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Clinical Decision Support Technology to Increase Advance Care Planning in the Primary Care Setting

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Abstract
Physicians are often unable to guide patients through the advance care planning (ACP) process due to cost and time constraints. We conducted a retrospective analysis in the primary care setting targeting older adults without an advance medical directive (AMD). An ACP educational packet was sent to intervention patients before their health maintenance examination (HME). Additionally, their physicians had access to a computerized clinical decision support system on AMD completion at the time of the HME. Control participants' physicians had access to the computerized decision support system and traditional resources only. All participants who received the packet were sent a follow-up survey. In all, 21.6% of intervention participants completed an AMD, compared with 4.1% of control participants. Combining clinical decision support systems and standardized processes enhances the ACP process.

Keywords
advance care planning, electronic decision support, patient education, primary care, advance medical directive, barriers

Introduction

Advance care planning (ACP) is an established process for patients to communicate their preferences for medical care during critical illness, should they ever lose their capacity to make medical decisions or articulate their wishes.[1] Benefits of this process include patient empowerment, autonomy, and decreased resource utilization.[2] Completion of the advance medical directive (AMD) is an essential component of the ACP process. Despite the established benefits, AMD completion rates remain low, both nationally and locally.[3] The most effective method of encouraging patients and their families to participate in this process has not been established.[3,4]

Other investigators have described single-modality interventions such as physician training sessions, computer-generated reminders for providers, appointments scheduled to discuss ACP, interactive seminars, and prolongation of the health maintenance examination (HME) visit.[5-8] Many of these interventions have been temporarily successful in improving AMD completion but are difficult to sustain long term due to financial and time constraints.[3] Sustainable, cost-effective interventions to encourage patients and their families to participate in the ACP process before the development of critical illness are needed. Our study addresses these issues by electronically identifying older adults without a completed AMD and using an automated protocol to deliver a multimodal educational intervention aimed at promotion of ACP.

Studies have reported that only half of the recommended services for prevention and chronic-condition management are delivered to adults in the United States.[9] Most of the adults in the United States receive their care from primary care physicians, who are responsible for providing acute-illness care, chronic-disease management, and preventive services. Previous studies have documented that primary care physicians do not have enough time to provide the recommended preventive services[9,10] and chronic-condition management[11] for the average panel of 2500 patients. Recent estimates predict that, even with information systems in place, primary care physicians would have to spend an average of 21.7 h/d to provide all the recommended services for chronic-condition management,

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preventive services, and acute-illness care.[12] The care team approach, in which many of the tasks of the primary care physician are fulfilled by allied health staff empowered with information systems and well-defined roles,[12-14] has been reported to be successful. Similarly, counseling for ACP could be accomplished by the primary care practices if the appropriate information systems and processes were available.

We hypothesized that a multimodal patient education intervention targeting patients at increased risk of health deterioration would not only increase patient understanding of the ACP process but would also motivate them to complete a written AMD.

Methods

Our 23-week intervention was carefully administered to a representative population of patients seeking care at Mayo Clinic Rochester.

Population and Setting

At the time of the intervention, the Division of Primary Care Internal Medicine (PCIM) at Mayo Clinic Rochester was comprised of 46 general internists and 6 mid-level providers. This division provides primary care to residents of Olmsted County and surrounding areas and to Mayo Clinic employees and their dependents. Most patient visits occur at 1 of 4 sites on the downtown campus.

Intervention

As part of a divisional quality-improvement initiative aimed at improving rates of AMD completion, patients 60 years or older seeking an HME appointment were assessed for their AMD status. Before their visit, we used the Generic Disease Management System (GDMS) to identify patients who did not have a completed AMD stored permanently in our electronic application for clinical notes.

Generic disease management system is a Web-based application that uses GE Web Services and a MSQweb.net platform to retrieve patients' vital statistics (eg, blood pressure, weight, and body mass index), age, demographic information, prior diagnoses, allergies, previous preventive services (eg, immunizations, cancer and metabolic screenings, laboratory test results pertaining to diabetes, coronary artery disease, asthma, and depression), and AMD data from different clinical information systems.

The GDMS includes a rules-based application in which national guidelines for age-specific, gender-specific preventive services and for process and outcome measures for diabetes and coronary artery disease have been coded. On the basis of the data from Web services, the rules provide point-of-care decision support regarding the services that the patient needs at any visit. If no AMD is detected in the electronic medical record (EMR), the GDMS application recommends it to the patient and his or her provider in real time. The patient is given a paper copy of all recommended services at the time of the visit.

About 2 or 3 weeks before the scheduled HME, patients receiving care in the 2 selected PCIM sites were sent a packet of printed educational resources about ACP. Nursing home residents and non–English-speaking patients were not included in the 23-week pilot.

In the packet, a cover letter from the patient's care team explained the purpose of each of the educational resources and advised the patient to review the materials with loved ones and bring a copy of his or her completed AMD to their upcoming appointment. The resources included (1) *Questions and Answers Regarding Minnesota Law on Advance Directives*, published by Mayo Clinic; (2) *Advance Medical Directives*, a booklet with interactive exercises aimed at helping patients communicate their values and treatment wishes, published by Krames; (3) an invitation to attend a free, live open-forum patient education presentation on ACP; and (4) a state of Minnesota-accepted AMD form. These items were specifically chosen to meet the needs of a broad range of individuals with diverse learning styles and preferences.

Patients who made health maintenance appointments in the 2 other sites of the division received usual care. Their providers had access to the GDMS preventive service guide and same educational materials, but the patients did not receive any before their scheduled appointment. Four weeks after the health maintenance appointment, we reviewed the Mayo Clinic EMR for each patient to identify those who had completed an AMD during the pilot.

Follow-Up Survey

About 1 month after mailing the resource packet, we invited patients, who had been sent the resource packet, to complete a follow-up survey. An institutional review board (IRB)-approved consent form was included with the written questionnaire. The survey asked respondents about their demographic characteristics and use of the printed resources and how these educational materials affected their understanding of and motivation to complete the ACP process.

Outcome Measures

The primary outcome of interest in our retrospective analysis was the proportion of participants who completed and turned in an AMD during the pilot.

Secondary outcomes included identification of patient preferences for type of educational resources (eg, case examples, didactic text, and live discussion) and identification of the resources that most motivated patients to complete the AMD. In addition, obstacles preventing completion of the AMD were explored with patients who did not complete one.

Statistical Analysis

The allocation of patients to the intervention or control group depended on the PCIM site where they received their primary care. Patients receiving longitudinal primary care on the

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sixth-floor sections of the division were included in the intervention group, whereas those receiving primary care on the first and fifth floors were included in the control group.

To determine the effect of the educational mailing on AMD completion, the 2 groups' proportion of AMD completion was compared with a 2 × 2 table and the Fisher exact test *P* value. Patient demographics, AMD status, Charlson comorbidity index, and functional status surrogates were obtained from the EMR. Diagnoses used to create the Charlson comorbidity index were gathered from hospital billing data for 1 year before the study end date. Comparison of AMD completion and demographic, functional status, and comorbidity information was made using SAS version 9.1. Statistical Package for the Social Sciences (SPSS) software was used to analyze patient follow-up survey data.

Human Participants' Protection

Mailing educational materials before patients' scheduled health maintenance visits was designed as a practice-based quality-improvement project. After feasibility of this method of patient education was established, the Mayo Clinic IRB deemed a retrospective analysis of this data exempt and approved the follow-up survey and associated informed consent form.

Results

Impact of Educational Resource Packet Mailing

A total of 574 patients were scheduled for a routine HME in the designated intervention sections of the practice. In all, 146 patients were seen for the same visit type at the practice sites designated to provide only the usual care. A comparison of baseline demographic factors, functional status, and comorbid conditions is detailed in Table 1. Both groups of patients were similar in all respects, except for the highest level of education attained and their difficulty navigating stairs independently.

The study population (N = 720) was also compared with the overall practice's population of older adults who sought care during the intervention (N = 5641). Patients in this comparison group were seen for visit types other than routine health maintenance (eg, acute-care visits). Patients in the study population were more likely to be younger, married, and independent in their activities of daily living. In addition, patients in the study group had a lower mean Charlson comorbidity index (3.85 vs 4.55, $P < .0001$) than those not seeking routine health maintenance visits.

Table 2 depicts the overall effect of the multimodal education intervention. After the intervention, 21.6% of the patients who received the resource packet had completed and submitted an AMD, compared with 4.1% of those who received usual care ($P < .0001$).

Table 1. Baseline Demographic and Functional Characteristics of Participants

Characteristics	Education Group (N = 574), n (%)	Usual Care (N = 146), n (%)	*P* Value
Female	322 (56.1)	72 (49.3)	.142
Age group			
65-74	308 (53.7)	88 (60.3)	.407
75-84	209 (36.4)	47 (32.2)	
85-94	53 (9.2)	11 (7.5)	
>95	4 (0.7)	0 (0)	
Marital status			
Married	434 (75.6)	107 (73.3)	.524
Divorced	36 (6.3)	8 (5.5)	
Single	31 (5.4)	6 (4.1)	
Widowed	73 (12.7)	25 (17.1)	
Race			
White	536 (93.4)	140 (95.9)	.321
Black	1 (0.2)	0 (0)	
American Indian/Alaska Native	2 (0.4)	0 (0)	
Native Hawaiian/Pacific Islander	1 (0.2)	0 (0)	
Asian	6 (1.0)	4 (2.7)	
Other	2 (0.4)	0 (0)	
Unknown	26 (4.5)	2 (1.4)	
Highest level of education			
Eighth grade or less	14 (3.0)	9 (7.1)	.038
Some high school, did not graduate	12 (2.5)	7 (5.5)	
High school graduate/GED	180 (37.9)	50 (39.4)	
Some college/2-year degree	106 (22.3)	30 (23.6)	
4-year college graduate	80 (16.8)	19 (15.0)	
Postgraduate studies	83 (17.5)	12 (9.5)	
Living environment			
House	407 (84.6)	119 (89.5)	.445
Assisted living	53 (11.0)	11 (8.3)	
Nursing home	3 (0.6)	1 (0.8)	
Other	18 (3.7)	2 (1.5)	
Living arrangements			
Live alone	88 (18.2)	25 (19.1)	.582
With spouse	364 (75.2)	94 (71.8)	
With domestic partner	2 (0.4)	2 (1.5)	
With family	18 (3.7)	7 (5.3)	
Other	12 (2.5)	3 (2.3)	
Have assistance from family and friends	301 (64.2)	85 (63.9)	.954
Functional status			
Rely on assistive devices	46 (9.8)	15 (11.2)	.628
Difficulty performing: basic activities of daily living			
Using toilet	3 (.7)	0 (0)	.371
Bathing	11 (2.4)	1 (0.8)	.278
Getting in/out of bed	3 (0.7)	1 (0.8)	.841
Feeding yourself	2 (0.4)	1 (0.8)	.597
Walking	38 (8.4)	6 (5.0)	.215
Dressing	7 (1.6)	2 (1.7)	.924
Climbing stairs	62 (13.7)	8 (6.7)	.037
Difficulty performing: instrumental activities of daily living			
Preparing meals	17 (3.8)	1 (0.8)	.103
Housekeeping	27 (6.0)	3 (2.5)	.130
Managing medication	11 (2.4)	1 (0.8)	.278
Using transportation	8 (1.8)	2 (1.7)	.941
Charlson Comorbidity Index score (age and severity adjusted)			
Mean	3.87	3.79	.721
SD	2.25	2.02	

Abbreviations: GED, general educational development; SD, standard deviation.

Follow-Up Survey

In addition to measuring the success of our intervention, our study also yielded valuable information about patients' thought

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Table 2. Completion of Advance Medical Directive Following Intervention

	Education Group (N = 574)	Usual Care (N = 146)	*P* Value
N (%)	124 (21.6)	6 (4.1)	<.0001

Table 3. Respondents' Preferences for Learning About Advance Care Planning[a]

Educational Method	All Responders (N = 72), Frequency (%)	Did Complete AMD (N = 41), Frequency (%)	Did Not Complete AMD (N = 31), Frequency (%)
Written factual materials	58 (80.6)	35 (85.4)	23 (74.2)
Personal discussion with medical provider	27 (37.5)	17 (41.5)	10 (32.3)
Written case stories	11 (15.3)	8 (19.5)	3 (9.7)
Video/TV	8 (11.1)	6 (14.6)	2 (6.5)
Internet/electronic	4 (5.6)	2 (4.9)	2 (6.5)
Other	4 (5.6)	2 (4.9)	2 (6.5)
Individual			
Family	53 (73.6)	29 (70.7)	24 (77.4)
Primary care providers	38 (52.8)	20 (48.8)	18 (58.1)
Patient educators	18 (25)	11 (26.8)	7 (22.6)
Mid-level providers	15 (20.8)	8 (19.5)	7 (22.6)
Lawyers/paralegals	15 (20.8)	8 (19.5)	7 (22.6)
Hospital physicians	9 (12.5)	5 (12.2)	4 (12.9)
Nurses	7 (9.7)	4 (9.8)	3 (9.7)
Social workers	3 (4.2)	2 (4.9)	1 (3.2)
Religious leaders	2 (2.8)	2 (4.9)	0 (0)

Abbreviation: AMD, advance medical directive.
[a] Survey respondents could choose multiple options.

processes and preferences regarding ACP. Patients sent the educational resource packet were sent a follow-up survey after their scheduled appointment. Of the 574 patients in this group, 72 (12.5%) returned a completed survey. In all, 41 (57%) survey respondents completed their AMD and shared this plan with their primary care physician at the time of data analysis. In all, 44% respondents stated that they had read 100% of the Mayo Clinic-produced resource that answered commonly asked questions about Minnesota ACP law, with 52% stating that it had motivated them to complete their AMD by at least 75%. Fifty-four percent of respondents stated that they had read 100% of the Krames resource, which guided readers through interactive exercises aimed at helping them identify key goals and preferences, with 44.1% stating that it had motivated them to complete their AMD by at least 75%. Only 7% of survey respondents stated that they had attended the live educational session. Forty-three percent stated that they decided to complete their AMD because they received the resource packet in the mail before their office visit.

Surveyed patients were asked which type of learning resources they preferred when learning about ACP, and most respondents said they preferred written materials to electronic ones. Patients were also asked who should help patients think about and understand ACP, and most cited their family members (Table 3). Patients who did not give their physician a completed AMD were asked about barriers that prevented them from doing so. The results are delineated in Table 4.

Table 4. Barriers to Advance Care Planning Among Patients Who Did Not Complete an AMD

Barrier	Frequency (%), N = 31
I am not sure what my wishes are	12 (38.7)
Do not want to think about it	4 (12.9)
Do not need one, physician/family know what I would want	4 (12.9)
Do not know enough about topic	4 (12.9)
I am healthy	4 (12.9)
I am working on it now	3 (9.6)
Procrastination	2 (6.5)
Physician has not yet recommended	2 (6.5)
Materials were too difficult to understand	2 (6.5)
Not enough time	2 (6.5)
Religious/cultural values	2 (6.5)
Too depressing/makes me anxious	1 (3.2)
Do not want to upset family members	1 (3.2)

Abbreviation: AMD, advance medical directive.

Discussion

In this study, we showed that a well-timed, targeted, multimodal educational intervention increased the completion of AMDs by 17.5%. Use of an electronic clinical decision support system that provided information about patients' preventive service needs enabled physicians and allied health staff to provide optimal preventive care to a large population of patients with diverse needs. The AMD completion rate was significantly higher in our intervention group than in the control group, whose physicians also were electronically prompted to counsel patients about ACP, demonstrating that an organized patient education process such as a previsit resource mailing needs to be in place for a clinical decision support system like GDMS to be effective.

This study addresses several barriers that other primary care practices have encountered in the ACP process. Other investigators have found that common physician-specific barriers to ACP counseling are lack of time during the clinical encounter, perceived low health literacy of patients, and lack of privacy for discussion.[3,6,15-17] Our intervention, which combined the philosophy of "just-in-time learning" with the efficiency of an electronic preventive service guide, allowed our primary care teams to provide the right resources to the right patients at a critical time. In turn, physicians were not responsible for introducing this complicated topic but were available during the HME if the patient had questions not covered by the previsit materials. In addition, patients could take as much time as they needed to review materials with loved ones before their visit.

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Single-modality interventions such as previsit patient mailings and point-of-care physician reminders to counsel patients about ACP have been previously studied[18,19]; however, our study expands on these results by combining these 2 strategies and by surveying patients about which aspects of the intervention most motivated them to complete their AMD. In a trial conducted by Rubin and colleagues,[20] a mailed educational pamphlet increased AMD completion rates by 18% over baseline, whereas the previsit resource packet used in our study increased AMD completion rates by nearly 22%. We hypothesize that our intervention's success is at least partially related to the timing of the mailing, which was linked to a scheduled visit, and that patients were encouraged to bring their completed AMD to that visit. In addition, instead of including only written materials, which may not be suitable for patients with vision impairment or low literacy, we also invited patients to attend a live group discussion of ACP. Dexter and colleagues found that a computer-generated reminder to physicians at an office visit had a favorable effect on the frequency of AMD discussions between patients and their primary caregivers and the subsequent completion of an AMD[8]; however, this and other physician-only–oriented modalities may result in lengthy discussions and prolonged visits that busy primary care practices cannot accommodate.

As our country addresses the shortage of primary care physicians coupled with a growing list of recommended services and counseling, a team-based approach in which trained allied health staff can fulfill the preventive service needs of patients could prove extremely beneficial. As we observed, practices need both clinical decision support systems and standardized processes to successfully deliver this care. Having just the clinical decision support system to generate alerts for a primary care provider who might already be overwhelmed with the needs of their patients for acute-illness care and chronic-disease management might not be successful unless their processes allow other team members to fulfill those tasks. Such an approach might help not only with promoting ACP but also with addressing other preventive service needs and chronic-condition management using a similar approach.

Despite the lower-than-expected response rate, our follow-up survey yielded a number of noteworthy results. First, despite our society's trend toward electronic learning modalities, the vast majority of respondents preferred written materials to videotaped and Internet-based materials and personal discussions with their provider. This finding supports the results of a study conducted by Betz-Brown and colleagues, which revealed that mailing an ACP video with written ACP materials did not significantly improve AMD completion rates over those of mailing written materials only. In fact, these researchers found that the ACP video actually made patients more likely to cite even more reasons why they would not complete an AMD.[7]

Second, our survey revealed that the most common reason for not completing an AMD was that patients had not identified their wishes. This barrier differs from the most frequently cited barriers in a number of other large surveys. In other studies that surveyed patients about obstacles to ACP, most patients cited difficulty completing documents, the distressing nature of the topic, lack of knowledge about the topic, and inconsistency with religious beliefs as the biggest barriers.[17,21-23] It is likely that patients who are still unsure about their wishes after using educational resources will need more individualized resources to help them define their goals of care and end-of-life treatment preferences as they progress along the stages of readiness.[21] In these cases, multiple discussions over time with their loved ones and health care team may be more appropriate.

Several limitations in this study should be recognized. First, our comparison analysis of the studied group and the general patient population receiving care during the study period revealed that patients in the study group were generally younger and more physically active than those scheduled for acute-care visits. Similarly, most participants identified themselves as white and as high school graduates. This may limit our ability to immediately generalize our findings to more culturally diverse primary care populations. Second, the printed education materials we provided perhaps do not effectively reach patients with low literacy or vision impairment; however, by adding an option to attend a live presentation about ACP, our group may have attenuated the impact of these barriers. Third, our follow-up survey yielded a low response rate. Factors that may have impacted this rate include the potentially distressing nature of the survey topic and inherent costs of survey participation (eg, time and perceived burden).[24] Future efforts to better characterize the ACP preferences of older patients may be enhanced with patient reminders or other tangible incentives.

The process of ACP is more complex than just filling out a directive form at an office visit. Advance care planning requires patients to examine their values and goals in the context of their overall health status. Interventions such as the one described here that encourage patients to explore different ACP educational modalities in their own time allow patients to give this important topic the consideration and attention it deserves. Our study establishes that linking electronic preventive service reminder systems with patient education resources is a feasible way to help patients document their ACP preferences. Furthermore, this intervention demonstrates how a simple process change using existing electronic resources can affect the quality of care at the end of life. Future studies examining care processes like these delivered to more diverse patient populations are needed.

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Declaration of Conflicting Interests

The author(s) declared a potential conflict of interest (e.g. a financial relationship with the commercial organizations or products discussed in this article) as follows: Dr Chaudhry is an employee of Mayo Clinic

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and the inventor of GDMS referenced in this article. Mayo Clinic has licensed this technology to a commercial entity (Vitalhealth Software) but to date has received no royalties. Dr Chaudhry receives no royalties from the licensing of this technology.

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