
eHealth Systems Across Boundaries

Peggy Gregory

School of Computing, Engineering
and Physical Sciences
University of Central Lancashire
Preston, Lancashire, PR1 2HE UK
ajgregory@uclan.ac.uk

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Abstract

In this position paper I discuss findings from a recent qualitative study into a diabetes eHealth system that facilitated communication and data sharing between patients and clinicians. Findings indicate that the experience of chronic illness impacts on patients' use of such systems. This work shows the importance of understanding how eHealth technologies linking clinical and non-clinical environments cross and transform boundaries between patients and practitioners. Future challenges in the field are to design eHealth systems that take account of patients' illness experiences as well as best healthcare practices, and that can be meaningful across social worlds.

Author Keywords

Patient-centered information systems; Usability;
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ACM Classification Keywords

J.3 Life and Medical Sciences: medical information systems

Introduction

Digital technology has been introduced into every aspect of healthcare, from complex embedded systems to electronic patient record systems [1, 2]. Many new health technologies are work-based systems designed to be used by clinicians and administrators. However,

there are also a growing number of home-based systems designed for patients, and patients are increasingly using the Internet as a source of health information [3]. Another new area is technology that can be used by healthcare practitioners and patients. Such systems shift the boundaries of health communication.

Diabetes eHealth study

The author has undertaken a longitudinal, qualitative study investigating patient and practitioner experiences of using a diabetes eHealth system [4]. A system was designed and built to facilitate communication between patients and practitioners that was used at home by patients and at the clinic by primary care health practitioners. The aim of the study was to investigate participants' experiences of using the system, but much of the focus was on patient experiences.

The system designed and built for the study provided patients with facilities to upload and view their blood glucose readings, set targets, read news and information about diabetes, use a diet and exercise email intervention, communicate with practitioners through a messaging service, and post to a discussion board (accessible to all patients and practitioners taking part in the study). Health practitioners were provided with facilities to check patients' blood glucose readings, send messages to individual patients and post to the discussion board.

The study took place in a general practice in Northern England. Thirty-eight patients were recruited to use the system for six months each, and four primary healthcare practitioners used the system throughout the study period. Qualitative data was collected through

semi-structured interviews. Each patient was interviewed three times, and each practitioner twice during the study period. Data was analyzed using a grounded theory approach [5]. Interviews were coded, subcategories and categories formed, and a conceptual framework was developed. From this analysis, emerging themes and attributes of the system were identified.

Emerging themes

Several interesting findings came from the study.

Patient experiences

The study found that patients experienced the system as part of their diabetes management process. The chronic and varied nature of a patients' personal diabetes experience was found to greatly influence how they used the system. The system enhanced two aspects of patients' health experiences: self-management and support-seeking. Patients' engagement with the system varied according to their health history, health experiences and expectations. As a consequence there were considerable individual variations in the way patients used the system. Radical changes in health behaviors were not reported, but those who became engaged with using the system reported changed behaviors and attitudes. Benefits reported were: changes in health approach, better focus on diabetes, improvements to health management and learning. However, patients who felt overwhelmed by health or other problems were less likely to use the system or gain benefits from it. Practitioners' views of the system were that it provided a way for patients to learn about self-management and that it was more useful as a self-learning tool than as a care tool. These findings are important as they indicate

that the nature of health problems impacts on the way participants access eHealth systems.

Boundary structure

A key feature of the system investigated was that it crossed the boundary between the personal sphere of diabetes self-management and the external sphere of diabetes support-seeking, by co-locating both spheres. It also crossed the boundaries between different environments: the home, the clinic, and the diabetes support group.

By crossing the boundary between different spheres the health system shares similarities with the concept of a boundary object [6, 7]. Star and Griesemer use the concept to explain how heterogeneity and cooperation is achieved when managing objects from different social worlds. The three distinct user groups in this study - patients with diabetes, GP's, and nurses - all inhabit different social worlds. When users communicate through the system they approach it intellectually, emotionally, and experientially with different understandings of diabetes. However, in order to communicate effectively through the system users need to create alliances through shared understandings. This was found to be particularly important on the discussion board because of the lack of contextual cues about other participants. During the study some incidents were observed in which misunderstanding and misinterpretations led to participants questioning the usefulness of the system. System design needs to take into account ways in which participant alliances can be effectively built without compromising user security.

Patient responses

Patients expressed a range of views about the system. These provide insights into how they envisaged the system at different stages of the study and how they interacted with it. It was viewed variously as a tool for helping to manage specific problems, a general background support tool, a help with focus, a help with motivation, a communication tool, a self-management tool, an information tool, and a tool for the doctor.

Patients talked about responses they had to the system while they were using it. These included feeling watched, being comforted, not feeling alone, not knowing the identity of others, being aware of using an impersonal and automated system. However responses were not uniform and conflicts were noted. For instance, some participants reported that being watched motivated them, whereas others found it off-putting, and others were unaware of it.

System qualities

As participants engaged with the system, conflicts emerged between being observed and being ignored; being trusting and being untrusting; being visible and being invisible; being private and being public. These conflicts exemplified system qualities such as surveillance, trustworthiness, visibility and anonymity, but they also reflect participants' experiences of living with a chronic illness.

Findings from this study indicate that the eHealth system changes the communication that occurs between patients and clinicians in ways that challenge both parties. This is partly because the system introduces factors that do not exist in face-to-face communication – such as the possibilities of

anonymous contributions, covert surveillance and asynchronous messaging. However, the study also found that the personal nature of illness, the problems of dealing with chronic illness and the internal narrative that patients engaged in while managing their health, also affected the way they used the system.

Future challenges

Participants' responses to the system suggest that a 'one size fits all' approach is not appropriate. Design challenges include ascertaining how to engage patients who have different health experiences and hence different expectations. In order to support those with chronic disease, concepts such as the illness trajectory may provide insights that aid better design [8].

One of the core facilities in the system developed for this study was the sharing of blood glucose readings. This was not found to be beneficial for all participants. Future studies should investigate other models for data sharing, particularly looking at the needs of different groups of patients. For instance, while some patients find ongoing data sharing useful, others may only need to share data occasionally when they have a specific problem. Additionally, areas for further investigation are the impact and experience of health surveillance.

Evidence from this study indicates that participants often felt alone with diabetes and wanted to share their experiences with others and to communicate with health practitioners in safe, trusted environments. Further studies of discussion boards, chat rooms, virtual support groups and systems for communicating electronically with health-care practitioners are worth pursuing. Aspects of such systems that need investigating are anonymity, trust, virtual presence,

and the impact of communicating between home and clinical environments.

Finally, novel technologies such as ambient and tangible systems may offer alternative ways of supporting the health needs of those with chronic disease. These technologies may provide the subtle, focused support identified by some users in this study.

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