Exploring the e-Patient Phenomenon in Nursing

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Sigma Theta Tau International Research Conference
August 2, 2012

From: 1· the UC Davis Betty Irene Moore School of Nursing & 2· University of Maryland Baltimore
Disclosures

There are no relationships to disclose
Goals of the Presentation

• Examine the e-patient phenomenon in the literature
• Provide examples of e-patient engagement in information-seeking
• Describe the application of an informatics framework for understanding the e-patient phenomenon
• Provide implications for nurse researchers and nurse clinicians
Exploration of the e-patient phenomenon in nursing informatics

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ARTICLE INFO ABSTRACT
Availability of information on the internet has changed the knowledge power structure between patients and providers

New phenomenon-the e-patient (a responsible participant)
What is an e-Patient?

- Term coined by Tom Ferguson, MD founder of the Society for Participatory Medicine organization [http://participatorymedicine.org/about/](http://participatorymedicine.org/about/)
- e-patients are empowered, engaged, equipped and enabled
- A patient playing an active role in his or her care
The e-Patient Phenomenon

- 175 million people in 2010 used the Internet to look up health information (Harris Organization, 2010)

- Individuals (3 groups)*:
  - well
  - new medical challenges
  - chronic disease

- Caregivers

*http://e-patients.net/e-Patients_White_Paper.pdf
Leading the e-Patient Phenomenon

“Laugh, Sing, and Eat Like a Pig: How an Empowered Patient Beat Stage IV Cancer (And What Healthcare Can Learn from It)”

- 2009 Health Leader magazine’s “Twenty People Who make Healthcare Better” award
- Co-chair of the board of directors for the Society for Participatory Medicine

http://www.youtube.com/watch?v=0b4li7N7Ck&feature=related
People with extremely rare diseases are often scattered across the world, and any one hospital has a hard time locating enough individuals to conduct meaningful research.

But one woman with an extremely rare heart condition managed to do what many hospitals couldn't. Katherine Leon connected with enough people online to interest the Mayo Clinic in a research trial.
Nursing Informatics

• A specialty that integrates nursing science, computer science, and information science to manage and communicate data, information, knowledge, and wisdom in nursing practice (American Nurses Association, 2008)

• Can aid in development of tools or technological methods to facilitate patient education
Conceptualization of Nursing Informatics - DIKW Model
Discrete, objective facts or observations (Rowley & Hartley, 2008)
Results from the structuring and organizing of data that gives the data **context** and **meaning** (Matney, et al., 2011; Rowley & Hartley, 2008)
Develops when information is synthesized into formal relationships (Matney et al., 2011)
The appropriate use of knowledge to manage and solve human problems (ANA 2008)

The application of knowledge to achieve wisdom requires judgment and values that are unique to the individual (Matney, et al., 2011)
DIKW Collaboration Model
“It’s an aggregation of many facts, put into perspective through years of experience at seeing how things worked out. Note I am not asserting that such wisdom emerges whenever patients gather. This is what you get with a savvy, seasoned community. If that’s not wisdom, I don’t know what it is ....”
Summary

• Develop understanding together
• Patients share data that providers might not have
• Clinicians can help e-patients understand the quality and meaning of internet information and health records (e.g. lab values)
• Current Issues: Patients demanding access to records and creating a mandate for policy change
Next Steps

Research
• Conceptual: Who is the e-patient?
• Methodological: How to measure concepts

Practice
• Prepare clinicians to partner and support the e-patient
• Introduce resources available for patient self-help to clinicians
  • websites, blogs, social networks, chat rooms, on-line groups, etc.
Questions?