

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

Melissa W. Wachterman, MD, MSc, MPH; Corey Pilver, PhD; Dawn Smith, MS; Mary Ersek, PhD, RN; Stuart R. Lipsitz, ScD; Nancy L. Keating, MD, MPH

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

OBJECTIVE To compare patterns of end-of-life care and family-rated quality of care for patients dying with different serious illnesses.

DESIGN, SETTING, AND PARTICIPANTS A retrospective cross-sectional study was conducted in all 146 inpatient facilities within the Veteran Affairs health system among patients who died in inpatient facilities between October 1, 2009, and September 30, 2012, with clinical diagnoses categorized as end-stage renal disease (ESRD), cancer, cardiopulmonary failure (congestive heart failure or chronic obstructive pulmonary disease), dementia, frailty, or other conditions. Data analysis was conducted from April 1, 2014, to February 10, 2016.

MAIN OUTCOMES AND MEASURES Palliative care consultations, do-not-resuscitate orders, death in inpatient hospices, death in the intensive care unit, and family-reported quality of end-of-life care.

RESULTS Among 57 753 decedents, approximately half of the patients with ESRD, cardiopulmonary failure, or frailty received palliative care consultations (adjusted proportions, 50.4%, 46.7%, and 43.7%, respectively) vs 73.5% of patients with cancer and 61.4% of patients with dementia ($P < .001$). Approximately one-third of patients with ESRD, cardiopulmonary failure, or frailty (adjusted proportions, 32.3%, 34.1%, and 35.2%, respectively) died in the intensive care unit, more than double the rates among patients with cancer and those with dementia (13.4% and 8.9%, respectively) ($P < .001$). Rates of excellent quality of end-of-life care reported by 34 005 decedents' families were similar for patients with cancer and those with dementia (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 $P \leq .02$ vs patients with cancer). This quality advantage was mediated by palliative care consultation, setting of death, and a code status of do-not-resuscitate; adjustment for these variables rendered the association between diagnosis and overall end-of-life care quality nonsignificant.

CONCLUSIONS AND RELEVANCE Family-reported quality of end-of-life care was significantly better for patients with cancer and those with dementia than for patients with ESRD, cardiopulmonary failure, or frailty, largely owing to higher rates of palliative care consultation and do-not-resuscitate orders and fewer deaths in the intensive care unit among patients with cancer and those with dementia. 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.

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Author Affiliations: Author affiliations are listed at the end of this article.

Corresponding Author: Melissa W. Wachterman, MD, MSc, MPH, Section of General Internal Medicine, VA Boston Healthcare System, 150 S Huntington Ave, Building 9, Boston, MA 02130 (mwachterman@partners.org).

Most individuals in the United States die of conditions other than cancer.¹ However, historically, efforts to improve end-of-life care have focused primarily on patients with 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 US 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 with those with cancer⁵—but much is still unknown. Moreover, previous work has typically been limited to administrative data or review of medical records,⁴⁻⁷ which do not include patient or family perspectives. To address these issues, 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 the quality of end-of-life care.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] or 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 2 data sources from PROMISE: review of medical records and the Bereaved Family Survey.

Data from review of medical records for nearly every patient who died in a VA inpatient facility, including acute care, long-term care, and inpatient hospice, were abstracted by hand before 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 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 (2403 deaths [3.8%]).

The PROMISE Center also uses the Bereaved Family Survey to ask patients' families about the quality of care that their loved ones received in the last month of life. This study was approved by the Philadelphia VA Medical Center Institutional Review Board. Verbal informed consent was obtained from families who participated in the Bereaved Family Survey by telephone and, for those who completed the survey by mail, consent was implied by return of the survey.

Study Cohort

Among 58 408 patients who died in one of the 146 VA facilities nationwide between October 1, 2009, and September 30,

Key Points

Question How does the quality of end-of-life care compare for patients dying with different serious illnesses?

Findings In this cross-sectional study, diagnosis was significantly associated with the adjusted proportion of veteran decedents who received palliative care consultations (cancer, 74%; dementia, 61%; end-stage renal disease, 50%; cardiopulmonary failure, 47%; and frailty, 44%) and who, per next of kin, received excellent care (cancer, 59%; dementia, 59%; end-stage renal disease, 55%; cardiopulmonary failure, 55%; and frailty, 54%).

Meaning Health care professionals and policy makers need to pay particular attention to improving end-of-life care for patients with end-stage renal disease, cardiopulmonary failure, and frailty.

2012, a total of 655 (1.1%) were ineligible for our analyses owing to missing *International Classification of Diseases, Ninth Revision (ICD-9)* data. Thus, analyses of data from medical records included 57 753 patients. Of these patients, 4331 had incorrect contact information for their next of kin, which left 53 422 next of kin eligible for the Bereaved Family Survey. Of those, 34 015 completed the survey (response rate, 63.7%). Survey weights could not be calculated for 10 respondents owing to incomplete covariate data, producing a final survey cohort of 34 005 (eAppendix in the [Supplement](#)).

Outcomes

From review of medical records, we obtained several measures of care at the end of life that have been associated with high-quality end-of-life care: palliative care consultation in the last 90 days of life^{10,16}; do-not-resuscitate order at the time of death, which may reflect a discussion about goals of care^{13,17}; and death in a hospice or palliative care unit.^{18,19} We also examined 1 measure—death in the intensive care unit (ICU)—associated with worse family-reported quality of care.²⁰⁻²⁴

Using the Bereaved Family Survey, we examined family members' assessment of the quality of end-of-life care.²⁵ Our primary measure was the family's global rating of quality on a 5-point Likert scale, which we dichotomized as excellent vs all other categories. In a sensitivity analysis comparing all 5 ratings ranging from poor to excellent using ordered logistic regression, results were similar.

We also examined 4 questions about communication with health care professionals: "providers always listened to concerns," "providers always provided desired medical treatment," "providers always kept family informed," and "providers always gave enough emotional support," as well as 2 questions about the presence and frequency of pain.

Independent Variables

Our independent variable of interest was the patient's diagnosis of serious illness, 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 diagnoses on the death certificate since past research found the latter to be unreliable.^{26,27} Each inpatient admission was associated with 1 primary diagnosis and potentially

1 or more 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 the following 6 mutually exclusive categories of diagnosis: end-stage renal disease (ESRD), cancer, cardiopulmonary failure (CHF or COPD), dementia, frailty, and other.^{6,7,28-30} Decedents with 1 or more primary diagnoses of ESRD, cancer, cardiopulmonary failure, dementia, or frailty were categorized using the above hierarchy (eAppendix in the Supplement). For those with none of the 5 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 disease, stroke, hip fracture, delirium, pneumonia, incontinence, dehydration, leg cellulitis, or syncope. Cardiopulmonary failure included CHF or COPD.

We conducted 3 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 the frailty and "other" diagnosis categories.

We adjusted for age, sex, race/ethnicity, comorbidity, and relationship of next of kin, which came from the VA's Corporate Data Warehouse. Comorbidity was measured using the Deyo adaptation of the Charlson Comorbidity Index³¹ applied to inpatient ICD-9 codes (eAppendix in the Supplement). The unweighted number of comorbidities was categorized as 0, 1 to 3, and 4 or more comorbidities.^{32,33}

Statistical Analysis and Survey Weights

Data analysis was conducted from April 1, 2014, to February 10, 2016. To compare measures of care and family ratings of quality of end-of-life care 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/ethnicity, sex, 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 vs cancer.

We next assessed whether the association between diagnosis and family-reported quality of care 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 of care, we added these 3 variables to the models assessing associations between diagnosis and family-reported quality of care. We included all settings of death (ICU, hospital non-ICU, nursing home, and 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.

Twenty-five patients were missing covariate data and were excluded from statistical models. Missing outcomes data from

medical records were infrequent (do-not-resuscitate order, 21 [0.04%]; death in the ICU, 12 [0.02%]). Missing outcomes data from surveys were also infrequent for most outcomes (missing data: overall rating of care excellent, 1.4%; health care providers always listened to concerns, 2.6%; provision of desired medical treatment, 3.5%; health care providers always informed family, 1.9%; health care providers gave enough emotional support, 3.0%) with the exception of frequent uncontrolled pain (missing for 13.7%).

We adjusted for nonresponse to 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 (682 of 2266 [30.1%]) compared with other diagnosis groups (range, 484 of 3676 [13.2%] to 4548 of 23 532 [19.3%]). 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 in the Supplement. 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 in the Supplement for unadjusted proportions). For all outcomes, both unadjusted and adjusted proportions differed significantly by diagnosis (*P* ≤ .003 for all models). In adjusted analyses, only half of the patients with ESRD and less than half of the patients with cardiopulmonary failure or frailty received palliative care consultations in the last 90 days of life (adjusted proportions, 50.4%, 46.7%, and 43.7%, respectively) (Table 2). In contrast, 73.5% of patients with cancer and 61.4% of patients with dementia 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% of patients with cancer and those with dementia, respectively. Conversely, 42.9% of patients with cancer and 32.3% of those with dementia died in inpatient hospice units, compared with less than one-fourth of patients with ESRD, cardiopulmonary failure, or frailty (adjusted proportions, 24.3%, 22.9%, and 20.3%, respectively). Patients with cancer and those with dementia had higher rates of do-not-resuscitate orders at the time of death (adjusted proportions, 95.3% and 93.5%, respectively) than did patients with ESRD (87.0%), cardiopulmonary failure (86.3%),

Table 1. Characteristics of Veterans Who Died in Veterans Affairs Inpatient Settings Nationally

| Characteristic | Value ^a | | | | | | |
|--------------------------------|------------------------------|------------------------|------------------------|--------------------|---|-----------------------|---------------------|
| | Total Sample (N = 57 753) | Cancer (N = 23 532) | Dementia (N = 3676) | ESRD (N = 2266) | Cardiopulmonary Failure (N = 13 864) | Frailty (N = 9935) | Other (N = 4480) |
| Age, mean (SD), y ^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, y ^b | | | | | | | |
| <60 | 6855 (11.9) | 3391 (14.4) | 84 (2.3) | 316 (13.9) | 983 (7.1) | 1109 (11.2) | 972 (21.7) |
| 60-69 | 16 535 (28.6) | 8443 (35.9) | 335 (9.1) | 824 (36.4) | 3228 (23.3) | 2348 (23.6) | 1357 (30.3) |
| 70-79 | 12 591 (21.8) | 5368 (22.8) | 677 (18.4) | 520 (22.9) | 3345 (24.1) | 1963 (19.8) | 718 (16.0) |
| 80-89 | 16 996 (29.4) | 5284 (22.5) | 1903 (51.8) | 518 (22.9) | 4849 (35.0) | 3376 (34.0) | 1066 (23.8) |
| >89 | 4755 (8.2) | 1038 (4.4) | 676 (18.4) | 87 (3.8) | 1452 (10.5) | 1135 (11.4) | 367 (8.2) |
| Male sex ^b | 56 484 (97.8) | 23 020 (97.8) | 3605 (98.1) | 2234 (98.6) | 13 582 (98.0) | 9691 (97.5) | 4352 (97.1) |
| Race | | | | | | | |
| White | 42 601 (73.8) | 16 853 (71.6) | 2824 (76.8) | 1388 (61.3) | 10 836 (78.2) | 7438 (74.9) | 3262 (72.8) |
| African American | 9919 (17.2) | 4548 (19.3) | 484 (13.2) | 682 (30.1) | 1867 (13.5) | 1601 (16.1) | 737 (16.5) |
| Asian and other | 954 (1.7) | 385 (1.6) | 69 (1.9) | 57 (2.5) | 201 (1.4) | 164 (1.7) | 78 (1.7) |
| Unknown | 4279 (7.4) | 1746 (7.4) | 299 (8.1) | 139 (6.1) | 960 (6.9) | 732 (7.4) | 403 (9.0) |
| Next of kin ^b | | | | | | | |
| Spouse | 22 298 (38.6) | 8542 (36.3) | 1719 (46.8) | 1008 (44.5) | 5476 (39.5) | 3876 (39.0) | 1677 (37.4) |
| Child | 18 951 (32.8) | 7254 (30.8) | 1354 (36.8) | 656 (28.9) | 4932 (35.6) | 3410 (34.3) | 1345 (30.0) |
| Sibling | 8093 (14.0) | 4075 (17.3) | 223 (6.1) | 309 (13.6) | 1625 (11.7) | 1200 (12.1) | 661 (14.8) |
| Other | 8030 (13.9) | 3480 (14.8) | 365 (9.9) | 283 (12.5) | 1751 (12.6) | 1387 (14.0) | 764 (17.1) |
| None | 372 (0.6) | 179 (0.8) | 15 (0.4) | 9 (0.4) | 75 (0.5) | 61 (0.6) | 33 (0.7) |
| Charlson Comorbidities, No. | | | | | | | |
| 0 (best health) | 12 333 (21.4) | 6361 (27.0) | 960 (26.1) | 194 (8.6) | 2068 (14.9) | 1398 (14.1) | 1352 (30.2) |
| 1-3 (average health) | 39 013 (67.6) | 15 711 (66.8) | 2424 (65.9) | 1553 (68.5) | 9596 (69.2) | 6768 (68.1) | 2961 (66.1) |
| ≥4 (worst health) | 6407 (11.1) | 1460 (6.2) | 292 (7.9) | 519 (22.9) | 2200 (15.9) | 1769 (17.8) | 167 (3.7) |
| Setting of death ^b | | | | | | | |
| ICU | 13 959 (24.2) | 3447 (14.6) | 240 (6.5) | 800 (35.3) | 4408 (31.8) | 3301 (33.2) | 1763 (39.4) |
| Hospital, non-ICU | 14 074 (24.4) | 4933 (21.0) | 652 (17.7) | 578 (25.5) | 3696 (26.7) | 3108 (31.3) | 1107 (24.7) |
| Nursing home | 11 810 (20.4) | 5284 (22.5) | 1508 (41.0) | 363 (16.0) | 2494 (18.0) | 1458 (14.7) | 703 (15.7) |
| Inpatient hospice | 17 898 (31.0) | 9865 (41.9) | 1276 (34.7) | 524 (23.1) | 3260 (23.5) | 2066 (20.8) | 907 (20.2) |

Abbreviations: ESRD, end-stage renal disease; ICU, intensive care unit.

^a Data are presented as No. (%) unless otherwise noted. Column % may not total 100 owing to rounding.

^b Data were missing for age (n = 21), sex (n = 16), next of kin (n = 9), and setting of death (n = 12). Column numbers may not sum to total number owing to missing data.

or frailty (88.6%). For each outcome, pairwise comparisons between cancer and other diagnoses were significant ($P < .003$).

Table 2 shows that rates of family-reported excellent overall quality of end-of-life care were similar for patients with cancer and those with dementia (adjusted proportions, 59.2% and 59.3%, respectively; $P = .61$), but were lower, relative to cancer, for patients with ESRD, cardiopulmonary failure, or frailty (54.8%, 54.8%, and 53.7%, respectively; all $P \leq .02$).

Family members' evaluation of communication with health care professionals 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 patients with cancer, ESRD, cardiopulmonary failure, or frailty (adjusted proportions, 55.0%, 54.3%, 55.9%, and 53.3%, respectively), but was significantly lower among patients with dementia (49.4%; $P < .001$ compared with patients with cancer).

Setting of death, palliative care consultation, and do-not-resuscitate order at death were independently associated with family-reported overall quality of end-of-life care ($P \leq .001$) 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 association nonsignificant ($P = .87$) (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 do-not-resuscitate orders remained significant for 3 of the 4 settings (ICU, hospital non-ICU, and nursing home).

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 in the Supplement). Analyses with cardiopulmonary failure examined as CHF and COPD separately suggested that patients with COPD tended to have better end-of-life care outcomes than patients with CHF, but left other findings largely unchanged. Sensitivity analyses combining frailty with the category of "other" diagnoses also produced very similar results to our primary analyses.

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

| Outcomes | No. (%) | | | | | | P Value ^b |
|--|---------------|-------------------|-------------------|-------------------------|-------------------|-------------------|----------------------|
| | Cancer | Dementia | ESRD | Cardiopulmonary Failure | Frailty | Other | |
| All veteran decedents (n = 57 728) ^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 ^f | 54.8 ^g | 53.7 ^g | 55.0 ^g | <.001 |
| Health care professionals always listened to concerns | 73.8 | 75.7 | 68.6 ^g | 71.5 ^g | 70.5 ^g | 73.0 | <.001 |
| Health care professionals always provided the medical treatment that patient and family wanted | 79.1 | 80.4 | 73.4 ^g | 76.8 ^g | 76.5 ^g | 77.4 | <.001 |
| Health care professionals always kept family informed about patient's condition and treatment | 68.2 | 71.1 ^f | 63.8 ^h | 65.9 ^g | 66.6 | 67.5 | .001 |
| Health care professionals always gave enough emotional support prior to the patient's death | 64.6 | 67.5 ^f | 61.5 | 62.1 ^g | 62.0 ^f | 63.3 | <.001 |
| Patient had frequent uncontrolled pain ⁱ | 55.0 | 49.4 ^g | 54.3 | 55.9 | 53.3 | 55.3 | .003 |

Abbreviation: ESRD, end-stage renal disease.

^a Analyses adjusted for age, race, sex, next-of-kin relationship, and comorbidity, and clustered by facility.

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

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

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

^e Among the 34 005 Bereaved Family Survey participants for whom survey

weight could be calculated. Sample size varies to reflect percentage of missing data for individual survey items: overall rating (1.4), health care professionals always listened to concerns (2.6), provision of desired medical treatment (3.5), health care professionals informed family (1.9), health care professionals gave enough emotional support (3.0), and patient had frequent uncontrolled pain (13.7).

^f P < .05 for the comparison of each diagnosis vs cancer.

^g P < .001 for the comparison of each diagnosis vs cancer.

^h P < .01 for the comparison of each diagnosis vs cancer.

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

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

| Outcomes | Cancer | Dementia | ESRD | Cardiopulmonary Failure | Frailty | Other | P Value ^b |
|--|--------|-------------------|-------------------|-------------------------|-------------------|-------------------|----------------------|
| Bereaved Family Survey participants ^{c,d} | | | | | | | |
| Overall rating of patient's care was excellent | 56.4 | 57.7 | 56.4 | 56.7 | 56.0 | 57.4 | .87 |
| Health care professionals always listened to concerns | 72.1 | 75.1 ^e | 70.0 | 73.0 | 72.1 | 74.9 ^e | .01 |
| Health care professionals always provided the medical treatment that patient and family wanted | 77.6 | 79.5 | 74.5 ^e | 78.0 | 77.9 | 78.9 | .14 |
| Health care professionals always kept family informed about patient's condition and treatment | 66.4 | 70.4 ^f | 65.1 | 67.3 | 68.1 | 69.4 ^e | <.01 |
| Health care professionals always gave enough emotional support prior to the patient's death | 62.3 | 66.2 ^e | 63.0 | 63.8 | 63.9 ^g | 65.4 ^e | .01 |
| Patient had frequent uncontrolled pain ^h | 55.9 | 50.1 ^f | 53.6 | 55.2 | 52.3 ^f | 54.3 | <.001 |

Abbreviations: DNR, do-not-resuscitate; ESRD, end-stage renal disease.

^a Analyses adjusted for age, race, sex, 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 nonresponse. 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 percentage of missing

data for individual survey items: overall rating (1.4), health care professionals always listened to concerns (2.6), provision of desired medical treatment (3.5), health care professionals informed family (1.9), health care professionals gave enough emotional support (3.0), and patient had frequent uncontrolled pain (13.7).

^e P < .01 for the comparison of each diagnosis vs cancer.

^f P < .001 for the comparison of each diagnosis vs cancer.

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

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

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 quality of end-of-life care.^{10,16,17,20-24,34-38} Patients with end-organ failure and frailty generally received lower-quality end-of-life care than did patients with cancer or dementia.

Specifically, individuals with end-organ failure were less likely than those with cancer or dementia to receive a palliative care consultation or have a do-not-resuscitate order, 2 measures associated with high-quality end-of-life care.^{10,16,17,34-38} Consistent with prior work comparing patients with COPD and those with cancer,⁵ we found that patients with end-organ failure or frailty were more likely than patients with cancer and those with dementia to die in the ICU, a measure of end-of-life treatment intensity associated with poor symptom control and bereavement outcomes.^{10,20-24,39} Conversely, death in a hospice unit—the inpatient setting with the highest level of family-reported quality¹³—was more common among patients with cancer and those with dementia than among those with end-organ failure or frailty. Finally, overall quality of end-of-life care was rated more favorably by family members of patients with cancer and those with dementia than by family members 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 quality of end-of-life care. Our analysis stratified by setting of death also emphasizes 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, or 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—those with end-organ failure or frailty—also had lower rates of families reporting that their health care professionals offered the medical treatment that the patient and family wanted. This finding 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.^{7,28} However, when these interventions are no longer beneficial, it can be a difficult transition for patients, families, and health care professionals. 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. Use of measures of treatment intensity as quality indicators has been limited primarily to the field of oncology.⁴⁰ However, the frequency of high-intensity care for patients with end-organ failure in our study suggests potential for use of these measures of treatment intensity as quality indicators among patients dying of other conditions as well.

Another important finding was the high prevalence of pain among these 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 rates of frequent, uncontrolled pain similar to those of patients with cancer (a group generally considered to be at high risk for pain) suggests another opportunity to improve care. The lower rates of uncontrolled pain in patients with dementia must be viewed with caution since pain is often underappreciated in this population, even by family members.⁴¹

The strengths of our study include a large national cohort with a rich set of outcomes on end-of-life care from both review of medical records 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 life⁴² (the most common setting of death nationally^{43,44}) 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 and those with cancer is novel, and suggests that the substantial body of research aimed at improving end-of-life care for patients with dementia may be having an effect.⁴⁵⁻⁴⁷

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,^{6,7,28} there are challenges in doing so. Using mutually exclusive diagnosis groups does not address multimorbidity. We adjusted for comorbidity in our models; however, the experience of end-of-life care for patients with multiple conditions could differ substantially from the experiences of those with 1 condition. Defining frailty is particularly difficult, especially using administrative data,²⁸ since frailty can exist along with other conditions and may reflect substantial clinical heterogeneity. Results were very similar when combining patients with a diagnosis of frailty into the broader group of patients with diagnoses of “other” conditions. Second, our findings may not be generalizable to patients outside of the VA,

although some research comparing quality of end-of-life care between VA and non-VA health care facilities suggests that care may be similar.⁴⁸ 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 (63.7%), nonresponse bias is possible. We attempted to minimize this possibility 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 agreement between patients and family members is high for ratings of quality of care, it is lower for ratings of subjective symptoms,⁴⁹ which could affect the validity of our pain-related analyses.

Conclusions

While there is room for improvement in end-of-life care across all diagnoses, family-reported quality of end-of-life care was significantly better for patients with cancer and those with dementia than for patients with ESRD, cardiopulmonary failure, or frailty. This quality advantage was mediated by palliative care consultation, do-not-resuscitate orders, and setting of death. Increasing access to palliative care and increasing the rates of 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.

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Author Affiliations: Section of General Internal Medicine, VA Boston Healthcare System, Boston, Massachusetts (Wachterman); Division of General Internal Medicine, Brigham and Women's Hospital, Boston, Massachusetts (Wachterman, Lipsitz, Keating); Department of Psychosocial Oncology and Palliative Care, Dana Farber Cancer Institute, Boston, Massachusetts (Wachterman); Center for Healthcare Organization and Implementation Research, VA Boston Healthcare System, Boston, Massachusetts (Pilver); Tufts Health Plan, Watertown, Massachusetts (Pilver); Center for Health Equity Research and Promotion, Department of Veterans Affairs Medical Center, Philadelphia, Pennsylvania (Smith, Ersek); University of Pennsylvania School of Nursing, Philadelphia (Ersek); Department of Health Care Policy, Harvard Medical School, Boston, Massachusetts (Keating).

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Study concept and design: Wachterman, Ersek, Lipsitz, Keating.

Acquisition, analysis, or interpretation of data: All authors.

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Critical revision of the manuscript for important intellectual content: Ersek, Lipsitz, Keating.

Statistical analysis: Wachterman, Pilver, Smith, Lipsitz, Keating.

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Invited Commentary

Family Assessment of Quality of Care in the Last Month of Life

Stacy M. Fischer, MD; David Bekelman, MD, MPH; F. Amos Bailey, MD

There is often a fog that descends on patients, families, and health care professionals when they are navigating the difficult situation at the end of life. There is a lack of clarity regarding the trajectory of the illness, the true burdens and benefits of the myriad interventions, and how best to integrate palliative care into the overall care plan. In some illnesses, such as progressive cancer and dementia, there may be more clarity than in other conditions, such as advanced organ failure; this clarity can make overall decision making easier.

In this issue of *JAMA Internal Medicine*, Wachterman and colleagues¹ expand on research based on the growing Veterans Affairs (VA) database from the Bereaved Family

Survey. The VA health system attempts to administer the Bereaved Family Survey to caregivers of every veteran who dies within a VA inpatient setting, both acute and long-term care. The VA health system contacts the next of kin of these veterans and asks them to reflect on the overall quality of care provided in the last month of life. In addition, the survey also includes very specific questions, such as “How much of the time were the staff who took care of him willing to take time to listen?” and “How often did the staff provide him with the medication and medical treatment that you and he wanted?”² Between October 2009 and September 2012, a total of 57 753 veterans died within a VA inpatient setting and the Bereaved Family Survey was completed by the family of 34 005 (58.8% of all deaths). These



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