Evaluation of a Web-Based Patient Portal for Chronic Disease Management

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Abstract. Chronic disease directly affects more than 9 million Canadians. Efficient strategies are needed to cope with the demand on health care services and to increase patient adherence to treatment. Emerging web 2.0 technologies present viable options for patient engagement in health care. We undertook a pilot project to assess the feasibility of two chronic disease management patient portals. A total of 35 patients participated in the assessment. Portals were evaluated for participant expectations, motivations, usability, and recommendations for future iterations. Findings suggest the features of this portal were useful. Important issues to participants include access to their medical record, communication with health care professionals and other participants regarding topics of interest, keeping track of biometrics, and keeping up with the latest clinical studies.

Keywords: Diabetes, Prostate Cancer, Web 2.0, Chronic Disease, Health Portal.

1 Introduction

Currently, more than 9 million people are suffering from chronic disease in Canada [1]. Accounting for nearly 87% of all disability in the country and consuming over 67% of all healthcare costs, chronic disease poses an incredible burden on the Canadian healthcare system. By 2015, the World Health Organization predicts that chronic disease will account for 89% of all Canadian deaths [2].

In Ontario, Canada, the impact is just as severe. Approximately 1 in 3 people suffer from at least one chronic disease in the province, costing the healthcare system a total of 80 billion dollars annually [3]. The impact of adverse effects of chronic disease are especially salient in Southwestern Ontario where rates of chronic disease, particularly prostate cancer and type II diabetes, are disproportionately higher than in other regions of the province [4]. A 2011 report by the Canadian Cancer Society found prostate cancer to be the most frequently diagnosed cancer in Ontario followed by breast cancer and colorectal cancer [5].

Canada, like most developed countries have a cohort of aging baby-boomers. In Southwestern Ontario the prevalence of diabetes and cancers continues to grow at an

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alarming rate. However notwithstanding current strategies to mitigate the prevalence and severity of the diseases, Ontario's healthcare system is underperforming with regards to chronic disease management and treatment [3]. Increasing chronic disease patient participatory care needs requires innovative use of communication technology, including interactive, tailored programs with feedback and social support through networks, not to mention access to care.

1.1 Study Objective

In conjunction with a web portal provider - we developed, implemented and evaluated a web-based chronic disease management system for patients suffering from diabetes (My Diabetes Wellness Portal™) and prostate cancer (ProPortal™), respectively (MedManager Interactive Corp., Waterloo, ON). The goal of this pilot project is to test the effectiveness and usability of an interactive web-based patient portal in providing prostate cancer, and diabetes patients with the knowledge guidance and education they need to help them understand their disease.

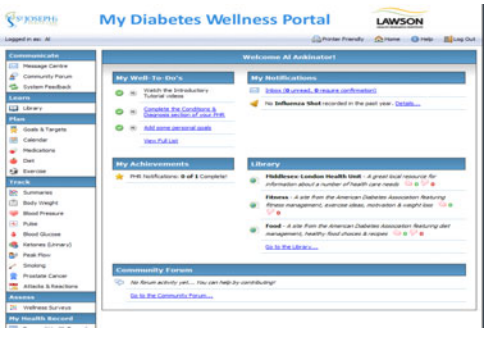

Fig. 1. My Diabetes Wellness Portal™ interface. Features of this portal can be seen in the side bar located on the left-hand side.

2 Methods

We designed and implemented a pilot study where patients from each disease cohort were allocated to one group per portal and followed for 6 months. All patients were given access to usual care (print material, advice from their physician and other health providers) and new sources of education, via the web-based portal. Patients had access to self-monitoring tools, and the ability to track disease-related metrics. Our ethics committee (University of Western Ontario) found this approach acceptable (REB #16100E).

Two disease cohorts were targeted through convenience sampling. Patients diagnosed with prostate cancer, including first and second line, of any age, were approached to participate. Patients with type II diabetes were invited to participate.

This cohort was chosen as the disease requires many variables to be managed to achieve optimal care. In both populations patients needed to have access to a computer and the internet. Patients with comorbidities were not excluded. This allowed us to have a fully representative population. We were not concerned with the age range between cohorts (prostate cancer patients are generally an older cohort) as we were not comparing cohorts. Rather this range allowed us to examine possible barriers to use of web 2.0.

Patients were recruited by the physicians and educators at the London Health Sciences Centre. One clinic was located in the Cancer Program, the other in Endocrinology Care. These clinics are ideal as a large number of patients from practices in South-western Ontario are referred for treatment. In addition to face-to-face recruitment, mail outs were sent to patients. We aimed to recruit a total of 50 patients for each condition.

The patient letter of information and consent clearly explained the nature of what data was going to be stored and how this was going to be stored. The data stored is encrypted, and the portal company did not have access to any data. Data is stored behind a secure hospital firewall and backed up nightly. The principal investigator, physician, research assistant and healthcare provider on the team (a social worker, and a pharmacist) had access to the portal. Patients were given randomly generated logins which they changed in order to ensure confidentiality. Disease specific data for the site is provided through manual entry (information entered by the patient) and HL7 data transfer.

An interactive, guided help video is available on the portal. Upon signing in, the help video would pop up. A toll-free helpline was established for participants experiencing difficulties. This was manned by the portal provider. Participants were also able to call the research assistant if an issue arose.

We initiated the study in September 2009. Each portal was monitored by a healthcare provider. The portal enables participants to track their disease-related metrics (e.g., diabetes patients could download readings from their blood glucose monitor) and visualize the data via graphs. External notifications based on goals set by patients are automatically sent. Evidence-based educational material, chosen by healthcare providers on the team, was accessible through the portal. Patient-to-patient and patient-to-provider interaction was available through a community forum and short messaging service.

The feasibility of this portal is assessed by a telephonic survey and a focus group. A 10 minute telephonic survey was administered to patients from both portals. This survey consists of 28 likert scale items and 4 open-ended questions. It was created to assess patient experience with the portals over the course of 3 months. Questions were derived from a questionnaire developed by Evangelista et al., (2006) [6] as well as an expert panel of software developers, and healthcare providers (specifically, team members). Items evaluated: motivation to use the portal, expectations, usability, aesthetics, specific features, support team service, and benefit to health. Responses to the survey were analyzed according to frequency and were subsequently grouped into the themes.

Focus groups were held, at study closure, with participants from each portal, to provide in-depth understanding of portal experience. A focus group is a qualitative research data collection method. Focus groups are particularly useful for exploring opinions, preferences and experiences of a study [7, 8]. Focus groups "have an advantage for researchers in the field of health and medicine...they can encourage participation from people reluctant to be interviewed on their own or who feel they have nothing to say" p.299[9]. Focus group validity is recognized by considering the participants' responses as "an accurate representation of the perceptions of reality for the group members and therefore valid" p.489 [10]. According to Calder [7] enough focus group sessions have been held when it is possible for the moderator to anticipate what will be said next. A semi-structured interview schedule was developed, aimed at developing iterations of the portal that would provide optimal support for managing a disease. The themes explored within the focus groups included: motivations and expectations of the project, usability of the portal, reasons for usage or non-usage of the community forum, and suggestions for the next portal prototype. Two facilitators were present at each focus group (SG, and FG-S). These sessions were audio recorded.

3 Analysis

Data from the telephonic questionnaire was entered into SPSS (Chicago, Il.) where the frequency of items was computed. Open-ended questions were grouped into themes initially laid out by the areas delineated in the survey. In addition, usage statistics were collected through the backend of the portal. This provided data on number of logins, time spent on each task etc.

The two focus group sessions (one for each cohort) were audio recorded and the raw data was transcribed by a moderator (S.G). This data was analyzed according to thematic analysis. Qualitative thematic analysis provides a rigorous method of analysis across which a gathered data set will be searched and organized in to pre-empted and emergent themes (repeated units of meaning or patterns) [11; 12] This analysis requires that initial codes be generated after transcription, searching for patterns across the data set, reviewing the themes, defining and naming themes, as well as reporting issues considered relevant to the research question.

4 Results

Thirty-four out of 64 participants completed the survey (at the time of the survey, 64 participants were enrolled in the study). Ten male and five female My Diabetes Wellness Portal™ (MyDWP) participants completed the survey – the majority of which (5 participants) were between the ages of 40 to50 years. The majority of ProPortal™ (ProP) participants (n=19) who completed the survey were between the ages of 73-83 years (8 participants). At study closure, when the focus groups were conducted, a total of 99 participants (46 MyDWP participants, and 53 ProP participants) had consented to the study. Five ProP, and 2 MyDWP participants took

part in the focus groups. Findings from both the survey and focus groups are reported within themes in the table below.

Table 1. Survey and focus groups findings across both cohorts

Themes	Findings
Motivations	Expand knowledge base and receive Canadian content Sense of community and social network. Help others. Find out how to improve overall health.
Expectations	Involvement of primary physician. Complete medical record history pertaining to disease to be available via portal. System to be available to hospital personnel.
Usability	Easy to navigate, well-organized, clear, caught-on quickly. Feelings of frustration at missing medical information led to discontinued use.
Portal Usage	Time spent on MyDWP: average 15.60 minutes with average participant login of 1.64 per day. Time spent on ProP: 17.58 minutes with average participant login of 0.66 times per day. Frequency of login related to checking for new information and postings.
Privacy & Security	Felt personal information secure and protected.
Features	
Community Forum	Lack of participation by participants and healthcare team. Wanted to see more activity. Recommendations: Discussion led by healthcare provider on topic chosen by participants.
Tracking Tools	Well-liked and used. Need to combine items of likeness.
External Notification	'No new messages' led to turning off feature.
Personal Health Record	MyDWP: liked ability to upload glucometer readings. However, some glucometers were not compatible with the system. Delay between results and appearance on portal. Results uploaded were close to unreadable. ProP: Wanted portal pre-populated with biometric data.

Table 1. *(continued)*

Future Portal Recommendations	
Design	Ability to design guest accounts. Visual identifiers for healthcare team. One main portal with functionality to choose co-morbidity. Receive notification of portal updates and reminders. Relational graphing of biometrics. Glossary of acronyms. Intuitive system.
Pedagogy	Video clips of talks/programs/recent news. "Frequently Asked Questions" Information on new study findings and products.
Medical Records	Clinicians to make recommendations based on info entered by participants.
Economic Costs	Portal of worth and would pay a fee for that. Build into insurance of chronic disease.

5 Discussion

With 1 in 20 diabetes patients in Ontario experiencing major complications within a year, [13] & 1 in 7 Canadian men at risk for prostate cancer [14], it is essential we explore the feasibility of tailored, interactive web-based portals to encourage patient self-monitoring. Regardless of age (majority between 61-83 years old) 58 participants logged in and used the portal. The majority of participants derived benefit from the tools provided, however they wanted a more interactive social medium.

Future forays into web-based self-management programs need to engage participants in evaluation to ensure sustainability. Participant recommendations include emphasis on the social aspects of the portal, as well as integration of pre-populated medical records for tracking. Self-management opportunities will support future actions based on engaging patients in evaluation and improvements to these portals. Their suggestions include, specifically increasing forum activity- for chats and provider–patient interactions, posted clinician recommendations and pre-populated medical records for tracking.

5.1 Study Limitations

Despite the initial sample size of 64 participants (size of the sample at the telephonic interview time period), only 33 patients completed the survey and only 7 participated in the focus group (an effort was made to contact all participants). This concern summons question bias. Did non-compliant users not respond to the survey? Would their answers have provided different information than what was collected? Additionally, questions regarding the motives of focus group participants and what

implications these motivations may have had on study results must also be considered. Repeating the trial with a larger sample size will improve the validity and generalizability of the study; in painting a more accurate picture of the MyDWP, researchers can accurately assess the portal's effectiveness. In the future, it may be beneficial to apply the technology adoption model (TAM) to determine user acceptance of the portal and to make study outcomes more generalizable to the research population.

6 Conclusion

This pilot study marks an important journey into e-based chronic disease management in Canada. As the role patients with chronic disease play in their 'healthfulness' (as opposed to illness) becomes larger, cost-effective avenues to explore self-management become crucial to the survival of our healthcare system. By learning from the findings discussed in this paper, researchers will be able to deploy future iterations of portals that encompass more of what patients want to see. Issues of importance to participants include access to their medical record, communication with health care professionals and other participants regarding topics of interest, keeping track of biometrics, and keeping up with the latest clinical studies.

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