

Chapter 14: End-of-life Care for Patients With End-Stage Renal Disease: 2000-2013

- Between 2000 and 2013:
 - 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% (Figure 3.a).
 - The percentage of Medicare beneficiaries with ESRD receiving an intensive procedure during the last 90 days of life increased from 28% to 34% (Figure 4.a).
 - The percentage of Medicare beneficiaries with ESRD who died in the hospital decreased from 49% to 39% (Figure 5.a).
 - The percentage of patients with ESRD who received care in a nursing facility (skilled nursing or nursing home) during the last year of life increased from 37% to 46% (Figure 6.a).
 - The percentage of patients who discontinued maintenance dialysis treatments before death increased from 20% to 24% (Figure 7.a).
 - The percentage of Medicare beneficiaries with ESRD receiving hospice care at the time of death increased from 11% to 27% (Figure 8.a).
- Most patients receive hospice services only after discontinuing dialysis treatments. From 2004-2013, hospice use prior to death based on the CMS Death Notification form increased from 59% to 82% among patients who discontinued dialysis treatments, and from 5% to 8% among those who did not.
- Median per person costs under Medicare Parts A and B in 2013 were \$119,937 over the last year of life, \$20,731 over the last 30 days of life, and \$8,180 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 \$1,553 for those referred to hospice more than 2 weeks before death to \$11,036 for those not referred until the last 2 days of life (Figures 9.a & 9.b).

Introduction

In this chapter, we update information included in Chapter 14 of the 2015 Annual Data Report (ADR) on treatment practices, patterns of health care utilization, and costs at the end of life to include the 14-year period from 2000 through 2013 among decedents with ESRD. New to this year's chapter is information on nursing facility use during the last year of life. Nursing facilities provide a variety of care services. Skilled nursing facilities (SNF) provide skilled nursing or medical care and rehabilitation following hospitalization. Nursing homes provide custodial care for patients who are no longer able to live

independently. Medicare beneficiaries can receive up to 100 days of care in a SNF after hospitalizations lasting three or more days. Frequent use of nursing facilities (i.e. SNFs and/or nursing homes) near the end of life not only implies a large burden of disability in the population, but may have implications for the delivery of end-of-life care to patients with end-stage renal disease (ESRD). Frequent transitions in the site of care can be burdensome to patients and may increase fragmentation of care. These concerns may be especially relevant to patients with ESRD for whom admission to a nursing facility may also entail transitioning to a new dialysis facility.

This chapter is divided into the following six 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) Nursing Facility Utilization During the Last Year of Life; (4) Patterns of Dialysis Discontinuation Before Death; (5) Patterns of Hospice Utilization Before Death; and (6) End-of-life Costs for Services Under Medicare Parts A and B.

Methods

Data supporting these analyses were derived from the 2016 version of the public-use Standard Analysis Files (SAFs) supplied by the USRDS Coordinating Center at the University of Michigan, specifically the Patients file, the MEDEVID file, the RXHIST file, the PAYHIST file, the Death file, and linked Medicare Institutional and Physician/Supplier claims. We also include information from the Minimum Patient Dataset for patients with ESRD.

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 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 a minority of patients aged 19 years or younger at the time of death, we do not report stratified results for this age group. With the exception of analyses of nursing facility utilization in the last year of life, these younger 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. Each patient's most recent ESRD treatment modality before death was ascertained from the RXHIST file. We used Medicare Institutional claims to ascertain dates of

hospital admission (which included admissions to short- and long-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 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).

To characterize nursing facility use in the last year of life, we restricted the cohort to patients who were at least 20 years of age at the time of death, had been treated for ESRD for at least one year, and had continuous Medicare Parts A & B coverage during the last year of life. We ascertained nursing facility use using Medicare claims – HCFASAF=N in Part A claims or PLCSRV=31-33 in Part B claims. To determine the number of days patients received care in a nursing facility in the last year of life, we assigned each day in the patient's last year of life to their location of care, based on Medicare claims (Wei, 2014; Intrator, 2011). We first used Part A claims, assigning hospital days, followed by nursing facility days, hospice days, and home health days, in this order. Next, using Part B claims, we then assigned, in order, home health days, nursing facility days, and assisted living facility days. Next, we assigned any days with an unknown location of care to the nursing facility, if: (1) the interval between 2 consecutive nursing facility claims was ≤ 90 days with no claims in between and with at least one claim being a Part B claim, (2) the interval between a nursing facility Part B claim and another institutional claim (hospital, hospice or assisted living) was ≤ 31 days and there were no claims in between, or (3) the interval between a nursing facility Part B claim and death was ≤ 31 days and there were no claims in between. When the start or end of a nursing facility

claim fell on the same day as the start or end of another claim, (e.g. hospital discharge occurring on the same day as a nursing facility admission), we assigned the overlap day to a nursing facility stay. To verify the accuracy of this approach, we used admission and discharge information from the Minimum Dataset, a national registry of nursing home patients, which was available to us only for patients who were admitted to a nursing home between 2000 and 2010 (Centers for Medicare & Medicaid, 2012). We found that the claims-based approach described above underestimated total days in a nursing facility by an average of 3 days compared with registry data.

The Centers for Medicare & Medicaid Services (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 for patients who discontinued treatment, 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 hospice 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. These two sources do not agree perfectly, in part, because there are differences in how each measure is 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 the 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 over shorter time periods before death) 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 pro-rated. Cost calculations do not include Medicare Part D costs, Medicaid costs, Medicare copayments, or other health care costs for Medicare beneficiaries.

Analyses reported in Chapter 14 of the 2015 ADR were restricted to decedents with a first ESRD service date in 1995 or later. We have removed this restriction in the current chapter. This change combined with updates to the source data from USRDS has resulted in small changes to results reported in Chapter 14 of the 2015 ADR for earlier time periods.

Characteristics of Decedents With ESRD

We identified a total of 1,201,415 patients listed in the USRDS Database who died between calendar years 2000 and 2013. The mean age (\pm standard deviation) of decedents was 68.5 (\pm 13.7) years (Table 14.1). Patients aged 45-64 years comprised the largest group of decedents (28.6%) and more than 80% of decedents were between the ages of 45 and 84 years of age at the time of death. Overall, 67.1% of decedents were White, 27.4% were Black/African American (hereafter, Black), 3.3% were Asian, 1.1% were Native American, 1.0% were of Other race and 10.7% were of Hispanic ethnicity. Overall 54.4% of patients were male. The most recent modality prior to death was hemodialysis in 88.5% of patients, peritoneal dialysis in 5.5%, and

transplant in 5.2% (0.8% were missing information on modality). During 2000-2013, the mean age of decedents rose from 67.5 (\pm 13.7) years to 69.2 (\pm 13.2) years, and the percentage of patients aged 85 years and older at the time of death increased from 8.4% to 12.9%. There was little change in racial, ethnic, and gender composition over time. The percentage of decedents with peritoneal dialysis as their most recent modality decreased over time until 2007, increasing slightly since this time. The percentage of decedents who had received a kidney transplant has increased over time. The percentage of patients with Medicare Parts A and B as primary payer during the last 90 days of life ranged from a low of 66.6% in 2013 and a high of 75.0% in 2003.

vol 2 Table 14.1 Characteristics of decedents with ESRD by death year, 2000-2013

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total
n	72,814	76,865	79,489	82,382	84,057	85,792	87,500	87,526	88,329	89,855	90,563	91,775	91,781	92,687	1,201,415
%	6.1	6.4	6.6	6.9	7.0	7.1	7.3	7.3	7.4	7.5	7.5	7.6	7.6	7.7	100
Age (mean)	67.5 (13.7)	67.6 (13.8)	67.8 (13.8)	67.9 (13.8)	68.1 (13.7)	68.3 (13.8)	68.5 (13.8)	68.6 (13.8)	68.8 (13.6)	68.7 (13.7)	69.0 (13.5)	69.1 (13.4)	69.2 (13.4)	69.2 (13.2)	68.5 (13.7)
Age Category															
0-19	0.2	0.2	0.2	0.2	0.2	0.2	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1
20-44	6.4	6.3	6.1	5.7	5.6	5.4	5.1	5.1	4.8	4.8	4.4	4.3	4.2	4.0	5.1
45-64	27.9	28.3	28.1	28.7	28.8	28.6	29.1	28.7	28.7	29.0	28.9	28.8	28.3	28.0	28.6
65-74	28.6	27.9	27.5	27.0	26.7	26.2	25.7	25.9	26.3	26.5	26.6	26.9	27.7	28.5	27.0
75-84	28.5	28.7	28.8	28.8	28.9	29.0	28.6	28.5	27.9	27.4	27.3	27.0	26.7	26.6	28.0
≥85	8.4	8.7	9.4	9.7	10.0	10.7	11.3	11.8	12.1	12.2	12.7	13.0	13.1	12.9	11.2
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	1.0	1.0	0.9	1.1
Asian	2.8	2.8	2.9	3.0	3.0	3.2	3.2	3.4	3.3	3.5	3.5	3.7	3.7	3.7	3.3
Black/African American	28.1	28.3	28.0	28.1	28.4	28.0	27.7	27.4	27.3	27.1	26.7	26.4	26.1	26.0	27.4
White	66.0	65.9	66.2	65.8	65.5	66.3	67.1	67.2	67.4	67.5	68.0	68.2	68.7	69.1	67.1
Unknown	0.2	0.1	0.2	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.2	0.1	0.1
Other	1.7	1.7	1.7	1.8	1.8	1.2	0.9	0.8	0.8	0.7	0.6	0.6	0.4	0.2	1.0
Hispanic															
No	72.9	76.4	79.1	80.6	81.9	82.9	83.8	84.6	84.8	84.8	85.0	84.9	84.5	84.6	82.4
Yes	8.6	9.2	9.5	10.0	10.2	10.5	10.6	10.6	10.9	11.3	11.4	11.9	11.9	11.7	10.7
Unknown	15.4	11.8	9.2	7.2	5.8	4.7	3.8	3.2	2.6	2.3	2.0	1.7	1.6	1.4	4.9
Missing	3.2	2.6	2.2	2.2	2.1	1.9	1.8	1.6	1.6	1.6	1.6	1.6	2.1	2.2	2.0
Sex															
Male	47.8	47.6	47.5	46.9	46.3	46.0	45.8	45.3	44.9	44.3	44.2	43.8	43.6	45.4	45.6
Female	52.2	52.4	52.5	53.2	53.7	54.0	54.2	54.7	55.1	55.7	55.8	56.2	56.4	54.5	54.4
Last Treatment Modality															
Hemodialysis	86.7	87.4	88.2	88.5	88.7	88.8	89.0	89.3	89.1	89.1	89.0	88.4	87.9	88.1	88.5
Peritoneal Dialysis	7.7	7.1	6.5	6.0	5.8	5.3	5.1	4.7	4.7	4.5	4.5	4.8	5.2	5.7	5.5
Transplant	4.7	4.7	4.5	4.7	4.7	5.0	5.0	5.2	5.2	5.5	5.6	5.8	6.1	6.1	5.2
Missing	1.0	0.9	0.8	0.8	0.8	0.9	0.9	0.9	1.0	1.0	0.9	0.9	0.8	0.1	0.8
Medicare Parts A&B as primary payer during last 90 days of life															
Yes	73.4	73.4	74.4	75.0	74.9	74.3	73.2	71.5	69.6	68.8	68.1	67.7	67.5	66.6	71.2

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 2000-2013: (1) hospital admission; (2) days spent in the hospital; (3) ICU admission; (4) receipt of intensive procedures; and (5) inpatient deaths.

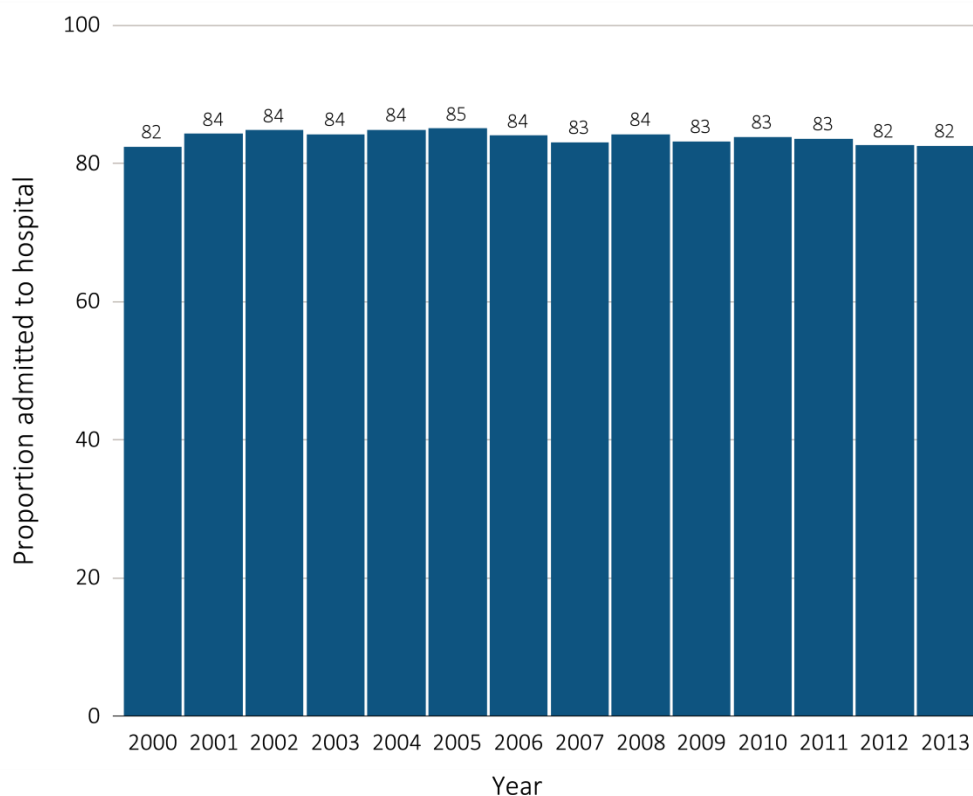
HOSPITAL ADMISSION

Overall, 83.4% of patients were hospitalized during the last 90 days of life (Figure 14.1). The percentage of patients admitted to the hospital was highest for those aged 75-84 years (84.7%) and lowest for those aged 45-64 years (81.2%). Hospital admission was most common in Blacks (84.3%) and least common in

Asians (80.6%), was more common in Hispanics vs. non-Hispanics (84.6% vs. 83.6%), in women vs. men (85.8% vs. 81.4%), and in those whose most recent modality was hemodialysis vs. peritoneal dialysis vs. transplant (83.7% vs. 82.0% 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, 27.0% 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 26.4% in 2000 to 27.6% in 2013.

vol 2 Figure 14.1 Hospital admission during the last 90 days of life among Medicare beneficiaries with ESRD, 2000-2013



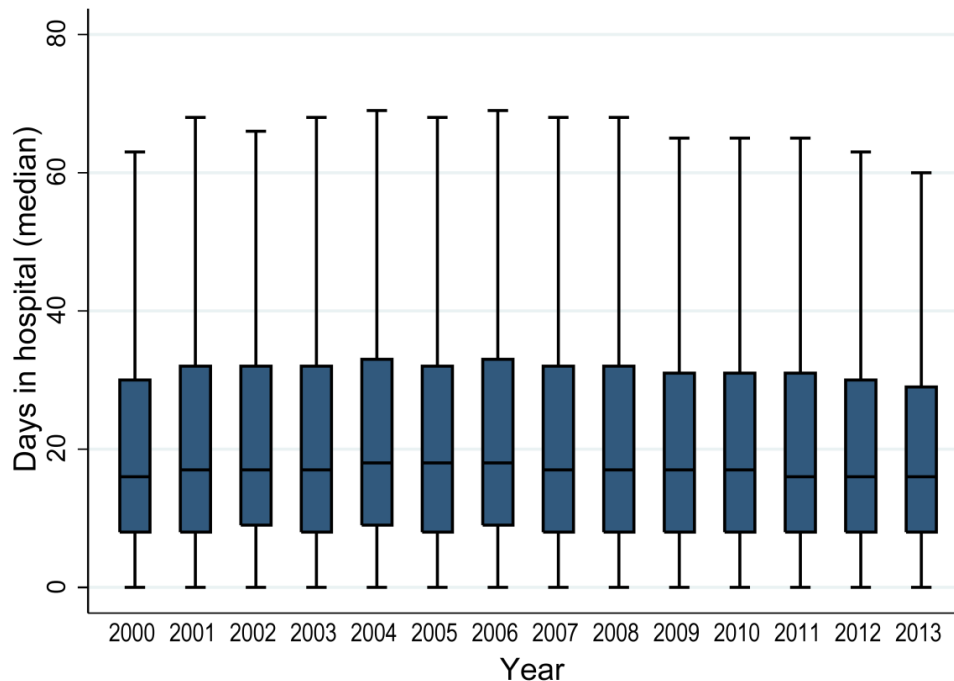
Data Source: Special analyses, USRDS ESRD Database. Denominator is all decedents with Medicare Parts A and B throughout the last 90 days of life. Includes hospital stays in both short- and long-stay hospitals. Abbreviation: ESRD, end-stage renal disease.

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 2 admissions during this time frame (interquartile range [IQR], 1, 3) and 27.7% 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. Those admitted to the hospital during the last 90 days of life spent a median of 17 days in the hospital (IQR, 8, 31) (Figure 14.2). The median number of days spent in the hospital during the last 90 days of life changed very little from 2000 through 2013.

vol 2 Figure 14.2 Days spent in the hospital during the last 90 days of life among Medicare beneficiaries with ESRD, 2000-2013



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.

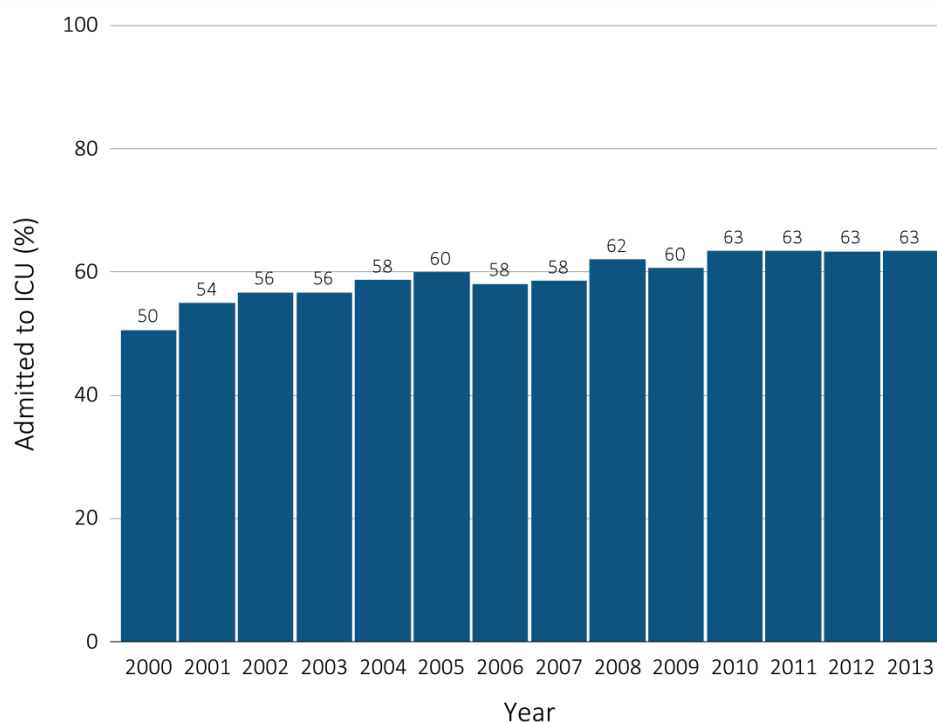
ICU ADMISSION

Overall, 59.0% of patients were admitted to an ICU during the last 90 days of life (Figure 14.3). The percentage admitted to the ICU was highest for those aged 65-74 years (61.3%) and lowest for those aged 85 years and older (51.7%), was highest for Asians (62.6%) and lowest for patients of Other race (46.9%), was higher for Hispanics vs. non-Hispanics (63.6% vs. 58.9%), was slightly higher for women vs. men (60.5% vs. 57.7%), and was similar in patients whose most

recent modality was hemodialysis vs. peritoneal dialysis vs. transplant (59.2% vs. 57.4% vs. 57.2%). Over time, the percentage of patients admitted to the ICU during the last 90 days of life increased from 50.1% in 2000 to 62.9% in 2013. There was an increase in the percentage of patients admitted to the ICU over time among all subgroups examined. The percentage of patients admitted to an ICU in the last three months of life ranged from 28.9% to 71.9% across states in the continental United States. More intensive use of ICU was found in the Southern tier of states.

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, 2000-2013

(a) ICU admission by year, overall



(b) ICU admission by age

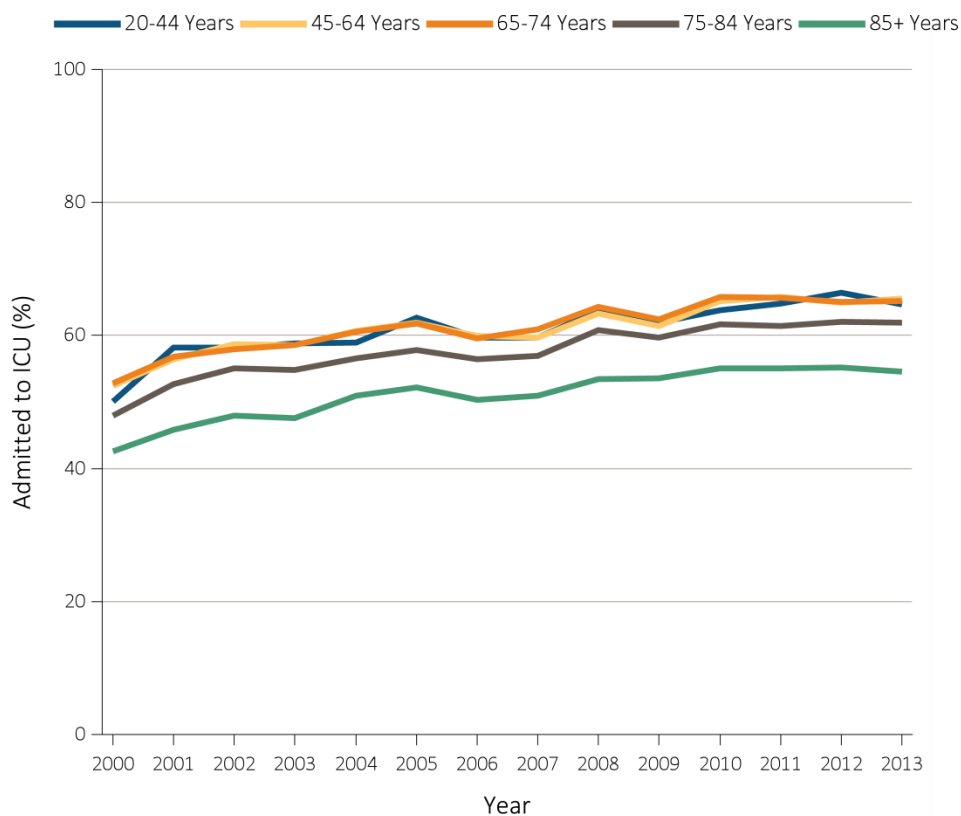


Figure 14.3 continued on next page.

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, 2000-2013 (*continued*)

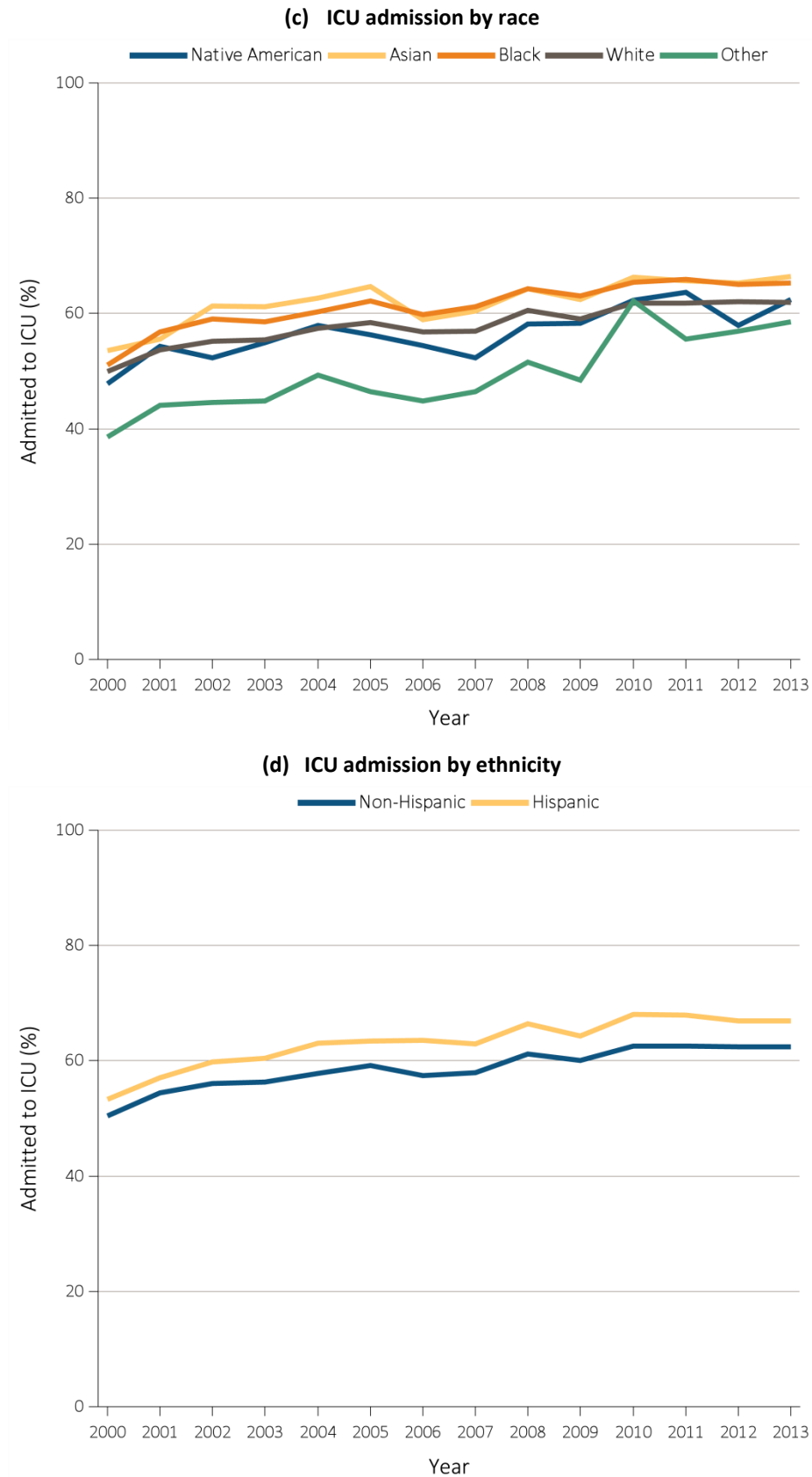


Figure 14.3 continued on next page.

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, 2000-2013 (*continued*)

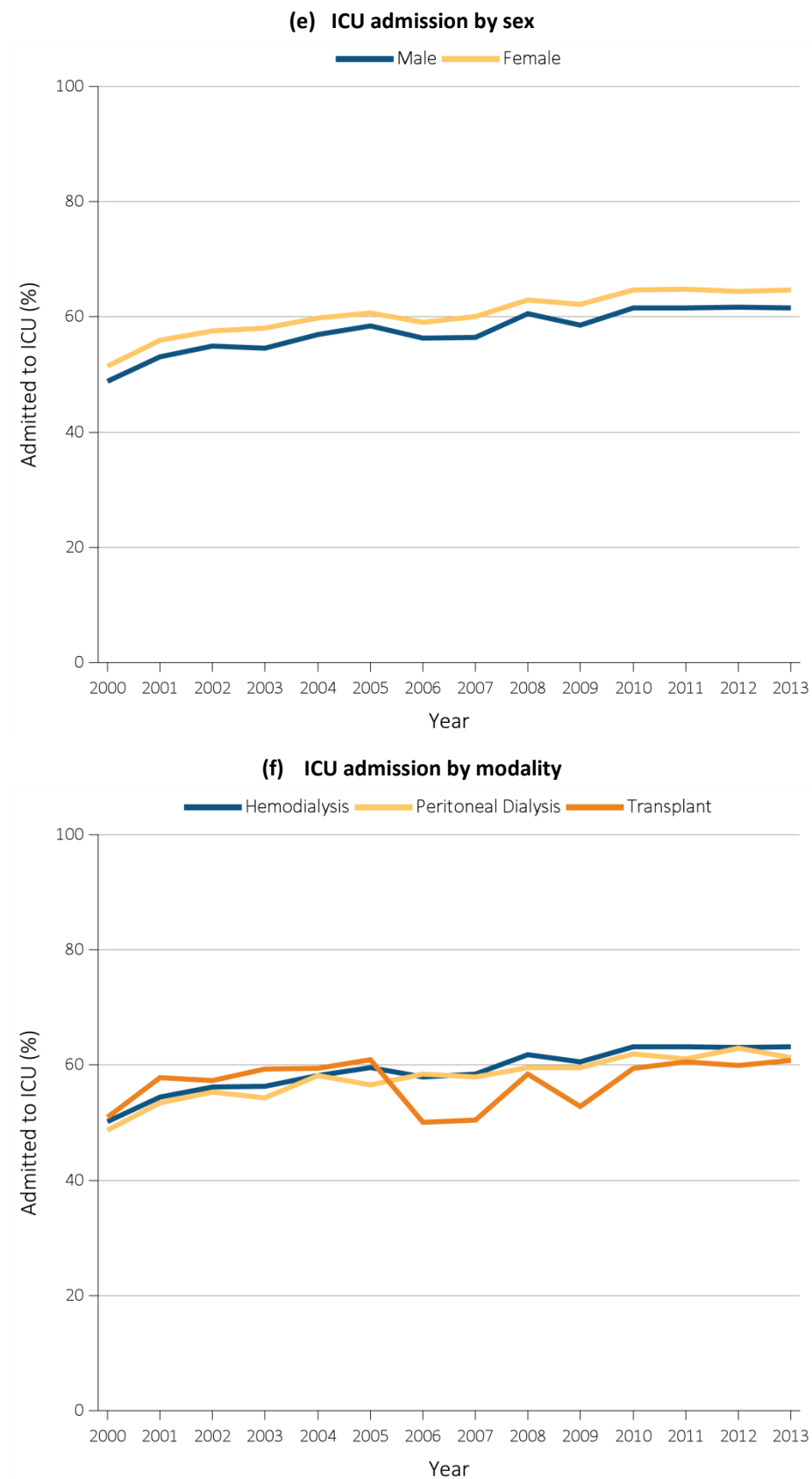
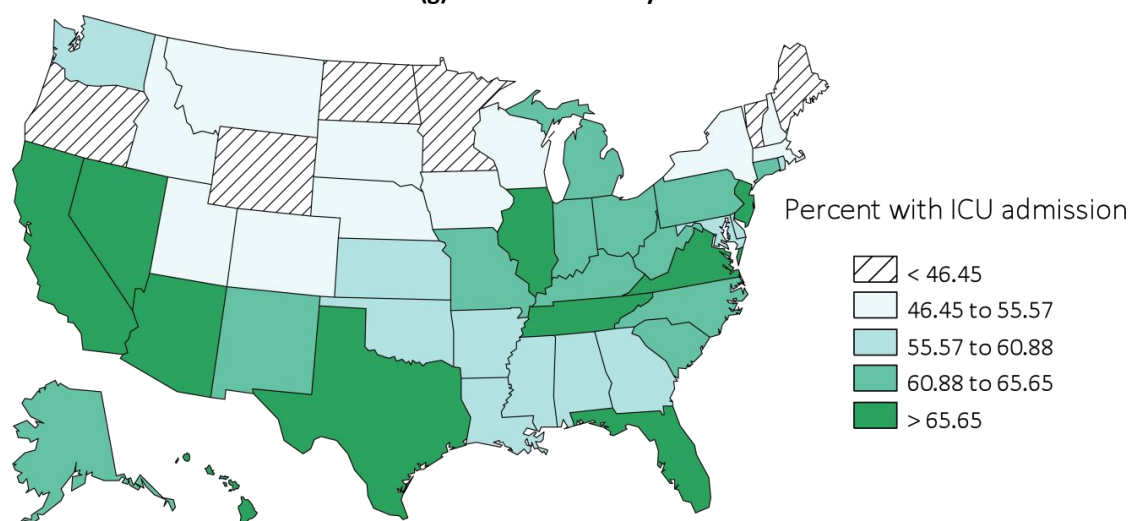


Figure 14.3 continued on next page.

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, 2000-2013 (*continued*)

(g) ICU admission by state



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 and 26.0% of patients were intubated or received mechanical ventilation (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 (42.5%) and lowest for those aged 85 years and older (20.7%), was highest for Blacks (41.2%) and lowest for Whites (28.5%), was higher for Hispanics vs. non-Hispanics (38.4% vs. 31.6%), was slightly higher for women vs. men (33.4% vs. 31.5%), and was higher for those with transplant vs. hemodialysis vs. peritoneal dialysis as the most recent modality (38.0%

vs. 32.2% vs. 30.5%). Over time, the percentage of patients who received an intensive procedure increased from 28.2% in 2000 to 34.4% in 2013. The percentage of patients who were intubated or received mechanical ventilation during the last 90 days of life increased from 21.4% to 29.6% over the same time period. The percentage of patients receiving an intensive procedure increased over time for most subgroups examined. The percentage of patients who received an intensive procedure during the last 90 days of life ranged from 14.6% to 46.4% across states in the continental United States. Use of intensive procedures roughly paralleled ICU use by region. Higher rates were found in the Southern tier of States.

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, 2000-2013

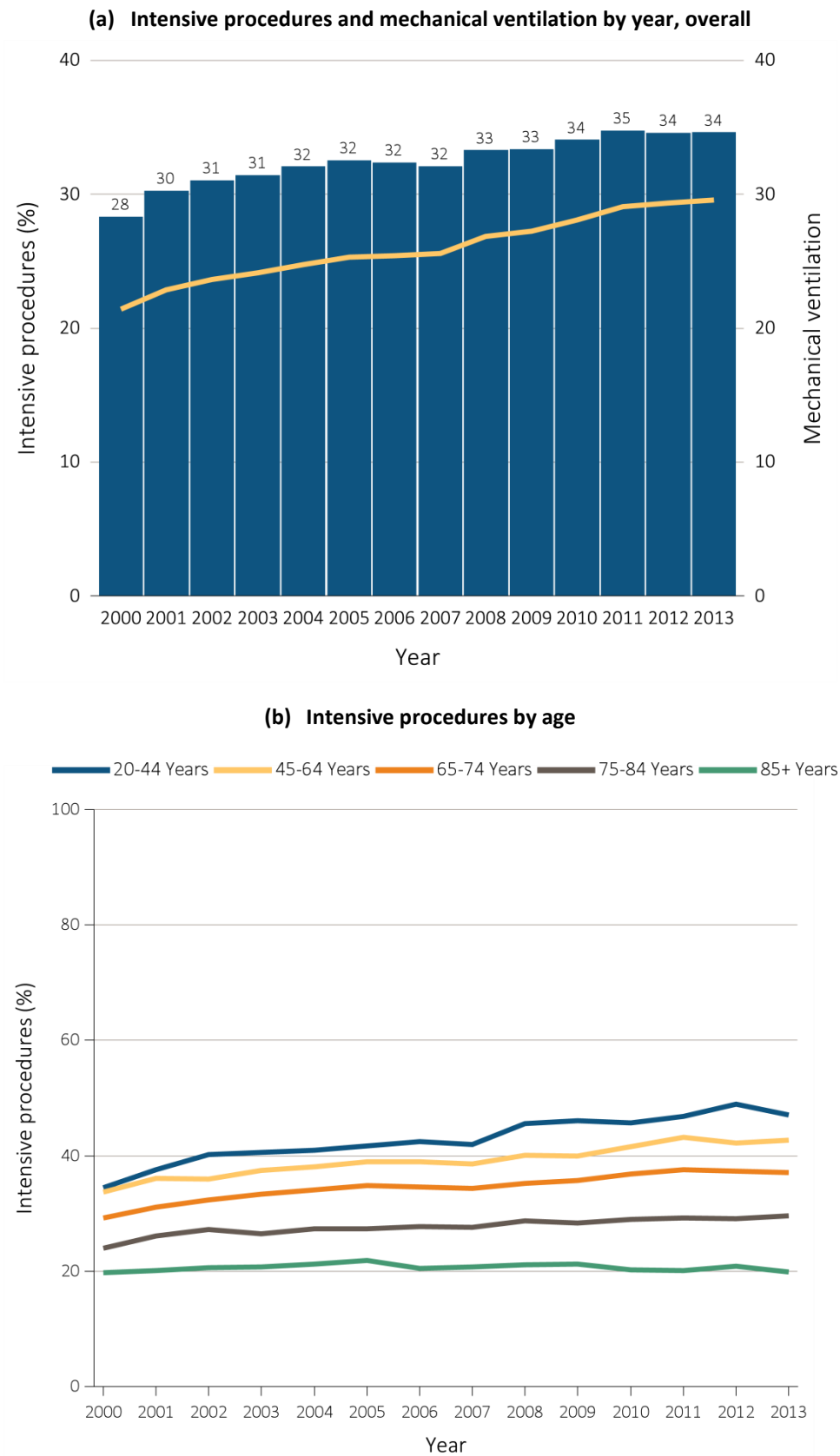


Figure 14.4 continued on next page.

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, 2000-2013 (*continued*)

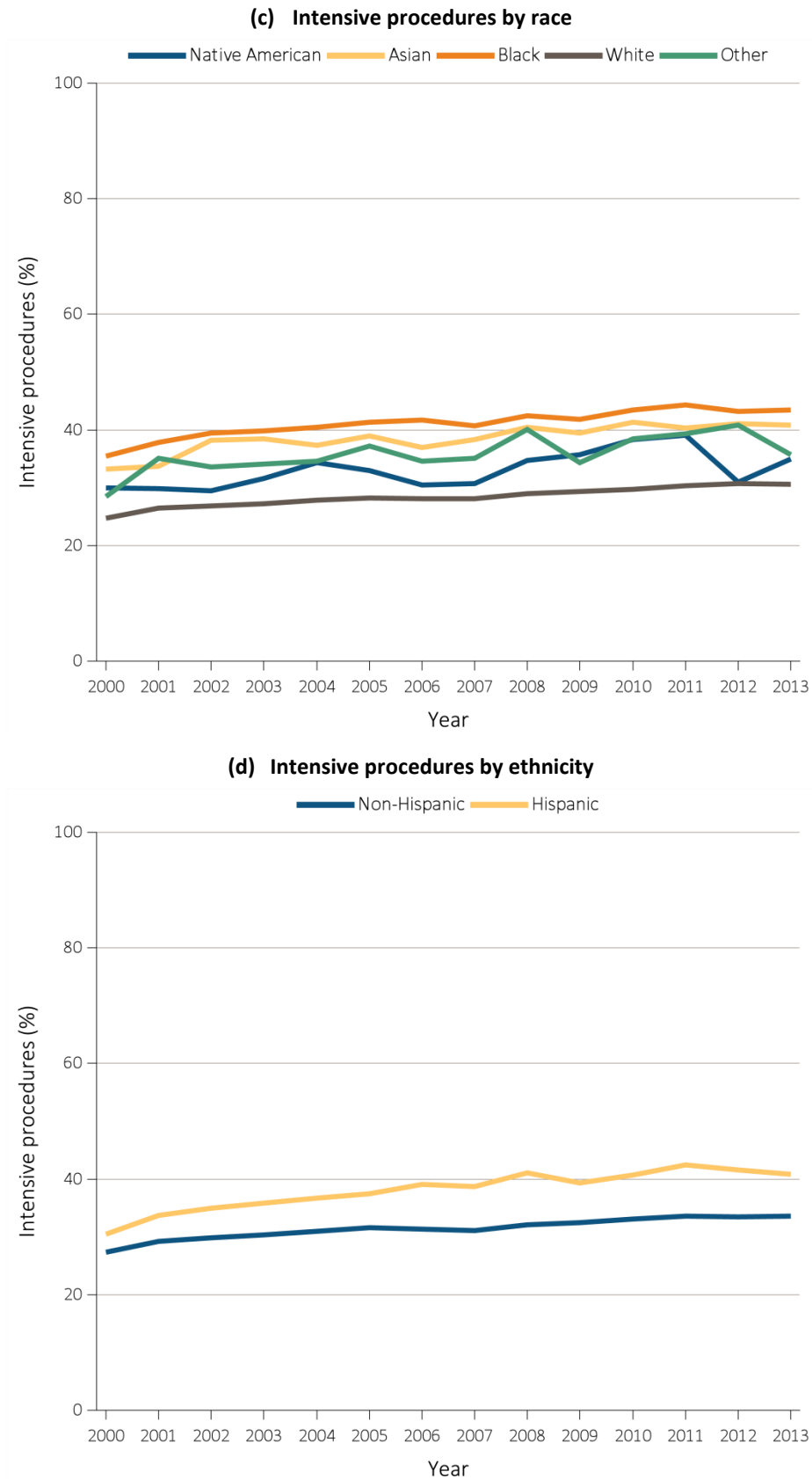


Figure 14.4 continued on next page.

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, 2000-2013 (*continued*)

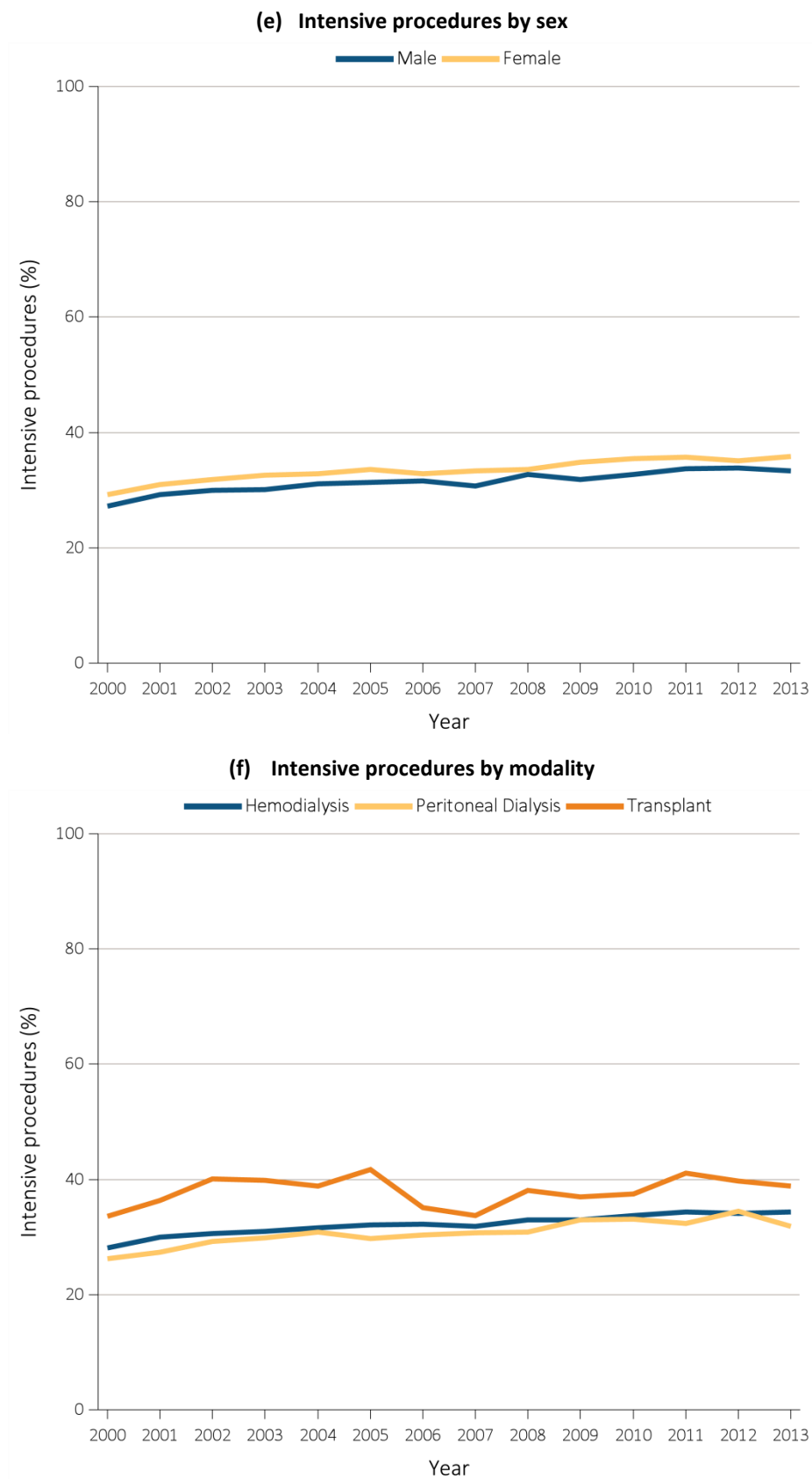
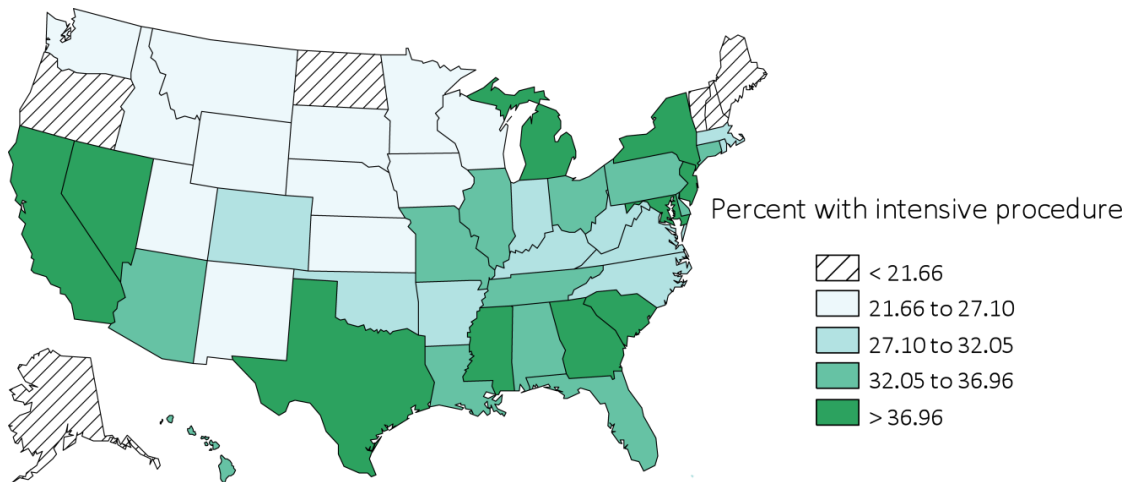


Figure 14.4 continued on next page.

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, 2000-2013 (*continued*)

(g) Intensive procedures 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. 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 DEATHS

Based on Medicare Institutional claims, 45.1% of patients died in the hospital during 2000-2013 (Figure 14.5). The proportion of inpatient deaths was highest for those aged 20-44 years (49.5%) and lowest for those aged 85 years and older (37.0%). Death in the hospital was most common in those of Other race (53.2%) and least common in Whites (42.9%), was more common in Hispanics vs. non-Hispanics (50.5% vs. 44.1%), was more common in women vs. men (46.8% vs. 43.7%), and was more common in patients whose most recent modality was transplant vs. peritoneal dialysis vs. hemodialysis (49.3% vs. 48.5%

vs. 44.7%). Over time, the percentage of inpatient deaths decreased from 49.2% in 2000 to 39.4% in 2013; 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 68.5% in 2000 to 59.0% in 2013. The sensitivity and specificity of the CMS Death Notification form for detecting inpatient deaths based on Medicare claims were 93% 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, 2000-2013

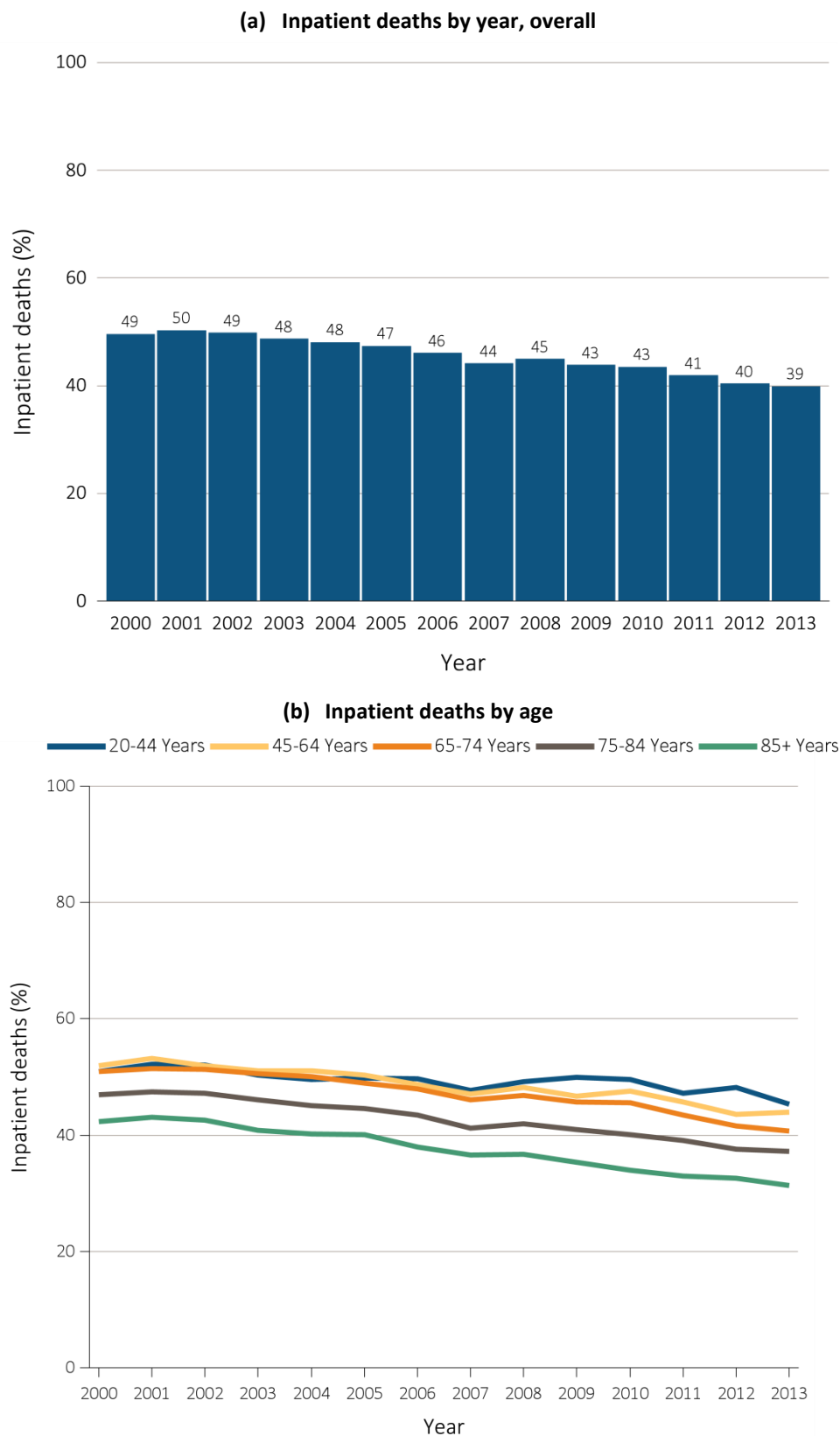


Figure 14.5 continued on next page.

vol 2 Figure 14.5 Inpatient deaths among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2013 (*continued*)

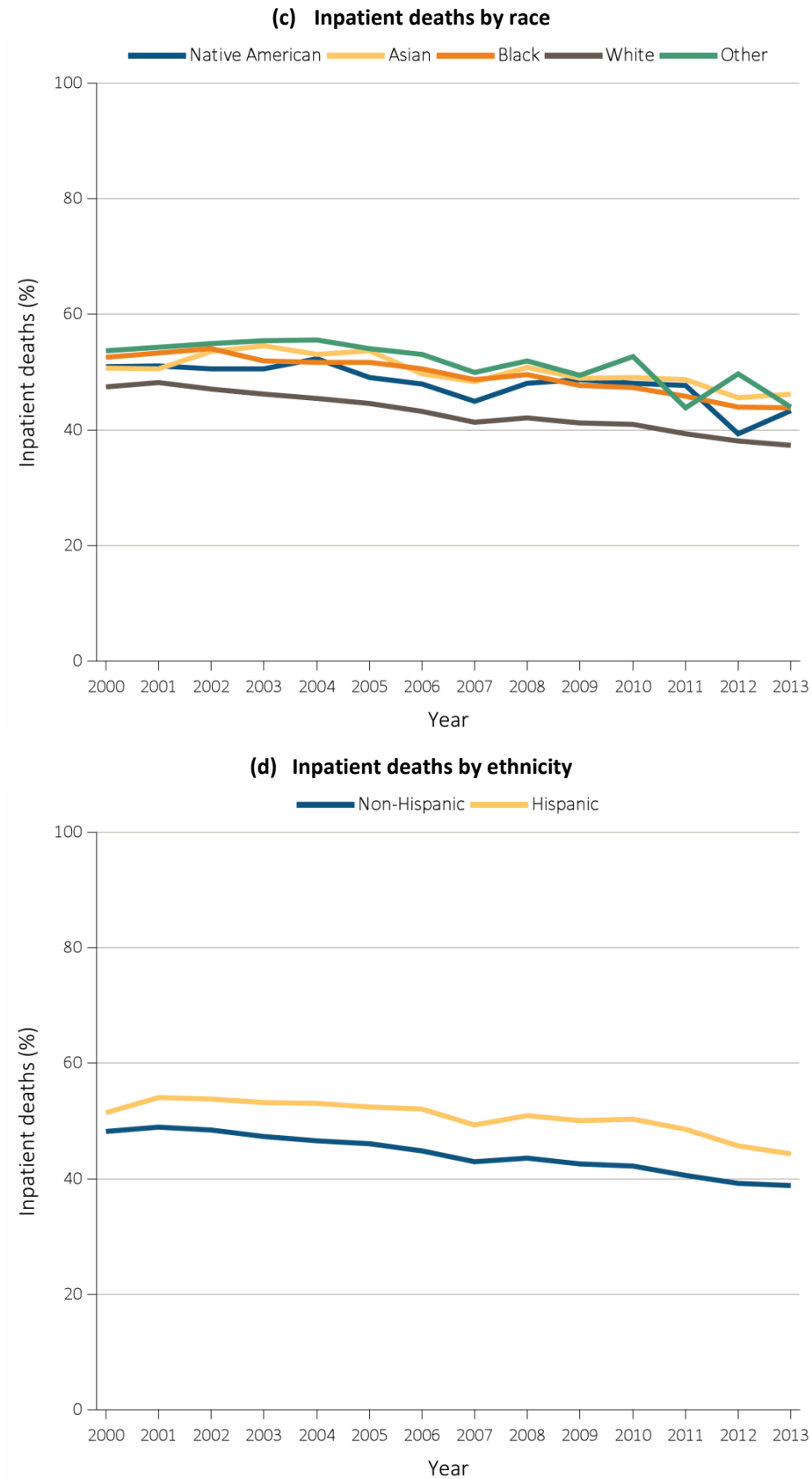
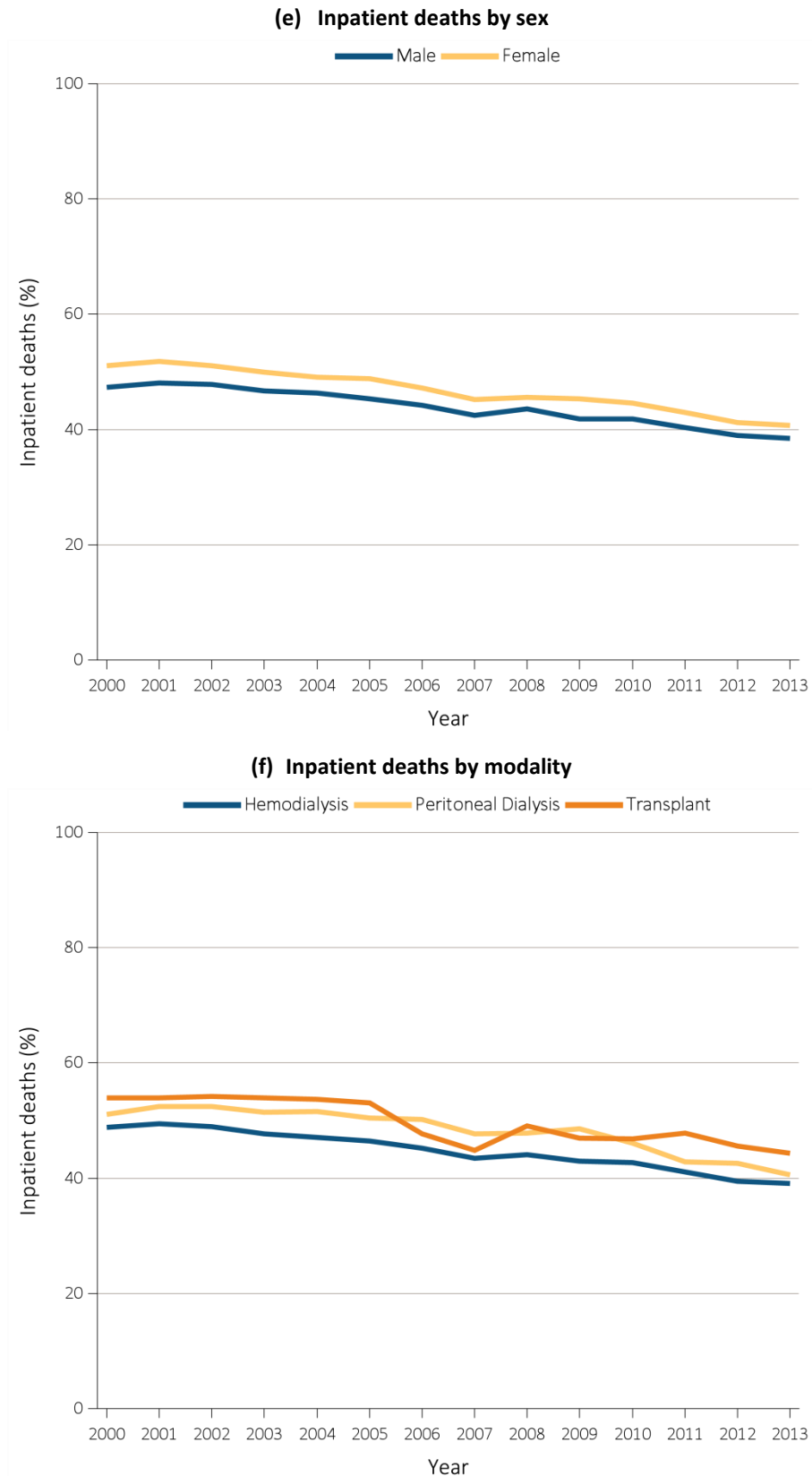


Figure 14.5 continued on next page.

vol 2 Figure 14.5 Inpatient deaths among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2013 (*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.

Nursing Facility Utilization in the Last Year of Life

We identified a total of 257,022 patients who received care in a nursing facility (i.e., SNF and/or nursing home) in the last year of life (Table 14.2). The average age of decedents who received care in a

nursing facility during the last year of life was 71 ± 12 years and the median ESRD vintage was 4 (IQR 2, 6) years (Figure 14.6). The characteristics of decedents with ESRD who received care in a nursing facility during in the last year of life did not change substantially between 2000 and 2013.

vol 2 Table 14.2 Characteristics of ESRD patients receiving care in a nursing facility during the last year of life: 2000-2013

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total
N	13,818	14,780	16,026	16,999	18,223	18,683	18,722	18,313	18,996	19,122	19,704	20,918	21,026	21,692	257,022
Age, mean (std)	70.5(11.9)	70.5(12.1)	70.8(12.0)	71.0(12.0)	70.9(12.0)	71.3(12.0)	71.3(12.1)	71.4(12.1)	71.7(12.0)	71.5(12.1)	71.5(12.0)	71.6(11.9)	71.5(12.1)	71.4(12.0)	71.3(12.0)
Vintage of ESRD, year, mean (std)	4(4)	5(4)	5(4)	5(4)	5(4)	5(4)	5(4)	5(4)	5(4)	5(4)	5(5)	6(5)	6(5)	6(5)	5(4)
Vintage of ESRD, year, median (q1,q3)	3(2,6)	3(2,6)	4(2,6)	4(2,6)	4(2,6)	4(2,6)	4(2,6)	4(2,6)	4(2,6)	4(2,7)	4(2,7)	4(2,7)	4(2,7)	4(3,8)	4(2,6)
Age Category															
20-44	3.5	3.6	3.3	3.0	3.1	2.8	2.8	2.7	2.5	2.3	2.3	2.1	2.3	2.2	2.7
45-64	22.3	22.7	22.1	23.0	22.9	22.6	23.5	22.9	22.6	23.8	24.3	24.0	24.9	24.3	23.4
65-74	32.4	31.4	30.9	29.6	29.8	29.0	28.3	28.9	28.9	28.9	28.9	29.4	28.6	30.1	29.5
75-84	32.7	33.0	33.7	34.1	34.0	34.4	33.2	33.0	32.7	31.4	31.0	30.6	30.4	29.6	32.3
>=85	9.1	9.4	10.1	10.3	10.2	11.1	12.2	12.5	13.2	13.5	13.5	13.9	13.9	13.8	12.1
Race															
Native American	1.4	1.0	1.3	1.1	1.1	1.1	1.1	1.1	1.1	1.0	1.0	1.1	1.0	1.0	1.1
Asian	1.9	1.9	1.9	2.2	2.0	2.1	2.3	2.3	2.4	2.5	2.5	2.6	2.8	2.9	2.3
Black/African American	29.6	29.9	29.3	29.1	30.0	29.1	29.6	29.5	28.3	28.9	28.3	28.3	28.4	27.7	28.9
White	66.5	66.3	66.5	66.7	66.0	67.1	66.7	66.8	67.7	67.2	67.8	67.5	67.5	68.2	67.1
Unknown	0.1	0.1	0.1	0.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.0
Other	0.6	0.8	0.9	0.9	0.8	0.5	0.3	0.3	0.4	0.4	0.3	0.4	0.3	0.2	0.5
Hispanic															
Missing on Hispanic	0.4	0.5	0.4	0.3	0.3	0.4	0.3	0.2	0.4	0.4	0.4	0.4	0.5	0.5	0.4
Hispanic	8.0	8.5	8.5	8.9	8.6	9.2	8.9	9.0	8.9	9.6	9.3	9.9	10.7	10.8	9.3
Non-Hispanic	81.0	84.7	87.1	88.4	89.2	89.0	89.8	90.1	90.0	89.4	89.7	89.1	88.4	88.4	88.4
Unknown	10.7	6.3	4.0	2.4	1.8	1.5	0.9	0.7	0.8	0.7	0.6	0.6	0.4	0.3	2.0
Sex*															
Male	46.0	46.7	46.6	47.0	48.7	48.9	49.3	50.0	50.3	51.4	51.5	51.7	51.7	51.6	49.6
Female	54.0	53.3	53.4	53.0	51.3	51.1	50.6	50.0	49.7	48.6	48.5	48.3	48.3	48.4	50.4
Last Treatment Modality															
Missing on modality	9.7	10.7	11.6	11.1	11.8	12.3	13.1	12.4	16.2	14.5	15.2	15.5	16.0	16.6	13.6
Hemodialysis	82.0	82.0	82.0	82.4	81.8	81.8	81.1	82.1	78.1	79.7	78.8	77.9	76.9	76.1	80.0
Peritoneal dialysis	5.4	4.1	3.6	3.4	3.2	2.7	2.8	2.5	2.3	2.0	2.1	2.4	2.5	2.6	2.9
Transplant	2.9	3.2	2.9	3.1	3.2	3.1	3.1	3.1	3.4	3.7	3.9	4.1	4.6	4.7	3.6
Dual eligibility															
Missing on dual eligibility	10.1	10.2	10.7	10.1	9.8	9.5	9.1	9.0	9.4	9.4	9.8	9.3	9.8	4.7	9.3
Dual eligibility	53.6	54.0	53.5	54.5	53.5	53.0	53.8	54.1	54.0	53.6	54.0	53.6	53.0	56.0	53.9
Non-dual eligibility	36.3	35.7	35.8	35.4	36.7	37.6	37.1	36.9	36.6	37.0	36.2	37.1	37.2	39.3	36.9
Medicare Parts A&B as primary payer during last 365 days of life															
Yes	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Data Source: Special analyses, USRDS ESRD Database. *Represents percentages that may not add up to 100% due to missing values. The denominator population is all ESRD patients who were at least 20 years of age at the time of death, received treatment for ESRD for at least one year, and had continuous Medicare Parts A&B coverage during the last year of life. Nursing facility use was ascertained using Medicare claims. Abbreviation: ESRD, end-stage renal disease.

Overall, 42.0% of patients with ESRD received care in a nursing facility during the last year of life, increasing from 37.4% in 2000 to 46.1% in 2013. Nursing facility care at the end of life increased among all age groups between 2000 and 2013, with the highest use among the oldest age group, those aged 85 and older (57.2%). Women were more likely than men to receive nursing facility care at the end of life (46.1% vs. 38.3%). Whites were more likely to receive nursing facility care at the end of life compared to Blacks, Asians, and those of Other race (43.5% vs. 40.4% vs. 33.5% vs. 23.0%), and non-Hispanics were more likely to receive nursing facility care than Hispanics (43.2% vs. 34.1%). There were marked differences in receipt of nursing facility care at the end of life by modality, with the highest percentage among patients receiving hemodialysis (43.0%), followed by transplant recipients (27.8%), followed by those receiving peritoneal dialysis (22.3%). Notably, patients receiving peritoneal dialysis were the only group for whom nursing facility care at the end of life decreased over time, from 25.8% in 2000 to 23.6% in 2013.

An increase over time in the percentage of patients receiving nursing facility care at the end of life was accompanied by an increase in the total number of days spent in a nursing facility at the end of life. Overall, those admitted to a nursing facility in the last year of life spent a median of 54 days (IQR 18, 162) in a nursing

facility, increasing from 43 days (IQR 14, 144) in 2000 to 57 days (IQR 20, 166) in 2013. The median number of nursing facility days covered by Medicare Part A claims, which is part of the post-acute hospitalization SNF benefit, was 30 (IQR 8, 75). Median number of nursing facility days increased over time for all age groups except for those aged 85 years and older. Among this age group, the median number of days spent in a nursing facility during the last year of life decreased from 71 days (IQR 19, 228) to 63 days (IQR 23, 194) between 2000 and 2013. Consequently, by 2013 there were only modest differences across age groups in the number of days spent in a nursing facility during the last year of life. There were large differences in the median number of days spent in a nursing facility by race. Asians (59 days [IQR 16, 204]) and Blacks (64 days [IQR 20, 195]) had the highest median number of nursing facility days, whereas Whites had shorter median nursing facility days (50 days [IQR 17, 147]). Median nursing facility days also differed substantially by modality, with hemodialysis patients spending the longest median number of days in a nursing facility (56 days [IQR 19, 169]), as compared with transplant recipients (31 days [IQR 11, 84]) and peritoneal dialysis patients (25 days [IQR 8, 77]).

vol 2 Figure 14.6 Nursing facility utilization in the last year of life among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2013

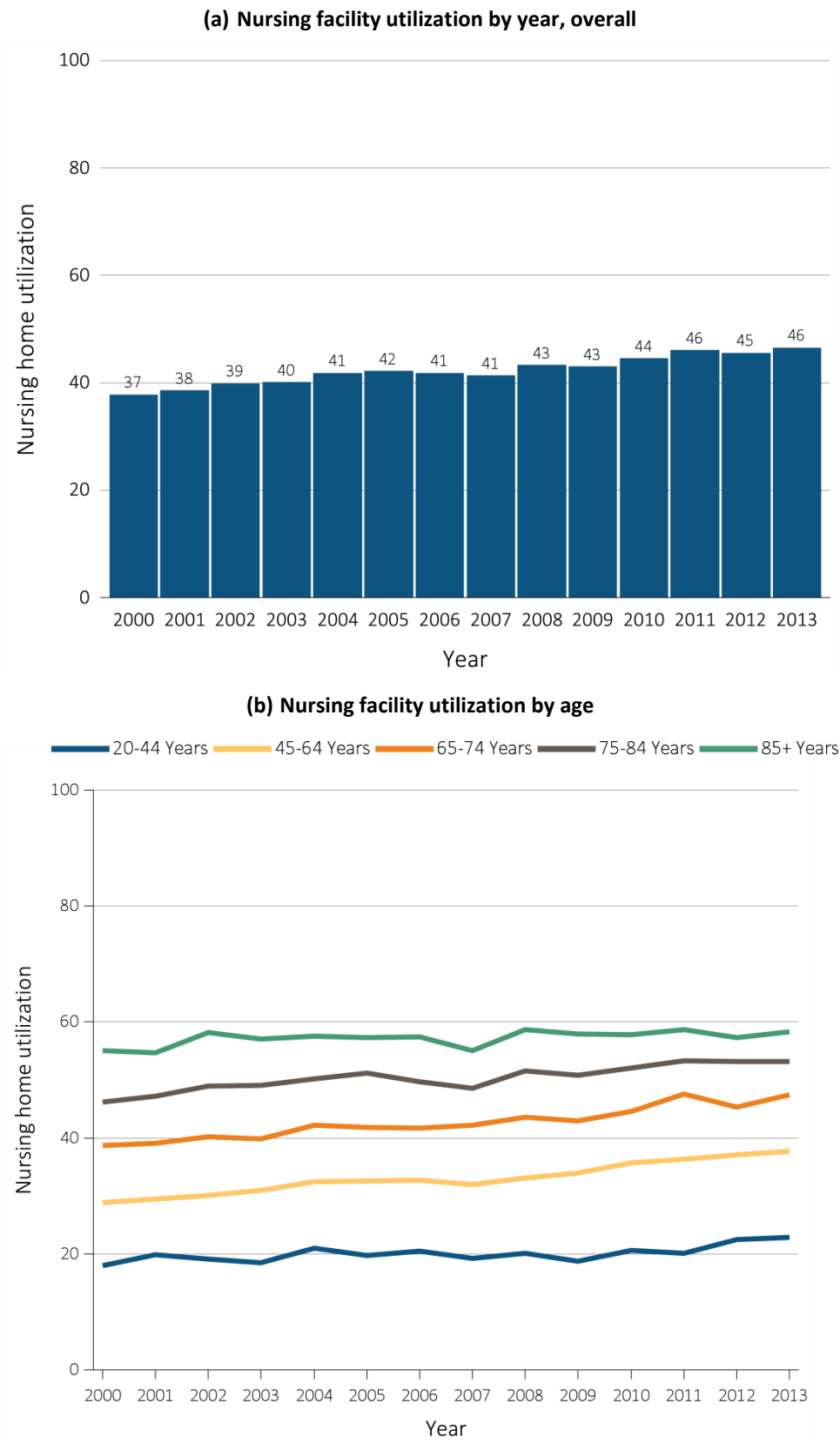


Figure 14.6 continued on next page.

vol 2 Figure 14.6 Nursing facility utilization in the last year of life among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2013 (*continued*)

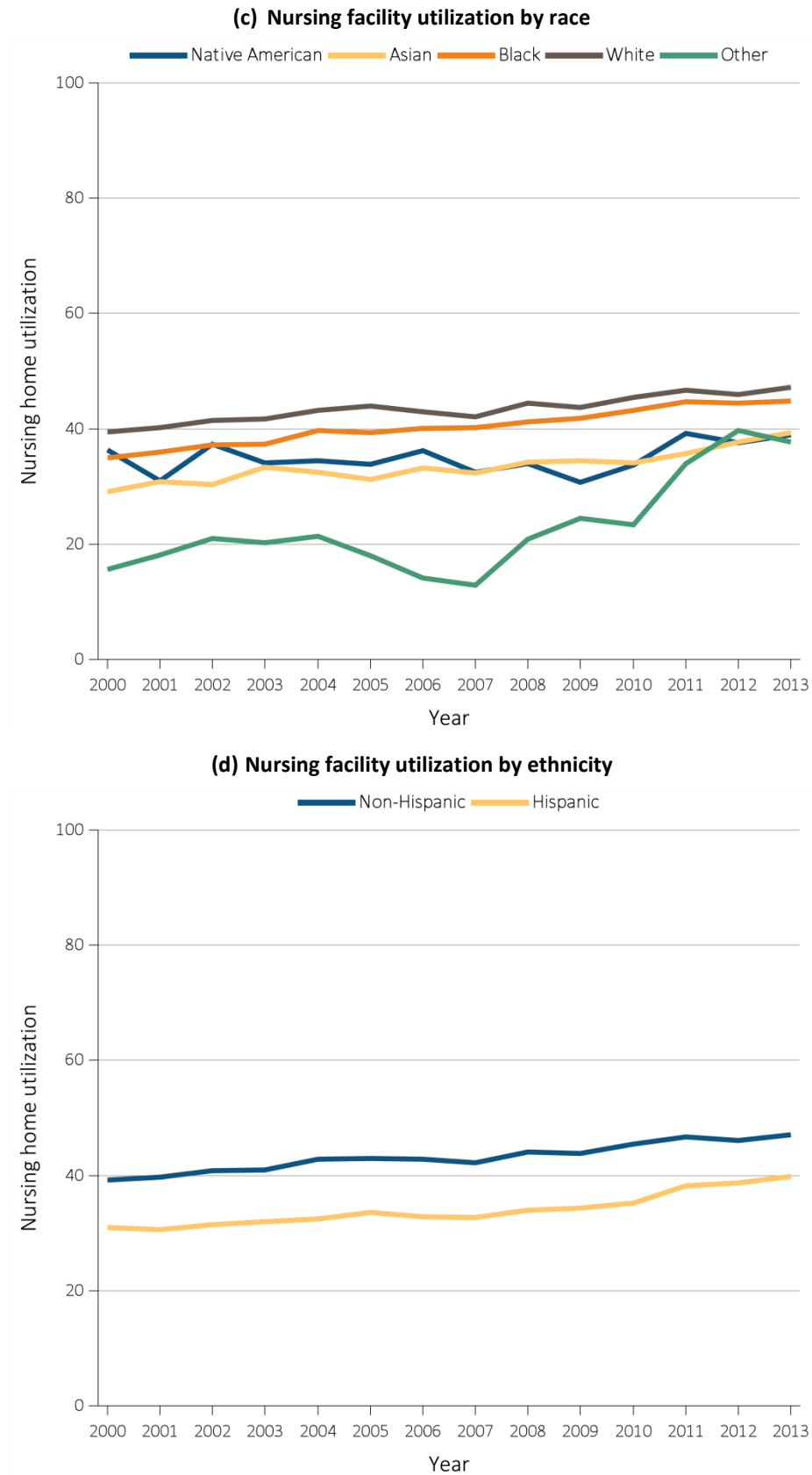
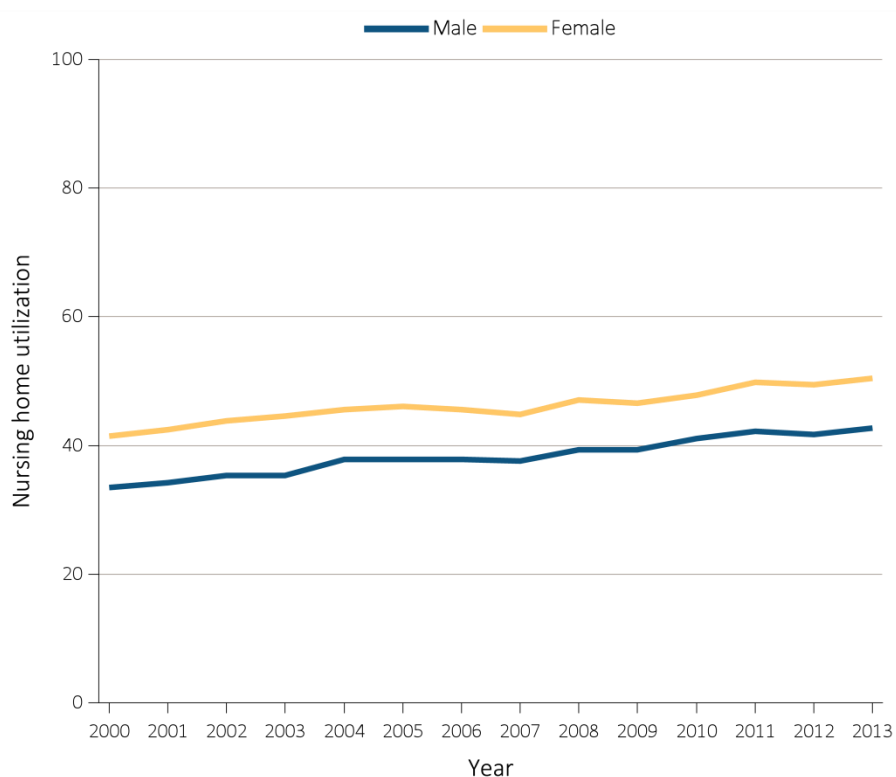


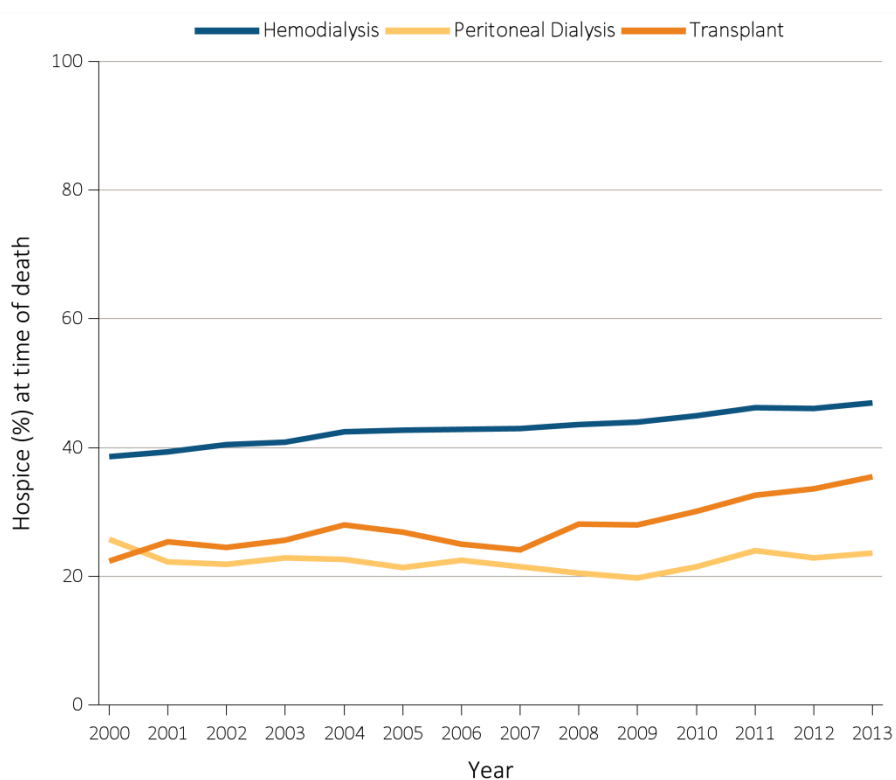
Figure 14.6 continued on next page.

vol 2 Figure 14.6 Nursing facility utilization in the last year of life among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2013 (*continued*)

(e) Nursing facility utilization by sex



(f) Nursing facility utilization by modality



Data Source: Special analyses, USRDS ESRD Database. Denominator population is all decedents admitted to a nursing home during the last year of life. Abbreviation: ESRD, end-stage renal disease.

Dialysis Discontinuation Before Death

Overall, 23.4% 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 (Figure 14.7). The frequency of dialysis discontinuation before death was highest for patients aged 85 years and older (34.1%) and lowest for those aged 20-44 years (11.2%), was highest for Whites (27.6%) and lowest for patients of Other race (10.6%), was higher for non-Hispanics vs. Hispanics (22.3% vs. 17.9%), was higher for women vs. men (24.0% vs. 22.0%), and for those whose most recent modality was hemodialysis vs. peritoneal dialysis (23.4% vs. 22.3%). 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 (4 days, IQR, 2, 8 days) vs. hemodialysis (7 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 upward trend in the percentage of decedents who discontinued dialysis before death from 19.6% in 2000 to 25.8% in 2011, with a slight decrease more recently to 23.8% in 2013. The percentage of decedents who discontinued dialysis generally increased over time for most subgroups examined over this time period. The percentage of patients who discontinued dialysis before death ranged from 12.7% to 47.6% across states in the continental United States. The lowest rates of discontinuation occurred in the Southern tier of states, roughly paralleling higher rates of intensive procedures and ICU use at the end of life.

vol 2 Figure 14.7 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2013

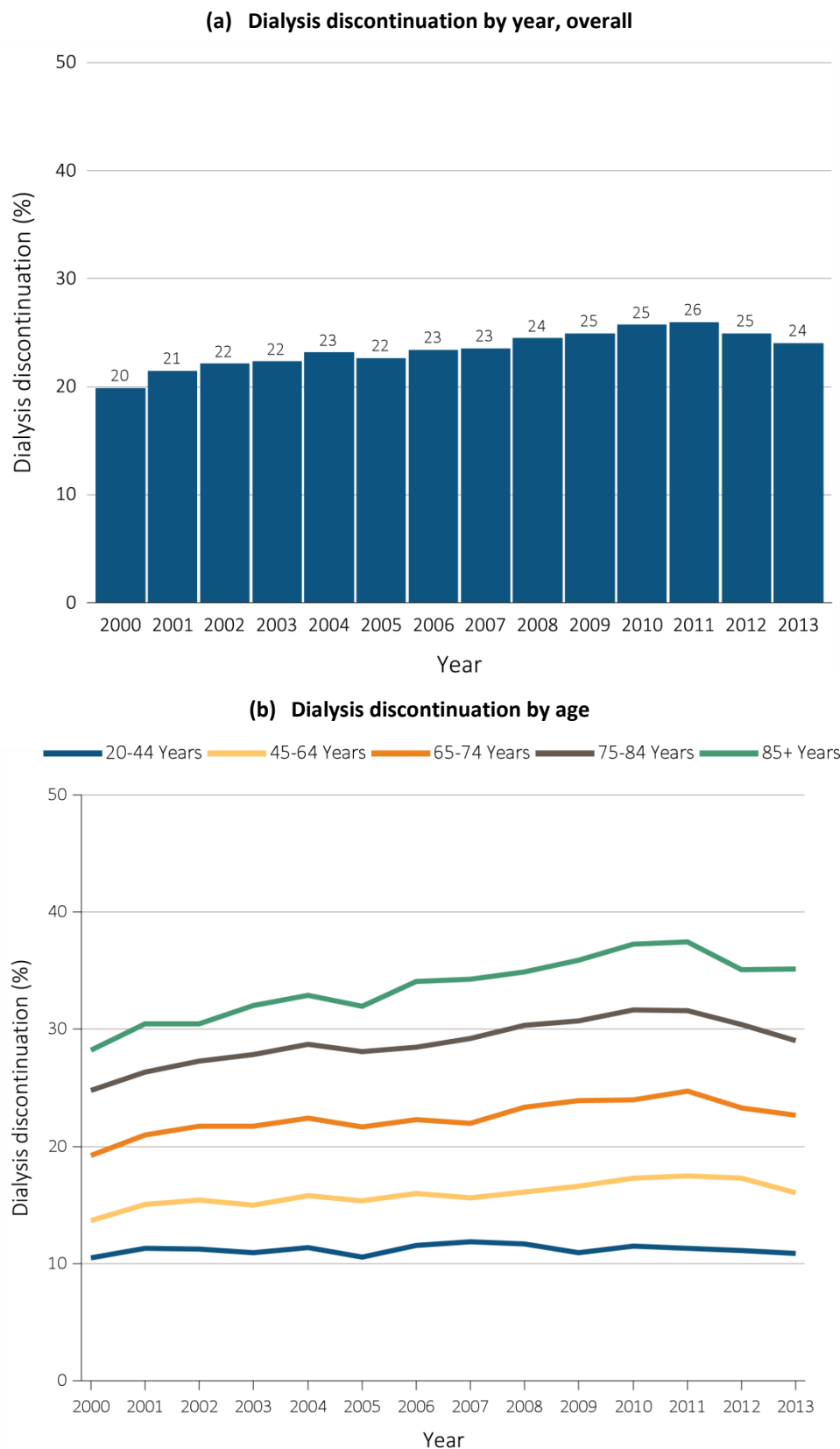


Figure 14.7 continued on next page.

vol 2 Figure 14.7 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2013 (*continued*)

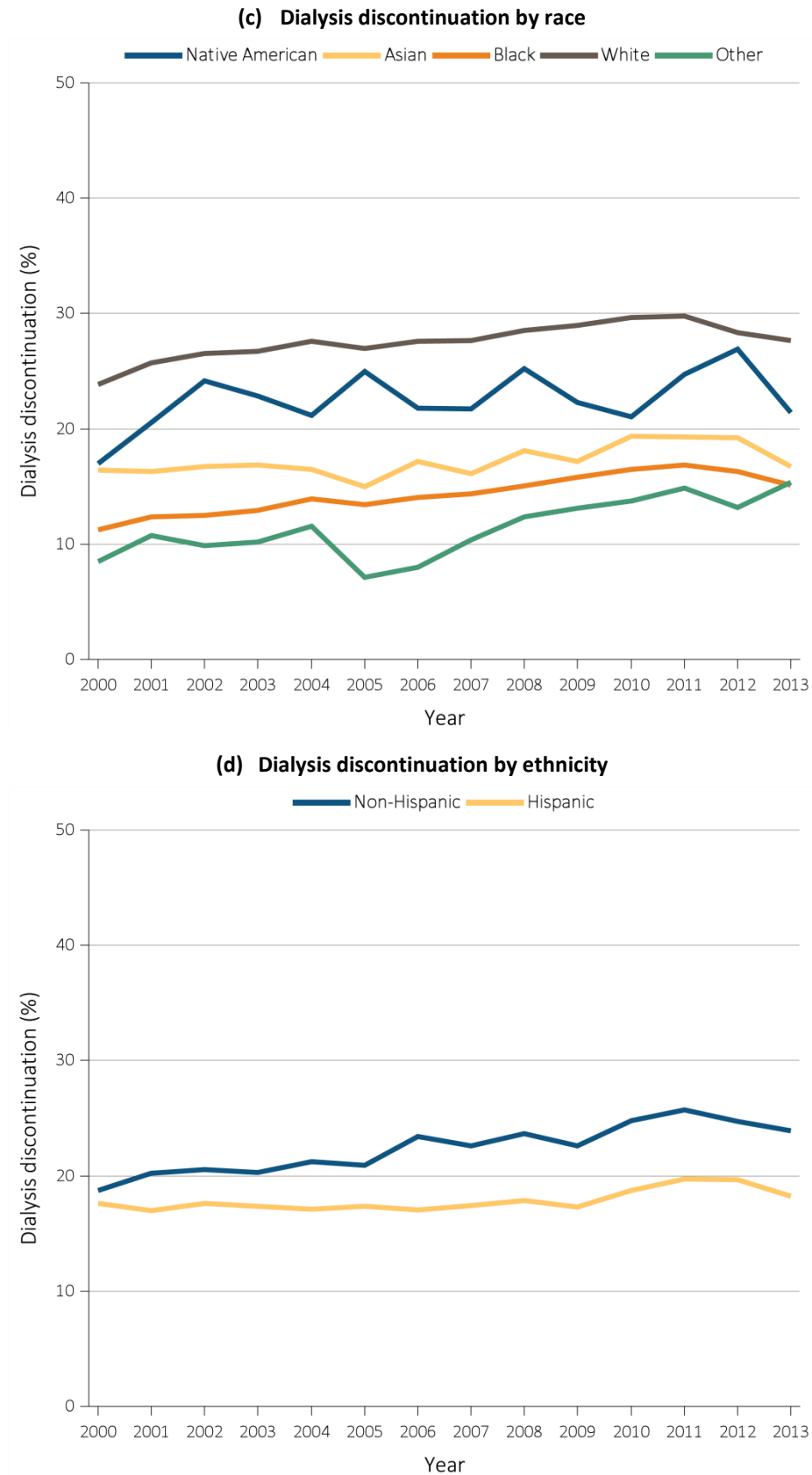


Figure 14.7 continued on next page.

vol 2 Figure 14.7 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2013 (*continued*)

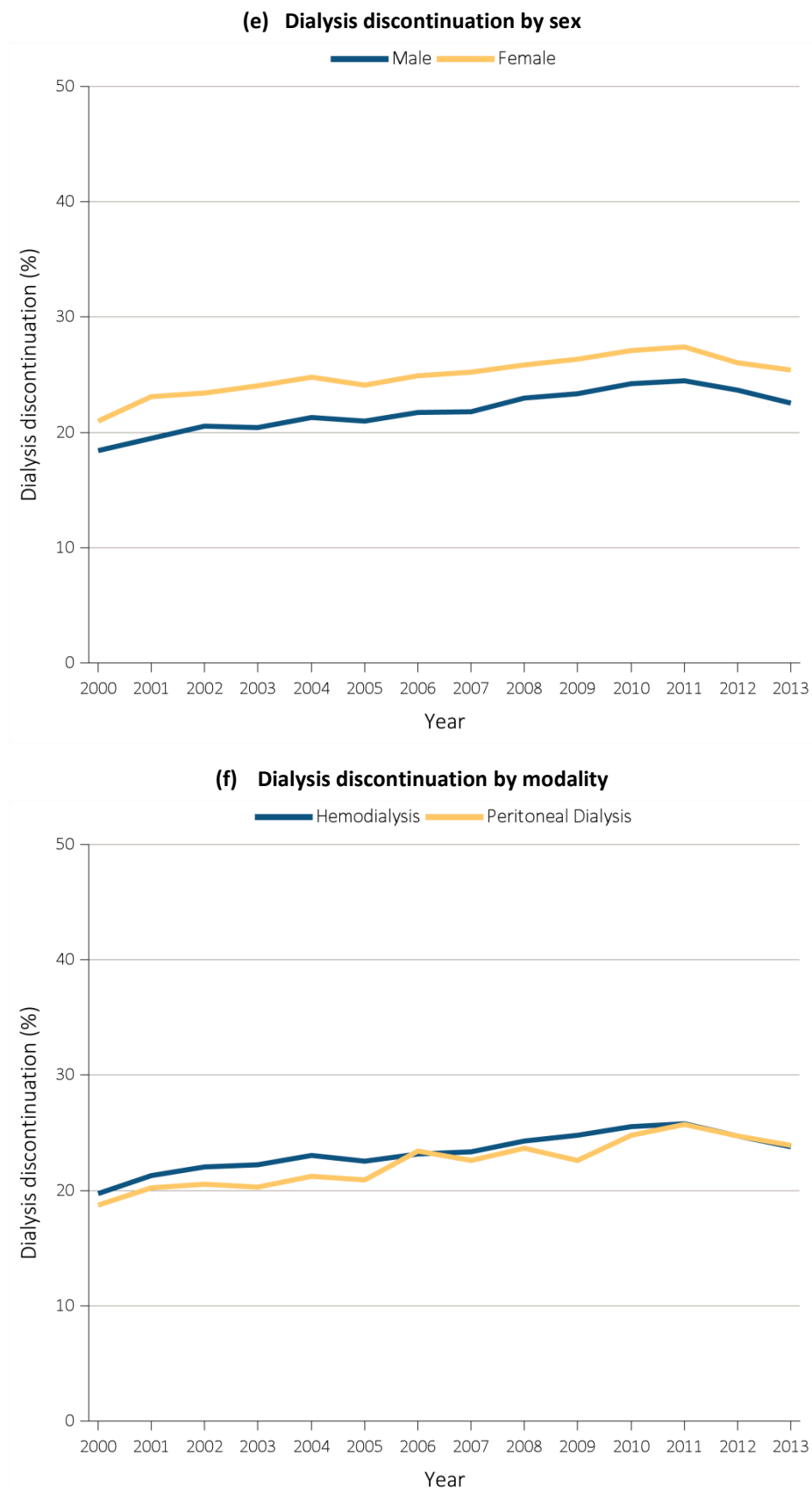
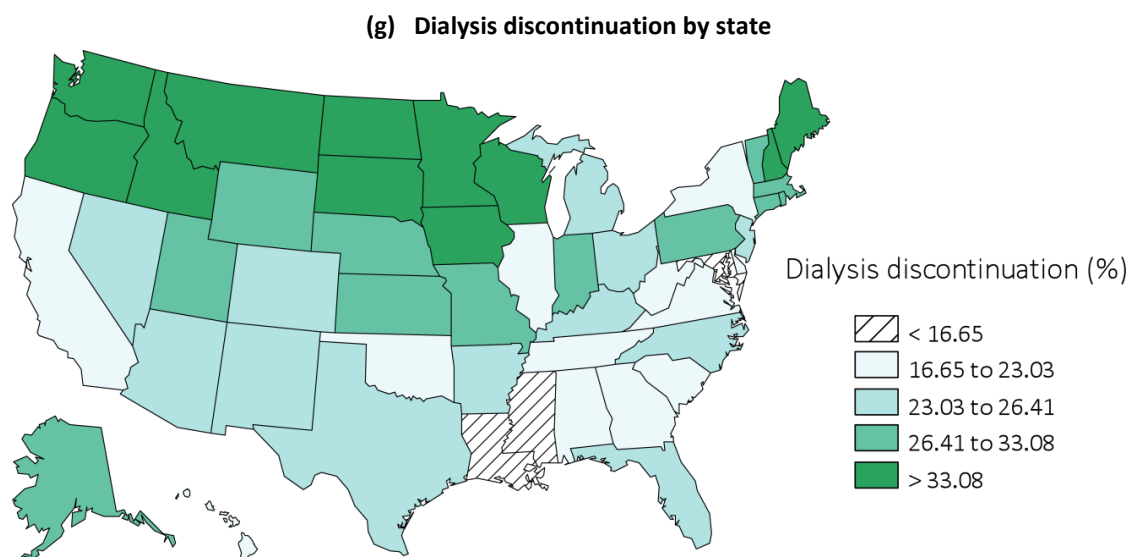


Figure 14.7 continued on next page.

vol 2 Figure 14.7 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2013 (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.

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 (Figure 14.8). Use of hospice services was highest for patients aged 85 years and older (29.4%) and lowest for those aged 20-44 years (7.0%), was highest for Whites (22.7%) and lowest for those of Other race (7.7%), was higher for non-Hispanics vs. Hispanics (20.2% vs. 15.5%), was higher for women vs. men (20.2% vs. 18.4%), and was higher for those whose most recent modality was hemodialysis vs. peritoneal dialysis vs. transplant (19.3% vs. 18.6% vs. 18.3%). The percentage of patients receiving hospice services at the time of death based on Medicare claims differed markedly according to whether patients did or did not discontinue dialysis based on the CMS Death Notification form (53.2 % vs. 9.1%), most likely reflecting both the intertwined nature of these two treatment decisions and 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 26.6% in 2013; hospice utilization increased over time for most subgroups. Hospice use at the time of death ranged from 14.7% to 39.8% across states in the continental United States, although regional patterns of hospice use did not correspond with those of other markers of healthcare intensity such as use of intensive procedures, ICU admission and dialysis discontinuation. 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 39.6% of patients had their first claim for hospice ≤ 3 days before death.

Figure 14.8 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 Death Notification form, 24.0% of decedents for whom this information was available were reported to have received hospice care before death (data available only from 2004-2013). 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. As for claims-based analyses, 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: 74.3% of those who had discontinued dialysis before death received hospice as compared with 6.7% of those who had not

discontinued dialysis. From 2004-2013, the percentage of patients who received hospice care prior to death based on the CMS Death Notification form increased from 17.5% to 27.5% in the overall population for whom this was reported, from 59.3% to 81.5% for those who discontinued dialysis treatments before death, and from 5.4% to 7.8% for those who did not.

vol 2 Figure 14.8 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, 2000-2013

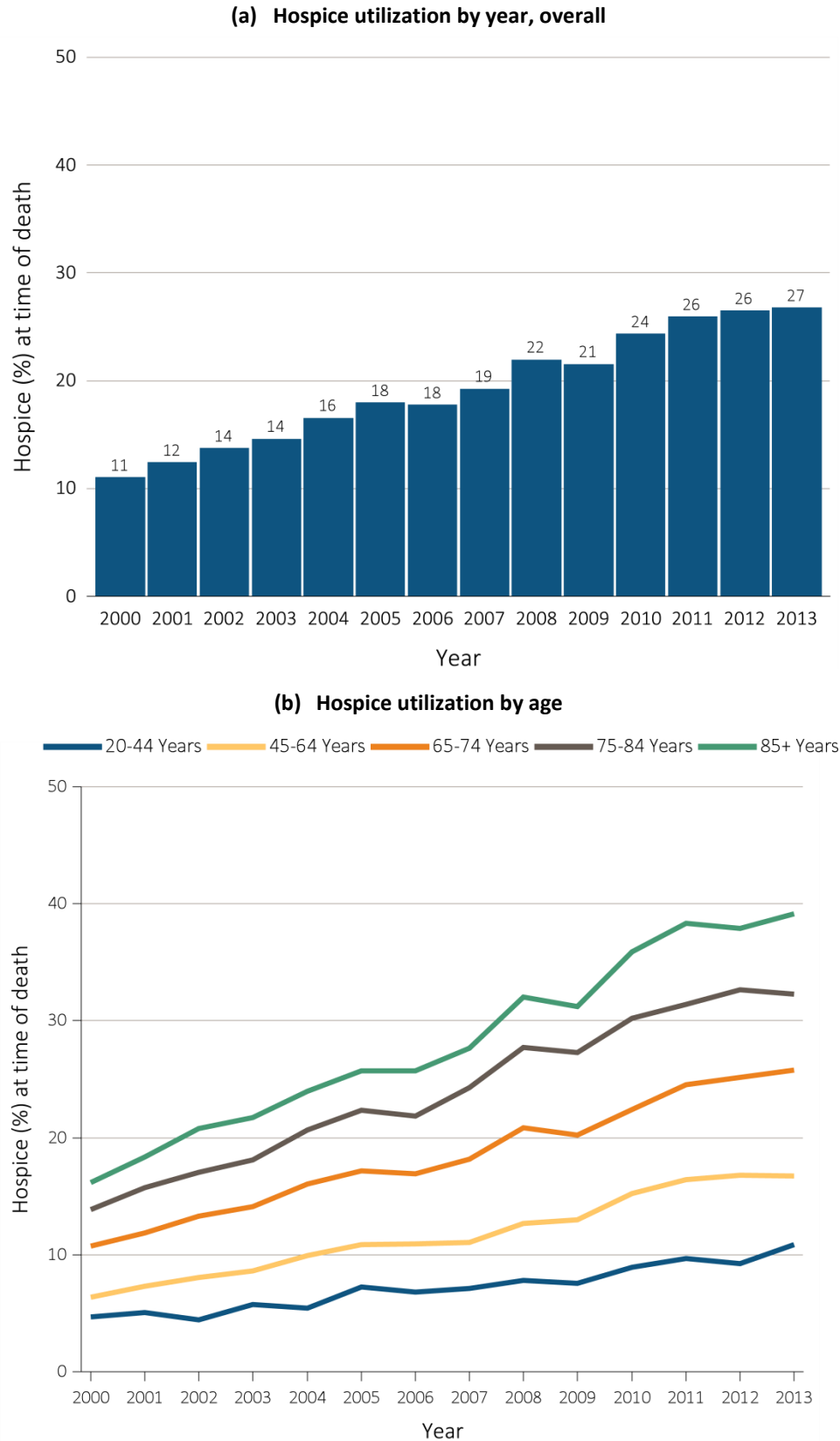


Figure 14.8 continued on next page.

vol 2 Figure 14.8 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, 2000-2013 (*continued*)

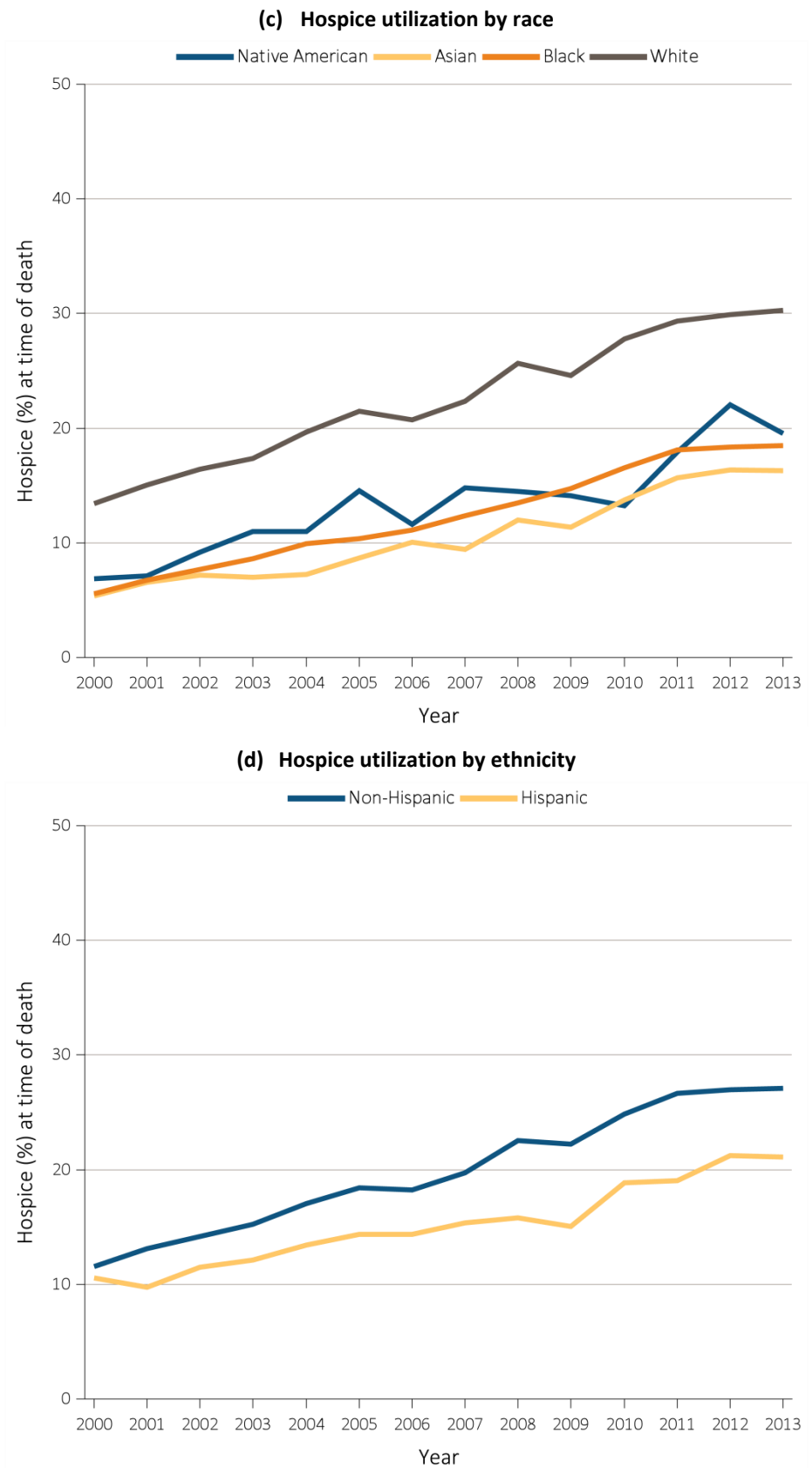


Figure 14.8 continued on next page.

vol 2 Figure 14.8 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, 2000-2013 (*continued*)

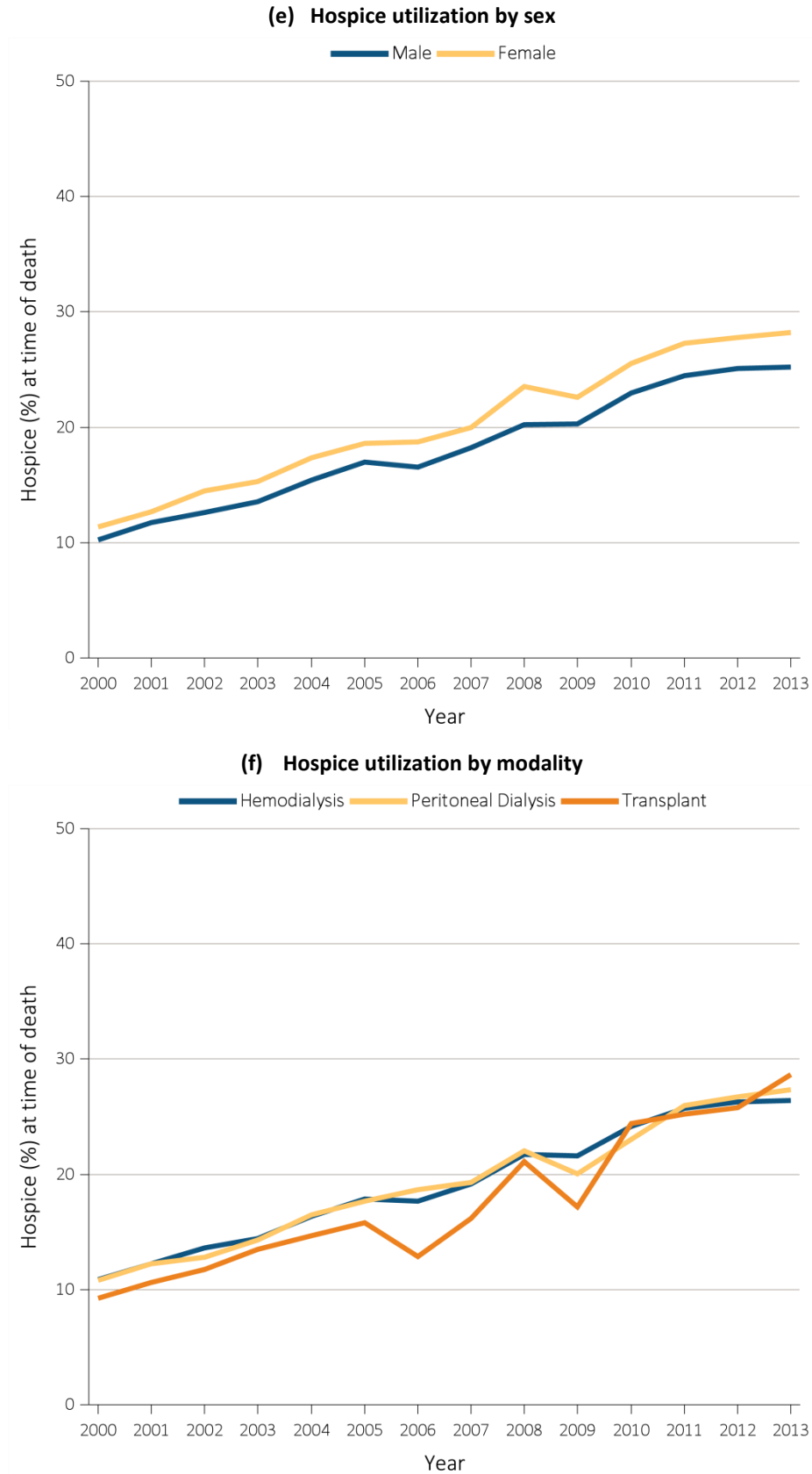
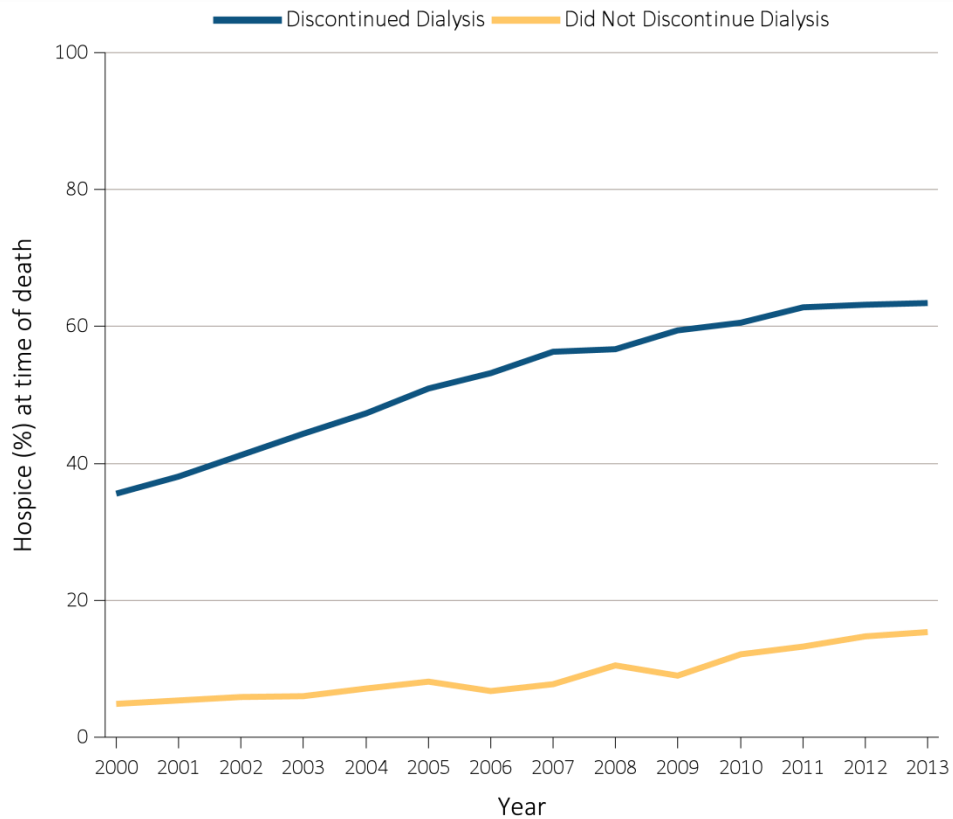


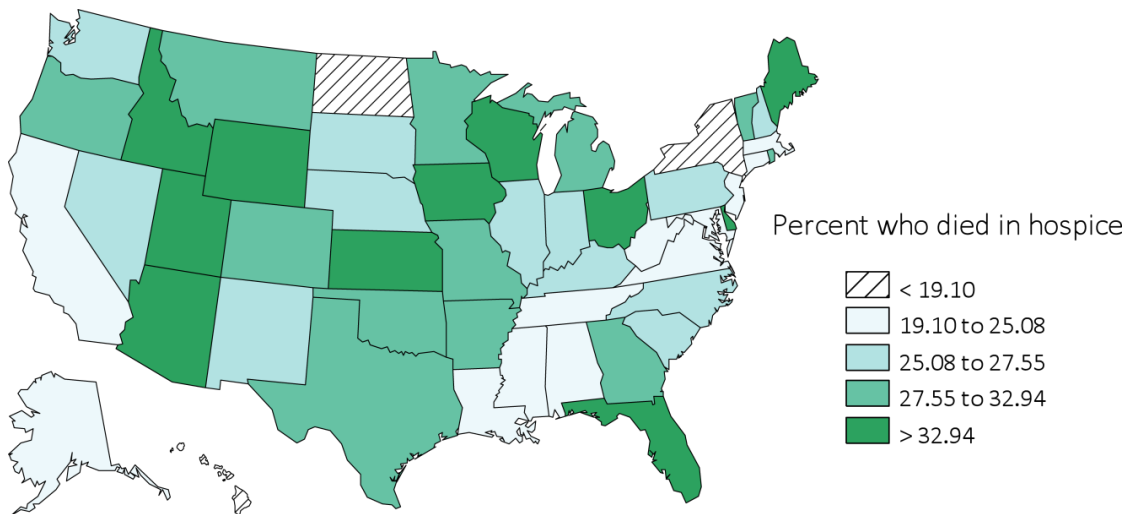
Figure 14.8 continued on next page.

vol 2 Figure 14.8 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, 2000-2013 (*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.

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

For ESRD patients who died in 2013, median per person costs under Medicare Parts A and B were \$119,937 (IQR \$ 77,216, \$ 181,469) over the last year of life, \$20,731 (IQR, \$9,944, \$36,147) over the last 30 days of life, and \$8,180 (IQR, \$ 1,893, \$ 15,403) over the last 7 days of life (Figure 14.9). 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 \$8,351 for those referred to hospice more than 2 weeks before death

(IQR, \$5,514, \$16,285) to \$24,405 for those first referred to hospice 2 days or less before death (IQR, \$15,906, \$37,238), as compared with the referent group without a claim for hospice during the last 90 days of life (\$22,000; IQR, \$10,675, \$39,119). Median costs during the last 7 days of life were also lower for those referred earlier to hospice, ranging from \$1,553 (IQR, \$1,199, \$2,842) for those referred more than 2 weeks before death to \$11,036 (IQR, \$5,486, \$15,645) 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 (\$10,441; IQR, \$2,455, \$17,330).

vol 2 Figure 14.9 Costs in the (a) last 30 days of life, and (b) last 7 days of life in relation to timing of hospice care, 2013

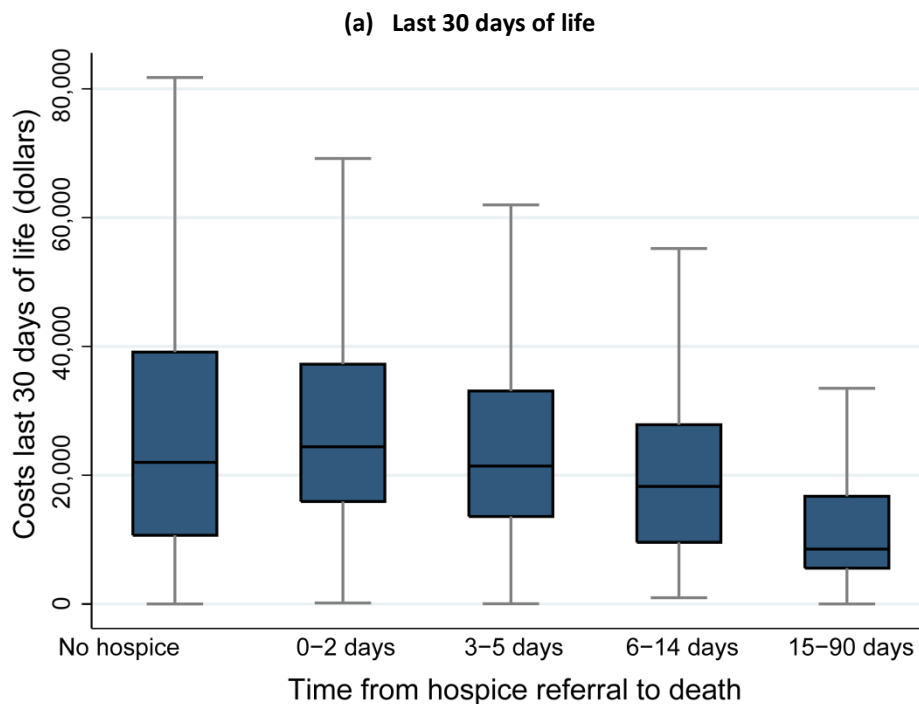
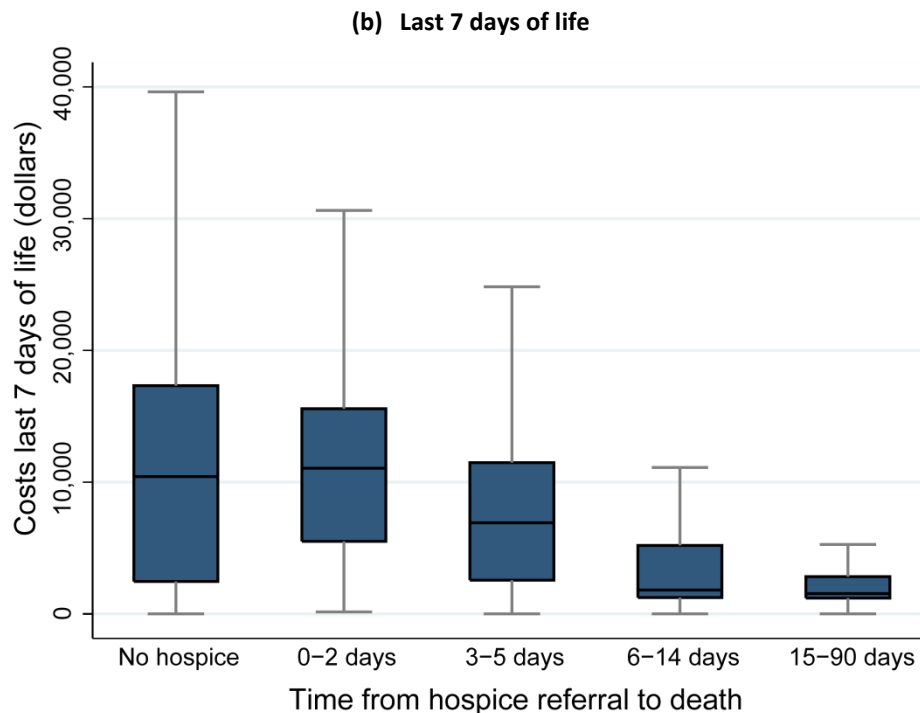


Figure 14.9 continued on next page.

vol 2 Figure 14.9 Costs in the (a) last 30 days of life, and (b) last 7 days of life in relation to timing of hospice care, 2013 (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 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.

Summary

From 2000-2013, 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 nursing home utilization, 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.

References

Barnato AE, Farrell MH, Chang CC, Lave JR, Roberts MS, Angus DC. Development and validation of hospital “end-of-life” treatment intensity measures. *Med Care* 2009;47(10):1098-1105.

Centers for Medicare & Medicaid, Minimum Data Set 3.0 Public Reports: MDS 3.0 Frequency Report. <https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports/index.html>. Page last updated: November 14, 2012. Accessed on June 15, 2016.

Intrator O, Hiris J, Berg K, Miller SC, Mor V. The residential history file: Studying nursing home residents' long-term care histories(*). *Health Serv Res* 2011;46(1 Pt 1):120-137.

Wei YJ, Simoni-Wastila L, Zuckerman IH, Brandt N, Lucas JA. Algorithm for identifying nursing home days using Medicare claims and minimum data set assessment data. *Med Care* 2014