientific Autobiography and Other Papers*.¹¹ Nobel prize winning physicist Max Planck said the single most stunning thing I've ever read about the work of paradigm change:

A new scientific truth does not triumph by convincing its opponents and making them see the light, but rather because its opponents eventually die, and a new generation grows up that is familiar with it.

As a business person who lived through wrenching change in his own industry – graphic arts technology, of all things – I know that it's possible for an industry to collapse. And I can tell you first-hand, if hospitals start to close, I want the survivors to include those who know what *care* is ... in the eyes of the people whose lives are at risk.

Kuhn established that change in a scientific field is not just science but includes culture, and the whole process cannot be understood properly without acknowledging both. I propose that the converse is also true: when we're managing a sociological / cultural change to one of true

patient involvement, it behooves us to learn from science *qua* science: we must plan separately for the work of spreading the word and following up persistently, for years, until Planck's "new generation" has turned the tide. But we must start now, and we must persist – our language must be in accordance with the way of things, or our affairs cannot be carried on to success.

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