

Family Perspectives on Hospice Care Experiences of Patients with Cancer

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A B S T R A C T

Purpose

To determine whether hospice use by patients with cancer is associated with their families' perceptions of patients' symptoms, goal attainment, and quality of end-of-life (EOL) care.

Methods

We interviewed 2,307 families of deceased patients with advanced lung or colorectal cancer who were enrolled in the Cancer Care Outcomes Research and Surveillance study (a multiregional, prospective, observational study) and died by 2011. We used propensity-score matching to compare family-reported outcomes for patients who did and did not receive hospice care, including the presence and relief of common symptoms (ie, pain, dyspnea), concordance with patients' wishes for EOL care and place of death, and quality of EOL care. We also examined associations between hospice length of stay and these outcomes among hospice enrollees.

Results

In a propensity-score-matched sample of 1,970 individuals, families of patients enrolled in hospice reported more pain in their patient compared with those not enrolled in hospice. However, families of patients enrolled in hospice more often reported that patients received "just the right amount" of pain medicine (80% v 73%; adjusted difference, 7 percentage points; 95% confidence interval [CI], 1 to 12 percentage points) and help with dyspnea (78% v 70%; adjusted difference, 8 percentage points; 95% CI, 2 to 13 percentage points). Families of patients enrolled in hospice also more often reported that patients' EOL wishes were followed (80% v 74%; adjusted difference, 6 percentage points; 95% CI, 2 to 11 percentage points) and "excellent" quality EOL care (57% v 42%; adjusted difference, 15 percentage points; 95% CI, 11 to 20). Families of patients who received > 30 days of hospice care reported the highest quality EOL outcomes.

Conclusion

Hospice care is associated with better symptom relief, patient-goal attainment, and quality of EOL care. Encouraging earlier and increased hospice enrollment may improve EOL experiences for patients with cancer and their families.

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INTRODUCTION

Patients with advanced cancer often experience pain, dyspnea, and distress at the end of life (EOL), and use intensive, hospital-based services near death.¹⁻³ Hospice offers an alternative, patient-centered model of care focused on relieving suffering, and often delivers services within the home environment. ASCO recently adopted timely hospice enrollment (defined as > 3 days before death) as a key quality measure for patients with incurable, poor-prognosis cancers⁴ because hospice has been associated with less hospital-based EOL medical care, better quality of life, and improved caregiver outcomes.^{2,5-9}

Despite this, few studies have examined the associations between receipt of hospice and the symptoms experienced by patients with advanced cancer and receipt of medical care congruent with their preferences.⁷ Similarly, few studies have assessed whether these outcomes differ by the duration of hospice enrollment.^{2,10-14} This is important because although hospice use has increased since the 1990s,^{3,15} many patients with advanced cancer are enrolled ≤ 3 days of death.³

In this study, we examined whether hospice was associated with family members' reports of the presence and relief of common symptoms, patient-goal attainment, and quality of EOL care, using data from the Cancer Care Outcomes

ASSOCIATED CONTENT

Appendix
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Research and Surveillance (CanCORS) Consortium. We also assessed whether longer hospice stays were associated with better family-reported outcomes among hospice enrollees.

METHODS

Dataset

Data came from the CanCORS I and II studies, which enrolled participants from 2003 through 2005 and followed patients or family through 2011. CanCORS enrolled patients with newly diagnosed lung or colorectal cancers from five regions (northern California; Los Angeles County, California; North Carolina; Iowa; and Alabama), five integrated health systems, and 15 Veterans Affairs hospitals.¹⁶ CanCORS participants were representative of patients diagnosed with lung or colorectal cancer in the US regions covered by the SEER program.¹⁷

Trained staff interviewed participants (or a family member or close friend, if the patient was too ill or had died) in English, Spanish, or Chinese, using computer-assisted telephone software at three time points after diagnosis: (1) approximately 4 to 6 months, (2) 1 year (for patients alive at the first interview), and (3) 5 to 7 years later (for patients alive 1 year after diagnosis). The study was approved by the institutional review boards at all sites.

Cohort

The study cohort included participants with advanced-stage lung or colorectal cancer at diagnosis or recurrence who died by 2011 and whose family or close friend participated in a postdeath interview. For patients deceased at the time of initial study contact, the next of kin was invited to participate. Patients who were alive for the first 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 (eg, spouse/partner, child) we refer to respondents as family. The final cohort included 2,307 decedents.

Outcome Variables

Outcomes of interest included family members’ perceptions of patients’ symptom prevalence and control, concordance of EOL care with patients’ preferences, and quality of EOL care. Specifically, we examined symptom burden (ie, pain or dyspnea), symptom control, overall quality of EOL care, and goal attainment (ie, whether patients’ EOL wishes were followed and whether they died in their preferred place).

To assess symptoms, family members were asked whether, in the last days to weeks of life, patients had “pain or took pain medication” (yes/no) or had “shortness of breath” (yes/no). Family members who affirmed the presence of pain or dyspnea were asked the following: “How much medicine did the patient receive for his/her pain?” and/or “How much help...with his/her breathing did the patient receive?” Response options included “less than he/she wanted,” “just the right amount,” and “more than he/she wanted.”

We examined concordance with patients’ previously stated wishes for EOL care, asking the family: “During the last month of life, did he/she prefer a course of treatment that focused on extending life as much as possible, even if it meant more pain and discomfort, or on a plan that focused on relieving pain and discomfort as much as possible, even if that meant not living as long?” Next, family members were asked: “To what extent were these wishes followed in the medical treatment he/she received during the last month of life?” Response options included: “a great deal,” “somewhat,” “not at all,” “don’t know,” or “refused.” We defined concordance as family who responded “a great deal” to this question. We also assessed the concordance between the patients’ previously stated preferred place of death (reported by family) and where patients actually died. We defined concordance as patients whose actual place of death matched their preferred place. Family members also rated the overall quality of care received by patients in the last place where they spent ≥ 48 hours before death (rating options were excellent, very good, good, fair, or poor). We defined high-quality EOL care as care that was rated excellent.

Independent Variables

Receipt of hospice was assessed by asking the family whether the patient ever received hospice care (yes/no). The family reported the duration of hospice services received, categorized as ≤ 3 days, 4 to 7 days, 8 to 30 days, or > 30 days before death. We compared ≤ 3 days of hospice services with longer stays because prior studies suggested that short hospice stays are associated with worse patient quality of life and EOL care, compared with longer durations.^{2,5}

Additional Baseline Covariates

Sociodemographic characteristics and treatment preferences. In the baseline survey, patients or their family reported sex, age at death, race/ethnicity, marital status, whether English was spoken at home, education, income, and insurance.

Clinical covariates. Cancer type and stage at diagnosis data were obtained from the medical record or, if unavailable, from cancer registries. The family reported patients’ smoking status, comorbid medical conditions, and receipt of cancer-directed surgery, chemotherapy, or radiation. We also documented the region where patients resided and whether they received treatment within an integrated health-care system.

Statistical Analysis

We compared, with descriptive statistics, sociodemographic and clinical characteristics between patients who did or did not receive hospice care. We examined family-reported outcomes by hospice enrollment after using propensity score matching to balance measurable confounders between those who received hospice and those who did not.¹⁸ We used logistic regression to assess patient factors associated with hospice and then matched nonhospice enrollees with hospice enrollees based on their estimated propensity of hospice enrollment using 1:1 matching via a greedy algorithm with a caliper of 0.20. Standardized differences in observable characteristics of the matched cohort were $\leq 7\%$ (Appendix Table A1, online only).

We compared relief of EOL symptoms, concordance with family-reported patient EOL preferences, and family-reported quality of EOL care, using separate logistic regression models among the propensity-matched cohort. We fit linear-binomial models with an identity link to estimate adjusted differences in the likelihood of each outcome.¹⁹

In a second set of analyses among patients enrolled in hospice, we examined associations between each of the dependent variables and hospice length of stay (categorized with indicator variables as ≤ 3 days, 4 to 7 days, 8 to 30 days, > 30 days), while adjusting for all the covariates described. We calculated adjusted rates for each outcome by hospice duration, using ≤ 3 days as the reference category.

Missing data on outcomes varied between 1% (quality of EOL care) and 19% (EOL wishes); missing data for covariates ranged between 1% (stage) and 15% (income). We used multiple imputation methods to create five complete data sets, imputing values for missing outcomes and covariates, and repeated all analyses on each imputed data set, combining results using standard methods for multiple imputed data for our primary analysis.^{20,21} Sensitivity analyses were conducted to examine associations between hospice and each outcome in a second sample without imputation of outcome data. Because patients with lung and colorectal cancer may differ, we repeated analyses stratified by disease site tested for the interaction of hospice and disease site. Two-sided P values $< .05$ were considered statistically significant; analyses were performed using SAS software, version 9.2 (SAS Institute, Cary, NC).

RESULTS

Among 3,737 participants with advanced-stage cancer at diagnosis or recurrence, 2,307 had an after-death family interview and were included in the cohort. These individuals were older, less educated, and had more advanced-stage disease and comorbid medical conditions than participants without an after-death interview; they

Table 1. Patient Characteristics by Hospice Enrollment

Characteristic*	Unadjusted			After Propensity Score Matching		
	Hospice (n = 1,257)	No Hospice (n = 1,050)	P	Hospice (n = 985)	No Hospice (n = 985)	P
Males (%)	52	58	.005	50	51	.6
Age at death, years (%)			.3			1
< 55	12	11		11	11	
55-64	23	22		23	23	
65-74	30	34		33	32	
≥ 75	35	33		33	34	
Race/ethnicity (%)			< .001			.4
White	81	68		75	73	
Black	9	13		12	12	
Hispanic	4	9		5	7	
Asian/Pacific Islander	3	6		4	5	
Other	4	5		5	5	
Married (%)	60	61	.9	61	62	.7
Spoke English at home (%)	94	89	< .001	93	92	.1
Education (%)			0.9			.9
Less than high school graduate	23	23		22	22	
High school graduate	60	59		61	60	
College graduate	17	18		17	18	
Income, US\$ (%)			.2			.7
< 20,000	34	34		33	34	
20,000-39,999	34	32		33	32	
40,000-59,999	17	16		17	17	
≥ 60,000	15	18		16	18	
Insurance (%)	91	89	.5	91	91	.9
Region (%)			< .001			.6
Midwest	27	19		22	21	
South	24	25		28	27	
West	49	56		50	53	
Integrated health-care system (%)			< .001			0.9
Yes	36	28		31	30	
No	64	72		69	70	
Primary cancer (%)			.2			1
Lung	80	77		71	71	
Colorectal	20	23		29	29	
Stage at diagnosis (%)			.6			.6
I/II	9	10		10	11	
IIIA	3	3		4	3	
IIIB, IIIC, IV	87	88		87	87	
Ever smoker (%)	85	82	.2	83	83	1
Comorbid conditions before death (%)			.3			1
0	37	37		37	38	
1	34	36		35	35	
≥ 2	29	27		28	28	
Preferred course of treatment in last month of life			< .001			.1
Extend life as much as possible	24	39		32	35	
Relieve pain or discomfort as much as possible	76	61		68	65	
Cancer-directed therapy			.005			.6
Surgery	29	34		32	33	
Chemotherapy	56	60	.04	60	59	.8
Radiation	36	34	.6	35	34	.8
Days between diagnosis and death, mean (SD)	422 (570)	362 (567)	.01	403 (545)	385 (589)	.5
Days between death and family interview, mean no. (SD)	532 (757)	460 (698)	.02	530 (766)	490 (720)	.3
Respondent, (%)			0.04			1
Spouse/partner	48	46		48	48	
Child or daughter/son-in-law	33	31		32	32	
Other relative	12	16		14	15	
Friend/other	6	7		6	6	

Abbreviation: SD, standard deviation.

*Missing data: education (n = 10), income (n = 163), stage (n = 12), comorbid conditions (n = 10).

also received fewer cancer-directed therapies (Appendix Table A2, online only).

Among these 2,307 participants, 1,257 (55%) enrolled in hospice before death. Those enrolled in hospice were more likely to be non-Hispanic white (81% v 68%; $P < .001$), speak English at home (94% v 89%; $P < .001$), and receive care in an integrated health system (36% v 28%; $P < .001$) than those who did not receive hospice (Table 1). They were also more likely to have a family-reported preference for pain relief over life extension (76% v 61%; $P < .001$), and less likely to have received surgery (29% v 34%; $P = .005$) or chemotherapy (56% v 60%; $P = .04$).

Family-Reported Outcomes by Hospice Enrollment

Among the 1,050 patients who did not enroll in hospice, 985 were matched with a patient who was enrolled in hospice, resulting in a final cohort of 1,970 patients (985 matched pairs; Table 1). In adjusted analyses (Table 2), families of patients who received hospice care were more likely to report pain or use of pain medication, compared with those not receiving hospice (91% v 81%; adjusted difference, 10 percentage points; 95% CI, 7 to 13 percentage points). Among those who reported symptoms, families of patients enrolled in hospice were more likely to report that patients received “just the right amount of pain medicine” (80% v 73%; adjusted difference, 7 percentage points; 95% CI, 1 to 12 percentage points) and “just the right amount of help with breathing” (78% v 70%; adjusted difference, 8 percentage points; 95% CI, 2 to 13 percentage points), compared with those not enrolled in hospice. They were also less likely to report receiving “too little pain medicine” (8% v 11%; adjusted difference, 3 percentage points; 95% CI, 0 to 6 percentage points) or “less help with breathing than wanted” (12% v 18%; adjusted difference, 6 percentage points; 95% CI, 2 to 11 percentage points). Families of hospice enrollees were not more likely to report that patients received “too much pain medicine.”

Families of patients enrolled in hospice were more likely to report that patients’ EOL wishes were followed “a great deal” (80% v 74%; adjusted difference, 6 percentage points; 95% CI, 2 to 11

percentage points). Decedents who received hospice care were also more likely to die in their preferred place (68% v 39%; adjusted difference, 29 percentage points; 95% CI, 23 to 34 percentage points). Families also reported excellent quality of EOL care more often for patients who received hospice (57% v 42%; adjusted difference, 15 percentage points; 95% CI, 11 to 20; Table 2), compared with those who did not.

Family-Reported Outcomes by Hospice Length of Stay

Among the 1,257 patients enrolled in hospice, the median length of enrollment was 21 days (interquartile range, 7 to 56 days). Overall, longer hospice stays were associated with family perceptions that patients received “just the right amount of pain medication,” greater patient-goal attainment, and higher rates of family-reported excellent quality of EOL care, compared with short stays (Table 3; Fig 1). Specifically, families of patients who received > 30 days of hospice care more often reported “just the right amount of pain medicine” than those enrolled ≤ 3 days (85% v 76%; adjusted difference, 9 percentage points; 95% CI, 2 to 16). Similarly, families of patients who received ≥ 8 days of hospice less often reported that patients received “too little pain medicine” compared with those enrolled ≤ 3 days; findings were similar when comparing > 30 days with ≤ 3 days of hospice. Family-reported help with dyspnea did not vary by hospice duration.

Families of patients who received > 30 days of hospice more often reported that patients’ EOL wishes were followed “a great deal” compared with patients enrolled ≤ 3 days (87% v 79%; adjusted difference, 8 percentage points; 95% CI, 1 to 15) and more often rated the quality of EOL care “excellent” (65% v 50%; adjusted difference, 15 percentage points; 95% CI, 6 to 23). The longer patients were enrolled in hospice, the more likely they were to die in their preferred place.

Sensitivity Analyses

In sensitivity analyses, we examined associations between hospice enrollment and each outcome after excluding individuals

Table 2. Hospice and Family-Reported End-of-Life Symptoms, Care Quality, and Goal Attainment in Propensity-Matched Sample

Family-Reported Outcomes in the Last Month	Unadjusted	Adjusted			95% CI for Risk Difference	P
	Proportion (%)	Hospice (n = 985), %	No Hospice (n = 985), %	Risk Difference		
Proportion reporting symptoms						
Pain or use of pain medicine	1,555/1,806 (86)	91	81	10	7 to 13	< .001
Trouble breathing	1,313/1,816 (72)	71	74	-3	-8 to 1	.1
Control of pain						
Just the right amount of pain medicine	1,145/1,555 (77)	80	73	7	1 to 12	.02
Too much pain medicine	155/1,555 (10)	10	11	-1	-5 to 4	.9
Too little pain medicine	136/1,555 (9)	8	11	-3	-6 to 0	.046
Help with breathing						
Just the right amount of help with breathing	954/1,313 (74)	78	70	8	2 to 13	.005
More help with breathing than wanted	112/1,313 (9)	9	8	1	-3 to 4	.9
Less help with breathing than wanted	198/1,313 (15)	12	18	-6	-11 to -2	.003
Proportion reporting excellent EOL care quality and patient goal attainment						
Excellent quality EOL care	878/1,816 (48)	57	42	15	11 to 20	< .001
EOL wishes followed a great deal	1164/1,514 (77)	80	74	6	2 to 11	.006
Death in preferred place	961/1,801 (53)	68	39	29	23 to 34	< .001

Abbreviation: EOL, end of life.

Table 3. Adjusted Associations Between Hospice Length of Stay and Family-Reported End-of-Life Symptoms, Care Quality, and Goal Attainment Among Patients Enrolled in Hospice (n = 1,257)

Family-Reported Outcomes in the Last Month	Unadjusted		Adjusted		
	No.	%	Risk Difference Compared With ≤ 3 Days	95% CI for Risk Difference	P
Proportion reporting symptoms					
Pain or use of pain medicine	1,138/1,247	91			
≤ 3 days of hospice		87			
4-7 days		95	8	2 to 14	.009
8-30 days		93	6	2 to 11	.01
> 30 days		90	3	-2 to 8	.2
Trouble breathing	891/1,254	71			
≤ 3 days of hospice		70			
4-7 days		69	-1	-11 to 8	.8
8-30 days		70	0	-8 to 7	1
> 30 days		74	4	-4 to 11	.4
Control of pain					
Just the right amount of pain medicine	904/1,138	79			
≤ 3 days of hospice		76			
4-7 days		79	3	-6 to 11	.6
8-30 days		81	5	-2 to 12	.2
> 30 days		85	9	2 to 16	.02
Too much pain medicine	110/1,138	10			
≤ 3 days of hospice		9			
4-7 days		12	3	-3 to 10	.3
8-30 days		11	2	-4 to 8	.5
> 30 days		9	0	-6 to 6	1
Too little pain medicine	97/1,138	9			
≤ 3 days of hospice		15			
4-7 days		9	-6	-12 to 0	.05
8-30 days		8	-7	-12 to -2	.008
> 30 days		6	-9	-14 to -3	.002
Help with breathing					
Just the right amount of help with breathing	712/891	80			
≤ 3 days of hospice		80			
4-7 days		78	-2	-12 to 8	.7
8-30 days		83	3	-5 to 11	.4
> 30 days		81	1	-7 to 10	.7
More help with breathing than wanted	72/891	8			
≤ 3 days of hospice		9			
4-7 days		8	0	-8 to 7	1
8-30 days		7	-2	-7 to 4	.5
> 30 days		9	0	-5 to 6	.9
Less help with breathing than wanted	93/877	11			
≤ 3 days of hospice		12			
4-7 days		14	2	-6 to 10	.6
8-30 days		10	-2	-8 to 5	.6
> 30 days		10	-2	-9 to 5	.6
Proportion reporting excellent EOL care quality and patient goal attainment					
Excellent quality EOL care	1,029/1,254	80			
≤ 3 days of hospice		50			
4-7 days		56	6	-5 to 16	.3
8-30 days		54	3	-5 to 11	.4
> 30 days		65	15	6 to 23	< .001
End-of-life wishes followed a great deal	931/1,132	82			
≤ 3 days of hospice		79			
4-7 days		80	1	-8 to 10	.8
8-30 days		80	1	-6 to 8	.9
> 30 days		87	8	1 to 15	.02
Death in preferred place	821/1,245	66			
≤ 3 days of hospice		48			
4-7 days		61	14	4 to 23	.004
8-30 days		67	20	12 to 27	< .001
> 30 days		75	28	20 to 35	< .001

Abbreviation: EOL, end of life.

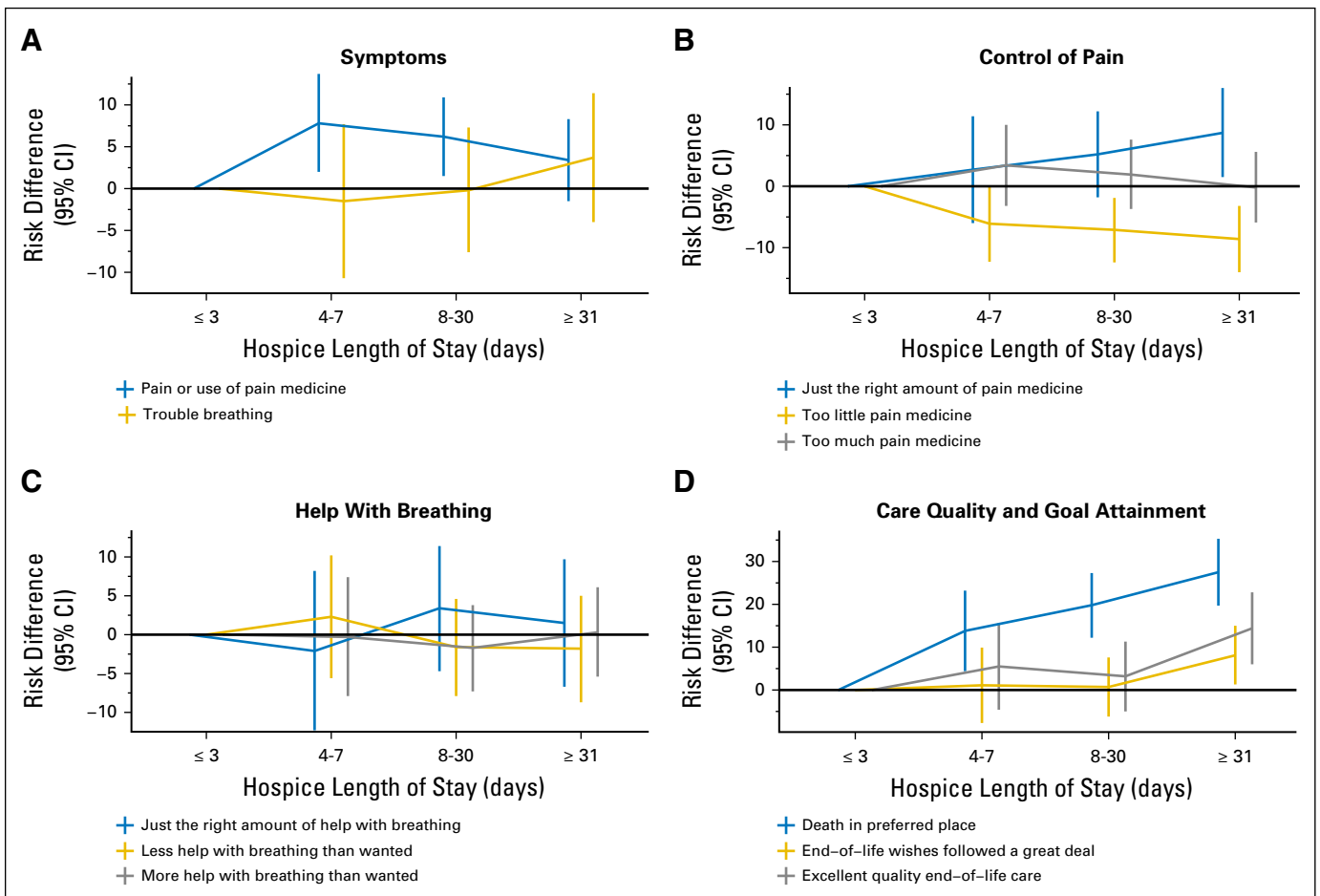


Fig 1. Adjusted associations between hospice length of stay and family-reported end-of-life outcomes among patients enrolled in hospice (n = 1,257), expressed as risk differences and 95% CI (bars), compared with the reference (≤ 3 days): (A) symptoms, (B) control of pain, (C) help with breathing, and (D) care quality and goal attainment. Analyses adjusted for all patient characteristics listed in Table 1, independent of significance.

with missing values for dependent variables. The results were consistent with the main findings except that associations between hospice and “EOL wishes followed a great deal” no longer reached statistical significance (data not shown). Results were also similar when stratified by cancer type ($P \geq .09$ for interaction between hospice and cancer type for all outcomes; data not shown).

DISCUSSION

In this large, population-based cohort study of patients with advanced-stage cancer and high symptom burden, family members of patients enrolled in hospice were more likely to report that patients received “just the right” level of help with pain and dyspnea—not “too much,” or “too little.” Hospice use was also associated with higher rates of family-reported patient-goal attainment and quality of EOL care. In addition, patients who received > 30 days of hospice were more likely to receive optimal pain management, care that was congruent with their wishes, and care that family described as of “excellent” quality, compared with patients enrolled for ≤ 3 days. Together, our findings suggest that encouraging hospice enrollment, particularly enrollment weeks before death, may improve EOL experiences of patients with cancer.

To date, relatively few studies have examined bereaved family members’ perspectives on hospice care in population-based cohorts. We found that fewer than half of family members reported “excellent” quality of EOL care and nearly one-quarter felt that patients’ EOL wishes were not followed a “great deal.” These results demonstrate that a substantial proportion of patients with cancer have unmet needs close to death. Our examination of the prevalence and relief of symptoms by receipt of hospice services extends findings from earlier studies,^{7,22} demonstrating that although patients enrolled in hospice have more symptoms, their symptoms are better controlled overall. Of note, the families of patients enrolled in hospice were not more likely to report that patients received “too much” pain medicine; rather, they were more likely to report that patients received “just the right amount.”

A unique feature of this study was our ability to examine the relationship between the length of hospice enrollment and several important patient- and family-centered EOL outcomes, while adjusting for patients’ treatment preferences. Existing quality measures, endorsed by the National Quality Forum and ASCO, identify ≤ 3 days and ≤ 7 days of hospice services as poor-quality EOL care.^{23,24} Consistent with this, one prior study demonstrated that patients who received < 1 week of hospice care reported similar quality EOL care to those not receiving hospice.² In our

study, the families of patients who received > 8 days of hospice care were more likely to report that patients died in their preferred place and less likely to report inadequate pain control, compared with ≤ 3 days. However, > 70% of patients with lung or colorectal cancer experienced difficulty breathing, and relief of dyspnea did not vary by hospice length of stay; future studies should examine strategies to manage dyspnea more effectively. Additionally, we observed few differences between patients with very short stays (≤ 3 days) and moderately short stays (4 to 7 or 8 to 30 days); the best outcomes were generally seen in patients who received > 30 days of hospice.

Although early hospice enrollment may not be possible for all patients,¹⁰ our data suggest that more attention should be focused on efforts to enroll patients with cancer into hospice earlier because the median length of stay for patients enrolled in hospice care in the United States is only 17.4 days.²⁵ The requirement to forego cancer-directed therapy remains a major barrier to early hospice referral^{26,27}; however, early palliative care is associated with earlier discontinuation of chemotherapy and hospice referrals, without impacting the number of chemotherapy regimens received.²⁸

Our study had some limitations. Although CanCORS participants were representative of patients diagnosed with lung and colorectal cancers in SEER regions,¹⁷ our findings may not be generalizable to patients with other cancers or those without involved family caregivers. In addition, although we measured and adjusted for many of the patient and caregiver characteristics that influence hospice enrollment (eg, treatment preferences), other confounding influences may not have been measured (eg, we lacked information about patients' rate of functional decline and referring providers, both of which influence the intensity of EOL care provided).^{29,30} Moreover, patients with long hospice length of stays may differ from patients with shorter stays in ways that we could not measure. The data are older, particularly for patients who died soon after diagnosis. However, recent evidence demonstrates that EOL care remains intensive^{3,22,31}; thus, patients' and family members' experiences are likely to be similar today. Finally, we relied on family members' reports of patients' preferred and actual place of death to determine goal attainment.

Despite these limitations, our study has many strengths. The study population included patients of all ages (36% were < 65 years of age) with a wide range of insurance types, which has previously been associated with hospice lengths of stay.³² It also

included patients who recurred with advanced cancer and may have different experiences near death than patients with advanced cancer at diagnosis.

In conclusion, despite a higher symptom burden among patients enrolled in hospice, hospice care was associated with better symptom management, patient-goal attainment, and quality of EOL care. In addition, patients who received > 30 days of hospice care had the best family-reported EOL outcomes, compared with those who received ≤ 3 days. Together, these results suggest that current EOL care quality measures may be too narrowly focused on increasing hospice enrollment to > 3 or > 7 days of services. Future studies should examine whether multifaceted approaches (eg, early palliative care referrals,³³ sensitive provision of information about hospice care early in the disease course, and an audit and feedback system to monitor physicians' rates and timing of hospice referrals) might result in the provision of more preference-sensitive, high-quality, and value-based EOL care for patients with cancer. Future studies should also examine the impact of cancer immunotherapy on the timing of hospice referral; although these therapies are often less toxic than chemotherapy, they may be increasingly used in the last weeks of life.³⁴

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at ascopubs.org/journal/jco.

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Manuscript writing: All authors

Final approval of manuscript: All authors

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REFERENCES

1. Teunissen SC, Wesker W, Kruitwagen C, et al: Symptom prevalence in patients with incurable cancer: A systematic review. *J Pain Symptom Manage* 34:94-104, 2007
2. Wright AA, Zhang B, Ray A, et al: Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 300:1665-1673, 2008
3. Teno JM, Gozalo PL, Bynum JP, et al: Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 309:470-477, 2013
4. American Society of Clinical Oncology: The Quality Oncology Practice Initiative. 2013. <http://qopi.asco.org/program.html>.

5. Wright AA, Keating NL, Ayanian JZ, et al: Family perspectives on aggressive cancer care near the end of life. *JAMA* 315:284-292, 2016
6. Wright AA, Keating NL, Balboni TA, et al: Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol* 28:4457-4464, 2010
7. Teno JM, Clarridge BR, Casey V, et al: Family perspectives on end-of-life care at the last place of care. *JAMA* 291:88-93, 2004
8. Obermeyer Z, Makar M, Abujaber S, et al: Association between the Medicare hospice benefit and health care utilization and costs for patients with poor-prognosis cancer. *JAMA* 312:1888-1896, 2014
9. Ornstein KA, Aldridge MD, Garrido MM, et al: Association between hospice use and depressive symptoms in surviving spouses. *JAMA Intern Med* 175:1138-1146, 2015

10. Teno JM, Casarett D, Spence C, et al: Is it "too late" or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less. *J Pain Symptom Manage* 43:732-738, 2012
11. Rickerson E, Harrold J, Kapo J, et al: Timing of hospice referral and families' perceptions of services: Are earlier hospice referrals better? *J Am Geriatr Soc* 53:819-823, 2005
12. Schockett ER, Teno JM, Miller SC, et al: Late referral to hospice and bereaved family member perception of quality of end-of-life care. *J Pain Symptom Manage* 30:400-407, 2005
13. Yamagishi A, Morita T, Kawagoe S, et al: Length of home hospice care, family-perceived timing of referrals, perceived quality of care, and quality of death and dying in terminally ill cancer patients who died at home. *Support Care Cancer* 23:491-499, 2015

14. Miller SC, Kinzbrunner B, Pettit P, et al: How does the timing of hospice referral influence hospice care in the last days of life? *J Am Geriatr Soc* 51: 798-806, 2003
15. Wright AA, Hatfield LA, Earle CC, et al: End-of-life care for older patients with ovarian cancer is intensive despite high rates of hospice use. *J Clin Oncol* 32:3534-3539, 2014
16. Ayanian JZ, Chrischilles EA, Fletcher RH, et al: Representativeness of participants in the cancer care Outcomes Research and Surveillance Consortium. *J Clin Oncol* 22:2992-2996, 2004
17. Catalano PJ, Ayanian JZ, Weeks JC, et al: Representativeness of participants in the cancer care outcomes research and surveillance consortium relative to the Surveillance, Epidemiology, and End Results program. *Med Care* 51:e9-e15, 2013
18. Rosenbaum PR RD: Reducing bias in observational studies using subclassification on the propensity score. *J Am Stat Assoc* 79:516-524, 1984
19. Spiegelman D, Hertzmark E: Easy SAS calculations for risk or prevalence ratios and differences. *Am J Epidemiol* 162:199-200, 2005
20. Resche-Rigon M, White IR, Bartlett JW, et al: Multiple imputation for handling systematically missing confounders in meta-analysis of individual participant data. *Stat Med* 32:4890-4905, 2013
21. He Y, Zaslavsky AM, Landrum MB, et al: Multiple imputation in a large-scale complex survey: A practical guide. *Stat Methods Med Res* 19: 653-670, 2010
22. Teno JM, Freedman VA, Kasper JD, et al: Is care for the dying improving in the United States? *J Palliat Med* 18:662-666, 2015
23. National Quality Forum: Cancer Endorsement Maintenance 2011. http://www.qualityforum.org/Projects/Cancer_Endorsement_Maintenance_2011.aspx
24. Earle CC, Landrum MB, Souza JM, et al: Aggressiveness of cancer care near the end of life: Is it a quality-of-care issue? *J Clin Oncol* 26:3860-3866, 2008
25. National Hospice and Palliative Care Organization: NHPCO Facts and Figures: Hospice care in America. 2015 Edition. Alexandria, VA, National Hospice and Palliative Care Organization, 2015, p. 5
26. Wright AA, Katz IT: Letting go of the rope—aggressive treatment, hospice care, and open access. *N Engl J Med* 357:324-327, 2007
27. Casarett DJ, Fishman JM, Lu HL, et al: The terrible choice: Re-evaluating hospice eligibility criteria for cancer. *J Clin Oncol* 27:953-959, 2009
28. Greer JA, Pirl WF, Jackson VA, et al: Effect of early palliative care on chemotherapy use and end-of-life care in patients with metastatic non-small-cell lung cancer. *J Clin Oncol* 30:394-400, 2012
29. Kelley AS, Ettner SL, Morrison RS, et al: Determinants of medical expenditures in the last 6 months of life. *Ann Intern Med* 154:235-242, 2011
30. Obermeyer Z, Powers BW, Makar M, et al: Physician characteristics strongly predict patient enrollment in hospice. *Health Aff (Millwood)* 34: 993-1000, 2015
31. Chen RC FA, Tian F, Basak R, et al: Aggressive care at the end-of-life for younger patients with cancer: Impact of ASCO's Choosing Wisely campaign. *J Clin Oncol* 34, 2016 (suppl; abstr LBA10033)
32. O'Connor NR, Hu R, Harris PS, et al: Hospice admissions for cancer in the final days of life: Independent predictors and implications for quality measures. *J Clin Oncol* 32:3184-3189, 2014
33. Temel JS, Greer JA, Muzikansky A, et al: Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363:733-742, 2010
34. Nipp RD BA, Rubin KM, Blackmon SM, et al: Palliative care and hospice use among melanoma patients treated with immunotherapy. *J Clin Oncol* 33, 2015 (suppl 29S; abstr 116)

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Family Perspectives on Hospice Care Experiences of Patients With Cancer

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Appendix

Table A1. Standardized Differences Before and After Propensity Score Matching		
Characteristic	Before Matching	After Matching
Male patients	-12	-3
Age at death, years		
< 55	4	0
55-64	2	-1
65-74	-8	1
≥ 75	3	-1
Race/ethnicity		
White	30	5
Black	-11	1
Hispanic	-21	-7
Asian/Pacific Islander	-15	-6
Other	-7	2
Married	-1	-2
Spoke English at home	16	7
Education		
Less than high school graduate	1	-2
High school graduate	1	3
College graduate	-2	-1
Income, US\$ (%)		
< 20,000	0	-1
20,000-39,999	5	4
40,000-59,999	3	2
≥ 60,000	-9	-4
Uninsured	3	0
Region		
Midwest	21	2
South	-2	4
West	-16	-5
Not integrated health-care system	-16	-2
Stage at diagnosis		
I/II	-4	-3
IIIA	3	4
IIIB, IIIC, IV	1	1
Ever smoker	6	0
Comorbid conditions before death, No.		
0	1	-1
1	-5	0
≥ 2	7	1
Preference for life-extending therapy	-34	-7
Cancer-directed therapy		
Surgery	-12	-2
Chemotherapy	-9	1
Radiation	3	1
Time between diagnosis and death	0	0
Time between death and family interview	0	0
Respondent		
Spouse/partner	4	0
Child or daughter/son-in-law	6	0
Other relative	-11	-2
Friend/other	-3	1

Table A2. Participants Included in Study Cohort Versus Those Excluded, Based on Availability of Postdeath Family Interview

Characteristic	Included, No. (N = 3,737)	Excluded, No. (N = 1,430)	P
Male patients	61	58	.2
Age at death, years			< .001
< 55	12	22	
55-64	23	29	
65-74	32	30	
≥ 75	34	20	
Race/ethnicity			< .001
White	75	62	
Black	11	16	
Hispanic	6	8	
Asian/Pacific Islander	4	8	
Other	5	7	
Married	61	56	.005
Spoke English at home	91	81	< .001
Education			.01
Less than high school graduate	23	21	
High school graduate	60	57	
College graduate	18	22	
Income, US\$ (%)			< .001
< 20,000	36	24	
20,000-39,999	32	22	
40,000-59,999	15	10	
≥ 60,000	17	15	
Missing	0	29	
Uninsured	12	24	< .001
Region			< .001
Midwest	23	14	
South	25	28	
West	52	58	
Not integrated health-care system	68	64	< .001
Lung cancer	78	66	< .001
Stage at diagnosis			< .001
I/II	10	0	
IIIA	3	23	
IIIB, IIIC, IV	88	77	
Ever smoker	77	76	.3
Comorbid conditions before death			< .001
0	38	50	
1	35	33	
≥ 2	28	17	
Cancer-directed therapy			
Surgery	31	43	< .001
Chemotherapy	57	82	< .001
Radiation	35	34	.5