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End-of-Life Care for Patients With Advanced Kidney Disease in the US Veterans Affairs Health Care System, 2000–2011

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Abstract

Background—Little is known about patterns of end-of-life care for patients with advanced kidney disease not treated with maintenance dialysis.

Study Design—Case series.

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Setting & Participants—A sample of 14,071 patients with a sustained estimated glomerular filtration rate <15 ml/min/1.73m² treated in the US Veterans Affairs (VA) health care system who died during 2000–2011. Prior to death, 12,756 of these patients had been treated with dialysis, 503 had been discussing and/or preparing for dialysis, and, for 812, there had been a decision not to pursue dialysis.

Outcomes—Hospitalization and receipt of an intensive procedure during the final month of life, in-hospital death, and palliative care consultation and hospice enrollment prior to death.

Results—Compared with decedents treated with dialysis, those for whom a decision not to pursue dialysis had been made were less often hospitalized (57.3% vs. 76.8%; OR, 0.40 [95% CI, 0.34–0.46]), were less often the recipient of an intensive procedure (3.5% vs. 24.6%; OR, 0.15 [95% CI, 0.10–0.22]), more often the recipient of a palliative care consultation (52.6% vs. 21.6%; OR, 4.19 [95% CI, 3.58–4.90]), more often used hospice services (38.7% vs. 18.2%; OR, 3.32 [95% CI, 2.83–3.89]) and died less frequently in a hospital (41.4% vs. 57.3%; OR, 0.78 [95% CI, 0.74–0.82]). Hospitalization (55.5%; OR, 0.39 [95% CI, 0.32–0.46]), receipt of an intensive procedure (13.7%; OR, 0.60 [95% CI, 0.46–0.77]), and in-hospital death (39.0%; OR, 0.47 [95% CI, 0.39–0.56]) were also less common among decedents who had been discussing and/or preparing for dialysis, but their utilization of palliative care and hospice services were similar.

Limitations—Findings may not be generalizable to groups not well-represented in the VA health care system.

Conclusions—Among decedents, patients not treated with dialysis prior to death received less intensive patterns of end-of-life care than those treated with dialysis. Decedents for whom there had been a decision not to pursue dialysis prior to death were more likely to receive palliative care and hospice.

Index words

chronic kidney disease (CKD); kidney failure; dialysis; conservative care; palliative care; hospice; end-of-life care; intensive treatment; health care intensity

Although advances in medical science and technology have led to improvements in population health and longevity, the potential benefits of interventions intended to prolong life tend to diminish as patients approach the end of life. For patients with advanced chronic kidney disease (CKD), potential gains in longevity with maintenance dialysis are sometimes offset by the challenges that can be associated with this treatment such as more frequent interaction with the healthcare system,^{1,2} and loss of employment, independence, and physical and social function,^{3–5} especially given the uncertain affect of dialysis on symptom burden.^{6,7}

In other developed countries, there is growing experience with models of conservative care intended to support patients with advanced CKD who do not plan to pursue dialysis. Several observational studies conducted in Europe and Asia suggest that older patients (75 years or older) with a high burden of comorbidity and poor functional status who opt for conservative management may have a life expectancy^{8–12} and quality of life^{13,14} comparable to those who initiate dialysis. Based on data from outside the United States, patients with advanced

CKD opting for conservative management also spend less time in the hospital toward the end of life,^{2,11} are less likely to receive invasive procedures¹¹ and to die in the hospital,^{2,10,11,15,16} and are more likely to receive palliative care and hospice.^{10,11,16}

Concerted efforts to establish conservative care programs as a therapeutic alternative to maintenance dialysis in the United States lag considerably behind some other developed countries. Older patients with advanced CKD are far more likely to be treated with dialysis in the United States than in other developed countries,¹⁷ and qualitative data suggest that US patients seem to view maintenance dialysis as a treatment that will inevitably be “needed” rather than as a distinct treatment “choice.”^{18–20} To our knowledge, no prior studies have compared patterns of end-of-life care among US patients with advanced CKD treated and not treated with dialysis.

Methods

Study Population

We conducted a retrospective review of patterns of end-of-life care among decedents of a previously assembled national cohort of 28,568 adults with at least two outpatient measures of an estimated glomerular filtration rate (eGFR) <15 ml/min/1.73m² drawn at least 90 days apart within the US Veterans Affairs (VA) health care system during the period 2000–2009.¹⁷ As previously described,¹⁷ we used a combination of administrative and clinical data from VA data sources, the US Renal Data System (USRDS)—a national registry for treated end-stage renal disease—and Medicare claims to define and characterize the original study cohort. Patients entered the cohort on the date of their second eGFR <15 ml/min/1.73m² and were followed up through their date of death or October 1, 2011, whichever came first. The current case series excludes cohort members who received a kidney transplant (n=1,551) and is restricted to cohort members who died during follow-up (n=20,280) (Figure 1).

As described previously,¹⁷ we categorized patients according to their treatment status with respect to dialysis. Briefly, we considered patients who were enrolled in USRDS or had at least one dialysis procedure code in VA or Medicare files prior to death as having been treated with dialysis (n=12,358). We performed a detailed review of the VA-wide electronic medical record for a random sample of the remaining 7,922 patients in order to confirm that they had not received dialysis and to characterize their treatment status closest to the time of death. Of the 1,713 patients selected for chart review, 398 had in fact received dialysis prior to death (for analytic purposes, these patients were included in the aforementioned group treated with dialysis), 503 were discussing and/or preparing for dialysis but had not initiated dialysis prior to death, and, in 812, an implicit or explicit decision was made by the patients themselves, their family members and/or providers not to pursue dialysis prior to death (Figure 1).

End-of-Life Care

We ascertained whether decedents had been hospitalized and had received an intensive procedure (cardiopulmonary resuscitation, mechanical ventilation or artificial enteral

nutrition) during the final month of life, had died in the hospital, and had received a palliative care consultation and/or hospice care prior to death from VA and Fee-Basis administrative files (which include information on care received both within the VA and outside the VA but paid for by the VA) and Medicare Institutional and Physician Supplier claims. We also ascertained the number of days spent in the hospital during the final month of life and the timing of first palliative care consultation and hospice enrollment in relation to death.

Decedent Characteristics

We used the VA Decision Support System Laboratory Results File to ascertain outpatient serum creatinine measurements and calculated each patient's eGFR using the MDRD (Modification of Diet in Renal Disease) Study equation. We obtained information on race (categorized as white, black and other), sex and age (categorized as <65, 65–74, 75–84 and 85 years) at the time of each patient's second eGFR <15 ml/min/1.73m² from the VA Vital Status File. We used both VA administrative data and Medicare claims to obtain information on nephrology clinic visits (categorized as no prior visits, 1–3 clinic visits, and 4 visits) and the following co-morbidities based on the presence of relevant diagnostic codes on at least two claims during the year prior to the date of the second eGFR <15 ml/min/1.73m²: coronary artery disease, congestive heart failure, chronic obstructive pulmonary disease, cirrhosis, peripheral artery disease, hypertension, diabetes, dementia, cancer, and stroke. We also categorized patients by tertile of Gagne comorbidity score²¹ as having low (scores < 4), moderate (score = 4–6) or high (score >6) comorbid burden based on diagnostic codes in VA administrative files and Medicare claims during the year before their second eGFR <15 ml/min/1.73m².

Analytical Approach

We compared characteristics of decedents categorized according to their treatment status at the time of death using chi-square tests and ANOVA as appropriate. We tested for differences in patterns of end-of-life care between treatment groups using logistic or linear regression models, as appropriate, and included all measured patient characteristics and calendar year of death.

We used SAS, version 9 (SAS Institute Inc., Cary, NC) to construct the analytic dataset, and SPSS version 19 (IBM SPSS, Somers, NY) to conduct statistical analyses.

Results

Decedent Characteristics

Median time from the date of the second eGFR <15 ml/min/1.73m² to death was 32.0 (interquartile range [IQR], 16.0–53.8) months for decedents who had received dialysis, 6.8 (IQR, 2.2–16.6) months for those who had been discussing and/or preparing for dialysis, and 5.7 (IQR, 1.1–17.2) months for those in whom there had been a decision against dialysis (p-value <0.001). The mean value of the second eGFR <15 ml/min/1.73m² was 11.3±2.6 ml/min/1.73m² for decedents who had been treated with dialysis, 12.0±2.3 ml/min/1.73m² for those who had been discussing and/or preparing for dialysis, and 11.7±2.5 ml/min/

1.73m² for those in whom there had been a decision against dialysis (p-value <0.001). As compared with decedents who had received dialysis, those who were discussing and/or preparing for dialysis and those in whom there was a decision against dialysis tended to be older, less often black, and to have a higher burden of comorbidity and less nephrology care (Table 1). Most comorbidities were also more prevalent among decedents not treated with dialysis.

End-of-Life Care

As compared with decedents who had been treated with dialysis, those for whom there had been a decision not to pursue dialysis were less likely to have been hospitalized during the final month of life (57.3% vs. 76.8%; odds ratio [OR], 0.40; 95% confidence interval [CI], 0.34–0.46), were less likely to have received an intensive procedure during the final month of life (3.5% vs. 24.6%; OR, 0.15 [95% CI, 0.10–0.22]) and to have died in the hospital (41.4% vs. 57.3%; OR, 0.78 [95% CI, 0.74–0.82]), and were more likely to have received a palliative care consultation (52.6% vs. 21.6%; OR, 4.19 [95% CI, 3.58–4.90]) and hospice care (38.7% vs. 18.2%; OR, 3.32 [95% CI, 2.83–3.89]) (Figure 2). Decedents in whom there had been a decision not to pursue dialysis also spent fewer days in the hospital during the last month of life (median of 10.0 [IQR, 4.0–24.0] vs. 14.0 [IQR, 6.0–28.0] days; p-value <0.001), and received longer periods of palliative care (median of 27.0 [IQR, 5.0–81.0] vs. 7.0 [IQR, 3.0–29.0] days; p-value <0.001) and hospice services (median of 14.0 [IQR, 1.0–68.0] vs. 6.0 [IQR, 2.0–32.0] days; p-value <0.001) than those treated with dialysis (Table 2). Hospitalization (55.5%; OR, 0.39 [95% CI, 0.32–0.46]) and receipt of an intensive procedure (13.7%; OR, 0.60 [95% CI, 0.46–0.77]) during the final month of life and in-hospital death (39.0%; OR, 0.47 [95% CI, 0.39–0.56]) were also less common among decedents discussing and/or preparing for dialysis as compared with those treated with dialysis. However, their utilization of palliative care (16.7%; OR, 0.78 [95% CI, 0.61–1.01]) and hospice services (14.3%; OR, 0.86 [95% CI, 0.67–1.12]) was no different than for those treated with dialysis.

Discussion

We believe this study providing information on patterns of end-of-life care among US patients with advanced CKD not treated with dialysis is novel. Consistent with prior studies conducted outside the United States,^{2,10,11,15,16} patients with advanced CKD not treated with dialysis prior to death—especially those for whom there was a decision not to pursue dialysis—received less intensive patterns of inpatient care near the end of life than those treated with dialysis. They were less likely to be hospitalized and to receive invasive procedures intended to prolong life, spent less time in the hospital, and were less likely to die in the hospital than patients who received dialysis prior to death. However, only the subgroup of patients for whom there had been an implicit or explicit decision not to pursue dialysis prior to death were more likely than those treated with dialysis to have received a palliative care consultation and hospice, and tended to receive these services for longer periods of time before death.

Hospice utilization under Medicare is known to be low among patients treated with maintenance dialysis and is often accompanied by discontinuation of dialysis.²² The strong association between hospice utilization and dialysis discontinuation among patients on dialysis is often attributed to barriers to reimbursement for concurrent receipt of dialysis and hospice care under the Medicare Program, which can have the effect of forcing patients to choose between these two benefits.²³ Nevertheless, hospice use among members of this veteran sample treated with dialysis prior to death (18.2%)—for whom there are theoretically fewer regulatory barriers to concurrent receipt of dialysis and hospice services—was comparable to that reported for Medicare beneficiaries on dialysis who died during the same time frame (17.9%).²² Furthermore, rates of palliative care consultation (for which there are no such regulatory barriers under Medicare or within the VA) and hospice enrollment were only higher for patients not treated with dialysis when there had been an implicit or explicit decision not to pursue dialysis prior to death. Rates of hospice and palliative care utilization for patients discussing and/or preparing for dialysis at the time of death were no different than for those treated with dialysis. These findings suggest that unless there is a concrete decision not to pursue dialysis, utilization of palliative care and hospice services may be as limited for patients with advanced CKD not on dialysis as for those already receiving dialysis.

In other countries with established conservative care pathways for patients with advanced CKD, the decision not to pursue dialysis tends to be a proactive choice to enter a multidisciplinary supportive care program that integrates palliative care and hospice services early in the course of advanced CKD.^{2,8–10,13,15,24–27} In the current study, median time from date of the second eGFR <15ml/min/1.73m² to death among patients in whom there had been a decision not to pursue dialysis was only 5.7 months and is considerably shorter than the median survival reported for most conservatively managed cohorts described in the literature (4.9–30.4 months) (Figure 3),^{2,8–16,25–32} likely reflecting that this decision occurred among patients with an extremely poor prognosis and/or relatively late in their illness trajectory. While some patients in the current study did decide not to pursue dialysis (or their family members and/or providers made this decision for them) prior to death, it is noteworthy that the frequency of palliative care consultation (52.6%) and hospice use (38.7%) among these patients were far lower than for most conservatively managed cohorts previously described in the literature (Figure 4).^{2,10,11,15,16,25,27} Levels of healthcare intensity near the end of life were also quite high for patients in our study for whom there had been a decision not to pursue dialysis prior to death; most (57.3%) were hospitalized during their final month of life, and half spent more than a third of their last month of life in the hospital. Most likely, these findings suggest that the transition to palliative care and hospice services for patients in whom there was a decision not to pursue dialysis tended to occur only after an initial trial of more aggressive care near the end of life.

The VA is the largest integrated healthcare system in the United States and affords a unique window on the care of patients with advanced CKD not treated with dialysis—a group not captured in national registry data. Nevertheless, our results must be interpreted with the following considerations in mind. First, findings may not be generalizable to nonveterans, women, and other groups not well represented in the VA. Second, we relied solely on the VA electronic medical record to assign treatment status, leaving open the possibility for

misclassification among patients who were receiving care outside the VA. Because their treatment status was known, we also did not review the medical records for the large majority of patients treated with dialysis. Third, the medical record and administrative data provide only limited insight into patients' treatment preferences, their experience of the decision-making process for dialysis and the quality of end-of-life care. Fourth, categorization of patients in the current study was based on the most recent documented treatment plan in the medical record at the time of death, which enabled us to distinguish those for whom there had been a decision not to pursue dialysis and those who did not receive dialysis but were discussing and/or preparing for it prior to death. This may limit literature comparisons because most prior studies followed up patients prospectively from the time of their initial documentation of treatment preference and consequently included large numbers (15.2%–72.1%) of patients in the dialysis group who did not go on to initiate dialysis during follow-up as well as a smaller number of patients who elected for conservative treatment but went on to initiate dialysis.^{8–12,15,16} Both methods of categorization miss some of the complexity of decision-making for dialysis in which patients' treatment preferences can change over time.^{17,19} Last but not least, the results of this retrospective review is limited to decedents and cannot support inferences about prognosis or downstream care for patients approaching decisions about dialysis.

In this national sample of veterans with advanced CKD who died during the period 2000–2011, those not treated with dialysis prior to death—especially those for whom there had been a decision not to pursue dialysis—received less intensive patterns of end-of-life care than those treated with dialysis. Conversely, utilization of palliative care and hospice services seemed to be strongly tied to the decision not to pursue dialysis and, as compared with reports from conservatively managed cohorts outside the United States, seemed to have occurred in a less proactive fashion among relatively sicker patients and/or later in the course of illness. Collectively, our findings highlight opportunities for better integration of hospice and palliative care services into contemporary models of care for patients with advanced CKD.

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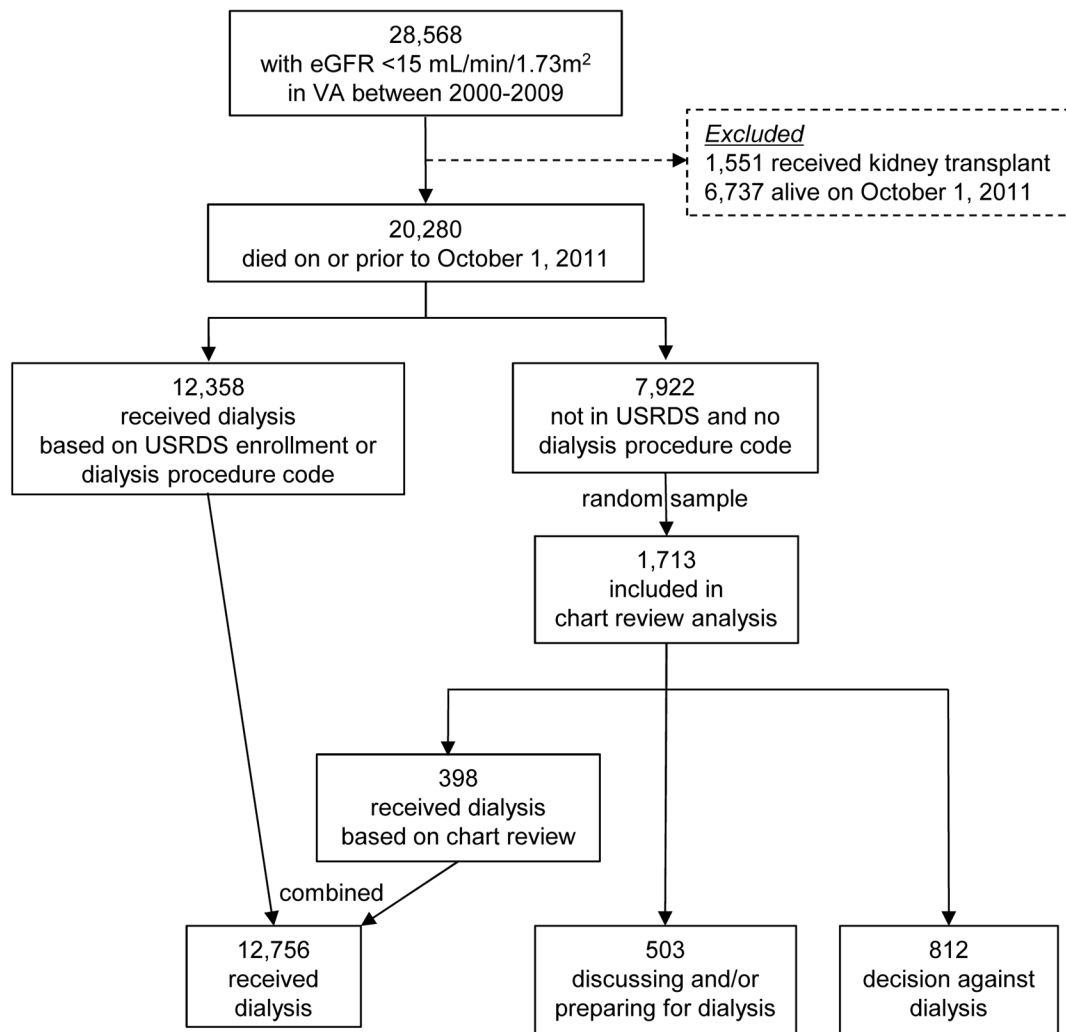


Figure 1. Derivation of decedent sample

Note: a flow chart of the full cohort derivation is provided in Wong et al.¹⁷ (Abbreviations: eGFR, estimated glomerular filtration rate; VA, Veterans Affairs; USRDS, United States Renal Data System)

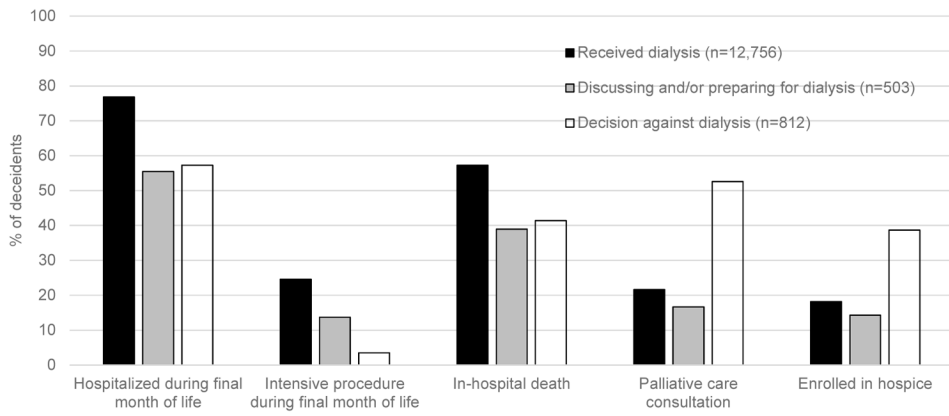


Figure 2. End-of-life care among decedents with advanced kidney disease

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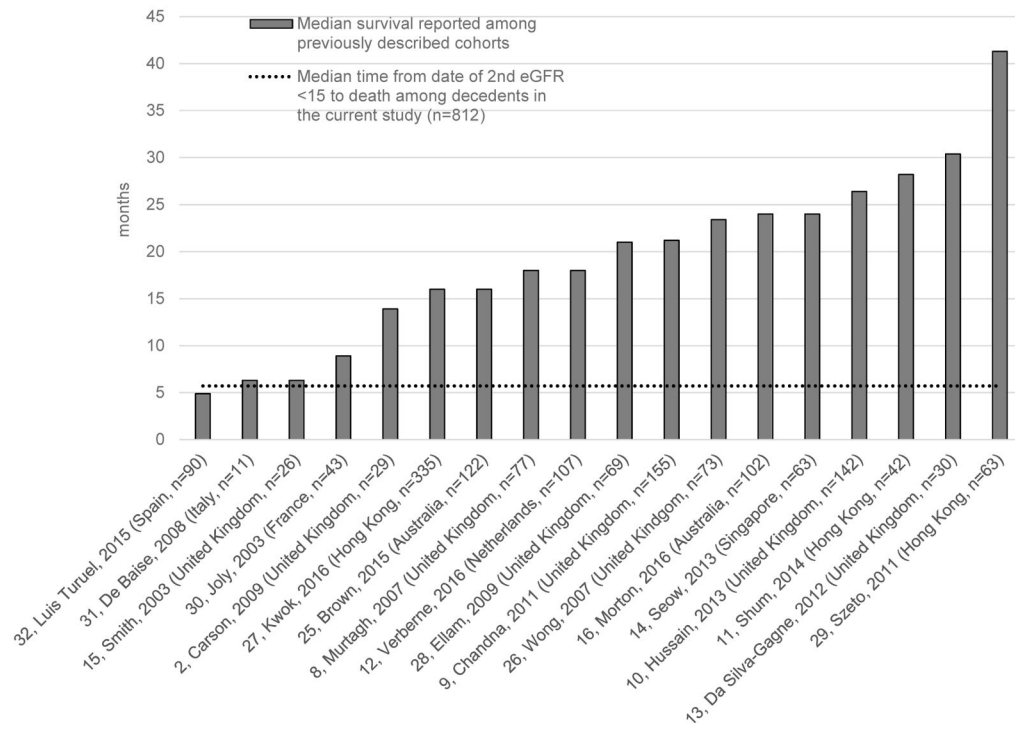


Figure 3. Survival among patients in whom there was a decision not to pursue maintenance dialysis reported in the literature
 (the dashed line indicates median time from date of second eGFR <15ml/min/1.73m² to death among decedents for whom there was a decision not to pursue dialysis in the current study; data limited to studies published in English; studies are indicated by following: reference number, first author, year of publication (country, study size)).

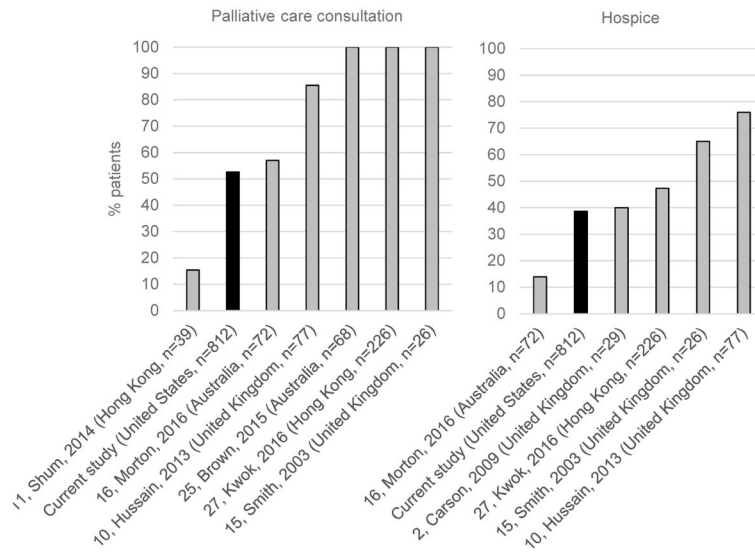


Figure 4. Utilization of palliative care consultation and hospice services among patients for whom there was a decision not to pursue maintenance dialysis prior to death (data limited to studies published in English; studies are indicated by following: reference number, first author, year of publication (country, total number of decedents)).

Table 1

Characteristics of decedents with advanced kidney disease

	Received dialysis (n=12,756)	Discussing and/or preparing for dialysis (n=503)	Decision against dialysis (n=812)	p-value
Age				<0.001
<65 y	4767 (37.4)	172 (34.2)	145 (17.9)	
65–74 y	3984 (31.2)	145 (28.8)	173 (21.3)	
75–84 y	3572 (28.0)	149 (29.6)	351 (43.2)	
85 y	433 (3.4)	37 (7.4)	143 (17.6)	
Race				<0.001
White	7941 (62.3)	293 (58.3)	542 (66.8)	
Black	3596 (28.2)	99 (19.7)	156 (19.2)	
Other	1219 (9.6)	111 (22.1)	114 (14.0)	
Sex				0.9
Female	159 (1.3)	6 (1.2)	9 (1.1)	
Male	12597 (98.8)	497 (98.8)	803 (98.9)	
Burden of comorbidity				<0.001
Low	4579 (35.9)	130 (25.8)	175 (21.6)	
Moderate	5088 (39.9)	205 (40.8)	278 (34.2)	
High	3025 (23.7)	167 (33.2)	350 (43.1)	
Missing	64 (0.5)	1 (0.2)	9 (1.1)	
Comorbidities				
Hypertension	11875 (93.1)	466 (92.6)	722 (88.9)	<0.001
Coronary artery disease	5412 (42.4)	240 (47.7)	374 (46.1)	0.01
Congestive heart failure	4268 (33.5)	188 (37.4)	344 (42.4)	<0.001
Diabetes mellitus	8101 (63.5)	275 (54.7)	428 (52.7)	<0.001
Peripheral artery disease	1976 (15.5)	83 (16.5)	137 (16.8)	0.5
Cancer	2381 (18.7)	143 (28.4)	261 (32.1)	<0.001
Chronic obstructive pulmonary disease	2326 (18.2)	132 (26.2)	234 (28.8)	<0.001
Dementia	226 (1.8)	18 (3.6)	73 (9.0)	<0.001
Stroke	1097 (8.6)	51 (10.1)	106 (13.1)	<0.001
Cirrhosis	162 (1.3)	15 (3.0)	17 (2.1)	0.001
Nephrology care in year prior				<0.001
None	3039 (23.8)	174 (34.6)	380 (46.8)	
1–3 clinic visits	5095 (39.9)	196 (39.0)	285 (35.1)	
4 clinic visits	4622 (36.2)	133 (26.4)	147 (18.1)	

Note: Values are given as number (percentage). Characteristics were ascertained at date of second eGFR <15 ml/min/1.73 m².

End-of-life care among decedents with advanced kidney disease

Table 2

	Received dialysis (n=12,756)		Discussing and/or preparing for dialysis (n=503)		Decision against dialysis (n=812)	
	median [IQR]	p-value ^a	median [IQR]	p-value ^a	median [IQR]	p-value ^a
Days hospitalized during final month of life	14.0 [6.0–28.0]	<0.001	8.0 [3.0–21.0]	<0.001	10.0 [4.0–24.0]	<0.001
Days prior to death of first palliative care encounter	7.0 [3.0–29.0]	0.3	8.0 [3.0–27.8]	0.3	27.0 [5.0–81.0]	<0.001
Days enrolled in hospice	6.0 [2.0–32.0]	0.5	8.0 [2.0–27.8]	0.5	14.0 [1.0–68.0]	0.07

Abbreviation: IQR, interquartile range

^a reference group is patients who received dialysis; linear regression models adjusted for age, race, sex, comorbidity burden, comorbidities, prior nephrology care, and year of death