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Advance Care Planning and the Quality of End-of-Life Care among Older Adults

Kara E. Bischoff, MD¹, Rebecca Sudore, MD^{2,3}, Yinghui Miao, MPH^{2,3}, W. John Boscardin, PhD^{2,3}, and Alexander K. Smith, MD, MS, MPH^{2,3}

¹Department of Medicine, University of California at San Francisco, San Francisco, CA

²Division of Geriatrics, Department of Medicine, University of California at San Francisco, San Francisco, CA

³Veterans Affairs Medical Center, San Francisco, CA

Abstract

Background—Advance care planning is increasingly common, but whether it influences end-of-life quality of care remains controversial.

Design—Medicare data and survey data from the Health and Retirement Study were combined to determine whether advance care planning was associated with quality metrics.

Setting—The nationally representative Health and Retirement Study.

Participants—4394 decedent subjects (mean age 82.6 years at death, 55% women).

Measurements—Advance care planning was defined as having an advance directive, durable power of attorney or having discussed preferences for end-of-life care with a next-of-kin. Outcomes included previously reported quality metrics observed during the last month of life (rates of hospital admission, in-hospital death, >14 days in the hospital, intensive care unit admission, >1 emergency department visit, hospice admission, and length of hospice 3 days).

Results—Seventy-six percent of subjects engaged in advance care planning. Ninety-two percent of advance directives stated a preference to prioritize comfort. After adjustment, subjects who engaged in advance care planning were less likely to die in a hospital (adjusted RR 0.87, 95% CI 0.80-0.94), more likely to be enrolled in hospice (aRR 1.68, 1.43-1.97), and less likely to receive hospice for 3 days before death (aRR 0.88, 0.85-0.91). Having an advance directive, a durable-power-of-attorney or an advance care planning discussion were each independently associated with a significant increase in hospice use (p<0.01 for all).

Conclusion—Advance care planning was associated with improved quality of care at the end of life, including less in-hospital death and increased use of hospice. Having an advance directive, assigning a durable power of attorney and conducting advance care planning discussions are all important elements of advance care planning.

Address correspondence requests to: Kara E. Bischoff, MD M-983, Moffitt Hospital 505 Parnassus Avenue San Francisco, CA 94143 Phone: 415-606-1041 Fax: 415-750-6641 kara.bischoff@ucsf.edu.

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Keywords

Advance care planning; advance directives; end-of-life; quality

INTRODUCTION

Advance care planning refers to the process by which people express their values and priorities with the goal of preparing for care at the end of life that is in accordance with their personal preferences. Advance care planning can be a complex process requiring many conversations over time; decisions and discussions are often documented through the completion of an advance directive or assignment of a durable power of attorney for healthcare.

The majority of the existing literature about advance care planning has studied the effects of advance directives alone, without considering other aspects of advance care planning. Having a discussion about goals, values and preferences for end of life care and assigning a durable power of attorney are arguably as important as completion of an advance directive(1). The focus of the literature has been on the ability of advance directives to control costs at the end-of-life; results are mixed but largely discouraging, leading some to feel that advance directives should be abandoned(2-5). More recent studies have reinvigorated the conversation about the need for and role of advance directives(6, 7). For example, a paper by Silviera et al. highlighted that over 70% of patients who face treatment decisions at the end of life require substituted judgment, and the majority of proxies feel that their loved ones received end-of-life care consistent with their previously expressed preferences. While these results are encouraging, the near exclusive focus on advance directives limits our ability to evaluate the advance care planning process as a whole, including other elements of the process such as discussing wishes and assigning a durable power of attorney(1, 8, 9).

Further, while much emphasis has been on cost, it is not known whether advance care planning affects the quality of care received at the end of life. Several studies have begun to define metrics for assessing quality of care at the end-of-life. For instance Earle et al. has defined evidenced-based end-of-life quality metrics, including a high proportion of deaths outside of the hospital, a low number of hospital and intensive care unit days at the end of life, and a high rate of hospice enrollment greater than 72 hours prior to death(10, 11).

Using end-of-life quality metrics developed by Earle et al., we set out to determine whether advance care planning, broadly defined as having completed an advance directive, assigned a durable power of attorney or having had an advance care planning discussion with a next of kin, affects the quality of care received at the end of life among older adults. We also assessed the independent impact of each component of the advance care planning process. Finally, we investigated whether specifically expressed goals of care are associated with the type of end-of-life care received.

METHODS

Study population and data sources

Our study population included decedents of the Health and Retirement Study cohort, which is a community-based sample of approximately 22,000 Americans over the age of 50 who have been surveyed biennially since 1992 with the goal of illuminating trends in wealth and health throughout late life. The Health and Retirement Study samples households across the United States using national area probability sampling, with oversampling of African

Americans and Hispanics as well as residents of Florida. When members of the Health and Retirement Study cohort die, exit interviews are completed with a healthcare proxy within 24 months of the death. Informed consent was obtained from both subjects and their healthcare proxies in the original Health and Retirement Study. Further details of the Health and Retirement Study design are available elsewhere(12).

We included the 6942 Health and Retirement Study respondents who were Medicare beneficiaries and died between 1993 and 2007. We excluded 379 people who did not have an exit interview completed by a proxy after their death, 132 people who did not have valid Health and Retirement Study survey weight, 188 people who were younger than 65 at the time of their death, 967 people who were not enrolled in Medicare fee-for-service during the last month of life (as Medicare defined our primary outcome measure), and 882 people whose exit interviews did not contain complete information regarding advance directive completion or durable power of attorney assignment (item response rates 99% and 99% respectively). Our study population therefore consisted of 4394 subjects.

This study was exempted by the Institutional Review Board of the University of California at San Francisco.

Outcomes

Our outcomes included evidenced-based end-of-life health services quality metrics (10, 11). Quality metrics included: hospital admission in the last month of life, in-hospital death, spending more than 14 days in the hospital during the last month of life, intensive care unit admission in the last month of life, more than one emergency department visit in the last month of life, hospice admission, and length of hospice stay three or fewer days before death. All health care utilization quality metrics were determined from Medicare data.

Predictors

Our primary predictor was advance care planning, determined by asking proxies during the exit interview if the subject had: 1) engaged in an advance care planning discussion ("Did [the decedent] ever discuss with you or anyone else the treatment or care she/he wanted to receive in the final days of [her/his] life?"); 2) documented preferences in an advance directive ("Did [the decedent]... provide written instructions about the treatment or care she/he wanted to receive during the final days of his/her life"); or 3) assigned a durable power of attorney ("Did [the decedent]... make any legal arrangements for a specific person or persons to make decisions about his/her care or medical treatment if she/he could not make those decisions him/herself? This is sometimes called a Durable Power of Attorney for Health Care.")

Secondarily, we determined whether healthcare utilization varied based on the preferences that subjects expressed in their advance directives, according to the exit interview. These preferences were categorized as all care possible ("a desire to receive all care possible under any circumstances in order to prolong life"), some limits ("a desire to limit care in certain situations"), and comfort care ("a desire to keep him/her comfortable and pain free but to forego extensive measures to prolong life").

Covariates were determined from Health and Retirement Study subject interviews as well as exit interviews with proxies. They included demographic characteristics (age at death, gender, race/ethnicity, married/partnered status, net worth, and year of death), comorbidities (history of cancer, hypertension, diabetes, lung disease, heart disease, stroke and cognitive impairment), and a functional limitations score (range 0-6 based on number of activities requiring assistance during the last three months of life: walking, toileting, bathing, transferring, eating and dressing).

Statistical analysis

All analyses are weighted for subjects' differential probability of selection into the Health and Retirement Study population, taking into account the Health and Retirement Study's complex design. We estimated the validity of the HRS survey data by comparing the number of interviewed healthcare proxies who reported that the subject died in the hospital to the actual number of subjects who died in the hospital per Medicare records. We also calculated the trend in advance care planning documentation over time.

For quality outcomes, bivariable analyses estimated the predicted prevalence of each of our metrics of quality end-of-life care by history of advance care planning (yes/no). To determine if differences in care were due to confounding, we ran multivariable Poisson regressions with adjustment for all demographic and clinical covariates in order to directly estimate adjusted relative prevalences of the quality metrics by history of advance care planning(13).

To investigate which component of the advance care planning process had the greatest impact on outcomes, we compared the quality metrics for subjects who completed an advance directive only, assigned a durable power of attorney only, or had an advance care planning discussion only, compared to subjects who did not engage in advance care planning.

We then investigated whether the specific preferences expressed in subjects' advance directives were associated with the healthcare they received, after adjustment, by modeling differences in quality metrics according to preferences for care reported in the advance directive (i.e. 'all care possible', 'some limits', or 'comfort care').

All analyses were completed using Stata software version 12.1 (StataCorp, College Station, TX), and SAS version 9.2 (SAS Institute, Inc., Cary, NC).

RESULTS

Study population

Characteristics of the study population are shown in Table 1. Decedents were of advanced age, with 80% of subjects over age 75 at the time of death. Fifty-five percent were women. Thirty percent of proxies interviewed during the exit interviews about subjects' advance care planning documents were spouses and 65% were other relatives, the large majority of which were children of the decedents. The mean time from death to exit interview completion was 13.5 months (SD 9.1 months). Ninety-one percent (1343/1472) of subjects who died in the hospital, according to Medicare claims data, were also reported as having died in the hospital per their proxy in the HRS exit interviews.

Among the 4394 study subjects, 76% of people engaged in advance care planning. This included 2.8% of people who had an advance directive only, 9.3% who had a durable power of attorney only, 13.9% who reported an advance care planning discussion only, 9.4% who had both an advance directive and a durable power of attorney, 5.9% who had an advance directive and reported having an advance care planning discussion, 8.8% who had a durable power of attorney and reported a discussion, and 26.0% who reported all three components of advance care planning.

The mean time from completion of an advance directive to death was 61 months, with median of 37 months (IQR 11-91 months). The mean time from assignment of a durable power of attorney to death was 56 months, with median of 34 months (IQR 10-80 months). Advance care planning became increasingly common among decedents in the years between

1993 and 2007 (p-value for trend <0.001). Less than half of the subjects who died before 1997 had engaged in advance care planning, while more than half of the subjects who died in and after 1997 had engaged in advance care planning. Seventy-two percent of subjects who died in 2007, the last year in our study period, completed advance care planning documents. Older decedents, women, Caucasians, unpartnered individuals, decedents with greater net worth and long-term residents of nursing homes were more likely to have engaged in advance care planning, whereas decedents with better functional status were less likely (p<0.01 for each comparison).

Ninety-two percent of people who completed an advance directive stated a preference to prioritize comfort and forgo extensive measures to prolong life, while 5% expressed a desire to limit care in certain situations and 3% requested all care possible.

Advance care planning and quality metrics

Decedents whose proxies reported they engaged in advance care planning were less likely to die in the hospital (unadjusted prevalence 39.2% v. 49.0%, p<0.001), less likely to spend more than two weeks in the hospital during the last month of life (10.3% v. 14.1%, p<0.001), more likely to enroll in hospice (33.3% v. 17.6%, p<0.001), and less likely to be admitted to hospice for 3 or fewer days (71.9% v. 85.1%, p<0.001). They were also less likely to be have more than one emergency department visit in the last month of life (14.0% v. 16.4%, p=0.05) and less likely to be admitted to the intensive care unit (23.6% v. 26.9%, p=0.04) but these results were of borderline statistical significance. There was no significant difference in the rate of hospital admission during the last month of life (56.2% v. 58.0%, p=0.28).

After adjusting for demographic and clinical covariates, statistically-significant differences between decedents whose proxies reported they engaged in advance care planning and those who did not persisted for the outcomes of death in the hospital, hospice admission and enrollment in hospice three or fewer days before death (Table 2). The difference in the proportion of people who were hospitalized for more than 14 days in their last month of life was of borderline statistical significance. There were no significant differences between groups in terms of the proportion of decedents who were admitted to the hospital or intensive care unit or had multiple emergency department visits in the last month of life.

Individual elements of ACP and end-of-life quality

When compared to subjects who had no evidence of advance care planning, having an advance directive alone was associated with 69% less risk of lengthy hospitalizations in the last month of life and having either an advance directive, a durable power of attorney or having had an advance care planning discussion alone was significantly associated with hospice admission and longer length of stay in hospice (Table 3).

Stated preferences and end-of-life quality

People who documented a preference for "comfort care" in their advance directive (per proxy report) had less in-hospital death, were less often hospitalized for more than two weeks of their final month of life, were more often enrolled in hospice and less often had brief hospice stays compared to the baseline group of people who did not engage in advance care planning (Table 4). On the other hand, people who documented a preference for "all care possible" in their advance directive more often had multiple emergency department visits in the last month of life and they had a trend towards more hospital admissions, but they were also more likely to be enrolled in hospice than the group of patients who did not engage in advance care planning. However, because numbers of subjects who had expressed a preference for "all care possible" were small, we consider these latter findings exploratory.

DISCUSSION

Our study was the first to examine the relationship between advance care planning and the quality of end-of-life care, as measured by the rates of care consistent with preexisting quality metrics(10, 11). We found that most older adults engage in advance care planning prior to death and advance care planning became increasingly common in decedents throughout our fourteen-year study period. Older adults who engage in advance care planning typically do so multiple years prior to death and assignment of a durable power of attorney was more common than completion of an advance directive, which emphasizes how the advance care planning represented in our study is distinct from the inpatient code discussions that have been studied in the majority of the existing advance care planning literature(4, 14). Like previous studies, we showed that the preponderance of people who engage in advance care planning express a preference to prioritize comfort in late-life and forego extensive measures to prolong life(6).

Our primary finding was that advance care planning is associated with a lower rate of inhospital death and increased hospice use, but no significant change in the rate of hospitalization, intensive care unit admission or frequent emergency department visits in the last month of life. There appears to be utility in each aspect of advance care planning that we studied - completing an advance directive, assigning a durable power of attorney and having an advance care planning discussion with next of kin - albeit in somewhat different ways. Additionally, end-of-life care tends to correlate to the preferences expressed in subjects' advance directives.

Our study makes several important contributions to the existing literature. First, by defining advance care planning more broadly than the mere completion of an advance directive, we more accurately captured the real-world advance care planning that is occurring among seniors. This is important given that our findings suggest that each aspect of advance care planning impacts end-of-life care. Second, we focused explicitly on the association between advance care planning and the quality of end-of-life care, rather than costs, helping to reframe the discussion about the impact of advance care planning. Third, by combining Medicare data with a large, nationally representative study, we were able to show that advance care planning is associated with objective measures of end-of-life quality: less inhospital death and more hospice use.

The finding that having an advance directive, a durable power of attorney and an advance care planning discussion are each associated with end-of-life care has implications both for traditional practitioners, who have focused primarily on completing advance directives, as well as for practitioners who see minority populations, where studies suggest a general preference for discussing advance care planning but reluctance to sign advance care planning documents(15). It may be that neither approach alone has the full impact of multimodal advance care planning.

While there was no statistically significant difference in the rate of hospitalization during the last month of life between decedents who did and did not complete advance care planning, there was a significant difference in the rate of in-hospital mortality between these groups. These findings suggest that older adults who engage in advance care planning are often admitted to the hospital in the last month of life but are more likely to be discharged to home or to a non-acute facility before their death, rather than remain in the hospital for their final days to weeks. It is unclear how brief, non-terminal hospitalizations affect quality of life for the majority of people who prioritize comfort at the end of life. Given their frequency, this is an important topic for further study.

The primary limitation of this study is the use of healthcare proxy report, which occurred an average of 13.5 months after subjects' deaths, for information about whether subjects completed advance care planning documents and the preferences expressed in those documents. This data is subject to recall bias. However, proxy reports are commonly used for studies of end-of-life experiences, we relied on only basic information from proxies that they would be reasonably expected to recall, and we found good agreement between proxies' reports and Medicare claims data about location of death(6, 16). Future studies with prospective documentation of subjects' preferences prior to death could eliminate this concern altogether, but would be expensive and time-consuming to perform on such a large scale as this study. Our observational study design means that we can only report associations and cannot conclude that advance care planning causes changes in healthcare utilization. However, given that the advance directive and durable power of attorney documents we studied were completed many months before death in this longitudinal study, it is unlikely that the direction of causality is reversed. While statistically significant associations between ACP and in-hospital death as well as hospice use were seen, confidence intervals were also wide, indicating the heterogeneous, complex association between ACP and EOL care. Undoubtedly, many other factors that were not captured in this study are also associated with the type of EOL care received. This study was not designed to give a detailed answer to the question of how advance care planning is currently occurring and how it could be better performed in future. We have basic information about what the advance care planning process entailed (creation of an advance directive, assignment of a durable power of attorney, or discussion about preferences with a healthcare proxy), but we do not know whether it was performed with the help of a doctor and whether it occurred as a longitudinal process over time. Understanding these issues better through further studies could be instructive for future advance care planning efforts.

In summary, in this large population-based study of older adults, we found that advance care planning is associated with decreased in-hospital death and increased hospice use. All components of advance care planning are associated with the end-of-life care received and should be considered in future clinical care and research.

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Table 1Patient Characteristics by Advanced Care Planning Group

Characteristics	All Respondents N=4394	No ACP n=1164	ACP n=3230	P Value
Age at death, in years				
Mean (SD)	82.6	81.5	83.0	< 0.001
Median (IQR)	82.8	81.5	83.3	
Gender, %				
Male	45.3	49.6	43.9	0.001
Female	54.7	50.4	56.1	
Race/Ethnicity, %				
White	86.3	71.1	91.1	< 0.001
Hispanic	3.7	8.1	2.2	
Black	8.9	18.8	5.8	
Other	1.1	2.1	0.8	
Married/partnered, %	41.0	46.6	39.3	< 0.001
Quartile of net worth, %				
\$6000	25.1	33.8	22.4	< 0.001
>\$6000-81000	25.0	28.1	24.0	
>\$81,000–239,000	24.9	22.6	25.6	
\$239,000	25.0	15.5	28.0	
Nursing home resident prior to the last month of life, %	33.8	26.6	36.1	< 0.001
History of cancer, %	25.0	21.1	26.2	0.01
History of hypertension, %	62.2	63.5	61.8	0.43
History of diabetes, %	24.3	26.2	23.6	0.06
History of lung disease, %	21.8	20.5	22.2	0.29
History of heart disease, %	50.6	48.3	51.3	0.15
Cognitive impairment, %	28.3	31.8	27.2	0.01
Functional limitation score, Median (IQR)	3 (0, 5)	1 (0, 4)	3 (0, 5)	< 0.001
Months between decedents' death and proxy's interview				
Mean (SD)	13.5 (9.1)	14.2 (9.8)	13.3 (8.9)	0.01
Median (IQR)	13 (7, 19)	14 (7, 19)	13 (7, 18)	

ACP = advance care planning, SD = standard deviation, IQR = interquartile range

Reported values incorporate survey weights to account for the complex survey design.

Married/partnered status, quartile of net worth, and comorbidities were determined from last survey of life.

Functional limitations were measured as needing help with dressing, walking, bathing, eating, getting into bed and toileting (per questions in the exit interview) during the last 3 months of life. The functional limitation score was 0-6 based on number of positive responses.

Table 2

Adjusted Association between Advance Care Planning and Quality End-of-life Care

Metrics	Adjusted RR for ACP v. no-ACP (95% CI)	P Value
Hospital admission	1.01 (0.95 – 1.07)	0.83
In-hospital death	0.87 (0.80 – 0.94)	0.001
>14 days in hospital	0.81 (0.66 – 0.99)	0.04
ICU admission	0.92 (0.81 – 1.05)	0.21
>1 ED visits	0.91 (0.76 – 1.08)	0.27
Hospice admission	1.68 (1.43 – 1.97)	< 0.001
Length of hospice stay 3 days	0.88 (0.85 – 0.91)	< 0.001

RR = relative risk, ACP = advance care planning, ICU = intensive care unit, ED = emergency department

Relative Risk was estimated by Poisson regression with point and variance estimates by using jackknife replication method.

Reported values incorporate survey weights to account for the complex survey design.

Covariates include demographic characteristics (age at death, gender, race/ethnicity, married/partnered status, net worth, year of death) and medical comorbidities (cancer, hypertension, diabetes, lung diseases, heart diseases, stroke, and cognitive impairment).

Table 3
Association between Advance Care Planning and Quality End-of-life Care

Metrics	Adjusted RR (95	P Value	
Hospital admission	AD only vs. no-ACP	0.92 (0.78-1.09)	0.33
	DPOA only vs. no-ACP	0.98 (0.86-1.12)	0.82
	Discussion only vs. no-ACP	1.05 (0.96-1.15)	0.26
In-hospital death	AD only vs. no-ACP	0.86 (0.73-1.01)	0.07
	DPOA only vs. no-ACP	0.88 (0.78-1.00)	0.05
	Discussion only vs. no-ACP	1.02 (0.92-1.14)	0.64
> 14 days in hospital	AD only vs. no-ACP	0.31 (0.13-0.73)	0.008
	DPOA only vs. no-ACP	0.96 (0.67-1.39)	0.84
	Discussion only vs. no-ACP	0.97 (0.77-1.22)	0.77
ICU admission	AD only vs. no-ACP	0.81 (0.55-1.18)	0.26
	DPOA only vs. no-ACP	0.90 (0.72-1.14)	0.38
	Discussion only vs. no-ACP	1.02 (0.90-1.17)	0.72
> 1 ED visits	AD only vs. no-ACP	1.04 (0.65-1.66)	0.87
	DPOA only vs. no-ACP	0.97 (0.71-1.34)	0.87
	Discussion only vs. no-ACP	0.89 (0.70-1.13)	0.33
Hospice admission	AD only vs. no-ACP	1.67 (1.20-2.33)	0.003
	DPOA only vs. no-ACP	1.40 (1.12-1.76)	0.004
	Discussion only vs. no-ACP	1.48 (1.24-1.76)	< 0.001
Length of hospice stay 3 days	AD only vs. no-ACP	0.88 (0.78-0.99)	0.03
	DPOA only vs. no-ACP	0.93 (0.88-0.99)	0.02
	Discussion only vs. no-ACP	0.92 (0.87-0.96)	0.001

RR = relative risk, AD = advance directive, ACP = advance care planning, DPOA = durable power of attorney, ICU = intensive care unit, ED = emergency department

Relative Risk was estimated by Poisson regression with point and variance estimates by using jackknife replication method.

Reported values incorporate survey weights to account for the complex survey design.

Covariates include demographic characteristics (age at death, gender, race/ethnicity, married/partnered status, net worth, year of death) and medical comorbidities (cancer, hypertension, diabetes, lung diseases, heart diseases, stroke, and cognitive impairment).

 Table 4

 Association between Expressed Preferences and Quality End-of-life Care

Metric	Adjusted RR (95% CI)	P Value
Hospital admission		
Comfort Care vs. No-ACP	0.97 (0.91 – 1.04)	0.44
Some Limits vs. No-ACP	0.88 (0.66 – 1.17)	0.37
All Care Possible vs. No-ACP	1.19 (0.98 – 1.45)	0.09
In-hospital death		
Comfort Care vs. No-ACP	0.78 (0.71 – 0.86)	< 0.001
Some Limits vs. No-ACP	0.80 (0.61 – 1.06)	0.12
All Care Possible vs. No-ACP	0.82 (0.59 – 1.13)	0.23
>14 days in hospital		
Comfort Care vs. No-ACP	0.65 (0.50 – 0.85)	0.002
Some Limits vs. No-ACP	0.57 (0.28 – 1.15)	0.11
All Care Possible vs. No-ACP	1.28 (0.76 – 2.18)	0.35
ICU admission		
Comfort Care vs. No-ACP	0.86 (0.74 – 1.01)	0.07
Some Limits vs. No-ACP	0.72 (0.43 – 1.21)	0.21
All Care Possible vs. No-ACP	1.10 (0.72 – 1.69)	0.66
>1 ED visits		
Comfort Care vs. No-ACP	0.85 (0.69 – 1.05)	0.13
Some Limits vs. No-ACP	0.76 (0.40 – 1.42)	0.38
All Care Possible vs. No-ACP	1.62 (1.05 – 2.49)	0.03
Hospice admission		
Comfort Care vs. No-ACP	1.88 (1.59 – 2.22)	< 0.001
Some Limits vs. No-ACP	1.83 (1.35 – 2.48)	< 0.001
All Care Possible vs. No-ACP	1.85 (1.26 – 2.74)	0.003
Length of hospice stay 3 or fewer days		
Comfort Care vs. No-ACP	0.84 (0.81 – 0.87)	< 0.001
Some Limits vs. No-ACP	0.91 (0.80 – 1.04)	0.17
All Care Possible vs. No-ACP	0.88 (0.74 – 1.05)	0.16

 $RR = relative \ risk, \ ACP = advance \ care \ planning, \ ICU = intensive \ care \ unit, \ ED = emergency \ department$

Relative Risk was estimated by Poisson regression with point and variance estimates by using jackknife replication method.

Reported values incorporate survey weights to account for the complex survey design.

Covariates include demographic characteristics (age at death, gender, race/ethnicity, married/partnered status, net worth, year of death) and medical comorbidities (cancer, hypertension, diabetes, lung diseases, heart diseases, stroke, and cognitive impairment).