Does Receipt of Recommended Elements of Palliative Care Precede In-Hospital Death or Hospice Referral?

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Abstract

Context. Palliative care aligns treatments with patients' values and improves quality of life, yet whether receipt of recommended elements of palliative care is associated with end-of-life outcomes is understudied.

Objectives. To assess whether recommended elements of palliative care (pain and symptom management, goals of care, and spiritual care) precede in-hospital death and hospice referral and whether delivery by specialty palliative care affects that relationship.

Methods. We conducted structured chart reviews for decedents with late-stage cancer, dementia, and chronic kidney disease with a hospital admission during the six months preceding death. Measures included receipt of recommended elements of palliative care delivered by any clinician and specialty palliative care consult. We assessed associations between recommended elements of palliative care and in-hospital death and hospice referral using multivariable Poisson regression models.

Results. Of 402 decedents, 67 (16.7%) died in hospital, and 168 (41.8%) had hospice referral. Among elements of palliative care, only goals-of-care discussion was associated with in-hospital death (incidence rate ratio [IRR] 1.37; 95% CI 1.01−1.84) and hospice referral (IRR 1.85; 95% CI 1.31−2.61). Specialty palliative care consult was associated with a lower likelihood of in-hospital death (IRR 0.57; 95% CI 0.44−0.73) and a higher likelihood of hospice referral (IRR 1.45; 95% CI 1.12−1.89) compared with no consult.

Conclusion. Goals-of-care discussions by different types of clinicians commonly precede end-of-life care in hospital or hospice. However, engagement with specialty palliative care reduced in-hospital death and increased hospice referral. Understanding the causal pathways of goals-of-care discussions may help build primary palliative care interventions to support patients near the end of life. J Pain Symptom Manage 2020;59:778−786.

Introduction

Palliative care for patients with serious illness improves quality of life, reduces symptom burden, enhances communication about treatment preferences, and decreases the use of intensive medical treatment near death.[1] Recommended elements of palliative care may be delivered by board-certified

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palliative care specialists (specialty palliative care) or other clinicians who treat patients with serious illness (primary palliative care).[2] National consensus practice standards have defined eight domains of quality palliative care: structural, physical, psychological, social, spiritual and existential, cultural, imminent dying, and ethical and legal aspects of care.[3] Each domain includes recommended elements of palliative care, such as pain and symptom management, goals-of-care discussions, and screening for spiritual care needs.[4] By delivering these recommended elements of palliative care, all clinicians may address the needs of patients with serious illness nearing the end of life.

Many patients near the end of life have a goal of staying out of the hospital.[5,6] Although an in-hospital death does not inherently indicate low-quality end-of-life care, most U.S. adults prefer to die at home.[7,8] Although home-based care is not always feasible, hospice care is equipped to support patients and their families throughout the dying process, whether at home, in nursing homes, or in inpatient hospice units. Hospice care outside the hospital results in high satisfaction with end-of-life care and fewer hospital transfers close to death.[9] Evidence supports early palliative care as effective to promote hospice and reduce hospitalizations near the end of life.[10] However, very limited research addresses whether care must be delivered by palliative care specialists to promote these outcomes.

Although there are many recommended elements of palliative care, we focused on three with high potential to affect in-hospital death and hospice referral, based on the structure, process, and outcomes framework of Donabedian.[11] First, symptom management may prevent symptom exacerbations that result in hospitalizations, reducing the likelihood of any given patient dying in the hospital. Second, goals-of-care discussions may limit aggressive treatment inconsistent with patients' values and preferences, particularly as they near the end of life, and thus facilitate transition away from acute care to hospice care.[1,12] Third, spiritual care may address anticipatory grief and existential concerns, allowing patients and families to face approaching death with greater peace and acceptance.[13]

The purpose of this study was to use data from retrospective chart reviews of decedents with serious illness to assess whether receipt of recommended elements of palliative care—specifically, pain and symptom management, goals-of-care discussions, and spiritual care—delivered by any clinician (specialty or primary palliative care) preceded two separate outcomes: in-hospital death and hospice referral (regardless of setting: inpatient hospice facility; community-based hospice at home; in nursing home, etc.). We also

examined the role of specialty palliative care as a predictor of these outcomes. We hypothesized that receipt of symptom management, goals-of-care discussions, and spiritual care precede both death outside the hospital and hospice referral, and that involvement of specialty palliative care enhances the relationships between the elements of palliative care and outcomes.[14]

Methods

Study Sample and Setting

We used data from retrospective chart reviews of decedents with serious illness for this study. The study was conducted at the University of North Carolina Medical Center, a 929-bed public teaching hospital in central North Carolina. We identified decedents with a diagnosis of late-stage cancer, dementia, or chronic kidney disease (CKD).[15,16] We selected these conditions based on their high palliative care need.[17−22] From January 12 to December 31, 2017, we included consecutive decedents until each group had 134 decedents, the number needed to capture a representative sample of decedents with serious illness who were hospitalized in their last six months of life.

Decedents were eligible if they had late-stage disease defined as Stage 4 solid-tumor cancer, Stage 5−7 dementia (moderate, moderately severe, and severe) using the Global Deterioration Scale (GDS), or Stage 4−5 CKD;[23] and an acute nonplanned hospitalization at the study site lasting at least 24 hours during the six months preceding death. Decedents were excluded if they were prisoners at the time of admission, were younger than 18 years, or had been at an outside hospital for >24 hours before transfer to the study site.[24] All study procedures were approved by the University of North Carolina Institutional Review Board.

Data Collection: Chart Reviews

We conducted structured electronic health record (EHR) chart reviews to abstract data on receipt and timing of three recommended elements of palliative care (pain and symptom management, goals of care, and spiritual care), disease characteristics, repeat hospital encounters, specialty palliative care consultation, demographics, comorbid diagnoses, in-hospital death, and hospice referral.[25] The index admission was defined as the first hospitalization in the last 180 days of life.

Two experienced chart abstractors (N. C. E. and K. L. W.) were trained to ensure consistency in the chart review. Both reviewers abstracted data from the same set of 21 decedents, compared findings, and adjudicated any discrepancies. Decisions were logged in an

operational guide to support consistency over time. They had high inter-rater reliability (kappa 0.84). One reviewer (N. C. E.) conducted the remaining chart reviews with frequent discussion with the other reviewer (K. L. W.) to clarify uncertainties and prevent drift. At the midpoint, both reviewers double-abstracted an additional 15 charts (five from each disease group) to assess for drift.

Measures of Predictors: Recommended Elements of Palliative Care
Pain and Symptom Management. We derived a composite score of screening and treatment information documented in the EHR within two days of index admission in physicians and advance practice provider notes or in the medication record. Both physical and psychological symptoms were summarized, specifically, pain, dyspnea, constipation, nausea/vomiting, appetite, fatigue, depression, anxiety, hypoactive delirium/decreased level of consciousness, and hyperactive delirium/agitation. These symptoms were derived from the McCorkle and Young Symptom Distress Scale, which has been tested across serious illness diagnoses.[26,27] The 10-point composite Pain and Symptom Management Index was calculated by summing one point for each symptom that was either screened and absent or screened and treated, if present. Scores range from 0 to 10, and higher scores indicate more comprehensive symptom management.[28]

Goals of Care. The presence of goals-of-care discussions was operationalized by capturing whether clinicians and decedents/families discussed an overall goal of care to guide treatment, broadly categorized as prolong life, support function, improve comfort, or undecided. We searched notes written by physicians and advance practice providers between the index date and date of death. Baseline data were from the history and physical note in the EHR that was associated with the index hospitalization.

Spiritual Care. The presence of spiritual care was operationalized by measuring screening for spiritual needs (e.g., desire to see hospital chaplaincy or community spiritual care provider) and, separately, addressing spiritual care needs if patients desired intervention (e.g., consulting chaplaincy, documentation of community spiritual care provider visit). We searched notes of all provider types between the index date and date of death.

Covariates
Disease Group. Diagnosis was categorized as either cancer, dementia, or CKD. We extracted cancer type (e.g., lung, breast), dementia stage (GDS 5, 6, or 7),

and CKD stage (4 or 5) and whether each decedent was on dialysis, had a previous transplant, or was waiting for transplant at index admission. For decedents with more than one of these three diagnoses, we selected the most life-limiting diagnosis during the hospital admission.

Hospital Encounters. We computed the total number of emergency department and unplanned hospital admissions in the 180 days preceding the index hospitalization. Chart reviews also captured encounters at other health systems using the Epic EHR *Care Everywhere* module (allowing clinicians to access information on their patients from other health systems that also use an Epic EHR).

Specialty Palliative Care Consults. Via palliative care EHR notes, we captured whether decedents received a specialty palliative care consult between their index admission date and date of death. Specialty palliative care was delivered by either a physician attending, a physician fellow, or a nurse practitioner on a single inpatient specialty palliative care consult service.

Demographic Characteristics. We abstracted decedents' age at death, gender, race, ethnicity, insurance status, and preadmission living place.

Charlson Comorbidity Index. The Charlson Comorbidity Index (CCI) is a prognostic tool that scores comorbid conditions to indicate overall illness burden (range 0–37; higher scores indicate higher disease burden).[29] We also calculated the adjusted CCI, which indicates the comorbidity score without the points associated with a decedent's primary life-limiting illness. Points were deducted for cancer (six points), dementia (one point), and CKD (two points) to provide a picture of the comorbidity burden within each group of decedents.

Outcome Measures
In-Hospital Death. Place of death was determined from EHR documentation, death certificates when available in the EHR, and obituary search. If a death occurred within 14 days of the final hospital discharge and there was no other evidence of place of death, we defined the location of death as the discharge location.

Hospice Referral. Hospice referral was assessed in the inpatient and outpatient records, operationalized as a binary indicator of whether a decedent was referred to hospice (in any form, e.g., inpatient hospice, hospice at home) from the time of index admission until death.

Analysis

After describing the sample stratified by disease group, we conducted bivariate analyses to assess the unadjusted relationship between our predictor variables and primary outcomes.

We ran modified Poisson models to examine the associations of pain and symptom management, goals of care, and spiritual care with the two primary outcomes: in-hospital death vs. other places of death and hospice referral vs. no hospice referral, respectively. Next, we ran modified Poisson models for each of the two outcomes including only one primary predictor (pain and symptom management, goals of care, and spiritual care). Modified Poisson models allow interpretation of a binary outcome using an incidence rate ratio (IRR).[30,31] All analyses controlled for age, race, gender, insurance status, unadjusted CCI, specialty palliative care consult, and the number of hospital encounters (hospitalizations and ED visits) in the 180 days preceding the index visit, and preadmission living place. All statistical tests were two-tailed with a 0.05 significance level; we report 95% CIs.

Power. Sample size was calculated for 0.80 power using existing data on death in-hospital and hospice referral in similar populations.[32,33] Adjusting for the number of variables in the models,[10−13] the final target sample size was 356.[34] All analyses were conducted using Stata 14 (Stata Corp, College Park, TX).

Results

We reviewed the medical records of 402 decedents with late-stage cancer ($n = 134$), dementia ($n = 134$), or CKD ($n = 134$). The study sample was 53.5% female, 61.2% white, and the mean age was 72 years. The median time from index admission to death was 55 days (Table 1). Decedents with cancer most frequently had lung (21.6%), breast (14.9%), or colorectal (10.5%) cancer. About half (51.5%) of decedents with dementia had GDS Stage 6 disease, 35.1% GDS Stage 5, and 13.4% GDS Stage 7. Two-thirds (67.2%) of decedents with CKD had Stage 5 disease, and more than half (57.5%) were on dialysis at the time of index admission.

Recommended Elements of Palliative Care
Pain and Symptom Management. The cohort had a mean of 2.9 (SD 1.7) symptoms appropriately managed (screened negative or screened positive and treated) on the Pain and Symptom Management Index (range 0−10; higher scores indicating more appropriate management). Stratified by disease group, the mean index scores were 3.6 (SD 1.9) for cancer, 2.4 (SD 1.5) for dementia, and 2.8 (SD 1.4) for CKD ($P < 0.00$).

Goals of Care. Seventy-five percent ($n = 303$) of decedents had documentation of at least one goals-of-care discussion. Relatively more decedents with cancer had goals-of-care discussions ($n = 108$; 80.6%) compared with those with dementia ($n = 100$; 74.6%) or CKD ($n = 95$; 70.9%).

Spiritual Care. Fifty-five percent of decedents ($n = 221$) were screened for spiritual care needs. Among those screened, all patients who expressed a desire to receive spiritual care received it ($n = 202$). Decedents with dementia were screened relatively less frequently ($n = 56$; 41.8%) compared with cancer ($n = 82$; 61.2%) and CKD ($n = 83$; 61.9%).

Specialty Palliative Care Consults
In the full cohort, 35% of decedents received a specialty palliative care consult during an inpatient stay. More decedents with cancer ($n = 71$; 53.0%) received consults than those with dementia ($n = 32$; 23.9%) or CKD ($n = 42$; 31.3%) ($P < 0.00$).

In-Hospital Death and Place of Death
Forty percent ($n = 157$) of decedents died in the hospital setting, 43 of whom (27.3%) died on withdrawal of life-sustaining treatment (e.g., ventilator support). One-quarter ($n = 102$; 25.4%) died at home, 51 in a nursing home (12.7%), and 50 in inpatient hospice (12.4%). Decedents with CKD were more likely to die in the hospital ($n = 79$; 59.0%) compared with decedents with cancer ($n = 45$; 33.6%) or dementia ($n = 33$; 24.6%). About one-quarter of decedents with dementia died in a nursing home setting ($n = 36$; 26.9%). A plurality of decedents with cancer died at home ($n = 51$; 38.1%), which is twice the frequency for those with dementia ($n = 26$; 19.4%) or CKD ($n = 25$; 18.7%) ($P < 0.00$).

Hospice
Forty-two percent of decedents ($n = 168$) were referred to hospice. Decedents with cancer were referred to hospice relatively more frequently ($n = 82$; 61.2%) than those with dementia ($n = 55$; 41.0%) or CKD ($n = 31$; 23.1%) ($P < 0.00$).

Multivariable Models
In-Hospital Death. Goals-of-care discussion was associated with a higher likelihood of death in the hospital setting (IRR 1.37; 95% CI 1.01−1.84), after adjusting for age, race, gender, insurance status, unadjusted CCI, specialty palliative care consult, and the number of hospital encounters (hospitalizations and

Table 1
Decedent Characteristics

Variable, n (%)	Cancer (N = 134)	Dementia (N = 134)	CKD (N = 134)	Total (N = 402)
Age, mean (SD)	64.4 (12.5)	83.69 (10.5)	66.38 (14.6)	71.49 (15.3)
Gender, female	76 (56.7)	78 (58.2)	61 (45.5)	215 (53.5)
Race				
White	85 (63.4)	91 (67.9)	70 (52.2)	246 (61.2)
Black	42 (31.3)	36 (26.9)	58 (43.3)	136 (33.8)
Other	7 (5.2)	7 (5.2)	6 (4.5)	20 (49.8)
Ethnicity, Hispanic/Latino	3 (2.2)	0	4 (3.0)	7 (1.7)
Insurance status (some patients >1)				
Private	58 (43.3)	25 (18.7)	34 (25.4)	117 (29.1)
Medicare	76 (56.7)	130 (97.0)	116 (86.6)	322 (80.1)
Medicaid	25 (18.7)	21 (15.7)	33 (24.6)	79 (19.7)
Tricare	6 (4.5)	7 (5.2)	6 (4.5)	19 (4.7)
Uninsured	9 (6.7)	0	3 (2.2)	12 (3.0)
Time from index admit to death, median days (range)	58.5 (1−175)	50 (2−179)	55 (1−180)	55 (1−180)
Preindex admission residence				
Home	128 (95.5)	68 (50.8)	119 (88.8)	315 (78.4)
SNF/NH	2 (1.5)	54 (40.3)	8 (6.0)	64 (15.9)
ILF/ALF	3 (2.2)	12 (9.0)	6 (4.5)	21 (5.2)
Other	1 (0.8)	0	1 (0.8)	2 (0.5)
Index admission discharge location				
Death in hospital	20 (14.9)	20 (14.9)	27 (20.2)	67 (16.7)
Home	92 (68.7)	25 (18.7)	68 (50.8)	185 (46.0)
SNF/NH/LTAC	11 (8.2)	71 (53.0)	24 (17.9)	106 (26.4)
ILF/ALF	2 (1.5)	4 (3.0)	3 (2.2)	9 (2.2)
Inpatient hospice	7 (5.2)	10 (7.5)	4 (3.0)	21 (5.2)
Hospital transfer	1 (0.8)	2 (1.5)	4 (3.0)	7 (1.7)
Acute inpatient rehabilitation	1 (0.8)	2 (1.5)	4 (3.0)	7 (1.7)
CCI, mean (SD)	7.23 (1.5)	3.59 (2.4)	5.71 (2.0)	5.51 (2.5)
CCI adjusted for primary diagnosis, mean (SD)	1.23 (1.5)	2.59 (2.4)	3.71 (2.0)	2.51 (2.2)
Specialty palliative care consult	71 (53.0)	32 (23.9)	42 (31.3)	145 (36.1)
Place of death				
Hospital	45 (33.6)	33 (24.6)	79 (59.0)	157 (39.1)
Intensive care unit	20 (44.4)	11 (33.3)	44 (55.7)	75 (47.8)
On withdrawal of life-sustaining treatment	9 (45.0)	8 (72.7)	26 (59.1)	43 (57.3)
Home	51 (38.1)	26 (19.4)	25 (18.7)	102 (25.3)
SNF/NH/ALF/inpatient rehabilitation	4 (3.0)	36 (26.9)	13 (9.7)	53 (13.2)
Inpatient hospice	23 (17.2)	17 (12.7)	10 (7.5)	50 (12.4)
Unknown	11 (8.2)	22 (16.4)	7 (5.2)	40 (10.0)
Referral to hospice	82 (61.2)	55 (41.0)	31 (23.1)	168 (41.8)
Pain and Symptom Management Index, mean (SD)	2.9 (1.7)	3.6 (1.9)	2.4 (1.5)	2.8 (1.4)
Goals-of-care discussion	108 (80.6)	100 (74.6)	95 (70.9)	303 (75.4)
Spiritual care needs screened	82 (61.2)	56 (41.8)	83 (61.9)	221 (55.0)

CKD = chronic kidney disease; SNF = skilled nursing facility; NH = nursing home; ILF = independent living facility; ALF = assisted living facility; LTAC = long-term acute care; CCI = Charlson Comorbidity Index.

emergency department visits), and preadmission living place. Likewise, screening for spiritual care needs was also associated with a higher likelihood of in-hospital death (IRR 2.62; 95% CI 1.94−3.54). Decedents with CKD were more likely to die in the hospital setting than those with cancer (IRR 1.71; 95% CI 1.29−2.26). In terms of specialty palliative care, a consult was associated with a lower likelihood of in-hospital death compared with patients who did not receive a consult (IRR 0.57; 95% CI 0.44−0.73) (Table 2).

Hospice Referral. Decedents who had a goals-of-care discussion were more likely to be referred to hospice (IRR 1.85; 95% CI 1.31−2.61). Decedents with dementia (IRR 0.65; 95% CI 0.43−0.98) or CKD (IRR 0.45; 95% CI 0.32−0.65) were less likely to be referred to hospice than those with cancer (reference group). Furthermore, patients receiving specialty palliative care consults had a higher likelihood of hospice referral compared with those who did not receive a specialty palliative care consult (IRR 1.45; 95% CI 1.12−1.89) (Table 3).

Discussion

Clinical trials provide support for the positive effect of both specialty and primary palliative care on the quality and outcomes of care in serious illness, yet the causal mechanisms linking individual

Table 2
Factors That Precede In-Hospital Death, IRR

Predictor	Unadjusted, Bivariate	Full Model	Adjusted, Pain & Symptom Management	Adjusted, Primary Predictor: Goals of Care	Adjusted, Primary Predictor: Spiritual Care
			IRR (95% CI)		
Outcome: death in hospital					
Pain & symptom management	0.91 (0.84, 1.00)	0.93 (0.87, 1.00)	0.93 (0.85, 1.01)		
Goals of care	1.33 (0.96, 1.84)	1.37 (1.01, 1.84)[a]		1.61 (1.19, 2.18)[a]	
Spiritual care	2.85 (2.07, 3.93)[a]	2.62 (1.94, 3.54)[a]			2.74 (2.03, 3.70)[a]
Disease state (reference: cancer)					
Dementia	0.73 (0.50, 1.07)	0.90 (0.56, 1.45)	0.97 (0.59, 1.62)	1.04 (0.62, 1.73)	1.00 (0.62, 1.56)
CKD	1.76 (1.33, 2.32)[a]	1.71 (1.29, 2.26)[a]	1.84 (1.35, 2.50)[a]	1.95 (1.42, 2.68)[a]	1.72 (1.31, 2.27)[a]
Time from index admission to death	0.99 (0.99, 1.00)	0.99 (0.99, 1.00)[a]	0.99 (0.99, 1.00)[a]	0.99 (0.99, 1.00)[a]	0.99 (0.99, 1.00)[a]
Palliative care consult	0.73 (0.56, 0.97)[a]	0.57 (0.44, 0.73)[a]	0.76 (0.59, 1.00)[a]	0.63 (0.48, 0.82)[a]	0.59 (0.46, 0.75)[a]

IRR = incidence rate ratio; CKD = chronic kidney disease.
We controlled for age, race, gender, insurance status, Charlson Comorbidity Index, number of encounters (hospital admissions and emergency department visits), and preadmission living place.
[a]$P < 0.05$.

recommended elements of palliative care and outcomes remains unclear.[1] In this study, we examined associations between recommended elements of palliative care, regardless of the treating clinicians, and outcomes of decedents with serious illness to identify elements that may be critical to design of primary palliative care interventions. Goals-of-care discussions and spiritual care were each associated with in-hospital death, although goals-of-care discussions were also associated with hospice referral.

Goals-of-care discussions were frequent precursors of hospice referral, yet only involvement of specialty palliative care predicted transitions from hospitals for end-of-life care. Possible explanations for this include that specialty palliative care clinicians may hold discussions earlier in the illness trajectory, or

they may communicate options for community-based services or setting of care more effectively than other clinicians.[35] About half of in-hospital deaths were in the intensive care unit, most of which occurred very soon after withdrawal of life-sustaining treatments; for many of these patients, transfer out of the hospital before death is not feasible, although care is likely consistent with goals that were discerned during goals-of-care discussion. Although this likely enhances the association of goals-of-care discussions and in-hospital death, the conversations—whether led by specialty palliative care or other clinicians—are important for delivering goal-concordant care.[36] Understanding and enhancing both specialty and primary palliative care mechanisms are important for meeting the needs of patients with serious illness, particularly in the face

Table 3
Factors That Precede Hospice Referral, IRR

	Unadjusted, Bivariate	Full Model	Adjusted, Pain & Symptom Management	Adjusted, Primary Predictor: Goals of Care	Adjusted, Primary Predictor: Spiritual Care
Outcome: Hospice			IRR (95% CI)		
Pain & symptom management	1.03 (0.99, 1.08)	1.02 (0.96, 1.08)	1.04 (1.00, 1.10)[a]		
Goals of care	0.77 (0.63, 0.94)[a]	1.85 (1.31, 2.61)[a]		1.69 (1.19, 2.40)[a]	
Spiritual care	0.71 (0.59, 0.84)[a]	0.58 (0.45, 0.74)			0.61 (0.48, 0.78)[a]
Disease state (reference: cancer)					
Dementia	0.93 (0.77, 1.13)	0.65 (0.43, 0.98)[a]	0.63 (0.42, 0.96)[a]	0.58 (0.39, 0.88)[a]	0.64 (0.42, 0.96)[a]
CKD	0.74 (0.56, 0.96)[a]	0.45 (0.32, 0.65)[a]	0.43 (0.30, 0.62)[a]	0.41 (0.29, 0.59)[a]	0.45 (0.32, 0.63)[a]
Time from index admission to death	1.00 (1.00, 1.00)	1.00 (1.00, 1.01)[a]	1.00 (1.00, 1.01)[a]	1.00 (1.00, 1.01)[a]	1.00 (1.00, 1.01)[a]
Palliative care consult	0.99 (0.83, 1.18)	1.45 (1.12, 1.89)[a]	1.44 (1.13, 1.84)[a]	1.29 (1.01, 1.66)[a]	1.72 (1.35, 2.19)[a]

IRR = incidence rate ratio; CKD = chronic kidney disease.
We controlled for age, race, gender, insurance status, Charlson Comorbidity Index, number of encounters (hospital admissions and emergency department visits), and preadmission living place.
[a]$P < 0.05$.

of the specialty palliative care workforce shortage and maldistribution.[2] As in this study, examining relationships between outcomes and specific elements of palliative care (rather than palliative care broadly) is important for developing feasible and effective primary palliative care interventions for patients with serious illness who often have complex and competing priorities.[37]

Goals-of-care discussions are happening in the hospital for patients very near death, perhaps prompting hospice referral where appropriate, although many of those patients may be too unstable to leave the hospital before their death, consistent with findings that goals-of-care discussions were associated with in-hospital death; this is also consistent with prior findings (including in this cohort) indicating goals-of-care discussions and transitions to comfort and hospice happen very late in disease trajectories.[5,24,38] Future research can investigate ways both specialty and primary palliative care clinicians communicate and support decision making, and how the processes can be improved, including having these discussions earlier in an effort to promote patient-centered care.[39] For example, early and frequent communication may support transitions to hospice when patients are ready, allowing them to fully gain benefits from hospice services.[40] Further research can also investigate what palliative care specialists are doing (e.g., thorough goals-of-care discussions, symptom management) that may be transferable to primary palliative care clinicians.

Our findings also highlight differences across diseases that may illuminate potential intervention points. Decedents with cancer were more likely to die in hospice than decedents with dementia or CKD. Historically, hospice and palliative care grew out of oncology and subsequently expanded to other serious illnesses, yielding relatively better-integrated services in oncology.[41,42] Improving palliative care in nephrology calls for better incorporation of patient-centered decision making, disease-specific symptom management, and expanding specialty palliative care resources for patients with late-stage CKD.[22] Likewise, patients with late-stage dementia and their families face disease-specific barriers, including death in nursing homes; traditional models of palliative care and hospice may need to be adapted for dementia-specific symptom management, more intensive psychosocial support for families, and fewer specialty palliative care resources.[43,44]

We used EHR phenotypes (structured search algorithms for EHR data) to identify eligible patient records and then conducted manual chart reviews to obtain detailed information about the recommended elements of palliative care and end-of-life outcomes for decedents with serious illness. Although more labor intensive than electronic queries, manual chart review yields the richest data when considering note-based text and unstructured data. Methods such as EHR phenotypes, natural language processing, and machine learning have potential to enhance the use of large analytic data sets (e.g., claims data, EHR data) and improve efficiency in extracting note-based EHR data. Although research is ongoing, these methods are not yet well developed enough to provide granular note-level data, particularly across institutions, which still have incongruent EHRs and documentation practices.

Limitations

This study was conducted at one public teaching hospital; although it is a large and diverse public hospital serving traditionally underserved populations, generalizability is limited. We are not able to assess causal mechanisms of in-hospital death or hospice referral based on the cross-sectional data in our models. Because of limitations in EHR data, we were not able to do a more complete analysis of place of death, beyond whether patients died in the hospital, or robust information about factors supporting death at home.

Conclusions

Goals-of-care discussions and spiritual care are associated with both in-hospital death and hospice referral. These findings support evidence that elements of palliative care may be delivered in acute settings late in the disease trajectory, often too near the end of life to shift care trajectories before death. Specialty palliative care involvement increased hospice referral and decreased in-hospital death, which is concordant with many patients' preferences.[8] Adapting specialty palliative care efforts (e.g., robust goals-of-care discussion) to primary palliative care may facilitate more goal-concordant care near the end of life.

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