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## AGING & HEALTH

# Hospice Use And End-Of-Life Spending Trajectories In Medicare Beneficiaries On Hemodialysis

**ABSTRACT** Infrequent and late referral to hospice among patients on dialysis likely reflects the impact of a Medicare payment policy that discourages the concurrent receipt of these services, but it may also reflect these patients' less predictable illness trajectories. Among a national cohort of patients on hemodialysis, we identified four distinct spending trajectories during the last year of life that represented markedly different intensities of care. Within the cohort, 9 percent had escalating spending and 13 percent had persistently high spending throughout the last year of life, while 41 percent had relatively low spending with late escalation, and 37 percent had moderate spending with late escalation. Across the four groups, the percentages of patients enrolled in hospice at the time of death were uniformly low ranging from only 19 percent of those with persistently high costs to 21 percent of those with moderate costs and the median number of days spent in hospice during the last year of life was virtually the same (either five or six days). These findings signal the need for greater flexibility in the provision of end-of-life care in this population.

Congress created the Medicare hospice benefit in 1982 as part of the Tax Equity and Fiscal Responsibility Act; the benefit became permanent in 1986 and has been part of Medicare coverage ever since. To qualify for hospice under Medicare, patients must have a life expectancy of six months or less that is attributable to a terminal diagnosis. After a patient enrolls in hospice, Medicare will no longer cover "curative" treatments related to the patient's terminal diagnosis.<sup>1-3</sup> Initially, the hospice benefit was used primarily to support the care of patients dying of cancer and their families,<sup>1,2</sup> but in recent years it has been expanded to cover a growing number of patients dying of causes other than cancer.

For a variety of reasons, there is some concern that, as currently configured, the Medicare hospice program is poorly equipped to meet the

needs of beneficiaries dying of conditions other than cancer.<sup>1,2</sup> For patients with multiple comorbid conditions, it may be unrealistic to attribute limited life expectancy to a single condition.<sup>1,2,4,5</sup> Furthermore, the distinction between "curative" and "palliative" treatments ignores the reality that some treatments (for example, dialysis) can serve either of these goals in different contexts.<sup>1-3,6,7</sup> And the requirement that patients have a life expectancy of six months or less means that beneficiaries with a more predictable downward course of illness (in whom death may be more expected) are more likely than others to receive these services. For example, in a recent study conducted among Medicare beneficiaries ages 66–99, hospice use varied substantially by end-of-life spending trajectory.<sup>4</sup> Among beneficiaries with relatively low spending during the last year of life, only 33 percent were enrolled in

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hospice, compared with 52 percent of beneficiaries with a progressive increase in spending throughout the last year of life.

Hospice enrollment for Medicare beneficiaries receiving maintenance dialysis for end-stage renal disease occurs less than half as often and much closer to the time of death, compared to the general Medicare population.<sup>8–11</sup> Infrequent and late hospice referral among Medicare beneficiaries on dialysis likely reflects, at least in part, the unique implications of Medicare hospice eligibility criteria for this population.<sup>9</sup> Because dialysis is considered a “curative” treatment, Medicare will no longer cover the costs of dialysis for patients dying of renal failure after they enter hospice. This usually means that these patients must stop dialysis to enter hospice, even if dialysis is helping palliate the symptoms of advanced kidney disease.<sup>7–9</sup> While stopping dialysis at the time of hospice enrollment may align with the goals of some patients,<sup>12</sup> for others this may represent a forced choice between two potential beneficial treatments.<sup>3,6,7</sup>

The requirement that patients dying of renal failure stop dialysis to qualify for the Medicare hospice benefit probably discourages and delays hospice enrollment and—because most patients do not live very long after stopping dialysis<sup>13</sup>—effectively restricts the length of time that can be spent in hospice for members of this population. However, it is also possible that patterns of hospice referral among the subset of Medicare beneficiaries on dialysis reflect their less predictable illness trajectories, as is the case for members of the wider Medicare population with less predictable illness trajectories. We designed a study to compare rates and timing of hospice referral among Medicare beneficiaries on dialysis with differing premorbid illness trajectories. The purpose of this study was to determine whether hospice referral occurred infrequently and close to the time of death even among members of this population with a more predictable downward course of illness.

## Study Data And Methods

**OVERVIEW** We used patients’ health care spending trajectories during the last year of life as a proxy for end-of-life illness trajectories among a national cohort of Medicare beneficiaries treated with maintenance dialysis. As described in more detail below, we used group-based trajectory modeling<sup>14</sup> to identify groups of cohort members with distinct spending trajectories during the last year of life. We then described the characteristics and patterns of inpatient, skilled nursing facility, and hospice use of patients within each spending trajectory group.

**STUDY POPULATION** We used data from the 2017 version of the public-use United States Renal Data System Standard Analysis Files linked to Medicare Part A and B claims.<sup>15</sup> We identified a decedent cohort of all patients registered in the system who died in the period 2000–14. We excluded patients who died at ages younger than eighteen or older than one hundred, those who did not have Medicare Parts A and B throughout the last year of life, those whose last recorded treatment modality was not hemodialysis (for example, peritoneal dialysis, or transplant), and those who received a kidney transplant in the last year of life. To exclude patients who were unlikely to have received hemodialysis under fee-for-service Medicare, we also excluded patients with quarterly spending of less than \$2,000 (the approximate monthly cost of dialysis treatments) during the last year of life.

Nearly 1.3 million patients registered in the United States Renal Data System (USRDS) died in 2000–14. Of these, we excluded 1,524 patients who died at ages younger than eighteen or older than one hundred, 439,008 who did not have Medicare Parts A and B throughout the last year of life, 87,060 whose last treatment modality before death was not hemodialysis, 595 who had a kidney transplant in the last year of life, and 130,003 whose Medicare Parts A and B spending was less than \$2,000 in one or more of the four quarters before death. This yielded an analytic cohort of 639,466 patients. (For a full description of the cohort derivation, see online appendix figure 1.)<sup>16</sup>

**STUDY VARIABLES** The USRDS Patients file was used to ascertain demographic characteristics, including age at the time of death, sex, race (categorized as black, white, Native American, Asian, and other or unknown), and Hispanic ethnicity. We used the system’s Patients and Treatment History files to ascertain time since onset of end-stage renal disease and restrict the cohort to patients for whom hemodialysis was the most recent modality at the time of death (versus peritoneal dialysis or transplant). We used *International Classification of Diseases*, Ninth Revision (ICD-9), diagnostic codes to search Medicare Institutional and Physician Supplier (Carrier File) inpatient and outpatient claims during the year before death to identify comorbid conditions (diabetes mellitus, coronary artery disease, stroke, peripheral arterial disease, congestive heart failure, emphysema, cancer, dementia, and cirrhosis) and to calculate an overall comorbidity index (Quan score).<sup>17</sup> We used information from the CMS Death Notification Form to determine whether dialysis had been discontinued before death. Regional health care intensity was based on average inpatient

health care spending during the last six months of life in each patient's hospital referral region of residence closest to the time of death, as reported in the *Dartmouth Atlas of Health Care* for 2014 and categorized by quintile.<sup>18</sup>

We used Medicare Institutional and Physician Supplier claims to examine patterns of health care utilization during the last year of life, including hospital admission, intensive or coronary care unit (ICU) admission, receipt of an inpatient intensive procedure, admission to a skilled nursing facility, and receipt of hospice care. Revenue center codes 020x and 021x in institutional claims were used to identify ICU use. *Intensive procedures* were defined based on an ICD-9 procedure code search of inpatient Medicare institutional claims as follows: intubation and mechanical ventilation (ICD-9 codes 96.04, 96.05, and 96.7x); tracheostomy (ICD-9 codes 31.1, 31.21, and 31.29); artificial feeding, defined as gastrostomy tube insertion (ICD-9 codes 43.2, 43.11, 43.19, 43.2, and 44.32) or enteral or parenteral nutrition (ICD-9 codes 96.6 and 99.15); and cardiopulmonary resuscitation (ICD-9 codes 99.60 and 99.63).<sup>19</sup> Using both Institutional and Physician Supplier claims, we calculated total costs for Medicare Parts A and B services for each patient during the last four quarter-years of life using payments to Medicare standardized to the 2014 Consumer Price Index. These included costs for inpatient and outpatient care, home health care, durable medical equipment, and hospice services; they did not include pharmacy costs. Costs were log-transformed to accommodate positive skewness.

**ANALYSES** Group-based trajectory modeling was completed using the procedure TRAJ and implemented using SAS, version 9.4.<sup>20</sup> Modeling started with a one-group model identified as a second-order equation.<sup>21</sup> Subsequent models were created by altering the number of groups and equation order. The criteria used to compare model improvement included examining class membership, average posterior probability of assignment, and changes in the Bayesian information criteria.<sup>22</sup> We required our models to include a minimum of 5 percent class membership. We required the average posterior probability of assignment for each class to exceed 70 percent. The log of two times the change in Bayesian information criteria scores had to indicate positive to strong model improvement (typically a value of at least 4).<sup>23</sup> Finally, proposed models were compared to the maximum number of groups estimated using a priori knowledge.<sup>24</sup>

We described the characteristics of patients in each trajectory group and their patterns of inpatient, skilled nursing facility, and hospice use during the last year of life. Categorical variables

are presented as percentages, while continuous variables are presented as mean or median values (with standard deviations and interquartile ranges, respectively), as appropriate.

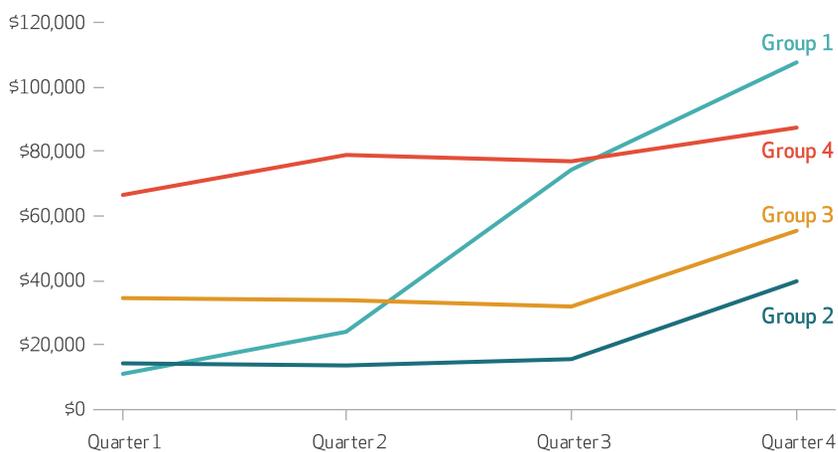
Because mortality rates are extremely high during the first year after dialysis initiation and because spending trajectories for patients who died within a year of starting dialysis included some spending that accrued before dialysis was initiated, we conducted sensitivity analyses after stratification by timing of death in relation to onset of end-stage renal disease (categorized as died one year or less versus more than one year after onset). We also examined differences in receipt of hospice care at the time of death and days spent in hospice during the last year of life across trajectory groups, according to whether or not patients had discontinued dialysis before death, their age at the time of death (ages sixty-five or younger versus older than sixty-five), average end-of-life intensity of care in their most recent hospital referral region of residence, and when they died (2000–04 versus 2010–14).

**LIMITATIONS** Our study had several limitations. First, because it was conducted among fee-for-service Medicare beneficiaries, the results might not be generalizable to other groups (for example, people covered by Medicare Advantage, private health insurance, the Department of Veterans Affairs, or the Department of Defense).

Second, because our results pertain only to patients treated with chronic hemodialysis, they

**EXHIBIT 1**

**Mean Medicare Parts A and B spending for patients on hemodialysis in the four quarters of the last year of life, by spending trajectory group, 2000–14**



**SOURCE** Authors' analysis of data from the United States Renal Data System linked to Medicare Parts A and B claims for decedents during the last year of life, 2000–14. **NOTE** Group 1 consists of patients with escalating spending during all four quarters, group 2 of patients with relatively low spending in the first three quarters that escalated after that, group 3 of patients with moderate but escalating spending, and group 4 of patients with persistently high spending.

might not be generalizable to other groups with end-stage renal disease, such as those treated with peritoneal dialysis, those with a functioning kidney transplant, and those who did not initiate dialysis before death.

Third, the minimum quarterly cost requirement may have biased the selection of patients who died within a year of starting dialysis and excluded otherwise eligible patients with lower levels of spending.

Finally, spending trajectories and patterns of health care use offer only a rough proxy for ill-

ness trajectories.

## Study Results

Cohort members followed one of four distinct spending trajectories during the last year of life (exhibit 1): 60,881 (9 percent) had escalating spending during all four quarters (group 1), 260,132 (41 percent) had relatively low spending for the first three quarters with escalation during the final quarter (group 2), 236,291 (37 percent) had moderate spending for the first three quar-

### EXHIBIT 2

#### Spending by and characteristics of patients on hemodialysis in the last year of life, by spending trajectory group

	Group 1	Group 2	Group 3	Group 4
Number (%)	60,881 (9%)	260,132 (41%)	236,291 (37%)	82,162 (13%)
<b>MEDIAN MEDICARE PARTS A AND B SPENDING DURING LAST YEAR OF LIFE</b>				
Total	\$193,930	\$78,670	\$149,408	\$279,321
Total IQR	(154,650, 250,396)	(61,064, 97,120)	(123,503, 180,818)	(239,679, 342,847)
Inpatient	\$128,514	\$26,189	\$72,842	\$187,146
Inpatient IQR	(90,275, 186,588)	(11,813, 45,796)	(47,929, 104,552)	(141,929, 253,089)
<b>DEMOGRAPHIC CHARACTERISTICS</b>				
Mean age in years (SD)	70 (12)	71 (13)	70 (13)	67 (13)
Male	52%	56%	51%	50%
Race				
Black	30	27	31	36
White	65	68	65	59
Native American	1	2	1	1
Asian	3	3	2	3
Other or unknown	1	1	1	1
Ethnicity				
Hispanic	10	10	10	12
Unknown or missing	5	6	6	4
<b>COMORBID CONDITIONS</b>				
Diabetes mellitus	83%	71%	81%	89%
Coronary artery disease	84	69	82	88
Stroke	48	30	43	56
Peripheral artery disease	58	38	56	68
Congestive heart failure	89	72	87	93
Emphysema	56	40	54	64
Cancer	30	23	27	29
Dementia	21	12	19	27
Cirrhosis	8	4	7	10
Median Quan score (IQR)	10 (8, 12)	8 (6, 9)	9 (8, 11)	10 (9, 12)
<b>YEAR OF DEATH</b>				
2000–04	30%	30%	33%	30%
2005–09	36	33	35	37
2010–14	35	37	32	34
<b>HOSPITAL REFERRAL REGION QUINTILE OF HEALTH CARE SPENDING</b>				
1 (lowest)	9%	13%	10%	7%
2	13	16	14	11
3	20	21	20	18
4	22	22	23	22
5 (highest)	37	27	32	42
Missing	1	2	2	1

**SOURCE** Authors' analysis of data from the United States Renal Data System linked to Medicare Parts A and B claims for decedents during the last year of life, 2000–14. **NOTES** The four groups are explained in the notes to exhibit 1. IQR is interquartile range. SD is standard deviation. Quan score is a Charlson comorbidity index adapted for administrative data (see note 17 in text). On a scale of 0 to 33, higher scores indicate a progressively higher overall burden of comorbidity.

ters with escalation during the final quarter (group 3), and 82,162 (13 percent) had persistently high spending during all four quarters (group 4).

Median Medicare Parts A and B spending during the final year of life was \$193,930 for group 1, \$78,670 for group 2, \$149,408 for group 3, and \$279,321 for group 4 (exhibit 2). The proportion of all spending that accrued in the inpatient setting ranged from 33 percent for group 2 to 67 percent for group 4. Spending in the final year of life was higher for patients who died within a year of starting dialysis than for other patients. However, patterns of spending were similar across trajectory groups, with the lowest spending noted for group 2 and the highest for group 4. (For results after stratification by time since dialysis initiation, see appendix table 1.)<sup>16</sup>

**PATIENT CHARACTERISTICS** There were systematic differences in the characteristics of patients with differing spending trajectories (exhibit 2). Compared with other groups, group 4 patients were, on average, younger and included the highest percentages of women and African Americans, had the highest prevalence of most of the comorbid conditions, and included the highest percentage of patients living in hospital referral regions in the highest quintile of average spending in the last six months of life. (For results after stratification by time since dialysis initiation, see appendix table 1.)<sup>16</sup>

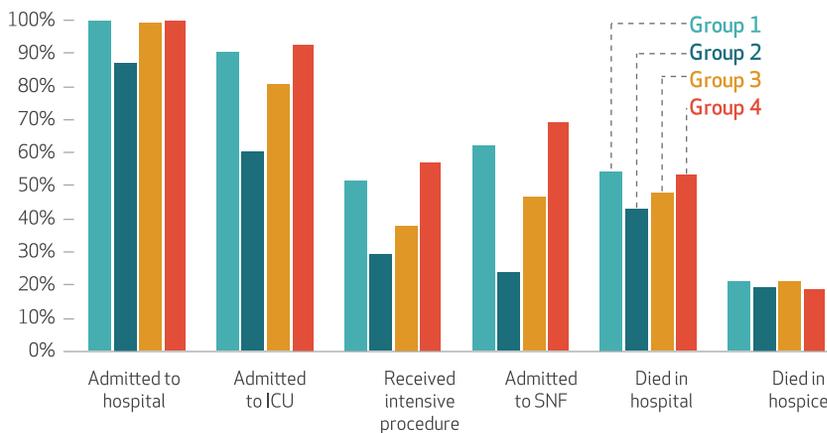
**HEALTH CARE INTENSITY DURING THE LAST YEAR OF LIFE** Levels of health care intensity during the last year of life were lowest for group 2 and highest for group 4 for all but one measure, died in hospice (exhibit 3). Results were similar after stratification by whether patients died within a year of onset of end-stage renal disease. (For results after stratification by time since dialysis initiation, see appendix figures 2a and 2b.)<sup>16</sup>

The median number of days spent in the hospital among those admitted ranged from 14 (interquartile range: 7, 25) for group 2 to 86 (IQR: 60, 120) for group 4 (exhibit 4). The median number of days spent in the ICU among those admitted ranged from 5 (IQR: 2, 11) for group 2 to 21 (IQR: 9, 39) for group 4. The median number of days spent in a skilled nursing facility among those admitted ranged from 23 (IQR: 11, 45) for group 2 to 76 (IQR: 32, 102) for group 4. Results were similar after stratification by timing of death in relation to onset of end-stage renal disease. (For results after stratification by time since dialysis initiation, see appendix figures 3a and 3b.)<sup>16</sup>

**HOSPICE REFERRAL** The shares of patients enrolled in hospice at the time of death varied by only two percentage points from 19 percent for group 4 to 21 percent for group 3 (exhibit 3). The

### EXHIBIT 3

Measures of health care intensity during the last year of life among patients on hemodialysis, by spending trajectory group

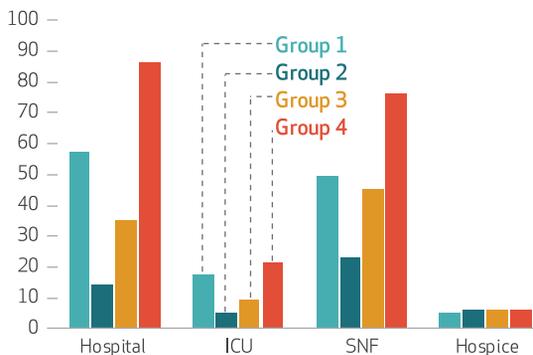


**SOURCE** Authors' analysis of data from the United States Renal Data System linked to Medicare Parts A and B claims for decedents during the last year of life, 2000-14. **NOTES** The four groups are explained in the notes to exhibit 1. Intensive procedures are explained in the text. ICU is intensive care unit or coronary care unit. SNF is skilled nursing facility.

median number of days spent in hospice during the last year of life among those enrolled varied by only a day, ranging from five days for group 1 to six days for all other groups (exhibit 4). Hospice enrollment at the time of death was higher and varied more across spending trajectory groups for patients who died within a year of starting dialysis than for other patients, but there was little variation in the median number

### EXHIBIT 4

Median number of days spent by patients on hemodialysis in different care settings during the last year of life, by spending trajectory group



**SOURCE** Authors' analysis of data from the United States Renal Data System linked to Medicare Parts A and B claims for decedents during the last year of life, 2000-14. **NOTES** The four groups are explained in the notes to exhibit 1. ICU is intensive care unit or coronary care unit. SNF is skilled nursing facility. Median days spent in each setting are reported for the denominator of all patients admitted to that setting at least once during the last year of life.

of days spent in hospice by time since dialysis initiation. (For results after stratification by time since dialysis initiation, see appendix figures 2a, 2b, 3a, and 3b.)<sup>16</sup>

**SENSITIVITY ANALYSES** More than half of the patients who discontinued dialysis before death were receiving hospice services at the time of death, compared with less than 10 percent of those patients who did not discontinue dialysis (exhibit 5). However, the percentage of patients who died in hospice did not vary greatly across trajectory groups after stratification by whether dialysis had been discontinued. Among those who died in hospice, most had discontinued dialysis before death, ranging from 70 percent of those in group 4 to 78 percent of those in group 2 (data not shown). The median number of days spent in hospice during the last year of life among those who discontinued dialysis was five

for all trajectory groups, but among those who did not discontinue dialysis the number varied from five to nine days across groups (exhibit 5).

While there were systematic differences in the frequency and timing of hospice referral by age group, regional health care spending, and time period, within each of these strata there was little variation in these measures across cost trajectory groups. (For results of stratified analyses, see appendix figures 4a–c and 5a–c.)<sup>16</sup>

## Discussion

Despite marked heterogeneity in the intensity of inpatient and skilled nursing facility care during the final year of life among Medicare beneficiaries on hemodialysis, the use and timing of hospice services were remarkably uniform. Regardless of cost trajectory, rates of hospice enrollment were less than one-half, and median time spent in hospice less than one-third, those reported for the overall Medicare population.<sup>1,4,11,25</sup>

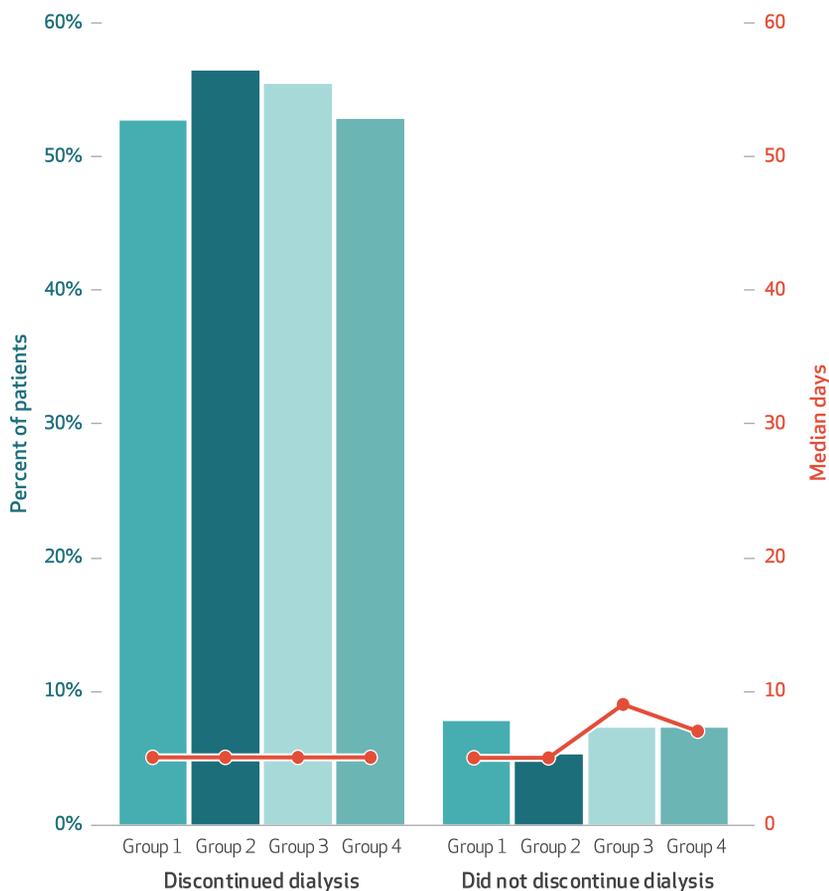
Prior studies have reported infrequent and late hospice referral coupled with relatively high levels of health care use during discrete time periods before death among patients with end-stage renal disease, compared with other populations with chronic illness.<sup>8,10,26–28</sup> We are not aware of any prior studies that have examined longitudinal patterns of spending and health care use in this population or evaluated for heterogeneity in these measures. Despite marked heterogeneity across trajectory groups in spending and inpatient and skilled nursing facility use, we found almost no variation in the frequency of hospice enrollment or time spent in hospice. These results contrast sharply with those for the general Medicare population, for whom patterns of hospice enrollment appear to be far more sensitive to differences in end-of-life spending trajectories.<sup>4</sup>

These findings likely reflect, at least in part, the rigidities of a Medicare payment policy that effectively prohibits concurrent receipt of dialysis and hospice services for most patients with end-stage renal disease. However, it is noteworthy that even members of this cohort who were able to receive hospice care without discontinuing dialysis spent much shorter periods of time in hospice during the last year of life than reported for the wider Medicare population (a median of seventeen days in 2015).<sup>11</sup> This finding seems to suggest that there are probably other barriers to integration of hospice into the care of patients on dialysis.<sup>7,29–33</sup>

More broadly, our findings indicate that current approaches to the provision of end-of-life care for patients on hemodialysis are insuffi-

### EXHIBIT 5

**Percentages of patients on hemodialysis enrolled in hospice at the time of death and median hospice days for those patients in the last year of life, by whether dialysis was discontinued before death and spending trajectory group**



**SOURCE** Authors' analysis of linked United States Renal Data System linked to Medicare Parts A and B claims for decedents during the last year of life, 2000–14. **NOTE** The four groups are explained in the notes to exhibit 1. Median days spent in each setting are reported for the denominator of all patients admitted to that setting at least once during the last year of life.

ciently flexible to accommodate what appears to be marked heterogeneity in end-of-life illness trajectories within this population. More work is needed to understand the challenges of end-of-life care transitions from the perspective of dialysis patients and those who care for them and to identify opportunities for improvement.

The Center for Medicare and Medicaid Innovation is testing several care models that we believe could be adapted to support a more flexible approach to provision of end-of-life care for this population. The Medicare Care Choices Model allows patients to receive hospice-like support services in concert with curative care but is currently restricted to beneficiaries with a terminal diagnosis of advanced cancer, chronic obstructive pulmonary disease, congestive heart failure, or HIV/AIDS.<sup>34</sup> The ESRD Seamless Care Organization (ESCO) Model is a comprehensive value-based approach to care that is currently being implemented by selected dialysis providers across the United States.<sup>35</sup> Although Medicare rules about concurrent provision of dialysis and hospice services apply to ESCO patients, several ESCOs are deploying strategies to make

care more patient-centered and facilitate timely access to palliative care and hospice services.<sup>35</sup> These kinds of efforts to support earlier integration of palliative care services for patients on dialysis may help better align care with patients' goals and values and streamline transitions to hospice toward the end of life.

## Conclusion

Patterns of use and timing of hospice among Medicare beneficiaries on hemodialysis were strikingly uniform among patients with diverse end-of-life spending trajectories and levels of health care intensity. Regardless of premorbid spending trajectory and intensity of care, use of hospice services among patients on hemodialysis occurred far less frequently and closer to the time of death than was the case for the overall Medicare population. These findings likely reflect the impact of policy and perhaps other barriers to the receipt of hospice care for patients on hemodialysis and signal the need for more flexible approaches to the provision of end-of-life care for members of this population. ■

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review or approval of the manuscript; or decision to submit for publication. The interpretation of these data is the sole responsibility of the authors and does not reflect the opinion of the Department of Veterans Affairs or the United States Renal Data System.

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## Queries

1. Paragraph beginning “Median,” sentence beginning “The proportion,” we pointed out that the information in the sentence does not appear in any exhibit, and we asked you to identify the source for the editors. You did not respond, so please do so now.
2. Paragraph beginning “Patient Characteristics,” we pointed out your inconsistent use of phrasing for racial groups. Earlier in the article you used “black,” but you did not change anything here. Please use consistent phrasing for racial groups throughout, including here.
3. First paragraph below “Sensitivity analyses” subhead, we added “(data not shown)” in response to the answer to our query. Please verify.
4. In acknowledgment, we questioned the phrasing “was submitted at.” You did not address our concern there but responded to another part of the acknowledgment. Please explain what you mean by “submitted at an annual meeting” – presented or something else?