Original Investigation

Family Perspectives on Aggressive Cancer Care Near the End of Life

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IMPORTANCE Patients with advanced-stage cancer are receiving increasingly aggressive medical care near death, despite growing concerns that this reflects poor-quality care.

OBJECTIVE To assess the association of aggressive end-of-life care with bereaved family members' perceptions of the quality of end-of-life care and patients' goal attainment.

DESIGN, SETTING, AND PARTICIPANTS Interviews with 1146 family members of Medicare patients with advanced-stage lung or colorectal cancer in the Cancer Care Outcomes Research and Surveillance study (a multiregional, prospective, observational study) who died by the end of 2011 (median, 144.5 days after death; interquartile range, 85.0-551.0 days).

EXPOSURES Claims-based quality measures of aggressive end-of-life care (ie, intensive care unit [ICU] admission or repeated hospitalizations or emergency department visits during the last month of life; chemotherapy ≤2 weeks of death; no hospice or ≤3 days of hospice services; and deaths occurring in the hospital).

MAIN OUTCOMES AND MEASURES Family member–reported quality rating of "excellent" for end-of-life care. Secondary outcomes included patients' goal attainment (ie, end-of-life care congruent with patients' wishes and location of death occurred in preferred place).

RESULTS Of 1146 patients with cancer (median age, 76.0 years [interquartile range, 65.0-87.0 years]; 55.8% male), bereaved family members reported excellent end-of-life care for 51.3%. Family members reported excellent end-of-life care more often for patients who received hospice care for longer than 3 days (58.8% [352/599]) than those who did not receive hospice care or received 3 or fewer days (43.1% [236/547]) (adjusted difference, 16.5 percentage points [95% CI, 10.7 to 22.4 percentage points]). In contrast, family members of patients admitted to an ICU within 30 days of death reported excellent end-of-life care less often (45.0% [68/151]) than those who were not admitted to an ICU within 30 days of death (52.3% [520/995]) (adjusted difference, −9.4 percentage points [95% CI, −18.2 to −0.6 percentage points]). Similarly, family members of patients who died in the hospital reported excellent end-of-life care less often (42.2% [194/460]) than those who did not die in the hospital (57.4% [394/686]) (adjusted difference, −17.0 percentage points [95% CI, −22.9 to −11.1 percentage points]). Family members of patients who did not receive hospice care or received 3 or fewer days were less likely to report that patients died in their preferred location (40.0% [152/380]) than those who received hospice care for longer than 3 days (72.8% [287/394]) (adjusted difference, −34.4 percentage points [95% CI, −41.7 to −27.0 percentage points]).

CONCLUSIONS AND RELEVANCE Among family members of older patients with fee-for service Medicare who died of lung or colorectal cancer, earlier hospice enrollment, avoidance of ICU admissions within 30 days of death, and death occurring outside the hospital were associated with perceptions of better end-of-life care. These findings are supportive of advance care planning consistent with the preferences of patients.

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Patients with advanced-stage cancer receive aggressive medical care at the end of life,[1] despite increasing evidence that high-intensity treatments may not be associated with better patient quality of life, outcomes, or caregiver bereavement.[2] The National Quality Forum and the American Society of Clinical Oncology have jointly endorsed several indicators of overly aggressive end-of-life care (developed by Earle et al[3]), including repeated hospitalizations, emergency department visits, or admission to an intensive care unit (ICU) within the last month of life, patient receipt of chemotherapy within 2 weeks prior to death, and late or absent hospice referrals.[4]

The end-of-life care measures of the National Quality Forum and the American Society of Clinical Oncology are integrated into the Society's Quality Oncology Practice Initiative[5] and will likely become more important because the Patient Protection and Affordable Care Act mandates public reporting of quality metrics and has linked incentive and penalty payments to similar indicators (eg, the Centers for Medicare & Medicaid Services Oncology Care Model).[6] Improving end-of-life care offers an opportunity to improve the dying experience of patients with cancer, more effectively use resources,[7] and potentially prolong survival.[8]

Few studies have examined whether these aggressive end-of-life care measures reflect patients' preferences or bereaved family members' perceptions and expectations of the quality of end-of-life care. In this study, we assessed the relationship between aggressive end-of-life care and family member–reported quality ratings of end-of-life care using data from the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium.[9] We also examined patient goal attainment, which was based on (1) whether patients treated with aggressive care near death received care that was congruent with their preferences and (2) if their death occurred in their preferred place.

Methods

Data Sources

Data came from the CanCORS and CanCORS II studies linked to Medicare claims from 2003 through 2011. As described previously,[9,10] CanCORS enrolled patients newly diagnosed with lung or colorectal cancer during 2003 through 2005 from 5 regions (northern California; Los Angeles County, California; North Carolina; Iowa; and Alabama) and 5 integrated health systems. Trained staff interviewed participants or their family in English, Spanish, or Chinese using computer-assisted telephone interview software (1) approximately 4 to 6 months after cancer diagnosis, (2) 1 year after diagnosis (for patients alive at the time of the first interview), and (3) 5 to 7 years after diagnosis (for patients alive 1 year after diagnosis). The study protocol was approved by institutional review boards at all participating sites and all participants provided informed consent.

For this analysis, a family member or close friend of the deceased patient was interviewed after the patient's death about the patient's treatment preferences,[11] symptoms near death, end-of-life wishes, preferred place of death, the quality of end-of-life care, and location of death. If the patient was deceased at the initial study contact, the next-of-kin was in-vited to participate. Patients who were alive for the baseline interview were asked to identify a primary family member or friend "familiar with your care since diagnosis" and a secondary respondent (in case the first could not be reached). Because 95% of interviews were completed by family (defined as spouse or partner, child, other relative, or friend), we will hereafter refer to respondents as family members.

We measured the intensity of end-of-life care received by participants enrolled in the traditional fee-for-service Medicare plan by obtaining claims data with approval from the Centers for Medicare & Medicaid Services privacy board. Potentially eligible enrollees were linked using a common matching algorithm based on Social Security number, date of birth, and sex,[12] which matched 81.5% of CanCORS enrollees aged 65 years or older to Medicare data.

Study Population

The CanCORS participants who were diagnosed or experienced advanced lung or colorectal cancer recurrence, died by 2011, were aged 65 years or older, and continuously enrolled in Medicare parts A and B fee-for-service for 3 months or longer before death were included.

Outcome Variables

We examined family member–reported ratings of the quality of end-of-life care and 2 measures of patient goal attainment. To assess care quality, family members were asked: "Overall, how would you rate the care received [at the last place where care was provided]? Would you say it was excellent, very good, good, fair, or poor?" We defined high-quality end-of-life care as that which family members rated as excellent.[13]

We assessed patient goal attainment using 2 measures. First, family members were asked "In your opinion, to what extent were [the patient's] wishes followed in the medical care received in the last month of life?" Goal attainment was defined as care that "followed patients' wishes a great deal." In addition, family were asked where the patient's preferred and actual places of death were; by design, these questions were separated by more than 40 questions to minimize conscious comparison, but included similar categories.

Categories of preferred location of death included hospital, home, relative's home, nursing facility, and other. Categories of actual place of death included hospital, home, nursing home, hospice inpatient unit, and other (specify). Patients whose actual place of death matched their preferred place were considered to have achieved goal attainment. Preferences for home were considered to match if the patient died at home or at a relative's home. For the small number of patients who died in a hospice inpatient unit or "other" that could not be assigned to a preexisting preference category, the variable was coded as unknown.

Independent Variables

We previously developed 5 measures of aggressive end-of-life care that address (1) overuse of chemotherapy near death, (2) possible misuse of treatments resulting in emergency department visits, hospitalizations, or ICU stays, and (3) underuse of hospice. These measures were developed through

literature reviews and focus groups with patients, families, and an expert panel.[3] We identified aggressive end-of-life care using Medicare claims data.[14,15] We examined deaths that occurred in hospitals using family member–reported location of death because hospital deaths have been associated with worse family member–reported patient quality of life near death compared with home deaths, and increased psychiatric morbidity among caregivers.[16]

Control Variables

We obtained information about patients' sociodemographic characteristics (age, marital status, education, and income), overall health status, comorbid conditions, depression, and treatment preferences from family members who completed the after-death interview. Race/ethnicity was analyzed as a potential determinant of the quality of end-of-life care because patients may vary in their treatment preferences, advance care planning, and health care use.[17] Cancer stage at diagnosis and type was obtained through medical record abstraction or, if unavailable, from cancer registries.

We also adjusted for geographic region and enrollment in an integrated health system, which included 5 sites and Kaiser Permanente of Northern or Southern California. In addition, we adjusted for time from diagnosis to death as a linear variable, family respondent (eg, spouse or partner, child, other relative, or friend), and time from death to interview completion as a linear variable. In additional analyses, we tested for interactions between time from death to interview completion and respondent role; none of the interactions were statistically significant, so the models included only the main effects.

Statistical Analyses

Descriptive statistics were used to characterize family member–rated quality of end-of-life care, patient goal attainment, and rates of aggressive end-of-life care according to patient preferences. We examined associations between aggressive end-of-life care and family member–reported (1) excellent quality end-of-life care, (2) care consistent with patient wishes, and (3) death in preferred place using regression models, adjusted for all other covariates, regardless of statistical significance. For each dependent variable, separate models were fit for each indicator of aggressive end-of-life care, adjusting for the patient characteristics described. We fit linear-binomial models with an identity link to estimate adjusted differences in the likelihood of each outcome.[18]

In each model, we only included patients without missing data for that outcome measure. Because covariate information was missing for between 0.8% (education level) to 10% (patient treatment preferences) of the cohort, we used multiple imputation methods to create 5 complete data sets and repeated all analyses on each imputed data set, combining results using standard methods for multiply-imputed data.[19]

Sensitivity analyses were conducted to examine associations between patient preference for life-extending treatments and receipt of aggressive care over shorter periods (ie, ≤90 days and ≤180 days from diagnosis to death). We examined the effect of recategorizing family member–reported quality ratings for end-of-life care as "excellent and very

good" vs "good, fair, and poor" and as an ordinal model. We also fit models that included family members' contact with patients during the last week as a proxy for closeness. We repeated these analyses among a subset of the total cohort with information from the baseline interview and the 1-year follow-up interview, both with and without family member–reported frequency of discussing important medical decisions with the patient. Next, we examined the effect of including patients' symptoms at the end-of-life (eg, pain and difficulty breathing) and how well these were controlled because uncontrolled symptoms often precipitate hospitalizations near death. In addition, we repeated all analyses stratified by disease site.

Two-sided P values <.05 were considered statistically significant. All statistical analyses were performed using SAS software version 9.3 (SAS Institute Inc).

Results

Among 3620 patients who were diagnosed with or experienced advanced-stage cancer recurrence, 2011 were linked to medical claims; of these, 1847 had died by the end of 2011 and 1713 were aged 65 years or older as of 3 months before death (linkage rate with claims was >90% across all sites for patients aged ≥65 years). We excluded 449 patients for whom we did not have an after-death interview from a family member (the after-death interviews were available for 73.8% of potentially eligible patients). We also excluded 92 patients who were not continuously enrolled in Medicare parts A and B fee-for-service as of 3 months before death and 26 patients for whom the family member did not rate the quality of end-of-life care, leaving a final study population of 1146 patients (median age, 76.0 years [interquartile range, 65.0-87.0 years]).

Most of the study population had stage IV disease at diagnosis (**Table 1**). Lung cancer decedents had much shorter median survival times than colorectal cancer decedents (122.5 days vs 572.0 days, respectively), and were more likely to die during 2003 through 2005 compared with later (85.0% vs 50.0%, respectively; P < .001) (eTable 1 in the Supplement). More than 80% of family members were spouses or children; 15.2% were other relatives or friends (**Table 2**). Family members reported a median of 7.0 days (interquartile range, 6.0-7.0 days) of contact with patients during the last week of life. The median time between patient death and the after-death interview was 144.5 days (interquartile range, 85.0-551.0 days). Patients with an after-death interview did not differ significantly from patients without one by cancer type or sex; however, they were more likely to be older, white, and have died within 3 months of cancer diagnosis (eTable 2 in the Supplement).

Overall, family members reported that the quality of end-of-life care was excellent for 51.3% of decedents, very good for 27.8%, and good, fair, or poor for 20.9% (**Table 3**). Among family members, 81.1% indicated that patients' end-of-life wishes were followed a "great deal," whereas 18.9% reported that end-of-life care was "somewhat" or "not at all" consistent with patients' wishes; only 56.7% of patients died in their preferred location.

Table 1. Patient Characteristics[a]

	Total (N = 1146)	Lung Cancer (n = 886)	Colorectal Cancer (n = 260)
Male sex	639 (55.8)	514 (58.0)	125 (48.1)
Age at death, y			
65-69	204 (17.8)	170 (19.2)	34 (13.1)
70-74	273 (23.8)	222 (25.1)	51 (19.6)
75-79	260 (22.7)	215 (24.3)	45 (17.3)
≥80	409 (35.5)	279 (31.5)	130 (50.0)
Race/ethnicity			
White	923 (80.5)	726 (81.9)	197 (75.8)
Black	85 (7.4)	54 (6.1)	31 (11.9)
Hispanic	58 (5.1)	45 (5.1)	13 (5.0)
Asian/Pacific Islander	41 (3.6)	31 (3.5)	10 (3.9)
Other[b]	39 (3.4)	30 (3.4)	9 (3.5)
Education level			
≤High school graduate	285 (25.1)	231 (26.3)	54 (21.1)
High school graduate	658 (57.9)	514 (58.4)	144 (56.3)
College graduate	193 (17.0)	135 (15.3)	58 (22.7)
Household income, $			
<20 000	352 (33.5)	270 (32.9)	82 (35.5)
20 000-39 999	385 (36.6)	318 (38.8)	67 (29.0)
40 000-59 999	177 (16.8)	139 (17.0)	38 (16.5)
≥60 000	137 (13.0)	93 (11.3)	44 (19.0)
Married	658 (57.4)	521 (58.8)	137 (52.7)
Region			
Midwest	316 (27.6)	312 (35.3)	4 (1.5)
South	194 (17.0)	95 (10.7)	99 (38.1)
West	634 (55.4)	477 (54.0)	157 (60.4)
Integrated health care system	302 (26.4)	227 (25.6)	75 (28.9)
Cancer stage at diagnosis			
I	76 (6.9)	55 (6.3)	21 (9.6)
II	20 (1.8)	16 (1.8)	4 (1.8)
III	277 (25.2)	228 (25.9)	49 (22.5)
IV	725 (66.0)	581 (66.0)	144 (66.1)
No. of comorbid conditions before death			
0	357 (31.2)	256 (28.9)	101 (38.9)
1	408 (35.6)	322 (36.3)	86 (33.1)
≥2	381 (33.3)	308 (34.8)	73 (28.1)
Depression	265 (23.1)	210 (23.7)	55 (21.2)
Time from diagnosis to death, median (IQR), d	144.5 (54.0-485.0)	122.5 (47.0-305.0)	572.0 (103.0-1504.0)
Timing of after-death interview			
Baseline (3-6 mo after diagnosis)	615 (53.7)	534 (60.3)	81 (31.2)
Follow-up (12 mo after diagnosis)	231 (20.2)	192 (21.7)	39 (15.0)
Long-term follow-up (7 y after diagnosis)	300 (26.2)	160 (18.1)	140 (53.9)
Preferred course of treatment during last mo of life[c]			
Extend life as much as possible	332 (29.0)	264 (29.8)	68 (26.2)
Relieve pain or discomfort as much as possible	776 (67.7)	608 (68.6)	168 (64.6)
Do not know or refused to answer	38 (3.3)	14 (1.6)	24 (9.2)

Abbreviation: IQR, interquartile range.

[a] Data are expressed as No. (%) unless otherwise indicated. There were missing data for the following characteristics: education level (n = 10), household income (n = 95), region (n = 2, Northeast), cancer stage at diagnosis (n = 48).

[b] American Indian, Alaska Native, Native Hawaiian, or other (specify).

[c] Reported by family member (defined as spouse or partner, child, other relative, or friend or other).

Table 2. Family Member Characteristics[a]

	Total (N = 1146)	Lung Cancer (n = 886)	Colorectal Cancer (n = 260)
Family member relationship with patient[b]			
Spouse or partner	498 (43.5)	401 (45.3)	97 (37.3)
Child	474 (41.4)	364 (41.1)	110 (42.3)
Other relative	113 (9.9)	75 (8.5)	38 (14.6)
Friend or other	61 (5.3)	46 (5.2)	15 (5.8)
Accompanied patient to physician appointments			
Always	449 (58.0)	388 (58.3)	61 (56.5)
Usually	136 (17.6)	121 (18.2)	15 (13.9)
Sometimes	127 (16.4)	107 (16.1)	20 (18.5)
Never	62 (8.0)	50 (7.5)	12 (11.1)
Discussed important medical decisions regarding cancer			
Always	464 (60.0)	415 (62.3)	49 (45.4)
Usually	92 (11.9)	81 (12.2)	11 (10.2)
Sometimes	136 (17.6)	109 (16.4)	27 (25.0)
Never	82 (10.6)	61 (9.2)	21 (19.4)
Male sex, No./total (%)	189/774 (24.4)	158/666 (23.7)	31/108 (28.7)
Race/ethnicity			
White	622 (83.4)	548 (85.0)	74 (73.3)
Black	50 (6.7)	36 (5.6)	14 (13.9)
Hispanic	40 (5.4)	33 (5.1)	7 (6.9)
Asian/Pacific Islander	34 (4.6)	28 (4.3)	6 (5.9)
Days of contact with patient during last wk of life, median (IQR)	7.0 (6.0-7.0)	7.0 (6.0-7.0)	1.0 (1.0-7.0)
Time between death and after-death interview, median (IQR), d	144.5 (85.0-551.0)	131.0 (78.0-246.0)	539.0 (116.5-1560.0)

Abbreviation: IQR, interquartile range.

[a] Data are expressed as No. (%) unless otherwise indicated. There were missing data for the following characteristics: accompanied patient to physician appointments (n = 372), discussed important medical decisions regarding cancer (n = 372), male sex (n = 372), race/ethnicity (n = 400), and days of contact with patient during last week of life (n = 74).

[b] Respondents were asked to describe his/her relationship with the patient and report how many days he/she was in contact with the patient during the last week of life; however, questions about frequency of accompanying patient to physician appointments, discussing important medical decisions regarding cancer, sex, and race/ethnicity were only asked during the baseline decedent interview and the decedent interview (conducted 1 year after diagnosis and not the decedent interview conducted 5-7 years after diagnosis).

Table 3. Family Member–Reported Quality of End-of-Life Care and Patient Goal Attainment

	No. (%)			
	Total (N = 1146)	Lung Cancer (n = 886)	Colorectal Cancer (n = 260)	P Value[a]
Overall quality of end-of-life care				
Excellent	588 (51.3)	474 (53.5)	114 (43.9)	
Very good	318 (27.8)	250 (28.2)	68 (26.2)	<.001
Good, fair, or poor	240 (20.9)	162 (18.3)	78 (30.0)	
End-of-life wishes followed[b]				
A great deal	754/930 (81.1)	602/731 (82.3)	152/199 (76.4)	
Somewhat	145/930 (15.6)	109/731 (14.9)	36/199 (18.1)	.07
Not at all	31/930 (3.3)	20/731 (2.7)	11/199 (5.5)	
Death occurred in patient's preferred place	439 (56.7)[c]	386 (58.3)	53 (47.3)	.03

[a] Assesses differences between family member–rated quality of end-of-life care and patient goal attainment.

[b] There were 216 family members who responded "unknown" and were excluded. Data are expressed as No./total (%).

[c] Analyses included 774 interviews from family members; 372 family members who responded "unknown" were excluded.

Patient Preferences and Aggressive End-of-Life Care

Patients' treatment preferences were significantly associated with the medical care received near death (**Table 4**). For example, patients who preferred life-extending therapies were more likely to receive chemotherapy within 2 weeks of death than those who preferred comfort care (12.4% vs 3.9%, respectively; $P < .001$), and were more likely to receive 3 or fewer days of hospice care (64.2% vs 41.0%, respectively; $P < .001$). Results were similar among patients with shorter survival times (eTables 3 and 4 in the Supplement).

Table 4. Relationship Between Family Member–Reported Treatment Preferences of the Patient and the Patient's Receipt of Aggressive End-of-Life Care[a]

Type of Aggressive End-of-Life Care	Total (N = 1146)	Among Patients Reporting Preference[b]		P Value[c]
		Extend Life vs RelieveSymptoms (n = 332)	Relieve Symptoms vs Extend Life (n = 776)	
During last mo of life				
Intensive care unit admission	151 (13.2)	53 (16.0)	94 (12.1)	.08
≥2 Hospitalizations	70 (6.1)	32 (9.6)	37 (4.8)	.002
≥2 Emergency department visits	90 (7.9)	31 (9.3)	57 (7.4)	.26
Chemotherapy ≤2 wk before death	75 (6.5)	41 (12.4)	30 (3.9)	<.001
No hospice care or ≤3 d before death	547 (47.7)	213 (64.2)	334 (41.0)	<.001
Death occurred in hospital	460 (40.1)	155 (46.7)	301 (38.8)	.01

[a] Data are expressed as No. (%) unless otherwise indicated.

[b] Analyses excluded 38 family members who responded "do not know" or refused to answer.

[c] Assesses differences for individuals who experienced aggressive care vs those who did not.

Table 5. Associations Between Aggressive End-of-Life Care and Family Members' Overall Rating of the Quality of a Patient's End-of-Life Care

Type of Aggressive End-of-Life Care	Total No. (%) (N = 1146)	Family Member–Rated End-of-Life Care as Excellent Quality			P Value[b]
		Unadjusted No. (%)	Adjusted		
			%	Risk Difference (95% CI)[a]	
During last mo of life					
Intensive care unit admission					
No	995 (86.8)	520 (52.3)	52.5	−9.4 (−18.2 to −0.6)	.04
Yes	151 (13.1)	68 (45.0)	43.1		
≥2 Hospitalizations					
No	1076 (93.9)	556 (51.7)	51.8	−8.5 (−20.8 to 3.8)	.17
Yes	70 (6.1)	32 (45.7)	43.3		
≥2 Emergency department visits					
No	1056 (92.1)	542 (51.3)	51.4	−1.5 (−12.8 to 9.7)	.79
Yes	90 (7.9)	46 (51.1)	49.9		
Chemotherapy ≤2 wk before death					
No	1071 (93.5)	551 (51.5)	51.5	−2.6 (−14.8 to 9.6)	.68
Yes	75 (6.5)	37 (49.3)	48.9		
No hospice or ≤3 d before death					
No	599 (52.3)	352 (58.8)	59.3	−16.5 (−22.4 to −10.7)	<.001
Yes	547 (47.7)	236 (43.1)	42.8		
Death occurred in hospital					
No	686 (59.9)	394 (57.4)	58.0	−17.0 (−22.9 to −11.1)	<.001
Yes	460 (40.1)	194 (42.2)	41.0		

[a] Adjusted for sex, age, race/ethnicity, education, income, marital status, region, integrated health system, cancer stage, comorbid conditions, depression, time from diagnosis to death, respondent, treatment preferences, cancer type, and time between death and decedent interview using linear-binomial models with an identity link.

[b] Assesses differences for patients who experienced aggressive care vs those who did not.

Aggressive Treatment and Family Member–Rated Quality of End-of-Life Care

In adjusted analyses, family members reported excellent end-of-life care more often for patients who received hospice care for longer than 3 days (58.8% [352/599]) than those who did not receive hospice care or received 3 or fewer days (43.1% [236/547]) (adjusted difference, 16.5 percentage points [95% CI, 10.7 to 22.4 percentage points]; Table 5). In contrast, family members of patients admitted to an ICU within 30 days of death reported excellent end-of-life care less often (45.0% [68/151]) than those who were not admitted to an ICU within 30 days of death (52.3% [520/995]) (adjusted difference, −9.4 percent-

age points [95% CI, −18.2 to −0.6 percentage points]). Similarly, family members of patients who died in the hospital reported excellent end-of-life care less often (42.2% [194/460]) than those who did not die in the hospital (57.4% [394/686]) (adjusted difference, −17.0 percentage points [95% CI, −22.9 to −11.1 percentage points]). Family member-reported end-of-life care quality ratings were not significantly different in patients with frequent use (≥2 visits) of the emergency department during the last month of life (51.1% [46/90]) and in those without such use (51.3% [542/1056]) (adjusted difference, −1.5 percentage points [95% CI, −12.8 to 9.7 percentage points]) and in patients who received chemotherapy within 2 weeks of death

Table 6. Associations Between Aggressive End-of-Life Care and Patient Receipt of Goal-Concordant End-of-Life Care

Type of Aggressive End-of-Life Care	Family Member Reported That End-of-Life Wishes of Patient Were Followed[a]				Family Member Reported That Patient Died in Preferred Place[c]			
	Unadjusted No./Total (%) (n = 930)	Adjusted		P Value[d]	Unadjusted No./Total (%) (n = 774)	Adjusted[b]		P Value[d]
		%	Risk Difference (95% CI)[b]			%	Risk Difference (95% CI)	
During last mo of life								
Intensive care unit admission								
No	662/814 (81.3)	80.0	−3.5 (−12.5 to 5.4)	.43	404/682 (59.2)	59.4	−22.8 (−33.5 to −12.0)	<.001
Yes	92/116 (79.3)	76.5			35/92 (38.0)	36.6		
≥2 Hospitalizations								
No	707/872 (81.1)	79.7	1.1 (−12.4 to 10.2)	.85	419/731 (57.3)	57.1	−8.8 (−24.2 to 6.7)	.27
Yes	47/58 (81.0)	78.6			20/43 (46.5)	48.3		
≥2 Emergency department visits								
No	700/861 (81.3)	79.9	−4.3 (−15.2 to 6.6)	.44	407/712 (57.2)	56.8	−2.7 (−15.6 to 10.2)	.68
Yes	54/69 (78.3)	75.6			32/62 (51.6)	54.1		
Chemotherapy ≤2 wk before death								
No	709/871 (81.4)	79.9	−4.9 (−16.5 to 6.6)	.40	423/736 (57.5)	57.5	−17.7 (−34.0 to −1.4)	.03
Yes	45/59 (76.3)	75.0			16/38 (42.1)	39.8		
No hospice or ≤3 d before death								
No	435/515 (84.5)	81.1	−5.2 (−11.2 to −0.8)	.02	287/394 (72.8)	74.0	−34.4 (−41.7 to −27.0)	<.001
Yes	319/415 (76.9)	75.9			152/380 (40.0)	39.6		
Death occurred in hospital								
No	478/576 (83.0)	81.5	−3.9 (−9.6 to 1.7)	.17	358/449 (79.7)	77.9	−50.5 (−57.1 to −43.9)	<.001
Yes	276/354 (78.0)	77.6			81/325 (24.9)	27.4		

[a] Analyses examining whether patients' end-of-life wishes were "followed a great deal" included 930 interviews from family members; 216 family members who responded "unknown" were excluded.

[b] Adjusted for sex, age, race/ethnicity, education, income, marital status, region, integrated health system, cancer stage, comorbid conditions, depression, time from diagnosis to death, respondent, treatment preferences, cancer type, and time between death and decedent interview using linear-binomial models with an identity link.

[c] Analyses included 774 interviews from family members; 372 family members who responded "unknown" were excluded.

[d] Assesses differences for patients who experienced aggressive care vs those who did not.

(49.3% [37/75]) and in those who did not receive chemotherapy (51.5% [551/1071]) (adjusted difference, −2.6 percentage points [95% CI, −14.8 to 9.6 percentage points]).

Aggressive End-of-Life Care and Patient Goal Attainment

Family members of patients who did not receive hospice care or received 3 or fewer days were less likely to report that patients died in their preferred place (40.0% [152/380]) than those who received hospice care for longer than 3 days (72.8% [287/394]) (adjusted difference, −34.4 percentage points [95% CI, −41.7 to −27.0 percentage points]; Table 6). Patients who were admitted to an ICU during the last month of life were less likely to die in their preferred place (38.0% [35/92]) than those who were not admitted to the ICU (59.2% [404/682]) (adjusted difference, −22.8 percentage points [95% CI, −33.5 to −12.0 percentage points]). Patients who received chemotherapy within 2 weeks of death were less likely to die in their preferred place (42.1% [16/38]) than those who did not receive chemotherapy near the end of life (57.5% [423/736]) (adjusted difference, −17.7 percentage points [95% CI, −34.0 to −1.4 percentage points]).

In sensitivity analyses that recategorized family member–reported quality of end-of-life care as "excellent" and "very good" vs "good," "fair," and "poor," and as an ordinal model, the results were consistent with the main findings. There were few differences in the models that included family member–reported contact with patients during the last week or frequency of discussions of important medical decisions with patients. We also found few differences in results from analyses that included family member–reported measures of patients' symptoms, and whether they were adequately controlled (eTables 5 and 6 in the Supplement).

In addition, the results were comparable in the models stratified by cancer type except that ICU admissions were not associated with family member–reported quality of end-of-life care. Family members of patients with colorectal cancer who did not receive hospice care or received 3 or fewer days before death were less likely to report that patients' wishes were followed "a great deal" (66.6%) than those who received hospice care for longer than 3 days (84.4%) (adjusted difference, −17.8 percentage points [95% CI, −28.9 to −6.7 percentage points]; P = .002).

Discussion

In this diverse population-based cohort, we found that 3 measures of aggressive end-of-life care (ICU admission within 30 days of death, no hospice care or ≤3 days of hospice services, and deaths occurring in the hospital) were associated with relatively large differences in family member–reported quality ratings for end-of-life care and a lower likelihood that patients

with advanced-stage cancer received care congruent with their preferences. Our findings suggest that efforts to increase earlier hospice enrollment and avoidance of ICU admissions and hospital deaths might improve the quality of end-of-life care. For example, implementation of multifaceted approaches (eg, enhanced counseling of patients and families, early palliative care referrals, and an audit and feedback system to monitor physicians' use of aggressive end-of-life care) might result in more preference-sensitive care for patients and overall improved quality of end-of-life care.[2,16]

To our knowledge, this study is one of the first empirical validations of these aggressive end-of-life care indicators using patient- and family member–centered outcomes in a population-based cohort. These findings may have policy implications because administrative database indicators[4] are becoming increasingly feasible to assess with the expansion of electronic health records under the Health Information Technology for Economic and Clinical Health Act. This is particularly noteworthy given increasing evidence that physicians' characteristics and beliefs are one of the strongest predictors of end-of-life care,[20,21] suggesting that modifications to physicians' practices may result in significant improvements.

Several studies have previously documented an association between less-aggressive end-of-life care and improved patient quality of life near death.[2,8,16,22-25] Our study extends this research by demonstrating similar associations with family member–rated quality for end-of-life care in a large cohort of patients treated in community settings in multiple regions of the United States. In addition, we assessed patients' preferences for care and found that most older patients with fee-for-service Medicare wanted palliative treatments more than life-extending care, and preferred to die at home, which is similar to the findings from other studies.[26,27] Such preferences were strongly associated with the aggressiveness of end-of-life care received.

Although existing quality measures characterize the repeated use of emergency visits near death as poor quality care, we did not observe a difference in family member–reported ratings by this measure, perhaps because some patients or caregivers may be unprepared or unable to manage acute symptoms at home.[28] The lack of validation of this indicator suggests that some aggressive care measures may be less salient to patients and families.

Similarly, we found no differences in family member–rated quality of end-of-life care among patients who received chemotherapy within 2 weeks of death compared with those who did not, although the study was underpowered to detect these differences because less than 7% of patients received chemotherapy within this period close to death. Nevertheless, chemotherapy use within 2 weeks of death was associated with a decreased likelihood that patients' died in their preferred place, which is consistent with another study.[29]

Our study had some limitations. Although the patients who enrolled in CanCORS were representative of patients diagnosed with lung and colorectal cancer in the US regions covered by the Surveillance, Epidemiology, and End Results registries,[30] we studied older patients with lung and colorectal cancers insured by Medicare who died predominantly before 2008. We had to exclude many patients who were not enrolled in Medicare fee-for-service plans or whose family members could not be reached. Our findings may not be generalizable to patients who are younger, commercially insured, uninsured, treated in Veteran's Administration hospitals, have other diseases, or died more recently. The data are older, particularly for patients who died soon after diagnosis, due to the time involved with linking interview and claims data.

However, one of the study's strengths is that it includes patients who were longer-term cancer survivors who may have different experiences near death. In addition, recent data demonstrate that end-of-life care among Medicare beneficiaries remains intensive (ICU admissions and late hospice enrollments are increasing over time)[1]; thus patients' and family members' experiences are likely to be similar today. Our results may be subject to unmeasured confounding related to unsuccessful linkages to Medicare claims. However, our family member–reported rates of "excellent" quality for end-of-life care and receipt of care that was not consistent with patients' preferences are similar to another population-based study of patients who died from diverse diseases and were insured by Medicare fee-for-service and health maintenance organization plans.[31]

Family members reported on patients' end-of-life experiences at variable time points after death, and some may have forgotten details over time. Although a recent study demonstrates moderate to high stability in bereaved family members' assessments of patients' end-of-life experiences over time,[32] future research should examine family members' recall over longer durations. We relied on family members' reports of patients' preferred and actual place of death to determine goal attainment. Nevertheless, these questions were separated by at least 40 questions to minimize conscious comparisons. In addition, the study was underpowered to examine some associations (eg, we had 80% power to detect a 17% absolute difference in the quality of end-of-life care between patients who were and were not hospitalized ≥2 times during the last month of life, but this outcome was relatively infrequent).

Conclusions

Among family members of older patients with fee-for service Medicare who died of lung or colorectal cancer, earlier hospice enrollment, avoidance of ICU admissions within 30 days of death, and death occurring outside the hospital were associated with perceptions of better end-of-life care. These findings are supportive of advance care planning consistent with the preferences of patients.

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