Serious Illness and End-of-Life Treatments for Nurses Compared with the General Population

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See related editorial by Matlock and Fischer

OBJECTIVES: As key team members caring for people with advanced illness, nurses teach patients and families about managing their illnesses and help them to understand their options. Our objective was to determine if nurses' personal healthcare experience with serious illness and end-of-life (EOL) care differs from the general population as was shown for physicians.

DESIGN: Observational propensity-matched cohort study.

SETTING: Fee-for-service Medicare.

PARTICIPANTS: Nurses' Health Study (NHS) and a random 20% national sample of Medicare beneficiaries aged 66 years or older with Alzheimer's disease and related dementias (ADRD) or congestive heart failure (CHF) diagnosed in the hospital.

MEASUREMENTS: Characteristics of care during the first year after diagnosis and the last 6 months of life (EOL).

RESULTS: Among 57 660 NHS participants, 7380 had ADRD and 5375 had CHF; 3227 ADRD patients and 2899 CHF patients subsequently died. Care patterns in the first year were similar for NHS participants and the matched national sample: hospitalization rates, emergency visits, and preventable hospitalizations were no different in either disease. Ambulatory visits were slightly higher for NHS participants than the national sample with ADRD (13.1 vs 12.5 visits; $P < .01$) and with CHF (13.7 vs 12.5; $P < .001$). Decedents in the NHS and national sample had similar acute care use (hospitalization and emergency visits) in both diseases, but those with ADRD were less likely to use life-prolonging treatments such as mechanical ventilation (10.9% vs 13.5%; $P = .001$), less likely to die in a hospital with a stay in the intensive care unit (10.4% vs 12.1%; $P = .03$), and more likely to use hospice (58.9% vs 54.8%; $P < .001$). CHF at the EOL results were similar.

CONCLUSIONS: Nurses with newly identified serious illness experience similar care as the general Medicare population. However, at EOL, nurses are more likely to choose less aggressive treatments than the patients for whom they care. **J Am Geriatr Soc 67:1582–1589, 2019.**

Key words: nurses; end of life; Medicare; Alzheimer's disease; congestive heart failure

People diagnosed with a serious illness face challenging decisions about achieving their personal healthcare goals including how to manage their disease and what care they prefer as end of life (EOL) nears. Healthcare professionals have a critical role in helping their patients make these decisions. Initiatives, such as the Serious Illness Conversation Guide,[1] have focused efforts on improving clinicians' ability to engage with patients and their families on this topic. Part of that engagement is acknowledging how their own attitudes, experience, and preferences may influence what they recommend for others. Therefore, an important aspect of improving decisions regarding serious illness is understanding the experience and preferences of clinicians regarding their own serious illness.

Several studies indicate that physicians often prefer care that differs from both what they recommend or provide for patients and from what they receive at the end of their own lives.[2-9] Yet little attention has focused on nurses, despite their large role in healthcare. Nurses often take on the role of educator and spend more time one on one with patients and their families than other team members, especially in the hospital setting. Nurses have an important influence on patients' knowledge about managing their serious illness and understanding their options, likely informed by their training and their personal attitudes regarding healthcare and EOL.

In this study, we compare the type of care received by nurses who participated in the Nurses' Health Study (NHS)[10] with the type of care received by similar women in the general

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DOI: 10.1111/jgs.16044

0002-8614/19/$15.00

Medicare population for diseases that have high mortality and may be amenable to chronic disease management and advance care planning. We focused on two serious conditions: Alzheimer's disease and related dementias (ADRD) and congestive heart failure (CHF) serious enough to require hospitalization. We compared the type of services used during two distinct stages of disease: in the first year after illness identification and in the 6 months before death. We hypothesized that due to their clinical training and professional exposure to serious illness, nurses would experience better quality care (fewer urgent or potentially preventable admissions) and less intensive EOL services. As a secondary analysis, we compared the NHS nurses with a general population of men.

METHODS

We conducted an observational cohort study in which women participating in the NHS cohort who were aged 66 years or older were linked to their Medicare fee-for-service (FFS) claims data; we compared the care of women diagnosed with ADRD and CHF with propensity-matched cohorts of women drawn from a 20% national sample of FFS Medicare beneficiaries. All methods described were repeated for comparison with a similar sample of men.

Data Sources

Nurses' Health Study

The NHS is based at Brigham and Women's Hospital in Boston, Massachusetts. The initial cohort was identified in 1976 when 121 700 female registered nurses, aged 30 to 55 years living in one of 11 states, returned a mailed questionnaire. Women have been followed for the last 42 years with 90% follow-up. The nurses have since migrated to all 50 states and aged into Medicare.

Medicare Linkage

In August 2013, NHS participants were notified of the planned Medicare linkage and were given the option to opt out of this research; 390 (.4%) women of the 97 729 active NHS participants alive and 65 years or older did so. Participants included in this study had to reside in US hospital referral regions (HRRs)[11] and be enrolled in FFS Medicare Parts A or B for the relevant observation periods as described later.

Medicare 20% Random Sample

The comparator Medicare cohort of women was derived from a random 20% sample of all Medicare beneficiaries in the United States, restricted to residents of HRRs where NHS participants reside and to beneficiaries with Parts A and B FFS coverage for each period of observation. NHS participants were excluded from the national sample.

Cohort Creation

For each study sample (NHS participants, 20% national sample of women), we created four disease cohorts. The disease cohorts for each sample were identified using only information from 2006 to 2012 Medicare administrative data. First, we identified people newly diagnosed with ADRD or with CHF severe enough to require hospitalization. For ADRD, we found the first inpatient or outpatient claim with a diagnostic code included in the chronic condition warehouse (CCW) definition and kept cases when no similar claim was found in the prior year. For CHF, we used the CCW diagnostic codes found as the primary diagnosis on a hospital claim. The reason for requiring hospitalization to enter the cohort was to account for the low specificity of CHF diagnoses in claims[12-14] and the desire to capture disease cohorts with a similar risk of death over the observation period. Second, we selected people among the newly identified cases who died within our observation period. Once cases were selected, we excluded patients for whom we would not be able to observe utilization in the time windows of interest (1 year before and after cohort entry and 6 months before death) because of changing enrollment in Medicare Parts A or B or entry into managed care.

Outcome Measures

For the year after a new diagnosis of ADRD or the first hospitalization for CHF, we measured use of the hospital, potentially preventable hospitalization, and emergency department visits. Additionally, we assessed the volume of ambulatory visits and type of specialties visited to assess whether nurses were more likely to access care or specialists. For decedents, we measured the place of death, use of hospice, use of life-prolonging treatments (including mechanical ventilation, dialysis, and feeding tubes) as well as use of the hospital and other types of services in the last 6 months of life.

Covariates

Variables used to perform matching were obtained from Medicare administrative data including demographics, date of birth and death, race, ZIP Code of residence, and health status. ZIP Codes were used to identify 2010 US Census Tract median household income and HRR. We measured the number and type of comorbid conditions in the year before cohort entry by the presence of either one inpatient or two outpatient claims 7 days apart for conditions included in the Elixhauser comorbidity score.[15,16]

A covariate not used in matching was nursing home residence. We linked to the Minimum Data Set that includes all nursing home stays to identify people who, before cohort entry, were long-term nursing home residents based on having spent at least 100 days in a nursing home.

Statistical Analysis

Descriptive analyses of differences between NHS and the 20% Medicare sample of women were compared using either two-sided t tests (for continuous variables) or χ^2 tests (for categorical variables). Given expected and observed imbalances in factors such as socioeconomics and demographics between the NHS participants and the general population, propensity score matching was used to balance observable factors between the study samples. Scores were estimated using logistic regression to determine the likelihood that a woman would have participated in the NHS, based on the covariates just listed.

Propensity score matching was performed using a nearest neighbor matching algorithm to obtain a 1:1 match without replacement between NHS participants and the 20% Medicare sample of women. An optimal caliper equal to .2 times the standard deviation of the logit of the propensity scores was used to match the logit of the propensity scores, and a 100% match was obtained. Finally, the balance in the observable confounders between the NHS participants and the matched cohort from the 20% sample was verified using a standardized difference of means greater than .10 as the minimum threshold for cohorts to be deemed unbalanced for that factor.[17]

After propensity score matching was complete, outcomes of interest for the NHS and the 20% Medicare sample were compared using either two-sided *t* tests or χ^2 tests as appropriate. All analyses were repeated for comparison with a similarly matched sample of men. Analyses were conducted using Stata v.14.1 (College Station, TX) and SAS v.9.4 (Cary, NC). This study was approved by institutional review boards at Brigham and Women's Hospital and Dartmouth College.

RESULTS

From the NHS study eligible participants (N = 57 660), we identified 7380 women with newly identified ADRD and 5375 with CHF. Among them, 3227 with ADRD and 2899 with CHF died by the end of our observation period. Before propensity matching, we compared the NHS participants with the national sample of women; NHS participants were more likely to be white, less likely to be dually eligible for Medicaid, and lived in higher income ZIP Codes (shown in Supplementary Tables S1 and S2). There were small differences in age and comorbidity count between nurses and the national sample across diagnosis (ADRD or CHF) and stage of disease (newly identified or EOL) cohorts. Once propensity matched, all four cohorts were well balanced, as shown in Tables 1 and 2.

Table 3 compares utilization in nurses newly identified with a serious illness compared with the matched 20% national sample of similar women in Medicare. In general, acute care use was similar with small statistical differences in ambulatory visit rates. In newly identified ADRD, hospitalization rates, potentially preventable hospitalizations, and emergency department visits were

Table 1. Characteristics of NHS Participants and Propensity-Matched Women from National Sample Newly Identified with ADRD or CHF

	Newly identified dementia			Newly identified CHF		
	NHS participants	Matched	Std diff	NHS participants	Matched	Std diff
Eligible beneficiaries	57 660	3 610 529		57 660	3 610 529	
Eligible beneficiaries with diagnosis	7380	568 644		5375	461 632	
Selected beneficiaries	7380 (100)	7380 (100)		5375 (100)	5375 (100)	
Demographics	N (%) unless otherwise indicated					
Age at diagnosis, mean (SD)	80.68 (5.5)	80.75 (6.7)	.01	80.18 (5.8)	80.23 (7.2)	.00
Race						
White	7123 (96.5)	7139 (96.7)	.01	5207 (96.9)	5198 (96.7)	.01
Black	126 (1.7)	120 (1.6)	.01	93 (1.7)	108 (2)	.02
Hispanic	50 (.7)	59 (.8)	.02	34 (.6)	28 (.5)	.01
Other	81 (1.1)	62 (.8)	.02	41 (.8)	41 (.8)	.01
Dual eligible for Medicaid	477 (6.5)	444 (6)	.02	279 (5.2)	275 (5.1)	.00
Median household income, mean (SD)	66 374 (28 702)	66 276 (31 201)	.01	64 801 (27 271)	64 663 (29 659)	.01
Nursing home resident	659 (8.9)	562 (7.6)	.07	387 (7.2)	282 (5.2)	.10
During 90 d before diagnosis						
Any nursing home stay	1111 (15.1)	1039 (14.1)	.04	582 (10.8)	522 (9.7)	.06
Any home health services	1056 (14.3)	1169 (15.8)	.05	850 (15.8)	942 (17.5)	.05
Any hospice services	80 (1.1)	79 (1.1)	.01	24 (.4)	22 (.4)	.01
During year before diagnosis						
Hospitalizations, mean (SD)	.92 (1.5)	.95 (1.5)	.01	1.65 (1.4)	1.68 (1.5)	.01
Ambulatory visits, mean (SD)	24.73 (34.1)	23.75 (32.9)	.02	26.81 (34.5)	25.42 (34.9)	.02
Comorbid conditions						
Comorbidity count, mean (SD)	2.41 (2.3)	2.38 (2.3)	.00	3.13 (2.4)	3.15 (2.4)	.00
Hypertension	4498 (60.9)	4484 (60.8)	.01	3657 (68)	3720 (69.2)	.02
Diabetes	1258 (17)	1257 (17)	.00	1321 (24.6)	1339 (24.9)	.01
Deficiency anemias	1026 (13.9)	1023 (13.9)	.00	1078 (20.1)	1110 (20.7)	.02
Fluid electrolyte disorders	1046 (14.2)	1020 (13.8)	.01	936 (17.4)	978 (18.2)	.02
Hypothyroidism	1398 (18.9)	1407 (19.1)	.00	985 (18.3)	960 (17.9)	.01
Chronic obstructive lung disease	1074 (14.6)	1053 (14.3)	.01	1290 (24)	1319 (24.5)	.01
Congestive heart failure	773 (10.5)	748 (10.1)	.02	1316 (24.5)	1311 (24.4)	.01
Other neurologic disorders	1223 (16.6)	1211 (16.4)	.00	612 (11.4)	599 (11.1)	.03
Depression	761 (10.3)	793 (10.7)	.01	442 (8.2)	426 (7.9)	.02
Renal failure	483 (6.5)	466 (6.3)	.01	705 (13.1)	702 (13.1)	.01
Psychoses	569 (7.7)	576 (7.8)	.01	272 (5.1)	286 (5.3)	.00

Abbreviations: CHF, congestive heart failure; NHS, Nurses' Health Study; SD, standard deviation.

Table 2. Characteristics of Nurses' Health Study Participants and Propensity-Matched Women from national sample who died with ADRD or CHF

	EOL dementia			EOL CHF		
	NHS participants	Matched	Std diff	NHS participants	Matched	Std diff
Eligible beneficiaries	57 660	3 610 529		57 660	3 610 529	
Eligible beneficiaries with diagnosis	7380	568 644		5375	461 632	
Beneficiaries who died	3227	3227		2899	2899	
Died within 1 y of cohort entry	1213 (37.6)	1316 (40.8)	.06	1532 (52.8)	1576 (54.4)	.03
Demographics	N (%) unless otherwise indicted					
Age at death, mean(SD)	82.98 (5.0)	83.11 (6.5)	.02	81.91 (5.4)	81.99 (7.0)	.01
Race						
White	3124 (96.8)	3135 (97.1)	.01	2803 (96.7)	2803 (96.7)	.01
Black	48 (1.5)	41 (1.3)	.02	49 (1.7)	48 (1.7)	.00
Hispanic	24 (.7)	22 (.7)	.00	15 (.5)	15 (.5)	.01
Other	31 (1)	29 (.9)	.00	32 (1.1)	33 (1.1)	.02
Dual eligible for Medicaid	301 (9.3)	300 (9.3)	.00	195 (6.7)	177 (6.1)	.03
Median household income, mean (SD)	65 564 (28 098)	65 001 (30 053)	.01	64 364 (27 917)	65 120 (30 430)	.01
Nursing home resident	429 (13.3)	326 (10.1)	.11	288 (9.9)	199 (6.9)	.13
During 90 d before diagnosis						
Any nursing home stay	701 (21.7)	590 (18.3)	.09	426 (14.7)	365 (12.6)	.08
Any home health services	636 (19.7)	644 (20)	.01	576 (19.9)	639 (22)	.05
Any hospice services	70 (2.2)	62 (1.9)	.02	22 (.8)	29 (1)	.03
During 365 d before diagnosis						
Hospitalizations, mean (SD)	1.3 (1.8)	1.3 (1.8)	.01	1.8 (1.6)	1.8 (1.6)	.00
Ambulatory visits, mean (SD)	24.6 (35.6)	23.4 (34.8)	.02	26.2 (34.8)	22.6 (31.9)	.06
Comorbid condition count, mean (SD)	2.8 (2.6)	2.7 (2.6)	.01	3.4 (2.6)	3.4 (2.7)	.01

Abbreviations: CHF, congestive heart failure; EOL, end of life; NHS, Nurses' Health Study; SD, standard deviation.

no different between NHS and the national sample. No meaningful differences were found when comparing NHS and national sample CHF cohorts (the difference in preventable hospitalization rates, .50 vs .54 [P = .02], was statistically significant but unlikely to be clinically meaningful). Ambulatory visit rates in both the ADRD and CHF cohorts were approximately .5 to 1 visit per person higher in nurses compared with the national sample with the difference arising from use of specialists, with nurses having more visits to cardiologists and neurologists.

Table 3. Utilization in year after NHS participants and propensity-matched women from national sample were newly identified with ADRD or CHF

	Dementia			CHF		
	NHS participants	Matched sample		NHS participants	Matched sample	
Beneficiaries with diagnosis, n	7380	7380		5375	5375	
First year utilization, rate per person	Mean (95% CI)		*P* value	Mean (95% CI)		*P* value
Hospitalizations	1.1 (1.07-1.15)	1.16 (1.12-1.2)	.055	2.26 (2.21-2.31)	2.32 (2.27-2.38)	.077
Hospital days	17.3 (16.29-18.32)	18.6 (17.53-19.67)	.084	24.51 (23.51-25.52)	25.12 (24.08-26.16)	.41
Potential preventable hospitalization	.14 (.13-.15)	.15 (.14-.17)	.060	.5 (.48-.53)	.54 (.52-.56)	.018
Emergency department visits	.3 (.29-.32)	.3 (.29-.31)	.86	.29 (.28-.32)	.3 (.28-.32)	.90
Ambulatory E&M visits	11.35 (11.11-11.6)	10.74 (10.5-12.01)	<.001	12.76 (12.42-13.11)	11.85 (11.53-12.18)	<.001
Primary care visits	6.73 (6.56-6.91)	6.59 (6.43-6.76)	.25	6.3 (6.09-6.50)	6.25 (6.06-6.46)	.78
All specialty care visits	4.62 (4.48-4.76)	4.14 (4-4.29)	<.001	6.46 (6.24-6.69)	5.59 (5.38-5.81)	<.001
Cardiology visits	.65 (.6-.7)	.57 (.53-.62)	.019	2.02 (1.92-2.12)	1.79 (1.69-1.89)	.001
Psychiatry visits	.18 (.15-.21)	.17 (.15-.2)	.80	.06 (.04-.09)	.04 (.03-.06)	.11
Neurology visits	.67 (.63-.71)	.57 (.54-.6)	<.001	.2 (.18-.23)	.13 (.12-.16)	<.001

Abbreviations: ADRD, Alzheimer's disease and related dementias; CHF, congestive heart failure; CI, confidence interval; E&M, evaluation and management; NHS, Nurses' Health Study.

Acute care use during the last 6 months of life in both the ADRD and CHF cohorts was also similar. Hospitalization rates, although statistically different, are clinically close in nurses compared with the national sample (1.0 vs 1.1 per person with ADRD, $P = .007$, and 1.6 vs 1.7 with CHF, $P = .04$) and had overlapping confidence intervals (CIs). Other service use including post-acute skilled nursing facility stays, emergency visits, and ambulatory care visits were no different between nurses and the national sample; home health use in CHF was slightly higher in nurses.

We found differences in treatments used at the EOL and place of death (Table 4 and Figure 1). In ADRD, nurses were less likely to use life-prolonging treatments including ventilator support, dialysis, or feeding tubes, compared with the national sample during the last 6 months of life (10.9% [95% CI = 9.82-12.0] vs 13.5% [95% CI = 12.38-14.77]; $P = .001$), less likely to have a terminal hospitalization that included an intensive care unit (ICU) stay (10.4% [95% CI = 9.32-11.45] vs 12.1% [95% CI = 11.0-13.2]; $P = .03$), and more likely to participate in hospice (58.2% [95% CI = 56.47-59.91] vs 54.2% [95% CI = 52.49-55.96]; $P = .001$). They were also less likely to die in a hospital (16.9% [95% CI = 15.57-18.15] vs 19.2% [95% CI = 17.85-20.57]; $P = .014$) with a slightly higher proportion dying in the community (50.0% [95% CI = 48.21-51.69] vs 47.5% [95% CI = 45.77-49.25]; $P = .05$). These findings were present in the CHF cohorts with a smaller magnitude of difference, with the exception that no difference was found between nurses and the general Medicare population of women for dying in a hospital with or without an ICU stay.

Although all of the NHS participants were women, we tested whether there may be utilization differences between nurses and a matched sample of men (match results in

Table 4. End-of-Life Utilization and Treatments among NHS Participants and Propensity-Matched Women from National Sample with ADRD or CHF

	Dementia			CHF		
	NHS participants	Matched sample		NHS participants	Matched sample	
Beneficiaries who died, n	3227	3227		2899	2899	
Utilization during 6 mo of life, rate per person	Mean or % (95% CI)		*P* value	Mean or % (95% CI)		*P* value
Hospitalizations	1.02 (.98-1.07)	1.1 (1.06-1.15)	.007	1.6 (1.54-1.65)	1.67 (1.61-1.72)	.039
Hospital days	6.54 (6.21-6.88)	7.24 (6.86-7.63)	.007	11.7 (11.21-12.2)	12.22 (11.71-12.74)	.15
Emergency department visits	.34 (.31-.36)	.35 (.33-.38)	.35	.3 (.3-.36)	.34 (.32-.37)	.42
Skilled nursing facility discharges	.48 (.45-.52)	.49 (.46-.52)	.81	.5 (.51-.58)	.57 (.54-.61)	.29
Skilled nursing facility days	11.96 (11.12-12.81)	12.57 (11.7-53.3)	.32	11.7 (10.82-12.51)	12.28 (11.4-13.16)	.32
Any nursing home stay (skilled or long term), %	54.6 (52.86-56.33)	53.3 (55.03-69.32)	.29	48.4 (46.53-50.2)	46.53 (44.7-48.37)	.16
Nursing home days	53.48 (51.05-55.92)	51.39 (49-53.79)	.23	35.3 (33.23-37.42)	32.67 (30.64-34.7)	.073
Any home health service use, %	33.37 (31.75-35.03)	33.99 (35.66-51.56)	.60	41 (39.22-42.83)	44.64 (42.82-46.47)	.005
Ambulatory E&M visits	7.52 (7.22-7.82)	8.23 (6.91-7.48)	.12	8.4 (8.13-8.76)	7.82 (7.53-8.13)	.005
Location on date of death						
Hospital, %	16.86 (15.57-18.15)	19.21 (17.85-20.57)	.014	32.32 (30.62-34.02)	34.18 (32.46-35.91)	.13
Skilled nursing facility, %	8.4 (7.46-9.41)	9.23 (8.26-10.29)	.24	8.1 (7.17-9.2)	9.52 (8.48-10.65)	.064
Long-term nursing home, %	24.05 (22.58-25.56)	23.4 (21.94-24.9)	.54	13.6 (12.4-14.93)	12.59 (11.4-13.85)	.24
Community, %	49.95 (48.21-51.69)	47.51 (45.77-49.25)	.049	44.4 (42.61-46.26)	41.77 (39.97-43.59)	.041
EOL treatments						
Any life-prolonging treatments[a] (%)	10.88 (9.82-12)	13.54 (12.38-14.77)	.001	21.6 (20.14-23.17)	24.15 (22.6-25.75)	.023
Terminal hospitalization with ICU stay (%)	10.35 (9.32-11.45)	12.05 (10.95-13.23)	.03	22.6 (21.05-24.13)	22.97 (21.45-24.55)	.71
Hospice enrolled in last 30 d of life (%)	58.2 (56.47-59.91)	54.23 (52.49-55.96)	.001	47.4 (45.56-49.23)	44.46 (42.64-46.29)	.025

Abbreviations: ADRD, Alzheimer's disease and related dementias; CHF, congestive heart failure; CI, confidence interval; E&M, evaluation and management; EOL, end of life; ICU, intensive care unit; NHS, Nurses' Health Study.

[a]Life-prolonging treatments = ventilator, dialysis, feeding tube.

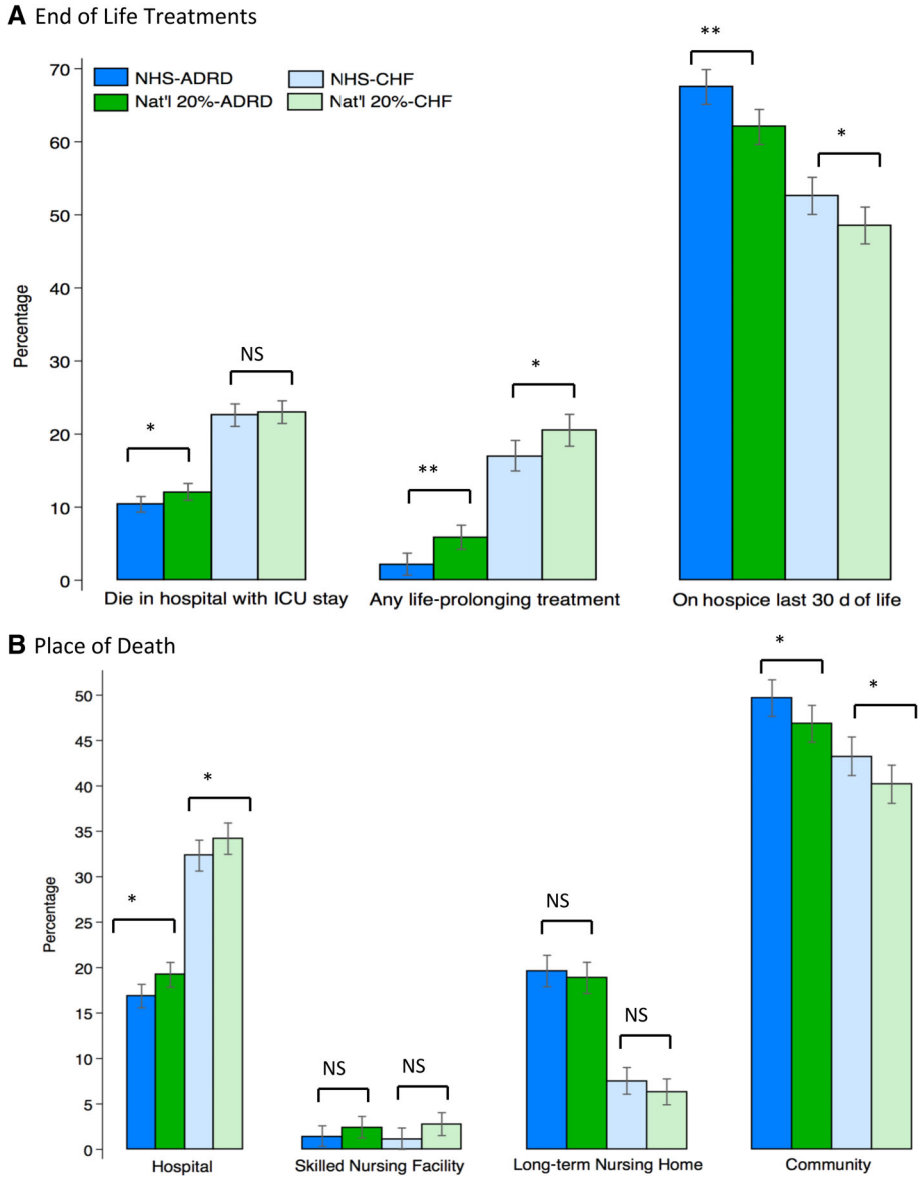

Figure 1. End-of-life treatments and place of death among Nurses' Health Study (NHS) and 20% national sample decedents with Alzheimer's disease and related dementias (ADRD) or congestive heart failure (CHF). *$P < .05$; **$P < .001$; ICU, intensive care unit; NS, nonsignificant.

Supplementary Tables S3 and S4) and found the same patterns for newly identified cases (Supplementary Table S5). At EOL, nurses had lower hospitalization and intensive EOL treatments than men, similar to the comparison with women (Supplementary Table S6). Community as a place of death was the same, but men were more likely to die in the hospital, whereas nurses more likely to die in the nursing home, a difference not observed when comparing the nurses with a sample of matched women.

DISCUSSION

Nurses are critical team members as primary points of access, educators, and often care coordinators for patients with a serious illness, a population in particular need of EOL care planning. Nurses, like physicians, engage with patients and their families who are making important decisions about serious illness. There is a growing literature on the treatment that physicians receive at the end of their own lives. In this study we focus on nurses as the other care team member important for patient and family education. Our main findings are that nurses' utilization is largely similar to the general population except for nurses' lower use of the most intensive services at the EOL and higher use of hospice, particularly for ADRD, which is a long progressive illness.

Nurses' education and experience managing people who are ill may lead to personal treatment decisions, such as what type of doctor to see or the nature of treatments near the EOL, that differ from the general population. In the case of physicians, several survey studies indicate that physicians prefer less aggressive care at EOL and support the use of advanced directives.[3-5,7,8] No similar survey data on nurses' preferences are currently available, although we can examine healthcare received at the EOL. Studies of EOL treatments doctors

receive showed they use the hospital similarly to the general population, with perhaps more ICU use but also more hospice,[6] and their care is comparable with that of lawyers[9] and a diverse set of clinicians.[2] Our examination of the care that nurses receive demonstrates differences in specific EOL treatments that are larger and more consistent than those found for doctors including more use of hospice, less use of the ICU during terminal hospitalizations, and less use of life-prolonging treatments (ventilators, dialysis, or feeding tubes).

Whereas studies of health utilization among physicians with serious illness have only examined the last phase of life, we expanded on this approach, examining health utilization by nurses in the year following diagnosis and at EOL. We found that nurses do not receive better quality of care as measured by preventable hospitalizations and emergency visits, but they are slightly more likely to access specialty care and have more ambulatory visits. It is possible that the earlier engagement of disease experts and more ambulatory care could contribute to the differences we find at EOL that are particularly large in the context of ADRD. The differences for CHF are similar to the ADRD results with the exception that nurses do not differ from the national sample in use of the ICU during a terminal hospitalization. The similarity of nurses to the general population in terminal hospital stay with ICU use may reflect the greater likelihood of an acute cardiac event leading to a coronary care unit stay in CHF compared with ADRD or from less recognition of CHF as a life-limiting disease in the way ADRD is recognized.

Less aggressive EOL treatments for nurses compared with the general population raises the critical question of *why* the differences occur. A potential explanation is that the work experience as nurses informs their personal choices or their advanced care planning. We recently showed that a high proportion (84%) of nurses have advance care planning documentation that may empower proxy decision makers, as is often necessary with ADRD, to direct care toward the nurses' prespecified wishes.[18] Future studies on how nurses navigate the health system when they have a serious illness may allow us to leverage those experiences and inform development of the nurse educator role to improve advance care planning. Although nurses may be able to advise during advanced care planning, the current literature suggests that this role has been broached only for nurse practitioners, who can practice independently of physicians in many states, and for critical care nurses.[19-22] Izumi suggests that by not accessing the wider nurse workforce, we are missing an opportunity to improve advanced care planning.[23] Yet nurses faces multiple barriers to fulfill this role including inadequate training, lack of role clarity, and the need to work within team hierarchies.[23]

This study highlights another important avenue for future research. A potential use of the NHS survey data collected over 40 years linked to Medicare data is to study early and midlife predictors of health outcomes of women in late life. Our finding that healthcare is similar for nurses and the general population except very near death reduces concerns about the generalizability of these future studies. This application of the NHS data has begun in studies of cancer, preventive care, and cognitive impairment.[24-26] Concerns about generalizability also motivated comparing with men, in which we found no difference in early disease but larger differences at the EOL. EOL care differences between the nurses and men may be driven by sex as well as professional healthcare experience.

This study has important limitations. First, a specific concern is that nurses may be diagnosed earlier that could allow more time for advance care planning, but we cannot detect disease stage using administrative data. This concern, in part, motivated our examination of newly identified cases and EOL care. The proportion of nurses who die within a year of diagnosis in both ADRD and CHF was slightly lower (1.5%-2%) than the general population, suggesting the nurses may be diagnosed earlier or are healthier; however, these differences were not large enough to unbalance the samples. In addition, the NHS and general population cohorts were close in age and other illness variables before and after matching, lowering the likelihood that our results are substantively influenced by this potential bias. Second, matching was possible only for factors that were measurable in the administrative data; therefore, confounding by other unmeasured factors, such as education, could exist. Third, although propensity matching makes an internally valid comparison, generalizability to nurses and Medicare beneficiaries not represented in this study (such as those enrolled in managed care) is potentially limited. Similarly, representation of minorities is low in the parent NHS that limits generalizability to minority populations.

In conclusion, as frontline clinicians, nurses both deliver care and observe firsthand the promises, limitations, and burdens of medical care. In a national sample of nurses living with serious illness, we find that nurses experience similar care as non-nurses in the year following diagnosis, but they tend to receive less aggressive treatments at EOL. Incorporating nurses into studies of what drives care decisions and how to best support patient decision making is an important and under-tapped opportunity.

ACKNOWLEDGMENTS

Conflict of interests: The authors have declared no conflicts of interest for this article.

Author Contributions: Multiple authors were involved in each stage of the study including study concept and design (Bynum, Grodstein), acquisition of subjects and/or data (Bynum, Grodstein), analysis and interpretation of data (Bynum, Grodstein, Austin, Passow, and Carmichael), and preparation and approval of the manuscript (Bynum, Grodstein, Austin, Passow, and Carmichael).

Sponsor's Role: This research is funded by grants from the National Institute on Aging (R21 AG045618 and P01 AG019783). The sponsor had no role in the design and conduct of this study; preparation, review, or approval of the manuscript.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

Supplementary Table S1: Characteristics of NHS Participants and 20% Random National Sample of Women Newly Identified with ADRD or CHF[a].

[a]N (%) unless otherwise indicated.

Supplementary Table S2: Characteristics of NHS Participants and 20% Random National Sample and Propensity-Matched Sample of Women Who Died with ADRD or CHF.

Supplementary Table S3: Characteristics of NHS Participants and 20% Random National Sample and Propensity-Matched Sample of Men Newly Identified with ADRD or CHF.

Supplementary Table S4: Characteristics of NHS Participants and 20% Random National Sample and Propensity-Matched Sample of Men Who Died with ADRD or CHF.

Supplementary Table S5: Utilization in Year After NHS Participants and Propensity-Matched Men from National Sample Were Newly Identified with ADRD or CHF.

Supplementary Table S6: End-of-Life Utilization and Treatments among NHS Participants and Propensity-Matched Men from National Sample with ADRD or CHF.