

Chapter 12: End-of-life Care for Patients with End-Stage Renal Disease, 2000-2014

- This year we introduce information regarding patients' inpatient surgical procedures during their last 90 days of life, and an examination of the prevalence and content of advance directives among nursing home residents during the last year of life.
- Between 2000 and 2014:
 - o The percentage of Medicare beneficiaries with end-stage renal disease (ESRD) admitted to an intensive or coronary care unit during the last 90 days of life increased from 50% to 62% (Figure 12.3).
 - The percentage of Medicare beneficiaries with ESRD who received an intensive procedure during the last
 90 days of life increased from 28% to 34% (Figure 12.4).
 - o The percentage of Medicare beneficiaries with ESRD who received an inpatient surgical procedure within the last 90 days of life decreased from 33% to 27% (Figure 12.5).
 - The percentage of Medicare beneficiaries with ESRD who died in the hospital decreased from 49% to 40% (Figure 12.6).
 - The percentage of Medicare beneficiaries with ESRD who received care in a skilled nursing facility (SNF) during the last 90 days of life increased from 24% to 32% (Figure 12.7).
 - The percentage of patients with ESRD who discontinued maintenance dialysis treatments before death increased from 20% in 2000 to 26% in 2011, then decreased to 24% in 2014 (Figure 12.8).
 - The percentage of Medicare beneficiaries with ESRD receiving hospice care at the time of death increased from 11% to 27% (Figure 12.9), with the most marked increases occurring among those who discontinued dialysis.
- The percentage of deceased ESRD nursing home residents who had an advance directive in the year before their death declined from 47% in 2000 to 41% in 2010 (Figure 12.10).
- Median 2014 per person costs under Medicare Parts A and B were \$119,525 over the last year of life, \$20,165 over the last 30 days of life, and \$7,396 over the last seven days of life.

Introduction

In this chapter, we update information on treatment practices, inpatient, skilled nursing facility (SNF), and hospice utilization, and costs at the end of life among decedents with end-stage renal disease (ESRD). We provide new information on inpatient surgical procedures during the last 90 days of life and use of advance directives among nursing home residents. We present trends in all measures for the 15-year period from 2000 through 2014, with the exception of 2000-2010 trends in the prevalence and content of advance directives among patients with

ESRD who resided in a nursing facility during the last year of life.

This chapter is divided into the following sections: (1) characteristics of decedents with ESRD, (2) patterns of inpatient utilization during the last 90 days of life among Medicare beneficiaries with ESRD, (3) skilled nursing facility utilization during the last 90 days of life, (4) patterns of dialysis discontinuation before death, (5) patterns of hospice utilization before death, (6) use of advance directives among nursing home residents, and (7) end-of-life costs for services under Medicare Parts A and B.

Methods

Data supporting analyses for this chapter were derived from the 2016 version of the public-use Standard Analysis Files (SAFs) supplied by the United States Renal Data System (USRDS) Coordinating Center at the University of Michigan. Specific SAFs included the Patients file, the MEDEVID file, the RXHIST file, the PAYHIST file, the Death file, the Residence file, and linked Medicare Institutional and Physician/Supplier claims. We used the Minimum Patient Dataset (available to us only for the years 2000 to 2010) to obtain advance directive information for patients with ESRD who resided in a nursing home during their last year of life.

Because complete information on Medicare utilization and costs are only available for patients with fee-for-service Medicare Parts A and B, analyses that rely on these measures were restricted to patients for whom Medicare Parts A and B were the primary payers throughout the relevant period, and whose care was not covered by a health maintenance organization (HMO). We used the PAYHIST file to track primary payer for each patient over time, and to identify denominator populations of fee-for-service beneficiaries with Medicare Parts A and B as primary payer throughout times relevant to each analysis (e.g., last 90 days of life). Because Medicare Parts A and B were listed as the primary payer for a minority of patients aged 19 years or younger at the time of death, we do not report stratified results for this age group. These younger patients are included in the denominator for all calculations except for those describing use of advance directives among nursing home residents.

We used the Patients file to obtain information on age at death, sex, race, and ethnicity. Each patient's most recent ESRD treatment modality before death was ascertained from the RXHIST file. Medicare Institutional claims were used to identify dates of short- and long-stay hospital admissions, dates of SNF admission (HCFASAF=S), dates of hospice utilization (HCFASAF=H), and receipt of hospice care at the time of death (HCFASAF=H on or after the date of death or Discharge Status from hospice=40, 41, or 42). Episodes of ICU utilization were captured using intensive and

coronary care unit revenue center codes contained in Medicare Institutional claims (020x and 021x).

We used an ICD-9 procedure code search of Medicare Institutional claims to capture intensive procedures occurring during hospital admissions. These procedures included intubation and mechanical ventilation (ICD-9 codes 96.04, 96.05, 96.7x), tracheostomy (ICD-9 codes 31.1, 31.21, 31.29), gastrostomy tube insertion (ICD-9 codes 43.2, 43.11, 43.19, 43.2, 44.32), enteral or parenteral nutrition (ICD-9 codes 96.6 and 99.15), and cardiopulmonary resuscitation (CPR, ICD-9 codes 99.60, 99.63; Barnato et al., 2009). Inpatient surgical procedures were ascertained using a previously published approach (Kwok et al., 2011).

The Centers for Medicare & Medicaid Services (CMS) Death Notification form (CMS 2746) reports provider responses to questions about whether renal replacement therapy (RRT) was discontinued before death, the date of the last dialysis treatment before death for patients who discontinued treatment, and whether the patient was receiving hospice care prior to death. Analyses based on the CMS 2746 were conducted among those with complete information for the relevant data element.

Analyses of hospice use and date of last dialysis treatment from the Death Notification form were available for most decedents from 2004 onward. Information on treatment discontinuation before death was available throughout the period of study. Analyses of discontinuation were restricted to patients for whom dialysis was listed as the most recent modality. While most measures of hospice utilization at the end of life reported in this chapter were obtained from Medicare claims, these were supplemented with information from the CMS 2746 on place of death, hospice utilization, and date of last dialysis treatment. There was not perfect agreement between these two data sources due to differences in methods for hospice ascertainment, denominator populations, and periods studied.

We used the Minimum Dataset (MDS) for the years 2000 to 2010 to obtain advance directive information for patients with ESRD who resided in a nursing home during their last year of life. To characterize advance directive use, we identified patients with ESRD who

died between 2000 and 2010, and had an advance directive assessment recorded in the MDS during the last year of life. We restricted the cohort to patients 20 years of age or older at the time of death, who had been treated with dialysis or kidney transplantation for at least 90 days inclusive of the date of death, and had complete demographic information (N=334,607). We used the last available non-missing advance directive assessment to characterize the prevalence and content of advance directives. Respondents recorded whether there was documentation in the patient's medical record of a living will, a surrogate decision maker (durable power of attorney for health care), and one or more of the following treatment limitations: do not resuscitate (DNR), do not hospitalize (DNH), feeding restrictions, medication restrictions, and other treatment restrictions. We considered documentation of a living will, a surrogate decision maker, or a treatment limitation as an indication of an advance directive. We further categorized patients according to the presence or absence of a directive specifying the treatment limitations, and the presence or absence of a surrogate decision maker.

Costs for Medicare Part A and B services were calculated using the payments to Medicare recorded in both Institutional (CLM_AMT) and Physician Supplier (PMTAMT) claims. Patients for whom Medicare Parts A and B were listed as the primary payer in the PAYHIST file but who had zero or negative costs during the time frame of interest (e.g. last year, 90, or 30 days of life) were excluded from cost analyses. Medicare Part A payments for hospital stays were calculated by adding the CLM_AMT to the pass-through payments for each stay (PER_DIEM*CVR_DCNT). Costs for hospital and skilled nursing facility admissions spanning the period of interest were pro-rated. Cost calculations did not include Medicare Part D costs, Medicaid costs, Medicare copayments, or other health care costs for Medicare beneficiaries.

Characteristics of Decedents with ESRD

We identified 1,297,656 patients listed in the USRDS Patients file who died between calendar years 2000 and 2014. The mean age (± standard deviation) of decedents was 68.6 (±13.6) years (Table 12.1). Patients aged 45-64 years comprised the largest group of decedents (28.5%) and more than 80% of decedents were between the ages of 45 and 84 at the time of death. Overall, 67.3% of decedents were White, 27.3% were Black/African American, 3.3% were Asian, 1.1% were Native American/Alaska Native, 1% were of other race, and 10.8% were of Hispanic ethnicity. Overall 54.7% of patients were male.

The most recent modality prior to death was hemodialysis (HD) in 88.3% of patients, peritoneal dialysis (PD) in 5.5%, and transplant in 5.3% (o.8% of patients were missing information on modality). During 2000-2014, the mean age of decedents rose from 67.5 (±13.7) years to 69.2 (±13.1) years, and the percentage of patients aged 85 years and older at the time of death increased from 8.4% to 12.6%. There was little change in racial, ethnic, and gender composition over time. The percentage of decedents with PD as their most recent modality decreased over time until 2007, increasing slightly thereafter. The percentage of decedents who had received a kidney transplant increased over time. The percentage of patients with Medicare Parts A and B as primary payer during the last 90 days of life ranged between a low of 63.8% in 2014 and a high of 75.0% in 2003.

vol 2 Table 12.1 Characteristics of decedents with ESRD by death year, 2000-2014

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Total
n	72,803	76,882	79,501	82,432	84,109	85,835	87,539	87,569	88,379	89,894	90,620	91,831	91,847	92,794	95,621	1,297,656
%	5.6	5.9	6.1	6.4	6.5	6.6	6.7	6.7	6.8	6.9	7.0	7.1	7.1	7.2	7.4	
Age (mean)	67.48	67.57	67.83	67.93	68.12	68.31	68.45	68.61	68.75	68.73	69.02	69.13	69.20	69.24	69.22	68.55
• ,	(13.73)	(13.82)	(13.82)	(13.79)	(13.74)	(13.81)	(13.78)	(13.76)	(13.65)	(13.65)	(13.54)	(13.44)	(13.37)	(13.21)	(13.11)	(13.62)
Age Category																
0-19	0.17	0.15	0.15	0.18	0.15	0.16	0.14	0.1	0.12	0.11	0.13	0.08	0.09	0.08	0.08	0.12
20-44	6.43	6.29	6.14	5.73	5.56	5.41	5.15	5.08	4.78	4.77	4.35	4.26	4.16	3.97	3.96	5.01
45-64	27.94	28.29	28.07	28.68	28.75	28.62	29.08	28.70	28.72	29.04	28.92	28.78	28.32	28.05	27.92	28.53
65-74	28.60	27.92	27.49	26.96	26.65	26.15	25.73	25.86	26.33	26.46	26.59	26.87	27.67	28.45	28.96	27.10
75-84	28.50	28.65	28.76	28.77	28.90	28.99	28.62	28.51	27.93	27.38	27.27	27.01	26.67	26.58	26.53	27.89
≥85	8.36	8.70	9.39	9.69	9.99	10.67	11.28	11.75	12.12	12.24	12.74	13.00	13.08	12.87	12.56	11.34
Race																
Native American	1.23	1.11	1.14	1.12	1.11	1.16	1.08	1.08	1.14	1.14	1.06	1.04	1.02	0.92	0.95	1.08
Asian	2.79	2.81	2.87	3.01	3.03	3.20	3.24	3.39	3.27	3.45	3.50	3.66	3.67	3.66	3.89	3.32
Black/African American	28.15	28.30	27.95	28.14	28.37	28.04	27.67	27.45	27.33	27.13	26.72	26.38	26.15	26.03	25.91	27.26
White	65.95	65.91	66.16	65.78	65.53	66.26	67.07	67.26	67.41	67.52	68.05	68.25	68.67	69.07	68.92	67.26
Unknown	0.20	0.14	0.14	0.13	0.12	0.11	0.08	0.06	0.10	0.09	0.08	0.09	0.12	0.09	0.11	0.11
Other	1.68	1.74	1.75	1.82	1.84	1.24	0.86	0.76	0.75	0.67	0.59	0.57	0.36	0.23	0.23	0.97
Hispanic																
No	72.84	76.38	79.05	80.55	81.89	82.88	83.82	84.60	84.79	84.78	84.97	84.84	84.45	84.60	84.27	82.55
Yes	8.57	9.18	9.53	9.99	10.20	10.49	10.57	10.62	10.92	11.30	11.40	11.87	11.90	11.72	11.98	10.75
Unknown	15.43	11.80	9.18	7.24	5.79	4.74	3.79	3.22	2.62	2.33	2.04	1.71	1.57	1.45	1.33	4.67
Missing	3.16	2.64	2.25	2.23	2.11	1.89	1.82	1.57	1.67	1.59	1.58	1.57	2.08	2.23	2.42	2.03
Sex																
Female	47.83	47.55	47.47	46.87	46.28	45.94	45.77	45.30	44.86	44.27	44.18	43.83	43.61	43.72	43.35	45.28
Male	52.17	52.45	52.53	53.13	53.67	54.02	54.20	54.67	55.12	55.71	55.81	56.16	56.39	56.27	56.65	54.70
Missing	0.00	0.00	n/a	0.01	0.05	0.04	0.03	0.03	0.02	0.02	0.02	0.01	0.00	0.01	0.00	0.02
Last Treatment Modality																
Hemodialysis	86.77	87.4	88.2	88.46	88.65	88.76	88.92	89.2	89.08	89.02	88.92	88.33	87.79	88.00	87.24	88.33
Peritoneal Dialysis	7.61	7.04	6.44	6.02	5.82	5.32	5.07	4.74	4.72	4.46	4.5	4.83	5.24	5.64	6.08	5.52
Transplant	4.66	4.67	4.55	4.73	4.69	4.99	5.06	5.18	5.19	5.55	5.63	5.86	6.15	6.14	6.43	5.34
Missing	0.95	0.89	0.82	0.79	0.84	0.93	0.95	0.88	1.01	0.97	0.96	0.97	0.82	0.21	0.25	0.81
Medicare Parts A & B as ESRD Payer for Last 3-months of Life (Yes)	73.40	73.37	74.37	74.98	74.93	74.31	73.15	71.52	69.56	68.81	68.02	66.92	66.69	65.80	63.79	70.43

Data Source: Special analyses, USRDS ESRD Database. Denominator is all decedents. Abbreviation: ESRD, end-stage renal disease.

Inpatient Utilization during the Last 90 Days of Life among Medicare Beneficiaries with ESRD

In this section, we describe the following measures of inpatient utilization during the last 90 days of life, among fee-for-service Medicare beneficiaries with ESRD from 2000-2014: (1) hospital admission, (2) days spent in the hospital, (3) ICU admission, (4) receipt of intensive procedures, (5) receipt of inpatient surgical procedures, and (6) inpatient deaths.

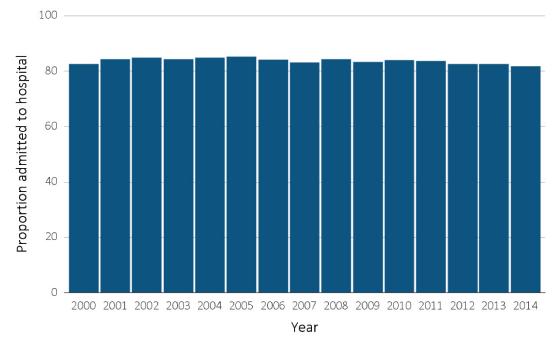
HOSPITAL ADMISSION

Overall, 83.4% of patients were hospitalized during the last 90 days of life (Figure 12.1). The percentage of patients admitted to the hospital was highest for those aged 75-84 years (84.6%) and lowest for those aged

45-64 years (81.2%). Hospital admission was most common in Blacks (84.1%) and least common in Asians (80.7%), and was more common in Hispanics than non-Hispanics (84.4% vs. 83.5%). Females had more admissions than did males (85.6% vs. 81.2%), as did those whose most recent modality was HD rather than PD or transplant (83.6% vs. 81.8% vs. 78.3%). The proportion of patients admitted to the hospital during the last 90 days of life either remained the same or decreased slightly in all subgroups examined.

Overall, 27.1% of decedents were admitted to and/or discharged from the hospital within three days of death. These patients did not vary greatly by age, race, ethnicity, gender, or most recent modality. Over time, the frequency of these potentially burdensome transitions increased slightly, from 26.3% in 2000 to 28.2% in 2014.

vol 2 Figure 12.1 Hospital admission during the last 90 days of life among Medicare beneficiaries with ESRD, 2000-2014



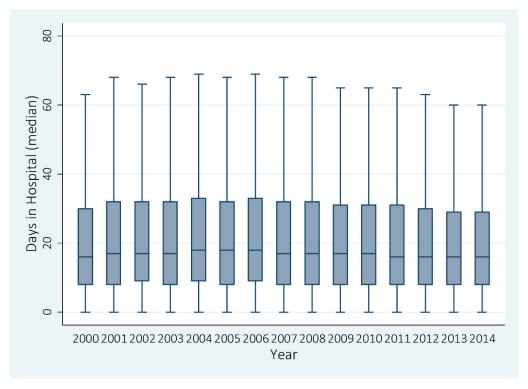
Data Source: Special analyses, USRDS ESRD Database. Denominator is all decedents with Medicare Parts A and B throughout the last 90 days of life. Includes hospital stays in both short- and long-stay hospitals. Abbreviation: ESRD, end-stage renal disease.

DAYS SPENT IN THE HOSPITAL

Patients with Medicare Parts A and B who were admitted to the hospital at least once during the last 90 days of life had a median of two admissions during this period (interquartile range [IQR], 1, 3) and 27.6% had three or more admissions. The percentage of

patients admitted to the hospital and the median number of admissions were stable over time, and similar in all subgroups. Those admitted to the hospital during the last 90 days of life had a median stay of 17 days (IQR, 8, 31; Figure 12.2). The median number of days spent in the hospital during the last 90 days of life changed very little over time.

vol 2 Figure 12.2 Days spent in the hospital during the last 90 days of life among Medicare beneficiaries with ESRD, 2000-2014



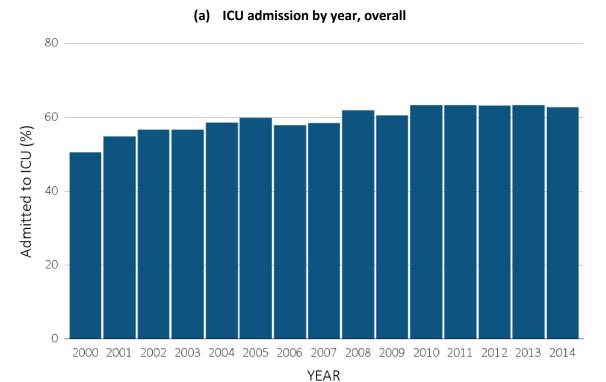
Data Source: Special Analyses, USRDS ESRD Database. Denominator is all decedents with Medicare Parts A and B throughout the last 90 days of life who were admitted to the hospital at least once. Includes hospital stays in both short- and long-stay hospitals. Explanation of box plot: The lower border of the box is the first quartile and the upper border is the third quartile of the distribution, the length of the box is the interquartile range and the line in the middle of the box is the median value. The whiskers (vertical lines above and below each box) extend from the lowest value of the distribution that is \geq the first quartile minus 1.5 times the interquartile range at the bottom to the highest value of the distribution that is \leq the third quartile plus 1.5 times the interquartile range at the top. Values outside this range (outliers) are not plotted. Abbreviation: ESRD, end-stage renal disease.

ICU ADMISSION

Overall, 59.2% of patients were admitted to an ICU during the last 90 days of life (Figure 12.3). The percentage admitted to an ICU was highest among those aged 65-74 years (61.6%) and lowest for those aged 85 years and older (51.8%). ICU admission was highest for Asians (62.9%) and lowest for patients of Other race (47.2%), was higher for Hispanics than non-Hispanics (63.8% vs. 59.1%), was higher for females than males (60.7% vs. 57.9%), and was similar

in patients whose most recent modality was HD rather than PD or transplant (59.4% vs. 57.8% vs. 57.5%). Over time, the percentage of patients admitted to the ICU during the last 90 days of life increased from 50.1% in 2000 to 62.4% in 2014. Over time and among all subgroups examined, there was an increase in the percentage of patients admitted to the ICU. The proportion of those admitted to an ICU in the last 90 days of life ranged from 33.3% to 70.9% across states in the continental United States (U.S.; Figure 12.3.g).

vol 2 Figure 12.3 ICU admission during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014



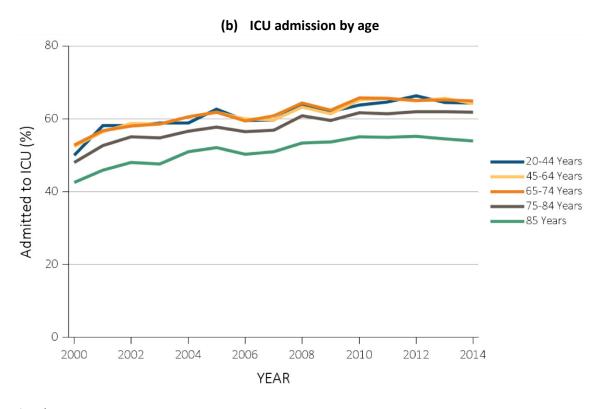


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vol 2 Figure 12.3 ICU admission during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)

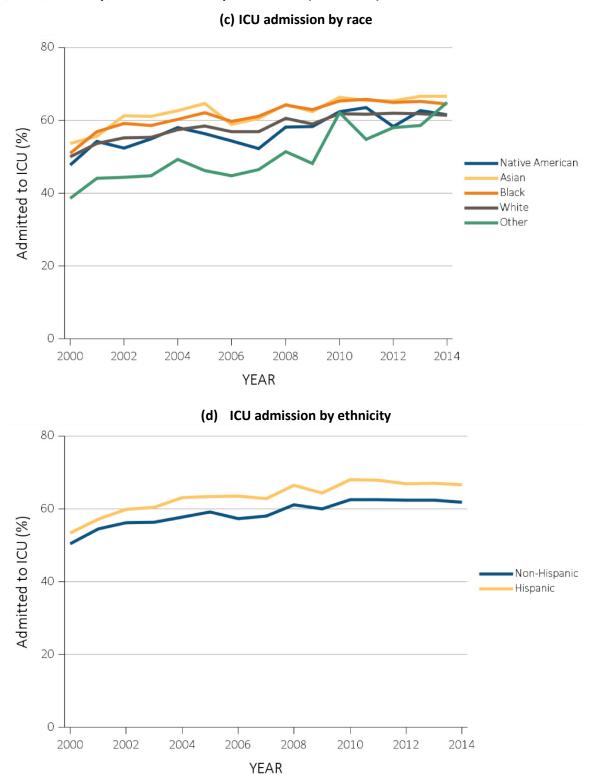
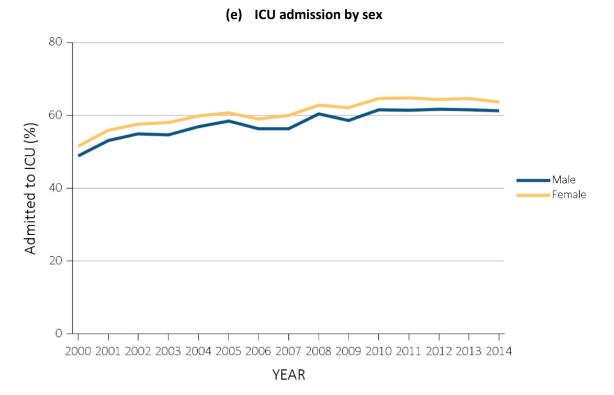


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vol 2 Figure 12.3 ICU admission during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)



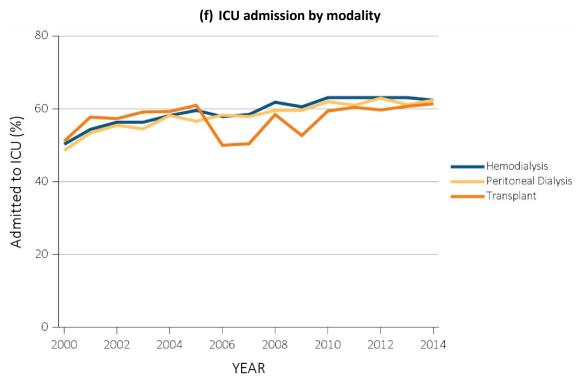
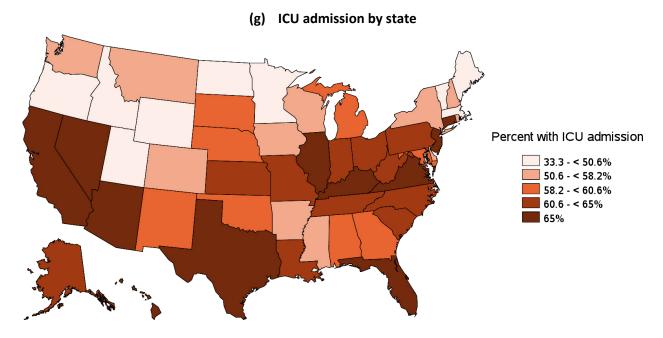


Figure 12.3 continued on next page.

vol 2 Figure 12.3 ICU admission during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)



Data Source: Special Analyses, USRDS ESRD Database. Denominator is all decedents with Medicare Parts A and B throughout the last 90 days of life. ICU admission was identified using ICU revenue center codes in Medicare Institutional claims. Abbreviations: ESRD, end-stage renal disease; ICU, Intensive care unit.

INTENSIVE PROCEDURES

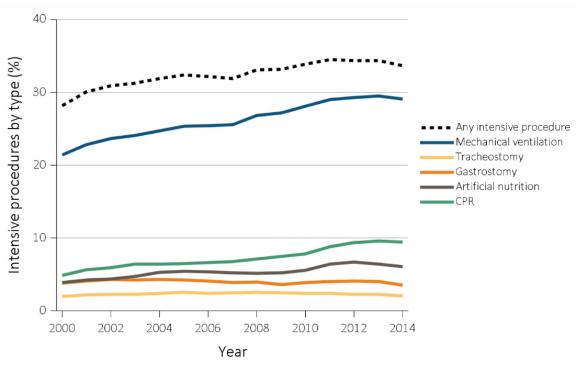
A total of 32.4% of decedents had an inpatient intensive procedure during the last 90 days of life; the most common procedure was intubation/mechanical ventilation (Figure 12.4). The percentage of patients receiving intensive procedures during the last 90 days of life was highest for those aged 20-44 years (42.7%) and lowest for those aged 85 years and older (20.6%). The rate of intensive procedures was highest for Blacks (41.2%) and lowest for Whites (28.6%), and was higher for Hispanics than non-Hispanics (38.5% vs. 31.7%). The percentage was also higher for females

than males (33.5% vs. 31.6%), and was higher for those using transplant as their most recent modality rather than HD or PD (38.1% vs. 32.3% vs. 30.6%).

The percentage of patients who received an intensive procedure increased from 28.2% in 2000 to 33.7% in 2014. Those who were intubated, or who received mechanical ventilation during the last 90 days of life increased from 21.4% to 29.1% over the same period. The percentage of patients receiving an intensive procedure increased over time for most subgroups examined, and ranged from 12.0% to 44.3% across states in the continental U.S.

vol 2 Figure 12.4 Intensive procedures during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014

(a) Intensive procedures by sub-type and year, overall



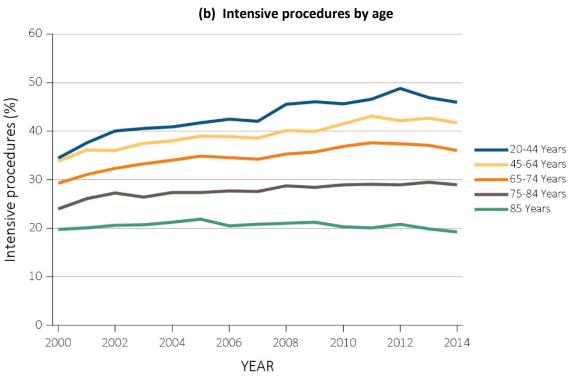
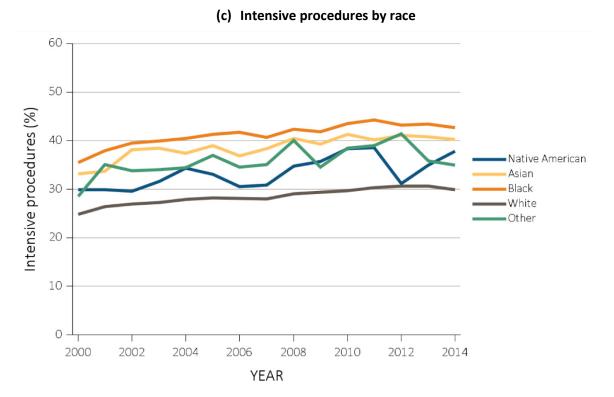


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vol 2 Figure 12.4 Intensive procedures during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)



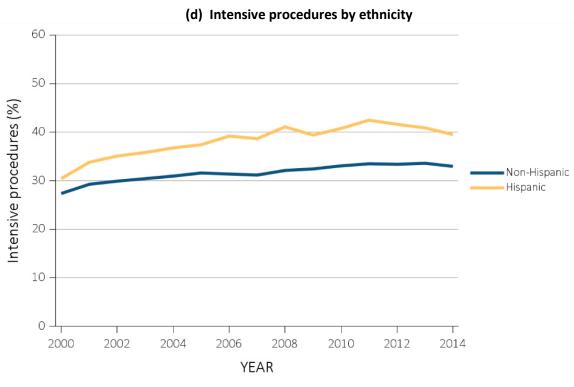
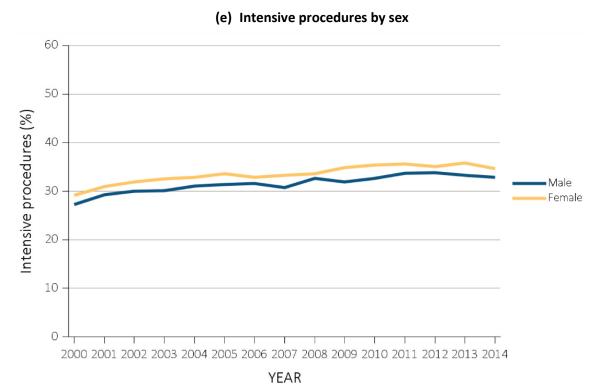


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vol 2 Figure 12.4 Intensive procedures during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)



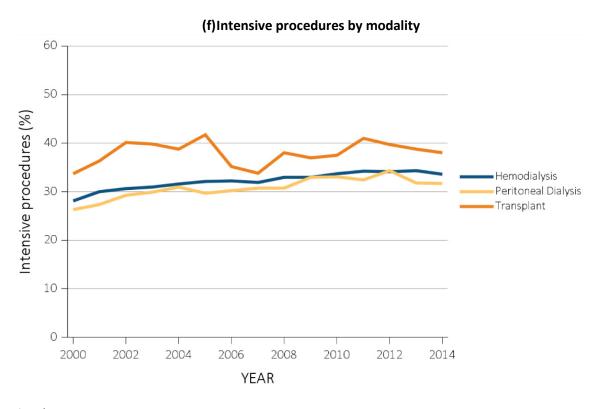
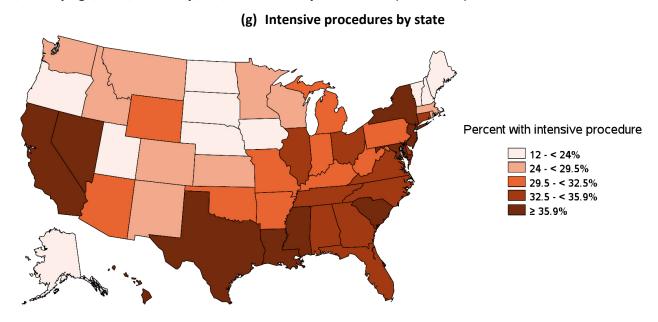


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vol 2 Figure 12.4 Intensive procedures during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)



Data Source: Special analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Intensive procedures were identified by ICD-9 procedure code search of Medicare Institutional claims from short- and long-stay hospitals. The yellow line in panel (a) denotes the percentage of patients who were intubated or received mechanical ventilation. Abbreviation: ESRD, end-stage renal disease.

INPATIENT SURGICAL PROCEDURES

Overall, 29.9% of patients received an inpatient surgical procedure during the last 90 days of life (Figure 12.5). The percentage was lowest for those aged 85 years and older (22.6%) and highest for those aged 45-64 years (32.3%). The rate of such procedures was highest for Blacks (33.1%) and lowest for Whites

(28.6%), and higher for Hispanics vs. non-Hispanics (32.7% vs. 29.4%). Females had more procedures than males (30.7% vs. 29.2%), as did those receiving PD versus transplant versus HD (33.4% vs. 31.6% vs. 29.6%). The percentage of patients receiving an inpatient surgical procedure decreased from 32.5% in 2000 to 26.7% in 2014. Similar trends were present for most subgroups examined.

vol 2 Figure 12.5 Inpatient surgical procedures among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014



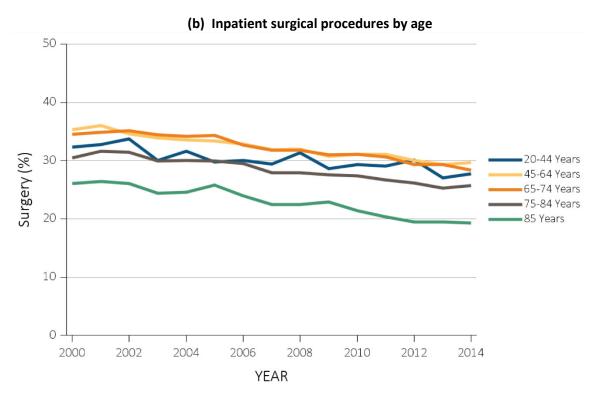
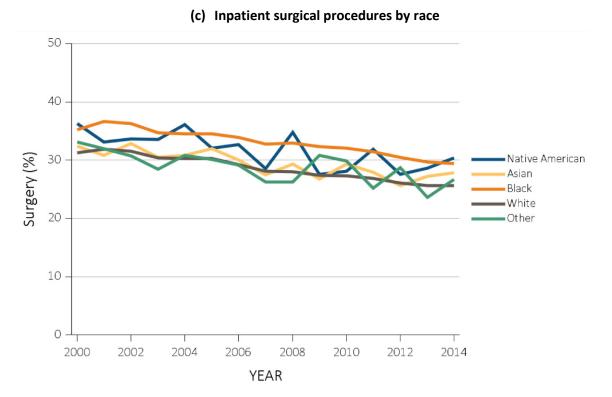


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vol 2 Figure 12.5 Inpatient surgical procedures among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)



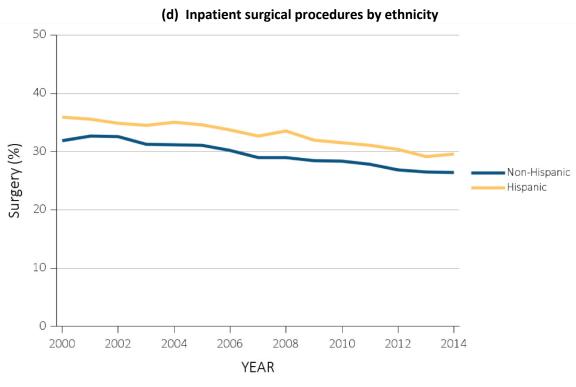
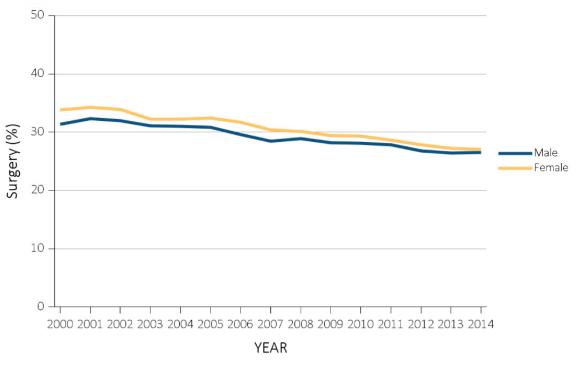
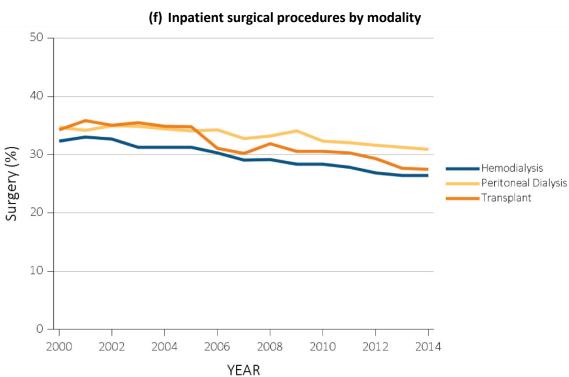


Figure 12.5 continued on next page.

vol 2 Figure 12.5 Inpatient surgical procedures among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)







Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Inpatient surgical procedures identified by ICD-9 code search. Abbreviation: ESRD, end-stage renal disease.

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INPATIENT DEATHS

Based on Medicare Institutional claims, 44.7% of ESRD deaths occurred in the hospital during 2000-2014 (Figure 12.6). The proportion of inpatient deaths was highest for those aged 20-44 years (49.3%) and lowest for those aged 85 years and older (36.6%). Death in the hospital was most common for those of Other races (53.0%) and least common in Whites (42.6%), and was more common in Hispanics than non-Hispanics (50.1% vs. 43.8%). Inpatient death was also more common in females than males (46.4% vs. 43.3%), and in patients whose most recent modality

was transplant rather than PD or HD (48.9% vs. 48.0% vs. 44.3%).

The percentage of inpatient deaths decreased from 49.2% in 2000 to 39.6% in 2014; a decline was present for most subgroups examined. When we instead used information from the CMS 2746, 62.6% of decedents for whom this information was available were reported to have died in the hospital, declining from 68.5% in 2000 to 58.4% in 2014. Among patients with complete information from both sources, the sensitivity and specificity of the CMS 2746 form for detecting inpatient deaths based on Medicare claims were 93% and 63%.

vol 2 Figure 12.6 Inpatient deaths among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014

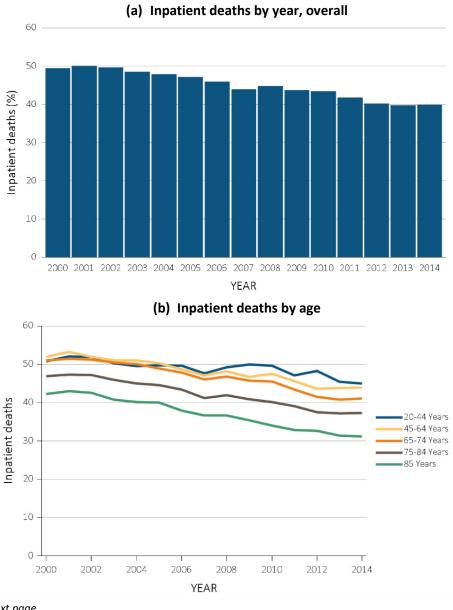
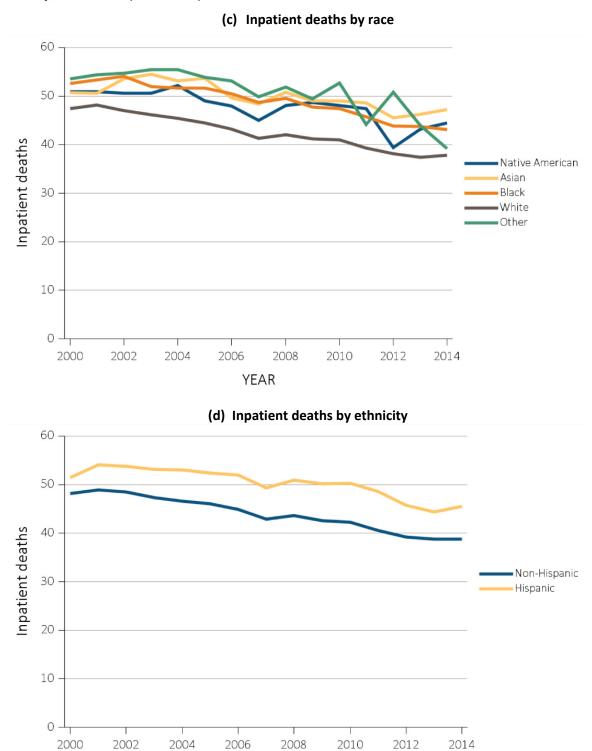


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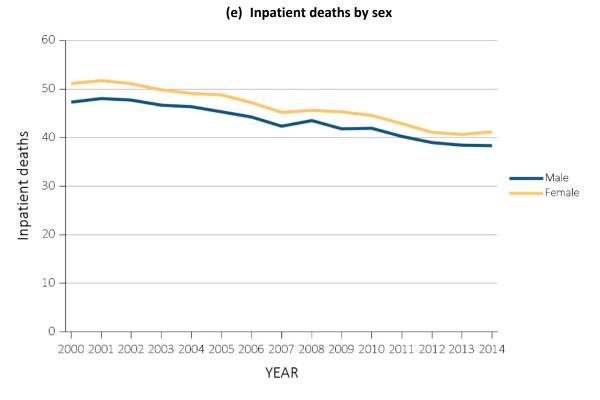
vol 2 Figure 12.6 Inpatient deaths among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)

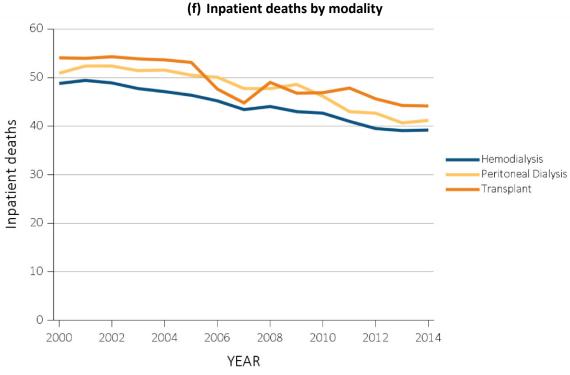


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vol 2 Figure 12.6 Inpatient deaths among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)





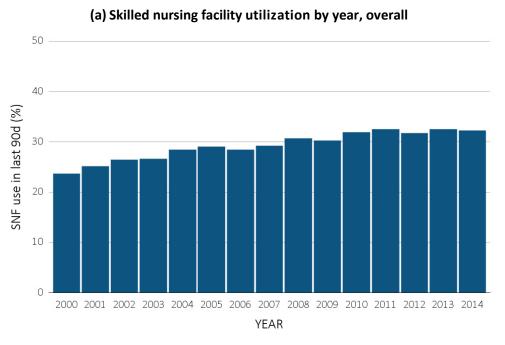
Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Includes deaths occurring in short- and long-stay hospitals. Abbreviation: ESRD, end-stage renal disease.

Skilled Nursing Facility Utilization

Overall, 29.1% of patients were admitted to a SNF during the last 90 days of life (Figure 12.7). Skilled nursing facility use was highest for those aged 85 years and older (39.9%) and lowest for those aged 20-44 years (10.4%). Use was highest for Whites (30.8%) and lowest for those of Other races (12.2%), and was lower for Hispanics than non-Hispanics (22.2% vs. 30.6%).

Skilled nursing facility use was higher among females than males (31.5% vs. 27.1%), and for those whose most recent modality at the time of death was HD rather than transplant or PD (30.6% vs. 17.7% vs. 15.1%). The percentage of patients admitted to a SNF in the last 90 days of life increased from 23.5% in 2000 to 32.1% in 2014. A similar increase in SNF use was present for most subgroups examined.

vol 2 Figure 12.7 Skilled nursing facility utilization among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014



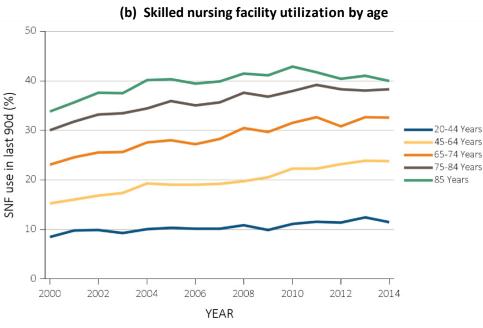
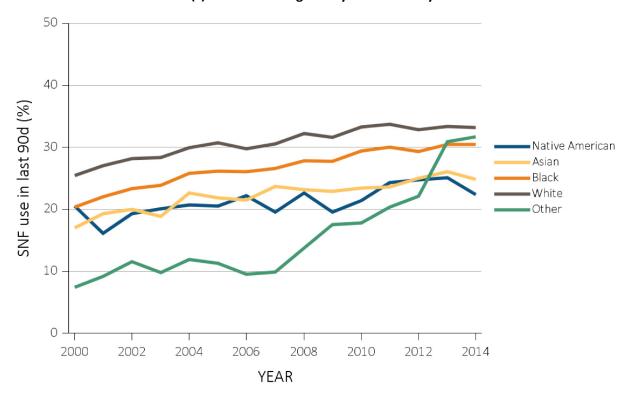


Figure 12.7 continued on next page.

vol 2 Figure 12.7 Skilled nursing facility utilization among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)

(c) Skilled nursing facility utilization by race



(d) Skilled nursing facility utilization by ethnicity

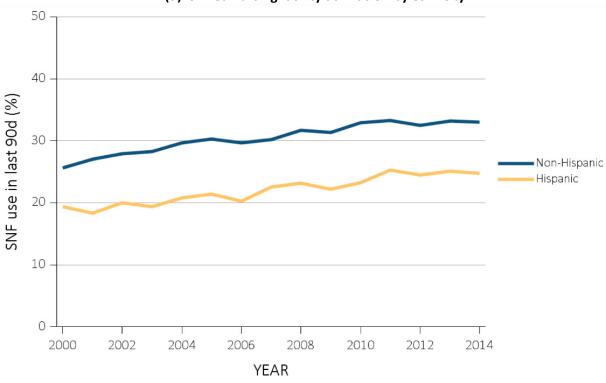
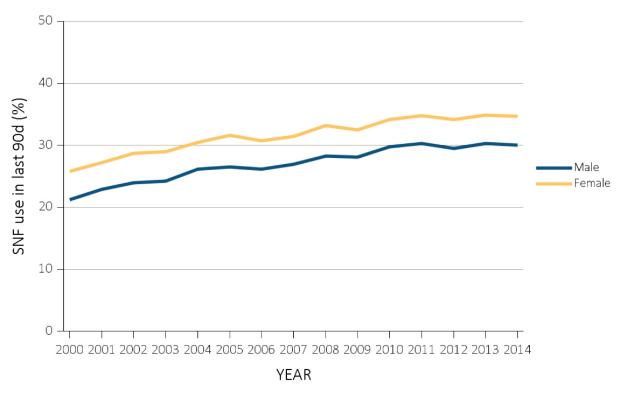


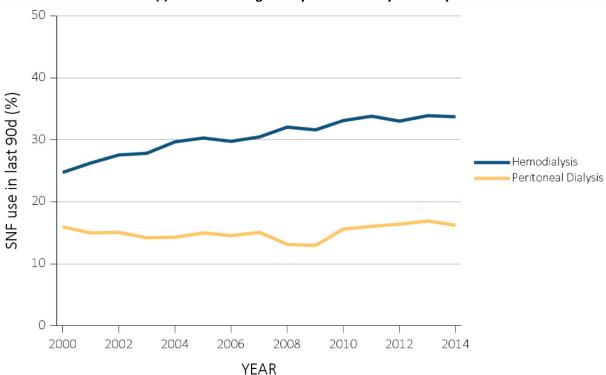
Figure 12.7 continued on next page.

vol 2 Figure 12.7 Skilled nursing facility utilization among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)

(e) Skilled nursing facility utilization by sex







Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Abbreviation: ESRD, end-stage renal disease.

Dialysis Discontinuation before Death

Overall, 23.4% of patients with either HD or PD listed on the CMS 2746 as their most recent modality were reported to have discontinued dialysis treatments before death (Figure 12.8). The frequency of dialysis discontinuation before death was highest for patients aged 85 years and older (34.2%) and lowest for those aged 20-44 years (11.2%). Discontinuation was highest for Whites (27.6%), and lowest for patients of Other races (10.6%), and was higher for non-Hispanics than Hispanics (24.6% vs. 18.0%). Dialysis discontinuation before death was also higher for females than males (24.9% vs. 21.4%), and for those whose most recent modality was HD rather than PD (23.5% vs. 22.4%).

The median time from discontinuation of dialysis to death as reported on the CMS 2746 form was six days (IQR, 3, 12 days). This interval was slightly shorter for those treated with PD (four days, IQR, 2, eight days) than for those treated with HD (seven days, IOR, 4, 12 days), and slightly longer for those who received hospice (seven days, IQR, 4, 13 days) as compared to those who did not (four days, IQR, 2, eight days). The percentage who discontinued dialysis treatment before death increased from 19.6% in 2000 to 25.8% in 2011, decreasing thereafter to 23.8% in 2014. Trends in dialysis discontinuation were similar for most subgroups examined. There was wide geographical variation in discontinuation of dialysis, ranging from 4.4% to 42.2% across states in the continental U.S. This extensive range raises questions about the uniformity of reporting.

vol 2 Figure 12.8 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2014

(a) Dialysis discontinuation by year, overall

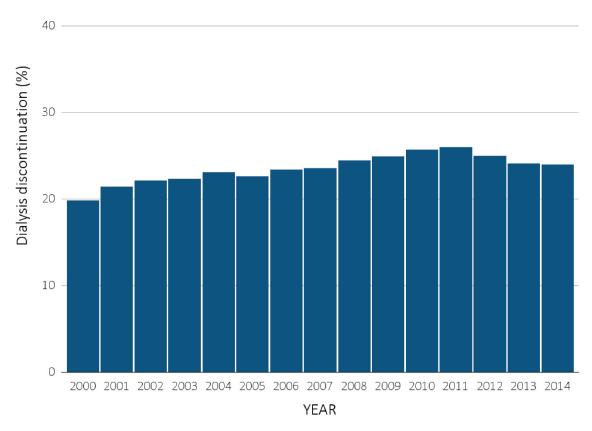
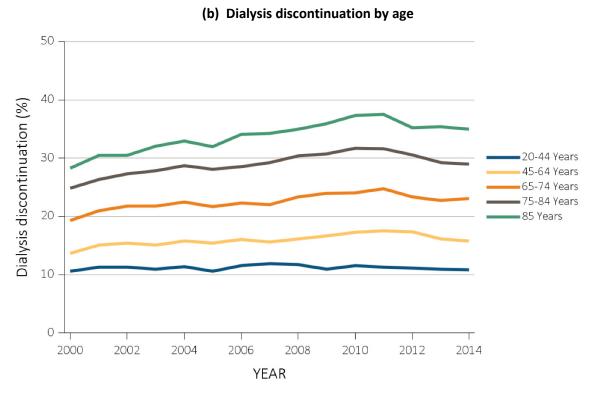


Figure 12.8 continued on next page.

vol 2 Figure 12.8 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)



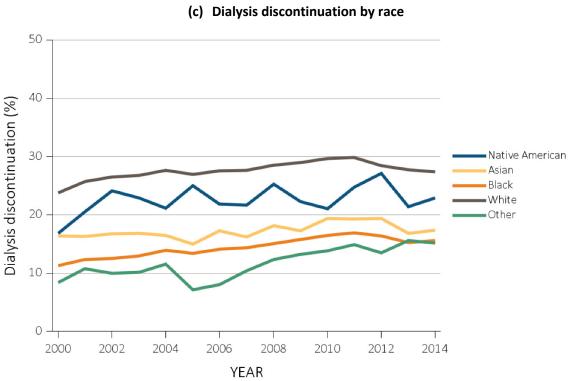
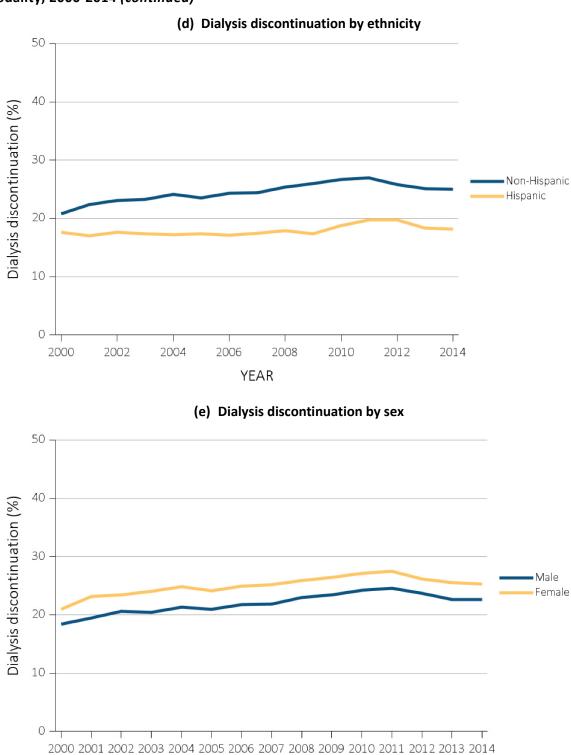


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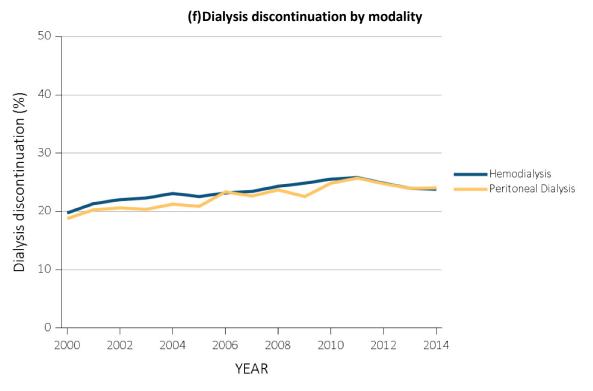
vol 2 Figure 12.8 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)

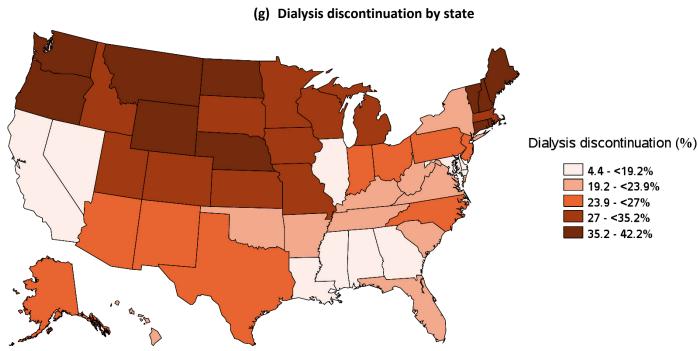


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Figure 12.8 continued on next page.

vol 2 Figure 12.8 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2014 (continued)





Data Source: Special analyses, USRDS ESRD Database. Denominator population is all patients with complete data on dialysis discontinuation from the CMS ESRD Death Notification form (CMS 2746). Abbreviation: ESRD, end-stage renal disease.

vol 2 Table 12.2 Characteristics of patients with ESRD who resided in nursing home during the last year of life, 2000-2010 2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 2010 **Total** 23237 25789 27216 30307 31205 33518 33337 28743 33323 33452 34480 334607 n 71.93 (11.32) 71.89 (11.45) 72.13 (11.50) 72.25 (11.45) 72.14 (11.59) 72.44 (11.54) 72.07 (11.90) 72.06 (11.96) 72.09 (11.87) 72.07 (11.85) 71.96 (11.86) 72.10 (11.69) Age, mean (std) Age Category 2.50 2.41 2.04 20-44 2.51 2.52 2.19 2.33 2.14 2.38 2.21 1.97 2.28 45-64 18.93 19.48 19.04 19.94 20.38 19.94 21.82 21.92 22.22 22.82 23.36 21.05 65-74 31.85 31.05 30.41 29.31 29.22 28.56 27.3 27.45 27.78 28.04 28.13 28.84 75-84 36.17 36.36 36.57 36.67 36.02 36.81 35.48 34.74 34.1 33.28 32.36 35.21 >=85 10.54 10.60 11.46 11.9 12.05 12.56 12.99 13.52 13.69 13.9 14.12 12.62 Vintage, mean (std) 1.04(1.70) 1.12(1.78) 1.22(1.91) 0.96(1.57)0.99(1.57)1.01(1.61) 1.03(1.69) 1.05(1.72) 1.08(1.75) 1.18(1.83) 1.20(1.91) 1.09(1.75) Vintage Category 70.50 69.96 69.57 70 69.64 68.78 65.92 65.62 68.31 69.68 67.44 66.11 <1yr 17.09 17.02 1-3yrs 17.78 17.65 18.17 17.02 17.41 18.12 18.76 18.21 18.26 17.79 >3yr 8.64 8.99 9.34 9.77 10.03 9.97 10.31 10.91 11.48 11.98 12.27 10.45 Missing 3.08 3.39 2.93 3.14 3.31 3.32 3.5 3.53 3.65 3.9 3.85 3.44 Race 0.93 0.89 0.87 0.91 Native American 1.11 0.88 1.04 0.89 0.87 0.85 0.94 0.86 2.07 2.23 Asian 1.99 2.16 2.2 2.27 2.38 2.53 2.37 2.48 2.48 2.31 Black/African American 25.83 26.13 26 26.16 26.76 26.37 26.58 26.74 26.51 27 26.65 26.47 White 70.49 70.13 69.3 70.01 69.57 69.27 69.68 69.81 70.15 69.96 69.83 69.85 0.59 0.3 Other 0.71 0.75 0.79 0.77 0.47 0.32 0.34 0.37 0.33 0.5 Hispanic Non-Hispanic 77.28 80.59 83.25 84.33 85.71 86.36 87.41 87.73 88.04 88.26 88.46 85.61 Hispanic 6.53 6.65 6.92 7.23 7.05 7.68 7.38 7.81 7.93 7.93 8.09 7.44 Missing/Unknown 7.24 6.95 16.19 12.76 9.83 8.45 5.96 5.21 4.45 4.03 3.81 3.45 Sex 47.97 Male 46.67 47.28 47.33 49.1 48.96 49.78 50.24 50.83 51.69 51.76 49.43 Female 53.33 52.72 52.67 52.03 50.9 51.04 50.22 49.76 49.17 48.31 48.24 50.57 Last Treatment Modality 92.09 92.50 93.5 93.72 93.7 94.02 94.26 94.08 93.77 Hemodialysis 94.15 94.27 94.36 Peritoneal Dialysis 2.98 4.83 4.11 3.57 3.14 2.53 2.48 2.21 2.09 1.74 2.07 2.78 1.99 2.39 2.77 Transplant 2.08 2.27 2.24 2.46 2.55 2.87 3.21 3.11 2.58 Missing/Unknown 1.00 1.12 0.94 0.9 0.85 0.93 0.95 0.75 0.78 0.69 0.73 0.86 Impaired Decision Making 63.72 63.93 63.69 63.52 63.18 63.81 64.74 64.92 64.64 64.06 66.31 64.28 No 36.28 36.82 Yes 36.07 36.31 36.48 36.19 35.24 34.64 34.86 35.52 33.27 35.54

Data Source: Includes only patients with a record in the Minimum Data Set that was linked to USRDS between 2000 and 2010. Denominator population is patients with ESRD who died between 2000 and 2010, who were at least 20 years of age at the time of death, received treatment for ESRD for at least 90days, had an advance directive assessment recorded in the Minimum Dataset in the last year of life, and complete demographic information. Abbreviation: ESRD, end-stage renal disease.

0.01

99.5

0.5

0.02

99.53

0.47

0.44

99.53

0.47

0.5

99.62

0.38

0.43

99.53

0.47

0.41

99.6

0.4

0.18

99.4

0.6

N/A

99.51

0.49

Missing

Yes

Legal Guardian No N/A

98.80

1.20

N/A

98.89

1.11

N/A

99.06

0.94

N/A

99.5

0.5

Patterns of Hospice Utilization before Death

Overall, 19.7% of patients with Medicare Parts A and B as primary payer were receiving hospice at the time of death, based on Medicare Institutional claims (Figure 12.9). Use of hospice services was highest for patients aged 85 years and older (30.1%) and lowest for those aged 20-44 years (7.2%). Hospice use was highest for Whites (23.2%), lowest for those of Other races (7.8%), and higher for non-Hispanics than Hispanics (20.7% vs. 15.9%). Females were more likely to receive hospice than males (20.7% vs. 18.9%), as were those whose most recent modality was HD rather than PD or transplant (19.8% vs. 19.3% vs. 19.3%).

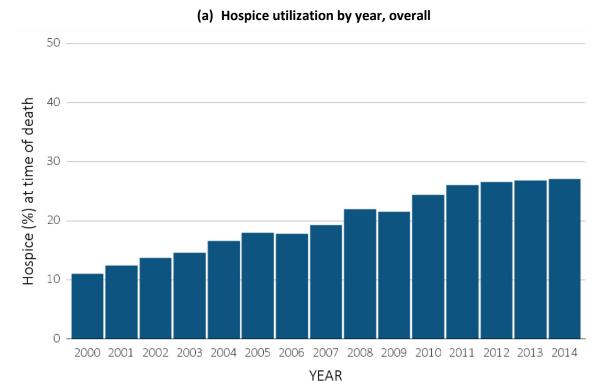
Based on Medicare claims, the percentage of patients receiving hospice services at the time of death differed markedly depending on whether the CMS 2746 form indicated that they did or did not discontinue dialysis (53.9 % vs. 9.5%). This likely reflects both the intertwined nature of these two treatment decisions, and the financial and regulatory barriers to concurrent receipt of dialysis and hospice services for many patients with ESRD (Murray et al., 2006). The percentage of patients receiving hospice services at the time of death increased from 10.8% in 2000 to 26.8% in 2014. Hospice utilization increased over time for most subgroups, but an upward trend was far more pronounced for those who discontinued dialysis as compared with those who did not. Hospice use at the time of death ranged from 13.2% to 40.8% across states in the continental U.S.

Overall, 21.6% of patients with Medicare Parts A and B as primary payer had an institutional claim for hospice in the last 90 days of life. Among these, the median interval between the first claim for hospice and death was five days (IQR, 2, 13 days), and 39.7% of patients had their first claim for hospice \leq 3 days before death.

Figure 12.9 shows trends in receipt of hospice care at the time of death, based on Medicare claims. In a separate analysis using information on hospice use from the CMS 2746 form, 24.5% of decedents for whom this information was available were reported to have received hospice care before death (data were available only from 2004-2014). The sensitivity and specificity of the CMS 2746 form for detecting hospice at the time of death based on Medicare claims were 83% and 92%, among patients with complete information from both sources. As for claims-based analyses, the percentage of patients who received hospice care before death based on the CMS 2746 form was highly correlated with dialysis discontinuation before death—75.2% of those who had discontinued dialysis before death received hospice as compared with 6.8% of those who had not.

From 2004-2014, the percentage of patients who received hospice care prior to death based on the CMS 2746 form increased from 17.5% to 28.1% in the overall population for whom this was reported, from 59.3% to 82.2% for the sub-group who discontinued dialysis treatments before death, and from 5.4% to 8.0% for the remaining patients who did not.

vol 2 Figure 12.9 Hospice utilization at the time of death among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, modality, and whether dialysis was discontinued, 2000-2014



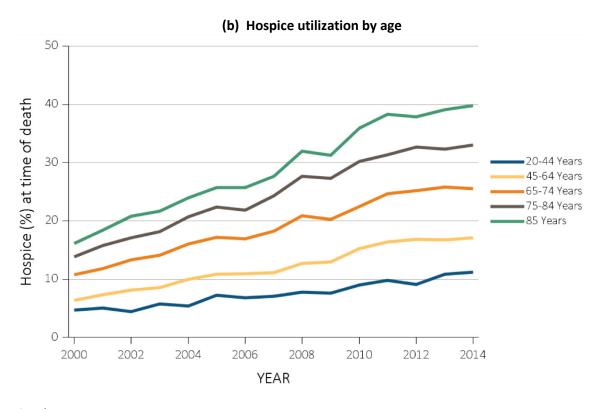
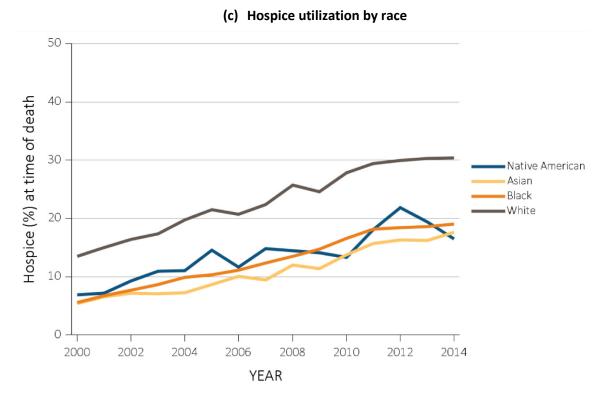


Figure 12.9 continued on next page.

vol 2 Figure 12.9 Hospice utilization at the time of death among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, modality, and whether dialysis was discontinued, 2000-2014 (continued)



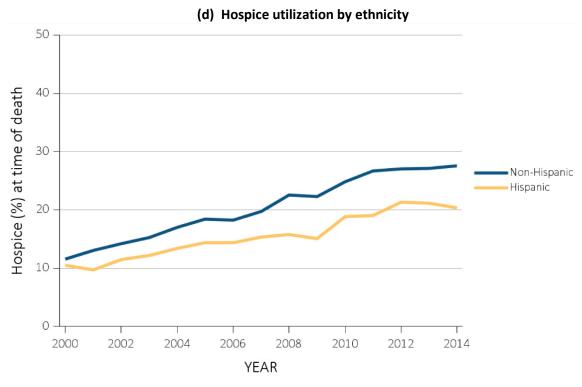
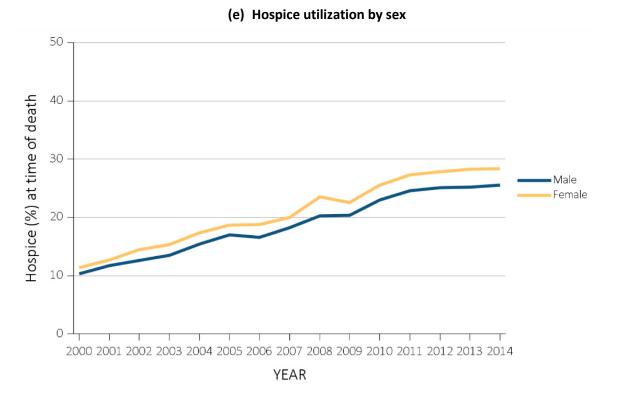


Figure 12.9 continued on next page.

vol 2 Figure 12.9 Hospice utilization at the time of death among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, modality, and whether dialysis was discontinued, 2000-2014 (continued)



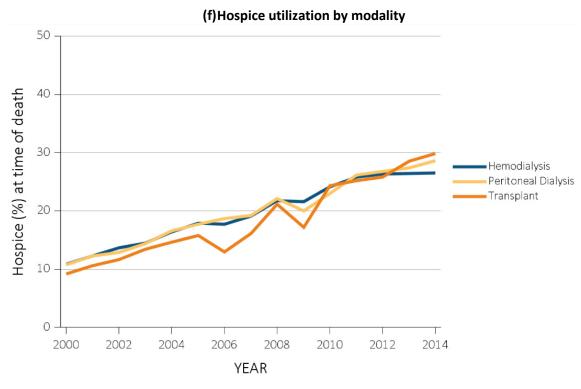
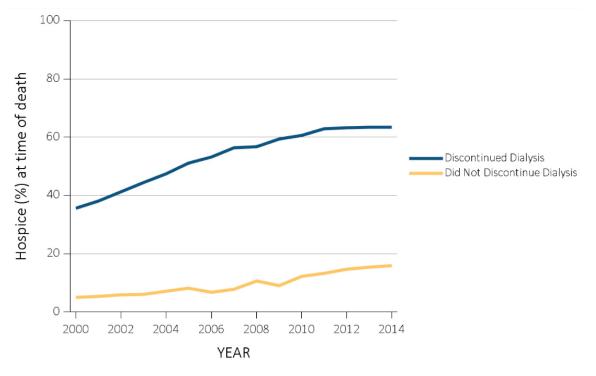


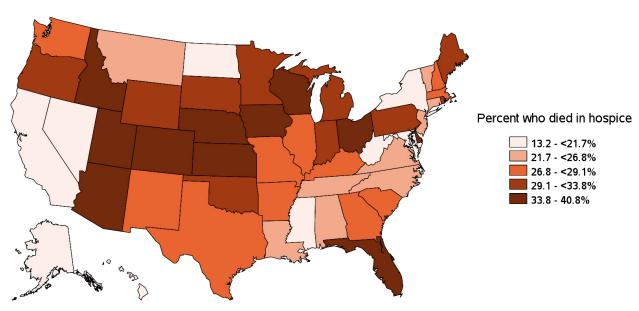
Figure 12.9 continued on next page.

vol 2 Figure 12.9 Hospice utilization at the time of death among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, modality, and whether dialysis was discontinued, 2000-2014 (continued)

(g) Hospice utilization by whether patients discontinued dialysis before death



(h) Hospice Utilization by State



Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Receipt of hospice care at the time of death was defined as having a claim in the Hospice SAF on or after the date of death or Discharge Status from hospice=40, 41, or 42. Abbreviation: ESRD, end-stage renal disease.

Advance Directives among ESRD Patients Residing in a Nursing Home in the Last Year of Life

We identified 334,607 nursing home ESRD decedents who between 2000 and 2010 had an advance directive assessment recorded in the MDS in the last year of life (Table 12.2). The average age of decedents who received care in a nursing facility during the last year of life was 72 ±12 years, with a mean time since onset of ESRD of

1 ± 2 years. The most recent modality was HD in 94% of patients, with and PD and transplant each in only 3% of patients.

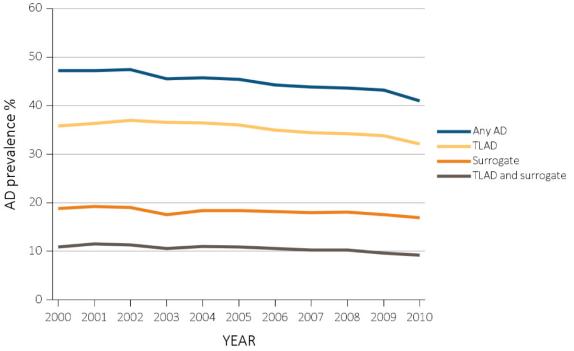
Overall, 36% of patients had impaired decisionmaking capacity as assessed by nursing home staff, and <1% had a legal guardian. From 2000 to 2010,

mean time since dialysis initiation among decedents increased, as did the percentage of males, non-Whites, patients of Hispanic ethnicity, patients receiving HD (vs. other renal replacement modalities), and patients with impaired decision-making capacity. These rates are much lower than for nursing home decedents with other serious illnesses (Kurella et al., 2017).

The percentage of patients with any type of advance directive declined from 47% in 2000 to 41% in 2010 (Figure 12.10). Similarly, the percentage of patients with a treatment limiting advance directive decreased from 36% in 2000 to 32% in 2010, and the percentage with a surrogate decision maker declined from 19% in 2000 to 17% in 2010. The percentage of patients with both a treatment-limiting directive and a surrogate decision maker declined from 11% in 2000 to 9% in 2010.

vol 2 Figure 12.10 Advance directive prevalence before death among Nursing Home ESRD decedents with ESRD overall, and by age, race, ethnicity, sex, modality, vintage, and impaired decision making, 2000-2010

(a) Advance directive prevalence by year, overall



(b) Advance directive prevalence by age

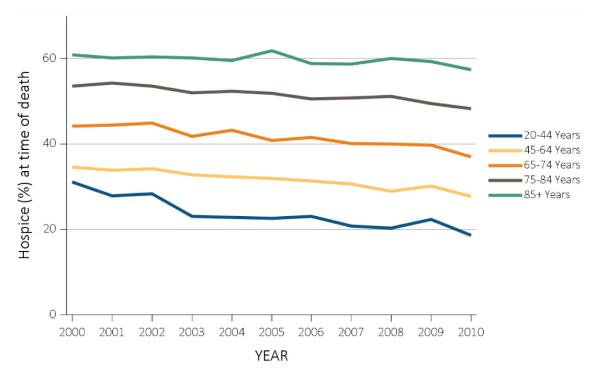
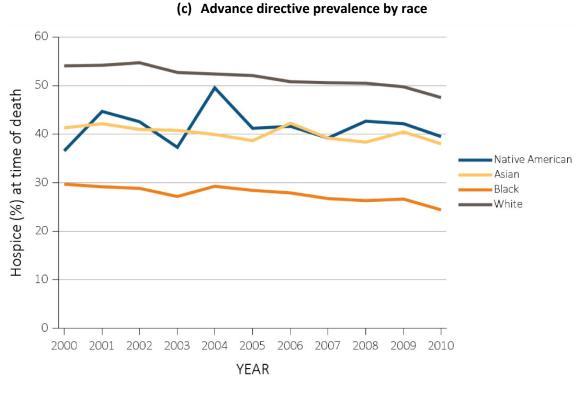


Figure 12.10 continued on next page.

vol 2 Figure 12.10 Advance directive prevalence before death among Nursing Home ESRD decedents overall, and by age, race, ethnicity, sex, modality, vintage, and impaired decision making, 2000-2010 (continued)



(d) Advance directive prevalence by ethnicity

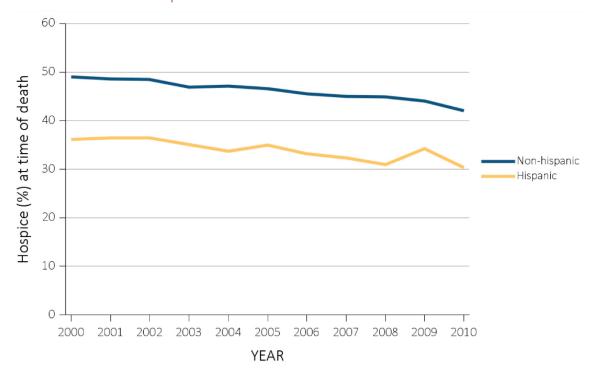
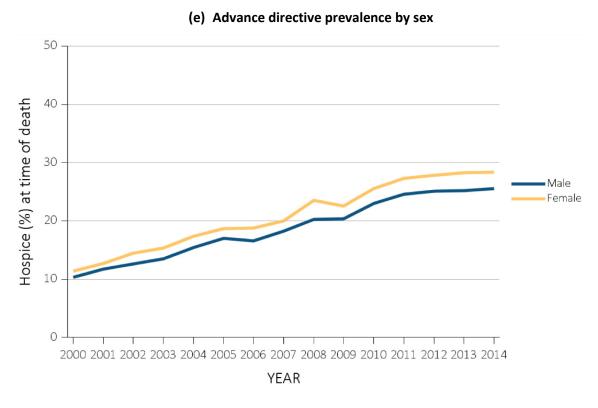


Figure 12.10 continued on next page.

vol 2 Figure 12.10 Advance directive prevalence before death among Nursing Home ESRD decedents overall, and by age, race, ethnicity, sex, modality, vintage, and impaired decision making, 2000-2010 (continued)



(f) Advance directive prevalence by modality

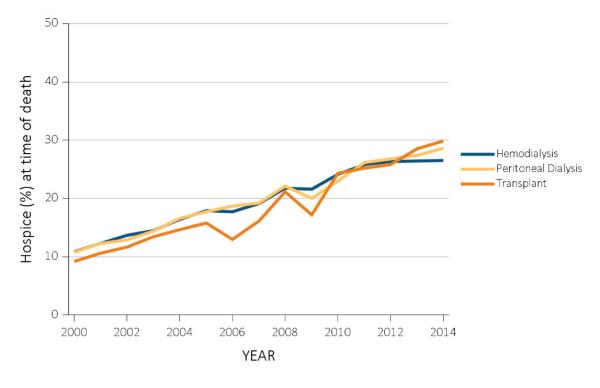
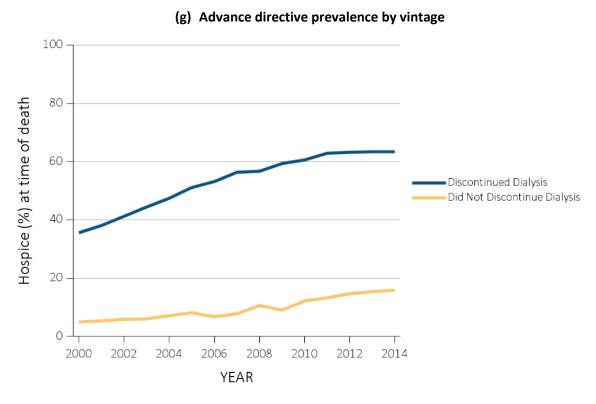


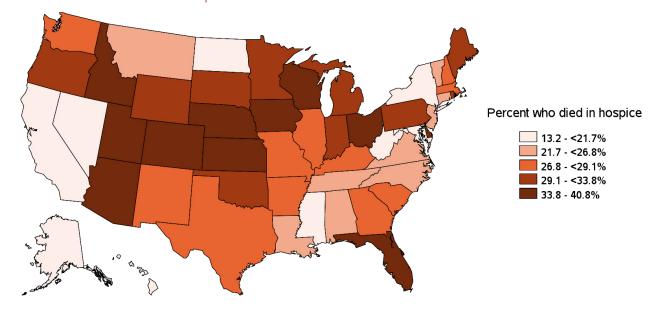
Figure 12.10 continued on next page.

vol 2 Figure 12.10 Advance directive prevalence before death among Nursing Home ESRD decedents overall, and by age, race, ethnicity, sex, modality, vintage, and impaired decision making, 2000-2010 (continued)



(h) Advance directive prevalence by impaired decision making

2017 USRDS ANNUAL DATA REPORT | VOLUME 2 - ESRD IN THE UNITED STATES

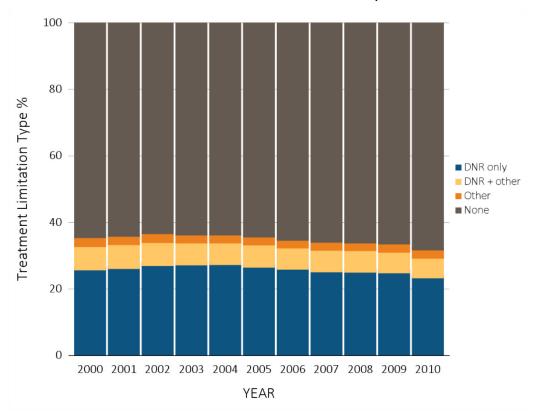


Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Receipt of hospice care at the time of death was defined as having a claim in the Hospice SAF on or after the date of death or Discharge Status from hospice=40, 41, or 42. Abbreviation: ESRD, end-stage renal disease.

In 2000, the prevalence of advance directives was lowest for those less than 45 years of age (31%) and highest for those aged ≥85 years (61%). The prevalence was also highest for Whites (54%), lowest for those of Other races (28%), and was lower for Hispanics than non-Hispanics (36% vs. 49%). Use of advance directives was similar for males and females, was lower for patients who had a kidney transplant or were receiving HD (46%-47%) than for those on PD (53%), and did not vary greatly by time since onset of ESRD. The prevalence of advance directives was higher for those with impaired decision-making capacity than those without (55% vs. 43%). The prevalence of advance directives declined from 2000 to 2010 for almost all sub-groups, with the most pronounced decrement occurring among patients younger than 45 years, those receiving PD, and those who started RRT within a year of death.

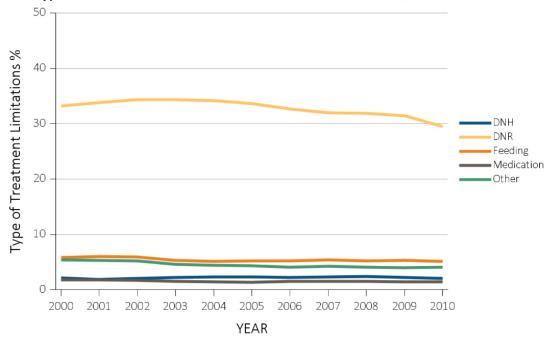
The percentage of patients with a treatmentlimiting directive decreased from 36% in 2000 to 32% in 2010. Most of these patients had a do not resuscitate (DNR) order either alone, or in combination with other treatment limitations (Figure 12.11). The percentage of patients with a DNR declined slightly over time, whereas the percentage with other treatment limitations remained stable (Figure 12.12). Patients with impaired decision-making capacity had a higher prevalence of each advance directive component compared to patients without this impairment (Figure 12.13). Nevertheless, only 52% of patients with impaired decision-making capacity had an advance directive. Impaired decision-making capacity was more common among older patients, patients of Black or Asian race, and those who were receiving HD rather than PD or transplant. (Figure 12.14).

vol 2 Figure 12.11 Percent with treatment limitation in advance directives, 2000-2010



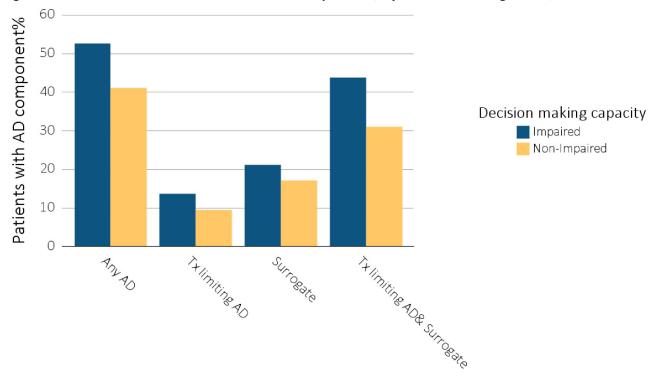
Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Receipt of hospice care at the time of death was defined as having a claim in the Hospice SAF on or after the date of death or Discharge Status from hospice=40, 41, or 42. Abbreviation: DNR, do not resuscitate; ESRD, end-stage renal disease.

vol 2 Figure 12.12 Type of treatment limitations listed in advance directives, 2000-2010



Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Receipt of hospice care at the time of death was defined as having a claim in the Hospice SAF on or after the date of death or Discharge Status from hospice=40, 41, or 42. Abbreviation: DNR, do not resuscitate; ESRD, end-stage renal disease.

vol 2 Figure 12.13 Prevalence of advance directive components, by decision-making status, 2000-2010



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vol 2 Figure 12.14 Prevalence of impaired decision-making capacity, by patient characteristics

(a) Prevalence of impaired decision making capacity, by sex

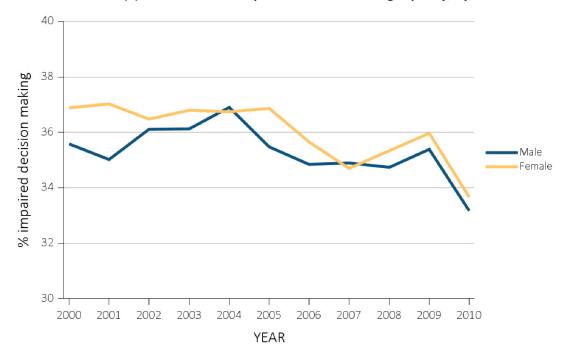
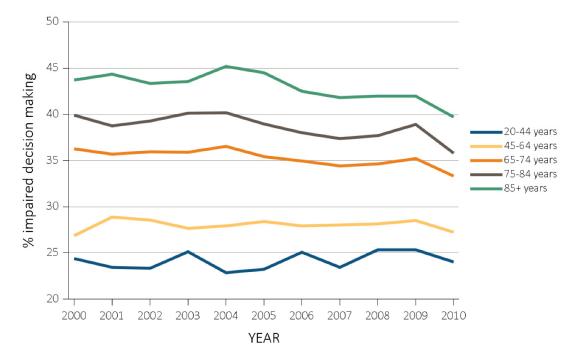


Figure 12.14 continued on next page.

vol 2 Figure 12.14 Prevalence of impaired decision-making capacity, by patient characteristics (continued)

(b) Prevalence of impaired decision making capacity, by age at death



(c) Prevalence of impaired decision making capacity, by modality

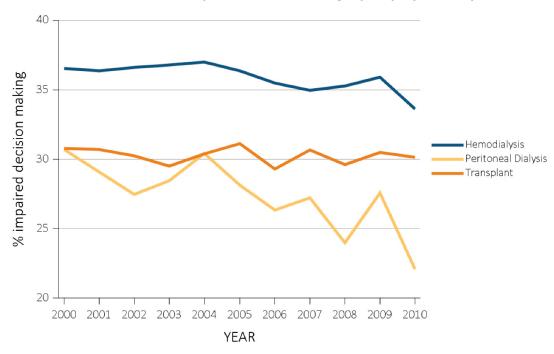
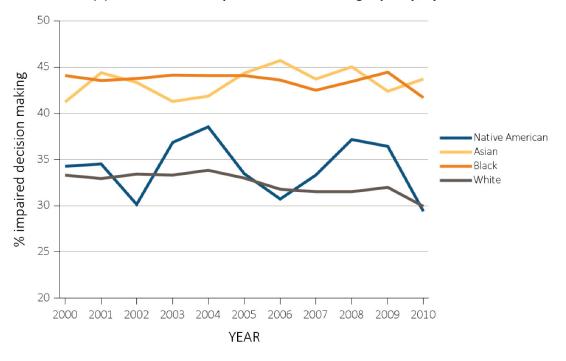


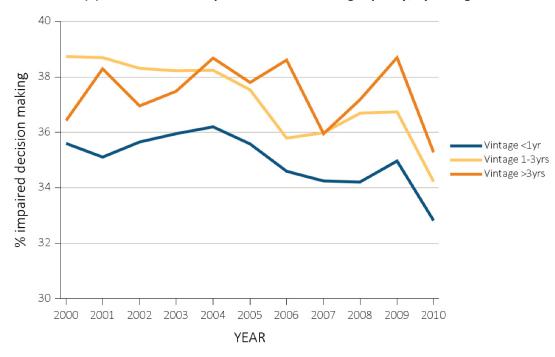
Figure 12.14 continued on next page.

vol 2 Figure 12.14 Prevalence of impaired decision-making capacity, by patient characteristics (continued)

(d) Prevalence of impaired decision making capacity, by race



(e) Prevalence of impaired decision making capacity, by vintage



Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Receipt of hospice care at the time of death was defined as having a claim in the Hospice SAF on or after the date of death or Discharge Status from hospice=40, 41, or 42.

Costs in the Last Year, Month, and Week of Life

For ESRD patients who died in 2014, median per person costs under Medicare Parts A and B were \$119,525 (IQR \$75,886, \$182,091) over the last year of life, \$20,165 (IQR, \$8,982, \$35,555) over the last 30 days of life, and \$7,396 (IQR, \$1,723, \$14,958 over the last seven days of life (Figure 12.15).

Median costs over the last 30 days of life were progressively lower for patients with a longer time interval between the first claim for hospice and death. These costs ranged from \$8,038 for those referred to hospice more than two weeks before death (IQR,

\$5,213, \$16,125) to \$23,847 for those first referred to hospice two days or less before death (IQR, \$15,387, \$37,811), as compared with the referent group without a claim for hospice during the last 90 days of life (\$21,204; IQR, \$9,292, \$38,076).

Median costs during the last seven days of life were also lower for those referred earlier to hospice. These costs ranged from \$1,424 (IQR, \$1,166, \$2,627) for those referred more than two weeks before death to \$10,674 (IQR, \$4,623, \$15,266) for those not referred until the last two days of life, as compared with the referent group without a claim for hospice during the last 90 days of life (\$9,617; IQR, \$2,123, \$16,793).

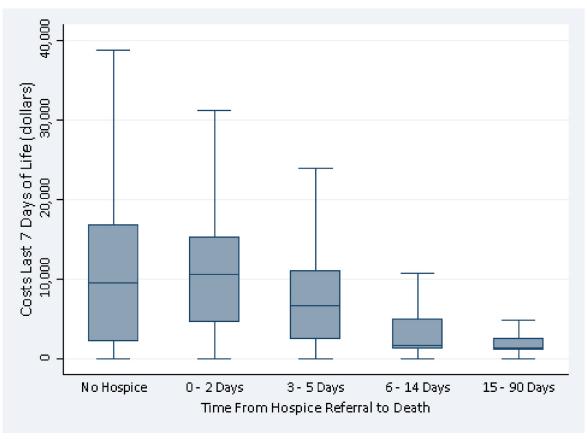
vol 2 Figure 12.15 Costs in the (a) last 30 days of life, and (b) last 7 days of life in relation to timing of hospice care, 2014

(a) Last 30 days of life (b) Coord (c) Coord

Figure 12.15 continued on next page.

vol 2 Figure 12.15 Costs in the (a) last 30 days of life, and (b) last 7 days of life in relation to timing of hospice care, 2014

(b) Last 7 days of life



Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life exclusive of those patients without any costs during the last 30 days of life and those with negative costs. Date of the first claim in the Hospice SAF (HCFASAF=H) within the last 90 days of life is taken as the date of first receipt of hospice services. Timing of hospice referral in relation to death was categorized as 0-2 days, 3-5 days 6-14 days and 15-90 days). Explanation of box plot: the lower border of the box is the first quartile and the upper border is the third quartile of the distribution, the length of the box is the interquartile range, and the line in the middle of the box is the median value. The whiskers extend from the lowest value of the distribution that is \geq the first quartile minus 1.5 times the interquartile range at the bottom to the highest value of the distribution that is \leq the third quartile plus 1.5 times the interquartile range at the top. Values outside this range (outliers) are not plotted.

References

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