

Exploring the e-Patient Phenomenon in Nursing

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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

e-Patient Paper

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Exploration of the e-patient phenomenon in nursing informatics

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ARTICLE INFO

ABSTRACT

Background

- 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/>
- 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



e-Patient Dave

<http://www.youtube.com/watch?v=ob4li7N7Ck&feature=related>

The Growing e-Patient Movement

The screenshot displays the PatientsLikeMe website interface. At the top, the logo "patientslikeme®" is on the left, and the user "MH1202" is welcomed on the right, with links for Account, Settings, and Log out. Below the header, a navigation bar includes "My Profile", "Patients", "Forum", "Treatments", "Symptoms", and "Research". A search bar and links for "Search", "FAQ", and "Crisis" are also present. The main content area shows the user's profile for "MH1202", with a primary condition of "Diabetes Type 2". The profile includes a "My Feed" section, a "What's New" section, and a "My Health Data" section. A yellow banner prompts the user to "Complete your Condition History". At the bottom, a section titled "There's lots to follow on PatientsLikeMe" offers options to follow "Patients", "Forum posts", and "Conditions".

patientslikeme®

Welcome MH1202 | Account | Settings | Log out

My Profile | Patients | Forum | Treatments | Symptoms | Research

Search this site | Search | FAQ | Crisis

My Profile > My Feed

Show/hide guides for this page

What's New

- MyJournal
- My Feed
- Followers (0)
- Following (0)

My Health Data

- My Charts
- My Conditions
- My Treatments
- My Symptoms
- InstantMe
- Quality of Life
- Labs & Tests

MHI202

Age: + Add

Primary Condition: Diabetes Type 2

First symptom: + Add

Diagnosis: + Add

See more

Add Photo

Add InstantMe

Complete your Condition History

Sharing a bit more about your condition will help put your information in context.

There's lots to follow on PatientsLikeMe

Follow

Patients

Forum posts

Conditions

The Growing e-Patient Movement

Patients Find Each Other Online To Jump-Start Medical Research

by GRETCHEN CUDA-KROEN



Listen to the Story

Morning Edition

[4 min 30 sec]

- + Add to Playlist
- ↓ Download
- 📄 Transcript



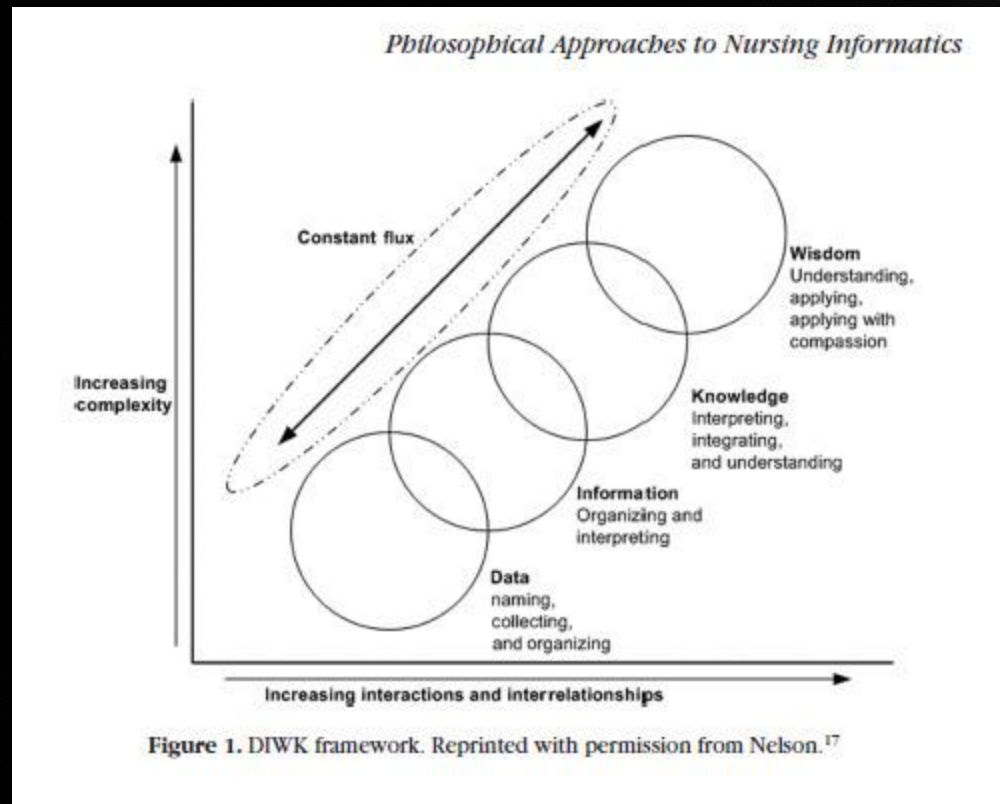
People with [extremely rare diseases](#) are often scattered across the world, and any one hospital has a hard time locating enough individuals to conduct meaningful research.

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



DIKW - Data

*Discrete, objective facts
or observations* (Rowley &
Hartley, 2008)

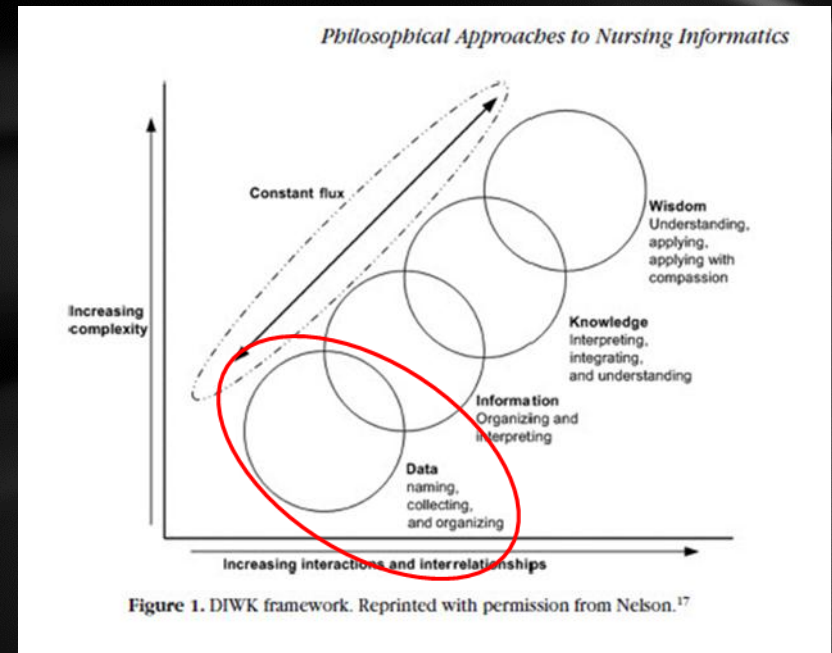
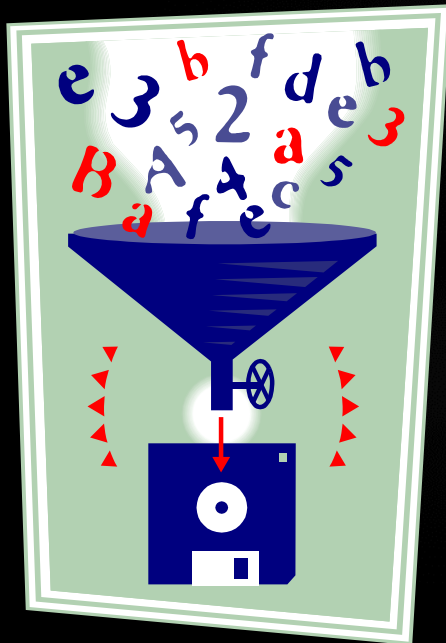
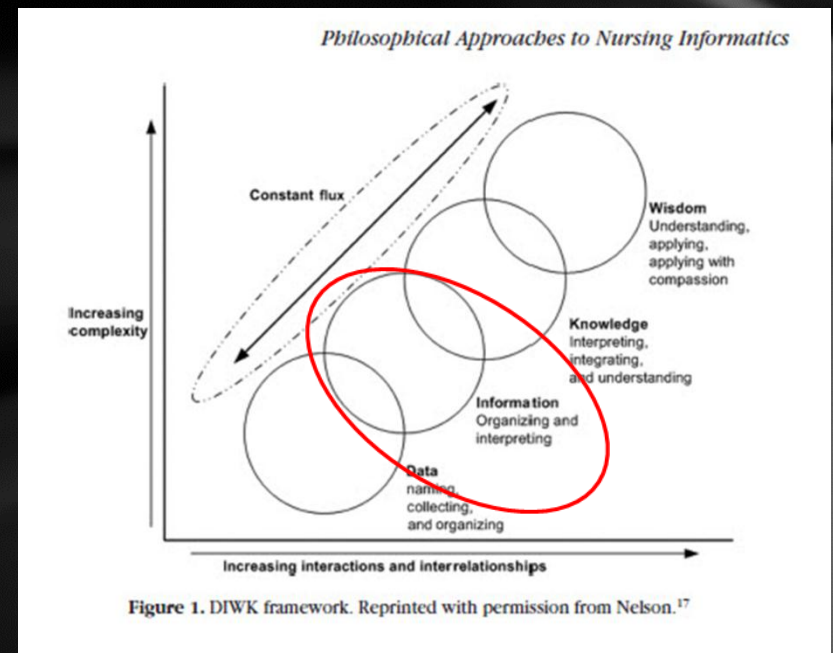
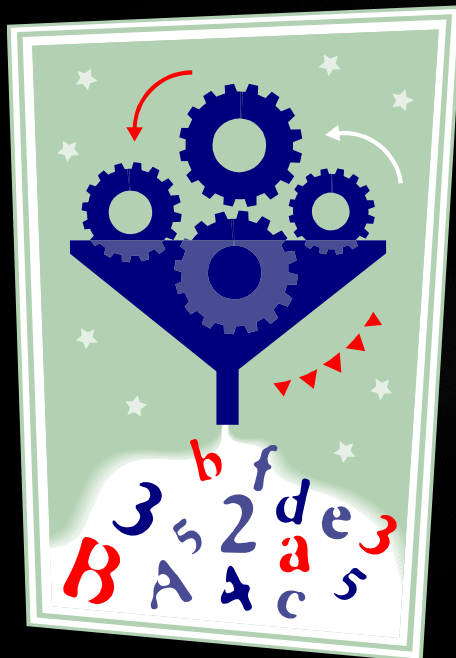


Figure 1. DIKW framework. Reprinted with permission from Nelson.¹⁷

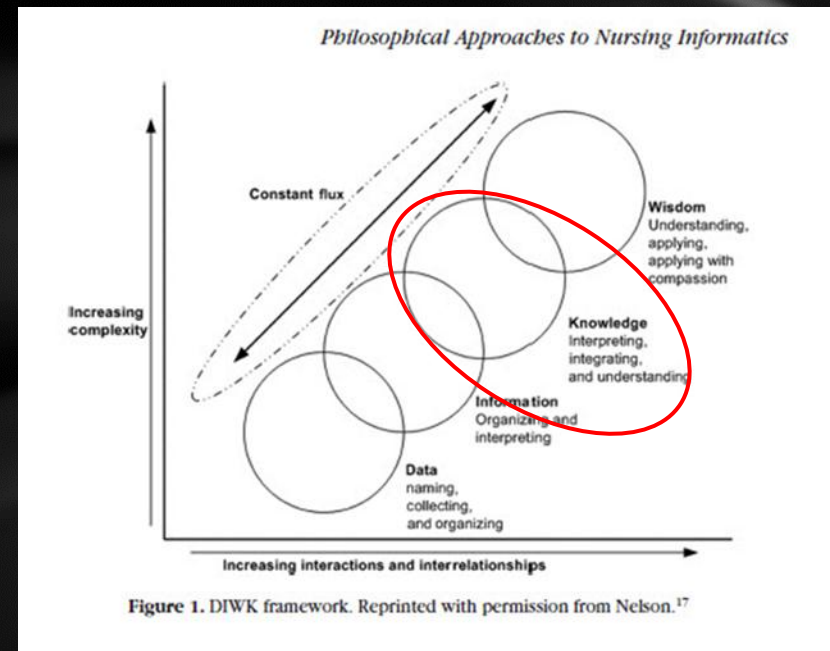
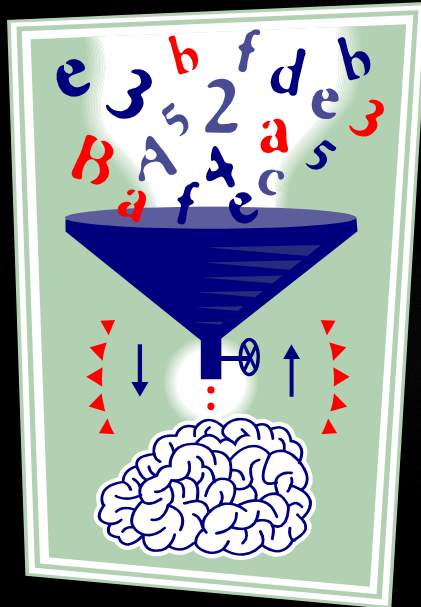
DIKW - Information

*Results from the structuring and organizing of data that gives the data **context** and **meaning** (Matney, et al., 2011; Rowley & Hartley, 2008)*



DIKW - Knowledge

Develops when information is synthesized into formal relationships (Matney et al., 2011)

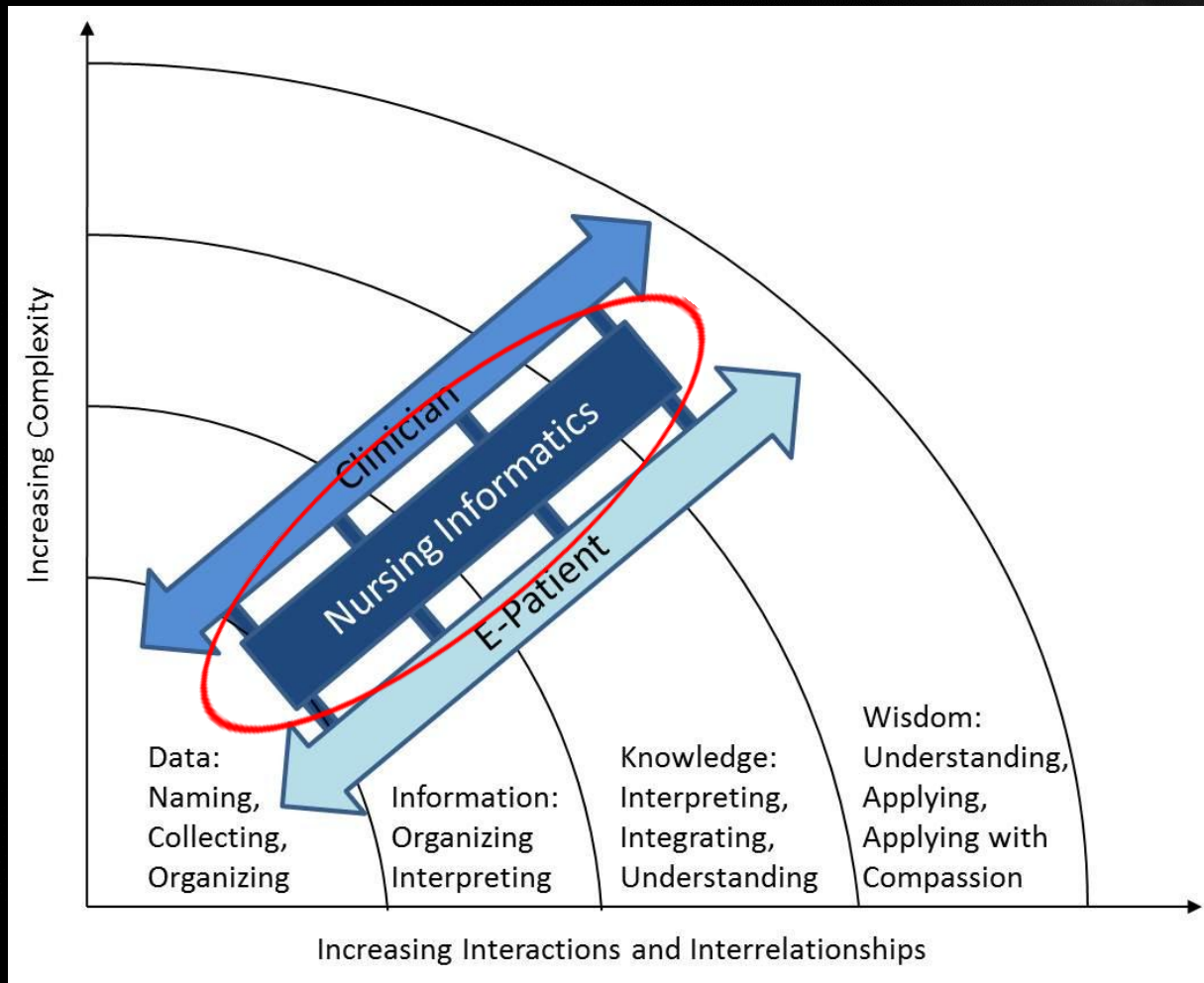


DIKW - Wisdom



- 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



e-Patient Dave on Shared Wisdom

“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?

