Patients, care partners, and shared access to the patient portal: online practices at an integrated health system

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ABSTRACT

Objective To describe the characteristics and online practices of patients and "care partners" who share explicit access to a patient portal account at a large integrated health system that implemented shared access functionality in 2003.

Materials and Methods Survey of 323 patients and 389 care partners at Geisinger Health System with linked information regarding access and use of patient portal functionality.

Results Few (0.4%) registered adult patient portal users shared access to their account. Patients varied in age (range: 18-102); more than half had a high school education or less (53.6%). Patient motivations for sharing access included: to help manage care (41.9%), for emergency reasons (29.7%), lack of technology experience (18.4%), or care partner request (10.0%). Care partners were parents (39.8%), adult children (27.9%), spouses (26.2%), and other relatives (6.1%). Patients were more likely than care partners to have inadequate health literacy (54.8% versus 8.8%, P < .001) and less confident in their ability to manage their care (53.0% versus 88.1%; P < .001). Care partners were more likely than patients to perform health management activities electronically (95.5% versus 48.4%; P < .001), access the patient portal (89.2% versus 30.3%; P < .001), and use patient portal functionality such as secure messaging (39.6% versus 13.9%; P < .001). Care partners used their own credentials (89.1%) and patient credentials (23.3%) to access the patient portal.

Discussion and Conclusion Shared access is an underused strategy that may bridge patients' health literacy deficits and lack of technology experience and that helps but does not fully resolve concerns regarding patient and care partner identity credentials.

Keywords: health information technology, electronic health records, consumer health information, health literacy

BACKGROUND AND SIGNIFICANCE

The patient portal, defined as a personal health record that is tethered to a provider-sponsored electronic health record, has assumed a prominent role in efforts to engage patients in their care. Through a patient portal, individuals may view laboratory test results and sections of their medical record, perform health management activities such as filling prescriptions or scheduling medical appointments, and communicate with health professionals using secure email. Early studies describing outcomes of use of the patient portal are mixed but suggest that it substitutes in-person and telephone contacts with providers, and is associated with improved patient retention, quality of care, and adherence to prescribed treatments.

However, not all patients are equally likely to access or are capable of using a computer or mobile device. Those who are older and less educated, with less technology experience and fewer economic resources, are less likely to use a patient portal^{8–11} and less able to perform health management tasks electronically.¹² In light of the rapid spread of health information technology and a growing reliance on secure messaging as a mainstream mode of communication, ^{7,13} there is a pressing need to identify and disseminate strategies that bridge this "digital divide."^{14,15}

Patients with some of the most complex health needs navigate health system processes with family members or close friends who schedule and attend medical visits, coordinate care, manage medications, assist with self-care tasks, and facilitate transitions across

settings of care. ^{16,17} Likewise, persons with inadequate health literacy more often express a desire for and benefit from the involvement of family members during in-person medical visits. ^{18–21} Prior studies have found that family members facilitate patient access and use of the patient portal ^{22,23} and may informally use the patient portal themselves. ³ As many patients are interested in sharing electronic health information with family members or close friends, ^{2,22–24} strategies that allow patients to clarify and execute preferences for engaging family members or friends in care merit attention and could have utility.

OBJECTIVE

Some electronic health record vendors have the capacity to allow patients to share access to their patient portal account with a family member or friend through "proxy" portal account functionality. National information regarding use of shared access does not exist, but available information indicates that health system implementation of shared access functionality has been variable and that patient uptake is limited. Prior studies have evaluated patients' experiences with accessing and using their own patient portal account and preferences for sharing their electronic health information with others. However, no studies to date have examined the motivations underlying patients' decisions to explicitly share access to their patient portal account or the identities of the individuals they select to share access to their account, referred to herein as "care partners."

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The objective of this study was to examine the characteristics, circumstances, and online practices of patients and care partners at a large integrated health system with an established electronic medical record that has more than a decade of experience operating a patient portal with shared access functionality.

MATERIALS AND METHODS

Setting

Geisinger Health System is an integrated health system providing comprehensive medical care to approximately 3 million patients living in central Pennsylvania. The physician-led health system employs more than 1000 physicians and 600 advanced practitioners and operates more than 2000 licensed beds across 8 hospital campuses. Geisinger Health System implemented its electronic health record in 1996 and its patient portal, MyGeisinger, has been operational since 2001. Since 2003. MyGeisinger has allowed patients to share access to their patient portal account with care partners. To grant shared (proxy) access, patients must provide written documentation authorizing their designated care partners to have access to their MyGeisinger account, or care partners may provide written documentation that they have power of attorney for the patient. Care partners are provided with credentials (login and password) that allow them to access the electronic medical record and communicate on behalf of patients with health professionals involved in their care. Care partners are asked to accept a shared access disclaimer affirming their relationship with the patient each time they enter a patient record. Patients may elect to share access to their patient portal account with more than one care partner, and care partners may share access to the patient portal accounts of more than one patient. Some care partners may informally access the patient portal with patient credentials; however, these interactions cannot be distinguished from patient interactions and are documented as being undertaken by the patient.

Participants and Participant Recruitment

Geisinger patients aged 18 and older who authorized a care partner to share access to their patient portal account as of April 9, 2014, were eligible for this study, as were their care partners. Because we expected that patients who shared access to their patient portal account would vary in technology access and ability to complete an electronic survey, we recruited patients and care partners using a phased approach and 3 modes of data collection. Patients and their care partners were initially contacted using secure messaging through their patient portal accounts. Eligible patients and care partners received an electronic message explaining the purpose of the study and inviting them to answer a brief online survey. Two weeks later a reminder email was sent to all eligible patients and care partners who had not completed the initial electronic survey and had not declined participation. Four weeks after the initial email, eligible patients and care partners who had not responded to the survey and had not declined participation were mailed a letter explaining the purpose of the study and inviting them to complete a paper survey, or to opt out of the study by calling a toll-free telephone number. Eligible patients and care partners who did not opt out of the survey were contacted by telephone and offered participation in a telephone survey. Participant consent varied by mode of survey administration. Those who responded to electronic or telephone surveys provided electronic or oral consent, respectively, whereas those who responded by postal survey gave implied consent by returning their completed survey. So as to be able to characterize the study population, we obtained a waiver of consent to extract demographic and health services utilization information from eligible patients' electronic health records. Our study protocol

was approved by the Geisinger Health System Institutional Review Board (2013-0423).

Patient and Care Partner Characteristics

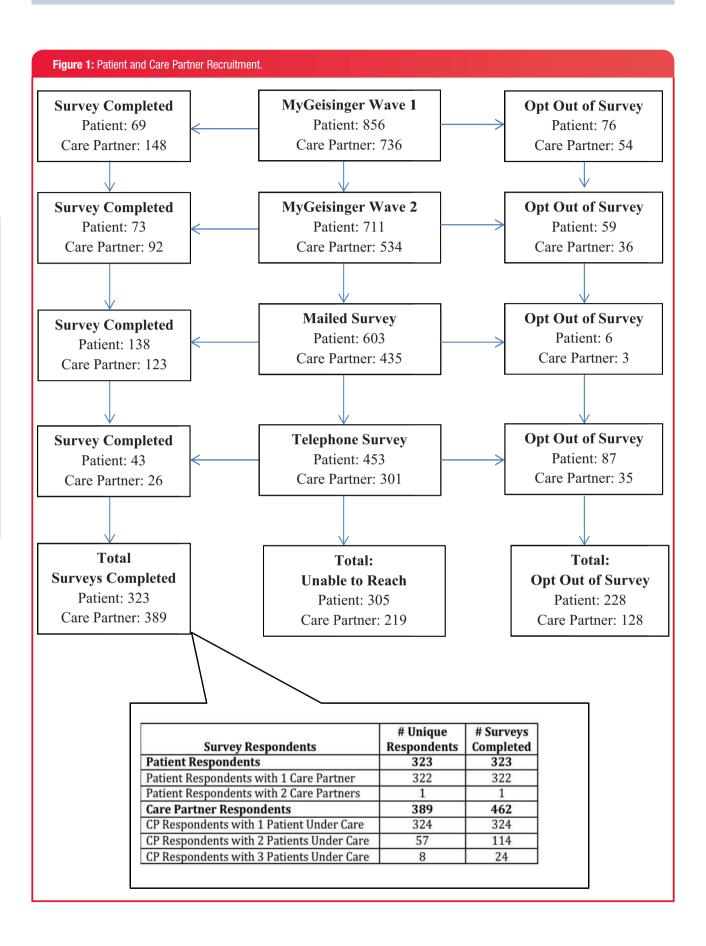
Information about eligible patients' age, gender, race/ethnicity, medical conditions, prescription drug use, and prior health services use was extracted from the electronic health record. This information was used to construct a summary measure of patient comorbidity, using the Charlson comorbidity index.³⁰ We asked patients and care partner participants to report sociodemographic characteristics, health status, online practices, use of health information technology, and perceived preparedness to undertake health management activities. To obtain a measure of self-reported health literacy, we administered a health literacy screening question ("How confident are you filling out medical forms by yourself?") that has been validated with other more extensive health literacy measures.³¹ In keeping with prior studies, we considered responses of "somewhat." "a little bit." or "not at all" as inadequate health literacy; responses of "don't know" were categorized as missing. Patients were asked for the reason they shared access to their patient portal account with a care partner. Care partners were asked about their relationship to the patient, travel time to reach the patient's place of residence, frequency of interactions with the patient. and whether they had power of attorney for the patient. The relationships of 54 care partners were recoded based on biological plausibility of their age (eg, when a care partner was 18-40 years older than a patient <25 years of age, we assumed he or she was a parent rather than an adult child). Care partners who indicated that they performed one or more health management activities using a computer were asked whether they accessed the patient's health information using their own or the patient's credentials/login when accessing MyGeisinger. Patient and care partner online practices were examined from self-reported survey responses as well as date- and timestamped digital recordings of MvGeisinger interactions between July 19, 2013, and July 18, 2014.

Statistical Analysis

Information from the electronic health record was used to compare characteristics of eligible patients who responded to the survey with those who opted out or who could not be reached. Characteristics of patients and care partners were examined using simple descriptive statistics (frequency distributions, group means), stratified by patient age. We separately examined patient and care partner sociodemographic and health characteristics and attributes of their relationship, including nature and frequency of contact. To examine clinical and quality-of-care implications of shared access, we compared patient and care partner educational attainment, health literacy, and perceived preparedness to undertake patient health management activities. Finally, we compared patients' and care partners' online practices based on responses to survey questions as well as digital recordings of actual MyGeisinger use. Between-group and age differences for respondents and nonrespondents were evaluated using chi-square or Fisher's exact tests of statistical significance, as appropriate. Comparisons of patients and care partners were determined using generalized estimating equations to take into account correlations between observations. As item nonresponse was low, we report the extent of missingness in each table and provide estimates for participants who responded. All analyses were performed using SAS version 9.4.32

RESULTS

Approximately 240 000 adult patients registered for MyGeisinger as of April 2014, of whom 856 (0.4%) shared access to their account with a



RESEARCH AND APPLICATIONS

care partner and were eligible for this study. Of those 856 eligible patients, 323 (37.7%) completed a survey, 226 (26.4%) refused participation, and 307 (35.8%) could not be reached (Figure 1). Of 736 eligible care partners, 389 (52.8%) completed a survey, 128 (17.4%) refused participation, and 219 (29.8%) could not be reached. Patient respondents were more likely to be female (P= .004) but did not differ significantly from nonrespondents in their age, number of prescribed medications, dementia diagnosis, comorbidity profile, prior-year hospitalization, or prior-year emergency room use (Table 1).

Eligible patients varied in age from 18 to 102 years, and were relatively evenly represented among young adults <25 years (34.3%), working-age adults 25-64 years (28.4%), and adults 65 years or older (37.3%). Approximately 10% of patients were hospitalized and 20% had 1 or more emergency department visits in the previous year within the Geisinger Health System. Few patients had a diagnosis of dementia (4.7%). Nearly 1 in 4 patient respondents (23.7%) rated their health as fair or poor (Table 2). Patients indicated that they shared access to their patient portal account to facilitate involvement of care partners in managing health care activities (41.9%), for emergency reasons (29.7%), because they themselves do not use a computer (18.4%), or because shared access was requested by their care partner (10.0%). These reasons varied significantly by age. Older adults most often shared access to their patient portal account due to lack of computer use (40.5%), working-age adults most often shared access for emergency reasons (47.6%), and young adults most often shared access to facilitate help from their care partner with health management activities (62.6%).

Care partners were parents (39.8%), adult children (27.9%), spouses (26.2%), and other relatives or friends (6.1%); few (<1%) were hired caregivers or friends. Most patients shared access with a care partner who was employed (69.2%) and lived with (57.0%) or in close proximity to (19.3%) the patient, with whom they communicated daily (73.6%). Nearly half (46.5%) of care partners reported having power of attorney for the patient. Most care partners (90.5%) were also patients of the Geisinger Health System. Of this group, nearly all (96.5%) indicated that they access MyGeisinger for information about their own health.

Patients were twice as likely as care partners to have a high school education or less (53.6% versus 22.0%) and were half as likely to have obtained a college degree or more (21.8% and 44.3%, respectively, P < .001; Table 3). Patients were more than 6 times as likely to have inadequate health literacy as compared with care partners (54.8% versus 8.8%, respectively, P < .001). Patients were less likely than care partners to report being "quite a bit" or "very" prepared to manage their health (53.0% versus 88.1%), health information (43.2% versus 89.1%), and office visits with health professionals (66.7% versus 86.4%), and to understand their plan of care (61.3% versus 83.4%) and their health and medical conditions (67.5% versus 90.7%; P < .001, all contrasts).

Care partners were more likely than patients to report using the Internet daily (87.6% versus 55.0%, P < .001) and using a computer to perform health management activities (95.5% and 48.4%, P < .001; Table 4). Care partners and patients reported using a computer most often to find health information (81.8% and 43.1%, respectively), track the patient's medical information (79.1% and 28.5%), communicate with the patient's doctor (68.3% and 26.1%), and schedule medical appointments (53.7% and 24.1%), and less often to fill prescriptions for medications or medical supplies (39.9% and 19.9%) or to check billing (31.1% and 18.2%). Most (89.1%) care partners reported that they used their own credentials to access the patient's health information through the patient portal, but nearly 1 in

Table 1: Characteristics of patients who have shared access to their patient portal account with a care partner, stratified by participation in study

Patient characteristics	Nonrespondent (%)	Respondent (%)	Total (%)	<i>P</i> -value
Number	533 (62)	323 (38)	856 (100)	
Age (years)				.216
<25	35.1	33.1	34.3	
25–64	29.8	26.0	28.4	
65 or older	35.1	40.9	37.3	
Gender				.004
Male	56.1	45.8	52.2	
Female	43.9	54.2	47.8	
Numbers of medication subclasses ^a				.464
<5	38.9	34.7	37.3	
5–10	32.1	34.1	32.8	
10+	29.0	31.3	29.9	
Prior-year emergency room visit ^a				.462
None	80.5	78.4	79.7	
1 or more	19.5	21.6	20.3	
Prior-year hospitalization ^a				.261
None	90.8	88.4	89.9	
1 or more	9.2	11.6	10.1	
Dementia diagnosis ^a				.164
No	94.5	96.6	95.3	
Yes	5.5	3.4	4.7	
Charlson Comorbidity Index ^a				.266
0	57.1	51.9	55.1	
1	20.8	21.6	21.1	
2	10.9	10.9	10.9	
3	11.3	15.6	12.9	

^aBased on 524 nonrespondents and 320 respondents with sufficient electronic health record data to construct measures; 9 nonrespondents and 3 respondents without a Geisinger primary care physician or any health system encounters, prescribed medications, or diagnosed conditions were excluded.

4 (23.3%) reported using patient credentials. Care partners were 3 times as likely as patients to have accessed the patient's portal account in the prior year (89.2% versus 30.3%, P<.001), to have viewed information about the patient's health (P<.001 all contrasts), or to have engaged in sending direct email messages to health care providers (39.6% versus 13.9%, P<.001).

Study Participant Characteristics	Age of Patient (column %)			Total (%)	<i>P</i> -value
Patient Characteristics	<25 years	25–64 years	65 + years		
Distribution by age (row %)	107 (33.1)	84 (26.0)	132 (40.9)	323 (100.0)	
Self-rated health					<.001
Excellent or very good	59.8	41.0	26.7	41.4	
Good	31.8	37.3	35.9	34.9	
Fair or poor	8.4	21.7	37.4	23.7	
Reason for granting shared access					<.001
Do not use a computer	0.9	6.1	40.5	18.4	
Care partner helps me manage my health	62.6	34.1	29.8	41.9	
In case of emergency	22.4	47.6	24.4	29.7	
Because my care partner asked me	14.0	12.2	5.3	10.1	
Care Partner Characteristics					
Distribution by patient age	155 (33.5)	127 (27.5)	180 (39.0)	462 (100.0)	
Relationship to patient					<.001
Parent	96.8	26.0	0.6	39.8	
Adult child	0.0	1.6	70.6	27.9	
Spouse	1.3	63.8	21.1	26.2	
Other relative or friend	1.9	8.7	7.8	6.1	
Employment ^a					.363
Employed or self-employed	82.1	71.8	63.4	72.0	
Homemaker or student	9.3	7.3	2.3	6.0	
Unemployed or unable to work	6.6	5.6	6.3	6.2	
Retired	2.0	15.3	28.0	15.8	
Frequency of communication with patient					<.001
Daily	78.1	87.4	60.0	73.6	
Every few days	16.8	5.5	28.9	18.4	
Once per week or less often	5.2	7.1	11.1	8.0	
Travel time to patient residence					<.001
Co-reside	71.4	79.5	28.9	57.0	
<15 min	7.1	9.4	36.7	19.3	
15–60 min	6.5	5.5	21.7	12.1	
>60 min	14.9	5.5	12.8	11.5	
Power of attorney for patient ^a	26.5	41.7	66.7	46.5	<.001

altem nonresponse < 1.0%, with the exception of care partner employment (2.6%) and power of attorney status (8.4%).

DISCUSSION

This is the first study to describe the motivations, characteristics, and online practices of patients who have explicitly shared access to their patient portal accounts with care partners. We found that patient and care partner registration for shared access was low more than a decade after implementing this functionality at a large integrated health system with an established electronic health record. Patients varied widely in age and in motivations for sharing access to their patient

portal account; more than half had inadequate health literacy and a high school education or less. Care partners were overwhelmingly family members who were comparatively better educated, more confident in their ability to manage aspects of patient health, and more frequent users of health information technology than patients. Relative to patients, care partners were more likely to perform health management activities electronically and to use features of patient portal functionality such as direct messaging. Although most care partners

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Table 3: Patient and care partner educational attainment, health literacy, perceived ability to manage health

Educational Attainment, Health Literacy, and Perceived Ability to Manage Patient Health	Patient (%)	Care Partner (%)	<i>P</i> -value
Educational attainment ^{a,b}			<.001
High school or less	53.6	22.0	
Some college or 2-year degree	24.6	33.7	
College or beyond	21.8	44.3	
Health literacy (confidence completing medical forms) ^a			<.001
Extremely or quite a bit	45.2	91.2	
Somewhat, a little bit, or not at all	54.8	8.8	
Preparedness to manage your (the patient's) care			<.001
Quite a bit or very	53.0	88.1	
Not at all, a little bit, somewhat	47.0	11.9	
Preparedness to manage your (the patient's) health information ^b			<.001
Quite a bit or very	43.2	89.1	
Not at all, a little bit, somewhat	56.8	10.9	
Preparedness for office visits (you attend with the patient) ^b			<.001
Quite a bit or very	66.7	83.4	
Not at all, a little bit, somewhat	33.3	13.6	
Understanding of your (the patient's) plan of care			<.001
Quite a bit or very	61.3	83.4	
Not at all, a little bit, somewhat	38.8	16.6	
Understanding of your (the patient's) health and medical conditions			<.001
Quite a bit or very	67.5	90.7	
Not at all, a little bit, somewhat	32.5	9.3	

^aResponses are presented for 389 care partners with shared access to the patient portal accounts of 462 patients. Care partner responses regarding perceived preparedness to undertake health management activities are based on responses specific to the 462 patients for whom they have access to the patient portal account. ^bItem nonresponse <1.0%, with the exception of patient education (1.9%), patient-reported preparedness to manage health information (2.5%), and care partner—reported preparedness for office visits (1.5%).

accessed the patient portal using their own credentials, nearly 1 in 4 reported accessing the patient portal using patient credentials. Taken together, the study results suggest that shared access is an underused strategy that may help bridge patients' health literacy deficits and lack of technology experience by allowing family members to participate in care. Results indicate that shared access helps but does not fully overcome the challenges of differentiating patients and care partners in electronic health system interactions.

The limited uptake of shared access to the patient portal found in this and one other $study^{27}$ stand in stark contrast with patients'

Table 4: Self-reported and actual online practices of patients and care partners

Self-Reported Online Practices ^{a,b}	Patient (%)	Care Partner (%)	<i>P</i> -value
Self-reported frequency of Internet use			
Daily	55.0	87.6	
Every few days	3.6	7.0	
About once a week	2.9	2.3	
Every few weeks	0.0	1.0	
Rarely or never	38.5	2.1	<.001
Perform health management activities electronically			<.001
Find information online	43.1	81.8	
Track medical information (eg, lab results)	28.5	79.1	
Communicate with health providers	26.1	68.3	
Track health information (eg,blood pressure)	23.4	60.0	
Schedule appointments	24.1	53.7	
Fill medications or obtain medical supplies	19.9	39.9	
Check billing information	18.2	31.1	
Performed 1 or more of the above activities electronically	48.4	95.5	
Credentials used by care partner to access patient portal ^c			
Reports having used own (care partner) credentials		89.1	
Reports having used patient credentials		23.3	
Actual Online Practices Using MyGei	singer ^d		
Logged in to MyGeisinger	30.3	89.2	<.001
Viewed laboratory results	21.4	59.5	<.001
Viewed medication list	20.4	52.2	<.001
Viewed patient problem list	18.0	47.8	<.001
Viewed admission records	13.0	24.5	<.001
Viewed or scheduled medical appointments	9.6	24.0	<.001
Direct email message sent to health care providers	13.9	39.6	<.001

^aCare partner responses are based on 389 distinct care partners with shared access to the patient portal accounts of 462 patients (some care partners had shared access for more than 1 patient). ^bItem nonresponse varied from 3.7% to 5.0% for patients and was <1.0% for care partners, with the exception of responses regarding filling medication prescriptions or obtaining medical supplies (1.3%) and checking billing information (1.1%). ^cResponses are not mutually exclusive and may therefore sum to >100%. ^dInformation from date-and time-stamped MyGeisinger interactions between July 19, 2013, and July 18, 2014.

expressed preferences for sharing their electronic health information with family members and close friends. 2,22-24 A survey of out-ofhome family caregivers identified numerous barriers to technology use, including poor awareness, cumbersome credentialing processes, and restrictive registration protocols meant to safeguard data privacy and security.33 Variable state laws affect provider implementation of patient portal access, most notably for adolescents.³⁴ Some organizations do not offer shared access functionality as a part of the patient portal.³⁵ Without the ability to access the patient portal using their own credentials, some family members may instead access the patient portal under the guise of being the patient, using the patient's credentials.³ In this study, nearly 1 in 4 care partners stated that they access the patient's portal account using patient credentials rather than their own. While we did not ask the reasons care partners chose to use patient credentials rather than their own, these findings suggest that the availability of shared access functionality may not be sufficient to differentiate its value beyond that of patient access, especially if use of shared access functionality involves additional steps relative to patient access. As learning health systems seek to effectively engage patients and families, the ability to distinguish whether they are electronically interacting with patients, family members, or both will be increasingly important in the delivery of appropriate care. Efforts to streamline credentialing processes, simplify functionality, and promote use of shared access may help to achieve this goal.

The wide variability in patients' motivations for sharing access to their patient portal account reflects diverse circumstances and multifaceted ways in which family members facilitate care. Other studies have found that nearly all patients want control over their electronic health information, but they vary considerably in preferences for sharing their information with others. Affording patients the ability to selectively authorize whether and which care partners may interact with the health system on their behalf, and what privileges they are granted, Affording patients the ability are granted, and what privileges they are granted, and what privileges they are granted, access from patient access. Attending to diverse patient capabilities, motivations, and preferences will be important if health information technology is to attain its promise as a vehicle for engaging patients.

The finding that care partners were 6 times less likely than patients to have inadequate health literacy is consistent with foundational frameworks^{37,38} and accumulating evidence that persons with low educational attainment and inadequate health literacy more often desire and benefit from the active involvement of family members and friends in face-to-face interactions with health care professionals^{18–21,39} and online health system interactions.^{22,23} Collectively, this literature suggests that more widespread and systematic clarification and execution of patients' desire to provide family members and friends with access to their patient portal account may be an effective way to attenuate socioeconomic disparities in computer access and use within the context of a health system that is increasingly reliant on electronic health information.

Study results are subject to several limitations. Our study sample focused exclusively on patients and care partners who registered to explicitly share access to the patient portal account, and we are therefore unable to comment on the characteristics, motivations, or online practices of family members or friends who have not been explicitly granted shared access and informally access the patient portal account using patient credentials. As we report on the experiences of patients and care partners at a single health system, our findings may not generalize to other electronic health record vendors, provider systems, or regions of the country. The patient response rate in this study was low, but is comparable to other studies that have targeted more

vulnerable patient subgroups^{40–42} and surveys of registered patient portal users.^{2,24} Patient participation varied significantly by gender, but did not vary by other patient characteristics, including age, dementia diagnosis, number of prescribed medications, or prior health services use. Patient participation did not vary significantly by comorbidity burden, although reliance on an inpatient comorbidity index may have limited our ability to detect modest granular differences in comorbidity within an ambulatory population. Assessment of patient and care partner health literacy and confidence in managing health care activities was limited to self-reported measures. However, that care partners were found to be significantly more likely than patients to perform health care activities electronically using both self-reported and actual measures of MyGeisinger use indicates that findings regarding online practices are robust with regard to biases associated with self-reported information.

Results from this study do not provide insight regarding reasons for the low uptake of shared access or the extent to which family members or friends informally access the patient portal accounts of the much larger population of registered patient portal users who have not explicitly shared access to their account with a care partner. We are also not able to comment on whether the use of shared access affects patient treatment adherence, health services utilization, or clinical outcomes. Further research is needed to determine whether specific organizational, patient, or care partner factors are influential in the adoption of shared access, as well as to identify strategies that might be used to overcome sociotechnical challenges that have limited its dissemination. ^{26,43,44} As not all patients have or desire the involvement of family members or close friends in their care, the dissemination of shared access may attenuate, but will not be sufficient to fully overcome all socioeconomic barriers in patient portal access and use.

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CONCLUSION

Adoption of shared access functionality was low more than a decade after its implementation at a large integrated health system with an established electronic health record. Care partners were better equipped and more likely than patients to access and use the patient portal. Although most care partners used their own credentials to access the patient portal, nearly 1 in 4 used patient credentials. Study findings indicate that shared access facilitates the ability of care partners to interact with the health system on behalf of patients and that it helps but does not fully overcome challenges of differentiating patients and care partners in electronic health system interactions. In light of the accelerating spread of health information technology and increasing use of secure messaging for patient-provider communication, proper use of identity credentials will be increasingly important in the delivery of person-centered, safe, and clinically appropriate care, as will strategies that allow patients to clarify and execute their desire to involve family members or friends in their care.

AUTHORS' CONTRIBUTIONS

Substantial contributions to conception and design (D.C., J.A.G., J.D.D., J.L.W., R.A.S., C.Y.), or acquisition of data (A.B., D.C.), or analysis and interpretation of data (A.B., D.C., J.A.G., J.D.D., J.L.W., R.A.S.); drafting the article (J.L.W.) or revising it critically for important intellectual content (D.C., J.A.G., J.D.D., R.A.S., C.Y.); and final approval of the version to be published (A.B., D.C., J.A.G., J.D.D., J.L.W., R.A.S., C.Y.). A.B. and D.C. had full access to data in the study, and all authors take responsibility for the integrity of the data and accuracy of the data analysis.

CONFLICT OF INTEREST

The authors declare that they do not have a conflict of interest.

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REFERENCES

- Ricciardi L, Mostashari F, Murphy J, Daniel JG, Siminerio EP. A national action plan to support consumer engagement via e-health. *Health Aff.* 2013;32(2):376–384.
- Delbanco T, Walker J, Bell SK, et al. Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. Annl Int Med. 2012;157(7):461–470.
- Goldzweig CL, Orshansky G, Paige NM, et al. Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. Annl Int Med. 2013;159(10):677–687.
- Ammenwerth E, Schnell-Inderst P, Hoerbst A. The impact of electronic patient portals on patient care: a systematic review of controlled trials. *J Med Internet Res.* 2012;14(6):e162.
- Otte-Trojel T, de Bont A, Rundall TG, van de Klundert J. How outcomes are achieved through patient portals: a realist review. J Am Med Inform Assoc. 2014;21(4):751–757.
- Sarkar U, Lyles CR, Parker MM, et al. Use of the refill function through an online patient portal is associated with improved adherence to statins in an integrated health system. Med Care. 2014;52(3):194–201.
- Garrido T, Meng D, Wang JJ, Palen TE, Kanter MH. Secure E-mailing between physicians and patients: transformational change in ambulatory care. *J Ambulatory Care Manag.* 2014;37(3):211–218.
- Palen TE, Ross C, Powers JD, Xu S. Association of online patient access to clinicians and medical records with use of clinical services. *JAMA*. 2012;308(19):2012–2019.
- Sarkar U, Karter AJ, Liu JY, et al. Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. J Am Med Inform Assoc. 2011;18(3):318–321.
- 10. Yamin CK, Emani S, Williams DH, *et al.* The digital divide in adoption and use of a personal health record. *Arch Int Med.* 2011;171(6):568–574.
- Smith SG, O'Conor R, Aitken W, Curtis LM, Wolf MS, Goel MS. Disparities in registration and use of an online patient portal among older adults: findings from the LitCog cohort. *J Am Med Inform Assoc.* 2015;22(4):888–895.
- Taha J, Czaja SJ, Sharit J, Morrow DG. Factors affecting usage of a personal health record (PHR) to manage health. *Psychol Aging*. 2013;28(4): 1124–1139.
- Hsiao CJ, Jha AK, King J, Patel V, Furukawa MF, Mostashari F. Office-based physicians are responding to incentives and assistance by adopting and using electronic health records. *Health Affairs*. 2013;32(8):1470–1477.
- Koh HK, Brach C, Harris LM, Parchman ML. A proposed 'health literate care model' would constitute a systems approach to improving patients' engagement in care. *Health Aff.* 2013;32(2):357–367.
- DeWalt DA, Broucksou KA, Hawk V, et al. Developing and testing the health literacy universal precautions toolkit. Nurs Outlook. 2011;59(2):85–94.
- Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. New EnglJ Med. 2013;368(14): 1326–1334.
- IOM. Retooling for an Aging America: Building the Health Care Workforce. Washington, DC: The National Academies Press; 2008.
- Wolff J, Roter D. Family presence in routine medical visits: a meta-analytical review. Soc SciMed. 2011;72(6):823–831.
- 19. Smith SK, Dixon A, Trevena L, Nutbeam D, McCaffery KJ. Exploring patient involvement in healthcare decision making across different education

- and functional health literacy groups. Soc Sci Med. 2009;69(12): 1805–1812
- Gaglio B, Glasgow RE, Bull SS. Do patient preferences for health information vary by health literacy or numeracy? A qualitative assessment. J Health Commun. 2012;17 (Suppl 3):109–121.
- Laidsaar-Powell RC, Butow PN, Bu S, et al. Physician-patient-companion communication and decision-making: a systematic review of triadic medical consultations. Patient Educ Counsel. 2013;91(1):3–13.
- Woods SS, Schwartz E, Tuepker A, et al. Patient experiences with full electronic access to health records and clinical notes through the My HealtheVet Personal Health Record Pilot: qualitative study. J Med Internet Res. 2013;15(3):e65.
- Mayberry LS, Kripalani S, Rothman RL, Osborn CY. Bridging the digital divide in diabetes: family support and implications for health literacy. *Diabetes Technol Ther*. 2011;13(10):1005–1012.
- Zulman DM, Nazi KM, Turvey CL, Wagner TH, Woods SS, An LC. Patient interest in sharing personal health record information: a web-based survey. *Annl Int Med.* 2011;155(12):805–810.
- PSTT H. Epic Patient Portal Use by Proxies. Washington, DC: Health Information Technology Policy Committee, Privacy and Security Tiger Team; 2014.
- Sarkar U, Bates DW. Care partners and online patient portals. JAMA. 2014;311(4):357–358.
- Osborn CY, Rosenbloom ST, Stenner SP, et al. MyHealthAtVanderbilt: policies and procedures governing patient portal functionality. J Am Med Inform Assoc. 2011;18 (Suppl 1):i18–i23.
- Caine K, Hanania R. Patients want granular privacy control over health information in electronic medical records. J Am Med Inform Assoc. 2013;20(1):7–15.
- Crotty BH, Walker J, Dierks M, et al. Information sharing preferences of older patients and their families. JAMA Int Med. 2015;175(9) Available at: http://www.ncbi.nlm.nih.gov/pubmed/26147401.
- Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis*. 1987;40(5):373–383.
- Wallace LS, Rogers ES, Roskos SE, Holiday DB, Weiss BD. Brief report: screening items to identify patients with limited health literacy skills. *J Genl Int Med*. 2006;21(8):874–877.
- SAS Institute I. SAS Software. 8.1 edn. Cary, NC: SAS Institute 2000. http://www.sas.com/en_us/software/sas9.html.
- Zulman DM, Piette JD, Jenchura EC, Asch SM, Rosland AM. Facilitating outof-home caregiving through health information technology: survey of informal caregivers' current practices, interests, and perceived barriers. *J Med Internet Res.* 2013;15(7):e123.
- Bayer R, Santelli J, Klitzman R. New challenges for electronic health records: confidentiality and access to sensitive health information about parents and adolescents. *JAMA*. 2015;313(1):29–30.
- 35. United States Department of Veterans Affairs. My HealtheVet Account Types. March 2013 [cited January 31, 2015]. https://www.myhealth.va.gov/mhv-portal-web/anonymous.portal?_nfpb=true&_nfto=false&_page Label=spotlightArchive&contentPage=ipa/mhv_account_status-definitions. html&WT.ac=splash_account_types. Accessed January 15, 2015.
- Caine K, Kohn S, Lawrence C, Hanania R, Meslin EM, Tierney WM. Designing a patient-centered user interface for access decisions about ehr data: implications from patient interviews. *J General Int Med.* 2015;30 (Suppl 1): 7–16.
- Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. Am J Health Behav. 2007;31 (Suppl 1): S19–S26.
- Price EL, Bereknyei S, Kuby A, Levinson W, Braddock CH 3rd. New elements for informed decision making: A qualitative study of older adults' views. Patient Educ Counsel. 2012;86(3):335–341.
- Garcia CH, Espinoza SE, Lichtenstein M, Hazuda HP. Health literacy associations between Hispanic elderly patients and their caregivers. *J Health Commun.* 2013;18 (Suppl 1):256–272.
- Voils CI, Yancy WS Jr, Weinberger M, et al. The trials and tribulations of enrolling couples in a randomized, controlled trial: a self-management program for hyperlipidemia as a model. Patient Educ Counsel. 2010.

- Steinhauser KE, Clipp EC, Hays JC, et al. Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. Palliat Med. 2006;20(8):745–754.
- Trivedi RB, Szarka JG, Beaver K, et al. Recruitment and retention rates in behavioral trials involving patients and a support person: a systematic review. Contemporary Clin Trials. 2013;36(1):307–318.
- Wells S, Rozenblum R, Park A, Dunn M, Bates DW. Organizational strategies for promoting patient and provider uptake of personal health records. *J Am Med Inform Assoc.* 2014;22(1):213–222.
- Ancker JS, Miller MC, Patel V, Kaushal R, Investigators H. Sociotechnical challenges to developing technologies for patient access to health information exchange data. *J Am Med Inform Assoc.* 2014;21(4):664–670.

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