

ANALYSIS



SPOTLIGHT: PATIENT CENTRED CARE

From patient centred to people powered: autonomy on the rise

Following in the path of feminists and civil rights leaders, informed patients are building a progressive social movement to improve medical care. **Dave deBronkart** says medicine should let patients help improve care, share responsibility, and think for themselves

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The practice of medicine is intellectually demanding: it requires specialised skills and decades of training and experience. Understandably, the accepted model that has guided us for centuries is “doctor knows best.” As recently as 2001 the American Medical Association proposed this new year’s resolution to patients:

“Only your physician has the necessary experience and expertise to diagnose and treat medical conditions. Trust your doctor, not a chat room.”¹

A decade later pronouncements from the Institute of Medicine, the Mayo Clinic, the World Health Organization, and others suggest that patients—individuals without specialised training—should be treated as genuine, value contributing partners in the work of medicine.^{2,3}

If the American Medical Association in 2001 and the Belgian government (which ran a paternalistic “Don’t google” your health problems campaign last year⁵) are right, then the Institute of Medicine and WHO have gone mad. But I believe the opposite is true and that our thinking must change.

Inclusive approach

I have recently been appointed the 2015 visiting professor in internal medicine at the Mayo Clinic, simply on the basis of my experience with my disease and my subsequent work to change medicine’s thinking so others might benefit. I don’t reject physicians (they saved my life), and I don’t assert that patients know everything. I do know first hand that patients can truly add value, and explain why in my book, *Let Patients Help*.

A growing movement, exemplified by the Society for Participatory Medicine (www.ParticipatoryMedicine.org) and the annual Stanford Medicine X conference (<http://medicinex.stanford.edu/>), asserts that patients and clinicians must collaborate. Central to its belief is that whereas the physician brings training and clinical expertise, patients bring their life

experience, their deep investment in the outcome of their case, their skills and resilience, and a unique perspective on needs and priorities. The movement recognises patient autonomy as a valid priority and patients’ hearts and minds as essential contributions to the best possible care. We believe that medicine cannot achieve its potential if it ignores the voice of thinking patients.

This movement is not anti-physician, it’s about partnership. When I had cancer diagnosed,⁴ I received the very best care I could find, but I didn’t sit back and expect to be saved: I joined an online patient community, and my oncologist says that members’ practical advice may have helped me to tolerate the treatment that saved my life. What if I’d followed the AMA’s advice and stayed away from chat rooms?

The internet has let many such “e-patients” (empowered, engaged, equipped, enabled) be heard by other patients, physicians, and policy makers (box). Dozens have served as “e-patient scholars” and advisers to MedX and other forums. In so doing they are growing a new reality, contributing to improved care for themselves and others. They are creators of a social movement, a shift in roles as profound as women’s liberation, racial equality, gay rights, and disability rights.

The internet has changed the infrastructure of information flow

Thomas Kuhn’s masterpiece *The Structure of Scientific Revolutions*⁶ showed that when too many cases arise that cannot be explained by a profession’s model, a crisis develops that leads to revolution. This may be what we are seeing in medicine. Clinicians’ skills are obviously essential, but something has changed in the environment—the flow of knowledge—and it is altering what’s possible. Because of it, we may be on the verge of needing a new science to understand and optimise the role of the patient—a science of patient engagement.

Empowered and engaged patients

Kathi Apostilidis, Athens

After having breast cancer diagnosed in 1990 and again in 2001, Kathi (@KGAPo) researched and identified treatment options (her physicians hadn't offered) that improved outcomes for patients. She is currently vice president of the European Cancer Patient Coalition, which brings together over 100 patient communities to advocate for patient empowerment and patient centred government policies; she also runs an annual Patient Power conference in Greece.

Hugo Campos, Oakland, California

Graphic designer Hugo Campos (@HugoOC) has an implanted cardioverter-defibrillator to protect against sudden cardiac death from his arrhythmia. He's grateful for it and wants to self monitor and understand what triggers his arrhythmia. But the device maker says he's not the customer—the doctor is—and physicians aren't asking for patient access. Hugo has drawn media attention to the need for patients to be supported to self manage their conditions (www.wsj.com/articles/SB10001424052970203937004578078820874744076) and has used his graphic skills to show how much time they spend doing this.

Regina Holliday, Maryland (reginaholiday.blogspot.com)

When her husband died at 39 from renal cell carcinoma Regina (@ReginaHolliday) learnt about medicine's weaknesses and then about social media's power to give people, especially those who are disadvantaged, a voice. A skilled storyteller in paints and words, she painted a mural of her husband's death (www.bmj.com/bmj/section-pdf/186330/0 page 3). She has gone on to paint medical stories on jackets and encourages others to do the same. Her "walking gallery of healthcare" (<http://vimeo.com/80009527>) has become a patient advocacy movement.

Tal Golesworthy, Cheltenham

Faced with surgery for aortic disease due to Marfan's syndrome, Tal learnt that even the best available surgery left patients with long term problems. In collaboration with his physicians, Tal led a team of engineers to design a process that produced a customised textile mesh jacket to wrap the aorta, which resulted in a quicker and safer procedure. His PEARS (personalised external aortic root support) device has been used successfully in other patients (doi:10.1136/heartjnl-2013-305132). His TED talk about it has 1.1 million views (<http://on.ted.com/Golesworthy>)

Kelly Young, Florida

Kelly Young (@RAWarrior) formed the Rheumatoid Patient Foundation (<http://rheum4us.org/>). One of her primary objectives is to raise health professionals' awareness of the nature of rheumatoid arthritis and rename the condition rheumatoid disease. She writes about the patient's experience, its treatments, the patient's perspective (which is often contrary to the literature), and published evidence that is unknown to many clinicians (doi:10.1136/bmj.f2901)

Value in medicine depends on knowledge, and in the past two decades the flow of knowledge has undergone a state change, from closed system to open network. Not only is it possible today for patients to see (and tell each other about) the same information that clinicians see; they can also connect with patient peers near and far to discuss topics they care about. They have eyes, ears, and a voice that they've never had before. These are the precursors of autonomy, emancipation, and self determination.

The change is illustrated by a visual model created five years ago by Lucien Engelen at Radboud University Medical Center in the Netherlands and Marco Derksen. It suggests that knowledge is like a nutrient that enables a more robust response, with the internet as its capillaries. Ultimately, knowledge flows through a network of networks, which makes it far easier to obtain optimal information on any clinical case and thus get optimal outcomes.

This doesn't make patients oncologists. It does mean patients can truly know things they couldn't in the past—even things some clinicians don't.⁷ The clinician's response to this change can be decisive: forward thinking doctors, such as those who treated Janet Freeman-Daily,⁸ welcome such contributions and share them with colleagues; by contrast, outdated attitudes can lead to informed patients being treated as near criminals, as happened in the Ashya King case last year.⁹

A crisis in confidence can be caused by a clinician who asserts, "Nothing could have changed that I haven't heard of," because that itself is unscientific. The much praised book *The Half-Life of Facts* notes that current truth changes faster in medicine than almost anywhere else,¹⁰ but overworked clinicians can hardly afford to spend more time reading. It makes sense to let patients help be bloodhounds for information. I speak from experience when I say that a person in trouble can be highly motivated. To have that urge discouraged throws into question the clinician's priorities.

When an oppressed class learns to think for itself, people start wanting autonomy as individuals, then self determination for

their peers. That is the start of a social movement, bringing with it cries for justice.

Towards a new model

If "doctor knows best" is no longer reliable for predicting the best outcome for patients, it can no longer serve for planning the future. The e-patient communities are already at work exploring new models in collaboration with providers who welcome them. Together, can we be scientific, and research this? Can we probe, analyse, and explore the extents and limitations of patient contributed value, and the mechanisms by which it can improve care?

Kuhn documented that many sciences have evolved as our powers of observation expanded, and, often, established theories (for example, Isaac Newton's) turn out to be constrained cases of a more universal rule (relativity). It now seems that "doctor knows best" exemplifies a more general rule: "Those with skill and useful knowledge know best."

Generations ago it was largely only physicians who had current knowledge. Today that is not a given, but even the most emancipated patient cannot deny the value of clinical experience. One of the first tips I got from my patient community was to find a specialist centre that's dealt with a lot of similar cases to mine.

So perhaps a new draft of the model of care would be: "Useful knowledge plus clinical experience plus what the patient wants leads to best care."

Let patients help share the work

A person who knows nothing must necessarily be cared for by wise people providing paternalistic care. But as with the growth of a child, at some point not only does autonomy increase; so does ability to comprehend. If a person is kept in the dark others underestimate their potential, and they can never share the responsibility that comes with emancipation. As Hugo recently said in the Society for Participatory Medicine blog:

“Autonomy is true empowerment. It promotes patient responsibility and holds the promise to lead us to more engagement and better health. We must move beyond participatory medicine and focus on educating, enabling, and equipping patients with the tools necessary to master autonomy and the art of self care.”¹¹

Patient powered healthcare is no insult to clinicians any more than home thermometers insult paediatricians or home glucose tests insult endocrinologists, nor any more than a drowning swimmer insults a lifeguard by climbing onto a raft. Independence is a good thing, and we applaud the many who welcome the new world. Join us.

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