

How Patient-Based Information Technology can Enhance Quality and Reduce Errors

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*The Quality Colloquium at Harvard
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Using Social Networks to help Reduce Errors and Enhance Quality

- ▲ *Patients are using the Internet on their own to form communities that collaborate and provide support.*
- ▲ *As healthcare professionals, we need to find these communities, recognize them, and work with them to help reduce errors and enhance quality.*

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Patients are online and creating communities

- ▲ *Networks of "informal" caregivers pre-date the internet*
- ▲ *Technology now enhances ability of people with common interests to find each other*
- ▲ *Communities of Practice develop, but do not usually include providers*

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Healthcare Professionals can help foster these communities

- ▲ *We can help create spaces where they can grow (BrainTalk, ACOR)*
- ▲ *We can help create spaces where healthcare professionals can be introduced to these communities (PatientWeb, Liferaft)*

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Exchange of information

- ▲ *Exchanges that occur are largely invisible to providers, but accounts for more exchange of health related information than all professional encounters*
- ▲ *Patients and their caregivers have more time and greater motivation to invest in and help each other than any single healthcare professional can hope to achieve*

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It's the system, not the individual

- ▲ *The system provides the filtering so individuals can make sense of and apply the wealth of information*
- ▲ *The whole is greater than the sum of the parts. "all of us" are always much smarter than "one of us"*
- ▲ *Consider the possibility that a large group of motivated, "connected" patients may actually "know more" than a single medical sub-specialist*

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Engaging Providers

- ▲ *Health care providers are rarely part of these patient networks*
- ▲ *Largely historical snubbing of lay experts*
- ▲ *By integrating providers and single issue patient groups, quality improves and errors can be reduced*

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Leveraging the networks

- ▲ *Networks of patients work together with their clinician providers*
- ▲ *Instant communication, 24/7 support on a global scale*
- ▲ *Seed the networks with quality information*
- ▲ *Learn from the networks what could never be learned in a few face-to-face provider-patient interactions*
- ▲ *Encourage the growth of "expert patients"*

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e.g. Avonex

- ▲ *Errors related to teaching self care are frequent.*
- ▲ *Traditional model employs nurse specialist in the hospital, and visiting nurse at home. However, reimbursement problems, cultural disparities and other hurdles limit effectiveness*
- ▲ *MS patients use online chat room to offer advice, teaching and support for weekly injections*

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e.g. Studying Tips

- ▲ *Anti-convulsants can dull cognition*
- ▲ *We observed that epilepsy patients counseled each other effectively about how to overcome this problem*
- ▲ *Providers bring the science to this conversation and stimulate the dialog*

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e.g. The Liferaft Group

- ▲ *An online support group for people with gastro-intestinal stromal tumors*
- ▲ *The group has initiated clinical research - collecting data on side-effects, dose-response curves etc.*
- ▲ *Clinician-scientists are recognizing the value of the data collected, and are supporting this effort*

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e.g. Patient-Physician Journal Clubs

- ▲ *Collections of patients with a common disease (e.g. epilepsy) who share common physicians can work together to keep the physicians more abreast of the literature*
- ▲ *Patients using PatientWeb (closed online discussion) find and discuss articles about epilepsy together with their doctor*

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Final Thoughts

- ▲ *Quality comes in many forms, and all must be open to what patient communities can bring to healthcare*
- ▲ *Just as providers use peer professional networks, patient networks also yield high quality information which improves care.*

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