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Title: Predictors of advance care planning in older women: the Nurses' Health Study

Running title: Advance care planning in older women

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ABSTRACT:

Background/Objectives: Relatively little is known regarding predictors of advance care planning (ACP) in former nurses. We aimed to evaluate potential predictors of ACP documentation and discussion.

Design: Cross-sectional study, 2012-2014.

Setting: Nurses' Health Study.

Participants: 60,917 community-dwelling female nurses aged 66-93 years living across the US.

Measurements: Based on self-reports, participants were categorized as having a) only ACP documentation, b) ACP documentation and a recent ACP discussion with a health care provider; or c) neither. Multivariable log-binomial models were used to estimate prevalence ratios (PRs) and 95% confidence intervals (CIs) of the two separate ACP categories versus those with neither. We evaluated various demographic, health and social factors.

Results: The large majority (84%) reported ACP documentation, while 35% reported a recent ACP discussion. Demographic factors, such as age and race were associated with both ACP categories. In multivariable analyses, race was most strongly associated: compared to Caucasians, African-Americans were 27% less likely (PR=0.73; 95%CI:0.69,0.78) to report ACP documentation alone and 41% (PR=0.59; 95%CI:0.54,0.66) less likely to report documentation with discussion. Additionally, health/health care-related characteristics were more strongly associated with ACP documentation plus discussion. Women with functional limitations (PR=1.15; 95%CI:1.10,1.20), women who were recently hospitalized (PR=1.10; 95%CI:1.08,1.12) or women who had seen a physician for health symptoms (PR=1.43; 95%CI:1.35,1.52) or screening (PR=1.40; 95%CI:1.32,1.49) were more likely to report having both ACP documentation and discussion. Social factors showed limited relationships

with ACP documentation only; for documentation plus discussion, being widowed and living alone was associated with higher prevalence (PR=1.21; 95%CI:1.19,1.24) and having little emotional support was associated with lower prevalence (PR=0.84; 95%CI:0.81,0.86).

Conclusions: Among older nurses, most of whom reported having documented ACP, 35% reported recent patient-clinician ACP discussions, indicating a major participatory gap in an element critical to ACP effectiveness. Even in nurses, African-Americans reported less ACP documentation or discussion.

Key words: advance care planning, nurses, community-dwelling; epidemiology

Introduction

A recent Institute of Medicine report[1] identified advance care planning (ACP), typically in the form of living wills and the designation of a health care proxy, as essential for improving end-of-life (EOL) care by promoting patient autonomy concerning medical care decisions.[2] There is growing recognition, however, that relying on ACP documentation alone may be inadequate.[3,4] To align care more consistently with patients' preferences, it is critically important to foster ongoing discussions between patients and their health care providers. Without clear communications about goals of care and care trajectories, health care providers may be unable to deliver high quality, patient-centered care. Moreover, because patients' health conditions and preferences for EOL care may change over time, it is essential that such discussions continue and evolve with a patient's prognosis and current health status.[3-6]

Despite its recognized importance, there have been relatively fewer studies about the predictors of having ACP discussions with a physician among community-dwelling older populations.[7-12] In particular, there is a dearth of studies concerning ACP among nurses, an important group of clinicians, especially for individuals with serious illness. Nurses play a central role in providing clinical care and patient education and support during important medical decisions.[13-15] While it is known that health care providers' ACP attitudes and preferences may influence those of their patients,[16-19] the ACP use of nurses has received very limited study.[20,21]

Thus, the purpose of this study was to evaluate predictors of patient-clinician ACP discussions and those of ACP documentation (which may be different from each other[22]) among older community-dwelling nurses. We used data from the ongoing Nurses' Health Study of approximately 60,000

women aged 66-93 years who had been followed for 40+ years. We hypothesized that demographic, health status and social predictors would be related to ACP documentation and discussions,[23] providing insights about facilitators or barriers to ACP engagement among older nurses.

Methods

Study Population

The Nurses' Health Study began in 1976 as a prospective cohort of married female registered nurses in 11 states;[24] the resulting closed cohort of women are followed every two years via mailed questionnaires on health and lifestyle. The study collected information on ACP in the 2012 questionnaire (completed from June 2012 to May 2014); of the 61,829 respondents, we excluded 602 women with missing ACP documentation information and 1,010 women who reported living in assisted living facilities or nursing homes. Thus, we included 60,217 community-dwelling women aged 66 to 93 years with complete ACP documentation data. In secondary analyses, to evaluate whether prevalence estimates and predictors of ACP differ in those closer to the EOL, we studied a subset of 5,112 women who provided ACP information in 2012-14 and who subsequently died (through January 2018). This study was approved by the Institutional Review Board of the Brigham and Women's Hospital.

ACP Status Assessment

To ascertain ACP documentation status, the NHS questionnaire included items asking participants whether they had established any form of ACP in the event of serious illness, including:

1) health care proxy/durable power of attorney for health care; 2) Physician Orders for Life Sustaining Treatment (POLST); 3) living will; and 4) "other" forms. Additionally, participants were asked if they had a discussion with their health care provider over the past year about the kind of medical care they would want if faced with a serious illness (yes/no);[25] henceforth, this type of discussion will be referred to as "ACP discussion".

Assessment of ACP predictors

On the biennial questionnaires since 1976, participants have been regularly asked about a range of factors, including 1) demographic traits: age, race/ethnicity, education, median household income (based on census tract of a participant's zip code), state of residence by census divisions (as of 2010); 2) health care utilization and health status: hospitalization for ≥2 nights in the past year, physician exams (separately for screening and for symptoms) in the past 2 years, instrumental activities of daily living (IADL),[26] and diagnoses such as cancer, cardiovascular/respiratory diseases, and neurological diseases; and 3) social factors: social integration (i.e., participation in a broad range of social relationships) as measured by the Berkman-Syme Social Network Index,[27] frequency of the availability of someone providing emotional support, residential setting (i.e., living in the general community versus a senior community for those aged 55+ years), current marital status/living arrangement, and loss of family/friends in the past 2 years.

Statistical Analysis

First, using data from 60,217 participants, we describe the status of ACP documentation and discussion using frequencies and percentages. Second, for the analysis of predictors of ACP status,

we restricted the population to 58,582 women after excluding 948 women without a response to the ACP discussion question and 687 women who reported ACP discussion only and no ACP documentation, as this group was too small to analyze separately. We calculated the age-adjusted frequencies of the various factors evaluated. Then using those with neither ACP documentation nor discussion as the reference group, we evaluated, in two separate models, the predictors of 1) ACP documentation only and 2) ACP documentation with discussion. Because of the high prevalence of ACP completion, rather than estimating odds ratios, we used multivariable-adjusted log-binomial models to estimate prevalence ratios (PRs) and 95% confidence intervals (CIs)[28,29] to evaluate the independent associations between participant characteristics and each of the two ACP categories. To test whether associations between a predictor for documentation alone was significantly different from that for documentation with discussion, we conducted multivariable-adjusted analyses directly comparing just these two groups (with documentation alone as the reference group).

To investigate whether associations of various predictors to ACP may differ among individuals closer to death, we also conducted similar analyses among participants who died through January 2018 after answering the 2012 ACP questions. All statistical tests were two-sided with α=0.05. For analyses, SAS (version 9.4, SAS Institute Inc., Cary, NC) was used.

Results

The participants were on average 76.6 years of age. Most were Caucasian (98%), and 48% lived in the Northeast, with 17% living in the Midwest, 21% in the South, and 14% in the Western US.

Participants' education levels were high as they were all registered nurses: 71% obtained an associate's degree, 19% obtained a bachelor's degree, and 10% had a graduate degree.

Prevalence of ACP documentation and discussion among all 60,217 participants

Among all participants, 84% reported ACP documentation (Table 1), with the health care proxy (68%) and living will (63%) being the most common types; POLST was the least common (19%). In terms of combinations of the types of ACP documentation (Table 1), some had all three types (18%), and the most common combination was having both a health care proxy and living will (39%). ACP discussions with health care providers about the kind of medical care participants would want if faced with a serious illness were much less common. Overall, 35% of participants (Figure 1) reported having an ACP discussion with a physician in the prior year, almost all of whom also reported having ACP documentation.

Prevalence of ACP documentation and discussion among 5323 participants who died after responding to the 2012 questionnaire

Among participants who died subsequent to responding to the ACP items, the prevalence of documented ACP was 89% (Table 1). In this group, having a proxy and living will was also the most common combination of documented ACP (33%); however, the second most common combination of documented ACP was having all three major ACP documents of proxy, living will and POLST (23%). Notably, the prevalence of ACP discussions was 51%.

Predictors of ACP documentation only and ACP documentation with discussion (n=58,582)

Demographic characteristics. Demographic factors were among the strongest predictors of ACP (Table 2). Older age was associated with a 10-20% greater prevalence of documentation and was even more strongly associated with documentation with discussion. For example, compared to those who were 65-69 years of age, those 90 years or older had a 18% higher prevalence of documentation (PR:1.18; 95% CI:1.13,1.23) and 28% higher prevalence of documentation with discussion (PR:1.28; 95% CI:1.23,1.34). The strongest demographic factor was race, which was also more strongly associated with discussion with documentation than documentation alone. In age-adjusted frequencies, among Caucasians, 15% reported neither, 50% reported having documentation only and 35% reported documentation with discussion in the prior year; however, among African-Americans (793 respondents, or 1% of the population), 33% reported neither, 43% reported having documentation only and 24% reported documentation and discussion in the prior year. In multivariable-adjusted analyses, African-Americans had 27% lower prevalence of ACP documentation, compared to Caucasians (PR:0.73; 95% CI:0.69,0.78) and reported ACP discussions with documentation 41% less often (PR:0.59; 95% CI: 0.54,0.66). Having a graduate degree, compared to an associate's degree, was associated with documentation alone (PR:1.10; 95% CI: 1.08,1.11) and with ACP documentation plus discussion (PR:1.15; 95% CI: 1.13,1.18).

Health status / health care utilization. Indicators of health conditions and interactions with the health system generally had little or no association with ACP documentation alone but were associated with added discussions (p-values for significant differences were all <0.0001), underscoring the importance of these factors in patient-provider discussions. In particular, those who reported having had a physician exam in the last 2 years for screening purposes had 11% (PR:1.11; 95% CI:1.08,1.15) higher prevalence of documentation alone and a 13% (PR:1.13; 95% CI:1.09,1.17)

higher prevalence if the exam was for symptoms; the corresponding percentages for reporting both documentation and discussion were much higher: 40% (PR:1.40; 95% CI:1.32,1.49) and 43% (PR:1.43; 95% CI:1.35,1.52) higher prevalence estimates, respectively. Greater limitations in IADL were not associated with ACP documentation only but were associated with a 15% higher likelihood of documentation with discussions (PR:1.15; 95% CI:1.10,1.20).

Social factors. Social factors also played a role in having ACP documentation, and associations were generally stronger for ACP documentation with added discussions (Table 3). Women with low levels of social integration (or most isolated)[27] as measured by the Berkman-Syme Social Network Index were approximately 15% less likely to have both documentation and a recent discussion (PR:0.85; 95% CI:0.80,0.90). In addition, participants reporting the least frequent availability of emotional support compared to those with the most frequent had a 16% lower prevalence (PR:0.84; 95% CI:0.81,0.86) of documentation with discussions. Residing in a senior community setting was associated with a 13% higher prevalence of combined documentation and discussion (PR:1.13; 95% CI:1.11,1.15). We also considered widowhood and women's reports of a family member's or close friend's recent death; both were stronger factors for discussion with documentation than documentation alone. In particular, those living alone who had experiences of death in those close to them were almost 20% more likely to have both ACP documentation and recent ACP discussions than women who were living with a spouse or partner (PR:1.21; 95% CI:1.19,1.24).

Predictors of ACP documentation only and ACP documentation and discussion near the EOL (n=5112).

For the analysis of predictors of ACP status among those closer to EOL, we restricted the analytic population to 5112 women after excluding 125 women without a response to the ACP discussion question and 86 women who reported ACP discussion only and no ACP documentation. In this subset of women near the EOL (Tables 4 and 5), associations between predictors and ACP documentation only and ACP documentation and discussions were generally similar to those observed in all women. Indicators of poorer health (e.g., hospitalization, recent physician exams, and greater number of IADL limitations) were associated with having documentation and discussions, but not related to having documentation alone. Compared to those who died of cancer (the most common cause of death), those who died of cardiovascular or neurodegenerative disease were less likely to have ACP.

Discussion

We observed that ACP documentation was highly prevalent among older community-dwelling nurses, which we expected given their education, medical training, and likely greater exposure to EOL issues. Yet, recent discussions between participants and their health care providers about what they would want in the event of a serious illness were less common. Overall, interestingly, we found that our findings in community-dwelling nurses regarding predictors of ACP were quite similar to findings previously reported among institutionalized patients and patients at the EOL[30-36] (such as African-American race, illness, a recent experience of death in close friends or family, and greater social support).[7-9,11,18,19,25,37-42]

Among these former nurses, while the prevalence for ACP documentation was high at 84%, the prevalence for recent ACP discussions with physicians was much lower at 35%. Yet, the evidence is increasingly clear that efforts to facilitate patient-centered EOL care should focus on encouraging ongoing patient-clinician ACP discussions.[22,43,44] For example, in the SUPPORT study,[45,46] an intervention to increase written directives did not lead to improved EOL care, in part, because most physicians were unaware of patients' written directives;[47] furthermore, written directives may be even less effective if preferences for EOL care change with time. Thus, the fact that the prevalence of such discussions is less than half that of ACP documentation points to a substantial communication gap to be addressed. The low prevalence of ACP discussions has been previously observed: other studies have found that only 12-34% of community-dwelling older people who completed advance directives recently discussed their treatment wishes with their physicians.[9,10,48] These results have important implications for policy and clinical practice. Overall, ACP communication with health care providers was substantially lower than ACP documentation even among these former nurses. Thus, there is a need to increase awareness, in both patients and clinicians, about the critical importance of having ACP conversations that continue even after ACP documentation is completed. Moreover, the findings suggest that previously identified barriers to such communications for clinicians (e.g., lack of time, ACP training, etc.) and patients (e.g., lack of awareness, reluctance to talk about death, relying on physician to initiate ACP, etc.),[1,43,49-52] likely are inadequately addressed by the health care system, particularly for those patients who are minorities.

Despite participants being health professionals with medical training and access to health care, African-American respondents had substantially lower levels of ACP documentation only and ACP documentation with a recent discussion. These findings are similar to prior studies,[19,53,54] including

one of 502 physicians[19] where African-Americans had a lower prevalence of ACP documentation. In our cohort of nurses with their similar education levels and health care backgrounds, the persistent racial differences in ACP highlight the importance of better addressing the range of factors limiting ACP participation in minorities,[37,55] as this limited participation may lead to EOL care that is not goal-aligned.[1,56,57] Reviews[23,58] have found, particularly for older generations of African-Americans, that barriers such as communication problems with physicians and mistrust of the health care system were obstacles for ACP engagement; our findings may indicate that such communication issues and mistrust may be deeply embedded, as they persist even among former nurses, or there may be other barriers which are as yet unidentified.

Other strong predictors of ACP discussion and documentation were health/health-care related factors. Although having a chronic progressive illness and reports of recent health care utilization had very modest associations with ACP documentation only in our participants (consistent with a recent large systematic review on the prevalence of advanced directives),[59] ill health and greater health care utilization were among the strongest predictors of documentation accompanied by recent discussion, perhaps pointing to the tendency to delay discussions about ACP with health care providers.[60,61] One finding of note was that having a physician exam for only screening purposes was associated with a 40% greater prevalence of documentation and discussion, possibly reflecting the role of the primary care physician in facilitating ACP.[58] A policy implication is that interventions such as Medicare's decision to reimburse physicians for Annual Wellness Visits and ACP counseling, effective January 1, 2016, could play an important role in increasing ACP discussions in the future.[43]

This study has several limitations that warrant consideration. Our participants were former nurses who were a unique cohort of women; thus, our findings may not generalizable to a general

population of older persons. In addition, we do not have direct information on participants' own knowledge about or attitudes toward[62] the importance of having ACP discussions with health-care providers, thus, we were not able to study this particular aspect of ACP determination. Also, some of the gaps in ACP discussion with health-care providers may be attributable to provider characteristics, which we could not assess in this study. Our study was based on responses to a self-administered questionnaire without any objective confirmation of participants' ACP status, and there may be some recall bias; however, this possibility is likely low, especially for ACP discussions, where we inquired about the most recent year. Moreover, many other studies of ACP rely on family members to provide information on patients' ACP,[5,63,64] and thus our direct request for information from patients is likely more accurate. Our study was cross-sectional, thus, we cannot infer temporality of associations; however, it seems unlikely that this would impact most of the associations we observed, such as racial differences in ACP. ACP data were collected from 2012-2014, which pre-dated Medicare's decision on physician reimbursement for ACP discussions that went into effect in 2016.[65] In future studies, we will be able to follow our participants who later died to assess EOL health service use related to their ACP status and also study how Medicare reimbursement policy changes influence use of ACP.

In conclusion, even among older nurses, most of whom had documented ACP, 35% had a recent patient-clinician ACP discussion, indicating a major participatory gap in an element critical to ACP effectiveness. Moreover, even in this population of educated health professionals, race was a strong factor associated with a lower likelihood of having ACP documentation and discussion, indicating that there are likely many substantial barriers to ACP among racial minorities. Our observation that patient-clinician ACP discussions occurred more frequently in those closer to EOL

indicates that these discussions may be occurring late in the disease course.[60,61] Thus, our study calls to attention the persistent barriers to regular patient-clinician ACP discussions. Future research is clearly needed to develop and test interventions to improve the rate of patient-clinician ACP discussions, particularly in community-dwelling populations, who make up the vast majority of older persons.

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Conflict of Interest

None of the authors have conflicts of interest, including financial interests, activities, relationships and affiliations.

Authors' Contributions

Drs. Grodstein, Stevenson, Bynum and Kang contributed to the study conception and design. Drs. Grodstein and Stevenson contributed to the acquisition of data. All authors contributed to the analysis and interpretation of data. Drs. Kang, Grodstein and Zhang contributed to the drafting of manuscript. All authors contributed to the critical revision of the manuscript.

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Figure 1. Prevalence of advance care planning (ACP) documentation and discussion in the Nurses' Health Study.

Among 98.4% (n=59269) with complete responses to both questions on documented ACP and ACP discussion, the frequency of combinations of ACP documentation and discussion

Table 1. Prevalence of ACP documentation and discussion

Among all participants (n=60217)	Frequency (%, n)
Documented ACP	
No	16% (n= 9474)
Yes	84% (n=50743)
Most common distinct patterns among those with documented ACP (n=50743)	
Proxy and living will	39% (n=19575)
Proxy only	19% (n= 9842)
Proxy, living will and POLST	18% (n= 9060)
Living will only	16% (n= 8127)
Other combinations	8% (n= 4139)
Among 98.4% with complete responses to both questions on documented ACP and ACP discussion (n=59269)	Frequency (%, n)
ACP discussion in the past year with a healthcare provider	
No	65% (n=38231)
Yes	35% (n=21038)
Among all participants (n=5323) who provided ACP information in 2012 and subsequently died within 5 years	Frequency (%, n)
Documented ACP	
No	11% (n= 585)
Yes	89% (n=4738)
Most common distinct patterns of documented ACP (n=4738)	
Proxy and living will	34% (n=1588)
Proxy, living will and POLST	23% (n=1077)
Proxy only	18% (n= 832)
Living will only	16% (n= 747)
Other combinations	10% (n= 494)
Among 97.7% with complete responses to both questions on documented ACP and ACP discussion (n=5198)	Frequency (%, n)
ACP discussion in the past year with a healthcare provider	
No	49% (n=2597)
Yes	51% (n=2601)

Table 2. Multivariable-adjusted prevalence ratios (95% CI) for demographic and health care utilization / health status characteristics associated with ACP documentation and/or discussion in the Nurse's Health Study, 2012 (n=58582)*

	Neither (reference group; n=8723)	Documented ACP only (n=29508)		Documented ACP + ACP discussion (n=20351)	
	%†	%†	Prevalence ratio (95% CI)‡	%†	Prevalence ratio (95%CI)‡
Demographics					
Age					
65-69 (18%; n=10788)	23	50	1.00 (ref)	27	1.00 (ref)
70-74 (26%; n=15467)	17	53	1.10 (1.08, 1.12)	30	1.14 (1.10, 1.17)
75-79 (25%; n=14365)	13	52	1.15 (1.13, 1.17)	35	1.26 (1.22, 1.29)§
80-84 (17%; n=10224)	10	49	1.18 (1.16, 1.21)	41	1.32 (1.28, 1.36)§
85-89 (12%; n=6716)	8	47	1.20 (1.17, 1.22)	45	1.31 (1.27, 1.35)§
90+ (2% n=1022)	8	43	1.18 (1.13, 1.23)	49	1.28 (1.23, 1.34)§
Race					
Caucasian-American (98%; n=57158)	15	50	1.00 (ref)	35	1.00 (ref)
African-American (1%; n=793)	33	43	0.73 (0.69, 0.78)	24	0.59 (0.54, 0.66)§
Asian-American (1%; n=455)	13	63	1.05 (1.00, 1.10)	24	0.93 (0.85, 1.03)§
Other (0%; n=176)	16	43	0.95 (0.85, 1.06)	41	1.07 (0.94, 1.20)
Ethnicity					
Non-Latino (99%; n=58065)	15	50	1.00 (ref)	35	1.00 (ref)
Latino (1%; n=517)	20	47	0.93 (0.87, 0.99)	33	0.92 (0.84, 1.00)
Highest attained education					
Associate (71%; n=41537)	16	50	1.00 (ref)	34	1.00 (ref)
Bachelor (19%; n=11236)	13	51	1.05 (1.04, 1.06)	36	1.08 (1.06, 1.10)§
Graduate (10%; n=5809)	11	51	1.10 (1.08, 1.11)	38	1.15 (1.13, 1.18)§
Median household income (US$) of census tract					
<40000 (11%; n=6329)	18	47	1.00 (ref)	35	1.00 (ref)
40000-59999 (41%; n=23719)	15	49	1.05 (1.03, 1.07)	36	1.05 (1.02, 1.08)
60000-79999 (29%; n=17014)	14	52	1.08 (1.06, 1.11)	34	1.05 (1.03, 1.08)§
80000+ (19%; n=11418)	13	53	1.09 (1.07, 1.12)	34	1.05 (1.02, 1.08)§
Health care utilization/health status					
Hospitalization for at least 2+ nights in the past year					
No (85%; n= 49508)	15	52	1.00 (ref)	33	1.00 (ref)
Yes (15%; n= 8718)	12	43	1.02 (1.00, 1.03)	45	1.10 (1.08, 1.12)§
Physician exam in past 2 years					
No (4%; n=2180)	25	54	1.00 (ref)	21	1.00 (ref)
Yes, for screening (74%; n=43115)	15	51	1.11 (1.08, 1.15)	34	1.40 (1.32, 1.49)§
Yes, for symptoms (22%; n=12612)	13	48	1.13 (1.09, 1.17)	39	1.43 (1.35, 1.52)§
Instrumental Activities of Daily Living					
No limitations (68%; n=39160)	15	53	1.00 (ref)	32	1.00 (ref)
1-3 of 7 activities limited (26%; n=15190)	14	47	1.00 (0.98, 1.01)	39	1.05 (1.03, 1.07)§
4-6 of 7 activities limited (5%; n=2753)	15	36	0.99 (0.96, 1.02)	49	1.09 (1.06, 1.12)§
7 of 7 activities limited (1%; n=575)	11	33	1.02 (0.96, 1.08)	56	1.15 (1.10, 1.20)§
History of Progressive illness					
None (48%; n=28153)	16	53	1.00 (ref)	31	1.00 (ref)
Cancer only (16%; n=9424)	13	51	1.03 (1.02, 1.05)	36	1.09 (1.07, 1.11)§
Cardiovascular/respiratory disease only (24%; n=14002)	14	48	1.02 (1.01, 1.03)	38	1.09 (1.07, 1.11)§

Neurodegenerative disease only (1%; n=581)	16	47	0.99 (0.94, 1.05)	37	1.06 (1.00, 1.14)
Multiple progressive disease types (11%; n=6422)	12	46	1.03 (1.01, 1.05)	42	1.11 (1.08, 1.13)§

* Characteristics were assessed at various questionnaires from 1976. ACP discussion information was obtained from the 2012 questionnaire; race, ethnicity, education were assessed in 1992; median household income of census tract was based on 2010 participant residential information. Instrumental Activities of Daily Living included 7 items (ability to walk distances, go shopping, prepare meals, do housework, handle money, handle medications, and drive an automobile).

† Age-adjusted percentages (except for the three percentages for each age category, which were crude percentages).

‡ Multivariable-adjusted analyses adjusted for all other variables listed in the table, as well as census bureau divisions.

§ Indicates a significant difference in strength of association (i.e., difference in prevalence ratio) of covariates and the likelihood of having both ACP documentation and discussion compared to the likelihood of having only ACP documentation.

Table 3. Multivariable-adjusted prevalence ratios (95% CI) for social factors associated with ACP documentation and/or discussion in the Nurse's Health Study, 2012 (n=58582)*

	Neither (reference group; n=8723)	Documented ACP only (n=29508)		Documented ACP + ACP discussion (n=20351)	
	%†	%†	Prevalence ratio (95% CI)‡	%†	Prevalence ratio (95%CI)‡
Social factors					
Social network index score					
Highest social network: 4 (32%; n=18284)	15	54	1.00 (ref)	31	1.00 (ref)
3 (38%; n=21863)	14	50	0.96 (0.95, 0.98)	36	0.95 (0.93, 0.97)
2 (21%; n=11873)	16	49	0.94 (0.92, 0.96)	35	0.92 (0.90, 0.94)
1 (8%; n=4728)	18	46	0.90 (0.88, 0.92)	36	0.88 (0.85, 0.91)
Lowest social network: 0 (1%; n=861)	20	45	0.87 (0.82, 0.92)	35	0.85 (0.80, 0.90)
How often someone can provide emotional support					
All of the time (42%; n=24230)	13	49	1.00 (ref)	38	1.00 (ref)
Most of the time (36%; n=20733)	15	51	0.99 (0.97, 1.00)	34	0.95 (0.93, 0.96)§
Some of the time (14%; n=8384)	17	52	0.95 (0.94, 0.97)	31	0.88 (0.86, 0.90)§
A little / None of the time (8%; n=4834)	20	51	0.93 (0.91, 0.96)	29	0.84 (0.81, 0.86)§
Residential setting					
Wider community (90%; n=52836)	15	51	1.00 (ref)	34	1.00 (ref)
Senior community for older persons aged 55+ (10%; n=5746)	8	50	1.09 (1.08, 1.11)	42	1.13 (1.11, 1.15)§
Marital status and living arrangement					
Married/have domestic partner and living only with spouse/partner (58%; n=33908)	16	53	1.00 (ref)	31	1.00 (ref)
Widowed and living alone (26%; n=14939)	11	50	1.10 (1.09, 1.12)	39	1.21 (1.19, 1.24)§
Widowed and living with other family only (6%; n=3709)	16	46	1.05 (1.02, 1.08)	38	1.15 (1.12, 1.19)§
Other marital status/living arrangement (10%; n=5952)	15	44	1.01 (0.99, 1.04)	41	1.14 (1.11, 1.17)§
Experience of death of close person in past 2 years					
No (51%; n=29644)	16	51	1.00 (ref)	33	1.00 (ref)
Yes - spouse only (3%; n=1556)	12	47	1.00 (0.97, 1.04)	41	1.05 (1.01, 1.09)§
Yes - other family only (15%; n=8620)	16	50	0.99 (0.98, 1.01)	34	1.01 (0.99, 1.04)§
Yes - friend only (18%; n=10613)	13	51	1.04 (1.03, 1.06)	36	1.09 (1.07, 1.11)§
Yes - multiple types of close people (13%; n=7832)	13	48	1.03 (1.01, 1.05)	39	1.09 (1.07, 1.11)§

* Characteristics were assessed at various questionnaires from 1976. ACP discussion information was obtained from the 2012 questionnaire; race, ethnicity, education were assessed in 1992; median household income of census tract was based on 2010 participant residential information. Instrumental Activities of Daily Living included 7 items (ability to walk distances, go shopping, prepare meals, do housework, handle money, handle medications, and drive an automobile).

† Age-adjusted percentages (except for the three percentages for each age category, which were crude percentages).

‡ Multivariable-adjusted analyses adjusted for all other variables listed in the table, as well as census bureau divisions.

§ Indicates a significant difference in strength of association (i.e., difference in prevalence ratio) of covariates and the likelihood of having both ACP documentation and discussion compared to the likelihood of having only ACP documentation.

Table 4. Multivariable-adjusted prevalence ratios (95% CI) for demographic and health care utilization / health status characteristics associated with ACP documentation and/or discussion among women in the Nurses' Health Study participants who provided ACP information in 2012 and subsequently died (2012-2018; n=5112)*

	Neither (reference group; n=483)	Documented ACP only (n=2114)		Documented ACP + ACP discussion (n=2515)	
	%†	%†	Prevalence ratio (95% CI)‡	%†	Prevalence ratio (95% CI)‡
Demographics					
Age					
65-69 (4%; n=219)	10	41	1.00 (ref)	49	1.00 (ref)
70-74 (12%; n=593)	15	43	0.92 (0.82, 1.02)	42	0.87 (0.79, 0.95)
75-79 (20%; n=1013)	11	43	0.98 (0.89, 1.08)	46	0.93 (0.86, 1.02)
80-84 (27%; n=1370)	9	41	0.99 (0.90, 1.09)	50	0.96 (0.88, 1.04)
85-89 (30%; n=1557)	8	41	1.01 (0.92, 1.11)	51	0.95 (0.87, 1.03)
90+ (7%; n=360)	8	35	0.95 (0.84, 1.08)	57	0.92 (0.84, 1.01)
Race					
Caucasian-American (99%; n=5041)	9	41	1.00 (ref)	50	1.00 (ref)
African-American (1%; n=34)	21	30	0.81 (0.60, 1.10)	49	0.84 (0.64, 1.09)
Asian-American (0%; n=24)	6	78	1.18 (1.07, 1.30)	16	0.88 (0.59, 1.31)§
Other (0%; n=13)	15	58	0.94 (0.67, 1.31)	27	0.88 (0.48, 1.61)
Ethnicity					
Non-Latino (99%; n=5077)	10	41	1.00 (ref)	49	1.00 (ref)
Latino (1%; n=35)	10	38	0.93 (0.72, 1.20)	52	1.00 (0.84, 1.20)
Highest attained education					
Associate (75%; n=3838)	10	42	1.00 (ref)	48	1.00 (ref)
Bachelor (17%; n=855)	7	42	1.06 (1.01, 1.11)	51	1.07 (1.03, 1.11)
Graduate (8%; n=419)	7	37	1.07 (1.00, 1.14)	56	1.08 (1.03, 1.13)§
Median household income (US$) of census tract					
<40000 (12%; n=604)	12	41	1.00 (ref)	47	1.00 (ref)
40000-59999 (42%; n=2163)	9	41	1.04 (0.98, 1.11)	50	1.05 (0.99, 1.11)
60000-79999 (30%; n=1512)	9	42	1.04 (0.97, 1.11)	49	1.03 (0.98, 1.09)
80000+ (16%; n=826)	8	42	1.06 (0.98, 1.14)	50	1.05 (0.99, 1.12)
Health care utilization/health status					
Time to death					
≤1 year (18%; n=898)	7	37	1.00 (ref)	56	1.00 (ref)
1< and ≤2 years (21%; n=1083)	11	37	0.93 (0.88, 0.99)	52	0.96 (0.92, 1.01)
2< and ≤3 years (22%; n=1147)	9	41	0.99 (0.93, 1.05)	50	0.99 (0.95, 1.03)
3< years (39%; n=1984)	10	46	1.00 (0.95, 1.06)	44	0.97 (0.93, 1.01)§
Hospitalization for at least 2+ nights in the past year					
No (69%; n= 3477)	10	44	1.00 (ref)	46	1.00 (ref)
Yes (31%; n= 1578)	8	35	1.02 (0.98, 1.06)	57	1.05 (1.02, 1.09)§
Physician exam in past 2 years					
No (4%; n=217)	13	54	1.00 (ref)	33	1.00 (ref)
Yes, for screening (66%; n=3285)	10	43	1.00 (0.92, 1.09)	47	1.15 (1.02, 1.30)§
Yes, for symptoms (30%; n=1504)	8	35	0.99 (0.90, 1.08)	57	1.17 (1.03, 1.33)§
Instrumental Activities of Daily Living					
No limitations (34%; n=1711)	12	45	1.00 (ref)	43	1.00 (ref)
1-3 of 7 activities limited (41%; n=2064)	9	41	1.03 (0.99, 1.08)	50	1.07 (1.02, 1.11)§
4-6 of 7 activities limited (19%; n=941)	8	34	1.06 (1.00, 1.12)	58	1.13 (1.08, 1.19)§
7 of 7 activities limited (6%; n=298)	8	32	1.09 (0.99, 1.21)	60	1.19 (1.12, 1.28)§
Main confirmed cause of death					
Cancer (13%; n=684)	6	41	1.00 (ref)	53	1.00 (ref)
Cardiovascular disease (10%; n=508)	9	40	0.91 (0.84, 0.98)	51	0.93 (0.87, 0.98)
Respiratory disease (4%; n=226)	6	31	0.99 (0.90, 1.10)	63	1.00 (0.94, 1.07)§
Kidney disease (1%; n=38)	7	34	0.92 (0.73, 1.16)	59	1.02 (0.89, 1.16)
Neurodegenerative disease (6%; n=285)	13	44	0.90 (0.82, 0.99)	43	0.86 (0.79, 0.94)§

Injury (3%; n=147)	11	39	0.91 (0.81, 1.04)	50	0.92 (0.84, 1.01)
Infection (1%; n=66)	6	36	1.01 (0.87, 1.17)	58	0.97 (0.88, 1.08)
Cause not yet confirmed (62%; n=3158)	10	43	0.93 (0.88, 0.98)	47	0.92 (0.88, 0.95)

* Characteristics were assessed at various questionnaires from 1976. ACP discussion information was obtained from the 2012 questionnaire; race, ethnicity, education were assessed in 1992; median household income of census tract was based on 2010 participant residential information. Instrumental Activities of Daily Living included 7 items (ability to walk distances, go shopping, prepare meals, do housework, handle money, handle medications, and drive an automobile).
† Age-adjusted percentages (except for the three percentages for each age category, which were crude percentages).
† Multivariable-adjusted analyses adjusted for all other variables listed in the table, as well as census bureau divisions.
§ Indicates a significant difference in strength of association (difference in prevalence ratio) for covariates and likelihood of having both ACP documentation and discussion compared to likelihood of having only ACP documentation.

Table 5. Multivariable-adjusted prevalence ratios (95% CI) for social factors associated with ACP documentation and/or discussion among women in the Nurses' Health Study participants who provided ACP information in 2012 and subsequently died (2012-2018; n=5112)*

	Neither (reference group; n=483)	**Documented ACP only (n=2114)**		**Documented ACP + ACP discussion (n=2515)**	
	%†	%†	Prevalence ratio (95% CI)‡	%†	Prevalence ratio (95%CI)‡
Social factors					
Social network index score					
Highest social network: 4 (18%; n=896)	9	50	1.00 (ref)	41	1.00 (ref)
3 (38%; n=1901)	9	41	0.93 (0.88, 0.99)	50	0.97 (0.91, 1.03)§
2 (25%; n=1224)	10	40	0.91 (0.85, 0.97)	50	0.95 (0.89, 1.01)§
1 (15%; n=760)	8	36	0.92 (0.85, 0.99)	56	0.98 (0.91, 1.05)§
Lowest social network: 0 (4%; n=203)	10	38	0.91 (0.81, 1.03)	52	0.95 (0.86, 1.05)
How often someone can provide emotional support					
All of the time (38%; n=1905)	8	38	1.00 (ref)	54	1.00 (ref)
Most of the time (35%; n=1768)	9	41	0.96 (0.92, 1.01)	50	0.96 (0.93, 0.99)
Some of the time (17%; n=840)	12	44	0.94 (0.89, 0.99)	44	0.89 (0.85, 0.94)§
A little / None of the time (10%; n=522)	13	48	0.94 (0.88, 1.00)	39	0.87 (0.81, 0.93)§
Residential setting					
Wider community (84%; n=4308)	10	42	1.00 (ref)	48	1.00 (ref)
Senior community for older persons aged 55+ (16%; n=804)	5	37	1.10 (1.05, 1.15)	58	1.11 (1.07, 1.15)§
Marital status and living arrangement					
Married / have domestic partner and living only with spouse/partner (40%; n=2065)	11	46	1.00 (ref)	43	1.00 (ref)
Widowed and living alone (39%; n=1971)	7	40	1.10 (1.05, 1.16)	53	1.15 (1.09, 1.20)§
Widowed and living with other family only (11%; n=561)	12	36	1.00 (0.93, 1.09)	52	1.07 (1.00, 1.14)§
Other marital status and living arrangement (10%; n=507)	7	34	1.07 (0.99, 1.15)	59	1.13 (1.07, 1.19)§
Experience of death of close person in past 2 years					
No (46%; n=2327)	12	43	1.00 (ref)	45	1.00 (ref)
Yes - spouse only (4%; n=178)	6	42	1.05 (0.96, 1.15)	52	1.06 (0.98, 1.14)
Yes - other family only (14%; n=701)	9	43	1.05 (0.99, 1.11)	48	1.06 (1.01, 1.11)
Yes - friend only (20%; n=1016)	7	42	1.09 (1.04, 1.14)	51	1.10 (1.06, 1.15)§
Yes - multiple types of close people (17%; n=844)	7	34	1.04 (0.99, 1.10)	59	1.10 (1.06, 1.15)§

* Characteristics were assessed at various questionnaires from 1976. ACP discussion information was obtained from the 2012 questionnaire; race, ethnicity, education were assessed in 1992; median household income of census tract was based on 2010 participant residential information. Instrumental Activities of Daily Living included 7 items (ability to walk distances, go shopping, prepare meals, do housework, handle money, handle medications, and drive an automobile).
† Age-adjusted percentages (except for the three percentages for each age category, which were crude percentages).
† Multivariable-adjusted analyses adjusted for all other variables listed in the table, as well as census bureau divisions.

§ Indicates a significant difference in strength of association (difference in prevalence ratio) for covariates and likelihood of having both ACP documentation and discussion compared to likelihood of having only ACP documentation.