PATIENT ENGAGEMENT

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Health IT and Patient Engagement

The Cart Before the Horse

"Patient engagement is the blockbuster drug of the century,"[1] ...or so asserts health information technology futurist Leonard Kish. But like many transformational themes in healthcare, we do not have a commonly agreed upon definition of what exactly "patient engagement" is. Last year, the National eHealth Collaborative conducted a survey of stakeholders on various aspects of patient engagement. They found that three quarters of those surveyed believe patient engagement is a crucial factor in transforming health care transformation – but their opinions on just what patient engagement means varied greatly. Responses ranged from "patient uses educational material and online resources to learn about better health or their own health conditions" to "patient emails doctor or nurse with questions" to "patient makes medical appointments online."[2]

Despite no clear definition, these interpretations highlight two important points. First, patient engagement strategies often involve health IT. Second, what drives patient engagement closely mirrors a crucial goal at the heart of our disparate national healthcare agenda: Donald Berwick's Triple Aim: (1) to improve healthcare quality, (2) to increase healthcare access and (3) to reduce healthcare cost.[3]

Regardless of how we define patient engagement, people from a wide variety of ideologies and political views agree on two key challenges when measuring its practical meaning and effect.

First, defining patient engagement in terms of its underlying health IT raises a question: are we doing this in the wrong order? While health IT can support the Triple Aim, we must understand the patient engagement problem before suggesting any solutions, health IT-based or not. The relationship between patients and their healthcare team is bewilderingly complex. If we proceed without a fundamental understanding, we will have trouble connecting the dots of cause and effect, leaving us prone to magical thinking about health IT "solutions" that may have adverse effects.

Second, some early patient engagement data suggests that technology - driven patient engagement can have unintended consequences, a feature we have come to expect with technology. A study published in the *AMA Medical News* earlier this year found that in the hospital setting, engaged patients had longer hospital stays and higher costs than patients who delegated decision making to their providers.[4]

In addition, engaging patients through health IT efforts such as a patient portal can be challenging. At HIMSS13, Eric Manley, product manager of global business solutions at the Mayo clinic, reported that after three years, fewer than 5 percent of the nearly a quarter-million patients who signed up for online access through the patient portal had actually used it. To avoid these consequences, the first step is ensuring we have a full and deep understanding of the root cause of the problem.

Many patient engagement projects in the United States rely on the design and use of health IT tools and resources. Patient portals, personal health records, on-line patient education are a few examples of these health IT tools. Future efforts, at least for the near term, are very likely to continue seeking to leverage a range of health IT. Given this, it is important to look past the technology itself and more deeply understand what is at the core of patient engagement. Rob Lamberts describes this aptly by noting that by adopting a technology focus

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first, we risk failing to understand that at its core, patient engagement is about an ongoing relationship of trust, mutual respect and shared decision-making.[5] Central to this relationship is communication—communication that is timely, direct and distinctly informative, leading to deeper knowledge and understanding.

Dr. Lamberts further relates, "I was recently discussing my ideas on a communication-centered medical record with a colleague. At the end of my pontification, my friend agreed, saying: 'You are right; communication is an important part of health care.' I surprised him by disagreeing. Communication isn't important to health care, communication **is** health care." As Dr. Lamberst observes, giving patients tools such as a portal just lets them "...peer through a peephole and see parts of their medical records."

We could not agree more. This is why we worry about technology-led efforts to engage patients. Kendall Antekeier puts it succinctly: "Patient engagement is more than technology—and it's definitely not 'merely creating products that people want to use.'"[6]

It is quite possible that our technology-first approach to patient engagement faces a similar challenge. We tend to focus on technology as communication, rather than technology as an important tool for communication. It is seductively easy to classify the disengagement problem as first and foremost a lack of information and technology tools—and if we do so, our immediate response is to create these tools. Not that these tools and strategies are de facto bad—they are necessary but inadequate in developing the truly meaningful communication needed at the core of patient engagement.

There may be encouraging results from using health IT in this way. A 2012 AHRQ assessment demonstrated that ...substantial evidence exists confirming that health IT applications with (patient centered care)-related components have a positive effect on health care outcomes.[7] Nonetheless, it is worth considering whether the technology itself provides these benefits, or if technology is only the conduit. Stephen Wiljkins notes: "There is no app for engaging patients in their own health care absent a strong doctor-patient relationship... The role of physicians, hospitals and other providers is not so much one of needing to engage patients in their care. Rather, providers need to 'be more engaging' to patients who are already actively engaged in their health."[8]

Is it possible this failure has less to do with technology and more to do with how patients perceive their relationship and communication with their physicians? Is the problem really one of physicians simply

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being relatively "disengaging" rather than patients "not being engaged"?

We have understood for decades that patient-provider communication – typically in the exam room – is far from ideal. In the 2012 *Health Affairs* study, investigators found that shared decision-making suffers from a number of communication barriers.[9] "These include the fact that even relatively affluent and well-educated patients feel compelled to conform to socially sanctioned roles and defer to physicians during clinical consultations; that physicians can be authoritarian; and that the fear of being categorized as 'difficult' prevents patients from participating more fully in their own health care... We argue that physicians may not be aware of a need to create a safe environment for open communication to facilitate shared decision-making. Rigorous measures of patient engagement, and of the degree to which health care decisions truly reflect patient preferences, are needed to advance shared decision making in clinical practice."

Patients and physicians also appear to have very different ideas about where the problems lie. In 2011, *Consumer Reports* surveyed 660 physicians in the United States, as well as over 49,000 patients, seeking insight into how each group perceives the relationships between them.[10] Overall, the majority of patients (three out of four) stated they are highly satisfied with their physicians. Yet there were still complaints. For example, while nearly two-thirds of physicians stated that respect and courtesy from patients toward physicians would enable better care, 70 percent also felt that respect and appreciation from patients deteriorated from little to much worse. In other areas, there is a serious disconnect between how patients and physicians understand the same problems. Nearly four out of five patients indicated their physicians were successful in dealing with pain, discomfort or disability arising from various medical conditions. Yet only about a third of physicians felt they were very effective in this area. Nearly 90 percent of physicians would like their patients to keep an informal record of their treatments, tests and medications, yet only 33 percent of patients report doing so. The data from these surveys indicate that if patient engagement is first and foremost about effective communication within a trusting relationship, we still have a way to go.

We believe successful patient engagement requires a patient and provider relationship based on trust. Only that will enable communication and achieve the Berwick Triple Aim. In part, the challenge is also the problem illustrated by providers sharing healthcare data with patients, e.g., Cleveland Clinic's recent announcement that by 2014 patients can view nearly everything their physician sees in the medical record.[11] It is a data versus information problem. Raw data is just not meaningful to a typical patient. Interpretation of this data, making it useful patient information, is meaningful. For example, providing patients access to their medical records undoubtedly shares much more data than previously available – lab tests, imaging results, and provider notes, for example. But for the average patient, this wealth of data is a dearth of information. A patient logging on to their record and seeing "CHOL/HDL Ratio 2.2 1.5-5.0" now has accurate, precise and timely data, but without interpretation, it is not meaningful information. In fact, providing this data can cause patient frustration, fear or anger depending on the circumstances – behaviors completely counterproductive to patient engagement. Without a trusting relationship with their provider, who brings medical understanding to the raw data, this information fails to encourage useful, informed and shared decision making.

We believe we need strategies that transform healthcare data into information that providers and patients exchange in a trusting relationship. This requires building, or re-building, the patient and provider partnership.

To do this we must get back to basics. The lack of effective healthcare makes people miserable. Since healthcare providers are empathic professionals, such misery makes healthcare professional miserable, too. Empathy is at the very root of healthcare. In their 2006 paper, Bendapudi and colleagues assessed patient perspectives on what physician behaviors were most con-

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ducive to a trusting relationship.[12] They discovered seven: "The ideal physician is confident, empathetic, humane, personal, forthright, respectful, and thorough." To alleviate misery providers must return to empathizing with their patients, or sharing an understanding and appreciation of the patient's point of view. This kind of behavior builds trust and an effective platform where patients and providers jointly participate in sensible and meaningful information exchange. Once we establish or re-establish trust between patients and providers we have a basis for discovering a myriad of patient engagement solutions, including those that involve health IT. **JHIM**

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