

Project Title: Addressing Hospital Patient Information Needs Using a PHR Portal

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I. STRUCTURED ABSTRACT

PURPOSE: The purpose of this study is to determine the effects of an acute care portal intervention, including real-time access to the patient's electronic health record data, on patient activation, patient satisfaction, patient engagement with health information and 30-day hospital readmissions.

SCOPE: The proposed research aimed to demonstrate the potential for consumer health information technology to empower patients and caregivers as active participants in the inpatient care delivery process. It aimed to advance scientific knowledge in the field of patient-clinician communication, demonstrate new technical capabilities for sharing information among patients and their care teams, and improve patient activation, engagement and satisfaction.

METHOD: A randomized controlled trial was proposed to rigorously evaluate the impact of the inpatient PHR portal with patients from medical and surgical cardiac units at Columbia University Medical Center. We assessed the generalizability of the research by deploying the inpatient PHR portal at El Camino Hospital, a community hospital in Mountain View, California. Finally, we analyzed patient-entered questions and comments to characterize information needs of hospital patients and assessed the salience of patient-entered information to issues of care quality and safety.

RESULTS: There was no evidence of a difference in patient activation among patients assigned to the acute care portal intervention. Patients in the acute care portal group had lower 30-day hospital readmissions (5.5% vs. 12.9% tablet-only and 13.5% usual-care; $p=0.044$). There was evidence of a difference in patient engagement with health information between the acute care portal and tablet-only group, including better access to health information online (89.6% vs. 51.8%; $p<0.001$). Healthcare providers reported that patients found the portal useful and that the portal did not negatively impact healthcare delivery.

KEY WORDS: Randomized controlled trial, patient engagement, patient activation, medical informatics, patient-centered care, personal health records, patient-centered care

II. PURPOSE

Even though online access by patients to their health information is increasingly common, this practice remains relatively unstudied in the hospital setting. In 2015 there were over 35 million hospital discharges in the United States.¹ Many patients in the hospital have low activation, including those who come from urban, low-income backgrounds, and those with cardiac diagnoses.¹⁻³ One potential mechanism to increase patient activation is the adoption of acute care patient portals, or patient portals available in the hospital setting.^{1,2} Under the Meaningful Use electronic health record (EHR) adoption incentive program in the United States, hospitals must provide patients with the ability to electronically view, download, and transmit their own health information.¹ From 2013 to 2015, the proportion of healthcare organizations offering online patient portals increased from 43% to 92%.¹

The primary aim of this study was to evaluate the effect of a personalized inpatient portal intervention on patient engagement. The secondary aims were to characterize information needs of hospital patients, assess clinicians' attitudes toward patient engagement in the hospital setting, and evaluate the salience of patient-entered information to issues of care quality and safety. The third aims were to examine the intervention's effect on 30-day hospital readmission rate. Additionally, we assessed scalability and potential reach of the intervention by deploying the inpatient engagement technology in a community hospital on the West Coast.

III. SCOPE

BACKGROUND:

Although evidence indicates that better informed, more engaged patients have better health outcomes, information needs are often addressed inadequately, especially in hospital settings.³ This is particularly significant because there are over 35 million hospital admissions each year in the United States.¹ For hospitalized patients the lack of information contributes to anxiety and feelings of helplessness.² In acknowledgement of the prevailing feelings of uncertainty that accompany a hospital stay, a growing number of non-scientific publications have appeared, including books with titles such as “The Patient’s Checklist” and “Safe Patients, Smart Hospitals.”

CONTEXT:

Use of online patient portals is often limited to the ambulatory or home setting, although studies of hospital patients found that most (90%) desired access during hospitalization.⁸ As such, some organizations have adopted acute care patient portals^{6,1} because they offer a unique opportunity to increase transparency and engage vulnerable patients with their health information in real-time. Bedside access to personal health information may increase patient activation, safety, and satisfaction with hospitals and healthcare providers.^{2,3,4} However, few randomized clinical trials of acute care portals and their effectiveness on care delivery or patient activation exist.⁵

SETTING:

The study took place at The Columbia University Irving Medical Center and NewYork-Presbyterian Hospital located in New York City’s neighborhood of Washington Heights. The recruitment of patients was conducted on two medical post-surgical recovery units for cardiac patients. The Columbia University Medical Center Institutional Review Board approved the study. A secondary sub-study site was located at El Camino Hospital in Mountain View, California. Study participants were also recruited from two medical post-surgical units. The Palo Alto Medical Foundation approved of the study.

PARTICIPANTS:

The inclusion criteria for the study were English- or Spanish-speaking individuals who were 18 years or older and were admitted as patients to one of two medical and surgical cardiac units at NewYork-Presbyterian Hospital/Columbia University Medical Center. Patients were screened for cognitive impairment using the Mini Mental Status Examination⁶, and those scoring below nine on the exam are excluded from the trial. Patients are also excluded from participating if they were currently in a separate research study, unable to provide written informed consent, in contact isolation with an infectious disease or had been admitted to the hospital for more than two weeks. Participants provide written informed consent prior to enrollment and all data-management procedures are conducted in accordance with national and state regulations and local policies and procedures.

IV. METHODS

STUDY DESIGN: We conducted a three-arm randomized clinical trial in two cardiac medical-surgical units at an academic medical center in New York City between March 2014 and May 2017. Participants were randomized to one of the three arms: 1) usual care, 2) tablet with general internet access, and 3) tablet with access to the acute care portal. The unit of randomization was conducted by rooms in the cardiac units. Randomization based upon room assignment was done to minimize the potential for a crossover effect of the interventions among patients sharing a room. Patients, clinicians, and researchers were not blinded, due to the obvious nature of the intervention. All participants received evidence-based medical treatment. Participants completed baseline and follow-up assessments to assess changes in patient activation (primary outcome), engagement with health information, and all-cause 30-day hospital readmissions. After the trial's completion, we administered a separate survey with healthcare providers to assess the portal's usefulness and impact on care delivery. The institutional review board at Columbia University Medical Center approved the study.

DATA SOURCES/COLLECTION: Research coordinators collect baseline and follow-up data 3 to 5 days later using survey instruments. Data was managed using Qualtrics Survey Software (Qualtrics, Provo, UT). Research coordinators were trained on the study protocol prior to interaction with participants. They were also introduced to front-line medical and nursing staff and familiarized with the floor plans and room randomizations. Research coordinators followed specific guidelines and checklists to ensure that all data was collected and managed in a consistent manner.

INTERVENTIONS: The interventions were part of the arm 2 and arm 3 cohorts. Arm 2 received computer tablets with access to the Internet and could access websites such as WebMD. Arm 3 received tablets with an inpatient health portal. The portal contained the patient's clinical information updated directly from the hospital's electronic health record every 15 minutes. The portal's features included: (1) names and photos of care team members, (2) medications being administered, (3) short videos explaining the purpose of each medication as well as potential side effects, (4) links to comprehensive medication information from MedlinePlus, (5) documented allergies, (6) diagnostic test orders and results, (7) current documented diet, (8) vital signs and weight, (9) functionality to report pain level, (10) functionality to communicate comments and questions to care team members and (11) functionality to acknowledge care team members with a star rating.³³ User actions were recorded in an electronic system usage log. All features were available in English and Spanish. Each patient received a unique username and password. Between subjects, tablets (Apple iPads) were digitally cleared and physically sanitized in accordance with hospital infection prevention practices. Arm 3 participants were oriented to the personalized inpatient portal and a brief tutorial on available features was provided. Participants signed into the personalized inpatient portal using a username and password of their choice. If they forgot their password they were prompted to generate a new one. Both Arm 2 and Arm 3 participants had access to games and entertainment on their computer tablets.

A member of the study team visited participants in all three arms each day. During these visits, the research coordinator checked to see if participants in Arms 2 and 3 had any issues with device usability (ie: password, username, network connection). For participants in the control group, the research coordinator checked to make sure they were not discharged prior to the end of the study period. After participants complete the study, the iPads were thoroughly cleaned using tablet-friendly antibacterial wipes to ensure infection control between patient rooms.

Health care provider surveys:

Healthcare providers were administered a separate 22-item web-based paper-based survey including questions focused on provider perceptions of patient portal usage, perceived usefulness of portal features and impact on care delivery.

MEASURES:

Baseline Survey & Disease Severity:

The patient baseline survey included demographic characteristics, health literacy⁷, questions related to access to technology, clinical characteristics and patient activation. Patient clinical characteristics were abstracted from the electronic health record. Disease severity was quantified using the Charlson Comorbidity Index⁸ and All Patient Refined Diagnosis Related Group.^{9,10}

Portal Use:

In the portal group, we measured usage by assessing the median logins over the duration of median number of inpatient days. At the completion of the study, patient participants also completed a survey that asked questions about patient activation, engagement with health information, patient satisfaction, perceived usefulness and usability of portal features.

Patient Activation:

At baseline and 3–5 days follow-up, we administered the Patient Activation Measure (PAM)-13.¹⁸ The PAM assesses the knowledge, skills and confidence essential to managing one's own health and healthcare.¹⁸ The PAM-13 is a uni-dimensional, 13-item measure that reflects a developmental model of activation. The PAM-13 segments consumers into one of four progressively higher activation levels: 1) Disengaged and overwhelmed, 2) Becoming aware, but still struggling, 3) Taking action, or 4) Maintaining behaviors and pushing further. The PAM-13 has good psychometric properties¹¹⁻¹³ and has been validated in multiple outpatient settings. Tests of construct validity for the PAM-13 have strong associations with functional status (SF-36¹⁴ and SF-12¹⁵). The PAM-13 score has been used to predict health-care outcomes including medication adherence, emergency room utilization and hospitalization.^{16,17} A recent observational study of the PAM-13 found that levels were associated with many health outcomes including better clinical indicators, more healthy behaviors, and greater use of women's preventive screening tests, as well as with lower costs.¹⁸

Patient Survey:

In addition to the PAM-13, we administered a Patient Survey that included two scales which measured: 1) satisfaction with the hospitalization and perceived engagement with healthcare providers; and 2) perceived usefulness of the personalized inpatient portal. The perceived usefulness scale was administered only to patients in Arms 2 and 3 of the study (those who received tablet computers). The Patient Survey includes 21 items on satisfaction and engagement and 5 items on perceived usefulness. All questions were measured on a 5-point Likert-type scale and both scales will be summarized as a mean score and standard deviation. The Patient Survey was derived from the 26-item Telemedicine Satisfaction and Usefulness Questionnaire.¹⁹ The Telemedicine Satisfaction and Usefulness Questionnaire includes two sub-scales, satisfaction/engagement and usefulness, which have internal consistency reliabilities of 0.96 and 0.92, respectively.²⁹

Statistics & Analysis:

The sample size was determined based on the hypothesis that patient satisfaction and patient engagement during hospitalization would differ among the three arms. Assuming the difference in patient activation between Arm 1 (usual care) and Arm 2 (tablet-only) would be one-half of the difference between Arm 1 and arm 3. Using a pairwise effect size of 0.385 based on a web-based pilot

study¹ a sample size of 426 total patients was required to achieve power of 80% at alpha-level of 0.05 after Bonferroni correction. Baseline demographic, clinical diagnostic variables and outcomes were compared using Kruskal-Wallis test for continuous and ordinal variables, and Chi-squared or Fisher's exact test. In addition, baseline covariate adjusted comparison of outcome variables were conducted and the p-values were calculated using a Type 3 test in linear, logistic, or Cox models for continuous/ordinal, categorical, and time to event outcomes, respectively. Analyses were conducted using intention-to-treat principles with statistical software (SAS, version 9.4; SAS Institute).

LIMITATIONS: Study limitations include an imbalance in participant age across the three study arms. Younger age in the acute care portal arm could be explained by several factors. Older adults may have been less interested in participating in a randomized clinical trial and may have also self-selected out of participation after learning that they were being asked to use an iPad. The finding that younger participants were more likely to use the acute care portal was consistent with previous research.²¹ A second limitation is that we did not have access to hospitalization records outside of our hospital system. As such, we were unable to determine whether participants were being rehospitalized at other hospitals. We attempted to address this limitation by controlling for distance from the hospital and found no differences across study arms. A final limitation is that the study was conducted only in cardiac medical-surgical units at a large academic medical center with an internally developed acute care portal, thus introducing questions about study generalizability.

Future studies should consider why and how patient activation seems to increase over the course of a hospitalization, how to involve caregivers with proxy access to acute care portals, and whether the increase in patient activation over a hospitalization is consistent irrespective of whether the PAM is exclusively patient-reported (eliminating observer bias) or reported to a research assistant.

V. RESULTS

PRINCIPAL FINDINGS: There was no evidence of a difference in patient activation among patients assigned to the acute care portal intervention. Patients in the acute care portal group had lower 30-day hospital readmissions (5.5% vs. 12.9% tablet-only and 13.5% usual-care; $p=0.044$). There was evidence of a difference in patient engagement with health information between the acute care portal and tablet-only group, including better access to health information online (89.6% vs. 51.8%; $p<0.001$). Healthcare providers reported that patients found the portal useful and that the portal did not negatively impact healthcare delivery.

OUTCOMES:

A total of 426 participants were recruited. There was minimal attrition overall. The mean age of participants was 59.2 (± 16) years, 39% were female, 14% were African American, 25% were Latino and 12% spoke Spanish as a preferred language. In the portal group, participants had access to the portal for a median of 3.17 (± 3.67) days, with a median of 4.0 (± 6.24) total portal logins. Though there were significant differences in select demographic variables at baseline, after adjustment for age and “access to a computer or tablet at home,” these differences were balanced across the three arms. As such, all primary and secondary outcomes included adjustment for age and access to a computer or tablet at home. There were no differences in clinical severity based on the Charlson Comorbidity Index, All Patient Refined Diagnosis Related Groups (which measured severity of illness and risk of mortality), comorbid conditions, or distance from the hospital.

The overall Kaplan Meier estimate of readmission rate to our hospital within 30 days of being discharged from the index visit was 10.6% (45 of 426) (Table 2). There were significant differences in the readmission rate among three groups (5.5% in the portal group, 12.9% in the tablet-only group, and 13.5% in the usual-care group, overall $p=0.044$). Pairwise comparison showed that there was a significant difference between the portal group and the usual-care group (Bonferroni corrected $p=0.044$). The difference between portal and tablet-only was not significant (Bonferroni corrected $p=0.110$), neither was the difference between portal and usual care (Bonferroni corrected $p=1$).

Across all three groups, patients in the portal group were more likely to report that the care team uses information that patients provide to them (4.6 ± 0.6 vs 4.2 ± 0.9 (tablet) and 4.4 ± 0.7 (usual care); $p<0.001$). Between the two groups that had access to the tablets, there were significant differences in patient engagement with health information using a tablet. As compared to tablet only group, portal users reported being more likely to use the tablet to look up health information online (89.6% vs. 51.8%; $p<0.001$). Portal users were also less likely than the tablet-only group to use the tablet for entertainment (93.8% vs. 68.1%, $p<0.001$) and perceive that use of the tablet helped the care team understand patient problems (3.2 ± 1.0 vs. 2.6 ± 1.1 , $p=0.003$).

Overall, patients were highly satisfied with their healthcare and healthcare providers and there were no differences among the three groups. Patients reported being involved in their care, following the team’s advice, and being encouraged to participate in care. Both the tablet-only and acute care portal group reported high ease of use, learnability, and trust with the tablets.

Healthcare provider survey:

A total of 63 healthcare providers (11 attending physicians (17%), 17 physician assistants (27%), 33 nurses (52%), 1 medical director and 1 patient care director (3%)) completed a healthcare provider survey. All healthcare providers who were asked to complete the survey did so. Overall, 48% of

healthcare providers thought that most (> 75%) patients were using a tablet, smartphone or laptop during their hospital stay. Most healthcare providers thought that patients were primarily using the tablets to answer emails (n=34, 54%) and for entertainment (n=49, 78%). More than half of the healthcare providers were not sure if patients were using technologies to look up health information (n=33, 52%).

Healthcare providers perceived the portal as easy to use, learnable, and a convenient way to deliver health information to patients. There were no concerns about the patients' privacy or negative communication between patients and members of the healthcare team. Healthcare providers also perceived that the portal was useful to patients.

DISCUSSION:

Access to an acute care portal did not significantly improve patient activation, but it did improve patients' access to their health information and was associated with fewer 30-day hospital readmissions. These findings demonstrate the value of providing hospitalized patients with timely access to their electronic health record through a portal. Overall, the mean patient activation score increased from baseline to follow-up across all groups. The increase in activation over the course of a hospitalization may underscore the likelihood that patient activation is not an inherent, static trait; rather, it may be influenced by various factors and change over time. Potential influencers may be proximity to admission/discharge or the observer effect. In our study, patients in all three arms were visited by a research coordinator who administered the PAM-13 at baseline and follow-up. In this sample the patient activation scores were also high at baseline (86% of patients reported being highly activated) compared to other patient populations. In contrast, Schmaderer and colleagues reported on an inpatient population where 65% were highly activated;²³ Prey and colleagues reported that 60% were highly activated;²² and O'Leary and colleagues reported 64.1% were highly activated.^[36] Due to the high level of activation that patients reported at baseline, there may have been a ceiling effect of the patient activation measure in our study population. Higher self-reported activation is consistent with other studies of patient activation with diverse patient populations.²⁹ Hibbard and colleagues²⁴ report that social environments and socioeconomic status are both precursors to activation. The higher levels of patient activation we identified in this study could be linked with social-environmental factors, individual disease conditions, the inpatient hospitalization or personal health practices. Other common factors with a lack of witnessed effect in an effectiveness trial include lack of provider acceptance or lack of patient adherence.³² In our study, both patients and providers reported strong acceptance; however, usage of the portal could have impacted the effect on patient activation. Future studies should explore the potential for a "dose-response" effect of patient portal usage on patient activation.

Overall, the magnitude of the intervention's effect on 30-day all-cause readmissions was small, but the difference across groups was nevertheless surprising. Unmeasured confounding factors may have impacted 30-day hospital readmissions, such as patients' self-reported disease experience, caregiver support, family access to the portal, and existing relationships with healthcare providers. A study conducted at Mayo Clinic in Florida reported no differences in 30-day hospital readmissions between a group provided with an inpatient portal and a propensity score matched cohort (p=0.13).³¹ Further research should explore the potential impact of acute care portals on readmission, as well as the influence of potential effect modifiers such as relationship with healthcare providers or socioeconomic status.

Study limitations include an imbalance in participant age across the three study arms. Younger age in the acute care portal arm could be explained by several factors. Older adults may have been less

interested in participating in a randomized clinical trial and may have also self-selected out of participation after learning that they were being asked to use an iPad. The finding that younger participants were more likely to use the acute care portal was consistent with previous research.³¹ A second limitation is that we did not have access to hospitalization records outside of our hospital system. As such, we were unable to determine whether participants were being re-hospitalized at other hospitals. We attempted to address this limitation by controlling for distance from the hospital and found no differences across study arms. A final limitation is that the study was conducted only in cardiac medical-surgical units at a large academic medical center with an internally developed acute care portal, thus introducing questions about study generalizability.

Future studies should consider why and how patient activation seems to increase over the course of a hospitalization, how to involve caregivers with proxy access to acute care portals, and whether the increase in patient activation over a hospitalization is consistent irrespective of whether the PAM is exclusively patient-reported (eliminating observer bias) or reported to a research assistant

CONCLUSION

Overall, access to an acute care portal did not significantly improve patient activation, but it did improve patients' access to their health information and was associated with a lower 30-day hospital readmission rate. The findings of this pragmatic randomized clinical trial add to the early evidence on the benefits of providing hospital patients with transparent access to their personal health information. Greater transparency has the potential to translate into more informed decisions and behaviors that can positively impact medical decision-making.

SIGNIFICANCE: In this study, we found that patients who had access to the portal were more likely to use the tablet to access health information and less likely to use the tablet for entertainment and email compared to participants without access to health information on the tablet. When considering the wide availability of health information on the internet, one possible explanation for this finding is that when patients received a tablet with access to their own health information, they were more likely to perceive that the tablet was intended for accessing health information, rather than entertainment. This underscores the importance of clear communication about the purpose of using a device in the hospital. Simply handing tablets to patients seems unlikely to engage them in their healthcare. In addition, it was at the discretion of the patient how much they wanted to allow family members to view patient information from the portal. The use of the portal by other family members or caregivers was not directly measured.

IMPLICATIONS: Our study demonstrated that implementation of an acute care portal is possible in an urban, academic-medical center environment in a multilingual, multi-ethnic patient population. The results of this study are relevant to hospital administrators who are making decisions about the types of technology to use to measure care quality.

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