



Thematic Analysis of Hospice Mentions in the Health Records of Veterans with Advanced Kidney Disease

Ann M. O'Hare,^{1,2} Catherine R. Butler ,¹ Janelle S. Taylor,³ Susan P.Y. Wong,^{1,2} Elizabeth K. Vig,^{1,2} Ryan S. Laundry,² Melissa W. Wachterman,^{4,5} Paul L. Hebert,^{2,6} Chuan-Fen Liu,^{2,6} Nilka Rios-Burrows,⁷ and Claire A. Richards ^{2,8}

Due to the number of contributing authors, the affiliations are listed at the end of this article.

ABSTRACT

Background Patients with advanced kidney disease are less likely than many patients with other types of serious illness to enroll in hospice. Little is known about real-world clinical decision-making related to hospice for members of this population.

Methods We used a text search tool to conduct a thematic analysis of documentation pertaining to hospice in the electronic medical record system of the Department of Veterans Affairs, for a national sample of 1000 patients with advanced kidney disease between 2004 and 2014 who were followed until October 8, 2019.

Results Three dominant themes emerged from our qualitative analysis of the electronic medical records of 340 cohort members with notes containing hospice mentions: (1) hospice and usual care as antithetical care models: clinicians appeared to perceive a sharp demarcation between services that could be provided under hospice versus usual care and were often uncertain about hospice eligibility criteria. This could shape decision-making about hospice and dialysis and made it hard to individualize care; (2) hospice as a last resort: patients often were referred to hospice late in the course of illness and did not so much choose hospice as accept these services after all treatment options had been exhausted; and (3) care complexity: patients' complex care needs at the time of hospice referral could complicate transitions to hospice, stretch the limits of home hospice, and promote continued reliance on the acute care system.

Conclusions Our findings underscore the need to improve transitions to hospice for patients with advanced kidney disease as they approach the end of life.

JASN 31: ●●●-●●●, 2020. doi: <https://doi.org/10.1681/ASN.2020040473>

Mortality rates and symptom burden for patients with advanced kidney disease are comparable with those of patients with terminal cancer and other serious illnesses.^{1,2} However, terminally ill patients with advanced kidney disease are far less likely to use hospice services than other groups of patients approaching the end of life, and are referred to hospice much closer to the time of death.³⁻⁵ In 2015, 26% of Medicare beneficiaries on maintenance dialysis were receiving hospice services at the time of death as compared with almost half of all Medicare beneficiaries.^{2,3,6,7} Patients on maintenance dialysis also spend a shorter time in hospice than most Medicare beneficiaries (median of 5 versus 17 days).^{3,7}

Infrequent and late hospice referral among patients on maintenance dialysis have been attributed to a Medicare payment policy that will not provide reimbursement for life-sustaining treatments related to the primary hospice diagnosis,⁸ effectively forcing patients dying of kidney failure to choose

Received April 19, 2020. Accepted June 29, 2020.

Published online ahead of print. Publication date available at www.jasn.org.

Correspondence: Dr. Ann M. O'Hare, 111J Renal Dialysis Unit, Veterans Affairs Puget Sound Health Care System, 1660 South Columbian Way, Seattle, WA 98109. Email: ann.ohare@va.gov

Copyright © 2020 by the American Society of Nephrology

between hospice and dialysis.^{3,4,9} However, rates of hospice enrollment are also low in veterans on maintenance dialysis¹⁰ and among patients with advanced kidney disease not on dialysis,⁵ groups that should theoretically be less affected by Medicare payment rules around concurrent care. Thus, other considerations may also be important in understanding limited use of hospice services among patients with advanced kidney disease.

To date, relatively little empirical research has been published documenting how decisions about hospice unfold in real-world clinical settings among patients with advanced kidney disease. An understanding of the content and context of hospice discussions and transitions could help to inform efforts to improve end-of-life care for members of this population.

METHODS

Using a previously published approach,^{11,12} we conducted a qualitative analysis of text notes in the Department of Veterans Affairs (VA) electronic medical record (EMR) system to identify dominant themes pertaining to the content and context of documented mentions of the term “hospice” among patients with advanced kidney disease receiving care within the VA health care system. To accomplish this, we identified a national cohort of 130,374 veterans with advanced kidney disease defined as an eGFR <20 ml/min per 1.73 m² on at least two occasions at least 3 months apart between October 1, 1999 and December 31, 2014. As described elsewhere, we used clinical and administrative data from the VA, Medicare, and the US Renal Data System, a national ESKD registry, to assemble and characterize the cohort.^{10,13} Patients entered the cohort on the date of their second eGFR <20 ml/min per 1.73 m² during the observation period and were followed through their date of death or most recent documented clinical encounter within the VA system on or before October 8, 2019.

Data Collection

We selected a random sample of 1000 patients who entered the cohort in more recent years (after December 31, 2003) for in-depth chart review. We used the Veterans Indexed Search for Analysis (VISA) tool,¹² a Lucene-based text search tool, to search for mentions of the term hospice in the EMRs of these patients (stored as Text Integration Utilities notes in VA's Corporate Data Warehouse) during follow-up. This term appeared in 6745 notes belonging to 493 patients over the observation period. One team member (A.M.O., an academic nephrologist) reviewed all identified hospice mentions in order to exclude patients for whom this term appeared only as part of standard boiler-plate text (e.g., unchecked checklist item) or in reference to someone other than the patient (e.g., mention of a relative on hospice) ($n=153$), yielding an analytic cohort of 340 patients with at least one clinical note containing one or more valid hospice mentions.

Significance Statement

Little is known regarding how decisions about hospice referral among patients with advanced kidney disease unfold in real-world clinical settings. The authors identified three dominant themes in their qualitative analysis of documentation pertaining to hospice in the electronic medical records of members of a national sample of veterans with advanced kidney disease. First, hospice and usual care seemed to function as conflicting rather than complementary models of care. Second, patients were usually referred to hospice late in the course of illness after all other options had been exhausted. Third, patients' complex care needs sometimes complicated transitions to hospice, stretched the limits of home hospice, and fostered reliance on the acute medical system. These findings highlight the need to improve hospice transitions for patients with advanced kidney disease.

To describe patients' exposure to related care processes such as palliative care, advance care planning, and home care during follow-up, we used the VISA search tool to ascertain the percentage of patients with and without hospice mentions with one or more standard note titles containing the following terms: palliative (to capture notes by palliative care providers), advance directive (to capture notes in which patients were screened to see whether they had completed or might want to complete an advance directive or had an advance directive discussion), life-sustaining treatment (to capture notes completed under the VA's recent Life-Sustaining Treatment Decisions Initiative that is intended to promote discussion and documentation of goals of care), DNR (to capture notes documenting do-not-resuscitate discussions and/or status), and home health or HBPC (to capture notes related to care under the VA's Home-Based Primary Care Program).

Quantitative Analyses

We used SAS statistical software version 9.4 (SAS Institute) to assemble the cohort and Stata statistical software version 15 (StataCorp.) to compare the unadjusted characteristics and survival times of patients with versus without hospice mentions using t tests, chi-squared tests, and survival analysis as appropriate.

Qualitative Analyses

We used inductive content analysis, an unstructured approach to reading text aimed at identifying concepts or themes inherent to a phenomenon, to analyze notes with at least one valid mention of the term hospice.¹⁴ To accomplish this, we used the VISA search tool to abstract and code passages containing hospice mentions until reaching thematic saturation (the point at which no new codes emerged with additional record review), which occurred after reviewing notes from 82 randomly selected patients. Abstracted passages from the EMRs of these patients were then exported to a Microsoft Excel file and independently coded by a second team member (C.R.B., a senior nephrology research fellow). The two team members then together reviewed all codes and associated passages for these patients using an iterative and consensus-based

approach to resolve any differences or uncertainties in interpretation of passages, to identify emerging themes, and to organize these into larger thematic categories. To ensure that analyses were grounded in the data, A.M.O. and C.R.B. returned to abstracted passages and original notes in patients' EMRs as needed throughout the analysis and asked a third coauthor (E.K.V., an academic geriatrician and palliative care physician) to independently review abstracted passages. After developing and refining the coding schema, A.M.O. coded and abstracted passages from the EMRs of the remaining 258 cohort members to identify additional exemplar quotations for inclusion in manuscript tables. All authors provided iterative input on the thematic schema and interpretation of exemplar quotations during manuscript revision. The study was approved by the VA's Central Institutional Review Board.

RESULTS

Patient Characteristics

Among the random sample of 1000 patients selected for EMR review, those with at least one valid hospice mention ($n=340$) were older (mean age 74.3 ± 11.7 versus 70.1 ± 12.5 years; $P < 0.001$) and less likely to be black (18.8% versus 27.1%; $P = 0.004$) than those without mentions (Table 1). Patients with hospice mentions were also less likely than those without mentions to have been on maintenance dialysis at the time of cohort entry (12.4% versus 20.0%; $P < 0.001$). A higher proportion of patients with hospice mentions had diagnoses of cancer (29.4% versus 15.3%; $P < 0.001$) and dementia (9.4% versus 4.7%; $P = 0.004$), but the prevalence of other comorbid conditions was similar between groups. From the time of cohort entry on the date of each patient's second eGFR

< 20 ml/min per 1.73 m^2 between 2004 and 2014 through the end of follow-up on October 8, 2019, 94.1% of patients with, and 79.4% without hospice mentions died ($P < 0.001$). Median survival from the time of cohort entry to death or the end of follow-up ranged from 2.5 (interquartile range, 0.8–5.3) years for patients with hospice mentions to 4 (interquartile range, 1.7–8.5) years for those without mentions. The EMRs of patients with hospice mentions were more likely than those of patients without mentions to include note titles pertaining to palliative care (58.5% versus 4.4%; $P < 0.001$), advance care planning (70.6% versus 45%; $P < 0.001$), and home care (56.2% versus 29.4%; $P < 0.001$) during follow-up.

Thematic Analyses

Through qualitative analysis of notes containing hospice mentions, we identified the following three emergent themes: (1) hospice and usual care as antithetical care models, (2) hospice as a last resort, and (3) care complexity.

Theme 1: Hospice and Usual Care as Antithetical Care Models
Hospice and usual care seemed to function as antithetical rather than complementary models of care, which could shape decision-making about hospice and dialysis and make it difficult to individualize care (Table 2).

Understanding of Hospice Eligibility Criteria. The eligibility criteria of individual hospice organizations as reflected in clinician notes were framed in terms of qualifying conditions and allowed services. Whether accurate or not, patients', families', and clinicians' understanding of hospice eligibility criteria and what services could (and could not) be provided under hospice strongly shaped referral decisions (quotations [Q] 1–3). We also found instances where receipt of certain services while patients were on hospice (e.g., physical therapy,

Table 1. Characteristics of random sample of cohort members selected for chart review by presence of hospice mention

Characteristics	No Hospice Mention ($n=660$)	Hospice Mention ($n=340$)	P Value
Measures ascertained at cohort entry			
Mean age (SD)	70.1 (12.5)	74.3 (11.7)	< 0.001
Black, %	27.1	18.8	0.004
Female, %	4.7	2.4	0.07
Maintenance dialysis, %	20	12.4	< 0.001
Diabetes, %	63.3	60.9	0.45
Congestive heart failure, %	40.9	47.4	0.05
Cancer, %	15.3	29.4	< 0.001
Dementia, %	4.7	9.4	0.004
Peripheral arterial disease, %	25.8	29.1	0.26
Cerebrovascular disease, %	18.2	20.3	0.42
Measures ascertained during follow-up			
Died, %	79.4	94.1	< 0.001
Note title(s) pertaining to palliative care, %	4.4	58.5	< 0.001
Note title(s) pertaining to advance directives and/or advance care planning, %	45	70.6	< 0.001
Note title(s) pertaining to home care, %	29.4	56.2	< 0.001

Table 2. Hospice and usual care as antithetical care models (theme 1)

Quotation	Note Title	Exemplar Quotation
Subtheme 1: understanding of hospice eligibility criteria		
1	Social Work Note	Asked veteran why he had refused hospice care. Veteran said: "because they won't let me go to the hospital."
2	Geriatric Extended Care Consult	Guidelines for hospice suggest that a creatinine be >8 (>6 for patients with diabetes) [and] that there be persistent hyperkalemia. This veteran has neither.
3	Inpatient Treatment Plan Interdisciplinary Note	Not hospice per [physician] because there are many minor issues that could be treated such as pneumonia (for example) and wants option to transfer to acute. Some dysphagia issues.
4	Home Based Primary Care Note	Taken off hospice to receive additional physical therapy; caregiver states good results.
Subtheme 2: barriers to concurrent dialysis and hospice		
5	Palliative Care Consult	[Patient and wife] did meet with hospice which they refused due to [the] fact that hospice agency told them he needed to stop his hemodialysis treatment to be on hospice.
6	Hematology Oncology Consult	The patient has declined hospice care, because he heard that this would imply discontinuation of hemodialysis. He is not ready to die.
7	Social Work Note	She is concerned that veteran will suffer if dialysis is stopped, due to fluid overload. She inquires about hospice with continuing dialysis, which is not possible with hospice at [name of VA facility].
8	Palliative Care Note	Today's discussion confirmed that the goals are unchanged, and that discussions around bringing the Veteran home include rehospitalization and continued dialysis, goals that are not in line with hospice.
9	Palliative Care Consult	If patient's renal condition deteriorates further that [he] requires renal replacement therapy, then reason for hospice should be ESRD. At this time, patient wishes to receive hemodialysis if necessary and to continue with current medical treatment. Thus, this goes against hospice philosophy, and does not qualify him for hospice yet. If his condition were to be end-stage cardiac disease, then dialysis is considered a form of comfort measure to help with respiration and in this type of situation patients may enter hospice while on hemodialysis.
10	Palliative Care Consult	He is amenable to home hospice. . . and qualifies in our estimation under diagnosis of prostate cancer. Dialysis could continue with hospice care, as it is not related to the hospice diagnosis.
11	Social Work Note	In working with family on [discharge] plan, received call back from [name of hospice]. Since veteran's calciphylaxis is related to renal disease, Medicare will not allow dialysis and hospice care. However, VA contracts with [name of different hospice agency]. . . spoke with their director. . . as well as VA. . . administrator to verify that VA could cover cost of both fee basis hospice and fee basis dialysis, which was cleared.
12	Internal Medicine Inpatient Attending Note	Family requested home hospice under patient's Medicare. Wife asked if patient can continue on dialysis for a little while during home hospice. . . The hospice agency doctor would need to determine if patient can continue on dialysis during home hospice.
Subtheme 3: limited room for individualization		
13	Internal Medicine Resident Note	Macrocytic anemia-had plans for [darbopoeitin]-[discontinue darbepoeitin] with hospice plans.
14	Speech Pathology Note	Plan: Speech to follow up ×1 meal, however further speech therapy not indicated for dysphagia if patient transfers to hospice.
15	Pain Consult	The risks for chronic opioid therapy combined with benzodiazepine would DEFINITELY outweigh the benefits of therapy UNLESS he is a hospice care case (renal failure). I would refer patient back to [primary care provider] to be made [do not resuscitate] with hospice referral, otherwise he is at exceedingly high risk for an overdose event or falls event with more compression fractures.
16	Nursing Note	Could hear this resident crying/bellowing from quite a distance down the hallway. Went to her room to check on her only to find her crying and typing with her computer saying "having acute pain in pelvis and in neck" . . . I explained to her that we could offer more medication with a hospice status. . . She said via type "call doctor I will do hospice."
17	Internal Medicine Attending Note	Hydromorphone and lorazepam are "hospice only" medications, supplied in a "comfort pack." Since he is no longer in hospice, he should no longer need those medications, and I really am not willing to prescribe them.
18	Palliative Care Note	We discussed the fact that it is sometimes difficult to walk the middle ground i.e., that in the units [medical or surgical floors] sometimes teams are reluctant to use opioids for fear of shortening life. She again reiterated that she wanted her dad to be comfortable.
19	Physician Long Term Care Note	He continues to gain weight. . . As mentioned before I'm trying to refrain from doing laboratory studies since he is on hospice. However, with progression of his edema consistent with increasing heart failure, we will increase the torsemide to 80 mg each AM and add in metolazone 2.5 mg once a week.

Square brackets contain text substituted by the authors to spell out abbreviations, correct misspelling, and remove the names of individuals and institutions.

emergency room care) required or prompted discharge from hospice (Q4).

Barriers to Concurrent Dialysis and Hospice. The need, real or perceived, to stop or forgo dialysis in order to receive hospice services was a common barrier to hospice entry for members of this cohort (Q5–7). However, there did not appear to be a unified approach to decision making in this area. Some clinicians expressed the belief that patients could not continue to receive dialysis after hospice enrollment or that this was not consistent with hospice philosophy (Q8). Others understood this to depend on whether patients had a life-limiting condition other than kidney disease (Q9 and Q10). We also found examples of clinicians working with hospice agencies to secure concurrent dialysis and hospice care for veterans whose underlying renal disease did appear to be the primary indication for hospice (Q11). It was common for clinicians to document uncertainty about whether patients would be allowed to continue dialysis after electing hospice, and to defer this decision to individual hospice agencies (Q12).

Little Room for Individualization. The decision to transfer a patient to hospice often prompted reflexive changes to medications and treatments, with seemingly little consideration for whether these changes supported patients' goals (Q13 and Q14). Clinicians' understanding of what services could and could not be provided under usual care versus hospice both shaped referral decisions and limited their willingness and/or ability to individualize care, particularly in the context of symptom and pain management (Q15–17). Sometimes clinician notes alluded to the challenges of caring for patients while adhering to their understanding of the constraints on both usual (Q18) and hospice (Q19) care.

Theme 2: Hospice as a Last Resort

Patients were often referred to hospice late in the course of illness, at which time they did not so much choose hospice as accept these services when all treatment options had been exhausted (Table 3).

Readiness for Hospice Referral. Patients and families were not always ready to accept hospice services when these were offered (Q20–22), preferring to wait to see whether the patient's clinical status improved and/or until available diagnostic, therapeutic, and rehabilitative options had been attempted (Q23). Clinicians too tended to view hospice as a potential future option to be considered if the patient's clinical status worsened or failed to improve over time (Q24). In some instances, clinicians anticipated the need for hospice but waited to discuss this with patients and families until further treatment had been attempted or until they brought it up (Q25 and Q26).

Hospice Rarely an Active Choice. Patients and/or families were occasionally proactive in voicing a desire to pursue hospice (Q27), but in most instances they did not so much choose hospice as accept these services after all other options had been exhausted (Q28). Clinicians tended to offer hospice

services—and patients and families were more likely to accept these—when the patient was deteriorating despite escalation of care and/or when treatment options were running out (Q29–31). Clinicians often recommended hospice reflexively when there was a decision to discontinue dialysis (Q32), although sometimes patients and/or families were proactive in requesting hospice services under these circumstances (Q33).

Tension Around Hospice Referral. Although we did find mentions of hospice in outpatient notes, most appeared in inpatient notes in reference to discharge planning. The time when clinicians documented that they considered patients to be "candidates" or "appropriate" for hospice did not always coincide with when patients and families were ready to accept these services (Q34). It was common for hospice to be offered repeatedly by clinicians (Q35), with some patients and/or families never accepting these services and others not considering them until very late in the course of illness (Q36). Discussions about hospice conducted in the context of discharge planning could seem hurried (Q37), with patients feeling pressured to arrive at a decision (Q38) and/or being discharged to hospice without seeming to have understood the implications (Q39).

Theme 3: Care Complexity

Patients' complex care needs at the time hospice was considered could prevent or delay hospice enrollment, stretch the limits of home hospice, and promote continued reliance on the acute care system (Table 4).

Difficult Transitions to Hospice. When a decision was made to transfer a patient to hospice, much of the care they were receiving in the inpatient setting might be continued while waiting for hospice to be arranged (Q40–42). Medical teams were sometimes reluctant to transfer patients to hospice when acute medical issues had not been fully resolved (Q43) or the patient appeared too unstable for transfer (Q44). Sometimes efforts were made to complete, optimize, or escalate medical treatments to prepare for or facilitate hospice transfer (Q45 and Q46). These treatments sometimes had the potential to increase suffering (Q47 and Q48).

Stretching the Limits of Home Hospice. Home hospice was often not an option because of the complexity of patients' care needs (Q49) and/or the demands this would place on family (Q50 and Q51). In some cases, patients transitioned from home to inpatient hospice when their families could no longer cope (Q52 and Q53), although patients did not always qualify for inpatient hospice when home hospice was not an option (Q54). Patients' complex care needs could also complicate discharge from acute care to inpatient hospice (Q55).

Ongoing Use of the Acute Care System. Medical crises and patients' complex care needs could promote continued reliance on the acute medical system after hospice enrollment. This might occur on the advice of hospice staff when patients' needs could not be handled by community hospice organizations (Q56–58). Sometimes patients were advised at the time of

Table 3. Hospice as a last resort (theme 2)

Quotation	Note Title	Exemplar Quotation
Subtheme 1: readiness for hospice referral		
20	Social Work Note	He [patient] states that he understands that this option [hospice] is available to him however he would like to place that option on the “back burner” for now.
21	Discharge Plan	[Patient’s son] had stated several times “the word hospice really freaked my dad out. I really don’t think he’s ready for that.”
22	Internal Medicine Resident Note	[Patient’s wife] said she is not ready to face the fact that he might be dying . . .she says if patient gets out of the hospital this time, she would consider changing patient’s care to hospice.
23	Social Work Case Manager Note	[Patient’s wife] states she would be interested in home hospice, but not until [cancer] work up has been completed. She states she does not want to “give up” on patient. . .feels that unless patient has a firm diagnosis that she is “cheating him” out of life-prolonging medical treatment.
24	Internal Medicine Attending Note	If [patient] makes reasonable progress, will need to consider extended care facility placement; if no progress or deteriorates will consider Hospice.
25	Internal Medicine Inpatient Note	Overall prognosis still seems poor. . . Hospice consulted, staying in “background” for now. . .while continuing aggressive medical care in [intensive care unit]. May need to revisit w/ patient and family in next few days.
26	Hematology and Oncology Outpatient Note	Placement issues (possibly hospice) was not specifically discussed, but wife is aware of this option and the patient will let us know when he is ready.
Subtheme 2: Hospice rarely a proactive choice		
27	Internal Medicine Inpatient Note	Patient states he would like to leave the hospital and discontinue care, stating “I want that hospice thing.”
28	Hematology and Oncology Outpatient Note	Metastatic [non-small cell lung cancer] to multiple lobes of his right lung: patient declines any active treatment at this time and after a lengthy discussion with the family we have elected to enroll him in hospice.
29	Palliative Care Note	[Patient’s] daughter. . .will consult with. . .hospice sometime today. . .She is satisfied with the current plan and that all family members are in agreement and on “one page.” Satisfied that they had attempted hemodialysis.
30	Palliative Care Team Consult	Vascular surgery and podiatry have evaluated him. The patient would require possible bilateral [above knee amputations], a surgery that would have a near 100% risk of mortality; therefore, both services recommended hospice. The family is in agreement and has made the patient [do not resuscitate/do not intubate].
31	Internal Medicine Attending Note	[Patient] adamantly refuses colonoscopy to gauge severity of his Crohn’s with possible option(s) for therapy. . . patient/family will arrange for hospice services.
32	Internal Medicine Note	Renal discussed possible hemodialysis but patient is now REFUSING. . .If patient certain to refuse hemodialysis, then will need hospice consult ASAP.
33	Social Work Inpatient Consult	Patient has decided that he no longer wants to take dialysis and states he knows he won’t live for long without the dialysis. Patient requested to be referred to [specific hospice agency].
Subtheme 3: tension around hospice referral		
34	Internal Medicine Attending Note	Very poor prognosis, patient should be hospice, but he currently refuses hospice care.
35	Medicine History and Physical Examination Note	Will talk to family again today. They should consider hospice again for this patient; otherwise he may die here in the hospital.
36	Social Work Note	Vet’s wife was understandably tearful and stated she had decided this morning, before vet’s passing, to pursue hospice
37	Nursing Consult	Patient’s daughter was amendable to meeting with a hospice agency. She has stated that she is not prepared to receive her father back home on [date], she needs time to prepare the space he will be in. However, [physician] called to clarify that the veteran is actively dying and may only have a few days left.
38	Nursing Inpatient Note	Considering discontinuing hemodialysis and transitioning to hospice. . .States that he feels like the health care team is “pushing” him to make a decision. States he is not ready to make a decision and will not be until he is able to speak with his sister.
39	Palliative Care Note	[Patient’s niece] conveyed patient’s distress about the hospice visit. . .Patient didn’t understand why the nurse told her to stop taking some of her medication. Patient and niece were also surprised by the “6 months or less” prognosis.

Square brackets contain text substituted by the authors to spell out abbreviations, correct misspelling, and remove the names of individuals and institutions.

Table 4. Care complexity (theme 3)

Quotation	Note Title	Exemplar Quotation
Subtheme 1: difficult transitions to hospice		
40	Internal Medicine Inpatient Note	–PATIENT IS NOW DNR–technically comfort care but we are still treating him w/antibiotics and other meds as well as fluids and dialysis. No blood products, endoscopy, surgery, [vaso]pressors, [cardiopulmonary resuscitation], intubation, defibrillation. Hospice to place and evaluate him on Monday.
41	Transfer Summarization Note	Patient will continue to be full code while in the hospital and then transitioned to home hospice.
42	Internal Medicine Inpatient Note	Patient is now off of [vaso]pressors. [Gastroenterology] wanted to scope him today but patient is very adamant that he does not want this done and wants to be hospice care. . . While he is here, he is ok with getting blood products, lab draws, antibiotics and dialysis, but once he becomes hospice care he knows he may not be able to have some of these medical measures.
43	Discharge Summary	It was explained to family that he has multiple life-threatening medical problems at this time. . .and that it is not medically advisable for patient to go home. Despite these recommendations patient and his family wish to take patient home on hospice care.
44	Social Work Note	Staff felt that any move may be very difficult as the [patient] very fragile and a move may hasten his death.
45	Palliative Care Consult	They wish to take him home with home hospice support once his encephalopathy improves and the colitis is appropriately treated. Consider empirical therapy for presumed [<i>Clostridium difficile</i>].
46	Palliative Care Consult	Sons are in agreement with [do not resuscitate] and to stop [hemodialysis] when he goes home. I would recommend dialysis tomorrow and to make him as dry as he can tolerate. I think he should be ready to go on Monday with hospice. [Wife] wanted to know if that was a good plan. I told her there is a limited time to get him safely home.
47	Vascular Surgery Consult	87 yo male with ESRD who wants to go onto hospice and stop dialysis. . . Explained procedure for removal as well as option of leaving permcath[eter] in place with risk of infection that could cause a blood infection and take his life. Patient states, “just leave it” and that it isn’t bothering him. Both daughters agree with leaving it in place and not removing it and verbalize understanding of risk of infection. [Daughter] states “I don’t want him to have any more procedures.”
48	Nursing Inpatient Note	The goal of patient care is to return him back to his hospice care per family. Throughout the day he has been on 100% non-rebreather, he is unable to leave this facility on this type of oxygen supply and return to his extended care facility. Due to this, we are currently weaning him to 6L nasal cannula per MD order. . .Patient appears to be agitated and anxious at this time.
Subtheme 2: stretching the limits of home hospice		
49	Social Work Care Manager	I spoke with. . .Hospice agency to see if they could manage pleura catheter in the home setting. . . They are reluctant to agree to admit patient to home hospice once discharged if he has catheter.
50	Social Work Note	He is very focused on returning home, but the family does not feel that they care for him at this time (with current catheters, weakness, etc.).
51	Vascular Surgery Note	Privately, his daughter. . . discussed that caring for him even with the assistance of home hospice has become too much for them over the last few days.
52	Social Work Telephone Encounter Note	[Patient’s] daughter. . . called to discuss his need for inpatient hospice care. He has been followed by [home hospice] for a week. . .there are seven family members who take turns staying the night but feel they can’t cope with his current condition.
53	Inpatient Admission Attending Evaluation Note	Him and his wife anticipate placement in inpatient hospice due to his weak/almost bed bound state. He came to the hospital with his luggage.
54	Social Work Note	He has been turned down for inpatient hospice, spouse unable to provide the level of care he requires in the home and he is now a candidate for nursing home placement.
55	Social Work Note	They are both RNs and asked if patient may be [discharged] with his rectal tube and that they would help facilitate care at the [nursing home]...We stated our concern about discharging but have agreed that we may discharge him with his rectal tube and that his niece would be present at the assisted living home and spend the night with him. . .Hospice intake will be done tomorrow with contracted group at home.
Subtheme 3: ongoing use of the acute care system		
56	Physician Emergency Department Note	On hospice which sent him here since he cannot remain on hospice with the bleeding, per patient and son in law.

Table 4. Continued

Quotation	Note Title	Exemplar Quotation
57	Internal Medicine Admission Evaluation	Patient presents today for worsening diarrhea and needs beyond the scope of home hospice care. . . the plan for admission is specific work up of his acute on chronic diarrhea, [intravenous fluid] hydration and potential transfer to inpatient hospice once any reversible etiologies are addressed.
58	Case Manager Telephone Note	She and Hospice RN are concerned re: [patient’s] [arteriovenous] fistula, which is “much larger than usual,” has become larger in the last 24 hours. Contacted nephrology, who advised options of doing nothing (given hospice status), presenting to [emergency department], seeing her [primary care provider]. . . they will see [primary care provider].
59	Discharge Summary	Patient requested to be sent home with hospice. . . Foley removed that was placed on admission removed without issues. Hematuria thought to be secondary to foley trauma, if continues and patient/family requests consider urology consult.
60	Non-VA Note	Veteran rescinded hospice as he was short of breath and very uncomfortable at home. Veteran required BIPAP and was treated with [intravenous] Lasix.
61	Telephone Encounter Note	Phone call to veteran. He said that he called 911 rather than Hospice because he “didn’t think of calling Hospice. They needed immediate care.”
62	Physician Transfer Summarization	[hospice patient] was having a battery change of his pacemaker. Immediately following the procedure, he had acute onset of [shortness of breath] with rapid deterioration. Patient went into mixed respiratory failure for which he was placed on BIPAP. Diuresis was started and he did require being on Lasix drip at 30.
63	Urgent Care Note	Now under hospice care. . . patient’s son did not wish for father to be admitted. . . since goal of care is now comfort care. However, patient went to neurology [follow-up] today and was noted to be tired and pale, and noted a recent episode of chest pain, so was sent to urgent care for further eval[uation].
64	Care Coordination Telehealth	Instructed if symptoms worsen and [BP] is any lower to call 911 or come to [emergency department], especially with holiday weekend. Also reminded of nurse line and his hospice team is also available.
65	Social Work Note	It appears that Veteran was transferred to [emergency department] from dialysis without knowledge of hospice status.

Square brackets contain text substituted by the authors to spell out abbreviations, correct misspelling, and remove the names of individuals and institutions. DNR, do not resuscitate; MD, medical doctor; RN, registered nurse; BIPAP, bilevel positive airway pressure.

transfer to hospice to seek care if their medical issues worsened or did not resolve (Q59). Patients sometimes called 911 or went to the emergency room when their symptoms were poorly controlled rather than relying on the hospice agency (Q60 and Q61). Because of both patients’ complex medical needs and fragmentation of care across delivery systems, even routine interactions with the health system after hospice enrollment could lead to care escalation (Q62–65).

DISCUSSION

The modern hospice movement of the 1960s and 1970s grew out of a spiritual and nursing commitment to improving the care of dying patients, and offered an alternative to the medicalized approach to dying that was common even at that time.^{15–17} Integral to the hospice model was an individualized patient- and family-centered approach to care that prioritized relief of suffering. Our qualitative analysis of documentation pertaining to hospice in the EMRs of a national sample of veterans with advanced kidney disease suggested that transitions to hospice were often challenging and did not always seem to reflect the whole-person approach to care at the core of the modern hospice movement.^{16,17}

Among members of our cohort, a service-oriented, all-or-nothing approach to provision of both usual care and hospice served to prevent, delay, and complicate transitions to hospice and made it difficult to individualize care. Referrals to hospice typically occurred late in the course of illness when treatment options were limited and death imminent. At such times, patients did not so much choose hospice as passively accept these services. By the time they were referred to hospice, patients’ substantial care needs could complicate this transition, stretch the limits of home hospice, and promote ongoing reliance on the acute care system. These findings support the results of quantitative analyses of patterns of end-of-life care among Medicare beneficiaries by Teno *et al.*^{6,18} suggesting that hospice often functions as an add-on to intensive patterns of end-of-life care. They also resonate with the ethnographic work of Kaufman and colleagues describing older adults’ limited agency in shaping inpatient care and dialysis preparation, initiation, and discontinuation.^{19–23} Collectively, our findings argue for stronger efforts to meld curative and palliative approaches to care earlier in the illness trajectory for patients with advanced kidney disease and to foster more seamless and patient- and family-centered transitions to hospice.^{24–26}

Our study also offers useful insights about the unintended consequences of restricting access to concurrent dialysis and hospice care. Documentation in the EMRs of members of this cohort provides concrete evidence that being forced to choose between dialysis and hospice can cause undue suffering and discourage, delay, or prevent hospice enrollment. Although the VA system has no explicit rules precluding concurrent care, consistent with prior work in veterans with cancer,²⁷ there appeared to be limited uptake of concurrent care for members of this cohort with advanced kidney disease. Instead, hospice referral practices seemed to mirror community practices and Medicare rules around concurrent dialysis.²⁸ These practices also appeared to be quite variable, with critical decisions about whether patients could continue to receive dialysis after enrolling in hospice often left to the discretion of individual hospice organizations.^{24,29} There also seemed to be substantial variability in referral practices and a surprising lack of knowledge about hospice among clinicians. We suspect that greater clarity around VA concurrent care policy and more effective clinician education about hospice could help to improve access to hospice for veterans with advanced kidney disease who might benefit from these services. More broadly, our findings highlight the potential value of concurrent provision of dialysis and hospice services for patients with advanced kidney disease.

Although this study of medical record documentation provides a unique window on real-world hospice referral practices among veterans with advanced kidney disease, it does not provide direct information about the experiences and perspectives of patients, families, or clinicians. Our findings also largely pertain to care occurring before or around the time of hospice referral and during episodes of acute care after hospice enrollment. Because many veterans receive hospice care in the community and records of these encounters were not available to us in source data, our results provide limited information about hospice care itself or about transitions to hospice occurring outside the VA system. Although analysis of note titles suggested more limited uptake of palliative care and related care processes among patients without hospice mentions, because we did not conduct a qualitative analysis of the EMRs of these patients, this study provides limited insights about barriers to hospice referral among members of this population. Even among patients with a hospice mention, our study probably provides a relatively narrow window on broader conversations about goals of care and advance care planning. The long duration of the ascertainment period for hospice mentions also raises the possibility that some findings may not be relevant to contemporary practice. Finally, because our system serves a predominantly male veteran population, our findings may also not be generalizable to patients with advanced kidney disease cared for in other settings and to women and other groups poorly represented in our cohort. Nonetheless, the barriers to hospice use described here are especially striking in light of the VA's strong organizational

commitment to expanding access to hospice care and lack of formal rules precluding concurrent care.³⁰

In conclusion, hospice referral practices for members of a national cohort of patients with advanced kidney disease were not reflective of the whole-person approach to care that is integral to the modern hospice movement.³¹ A sharp demarcation between usual care and hospice, the tendency for hospice referral to occur very late in the course of illness and the substantial complexity of patients' care needs at this time made for challenging hospice transitions. These findings highlight the need for more seamless and more patient- and family-centered transitions to hospice for patients with advanced kidney disease approaching the end of life.

DISCLOSURES

C.A. Richards serves on the Editorial Board for the American Journal of Hospice and Palliative Medicine. All remaining authors have nothing to disclose.

FUNDING

This work was supported by a Department of Veterans Affairs Health Services Research and Development Service merit grant proposal to A. O'Hare, E. Vig, J. Taylor, P. Hebert, and C.-F. Liu (VA IIR 12-126, principal investigator: A. O'Hare) and an Interagency Agreement between the Centers for Disease Control and Prevention and the VA Puget Sound Health Care System (IAA15FED1505101, principal investigator: A. O'Hare), the VA Office of Academic Affiliations Advanced Fellowship in Health Services Research and Development (TPH 61-000-22, C. Richards), National Institute of Diabetes and Digestive and Kidney diseases institutional training grant 5T32DK007467-33 (to C. Butler), and the National Institute on Aging (5K23AG049088-05, M. Wachterman).

ACKNOWLEDGMENTS

We thank Mr. Jeff Todd-Stenberg, Dr. Pam Green, and Ms. Whitney Showalter at the Veterans Affairs Puget Sound Health Services Research and Development Center for Innovation for providing programming, regulatory, and organizational support for this project. We also thank Dr. Joan Teno at Oregon Health Sciences University (Portland, OR) and Dr. Vincent Mor at the Providence Veterans Affairs Medical Center and Brown University for providing valuable input on an earlier draft of this manuscript.

Dr. Ann M. O'Hare, Dr. Catherine R. Butler, Dr. Nilka Rios-Burrows, and Dr. Claire A. Richards designed the study. Dr. Ann M. O'Hare obtained funding. Dr. Ann M. O'Hare, Dr. Ryan S. Laundry, Dr. Claire A. Richards, Dr. Paul L. Hebert, and Dr. Chuan-Fen Liu obtained and formatted data. Dr. Ann M. O'Hare, Dr. Catherine R. Butler, and Dr. Elizabeth K. Vig participated in qualitative analyses. Dr. Ann M. O'Hare drafted the manuscript. All authors provided critical revision of manuscript drafts and approved submission of the final manuscript.

Dr. Ann M. O'Hare reports research grants from NIDDK, CDC, and VA HSR&D, operational project funding from the VA National Center for Ethics in Health Care, personal fees from Dialysis Clinic Inc., Fresenius Medical Care, the Health and Aging Policy Fellows Program, the University of Pennsylvania, the University of Alabama, Birmingham, the University of California, San Francisco, the Hammersmith Hospital, UpToDate, the Devenir Foundation,

membership of Editorial Boards for *JASN*, *CJASN* and *JAMA Internal Medicine*, personal fees from the American Society of Nephrology, Chugai Pharmaceutical Co. Ltd., Kaiser Permanente, Southern California, the Japanese Society for Dialysis Therapy, outside the submitted work. Dr. Catherine R. Butler reports grants from the National Institute of Diabetes and Digestive and Kidney Diseases, outside the submitted work. Dr. Susan P.Y. Wong receives research funding from the National Institutes of Health, VA National Center for Ethics in Health Care, National Palliative Care Research Center, and the Doris Duke Charitable Foundation, outside the submitted work.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention or the Department of Veterans Affairs.

REFERENCES

- Saini T, Murtagh FE, Dupont PJ, McKinnon PM, Hatfield P, Saunders Y: Comparative pilot study of symptoms and quality of life in cancer patients and patients with end stage renal disease. *Palliat Med* 20: 631–636, 2006
- Saran R, Robinson B, Abbott KC, Agodoa LYC, Bragg-Gresham J, Balkrishnan R, et al: US Renal Data System 2018 Annual Data Report: Epidemiology of kidney disease in the United States. *Am J Kidney Dis* 73: A7–A8, 2019
- Wachterman MW, Hailpern SM, Keating NL, Kurella Tamura M, O'Hare AM: Association between hospice length of stay, health care utilization, and Medicare costs at the end of life among patients who received maintenance hemodialysis. *JAMA Intern Med* 178: 792–799, 2018
- Murray AM, Arko C, Chen SC, Gilbertson DT, Moss AH: Use of hospice in the United States dialysis population. *Clin J Am Soc Nephrol* 1: 1248–1255, 2006
- Wong SPY, Yu MK, Green PK, Liu CF, Hebert PL, O'Hare AM: End-of-Life care for patients with advanced kidney disease in the US veterans Affairs health care system, 2000–2011. *Am J Kidney Dis* 72: 42–49, 2018
- Teno JM, Gozalo P, Trivedi AN, Bunker J, Lima J, Ogarek J, et al: Site of death, place of care, and health care transitions among US Medicare beneficiaries, 2000–2015. *JAMA* 320: 264–271, 2018
- Medicare Payment Advisory Commission: Hospice services. Available at: www.medpac.gov/docs/default-source/reports/mar19_medpac_ch12_sec.pdf 2019. Accessed July 23, 2020
- Casarett DJ, Fishman JM, Lu HL, O'Dwyer PJ, Barg FK, Naylor MD, et al: The terrible choice: Re-evaluating hospice eligibility criteria for cancer. *J Clin Oncol* 27: 953–959, 2009
- O'Hare AM, Hailpern SM, Wachterman M, Kreuter W, Katz R, Hall YN, et al: Hospice use and end-of-life spending trajectories in Medicare beneficiaries on hemodialysis. *Health Aff (Millwood)* 37: 980–987, 2018
- Richards CA, Hebert PL, Liu CF, Ersek M, Wachterman MW, Taylor LL, et al: Association of family ratings of quality of end-of-life care with stopping dialysis treatment and receipt of hospice services. *JAMA Netw Open* 2: e1913115, 2019
- Wong SP, Vig EK, Taylor JS, Burrows NR, Liu CF, Williams DE, et al: Timing of initiation of maintenance dialysis: A qualitative analysis of the electronic medical records of a National Cohort of Patients From the Department of Veterans Affairs. *JAMA Intern Med* 176: 228–235, 2016
- Wong SPY, McFarland LV, Liu CF, Laundry RJ, Hebert PL, O'Hare AM: Care practices for patients with advanced kidney disease who forgo maintenance dialysis. *JAMA Intern Med* 179: 305–313, 2019
- Richards CA, Liu CF, Hebert PL, Ersek M, Wachterman MW, Reinke LF, et al: Family perceptions of quality of end-of-life care for veterans with advanced CKD. *Clin J Am Soc Nephrol* 14: 1324–1335, 2019
- Krippendorff K: *Content Analysis: An Introduction to its Methodology*, Los Angeles, SAGE, 2018
- Clark D: *To Comfort Always: A History of Palliative Medicine Since the Nineteenth Century*, Oxford, UK, Oxford University Press, 2016
- Clark D: *Cicely Saunders: A Life and Legacy*, Oxford, UK, Oxford University Press, 2018
- Du Boulay S: *Cicely Saunders, Founder of the Modern Hospice Movement*, London, Hodder and Stoughton, 1984
- Teno JM, Gozalo PL, Bynum JP, Leland NE, Miller SC, Morden NE, et al: Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 309: 470–477, 2013
- Russ AJ, Shim JK, Kaufman SR: The value of "life at any cost": Talk about stopping kidney dialysis. *Soc Sci Med* 64: 2236–2247, 2007
- Russ AJ, Kaufman SR: Discernment rather than decision-making among elderly dialysis patients. *Semin Dial* 25: 31–32, 2012
- Kaufman SR, Shim JK, Russ AJ: Old age, life extension, and the character of medical choice. *J Gerontol B Psychol Sci Soc Sci* 61: S175–S184, 2006
- Kaufman SR: *And a Time to Die: How American Hospitals Shape the End of Life*, New York, Scribner, 2005
- Kaufman SR: *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line*, Durham, UK, Duke University Press, 2015
- Haverhals LM, Manheim CE, Mor V, Ersek M, Kinosian B, Lorenz KA, et al: The experience of providing hospice care concurrent with cancer treatment in the VA. *Support Care Cancer* 27: 1263–1270, 2019
- Mor V, Wagner TH, Levy C, Ersek M, Miller SC, Gidwani-Marszowski R, et al: Association of expanded VA hospice care with aggressive care and cost for veterans with advanced lung cancer. *JAMA Oncol* 5: 810–816, 2019
- O'Hare AM, Armistead N, Schrag WL, Diamond L, Moss AH: Patient-centered care: An opportunity to accomplish the "Three Aims" of the National Quality Strategy in the Medicare ESRD program. *Clin J Am Soc Nephrol* 9: 2189–2194, 2014
- Presley CJ, Han L, O'Leary JR, Zhu W, Corneau E, Chao H, et al.: Concurrent hospice care and cancer-directed treatment for advanced lung cancer and receipt of aggressive care at the end of life in the veteran's health administration [published online ahead of print Mar 2, 2020]. *J Palliat Med* doi:10.1089/jpm.2019.0485
- Mor V, Joyce NR, Coté DL, Gidwani RA, Ersek M, Levy CR, et al: The rise of concurrent care for veterans with advanced cancer at the end of life. *Cancer* 122: 782–790, 2016
- Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K: Why don't patients enroll in hospice? Can we do anything about it? *J Gen Intern Med* 25: 1009–1019, 2010
- Miller SC, Intrator O, Scott W, Shreve ST, Phibbs CS, Kinosian B, et al: Increasing veterans' hospice use: The veterans health administration's focus on improving end-of-life care. *Health Aff (Millwood)* 36: 1274–1282, 2017
- Saunders C: Hospice care. *Am J Med* 65: 726–728, 1978
- Saran R, Robinson B, Abbott KC, Agodoa LYC, Bhavne N, Bragg-Gresham J, et al: US Renal Data System 2017 Annual Data Report: Epidemiology of kidney disease in the United States. *Am J Kidney Dis* 71: A7, 2018

AFFILIATIONS

¹Department of Medicine, University of Washington, Seattle, Washington

²Hospital and Specialty Medicine, Geriatrics and Extended Care and Seattle–Denver Health Services Research and Development Center for Innovation, Veterans Affairs Puget Sound Health Care System, Seattle, Washington

³Department of Anthropology, University of Toronto, Toronto, Ontario, Canada

⁴Section of General Internal Medicine, Veterans Affairs Boston Health Care System, Boston, Massachusetts

⁵Department of Psychosocial Oncology and Palliative Care, Dana Farber Cancer Institute, Boston, Massachusetts

⁶Department of Health Services, University of Washington, Seattle, Washington

⁷Chronic Kidney Disease Initiative, Division of Diabetes Translation, Centers for Disease Control and Prevention, Atlanta, Georgia

⁸School of Nursing, University of Washington, Seattle, Washington