

Testing of a Tethered Personal Health Record Framework for Early End-of-Life Discussions

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Advan­ce care plan­ning (ACP) is associated with a variety of favorable outcomes, such as improved patient satisfaction with care, improved patient quality of life in terminal illness, and better psychological outcomes of grieving family members after patient death.¹⁻³ ACP is also associated with increased use of hospice, reduced intensive care unit use, and reduced costs for end-of-life care that patients do not necessarily want.³ However, rates of ACP and advance directives (ADs) completion remain persistently low (seldom >31%),^{4,6} even for patients with expected survival of less than 4 months.³

ACP delivery may not be considered a priority for care providers in a time-limited clinical encounter over more urgent competing concerns in the primary care setting.⁷ Additional barriers, such as a lack of ACP resources, lack of training in ACP conversations, and prognostic uncertainty in chronic disease have been reported by primary care providers, thus further complicating delivery.^{8,9} These barriers highlight the need for more accessible and time-efficient methods for recording patient ACP preferences in primary care. However, a construct for providing time-efficient, team-based ACP for busy outpatient primary care practices is needed to help ensure its prioritization.

Researchers have recognized the need for electronic tools that empower patients to engage in ACP.^{5,10,11} However, these currently do not automatically link resulting documents to the patient's electronic health record (EHR); in order for a patient's medical providers to access this documentation, the patient must intentionally provide it to them to file in the medical record. Nonetheless, electronic support tools are a promising approach to translation of validated ACP tools for use in resource-constrained primary care settings, especially if such tools can automatically interface with patients' medical records.

ACP communication employing EHR-tethered personal health records (PHRs), which allow patients and providers

ABSTRACT

Objectives: The process of planning for end-of-life decisions, also known as advance care planning (ACP), is associated with numerous positive outcomes, including improved patient satisfaction with care and improved patient quality of life in terminal illness. In this study, we sought to test a novel personal health record (PHR)-delivered ACP framework through a small-scale randomized trial of usual care practices versus PHR-delivered ACP.

Study Design: Randomized controlled pilot intervention.

Methods: A novel PHR-ACP tool was tested using data and feedback collected in a randomized controlled pilot intervention (n = 50). Participants in the control group received standard care for ACP conversations while participants randomized to the intervention group received a novel ACP framework through the electronic health record.

Results: The pilot study testing the ACP framework found that its use resulted in improved ACP documentation rates (P = .001) and quality (P = .007) compared with usual care.

Conclusions: Tethered PHR use as an initial ACP communication tool can improve outpatient documentation rates and quality. Future studies obtaining patient feedback on a revised framework and testing in a larger setting are needed to determine reproducibility of findings.

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to conduct secure electronic communication within the patient's medical record, can help overcome many barriers that have not yet been addressed with current ACP delivery strategies¹² (see **Table 1** for definitions of relevant terms). A PHR-based ACP framework¹³ can provide a construct for team-based, outpatient ACP communication that is individualized, efficient, structured, and automatically interfaced with a patient's medical record.¹⁴ Investigation of such a solution remains imperative because of patient satisfaction, disease understanding, and economic benefits of well documented ACP.¹⁻³ Although the use of PHRs has been proposed as a novel way to streamline ACP, such a system has yet to be tested or developed into a workflow that would fit into the primary care model.¹⁴

Take-Away Points

- Advance care planning (ACP)—planning for future health decisions while still able to voice personal preferences—improves patient care, family satisfaction, and medical costs.
- ACP is currently poorly delivered. We created a message system using patient portals to encourage physicians and patients to communicate about this topic.
- ACP documentation frequency and quality were dramatically improved when using this electronic health record messaging workflow.

Framework Intervention

All patients 50 years or older who were seen at the clinic were eligible for participation. No prior experience with computers or the institution's PHR (MyChart) was necessary, but patients were asked to complete MyChart registration upon their enrollment into the study if they had not already done so. Patients were approached for participation when they arrived for their clinical visits over a 3-month period. Patients who consented to participate in the study were then randomized into either a control or an intervention group. Those randomized to the intervention group received the developed PHR-ACP via their MyChart account; participants randomized to the control group received usual care (which included an institutional packet of information on ACP, state-issued documents about ADs, and encouragement to discuss any ACP questions with their provider).

Usual care practices reflected an established clinical workflow by general internal medicine practices (developed more than 3 years prior to study initiation in collaboration with social work and medical center leadership). Participant charts were reviewed at enrollment in order to collect descriptive information. Demographics are summarized in **Table 2**. Fifty total participants were enrolled in the pilot study, 31 of which were female. Forty-one participants were Caucasian, 5 were African American, 3 were identified as "other," and 1 participant was identified as "unknown."

METHODS

This study was approved by the Ohio State University Institutional Review Board.

Study Overview

In this study, we sought to test a novel PHR-delivered ACP framework (**eAppendix A**, [eAppendices available at www.ajmc.com]) through a small-scale randomized trial of usual care practices versus PHR-delivered ACP. Development of this framework has been previously described.¹⁵ Chart review was conducted pre-intervention and 6 weeks post intervention to examine the presence and quality of ACP documentation. The framework was tested using participants from an academic medical center primary care practice located in the Midwest—the same population used in previous studies exploring use of EHR technology in primary care settings.¹⁶

■ **Table 1.** Definition of Relevant Terms

Advance Care Planning	The process that clarifies personal preferences and results in a written advance directive for future medical decisions in the event of health decision-making incapacity. ^{15,16}
Advance Directive	Advance directives are legal documents that allow patients to document their decisions about end-of-life care, such as appointing healthcare decision makers and documenting decisions about preferences for care or quality of life. ¹⁷
Electronic Health Record	An electronic health record (EHR) is a digital version of a patient's paper chart. EHRs are real-time, patient-centered records that make information available instantly and securely to authorized users. While an EHR does contain the medical and treatment histories of patients, an EHR system is built to go beyond standard clinical data collected in a provider's office and can be inclusive of a broader view of a patient's care. ¹⁸
MyChart	Name of institution-specific personal health record.
Tethered Personal Health Record	A tethered, or connected, personal health record (PHR) is linked to a specific healthcare organization's electronic health record system or to a health plan's information system. With a tethered PHR, patients can access their own records through a secure portal and see, for example, the trend of their lab results over the last year, their immunization history, or due dates for screenings. ¹³

Table 2. Advance Care Planning Intervention Demographics at Baseline

	Control (n = 25)	Intervention (n = 23)
Age range, years	51-75	51-75
Median age, years	60	56
Caucasian	21	20
African American	2	3
Average number of chronic problems	14	12
Average number of prescription medications	9	7

The mean age for all participants was 58.5 years, with an age range of 50 to 75 years. Two participants randomized to the intervention group did not complete the study (as outlined in the results section), and 9 patients who were approached refused to participate in the study.

Participants were followed during a 6-week study period. At the end of the study period, a second chart review was completed to assess whether or not ACP documentation had been created or updated since recruitment. The quality of any resulting ACP documentation was graded based on a 20-point scale, entitled “Criteria for Scoring Quality of ACP Documentation” (eAppendix B). This scale was developed by the research team after reviewing state of science ACP reports, such as those from the United Kingdom National Health Service, the Australian Quality Advance Care Planning Board, and the National Hospice and Palliative Care Organization’s “Caring Connections” program.¹⁷⁻¹⁹ Although this scoring system has not been validated, it has been based on nationally and internationally accepted ACP documentation components. Development of the scoring system was necessary in order to quantify the quality of documentation present in the patient health record. Consensus points between the reports were included in the scale.

RESULTS

ACP Documentation

Two participants were removed from the data set; both participants had been randomized to the intervention group.

The first participant was a 65-year-old Caucasian male who did not have ACP documentation at recruitment; he died 2 weeks after recruitment. Chart review revealed that he did not have any resultant ACP at the 6-week follow-up. The second participant was a 63-year-old Caucasian male who did not have ACP documentation at contact. He was removed because he did not activate MyChart immediately after enrollment, as required for the study, although he did activate it after he was called to be notified about his ineligibility for the study. This participant did have resultant ACP from the intervention (as determined by chart review at the 6-week follow-up); however, he was not included in the analysis because his workflow did not adhere strictly to the study protocol. EHR reviews of both the control (n = 25) and intervention (n = 23) groups were completed to determine the presence of any type of ACP documentation at enrollment, and then again after a 6-week study period.

Pre-intervention showed that no participants from either the control or the intervention group had meaningful ACP documentation present at baseline. After the 6-week study period, 1 individual from the control group had any ACP documentation, while 10 members of the intervention group had ACP documentation present in their EHR (Table 3). A Fisher Exact test was used to determine the statistical significance of the observed changes in all types of ACP documentation after the intervention. The test resulted in a P value of .0011, indicating evidence of a relationship between the intervention and the likelihood of adding some type of ACP documentation (Table 3).

Participants in both the intervention and control groups varied in the type of ACP documentation present. Post-intervention analysis was further divided into subcategories of documentation status to better understand the influence on the type of documentation elicited by the intervention: 1) no ACP documentation, 2) MyChart ACP documentation, and 3) non-MyChart ACP documentation (Table 4).

The odds of an individual in the intervention group adding non-MyChart ACP documentation were 13.07 of those of an individual in the control group. None of the covariates added to the model were found to have a significant impact on the likelihood of adding non-MyChart ACP documentation.

Table 3. All Advance Care Planning Documentation^a

	Pre-Intervention		Post Intervention	
	No Documentation Present	Documentation Present	No Documentation Present	Documentation Present
Control (n = 25)	25	0	24	1
Intervention (n = 23)	23	0	13	10

^aAll P = .001.

Table 4. Type of Documentation at Follow-up

Group	No ACP	MyChart	Non-MyChart ACP
Control (n = 25)	24	0	1
Intervention (n = 23)	13	5 ^a	7 ^a

ACP indicates advance care planning.
^aTwo participants had both MyChart and non-MyChart ACP present; they were counted in both columns in this table.

ACP Quality

This scale was developed based on completion of ACP communication in several iterations. Because the study focused on an initial or preparatory, step for ACP, it was hypothesized that quality scores would improve, but remain in the lower (below 5) range. The number of individuals with each of the 4 observed scores at follow-up are presented in **Table 5**. The scores were an accumulation of all ACP documentation in the chart, including documentation from past providers.

A Mann-Whitney nonparametric analysis was used to test for significant differences in ACP quality between the 2 groups from baseline to follow-up. The test returned a *P* value of .007, giving evidence that individuals in the intervention group exhibited a greater average increase in their quality scores compared with those in the control group.

Among individuals in the control group, no quality scores changed from enrollment to follow-up, meaning all 25 control participants had resulting quality scores of 0. Among the intervention group, we observed individual score increases of 1, 2, and 3 points, as well as 3 other individuals whose scores increased by 4 points each.

DISCUSSION

The ACP process holds several advantages for patients as they plan for future care and results in more favorable outcomes; nevertheless, despite these benefits, documentation remains low. Our framework allows for ACP documentation to be accessible by the individual and their medical team when it is needed most. Past research has highlighted the importance of ACP tools in clinical settings^{17,18} and the particular effectiveness of the ACP tools that allow patients to edit and voice their personal wishes electronically, at their own convenience.¹⁵ This newly developed framework serves as a clinical ACP tool, yet it retains the benefits of patient-initiated electronic ACP documentation.

Deliveries of this framework to patients lead to significant improvement in both the rates and quality of resulting ACP documentation among patients who received the framework compared with those who re-

ceived standard clinical care. It is plausible that the impact on documentation of ACP in the EHR may have occurred as a result of the patients being prompted to state their preferences and not of the framework. Any intervention that facilitates ACP discussions between provider and patients, prior to crisis, is beneficial to both parties. By developing a PHR-based ACP framework, we did not seek to address a gap in ACP communication tools, because many such tools already exist. We sought to address the gap of ACP tools that easily integrate into primary care workflows, using existing resources like the increasingly ubiquitous PHR,^{11,20,21} without the requirement of additional resources—many of which are barriers to ACP delivery. The importance of our PHR ACP framework lies in not only the prompts for ACP, but also in the delivery mechanism of the prompts, allowing systematic assessment of ACP in a streamlined manner that is feasible for widespread use in primary care (eg, without the additional staff, office space, and face-to-face time required by currently available ACP methods).²²

The effectiveness of the described intervention highlights the potential positive impact on the presence and quality of ACP documentation for many patients. Normalizing the use of an electronic patient portal among target populations who may express aversion to, or lack the knowledge and confidence for, using such technology effectively is a barrier that cannot be easily overcome. Likewise, the dedication of staff and resources to ACP interactions and discussions is an important component to the success of any ACP process. It is also important to note that the developed framework is intended for the initial stages of ACP, not as a standalone solution in times of crisis or decline. Future research is necessary to investigate PHR interfaces in later stages of the ACP process.

Although these barriers are important to take into account, they should not deter future investigation and use of such a promising intervention. The initial promise of the PHR-ACP framework merits a larger scale trial of the framework; this project is underway. It is important that future studies test and refine the framework for use in minority populations so as to not widen the already existing disparities in minority ACP documentation.

Table 5. Advance Care Planning Quality at Follow-up^a

Group	Score = 0	Score = 1	Score = 2	Score = 6
Control (n = 25)	25	0	0	0
Intervention (n = 23)	13	4	5	1

^aAll *P* = .007.

Limitations

The study was limited in size and geographic scope. Although the intervention was small, it still produced statistically significant results and could easily be reproduced with a larger sample size to improve the strength of the preliminary findings. In addition, the development of the framework was within the cultural norms of the Midwest, so in order for the effectiveness of the framework to be optimized, similar testing and revisions would need to be made after testing outside of that region. It should also be noted that the study period of 6 weeks was relatively short; a longer study period may result in more robust documentation for both groups, but particularly the control group, as there may not have been adequate time for those patients to have had a follow-up visit to discuss ACP with their primary care provider.

In order to increase effectiveness, such an intervention would have to be paired with support for patients using MyChart. The intervention described dealt with only the content and was unable to modify the form and function of the electronic record as it is an institutional tool for a large academic medical center. However, information gained through this and other studies can be used to provide feedback in the process of improving the patient interface of EHRs.

For those patients who were able to overcome such barriers, the electronic ACP framework showed great potential in improving both documentation and quality of ACP in the EHR when compared with the standard of care. From a systems standpoint, our study team did include a liaison with the institutional information technology department servicing the EHR. Systems-level concerns unearthed during this study were relayed to the appropriate parties in a de-identified manner in order to stimulate institutional changes. We hope that such changes will also contribute to the success of the intervention in future, larger studies.

There were also several forms of non-MyChart ACP (direct physician entry) that were documented in the records of intervention group patients enrolled in the study during the study period. This study did not specifically explore how non-MyChart ACP documentation was brought up during the visit (eg, provider initiated or patient initiated). However, the presence of such documentation in the intervention group implies that the PHR-ACP framework not only stimulated direct patient entry of ACP preferences, but also stimulated provider-patient dialogue within the office visit. It is possible that patients brought up this topic after prompting from the ACP MyChart framework, but further investigation about the mechanism of this dialogue is needed.

CONCLUSIONS

This study set out to test a usable, patient-centered ACP framework to improve ACP documentation and, subsequently, to test the framework for feasibility and effectiveness. There is also strong evidence to support the influence of the framework intervention on improving the quality of ACP documentation compared with standard care, as well as the amount of improvement shown in the quality of documentation over the study period.

Future investigation should focus on larger, more diverse populations in order to improve the generalizability of this study and the framework. A larger, multi-clinic testing of the framework is planned in the next 6 months. Investigators and providers will also need to consider how to make the electronic framework more accessible to patients who face some barriers to navigating or accessing their EHR. Our research team has been collaborating with institutional information technology and biomedical informatics departments to improve MyChart for geriatric patients.

Although more work is needed to improve ACP documentation, both qualitative and quantitative evidence would suggest that the developed framework has the potential to successfully facilitate ACP through the PHR in outpatient practice, particularly in primary care. Incorporating the framework should be done with careful discussions with clinic providers in order to tailor workflows to individual practices.

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eAppendix A. PHR-Delivered ACP Framework

PHR-Delivered ACP Framework

Dear [Patient Name],

As a routine part of your health, we would like you to answer some questions. These questions help us know how we should take care of you in case you ever get too sick to speak for yourself. Your answers will be filed into your chart to help guide your future care. You can change your answers at any time.

Please think about these questions and talk about them with your loved ones. Send us back your answers when you are done.

If you are too sick to speak for yourself, who should make medical decisions for you?

Is there anyone you specifically would NOT want to make medical decisions for you?

What activities give your life quality?

What helps you cope during hard times (like the death of a loved one or a serious illness)?

If you would like to discuss your answers more with your physician during an appointment, please let us know. Our office has more resources to help you put your wishes in writing. Ask us for more information the next time you visit the clinic.

Thank you for your answers.

Sincerely,

[Physician Name], MD

[Nurse Name], RN

(Follow-up framework omitted)

eAppendix B

Criteria for scoring quality of ACP documentation in the EHR (Developed after review of Caring Connections, Australian State of Science on Quality Advance Care Planning)

Exploration of:

- i. Did you assess if patient can make own decisions (1 point)
- ii. Did you look at why patient is completing ACP document (1 point)
- iii. Does the patient understand the following:
 - a. Their illness? (1 point)
 2. Why they are doing ACP? (1 point)
 3. All the different ways they can document their future plans? (1 point)
 4. When documented preferences would be activated (when they are unable to voice their preferences)? (1 point)
 5. That the ACP document is not fixed in stone and can be changed as their wishes change? (1 point)
- iv. Patient values and circumstances:
 1. Does the patient have any cultural or religious preferences? (1 point)
 2. Does the patient have any past experiences with ACP? (1 point)
 3. Does the patient report any barriers to care? (1 point)
- v. Picking a decision maker: Did the documentation record:
 1. Who would serve as a healthcare agent? (1 point)
 2. Agent's willingness to participate in patient's care? (1 point)
 3. Agent's understanding of the patient goals, values, and beliefs? (1 point)
 4. Agent's ability to make decisions when under stress? (1 point)
 5. Agent's willingness to honor the patient's desires when ACP activated? (1 point)

6. Agent's participation in the ACP discussion (during visit or with patient)? (1 point)
 7. How much freedom the patient gives their agent to change his/her voiced preferences? (1 point)
- vi. What does the patient want to accomplish?
1. What contributes to a positive quality of life for the patient? (1 point)
 2. How would the patient envision his/ her care if s/he could not make own decisions, didn't know who s/he was, and/ or where s/he was (clinical situations such as dementia)? (1 point)
- vii. Seeing it through?
1. Did the patient get a follow up offer to have additional conversations if desired, including, but not limited to, referrals to sub-specialists, or inter-professional disciplines like social work, chaplaincy, etc answer questions about ACP? (1 point)

Applied to ACP documentation encounters in EHR.

ACP indicates advance care planning; EHR, electronic health record.