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Authors

Portz, Jennifer

Lum, Hillary

Bull, Sheana

et al.

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Perceptions of Patient Portal Use for Advance Directive Documentation among Older Adults with Multiple Chronic Conditions

Jennifer Dickman Portz, MSW, PhD^{1,2,3},

Hillary D. Lum, MD, PhD^{4,5},

Sheana Bull, MPH, PhD³,

Rebecca S. Boxer, MD²,

David B. Bekelman, MD, MPH^{1,5},

Kelsey L. Ford, MPH³,

Kathy Gleason, PhD²,

Alejandra Casillas, MD, MSH⁶,

Elizabeth A. Bayliss, MD, MPH^{2,7}

¹Division of General Internal Medicine, University of Colorado School of Medicine at the Anschutz Medical Campus, Aurora, Colorado

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

³Colorado School of Public Health, University of Colorado Anschutz Medical Campus, Aurora, Colorado

⁴Division of Geriatric Medicine, University of Colorado School of Medicine at the Anschutz Medical Campus, Aurora, Colorado

⁵VA Eastern Colorado Health Care System, Denver, Colorado

⁶Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine, UCLA, Los Angeles, California

⁷Department of Family Medicine, University of Colorado School of Medicine at the Anschutz Medical Campus, Aurora, Colorado

Abstract

Patient portals can play an innovative role in facilitating advanced care planning (ACP) and documenting advance directives (ADs) among older adults with multiple chronic conditions. The objective of this qualitative sub-study was to (1) understand older adults' use of an ACP patient portal section and (2) obtain user-design input on AD documentation features. Although some

Corresponding Author: Jennifer Dickman Portz, PhD, MSW, General Internal Medicine, University of Colorado Anschutz, Mailstop B119, 13001 East 17th Place, Aurora, Colorado 80045, Phone: 303-724-4438, jennifer.portz@cuanschutz.edu.

Declaration of interest statement

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older adults may be reluctant, participants reported likely to use a portal for ADs with proper portal design and support.

Keywords

Digital health; patient portal; health information technology; advance care planning; advance directive

Introduction

Advance care planning (ACP) is the process of supporting patients in understanding and sharing values, goals, and preferences related to future medical care (Sudore et al., 2017). This process may include the identification of a trusted person to make these medical decisions and completion of an advance directive (AD) (Houben et al., 2014). ADs include medical power of attorneys, living wills, and resuscitation directives. Once an AD is in place, it must be submitted to relevant health care systems and information about the AD is communicated with care teams to ensure people receive the care that is consistent with their goals (Teno et al., 2007). Well-documented ADs are shown to improve end-of-life care outcomes including increased utilization of hospice and palliative care and reduced hospitalization near death (Bischoff et al., 2013; Brinkman-Stoppelenburg et al., 2014).

Nearly 1.4 million older adults will die each year from a serious chronic illness, of which approximately 32% have 2+ chronic conditions and 14% have 6+ chronic conditions (Centers for Disease Control and Prevention, 2017; Centers for Medicare and Medicaid Services, 2012). Older adults with multiple chronic conditions (MCC) are at increased risk of premature death, hospitalization, receiving conflicting health care advice, and reduced quality of life (Morrison, 2013). Therefore, older adults with MCC are targeted for ACP and AD documentation efforts to improve quality of end-of-life care, patient and family satisfaction, and reduce health care costs (McCarthy et al., 2008). There are several initiatives to improve ACP and AD documentation including Medicare's recent reimbursement for ACP visits and patient-provider ACP conversations. Although completion rates are lower than desired (Jones et al., 2011; Rao et al., 2014), approximately 36.7% of patients have a complete AD (Yadav et al., 2017). Barriers to AD documentation are commonly associated with patient awareness, background and characteristics, provider attitudes and training, patient-family and patient-provider relationships (De Vleminck et al., 2013; Heyland, 2013; Lovell & Yates, 2014; Paladino et al., 2014). Even when complete, ADs are frequently under-recorded in electronic medical records (EMR) (Yung et al., 2010).

Technology can play a role in facilitating ACP and AD documentation in EMRs (Fine et al., 2016), particularly via the use of patient portals (Bose-Brill & Pressler, 2012), which are secure websites for personal health information and provider resources directly linked to an EMR. Older adults are increasingly using the internet and mobile platforms (Anderson & Perrin, 2017) to access health information and patient portals may provide an innovative method for promoting ACP and completing AD documentation. However, it is unknown whether older adults with MCC have usability concerns or other barriers to using patient portals for ACP and AD documentation. Understanding older adults' preferences

around using patient portals for ACP and AD documentation can inform the development of portals that are more patient-centered. Therefore, this qualitative study addresses the specific research question: What are the perceptions of older patients with MCC about using the patient portal for ACP and AD documentation?

Materials and Methods

This is a sub-study of a qualitative case study (Padgett, 2008) assessing the intent-to-use and user experience of Kaiser Permanente Colorado's (KPCO) patient portal, *My Health Manager* (Portz et al., 2019). As part of the larger study, specific questions related to ACP and AD were discussed during focus groups with study participants. The qualitative descriptive sub-study focused on understanding the use of the current *My Health Manager* ACP section and also obtaining user-design input on future AD documentation features. The current ACP section provides definitions for ADs, ACP resources, and external website links to complete ADs. Future AD documentation features for discussion included uploading completed ADs directly into the EMR via the *My Health Manager* portal. All study procedures were approved by the Kaiser Permanente Colorado Institutional Review Board.

Sample and Recruitment

Using purposeful and random sampling, participants were identified from the KPCO EMR. Inclusion criteria included: 65 years of age, KPCO member for 1 year, presence of multiple chronic conditions (Charlson Comorbidity Index > 2), and a patient with one of the participating KPCO study clinics. Non-English-speaking patients, individuals residing in skilled nursing facilities, and patients with a diagnosis of dementia were excluded from participation. To maximize the range of age and patient portal experience, the study team randomly sampled by age strata (65-75; 76-85; 86+ years) and portal user status (non-users and users) to identify 225 potential participants. Recruitment letters were mailed to potential participants and followed up by phone. Thirty-seven patients agreed to participate in a focus group, 13 patients did not show up to their scheduled group and were unable to contact for rescheduling, and 24 completed the study. Detailed recruitment procedures are documented elsewhere (Portz et al., 2019). Qualitative samples are not meant to be representative, but rather selective of individuals who can speak to the specific topic or research question (Patton, 2009). As such, older adults with MCC were explicitly targeted for advance care planning interventions. The sample was diverse in age range and patient portal utilization as described in Table 1.

Data Collection

Six 90-minute semi-structured focus groups were conducted. Groups ranged in size from 2-7 people. Prior to data collection, all participants were consented and administered a survey to collect demographic and technology utilization information. The focus group facilitators asked participants about technology use and probed specific questions about *My Health Manager* features. Using a projector, images of current *My Health Manager* ACP features were displayed and discussed. The group provided feedback on potential AD features. Questions on the focus group guide included: 1) 'are there features you might like to use?'; 2) 'are you interested in using the portal for AD documentation?'; 2) 'would you upload a

completed AD to the portal?'; and 3) 'what do you like or dislike about this feature?' Focus groups were audio recorded for accuracy in data collection.

Analysis

All audio-recordings were professionally transcribed verbatim for a content analysis. Two doctoral level researchers completed all phases of coding (JDP-Principle Investigator and KG-Professional Research Assistant), adhering to standard inductive qualitative practices (Saldana, 2015). An initial cycle of coding used *open coding* on data responses related only to ACP and AD questions listed above, creating researcher generated labels for participants' opinions and thoughts. The two coders met three times in-person to review codes, rectify disagreements, and collapse initial codes into broader categories, known as *axial coding* (Saldana, 2015). To present the results, a *heading and subheading* technique was used to organize the major findings as presented in Table 2. Although it is a coding option, qualitative studies do not typically report on counts, i.e. the specific number of statements or participants. Therefore, we report on themes, but also use qualitative words such as "many" or "few". This type of qualitative reporting is sometimes helpful for improved interpretation of the theme popularity or level of disagreement, among the sample (Saldana, 2015).

Results

Participants

Participant characteristics are shown in Table 1. Participants were an average of 78.4 years of age and primarily female. The sample consisted of highly-educated, middle income participants who use mobile and internet technologies. Nine participants did not use *My Health Manager*. Twenty-two participants stated they had some form of AD; however, many of those with a completed AD indicated they did not have the document on file with their medical provider.

Responses Regarding Portal Use for AD Documentation

Most participants reported interest in having AD documentation features available for information and uploading AD documents to the EMR. Participants indicated both concerns and positive benefits of using such a feature. A summary of responses is provided in Table 2.

Positive Intent to Use.—The majority of participants expressed the AD upload feature was valuable and useful. They indicated they would use the function when available. However, they offered specific suggestions for improving user experience. First, participants stated they needed to be able to find the ACP/AD information and features easily. At the time of the focus group, *My Health Manager* ACP resources were located under the tab "Health and Wellness". This was not a logical location in their opinion, and participants reported an inability to find the feature while navigating the site. Participants suggested that uploaded ADs should be available in both the EMR for their provider and in the portal for patients and caregivers. They wanted to easily access the current AD their health care providers would retrieve when necessary.

Participants also reported they would need professional help finalizing their AD, and would like this available through the portal. Many participants felt they could not complete ADs on their own. Participants indicated they would want a lawyer or medical provider to aid in this process. Availability of technical support to assist with the portal and trouble-shoot the upload function was important to potential users.

Potential Barriers.—Participants expressed a general lack of awareness around current *My Health Manager* ACP resources. They did not know ACP information was currently available and their providers had not talked to them about the portal for ACP purposes. Participant responses also suggested a lack of understanding in terms of definitions and documents. For example, when we asked who completed an AD, most participants indicated they did, yet most people specifically referred to these documents as “DNRs” (do not resuscitate orders) or estate planning, rather than goals of care documentation or identification of a healthcare decision maker.

A few participants indicated that they would not use the AD upload feature. They expressed security concerns as a primary issue. These participants explained the website was not safe or secure enough for this type of information. Others preferred AD information remain only in the hands of their family. Participants highlighted they had spoken with their family about ACP/AD issues. They felt their family would provide information to the health care team when needed or appropriate.

Discussion

ACP is shown to improve hospice referral and use, patient and caregiver quality of life, bereavement processes among caregivers, and increased patient goal concordant care at end-of-life (Brinkman-Stoppelenburg et al., 2014; Houben et al., 2014; Wright, 2008). All levels of ACP, even the process of documenting an AD alone, is associated with positive perceptions of end-of-life experiences (Levoy et al., 2020). Patient portal technology offers an innovative way to promote ACP and capture ADs among older adults with MCC. As the adoption and acceptability of patient portals grows, understanding technology perceptions of older adults remains critical for implementation and engagement of web-based ACP interventions. Based on the preliminary findings, some older adults may be reluctant to use a patient portal for AD documentation, while others are likely to use a portal for ACP information and ADs with proper portal design and embedded assistance for the AD-creation process.

For older patients to use the ACP and AD document features, the patient portal interface must be appealing from a user-centered design perspective. Older adults are more likely to adopt and engage with user-centered technologies (Fisk et al., 2009). However, many patient portals are not well-designed for older users, indicating a need to include older adults and their caregivers in the design process (Sakaguchi-Tang et al., 2017). For ACP and AD completion, features must be easy for patients to find on the portal or they are unlikely to use the system.

In addition to improving portal design, there are several suggestions for providers involved in AD documentation using patient portals. First, health care providers should advise patients about ACP and AD features available to them via the patient portal. The role of the provider to regularly initiate ACP conversations is an important first step in initiating documentation of treatment preferences and goals of care (Hemsley et al., 2019). Patients have previously identified the benefits of patient portal referral from their health care team (Jordan et al., 2019). Social workers are core members of the ACP provider team and are often responsible for ACP discussions. Social workers also report that on average at least 2 visits are needed to prepare an AD (Stein et al., 2017). Therefore, clinical and administrative social workers can use portal features to prepare patients and families for in-person conversations or follow-up. During conversations about AD features, providers can help motivate patients to use the portal by addressing possible security concerns and minor technical difficulties. Emphasizing the benefits of having an up-to-date AD available in the EMR may encourage older adults to use AD portal features.

Lack of time and physician awareness of social work specific ACP interventions are reported barriers to initiating conversations with patients among social workers (Gagliardi & Morassaei, 2019). The portal ACP tools could be used by social workers to help save time and remind other providers of completed ADs (Lakin et al., 2019). However, as our participants reported, older patients will also need help using these features. Offering technical assistance will allow older patients to quickly address issues while navigating the portal. Previous work suggests that tech-support and manuals increase older adults' adoption of new technologies (Mitzner et al., 2008). Patient portals should also consider best practices for design that address aging specific concerns such as hearing and visual impairments, including large fonts, appropriate coloring, and audio supports (Fisk et al., 2009).

Engaging caregivers and family in the portal ACP process may also help older patients use the features. Family members have been shown to be particularly helpful for informal tech-support (Mitzner et al., 2010). ACP is also a collaborative effort to ensure a patient's goals of care are well-known (Sudore et al., 2017). As indicated by our participants, ADs uploaded via the portal directly into the EMR should be available for patients and caregivers to access when needed. If the AD is not accessible to the patient and/or family, there is a missed opportunity for review and discussion that may lead to a better understanding of patient wishes or a need to revise the document. More research is needed to understand caregiver and family member engagement with ACP specific patient portal features.

Despite the study's contribution to the scarce literature in older adult patient portal use, there remains limitations. While the sample size is appropriate for formative research in user-centered design, it may bias findings. All participants were KPCO members and therefore obtained health coverage and access to health services. Variability in patient portal use among participants was achieved (i.e., including both portal users and non-users) however the sample lacked diverse input from underserved and minority populations. Although we used the Charlson Comorbidity Index (score > 2) as an inclusion criterion for the sampling frame to ensure potential participants had MCC, we did not document the severity of illnesses nor the specific conditions. These findings are also limited to older adults with MCC and may not be relevant to healthier older patients. Additionally, the sample collected

was a sub-study of a larger project assessing the user experience of the portal rather than targeting ACP and AD. Such limitations demand future interprofessional efforts to ensure patient portals are designed for widespread applicability across health care settings and among diverse populations.

Although some older adults with MCC may be reluctant to use a patient portal for ACP due to security concerns, unawareness of available resources, and preference for family involvement, user-centered design strategies such as easy-to-access resources, intuitive headings, access to technical help, and engaging family caregivers may encourage use. Further research is needed to determine if provider and family-caregiver supports facilitate ACP portal use and if AD documentation via a portal results in improved end-of-life outcomes for patients and their family.

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Table 1.

Participant Characteristics

	Total (N=24)
Age, <i>mean</i>	78.4±5.4
Portal User Status	
User, <i>n</i>	15
Non-User, <i>n</i>	9
Female, <i>n</i>	17
White, <i>n</i>	19
Hispanic, <i>n</i>	3
Education, <i>n</i>	
High School Graduate	6
Some College	9
College Graduate	9
Income	
<\$30,000	4
\$30,000 to \$49,999	13
\$50,000 +	4
Choose not to answer	3
Own Cell Phone	
Smart Phone	17
A regular or basic phone	6
Does not have a cell phone	1
Technology Utilization	
Email	22
Look up Information Online	21
Use Social Media	13
Play Computer Games	15
Video Chat	11
Instant Messaging	8

Table 2.

Response Summary of Portal Use for Advance Directive Documentation

Theme	Quotation
Positive Intent to Use	
<u>Portal Design</u>	
Location of feature on portal	“But see, that Health and Wellness doesn’t tell me it’s going to be an advance directive or anything. I’m the least bit—that doesn’t tell me anything.”
Access to AD	“Yes, definitely. There’s not really a way to check (with provider about current AD on file) without asking, because I know I have one at the hospital, which has to be done every year...But I don’t know if I’ve ever had one done here and there’s no way right now to check without asking.”
<u>Need for Professional Assistance</u>	
AD Documentation	“The only other thing about that would be, I don’t, I’m too tight to get a lawyer right now.”
Technical Help	“When you have a problem, I just call and ask for an IT person. I don’t want customer care because they’re not going to understand. An IT person can tell you in about three minutes where the problem is and where to go.”
Potential Barriers to Use	
<u>Lack of Awareness</u>	
About My Health Manager resources	“I didn’t even know that was there – it had that feature?”
About ACP and AD generally	“My husband and I recently moved into a retirement living place, and they ask you to prepare a DNR, and they say—there are some, I know, where my mom was, they have this big orange piece of paper on the inside of their door—“DNR,” but here, they just keep it in the office, and they said if they have to call 911 they can just pull it out and make copies.”
<u>Will not Upload AD</u>	
Security Concerns	“And that’s about it because I don’t like putting information out there.” “Other people don’t have access to my information – this is really protected, right?”
Preference to keep AD with family	“I didn’t go to an attorney because I’m a (legal professional). So I did a lot of my own documentation. But I have it at home. And any documentation that I have to get to the doctor, they’ll go through my family.” “It’s not anything I would use. My kids know, my kids have my information.”

AD: Advance directive; ACP: Advance care planning