

Use of Hospice in the United States Dialysis Population

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Hospice is recognized for providing excellent end-of-life care but may be underused by dialysis patients. Hospice use and related outcomes were measured among dialysis patients, and factors that were associated with hospice use were identified. The 2-yr US Renal Data System dialysis patients who died between January 1, 2001, and December 31, 2002, and hospice claims from the Centers for Medicare & Medicaid Services were examined to measure prevalence, factors, and costs that were associated with dialysis withdrawal and hospice use. Of the 115,239 deceased patients, 21.8% withdrew from dialysis and 13.5% used hospice. Of those who withdrew, 41.9% used hospice. Failure to thrive was the most common reason for dialysis withdrawal (42.9%). On multivariable logistic regression analysis, factors that were significantly associated with hospice referral among patients who withdrew from dialysis were age, race, reason for withdrawal, ability to walk or transfer at dialysis initiation, and state of residence. Among patients who withdrew from dialysis and used hospice, median cost of per-patient care during the last week of life was \$1858, compared with \$4878 for nonhospice patients ($P < 0.001$); hospitalization costs accounted for most of that difference. Only 22.9% of dialysis hospice patients died in the hospital, compared with 69.0% of nonhospice patients ($P < 0.001$). A minority of dialysis patients use hospice, even among patients who withdrew from dialysis, whose death usually is certain. Increased hospice use may enable more dialysis patients to die at home, with substantial cost savings. Research regarding additional benefits of hospice care for dialysis patients is needed.

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Hospice care is recognized for improving end-of-life treatment for dying patients, most often in their homes or hospice centers (1). Yet most dialysis patients die in the hospital and other institutional settings without hospice care, and up to 73% die with distressing pain, severe dyspnea, and other symptoms (2). Although dialysis patients in the United States have a high symptom burden equal to that of cancer patients (3,4), their 5-year survival rate is only approximately half that of cancer patients (5,6). The Medicare Payment Advisory Commission noted in its June 2004 report to Congress that ESRD beneficiaries have “low enrollment in the hospice benefit, despite their high mortality rates (p. 142)” (7). Our purpose was to define the extent and the possible causes of the discrepancy between the potential and actual use of hospice care among dialysis patients, focusing on those who withdraw from dialysis as being most likely to be appropriate for hospice care. To accomplish this, we measured hospice use in the US Medicare dialysis population and identified patient characteristics and outcomes that were associated with hospice care.

Materials and Methods

Data Sources and Patient Population

We used the US Renal Data System (USRDS) database to define a 2-yr cohort of patients who died between January 1, 2001, and December 31, 2002, and who were on dialysis immediately before death (including hemodialysis, peritoneal dialysis, and unspecified dialysis modality). To ensure that all costs were captured, Medicare was the primary payer for all patients who were included in the cohort; dialysis patients with other payers ($n = 32,858$; 22.2%) were excluded. This cohort was used to define three death-related characteristics: Age at death, cause of death, and location by state in which death occurred. A secondary 6-mo cohort was created as a subset of the primary cohort to examine costs of care and site of death. The secondary cohort carried the additional criterion that patients be on dialysis for the entire 6 mo before death.

Withdrawal status was determined from the Centers for Medicare & Medicaid Services (CMS) ESRD Death Notification Form (CMS-2746), which indicates whether the patient withdrew from dialysis and lists the following possible reasons for withdrawal: (1) Access failure, (2) transplant failure, (3) chronic failure to thrive, (4) acute medical complication, and (5) other. Data were listed as missing when the CMS-2746 form was incomplete and no reason for withdrawal was indicated.

Hospice status was determined from the CMS hospice claims Standard Analytical Files. A patient was classified as using hospice when a claim showed the patient in hospice on the date of death or when the discharge code from hospice was death.

Statistical Analyses

We measured the frequencies of withdrawal from dialysis and hospice use in the 2001 to 2002 2-yr cohort of patients by each category of withdrawal and hospice status: Withdrawal, yes/no; hospice, yes/no;

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withdrawal yes, hospice yes/no; withdrawal, no, hospice yes/no. We also examined the reason for withdrawal, Medicare costs during the last 6 mo and the last week of life, site of death, age at death, cause of death, and state of residence where death occurred. Bivariate analyses were used to measure differences between groups for both categorical (χ^2 test) and continuous (Wilcoxon rank sum) outcomes. Analyses were performed using SAS for Windows, version 8.2 (SAS Institute, Cary, NC).

To examine factors that were related to hospice referral, we used two separate logistic regression models. First, we measured the association between dialysis withdrawal and hospice referral, with age, gender, race, and state of residence as independent variables. Second, we ran the same model for only those patients who withdrew from dialysis and added cause of withdrawal as an independent variable. To examine state-by-state variation in hospice use, we analyzed the relationship between the percentage of patients who withdrew from dialysis and used hospice per state and two measures using the Pearson correlation coefficient: (1) The availability of hospices per million population per state (data from the National Hospice and Palliative Care Organization and 2000 US Census Bureau data) and (2) the percentage of the population that resided in rural areas per state (8). Because only aggregate data were used without individual patient identifiers, this study qualified for exemption from board review from the West Virginia University Institutional Review Board for the Protection of Human Subjects.

Results

In the USRDS 2001 to 2002 2-yr cohort, 115,239 patients met the inclusion criteria. Their characteristics are described in Table 1 by withdrawal and hospice status. Within the 2-yr cohort, 21.8% withdrew from dialysis and 13.5% used hospice. Of the patients who withdrew, 41.9% used hospice. Use of hospice and dialysis withdrawal both increased with age ($P < 0.001$ for both; Figure 1). In unadjusted bivariate analyses, those who withdrew or used hospice were on average approximately 5 yr older than those who did not (72.7 ± 11.8 versus 68.0 ± 13.4 yr [$P < 0.001$] for dialysis withdrawal and 73.4 ± 11.0 versus 68.6 ± 13.4 [$P < 0.001$] for hospice use).

Similarly, hospice use among patients who withdrew from dialysis increased steadily with age, from 34% in patients who

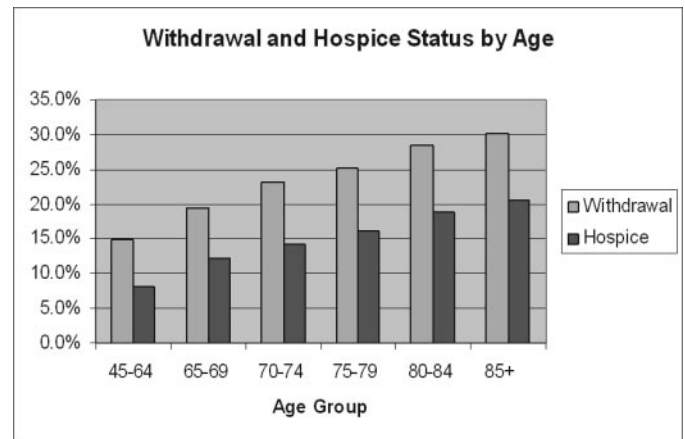


Figure 1. Dialysis withdrawal and hospice status by age, US Renal Data System (USRDS) 2001 to 2002 deceased cohort ($N = 115,239$).

were 45 to 64 yr of age to 46% of those who were 80 yr or older ($P < 0.001$). There were no significant differences in patient characteristics between patients who withdrew from dialysis and used hospice (withdrawal, yes; hospice, yes) and those who did not (withdrawal, yes; hospice, no)

Reasons for Withdrawal from Dialysis

In the 2-year cohort, failure to thrive was the most common reason for dialysis withdrawal, identified in 42.9% of patients, 48.5% of whom used hospice (data not shown). Medical complication was the second most common reason at 35.3% of patients, 30.7% of whom used hospice, followed by other reason in 19.8% of patients and access failure in 1.9%.

Factors Associated with Hospice Use

In a logistic regression model that was conducted in the primary cohort, dialysis withdrawal versus no withdrawal was strongly associated with hospice referral ($P < 0.001$), adjusted

Table 1. Dialysis withdrawal and hospice status of deceased patients, USRDS 2001 to 2002 cohort^a

Dialysis Withdrawal and Hospice Status	Deceased Patients ($N = 115,239$)	%	Mean Age (yr)	% Female	Race (%) ^b				Mean Months of Dialysis
					W	B	Hispanic	O	
Hospice, yes	15,565	13.5	73.4 ± 11.0^c	51.1 ^c	74.0	16.3	7.7	1.9	32.1 ± 34.7^c
Hospice, no	99,674	86.5	68.6 ± 13.4	48.1	55.3	30.7	10.0	4.0	37.0 ± 37.7
Withdrawal, yes	25,075	21.8	72.7 ± 11.8^d	52.4 ^d	73.1	16.4	7.5	3.0	33.1 ± 34.9^d
hospice, yes	10,518	41.9	73.9 ± 10.6	51.8	76.8	13.6	7.7	1.8	32.3 ± 34.1
hospice, no	14,557	58.1	71.7 ± 12.3	52.8	70.4	18.5	7.4	3.8	33.7 ± 35.6
Withdrawal, no	81,624	70.8	68.0 ± 13.4	47.4	52.5	32.7	10.7	4.1	37.3 ± 37.7
hospice, yes	2,751	3.4	71.7 ± 11.7	47.6	62.7	23.6	10.7	3.0	32.8 ± 34.5
hospice, no	78,873	96.6	67.9 ± 13.5	47.4	52.2	33.0	10.7	4.1	37.5 ± 37.8
Withdrawal status unknown	8,540	7.4	71.1 ± 13.2	47.4	64.1	27.0	6.1	2.8	35.6 ± 44.6

^aData are means \pm SD. B, black; Hisp, Hispanic; O, other; USRDS, US Renal Data System; W, white.

^bRace was significantly associated with both withdrawal and hospice status.

^cSignificant at $P < 0.001$ on bivariate tests of association between variable and hospice, yes, versus hospice, no.

^dSignificant at $P < 0.001$ on bivariate tests of association between variable and withdrawal, yes, versus withdrawal, no.

for age, gender, race, and state of residence (data not shown). Table 2 describes factors that were significantly associated with hospice use, using a similar logistic regression model that was conducted only among patients who withdrew from dialysis.

Age, race, primary diagnosis, reason for withdrawal, and state of residence all were significantly associated with hospice use ($P < 0.001$ for all covariates). Black patients and members of other races were least likely to use hospice; patients who with-

Table 2. Characteristics associated with hospice use in patients who withdrew from dialysis in the USRDS 2001 to 2002 deceased cohort, $n = 25,075^a$

Characteristic	<i>n</i>	%	Hospice Use (%)		<i>p</i> ^b	Adjusted OR (95% CI)	<i>p</i> ^c
			Yes	No			
All			41.9	58.1			
Age (yr)					<0.001		<0.001
0 to 44	700	2.8	28.1	71.9		Reference	
45 to 64	4207	16.8	34.2	65.8		1.29 (1.07 to 1.56)	
65 to 74	7447	29.7	41.7	58.3		1.72 (1.43 to 2.07)	
75 to 84	9621	38.4	44.8	55.2		1.87 (1.55 to 2.24)	
≥85	3100	12.4	47.2	52.8		2.09 (1.71 to 2.54)	
Gender					0.128		0.935
female	13,137	52.4	41.5	58.5		Reference	
male	11,938	47.6	42.4	57.6		1.00 (0.95 to 1.06)	
Race					<0.001		<0.001
white	18,326	73.1	44.1	55.9		Reference	
black	4121	16.4	34.8	65.2		0.72 (0.67 to 0.78)	
Hispanic	1882	7.5	43.1	56.9		0.80 (0.72 to 0.90)	
other	746	3.0	25.5	74.5		0.46 (0.38 to 0.55)	
Time on dialysis (yr)					<0.001		0.905
<3	16,052	64.0	42.8	57.2		1.00 (0.94 to 1.06)	
≥3	9023	36.0	40.4	59.6		Reference	
Modality ^d					0.711		0.146
hemodialysis	23,705	94.5	41.9	58.1		0.92 (0.81 to 1.03)	
peritoneal dialysis	1367	5.5	42.4	57.6		Reference	
Dependence for ADL ^e					<0.001		<0.001
yes	1321	5.3	37.1	62.9		0.78 (0.69 to 0.88)	
no	23,163	92.4	42.4	57.6		Reference	
Primary cause of renal failure					<0.001		0.007
diabetes	11,047	44.1	41.2	58.8		Reference	
hypertension	7202	28.7	43.6	56.4		0.95 (0.88 to 1.01)	
glomerulonephritis	1714	6.8	41.2	58.8		0.93 (0.84 to 1.05)	
cystic kidney disease	462	1.8	45.7	54.3		1.08 (0.89 to 1.33)	
urologic	516	2.1	46.1	53.9		1.08 (0.89 to 1.31)	
other	3021	12.0	41.8	58.2		0.98 (0.90 to 1.07)	
unknown or missing	1113	4.4	36.6	63.4		0.77 (0.67 to 0.88)	
Cause of dialysis withdrawal					<0.001		<0.001
access failure	471	1.9	42.3	57.7		0.95 (0.78 to 1.17)	
transplant failure	30	0.1	26.7	73.3		0.54 (0.22 to 1.34)	
failure to thrive	10,765	42.9	48.5	51.5		1.05 (0.98 to 1.12)	
medical complication	8845	35.3	30.7	69.3		0.50 (0.46 to 0.54)	
other	4964	19.8	47.7	52.3		Reference	
State of residence ^f	25,075	100.0	—	—	<0.001	—	<0.001

^aThe χ^2 test was used for comparisons between categorical variables. ADL, activities of daily living; CI, confidence interval; OR, odds ratio.

^b*P* for bivariate comparisons between those with and without hospice.

^cOn logistic regression.

^dData missing for three patients.

^eData missing for 591 patients. ADL assessment is completed at dialysis initiation.

^fState category was significant, but there was wide variation in the χ^2 results and OR.

drew from dialysis because of failure to thrive were most likely to use hospice. Patients who were unable either to walk or to transfer at dialysis initiation (as recorded on the CMS-2728 form) were significantly less likely to use hospice ($P < 0.001$).

Costs of End-of-Life Care and Site of Death

Table 3 shows the median total Medicare costs during the last 6 mo and the last week of life and the median number of hospital days in the last week of life, by withdrawal and hospice status, using the secondary 6-mo cohort ($n = 91,687$), which included only patients from the primary cohort who had 6 mo of follow-up data. Among patients who withdrew from dialysis and used hospice, the median cost of care during the last 6 mo was \$41,853, \$4097 less than that for nonhospice users; for the last week of care, the median cost was \$1858 for hospice users, \$3020 less than that for nonhospice users ($P < 0.001$ for both). Most cost differences were attributable to inpatient Medicare costs (not shown) as a result of increased hospital days for nonhospice patients *versus* hospice patients (4.0 *versus* 0.0 d; $P < 0.001$).

Table 4 shows the site of death for patients in the 6-mo cohort by withdrawal and hospice use. Among patients who withdrew from dialysis, those who used hospice were more than four times more likely to die at home instead of in the hospital, compared with those who did not use hospice (45.3 *versus* 10.8%, unadjusted). Likewise, only 22.9% of hospice patients died in the hospital, compared with 69.0% of nonhospice patients. Of all patients in the 6-mo cohort (withdrawal and nonwithdrawal) who died at home, only 29.6% used hospice (data not shown).

Table 5 describes the percentage of patients who withdrew from dialysis and used hospice by reason for withdrawal, grouped by site of death (home *versus* hospital). Among the patients who withdrew from dialysis and died at home, almost 25% did not use hospice. Among patients who withdrew as a result of failure to thrive, approximately 25% used hospice and died in the hospital, in contrast to 75% who used hospice and died at home. Of those who withdrew as a result of medical complications, 14% used hospice and died in the hospital com-

pared with 76% who used hospice and died at home. Those who withdrew as a result of medical complications constituted approximately 50% of all patients who withdrew from dialysis and died in the hospital, in contrast to approximately 25% of patients who withdrew from dialysis and died at home (Table 5).

Geographic Distribution of Hospice Use

Using the 2-yr 2001 to 2002 cohort, Figure 2 demonstrates the more than two-fold variation in the percentage by state of patients who withdrew from dialysis and used hospice. For example, although Iowa and Maine had similar rates of dialysis withdrawal, at 37.1 and 39.1%, respectively, 54.6% of patients who withdrew from dialysis in Iowa used hospice, compared with only 16.7% in Maine. In an analysis that included all 50 states, there was no correlation between the number of Medicare-certified hospices per million population and percentage of patients who withdrew from dialysis and used hospice care ($r = -0.0845$, $P = 0.55$). Alaska has the fewest hospices per capita with 4.8 hospices per million population; Wyoming has the most, with 36.5 hospices per million. However, there also was a significant inverse relationship between the percentage of the state population who lived in rural areas and the percentage of patients who withdrew from dialysis and used hospice; patients who resided in more rural states were less likely to use hospice ($r = -0.383$, $P = 0.006$).

The most common causes of death for the 2-year cohort are described in Table 6 by dialysis withdrawal and hospice status. For patients who withdrew from dialysis, cardiac combinations (21.4%) and other identified cause (16.6%) were the most common diagnoses; for hospice patients, they were unknown and missing (24.9%) and cardiac combinations (18.2%). Cardiac combinations included atherosclerotic heart disease, acute myocardial infarction, cardiac arrhythmia, cardiomyopathy, hyperkalemia, and pulmonary edema.

Malignancy was a more common diagnosis in the hospice group than in the withdrawal group, at 9.5 *versus* 7.2%; in contrast, septicemia and stroke were more common in the withdrawal group. Dementia rarely was identified as a cause of

Table 3. Median^a costs and hospital days for deceased patients, USRDS 6-mo cohort

Parameter	<i>n</i>	Median Cost, Last 6 Mo of Life (\$)	Median Cost, Last Week of Life (\$)	Median Hospital Days, Last Week of Life
Total cohort	91,687	42,978 (1,392,744)	4827 (255,881)	2.0 (156)
Hospice, yes	12,058	42,247 (322,979)	1883 (36,239)	0.0 (16)
Hospice, no	79,629	43,090 (1,392,744)	5428 (255,881)	2.0 (156)
Withdrawal, yes	19,517	44,222 (776,003)	3502 (106,988)	2.0 (17)
hospice, yes	8200	41,853 (322,054) ^b	1858 (32,992) ^b	0.0 (16) ^b
hospice, no	11,317	45,950 (776,003)	4878 (106,988)	4.0 (17)
Withdrawal, no	65,868	43,029 (1,392,744)	5547 (255,881)	2.0 (156)
hospice, yes	2165	45,736 (260,661)	2559 (36,239)	0.0 (8)
hospice, no	63,703	42,915 (1,392,744)	5663 (255,881)	2.0 (156)

^aMedian values given with (total range), instead of minimum and maximum because most minimums were 0.

^bSignificant at $P < 0.001$ on Wilcoxon rank test of association between variable and withdrawal, yes, hospice, yes, *versus* withdrawal, yes, hospice, no.

Table 4. Site of death and hospice days, USRDS 6-mo cohort

Parameter	n	Site of Death	%	Hospice Days (Mean ± SD)
Total cohort	91,687	Hospital	63.0	2.0 ± 12.6
		Home	16.7	
		Other	11.9	
		Unknown	8.4	
Hospice, yes	12,058	Hospital	22.9	14.2 ± 30.5
		Home	37.6	
Hospice, no	79,629	Hospital	69.0	0
		Home	13.6	
Withdrawal, yes	19,517	Hospital	49.2	4.4 ± 15.5
		Home	25.3	
Hospice, yes	8200	Hospital	22.5	10.1 ± 21.9
		Home	45.3	
Hospice, no	11,317	Hospital	68.5	0
		Home	10.8	
Withdrawal, no	65,868	Hospital	72.9	0.8 ± 9.0
		Home	15.8	
Hospice, yes	2165	Hospital	41.8	21.0 ± 40.3
		Home	37.3	
Hospice, no	63,703	Hospital	74.0	0
		Home	15.0	

Table 5. Percentage using hospice by reason for withdrawal and dying in hospital versus at home, USRDS 6-mo cohort

Reason for Withdrawal	Death in Hospital			Death at Home		
	n	Hospice Use (%)		n	Hospice Use (%)	
		No	Yes		No	Yes
Access failure	76	79.0	21.0	104	33.7	66.4
Treatment failure	6	100	0	5	60.0	40.0
Failure to thrive	3260	75.3	24.7	2613	24.4	75.6
Medical complication	4638	85.7	14.3	1113	24.3	75.7
Other	1516	77.5	22.5	1103	24.9	75.1
Total	9596	80.8	19.2	4938	24.8	75.2

death for either the withdrawal (1.4%) or the hospice group (1.3%). Overall, the percentage of patients with *unspecified* diagnoses, described as unknown or missing diagnoses, other cause, or other with <1% was very high for both groups: 35.8% for the withdrawal group and 45.9% for the hospice group.

Discussion

Dying patients with ESRD use hospice roughly half as often as dying patients in the United States as a whole (13.5 versus >22%) (9,10). For a patient to be eligible for hospice care, his or her attending physician must certify a life expectancy of 6 mo or less if the disease takes its normal course. After dialysis withdrawal, 96% of patients die within 30 d (2,11,12). Even

though death after dialysis withdrawal is much more predictable than death of cancer patients, the 41.9% hospice use rate of patients who withdraw from dialysis lags behind the >50% rate in cancer patients (13).

Most hospice dialysis patients seem to experience better pain control while dying at home than in the hospital (2). We found that dialysis patients who received hospice care were more than twice as likely to die at home compared with those without hospice care; median hospital days in the last week of life were reduced from 4.0 to 0.0 d, and the median cost of care for the last week of life for hospice patients was approximately one third that of nonhospice patients. For approximately half the patients who withdrew from dialysis and died in the hospital,

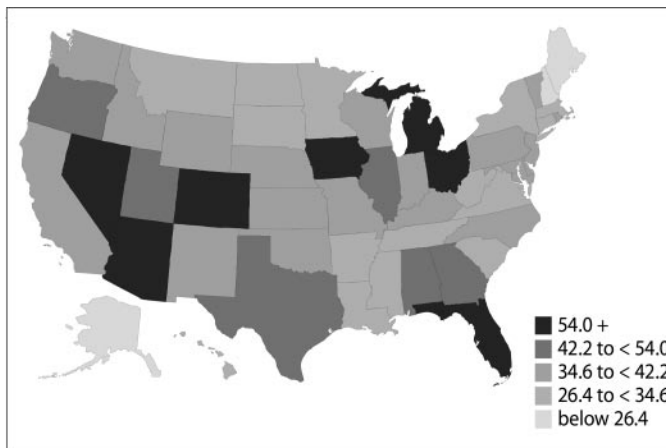


Figure 2. Percentage of patients who withdrew from dialysis and used hospice, by state, USRDS 2001 to 2002 deceased cohort ($N = 115,239$).

the reason listed for withdrawal was medical complications; these patients likely withdrew as a result of acute sepsis, severe congestive heart failure, or other acute complications. Approximately 70% of the remainder, however, withdrew as a result of failure to thrive, and many likely could have benefited from hospice care.

Factors Associated with Hospice Use

Dialysis patients were more likely to use hospice when they were older, were white, had failure to thrive as the reason for withdrawal, and were able to walk or transfer independently at dialysis initiation. Because ability to walk or transfer was measured at dialysis initiation, its predictive value of future use of hospice is unclear; longitudinal functional data are needed to determine whether an acute event such as a stroke and subsequent marked functional decline are associated with increased hospice use.

Among patients who withdrew because of failure to thrive, almost 50% used hospice, compared with less than one third of those who withdrew because of a medical complication. Patients with failure to thrive also constituted the majority of patients who died at home using hospice (43.6%). The high percentage (42.9%) of patients who withdrew as a result of failure to thrive may reflect the high prevalence of cognitive impairment and/or functional decline in hemodialysis patients (14). Patients with failure to thrive typically follow a course of gradual decline, allowing their families more time to prepare for end-of-life issues and thus to accept the hospice option more willingly than families of patients who withdraw after an unpredicted acute complication in the hospital. A gradual course of decline also gives physicians the ability to predict an imminent death and to help patients and families accept a limited life expectancy and plan accordingly, including consideration of hospice use.

State of residence also was strongly associated with hospice use (Figure 2). Geographic variation in hospice use has been noted in nondialysis patient populations (15–18). We found that

for withdrawing dialysis patients, the more rural their state of residence, the less likely their use of hospice. Additional unmeasured factors in our study that may influence hospice use include nephrologist comfort level with hospice referral, patient and family acceptance of hospice referral, availability of hospice services, understanding of the Medicare hospice benefit as it applies to dialysis patients by dialysis unit social workers, and hospice relationships with dialysis unit personnel.

Nephrologists may be uncomfortable with addressing end-of-life issues and hospice referral with their patients because end-of-life care is not well addressed in renal fellowship training; second-year fellows report feeling unprepared to care for their dying patients (19). Because of lack of education, many patients with ESRD and their families may not know that hospice is an option for them (20). Among patients who do not withdraw from dialysis but are enrolled in hospice, the average number of days in hospice is 21.0 (± 40.3) compared with 57 d in the nondialysis hospice population (21), indicating that even dialysis patients who do not withdraw have late referral to hospice.

Eligibility for the Hospice Benefit

Dialysis patients may receive both the Medicare ESRD benefit and the Medicare hospice benefit, but many dialysis units and hospice programs seem unaware of this eligibility. To continue dialysis under the Medicare dialysis benefit and also enroll in the Medicare hospice benefit, a patient must be certified by his or her attending physician to have (1) a life expectancy of 6 mo or less if the disease takes its normal course and (2) a terminal diagnosis for hospice other than kidney disease, such as cancer or end-stage heart disease (22). (Approximately 2750 of the 15,565 hospice patients with ESRD in our study had a terminal diagnosis of a nonrenal disease and continued dialysis.) The Mid-Atlantic Renal Coalition (ESRD Network 5), the Renal Physicians Association, the Forum of ESRD Networks, and the National Hospice and Palliative Care Association are working with CMS to improve understanding of the Medicare hospice coverage for patients with ESRD and dialysis providers.

Consideration of a Regularly Scheduled Prognostic Evaluation

Currently, there is no required process during maintenance dialysis to address the expected prognosis or the options of withdrawal and hospice. Physicians' asking the "surprise" question ("Would I be surprised if this patient died in the next year?") has been found to be helpful in identifying patients who are likely to die and to lead to increases in hospice referrals in primary care populations (23). This question has been recommended for regular use by nephrologists to help identify dialysis patients who are appropriate for palliative care intervention (24).

If the patient is deemed unlikely to survive this period, then this determination could trigger an assessment of his or her cognitive, nutritional, and functional status; pain and symptom burden; and self-reported quality of life. It would provide an

Table 6. Cause of death, USRDS 2001 to 2002 cohort, by dialysis withdrawal and hospice status

Cause of Death	Hospice (%; n = 15,565)	Withdrawn (%; n = 25,075)	All (%; N = 115,239)
Unknown and missing	24.9	9.1	16.4
Cardiac combinations ^a	18.2	21.4	22.3
Other identified cause	15.0	16.6	7.6
Cardiac arrest (cause unknown)	14.3	15.3	22.6
Malignancy	9.5	7.2	3.7
Septicemia	5.4	10.6	11.3
Stroke	3.0	5.5	4.2
Dementia	1.3	1.4	0.4
Cachexia	2.5	2.9	1.1
Other with <1% ^b	6.0	10.1	10.3

^aCardiac combinations included atherosclerotic heart disease, acute myocardial infarction, cardiac arrhythmia, cardiomyopathy, hyperkalemia, and pulmonary edema.

^bMost common of these diagnoses were pneumonia, ischemic bowel, ischemic brain damage, gastrointestinal hemorrhage, other hemorrhage, other infections, valvular heart disease, and chronic obstructive pulmonary disease.

opportune time to engage in advance care planning, including the patient's preferred site of death and desirability of hospice.

A brief cognitive assessment is critical to identify whether the patient has the decision-making capacity to participate in advance care planning or discussions with proxy decision makers and caregivers are needed to explore treatment goals. Thus far, the nephrology community has shied away from initiating such discussions, but patients' best interests are no longer served by clinicians' ignoring the need for them.

The strengths of our study include the large sample size of USRDS dialysis patients who are largely representative of the non-health maintenance organization dialysis Medicare population, with minimal loss to follow-up for death notification. The data enabled us to identify that age and state of residence are strongly associated with dialysis withdrawal and hospice referral and also to document important differences in outcomes between hospice and nonhospice dialysis patients.

Our results depend on the quality control of data input and the completion rate of the CMS-2746 form, which may vary widely among dialysis units, introducing potential ascertainment bias. The limited options on this form for identifying causes of death, reasons for dialysis withdrawal, and hospice use prevented more detailed analyses, such as reasons for nonreferral to hospice. We were unable to determine whether dying dialysis patients prefer hospice to nonhospice care or to measure the quality of end-of-life care that was received by patients dying with and without hospice care. This highlights the need for further improvement in the accuracy, detail, and completeness of USRDS end-of-life data collection on the CMS-2746 form for dialysis withdrawal and hospice patients. Our data also were limited in that patients whose primary payer was not Medicare were excluded, so our results may not be generalizable to all dialysis patients.

Three of the four possible reasons for dialysis withdrawal listed on the CMS-2746 form are vague, all except access failure, which is listed for 1.9% of patients. The withdrawal status of 8540 (7.4%) patients in the entire 2-yr cohort was unknown, and

the major cause of death for 25% of patients who died while receiving hospice care was unknown and missing. Failure to thrive (42.9%) is an inexact term that usually signifies significant impairment in one or more areas: Cognitive, functional, nutritional, or psychiatric, especially depression (25). More specific reasons for withdrawal on the CMS-2746 form would improve our understanding of the factors that contribute to the high rate of dialysis discontinuation in this country.

Our findings point to the opportunity to improve access to hospice for dialysis patients. To this end, ESRD recently was added to the list of hospice-appropriate diseases, joining cancer and heart, lung, and neurologic diseases (26). The American Society of Nephrology and the Renal Physicians Association also have published a clinical practice guideline and position statement that directly endorse hospice care for patients who have ESRD and are at the end of life (27,28). CMS recently added the following question to the revised CMS-2746 form, introduced in October 2004: "Was patient receiving hospice care before death?" Last, to determine whether hospice care provides higher quality end-of-life care than most patients currently receive, a prospective study of hospice use by dialysis patients is needed to measure the outcomes of pain and symptom management, emotional support, communication, and patient and family satisfaction.

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References

1. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V: Family perspectives on end-of-life care at the last place of care. *JAMA* 29: 88-93, 2004
2. Cohen LM, Germain M, Poppel DM, Woods A, Kjellstrand

- CM: Dialysis discontinuation and palliative care. *Am J Kidney Dis* 36: 140–144, 2000
3. Chang VT, Hwang SS, Feuerman M, Kasimis BS: Symptom and quality of life survey of medical oncology patients at a Veterans Affairs Medical Center: A role for symptom assessment. *Cancer* 88: 1175–1183, 2000
 4. Weisbord SD, Fried LF, Arnold RM, Fine MJ, Levenson DJ, Peterson RA, Switzer GE: The prevalence, severity, and importance of physical and emotional symptoms in chronic hemodialysis patients. *J Am Soc Nephrol* 16: 2487–2494, 2005
 5. United States Renal Data System: *USRDS 2003 Annual Data Report: Atlas of End-Stage Renal Disease in the United States*, Bethesda, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2003, p 500
 6. Surveillance, epidemiology, and end results (SEER) program 5-year relative survival rates, all sites, all ages, all races: SEER*Stat Database: Incidence-SEER 9 Regs public-use, Nov 2004 Sub (1973–2002), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch. Available: http://www.seer.cancer.gov/cgi-bin/csr/1975_2003/search.pl#results. Accessed June 27, 2005
 7. Medicare Payment Advisory Commission. Report to the Congress: New Approaches in Medicare, June 2004. Available: http://www.medpac.gov/publications%5Ccongressional_reports%5CJune04_ch6. Accessed May 3, 2005
 8. United States Census Bureau: Data with Detailed Tables, Table P2. Urban and Rural [6]-Universe: Total Population. Available: http://factfinder.census.gov/servlet/DTGeoSearchByListServlet?ds_name=DEC_2000_SF1_U&lang=en&ts=174320779387. Accessed May 2, 2006
 9. Characteristics of Hospice Care Discharges and Their Length of Service: United States, 2000, Table 1. Available: http://www.cdc.gov/nchs/data/series/sr_13/sr13_154.pdf. Accessed June 30, 2005
 10. Deaths, Percent of Total Deaths, and Death Rates for the 15 Leading Causes of Death in Selected Age Groups, by Race and Sex: United States, 2000. Available: http://www.cdc.gov/nchs/data/dvs/LCWK3_2000.pdf. Accessed June 30, 2005
 11. Neu S, Kjellstrand CM: Stopping long-term dialysis: An empirical study of withdrawal of life-supporting treatment. *N Engl J Med* 314: 14–20, 1986
 12. Sekkarie MA, Moss AH: Withholding and withdrawing dialysis: The role of physician specialty and education and patient functional status. *Am J Kidney Dis* 31: 464–472, 1998
 13. *Improving Palliative Care for Cancer*, edited by Foley KM, Gelband H, Washington, DC, National Academy Press, Institute of Medicine and National Research Council, 2001, p 14
 14. Murray AM, Knopman DS, Tupper D, Gilbertson DT, Pederson SL, Li S, Smith G, Hochhalter AK, Collins AJ, Kane RL: Cognitive impairment in hemodialysis patients is common. *Neurology* 67: 216–223, 2006
 15. Virnig BA, Kind S, McBean M, Fisher E: Geographic variation in hospice use prior to death. *J Am Geriatr Soc* 48: 1117–1125, 2000
 16. Virnig BE, McBean M, Kind S, Dholakia R: Hospice use before death: Variability across cancer diagnoses. *Med Care* 40: 73–78, 2002
 17. Casey MM, Moscovice IS, Virnig BA, Dunham SB: Providing hospice care in rural areas: Challenges and strategies. *Am J Hosp Palliat Med* 22: 363–368, 2005
 18. Gallo WT, Baker MJ, Bradley EH: Factors associated with home versus institutional death among cancer patients in Connecticut. *J Am Geriatr Soc* 49: 771–777, 2001
 19. Holley JL, Carmody SS, Moss AH, Sullivan AM, Cohen LM, Block SD, Arnold RM: The need for end-of-life care training in nephrology: National survey results of nephrology fellows. *Am J Kidney Dis* 42: 813–820, 2003
 20. Robert Wood Johnson Foundation: Promoting Excellence in End-of-Life Care: ESRD Workgroup Recommendations to the Field. Available: <http://www.promotingexcellence.org/i4a/pages/Index.cfm?pageID=3689>. Accessed on June 30, 2005
 21. National Hospice and Palliative Care Organization: Facts and Figures on Hospice Care in America. Available: http://www.nhpco.org/files/public/Facts_Figures_for2004data.pdf. Accessed on September 24, 2005
 22. United Government Services: Medicare Memo, December 19, 2005, No 2005-12. Available at: http://www.ugsmedicare.com/providers/medicare_memos/2005/documents/Medicare%20Memo-December%202005R.pdf. Accessed February 9, 2006
 23. Pattison M, Romer AL: Improving care through the end of life: Launching a primary care clinic-based program. *J Palliat Med* 4: 249–254, 2001
 24. Moss AH, Holley JL, Davison SN, Dart RA, Germain MJ, Cohen LM, Swartz RD: Core curriculum in nephrology: Palliative care. *Am J Kidney Dis* 43: 172–185, 2004
 25. Sarkisian CA, Lachs MS: “Failure to thrive” in older adults. *Ann Intern Med* 124: 1072–1078, 1996
 26. Mast KR, Salama M, Silverman GK, Arnold RM: End-of-life content in treatment guidelines for life-limiting diseases. *J Palliat Med* 7: 754–773, 2004
 27. Renal Physicians Association, American Society of Nephrology: *Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, Washington, DC, Renal Physicians Association, 2000
 28. Renal Physicians Association, American Society of Nephrology: *Position Paper on Quality Care at the End of Life*, Rockville, Renal Physicians Association, 2002