

Information seeking and information disclosure on health forums by chronic kidney disease patients

Kaitlin Light Costello

Doctoral candidate

School of Information and Library Science

University of North Carolina - Chapel Hill

... how can I overcome all of

Member created
Kidney Disorders Community

... how can I overcome all of

Information seeking

... who should I tell?

Disclosure

this feels like

Social support

This happened so fast...

Chronic kidney disease

Non-stigmatized, lifelong, chronic condition

Psychosocial challenges

Patient decision-making

Information needs of CKD patients

Symptoms

Disease progression

Impact on daily life

Meaning of test results

Financial future

Career/work opportunities

Coping with the disease

Choosing a treatment plan

Health information seeking

Multiple channels

Context of need determines
information sought

Experiential information

Health information disclosure

In-person encounters, diagnosis disclosure of stigmatized conditions

Emotional support? Practicing identity?

Online health information disclosure over time: a middle range-theory

Research problems

What is the process of personal health information disclosure online?

- What causes people to disclose online?
- Is there a pattern of disclosure events?
- Does disclosure change over time? How?
- What are the contextual conditions influencing disclosure?
- What facilitates disclosure? What are the obstacles?
- What are the outcomes of disclosure?

Grounded theory

Explain social interactions; build understandings of social phenomena

Processes and behaviors

Interpretive, reflective constructivist approach

Constant comparative method

Theoretical sampling

Data sources

Approximately 20 – 25 people with chronic kidney disease experiencing a transition in their illness

Semi-structured interviews (2 per participant)

Forum posts

Other data sources of theoretical relevance

Analysis

Constant comparative method to code interview transcripts and forum posts

Integrating codes to generate core concepts of theory

Memoing

Code: Seeking seekers

“I go out there fishing for people who are looking for information. And then I provide it.”

Memo (sample)

Brent is confident that his HCPs and in his own knowledge and understanding of his health (perhaps overly confident, as he expresses later in the interview, and as evident in the fistula fiasco) and he wants to share his knowledge with others. That's his express reason for going to the forum – he does not give advice, only factual information (see posts).

This is closely related to Joan looking for people to emotionally support on the forums – but she gives advice. Seeking seekers is not limited by support type. (See “Validating fears” memo.)

Related codes

- Information flowing *one-way*
- Having *curiosity, not gaps*
- Being (*overly?*) *confident* in knowledge
- Attributing gaps in knowledge to *medical teams... dropping the ball*
OR lack of effort OR *a time element*
(lack of access to HCPs)

Questions?

*Kaitlin Light Costello
Doctoral candidate
School of Information and Library Science
University of North Carolina - Chapel Hill*