

Characteristics of Patients and Proxy Caregivers Using Patient Portals in the Setting of Serious Illness and End of Life

Jennifer Dickman Portz, PhD, MSW,^{1,2,i} John David Powers, MS,² Alejandra Casillas, MD,³ Megan Baldwin, BA,² David B. Bekelman, MD, MPH,^{1,4} Ted E. Palen, MD,² Sheana Bull, PhD, MPH,⁵ Jean S. Kutner, MD, MSPH,¹ and Elizabeth Bayliss, MD, MPH²

Abstract

Background: There are few studies examining the usage and utility of patient portals among seriously ill and end-of-life populations and their caregivers.

Objective: The aim of this study was to describe portal user characteristics among patients and their caregivers (proxy login) at two time points: (1) the 12 months following an electronic medical record flag for serious illness and (2) during the last 12 months of life.

Methods: A retrospective cohort analysis of Kaiser Permanente Colorado (KPCO) patients with serious illness, as defined by Kaiser Permanente's prognostic algorithm, and their proxy caregivers was performed for the two time periods. Use was characterized as (1) the discrete number of days the portal was used and (2) the number of days that portal features were accessed. Differences in use by user characteristics were assessed.

Results: Patients flagged for serious illness ($N=6129$) were 70.4 ± 14.2 years of age, and used the portal on average 50.4 days. Patients ($N=6517$) in the last year of life were 76.7 ± 13.7 years of age and used the portal on average 43 days. Caregiver proxy use of the portal was low in both cohorts. Patients who were older, female, non-White, and healthier were less likely to use the portal.

Conclusions: In comparison with overall KPCO portal use and recent patient portal studies examining use patterns, patient portal use was high among patients flagged with serious illness and nearing the end of life. However, because use was associated with age, gender, and race, addressing barriers to portal adoption among underserved populations and caregiver proxies is key to better leveraging patient portal systems for palliative and end-of-life care.

Keywords: digital health; electronic medical record; patient portal utilization; personal health record

Introduction

NEARLY 2 MILLION PEOPLE die each year from serious chronic illness,¹ a health condition with high mortality risk that negatively impacts a person's daily functioning and quality of life or excessively strains their caregivers.² Patients with serious illness experience significant physical, spiritual, and psychological symptom burden and progressive dependence on their caregivers and family.³ Palliative care is an interprofessional and patient–family-centered approach for

addressing the physical, psychological, emotional, and spiritual suffering for patients with serious illness and their families.⁴ Patient portals provide an opportunity to facilitate palliative care and end-of-life (PCEOL) care among populations with serious illness by improving patient–provider communication, access to health information, self-management support, and symptom monitoring.

Patient portals⁵ are secure websites for personal health information and tailored resources linked to a patient's electronic health record. Patient portals commonly allow

¹Division of General Internal Medicine, University of Colorado Anschutz Medical, Aurora, Colorado, USA.

²Institute for Health Research, Kaiser Permanente Colorado, Aurora, Colorado, USA.

³Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine, UCLA, Los Angeles, California, USA.

⁴Department of Medicine, Department of Veterans Affairs, Eastern Colorado Health Care System, Aurora, Colorado, USA.

⁵mHealth Impact Lab, Colorado School of Public Health, University of Colorado, Aurora, Colorado, USA.

ⁱORCID ID (<https://orcid.org/0000-0003-3107-3598>).

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patients to digitally communicate with their providers, access test results, receive health education, and manage medications. Due to portability and 24-hour access, patient portals are one of the most widely used health information technologies.⁶ Patient portals house tools that may improve patient and family caregiver outcomes across the trajectory of serious illness, from first diagnosis to end of life. For example, several palliative care researchers are investigating the use of patient portals for advance care planning and oncology symptom monitoring.^{7,8} In our previous work, we assessed the usability and user experience specifically among patients with multiple chronic conditions. Our participants indicated that patient portals save time and money and avoid unnecessary trips to the clinic.⁹ However, the usability, acceptability, and utility of patient portals during the early stages of serious illness or the end of life have not yet been studied.^{7,10}

There are no studies investigating the utility and usage of patient portals among adult patients and their caregivers across the trajectory of palliative care, from onset of serious illness to end of life; these data are needed to inform patient portal strategies targeting PCEOL health outcomes such as symptom management, treatment preference, quality of life, caregiver distress, and family perceptions of care. This study uses Kaiser Permanente Colorado's (KPCO) established patient portal, My Health Manager (MHM), one of the most developed and fully integrated portal systems in the United States, to examine the utility of patient portals in the setting of PCEOL. The aims of this study are to describe MHM user characteristics among patients and their caregivers (through a proxy login option) at two time points in the setting of PCEOL: (1) the 12 months following the onset of serious illness and (2) during the last 12 months of life.

My Health Manager

Nearly a half million people use MHM each year. Sixty-three percent of all KPCO patients and 25% of KPCO patients over the age of 65 use MHM to access portal services. MHM offers a variety of programs (Fig. 1) to facilitate services and coordinate care. MHM allows caregivers to log in to the portal on behalf of a patient through the *caregiver login proxy* option with patient permission. To become a caregiver

proxy user, a patient can add caregivers to their portal through their profile settings and sign access authorization. Caregivers can also request authorization to add patients to their profile through profile settings.

Methods

This study included analyses of two retrospective cohorts using KPCO's MHM (Fig. 1). All study procedures were approved by KPCO's Institutional Review Board.

Cohort 1: Patients and their caregivers at the onset of serious illness cohort

The cohort consisted of 6129 patients with serious illness, over the age of 18, who were registered for MHM, and who became seriously ill between May 1, 2018, and June 30, 2018. To identify serious illness, we used KPCO's proprietary Care Group prognostic scoring, which is used in clinical practice for classifying patients who may benefit from a palliative care referral. The Kaiser Permanente prognostic algorithm uses a combination of diagnoses (ranging from various cancer types, cardio and respiratory disease, dementia, end-stage chronic heart failure or renal disease, and transplant to major mental health concerns), health risk scores, and care utilization factors to determine the severity of illness and categorizes patients as follows: Care Group 1—healthy; Care Group 2—chronic conditions; Care Group 3—advanced illness; and Care Group 4—end of life. For Cohort 1, only patients in Care Group 4 were included because patients in this score group have a 50% mortality rate at two years. Patients who were initially flagged for Care Group 4 between May 1, 2018, and June 30, 2018, were included to examine MHM use in the earlier stages of serious illness (i.e., 12 months postinitial onset of Care Group 4). Patients who died during the 12-month study period were excluded to ensure the complete analysis of patient portal use over a 12-month period. Patients with serious illness who died are the focus of Cohort 2 described below. The 148 proxy caregivers of patients identified in this cohort who were at least 18 years of age and used the patient portal as a proxy for the patient were also included. Patients and caregiver proxies are linked in the backend data.

FIG. 1. Screenshot of MHM. Description of various MHM tools. Visits and Appointments: users can schedule or cancel appointments; My Medical Record: users can view test results, immunization records, ongoing health concerns, and care plans; Pharmacy Center: users can manage prescriptions and order medications; Health Guides and Health Management Tools: users can access health resources and self-care tools for diet, exercise, smoking cessation, and disease-specific care; Message Center: users can e-mail their provider; and Recently Added Tools: eVisits and provider chat functions for nonemergent questions and visits. MHM, My Health Manager.

My Health Manager Tool	Functions Available
My Medical Record	Users can view test results, immunization records, ongoing health concerns, and care plans
Visits and Appointments	Users can schedule or cancel appointments
Message Center	Users can e-mail their provider
Pharmacy Center	Users can manage prescriptions and order medications
Health Guides and Health Management Tools	Users can access health resources and self-care tools for diet, exercise, smoking cessation, and disease-specific care
Recently Added Tools	eVisits and provider chat functions for nonemergent questions and visits

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TABLE 1. CHARACTERISTICS OF MY HEALTH MANAGER PATIENT AND CAREGIVER PROXY USERS

Characteristic	Onset of serious illness		Near end of life	
	Patients (N=6129)	Caregiver/proxy users (N=148)	Patients (N=6517)	Caregiver/proxy users (N=163)
Characteristic				
Age, ^a mean (SD)	70.4 (14.2)	59.6 (12.9)	76.7 (13.7)	61.0 (13.0)
Female, %	56.9	75.0	49.9	77.9
Care Group, ^b %				
Group 2: chronic illness			15.3	
Group 3: advanced illness			21.1	
Group 4: frailty and end of life	100		63.6	
Race, %				
American Indian/Alaska Native	0.9	0	<1.0	1.2
Asian	1.9	4.7	1.4	2.5
Black or African American	3.4	4.7	2.5	<1.0
Native Hawaiian/Pacific Islander	0.2	0	<1.0	<1.0
White	81.1	79.7	83.6	81.6
Other	3.6	3.4	3.3	3.7
Unknown or not reported	8.9	7.4	8.3	9.8
Hispanic, %	10.3	9.3	7.2	14.1
Portal tool use, mean (SD)				
Care team information	7.0 (8.7)	0 (0)	10.8 (12.0)	0 (0)
Cost and coverage	1.1 (2.6)	0 (0.09)	0.9 (2.4)	0.01 (0.13)
Health management guides	2.4 (4.3)	0.04 (0.47)	1.4 (3.0)	0.02 (0.36)
Laboratory and test results	11.7 (16.5)	0.19 (1.94)	11.4 (16.8)	0.19 (2.15)
Medical record	9.9 (13.4)	0.12 (1.31)	4.6 (8.5)	0.08 (1.26)
Medications	11.5 (17.8)	0.16 (1.99)	9.4 (16.2)	0.11 (1.65)
Recently added (eChat/eVisit)	25.0 (28.8)	0.26 (2.83)	11.2 (19.0)	0.16 (1.89)
Patient-provider communication	24.0 (25.8)	0.50 (4.50)	20.8 (25.6)	0.43 (4.41)
Visits and appointments	16.8 (22.4)	0.34 (3.66)	13.6 (19.1)	0.29 (3.53)

^aPatient age was calculated at time of Care Group flag for onset of serious illness or at date of death for the near end-of-life cohort. Caregiver age was calculated at the end of the study period.

^bCare Group flag in the last 12 months of life; if there are multiple flags, the Care Group closest to the time of death is reported. SD, standard deviation.

Cohort 2: Patients and their caregivers at the end-of-life cohort

The cohort consisted of 6517 patients with chronic or serious illness, over the age of 18, who were registered for MHM, and who died between January 1, 2016, and June 30, 2019. Having a chronic or serious illness was defined by having a KPCO Care Group 2–4 flag in the last 12 months of life. Those who died from something other than chronic illness (e.g., accident) were excluded from analysis. The 163 proxy caregivers of the patients identified in this cohort who were at least 18 years of age and used the patient portal as a proxy for the patient were also included.

Data extraction and analyses

Data were extracted from KPCO's integrated electronic medical record, KP HealthConnect—Epic Systems (Epic Ambulatory, versions 2014 through 2018), Death Records, Research Data Warehouse, and MHM databases. Data extracted included patient and caregiver characteristics (age, gender, race, ethnicity, and Care Group flag) and MHM utilization (MHM use dates and features used). Using raw utilization data, we calculated the number of days that MHM and specific features were used over the 12-month study period: 12 months post the onset of serious illness and 12

months before patient's death. We analyzed unadjusted and adjusted effects of patient characteristics on 12-month daily usage using a negative binomial generalized linear model with a log link to account for overdispersion in the Poisson model. All analyses were conducted using SAS statistical software, version 9.4 (SAS Institute, Inc., Cary, NC, USA).

Results

MHM users

The demographic characteristics of the two cohorts are listed in Table 1. The average age of patients was 70.4 years in the onset of serious illness cohort and 76.7 years in the end-of-life cohort. Caregivers were 60 and 61 years of age, respectively, and mostly female in both cohorts.

Caregiver use of MHM was low in both cohorts. Of the 6129 patients in the onset of serious illness cohort, 6030 used MHM at least once in the study period. Patients and caregivers used MHM on average 50.4 days in the 12 months following the onset of serious illness. Patients and caregivers in this cohort most commonly used new MHM features, including eChat functions and eVisits (25 days \pm 29), patient-provider communication tools (24 days \pm 26), and visit-scheduling options (17 days \pm 23). For the 6517 patients in the end-of-life cohort, 6308 used the portal at least once in the

TABLE 2. MY HEALTH MANAGER USE BY PATIENT CHARACTERISTICS

Characteristic	Onset of serious illness (N=6129)			Near end of life (N=6517)		
	Rate	95% CI		Rate	95% CI	
Overall	50.4	49.3	51.5	42.9	41.9	43.9
Age, years						
<20	48.3	17.2	79.4	0	0	0
20–29	49.5	36.4	62.6	38.1	24.1	52.2
30–39	63.1	55.3	71.0	40.1	30.6	49.6
40–49	55.8	50.7	60.8	44.4	37.9	51.0
50–59	55.6	52.1	59.2	52.6	47.8	57.4
60–69	55.4	53.0	57.7	51.8	49.0	54.6
70–79	53.1	51.0	55.2	49.7	47.6	51.8
80–89	42.8	40.8	44.9	38.6	37.0	40.1
90+	30.5	27.7	33.3	29.2	27.4	31.0
Gender						
Female	48.6	47.3	50.0	41.1	39.8	42.5
Male	52.8	51.0	54.5	44.6	43.2	46.0
Race						
American Indian/Alaska Native	51.8	40.0	63.6	49.9	36.1	63.7
Asian	41.6	33.6	49.5	41.1	33.5	48.7
Black or African American	44.9	38.9	50.9	32.5	27.5	37.6
Native Hawaiian or Other Pacific Islander	45.0	19.1	70.9	53.0	25.4	80.6
Other	40.5	35.1	45.8	39.8	34.5	45.1
Unknown or not reported	37.2	34.0	40.3	30.7	27.7	33.6
White	52.8	51.5	54.0	44.5	43.4	45.6
Care Group						
Group 2: chronic illness				29.8	27.8	31.7
Group 3: advanced illness				41.0	39.0	43.0
Group 4: frailty and end of life				46.7	45.4	48.0

CI, confidence interval.

last 12 months of life. Patients and caregivers used MHM for 43 days in the last 12 months of life. Users in this cohort also commonly used patient–provider communication (21 days ±26) and visit-scheduling tools (14 days ±19), but only used the new tools for 11 days ±19. Health management and cost coverage tools were the least used tools in both cohorts. As

seen in Tables 2 and 3, among the onset of serious illness cohort, rates of use of MHM were lower for females than for males (48.6 vs. 52.8), for Asians (41.6) and Blacks (44.9) than for Whites (52.8), and for users as they aged (usage by age group listed in Table 2). These trends were all seen for the near end-of-life cohorts. In this cohort, rates for use of MHM

TABLE 3. (ADJUSTED) RATES OF MY HEALTH MANAGER USAGE

Characteristic	Onset of serious illness (N=6129)		Near end of life (N=6517)	
	Rate ratio (95% CI)	p	Rate ratio (95% CI)	p
Age	0.990 (0.988–0.991)	<0.0001	0.985 (0.983–0.987)	<0.0001
Gender		<0.0001		0.0016
Female	0.905 (0.864–0.948)	<0.0001	0.925 (0.882–0.971)	0.0016
Male	Reference		Reference	
Race		<0.0001		<0.0001
American Indian/Alaska Native	0.950 (0.747–1.207)	0.6727	0.984 (0.748–1.293)	0.9051
Asian	0.759 (0.641–0.898)	0.0014	0.853 (0.693–1.050)	0.1330
Black or African American	0.803 (0.707–0.913)	0.0008	0.646 (0.553–0.756)	<0.0001
Native Hawaiian/Other Pacific Islander	0.804 (0.496–1.303)	0.3757	1.077 (0.641–1.809)	0.7793
Other	0.725 (0.640–0.821)	<0.0001	0.869 (0.759–0.995)	0.0424
Unknown or not reported	0.673 (0.620–0.730)	<0.0001	0.630 (0.577–0.689)	<0.0001
White	Reference		Reference	
Care Group				<0.0001
Group 2: chronic illness			0.576 (0.537–0.617)	<0.0001
Group 3: advanced illness			0.890 (0.838–0.946)	0.0002
Group 4: frailty and end of life			Reference	

were lower for females than for males (41.1 vs. 44.6), for Asians (41.1) and Blacks (32.5) than for Whites (44.5), and also for users as they aged.

Discussion

This is one of the first studies to examine the characteristics of patient portal users and use patterns in the setting of serious illness and end of life. In the KPCO system, patients and their caregivers are using their patient portal at the onset of serious illness and near the end of life. In comparison with other recent retrospective cohort studies investigating patient portal use patterns, usage rates among both cohorts are high. For example, the number of days that patients used the portal in a 12-month period among other studies in general primary care settings ranged from 18.5 days¹¹ to 27.2 days,¹² with some use estimates as low as 9.6 days.¹³ This finding aligns with other work suggesting that once registered for a patient portal, patients with poorer health status are more likely to use the portal.¹⁴ However, in the setting of serious illness, patients may be too fragile to use the portal, and caregivers may have used the member's login to the portal rather than using a proxy login. Therefore, the patient usage may actually reflect use by the caregiver on the patient's portal account. In the context of KPCO, the three-year average use is 2.9 logins per month among all MHM users. However, this is logins per month rather than days used per month, which is likely a lower estimate since logins can occur multiple times a day; again suggesting that use in the study cohorts is high. A strength of this study is that we examined both people in the early stages of serious illness and those in the last year of life and found similar results.

Although use of the portal was high, there were few caregiver proxy users. This may be due to caregivers logging in as the patient rather than setting up a separate account¹⁵. An estimated 50–65% of caregivers are interested in using technologies to support and monitor the health of their loved ones,^{15,16} yet patient portals are rarely designed to specifically support caregivers¹⁷ or PCEOL services. Barriers to proxy adoption include difficult and time-consuming processes to gain access and privacy concerns.^{17–19} However, proxies who use the portal find the systems convenient and timely, and the portal is seen as important tool for engaging family in care and health communication.^{20,21} In the setting of serious illness, patients will increasingly rely on the support of their family, friends, and love ones to manage their care. Therefore, it is particularly important to address identified proxy adoption barriers. Facilitating proxy portal adoption may allow for easier use, improved exchange of health information, and the inclusion of tools and resources specifically for caregivers.

While the majority of patient portal research is among populations in the United States, patient portals are rolling out across Western countries.²² For example, the United Kingdom has provided patient portal access through the National Health Service since 2015.²³ However, adoption and use rates in many non-US countries were found to be low and the functionality available across portals is not well described.²⁴ To increase general adoption globally, particularly among individuals with chronic and serious illness, researchers have called for increased attention to describing characteristics of current users, contextual factors of the

portal systems, and features available to patients and proxies.²² Our study contributes to this broader description of portal adoption and use in the specific context of serious illness; however, findings are unlikely to be generalizable to users beyond the KPCO system.

Patient-to-provider messaging was popular among both cohorts. Prior studies have affirmed that users value being able to communicate with providers and ask questions about nonemergent concerns.^{9,25,26} However, qualitative oncology patient portal research indicates that patient portal communication may have unintended negative consequences for patients with serious illness.^{10,27} For example, while receiving access to a simple blood test in primary care may be helpful to a patient, receiving a laboratory result related to a serious illness may indicate a treatment is no longer working. Patient portals may be a harmful method for delivering difficult news.

The new portal features, including eChat and eVisits, were the most commonly used tools among patients at the onset of serious illness. This is an unexpected finding, considering the older average age of the cohort. These tools are not commonly identified by older adults as preferred or highly valued features.¹⁴ With the onset of serious illness, there may be increased visits and interaction with the health system. Patients with serious illness may greatly benefit from the opportunity to meet with a provider using synchronous text and virtual telehealth.

Both cohorts were primarily White and female, and White users were more likely to use the portal versus non-White users. These findings support research indicating that Black and Latino patients are less likely to register for a patient portal.^{28,29} Low portal registration and use are attributed to lack of access to hardware (computer, tablet, and phone), English proficiency, lack of technical support, and stigmas/fears about privacy and relationship building through digital communication.³⁰ Because Black and Latino patients and their family caregivers are less likely to receive specialized palliative care,³¹ if these technical barriers are addressed, patient portals may be tools for increasing awareness and access to palliative care services.

Similar to prior patient portal research,³² MHM use significantly decreased with age. Use was lowest among the oldest age groups; however, the rate of MHM use was similar, 50–55 days per year, among 40–80-year-old users in both cohorts. In these cohorts, use remained high even among older adults. Previous research recommends patient portal training sessions for older adults and caregivers and publicizing portal information (i.e., the availability and benefits of use) in public and community spaces for reducing portal adoption disparities.³³ Integrating patient portal registration into clinical workflows and assigning helpers to facilitate adoption may lead to increased use.

There are several limitations to our work. First, the study was conducted in a single health system, in which patients frequently use the portal system and all were insured. The results reflect elective use rather than compulsory use and do not capture the patient portal interests of those not registered for MHM. While capturing use from the onset of serious illness until the time of death would better gauge longitudinal portal use, the cohorts were conceptualized and defined separately based on the separate questions about end-of-life and serious illness portal use. Our sample was primarily

White and non-Latino, which is neither representative of Colorado's nor KPCO's racial distribution, limiting our ability to generalize these findings to a broader population. Few proxy caregivers used the portal; therefore, we were unable to test the likelihood of accessing the portal by caregiver characteristics. We were also unable to capture caregiver use if they were using the portal with patient username and password credentials. While a prognostic score is valuable in identifying seriously ill patients, we were unable to differentiate between diagnosis types; users for cancer care may have different patient portal needs and preferences than those with end-stage renal disease. Using days used, rather than logins, results in the loss of granularity in use, particularly days when patients and caregivers used the portal several times in one day. We broadly captured use in tool categories rather than specific clicks or time spent on each tool. Use may also be better captured by active (messaging and refills) versus passive use (reviewing information), which is a growing use metric for portals. The cohorts examined were before the coronavirus disease (COVID-19) pandemic, and with the uptake of telehealth, the use patterns of portals may have changed.

With growing interest in patient portal use patterns in oncology^{27,34} and PCEOL, there is need for deeper understanding of how people at the onset of serious illness and end of life can be helped using patient portals. Future research should include eliciting patient and caregiver feedback about specific use patterns to identify the benefits of particular tools, challenges in registration and use, and the potential for new helpful features. While the association between patient portal use and improved health outcomes is mixed, patient portal use is shown to improve patient satisfaction.^{24,35} Future research should explore the impact of patient portal use on PCEOL-specific outcomes, such as advance directive documentation, quality-of-life measures, and hospice referral.

Conclusions

Among KPCO MHM users, portal use was high among patients at the onset of serious illness and nearing the end of life. Addressing barriers to portal adoption and use for caregiver proxies and underserved populations is key to better leveraging patient portal systems for PCEOL.

Authors' Contributions

This study was led by J.D. Portz. Data management was conducted and overseen by J.D. Powers and M.B., with design operationalized by J.D. Portz, A.C., D.B.B., T.E.P., S.B., J.S.K., and E.B. Analysis was completed by J.D. Powers. Manuscript sections were drafted and extensively reviewed by all authors.

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Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:
Jennifer Dickman Portz, PhD, MSW
Division of General Internal Medicine
University of Colorado Anschutz Medical
Mailstop B180
12631 East 17th Avenue
Aurora, CO 80045
USA

E-mail: jennifer.portz@cuanschutz.edu