Improving Informal Caregiver Engagement with a Patient Web Portal

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Abstract

Engaging individuals to proactively manage their health is a hallmark of patient-centered care. Despite advances with health technology, there remains scant information using patient web portals that involve informal caregivers (family and friends) in health care. An accountable care organization recently introduced a patient web portal whereby family and friend caregivers can access patient health records. Oftentimes, informal caregivers are the principal caregivers for chronically ill patients. We recently constructed a secure patient online portal (POP) that allows family and friends to access health information with the patient's permission. This feature is called a "care circle". It consists of individuals that have access to medical information through a web portal. Preliminary results show that the majority of proxy members would regularly use the web portal to help coordinate health care. Medical groups, including accountable care organizations and medical homes may consider offering web portals that engage family and friends to help promote continuity of care and adherence to clinical treatment.

Keywords: e-health; health engagement; medical records; web portal

1 Introduction

Health information technology is expanding rapidly as primary care medical groups in the United States continue to evolve. As electronic health records become more widespread due to Federal financial incentives, "meaningful use" objectives will aim to improve clinical care delivery and health outcomes [1]. Enhancing communication between patients and physicians, coordinating continuity of care, and evaluating quality measures are overall goals of this technology. Using secure patient web portals to improve care delivery and empower patients is well described in the literature [2-6]. Access to clinical information can promote positive health behaviors particularly in those with chronic diseases [2-5]. However, there are negative consequences with using this technology as well. Patient confusion with medical terminology and results, increased burden on health professionals, and integrating this technology in the clinician's daily work flow are potential challenges

that must be addressed [6].

Despite advances with health technology, there remains scant information using patient internet portals that involve informal caregivers (family and friends) in health care. Informal caregivers are oftentimes the principal caregivers in providing for chronically ill patients. In addition to helping the patient remain in their chosen residence, they need to monitor laboratory results, perform a variety of clinical duties such as wound dressing changes, advocate for their loved one, make medical appointments, and arrange for transportation.

We recently constructed a secure patient online portal (POP) that allows informal caregivers to access health information with the patient's permission. This feature is termed a "care circle". This feature attempts to "activate" family and friends in the patient's health care. Connecting informal caregivers with health technology is one of the goals of this online portal. By empowering patients and their informal caregivers with clinical knowledge, this may help in disease manage-

ment, decreasing health utilization, and enhancing clinical outcomes. Moreover, we addressed the potential for medical results and terminology confusion by using patient-friendly educational software embedded in the portal.

2 Methods

HealthCare Partners Medical Group (HCP) is an accountable care organization that takes global capitation risk in Southern California, Florida, and Nevada. As one of the largest providers of senior health care in Southern California, HCP has staff-model clinics and independent physician association (IPA) delivery systems for approximately one million patients. HCP uses a coordinated care model for a culturally diverse patient population with a wide array of socio-economic classes, comorbidities, and ages. Approximately half of HCP's patients are treated by 750 general practice physicians who are employed in a staff-model health maintenance organization; the remainder are cared for by 1,900 clinicians from regional affiliated IPAs. Previously, ethnic and racial affinity data were not obtained at our medical group. However, these data are currently being collected to enhance health equity and further promote culturally sensitive care.

At our organization, the patient web portal is called the patient online portal (POP). Patient information is embedded within a secure and encrypted network. The POP has a "care circle" feature that consists of two categories of individuals who can access health information with the patient's consent. The care circle is comprised of proxy and non-proxy member categories.

The proxy category is an individual who is authorized to speak and act for the patient. At our medical group, older patients (≥ 55 years old) are more inclined to have care circles than younger individuals. These individuals may designate with the portal a spouse, domestic partner, sibling, or unrelated friend to be part of the care circle, specifically a proxy member. However, what is required to establish a proxy account is an online statement attesting to the relationship between patient and proxy. Using the portal, the patient can also approve or disapprove a proxy member.

Although not required for a designated proxy, the proxy may indicate if they have any legal documentation of a patient/proxy relationship, such as a power of attorney, medical release of records, conservatorship, or proof of guardianship. For patients between the ages of 12 and 17 years old, proxy accounts are disallowed. Only one proxy account is permitted per patient. However, this may include a parent of three children

being a proxy for all three individuals. The prevailing laws of the states that our organization serve (California, Nevada, and Florida) allow patients eighteen years or older to create a proxy account. If a patient is incapacitated and cannot give approval, legal documentation is used to establish a proxy.

The proxy and non-proxy care circle members have access to confidential patient medical information. The patient explicitly acknowledges that they are specifically granting care circle members access to HIPAA (health insurance portability and accountability act)-restricted information; a username and password are provided from the portal. The proxy has the ability to 1) send messages to the patient's provider, or to other health personnel, 2) make patient appointments, 3) refill medications, and 4) use any other current POP functions. Physicians, nurses, and other allied health staff cannot approve or disapprove the designated proxy or non-proxy members. At any time the proxy can be replaced with a new proxy by the patient through the portal. If there are disagreements between the patient and proxy, there is no formal internal grievance process currently at our organization.

Non-proxy care circle members can also access a patient's medical record with the exception of making online payments. They cannot send electronic messages to clinicians, request appointments, or refill prescriptions. Non-proxy members are asked to join online by the proxy or patient. Unlike selecting a designated proxy member, the number of non-proxy members is unlimited. Active prescriptions are viewed by both proxy and non-proxy members, and refill requests can be performed by the proxy. Care circle members may access patient-oriented health education which is provided by an integrated e-health vendor within the web portal. The proxy may also send and receive electronic messages from the patient's health team for clinical input. Moreover, non-proxy members can only read these messages. The Figure shows a comparison of the differences between proxy versus non-proxy care circle members.

Three-hundred forty-three proxy members were surveyed with a questionnaire that evaluated their perceptions using the web portal. The table depicts those respondents who answered "most useful" to the respective questions.

3 Discussion

Patient-centered care is a system of clinical delivery that enhances health knowledge, promotes effective communication, and provides care tailored to the patient and their informal caregivers. Compared to evaluating

Proxy

- Speak and act for the patient

- Online statement attesting to patient-proxy relationship

- Access the patient's health information

- Send and receive messages from the patient's health team.

- Make appointments

- Refill prescriptions

- Make online payments

- View patient-oriented health literature

Non-Proxy

- Access the patient's health information

- Make online payments

- View patient-oriented health literature

- Read messages from the patient's health team.

Figure 1: Proxy versus Non-Proxy Care Circle Members

Questions	N	(%, N/343)
Ease of use	192	56.0
Examine laboratory results	217	63.2
Examine medications	211	61.4
Request prescription refills	200	58.3
Send messages to clinicians/health team	159	46.3
Registration	138	40.2
Request, reschedule, or cancel appointment	181	52.9
View and update personal information	178	52.0
View and update insurance information	153	44.5
Will use portal in the future	308 (Yes)	89.7

Table 1: Patient Web Portal Questionnaire Showing Absolute Number and Percentage of "Most Useful" Responses.

patients' experience with health technology and informatics, connecting proxies to this technology has been described much less in the literature. As shown in the Table, preliminary data from a survey shows that the majority of proxy respondents (90%) would continually use the portal. The surveys were completed with an online request for care circle members to complete a brief survey regarding the web portal; the response rate was 65%. The "most useful" response was observed in the following questions: examining laboratory results, examining medications, and requesting a prescription refill. As one of Southern California's largest providers of senior health care, many of our older patients present with multiple co-morbidities. We have several disease management programs that include emergency prescriptions for illnesses such as chronic obstructive pulmonary disease (COPD) [7]. For example, during COPD symptom exacerbation, steroids are administered by the patient with appropriate clinical support (chronic disease nurses). By empowering the proxy to request a prescription refill online, self-management by the patient and their informal caregivers can be initiated. This may potentially decrease health utilization thereby avoiding an emergency department visit, and having the patient remain at their chosen residence. Conversely, without a prescription refill, an urgent care visit may require a potentially preventable hospital admission or readmission.

Preliminary survey results indicate a mix of descriptive favorable and unfavorable remarks. Patients and care circle members responded to requests and activities generated by the portal. Favorable comments included, "Love the access to weight history and lab results, especially graph formats. "Having access to personal health data will allow me to take charge of improving my daughter's health." Another responded, "Being hearing impaired I tend to miss specifics that the doctor rattles off, and it is too difficult to reach the doctor by phone for questions." Other comments yielded barriers to the web portal: "The routine physical options refer to with or without PAP. Some men have no idea what that means and may request "with PAP." This highlights potential confusion with medical terminology and the necessity of patient education within the portal. Another commented on certain items lacking in the medical records, "I want to be able to access the lab work and x-rays, however, lab work and x-rays were not posted."

The following data are not available to patients and their care circle; infectious diseases, pathology reports, sexually transmitted diseases, drug screening, pregnancy, HIV tests, imaging studies, and medical procedures such as pulmonary functions tests and colonoscopy results. Although educational health information is embedded within the web portal, clinicians

correspond by telephone and mail to communicate the aforementioned results as required currently by state law. For permissible laboratory results, such as complete blood counts, cholesterol, and glycosylated hemoglobin, abnormal values are highlighted and informational icons present patient-friendly literature to help the care circle learn about the meaning of these results and to promote clinician follow-up.

At HCP, there is a policy on the types of clinical data made available through the portal. Current state law prohibits electronic transmission of some laboratory reports and results to patients. It is our goal to release as much as legally possible in the future. By helping patients and caregivers better understand medical information, this may decrease the potential for misinterpretation or confusion.

4 Conclusions

In conclusion, by connecting family and friends to health informatics with an online portal, the patient may be more activated in their health care. This may impact clinical metrics such as emergency department visits, hospital admissions, readmissions, complication rates, acuity of health issues through earlier intervention, and clinician visits. These metrics may shed light on the efficacy of informal caregiver involvement using web portals. Determining how to fully integrate this technology into daily clinical care and having health providers perceive this as a practical, time saving instrument remains paramount.

Acknowledgements

Conflicts of Interest

No competing financial interests exist.

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