Patient Engagement: 
Time to Shake the Foundations

COMMENTARY

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ABSTRACT

Something big is happening in healthcare. It’s not the new Apple Watch, 3D printing or the advent of personalized medicine. It’s people power. And, it is starting to shake up the very foundation on which healthcare systems around the world have been built. Healthcare professionals and hospitals are iconic features on a healthcare landscape that has been purpose-built with castles, moats and defence artillery. Turf protection, often under the guise of “patient protection,” has become so ingrained in the way things are that few recognize what it has become. Fooks et al. step gently into this somewhat dangerous territory for “insiders” of the system to tread; yet in my view, they do not go far enough.

While many excellent points are made in their article, the call to action by Fooks et al. (2015) is far too gentle. It is polite and respectful of the efforts that have been made to date, and logically lays out steps that can be taken to make the existing system more patient-centred. Evidence on the way patient engagement can be framed and how it can evolve is clearly presented, and winning conditions are identified for a future I think we would all like to see. All the right things are said in the article, but I can’t help feeling that if we focus on “embracing a patient-centred philosophy as a way to approach health system reform” (Fooks et al. 2015, p. 17) as the authors are suggesting, we will still be tinkering around the edges for years to come while change continues around us at breakneck speed.
I see a new world order emerging. One that doesn't wait for those we typically call “experts” to figure things out on their own. It's one that doesn't give higher status to professional “experts” just because they have a MD or RN designation after their name or an H on the hospital entrance. The new world order acknowledges that it is the expertise that patients and people living with chronic illness bring to the table that is just as important as the knowledge that professionals have earned through their training and experience.

In this situation, value is created when people with different and complementary areas of expertise are working together for a shared purpose. A tweet from @SaraRRiggarre, who is someone living with Parkinson’s disease, reminds us that “every year I spend 1 hour in healthcare, and 8,765 hours in self-care.” Sara is a champion for change. She sees herself as an expert who deserves as much recognition as the “professional expert” she consults with on an annual basis. The status of being a “lived experience expert” is one that Karen Nicole Smith (@KNSwriter), who is a KGH patient experience advisor, also says needs to become mainstream. The voices of people, who intermittently take on the role of “patient” when they interact with their healthcare providers, are voices that need to be heard. They are out there, but right now we are not listening very well.

An innovative leader from the Netherlands, Lucien Engelen (@LucienEngelen), points to the dramatic shift from an “ego” system mindset to one that puts the patient and his/her relationships with others into a broader ecosystem. I love this notion because it puts health and care into a broader societal context. It also removes the shackles of hierarchy and hierarchal relationships and stimulates innovation through collaboration. There is much to be learned from the work of the Canadian Foundation for Healthcare Improvement (CFHI) on how to accelerate the scale and spread of evidence-based innovative solutions through cross-country Collaboratives. The authors cite the Ontario Health Links model as another way people can engage with the broader health and social system. While there is merit to these new approaches for sure, they are still built upon traditional platforms, practices and assumptions guiding today's healthcare system. There are still gatekeepers, backwards pay models and cumbersome processes that are being patched together.

Fooks et al. (2015) speak directly to the need for payment reform and I agree with them and others that that this change on its own will not suffice. There has to be a logical connection and alignment among all the disparate parts of an ecosystem for it to flourish.

We have learned through the course of history that fundamental change takes time and progress does not take a linear path. One of the most lively and influential patient voices out there today Dave deBronkart (aka @e-PatientDave) compares what is happening with the patient engagement movement with what happens as scientific fields evolve. He reminds us of the writing of Thomas Kuhn, author of The Structure of Scientific Revolutions (1962) who said embracing a new paradigm is “like the man wearing inverted lenses.” The radical ideas of Einstein, Newton, Galileo and Copernicus were all initially swept aside as crazy and improbable. Gradually old paradigms were replaced with new ones that have become mainstream. If we contrast the time it took for shifts of the past to take hold and become the norm, with the speed by which consumer-focused inventions and digital innovations are disrupting industries like publishing, retail and banking, I would predict that change in healthcare will actually happen faster than most people think. Why? Because patients and people living with chronic illness will not wait for those of us...
in the traditional health and care systems to catch up. Younger generations of patients and providers will not tolerate the barriers we have thrown up in the past. They will enter the fray themselves and interact with those who are offering faster, better and cheaper ways to help them achieve their goals. Social media is a democratizing force that is changing the way people access and use knowledge and together with innovative digital technology, new open-access systems are rapidly redefining relationships and what it means to be an “expert.” Collaborative, peer to peer digital platforms such as Smart Patients provide real time opportunities for patients and families to learn from each other in safe, high quality online communities. Founders Gilles Frydman, a pioneer in the field of online patient communities, and Roni Zeiger, a practicing physician and former Google executive have a bold vision for changing the healthcare game. They are growing Smart Patients so that it not only connects patients to each other, but provides an innovative way for health system leaders to learn from patients and families in order to serve them better. This is a great example of the new collaborative health economy in action.

Tools that enable people to take hold of their own health and wellness, and to relate with the healthcare system in a whole new way, are also driving the creation of blockbuster technologies and new industries. A March 2015 PwC report, Global Health’s New Entrants: Meeting the World’s Consumer, says “healthcare will change dramatically as new entrants carve out their niche in the delivery and access of care.” What is interesting here is that people are not waiting to break down existing barriers and long-standing traditions of the healthcare system to generate new ways of doing things, they are doing something much more significant. Instead of fighting the healthcare barons, they are simply bypassing them to get what they need. This is not to say that medical specialists and hospitals will be obsolete, it’s just that they will not be the centre of the universe around which all other parts revolve. Traditional healthcare delivery channels will now have to create value within a much faster-moving, customer-centric, robust ecosystem or be left on the sidelines.

Sharing power is a lot harder than hoarding it and it is clear that the future is going to feel different for all of us. I can say firsthand, as a leader who opened the hospital decision-making vault, however, that once you start down this path, you will be forever changed. At KGH, we put a stake in the ground by declaring, “any decision in our organization where there is a material impact on the experience of patients, a patient will be at the table” (Kingston General Hospital 2015). The result? Conversations have changed and performance has improved. Staff say they feel more connected to the reason they went into healthcare in the first place, which is to make a difference in the lives of patients. Leadership is much more fulfilling when you step out and walk beside or even behind those who invite us into their lives. The authors remind us of the teachings of Don Berwick “the grandfather of all things quality.” (Fooks 2015; pg. 9) It was not until I listened to him talk about the power of seeing ourselves as “guests in the lives of patients” and not the other way around, that the penny dropped for me. I have always considered myself patient-centred, and yet when I dug deep and really looked at what we do and how we do it in healthcare, my restlessness with the status quo intensified. I think we have long passed the time for nudging ourselves to change. It’s time to listen, learn and lead alongside others. It’s time to democratize healthcare, and engaging patients as equal partners is key to the new world that we can create together.

I started my career on the front lines as a
Registered Nurse and I am not proposing that healthcare providers or provider organizations should take a backseat in reform, but we do need to move into co-pilot mode. While Fooks et al. set forth some specific ways we can move forward on this front, I maintain their recommendations do not go far or fast enough. We must come out of comfortable shadows of power we have enjoyed for literally hundreds of years and join the open-source era of our new collaborative economy. The castle and moat era of healthcare is over. People power is taking hold whether we are ready or not. I say, let’s get ready and join forces. Together we will be better.

References


