

Patients' experience with a diabetes support programme based on an interactive electronic medical record: qualitative study

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Abstract

Objective To describe the experiences of patients with type 2 diabetes in a web based disease management programme based on an interactive electronic medical record.

Design Qualitative analysis of semistructured interviews with patients enrolled in a diabetes care module that included access to their electronic medical record, secure email, ability to upload blood glucose readings, an education site with endorsed content, and an interactive online diary for entering exercise, diet, and medication.

Setting Patients' homes in Washington state, United States.

Participants Nine participants aged 45-65 completed interviews before and after they used the programme.

Results Six themes emerged: feeling that non-acute concerns are uniquely valued; enhanced sense of security about health and health care; frustration with unmet expectations; feeling more able to manage; valuing feedback; and difficulty fitting the programme into activities of daily life. Three themes—valuing non-acute concerns, feeling secure, and unmet expectations—have particular relevance to the design and use of web based tools for care of patients with diabetes and chronic medical conditions.

Conclusion Participants' experiences support further study of open access to the electronic medical record and online communication between patients and their care providers. The development of web based disease management programmes should take into account the specific needs and expectations of patients, and patients and providers should have candid discussions about what web based care can and cannot provide.

Introduction

Chronic medical conditions are a growing public health challenge. The focus on the clinic visit in current healthcare systems does not meet the needs of many patients with these conditions. A recent report from the Institute of Medicine suggested redesigning health care towards more continuous relationships between patients and providers.¹ Chronic disease management programmes that use web based communication offer an opportunity to shift the focus in health care away from the office and towards patients' daily lives at home, but little is known about the impact of using the web in the clinical care of patients with chronic disease. This new care environment may have unanticipated consequences on patients and their healthcare relationships.

We designed a web based diabetes support programme for patients based on Wagner's chronic care model.² Our programme consisted of access from home to the electronic

medical record, secure electronic communications between patients and providers, and interactive disease management tools. To better understand patients' experiences with the programme, we carried out a qualitative study examining patients' hopes and experiences with the pilot of the programme.

Participants and methods

The living with diabetes programme is a web based disease management module to support the care of patients with type 2 diabetes. A complete description of the module is given elsewhere.³ The programme targets four key domains in Wagner's chronic disease model: self management support for patients; delivery system design; clinical information systems; and clinical decision support (box). The web module itself consists of five web pages within a single secure website that allows patients and providers to communicate over the internet (see bmj.com).

The living with diabetes pilot study was run out of a general internal medicine clinic affiliated with the University of Washington; eight general internists were the primary care providers for the participants. All patients lived in the state of Washington, at distances ranging from 5 km to 480 km (3-291 miles) from the clinic. The study used a case manager model of chronic disease care.⁴ The case manager (a nurse practitioner) encouraged all patients to review their online medical record, upload blood glucose readings weekly, and send secure electronic mail as needed. For each patient in the study, providers responded to patients' messages Monday through Friday and reviewed uploaded blood glucose levels at least once a week.

Most components of the module were available to participants throughout the study period. However, two components of the module were delayed. The ability to graphically view blood glucose levels at home was not available until month 4 and the "my diabetes daily diary" did not become fully functional until month 6 of the pilot.

Using convenience sampling, we approached 35 patients at the general internal medicine clinic. Fifteen of those approached agreed to participate in the feasibility trial. For the qualitative study, we used purposive sampling to identify a subpopulation of 10 patients from the 15 originally recruited. In selecting these 10 patients we sought to ensure a range of patient characteristics including age, sex, years with diabetes, and distance from the clinic.⁵ One patient subsequently dropped out of the programme



Screen shots of the web links module are on bmj.com

and could not be reached for follow up after the first interview. The remaining nine patients (six men) made up the study sample. Participants were aged 43–65 (median 58) years and had had type 2 diabetes for one to 14 (median four) years. Eight were married or had partners, one was single; two had high school education, one college education, and four graduate school education; eight were white and one was African-American. Patients' degree of interaction with the programme varied. Some patients used it only a few times through the entire six month study period; others used it several times a week.

We interviewed the nine participants twice between October 2001 and December 2002—before and six months after enrolment in the programme. Interviews were semistructured and in-depth, and were carried out in patients' homes. In the first interview, the interviewer (JDR) asked participants about their interest in participating in the programme. Follow up questions explored and clarified the content of the programme and asked about the anticipated impact of the programme on participants' experience with diabetes and their relationship with their providers. Six months after the start of the programme,

participants were interviewed a second time (by JDR). In the second interview, participants were first asked to describe their experiences with the programme. Follow up questions explored and clarified the content of participants' responses. Participants were also asked about their perception of any impact the programme had had on their life with diabetes and their relationship with their primary care provider. Interviews ranged from 60 to 80 minutes. All interviews were audio taped, transcribed verbatim, and manually edited by the interviewer while listening to the tape of the interview.

Transcripts from the two interviews were independently read and analysed for common themes by two investigators (JDR, DR) in an approach informed by phenomenology.^{6–9} One coder was a physician and the other a psychologist. These authors met repeatedly to discuss themes and resolve discrepancies in thematic definitions. If new codes emerged, the codebook was modified and transcripts reread and recoded according to the clarified definitions. Micro codes were consolidated into major themes representing patients' experience. In a third round of interviews with six of the nine participants, these themes were reviewed and further clarified. These six participants were selected during the first two interviews for their ability to describe their lives with diabetes and their interactions with the module. We used QSR-NUD*IST qualitative data analysis software to manually record and compare coding of transcripts.

In our analysis, we sought to represent participants' actual experience of the programme by closely analysing their narrative descriptions of their hopes and interactions with the project. Rather than approach the narrative data with preconceived notions about what it might contain, we allowed themes to emerge from the data themselves.

Results

Six themes emerged from the data: feeling that non-acute concerns are uniquely valued; an enhanced sense of security about health and health care; frustration with unmet expectations; feeling more able to manage; valuing feedback; and difficulty fitting the programme into activities of daily life. We limit further discussion of results to three themes, which we believe represent important, unanticipated impacts of our programme.

Valuing non-acute concerns

In contrast to traditional processes of care, our programme provided an environment where patients' concerns about their chronic medical conditions were uniquely valued. In the first interview, participants highlighted how care through office visits and over the phone devalued many of their needs for managing their diabetes and other chronic medical conditions. Patients limited the care they sought from providers according to how sick they felt or how acute they perceived their need. After the start of the programme, participants expressed how much they appreciated an environment where their needs for managing their ongoing medical conditions were valued. A key element was patients' knowledge that providers could answer their email and other electronic communications at a time that providers found most convenient. A patient newly diagnosed as having diabetes reflected on how the programme relieved his frustration with getting the care he needed:

I know how busy they [providers] are and to get through to my doctor is sometimes really difficult. You call and they say, "Well, we can take a message and we'll get it to them," and then I say, "Well, could I talk to the nurse?" So this [living with diabetes programme] has just totally relieved that and I've felt good, because I don't want to just be calling

Design of the living with diabetes management programme (domains and interventions)

Self management support

- Promoted patient review of the electronic medical record at home over the web through My Health Record, a real-time view of the same record and interface used by providers and containing all clinical data since January 1994²²
- Provided remote collaboration and interactive feedback on automatically uploaded blood glucose readings over the internet through My Upload Meter
- Provided remote collaboration and interactive feedback on nutrition, medications, and exercise using a web based self management tool, My Diabetes Daily Diary
- Promoted and integrated secure email into ongoing care with diabetes case manager
- Provided general diabetes educational website with links to information endorsed by the medical director of the University of Washington Diabetes Care Center

Delivery system design

- Used case manager model²³
- Provided initial weekly follow up over the web for blood glucose levels and other self management needs
- Provided subsequent proactive follow up based on patient needs
- Promoted and integrated secure email exchanges into ongoing care
- Promoted and integrated patients' blood glucose and lifestyle information into ongoing care

Clinical information systems

- Provided ongoing tracking and documentation of patients' evidence based needs and care
- Used secure email integrated as part of the record

Decision support

- Used an interactive electronic medical record for collaborative decision support shared by both patient and provider:
 - Clinical reminders visible to both patient and provider
 - Single page summary of patient's clinical information relevant to diabetes
- Established provider decision support through patients' remote transmission of blood glucose readings, daily diary inputs, and secure email exchanges

the provider all the time about these details. I think with anybody that has a continuing sort of a terminal problem, the computer can really be a great help. (Patient 1)

Participants valued seeing the results of their medical testing online. In interviews before and after the intervention, participants emphasised the importance of laboratory tests helping them understand and track their health status. Seeing these results in the live record at home filled a need not previously met by the usual methods of reporting results. A participant described his experience before and after the start of the programme:

When I get them [results] handwritten or otherwise, I get a number, which before meant absolutely nothing to me. I didn't know what good cholesterol was and bad cholesterol and what the numbers were supposed to be. Just getting a lab report with a number meant really nothing to me. I didn't know whether I was well, or sick, or what. When I get my labs now [online], though, there'll be a little star if it's out of that range, so I'm aware of what needs to be medicated or worked [on]. (Patient 2)

Feeling secure

In the first interview, many participants were anxious about their health status and their distance from their provider. The second interview revealed that as patients uploaded and interacted with the information on their blood glucose levels and the lifestyle information in the module, they felt their provider was benevolently watching them. A 64 year old woman who used the programme to enhance her glycaemic control over the course of the study explained her feelings about the "virtual presence" of the nurse practitioner and her blood glucose levels this way:

If she [the nurse practitioner] saw the [blood glucose] numbers go crazy on the programme, she would email me and say, "What's going on?" That's the guardian angel, that's worth everything—you can't put a price on that. Because if you're alone, if you're going through what I'm going through now [managing my diabetes], having someone there, I would call that the guardian angel, someone who looks at the whole picture. (Patient 3)

Participants also felt safer having real-time access to their personal health information. Timely feedback on medical testing was especially important in dealing with worries, as described by a 61 year old participant:

I feel much safer now than I did before ... If I had to pick one thing out of how this [programme] has affected my life and my everyday living, [it's] the fact that I'm not chronically worrying about everything. If I didn't have any access to knowing what's going on with my health, I think I'd probably go back on ulcer medicine ... If I suddenly didn't have all this, I would probably be just a raving hypochondriac. (Patient 4)

Feelings of security associated with the programme were particularly apparent when patients considered the possibility that it might be stopped. A patient newly diagnosed as having diabetes who over the previous eight months had exclusively used the living with diabetes programme for his care expressed concern about the end of the programme this way:

That's started to concern me a little bit, because of the help I've received. But maybe I'm educated enough now—I've received enough of a challenge. You know, eventually you take the baby bottle away from a baby. And I have felt so comfortable with [the nurse practitioner] being right there. But supposing things start going wrong again, I would feel good to have the programme there. So I have a little bit of a concern if this [programme] is terminated. (Patient 1)

Disappointment from unmet expectations

Although most hopes for the programme were fulfilled, a few participants sometimes had remarkably frustrating experiences when the programme did not work as they expected. These

experiences stood in surprising contrast to participants' positive experiences described earlier. Patients attributed their frustrations to both technical failures and to unmet expectations for online communication with the nurse practitioner. Regardless of the identified source of disappointment, these experiences often left participants feeling disillusioned and cut off from health care. For example, one participant was concerned about a recent rise in her evening blood glucose levels, which she was unable to explain or control adequately. After uploading her blood glucose levels into the module, she hoped for some feedback about how to approach this change. For unclear reasons, she failed to get a response. She describes her disappointment:

Somebody should have been looking at them [the blood glucose levels], and if they were looking at them, I would have thought that they might have at least let me know that they were looking at them and that they understood what was going on. Maybe they looked at the record, I don't know, but they never let me know that they had done anything about it. I mean it was like sending it off into a void, into a black hole, and never hearing anything back. (Patient 5)

Participants with frustrating experiences also had positive experiences, but their frustrating or disappointing experiences had a negative impact on several of the more positive themes. If expectations for the programme were not met, participants felt their concerns were less valued rather than more valued, and they felt more isolated from their health care, rather than more connected. A patient explained his frustrations with being unable to get his computer to connect to the module:

There is a lot more to learn now that I can do it [the living with diabetes programme] again, now that I can communicate again. I kind of felt isolated. (Patient 4)

Discussion

Three themes emerged as important to the design and evaluation of web based care programmes. Firstly, the living with diabetes programme provided a unique environment where participants' chronic concerns were actively valued. Previous work has documented how our systems of care are poorly designed to meet the needs of patients with chronic illness.²⁻¹⁰ Our findings show that web based programmes such as ours may be particularly successful at dealing with those needs. Secondly, patients experienced an enhanced sense of security about their health and health care. This improved sense of security may promote healthy behaviours and better quality of life in patients with diabetes.¹¹ Finally, participants were profoundly disappointed when their expectations for the technology and communications of the programme were not met. Studies have shown that meeting patients' expectations is important not only for patient satisfaction but also for achieving better resolution of symptoms and reducing further use of healthcare resources.¹² Conversations with patients about their expectations for care can be challenging for doctors during office visits¹³; our study shows that it may be even more difficult to understand and address these expectations in web based health care.

The living with diabetes programme provided participants with a connection to providers and healthcare information that was different from their usual healthcare experience. Instead of episodic connections with providers at office visits, a provider was a continuous presence that watched benevolently from a distance as participants engaged in the daily activities of managing their diabetes. Having access to the electronic medical record, and particularly the results of medical testing, was also important to patients. This is consistent with several studies that have shown

What is already known on this topic

Web based programmes for management of chronic diseases can shift the focus in health care away from the office and towards patients' daily lives at home

Little is known about the impact of using the web in the clinical care of patients with chronic disease

What this study adds

Web based disease programmes can fill an important gap in how health care is currently provided for patients with chronic medical conditions

Programmes that include online communications and open access to the electronic medical record warrant further study in larger trials

Before and during the use of web based chronic care, patients and providers should discuss what the programme can and cannot deliver

the value of promoting patient review of the medical record as part of effective interventions in chronic disease management.¹⁴⁻²⁰

Patients' experience with the living with diabetes programme supports further study of web based programmes that are tightly integrated into patients' overall clinical care. A recent trial looking at web based support for self management of diabetes, separate from patients' usual care, showed that patients benefited from basic web services including general information, automated dietary goal setting, and periodic online assessments. In that trial, adding tailored self management did not show any benefit. Our results are consistent with the authors' conclusions, that benefit from tailored self management in web based diabetes care may require programmes that have stronger links to patients' existing clinical care.²¹

Limitations

Our study has a few limitations. Firstly, it is a pilot study in an academic medical centre; a community setting might have provided different findings. Because the interviewer was a doctor, patients may have responded differently than they would to a non-medical interviewer. Lastly, patients who either declined to participate or who were not approached about participating might have had different experiences with the programme than those who participated.

Conclusion and implications

Web based chronic care programmes have unique potential to shift care processes towards more continuous collaborative relationships between patients and providers. Our work supports further study of web based diabetes programmes that include online communications and open access to the electronic medical record. Our study also contributes to thinking about how to design future programmes. In particular, our themes highlight the importance of accounting for individual patients' needs. Before and during the use of web based chronic care, patients and providers should have candid discussions about what the programme can and cannot deliver.

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