

Knowledge, Attitudes, and Preferences Regarding Advance Directives Among Patients of a Managed Care Organization

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The media coverage surrounding the Terri Schiavo case¹ highlighted the need to explore ways to encourage patients of all ages to think about and document end-of-life (EOL) care wishes. Before and after this publicized and controversial case, there was much discussion about how to increase the number of people who have an advance directive (AD), as well as how to best facilitate the process.²⁻⁵ However, much of the research on knowledge and attitudes related to ADs has been among seniors,⁶⁻¹⁷ hospitalized patients,¹⁸⁻²⁵ or patients with critical or terminal illness.²⁶⁻³⁰ Although some work has been done among outpatients,^{9-11,13-17,31-37} information is limited about the association between age and knowledge or attitudes, as well as about patient preferences regarding initiation of EOL care discussions. We surveyed managed care organization (MCO) patients 20 years or older about knowledge, attitudes, experiences, and approaches to initiation of ADs.

METHODS

Subjects

Subjects included an age-stratified random sample of patients from a large MCO with approximately 700,000 members. The sample was drawn from patients who had obtained care in 1 of the plan's 19 owned clinics and who were members as of July 2005. Subjects were identified via electronic administrative records and were then stratified by 7 age decades (20-29, 30-39, 40-49, 50-59, 60-69, 70-79, or ≥80 years). Patients were included if they had 3 years of continuous enrollment before identification, were 20 years or older, had a valid telephone number, and were not found on research exclusion lists. Targeted subjects in each age stratum were randomly selected (numbers were computer generated) from a pool of 58,569 who met eligibility criteria. The sampling plan was to stop surveying participants in a given age category when we reached 20 respondents. Although sex was not a primary variable in our analysis, approximately half of the randomized patients targeted for survey were female, and half were male. Because the survey included questions about whether the issue of ADs was raised by a healthcare provider, selection criteria included a minimum enrollment of at least 3 years. This study was approved by the MCO's institutional review board, and participation served as a subject's consent to use his or her data.

Objectives: To examine attitudes, experiences, and preferences regarding advance directives (ADs) among adults of all ages.

Study Design: Subjects were surveyed regarding end-of-life (EOL) care wishes. The survey included items measuring knowledge, experiences, and attitudes regarding ADs, as well as preferences toward initiation of discussions.

Methods: Subjects included a random sample of patients (age range, 20 to >80 years) from a large midwestern managed care organization stratified by age decade. Descriptive statistics were used to summarize variables, and χ^2 tests were performed to examine differences by age category.

Results: One hundred eighty-seven surveys were completed. The likelihood of having completed an AD increased with age ($P < .001$). Of those without an AD, 44% reported having talked with someone about their wishes. Many (62%) subjects thought that it was up to them to raise the topic of EOL care. However, 70% of subjects reported that they would be comfortable if their provider initiated discussion. Participants 60 years or older were more likely to report being very comfortable with their provider bringing up the subject compared with those younger than 60 years (60% vs 39%, $P = .02$). Few differences were found by age.

Conclusions: Room for improvement exists for increasing the number of patients who complete an AD or engage in discussion of their wishes. Ways to involve healthcare providers in the process should be explored, as it seems that patients are receptive to physician-initiated discussions of ADs.

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Survey

The survey included 54 items measuring patient knowledge of terms, experiences, and attitudes related to EOL care decision making and preferences toward initiation of advance care planning discussions (a copy of the survey is available from the corresponding author). Items considered to be possible correlates of having an AD other than age (ie, self-rated health, having experienced the prolonged death of someone close, having made EOL care decisions for someone, marital status, and education) were also included. Our selection of variables was based on an extensive literature review, followed by input from health plan leaders about factors to help the MCO encourage completion of an AD or discussion of wishes. Items from the experiences component were adapted from those used by Silveira et al³¹ in examining outpatients' knowledge of their EOL options. Items measuring knowledge and preferences were created based on work done by others in these areas,^{11,12,30,31,33-35,37-39} as well as on experience of the study team (eg, expertise in hospice care and law). Items measuring attitudes were designed by Beck et al¹⁶ to examine attitudes and beliefs regarding life-sustaining treatment among senior MCO enrollees. The item measuring perceived health status was selected from the *SF-12 Physical and Mental Health Summary Scales*.⁴⁰ To ensure clarity and ease of administration among respondents of all ages, we pilot tested the survey with 14 subjects (1 man and 1 woman from each age stratum).

Subjects were mailed an invitation to participate in a 1-time telephone survey regarding EOL care wishes. All telephone surveys were conducted by a single interviewer (JM). At least 3 attempts were made to reach potential subjects via telephone. Initially, we planned to complete all surveys via telephone; however, we found it difficult to reach subjects, particularly those in the younger age groups (20-29 and 30-39 years). Therefore, after completing half of the targeted number of surveys by telephone, the remaining surveys were solicited by mail (mailed survey, followed by a reminder postcard 2 weeks later to nonresponders). The telephone survey was conducted between September 2005 and January 2006, and mail surveys were conducted from mid-March through May 2006.

Statistical Analysis

Descriptive statistics were used to summarize variables overall and by age. Because this was an exploratory examination, numerous bivariate comparisons were made. Contingency tables (7 age categories by typically 2 or 3 categories for the other variables tested) and overall χ^2 tests (Pearson product moment correlation and Mantel-Haenszel test) for the entire table assessed differences in knowledge, experiences, attitudes, and preferences by age, marital status, and education. To simplify presentation, age groups were recoded as younger

than 60 years and 60 years or older. Comparisons were made between experiences and the following possible correlates: self-rated health, having experienced the prolonged death of someone close, and having made EOL care decisions for someone. Comparisons between attitudes and these 3 variables were also made. To examine the effect of data collection mode, differences in experiences and knowledge were examined by whether the survey had been completed by telephone versus mail. For most items, missing values and "do not know" or "not sure" responses were removed for analysis purposes. However, because of the substantial proportion of subjects answering "do not know" for the attitude items, analysis of attitude statements retained uncertain responses. The results of all bivariate comparisons that were found to be statistically significant or suggestive are presented. In addition, unconditional logistic regression analysis was used to predict 2 experience variables (having completed an AD and having talked with someone about wishes) from age (<60 vs ≥ 60 years, added in the first model of the analysis), self-rated health and education (added in the second model), having experienced the prolonged death of someone close, and having made EOL care decisions for someone (added in the third model). An additional analysis included these predictors along with all 2-way interactions with age to test for possible moderation.

RESULTS

Subjects

Two hundred three members were initially selected as participants for the telephone survey. Thirty members could not be contacted because of disconnected telephone numbers or wrong addresses, and 6 members were unable to communicate via telephone. Of the remaining 167 members, 58 could not be reached after 3 attempts. Of 109 reached, 39 refused participation, and 70 surveys were completed, for a response rate of 64%.

Two hundred eighty-seven members were targeted for the mailed survey. Three persons were unreachable by mail, and 2 were unable to participate (non-English speaking or physically unable). Of 282 deemed eligible, 117 returned the survey, for a 41% response rate (4 declined participation, 2 returned surveys with too little information to be included, and 159 never responded). Although we intended to obtain 20 subjects per age stratum, for a total of 140 completed surveys, we kept all eligible surveys (N = 187) returned for analysis. We obtained at least 20 respondents in 5 of 7 age groups. However, for those aged 20 to 29 years, we received 14 completed surveys, and we received 17 for those aged 40 to 49 years. Patients younger than 50 years were less likely to respond compared with those 50 or older (26% vs 47%, $P < .001$). As an indicator of the precision of our findings, proportions computed on the total

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Table 1. Characteristics of Study Subjects Overall and by Age

Characteristic	No. (%)		
	Overall (N = 187)	<60 y (n = 92)	≥60 y (n = 95)
Race/ethnicity			
White	179 (96)	88 (96)	91 (96)
Other	4 (2)	3 (3)	1 (1)
Missing	4 (2)	1 (1)	3 (3)
Marital status			
Married	122 (65)	57 (62)	65 (68)
Part of an unmarried couple	8 (4)	8 (9)	0
Divorced	13 (7)	5 (5)	8 (8)
Widowed	22 (12)	1 (1)	21 (22)
Never married	19 (10)	18 (20)	1 (1)
Missing	3 (2)	3 (3)	0
Education			
<High school	9 (5)	1 (1)	8 (8)
High school or general equivalency diploma	33 (18)	7 (8)	26 (27)
College or technical school	95 (51)	53 (58)	42 (44)
Postgraduate	45 (24)	27 (29)	18 (19)
Do not know/refused	5 (3)	4 (4)	1 (1)
Age			
20-29	14 (8)	—	—
30-39	24 (13)	—	—
40-49	17 (9)	—	—
50-59	37 (20)	—	—
60-69	31 (17)	—	—
70-79	35 (19)	—	—
≥80	29 (16)	—	—
Sex			
Female	101 (54)	51 (55)	50 (53)
Male	86 (46)	41 (45)	45 (47)
Self-rated health			
Excellent	37 (20)	25 (27)	12 (13)
Very good	74 (40)	37 (40)	37 (39)
Good	59 (32)	25 (27)	34 (36)
Fair	10 (5)	2 (2)	8 (8)
Poor	4 (2)	3 (3)	1 (1)
Do not know	3 (2)	0	3 (3)

sample of 187 had a 95% confidence interval of 0.43 to 0.06 (for a proportion of 0.50).

Table 1 gives a breakdown of characteristics of participants overall and by age (<60 vs ≥60 years). Most participants were of white race/ethnicity. Approximately two-thirds

were married, and 75% had at least some college or technical school education. Slightly more than half were female. There were slightly more men among the nonresponders compared with those who completed the survey (54% male and 46% female nonresponders vs 46% male and 54% fe-

■ **Table 2.** Subject Responses to Knowledge Items Overall and by Age

Item	%								
	Overall (N = 187)			<60 y (n = 92)			≥60 y (n = 95)		
	Yes or True	No or False	NS	Yes or True	No or False	NS	Yes or True	No or False	NS
Knowledge of terms									
Heard of <i>living will</i>	99	1	0	99	1	0	99	1	0
Heard of <i>healthcare directive</i>	58	34	8	61	33	6	56	36	8
Heard of <i>durable power of attorney for healthcare</i>	58	36	6	48	47	5	68	25	7
Heard of <i>advance directive</i>	42	51	7	45	50	5	39	52	9
Knowledge of logistics									
Patients have a right to accept or refuse medical or surgical treatment	93	2	5	96	2	2	92	1	7
Patients have a right to accept or refuse life-sustaining treatments such as nutrition and hydration	81	10	9	80	14	6	81	6	13
Creating a document that provides directions for end-of-life or life-sustaining care requires the involvement of a lawyer	20	62	18	27	57	16	13	67	20
Once someone has documented their wishes for end-of-life or life-sustaining care, they cannot change their mind	3	92	5	1	96	3	5	89	6
>1 Person may be named to speak on your behalf about your end-of-life care wishes in the event you are unable to speak for yourself	72	9	19	65	11	24	78	7	15
NS indicates not sure.									

male responders, $P = .08$). More than 90% reported their health as good or better. Subjects who completed the survey by telephone were more likely to report having talked with someone about their wishes (62% vs 35%, $P = .005$). No other differences were found related to mode of administration.

Knowledge of AD Terms and Logistics

Subject awareness of terms related to EOL care planning was highly varied (Table 2). When asked which term they most closely associate with provision of directions for EOL care, 66% indicated living will. Almost all subjects were familiar with their right to accept or refuse treatment (ie, along the full continuum of care), and 81% knew that they had the right to accept or refuse life-sustaining treatments. Almost two-thirds were aware that creating an EOL care document does not require a lawyer. Approximately 92% recognized that documented decisions could be changed, and 72% knew that more than 1 person may be named to speak for them. No differences in knowledge of AD terms or logistics were found related to age (<60 vs ≥60 years).

Attitudes

Subjects thought that they and their families should have input regarding EOL care (Table 3). More than one-third

were unsure about their physician’s knowledge of their wishes. Conducting some surveys via telephone provided the opportunity to probe for further clarification when a “no” or “do not know” response was given. Those further questioned reported that they had not discussed the issue with their physician or that they did not have a regular care provider with whom they thought they could discuss such topics. No differences were found in attitudes by age (<60 vs ≥60 years).

Experiences

Completion of an AD was reported by 32%, and 5% stated that they were in the process or were thinking about creating one. Completion increased incrementally with age ($P < .001$). More than half of the subjects 60 years or older, 24% of subjects aged 50 to 59 years, 12% of subjects aged 40 to 49 years, and 4% of subjects aged 30 to 39 years reported having an AD. No subjects aged 20 to 29 years had completed a document. This strong association between completion of an AD and older age was consistent regardless of self-rated health. Age continued to be a predictor of having an AD in the regression analysis, with those 60 years or older being more likely to have completed an AD compared with those younger than 60 years (Table 4). The nested models given in Table 4 also indicate

Table 3. Subject Responses to Attitude Statements Overall and by Age

Statement	%								
	Overall (N = 187)			<60 y (n = 92)			≥60 y (n = 95)		
	Agree	Disagree	NS	Agree	Disagree	NS	Agree	Disagree	NS
People in good health do not need to think about preparing a living will	3	90	6	2	97	1	4	84	12
It is up to my physician to decide if I should receive life-sustaining treatment if I cannot speak for myself	7	77	16	3	88	9	11	66	23
I do not trust the medical system to make decisions about my medical care if I should become unable to communicate my wishes	27	50	24	28	51	21	25	48	26
I believe that my wishes should determine what life-sustaining treatment I should receive	87	2	11	91	2	7	83	2	15
Putting my wishes for life-sustaining treatment in writing is too binding	9	73	18	9	74	17	9	73	18
Having a durable power of attorney for healthcare means I can never get life-sustaining treatment	2	63	36	2	60	38	1	66	33
Discussing my wishes for life-sustaining treatment with my family would only lead to disagreement and conflict	1	85	14	2	87	11	0	82	18
My family understands my wishes for life-sustaining treatment	60	13	27	49	22	29	71	5	24
I prefer my family decide what kind of medical care is best for me if I should become unable to communicate my wishes	65	17	18	61	20	20	70	15	16
I can rely on my family to communicate my wishes even if my family does not all agree with my wishes	75	8	17	75	10	15	76	6	18
My physician clearly understands my wishes for life-sustaining treatment	15	42	43	8	55	37	22	28	50
I can rely on my physician to carry out my wishes for life-sustaining treatment even if he or she disagrees with my wishes	45	17	39	48	16	36	42	17	41

NS indicates not sure.

that the odds ratio for age changes little when other variables are included. No other variables in the equation were significant, and all 2-way interactions of other covariates with age were also not significant. Of those without an AD, 44% reported having talked with someone about their wishes. The proportion of subjects who had a discussion did not differ significantly by age. When the same regression models were used in predicting whether subjects had talked with someone about their wishes, no variables were significant.

Preferences

Asked in what setting and with whom they would like to discuss ADs, 54% reported a preference of discussing decisions with family rather than a provider. More than one-third (38%) reported no preference between these 2 choices (no significant differences by age). Completion of AD forms via mail was preferred by 60%, while 51% reported that they

would consider attending an educational session on ADs, and 45% reported that they would consider using telephone assistance to complete forms. Only about 40% of participants thought that they would complete AD forms if available on the Internet. Sixty-two percent reported that it was up to them (or the person for whom an AD was being created) to bring up the subject of EOL care wishes. However, 70% of respondents reported that they would be comfortable if their provider brought up the subject of an AD. Those 60 years or older were more likely to report being very comfortable with their provider bringing up the subject compared with those younger than 60 years (60% vs 39%, $P = .02$).

Correlates of Knowledge, Attitudes, Experiences, and Preferences

In addition to our main independent variable of interest (age), we examined differences in experiences and attitudes

■ **Table 4.** Logistic Regression Analysis Predicting Completing an Advance Directive and Talking to Someone About Wishes for End-of-Life Care

Dependent Variable	OR (95% CI) ^a		
	Model 1	Model 2	Model 3
Completed an Advance Directive			
Age, y			
≥60	9.03 (4.21-19.37)	11.13 (4.76-26.04)	10.78 (4.57-25.40)
<60	1 [Reference]	1 [Reference]	1 [Reference]
Self-rated health			
Excellent	—	1.65 (0.56-4.83)	1.64 (0.56-4.84)
Very good	—	1.54 (0.68-3.51)	1.54 (0.67-3.53)
Good/fair/poor	—	1 [Reference]	1 [Reference]
Education			
Postgraduate	—	1.83 (0.62-5.37)	1.78 (0.60-5.31)
College or technical school	—	0.87 (0.35-2.15)	0.85 (0.34-2.12)
≤High school	—	1 [Reference]	1 [Reference]
Experienced prolonged death of someone close			
Yes	—	—	1.17 (0.48-2.84)
No	—	—	1 [Reference]
Made end-of-life care decisions for someone			
Yes	—	—	1.12 (0.50-2.52)
No	—	—	1 [Reference]
Talked to Someone About Wishes for End-of-Life Care			
Age, y			
≥60	1.18 (0.50-2.77)	1.59 (0.63-4.03)	1.39 (0.53-3.63)
<60	1 [Reference]	1 [Reference]	1 [Reference]
Self-rated health			
Excellent	—	2.96 (0.94-9.26)	3.43 (1.05-11.18)
Very good	—	1.33 (0.53-3.38)	1.40 (0.55-3.60)
Good/fair/poor	—	1 [Reference]	1 [Reference]
Education			
Postgraduate	—	1.38 (0.36-5.33)	1.21 (0.30-4.83)
College or technical school	—	0.83 (0.26-2.59)	0.67 (0.20-2.23)
≤High school	—	1 [Reference]	1 [Reference]
Experienced prolonged death of someone close			
Yes	—	—	1.22 (0.48-3.09)
No	—	—	1 [Reference]
Made end-of-life care decisions for someone			
Yes	—	—	1.70 (0.63-4.54)
No	—	—	1 [Reference]
^a Nested models presented. Model 1 includes age. Model 2 adds self-rated health and education. Model 3 adds experienced prolonged death of someone close and made end-of-life care decisions for someone else.			

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Table 5. Significant or Suggestive Differences in Experiences, Knowledge, Attitudes, and Preferences by Independent Variables

Dependent Variable	Independent Variable, %			P
Experiences				
Completed an advance directive	Age, y			
	<60	≥60		
	13	61		<.001
Talked to someone about wishes for end-of-life care	Made End-of-Life Care Decisions for Someone			
	Yes	No		
	47	33		.06
	Self-Rated Health			
	Excellent	Very Good	Good/Poor	
	63	44	38	.07
Knowledge				
Heard of <i>advance directive</i>	Education			
	Postgraduate	>High School	≤High School	
	60	43	21	<.001
Heard of <i>healthcare directive</i>	78	63	29	<.001
>1 Person may be named to speak on your behalf	78	64	81	.08
Attitudes				
Do not know if "it is up to my physician to decide if I should receive life-sustaining treatment if I cannot speak for myself"	Self-Rated Health			
	Excellent	Very Good	Good/Poor	
	5	12	22	.048
Do not know if "I believe that my wishes should determine what life-sustaining treatment I should receive"	Education			
	Postgraduate	>High School	≤High School	
	2	11	17	.02
Preferences				
Very comfortable with provider initiation of advance directive discussion	Age, y			
	<60	≥60		
	39	60		.02
Would consider attending an educational session on advance directives	Marital Status			
	Married	Never Married	Separated/ Divorced/ Widowed	
	55	47	26	.02
Education				
Would consider using telephone assistance to complete advance directive	Postgraduate	>High School	≤High School	
	51	46	34	.02
Would be very likely to complete advance directive forms online	59	28	19	<.001

Take-Away Points

Most research on advance directives (ADs) has focused on seniors or patients with terminal illness. The findings on this topic among adults of all ages highlight the following:

- There is much room for improvement in increasing the number of patients who complete ADs or engage in discussion of wishes.
- Ways to involve providers in the process should be explored, as it seems that patients of all ages are receptive to physician-initiated discussion of ADs.
- Managed care organizations should build on their unique strengths, including multiple points for patient interaction and comprehensive documentation systems, to assist patients in advance care planning.

pletion of an AD with age (ie, older subjects were more likely) and the comfort level with provider-initiated discussions of EOL care wishes (ie, older subjects reported feeling very comfortable). We hypothesized that there might be more differences, particularly in regard to knowledge, with older subjects being more knowledgeable about issues related to EOL care

by self-reported health, having experienced the prolonged death of someone close, having made EOL care decisions for someone, marital status, and education. Directional differences were found, but none reached statistical significance. Of subjects without an AD, those who reported better health status were slightly more likely to have talked with someone about their wishes (Table 5). Subjects who perceived their health to be less than very good were more likely to answer “do not know” on several of the items measuring attitudes ($P < .05$ for all). Having experienced the prolonged death of someone close was not significantly associated with creating a document or having a discussion. Subjects who had made EOL care decisions for someone were slightly more likely to have completed an AD.

More than half of the married respondents would consider attending an educational session on ADs (Table 5). Subjects with more education were more likely to have heard of the terms *advance directive* and *healthcare directive*. Subjects with a high school education were slightly more likely to report that more than 1 person can be named to speak on their behalf. There was a significant difference in the number of subjects with a high school education or less compared with those with more education who were unsure about whether their wishes should determine what life-sustaining treatment they receive. Subjects with more education were more likely to report that they would consider using telephone assistance in completing an AD and were more likely to report that they would be very likely to complete AD forms online. There were no differences found in experiences with ADs by marital status or education.

DISCUSSION

We examined knowledge, attitudes, experiences, and preferences related to ADs and to documentation of EOL care wishes among members of a large comprehensive healthcare plan. To our knowledge, this examination is one of the first to explore these topics among a healthy outpatient population of adults of all ages. Surprisingly, few differences were found related to age. Positive findings included the association of com-

planning. However, the areas in which we found differences were not entirely unexpected.

This study was conducted in the Twin Cities metropolitan area of Minnesota. One of our most notable findings was the number of respondents who reported that living wills came to mind when they thought about documentation of wishes. Despite the fact that since 1998 *healthcare directive* has been the term in Minnesota for the document in which one describes EOL care wishes or names someone to speak for them, more than half of the subjects selected the term *living will* when asked which term they most closely associate with these directives. This finding indicates that more needs to be done to educate Minnesotans about the issues of advance care planning that are unique to this state. The significance of this finding is not merely a matter of a lack of knowledge of terminology. Healthcare directives in Minnesota and living wills available in other states include similar elements (ie, persons may provide information about care wishes, name someone to make decisions for them, or both). However, technical and legal differences exist between living wills and healthcare directives that go beyond terminology. Living wills only become active once someone is considered to have an illness from which he or she will not recover,⁴¹ whereas a healthcare directive becomes active when a medical professional determines that the patient does not have the capacity to speak for himself or herself.⁴² Subjects seem to be familiar with their rights regarding EOL care planning; however about one-third reported herein that they believe (or were not sure) that initiation of an AD requires a lawyer. Again, this finding indicates that more could be done to educate Minnesotans about AD logistics.

About one-third of our population completed an AD; percentages ranging from 10% to 43% continue to be cited for the prevalence of ADs, despite the fact that it has been several years since the conclusion of the Schiavo case.^{31,43} This case, which highlighted the fact that even young seemingly healthy people can become incapacitated and lose the ability to speak for themselves, was reported to have encouraged many people to examine the need to document their EOL wishes.⁴⁴⁻⁴⁸ Because of problems that have been reported to exist with enacting an

AD at the time when it is needed,⁴⁹⁻⁵² some have suggested that the creation of an AD is merely a means to an end; more valuable than documentation is the discussion of wishes with family and other loved ones.^{53,54} In our examination of those without an AD, fewer than half reported that they have talked, even informally, with someone about their wishes.

Overall, our findings indicated that patients want control over EOL care decisions themselves or want family or other loved ones to make those decisions. Patients also believe that it is their responsibility to raise the issue. However, most of our subjects reported that they would be comfortable if the provider brought up the topic. This finding is notable in light of the conclusions from other investigations that found that patients were waiting for providers to bring up the topic, while physicians were waiting for their patients to raise the issue.^{3,55,56}

One of the strengths of this examination is its subject population of MCO enrollees of all ages, as information about ADs among young adults and healthy adults is limited. Another strength of this study is the benefit provided by the qualitative information that we obtained from study subjects who participated in the telephone surveys. Follow-up questions among telephone survey subjects who reported that their provider did not understand their EOL care wishes indicated that in many cases this was because they had not discussed the topic with their physician or they did not have a primary care provider. This substantive information would not likely have been obtainable via mailed survey and was ultimately useful in understanding responses to this item. This examination also provides insight into conducting research on this topic among young adults. We found it difficult to connect via telephone with potential participants aged 20 to 40 years; therefore, a mail survey may be a better approach. Once we connected with members targeted for the telephone survey, almost two-thirds (64%) were willing to participate.

Our findings must be viewed in light of some significant limitations. Our study sample was small and homogeneous (ie, 96% were of white race/ethnicity), making it difficult to generalize results beyond those of our population of adult MCO members. The project was funded by a small 1-year grant, limiting our ability to target a larger sample. We had anticipated that this project, one of the first of its kind to examine ADs among young healthy adults, would be a first step to larger studies. Furthermore, although we obtained a good response for the telephone survey among members with whom contact was made (64%), response to the mailed survey was much lower (41%). As with any survey, it is possible that those who chose not to participate in our study had significantly different knowledge, experiences, attitudes, or preferences related to EOL care planning compared with those who responded.

CONCLUSIONS

There is much room for improvement in increasing the number of patients who complete an AD or, at the minimum, engage in a discussion of their wishes. Ways to involve health-care providers in the process should be explored, as it seems that patients of all ages are receptive to physician-initiated discussions of ADs. Some authors have suggested key elements of successful AD programs, including a focus on ongoing discussions of wishes rather than on completion of a single document (ie, the “process” rather than the “product”), facilitation of discussions by skilled providers, involvement of the family, systems in place to support planning, and documentation of wishes.^{2-5,57-62} These lessons could be used by MCOs to build on the unique strengths of an integrated care approach such as multiple points for patient interaction and comprehensive documentation systems to assist patients in advance care planning.

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