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

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Abstract

Objectives—End-of-life planning, known as advance care planning (ACP), is associated with numerous positive outcomes, such as improved patient satisfaction with care and improved patient quality of life in terminal illness. However, patient-provider ACP conversations are rarely performed or documented due to a number of barriers, including time required, perceived lack of skill, and a limited number of resources. Use of tethered personal health records (PHRs) may help streamline ACP conversations and documentations for outpatient workflows. Our objective was to develop an ACP-PHR framework that would be for use in a primary care, outpatient setting.

Study Design—Qualitative content analysis of focus groups and cognitive interviews (participatory design).

Methods—A novel PHR-ACP tool was developed and tested using data and feedback collected from 4 patient focus groups (n = 13), 1 provider focus group (n = 4), and cognitive interviews (n = 22).

Results—Patient focus groups helped develop a focused, 4-question PHR communication tool. Cognitive interviews revealed that, while patients felt framework content and workflow were generally intuitive, minor changes to content and workflow would optimize the framework.

Conclusions—A focused framework for electronic ACP communication using a patient portal tethered to the EHR was developed. This framework may provide an efficient way to have ACP conversations in busy outpatient settings.

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Advance care planning (ACP) clarifies personal preferences, resulting in written advance directives (ADs) for future medical decisions in the event of health decision- making incapacity.[1,2] It helps patients: a) reflect on goals, values, and beliefs; b) consider future treatment preferences; c) appoint a surrogate decision maker; and d) document their wishes regarding future medical treatment.[3] ACP is associated with improved patient satisfaction with care, improved quality of life in terminal illness, and better psychological outcomes of family members after patient death.[3–5] ACP is also associated with increased use of hospice, reduced intensive care unit use, and reduced costs for unwanted end-of-life care.[5] However, rates of completion remain low (seldom >31%),[6–8] even for patients with expected survival of less than 4 months.[3]

For providers in a time-limited encounter in the primary care setting, ACP delivery may not be considered a priority over competing concerns.[9] Additional barriers—such as a lack of training and resources, and prognostic uncertainty—have been reported by primary care providers.[10,11] These barriers highlight the need for more accessible and time-efficient methods for recording patient ACP preferences in primary care[12] that integrate nonphysician clinic providers into the communication process.[13] However, a construct for providing efficient, team-based ACP delivery for outpatient practices is needed to help ensure its prioritization.

While validated tools for ACP facilitation exist, they require dedicated time and personnel for administration that are not feasible for many practices. Researchers have recognized the need for electronic tools that empower patients to engage in ACP,[7,14–16] because currently, these stand-alone tools do not link documents to the patient's electronic health record (EHR), aka personal health record (PHR). In order for providers to access documentation, the patient must provide it to them to file in the medical record. Therefore, 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 the medical record.

This innovative systems-level solution can achieve higher rates of ACP and AD completion. Investigation of such a solution remains imperative because of patient satisfaction, disease understanding, and the economic benefits of well-documented ACP.[3–5]

METHODS

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

Study Overview

The framework was developed using a mixed methods approach over 2 phases: phase 1—initial framework development using review of literature and best practices in combination with focus group data to inform content; and phase 2—cognitive interviewing of patients to elicit feedback about the framework.

The original framework was established through review of best practices, and patient-desired content was derived from focus-group data. Common themes from delivery methods were summarized for focus-group participants. An interdisciplinary research team used focus-group feedback to inform development of the PHR-delivered ACP framework. The framework was presented during a focus group to all primary care providers practicing at the study site. Feedback about framework content and distribution was incorporated to create an initial draft of the PHR-delivered ACP framework. Additional primary-care patient participants (n = 22) were recruited to complete cognitive interviews. The research team used feedback from cognitive interviews to further revise the language and layout of the framework.

Focus Groups (phase 1)

Four patient-participant focus groups and 1 physician focus group were conducted to elicit preferences for a PHR-delivered ACP framework. These preferences were used to develop content, language, structure, and workflow for the framework. Four to 5 participants were recruited to each patient focus group based on best practice recommendations.[17] Purposive sampling was used to ensure robust African American participant involvement. Such feedback was necessary because African American patients are half as likely as Caucasian patients to participate in ACP using existing models.[18] All primary care providers at the clinical study site were recruited to participate in the physician focus group.

Take-Away Points

Patient-provider advance care planning (ACP) conversations are rarely documented because of time required. Patient portals can help improve ACP documentation and quality in outpatient settings.

- We used input from patients and providers to develop this framework for an outpatient primary care practice.
- Delivery requires cooperation among patients, physician, and support staff, but needs much less time than traditional office-based ACP conversations.
- Testing of the framework in different environments will be essential for dissemination and uptake.

Phase 1: Patient Participant Focus Groups

Demographics—Nineteen participants were recruited for 4 different focus groups. Inclusion criteria were: a) current patient at study site, b) aged over 50 years, c) diagnosis of 1 or more chronic diseases, and d) taking 1 or more prescription medications. Inclusion criterion for physician focus group was: primary care provider at study site. Patient participant focus group demographics are summarized in Table 1. Of the 4 patient focus groups, 2 had Caucasian participants and 2 had African-American participants. Race-specific patient focus groups were conducted to ensure that opinions of African American participants were fully voiced without influence from Caucasian participants.[19] Of the 19 subjects recruited, 6 were “no-shows” for their respective focus groups, leaving 13 total participants. Each focus group had between 2 and 4 participants due to “no-shows.” Of the participants, no subjects with less than a high school diploma consented to participate in the study. Six of the 13 participants reported having completed written ADs; no participants with a completed AD were African American.

Setting and content—All focus groups were facilitated by the same set of co-facilitators and were given/shown the same materials in order to inform discussion (eAppendix A [eAppendices are available at www.ajmc.com]). Educational information about ACP and PHRs were provided to participants at the beginning of the session. Participants were shown a brief video created by National Healthcare Decisions Day about ACP, and were given an informational brochure about MyChart, the institution’s tethered PHR, supported by the Epic EHR system. Educational materials, including a copy of the institution’s AD informational packet, were presented in binders that were distributed to each participant. The institutional AD packet contained an informational sheet about ADs, resources for discussing and developing ADs, and state-specific Health Care Power of Attorney and Living Will forms.

The binder also contained discussion questions and excerpts of ACP language employed in validated delivery systems.[2,20,21] Sample questions were selected after review of the CDC’s summary document on ACP resources for the public.[22] Discussions were initiated using a semi-structured format, each lasting approximately 60 minutes. One Caucasian participant in the first focus group was noted to be less vocal and participatory than others in the group.

Confidentiality, and the privacy of participants and content, were discussed prior to starting. The study team gave an introduction to ACP as a framework for conversation. Participants were subsequently asked about: a) personal experiences with end-of-life decisions and MyChart use, b) personal preferences on how their ACP plans should be communicated, c) willingness to use MyChart for ACP, and d) perceptions of sample ACP questions used in referenced validated face-to-face interventions (see Appendix A).[2,20,21] The same questions were asked during each focus group. Discussion content was used to develop an initial PHR communication framework and workflow for provider feedback.

Phase 1: Physician Focus Group

Demographics—The physician focus group was recruited from the practicing physicians at the study site. All 4 physicians were approached, and all participated in the focus group. Demographic information about physician participants is summarized below (Table 2). The physicians at the study site were all younger than 45 years; they had been in practice between 3 and 11 years.

Setting and content—Physician focus group participants were asked about: a) clinical experiences with ACP, b) clinical experiences using PHR; c) barriers to ACP in practice, d) willingness to engage in ACP using PHR, and e) feedback about draft of framework and proposed workflow. Discussion was initiated using a semi-structured format and lasted approximately 45 minutes.

Phase 1: Data Collection and Analysis Methods (all focus groups)

Data were collected through audio recordings and observational notes taken during the focus groups. Recordings were transcribed using detailed transcription and were transcribed by the same trained transcriptionist. Study researchers decided on the format of detailed transcription prior to initiation because it captures not only verbal content, but also conversational features such as pauses, stuttering, and interruptions. Such factors were taken into consideration during the analysis of the focus groups to better understand the context of different comments. This form of transcription helps capture emotions, such as enthusiasm and discomfort, in addition to content.

Content Analysis Method was selected because it allowed assessment of consensus categories for framework development. [23–27] Focused tape review of transcripts and field notes established narrative accuracy of data prior to analysis. Detailed transcripts were coded alongside field notes by 3 analysts. Each coded the transcript separately, and then compared results from the independent coding. To ensure confirmability and credibility of findings, focus group analysis was performed in 5 steps: 1) independent content category development; 2) independent identification of consensus categories; 3) development of a written template defining criteria for categories and subcategories (during a meeting among analysts); 4) initial assessment of inter-rater reliability; and 5) elimination of unreliable categories after discussion among raters.[27] Themes found to be common among the coders were summarized and considered for framework development. Additional peer debriefing with 2 members of the research team helped ensure credibility of findings. Content and consensus categories informed initial framework question development (eAppendix A).

Cognitive Interviews (phase 2)

Following development of the framework, primary care patients were approached during clinical visits to participate in cognitive interviews. Cognitive interviews were conducted to receive “real-time” patient participant feedback about the framework, including the content, structure, and manner in which it would be received (ie, over MyChart).[28] Patients aged 50 years or older were recruited to participate in 15-minute interviews during clinical sessions over a 6-week period. Demographics of cognitive interview participants are summarized in Table 3.

Participants were instructed to “think aloud” in order to provide immediate feedback on the content, structure, and layout of the framework as they read through it for the first time. The research assistants asked probing questions only about comments made by the participants. If a participant specifically requested help in navigating the PHR or the framework, the research assistant: a) provided targeted assistance, and b) documented participant difficulty with the domain for which help was requested. Participant comments were scribed by the research assistant immediately after the interview. Interviews were conducted until data saturation was reached.[29] Observations were then compiled and used to revise the initial framework.[30]

RESULTS

Focus Groups (phase 1)

Patient focus groups were analyzed using the scissor-and- sort method of transcripts and scribe notes.[31,32] Only elements that were identified by all 3 analysts were considered in assembling the framework. A summary of these elements was compiled and reviewed during framework development. Patient focus group analysis revealed several common preferences present in each of the respective groups: a preference for clear language in communication tools; endorsement of MyChart as a helpful communication tool; a need to qualify and disqualify preferred decision makers; and a desire to personalize content, often based on previous experiences (Table 4). These preferences were used to tailor an initial ACP framework for MyChart.

Cognitive Interviewing (phase 2)

Notes from the interviews were reviewed by 2 independent reviewers; a count of major themes was taken (Table 5) and categorized into “strengths” and “weaknesses.” Summary lists were compared and discrepancies were noted. Repeat review was conducted until analysts reached agreement in summaries.

Two of the most frequently mentioned “weaknesses” of the framework were that it was difficult to access MyChart—meaning they had difficulty logging in or registering for MyChart on their own (10 of 22)—and to locate the message within the account (14 of 22). These comments did not directly reflect the content of the framework, but they were still important considerations and were subsequently communicated to institutional information technology (IT) developers. Thirteen of the 22 participants mentioned that they would re-word questions. Other common themes were discomfort in answering the questions (5 of 22), need for an introduction to the framework (5 of 22), and desire for follow-up and discussion (5 of 22).

The physician focus group was also analyzed using a scissor-and-sort method.[32] Physician comments were used to prepare a specific office workflow for the framework distribution and inform a streamlined ACP framework seeking specific ACP elements. Broader concerns about PHR use and billing that were beyond the scope of ACP framework development and workflow were communicated with participant permission to IT and medical center management.

DISCUSSION

The ACP process holds several advantages for patients, yet documentation of ACP and ADs remain low. The use of an EHR to deliver and support the ACP process could be advantageous to both care providers and patients, offering a more efficient use of time and resources. Although stand-alone tools aid in the process, these tools do not interface with medical records. Our framework allows for ACP documentation to be accessible by the individual and their medical team when it is most needed. This newly developed framework serves as a clinical tool, yet retains benefits of patient-initiated electronic ACP documentation.

Through focus group testing, we determined that patients desired a clear, concise, and accessible communication tool that would allow them to voice wishes and desires during the ACP process. Provider feedback indicated that the framework should help patients reflect and give a starting point for the conversations, but emphasized that they wanted to know only “vital” information. Providers also voiced their desire for the framework to fit within the EHR and the clinical workflow. While cognitive interviewing using the framework confirmed that patients approved of the content and delivery method, it also highlighted the need for small edits to language and workflow.

Limitations

The focus groups had a high rate of “no-shows.” In addition, the study results would have been more generalizable had the study taken place across multiple clinics, not just a single clinical population. While minority participants were purposively sampled in focus groups, they were underrepresented during cognitive interviews. The use of only 1 physician focus group should also be considered, as resulting data may be incomplete. Although data from physician focus groups were consistent with those of similar studies, inclusion of a larger number of physicians may have yielded more reliable, complete results. That was not possible in this study, due to the small number of physicians at the study site. Future studies involving multiple practices will allow more robust exploration of perspectives about the framework. Ideally, additional focus groups would have been conducted in order to ensure saturation of opinion within the study population.

CONCLUSIONS

This project set out to develop a usable, patient-centered ACP framework to improve ACP documentation. Patient impressions reported during cognitive interviews suggested that patients found the framework accessible. The use of questions and content vetted by patients in the target population was an essential component of the development.

Future investigation should focus on larger, more diverse populations in order to improve the generalizability of this study and the framework. Investigators and providers will also need to consider how to make the electronic framework more accessible to patients who face some barrier to navigating or accessing their EHR.

Qualitative evidence would suggest that the developed framework would meet the needs of both patients and providers as a tool for documentation in the PHR, particularly in primary care. Incorporating the framework should be done with careful discussions with clinic providers in order to tailor workflows to individual practices (eAppendix B).

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Patient Focus Group Participant Demographics

Participant Race	Number	Gender, n	Median Age (years)	Home Internet Access	Completed Advance Directive	Active MyChart Account	Average Number Active Problems	Average Number of Prescription Medications
Caucasian	8	5F, 3M	67	6	6	6	10	5
African American	5	4F, 1M	69	3	0	2	13	9
Total	13	9F, 4M	69	9	6	8	11	7

F indicates female; M, male.

Table 2

Demographics of Physician Participants

Provider Number	Race	Gender	Age (years)	Years in Practice
1	Caucasian	Male	40–45	12
2	African American	Female	40–45	11
3	Caucasian	Female	35–40	5
4	Asian American	Female	30–35	3

Table 3

Cognitive Interview Participant Demographics (n = 22)

Demographic	**Number of Participants**
Age range	
52–65 years	16
66–75 years	4
75–90 years	1
≥91 years	1
Average age, years	62
Median age, years	58
Gender	
Male	8
Female	14
Minority participants	2

F indicates female; M, male.

Table 4

Framework Preferences From Focus Groups

Emphasized Preference	Question Posed	Sample of Supporting Quotations
Patient Focus Group Themes		
A desire for clear language	What do you think about the presented format to help you document your preferences?	"I would like to see…the various levels of care that could happen in the event that I cannot communicate, starting with a DNR at the top, which I think is probably the highest level." "There are [emphasis] levels in between that [DNR] and just giving me an aspirin." "Explain what the different options are…. The DNR and the 'withhold'—explain that better."
	What did you think about the forms and the language used?	"I thought it was very clear, very concise. I was, um, glad to see that definitions, words defined because, uh, one person's concept of a word may not be what is legally the meaning." "The language wasn't so medical or legal that it wouldn't be clear to a layperson."
Endorsement of MyChart as a helpful communication tool	Do you think MyChart would be helpful for ACP documentation?	"My doctor gets back to me right away. It is so easy to use. I don't know what I did without it." "It gives the person the time and that chance to do it [ACP] whenever they feel like it pretty much." "I could do it [ACP] in the middle of the night, or I could do it when I first wake up or however I feel." "You can do it [ACP] when you've got the time to do it." "Sending out ACP questions through MyChart would make it easier for doctor to answer the questions without taking up too much time."
A need to qualify and disqualify preferred decision-makers	Are there any questions that you feel must be included in the electronic questionnaire?	"Is there anyone you specifically would NOT want involved in helping to make healthcare decisions on your behalf?" (Echoes: "mmm-hmm.") "My husband and I put it in writing, if I get really sick, the forms say ONLY MY SON (emphasis) will make decisions for me, NOT my daughter." "Cuz when you're sick and in bed, you can't do nothin', you can't talk, you can't tell nobody— so somebody gonna say somethin'… Who? You have to give it to a family member? Which I wouldn't trust." "Everybody has one in their family."
A desire to personalize content, often based on previous experiences	Are there any questions that you feel must be included in the electronic questionnaire?	"Past experiences, um, with loved ones and family members, uh, can definitely shape your opinion how you face, uh, situations for yourself." "It seems to me that the, um, your previous experiences will certainly influence and probably inform the choices you have." "Any problems, issues, or even successes that are in your [health] experience, probably want to be discussed with the doctor."
	Is there anything else?	"It would be great if there was a page for this kind of stuff, you know." "I could write an essay on this stuff [ACP]."
Wanting to know "vital" information only		"Reflect away! Reflect away! Just don't give me the answers!" "Or you know—so those are, those are things that I need to know as far as medical decision making for that patient." "Are there any important details that you, after doing this reflection, are there any important details I should know, such as—maybe give them a few examples or something like that."
Application of broad questions for reflection purposes only, not clinical decision making		"… it's such a broad question, I fear what might come back…. Do all of that thinking and then come back to me and let me know what is it that either I can help you with or that you want me to do." "If you don't know where to start, here's a great question for you to start with: What is quality of life? What's important to you? But yeah, as far as this like return to me, like—yeah, no, no thank you."
Accessibility of the framework in a uniform location within the EHR		"…There isn't really a place that we can put that where people are going to find it. I've tried to put in, you know, if a patient says, "Oh, I'd really like my sister, and not my mom." Like I put that down, but is anyone really going to look at that? I don't know." "So it needs to become this kind of cultural shift to some extent as far as—it's there, it's in a consistent spot, and people go to look for it." "…It'll be interesting for me to know, to learn more about my patient, but it…I don't want that to be, I don't want those other really important things to be lost." "…That has to be, and then, in the ideal world, that's in some part of the chart that everyone can access…"

Emphasized Preference	Question Posed	Sample of Supporting Quotations
Staff support for responses to patients		"Structurally to have support staff do it and trained to do it because it's not really anything that other people can't do." "…The staff sees that there's someone scheduled for a physical or one of our high-yield patients are scheduled for an appointment next week, that you could send out some information about advance care planning that they could complete before the visit, send to me before the visit, I can review before the visit. Then that makes the conversation in the room much more focused and shorter."
Desiring reimbursement for time spent on MyChart-based ACP communication.		"But it's not well reimbursed and so it's a matter of, you know, how much time are you willing or able to spend there too? So right now there's—the only big incentive to use it is to make people happy." "…Because it's so poorly reimbursed and takes so much time, is that is a supplement for your care in the office and not a replacement for your care in the office …So if it's a supplement, fantastic. If it's a replacement, it's just going to end up consuming too much time." Facilitator: "So are there other things that would make the whole MyChart process more appealing to you or easier to you?" Reply: "I think if it were reimbursed and we would get credit for the time—" Facilitator: "And is that a possibility? Is there a push for that at all?" Reply: "In theory, there are some things that you can be reimbursed for, but one of the problems is that it can't be physician-initiated."

ACP indicates advance care planning; DNR, do-not-resuscitate order; EHR, electronic health record.

Table 5

Summary of Cognitive Interviews

Strengths of Framework
Easy to read/good layout (15 of 22)
Participants easily responded to framework (20 of 22)
Participants liked questions or thought it was good to think about the questions (7 of 22)
Weaknesses of Framework
Difficult to locate message in MyChart (14 of 22)
Discomfort in answering questions (5 of 22)
Difficulty accessing my chart—couldn't remember log-in info (10 of 22)
Re-wording of second and third questions (13 of 22)
Unsure how framework would be used/needs more introduction (5 of 22)
Need for provider follow-up/contact (5 of 22)
Permanence, fitting with existing advance directives (5 of 22)