Patient-Centered Online Disease Management Using a Personal Health Record System

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Organization: Palo Alto Medical Foundation
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Summary: Diabetes is a major, growing, and costly chronic disease in the United States; yet, implementation of recommended diabetes care is suboptimal and inconsistent for a sizable proportion of affected Americans. In an effort to reduce the treatment and adherence gaps in diabetes care, this study evaluated an online disease management system that actively supports a partnership between the patient and his or her multidisciplinary care management (CM) team. This program provided a platform for online disease management (ODM) for many different chronic conditions in a range of ambulatory care settings.

The CM team included a nurse diabetes care coordinator, a clinical pharmacist, a nutritionist, and the patient’s physician(s). The ODM system was integrated with Epic Systems’ EpicCare, a comprehensive, electronic health record (EHR) system that includes a personal health record (PHR) and secure patient-clinician messaging capabilities. Patients of the Palo Alto Medical Foundation (PAMF) have access to an integrated PHR called PAMFOonline, which is a customized version of Epic Systems’ MyChart PHR. PAMFOonline provides patients with: 1) a health summary from their EHR (diagnoses, medications, allergies, laboratory test results with physician annotations, immunizations, and a health maintenance schedule); 2) physician-endorsed information resources about health topics; 3) the ability to request a prescription renewal or appointment; 4) a list of pending appointments and laboratory orders; and 5) private notes by patients which are not visible to the clinical staff. In addition, patients can communicate electronically with their health care team.

Using a specially-designed wireless adaptor attached to their glucometer, patients uploaded their glucometer readings to their PHR. Once logged onto PAMFOonline, they viewed the information graphically and correlated their glucose trends with other information about their health behavior (e.g., diet, exercise, medication use). Utilizing the shared action plan developed specifically for each individual, the patient worked with the CM team, primarily via online communication, to adjust medications or make further lifestyle changes. Custom-tailored “nuggets” of patient education and advice were “dispensed” to a patient based on his or her specific clinical situation (e.g., responding to uploaded glucose readings, nutrition logs, test results, or patient questions). These “nuggets” included personalized text, videos, graphs, or hyperlinks on topics such as hypoglycemia, controlling food portions, and exercise. The project team also provided a diabetes summary report that consolidated all of a patient’s relevant diabetes information. An important topic of the report correlated the patient’s specific action plan with their risk of major complications (e.g., stroke, kidney failure, heart attack, blindness) from diabetes.
The project team evaluated the ODM program for diabetes in a randomized, controlled trial (RCT) of patients at PAMF who had inadequately-controlled type 2 diabetes, defined as hemoglobin A1c (HbA1c) greater than 7.5 percent, and did not have severe complications. The primary hypothesis under evaluation was that patients in the intervention arm would have lower HbA1c at 12 months post-randomization than those receiving usual medical care. Secondary hypotheses were that the intervention would be associated with: 1) improved self-management practices such as medication adherence, home monitoring of glucose and blood pressure, healthy diet, and regular exercise; 2) improved biologic measurements such as blood pressure and lipids; 3) better processes of care such as frequency of monitoring tests, lower cardiovascular risk, enhanced patient experience, and satisfaction with care; and 4) improved patient psychosocial well-being. These measures were assessed in both groups by laboratory testing, EHR data extraction, and an online questionnaire at baseline, 6 months, and 12 months post-randomization.

**Specific Aims:**

- Refine the Personalized Health Care Program platform with a particular focus on enhancing the customization capability of the ODM system and ensuring a seamless incorporation of ODM into the workflow of clinicians on the CM team and with the self-management process of patients. *(Achieved)*

- Evaluate the ODM program for diabetes relative to usual medical care, in a two-arm RCT. *(Achieved)*

- Disseminate results of the RCT in the scientific literature and deploy the Customized, Continuous Care Management program in PAMF and other ambulatory care settings for use with diabetes and other chronic conditions. *(Achieved)*

**2011 Activities:** The primary focus during this period was data collection and analysis. A 1-year no-cost extension provided adequate time for research assistants to continue to meet with patients passing their 6-month and 12-month anniversary, and conduct the appropriate data collection activities. As last self-reported in the AHRQ Research Reporting System, project progress was completely on track and project budget spending was on target. The project was completed in August 2011.

**Impact and Findings:** Over 61,000 home-monitored glucose readings were uploaded by participants in the intervention group over the course of the study. Patients maintained ongoing care management relationships with the care team, communicating consistently throughout the study. A total of 2,625 MyHealthOnline secure messages and 151 phone calls were initiated by patients over the 12-month intervention. The total time spent by the nurse care manager and registered dietician during the intervention ranged from 1 to 18 hours per patient, with an average of 6 hours per patient, including all remote contact, and individual and group sessions.

Compared to usual care, participants in the intervention group had significantly better control of their diabetes as measured by HbA1c at 6 months, but the difference was not statistically significant at 12 months. In a secondary analysis, significantly more patients in the intervention group improved control (i.e., >0.5% improvement in HbA1c) of their diabetes than usual care at both 6 months and 12 months. A majority of patients had an increase or a significant increase in confidence in their ability to manage their diabetes, make lifestyle changes, and maintain lifestyle changes. In addition, the majority of patients specified that, as a result of being enrolled in the program, they 1) took their medications more regularly; 2) made healthy food choices more often; 3) exercised more; 4) paid more attention to their diets; 5) completed laboratory tests more regularly; 6) tested glucose at home more often; and 7) kept up with preventative actions more routinely.
**Target Population:** Adults, Chronic Care*, Diabetes

**Strategic Goal:** Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

**Business Goal:** Implementation and Use

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*This target population is one of AHRQ’s priority populations.*