

Chapter 14: End-of-life Care for Patients With End-Stage Renal Disease: 2000-2012

- Between 2000 and 2012:
 - The percentage of Medicare beneficiaries with ESRD admitted to an intensive or coronary care unit during the last 90 days of life increased from 50% to 63%.
 - The percentage of Medicare beneficiaries with ESRD receiving an intensive procedure to prolong life during the last 90 days of life increased from 27% to 35%.
 - The percentage of Medicare beneficiaries with ESRD who died in the hospital decreased from 47% to 41%.
 - The percentage of patients who discontinued maintenance dialysis treatments before death increased from 19% to 25%.
 - The percentage of Medicare beneficiaries with ESRD receiving hospice care at the time of death increased from 11% to 25%.
- Most patients receive hospice services only after discontinuing dialysis treatments. From 2004-2012, hospice use prior to death increased from 59% to 80% among patients who discontinued dialysis treatments, but from only 5% to 7% among those who did not.
- Median per person costs under Medicare Parts A and B in 2012 were \$116,416 over the last year of life, \$21,121 over the last 30 days of life, and \$8,538 over the last 7 days of life.
- Costs during the final weeks of life were progressively lower for ESRD patients referred earlier to hospice. Median per person Medicare costs during the last 7 days of life ranged from \$1,649 for those referred to hospice more than 2 weeks before death to \$11,123 for those not referred until the last 2 days of life.

Introduction

The 2014 report from the Institute of Medicine (IOM) “Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life” summarizes contemporary patterns of end-of-life care for the U.S. population. The report references recent work by Teno et al. (2013) describing trends in health care utilization at the end of life among older fee-for-service Medicare beneficiaries from 2000-2009. Some of the trends described by these authors seem to reflect a move toward less aggressive end-of-life treatment practices over time: the percentage of patients dying during an acute hospital stay declined from 33.0% to 25.0% and the percentage receiving hospice at the end of life increased from 21.6% to 42.2%. However, other trends seem to suggest a move toward more intensive inpatient-oriented patterns

of care: the percentage of all patients with an acute hospital admission increased from 62.9% in 2000 to 69.3% in 2009; the percentage admitted to the intensive care unit (ICU) in the last month of life increased from 24.3% to 29.2%; the percentage who received mechanical ventilation during the last month of life increased from 8.3% to 9.3%; and the average time spent in the ICU during the last 90 days of life increased from 2.3 to 2.9 days. Teno et al. also noted an increase in the proportion of patients experiencing potentially burdensome health care transitions at the end of life. For example, the percentage of patients changing care settings during the last 3 days of life increased from 10.3% to 14.2%, the percentage admitted to the hospital 3 or more times during the last 90 days of life increased from 10.3% to 11.5%, and the percentage referred to hospice within 3 days of death increased from 4.6% to 9.8% (Teno, 2013).

The IOM report includes almost no information on patients with ESRD. Prior publications have described low rates of hospice referral, high rates of dialysis discontinuation before death, and high levels of health care utilization toward the end of life among patients receiving maintenance dialysis (Murray et al., 2006; Wong et al., 2012; Gessert et al., 2013; Murtagh et al., 2007; O'Hare et al., 2010). However, relatively little is known about national trends over time in patterns of end-of-life care in this population. In this chapter, we examine treatment practices, patterns of health care utilization, and costs during the final months of life among decedents with ESRD over the 13-year period from 2000 through 2012. The chapter is divided into the following five 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) Patterns of Dialysis Discontinuation Before Death; 4) Patterns of Hospice Utilization Before Death; and 5) End-of-life Costs for Services Under Medicare Parts A and B.

ANALYTICAL METHODS

Data supporting these analyses were derived from the 2014 version of the public-use Standard Analysis Files (SAFs) supplied by the USRDS Coordinating Center at the University of Michigan. These include the Patients file, the MEDEVID file, the RXHIST file, the PAYHIST file, the Death file, and linked Medicare Institutional and Physician Supplier claims.

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 with Medicare Parts A and B as the primary payer throughout the relevant time 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 Medicare beneficiaries with Medicare Parts A and B as primary payer throughout time periods relevant to each analysis (e.g., last 90 days of life). Because Medicare Parts A and B were listed as the primary payer for only a minority of patients aged 19 years or less at the time of death, we do not report stratified results for this age group, but these patients are included in the denominator for all calculations.

We used the Patients file to ascertain information on age at death, sex, race, and ethnicity. The RXHIST, MEDEVID and Patients files were used in combination to ascertain

each patient's most recent ESRD treatment modality before death. We used the most recent modality listed in the RXHIST file when available. If missing, we used transplant dates in the Patients file to identify those who had received a kidney transplant. For all other patients, we used treatment modality at initiation recorded in the MEDEVID file.

We used Medicare Institutional claims to ascertain dates of hospital admission (which included admissions to long and short stay hospitals), 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 in Medicare Institutional claims (020x and 021x). We used an ICD-9 procedure code search of Medicare Institutional claims for time periods when patients were hospitalized to capture inpatient intensive procedures. These 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).

The CMS Death Notification form (CMS 2746) reports provider responses to questions about whether renal replacement therapy was discontinued before death, the date of the last dialysis treatment before death, and whether the patient was receiving hospice care prior to death. Analyses based on the CMS Death Notification form 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 are 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 utilization at the end of life reported in this chapter were obtained from Medicare claims, these are supplemented with information on place of death, hospice utilization, and date of last dialysis treatment from the Death Notification form. Results for measures that are available in both Medicare claims and the CMS Death Notification form are not expected to be identical because there are differences in how measures are defined, in the denominator populations

with complete information for each measure, and in the time periods and methods of ascertainment.

Costs for Medicare Part A and B services were calculated using 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 primary payer in the PAYHIST file but had zero or negative costs during the last year of life (or last 30 days of life when calculating costs for the last 7 and 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 time period of interest (e.g., 90 days before death) were prorated. Cost calculations do not include Medicare Part D costs, Medicaid costs, Medicare copayments, or other health care costs for Medicare beneficiaries.

Characteristics of Decedents With ESRD

As shown in Table 14.1, we identified a total of 1,110,597 patients listed in USRDS who initiated dialysis in 1995 or later and died between calendar years 2000 and 2012 (Table 14.1). The mean age (\pm standard deviation) of decedents was 68.4 (\pm 13.7) years. Patients aged 75-84 years comprised the largest group of decedents and more than 80% of decedents were between the ages of 45 and 84 years at the time of death. Overall, 66.8% of decedents were White, 27.6% were Black, 3.3% were Asian, 1.1% were Native American, and 1.1% were of Other race. The most recent modality prior to death was hemodialysis in 88.3% of patients, peritoneal dialysis in 5.2%, and transplant in 5.0% (1.5% were missing information on modality). During 2000-2012, the mean age of decedents increased from 67.5 (\pm 13.7) years to 69.1 (\pm 13.4) years, and the percentage of patients aged 85 years and older at the time of death

vol 2 Table 14.1 Characteristics of decedents with ESRD by death year, 2000-2012

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Total
n	72,926	77,124	79,804	82,696	84,347	86,107	87,853	87,967	88,838	90,355	91,107	91,962	89,511	1,110,597
%	6.6	6.9	7.2	7.4	7.6	7.8	7.9	7.9	8.0	8.1	8.2	8.3	8.1	100.0
Age (mean)	67.5 (13.7)	67.5 (13.8)	67.8 (13.9)	67.9 (13.8)	68.1 (13.8)	68.4 (13.8)	68.4 (13.8)	68.5 (13.8)	68.75 (13.7)	68.6 (13.7)	68.9 (13.6)	69.0 (13.5)	69.1 (13.4)	68.4 (13.7)
Age Category														
0-19	0.2	0.2	0.2	0.2	0.2	0.2	0.2	0.1	0.1	0.1	0.2	0.1	0.1	0.2
20-44	6.8	6.6	6.6	6.2	5.9	5.8	5.6	5.5	5.2	5.1	4.7	4.6	4.5	5.6
45-64	28.8	29.2	29.0	29.6	29.7	29.5	30.1	30.0	29.9	30.3	30.1	30.2	30.0	29.7
65-74	29.1	28.4	27.9	27.3	27.0	26.6	25.9	25.9	26.4	26.6	26.7	26.7	27.7	27.1
75-84	27.6	27.8	28.1	28.1	28.3	28.4	28.2	28.0	27.5	26.9	26.7	26.6	26.1	27.5
≥85	7.4	7.8	8.3	8.7	8.9	9.6	10.1	10.6	10.9	11.1	11.6	11.8	11.8	10.0
Race														
Native American	1.2	1.1	1.1	1.1	1.1	1.2	1.1	1.1	1.1	1.1	1.1	1.1	1.0	1.1
Asian	2.8	2.8	2.9	3.0	3.0	3.2	3.3	3.4	3.3	3.5	3.5	3.7	3.7	3.3
Black	28.2	28.3	28.0	28.2	28.4	28.1	27.7	27.5	27.4	27.2	26.8	26.5	26.5	27.6
White	65.9	65.9	66.1	65.7	65.4	66.1	66.9	67.1	67.3	67.4	68.0	68.2	68.3	66.8
Unknown	0.3	0.2	0.2	0.2	0.3	0.2	0.2	0.2	0.2	0.1	0.1	0.1	0.1	0.2
Other	1.7	1.7	1.7	1.8	1.8	1.2	0.9	0.8	0.7	0.7	0.6	0.6	0.4	1.1
Hispanic														
No	71.2	75.1	78.1	79.8	81.3	82.4	83.3	84.1	84.4	84.4	84.6	84.5	84.3	81.6
Yes	8.3	9.0	9.4	9.8	10.0	10.3	10.4	10.4	10.7	11.0	11.1	11.6	11.7	10.4
Unknown	1.5	1.1	1.0	0.8	0.7	0.6	0.5	0.4	0.3	0.2	0.2	0.1	0.1	0.5
Missing	19.0	14.8	11.6	9.6	8.0	6.8	5.9	5.1	4.7	4.4	4.1	3.8	3.9	7.5
Sex														
Male	52.2	52.4	52.6	53.0	53.7	54.0	54.2	54.7	55.1	55.7	55.8	56.2	56.3	54.4
Female	47.8	47.6	47.4	47.0	46.3	46.0	45.8	45.3	44.8	44.2	44.2	43.8	43.7	45.6
Last Treatment Modality														
Hemodialysis	86.3	87.1	88.0	88.3	88.5	88.6	88.8	89.1	89.0	88.9	88.8	88.2	87.8	88.3
Peritoneal Dialysis	7.3	6.7	6.1	5.8	5.6	5.1	4.9	4.4	4.4	4.2	4.3	4.6	5.0	5.2
Transplant	4.6	4.5	4.5	4.5	4.4	4.7	4.8	5.0	5.0	5.4	5.4	5.7	5.8	5.0
Missing	1.9	1.7	1.5	1.5	1.5	1.5	1.6	1.5	1.6	1.6	1.5	1.5	1.4	1.5
Medicare Parts A&B as primary payer during last 3 months of life														
Yes	57.4	60.6	64.3	66.6	67.8	68.5	68.1	67.1	65.8	65.2	65.0	65.1	65.5	65.3

Data Source: Special analyses, USRDS ESRD Database. Denominator is all decedents.

increased from 7.4% to 11.8%. There was little change in racial and ethnic composition and a slight increase in the preponderance of male patients over time. The percentage of decedents with peritoneal dialysis as their most recent modality decreased over time and the percentage with transplant and hemodialysis increased. The percentage of patients with Medicare Parts A and B as primary payer during the last 90 days of life ranged between 57.4% and 68.5% over the period of study, peaking in 2005.

Inpatient Utilization During the Last 90 Days of Life Among Medicare Beneficiaries With ESRD

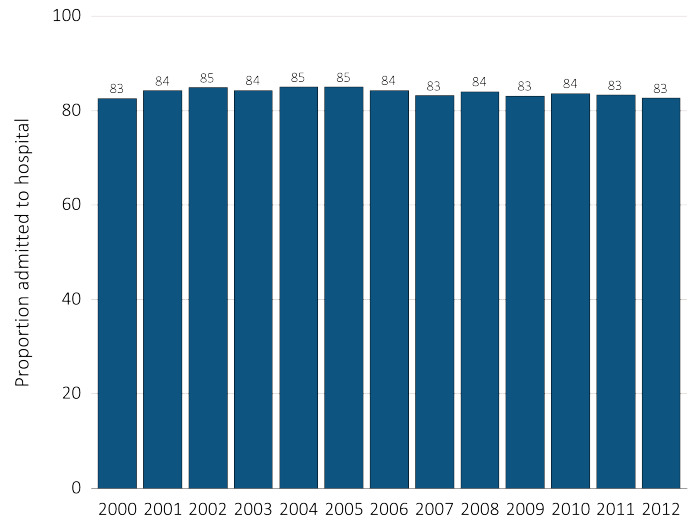
In this section, we describe the following measures of inpatient utilization during the last 90 days of life among fee-for-service Medicare beneficiaries from 2000-2012: (1) hospital admission; (2) days spent in the hospital; (3) ICU admission; (4) receipt of intensive procedures; and (5) inpatient deaths.

HOSPITAL ADMISSION

Figure 14.1 shows that, overall, 83.9% of patients were hospitalized during the last 90 days of life. The percentage of patients admitted to the hospital was highest for those aged 75-84 years (85.1%) and lowest for those aged 45-64 years (81.4%). Hospital admission was most common in Blacks (84.7%) and least common in those of Other race (83.9%), was more common in Hispanics vs. non-Hispanics (84.9% vs. 83.9%), in women vs. men (86.2% vs. 81.9%), and in those whose most recent modality was hemodialysis vs. peritoneal dialysis vs. transplant (84.1% vs. 82.8% vs. 78.9%). 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 3 days of death. The percentage of patients admitted or discharged within 3 days of death 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 26.0% in 2000 to 27.8% in 2012.

vol 2 Figure 14.1 Hospital admission during the last 90 days of life among Medicare beneficiaries with ESRD, 2000-2012

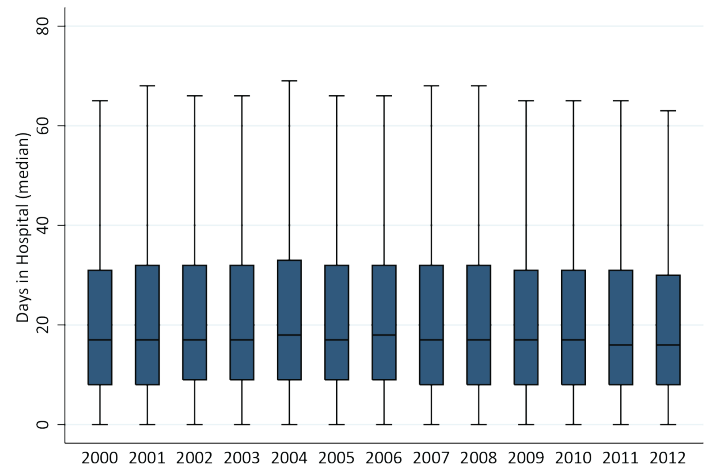


Data Source: Special analyses, USRDS ESRD Database. Denominator is all decedents with Medicare Parts A and B throughout the last 90 days of life. Includes hospital stays in both short and long stay hospitals.

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 2 admissions during this time (interquartile range [IQR], 1, 3) and 28.2% had 3 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. Figure 14.2 shows that those admitted to the hospital during the last 90 days of life spent a median of 17 days in the hospital (IQR, 8, 31). The median number of days spent in the hospital during the last 90 days of life changed very little from 2000 through 2012.

vol 2 Figure 14.2 Days spent in the hospital during the last 90 days of life among Medicare beneficiaries with ESRD, 2000-2012



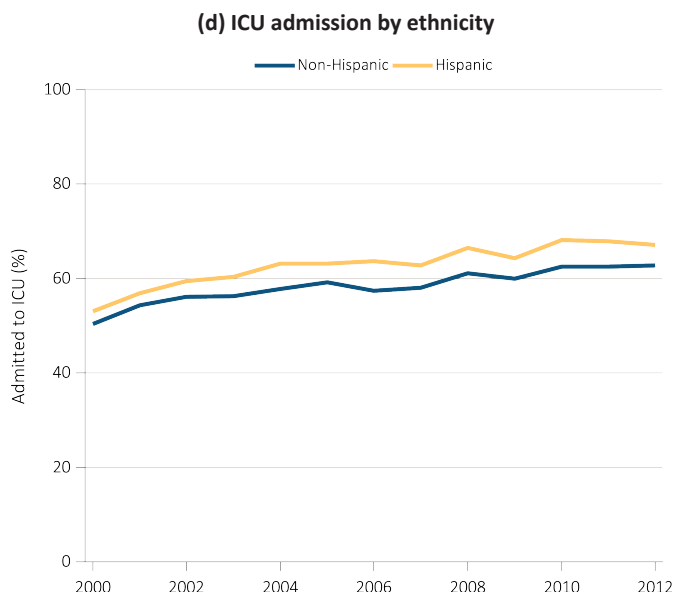
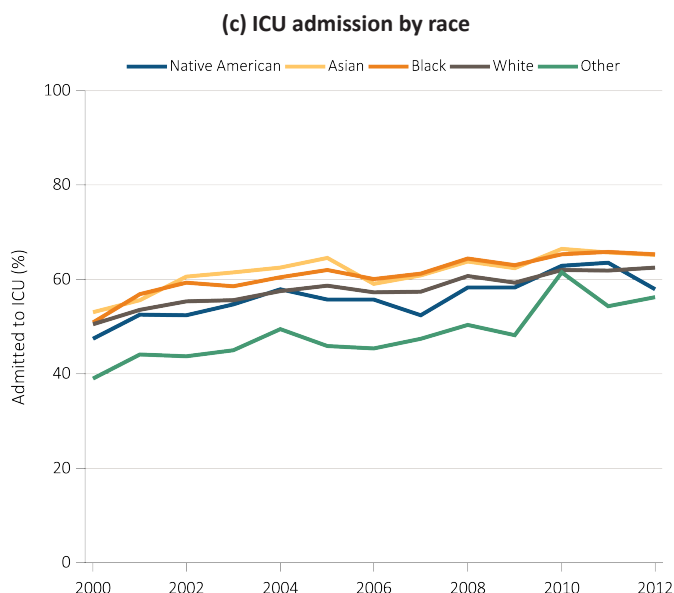
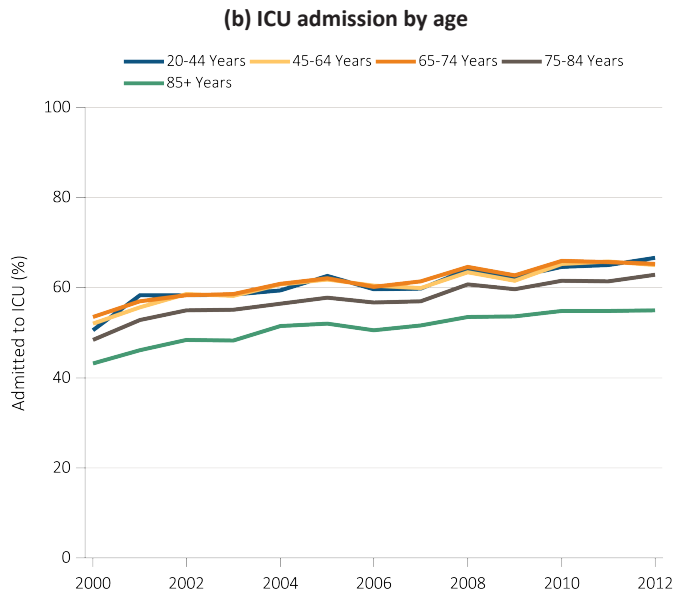
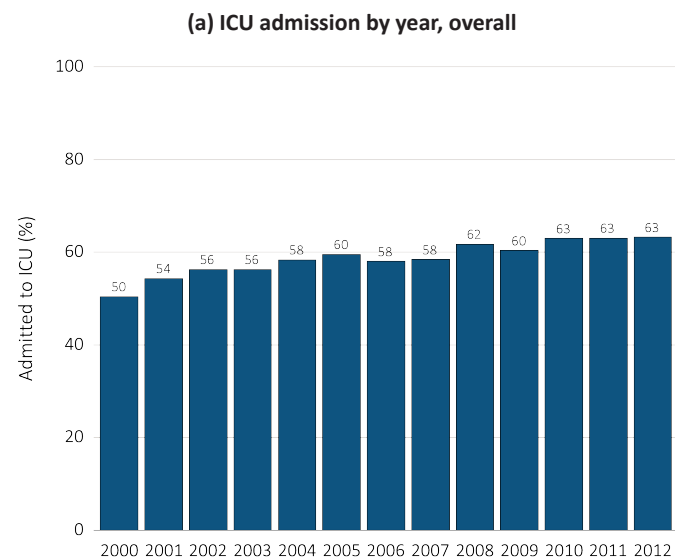
Data Source: Special analyses, USRDS ESRD Database. Denominator is all decedents with Medicare Parts A and B throughout the last 90 days of life who were admitted to the hospital at least once. Includes

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.

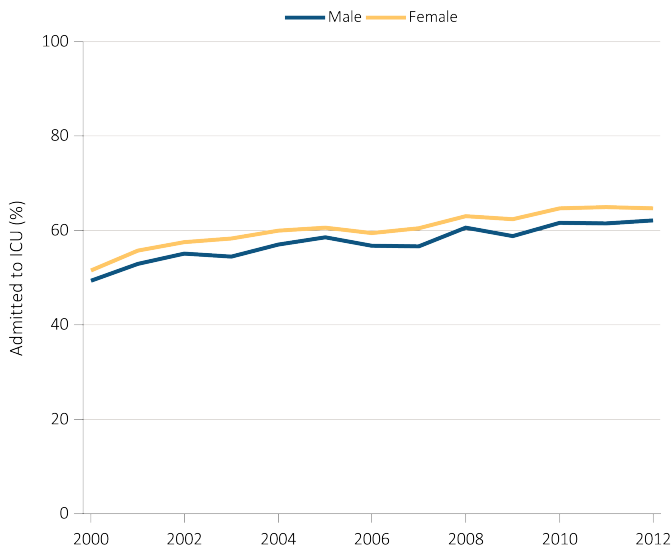
ICU ADMISSION

Overall, 59.0% of patients were admitted to an ICU during the last 90 days of life. As shown in Figure 14.3, the percentage admitted to the ICU was highest for those aged 65-74 years (61.4%) and lowest for those aged 85 years and older (51.7%), was highest for Asians (62.3%) and lowest for patients of Other race (46.7%), was higher for Hispanics vs. non-Hispanics (63.3% vs. 58.7%), was slightly higher for women vs. men (60.5% vs. 57.8%), and was similar in patients whose most recent modality was hemodialysis vs. peritoneal dialysis vs. transplant (59.1% vs. 58.6% vs. 58.1%). Over time, the percentage of patients admitted to the ICU during the last 90 days of life increased from 50.4% in 2000 to 63.3% in 2012. There was an increase in the percentage of patients admitted to the ICU over time among all subgroups examined.

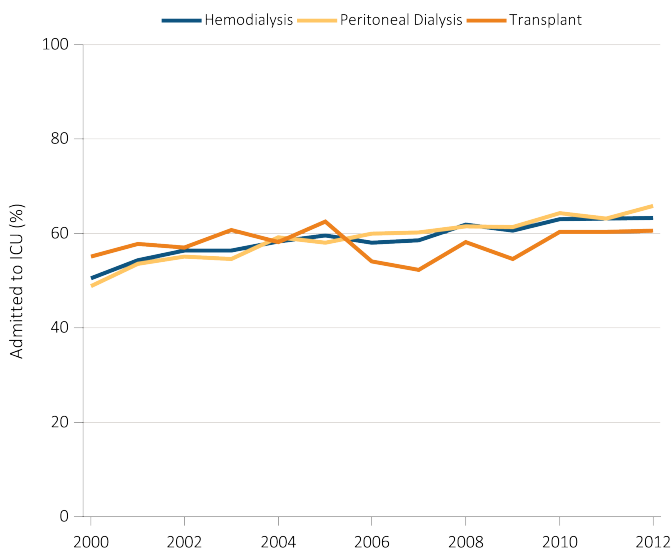
vol 2 Figure 14.3 ICU admission during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2012



(e) ICU admission by sex



(f) ICU admission by modality



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.

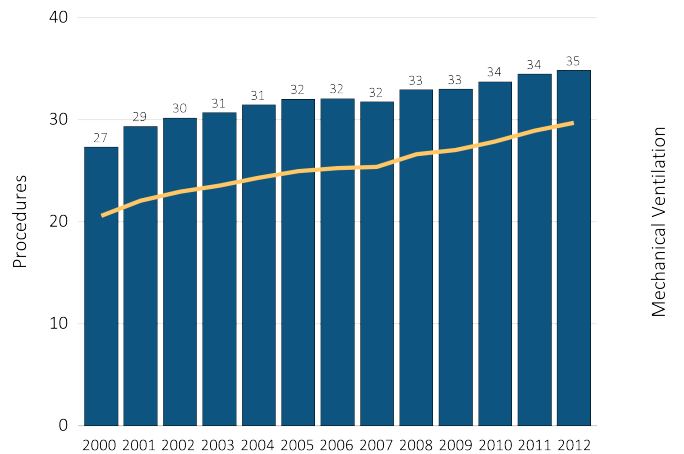
INTENSIVE PROCEDURES

Overall, 32.0% of decedents had an inpatient intensive procedure during the last 90 days of life and 25.4% of patients were intubated or received mechanical ventilation. As shown in Figure 14.4, the percentage of patients receiving intensive procedures during the last 90 days of life was highest for those aged 20-44 years (42.4%) and lowest for those aged 85 years and older (20.7%), was highest for Blacks (41.1%) and lowest for Whites (28.1%), was higher for Hispanics vs. non-Hispanics (38.2% vs. 31.3%), was slightly higher for women vs. men (33.1% vs. 31.1%), and was higher for those with transplant vs. peritoneal dialysis vs. hemodialysis as the most recent modality (39.1% vs. 32.0% vs. 31.9%). Over time, the percentage of patients who received an intensive

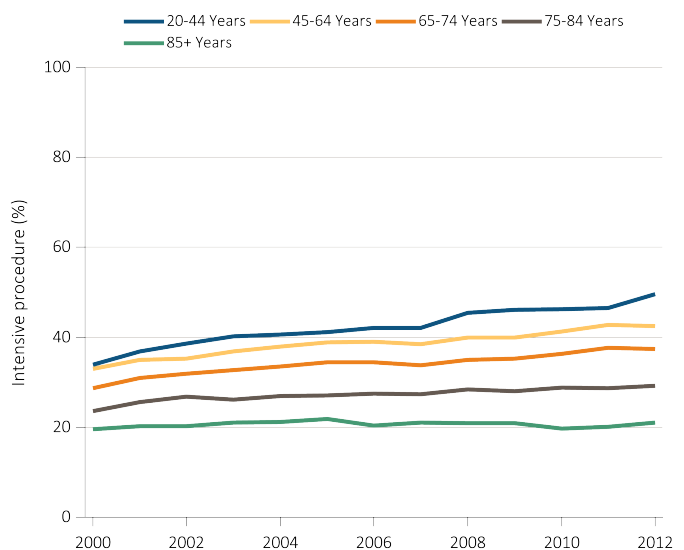
procedure increased from 27.3% in 2000 to 34.8% in 2012. The percentage of patients who were intubated or received mechanical ventilation during the last 90 days of life increased from 20.6% to 29.7% over the same time period. The percentage of patients receiving an intensive procedure increased over time for most subgroups examined.

vol 2 Figure 14.4 Intensive procedures during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2012

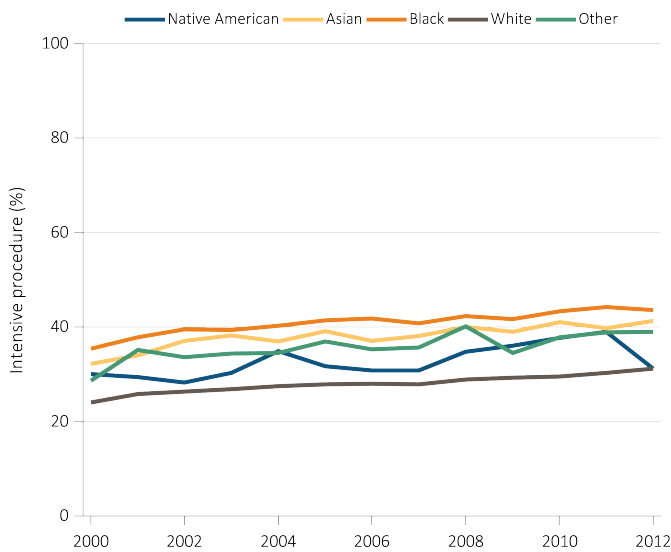
(a) Intensive procedures and mechanical ventilation by year, overall



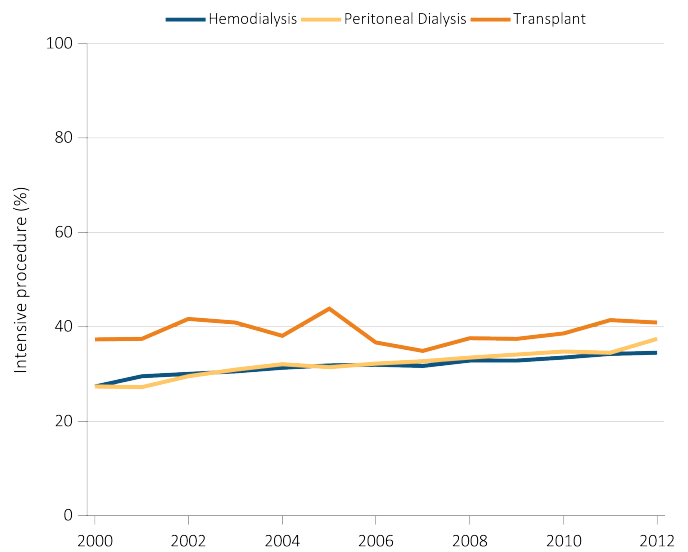
(b) Intensive procedures by age



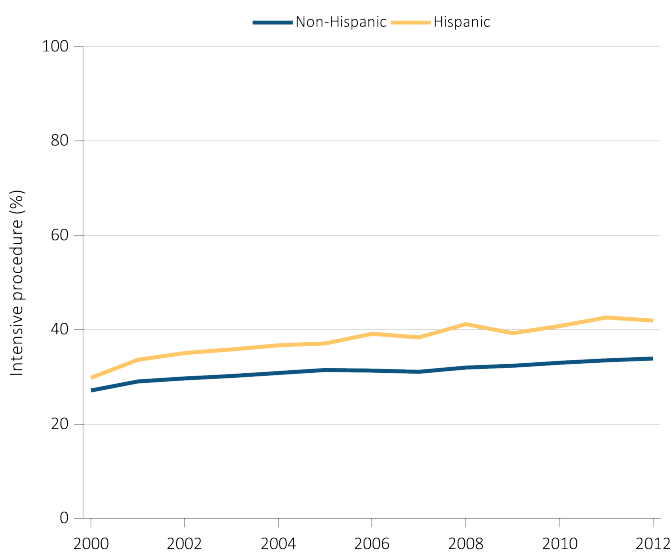
(c) Intensive procedures by race



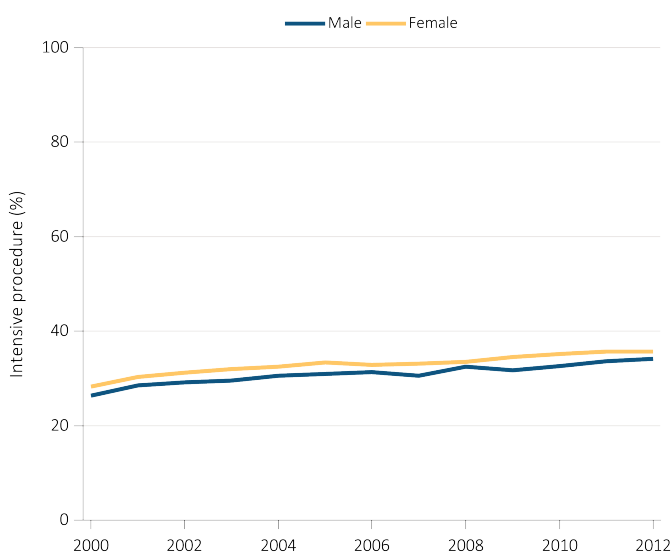
(f) Intensive procedures by modality



(d) Intensive procedures by ethnicity



(e) Intensive procedures by sex

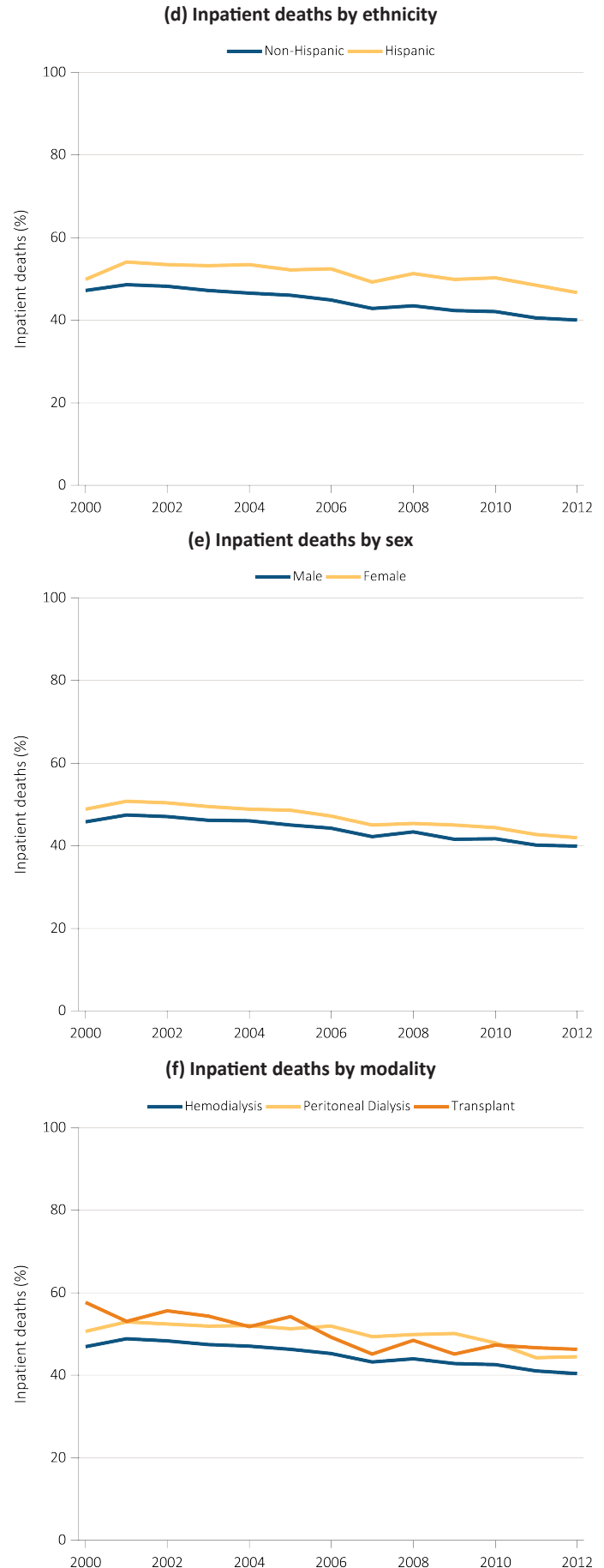
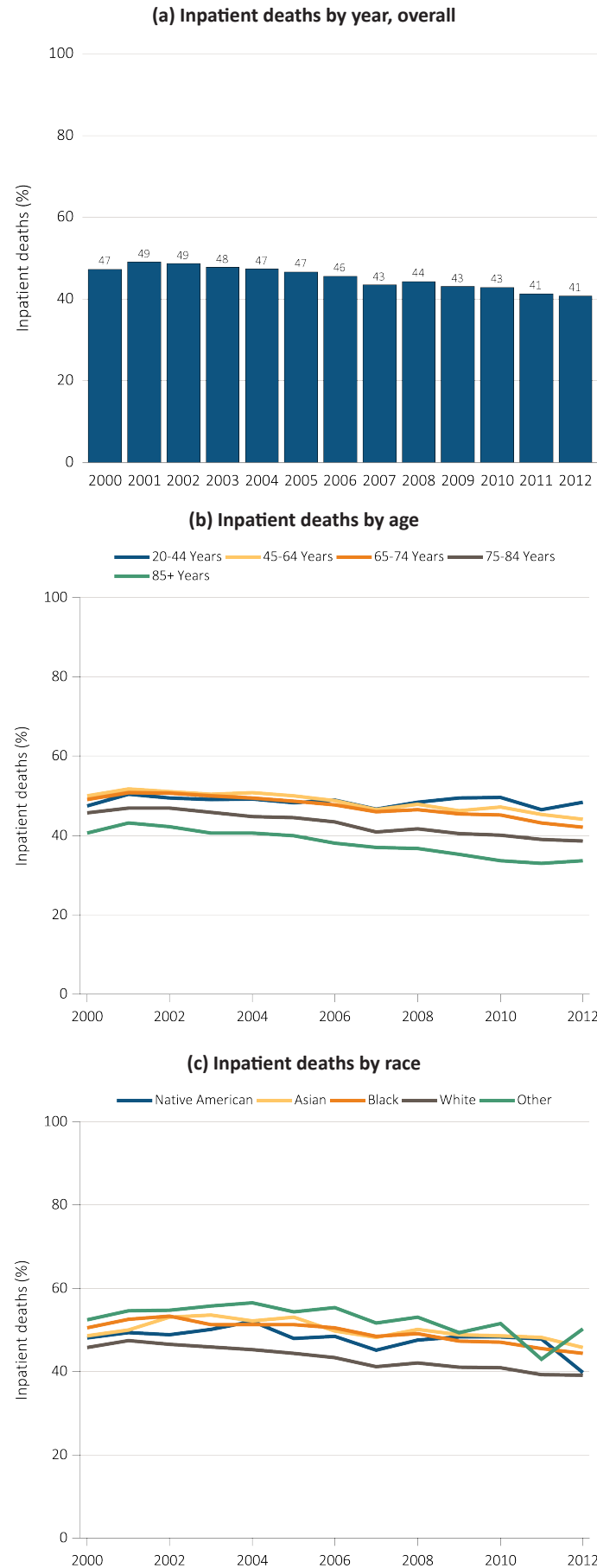


Data Source: Special analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Intensive procedures were identified by ICD-9 procedure code search of Medicare Institutional claims from short and long stay hospitals. The yellow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

INPATIENT DEATHS

Based on Medicare Institutional claims, 45.1% of patients died in the hospital. As shown in Figure 14.5, the proportion of inpatient deaths was highest for those aged 20-44 years (48.6%) and lowest for those aged 85 years and older (37.5%). Death in the hospital was most common in those of Other race (53.7%) and least common in Whites (43.1%), was more common in Hispanics vs. non-Hispanics (51.0% vs. 44.4%), was more common in women vs. men (46.7% vs. 43.7%), and was more common in patients whose most recent modality was peritoneal dialysis vs. transplant vs. hemodialysis (50.1% vs. 49.0% vs. 44.8%). Over time, the percentage of inpatient deaths decreased from 47.3% in 2000 to 40.8% in 2012; the percentage of inpatient deaths decreased over time for most subgroups examined. When we used information from the CMS Death Notification form, 63.2% of decedents for whom this information was available were reported to have died in the hospital, declining from 68.9% in 2000 to 59.0% in 2012. The sensitivity and specificity of the CMS Death Notification form for detecting inpatient deaths based on Medicare claims were 94% and 63%, respectively, among patients with complete information from both sources.

vol 2 Figure 14.5 Inpatient deaths among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2012

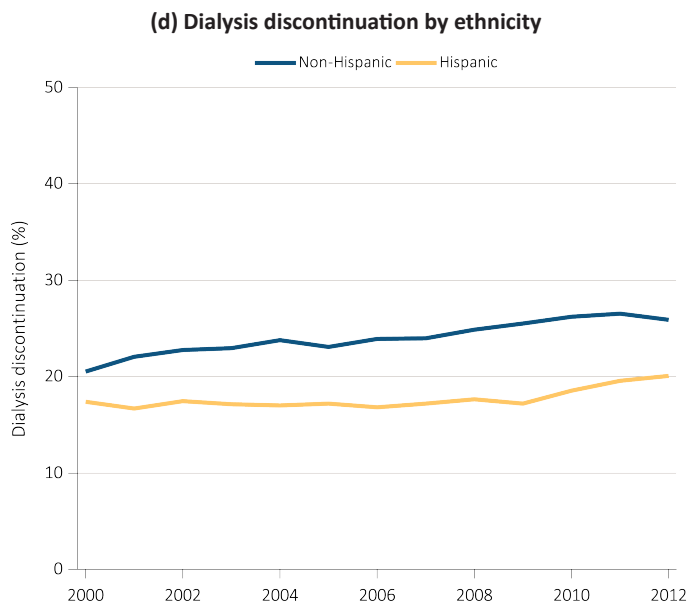
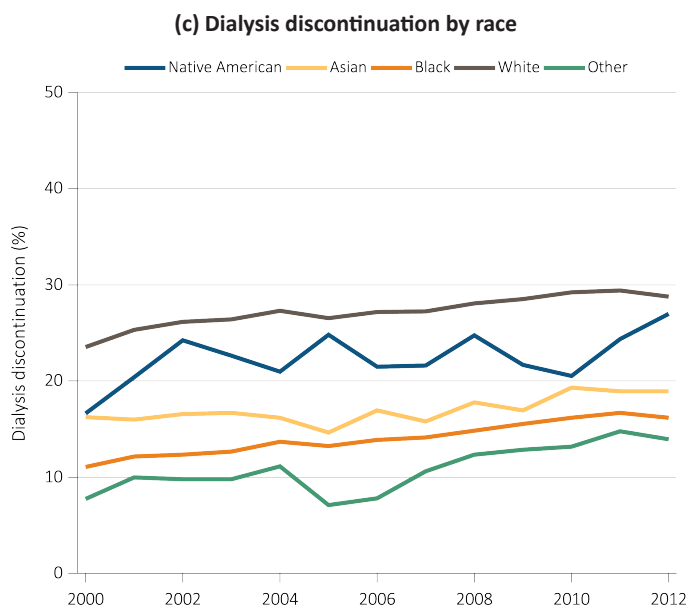
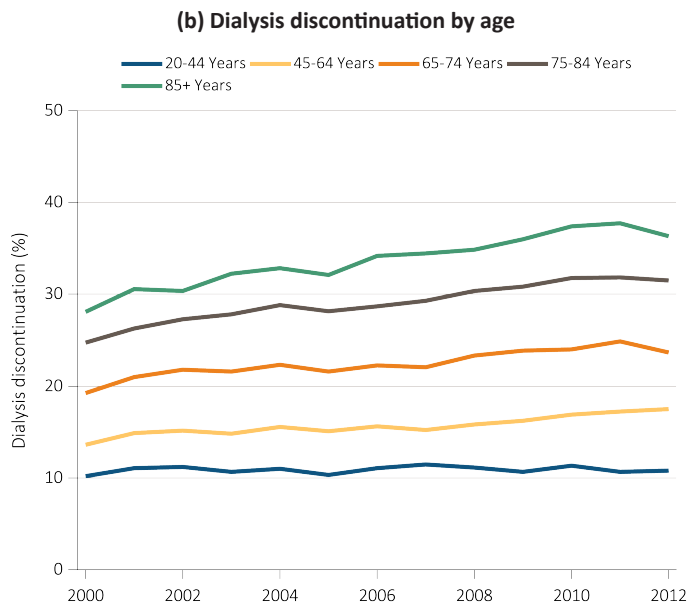
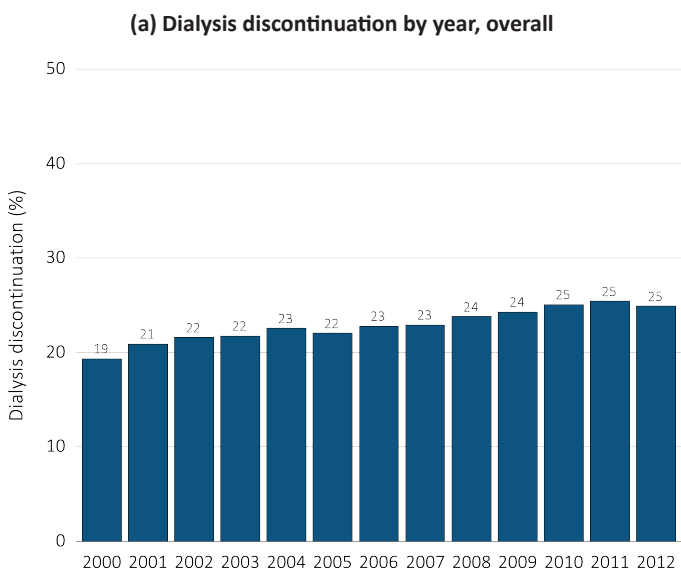


Data Source: Special analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Includes deaths occurring in short and long stay hospitals.

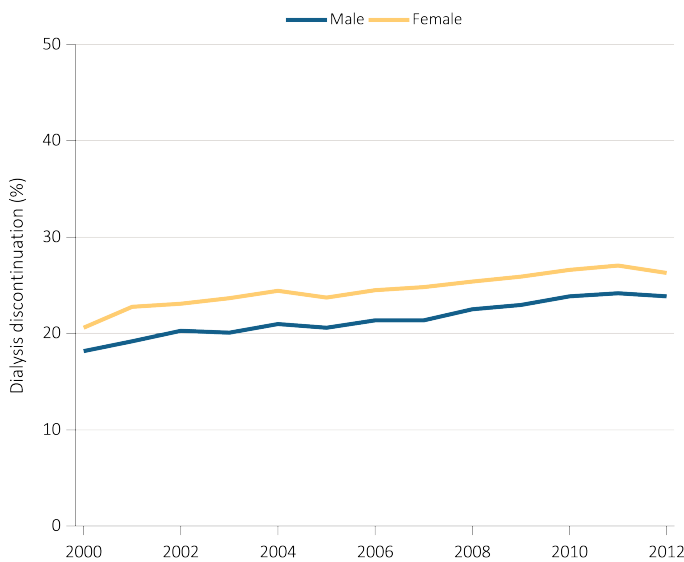
Dialysis Discontinuation Before Death

Overall, 23.0% of patients with either hemodialysis or peritoneal dialysis listed as their most recent modality were reported to have discontinued dialysis treatments before death on the CMS Death Notification Form. As shown in Figure 14.6, 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 (10.9%), was highest for Whites (27.3%) and lowest for patients of Other race (10.2%), was higher for non-Hispanics vs. Hispanics (24.2% vs. 17.8%), was higher for women vs. men (24.6% vs. 21.6%), and for those whose most recent modality was hemodialysis vs. peritoneal dialysis (23.3% vs. 18.6%). The median time from discontinuation to death as reported on the CMS Death Notification form was 6 days (IQR, 3, 12 days). This interval was slightly shorter for those treated with peritoneal dialysis (3 days, IQR, 2, 7 days) vs. hemodialysis (6 days, IQR, 3, 12 days), and slightly longer for those who received hospice (7 days, IQR, 4, 13 days) vs. those who did not (4 days, IQR, 2, 8 days). Over time, there was an increase in the percentage of decedents who discontinued dialysis before death from 19.3% in 2000 to 24.9% in 2012. The percentage of decedents who discontinued dialysis increased over time for most subgroups examined.

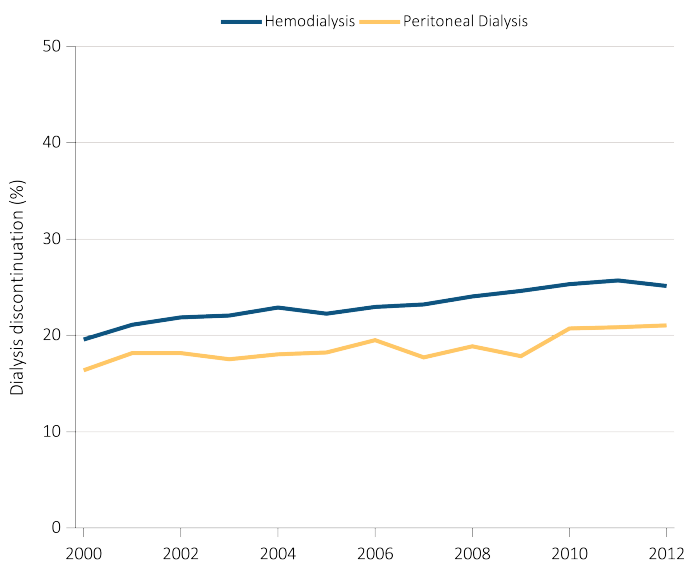
vol 2 Figure 14.6 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2012



(e) Dialysis discontinuation by sex



(f) Dialysis discontinuation by modality



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

Patterns of Hospice Utilization Before Death

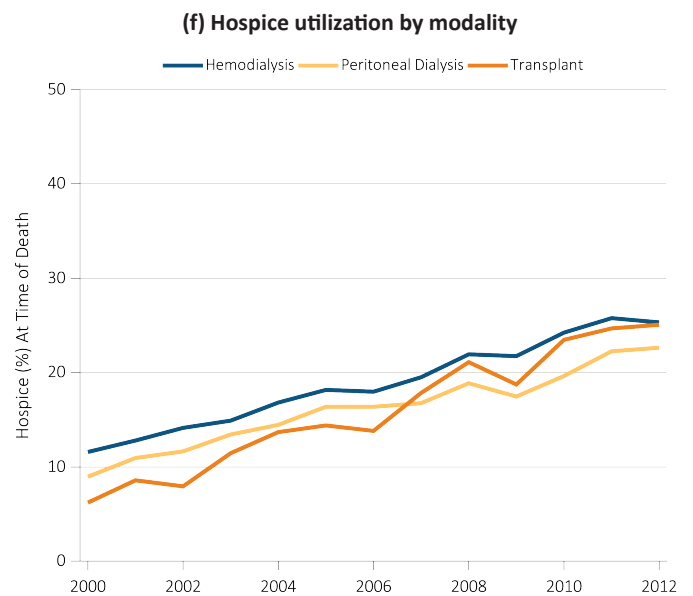
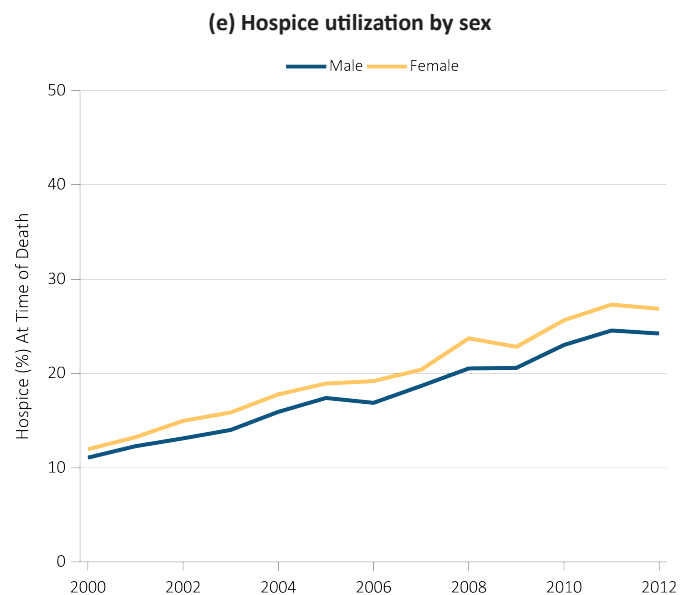
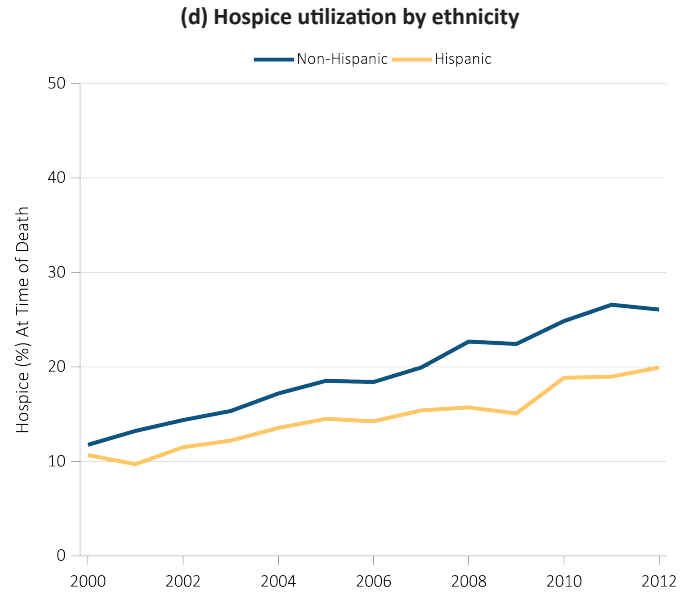
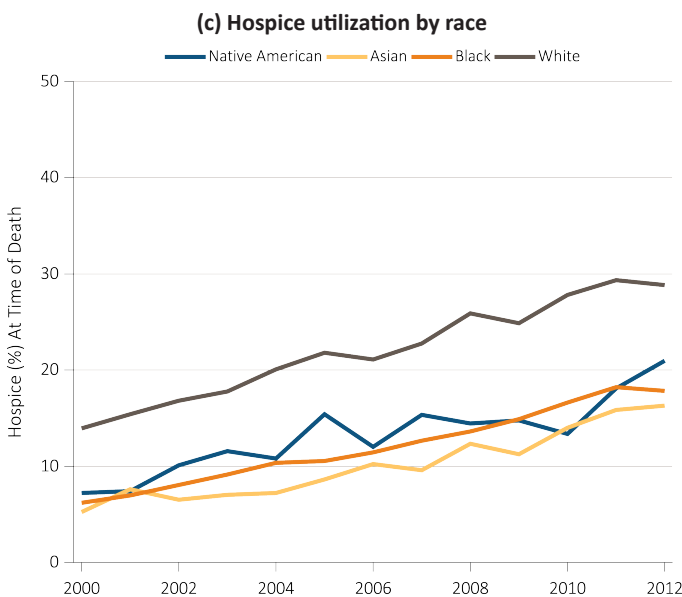
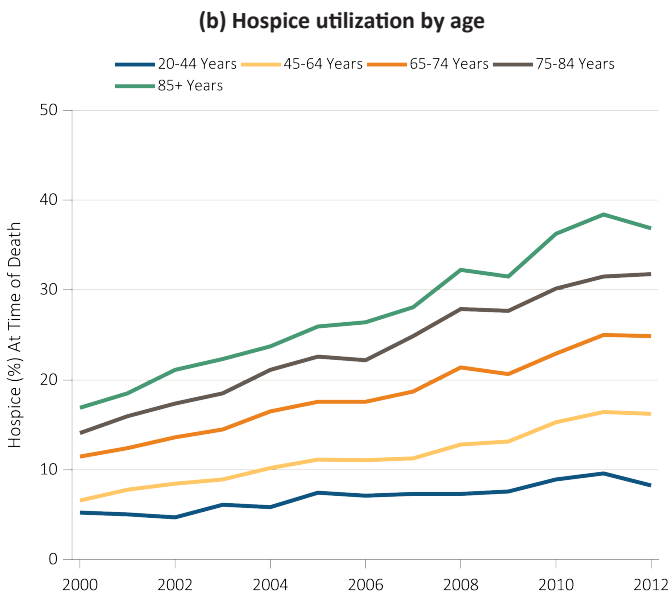
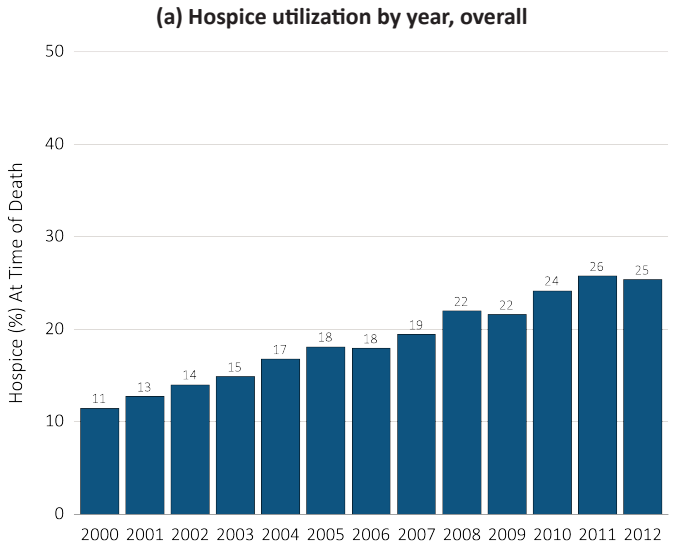
Overall, 19.2% of patients with Medicare Parts A and B as primary payer were receiving hospice at the time of death based on Medicare Institutional claims. As shown in Figure 14.7, use of hospice services was highest for patients aged 85 years and older (28.9%) and lowest for those aged 20-44 years (7.0%), was highest for Whites (22.4%) and lowest for those of Other race (7.5%), was higher for non-Hispanics vs. Hispanics (19.7% vs. 15.0%), was higher for women vs. men (20.1% vs. 18.3%), and was higher for those whose most recent modality was hemodialysis vs. transplant vs. peritoneal dialysis (19.2% vs. 18.3% vs. 15.9%). The

percentage of patients receiving hospice services at the time of death differed markedly according to whether patients did vs. did not discontinue dialysis (53.1% vs. 8.5%), most likely reflecting both the intertwined nature of these two treatment decisions 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 11.4% in 2000 to 25.4% in 2012; hospice utilization increased over time for most subgroups.

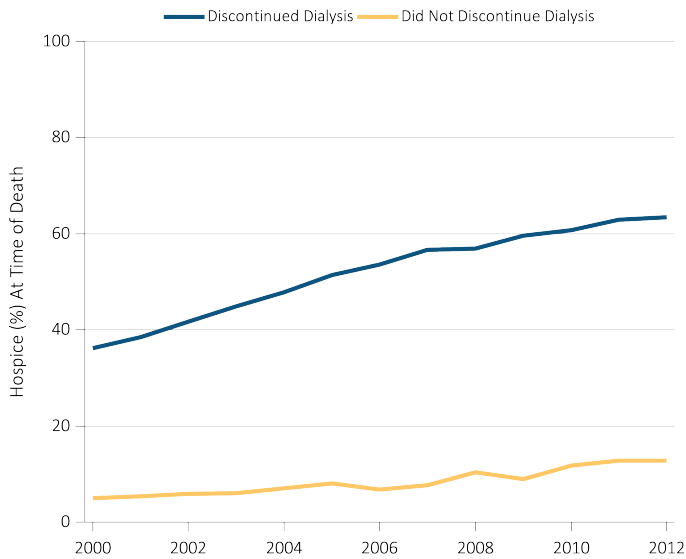
Overall, 21.1% of patients with Medicare Parts A and B as primary payer had an institutional claim for hospice in the last 90 days of life. Among these, the median interval between the first claim for hospice within this time frame and death was 5 days (IQR, 2, 13 days) and 39.8% of patients had their first claim for hospice ≤ 3 days before death.

When we used information on hospice referral before death from the CMS Death Notification form, 23.6% of decedents for whom this information was available were reported to have received hospice care before death (data available only from 2004-2012). The sensitivity and specificity of the CMS Death Notification form for detecting hospice at the time of death based on Medicare claims were 83% and 92%, respectively among patients with complete information from both sources. The percentage of patients who received hospice care before death based on the CMS Death Notification form was highly correlated with dialysis discontinuation before death: 73.4% of those who had discontinued dialysis before death received hospice as compared with 6.5% of those who had not discontinued dialysis. From 2004-2012, the percentage of patients who received hospice prior to death based on the CMS Death Notification form increased from 17.5% to 27.3% in the overall population for whom this was reported, from 59.3% to 80.1% for those who discontinued dialysis treatments before death, and from 5.4% to 7.4% for those who did not.

vol 2 Figure 14.7 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, 2000-2012



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



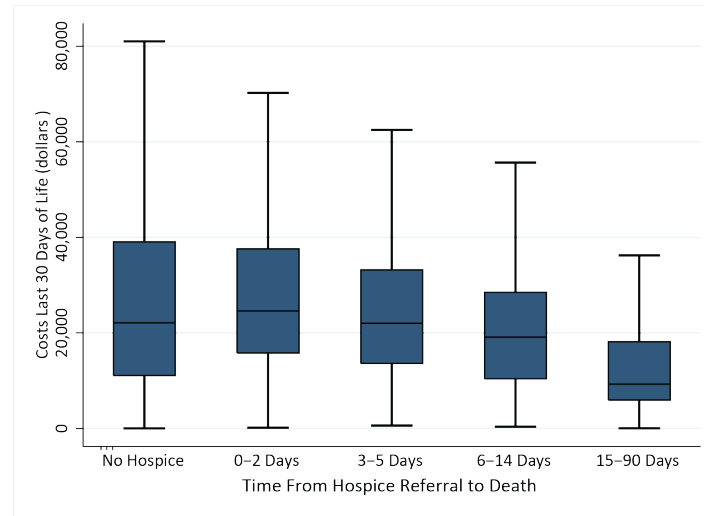
Data Source: Special analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Receipt of hospice care at the time of death was defined as having a claim in the Hospice SAF on or after the date of death or Discharge Status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

End-of-life Costs for Services Under Medicare Parts A and B

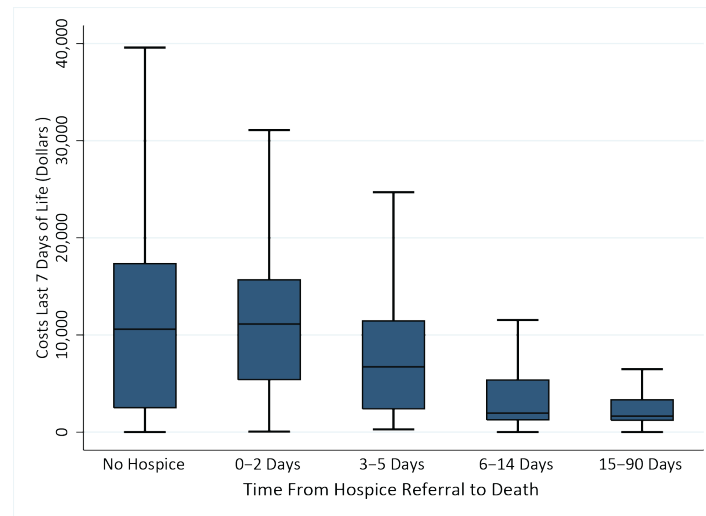
For ESRD patients who died in 2012, median per person costs under Medicare Parts A and B were \$116,416 (IQR, \$72,258, \$180,181) over the last year of life, \$21,121 (IQR, \$10,567, \$36,389) over the last 30 days of life, and \$8,538 (IQR, \$2,004, \$15,608) over the last 7 days of life (Figure 14.8). 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, ranging from \$9,264 for those referred to hospice more than 2 weeks before death (IQR, \$5,945, \$18,150) to \$24,590 for those first referred to hospice 2 days or less before death (IQR, \$15,804, \$37,597), as compared with the referent group without a claim for hospice during the last 90 days of life (\$22,122; IQR, \$11,080, \$39,055). Median costs during the last 7 days of life were also lower for those referred earlier to hospice, ranging from \$1,649 (IQR, \$1,219, \$3,334) for those referred more than 2 weeks before death to \$11,123 (IQR, \$5,320, \$15,651) for those not referred until the last 2 days of life, as compared with the referent group without a claim for hospice during the last 90 days of life (\$10,598; IQR, \$2,528, \$17,356).

vol 2 Figure 14.8 Costs in the (a) last 30 days of life, and (b) last 7 days of life in relation to timing of hospice care, 2012

(a) Last 30 days of life



(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 by quartile (1st quartile 0-2 days, 2nd quartile 3-5 days, 3rd quartile 6-14 days and 4th quartile 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.

Summary

From 2000-2012, there were marked increases in the intensity of inpatient care during the final months of life for patients with ESRD. Over the same time period, there was a decline in inpatient deaths, an increase in dialysis discontinuation and an increase in hospice utilization. Receipt of hospice services occurred less than a week before death in most cases, was closely tied to dialysis discontinuation, and was associated with lower costs during the last days and weeks of life. In summary, while there has been a trend toward greater use of hospice services in this population, referral to hospice still tends to occur very late in the course of illness only after all other options have been exhausted.

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Notes