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End-of-Life Discussions with Older Adults

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Abstract

Objectives—To determine the prevalence of end-of-life (EOL) conversations with older adults.

Design—National Health and Aging Trends Study (NHATS), a prospective, longitudinal survey of Medicare beneficiaries.

Setting—Nationally representative.

Participants—A sample drawn from Wave 2 of the NHATS.

Measurements—The main outcome was the report of an EOL planning discussion, based upon the participant's response to the question "Have you talked to anyone about the types of medical treatment you would want or not want if you became seriously ill in the future?"

Results—Sixty-one percent of the sample (n= 1,993 individuals, weighted n = 11,123,910) responded that they had discussed EOL treatment preferences with someone. In multivariate regression, factors associated with reporting an EOL discussion included being younger (adjusted odds ratio (AOR)=1.70, 95% confidence interval (CI)=1.17–2.47), having more education (high school degree: AOR=1.45, 95% CI=1.02–2.07; some college: AOR=2.03, 95% CI=1.40–2.95), and having multiple chronic conditions (AOR=1.25, 95% CI=1.01–1.55). Black race was associated with lower odds of reporting a discussion (AOR=0.46, 95% CI=0.33–0.65).

Conclusion—Forty percent of a nationally representative sample of Medicare beneficiaries had not discussed their preferences regarding EOL medical treatment. Promoting these conversations

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in clinical and nonclinical settings will be important to ensure that health care is delivered to individuals in a person-centered manner.

Keywords

end-of-life care preparation; Medicare; discussion

Improving the quality of end-of-life (EOL) care for individuals and their families has been a growing focus in health care, particularly because individuals are living longer and aging with multiple chronic conditions,¹ but numerous barriers, such as a fragmented healthcare system, the imprecision of correctly identifying an individual's prognosis and life expectancy, and deficiencies in providing access to needed healthcare services to the most vulnerable populations, have stymied these efforts. Among the structural and scientific barriers to improving EOL care, there have also been strong political forces that have delayed the passage of policies to promote high-quality EOL care. Despite these factors, in October 2015, the Centers for Medicare and Medicaid Services (CMS) successfully finalized a regulation to reimburse physicians and other healthcare professionals for advance care planning discussions.²

Advance care planning, long advocated by healthcare policy-makers and clinicians, is a process in which an individual reflects on and communicates his or her life values, goals, and treatment preferences.^{1, 3, 4} Although there are barriers to systematizing the content, execution, and acceptance of these communications⁵, several studies have documented the benefits of advance care planning to dying individuals and the health system at large. Conversations about EOL care preferences have been associated with greater likelihood of an individual receiving treatment that is consistent with his or her wishes, earlier referral to hospice, and overall better quality of life near death.⁶⁻⁸ One study also found that EOL care discussions are associated with lower healthcare costs in the last week of life.⁶

The creation of public policies and professional education and training to support and encourage advance care planning discussions with healthcare providers is necessary for a growing aging population, but these must occur alongside discussions between individuals and their families about serious illness, EOL care scenarios, and treatment preferences.⁴ In situations in which individuals are not able to make EOL care decisions for themselves because of physical or cognitive incapacity, families and caregivers face the burden of making medical decisions. Effective advance care planning helps to prepare surrogates for these situations and enables them to advocate for care that is consistent with the individual's values.

Much of the research thus far has focused on the occurrence of these discussions between individuals and their physicians, with one study from 2011 noting that only 1% of Medicare beneficiaries had EOL care discussions with their primary care physician during the course of routine care,⁹ but little is known about the level of public engagement in advance care planning and, in particular, the prevalence of discussions between individuals and their surrogates. Using a population-based sample of Medicare beneficiaries, the goal of this study was to characterize the frequency of advance care planning discussions between aging

individuals and their families and examine the factors associated with having this discussion among this population.

METHODS

Participants were sampled from the National Health and Aging Trends Study (NHATS) cohort.^{10, 11} NHATS is an annual longitudinal population-based survey of Medicare beneficiaries aged 65 and older residing in the contiguous United States, with oversampling of those aged 90 and older and non-Hispanic blacks.¹² Wave 1 of NHATS contained a sample of 8,245 persons, with a response rate of 70.9%. Annual in-person interviews are conducted (in English or Spanish) with study participants, and during Wave 2, one-third of the sample was randomly selected to complete questions regarding EOL care planning. The current study sample was limited to participants who were randomly selected for that module. Participants who had a missing response or responded “do not know” to the primary outcome measure were also excluded.

Measures

The main outcome was the report of an EOL care planning discussion, based upon the participant’s response to the question “Have you talked to anyone about the types of medical treatment you would want or not want if you became seriously ill in the future?” If yes, participants were then asked, “How is that person related to you?” Participants were allowed to identify more than one person to whom they had spoken. NHATS researchers coded responses to this question according to relationship categories created a priori. Participant responses regarding with whom they had discussed EOL care issues were further organized into five groups based on commonly used kinship categories: spouse or partner, child, sibling, other family (e.g., parent, aunt, niece, cousin), and other (e.g., friend, neighbor, coworker, roommate). Participants were also asked, “Have you made any legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself?” and “Do you have a living will or advance directive?”

Covariates hypothesized to be related to the outcome and found in previous studies to have an association with the completion of advance directives in the general population were included.¹³ Sociodemographic information included age, sex, race, marital status, highest education attained, residence, language, insurance, and geographic region. If a proxy was answering questions on behalf of the subject was also reported. Religiosity was assessed according to subject report of the importance of attending religious services as measured on a Likert scale. Measures of self-reported health and self-reported presence of 11 chronic conditions were used as a proxy for health status. A count was created of heart disease, hypertension, arthritis, osteoporosis, diabetes mellitus, lung disease, stroke, cancer, hip fracture, depression, and anxiety. Depressive symptoms and anxiety were measured using the four-item brief screening scale Patient Health Questionnaire-4 using the recommended cutoff of 3 or greater for each subscale.^{14, 15} Multiple chronic conditions was defined as the presence of two or more chronic conditions.¹⁶ The presence of prefrailty and frailty were ascertained using the Cardiovascular Health Study method, in which frailty is defined as the presence of three or more of unintentional weight loss, exhaustion, weakness (low grip

strength), slow walking speed, and low physical activity, and prefrailty is defined as the presence of one or two of those conditions.^{17, 18} Data were also included on whether the participant reported having a regular doctor, whether they had been hospitalized in the previous year, and their social network size, characterized by the number of people they “talk to about important things.”¹⁹ The proportion of respondents who died within the year after this interview (before the next survey wave) was measured.

To assess the relationship between advance care planning conversations and the desire for life-sustaining treatment in the setting of serious illness, two questions in the NHATS survey were asked in which the subject is asked to consider a hypothetical scenario and is asked whether they would want to receive or reject all life-sustaining treatments. In the first scenario, the subject is asked, “What if you could speak, walk, and recognize others, but you were in constant, severe physical pain? Would you want to receive life-prolonging treatments or stop all treatment?” In the second scenario, the subject is asked, “What if you were not in pain, but could not speak, walk, or recognize others?”

Statistical Analysis—Descriptive statistics were used to describe the proportion of respondents who reported a discussion of EOL care planning and the relationship of the individual with whom they had the discussion. The demographic and health characteristics of the sample were also characterized. Chi-square tests were then conducted, with statistical significance defined as $p < .05$ to compare the proportions of sociodemographic and health characteristics of individuals who did and did not report a discussion of EOL care planning. Chi-square tests were used to assess the relationship between reporting a discussion and responses to the hypothetical scenarios. A multivariate logistic regression model was developed to determine the factors that are associated with reporting any discussion about EOL medical care preferences. Sociodemographic characteristics, religiosity, social network size (as a continuous variable), recent hospitalization, presence of multiple chronic conditions, frailty, and presence of a living will were included as covariates. Power of attorney was not included as a covariate because of collinearity with the presence of a living will. A sensitivity analysis was performed in which the multivariate logistic regression model was repeated with each chronic condition included as an independent covariate. All analyses took into account the sample weights and sample design variables available in NHATS to generate weighted, nationally representative estimates, and 95% confidence intervals were generated for these estimates. All analyses were conducted using SAS version 9.3 (SAS Institute, Inc., Cary, NC). The institutional review board of the Icahn School of Medicine at Mount Sinai determined this study to be exempt (HS 15–00071).

RESULTS

The second wave of NHATS took place in 2012 and contained a sample of 7,075 individuals, of whom 2,205 were also randomly assigned questions pertaining to EOL care planning. Excluding individuals with missing data ($n=190$) and those who refused to answer or answered “do not know” in response to the question about EOL care planning discussions ($n=22$) left a final sample of 1,993 individuals (weighted $n=11,123,910$). Sixty-one percent of the sample responded that they had discussed EOL treatment preferences. Of those who had discussed EOL care, 15.0% (95% CI=12.9–17.1) reported discussing their

EOL care preferences with more than one kinship category; 37.1% (95% CI=34.4–39.8) reported discussions with their child, 25.5% with their spouse or partner (95% CI=23.1–27.9), 2.7% with siblings (95% CI=2.0–3.6), 2.8% with other family (95% CI=2.0–3.7), and 10.0% with others (10.0%, 95% CI=8.1–12.1). In bivariate analyses, a higher proportion of women (64.5%) than of men (56.2%) had discussed EOL treatment preferences ($p<.001$, Table 1), as had more white (66.2%) than black (40%) and other (37.1%) respondents ($p<.001$). A higher proportion of those who had completed some or more college (70.8%) and those without Medicaid (63.3%) had also had discussions ($p<.05$ for all comparisons). A significantly higher proportion of those who lived in the Midwest (66.9%) and West (66.8) had discussed EOL treatment than of those living in the South (54.5%) and Northeast (59.5%).

With respect to their health characteristics, individuals who reported fair or poor health were less likely to have discussed EOL care (55.8%) than those who reported excellent or good health (62.8%), and a higher proportion (61.6%) of those with a regular doctor reported discussions than of those without a regular doctor (59.4%) (all $p<.05$). Of those with frailty, 61.4% reported having these discussions, compared with 66.5% of those without frailty, and 58.3% of those with prefrailty, and 62.4% of English speakers reported having these discussions, compared with 21.7% of non-English speakers (all $p<.001$). A higher proportion of those with an advance directive (83.3%) or power of attorney (83.0%) reported having these discussions ($p<.05$ for both comparisons). No significant differences were found between the groups with respect to age, marital status, place of residence, religiosity, hospitalization in the previous year, number of chronic conditions, and survey response by a proxy ($p>.05$ for all comparisons). Individuals who had discussed EOL care planning had a larger social network (mean 2.1) than those who had not (mean 1.7) ($p<.001$). Of those who died during the following year, 68.2% had EOL discussions, compared with 60.8% of those who did not die ($p=.14$).

In bivariate analyses of the hypothetical scenarios (Table 2), a significantly higher proportion of those who wanted to stop or reject all treatments in the constant pain scenario (66.0%) discussed EOL care planning than of those who wanted to receive all treatments (53.3%, $p<.001$). This was similar to the cannot speak, walk, recognize scenario, in which a higher proportion who wanted to stop treatments had discussed (65.0%) than of those who wanted to receive all treatments (49.1%, $p<.001$).

In our multivariate logistic regression model, the factors independently associated with reporting an end-of-life care planning discussion included lower age (Adjusted Odds Ratio (AOR): 1.70, 95% Confidence Interval (CI): 1.17 – 2.47), having completed some college (AOR: 2.03, CI: 1.40 – 2.95) or completing a high school degree (AOR: 1.45, 95% CI: 1.02 – 2.07), multiple chronic conditions (AOR: 1.25, 95% CI: 1.01 – 1.55), increasing social network size (AOR: 1.19, 95% CI: 1.07 – 1.33), and having a living will (AOR: 7.53, 95% CI: 5.68 – 9.99) (Table 3). Compared to whites, blacks were less likely to report a discussion (AOR: 0.67, 95% CI: 0.45 – 0.98) as were those of other races (AOR: 0.45, 95% CI: 0.29 – 0.71). Several factors were not significantly related to the report of an end-of-life discussion, including sex, marital status, Medicaid, region, religiosity, having a regular doctor, self-reported health, the presence of frailty, and hospitalization within the previous year. In our

sensitivity analysis in which chronic conditions were included as independent covariates, no individual condition had an independent association.

DISCUSSION

This study of EOL care planning in older adults found that 61% reported having discussed their preferences regarding EOL medical treatment with someone. This is a higher proportion than found in the general population.²⁰ The current study is the first, to the knowledge of the authors, to examine the prevalence of EOL care planning discussions taking place beyond the clinical encounter in a nationally representative sample of elderly adults. After controlling for sociodemographic factors and health characteristics, white race, higher education, and having a living will were associated with greater odds of reporting this discussion, a finding that confirms what has been found in the general population.²¹ With regard to health characteristics, including several markers of morbidity and greater risk of mortality,^{22, 23} only the presence of multiple chronic conditions was associated with having an EOL discussion. This is consistent with a study assessing the factors associated with advance care planning with physicians, which greater higher odds in individuals who had been diagnosed with cancer or heart disease.⁹

The finding that white race and higher education were associated with greater likelihood of reporting an EOL discussion, regardless of health status, is consistent with previous reports that have examined the occurrence of these discussions with physicians.^{13, 24} In the literature examining advance directives and conversations with physicians, previous research has found that black individuals are less likely to have discussions with their physicians about EOL care, even though they may desire these conversations.²⁵ Another study of family members of black decedents found that they received less information and were more likely to report having problematic physician communication.²⁴ Although problems with trust or discordant culture may impede discussions with physicians, it had been hypothesized that race and education would not be significant predictors of reported discussions with family.²⁶ Instead, the findings suggest that there may be sociocultural factors that influence engagement in any discussion on the topic of death and dying, and this highlights the troubling potential for disparities with regard to EOL care for minorities.

In the hypothetical scenarios, unadjusted analyses showed that rejecting treatment was associated with greater likelihood of having an EOL care planning discussion, a finding consistent with observational data of lower EOL treatment intensity and advance care planning.²⁷

Several health characteristics known to be associated with greater risk of mortality were not predictive of having EOL discussions, which may suggest that the cultural avoidance of talking about death and dying is pervasive even in those at high risk of death. It is hoped that the growing efforts to stimulate public and private conversations about advance care planning and protecting individual autonomy will spur these discussions across the spectrum of health and illness.

These findings have important implications for health policy-makers and clinicians. First, they cast a bright light on the substantial continued effort that is needed to improve EOL care planning, specifically for older adults. Because a majority of deaths occur in older adults, it is troubling that nearly 40% of Medicare beneficiaries have not had any discussion of EOL treatment preferences with their families. In the adjusted model, age was a significant predictor of not having EOL discussions, a finding that contradicts earlier reports.¹ The new regulation to reimburse advance care planning services of physicians and others for Medicare beneficiaries has the potential to affect a significant proportion of the elderly population. It is increasingly recognized that advance care planning is a process that occurs and evolves over time, as a person's health status, needs, and goals change. Additionally, empowering physicians with the communication skills and tools to guide high-quality conversations about advance care planning has the potential to affect individuals with higher mortality risk, such as the oldest adults and frail individuals, as well as those with other characteristics that are less associated with having these conversations, including racial minorities and those with less than a college education. Unfortunately, individuals who were sicker were no more likely to have had EOL care planning discussions than those who were less sick, pointing to a failure in addressing those with greater need.

The medical literature contains some evidence that advance care planning can improve the quality of care for individuals and their families. For example, in a longitudinal study of 325 individuals with advanced cancer, EOL care planning discussions were shown to increase the likelihood that an individual would receive treatment consistent with his or her wishes.⁷ A randomized controlled trial of advance care planning in individuals aged 80 and older found that advance care planning was associated with significantly lower stress, anxiety, and depression in the family members of individuals who died.²⁸

There are limitations to this study that deserve attention. First, the findings do not provide an estimate of EOL care planning discussions between clinician and patient, because the NHATS study coded participants who may have reported talking to their physician as talking to "other nonrelative," but this category was less than 12% and also included lawyers and other nonrelatives. Second, although the proportion of the sample who died in the following year was reported on, because of lack of clinical data, it was not possible to capture the exact timing of when the conversation took place relative to the individual's death or to capture how it may have affected the quality of care at death. Third, it was not possible to characterize the depth and content of the discussions that took place. The extent to which the discussion prepared the surrogate for future decision-making could not be determined from the data available. Lastly, information was not available on 190 subjects with missing data, which may lead to bias. These cases represent nursing home residents who did not receive the full interview (by survey design), which limits the generalizability of the findings to the nursing home population.

In a heterogeneous society, exploring the reasons why 40% of older adults have not discussed EOL care preferences and studying the link between personal advance care planning discussions and quality of care will be important, but mechanisms to increase conversations between individuals and their families must take into account sociocultural norms and expectations. The recently finalized CMS regulation to reimburse physicians for

advance care planning is one potential mechanism, because it empowers clinicians and individuals to have conversations that might lead to substantial improvement in the quality of care that individuals and their families receive in the setting of serious illness and at the end of life. Nevertheless, the widespread reluctance in society to talk about death and dying (despite the extraordinary social and political effort of major foundations and others in the last several decades) suggests that, although advance care planning needs to be encouraged, how doctors talk to individuals must also be reformulated so that individual values can be maximized and medical treatment determined by personal goals is offered throughout the course of an individual's illness. Additionally, healthcare providers are uniquely positioned to encourage these discussions between individuals and their families and to work with individuals and their surrogates to translate what was discussed into a person-centered plan of care at the end of life. Although there are many grass-roots efforts to promote advance care planning, and greater coverage in the media, adding physicians' voices to the conversation about honoring individuals' values and preferences in the context of serious illness is an important element to ensure that the opportunities to have these conversations also occur with the most vulnerable and the sickest individuals.

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Table 1

Baseline Characteristics of Medicare Beneficiaries in NHATS Sample According to End-of-Life (EOL) Discussion Status

Characteristic	Total, N=11,123,910 ^a	Had Discussed EOL Treatment, n=6,765,881 (61%) ^{b,c}	P- Value ^d
	Weighted Value		
Age, %			.87
65–74	49.0	61.0	
75–84	36.6	60.0	
85	14.5	61.9	
Sex, %			<.001
Female	55.6	64.5	
Male	44.4	56.2	
Race, %			<.001
White	80.7	66.2	
Black	8.5	40.0	
Other	10.7	37.1	
Education, %			<.001
<High school	21.7	42.2	
High school	29.0	58.5	
Some college	49.3	70.8	
Married or living with a partner, %			.23
Yes	55.9	62.2	
No	44.1	59.1	
Medicaid, %			<.001
Yes	12.3	43.1	
No	87.7	63.3	
Place of residence, %			.80
Community	93.5	60.7	
Residential care	5.7	62.0	

Characteristic	Total, N=11,123,910 ^a	Had Discussed EOL Treatment, n=6,765,881 (61%) ^{b,c}	P- Value ^d
Nursing home	0.9	69.5	
Region, %			.008
Northeast	20.6	59.5	
Midwest	21.7	66.9	
South	36.5	54.5	
West	21.2	66.8	
Religious, %			.58
Yes	52.3	60.1	
No	47.7	61.6	
Self-reported health			.02
Excellent, very good, good	76.8	62.8	
Fair, poor	23.2	55.8	
Have a regular doctor			.006
Yes	94.0	61.6	
No	6.0	59.4	
Frailty			.02
Not frail	22.2	66.5	
Prefrail	54.8	58.3	
Frail	23.0	61.4	
Hospitalized in previous year, %			.68
Yes	22.6	60.7	
No	77.4	62.0	
Number of chronic conditions, %			.14
0	9.3	53.5	
1–3	65.5	62.0	
4–6	25.2	60.5	
English speaker, %			<.001
Yes	96.1	62.4	
No	3.9	21.7	

Characteristic	Total, N=11,123,910 ^a	Had Discussed EOL Treatment, n=6,765,881 (61%) ^{b,c}	P- Value ^d
Respondent, %			.70
Sample person	94.4	60.7	
Proxy	5.6	62.6	
Social network size, mean (range 0–5)	2.0	2.1	<.001
Had an advance directive or living will, %			<.001
Yes	53.6	83.3	
No	46.4	35.1	
Power of attorney, %			<.001
Yes	50.1	83.0	
No	49.9	38.6	
Died within 1 year of survey, %			.14
Yes	4.7	68.2	
No	95.3	60.5	

^aUnweighted n=1,993.

^bUnweighted n= 1,156.

^cReflects row percentages.

^dDerived from chi-square tests of proportions.

Table 2

Hypothetical Scenarios Regarding End-of-Life (EOL) Treatment

Scenario	Total, N=11,123,910	Had Discussed EOL Treatment, n=6,765,881 ^a	P- Value ^b
	Weighted %		
In constant pain			
Receive all treatments	24.0	53.3	<.001
Stop or reject all treatments	63.8	66.0	
Refused, did not know	12.2	47.5	
Could not speak, walk, recognize, %			
Receive all treatments	14.2	49.1	<.001
Stop or reject all treatments	75.7	65.0	
Refused, did not know	10.1	44.9	

Proxy respondents (5.6%) were not administered these questions

^aReflects row percentages

^bDerived from chi-square tests of proportions.

Table 3

Multivariate Logistic Regression of Characteristics Associated with Having an End-of-Life Discussion

Characteristic	Odds Ratio (95% Confidence Interval)
Age (reference 85)	
65–74	1.70 (1.17–2.47)
75–84	1.19 (0.80–1.77)
Female	1.24 (0.99–1.54)
Race (reference white)	
Black	0.67 (0.45–0.98)
Other	0.45 (0.29–0.71)
Education (reference <high school)	
High school, GED	1.45 (1.02–2.07)
Some college	2.03 (1.40–2.95)
Married	0.99 (0.72–1.35)
Medicaid	1.00 (0.66–1.18)
Region (reference northeast)	
Midwest	1.22 (0.76–1.96)
South	0.88 (0.56–1.38)
West	1.48 (0.88–2.50)
Religious	1.03 (0.78–1.35)
Social network ^a	1.14 (1.03–1.27)
Have a regular doctor	0.96 (0.60–1.54)
Self-reported health fair or poor	0.88 (0.66–1.18)
Multiple chronic conditions ^b	1.25 (1.01–1.55)
Frailty	1.18 (0.87–1.59)
Hospitalization within previous year	1.08 (0.75–1.58)
Had living will	7.53 (5.68–9.99)

^aIncluded as a continuous covariate (range 0–5).^b 2 chronic conditions.