Patient Centeredness

Using an Internet Comanagement Module to Improve the Quality of Chronic Disease Care

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Diabetes mellitus is the second most prevalent chronic medical condition in adult primary care practice. Randomized controlled trials have shown that intensive therapy aimed at nearly normalizing blood glucose levels—with "normal" defined as a glycohemoglobin (HbA1c) level between 4.0% and 6.0%—can decrease the development and progression of microvascular complications such as blindness and kidney failure. Improvements of 1.0% have been associated with 25%–30% declines in end-organ damage.[1,2] Unfortunately, the majority of patients with diabetes in the United States are not adequately treated. One recent survey concluded that only 44% of patients met the optimal target HbA1c of < 7.0%.[3]

Quality improvement efforts in diabetes have largely focused on enhancing the content of care during office visits. Two recent trials of traditional outreach, however, did demonstrate lowered HbA1c outcomes on average in intervention versus control patients. In one of these trials, which was conducted at our own "firm" (group practice), patients inadequately treated or lost to follow-up were called by a clinical pharmacist and encouraged to make appointments.[4–6] Marked improvement over time, however, was limited to patients with the poorest glycemic control at baseline (HbA1c > 8.0%). This may be due in part to the fact that only the sickest patients with diabetes are able to command either provider attention or time for office visits. Thus, it may be time to consider changes in how health care systems deliver chronic disease services.

Article-at-a-Glance

Background: Web-based applications have the potential to support the ongoing care needs of patients with chronic disease. At the University of Washington, a diabetes care module was developed, and the feasibility of allowing patients with type 2 diabetes to comanage their disease from home was pilot tested.

Methods: The disease management module consisted of five Web sites that enabled patients to access their electronic medical records; upload blood glucose readings; enter medication, nutrition, and exercise data into an online diary; communicate with providers by using clinical e-mail; and browse an education site with endorsed content. All data could be viewed by patients and providers in online trended displays that a nurse practitioner case manager used to review cases weekly.

Results: "Proof-of-concept" was demonstrated by the three pilot participants who were the module's most active users. For example, one newly diagnosed patient was started on an oral hypoglycemic, underwent two upward dose adjustments, and achieved control (glycohemoglobin [HbA1c] from 8.0% to 6.1%). His treatment was conducted by exchanging 14 e-mails based on the 231 glucose-meter readings sent from home without requiring in-person follow-up visits.

Conclusions: The Internet offers the opportunity to involve patients and providers in collaborative management of chronic diseases between office visits.

The MyUW (University of Washington) Portal

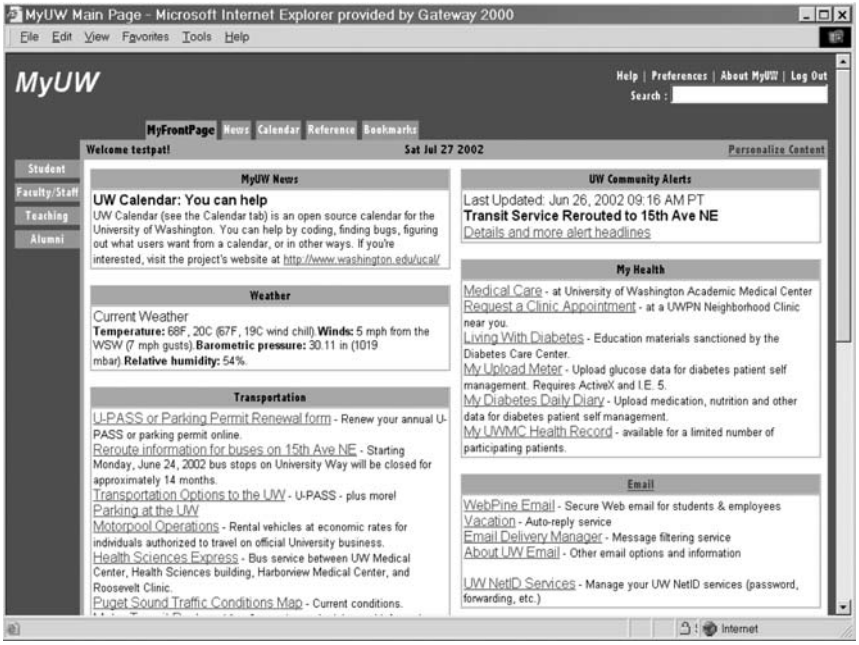

Figure 1. *University of Washington's MyUW portal for the test patient (testpat), including the My Health and Email channels, is shown.*

In this regard, the Institute of Medicine's report *Crossing the Quality Chasm* recommended a shift from care based primarily on office visits toward care based on continuous healing relationships.[7] Wagner et al.'s chronic care model has further highlighted the importance of moving away from the current focus on short and infrequent clinic encounters and toward involving patients in the comanagement of their illness between visits.[8] Yet the amount and differing types of information required for true ongoing collaborative management are not easily exchanged over the telephone or via fax. Moreover, the pressure of both patient and provider work schedules makes routine synchronous communication a scheduling nightmare.

The University of Washington (UW) had developed the first Internet electronic medical record, MINDscape, in 1995 and moved quickly to make it available to its providers and referring physicians over a five-state region.[9,10] Like most other clinical computing systems, MINDscape was originally designed to improve providers' ability to deliver office-based care. Accordingly, we—a team of investigators—undertook the development of a compatible Web-based diabetes care module to specifically test the feasibility of allowing patients with type 2 diabetes to comanage their disease from home, and we recently completed a six-month trial alpha test at UW's General Internal Medicine Clinic. Ten Internet-experienced patients (age range, 43–65 years) with type 2 diabetes (often triggered by excessive weight gain) participated.

This article discusses the diabetes comanagement module's components and the experience of the three patients who were its most active users. A randomized controlled trial to definitively assess the module's effects on utilization, clinical outcomes, and patient satisfaction is currently under way. Yet because these pilot cases illustrate how the Internet could be used to overcome common barriers in achieving adequate glycemic control, we felt these early apparent successes constituted a "proof-of-concept" worth reporting. Our experience also helped to clarify some of the challenges facing developers of Web-based disease management tools.

The Module's Web Sites

The module consists of five Web sites—available via links displayed within the University's MyUW portal (Figure 1, above)—that enable patients and providers to interact asynchronously over the Internet.

My Health Record

The My Health Record site provides a view of each patient's Web-based electronic medical record (MINDscape), the same record used by providers. All clinical data from January 1994 to present are available. Lab test results, transcribed notes, and so on can be accessed via individual tabs or alternatively via a summary page of diabetes care, the Chronic Illness Profile (ChIP) tab (Figure 2, page 445). Real-time prompts of the

need to obtain preventive services such as HbA1c determinations and retinal examinations can be viewed by clicking on the Reminders tab (Figure 3, below).

My Upload Meter

Patients can upload readings from digital glucose meters via serial cable connections to communications ports on their personal computers. Frequency of upload is individually determined with the case manager. The meters were donated by their manufacturer for distribution to patients who did not already own digital meters.

My Diabetes Daily Diary

In addition to uploading glucose readings, patients can manually enter information about their nutritional intake, use of insulin and oral hypoglycemic medications, and exercise levels. Patients can view simple trends of all data sent from home on the site's Chart tab (Figure 4, page 446). More sophisticated analyses (for example, calculations of blood glucose means and standard deviations) are available to providers within the CliniPro application developed by our industry partner. This is a non-Web-based diabetes-specific medical record that is currently used alongside MINDscape via terminal-server technology at the Diabetes Care Center, UW's specialty clinic for diabetes care. It was additionally licensed for use by the case manager during the trial.

The Problem List

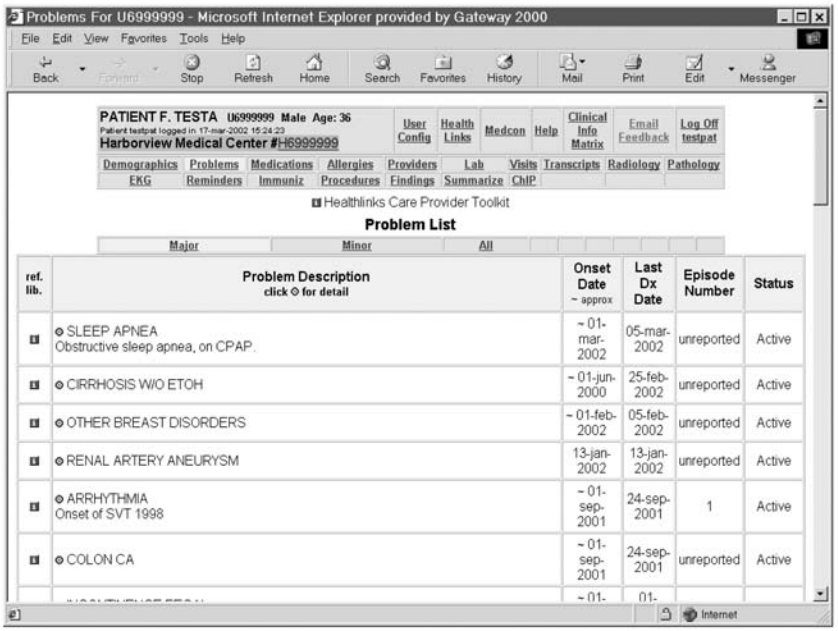

Figure 2. *The Problem List is the default first page of MINDscape. The tabs for accessing individual categories of data (for example, medications) are shown.*

The Reminders Tab

Figure 3. *This figure shows the reminders to receive diabetes-related and general age- and sex-specific preventive services.*

Trended Display of Data

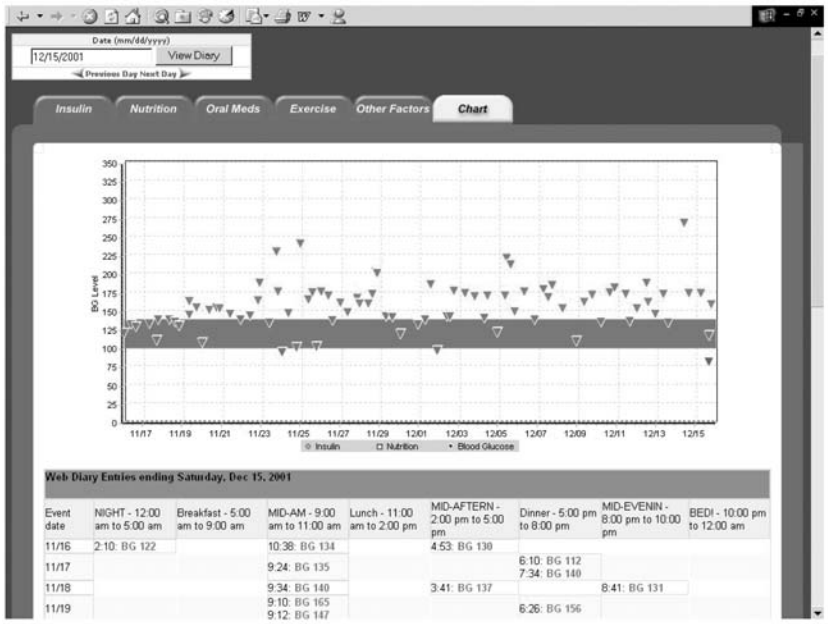

Figure 4. *This figure shows an example of a trended display of blood glucose readings sent from home over the Web which is available to patients by clicking on the Chart tab.*

Living with Diabetes

Materials and links to knowledge resources for diabetes care have been collected and are available on the Living with Diabetes patient education site (Figure 5, right). Unlike information generally available on the Web, however, all content can be recommended to patients as having been endorsed by the Diabetes Care Center's medical director. The site is transactional; for example, reference books cited can be ordered via a link to the university's bookstore. Natural language processing techniques are employed to answer queries about diabetes via an "Ask a Question" link.

Clinical E-mail

Patients are also given access to a clinical e-mail service, UW's WebPine application. Information is exchanged within a closed system—it does not travel over the Internet and is not retained on other media once it has been deleted.

Users are given an official UW NetID with which to access the portal, whose authentication and security infrastructure recognizes each user's status (as faculty, student, staff, or patient) and presents a customizable view from among more than 80 channels of linked information. Channel content includes weather information, ferry and bus transportation schedules, and local and national news. Links to confidential clinical information automatically require entry of the additional personal identification

The Living with Diabetes Patient Education Site

Figure 5. *All information and links on the Living with Diabetes patient education site were approved by the medical director of the University of Washington's Diabetes Care Center.*

Time-of-Day Plotted Blood Glucose Data for Mr. C.

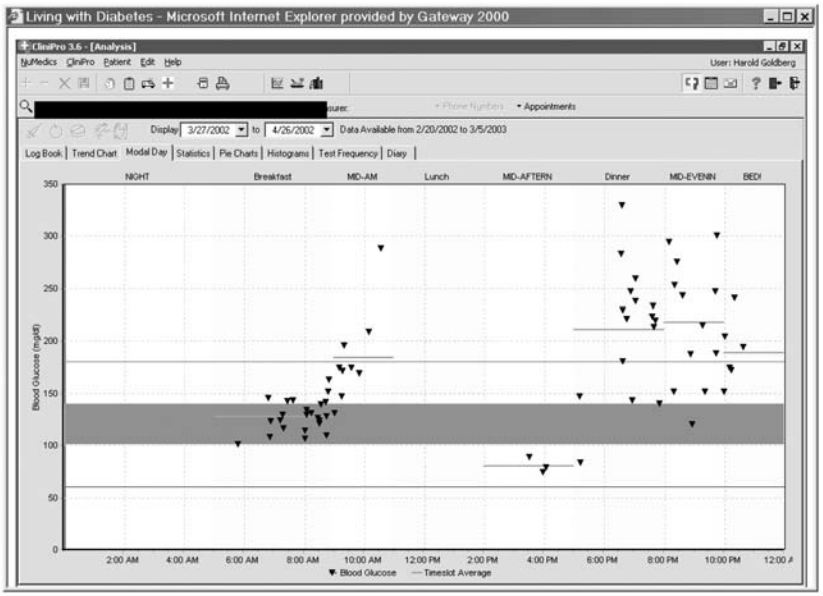

Figure 6. *Mr. C.'s pattern of normal morning but elevated postprandial blood glucose was unmasked when multiple daily readings sent from home were plotted by time of day.*

number located on a provided secure identification token. A new number appears each minute, preventing the unauthorized use of stolen or loaned static passwords.

A case management model involving the General Internal Medicine Clinic's nurse practitioner (NP) was adopted because its busy physician corps was reluctant to take on the time and costs involved in responding to patient-generated e-mails and data. Patients were introduced to the project at either a clinic visit or an in-home training session that lasted less than an hour. The NP case manager reviewed all data and e-mail sent from home at least weekly to ensure timely progress toward agreed-on treatment goals. She conferred with each patient's primary care physician (PCP) as indicated.

Case Studies

Motivating Patients by Building Relationships via Frequent Interaction

Mr. C. is a 72-year-old retired missionary who lives 20 miles north of his primary care clinic in Seattle. Mr. C. saw his PCP only twice in the year following the diagnosis of diabetes. He was told that his blood sugar levels were not high enough to warrant drug therapy and was advised to lose weight. This recommendation was based on once-daily, morning blood glucose readings that were noted to be near normal, in the low 100s. He was enrolled in the pilot study in March 2002 because his HbA1c level had remained at 8%, despite a year-long course of "lifestyle management." At the time of enrollment, he had one office visit with his NP case manager, where they developed a shared plan for frequent follow-up of blood glucose levels using the Web-based module.

Encouraged by the frequency of e-mailed feedback about his glycemic control, Mr. C. began obtaining multiple glucose readings during the day. When uploaded for analysis, these data unmasked the occurrence of postprandial (after-dinner) hyperglycemia, with blood glucose readings averaging above 200 (Figure 6, left). This remote contact with Mr. C. prompted his NP to start him on an oral hypoglycemic (glyburide). On the basis of 14 e-mail exchanges and 231 glucose readings sent from home during the subsequent four months (Figure 7, page 448), he additionally underwent two upward dose adjustments without requiring follow-up visits other than returning for a lab draw in May.

As indicated by the observed decline in HbA1c level from 8.0% to 6.1% (Table 1, page 448), near-normal control was achieved. Mr. C. stated in a posttest interview that the project "challenged" him to care for his diabetes by giving him a sense of connection with his NP and with his own health information. He also commented that the module accorded him

> That feeling of someone's there and is listening. I haven't had to go through trying to get to the doctor, go through the traffic, park, and all of that. Now, I know that is important too, that you see a person face to face, but I have felt that real confidence. I really feel like I know [my NP] Diane and I know she cares for me.

Four-Month Blood Glucose Data for Mr. C.

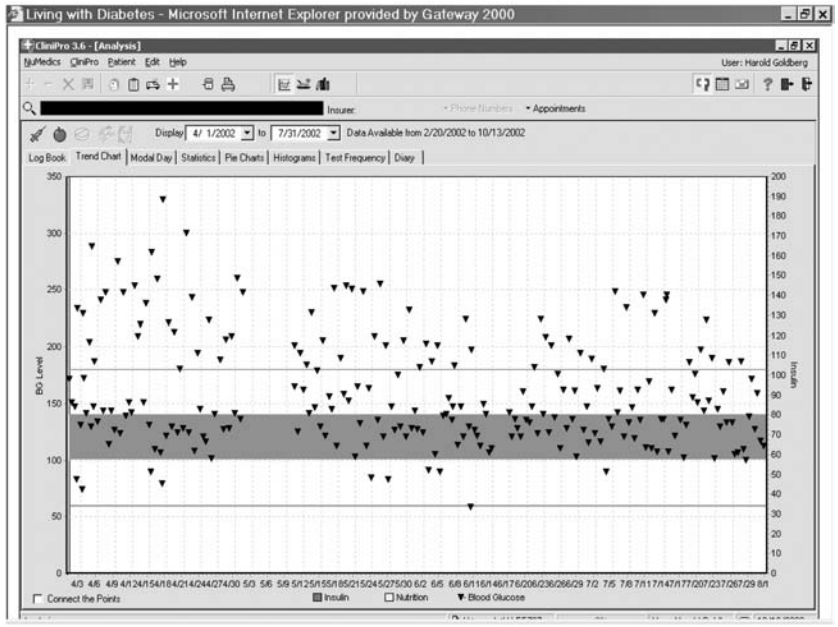

Figure 7. *Mr. C.'s blood glucose showed a downward trend for four months, including a one-week vacation, from the time that oral hypoglyemic therapy was begun over the Internet.*

Improving Patient Morale by Reporting Results Quickly

Mr. B. is retired and lives on one of the islands in Puget Sound. Because he does not drive a car, he must wait outside his house for the local shuttle to the ferry dock, take the ferry to the mainland, and then take two buses to get to his doctor appointment. Depending on traffic, this can take four hours or sometimes a whole day. "If it's pouring rain when I first go outside to wait," he confided, "sometimes I'll just go back into the house and forget the whole thing." Mr. B. had worked hard to control his diabetes with a combination of oral drugs and insulin injections. His PCP had recommended that he consider switching to a simpler regimen of higher doses of insulin, but Mr. B. was reluctant to do so until side effects, thought secondary to his oral hypoglycemics, forced the issue. During the next several months his glycemic control worsened. This prompted a series of frequent treatment changes, including the use of multiple insulins and even the reinstatement of an oral agent. It was at this point that he was enrolled in what his PCP called the "diabetes long-distance care program."

Mr. B. was helped through this confusing period by being able to e-mail his NP with questions regarding his insulin dosages and refill requests for prescriptions that were often changing. Given the difficulty of traveling to the mainland, he was especially pleased with the comfort and convenience of being able to negotiate dosage adjustments and view lab results immediately from his living room rather than having to wait to do so at his next office visit:

> I can build things up in my mind to a point where if I am being tested for something I am really kind of worried about, I don't want to wait three weeks if I have something in my mind telling me that maybe there is something wrong. Now I get [lab results] 24 hours later and they are right there. So that certainly makes me feel better. And I think that if I got some bad news, I can make it so much worse in three weeks of worrying than I can in 24 hours. That part of it especially just really thrills me, being able to know what's going on in my health right away.

Table 1. Mr. C.'s Blood Glucose and HbA1c Statistics, March–August 2002*

	Mar.	Apr.	May	Jun.	Jul.	Aug.
Mean mg/dL		172	165	145	150	
SD		61	47	35	40	6.1
HbA1c %	8.0		7.0			

* mg/dL, milligrams/deciliter; SD, standard deviation; HbA1c, glycohemoglobin.

Graph of HbA1c Data for Mr. B.

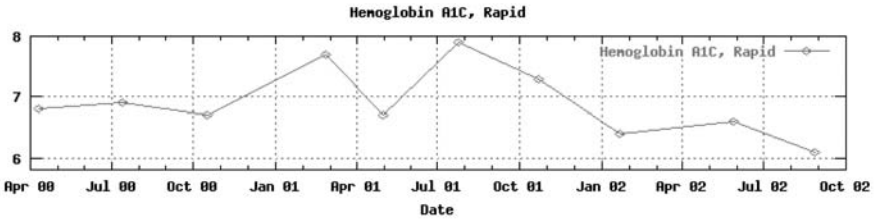

Figure 8. *This figure shows a graph of glycohemoglobin (HbA1c) results available to Mr. B. inside his MINDscape record.*

As shown in Figure 8 (above), since enrolling in the alpha test, Mr. B.'s HbA1c level, which had averaged 7.3% during the previous year, had dropped to 6.1%, the lowest value during his five-year tenure of care.

Providing the Tools to Support Self-Management

Ms. H. is a 65-year-old real estate agent in Seattle who suffers from obesity and related sleep apnea. She has been unable to lose weight in the past, in part because she shares a home with a Greek man who likes to bake baklava. By entering the serving sizes of her meals into the online daily diary, her carbohydrate counts (computed automatically) could be tracked over time (Figure 9, right). This helped her to lose 20 pounds, and her HbA1c levels decreased from 7.8% to 6.4%. She admitted in her interview

> The best I can do for myself is self-management and this [module] is the tool that helps me. It's brought me knowledge and understanding—a vehicle to learn more through. It's created a catalyst that I'll go look up things and learn about myself. I had never participated in any type of education about nutrition and blood sugar management other than I think two visits to a nutritionist when I was first diagnosed.

Ms. H. also found the reminders included in her medical record to be helpful and important "for us diabetics": "The other part of the program I think is great is 'my car repair manual.' The things I need to do that I haven't done like getting my mammogram, the eyes checked. Time can go so fast when you're busy. 'How long ago is it since you had your eyes examined?' 'Oh, three years ago.' I went and had it done yesterday. My computer's telling me that now."

Discussion

We believe that the case studies provided demonstrate the feasibility of supporting the collaborative management of chronic diseases such as diabetes over the Internet. Overall, 6 of the 10 patients were able to incorporate the module into their daily activities in a

Two-Week Blood Glucose and Carbohydrate Data for Ms. H.

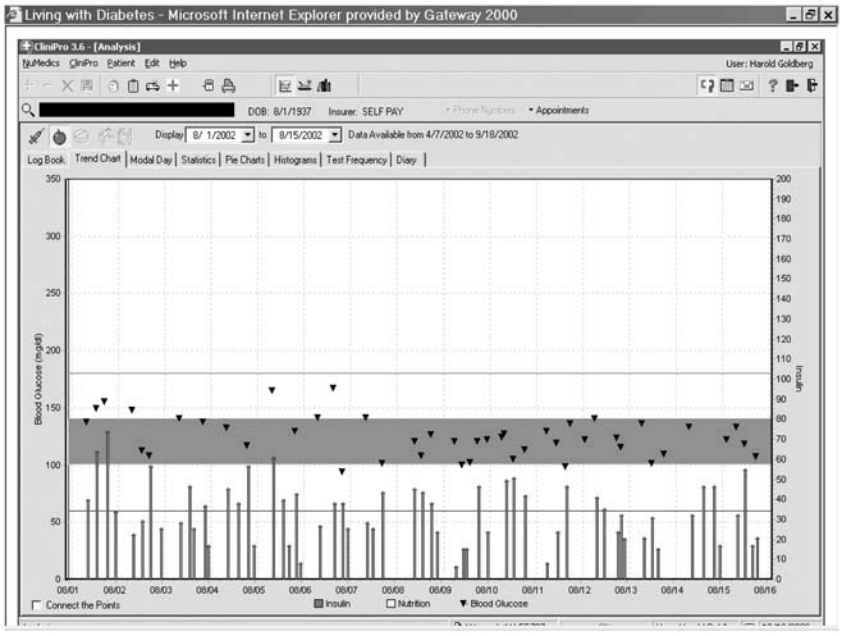

Figure 9. *Ms. H.'s blood glucose readings and carbohydrate counts trend downward in parallel for this two-week period.*

clinically meaningful way. The remainder either encountered technical problems or felt unengaged because they had already achieved adequate glycemic control. Several patients expressed the desire for improvement in the software tools provided to support self-management. We encountered no complaints related to providing patients access to their medical records.

The purpose of software pilot testing is to engender precisely this kind of feedback so it can be incorporated as development moves forward. The technical problems uncovered have been addressed. We are also currently in the process of adding a dedicated Self-Management Support Web site to the module. This second patient education site will be used by patients and providers to collaboratively generate short-term, achievable action plans that enhance self-efficacy by teaching problem-solving skills. The inclusion of such plans in patient education efforts appears to be a marker for success in improving clinical outcomes, especially among patients distracted by competing life problems not directly related to their chronic illnesses.[11] On balance, we found our early results sufficiently compelling to warrant proceeding with the randomized controlled trial under way in the General Internal Medicine Clinic. However, based on our pilot experience, this initial formal evaluation of our module is being limited to patients inadequately controlled at baseline (HbA1c > 7.0%).

The results of a controlled trial of a standalone Web site (Diabetes Network [D-Net]) intended to improve glycemic outcomes by providing tailored self-management training have been published recently.[12] In discussing the trial's negative findings, the authors acknowledged the lack of involvement of the primary care team on the site and recommended investigation of programs that create the kinds of stronger linkages to primary care inherent in the comanagement approach that we are advocating. Our ability to integrate the CliniPro application with an existing electronic medical record via standard (Health Level Seven) registration and laboratory interfaces suggests that such tight linkages can be readily achieved.

Controlled trials of comanagement Web sites will need to be conducted in several settings and among different populations of patients with diabetes. Our patients were sufficiently self-motivated to volunteer to take on the sometimes-frustrating task of working with a new, imperfect software package. The average type 2 diabetes patient, uninterested in participating in a developmental effort, might be far less motivated. Conversely, adolescent patients with type 1 diabetes may be even more interested in this type of module than most, given their greater general familiarity with computer applications and the Internet.[13] Although type 1 patients represent only 10% of all patients with diabetes, these individuals are even more susceptible than type 2 patients to its microvascular complications because of the early age of their diagnosis and the difficulty of controlling glycemia in the face of severe insulin deficiency. Disadvantaged diabetic patients with little or no computer literacy will also need to be exposed to Web-based e-health applications, lest we risk widening the existing digital divide.[14]

In addition to exploring trials among these additional diabetic patient populations, we are also exploring the conduct of trials among patients with other chronic illnesses, such as hypertension and bone marrow transplantation in the treatment of leukemia. Only through such controlled trials can the costs and benefits of new quality improvement interventions be accurately determined—an especially important consideration whenever the time and costs of widely implementing any proposed intervention are not trivial.[15,16]

Conclusions

We believe the cases reported demonstrate the feasibility of involving patients in comanaging their chronic diseases over the Web in between visits to the clinic. This is an arena where the asynchronicity offered by Internet interaction appears to offer a distinct advantage. If controlled trials confirm the promising findings of early demonstrations such as ours, perhaps insurers can be persuaded to someday cover the costs of Web-based disease management. J

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