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Quality of End-of-Life Care Provided to Patients with Different Serious Illnesses

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Abstract

Importance—Efforts to improve end-of-life care have focused primarily on cancer patients. High quality end-of-life care is also critical for patients with other illnesses.

Objective—Compare patterns of end-of-life care and family-rated quality of care for patients dying with different serious illnesses.

Design—Retrospective cross-sectional study.

Setting—All 146 inpatient facilities within the Veteran Affairs (VA) health system.

Participants—Patients who died in VA inpatient facilities between October 2009 and September 2012 with clinical diagnoses categorized as: end-stage renal disease (ESRD), cancer, cardiopulmonary failure (congestive heart failure/chronic obstructive pulmonary disease), dementia, frailty, or other conditions.

Main Measures—Palliative care consultation; do-not-resuscitate order; death in inpatient hospice; death in the intensive care unit (ICU); family-reported end-of-life care quality.

Results—Among 57,728 decedents, approximately half of patients with ESRD, cardiopulmonary failure or frailty received palliative care consultations (adjusted proportions 50.4%, 46.7%, and 43.7%, respectively) versus 73.5% of cancer patients and 61.4% of dementia patients ($P<.001$). Approximately one-third of patients with ESRD, cardiopulmonary failure, or frailty (adjusted proportions 32.3%, 34.1%, and 35.2% respectively) died in the ICU, more than double the rates among cancer and dementia patients (13.4% and 8.9%, respectively) ($P<.001$). Rates of excellent end-of-life care quality reported by 34,005 decedents' families were similar for cancer and dementia patients (adjusted proportions 59.2% and 59.3% [$P=.61$]), but lower for patients with ESRD, cardiopulmonary failure, or frailty (54.8%, 54.8%, and 53.7%, respectively; all $P=.015$ vs. cancer). This quality advantage was mediated by palliative care consultation, setting of death, and do-not-resuscitate order: adjustment for these variables rendered the relationship between diagnosis and overall end-of-life care quality non-significant ($P=.87$)

Conclusions and Relevance—Family-reported quality of end-of-life care was significantly better for cancer and dementia patients than for patients with ESRD, cardiopulmonary failure, or frailty, largely due to higher rates of palliative care consultation and do-not-resuscitate orders and fewer ICU deaths among cancer and dementia patients. Increasing access to palliative care and goals of care discussions that address code status and preferred setting of death, particularly for patients with end-organ failure and frailty, may improve the overall quality of end-of-life care for Americans dying of these illnesses.

INTRODUCTION

Most individuals in the United States die of conditions other than cancer.¹ Yet, historically, efforts to improve end-of-life care have focused primarily on cancer.^{2,3} More recently, there has been increasing recognition that high quality end-of-life care is also critical for patients with serious illnesses other than cancer, particularly with the aging of the U.S. population.

Few studies have compared patterns of end-of-life care and quality across different serious illnesses, and these studies have generally examined only a small number of diagnoses.^{4,5} Researchers have found differences in care between certain diagnoses—such as higher rates of mechanical ventilation among patients with chronic obstructive pulmonary disease (COPD) compared to cancer patients⁵—but much is still unknown. Moreover, previous work has typically been limited to administrative or chart review data,⁴⁻⁷ which do not include patient or family perspectives. To address these important questions, we compare quality of care for decedents across multiple diagnoses, the first study to do so, to our knowledge. Furthermore, our analysis takes advantage of a unique survey of bereaved family members. Such surveys can play a critical role in assessing end-of-life care quality.⁸⁻¹⁴ The aim of this study was to compare measures of care at the end of life and family-reported quality of care for patients with end-stage renal disease (ESRD), cancer, cardiopulmonary failure (congestive heart failure [CHF]/COPD), dementia, and frailty.

METHODS

Data Sources and Procedures

Our data were from the Veteran Affairs (VA) Performance Reporting and Outcomes Measurement to Improve the Standard of Care at the End-of-life (PROMISE) Center. We used two data sources from PROMISE: chart review and the Bereaved Family Survey.

Chart review data for nearly every patient who died in a VA inpatient facility, including acute care, long-term care, and inpatient hospice were abstracted by hand prior to October 1, 2012. Subsequently, except for setting of death, which was still abstracted by hand, data were derived from the VA's Corporate Data Warehouse that integrates databases containing clinical and administrative information.^{15,16} The only ineligible Veterans were those in a VA inpatient facility less than 24 hours in the last month of life or who died by suicide (< 4% of all deaths).

The PROMISE Center also surveys patients' families about the quality of care that their loved ones received in the last month of life using the Bereaved Family Survey. Human subjects approval was obtained from the Philadelphia VAMC institutional review board.

Study Cohort

Among 58,408 patients who died in one of the 146 VA facilities nationwide between October 2009 and September 2012, 655 (1.1%) patients were ineligible for our analyses due to missing ICD-9 data. Thus, chart review analyses included 57,753 patients. Of these, 4,331 had incorrect contact information for their next-of-kin. This left 53,422 next-of-kin eligible for the Bereaved Family Survey. Of those, 34,015 completed the survey (response rate 64%). Survey weights (described below) could not be calculated for 10 respondents due to incomplete covariate data, producing a final survey cohort of 34,005 (see eMethods).

Outcomes

From chart review, we obtained several measures of care at the end of life that have been associated with high-quality end-of-life care: 1) palliative care consultation in the last 90 days of life;^{10,17} 2) do-not-resuscitate order at the time of death, which may reflect a "goals of care" discussion;^{13,18} and 3) death in a hospice/palliative care unit.^{19,20} We also examined one measure, death in the intensive care unit (ICU), associated with worse family-reported quality.²¹⁻²⁵

Using the Bereaved Family Survey, we examined family members' assessment of end-of-life care quality.²⁶ Our primary measure was the family's global rating of quality on a 5-point Likert scale, which we dichotomized as "excellent" versus all other categories. In a sensitivity analysis comparing all five ratings ranging from "poor" to "excellent" using ordered logistic regression, results were similar (not presented).

We also examined four questions about provider communication: "providers always listened to concerns"; "providers always provided desired medical treatment"; "providers always kept family informed"; and "providers always gave enough emotional support", and two questions about the presence and frequency of pain.

Independent Variables

Our independent variable of interest was the patient's serious illness diagnosis, based on inpatient admissions in the last year of life, which likely reflects their most serious medical conditions near death. We used inpatient diagnoses rather than death certificate diagnoses since past research found the latter unreliable.^{27,28} Each inpatient admission was associated with one primary diagnosis and potentially secondary diagnoses. Patients could have admissions in addition to their terminal admission, each with a primary diagnosis. As in prior studies, we categorized patients into six mutually-exclusive diagnosis categories: (1) end-stage renal disease (ESRD), (2) cancer, (3) cardiopulmonary failure (CHF or COPD), (4) dementia, (5) frailty, and (6) other.^{6,7,29-31} Our approach was the following (see eMethods): 1) Decedents with one or more primary diagnoses for ESRD, cancer, cardiopulmonary failure, dementia or frailty were categorized using the above hierarchy. 2) For those with none of the five primary diagnoses in the last year of life, secondary diagnoses were examined, and decedents were categorized using the same hierarchy.⁶ As in previous work, frailty included Parkinson's disease, stroke, hip fracture, delirium, pneumonia, incontinence, dehydration, leg cellulitis, or syncope. Cardiopulmonary failure included CHF or COPD.⁶

We conducted three sensitivity analyses of diagnosis assignment. In the first, we categorized decedents using only hospitalizations within the last month of life. In the second, we divided cardiopulmonary failure into CHF and COPD as separate diagnoses. In the third, we combined frailty and "other" diagnosis categories.

Covariates—Age, gender, race, comorbidity, and relationship of next-of-kin came from the VA's Corporate Data Warehouse. Comorbidity was measured using the Deyo adaptation of the Charlson Comorbidity Index³² applied to inpatient ICD-9 codes (see eMethods). The unweighted number of comorbidities was categorized as: none, 1–3 comorbidities, and 4 comorbidities.^{33,34}

Statistical Analysis and Survey Weights

To compare measures of care and family ratings of end-of-life care quality among decedents with different serious illnesses, we used the Pearson χ^2 test to examine unadjusted associations and multivariable logistic analyses adjusted for decedent age, race, gender, relationship of next-of-kin, and comorbidity. We used generalized estimating equations to adjust standard errors for clustering of patients within facilities. We report adjusted proportions for each outcome by diagnosis and P-values both for the overall association of diagnosis with each dependent variable and for the comparison of each diagnosis versus cancer.

We next assessed whether the association between diagnosis and family-reported quality was mediated by differences across diagnoses in measures of end-of-life care. After documenting the association between diagnosis and these measures (palliative care consultation, do-not-resuscitate order, and setting of death) and between these measures and family-reported quality, we added these three variables to the models assessing associations between diagnosis and family-reported quality. We included all settings of death (ICU, hospital non-

ICU, nursing home, inpatient hospice) because of the important role that setting can play in end-of-life care. In sensitivity analyses we also examined the association between diagnosis and each outcome stratified by setting of death.

Missing covariate and chart review outcomes data were infrequent (<0.1%). The 25 patients with missing covariate data were excluded from models. Missing survey outcomes data were also infrequent (<4% for each outcome, except frequent uncontrolled pain [14%]).

We adjusted for nonresponse in the Bereaved Family Survey using inverse probability weights. Specifically, after fitting a logistic regression model predicting survey completion that included all covariates described above, we calculated a weight for each decedent equal to the reciprocal of the probability of that decedent's family member completing the survey.

RESULTS

Sample Characteristics

Table 1 presents demographic and clinical characteristics by diagnosis for the full cohort. Decedents with dementia, cardiopulmonary failure, and frailty were older than decedents in other diagnosis groups. A higher proportion of decedents with ESRD were African-American (30%) compared with other diagnosis groups (range 13–19%). Decedents with ESRD had the greatest comorbid disease burden. The characteristics of patients whose families completed the Bereaved Family Survey are presented in eTable 1. Compared with this group, decedents whose families did not respond to the survey were younger and more likely to be African-American.

End-of-Life Care Outcomes

Table 2 shows the adjusted proportions of each dependent variable by diagnosis (see eTable 2 for unadjusted proportions). For all outcomes, both unadjusted and adjusted proportions differed significantly by diagnosis ($P < .003$ for all models).

The upper half of Table 3 shows that, in adjusted analyses, only half of ESRD patients and less than half of cardiopulmonary failure or frailty patients received palliative care consultations in the last 90 days of life (adjusted proportions 50.4%, 46.7%, and 43.7%, respectively). In contrast, 73.5% of cancer patients and 61.4% of dementia patients received such consultations. Approximately one-third of patients with ESRD, cardiopulmonary failure, and frailty (adjusted proportions 32.3%, 34.1%, and 35.2%, respectively) died in the ICU, compared with 13.4% and 8.9% among cancer and dementia patients, respectively. Conversely, 42.9% of cancer patients and 32.3% of dementia patients died in inpatient hospice units, versus less than a quarter of ESRD, cardiopulmonary failure, and frailty patients (adjusted proportions 24.3%, 22.9%, and 20.3%). Cancer and dementia patients had higher rates of do-not-resuscitate orders at the time of death (adjusted proportions 95.3% and 93.5%) than patients with ESRD (87.0%), cardiopulmonary failure (86.3%), or frailty (88.6%). For each outcome, pairwise comparisons between cancer and other diagnoses were significant ($P < .003$).

The lower half of Table 3 shows that rates of family-reported excellent overall end-of-life care quality were similar for cancer and dementia patients (adjusted proportions 59.2% and 59.3% $P=.61$), but were lower, relative to cancer, for patients with ESRD, cardiopulmonary failure, or frailty (54.8%, 54.8%, and 53.7%, respectively; all $P < .015$).

Family members' evaluation of provider communication followed a similar pattern. However, among the 81.7% of decedents who had pain (based on family report), the proportion with frequent uncontrolled pain did not differ significantly among cancer, ESRD, cardiopulmonary failure, and frailty patients (adjusted proportions 55.0%, 54.3%, 55.9%, and 53.3%, respectively) but was significantly lower among dementia patients (49.4%, $P < .001$ compared with cancer).

Setting of death, palliative care consultation, and do-not-resuscitate order at death were all independently associated with family-reported overall quality of end-of-life care ($P < .001$) and with several other family-reported quality measures. Adjusting for these variables attenuated the association between diagnosis and overall family rating of care, rendering the relationship non-significant ($P=.87$) (Table 3). In sensitivity analyses stratified by setting of death, there was no longer a significant association between diagnosis and family-reported overall quality of end-of-life care for any setting. However, differences by diagnosis in rates of palliative care consultation and DNR orders remained significant for three of the four settings (ICU, hospital non-ICU, and nursing home) (results not shown).

A sensitivity analysis assigning decedents to diagnosis categories based on hospitalizations in the last month of life produced estimates very similar to our main findings (eTable 3). Analyses with cardiopulmonary failure examined as CHF and COPD separately suggested that COPD tended to have better end-of-life care quality outcomes than CHF, but left other findings largely unchanged (results not shown). Sensitivity analyses combining frailty with "other" also produced very similar results to our primary analyses (results not shown).

DISCUSSION

In a large national cohort of nearly all patients dying in VA inpatient facilities, we observed important differences in the end-of-life care received by individuals with different illnesses. Overall, we found that diagnosis was significantly associated with the quality of end-of-life care as measured both by family surveys and by several established measures of end-of-life care quality.^{10,17,18,21–25,35–39} Patients with end-organ failure and frailty generally received lower quality end-of-life care than patients with cancer or dementia.

Specifically, individuals with end-organ failure were less likely than those with cancer or dementia to receive palliative care consultation or have do-not-resuscitate orders, two measures associated with high-quality end-of-life care.^{10,17,18,35–39} Consistent with prior work comparing COPD and cancer,⁵ we found that patients with end-organ failure or frailty were more likely than patients with cancer and dementia to die in the ICU, a measure of end-of-life treatment intensity associated with poor symptom control and bereavement outcomes.^{10,21–25,40} Conversely, death in a hospice unit—the inpatient setting with the highest family-reported quality¹³—was more common among cancer and dementia patients

than those with end-organ failure or frailty. Finally, overall quality of end-of-life care was rated more favorably by family members of cancer and dementia patients than by those of patients with end-organ failure or frailty. These findings suggest a need for greater attention to diagnosis-related disparities in the quality of end-of-life care.

What factors explain these differences in end-of-life care across conditions? We found that the observed differences by diagnosis in setting of death, palliative care consultation, and do-not-resuscitate orders mediated most of the diagnosis-related variation in family-reported end-of-life care quality. Our analysis stratified by setting of death also emphasize that the setting of end-of-life care is a key driver of the differences in quality by diagnosis. These results suggest several actionable steps that may improve disparities in overall quality of end-of-life care, such as increasing access to palliative care and inpatient hospice for patients with ESRD, cardiopulmonary failure, and frailty, and increasing goals of care discussions that address code status and preferred setting of death for patients with these conditions.

Another potential contributor to our findings could be diagnosis-related differences in patient and/or family preferences. However, we found that the groups of patients who were less likely to receive palliative care consultation, less likely to have a do-not-resuscitate order, and more likely to die in the ICU—namely those with end-organ failure or frailty—also had lower rates of families reporting that their providers offered the medical treatment that the patient and family wanted. This is more consistent with the notion that some diagnosis groups experience a greater mismatch between the care they receive and their underlying preferences, rather than diagnosis groups exhibiting sharp differences in preferences.

Our findings may also reflect differences in perceptions regarding the treatability of different serious conditions and the reversibility of their associated acute complications. For instance, patients with end-organ failure often have a clinical trajectory marked by acute exacerbations that are temporarily responsive to interventions.^{7,29} But when these interventions are no longer beneficial, it can be a difficult transition for patients, families, and providers. Therefore, differences in quality by diagnosis may reflect a failure to accept impending death and de-escalate aggressive treatment in conditions characterized by chronic progressive end-organ failure. Although measures of treatment intensity have been used to assess quality in oncology,⁴¹ the frequency of high-intensity care for patients with end-organ failure in our study suggests potential for use of these as quality measures among patients dying of other conditions as well.

Another important finding was the high prevalence of pain among inpatient decedents. More than three-quarters of patients had pain in the last month of life, over half of whom had frequent uncontrolled pain, similar to results of a recent study among community-dwelling adults near the end of life.³⁰ Our finding that patients with end-organ failure and frailty had similar rates of frequent, uncontrolled pain as cancer patients (a group generally appreciated to be at high risk for pain) suggests another opportunity to improve care. The lower rates of uncontrolled pain in dementia patients must be viewed with caution since pain is often under-appreciated in this population, even by family members.⁴²

The strengths of our study include a large national cohort with a rich set of outcomes on end-of-life care from both chart review and a family survey, and—to our knowledge—one of the most comprehensive assessments to date of the quality of end-of-life care received by patients with different serious illnesses. Our study builds on past work on the quality of care provided to hospitalized patients at the end of life⁴³ (the most common setting of death nationally^{44,45}) by also including the growing number of patients dying in nursing homes and inpatient hospice.⁵ Our finding that measures of end-of-life care and family evaluations of care were similar for patients with dementia as for cancer patients is novel, and suggests that the substantial body of research aimed at improving end-of-life care for dementia patients may be having an impact.^{46–48}

Nonetheless, our study has several limitations. First, while previous studies have documented the value of classifying patients near the end of life into mutually exclusive diagnosis groups,^{6,7,29} there are challenges in doing so. Using mutually exclusive diagnosis groups does not address multi-morbidity. We adjusted for comorbidity in our models; however, the end-of-life care experience for patients with multiple conditions could differ substantially from the experiences of those with one condition. Defining frailty is particularly difficult, especially using administrative data,²⁹ since frailty can exist along with other conditions and may reflect substantial clinical heterogeneity. Results were very similar when combining “frailty” into the broader group of “other” conditions. Second, our findings may not generalize to patients outside of the VA, though some research comparing end-of-life care quality between VA and non-VA health care facilities suggests care may be similar.⁴⁹ Furthermore, this rich VA data source allowed for a more robust assessment of end-of-life care across multiple diagnoses than has otherwise been possible. Third, while our survey response rate was high (64%), nonresponse bias is possible. We attempted to minimize this by adjusting survey analyses for nonresponse. Fourth, while examining the timing of do-not-resuscitate orders and palliative care consultations relative to death would be informative, such information was unavailable. Finally, while past research documents that patient-family member agreement is high for quality of care ratings, it is lower for ratings of subjective symptoms,⁵⁰ which could affect the validity of our pain-related analyses.

In conclusion, while there is room for improvement in end-of-life care across all diagnoses, family-reported end-of-life care quality was significantly better for cancer and dementia patients than for patients with ESRD, cardiopulmonary failure, or frailty. This quality advantage was mediated by palliative care consultation, do-not-resuscitate order, and setting of death. Increasing access to palliative care and increasing goals of care discussions that address code status and preferred setting of death, particularly for patients with end-organ failure and frailty, may improve the quality of end-of-life care for Americans dying with these conditions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Study concept and design: Wachterman, Ersek, Keating.

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Data Access, Responsibility, and Analysis: Dr. Wachterman had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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Table 1

Characteristics of Veterans Who Died in VA Inpatient Settings Nationally (N=57,753)^a

Patient Characteristics	Total Sample 57,753 (100.0)	Cancer 23,532 (40.8)	Dementia 3676 (6.4)	End-stage Renal Disease 2266 (3.9)	Cardiopulmonary Failure 13,864 (24.0)	Frailty 9935 (17.2)	Other 4480 (7.7)
Age: mean age in years (SD) ^b	74.1 (12.0)	71.4 (11.2)	82.5 (9.1)	71.4 (11.2)	76.7 (11.2)	75.9 (12.4)	70.9 (13.6)
Age, years ^b							
<60	6855 (12)	3391 (14)	84 (2)	316 (14)	983 (7)	1109 (11)	972 (22)
60–69	16,535 (29)	8443 (36)	335 (9)	824 (36)	3228 (23)	2348 (24)	1357 (30)
70–79	12,591 (22)	5368 (23)	677 (18)	520 (23)	3345 (24)	1963 (20)	718 (16)
80–89	16,996 (29)	5284 (22)	1903 (52)	518 (23)	4849 (35)	3376 (34)	1066 (24)
>89	4755 (8)	1038 (4)	676 (18)	87 (4)	1452 (10)	1135 (11)	367 (8)
Gender: Male^b	56,484 (98)	23,020 (98)	3605 (98)	2234 (99)	13,582 (98)	9691 (98)	4352 (97)
Race							
White	42,601 (74)	16,853 (72)	2824 (77)	1388 (61)	10,836 (78)	7438 (75)	3262 (73)
African American	9919 (17)	4548 (19)	484 (13)	682 (30)	1867 (13)	1601 (16)	737 (16)
Asian & Other	954 (2)	385 (2)	69 (2)	57 (3)	201 (1)	164 (2)	78 (2)
Unknown	4279 (7)	1746 (7)	299 (8)	139 (6)	960 (7)	732 (7)	403 (9)
Next of kin^b							
Spouse	22,298 (39)	8542 (36)	1719 (47)	1008 (45)	5476 (40)	3876 (39)	1677 (37)
Child	18,951 (33)	7254 (31)	1354 (37)	656 (29)	4932 (36)	3410 (34)	1345 (30)
Sibling	8093 (14)	4075 (17)	223 (6)	309 (14)	1625 (12)	1200 (12)	661 (15)
Other	8030 (14)	3480 (15)	365 (10)	283 (12)	1751 (13)	1387 (14)	764 (17)
None	372 (1)	179 (1)	15 (0.4)	9 (0.4)	75 (0.5)	61 (0.6)	33 (0.7)
Number of Charlson Comorbidities							
0, Best health	12,333 (21)	6361 (27)	960 (26)	194 (9)	2068 (15)	1398 (14)	1352 (30)
1–3, Average health	39,013 (68)	15,711 (67)	2424 (66)	1553 (69)	9596 (69)	6768 (68)	2961 (66)
4, Worst health	6407 (11)	1460 (6)	292 (8)	519 (23)	2200 (16)	1769 (18)	167 (4)
Setting of Death							
Intensive Care Unit	13,959 (24)	3447 (15)	240 (7)	800 (35)	4408 (32)	3301 (33)	1763 (39)
Hospital, non-ICU	14,074 (24)	4933 (21)	652 (18)	578 (26)	3696 (27)	3108 (31)	1107 (25)

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Patient Characteristics	Total Sample 57,753 (100.0)	Cancer 23,532 (40.8)	Dementia 3676 (6.4)	End-stage Renal Disease 2266 (3.9)	Cardiopulmonary Failure 13,864 (24.0)	Frailty 9935 (17.2)	Other 4480 (7.7)
Nursing Home	11,810 (20)	5284 (22)	1508 (41)	363 (16)	2494 (18)	1458 (15)	703 (16)
Inpatient Hospice	17,898 (31)	9865 (42)	1276 (35)	524 (23)	3260 (24)	2066 (21)	907 (20)

^aData are presented as No. (column %) unless otherwise noted. Column % may not add to 100 due to rounding

^bData were missing for age (n=21), gender (n=16), next of kin (n=9), and setting of death (n=12). Column N's may not sum to total N due to missing data.

Table 2 Adjusted^a Proportions for Measures of Care at the End of Life and Family Perceptions of Quality Outcomes by Diagnosis

Outcomes	Cancer	Dementia	End-stage Renal Disease	Cardiopulmonary Failure	Frailty	Other	P Value ^b
All Veteran Decedents (N=57,728) (N (%))^c	23,523 (40.8)	3675 (6.4)	2265 (3.9)	13,854 (24.0)	9931 (17.2)	4480 (7.8)	
Measures of Care at the End of Life							
Palliative care consultation	73.5	61.4	50.4	46.7	43.7	41.5	<.001
Do-not-resuscitate order	95.3	93.5	87.0	86.3	88.6	83.9	<.001
Died in inpatient hospice	42.9	32.3	24.3	22.9	20.3	20.6	<.001
Died in the intensive care unit	13.4	8.9	32.3	34.1	35.2	37.4	<.001
Bereaved Family Survey Participants (n=34,005) (%)^{d,e}							
Overall rating of patient's care was excellent	59.2	59.3	54.8 ^h	54.8 ^f	53.7 ^f	55.0 ^f	<.001
Providers always listened to concerns	73.8	75.7	68.6 ^f	71.5 ^f	70.5 ^f	73.0	<.001
Providers always provided the medical treatment that patient and family wanted	79.1	80.4	73.4 ^f	76.8 ^f	76.5 ^f	77.4	<.001
Providers always kept family informed about patient's condition and treatment	68.2	71.1 ^h	63.8 ^g	65.9 ^f	66.6	67.5	.0011
Providers always gave enough emotional support prior to the patient's death	64.6	67.5 ^h	61.5	62.1 ^f	62.0 ^h	63.3	<.001
Patient had frequent uncontrolled pain ⁱ	55.0	49.4 ^f	54.3	55.9	53.3	55.3	.003

^aAnalyses adjusted for age, race, gender, next-of-kin relationship, and comorbidity, and clustered by facility.

^bP value for the overall association of diagnosis with each outcome

^cTable excludes 25 decedents from Table 1 who were missing covariate data. P < .003 for the comparison of each diagnosis versus cancer for all "measures of care at the end of life" outcomes

^dAnalyses weighted for survey non-response. Table excludes 10 Bereaved Family Survey participants for whom no survey weight could be calculated because of missing covariate data.

^eAmong the 34,005 Bereaved Family Survey participants for whom survey weight could be calculated. Sample size varies to reflect % missing data for individual survey items: overall rating (1.4), providers listened (2.6), provision of desired medical treatment (3.5), provider informed family (1.9), frequent uncontrolled pain (13.7), and providers gave enough emotional support (3.0)

^fP < .001 for the comparison of each diagnosis versus cancer

^gP < .01 for the comparison of each diagnosis versus cancer

^hP < .05 for the comparison of each diagnosis versus cancer

Includes only the 81.7% of patients who, per family report, experienced pain

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Table 3
Adjusted^a Proportions for Family Perceptions of End-of-Life Care Quality Outcomes by Diagnosis, Further Adjusted for Palliative Care Consultation, Setting of Death, and DNR Order

Outcomes	Cancer ^d	Dementia	End-stage Renal Disease	Cardiopulmonary Failure	Frailty	Other	P Value ^b
Bereaved Family Survey Participants^{c,d}	40.3	6.6	3.7	24.4	17.4	7.6	
Overall rating of patient's care was excellent	56.4	57.7	56.4	56.7	56.0	57.4	.87
Providers always listened to concerns	72.1	75.1 ^f	70.0	73.0	72.1	74.9 ^f	.013
Providers always provided the medical treatment that patient and family wanted	77.6	79.5	74.5 ^f	78.0	77.9	78.9	.14
Providers always kept family informed about patient's condition and treatment	66.4	70.4 ^e	65.1	67.3	68.1	69.4 ^f	.0095
Providers always gave enough emotional support prior to the patient's death	62.3	66.2 ^f	63.0	63.8	63.9 ^g	65.4 ^f	.013
Patient had frequent uncontrolled pain ^h	55.9	50.1 ^e	53.6	55.2	52.3 ^e	54.3	<.001

^a Analyses adjusted for age, race, gender, family relationship, comorbidity, palliative care consultation, setting of death, and DNR order, and clustered by facility.

^b P value for the overall association of diagnosis with each outcome

^c Analyses weighted for survey non-response. Table excludes 10 Bereaved Family Survey participants for whom no survey weight could be calculated because of missing covariate data.

^d Among the 34,005 Bereaved Family Survey participants for whom survey weight could be calculated. Sample size varies to reflect % missing data for individual survey items: overall rating (1.4), providers listened (2.6), provision of desired medical treatment (3.5), provider informed family (1.9), frequent uncontrolled pain (13.7), and providers gave enough emotional support (3.0)

^e P < .001 for the comparison of each diagnosis versus cancer

^f P < .01 for the comparison of each diagnosis versus cancer

^g P < .05 for the comparison of each diagnosis versus cancer

^h Includes only the 81.7% of patients who, per family report, experienced pain