
Sharing Medical Data vs. Health Knowledge in Chronic Illness Care

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Abstract

Chronic illnesses are becoming more prevalent worldwide breeding an interest in supporting patient care through electronic health information exchange. Through a study of diabetes patients and the specialists in their care network, the challenges involved in sharing health information from the two perspectives become apparent. There are opportunities in the design of electronic medical information exchange to support the patient's need for knowledge and specialist's need for data, bridging the gap that can lead to tensions and inefficiencies in the management of illness trajectories.

Author Keywords

Illness trajectory; self-care; medical data; healthcare

ACM Classification Keywords

H.5.m. [Information interfaces and presentation (e.g., HCI)]: Miscellaneous

Introduction

Chronic illnesses affect approximately half of all American and British adults – 133 million Americans and 17.5 million Britons [6,14] – and these numbers are expected to significantly rise over the next ten years. Chronic illness is one that can be controlled but not cured and thus requires a lifetime of ongoing care

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CHI'12, May 5–10, 2012, Austin, Texas, USA.
ACM 978-1-4503-1016-1/12/05.

in addition to ongoing communication between the patient and their healthcare providers.

This particular group of healthcare concerns has been a driving force behind many initiatives with Electronic Medical Records (EMR) in order to maintain and chart a patient's medical data over a lifetime. More recently, there has been a rise in Personal Health Records (PHR) systems, where patients collect and document their self-care activities and data from their healthcare providers. With the new GE-Microsoft joint venture aimed at global healthcare system transformation, system developers are now turning their attention to bridging the gap between patient and practitioner health information recording and management [4]. For instance, one of their first initiatives is to support data sharing between patients and their healthcare providers.

In long-term health management, there needs to be a symbiosis between the activities taken by the health practitioners and those taken by the patient in order to maintain a positive illness trajectory [12]. An illness trajectory is more than simply the data and information associated with the patient's illness. Rather, it is also a process that is embedded in a social framework that effects and mitigates how that data is gathered, used, understood, and acted upon. An understanding of how both patients and their network of healthcare providers regard the information they generate and share and how that plays a part in the illness trajectory is necessary to provide a perspective on how to design for a continuum of care in a socially situated manner.

For the following study, we have focused on one particularly prevalent chronic illness: diabetes. Through

a series of interviews with patients and health practitioners, we have uncovered a discrepancy between the two stakeholder groups in the types of information they want to have and want to share.

Background

There has been a recent shift towards patients taking a role in their own self-care and also some promising research about the benefit of patients having more responsibility in their own health management. Sharing information between patients and healthcare providers has been cited as having a positive effect on quality of care [3,5] including patient adherence to care plans [10]. With the adoption of new technologies to facilitate communications between healthcare providers and patients, the change in responsibilities may shift knowledge and expertise to the patient [1]. In discussing this move towards shared healthcare responsibility, Milewski and Parra even opt for the term 'social network' over the traditional 'care network' [7].

However, a number of studies have identified some barriers to sharing information between patients and their caregivers. When describing illnesses, physicians tend to create an illness representation from data driven interviews based on biomedical information while patients understand their illness through a narrative of episodes in how it disrupts their lives [9], and this narrative is not captured currently in their medical records [13]. In addition, a recent meta-review of studies on EMR-PHR information sharing highlighted obstacles to patient-accessible health records, including determining 'relevant' health information [2].

These concerns are exacerbated in the management of a chronic illness such as diabetes. Diabetes is a chronic

illness that grows more prevalent every year, with estimates that one in ten will have the condition by 2030 worldwide [8]. It effects the production of insulin, which is needed to process digested sugars and long-term excess levels of sugar can lead to serious complications including eye, foot, kidney and heart disease. As this is the case, diabetic patients tend to have a wide range of medical practitioners in their care network, including diabetes specialist nurses, dieticians, doctors, ophthalmologists, podiatrists, and midwives. This health condition needs to be cared for with a range of treatments including diet, exercise, and medication, all of which need to be balanced by the patient to self-control their levels of ingested glucose.

The factors around this chronic condition present an interesting case study for how medical information is used and shared over time and what this means not only for the design of shared electronic medical records, but also for the shift towards more patient centric care plans. As chronically ill patients and their caregivers have a different perspective on health records than the general patient population and general practitioners, the focus of this study is on the concerns surrounding information sharing between diabetic patients and their network of diabetes specialist healthcare providers. In the following, we discuss one such finding from this line of research to date: a difference in the perception of relevant information based on information use needs.

Methods

The data collection method centered on interviews of two important groups in a diabetic's care: diabetic patients and diabetic specialists. Diabetic patients are people who have been diagnosed with Type I or Type II

diabetes and are in charge of their own self-care. Diabetic specialists are those trained medical and health practitioners who specialize in diabetic care.

For the first group of stakeholders, we have interviewed 12 diabetes patients, attended three diabetes support groups and conducted one group interview with a diabetes support group, all in eastern England. For the second group of stakeholders, we interviewed six diabetes health specialists based in England: two senior diabetes consultants, a diabetes midwife, a diabetes nurse, a diabetes podiatrist, and a diabetes dietician.

All interviews were conducted in a semi-structured format with questions probing people's experiences with the current medical information exchange network as well as their preferences and concerns regarding information exchange. Questions were asked regarding ability to use, share, and access health information.

An open, iterative coding scheme was used for the qualitative data collected from the interviews conducted based on thematic analysis. Coding was organized first around three broad themes of use, sharing and access to health information, which then allowed deeper analysis into the differences and similarities between the needs and wants of the patient and specialist stakeholders.

Findings

Although currently in the UK patients have the legal right to see their medical information, this is often not seen in the specialist-patient exchange. There are patients, particularly older Type II patients, who do not feel like they can request documents or information beyond what the specialists share with them verbally.

In addition, it seems to be common practice for specialists not to share anything unless specifically requested for it. An older, male, Type II patient in the group interview shared the tactic of pretending the information was for the hospital and not him to get results:

"I've asked for my blood results, and the doctor kind of said 'Look, I can't work the printer. You've got to ask reception' and then of course you ask reception and then it is like getting blood out of a stain. So they've kind of got a misunderstanding and I've just let them have that. They were going to give it to me because they thought I wanted it for hospital, but I did get it. Eventually."

The specialist-patient exchanges that do occur are oftentimes not what the receiver needs or wants. For instance, information that the specialist provides the patient is not an exchange of knowledge, but rather an exchange of data, often without context. Many times the patient receives the same letter that goes back to their general practitioner with medical terms and numbers that do not aid the patient in understanding for the purpose of their own self-care. Patient 8 (Type II, 47 years old) is given letters with the results of her eye exam, but only to pass on to her doctor:

"When I go and get my retinas photographed at the opticians [...] quite often I get a paper letter that is sent to the doctor just to say that the results are normal".

If the patients do get more substantial information, it is reams of data with no context for interpretation – for instance, if the readings have risen since their last visit.

"They will write down my blood pressure, blood sugar levels and then one of the cholesterol readings but I am not too sure. I suppose I rely on my doctor to monitor what is going on, but I am interested, when I am in the surgery I ask them whether things are going up or down, whether there is improvement, whether I need to change my medication and that kind of thing."
(Patient 8, Type II, 47 years old)

As diabetes requires patient engagement in order to accurately control blood sugars, patients are actively turning to friends, family, support groups, online sources, and anything available to them to understand the condition and treatment options. Patient 2 (Type I, 36 years old) was unsatisfied by the level of information imparted on him when diagnosed a few years ago and took matters into his own hands:

"[They] basically told me to 'inject this much at this point in the day and inject this much at this point in the day, bye!' I was like 'oh, ok.' [...] I read up all about it. I thought well, 'how does it work?' I mean it can't make sense that you just inject the same every time, because I have noticed, pretty much the day I got home, I thought 'hang on a minute, why do I have low blood sugar today, and not the following day'. So I thought, let's look at the science behind this."

In contrast, the information that the patients bring to the specialists at appointments is often knowledge or information rather than data, which is not helpful for the specialists. For instance, news articles are brought to consultants and resulting discussions take up what the consultants think is precious time better used towards discussing more relevant data. Although patients that are more comfortable with technology are

already going online for information, many are gaining information from sources that are not the most accurate or efficient, such as word of mouth or sensationalist newspaper articles. When a veteran diabetes consultant was asked about internet articles patients bring into appointments, she described a more common occurrence:

"Not so much as people saying 'I saw this in the Daily Mail' [a middle-market tabloid newspaper in the UK]. So Type 2 diabetes disproportionately affects lower socio-economic class. So, you know, our waiting room is full of lorry drivers who read the Daily Mail. And they say 'Oh yeah, what's this?' or they hear something, and I don't ask them what the source is, whether they hear it via television or radio, web or a newspaper. It's not a great use of a brief clinical encounter to figure out where they heard it. I don't care where they heard it, just that they heard it, so I'll address it."

The information that healthcare specialists do want is associated with data and other pertinent information that informs the patient's plan of care as illustrated by the dietician and podiatrist we interviewed:

"[We] send people away writing food diaries and writing their blood glucose results down and what insulin taken." (Dietician)

"The things that happened in the past often are still effecting the patient in the future. Let's say they've been anorexic or something, you know, it may get deleted from the record and you don't know, and you wonder why they're not eating properly and not wanting to see a dietician and not taking care of themselves." (Podiatrist)

However, patients do not realize this information is what specialists need to know and are, thus, wary of such access. Patient 3's (Type I, 36 years old) opinion directly contradicts that of the podiatrist interviewed:

"They had got information that had nothing to do with anything really and I felt that that was inappropriate and too personal. Yeah, you know the podiatrist again, just qualified, knows nothing about me, doesn't know anything but I've got corns, why should they know [...] that my diabetes was out of control when I was 18? [...] It's got to be relevant, surely."

Conclusion

The opportunities and challenges for bridging the two settings are based on the disconnect between information needs and wants between the patients and the specialists. The patients want to give the specialists information that is important to themselves and specialists want to do the same when sharing with patients, causing tensions and inefficiencies in the shared responsibility of a patient's illness trajectory.

There is a clear interest in sharing information between both groups of stakeholders. They want to bridge this gap and view electronic records as the means to do that. Health specialists want their patients to record more data and share that with them, and patients want to be able to see and monitor the data the health practitioners collect to gain understanding about their condition, which are direct implications for the design of both EMR and PHR systems. From our interviews, the 'expert patient' can exist when this shared information exchange is supported to create knowledge, because as per Rowley: "Typically information is defined in terms

of data, knowledge in terms of information, and wisdom in terms of knowledge" [11].

The level of engagement with one's health and the information associated with it varies greatly, along with the abilities of the patients to effectively use and understand this information for their own self-care. The act of deciphering the reams of data available can be overwhelming for patients, which is apparent in their need to search for other sources to 'understand' their condition. Thus, it is more than simply sharing the information, but wrapping it up into knowledge that is the hefty challenge for EMR and PHR system designers. In addition, patients need to understand what their health practitioners need to know in order to create and monitor the best plan of care. As patients better understand what the specialists need to know, i.e. numerical data and facts regarding the patient's health and care, the more likely they will be able to collect and share this data with their specialist.

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