Patient Portal Usage and Outcomes Among Adult Patients with Uncontrolled Asthma

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Abstract

Background: Patient-clinician communication, essential for favorable asthma outcomes, increasingly relies on information technology including the electronic heath record-based patient portal. For patients with chronic disease living in low-income neighborhoods, the benefits of portal communication remain unclear.

Objective: To describe portal activities and association with 12-month outcomes among low-income asthma patients formally trained in portal use.

Methods: In a longitudinal observational study within a randomized controlled trial, 301 adults with uncontrolled asthma were taught 7 portal tasks: reviewing upcoming appointments, scheduling appointments, reviewing medications, locating lab results, locating immunization records, requesting refills, and messaging. Half of patients were randomized to receive up to 4 home visits by community health workers. Patients' portal use by activities, rate of usage over time, frequency of appointments with asthma physicians, and asthma control and quality of life were assessed over time and estimated as of 12 months from randomization.

Results: Fewer than 60% of patients used the portal independently. Among users, more than half used less than one episode per calendar quarter. The most frequent activities were reading messages and viewing lab results and least sending messages and making appointments. Higher rates of portal use were not associated with keeping regular appointments during follow-up, better asthma control, or higher quality of life at 12 months' post intervention.

Conclusion: Patients with uncontrolled asthma used the portal irregularly if at all, despite in-person training. Usage was not associated with regular appointments or with clinical outcomes. Patient portals need modification to accommodate low-income patients with uncontrolled asthma.

INTRODUCTION

Patient portals, or web-based patient-clinician communication links tethered to electronic health records, are a common technological feature of healthcare.(1) In theory, the portal offers patients real-time access to some information in their electronic health records that can enhance patient-clinician communication. The growth of and attention to patient portals arise out of provider financial incentives in Medicare and Medicaid Promoting Interoperability (formerly Meaningful Use) programs to encourage patients to participate in and make informed decisions about their care through improved online access to healthcare information.(2)

Prior surveys of patients at inner-city clinics have revealed interest in email contact between patients and their clinicians to improve communications and efficiency in their care.(3) Clinics that implemented patient portals have measured patient-initiated portal registration and usage among the general patient population.(1, 4) Still other studies (5-6) have evaluated simulated patient portal usage as a function of patient numeracy and literacy and internet experience in small samples of older adults. A recent systematic review found more research is needed on the adoption and use of web-based patient portal.(7)

As detailed in the Methods, we sought to investigate formally, the frequency of portal use by defining episodes of access, and the usage within these episodes among patients with poorly controlled asthma, frequent co-morbidities, and substantial economic and mobility disadvantages. Unlike other studies, ours sought to move beyond the process of patient portal use to estimate the association of portal usage rates with asthma outcomes over time. We conducted this observational study within a randomized controlled trial of the effectiveness of a home visitor program for adults with uncontrolled asthma from 2015 through 2017.(8)

METHODS

Patients

As previously reported (8), using a purposeful sample of clinicians who used the EHR and patients who were unfamiliar with portals, we designed a randomized controlled trial to estimate the incremental effect of home visitors on patient outcomes over time among patients who were formally introduced to and trained in the Epic MyChart portal. The research was approved by the University of Pennsylvania Institutional Review Board and registered with ClinicalTrials.gov (NCT02086565). We recruited 301 patients, 18 years or older, who had a diagnosis of asthma, were prescribed an inhaled corticosteroid,(8) and lived

in a Philadelphia neighborhood where at least 20% of households have incomes below the federal poverty level. Patients, recruited from 8 clinical sites (4 primary care, 3 asthma specialty clinics, one serving mostly Latino/Hispanic patients), were considered to have had uncontrolled asthma if they had required prednisone or had an ED visit or hospitalization for asthma in the year before enrollment. Participants were required to have used the portal, if at all, no more than 3 times.

On enrollment, all patients received training from a community health worker (CHW) on seven portal tasks: reviewing upcoming appointments, scheduling appointments, reviewing medication lists, locating lab results, locating immunization records, requesting refills, and messaging.(8,9) Following training, patients were tested on their ability to complete these tasks independently.

Patients were told that CHWs did not give medical advice. If medical questions arose, the CHW ensured that the primary team caring for the patient was contacted. Whenever the portal was opened and a message to a provider initiated, the EHR warned the patient that this was not an emergency line: "Please call 911 if you have an emergency or urgent medical question.

Home Visits and CHWs

CHWs, local residents with at least high-school diplomas, three years of work experience, and specially trained for this study (8) provided home-based, hands-on instruction on the registration for and use of the portal.

Half of the participants were randomized to receive four home visits by the CHWs. During home visits, CHWs assisted patients with care coordination and reviewed training in the use of the patient portal (8). Each 20- to 30-minute home visit had 2 parts: 1) reinforcing care coordination and 2) reviewing portal use and learning relevant information technology skills like email and googling.(8)

Internet access

We investigated providing a tablet to all participants, but stakeholders in the study (8) concluded that even with vendor discounts, tablets were a theft risk, mobile plans were too costly, and broadband installation in older homes was problematic. Subsidized internet service for public housing and low-income families with children did not cover all eligible patients.

At enrollment we recommended ways to access the internet: nearest library, nearest free hot spot (recognizing low income communities have fewer), and if accessible, using smartphone apps. In addition, all patients had wireless internet portal access when they visited the participating clinical sites before or after a visit.

Our design thus assumed that enrolled patients would have internet access representative of the community from which they were drawn –sections of Philadelphia characterized by high levels of poverty and generally poor housing.

Portal usage data

Data came from the raw transaction records of all portal usage of patients who consented to the study from before randomization and continuing through the last day of data collection. (Appendix). In brief, we tested the portal by using both tablet- and computer-based screens to enter individual transactions and then requested the raw data registered in the portal files. That approach allowed us to interpret properly each date-time transaction. We also confirmed the correspondence between the time of entering choices in the patient portal screen and the data and time of the transaction in the database.

Episodes of access to the portal

An episode of access to the portal is defined as access starting with a login, including intervening activity, and ending with a log-off. We identified within each episode all activities, such as "appointment schedule" or "renewal medication." We excluded from our data all portal usage episodes that occurred in the presence of a community health worker, that is, occurring on the day of a home or clinic visit or a patient contact.

After extracting the portal data activities from the two participating institutions (Table E2 and E3), we then categorized them into sets of "major activities" corresponding to the basic portal usage or tasks for which patients were trained in their orientation. (Table E3). Finally, we calculated the frequency of portal episodes and the rate for the duration of the patient's study involvement.

To estimate the association of patient-level factors and frequency of portal usage, we used contingency table methods that accounted as needed for the binary, ordinal, or nominal nature of the factors. In a simple longitudinal analysis, we estimated the association of any portal use and outcomes over time (asthma control and quality of life) (10-12), after controlling for baseline patient-level covariates. Specifically, using generalized estimating equations and an independence working correlation structure to allow for correlation of observations over time within patient, we fit a longitudinal model with time represented as a spline, baseline covariates, and exposure-by-time interactions. We then augmented the data to be able to predict from the original data to time from randomization to 12 months.

This approach allowed us to estimate expected values at 0 and 12 months of follow-up although no one was measured exactly at 12 months, and many patients were measured several months before and/or after 12 months. Additional details of our approach to the analysis of outcomes based on irregular data collection times appear elsewhere.(13) Finally, we examined the association of the overall rate of portal use during the course of the study and the probability that the patient would have seen a physician within the 6 months prior to each data collection time in keeping with guidelines for asthma patients.(14) This approach allowed examination of whether patients who visited their asthma clinicians regularly and within recommendations of existing guidelines might be more likely to use the portal.

RESULTS

Of the 301 study patients, all of whom received in-person training on access to and usage of the portal, 170 participants (56%) used the portal independently at least once, 58% in the

home visitor group and 55% in the portal-only group. Both intervention groups used the portal with the same rates. (Table I). However, our examination of raw data on individual patients suggested that some patients used the portal often, and within a single episode of use, completed activities as if they were either experiencing difficulty with the user interface or needed to check their information repeatedly. Sometimes within a single usage episode these patients toggled back and forth from one activity to another.

Regular usage was a distinct exception. Portal use over the entire enrollment in the study, which lasted as long as 33 months, was exceptionally sparse, especially when one considers that the patients suffered from uncontrolled asthma and often other chronic conditions. For example, of the 170 patients who used the portal, 53% (90/170) recorded episodes at most once every 3 months. Based on patient focus groups and pilot studies, half of potential study participants had computer access at home or work. In the patients actually enrolled, some could not or chose not to use the portal. (Table E1) "I had issues logging in and out so I never used it." and "Didn't really have time" were two examples from interviews. 16% expressed concern that portal information may not be confidential and 62% had little confidence that the portal could improve communication with their doctor. (Table E1)

Among the patients who used the portal at least once, the most frequent portal activities were passive, such as reading messages (85% of users), reviewing appointments (83%), and reviewing lab results (82%), rather than active, scheduling appointments, requesting refill of medications, and sending messages to health care personnel (Table II).

Portal usage and effect of home visits

There was little difference between groups, home visitor versus portal training only, in type or frequency of portal use activity (Table II). This lack of improvement in usage with regular home visits occurred in spite of the regular inquiry by the community health workers about access to the portal.

Portal activity categories by frequency of activity in episodes

Table III reports the activity category of portal usage and the frequency of occurrence in episodes (defined by logging on and off). Some activities were far more common than others. For example, patients read messages two or more times in more than 40% of all episodes. In these episodes, patients either viewed more than one message or they read one message and then reread the message. Likewise, reviewing appointment schedules or lab results occurred in many episodes of portal usage. By contrast, few episodes revealed portal usage scheduling appointments, medication review or refill, or immunization checks. Different portal activity selections received markedly varying usage.

Portal usage and frequency of visits

We found no association of the rate of portal usage during the patient's observation time and the degree to which the patient adhered to the guidelines (11) of having an asthma visit in the last six months.

Portal usage and asthma outcomes

Although we anticipated that more frequent portal usage might reflect increased communication with the physician and enhanced patient-involvement in care, we found no association between portal usage rates and the outcomes of asthma control or asthma quality of life at 12 months compared to baseline. In spite of the formal introduction and training, only 56% of the recruited patients ever used the portal. Table IVa reports the expected values of asthma control at 0 and 12 months by portal use (none or some). The subjects who did not use the portal improved more over time than those who did, but the confidence bounds were wide and included zero for the between group difference of changes over time. Table IVb reports the expected values of quality of life at 0 and 12 months by portal use (none or some). The subjects who used the portal improved only slightly more over time than those who did not, but the confidence bounds were wide and included zero for the between group difference of changes over time. We also found that patients with additional chronic diseases like diabetes and hypertension, or with evidence of uncontrolled asthma manifested by a hospitalization in the past year were less likely to use the portal. (Table E4). However, portal use was not associated with asthma severity measured by FEV1 (Table E5).

DISCUSSION

Among 301 adults with uncontrolled asthma, living in low income, high poverty neighborhoods in Philadelphia, we found only modest use of the patient portal, even after formal enrollment in the study and in-person training. This limited level of patient-initiated engagement with the electronic health record occurred in spite of planned and repeated education and contact with patients who after giving informed consent, agreed to participate in a study that could benefit them directly. Our experience of 56% usage tracks closely with the report of Ancker (4) and colleagues (60% usage among patients with an access code), Goel and colleagues (69% of those invited chose to participate) (15), and Smith and colleagues (16) (58%), but was more than that reported in other studies of 31% (17), 29% (18), and 16% (19). This degree of disinterest in the patient portal reflects the effort that lies ahead to implement portal-dependent interventions. One factor inhibiting use might be limited broadband access via a home computer.(20) For example, Graetz and colleagues (21) found that broadband access was an important factor to portal use. Our patient population relied heavily on cell phones, rather than home computers, for internet access. Although our testing of the portal showed good screen resolution on an ipad mini, and likely acceptable functionality using a smart phone, we surmise that patients could have avoided portal use without access to a home computer screen. We did not track the actual means of access to the portal used by our patients. If future research on portal usage reveals that internet access presents a barrier, then improved portal usage will likely require greater broadband access for populations known to have economic barriers.(22)

Among those who actually used the portal, frequency of use was highly variable and activities were more likely to involve reading results or messages than writing to clinicians or requesting appointments. This level of patient engagement occurred in practices that were aware of the ongoing initiative and is consistent with systematic reviews on the effects of portal usage on patient visit frequency, appointment making, or outcomes.(23)

This study has several strengths. It reports access of a population of patients, who were contacted repeatedly through formal, in-person education on portal usage. It allows examination of patient portal usage outside of specific coaching. Our study went beyond counting "clicks", when a user points to a menu choice and selects via a key or mouse. (24) We developed the "episode" as a more meaningful unit of analysis. Finally, our study measured disease specific outcome over time among patients with good portal follow-up.

Our findings support prior studies (16, 25) that suggest that the "digital divide" extends to the use of an internet-based portal, and perhaps especially among patients most in need of repeated contact with clinicians. These findings should not evoke surprise. Patients who live in poverty often lack home computers, and thus will be less likely to access web-based applications, including electronic-health-record-based patient portals. Effective portal use requires good and convenient internet access. We did not find such access availability at least for low-income patients with chronic conditions. Comparing data from the 2015 American Community Survey by the US Census Bureau, 53% of our patients owned a computer and 68% had an internet account compared to 78% and 77% nationally (See Table E1). (26) Some patients shunned the portal for fear that their private health information might become public. Many expressed doubt that it would improve communication with their doctor. Others relied on family and friends to access the portal. Our hands-on focused in-person portal training for all study participants did not raise usage rates much above 50%. Our results suggest that for inner city low income asthma patients, portals regardless of the elegance of design or ease of use, will not be effective at a population level when so many don't even attempt to log in.

Studies of patient portal activity should consider frequency and regularity of usage over time and not simply whether a patient activated an account. Even among the patients who invoked the portal during the study period, relatively few features saw regular use. One episode per 3 months, among patients with uncontrolled asthma and other chronic conditions reflects only intermittent contact with clinicians. In addition, even among users some portal options received little use. Appointment making activity was infrequent, perhaps because the give and take discussion required to marry the schedules of physician and patient occurs more efficiently via telephone.

Our findings on the lack of association of portal usage and frequency of appointments are also consistent with prior studies (27). However, we cannot tell from this analysis alone whether more appointments were the result of the patient being sicker and in need of more medical contact or whether more appointments resulted in more communication with the provider resulting in better health. The absence of association of key primary asthma-related outcomes, even among the patients with regular home visitors to offer guidance and assistance might reflect complex relationships between illness and use of a portal. Prior research (28) suggested that support for portal use would be necessary for patients with chronic diseases. But sicker patients might be more likely to use the portal for regular contact, or more likely to forego the portal in favor of more personal contact.

Expanded usage of the portal might not improve patient care if the time needed for clinicians to maintain electronic communication competes, as it does, with time for direct patient

contact at office visits.(29) Future studies of internet-based interventions or EHR features should always consider the impact on outcomes. Portal redesign, for example, with larger screens and flexible selections tailored to the illnesses and needs of the patient, might enhance the patient experience and produce higher rates of patient engagement. But such improvements might still not reach the patients who lack the internet infrastructure to participate with their care over the web.

These studies of transaction-based datasets have inherent limitations. We used only a single patient portal, Epic MyChart, and for that reason, we cannot predict what an attempt to reproduce these findings might uncover with alternative patient portals. Nor can we predict how next generation database designs might influence an investigator's findings of frequency of activities among patient users. To the extent that patient data transactions in a portal database might reflect patient responses to clinician activity, we cannot assume that the same patients using the same portal would experience the same frequency and type of portal activity with a different set of clinicians. We also cannot rule out that patients used the internet both outside of the portal and via link from within the portal to obtain general health care information. These activities are not tracked in the portal database.

In this study, our patients with asthma demonstrated limited acceptance of an electronic medical record patient portal, and the patterns of usage that did occur were not associated with clinical improvements. While holding great promise, future research on patient portals should focus on assuring access, effective education, and user interfaces that support patient-oriented outcomes. Revisions should focus on adaptions for older, more vulnerable groups.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Abbreviations used

CHW	Community Health Worker
EHR	Electronic Health Record
HV + PT	Home Visit plus portal training
PT	Portal training

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HIGHLIGHTS BOX

What is already known about this topic?

Patients increasingly are encouraged to communicate with their medical team through internet-based portals to the electronic medical record. Whether such communication is successful in low-income inner-city adults, a group with high asthma morbidity, is unknown.

What does this article add to our knowledge?

In these adults with uncontrolled asthma, living in low-income neighborhoods, the portal is rarely used. Lack of access is an important barrier. For those who used the portal, there was no association with asthma outcomes.

How does this study impact current management guidelines?"

Expectations about and implementation of web-based patient portals need revision to accommodate low–income patients with uncontrolled asthma and especially those with additional medical problems.

Table I.

Rates of portal episodes during the course of study in which all patients received portal training (PT). One half of the patients were randomized to additionally receive home visits from community health workers who assisted with asthma care coordination and reinforced training in the use of the patient portal (HV + PT).

	Home Visit and Portal Training (HV+ PT)	PT only	All
Rates of portal episodes by patient N(col %)	**N=151**	**N=150**	**N=301**
No usage	64(42%)	67(45%)	131(44%)
Less than once per quarter	46(30%)	44(29%)	90(30%)
Once per quarter up to 1/month	15(10%)	16(11%)	31(10%)
At least once per month	26(17%)	23(15%)	49(16%)

PT= Portal Training, HV + PT=Home Visits from community health workers in addition to Portal Training.

Note: Portal usage during the months of study participation was similar in the home visitor and the portal only groups. Rates do not include sessions on days when home visitor was working with participant.

Table II.

Portal activity by patient among patients who ever used the portal by intervention group: Portal only (PT) versus Home Visit in addition to portal training (HV + PT).

	Home Visit and Portal Training (HV+ PT)	Portal Training Only	All Patients
	N=87	N=83	N=170
Portal use by activity category among portal users	**n (% of portal users)**		
Read Message	75(86%)	69(83%)	144(85%)
Write Secure Message	30(34%)	24(29%)	54(32%)
Review lab result	76(87%)	63(76%)	139(82%)
Review appointment date/location	78(90%)	63(76%)	141(83%)
Schedule appointment	32(37%)	19(23%)	51(30%)
Review medication list	52(60%)	47(57%)	99(58%)
Review immunization record	48(55%)	40(48%)	88(48%)
Request medication renewal	52(60%)	41(49%)	93(55%)
Review visit information	49(56%)	44(53%)	93(55%)

Note: This table includes only patients who used the patient portal independently of any assistance from the study staff or home visitors. We exclude all portal usage on days during which there was staff contact with the patient. Portal usage was first identified by an episode of use – defined by a login and logoff or a lapse of time between keystroke. Then, we categorized patient portal usage at the patient keystroke level within episode and counted activity type per episode. Finally, we calculated the number of patients who had ever used the Portal for the key activities (See Appendix) for the definition of key activities in any portal usage episode between the time of randomization and the time of the last data collection. See technical appendix (Appendix) for details in methods for Portal data.

Table III.

Portal use by major activity and by episode (n=2720) during active study involvement among 170 patients who used the portal at least once.

Major Activity	Number (%) of Episodes without major activity	Number (%) of all episodes with 1 major activity	Number (%) of episodes with 2+ Major activities
Read Message	982(36.1)	545(20.0)	1193(43.9)
Send Message	2430(89.3)	232(8.5))	58(2.1)
Review Appointment	1463(54.8)	508(18.7)	749(27.5)
Schedule Appointment	2579(94.8)	124(4.6)	17(0.6)
Review Lab Results	1672(61.5)	254(9.3)	794(29.2)
Review Visit Results	2366(87.0)	144(5.3)	210(7.7)
Review Medications	2433(89.5)	176(6.5)	111(4.1)
Refill Medications	2456(90.3)	115(4.2)	149(5.5)
Review Immunizations	2525(92.8)	103(3.8)	92(3.4)

Note: Episodes were defined by a log in and log off, or by inactivity for more than 30 minutes. Each episode could have one or more activities of one or more types. Portal use activities were more often reading messages, monitoring appointments, and reviewing lab results. Less common activities were sending messages and scheduling appointments. An episode could have more than one type of major activity; if for example, a patient started an episode and read the same message more than one time or had more than one message to read. This repeated major activity in a single episode occurred in 43.9% of the episodes.

Table IV.

Association of asthma patient outcomes over 12 months of follow-up and their rate of portal usage.

a. Asthma control expected values at 0 and 12 months, by patient portal use.*

Patient group	n	Expected Value at 0 months	Expected Value at 12 months	Difference 0 to 12 months (95% CI†)
No Portal Use	131 (43.5%)	2.51	2.03	−0.48 (−0.76, −0.20)
Some Portal Use	170 (56.5%)	2.34	2.06	−0.29 (−0.58, −0.03)
Difference				+0.20 (−0.21,+0.57)

*Asthma control is measured by the Juniper Asthma Control Questionnaire.[12, 10] 1.5 or greater is the accepted threshold for lack of control.[10]

†Percentile confidence intervals (CI) using 999 bootstrap re-samplings.

b. Quality-of-life expected values at 0 and 12 months, by patient portal use.*

Patient group	n	Expected Value at 0 months	Expected Value at 12 months	Difference 0 to 12 months (95% CI†)
No Portal Use	131 (44%)	3.51	4.10	0.58 (0.23, 0.92)
Some Portal Use	170 (56%)	3.74	4.26	0.51 (0.23, 0.78)
Difference				−0.07 (−0.50,+0.35)

*Quality of life is measured by the Mini Asthma Quality of Life Questionnaire.[11] This 15-item questionnaire has a 7-point response scale. The score is the mean of the item results. A 0.5 unit change in score is considered clinically meaningful

†Percentile confidence intervals (CI) using 999 bootstrap re-samplings.

Note: Higher scores indicate better quality of life. Positive changes reflect improvement.