

Advanced Illness Care

Advance Care Planning and Health Care Preferences of Community-Dwelling Elders: The Framingham Heart Study

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Objective. The study objective was to describe self-reported advance care planning, health care preferences, use of advance directives, and health perceptions in a very elderly community-dwelling sample.

Methods. We interviewed surviving participants of the original cohort of the Framingham Heart Study who were cognitively intact and attended a routine research examination between February 2004 and October 2005. Participants were queried about discussions about end-of-life care, preferences for care, documentation of advance directives, and health perceptions.

Results. Among 220 community-dwelling respondents, 67% were women with a mean age of 88 years (range 84–100 years). Overall, 69% discussed their wishes for medical care at the end of life with someone, but only 17% discussed their wishes with a physician or health care provider. Two thirds had a health care proxy, 55% had a living will, and 41% had both. Most (80%) respondents preferred comfort care over life-extending care, and 71% preferred to die at home; however, substantially fewer respondents said they would rather die than receive specific life-prolonging interventions (chronic ventilator [63%] or feeding tube [64%]). Many were willing to endure distressing health states, with fewer than half indicating that they would rather die than live out their life in a great deal of pain (46%) or be confused and/or forgetful (45%) all of the time.

Conclusions. Although the vast majority of very elderly community-dwellers in this sample appear to prefer comfort measures at the end of life, many said they were willing to endure specific life-prolonging interventions and distressing health states to avoid death. Our results highlight the need for physicians to better understand patients' preferences and goals of care to help them make informed decisions at the end of life.

Key Words: Advance directives—Geriatrics—End-of-life care—Patient-centered care—Decision making.

ADVANCE care planning is one key element to achieving patient autonomy by allowing patients to participate in decisions about their medical care (1,2). However, many patients near the end of life lose decision-making capacity or become too ill to participate in such decisions (1). When this happens, patients' loved ones and physicians must make these difficult decisions, even though they may be unaware of or disagree with patients' preferences for care (3,4). Advance care planning is based on the premise that ongoing discussions about end-of-life issues accompanied by written advance directives are valuable to help loved ones, physicians, and other providers better understand and make treatment decisions consistent with patients' wishes, if the patient becomes incapacitated

(5–7). Experts recommend that advance care planning discussions be held before patients face an acute health crisis and that the process continue as patients age or their clinical situation changes (3,7). However, little is known about the extent to which advance care planning is happening among very elderly community-dwelling adults (8–11).

We surveyed surviving community-dwelling participants of the original cohort of the Framingham Heart Study (FHS), all of whom are older than 80 years, about advance care planning, use of advance directives, and preferences for health care. The FHS is a natural place to further our understanding of very elderly adults who have been followed closely for almost 60 years, and who are now approaching the end of their natural life span. The original cohort

participants have been followed extensively through adulthood to collect detailed medical and social information, with very little loss to follow-up. In this context, we examined the extent to which these very elderly community-dwelling adults report advance care planning and describe their preferences for care and reported use of advance directives, and we examined how these factors relate to social support, illness burden, physical functioning, cognitive functioning, depressive symptoms, health perceptions, and previous health care use.

METHODS

Data Collection

The FHS is a prospective observational cohort study that began in 1948 to investigate risk factors for cardiovascular disease and other health conditions. The original cohort consisted of 5209 participants (55% women) 30–62 years old at entry from Framingham, Massachusetts (12). Since study inception, participants have returned every 2 years for a routine research examination, which includes a physician-administered medical history, a medical assessment, and questionnaires administered by trained interviewers. Written informed consent was obtained from participants, and the Institutional Review Board at Boston Medical Center approved the examination content.

Study Sample

Surviving original cohort participants who attended their 28th biennial examination were eligible for this study if they were cognitively intact and community-dwelling. All examinations occurred between February 4, 2004 and October 26, 2005. Overall, 253 community-dwelling participants attended examination 28. Seventeen participants fulfilled criteria for significant cognitive impairment or dementia after review by the FHS Dementia Study investigators (13), and therefore were ineligible to answer questions related to advance care planning and health care preferences. Of the 236 eligible participants, 220 (93%) agreed to answer these questions. Overall, 60% of examinations for eligible participants occurred in the FHS clinic. The remainder occurred at off-site locations (e.g., private residences) often because of distance.

Advance Care Planning and Care Preferences

Twelve items were administered to assess advance care planning and preferences for care; 11 of these were administered in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments/Hospitalized Elderly Longitudinal Project (SUPPORT/HELP) Project and used in several published reports (14–16). Participants were asked whether they had talked to anyone about their wishes for medical care toward the end of life; had filled out a living will; and had completed a health care proxy. Those reporting a health care proxy were asked to identify that individual. Participants were asked whether they prefer a treatment plan focused on extending life as much as possible, even if it meant more pain and discomfort, or one focused on relieving pain and discomfort as much as possible, even if it meant not living as long. Participants reported

their willingness to endure certain health states including whether they would rather die. The hypothetical health states included being (i) in a great deal of pain all the time even with medications, (ii) attached to a ventilator or respirator all the time, (iii) fed through a tube all the time, (iv) unconscious or in a coma all the time, and (v) confused or forgetting all the time. Lastly, participants were asked where they would prefer to die.

Participants were queried about their perceptions of their own longevity and future physical functioning, factors that may influence advance care planning and care preferences. Specifically, they were asked, “What do you think the chances are that you would live 12 months or more?” and “What are the chances that you will be able to take care of yourself 12 months from now?”

Because of concerns about participant burden and the potential emotional content of the questions, the interviewer assessed participants’ willingness to respond to the questions and external behavior immediately following these questions. Interviewers documented whether the participant (i) stopped the interview, (ii) was visibly upset or bothered by any question(s), and/or (iii) had difficulty understanding any question(s).

Potential Correlates

Factors previously shown to correlate with advance care planning and preferences for care in seriously ill populations are collected routinely during biennial examinations. Socio-demographic characteristics included age, sex, place of residence, and education (obtained from baseline interview). Social support was assessed by marital status, living situation, and two Berkman (17) Social Network questionnaire items, which assessed whether participants had someone to listen to them and provide emotional support.

Perceived health was assessed by “In general, how is your health now?” Self-reported physical functioning was assessed by ability to perform activities of daily living (ADL) (eating, dressing, bathing, transferring, toileting, and walking about 50 yards) without human assistance (18) and ability to walk one-half mile without help (19). Cognitive functioning was assessed using the Mini-Mental State Examination (MMSE; scores ≥ 24 indicate no cognitive impairment) (20). Presence of depressive symptoms was assessed using the Center for Epidemiologic Studies Depression Scale (CES-D; scores ≥ 16 indicate significant depressive symptoms) (21). Use of health care services included hospitalizations, illness visits to doctor, check-ups by doctor, and nursing home or skilled nursing facility admission in previous 2 years. Comorbid illness was assessed by a documented history of diabetes, coronary heart disease, stroke, congestive heart failure, intermittent claudication, cancer, and/or hip fracture. These conditions were documented by chart review and validated by a panel of FHS investigators. Diabetes was defined by a causal blood sugar >200 mg/dL or self-reported use of oral hypoglycemic medications or insulin.

Statistical Analysis

All statistical analyses used SAS (version 9.1; SAS Institute, Cary, NC). We conducted bivariable analyses to

Table 1. Characteristics of Community-Dwelling Participants of the Framingham Heart Study by Sex ($N = 220$)

Characteristics	Women ($N = 147$) N (%)	Men ($N = 73$) N (%)	p Value
Age at interview, mean \pm SD	88.3 \pm 3.4	87.8 \pm 3.1	0.277
Education			
Less than high school graduate	32 (22)	19 (26)	
High school graduate	64 (44)	29 (40)	
More than high school	48 (33)	26 (34)	0.789
Place of residence			
Private residence	111 (76)	58 (79)	
Other (e.g., assisted living)	36 (24)	15 (21)	0.514
Social support			
Marital status			
Married	21 (14)	41 (58)	
Widow	111 (76)	29 (41)	
Other	15 (10)	1 (1)	<.001
Living situation			
Lives alone	87 (60)	22 (31)	
Lives with someone	59 (40)	50 (69)	<.001
Has someone to listen			
None of the time	7 (5)	1 (2)	
Some of the time	43 (30)	22 (32)	
All of the time	91 (65)	45 (66)	0.536
Has someone to provide emotional support and help make difficult decisions			
None of the time	6 (4)	3 (4)	
Some of the time	20 (14)	15 (22)	
All of the time	114 (81)	52 (74)	0.353
Clinical characteristics			
History of			
Cancer	39 (27)	26 (36)	0.164
Coronary heart disease	38 (26)	29 (40)	0.035
Stroke	10 (7)	17 (23)	<.001
Intermittent claudication	12 (9)	12 (16)	0.095
Congestive heart failure	14 (10)	9 (12)	0.522
Diabetes	18 (12)	11 (15)	0.560
Hip fracture	17 (12)	2 (3)	0.039
Number of comorbid illnesses			
None	56 (38)	13 (18)	
1	48 (33)	26 (36)	
2	29 (20)	23 (31)	
3 or more	14 (9)	11 (15)	0.002
Perceived health			
Excellent	25 (17)	12 (17)	
Good	95 (66)	45 (62)	
Fair/poor	24 (17)	15 (21)	0.571
Perceived chance of taking care of self in 12 mo			
90% or better	81 (55)	39 (54)	
About 75%	19 (13)	19 (26)	
50% or worse	37 (26)	12 (17)	
Unsure	9 (6)	2 (3)	0.053
Perceived chance of living 12 mo or longer			
90% or better	85 (55)	43 (60)	
About 75%	11 (7)	11 (15)	
50% or worse	39 (27)	13 (18)	
Unsure	12 (8)	5 (7)	0.211
CES-D score \geq 16, indicating significant depressive symptoms			
No	119 (82)	64 (89)	
Yes	27 (18)	8 (11)	0.176

Table 1. Characteristics of Community-Dwelling Participants of the Framingham Heart Study by Sex ($N = 220$) (Continued)

Characteristics	Women ($N = 147$) N (%)	Men ($N = 73$) N (%)	p Value
Cognitive status, MMSE score			
≥ 24	132 (90)	66 (90)	
< 24	15 (10)	7 (10)	0.886
ADL dependencies			
None	128 (87)	65 (89)	
1 or more	19 (13)	8 (11)	.676
Uses assistive device to perform ADL			
No	49 (33)	32 (44)	
Yes	98 (67)	41 (56)	0.120
Ability to walk a half mile without help			
Able	57 (39)	20 (28)	
Unable	63 (44)	43 (60)	
Doesn't do	25 (17)	9 (12)	0.078
Health care use since last exam Had	141 (97)	70 (96)	1
check up by doctor			
Illness visit to doctor			
No visit	96 (65)	39 (53)	
1	29 (20)	24 (33)	
2 or more	22 (15)	10 (14)	0.314
Hospitalization			
None	97 (66)	35 (48)	
1	28 (19)	24 (33)	
2 or more	22 (15)	14 (19)	0.041
Had nursing home stay	18 (12)	9 (12)	0.986

Notes: Number of observations with missing data: education ($n = 3$), marital status ($n = 2$), living alone ($n = 2$), having someone to listen to you ($n = 11$), having someone to provide emotional support and help make difficult decisions ($n = 10$), perceived ability to take care of self ($n = 2$), perception of living 12 months or longer ($n = 1$), Center for Epidemiologic Studies Depression Scale (CES-D) ($n = 2$), activities of daily living (ADL) ($n = 1$), ability to walk one-half mile without help ($n = 3$), interim check-up by doctor ($n = 1$).

SD = standard deviation; MMSE = Mini-Mental State Examination.

describe the sample and identify differences in advance care planning and health care preferences between men and women, and to identify factors associated with self-reported use of advance directives (having a health care proxy and living will). We used multivariable logistic regression to identify factors independently associated with advanced directives after adjusting for age and sex. Because advanced directives were relatively common ($>10\%$), we derived adjusted prevalence ratios (aPR) and 95% confidence intervals (CI) using a log binomial regression model (22).

RESULTS

Among the 220 community-dwelling respondents, 3 (1.3%) stopped before completing questions on advance care planning and preferences, and 12 (5.5%) appeared upset or bothered by one or more questions. The average age of respondents was 88 years, 67% were women, 64% were widowed, three-quarters achieved a high school education or higher, and nearly all reported a routine checkup within the past 2 years. Compared with men, women were less often married and more often living alone (Table 1). Men were more likely to have one or more comorbid conditions and to have been hospitalized than were women.

We observed no difference in advance care planning and health care preferences between men and women (Table 2). Overall, 69% of respondents reported discussing their

wishes for medical care at the end of life with someone, but only 17% of these respondents discussed their wishes with a physician or other health care provider. Among those who discussed their wishes for care, the vast majority talked with a family member. Almost two thirds reported having a health care proxy, 55% a living will, 70% had either, and 41% had both. Although 80% preferred comfort over life-extending care, a greater proportion of men reported that they prefer life-extending care. Most respondents preferred to die at home.

For each health state, a greater proportion of women than men reported that they would rather die than live out their life in a particular state (Figure 1). Although 4 of 5 respondents preferred comfort care, fewer respondents preferred death over living out their life attached to a ventilator (63%) or fed through a tube (64%) all the time. Respondents were more willing to endure symptoms of pain and confusion, with fewer than half indicating that they would rather die than live out their life in a great deal of pain (46%) or be forgetful or confused (45%) all of the time. In contrast, being unconscious or in a coma all the time was undesirable to most respondents, with 82% indicating that they would rather die.

Table 3 presents the proportion of respondents reporting advance directives across different factors. Having advanced directives was associated with higher education, living in a nonprivate residence, having someone to listen, and not

Table 2. Advance Care Planning and Health Care Preferences Among Community-Dwelling Elders ($N = 220$)

Advanced Care Planning	All Participants* <i>N</i> (%)	Women ($N = 147$) <i>N</i> (%)	Men ($N = 73$) <i>N</i> (%)
Discussed wishes for end-of-life care			
No	69 (31)	42 (29)	27 (37)
Yes	151 (69)	105 (71)	46 (63)
Among those who have discussed wishes, percentage who discussed with:	($n = 151$)	($n = 105$)	($n = 46$)
Family member	138 (91)	96 (91)	42 (91)
Physician/health care provider	25 (17)	17 (16)	8 (17)
Attorney	25 (17)	15 (14)	10 (21)
Friend	17 (11)	15 (14)	2 (4)
Clergy	5 (3)	3 (3)	2 (4)
Other	5 (3)	5 (5)	0 (0)
Completed advance directives (has health care proxy and living will)	91 (41)	60 (41)	31 (43)
Has health care proxy	136 (66)	92 (67)	44 (62)
Has living will	116 (55)	75 (54)	41 (57)
Preferences for goals of care			
Extend life as much as possible	18 (8)	8 (5)	10 (14)
Focused on comfort/pain relief	174 (80)	122 (84)	52 (72)
Unsure	26 (12)	16 (11)	10 (14)
Preference for place of death			
Home	139 (71)	93 (69)	46 (75)
Hospital	23 (12)	16 (12)	7 (12)
Hospice	14 (7)	12 (9)	2 (3)
Nursing home	2 (1)	2 (2)	0 (0)
Other	17 (9)	11 (8)	6 (10)

Note: *There were no statistically significant differences by sex. Number of observations with missing data: health care proxy ($n = 12$), living will ($n = 8$); preference for goals of care ($n = 2$), preference for place of death ($n = 25$).

having depressive symptoms. After adjusting for age and sex, only education and goals of care remained associated with having advance directives. Compared to participants with less than a high school education, those with a high school education (aPR = 1.63; 95% CI, 0.94–2.81) and more than a high school education (aPR = 2.40; 95% CI, 1.41–4.07) were more likely to have advance directives, although the former did not achieve statistical significance. Compared to participants who preferred comfort care, those preferring life-extending care were substantially less likely to have advance directives (aPR = 0.32; 95% CI, 0.11–0.90), whereas participants who were unsure about their preference were indistinguishable (aPR = 0.72; 95% CI, 0.40–1.27).

DISCUSSION

We studied advance care planning and health care preferences of community-dwelling participants of the FHS original cohort. These men and women, now 84–100 years old, have been followed for more than 60 years, and have made substantial contributions to our understanding of many disease processes, most notably cardiovascular disease (23). With the current study, this cohort provides important insight into our understanding of advance care planning and health care preferences of very elderly community-dwelling adults who are still cognitively intact and thus able to participate in discussions regarding their goals for care. The majority of respondents reported that they preferred comfort measures at the end of life and to die

at home. However, despite the cohort's advanced age and overwhelming preference for comfort measures, when presented with specific clinical scenarios many respondents said they were willing to endure specific life-prolonging interventions (chronic ventilator and feeding tube) to avoid death. Moreover, more than half of respondents said that they were willing to live out their life in a great deal of pain or being forgetful or confused rather than die.

There are several possible clinically relevant explanations for this finding. First, the framing of the questions about goals of care and hypothetical health states is very important. Patients likely do not fully understand what comfort care entails or the implications of specific life-prolonging interventions, and may not view these concepts as mutually exclusive. Moreover, patients' lack of knowledge and experience with specific medical interventions and hypothetical scenarios has been shown to cloud the relationship between goals of care and preferences for life-prolonging interventions (24). A recent study found that using video images to depict a patient living with advanced dementia had a significant impact on individuals' preferences for care by improving their understanding and ability to imagine themselves having advanced dementia (25). Prior to seeing the video, 50% of participants preferred comfort care and 21% preferred life-prolonging care. However, after seeing the video, almost 90% indicated they desired comfort care and none chose life-prolonging care. In our study, most respondents chose death over living the rest of their life in a coma or unconscious, possibly because this is a tangible

Respondent would rather die than spend all of the time in:

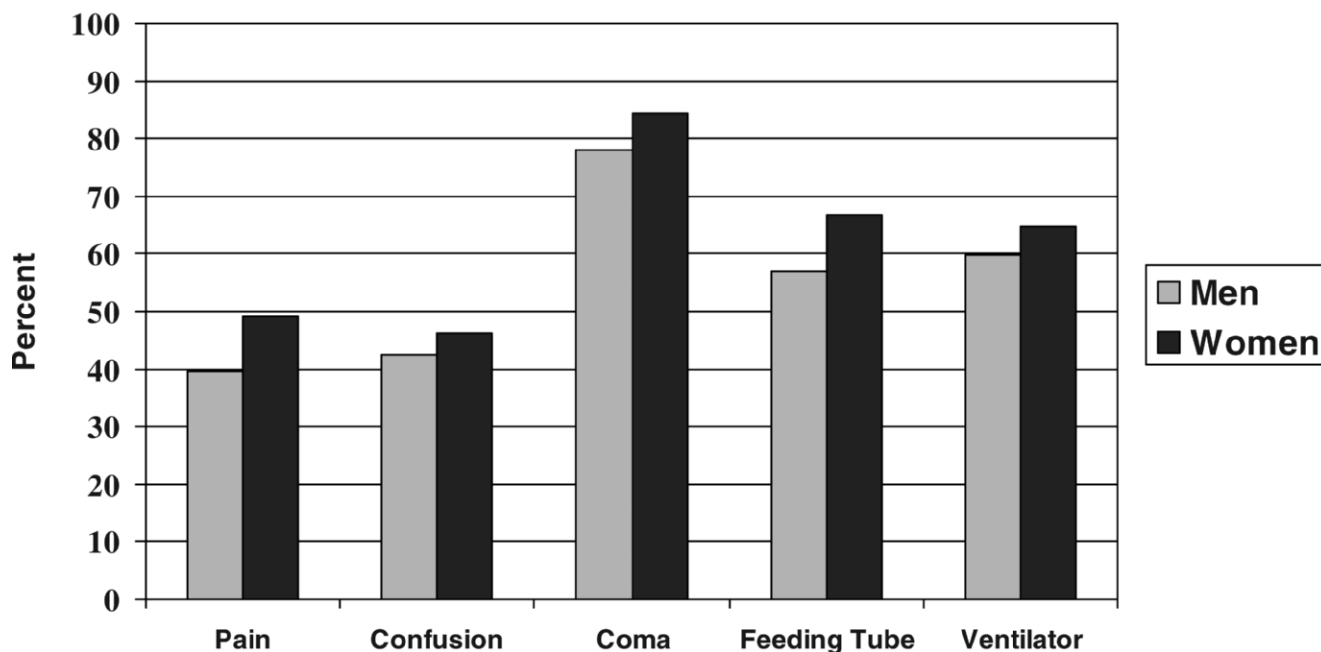


Figure 1. Preferences for future health states among community-dwelling elders ($n = 220$).

state that is more readily understood. Finally, qualitative data suggest that, when faced with hypothetical choices, patients place more emphasis on the outcome of an intervention (in this instance avoiding death) rather than the intervention itself (26). Nevertheless, given the inconsistency observed between reported goals of care and preferences for life-prolonging interventions and distressing health states, it is concerning that few of these very elderly respondents have discussed their wishes for end-of-life care with a health care provider.

More than 15 years ago, Lo and colleagues (27) recommended that physicians talk to their elderly patients about their wishes for care. Most physicians believe that it is their professional responsibility to help patients with advance care planning, with more than 80% of physicians reporting that they should initiate end-of-life discussions with patients (28). Therefore, it is troubling that, in this very elderly cohort where nearly all respondents reported having a recent routine check-up, only 12% of all respondents reported discussing their preferences with a physician or health care provider. Yet these findings are consistent with studies suggesting that discussions with physicians about end-of-life care were uncommon (10,11,29). We did find it encouraging that the vast majority of respondents had someone to provide emotional support, help make difficult decisions, and listen to them, and many reported that they had discussed their wishes for care with family members. Nonetheless, our findings highlight the need for physicians to have these discussions with very elderly patients to help their patients make informed decisions rooted in their values.

Our findings were remarkably consistent with those of seriously ill hospitalized patients 80 years old or older enrolled in HELP (15). Using the same set of questions asked in our study, HELP found that 73%–78% of very elderly adults preferred comfort care within 3–6 months prior to death. HELP also found that fewer patients would choose death rather than endure a lifetime of pain (48%) and confusion (35%) or be attached to a ventilator (70%) or feeding tube (50%) (15).

Few studies have actually examined advance care planning among community-dwelling elders (8–11). We found that two thirds of very elderly community-dwelling adults reported having a health care proxy, and about half had a living will. In contrast, a study of managed care patients 80 years old or older found that only 27% had been asked about their end-of-life preferences and that only 46% had advance directives documented in their chart (10). In a multiethnic sample of younger community-dwelling elders, Morrison and Meier (8) found that only 35% had a health care proxy.

There is some evidence that discussions about end-of-life care are helpful to patients. Patients who discussed end-of-life care with their physicians reported less fear and anxiety, a better understanding of their options for care, and a greater ability to make decisions and influence their medical care (30,31). Data suggest that completion of advance directives were associated with greater satisfaction (30,32), greater hospice use, and fewer concerns about communication (33). Despite national trends toward shared decision making, one third of the general adult population moderately or strongly

Table 3. Proportion of Community-Dwelling Elders With Advance Directives Across Selected Characteristics (N = 220)

Characteristics	Number With Characteristic (N)	% With Advance Directives*
Demographic characteristics		
Sex		
Female	147	40.8
Male	73	42.5
Education[†]		
Less than high school graduate	51	23.5
High school graduate	93	40.9
More than high school	73	54.8
Place of residence[†]		
Private residence	169	37.9
Other (e.g., assisted living)	51	52.9
Social support		
Marital status		
Married	62	46.8
Widow	140	41.4
Other	16	25
Living situation		
Lives alone	109	45
Lives with someone	109	36.7
Has someone to listen[†]		
None of the time	8	12.5
Some of the time	65	32.3
All of the time	136	49.3
Has someone to provide emotional support and help make difficult decisions		
None of the time	9	22.2
Some of the time	35	34.3
All of the time	166	45.2
Clinical characteristics		
Number of comorbid illnesses		
None	69	44.9
1	74	39.2
2	52	42.3
3 or more	25	36
Perceived health status		
Excellent	37	43.2
Good	140	41.4
Fair/poor	39	41
Perceived chance of living 12 months or longer		
90% or better	128	45.3
About 75%	22	31.8
50% or worse	52	36.5
Unsure	17	41.2
Perceived chance of taking care of self in 12 months		
90% or better	120	48.3
About 75%	38	36.8
50% or worse	49	28.6
Unsure	11	36.4
CES-D Score ≥ 16, indicating significant depressive symptoms[†]		
No	183	44.8
Yes	35	25.7

Table 3. Proportion of Community-Dwelling Elders With Advance Directives Across Selected Characteristics (N = 220) (Continued)

Characteristics	Number With Characteristic (N)	% With Advance Directives*
Cognitive status, MMSE score		
≥ 24	198	42.4
< 24	22	31.8
ADL dependencies		
None	193	43
1 or more	27	29.6
Uses assistive device to perform ADL		
No	81	45.7
Yes	139	38.9
Ability to walk one-half mile without help		
Able	106	49
Unable	77	33.8
Doesn't do	34	32.3
Health care use since last exam		
Check-up by doctor		
No	8	37.5
Yes	211	41.7
Illness visit to doctor		
No visit	135	37.8
1	53	52.8
2 or more	12	37.5
Hospitalization		
None	132	42.4
1	52	36.5
2 or more	36	44.4
Nursing home stay		
No	193	43.5
Yes	27	25.9

Notes: Number of observations with missing data: education (n = 3), marital status (n = 2), perceived health (n = 4), living alone (n = 2), having someone to listen to you (n = 11), having someone to provide emotional support and help make difficult decisions (n = 10), perceived health status (n = 4), perceived ability to take care of self (n = 13), perception of living 12 months or longer (n = 18), Center for Epidemiologic Studies Depression Scale (CES-D) (n = 2), activities of daily living (ADLs) (n = 1), interim check-up by doctor (n = 1).

*Percentages refer to proportions of participants with a particular characteristic who had an advance directive.

[†]p < .05.

MMSE = Mini-Mental State Examination.

agreed that they would prefer to leave decision making to their physician, with older adults and those in poorer health less likely to want to participate in decision making (34,35). Moreover, few desire tight control over medical decisions if unable to make their own decisions (36), and many community-dwelling elders trust that physicians would make the right care decisions should they become very sick (8).

Because many very elderly patients are clinically complex, advance care planning should not wait until patients face an acute medical crisis such as being hospitalized with life-threatening illness (4,7). Studies show that patients are open and willing to discuss advance care planning, but generally they would prefer that their physician raise the

topic (8,37). Even though most physicians believe it is their responsibility to have end-of-life discussions (28), some may be reluctant because a potentially time-consuming discussion may take away from other pressing clinical matters (38). Ideally, providers should begin talking to their elderly patients about advance care planning early and have ongoing discussions, especially with changes in health status (3). This will introduce concepts of end-of-life care while elderly patients are able to participate in the decision-making process and allow patients to re-evaluate their values as they age or experience changes in their clinical situation.

Advance directives assume that patients can anticipate their preferences for care for hypothetical future health states (8,39). However, there is little evidence that decisions patients make when relatively healthy can predict treatment choices when death is imminent (39). Although the vast majority of very elderly participants in our study could state their health care preferences and were not emotionally upset by the end-of-life content, some had difficulty. We found that higher education was strongly associated with advanced directives in the very elderly participants. Because an estimated 27% of older adults have below basic document literacy (40), health literacy may be an important and unrecognized barrier to completing advance directives. Moreover, treatment preferences appear to be only moderately stable over time, but preferences to refuse life-prolonging treatment tend to be more stable than preferences to receive life-prolonging treatment (41). Given the advanced age of our sample and that the majority preferred comfort measures, it is likely that their goals of care would be relatively stable, but it is unclear how their preferences for specific life-prolonging interventions and distressing health states would change.

Our findings should be interpreted within the context of important limitations. These findings reflect views of non-Hispanic white community-dwelling elders, most of whom still reside in the Northeast, and may not be representative of elders from racial and ethnic minority groups or other geographic regions. In particular, studies have consistently shown that African-American patients are more likely to undergo aggressive care, to prefer life-sustaining treatment, to want cardiopulmonary resuscitation, and to die in a hospital (11,32,42–48). African Americans are less likely to have discussions about life-sustaining treatments with physicians (49), and are much less accepting of advanced care planning. African Americans and Hispanic Americans have advanced directives less often than their white counterparts do (44,50–53). In addition, frail older ethnic minorities are less likely to self-express their own health care choices than are their white counterparts (54). Next, we were unable to look in-depth at any one topic or explore reasons why few very elderly community-dwelling adults discuss wishes for care with their providers. Finally, we relied on participants' self-report. It is possible that providers have addressed end-of-life issues with some participants, but participants did not recall or perceived the discussion differently. Although such information is subject to recall bias and participants' perceptions, perhaps it speaks to the quality of the patient-provider communication.

Summary

Many very elderly adults still reside in community settings and are capable of making treatment decisions near the end of life. Most elders were able to state their preferences, and few appeared upset or bothered when asked about end-of-life care. Although the majority of participants prefer comfort measures at the end of life, many indicated that they would endure life-prolonging interventions and distressing health states to avoid death. The reasons for this discrepancy are likely to be multifaceted. Yet, very few respondents reported having discussed their preferences with their providers. Future research should develop and test interventions to improve rates of end-of-life discussions in very elderly community-dwelling populations. These efforts should involve family members whenever possible. Discussions among the physician-patient-family triad may facilitate unified decision making that is informed and rooted in patients' values. Increased family involvement may help bridge outpatient and inpatient settings so that patients receive care that is consistent with their preferences.

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