Searching for information in online health communities

Yan Zhang, PhD
School of Information
University of Texas at Austin
yanz@ischool.utexas.edu
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YAHOO! ANSWERS

YouTube

Blogger

tudiabetes.org®

new to diabetes | type 1 | type 2 | insulin pumps

nutrition + recipes | for loved ones | control your diabetes | learn about complications

American Diabetes Association.

Community

Find Support Now

Join the conversation! Check out these message boards:

Adults Living with Type 1 | Adults Living with Type 2 | Recently Diagnosed | The Place for Parents | I Love Someone with Diabetes

patientslikeme®

WebMD® Community

diabetic connect

besuretotest

Peer-to-peer health care

- One in four internet users living with chronic ailment say they have gone online to find others with similar health concerns.
- Other users included:
  - People with rare conditions
  - Care givers
  - People who experienced a medical crisis in the past year
  - People who have experienced a significant change in their physical health (e.g., weight loss, pregnancy, or quitting smoking)
- Interventions targeting at improving patients' self-management abilities

Fox, S. (2011). Peer-to-peer healthcare Retrieved Dec. 13, 2013, from http://www.pewinternet.org/~/media//Files/Reports/2011/Pew_P2PHealthcare_2011.pdf

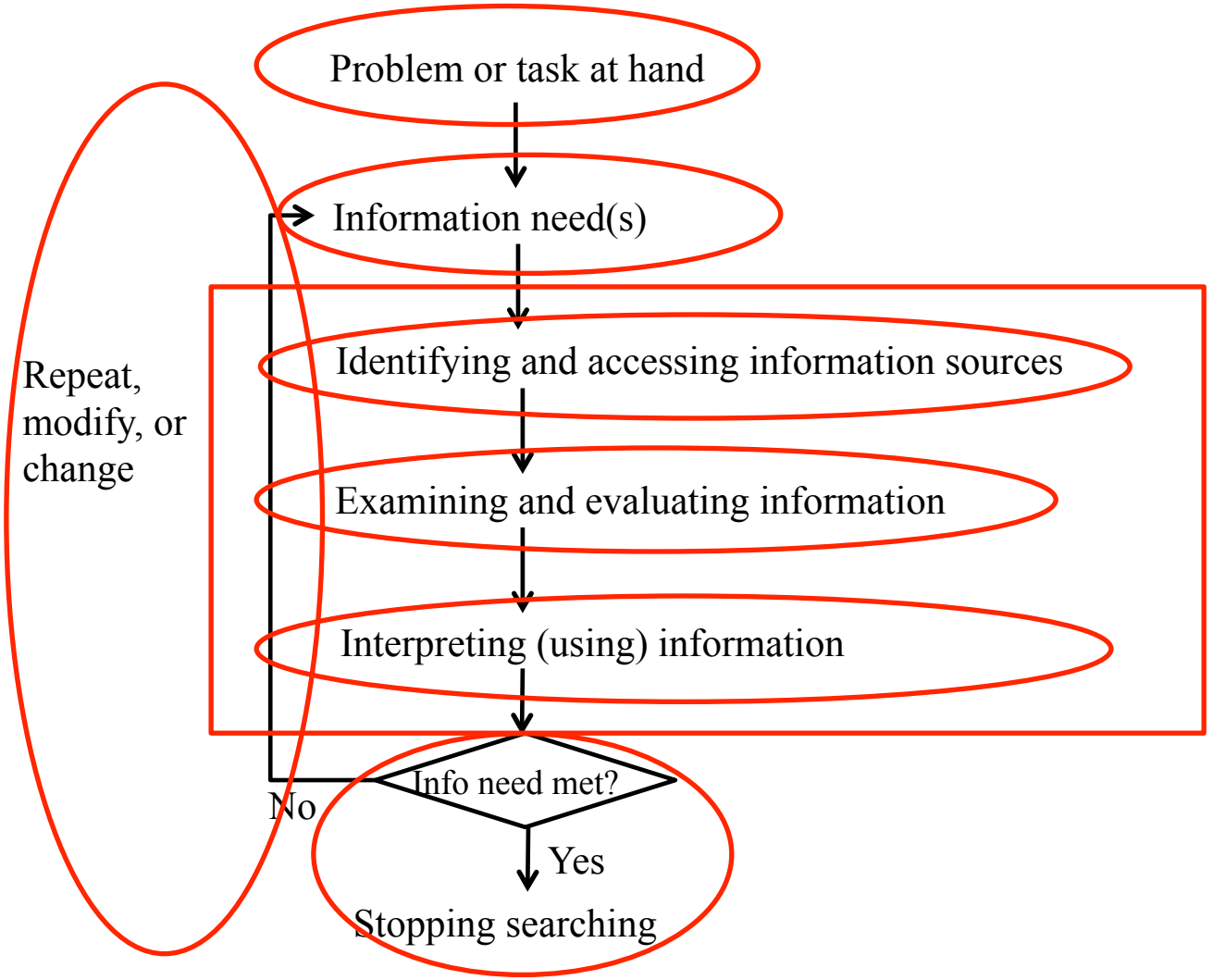
Positive impact of participation

- Improved competence in seeking health information and communicating with providers (Gustafson, et al., 2001; Coulson & Shaw, 2013)
- Increased social support and reduced social isolation (Hoybye, Johansen, Tjornhoj-Thomsen, 2005)
- Psychological benefits, such as emotional relief and improved outlook (Barak, Boniel-Nissim, & Suler, 2008; Winzelberg, 2003)
- Behavioral benefits, such as improved dietary behavior (Glasgow et al., 2003)
- Improved quality of life (Rains & Young, 2009)

Mechanisms of the positive effects

- Information-related behavior dominates conversations in online communities (Greene, Choudhry, Kilabuk, & Shrank, 2011; Zhang, He, & Sang, 2013)
- Information is the major mechanism contributing to the positive impact of online health communities (Barak, Boniel-Nissim, & Suler, 2008; Mo & Coulson, 2012; Nambisan, 2011)

A Schematic Model of Information Search



(Marchionini, 1997; Savolainen, 2006; Wilson, 1999)

Research questions

1. How do consumers identify online communities to access?
2. How do they search for information in the communities?
3. How do they evaluate the information?
4. How do they use information?

Research methods

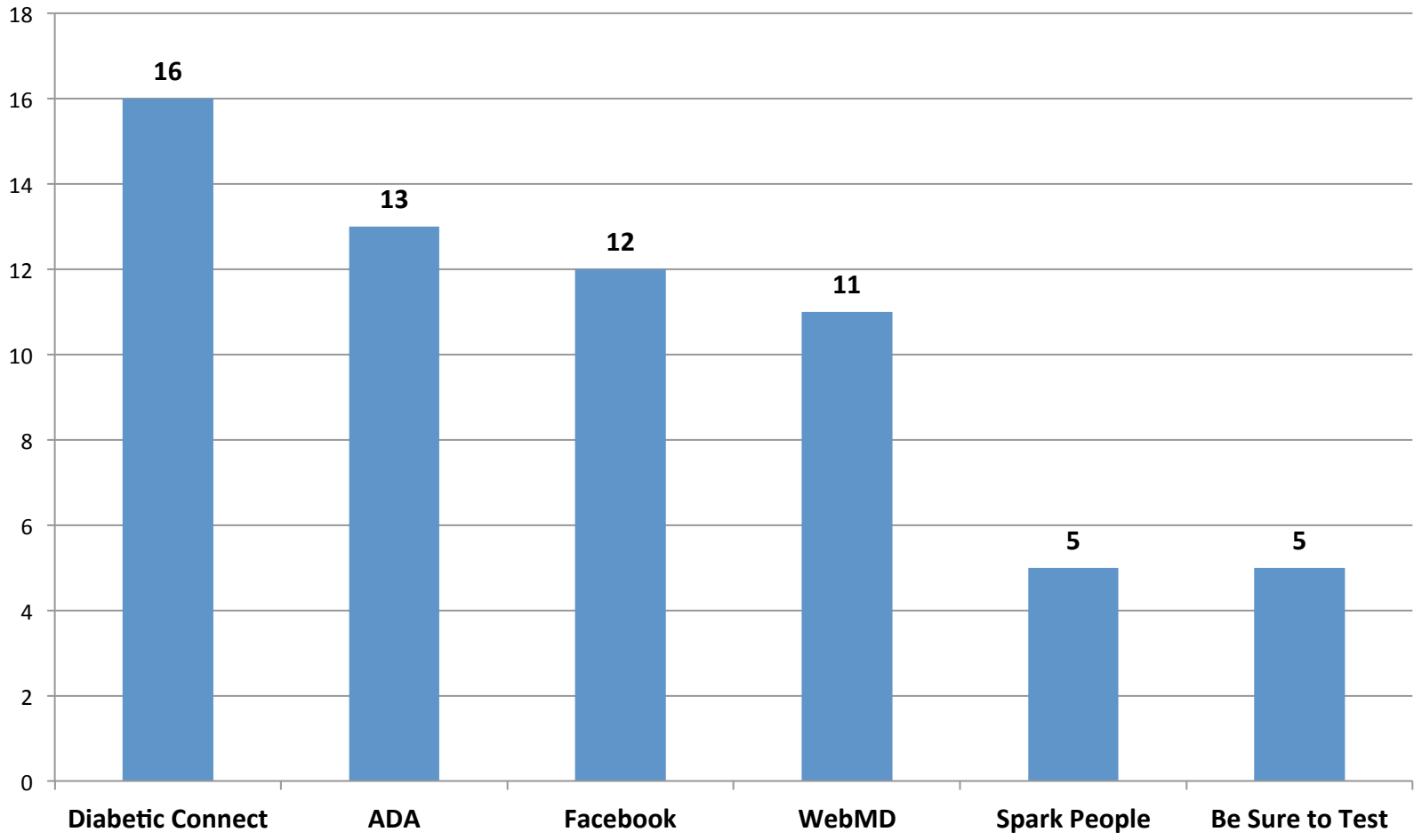
- Survey posted on Amazon Mechanical Turk
  - Demographics, and use of online communities
  - From November 12 to December 2, 2012
  - 212 responses; 72 were retained

- Descriptive statistics and qualitative content analysis

Demographics and use of online communities

- 32 males (44.4%) and 40 females (55.6%)
- 18 (25.0%) Type I diabetes, 20 (27.8%) Type II, 17 (23.6%) pre-diabetes, 16 (22.2%) caregivers, and one (1.4%) was diagnosed with PCOS and on diabetes medications and vulnerable to gestational diabetes.
- Age: 18-63; Mean = 33.4; SD = 10.5
- Reported using 1-9 communities; Mean = 2.5; SD = 1.4
- Length of usage: 3-120 months; Mean = 20.4; SD = 19.0
- Frequency of usage
  - 65.3% several times a week
  - 34.7% on a monthly basis

Most used online communities



Q1. Identifying communities to use

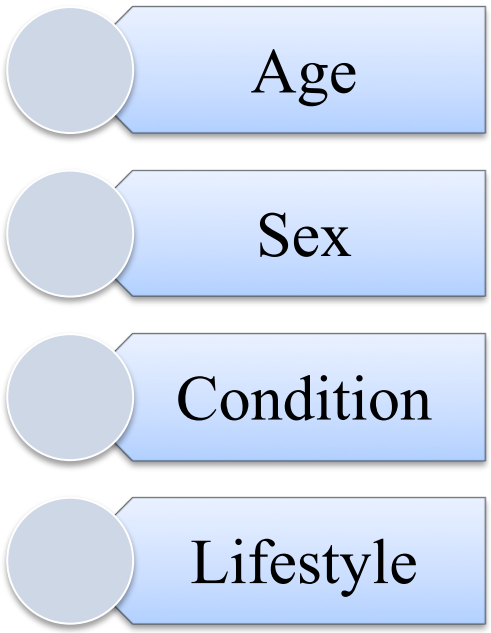
- Referred by family, friends, doctors, or peer patients
- Referred by recognized bloggers
- Ranked high in Google search results
- Ranked high in Facebook search results
- Familiarity with the platform (e.g., Facebook and WebMD)

Q2. Strategies of searching for information

- **Asking** questions
  - To the community
  - To experts or trusted peers
  - Send direct emails to mentors in the community
- **Participating** in discussion
- **Searching** old posts
- **Browsing** old posts
  - Look for posts with a lot of replies
  - Posts with recent dates, new posts
  - Sift through all
- **Chaining**
  - FB group → friends' wall

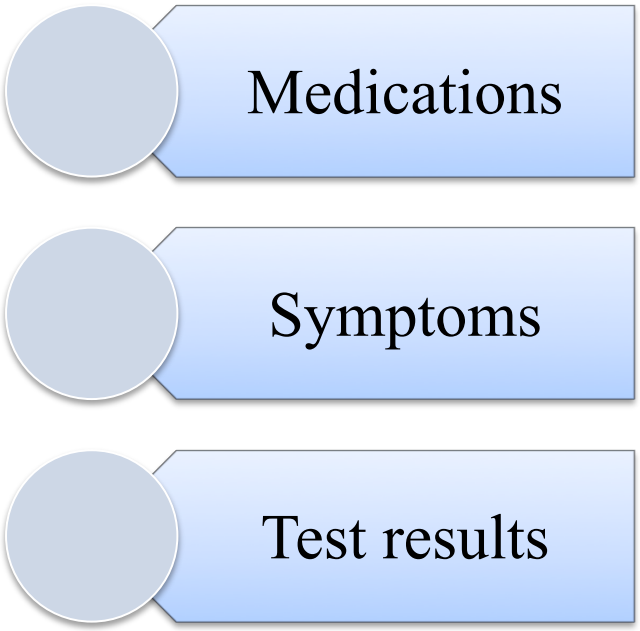
Q3. Evaluate information

- Relevance
  - Topic relevance
    - Lifestyle: e.g., diet, exercise, recipe
    - Medical information: medications, alternative medicines
    - Other people's experience, i.e., personal stories
    - Product information, e.g., insulin pumps
    - Events
    - Doctors
  - Personal relevance



"I [search for] specific messages, including ones that are tailored to women, my age group, and women with PCOS."

"I typically pay attention to information that is relevant to my dad, a man in his 50's that has recently been diagnosed with Diabetes. I search for people in similar lifestyle situations. For example, my father had to have a toe amputated and has ulcers on his feet, so running or using his feet extensively is out of the question. However, I look for low impact workouts, and also find foods that we would enjoy eating."



"I filter information based on what medications the poster takes and how they make [him/her] feel."

"I look mostly for [on American Diabetes Association community] how others are being treated for the same symptoms that I have, and results obtained from tests."

Evaluate information

- Quality
  - Community-enabled cues:
    - Source of information: posters' experiences and expertise, posters' identity
    - Peers' reactions
    - Writing style (spelling, use of slang, whether respectful of others)
  - Validation through third party sources
    - Discuss with doctors, family, and/or friends
    - Compared against my own knowledge
    - Compare to others sources found through search engines or other online communities
  - No evaluation

“I put a lot of faith into people's opinions and experiences. I think most people share them because they want to help others, so I take people's advice into account most of the time.”

Q4. Use information

- To become informed
  - Events
  - Products
- To gain knowledge
  - To understand diabetes
  - To formulate coping strategies, e.g., lifestyles
  - To help formulate questions to ask doctors
- Apply information
  - Herbs, cooking ideas, diets, exercise, products, medications…
- Share information

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Thank you!