Towards A Conceptual Model of Long-Term Online Health Information Behavior

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ABSTRACT

This work describes a qualitative study intended to build a model of online health information behaviors for people managing a chronic disease. Models of chronic disease care include a central role for the patient, while information behavior models in the information sciences describe how people use online resources. We propose to investigate the changing online information behaviors of e-patients as they manage a chronic disease over time. Results from a pilot study with eight participants suggest that e-patients rely on authorities (like WebMD and MayoClinic) in early stages of their self-management, and more on social media (like Facebook and YouTube) in later stages. Event-driven information needs arise due to unstable and acute states that have an impact on the patient's health and quality of life. Using an open coding process, we build a preliminary model of how online information behaviors develop in the context chronic disease self-management.

Author Keywords
Health Information Behaviors; Information Behavior Model

General Terms
Human Factors; Theory

INTRODUCTION

This work describes a qualitative research study that investigates the online information behaviors of people managing the chronic condition diabetes. Chronic disease self-management entails the patient making "day to day" decisions about an illness [2]. Diabetics self-manage their condition for a lifetime, and may gain considerable knowledge about the disease. People with chronic conditions make many care decisions without a doctor present. These laypersons, hereafter as *e-patients* [9], use online health information to help make decisions about their medical care and to access affective support.

We conducted a pilot study of in-depth interviews with

eight participants to investigate e-patient activities over time. Data analysis led us to draw a distinction between two primary types of information resources used by e-patients; medical *authorities* (e.g. MayoClinic.com) and peer-produced *social media* (e.g. Facebook). These resources are used for *event-driven* needs (e.g. investigating drug side-effects) and *persistent* information needs (e.g. dietary information). E-patients have differing needs and abilities in different stages of their disease management,. Preliminary results indicate that e-patients rely heavily on authorities providing information from medical authorities in early stages of their self-management, and more on social media sources that provide "patient like me" information in later stages.

CONCEPTUAL FRAMEWORK

Models of chronic disease management developed by medical professionals place the patient as a central figure in their own care, recognizing the need for an informed patient. Common themes are patient empowerment and self-management efficacy, providing patients the tools that will help improve outcomes [13]. However, the effect of online information resources has not yet been included in these models.

Chronic Illness Frameworks

Chronic Illness Trajectory Framework
Corbin & Strauss created a nursing model for chronic illness management based upon their *Chronic Illness Trajectory Framework* [5]. This framework is "a conceptual model built around the idea that chronic conditions have a course that varies and changes over time" [5:156]. The updated trajectory framework defines chronic disease management in eight stages: *pre-trajectory* (prior to the disease onset), *trajectory onset, stable, unstable, acute, crisis, comeback, downward,* and *dying* [6]. For the present study, the trajectory onset, stable, unstable, and acute stages are most significant as they are times when the e-patient is likely to access information resources.

Chronic Care Model
The *Chronic Care Model (CCM)* was originally developed as a guide to develop effective clinical care for chronic conditions and improve illness management [16,17]. Identified in the model are six elements*: community*

resources and policies, health care organization, self-management support, delivery system design, decision support, and clinical information systems. We are most concerned here with the initial three elements. Community resources and policies and health care organizations provide much of the context for chronic disease management. Finally, and most importantly for the purposes of this work, is self-management support that helps "patients and their families acquire the skills and confidence to manage their chronic illness" [3].

Online Health Information

Eysenbach's *apomediation* model [7] builds a bridge between chronic care models that put the patient in control of their own care and online health information behaviors by describing ways e-patients may find information resources through search, social media, and other channels. The e-patient in this model is no longer limited to passively receiving information from health providers. Rather, they move through the Web in a "berrypicking" fashion [1], visiting search engines, social media websites, online news media, and other resources.

Patient expertise complements the knowledge provided by medical experts [12]. In conditions such as diabetes where there may be conflicting points of view, e-patients may find information in social media that more readily matches their personal experiences than that found in the medical literature [15]. Even if these alternatives are not always endorsed by the medical establishment, they can provide "different possibilities for treatment and new ways to understand their illness" [15:590]. These differing viewpoints may be found by e-patients on social media websites.

RESEARCH QUESTIONS

Broom [4] suggests the "active" or "informed" patient is safer than the "passive" patient. We hope to expand the understanding of how active and informed e-patients use online resources. Specifically, we aim to characterize e-patient online information behaviors:

- How are online information resources used by e-patients as part of chronic disease self-management?

- What changes occur in e-patient utilization of different types of online resources over time?

METHODS

We take a "grounded theory" [10] approach in this study, with the analysis and model "grounded" in the data collected. Data was collected in one-time interviews conducted over the phone or in person where participants were asked to relate incidents in their self-management that led them to go online for diabetes health information.

Following each interview, transcripts were coded using the constant comparative method [10].

In order to gather retrospective data from participants we utilize the Critical Incident Technique (CIT) [8], an investigative method described for exploring qualitative research questions. CIT provides a methodology for collecting and analyzing activities and behaviors, and has been used in previous research studies in health sciences and information sciences. The technique elicits data from participants through interviews or questionnaires, and provides guidance for data analysis and interpretation.

Participants

Participants self-managing the chronic condition diabetes while using online resources were recruited using messages posted at the Drexel University campus and Internet message boards. We interviewed eight e-patients with reported ages ranging from 25 to 58 years old. Six of eight participants reported their race/ethnicity as white, one as Hispanic, and one South Asian. Year of first diagnosis ranged from 1972 to 2013. All participants had some level of education beyond high school, the least being an associate's degree and the highest level a Ph.D. All had access to high speed Internet connections, and all had searched for health information within the past three months.

RESULTS AND DISCUSSION

Preliminary Model

The e-patients interviewed in this work spend most of their lives in a stable condition. Accessing online information is reported for events such as investigating potential side effects of a new drug and persistent needs like diet information. E-patients access websites from medical authorities and social media, which are evaluated for relevance to the current need. Based on our participants' reports, we segment the experiences of our participants into three stages:

1. **Diagnosis**: Behaviors close to the time of diagnosis, the trajectory onset phase of diabetes.
2. **Intermediate**: After the e-patient leaves the trajectory onset phase and is comfortable self-managing their diabetes.
3. **Advanced**: When the e-patent has had substantial experience self-managing their diabetes through stable, unstable, and possibly acute phases.

Characteristics of Events and Health Information Behaviors

Information needs emerge from one-time unique events, and on-going persistent concerns. When instability in a condition emerges, e-patients then engage in event-driven information seeking. Persistent information needs, on the other hand, occur with some frequency, and are not due to instability in the e-patient's health.

	Stage 1: Diagnosis	Stage 2: Intermediate	Stage 3: Advanced
What information is wanted	Basic information about the disease diabetes, including necessary changes to diet and exercise.	Information about events, diet and exercise, and affective support.	Information for affective support is prominent, information about the e-patient's unique circumstances.
Why information is wanted	E-patients want to learn about their condition, how it will affect their lives, and what they should do to begin managing it.	In order to respond to events, persistent needs like diet and exercise, affective support.	In order to maintain a high quality of life, feel empowered, and plan for the future.
What information resources are utilized	E-patients want information primarily from medical experts, on websites operated by entities considered medical authorities.	E-patients look towards information from other patients with similar conditions and circumstances. Social media sources rise in use.	E-patients use both authorities and "patients like me", with the later more heavily utilized.
How information is evaluated	E-patients tend to visit known medical authorities.	E-patients begin using their knowledge of diabetes to judge information, and visit harder to evaluate sources.	E-patients compare information found online to their personal situation or experiences.

A model of health information behaviors as they evolve over time in patient self-management of a chronic condition

Our participant Laura summarized what appears to be typical information behavior in the disease trajectory as, "the most intensive period of online research was at the very beginning and then it's been more around specific questions." Examples of these specific questions include starting a new drug, or treating an illness like the flu. In response to events, participants utilized websites of medical authorities (like the Mayo Clinic) and social media resources. With the exception of diagnosis, events may re-occur at intervals over an e-patient's lifetime, however the circumstances will be unique each time. For example, a diabetic may change medicines several times, but the general information behaviors related to this type of event remains the same.

While in the stable phase of diabetes, participants reported two persistent needs, affective support from others and access to information related to their diet and exercise. E-patients reach others online synchronously and asynchronously through social media. Synchronous support can come from behaviors like "tagging" a post in Facebook with a contact's username to elicit a fast response. Asynchronous support is often reading about other e-patient experiences, such as a person's blog post. Mobile devices were reported to be used often when investigating diet and exercise questions.

Resources Utilized
E-patients appear to rely more on medical authorities when they are newly diagnosed, and social media later in their self-management. Social media was used for finding health information and affective support. As the e-patient learns about their unique condition over time, they tend to rely more heavily on their own learning and experience. One participant demonstrated how expertise is used to evaluate nutrition information found online, "I take the knowledge that I already have, if it's like a carbohydrate count, I have my best guess, and if what I am reading kind of lines up with that then I know it's pretty spot on." [Sara].

Evaluating Resources and Information
Evaluation occurs of both authority and social media resources. Our participant Rachel reported evaluating her Facebook friend, "the reason I go to her is she has had diabetes longer than I have, I know she is in really good control with her own management, and she is the one friend who is always posting about new research for sharing the new technology. She always has the newest pump or the

newest glucose monitor. So I feel like she is a good source, she is on top of her stuff." Authority websites are sometimes under particular scrutiny, as shown by comments like "I know you have to follow the money trail" [Laura]. E-patients sometimes "triangulate" resources, checking and verifying the information they find: "I used a couple of different sources. Not every site gave me the same information so I made sure I was reading the same thing across several sites" [Sara].

CONCLUSION AND FUTURE WORK

Our goal is to help e-patients effectively use online information resources to self-manage their conditions. One way to accomplish this may be to provide information directly relevant to an e-patient's current situation and anticipated need. Public web search, health, and social websites could track e-patient behaviors and predict personalized resources based on anticipated upcoming events and their corresponding information requirements. Additionally, many health systems now offer online health-management tools that include health information libraries. Based on our model, these tools may include their own authoritative and patient-like-me information based on e-patient characteristics like time with a condition, experience with events (like pregnancy), or predicted events (like expiration of an insulin pump). The next step in this work will be interviewing additional participants and revising the preliminary model developed in the study. We expect the model to evolve as we collect further data.

Results from our current study suggest that as e-patients move through the chronic disease trajectory, they begin to rely more on other patients to provide information for both medical information and affective support, turning to social media like Facebook or blogs. This mirrors the findings of previous studies among professionals; other people are important sources in health and other domains [11,14]. An e-patient in the early stages of their disease, near the time of diagnosis, is likely to find general resources useful because they need a broad overview of their condition. However, the same e-patient several years later may deem the site not useful, because they no longer need general information (having already learned it). We intend to model these evolving information behaviors with the hope that future systems can be built to support e-patient's changing needs with personalized information.

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