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Barriers of Obtaining Health Information Among Diabetes Patients

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Abstract

While healthcare information plays an essential role in the process of disease management, previous studies have shown that many patients may be unaware of the availability of certain healthcare information, thus leading to the progression of their diseases and deterioration of their health. This study explores the information seeking behaviors among patients with type-2 diabetes and explores the barriers that hinder effective healthcare information usages. 19 semi-structured interviews were carried out with patients and caregivers in various stages of diabetes disease management. Data analysis identified five major barriers for seeking health information: lack of motivation, passiveness, inconsistency of information, generality of information and loss of information. These findings call for the designing of active and personalized information delivery mechanisms.

Keywords:

Information management, Medical records, Access to information, Long-term care.

Introduction

The goal of achieving quality healthcare is a collaborative endeavor that requires input from both healthcare providers and patients [1]. Health information can educate patients to engage in decision-makings processes, understand their own health and actively manage their diseases. Yet, most healthcare information systems are designed primarily for physicians and other healthcare professionals [2]. Recent consumer health informatics initiatives advocate the role of patients in the process of obtaining and managing their own health information [3, 4], yet little is known about what support patient information needs [5].

Studies have found that many patients do not have adequate knowledge about their own diseases [6]. A study found that even for a common disease like diabetes, more than 50% of patients were unaware of potentially serious complications [6]. This raises the interesting question of why patients are not obtaining the vast amount of health information available to them.

Previous studies have looked into the topic of health information management and health information seeking behaviors among patients [7, 8, 9]. However, the focuses of these are mainly on information regarding homecare, such as glucose readings, magazine articles or patients' insurance information**.** Information about patients' encounters in healthcare settings is seldom considered as part of the health information seeking and management process. As various healthcare providers typically operate as separate "silos" without including patients in the healthcare process [10], seeking and obtaining one's own medical records should also be part of the health information seeking process.

In this study, we adopted a boarder view towards personal health information so as to include both the information gathered by patients, e.g. magazine articles, homecare diaries and information produced in healthcare settings, e.g. lab results, diagnoses and other clinical documentations. Since homecare information is produced by patients at home, there was no need to intentionally seek out it any more. Therefore, the scope of information seeking in this study focuses on Medicare information and external educational materials. We chose to study information seeking behaviors among type-2 diabetes patients. There are two reasons for this choice. First, for diabetics, obtaining health information and staying informed is crucial for maintaining self-care, where not only glucose levels, but also diet and exercise have to be controlled by patients themselves. Second, as a common disease, information about diabetes is readily available for patients. This eliminates the possibility of not having enough resources to look for health information. By limiting this study to one disease we avoid the influences of individual disease characteristics in the information seeking process. Due to the space limit, this paper we only introduce the findings regarding health information seeking behaviors and the implications of them for health information system design. The information management behaviors will be presented in our future work later on.

Methodology

We conducted 19 semi-structured interviews with patients with type-2 diabetes and their caregivers, such as family members or friends between June and September 2009. IRB approval was obtained from the university before the research work started. All the participants were recruited at an outpatient clinic located in southern California. One author was stationed in the patients' waiting room during the regular clinic hours and inquired patients if they were willing to participate in our study. We also left flyers in the front desk of the clinic with the researchers' contact information. Each participant was compensated with 40 dollars for their time.

As mentioned in the introduction, for this study we adopted a broader view towards personal health information where both health information generated in healthcare settings and gathered by patients at home are considered personal health information. Interviews often started by asking for the patients' own journeys about their diseases, followed by a series of questions regarding health information needs, information seeking and diabetic management behaviors. Table 1 lists the main categories of the interview questions. Each category of questions was probed further according to patients' responses.

Table 1 – Interview protocol of the study

Interview Questions:
Where do you obtain diabetes related information?
Do you think there's enough health information available?
What are the challenges for you to search for health information?
Do you request of copy of your medical records after medical visits?
What technologies and tools are you using in managing health information and diseases?
Other behaviors about dietary and exercises?

The interviews lasted approximately 60-minutes in length and were audio-recorded for further data analysis. All the interviews were conducted at the patients' homes – presumably an environment where they naturally keep their health information and engage in disease management activities. Since the interviews were conducted at patients' homes, occasionally family members would join the conversation or provide information upon participants' requests. Unless caregivers were interviewed separately as an interviewee, we counted the spondaic discussion with family members as one interview. Digital photos were taken (either during or after the interview) as tools and materials related to disease management, capturing the context and location of the artifacts.

Constant comparative method [11] was used in the study to extract different themes from the interview data. This method allowed the authors to use an iterative open coding strategy to summarize main themes from the data. The authors coded the text to break down, compare, and categorize the data into initial categories, and then further developed these categories into themes.

Results

We interviewed patients in different disease stages, from the recently diagnosed to those who suffer from multiple complications. The number of years the patients had been living with diabetes ranged from 3 to 39. Echoed with what we speculated in the earlier section, most participants believed that health information is radically available for them and that there is generally no difficulty obtaining such information on their own. However, purposely seeking that information seemed rare among the patients. In this section, we describe general information seeking behaviors, and introduce the barriers to information seeking that are identified in our analysis. We will then discuss the implications for designing systems to overcome these barriers. The findings presented in this section are generalized from major participants and represent the common concerns across all the patients we spoke with. Therefore, these findings indicate behaviors and challenges that can be generalized to the broader population of diabetes patients, and perhaps even to other chronic diseases sufferers.

In general, the diabetes patients were satisfied with the amount of health information available to them. No one in the study mentioned any difficulty seeking information on diabetes. 17 out of the 19 participants believed it was fairly easy to obtain health information. In addition, many patients believed they encountered more diabetes related information in their daily lives than in the recent past 5 years. This showed that at least for diabetes, a lack of available health information no longer hinders how patients seek and obtain health information. Healthcare providers are the major information sources for most patients, where they either pick up brochures in the waiting room or receive health information from providers. Other than healthcare providers, social networks are another important information source as a few patients claimed that they obtained information by "*play by ear*". About half of the patients search for health information on the Internet.

Although almost all commented that there is enough health information available for them, many patients admitted that they didn't engage in information seeking and disease management activities. Our analysis identified 5 barriers to understand the breakdowns in the information seeking process.

Motivation Fade Overtime

Interviews indicated that patients' health information needs are maintained largely on a "need to know basis", meaning they seldom look for health information to educate themselves unless they have been diagnosed with new complications – at which time it is impossible to revert to their previous health status. Most patients started collecting health information when they were first diagnosed with diabetes but discontinued the learning efforts shortly after they had a basic understanding about the disease.

> *Ah, well, ah, I think that it was since they told me I had diabetes. Both of my parents are diabetic. I saw them taking pill after pill. I don't want to see myself like that. At the beginning, I did the medications. You know. I did what I had to do. But now, I'm tired. I'll do it tomorrow. I'm at the point where I don't care much about anything.* (U05- line 118)

> *When I was first diagnosed because I want to know exactly what it is and how it affects me.* (U19-line47)

During the motivated information seeking stage, patients actively searched for health information in order to understand what diabetes was and how to manage it in general. Patients' motivation to seek healthcare information gradually faded overtime; many mentioned that they stopped reading and looking for new information after a couple of months.

However, the course of diabetes changes overtime. The health information patients obtain at the early stage of their disease may not be sufficient for the later stages of disease management.

This lack of motivation for health information seeking is partially a result of the misconception that diabetes is a stable illness and that there is no need to continue to learn more. Patients tend to believe that what they have learned should be sufficient for their disease management once they have a pretty good knowledge about diabetes. Lack of motivation also comes from the extremely long disease management process of an illness like diabetes. It is well known that there is no cure for diabetes, and once diagnosed, patients will have to deal with it for their entire lives. It is easy to feel motivated to learn to manage the disease, but it is challenging to continue to engage in information seeking activities. This explains why the patient's feeling of tired and not caring it anymore.

Passively Seeking Information

Many patients use "*accidentally*" to describe the way in which they seek health information. "Accidentally" means they seldom initiate the information seeking process, but pick up sporadic health information that they happen to see or hear. Most patients commented that other than their physicians, they accidentally read a few articles in medical journals placed in patient waiting rooms, or that they happened to get a few flyers about diabetes in the mail or read about it in the newspaper. "*Play by ear*" was also quoted by many patients indicating that the information picked up among their social network was a major source for them to learn diabetes management.

> *[I] Usually get our stuff from the clinic, like the pamphlets lying around. (*U04-line 52*)*

> *Ah, [information seeking is] not too complicated. It depends. You have to talk with your doctor. It depends if you have a good doctor at the time. (*U12-line152*)*

This passiveness reflects on the information sources where the patients obtain the healthcare information. Patients pick up information that happens to be available to them; *Accidentally*, *play by ear* or picking up things *lying around* all indicate the passive nature of patients' information seeking behaviors. They seldom initiate active information searching on their own but passively wait for information that happens to "be there". This passiveness indicates that patients may not obtain a comprehensive understanding about diabetes since they only receive information piece- by-piece from different sources.

Inconsistency of Information

Even though no one in the study thought obtaining information about diabetes was a difficult task, 6 out the 19 patients commented that occasionally the information they saw was conflicting. New information may conflict with what was learned from their providers, articles they read or their own experiences as patients.

> *I'm not real happy about a lot of the diabetic stuff that is out there. The diets and different things that they tell you have things like high fructose corn syrup in them and different things. I'm reading the ingredients and going, "ewhhhh," I would never put that in my body. Even on a regular basis I wouldn't do those things. There are a lot of things out there that I don't agree with at all. (*U08-line 110*)*

This quote shows that even for the small number of patients who are willing to actively seek health information, conflicting information discourages them from continuing seeking it since they don't know whether they can trust the information given to them or which information they should they trust. The quality of health information, therefore, hinders the way patients approach healthcare information and sometimes leads them to turn away from engaging in the active information seeking process.

Generality of Information

"Too general" is another term that was repetitively used by patients during the interviews. When being inquired about how they use healthcare information they picked up, most patients replied that they seldom read or use it. Although information about diabetes is available almost everywhere, it was often too general and only covered things they had already known for years.

> *Most of it I would say is irrelevant to my situation. All of them say don't eat a lot of sugar. You don't have to tell me that. (*U03-Line 73*)*

> *Ah, most of the information we get, we are already aware of at this time. So it's just like a reminder for me…. It's pretty clear and, ah, easy to remember because time and time again it's the same. (*U10-line 89*)*

The flyers and brochures patients collect in waiting rooms usually target newly diagnosed patients, with a hope to educate them about what diabetes is and common complications. However, most of the patients in our study had already gone through the initial learning stage of their illness and often found this information useless for their situation. As shown in the quotes, patients already know not to consume a lot of sugar and already know basic information about the illness and the importance of keeping their glucose in the normal ranges. The heath concerns that bother them currently are more specific, regarding complications they have or questions they have regarding the balance of medications among the multiple diseases they have. None of these issues can be found in brochures in patient waiting rooms or in their social networks.

Loss of Information

One question we explored in the study is whether or not diabetes patients seek the health information generated during their medical visits, *e.g.* information in medical records. 11 out of the 19 patients claimed that they keep a copy of their records at home, indicating a high awareness of owning medical records. However, further probing of this issue found that patients usually only have copies of their lab results rather than their entire medical records. Information such as written diagnoses, prescriptions and clinical notes are almost never pursued by patients at all. Nevertheless, when asked if they were willing to have a copy of their entire medical records, most patients said yes without hesitation. For them, keeping medical records is way to track the process of their diseases and be more aware of their own health issues.

> *Yes. I would like to know [information in the medical records], uh, to see what it was like. What is was like a year ago. Say, six months ago it was like this and then this happened or this is different. I guess it is just like to compare for myself how is my diabetes going (*U05-line 35*).*

It takes time and effort for patients to request the information that is produced during medical visits and patients often feel frustrated when they don't have control over the information in their records. None of the participants in our study have their entire records with them. Yet, the information in medical records plays an essential role in coordinating patients' healthcare among different providers.

> *I'm a contractor. I move around from state to state so I have to get a new doctor in a new state… They all want to start me over again at 10 units… I usually lose it [medical records]…I always feel unfortunate that they don't have a database that the doctors could feed it in, the web or something (*U03-Line 17*).*

As indicated in the above quote, information loss in transiting from different healthcare settings or from healthcare setting to patients' home may cause serious interruptions in the healthcare process. Some patients mentioned that they don't remember what doctors told them during the medical consolation. During consultation, some patients take notes about what they have been told, more just rely on their memories - a way that is presumably error-prone and easily leads to loss of information.

Discussion

The 5 barriers indentified in our study can be divided within the following categories: 1). passiveness and lack of motivation of the patients 2). non-specific, inconsistent health information and 3). loss of information produced in healthcare settings. In this section, we discuss the implications for designing future healthcare information tools to overcome these barriers.

Designing active information delivery system

Our study found that patients' motivation for seeking health information fades shortly after they obtained a basic understanding of their diseases. Yet, patients are not resistant to the healthcare information that is available to them despite seldom actively searching for it. This information seeking behaviors indicates that the design of health information portal should actively fill in sufficient health information to patients, especially at the very beginning of disease onset stage and then persistently motivate patients with new information. Doing so allow patients to obtain health information effortlessly. The health information sent to patients should be done on a long-term basis to keep them aware of the health risks throughout the course of their disease.

It is notable that online healthcare portal shows great potential in delivering health information actively to patients. A few of the Internet users mentioned that after subscribing to various online diabetes websites, they constantly receive health information. One patient told us: *I get a lot of things on there. I have to screen them quite a bit* (U18-line 39). However, the conveniences of the regular online information delivery are discounted when information are not specific to patients' individual needs. They may also overwhelmed by the amount of information sent to them and choose to ignore it completely.

Designing tailored information delivery system

We also identified factors in the sources of healthcare information that discourage patients from engaging in effective information seeking activities. Patient often encounter repetitive information that is too general for their own health, or they don't know which information they should trust since various information sources conflict with each other. These findings suggest health information should be tailored to fit with patient's personal needs. Personalization holds great promise to transform healthcare from "standard care" to "personalized care."

Compared with generic information, information that addresses individual needs is more likely to be read and have an effect on health behaviors [12, 13]. A survey [14] on available tailoring mechanisms in healthcare found that most tailoring criteria used in previous studies are based only on one health behavior and possible stages of change such as nutrition, exercise and in this study, information about type-2 diabetes. However, what we found has proven that even this level of personalization is still considered generic information. Patients require more specific health information to address information that they do not yet know, such as how to care for certain complications, how to deal with the interplay of multiple chronic cares and new solutions for self-care. Tailored information has to fit with the patients' deepest concerns as well as provide new and trusted information that they have not encountered before. Health information personalization is one goal of future personalized medicine [15].

Integrating medical records with information delivery

Patients in our study seldom seek for health information documented in their medical records and leave this valuable information with providers. This behavior has caused information loss in the transition from hospital visits to self-care at home. Patients do, however, wish to compare their health issues in different time spans or transmit this information among caregivers. Integrating two sources of information will give patients a continued and complete view of their healthcare and keep them informed about their health issues. In addition to this, since most patients have expressed the desire to obtain specific information regarding their recent discomforts or symptoms, a system that matches outside health information with information on patients' medical records would allow patients to receive personalized information particular to the issues they are concerned about in a timely manner. Accordingly, the integrated information delivery would motivate patients in searching for more health related information and engage in disease management process.

Conclusion

This study explores health information seeking behaviors among type-2 diabetes patients and identifies the barriers that prevent these patients from obtaining the healthcare information that is crucial for their disease management. These barriers fit under the categories of 1). passiveness and lack of motivation on the patients' side, 2). non-specific, inconsistent information available to patients and 3). loss of information produced in healthcare settings. An active and personalized information delivery portal that filters information based on individual needs and initiates information delivery should be able to overcome these barriers. Even though this current study targets diabetes patients, these findings may also be borrowed to direct healthcare information among patients suffering from other chronic diseases. This study is only the first step in an on-going project aimed to understanding patients' healthcare information seeking and management behaviors in the hopes of designing better information delivery systems in the future.

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