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Am J Hosp Palliat Care. Author manuscript; available in PMC 2019 August 01.

Published in final edited form as:

Am J Hosp Palliat Care. 2019 August ; 36(8): 682–687. doi:10.1177/1049909119832820.

Patient Perspectives on Advance Care Planning via a Patient Portal

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Abstract

Background: Patient portals can offer patients an opportunity to engage in the advance care planning (ACP) process outside of clinical visits.

Objective: To describe patient perspectives on use of patient portal-based ACP tools.

Design: Interviews with patients who used portal-based ACP tools. The tools included an electronic Medical Durable Power of Attorney (MDPOA) form to designate a medical decision maker, a patient-centered educational web page, online messaging, and patient access to completed advance directives stored in the electronic health record (EHR).

Setting: Regional health-care system with a common EHR.

Measurements: Semistructured interviews with purposefully sampled patients who used the ACP tools. Questions explored motivations for using the tools and perceptions about how the tools fit into ACP. Analysis followed a grounded hermeneutic editing approach.

Results: From 46 patients (mean age: 49, 63% female), 4 key themes emerged: (1) individualized explorations of the ACP tools, (2) personal initiation and engagement with ACP tools through the portal, (3) value of connecting ACP portal tools to clinical care, and (4) practicality of the ACP tools. Patients described benefits of communicating with health-care team members who referred them to online ACP tools, as well as having the electronic MDPOA form connected to clinical care.

Conclusions: Patients considered the portal-based ACP tools to be practical and feasible to use within the scope of their own ACP experiences. Further study is needed to understand whether

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Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Supplemental Material

Supplemental material for this article is available online.

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portal-based ACP tools increase the quality and quantity of ACP conversations and documentation that is available to inform medical decision-making.

Keywords

advance care planning; advance directive; electronic health record; patient portal; health information technology; qualitative

Introduction

Too often, key care planning documents such as Medical Durable Power of Attorney (MDPOA) forms, living wills, or Physician Order for Life-Sustaining Treatment forms are not available in the medical record during a medical crisis.[1] Individuals may believe they have advance care planning (ACP) documents in the electronic health record (EHR) when instead nothing is present or the documents no longer reflect the patient's preferences.[2] Because individuals with serious illnesses or unexpected medical emergencies often include high risk of lacking decision-making capacity, it is important that access to advance directives and accurate documentation of a medical decision maker be available in the health-care system.[3,4] Shared decision-making tools for ACP exist, and while some of these tools are web based, many do not link to the patient's EHR.[5,6]

The EHR-based tools may improve patient engagement in the ACP process through learning about the role of surrogate medical decision makers and thinking about and discussing future medical care preferences. Such tools may also increase availability of advance directives in the EHR.[7] An EHR-based patient portal provides patient access to a specific health-care organization's EHR through secure log in on a web page or mobile application.[8] Patient portal tools may include viewing medical information, exchanging electronic messages with healthcare team members, submitting questionnaires with patient information, or signing clinical or research consent forms. Recently, 2 pilot studies evaluated the use of electronic messaging via patient portal as an intervention to increase ACP communication.[9,10] Existing research shows that some patients perceive an online mechanism to complete advance directives as more convenient than a traditional paper copy.[11]

Given the resources needed for effective design and implementation of EHR-based tools, it is important to understand patient perspectives on feasibility, acceptability, and motivation for using such tools. Additionally, ACP tools should ideally complement other components of a patient's ACP process such as health-care interactions, legal input, or discussions with family and friends. As a regional health-care system, we developed multicomponent ACP tools in the patient portal.[12] The tools include: (1) ability to complete and electronically sign an MDPOA form, (2) a patient educational web page, (3) ability to send an online message to a centralized ACP support team, and (4) patient access to completed advance directives stored in the EHR. This study aims to describe patients' perspectives on the use of portal-based ACP tools including their motivations for using the tools and perceptions about how the tools fit into their personal ACP process.

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Methods

Design and Setting

This is an exploratory qualitative study of patients who used the portal-based ACP tools to understand their perspectives as a part of a system-wide quality improvement initiative to implement new ACP tools in a regional health-care system. UCHealth serves 3 large geographic regions in Colorado. The portal is a secure system that is available to all patients. In 2017, there were approximately 286 000 patients with a patient portal account, with an adoption rate of approximately 40% across the health-care system (based on active use within 30 days of a completed appointment). Portal users are of all ages (70% are between ages 30 and 69) and 61% are women. My Health Connection is the health-care system's brand name for the patient portal integrated with UCHealth's Epic EHR (Epic Systems, version 2017, Verona, Wisconsin). The portal-based ACP tools are available to all patients with a patient portal account and are described in Table 1. The availability of the tools was not directly advertised to patients. This initiative was approved by the institutional review board as a quality improvement initiative.

Participants

We recruited patients for telephone interviews from among the initial 254 patients who had used a portal-based ACP tool, such as completing an electronic MDPOA, visiting the portal ACP tools without taking further action, or contacting the ACP support team with a question or request. Potential interview candidates were purposefully sampled to include participants of different ages, sex, Colorado regions, and type of interaction with the ACP tools. Participants did not receive compensation for interviews. As part of the evaluation of a quality improvement initiative, informed consent was not required.

Data Collection

We contacted participants by telephone and interviewed them over the phone using an in-depth, semistructured interview guide (Online Appendix). Interviews lasted up to 40 minutes. Interview topics explored reasons or motivations for using the tools, experiences using the tools, and perceptions about how the tools fit into their personal ACP process. A research assistant (S.J.) with qualitative interviewing experience conducted interviews, which were audio recorded and transcribed, and maintained detailed field notes. The interviewer did not have any connection to patient care. Interviews were conducted until information saturation was achieved, where no new information was arising from the interviews. The response rate to invitation to participate in the interviews was 41%, based on inviting 113 individuals to participate. The Atlas.ti software version 7.5.18 was used for data storage, organization, and to facilitate data analysis. We abstracted patient and health-care characteristics from the EHR, including age, sex, and health-care system region.

Analysis

We inductively analyzed the data using a grounded hermeneutic editing approach, an extension of theme analysis.[13] This approach is a process where researchers immerse themselves in participants' worldview to interpret and identify meaningful everyday

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practices in order to systematically organize data through independent open coding. We used a team approach with analysts from diverse backgrounds (eg, geriatrics, health psychology, sociology, music therapy). In line with grounded hermeneutic editing approach, we prioritized an iterative analysis process whereby each team member first coded the data independently, and then we corroborated themes over time together, ensuring no new themes emerged across interviews as information saturation was achieved.[14] We continued to corroborate and legitimize themes by soliciting input on the interpretation of the analysis from the larger multidisciplinary project team (which includes expertise in medical informatics, population health, and clinical operations leadership) and presentation and feedback to palliative care stakeholders. This process of convening individuals with different perspectives facilitates a deeper understanding and enhances trustworthiness of the findings and highlights any implicit biases or assumptions on the part of the analytical team. We maintained a record of decision-making throughout the analytical process.

Results

Table 2 presents characteristics of 46 interview participants. Patients resided in all 3 health-care system regions and 4 other states. The majority of interviewees completed an electronic MDPOA (76%), while some visited the tools but took no further action (20%), and others used the ACP page to contact the ACP support team (4%).

Four key themes emerged related to patients' perspectives on using the ACP tools as part of future medical care planning: (1) individualized explorations of the ACP tools, (2) personal initiation and engagement with ACP tools through the portal, (3) value of connecting ACP portal tools to clinical care, and (4) practicality of the ACP tools.

Theme 1. Individualized Explorations of the ACP Tools

Patients described how they located the portal-based ACP tools, which primarily included self-initiated exploration of the patient portal and external recommendations from health-care team members. Patients described how familiarity with the patient portal helped them find the ACP tools, including ability to locate and complete the MDPOA form. For example, a 43-year-old man said,

> It was on the app and I just clicked on it and it said something about power of attorney, and I figured that might be a good idea, so I just went in and filled it out.

As an aspect of acceptability, patients appreciated the convenience of having the portal-based ACP tools available as part of routine care through their health-care system. A 30-year-old woman stated,

> I had surgery recently and so I was just trying to put my affairs in order and I just looked through your resources to see if you guys provided anything on that and you did. So being able to go online and kind of do a little research myself, it made me more comfortable with it, and then I could bring up that kind of conversation.

Patients also described the positive influence and recommendations from physicians and health-care team members that facilitated their ability to find the ACP tools. Notably, these

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recommendations were most influential when receptionists or medical assistants made informal suggestions that they complete an MDPOA form:

> When I was getting ready to go up [to the hospital] to be seen for my evaluation for transplant, I was told by the receptionist there that I might want to look at if there's any differences with the New Mexico power of attorney versus the Colorado one. If I'm going to be seen in both states, I want to have both forms. (48-year-old man)

Theme 2. Personal Initiation and Engagement with ACP Tools Through the Portal

Patients described their motivations and experiences that influenced why they chose to use the portal-based ACP tools once they located them. In general, patients' reasons for engaging in ACP via the portal were similar to reasons for engaging in ACP through other processes, such as clinic-based conversations. The ACP tools were described as helpful for alleviating future stress and uncertainty related to care preference decisions. Common reasons for appointing an MPDOA included current health issues or medical procedures, preparation in the event of a crisis, and desire to discuss and agree upon plans with family members. Participants also discussed the value of appointing an MDPOA in providing peace of mind for themselves, as well as reducing stress and burden for family members to make decisions on their behalf. As one 53-year-old woman said,

> I want to protect my family... for them not to have to worry about, you know, if something ever happens to mom, what should be done.

Patients' prior experiences with ACP discussions or documentation also prompted them to engage with the portal-based ACP tools. Many patients described personal stories of being a medical decision maker for someone else, discussing end-of-life issues with others, and valuing communication among family members. Through these previous experiences, patients were open to considering their own preferences for a medical decision maker and documenting them via the patient portal by completing an MDPOA form. For example, a 69-year-old woman described,

> My mother passed away several years ago, and then I had a sister who had a stroke ... and there's no way I wanted to go through the things that she went through during that time.

Prior employment experiences also fostered their engagement with the tools. Some patients discussed how their experiences as first responders to emergency situations (e.g., paramedic, law enforcement officer) or other healthcare professionals (eg, certified nursing assistant) increased their awareness of end-of-life care, prompting them to extend experiences from their occupation to their own lives and ACP actions:

> I was a paramedic and I had to deal with certain... situations looking at, "how do you want to handle this because I'm going to have to put you out. Who do you want to make decisions for you when I do this?" I had a wife actually tell the doctor, "just don't go into lifesaving anything." (43-year-old man)

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Theme 3. Value of Connecting ACP Portal Tools to Clinical Care

Patient experiences after using the ACP tools varied, including some examples of the value of having the ACP portal tools connected to clinical care. Several patients engaged in practical steps after using the ACP tools, such as sharing with their family members or health-care providers that they had recently assigned or updated their choice of medical decision maker. In some instances, such discussions also led patients to recommend the patient portal-based ACP tools to others. They were highly likely to recommend this process to others and appreciated the opportunity to appoint a medical decision maker prior to a significant life event or issue. A motivated 30-year-old woman said,

> Now I'm asking everybody around me if they have one just in case there's a car accident or something. There's nothing worse than putting your family in that situation where they are guessing, because if that comes up it's a hard enough situation as it is.

Alternatively, some patients stated that they felt comfortable and satisfied with using the ACP tools, such as completing an MDPOA form or sending a message to the support team, but did not feel the need to have follow-up discussion with their health-care provider.

Some patients also described the impact of having the MDPOA document in their record for health-care providers to directly access. Even within the short time since using the ACP tools, a few patients described examples where their use of the ACP tools benefitted them in a medical emergency. In one example, the health-care team retrieved the electronic MDPOA form through the portal:

> I was revived [in the hospital] and so when that happened they ended up pulling [the MDPOA form] there at the hospital and they discussed that with my parents and my grandmother. I hadn't spoken ... with them personally. I just filled it out on my own and then they discussed it with them there. (age and sex are not reported to maintain anonymity)

Theme 4. Practicality of the ACP Tools

In general, patients were satisfied with the ease of using the ACP tools. A 32-year-old woman stated,

> I liked your [online portal tools] better because everywhere can pull it up, and what if I forget, or what if it's such an emergency that we don't grab that booklet or something, you know?

Some patients also expressed the value of utilizing an electronic MDPOA form instead of paper forms for convenience, as this 28-year-old relayed,

> I had gotten the paper copy at the doctor and I was like, 'I don't want to deal with this. I'm going to see if they had one online or not.' It's just easier, I don't have to worry about sending things in.

Specific to the MDPOA form, a 36-year-old woman described the helpfulness of the follow-up process by the ACP support team,

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> I think it's nice that I got the confirmation [online message] to know for sure that it's in.

No patients expressed concerns about security or privacy issues relating to completing the MDPOA form through the patient portal. One person expressed instead, "it would be secure within the hands of [the healthcare system]" (24-year-old man).

Discussion

Patients from a wide age range and geographic regions used first-of-its-kind online patient portal ACP tools to appoint a medical decision maker as part of their future medical care planning process. The patients who used the portal-based ACP tools were younger compared to prior studies of individuals engaged in ACP,[15] adding to the work on acceptability of portal-based ACP tools across diverse patient characteristics. Overall, patients described the electronic MDPOA process as appropriate and accessible for appointing a medical decision maker. They emphasized the value of having an online tool that can communicate their preferences in a convenient and efficient way through the patient portal. Patients likely received recommendations to use the ACP tools by physicians or other medical staff, who became aware of the new portal tools through early educational outreach sessions to clinical staff teams. This initiative supports the potential clinical impact of a patient-initiated ACP process, especially among individuals who initiated their use of ACP tools based on their prior experiences with ACP or personal interest in completing or updating an MDPOA form. For future active promotion of patient-initiated ACP tools, dissemination strategies could include building provider and staff engagement by integrating ACP into clinic workflows, sending motivational electronic messaging to patients as part of population-based outreach, and offering patient classes that enhance use of the patient portal.

Given the increasing adoption of online systems to manage sensitive private information and maintain transparency (e.g., Open Notes, which allows patients to view their documented medical history), our results are timely in understanding how to effectively develop applications for health-care needs. This evaluation of portal-based ACP tools provides opportunities for future study within the context of a learning health-care system or system-wide palliative care approaches. One question is whether patients who choose to complete an electronic MDPOA have increased discussions about preferences for medical care with loved ones or health-care providers. Similarly, given the barriers to systematic implementation of ACP interventions into health-care settings,[16] further study is needed to understand health-care providers' perspectives on whether the availability of ACP tools facilitates recommendations about ACP engagement or influences clinical decision-making. Patient feedback related to experiences using the ACP tools highlighted areas for improvement and needs related to integration into clinical care. Challenges to optimizing use of the electronic MDPOA process include access to technology and both health and computer literacy; tools should accommodate variable literacy levels to the extent possible. Further evaluation is needed to understand whether and how patients used the patient educational resources that are available as part of the ACP tools.

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This initiative has several limitations. This clinical demonstration project was conducted in a single healthcare system. In particular, we were able to implement this electronic MDPOA process because Colorado law does not require that an MDPOA form be witnessed or notarized. Other health-care systems are developing similar patient portal-based processes that involve deciding on a medical decision maker, completing an electronic form, and then printing it so that it can be appropriately witnessed and shared with the health-care system.[17] Thus, these results are highly contextual and not generalizable.

In conclusion, this article summarizes the experiences of patients who appointed a medical decision maker or engaged with ACP tools using a novel electronic MDPOA process on a patient portal-based ACP web page. Patients were motivated to engage in the ACP process and found the tools to be accessible, and in many cases, a helpful part of their broader ACP discussions. Clinical settings can develop population health-based outreach processes to promote use of the electronic ACP tools, such as motivational online messages or outreach campaigns to raise awareness about the tools. Actionable tools for ACP in the patient portal can help health-care systems as they focus on providing high value, person-centered care that supports preventative health and patient self-management goals.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

The authors thank the UCHealth patients who provided feedback to evaluate and improve this process. This project would not have been possible without the significant organizational support of multiple UCHealth leaders and champions. The authors specifically thank Dr Jean Kutner, Dr CT Lin, Dr Lisa Schilling, Josh Conrad, Leah Rusinek, and Sally Nietfeld for their clinical leadership, population health and informatics expertise, and building and integrating the patient portal tools. The authors are also grateful to Dr Jodi Holtrop and Ms Elizabeth Staton for providing helpful input on early versions of this manuscript.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by The Colorado Health Foundation and in part by the National Institutes of Health (K76AG054782) and the Colorado Clinical & Translational Sciences Institute (CCTSI) with the Development and Informatics Service Center (DISC) grant support (NIH/NCRR Colorado CTSI Grant Number UL1 RR025780) for use of REDCap-based data management.

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Table 1.

Description of Portal-Based ACP Tools.

ACP Tool	Description
Complete a Medical Durable Power of Attorney (MDPOA) form	• Information about completing an MDPOA form • Asks patient to acknowledge that they wish to complete the MDPOA form • Patient enters medical decision-maker information exactly as it will appear on the legal document • After submission, patient can download and print the MDPOA, which includes “Electronically signed by: (Patient name) via My Health Connection” and a date and time stamp. • Completed MDPOA forms are stored in the EHR • ACP Support Team Coordinator responds with an electronic message to the patient, documents submission of the MDPOA in the EHR, and sends a notification by electronic message to the primary care provider.
Patient educational web page	• Overview and definitions of advance care planning terms • Links to external patient education web pages
Online messaging	• Patients can send a message to a centralized ACP support team with questions or requests for assistance
View advance directives	• Patients can view stored advance directives on file in their record via the patient portal

Abbreviations: ACP, advance care planning; EHR, electronic health record; MDPOA, Medical Durable Power of Attorney (electronic portal form available to patients aged 18 years and older).

Am J Hosp Palliat Care. Author manuscript; available in PMC 2019 August 01.

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Table 2.

Characteristics of Interviewed Patients Who Used the ACP Tools.

Characteristic	n (%)
Age, mean in years (range)	49(22–82)
Younger than 60 years old	31(67)
60 years and older	15(33)
Female	29(63)
Region	
Colorado residents—metro region	14(30)
Colorado residents—southern region	13(28)
Colorado residents—northern region	12(26)
Out of state residents	7(15)
Type of interaction with ACP tools	
Completed electronic MDPOA form	35(76)
Visited ACP tools without further action	9(20)
Contacted ACP support team	2(4.3)

Abbreviations: ACP, advance care planning; MDPOA, Medical Durable Power of Attorney (electronic portal form available to patients aged 18 years and older).

[a] n = 46.