# Chapter 12: End-of-life Care for Patients with End-Stage Renal Disease, 2000-2015

- Between 2000 and 2015:
  - 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 63% (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).
  - The percentage of Medicare beneficiaries with ESRD who died in the hospital decreased from 49% to 39% (Figure 12.5).
  - 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 23% to 32% (Figure 12.6).
  - Between 2012 and 2015:
  - The percentage of Medicare beneficiaries with ESRD seen by 10 or more physicians during the last 90 days ranged from 53% to 55% (Figure 12.7).
  - The percentage of Medicare beneficiaries with ESRD seen by 5 or more medical specialties during the last 90 days of life ranged from 65% to 62% (Figure 12.8).
  - Between 2000 and 2015:
  - The percentage of patients with ESRD who discontinued maintenance dialysis treatments before death increased from 19% to 23.3% (Figure 12.9).
  - The percentage of Medicare beneficiaries with ESRD who were enrolled in hospice at the time of death increased from 11% to 26% (Figure 12.10), with the most marked increases occurring among those who discontinued dialysis.
- For patients with ESRD who died in 2015, median per person costs under Medicare Parts A and B were $103,932 (IQR $65,345, $159,451) over the last year of life, $19,734 (IQR, $9,217, $34,979) over the last 30 days of life, and $7,687 (IQR, $1,866, $14,822) over the last seven days of life. Costs were progressively lower for patients who spent a longer period of time enrolled in hospice (Figure 12.11).

## 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) through 2015 using the most recently available data from the United States Renal Data System (USRDS) Coordinating Center. New to this chapter this year is information on the percentage of decedents seen by 10 or more physicians and the percentage seen by 5 or more specialists during the last 90 days of life from 2012-2015.

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) provider encounters during the last 90 days of life (5) patterns of dialysis discontinuation before death, (6) patterns of hospice utilization before death, 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 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.

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=N), dates of hospice utilization (HCFASAF=S), and receipt of hospice care at the time of death (HCFASAF=S on or after the date of death or Discharge Status from hospice=40, 41, or 42). Episodes of Intensive Care Unit (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).

We adapted two measures of physician care intensity at the end of life from the *Dartmouth Atlas of Healthcare*: the percentage of patients seeing 10 or more physicians in the last 90 days of life, and the percentage of patients seeing 5 or more medical specialties in the last 90 days of life. We used the Physician/Supplier Claims file to identify all physician claims during the last 90 days of life, and recorded the number of visits from unique physicians based on National Provider Identifier (NPI) and the provider's medical specialty, excluding non-physician specialties such as optometry and occupational therapy, and specialty codes associated with a supplier or facility rather than an individual provider (excluded codes: 00,41,42,43,45,47,48,49,50-65,67-69,71-75,80,87-89,95-97,99,AX,BX,C1). These analyses were limited to the years 2012 to 2015, because the NPI was not available prior to 2012.

Information on dialysis discontinuation before death comes from the Centers for Medicare & Medicaid Services (CMS) Death Notification form (CMS 2746). The denominator population includes all patients for whom dialysis was listed as the most recent modality before death on the 2746 form who had complete information on whether dialysis was discontinued before death. Information on hospice use as a function of whether dialysis was discontinued before death was obtained from the subset of Medicare beneficiaries in the denominator population, with complete information on whether dialysis was discontinued before death from the CMS 2746 form.

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.

Results for all years are based on the most current SAFs and linked Medicare claims from USRDS. Percentages in the text are rounded to the nearest whole number.

## Characteristics of Decedents with ESRD

We identified 1,397,039 patients listed in the USRDS Patients file who died between calendar years 2000 and 2015. The mean age (± standard deviation) of decedents was 68.6 (±13.6) years (Table 12.1). Overall, 67% of decedents were White, 27% were Black/African American, 1% were American Indian or Alaska Native, 3% were Asian, 1% were Pacific Islander or Native Hawaiian, and 1% were of Other race or Multiracial; 12% of decedents were Hispanic, 55% Non-Hispanic White, and 26% Non-Hispanic Black/African American; and 55% of decedents were male.

The most recent modality prior to death was hemodialysis (HD) in 88% of patients, peritoneal dialysis (PD) in 5%, and transplant in 5%. During 2000-2015, the mean age of decedents rose from 67.5 (±13.7) years to 69.3 (±13.1) years. The percentage of decedents of White race increased from 66% to 69% and the percentage of decedents of Black or African American race decreased from 28% to 26%. The percentage of decedents of Hispanic ethnicity increased from 10% to 13% over the same time period. The percentage of decedents who were male increased from 52% to 57%. The percentage of decedents with PD as their most recent modality ranged from 7% in 2000 to 4% in 2000-2010 to 6% in 2015. The percentage of decedents who had received a kidney transplant increased over time from 5% to 6%. The percentage of Medicare beneficiaries with ESRD with fee-for-service Medicare Parts A and B as primary payer during the last 90 days of life decreased from 73% to 62%.

**vol 2 Table 12.1 Characteristics of decedents with ESRD by death year, 2000-2015**

| | 2000 | 2003 | 2006 | 2009 | 2012 | 2015 | Total |
|---|---|---|---|---|---|---|---|
| **n** | 72,794 | 82,414 | 87,521 | 89,866 | 91,773 | 99,868 | 1,397,039 |
| **%** | 5.2 | 5.9 | 6.3 | 6.4 | 6.6 | 7.2 | |
| **Age (mean)** | 67.49 (13.73) | 67.94 (13.79) | 68.46 (13.78) | 68.73 (13.65) | 69.21 (13.37) | 69.27 (13.06) | 68.60 (13.58) |
| **Age category** | | | | | | | |
| 0-19 | 0.18 | 0.19 | 0.16 | 0.12 | 0.10 | 0.08 | 0.13 |
| 20-44 | 6.78 | 6.11 | 5.46 | 5.06 | 4.38 | 4.13 | 5.22 |
| 45-64 | 28.75 | 29.38 | 29.90 | 29.92 | 29.54 | 28.75 | 29.38 |
| 65-74 | 29.19 | 27.32 | 26.02 | 26.70 | 27.71 | 29.50 | 27.54 |
| 75-84 | 27.65 | 28.26 | 28.31 | 27.05 | 26.32 | 26.08 | 27.37 |
| ≥85 | 7.46 | 8.74 | 10.14 | 11.16 | 11.95 | 11.47 | 10.36 |
| Missing | | 0.00 | 0.00 | 0.00 | | | 0 |
| **Race*** | | | | | | | |
| White | 65.95 | 65.78 | 67.07 | 67.52 | 68.68 | 68.78 | 67.37 |
| Black | 28.15 | 28.14 | 27.67 | 27.12 | 26.14 | 26.04 | 27.17 |
| American Indian or Alaska Native | 1.23 | 1.12 | 1.08 | 1.14 | 1.02 | 0.94 | 1.07 |
| Asian | 2.24 | 2.34 | 2.46 | 2.63 | 2.90 | 3.10 | 2.61 |
| Native Hawaiian or Pacific Islander | 0.55 | 0.66 | 0.78 | 0.82 | 0.78 | 0.84 | 0.75 |
| Other or Multiracial | 1.68 | 1.82 | 0.86 | 0.67 | 0.37 | 0.22 | 0.92 |
| **Hispanic** | | | | | | | |
| Hispanic | 10.11 | 11.04 | 11.21 | 11.76 | 12.86 | 13.13 | 11.69 |
| Non-Hispanic White | 52.87 | 54.72 | 55.40 | 55.18 | 55.50 | 55.72 | 55.18 |
| Non-Hispanic Black/African American | 23.90 | 26.80 | 26.67 | 26.24 | 25.23 | 25.49 | 25.96 |
| Non-Hispanic Others | 5.19 | 5.16 | 5.53 | 5.89 | 5.85 | 5.28 | 5.49 |
| Unknown | 7.93 | 2.28 | 1.19 | 0.92 | 0.56 | 0.39 | 1.67 |
| **Sex** | | | | | | | |
| Female | 47.83 | 46.86 | 45.77 | 44.27 | 43.60 | 43.07 | 45.12 |
| Male | 52.17 | 53.13 | 54.20 | 55.71 | 56.39 | 56.93 | 54.86 |
| Missing | 0.00 | 0.01 | 0.03 | 0.02 | 0.00 | 0.01 | 0.02 |
| **Last treatment modality** | | | | | | | |
| Hemodialysis | 86.72 | 88.47 | 88.92 | 89.03 | 87.82 | 87.45 | 88.28 |
| Peritoneal dialysis | 7.38 | 5.86 | 4.89 | 4.31 | 5.1 | 5.87 | 5.39 |
| Transplant | 4.66 | 4.71 | 5.05 | 5.54 | 6.12 | 6.37 | 5.39 |
| Missing | 1.25 | 0.96 | 1.14 | 1.13 | 0.95 | 0.31 | 0.94 |
| **Medicare Parts A & B as ESRD payer for last 3-months of life (Yes)** | 73.46 | 75.09 | 73.59 | 69.33 | 67.25 | 62.16 | 70.19 |

*Data Source: Special analyses, USRDS ESRD Database. Denominator is all decedents. Abbreviation: ESRD, end-stage renal disease. * Race does not add up to 100%, because "unknown" category is not presented in this table.*

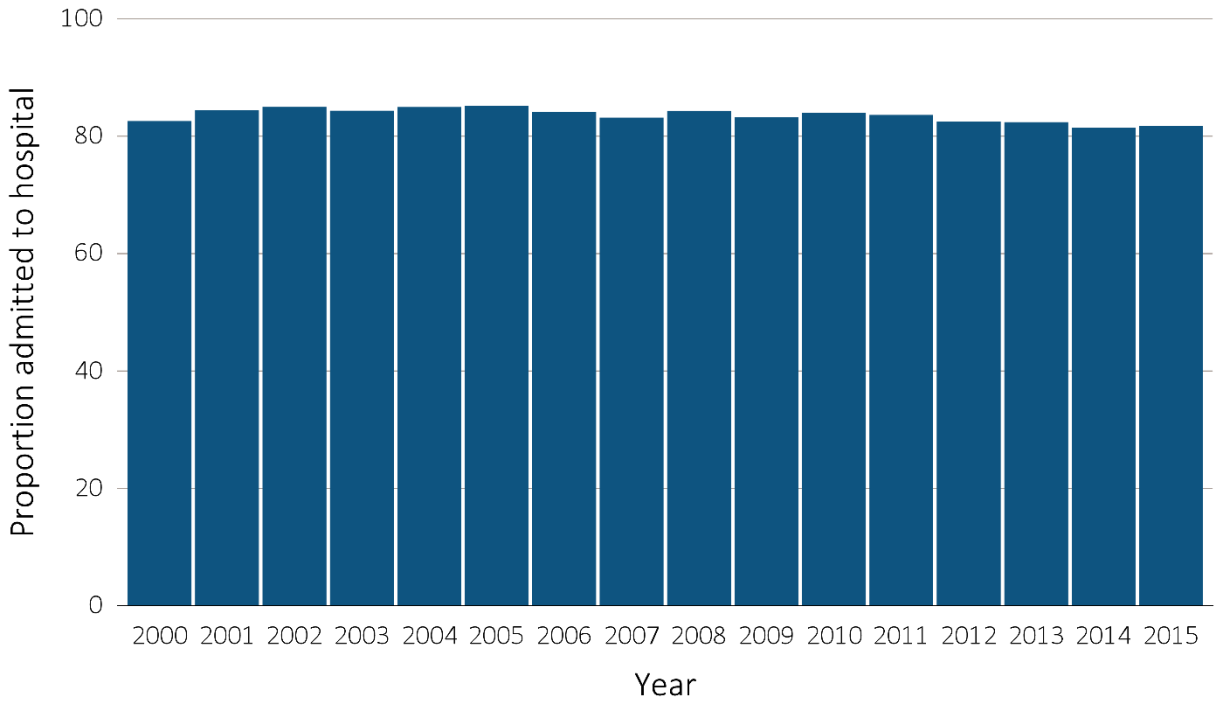
## Inpatient Utilization during the Last 90 Days of Life among Medicare Beneficiaries with ESRD

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 2000-2015: (1) hospital admission, (2) days spent in the hospital, (3) ICU admission, (4) receipt of intensive procedures, and (5) inpatient deaths.

### *Hospital admission*

More than 4 in every 5 patients were admitted to the hospital at least once during the last 90 days of life throughout the 16-year follow-up period, ranging from 81%-84% (Figure 12.1). This is higher than the rate of 65.2% reported for fee-for service Medicare beneficiaries for 2015 (Teno et al., 2018).

**vol 2 Figure 12.1 Hospital admission during the last 90 days of life among Medicare beneficiaries with ESRD, 2000-2015**

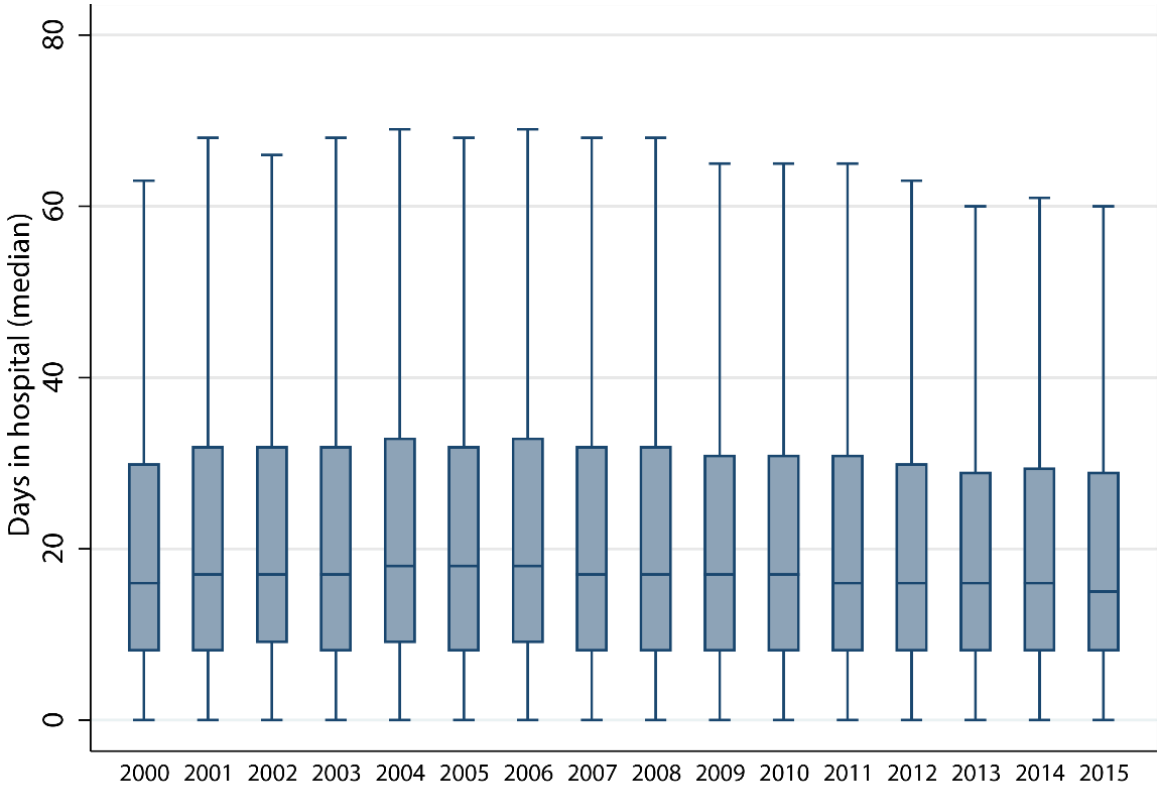



*Data Source: Special analyses, USRDS ESRD Database. Denominator is all decedents with Medicare Parts A and B throughout the last 90 days of life. Includes hospital stays in both short- and long-stay hospitals. Abbreviation: ESRD, end-stage renal disease.*

### *Days spent in the hospital*

Those admitted to the hospital at least once during the last 90 days of life spent a median stay of between 15 and 18 days in the hospital during each year of follow-up ranging from a high of 18 days in 2004-2006 to a low of 15 days in 2015 (Figure 12.2).

**vol 2 Figure 12.2 Days spent in the hospital during the last 90 days of life among Medicare beneficiaries with ESRD, 2000-2015**

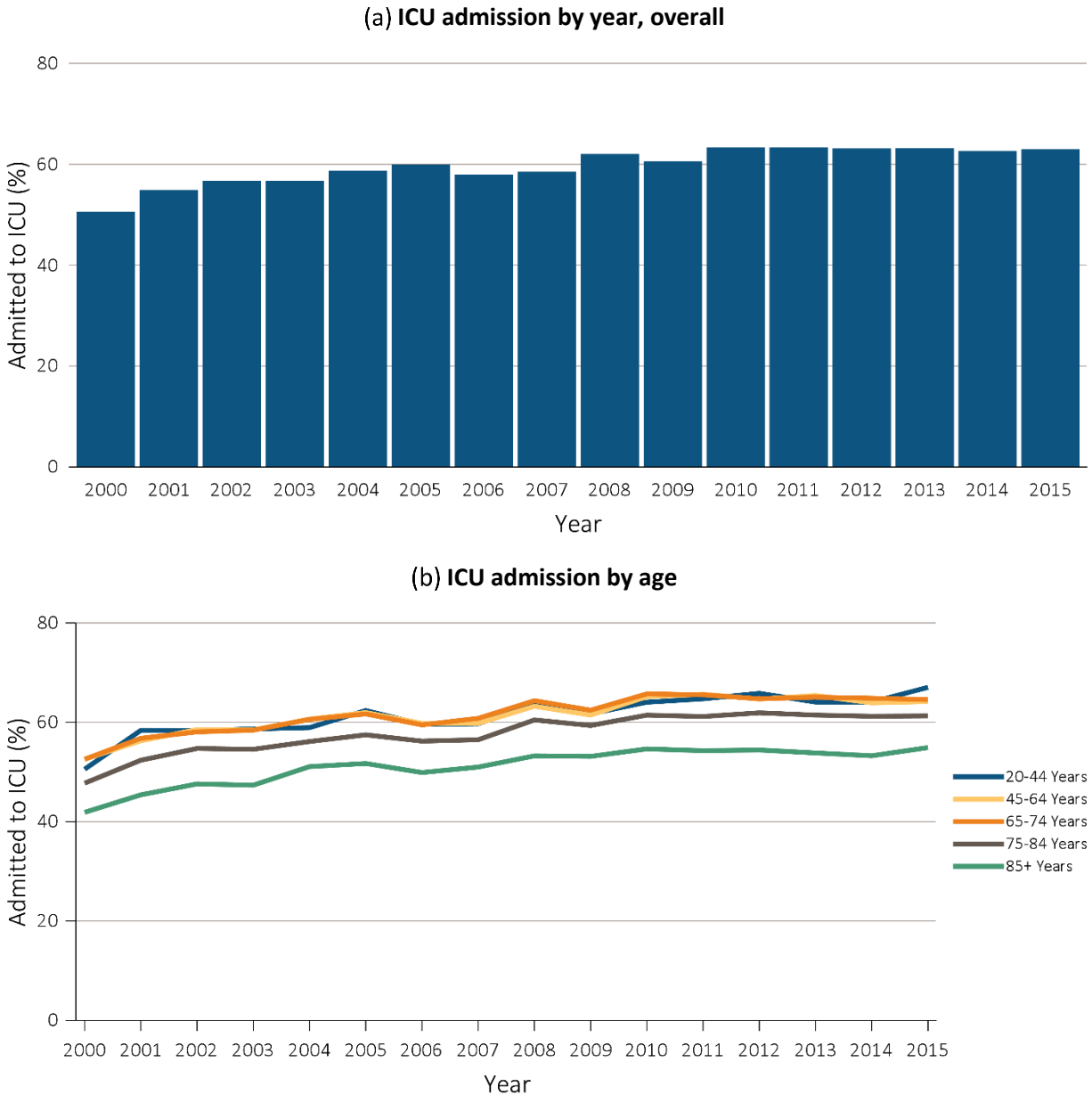



*Data Source: Special Analyses, USRDS ESRD Database. Denominator is all decedents with Medicare Parts A and B throughout the last 90 days of life who were admitted to the hospital at least once. Includes hospital stays in both short- and long-stay hospitals. Explanation of box plot: The lower border 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 ≥ the first quartile minus 1.5 times the interquartile range at the bottom to the highest value of the distribution that is ≤ 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*

The percentage of decedents admitted to an ICU in the last 90 days of life ranged from 50% in 2000 to 63% in 2015 (Figure 12.3) and varied by demographic characteristics, modality, and by U.S. state of residence (Figure 12.3.g). In 2015, 68% of young adults (20-44 years) had an ICU admission, decreasing to 56% among those 85 years and over. By region, the highest ICU use rates were in the Southwest and Midwest states.

**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, 2000-2015**

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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, 2000-2015 (continued)**

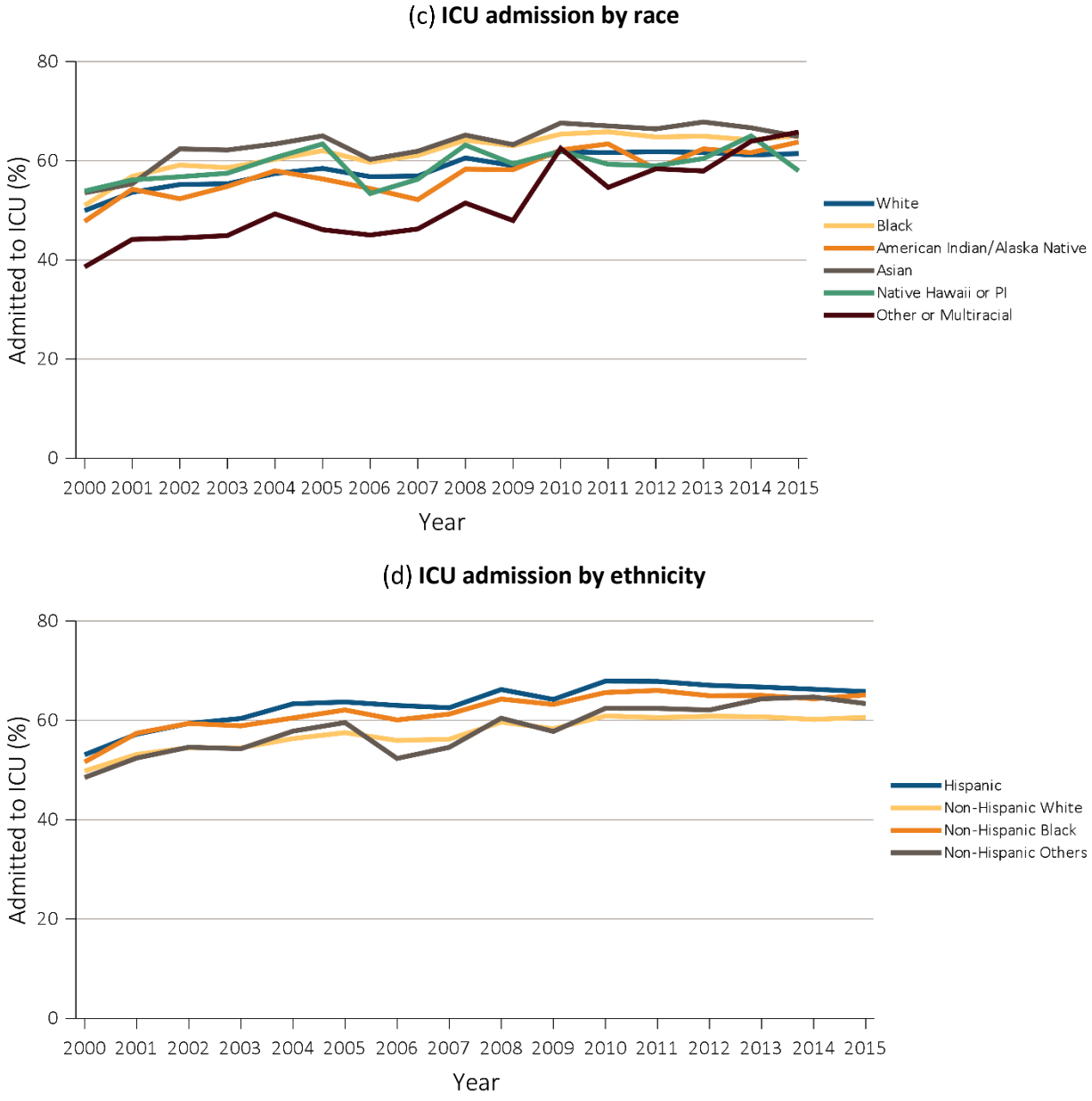



*Figure 12.3 continued on next page.*

**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, 2000-2015 (continued)**

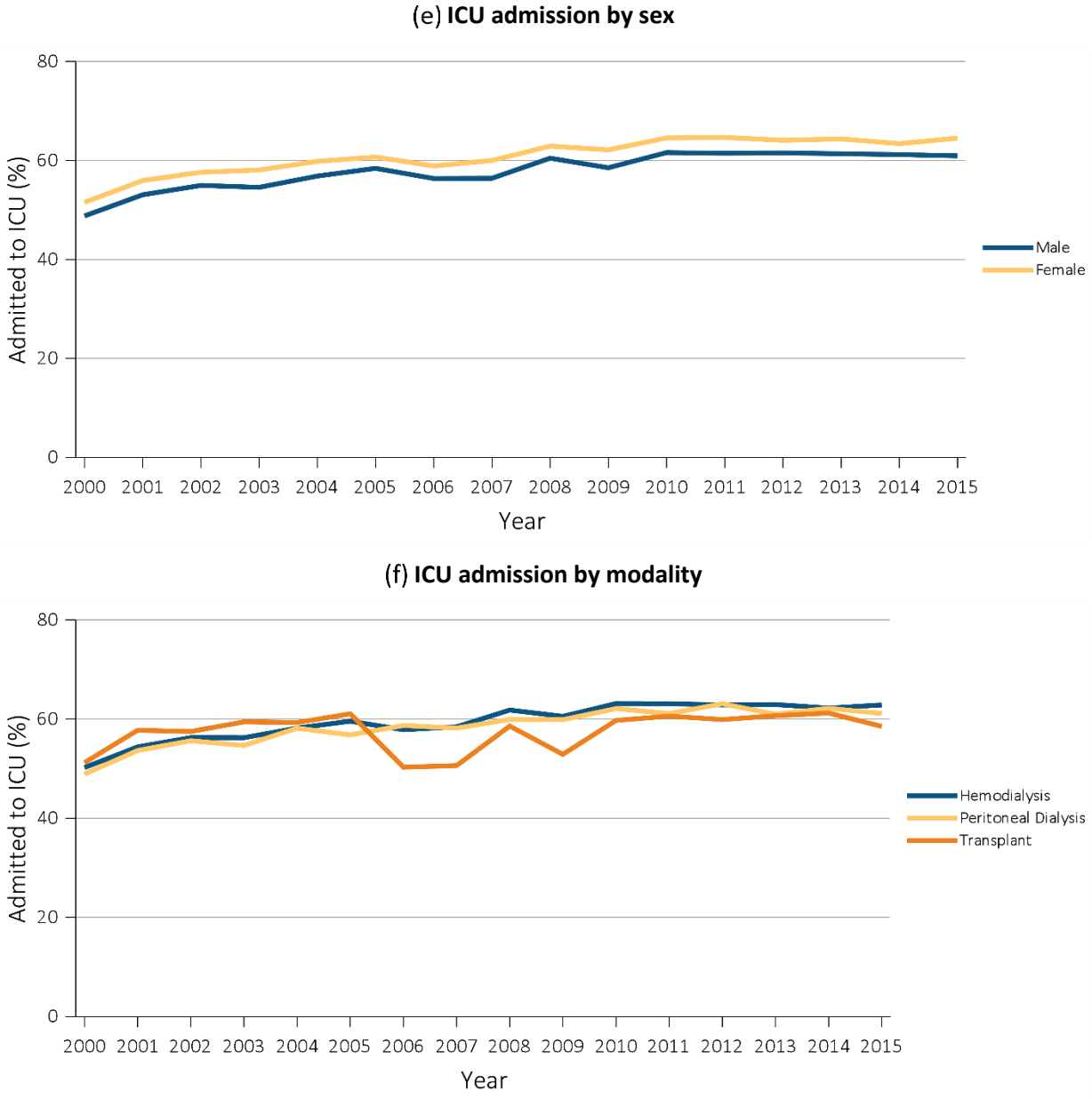
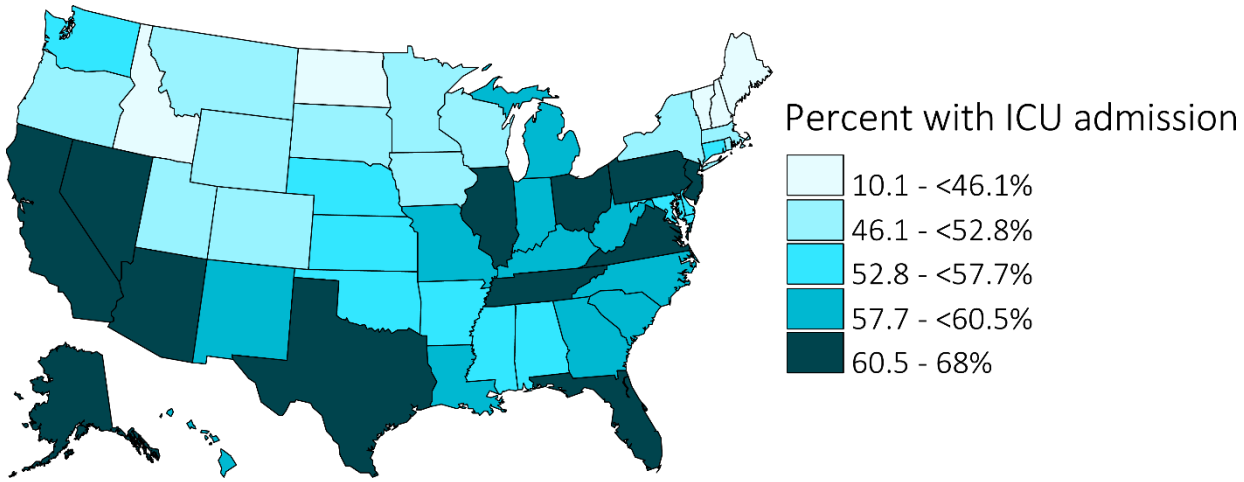



*Figure 12.3 continued on next page.*

**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, 2000-2015 (continued)**

(g) **ICU admission by state of residence**

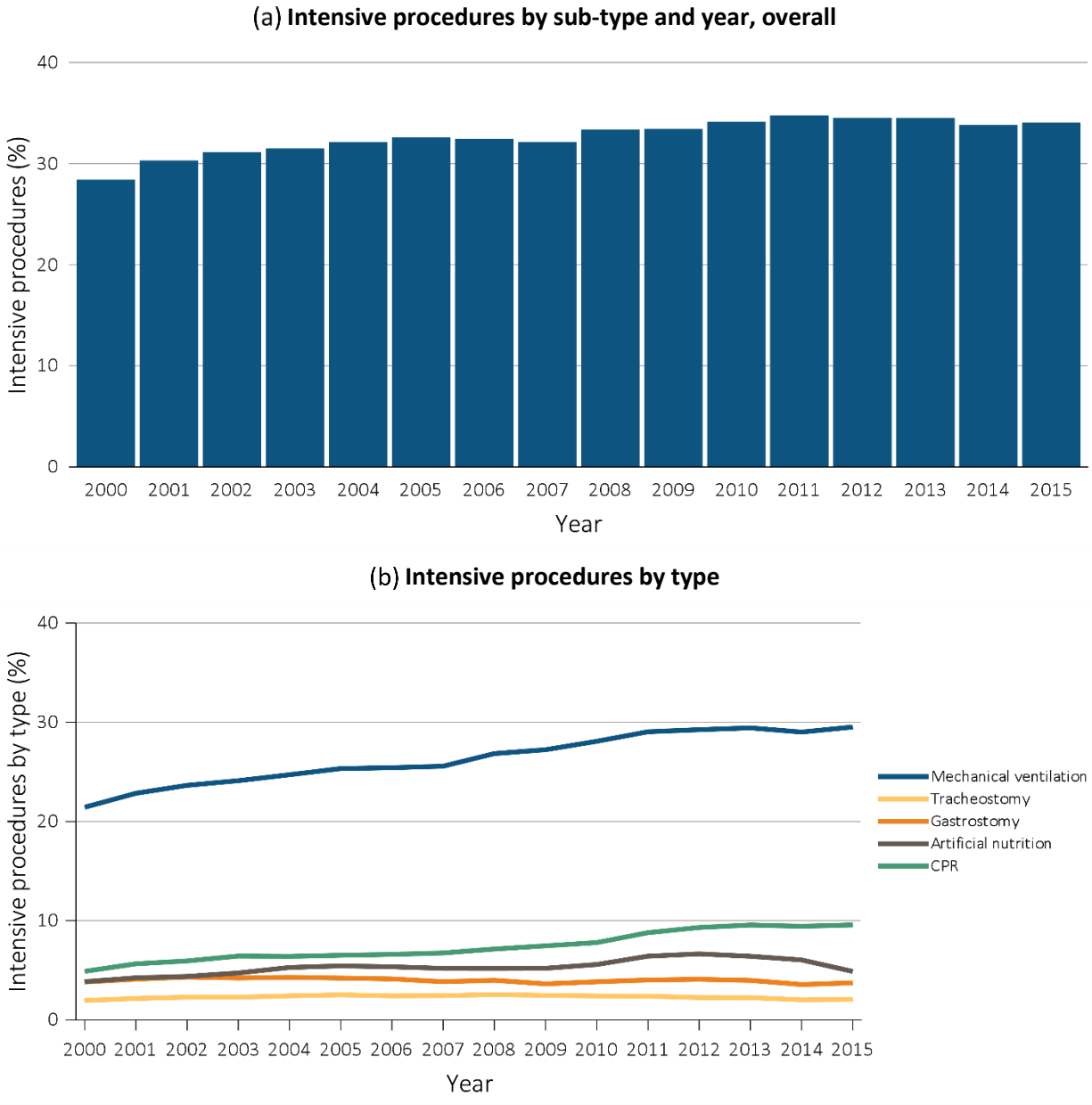



*Data Source: Special Analyses, USRDS ESRD Database. Denominator is all decedents with Medicare Parts A and B throughout the last 90 days of life. ICU admission was identified using ICU revenue center codes in Medicare Institutional claims. Abbreviations: ESRD, end-stage renal disease; ICU, Intensive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

### *INTENSIVE PROCEDURES*

The percentage of decedents who had an inpatient intensive procedure during the last 90 days of life ranged from 28% in 2000 to 34% in 2015. Intubation/mechanical ventilation was the most common intensive procedure, with the percentage of decedents receiving this procedure in the last 90 days of life ranging from 21% in 2000 to 30% in 2015. The percentage of decedents who received one or more intensive procedures during the last 90 days of life varied by demographic characteristics, modality, and by state of residence. Intensive procedures were used for 50% of the youngest age group (20-44 years) and only 20% of the oldest (85+ years). By region, use of intensive procedures was about twice as great in the Southeast and California as in the rest of the country.

**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, 2000-2015**

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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, 2000-2015 (continued)**

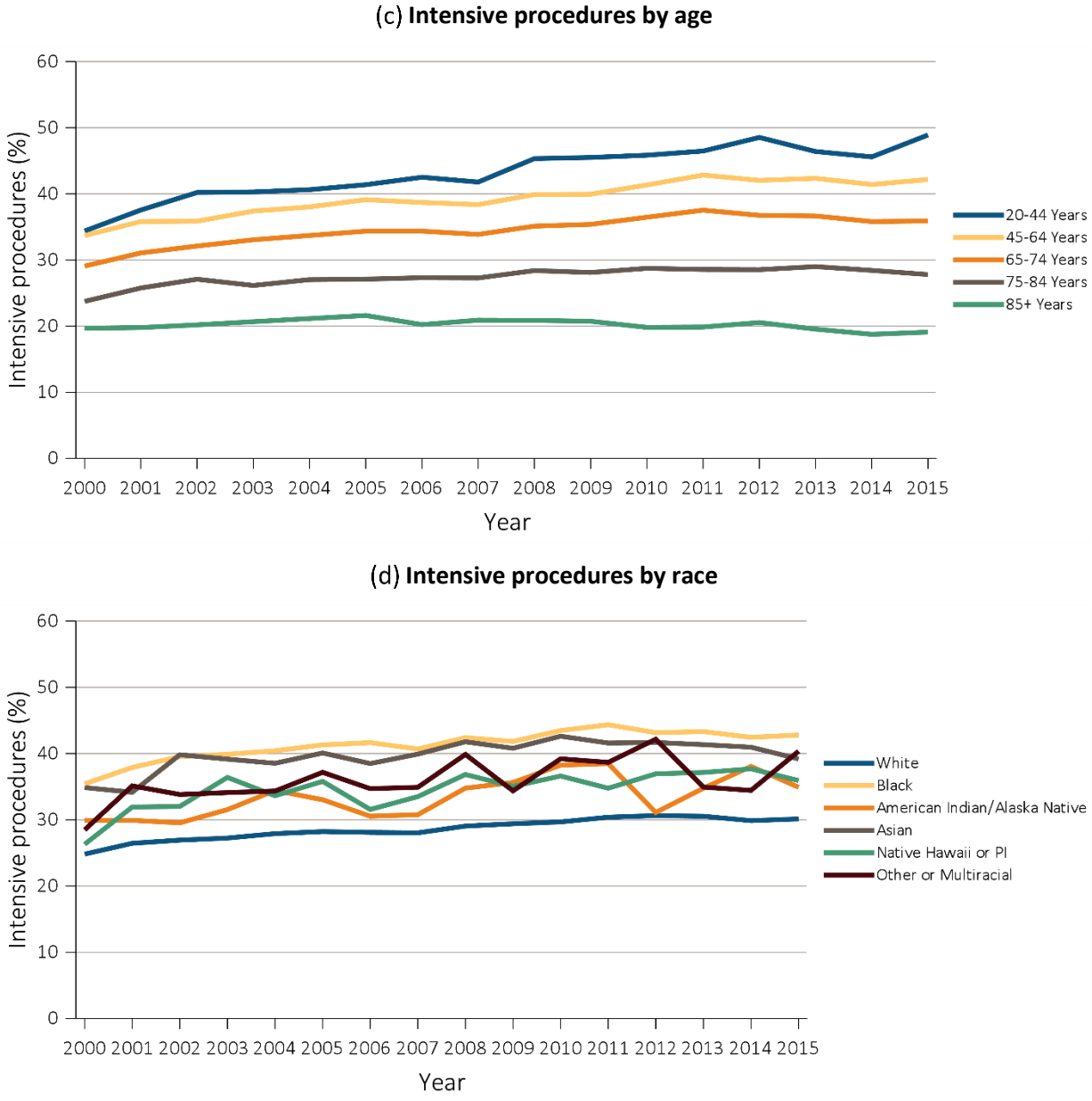
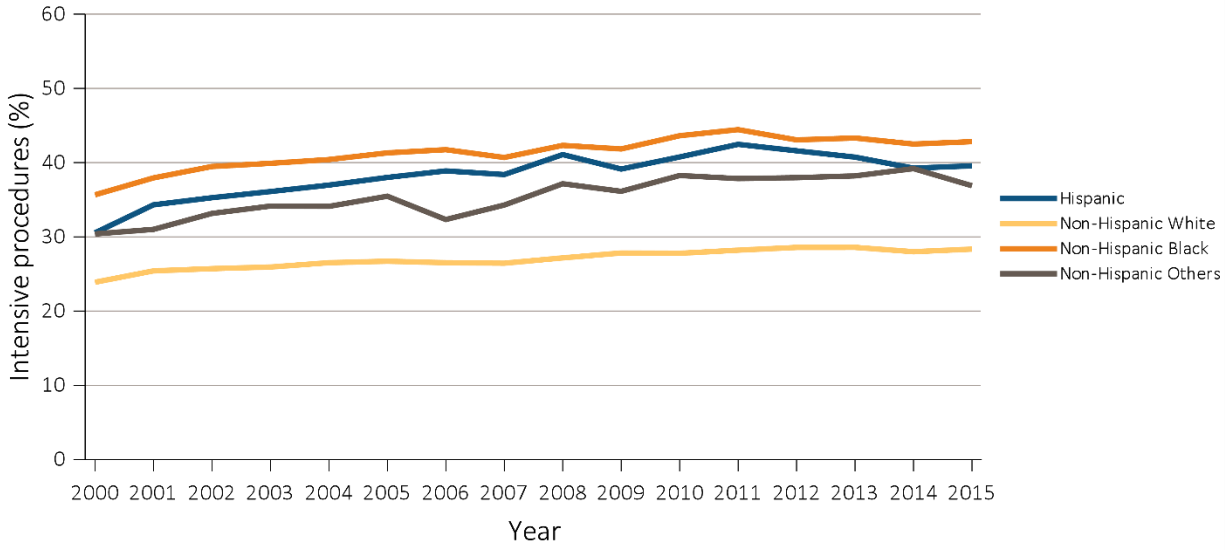



*Figure 12.4 continued on next page.*

**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, 2000-2015 (continued)**

(e) **Intensive procedures by ethnicity**




(f) **Intensive procedures by sex**

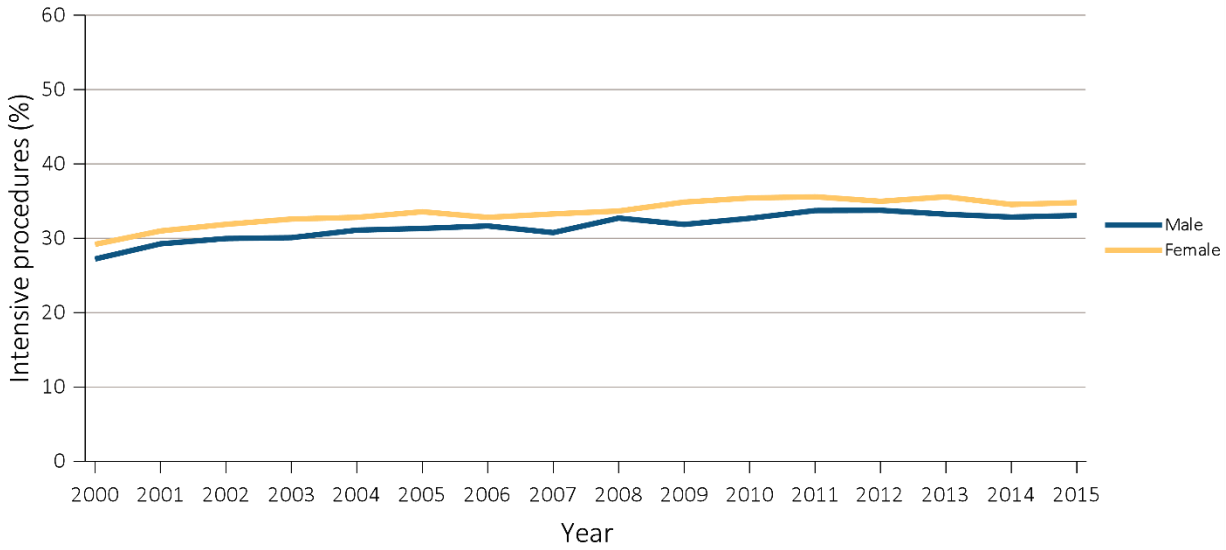
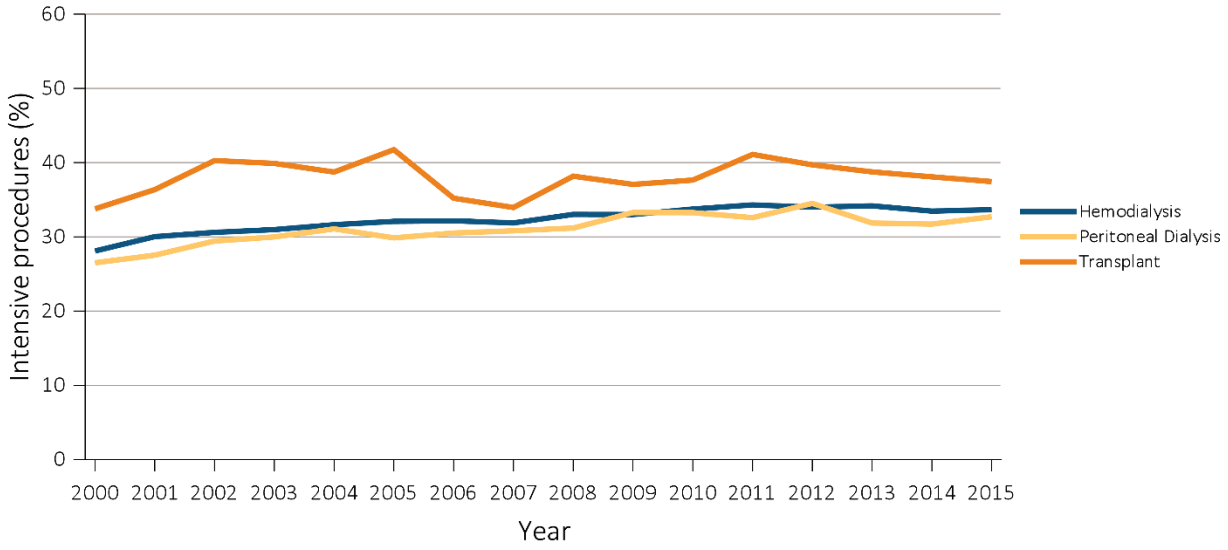


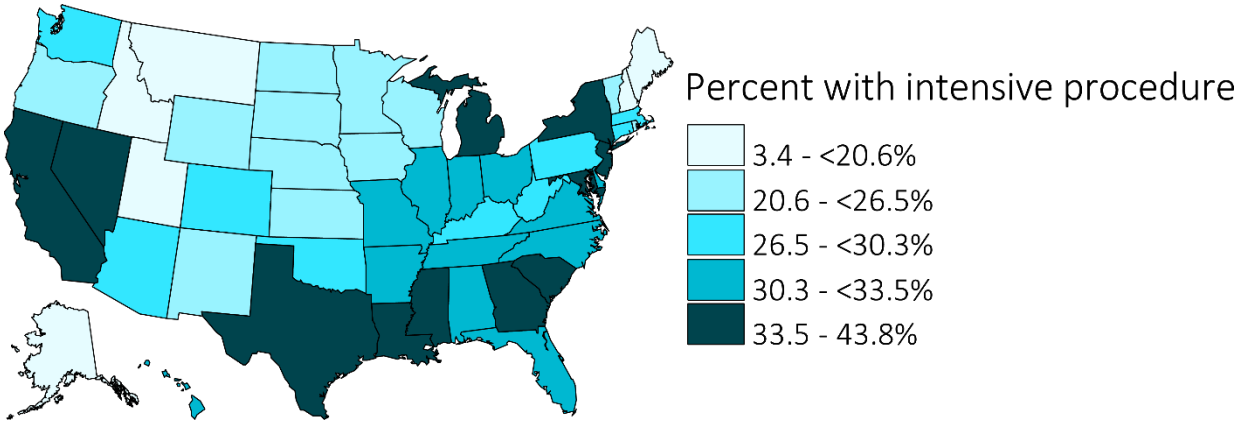

*Figure 12.4 continued on next page.*

**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, 2000-2015 (continued)**

(g) **Intensive procedures by modality**




(h) **Intensive procedures by state of residence**



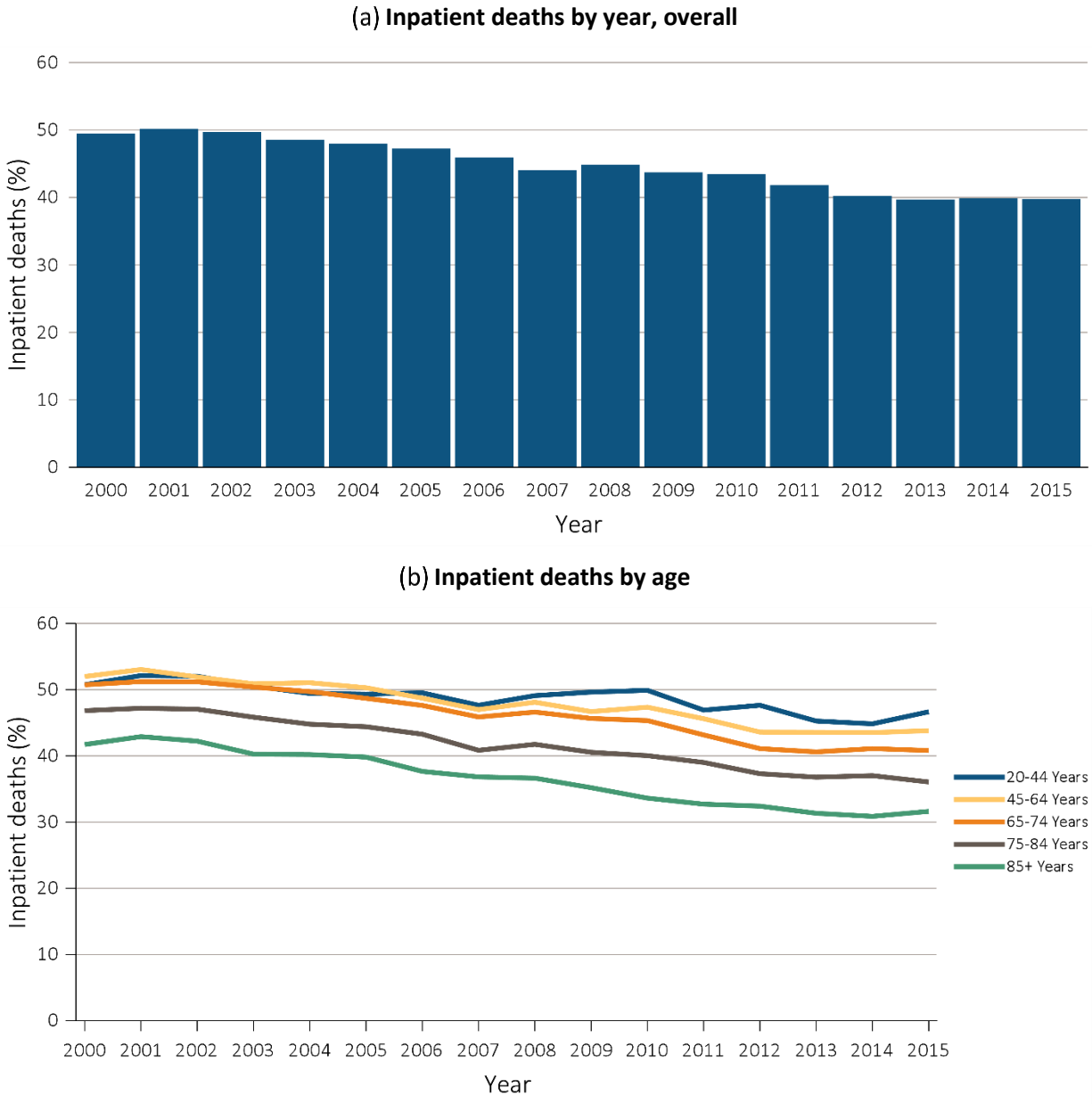

*Data Source: Special analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Intensive procedures were identified by ICD-9 procedure code search of Medicare Institutional claims from short- and long-stay hospitals. The yellow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

### *INPATIENT DEATHS*

The percentage of decedents with ESRD who died in the hospital based on Medicare claims decreased from 49% in 2000 to 39% in 2015 (Figure 12.6). By comparison, the percentage of fee-for-service Medicare beneficiaries dying during an acute hospital admission decreased from 32.6 in 2000 to 24.6% in 2009 (Teno et al., 2013).

The proportion of deaths occurring in the hospital varied by demographic characteristics and modality. The oldest decedents were the least likely to die in the hospital.

**vol 2 Figure 12.5 Inpatient deaths among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2015**

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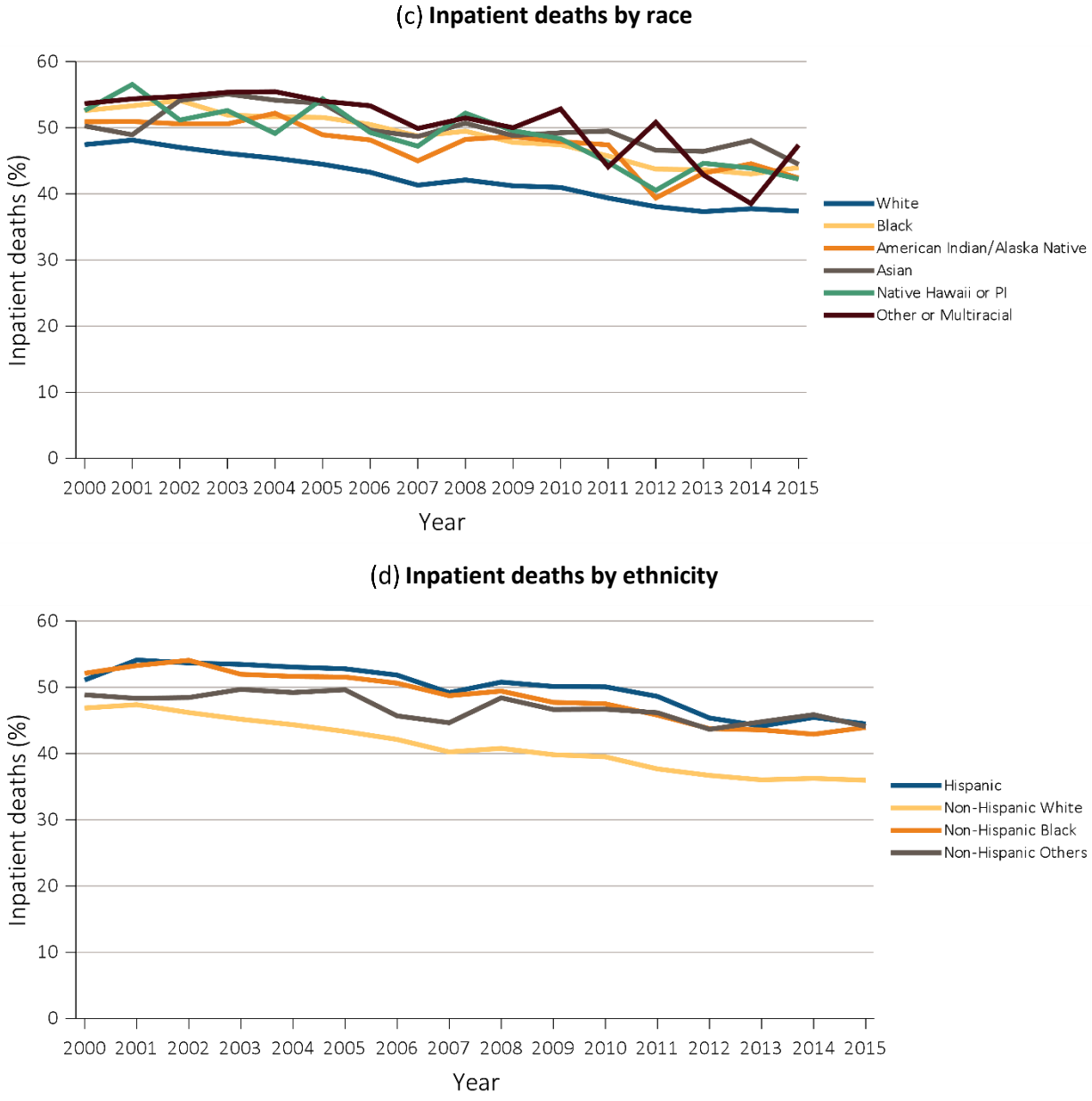
**vol 2 Figure 12.5 Inpatient deaths among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2015 (continued)**

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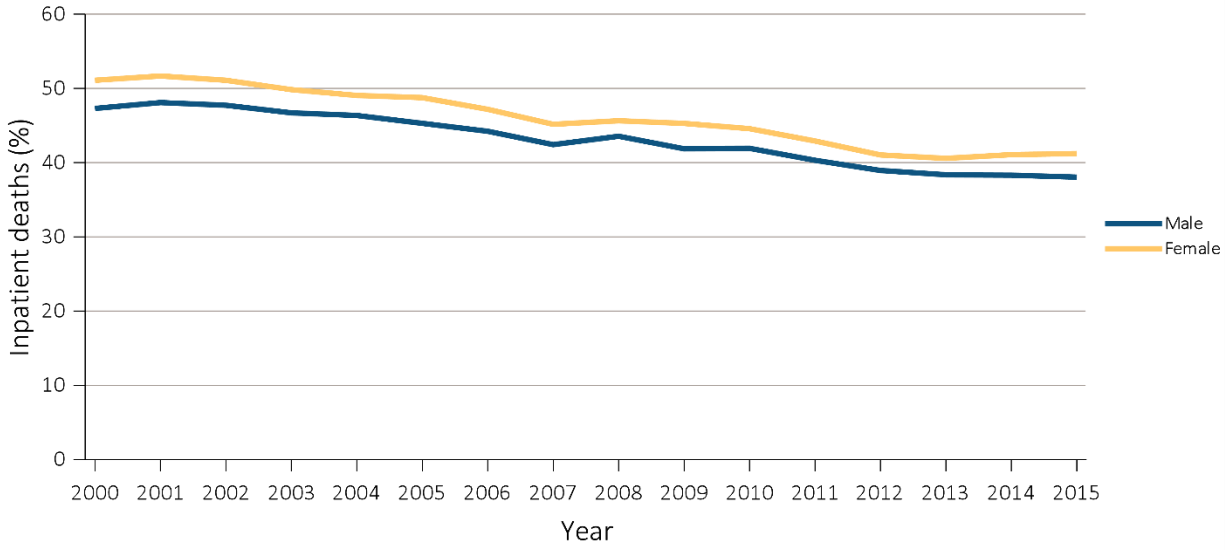
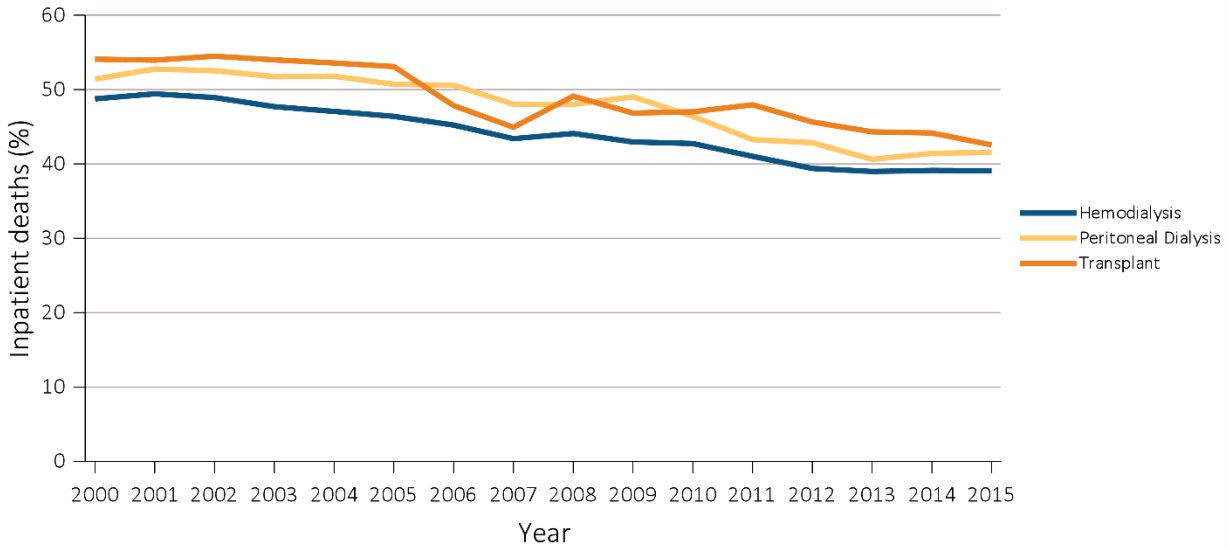
**vol 2 Figure 12.5 Inpatient deaths among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2015 (continued)**

(e) **Inpatient deaths by sex**




(f) **Inpatient deaths by modality**

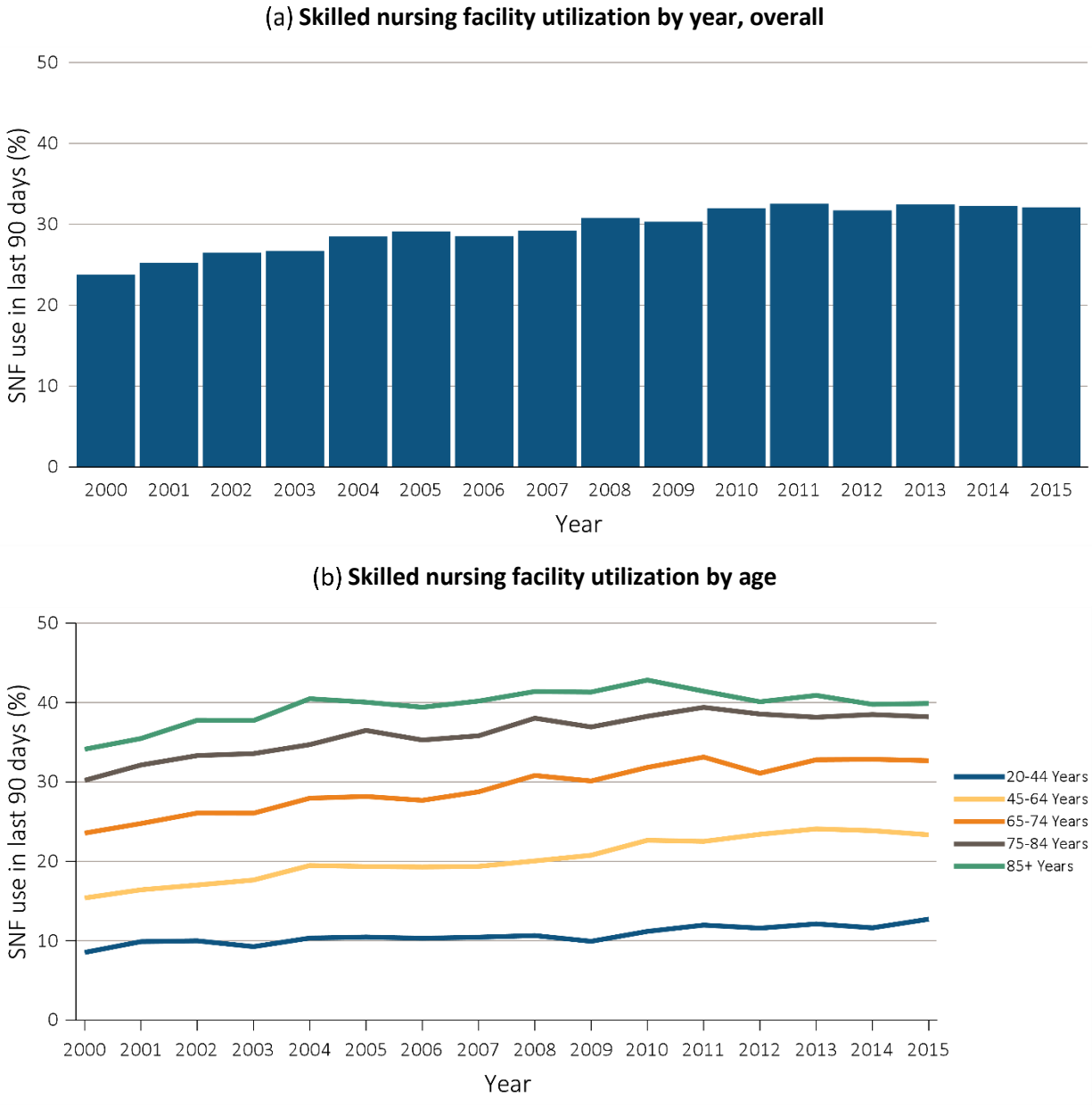



*Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Includes deaths occurring in short- and long-stay hospitals. Does not include observation stays. Abbreviation: ESRD, end-stage renal disease.*

## Skilled Nursing Facility Utilization

The percentage of decedents admitted to a SNF during the last 90 days of life ranged from 24% in 2000 to 32% in 2015 (Figure 12.7). The percentage of decedents admitted to a skilled nursing facility during this time frame varied by demographic characteristics and modality. Age was strongly related to SNF use, with those decedents 85 years and over 4 times as likely to have SNF use as the youngest age group (20-44 years). SNF use was also more prevalent among White beneficiaries.

**vol 2 Figure 12.6 Skilled nursing facility utilization among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2015**

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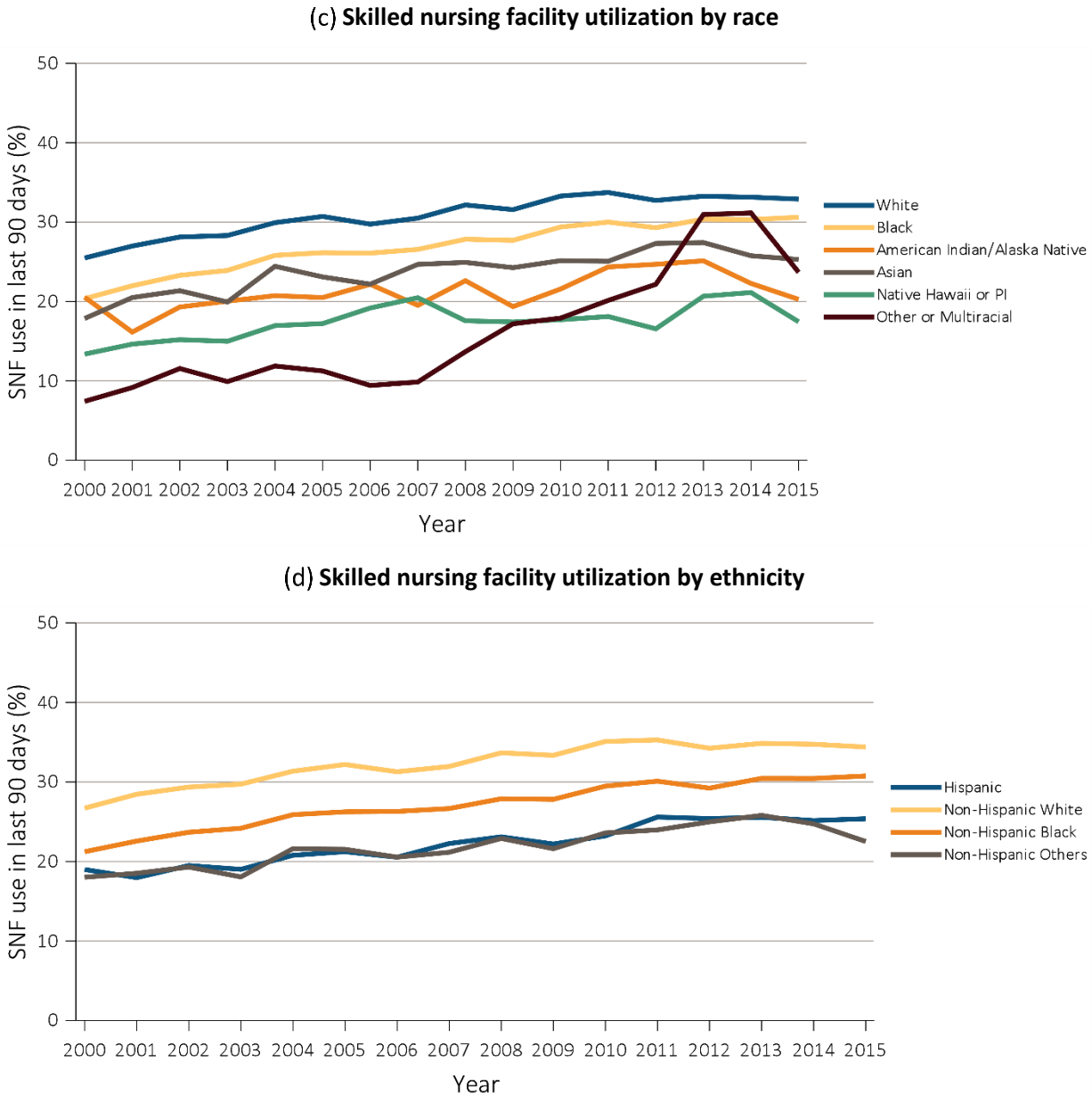
**vol 2 Figure 12.6 Skilled nursing facility utilization among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2015 (continued)**

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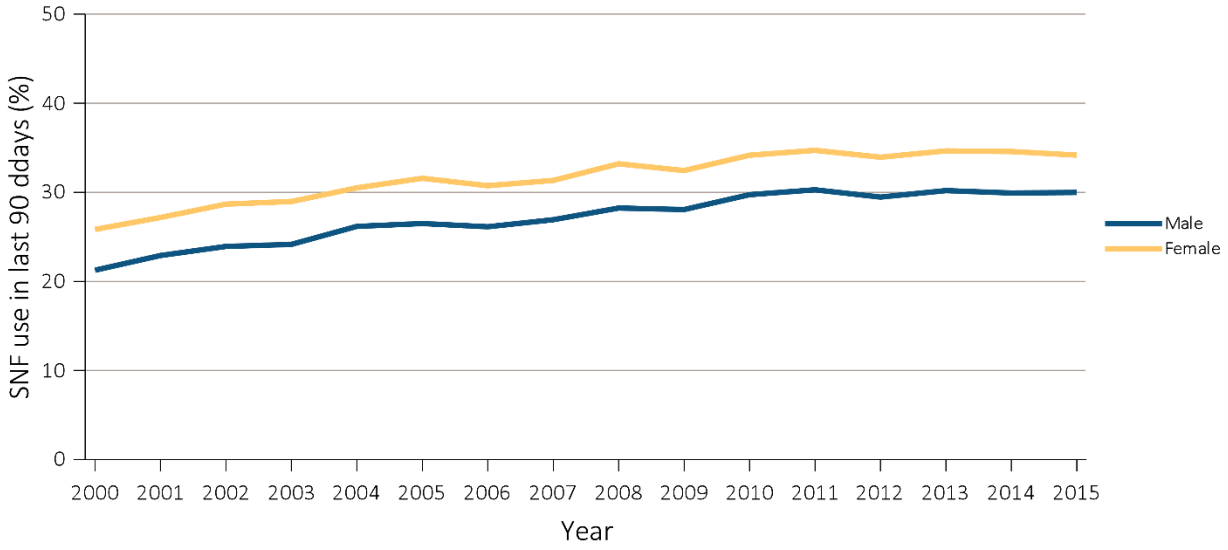
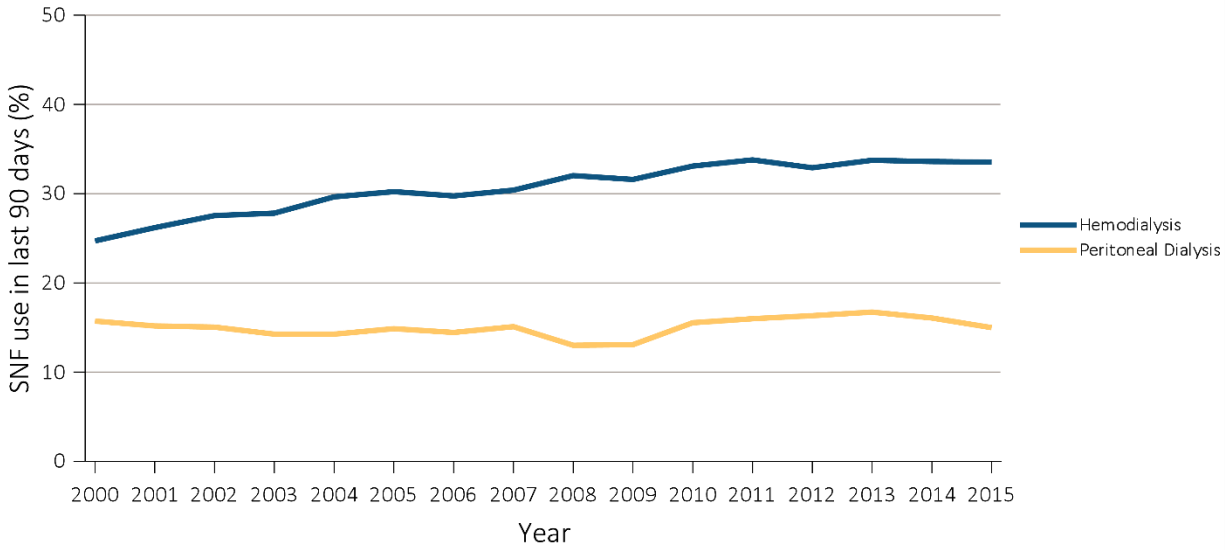
**vol 2 Figure 12.6 Skilled nursing facility utilization among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2015 (continued)**

(e) **Skilled nursing facility utilization by sex**




(f) **Skilled nursing facility utilization by modality**




*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. Abbreviations: ESRD, end-stage renal disease; SNF, skilled nursing facility.*

## Provider Encounters during the Last 90 Days of Life among Medicare Beneficiaries with ESRD

### *Percentage of patients seen by ≥10 physicians in last 90 days of life*

The percentage of patients who were seen by 10 or more physicians in the last 90 days of life changed little between 2012 and 2015 (from 53% to 55%). By comparison, 49.5% of fee-for-service Medicare beneficiaries were seen by 10 or more physicians in the last six months of life (*Dartmouth Atlas of Health Care*).

There was little variation by demographic characteristics, modality, and by state of residence. Higher rates were seen in the Eastern part of the United States than in the West.

**vol 2 Figure 12.7 Percentage of Medicare beneficiaries with ESRD seen by 10 or more physicians in the last 90 days of life, overall, and by age, race, ethnicity, sex, and modality, 2012-2015**

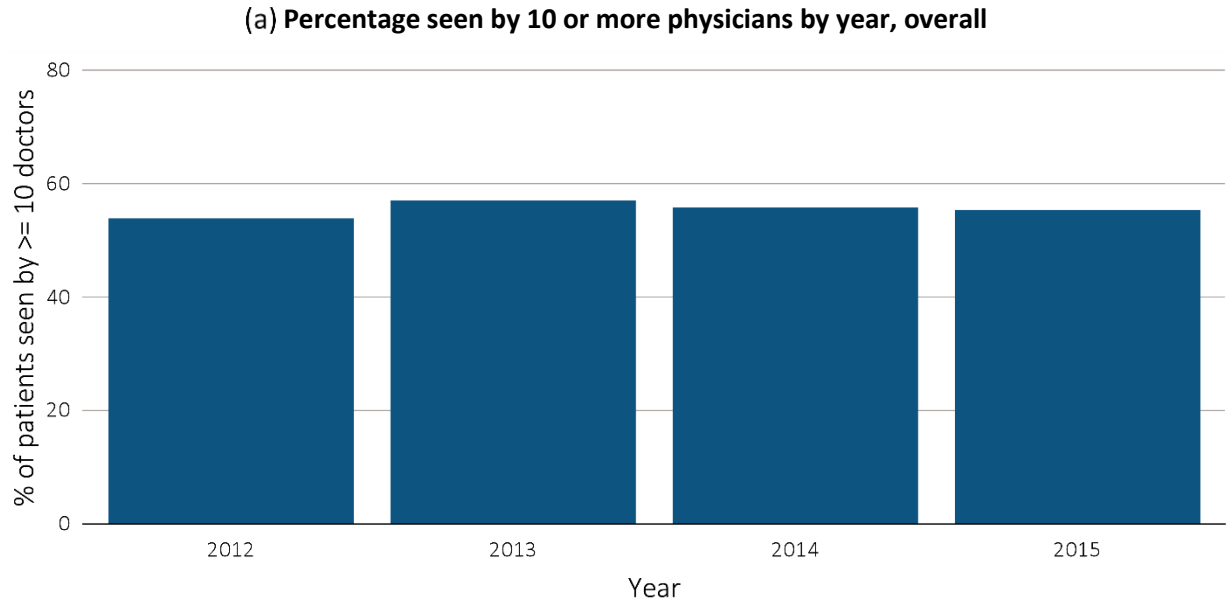
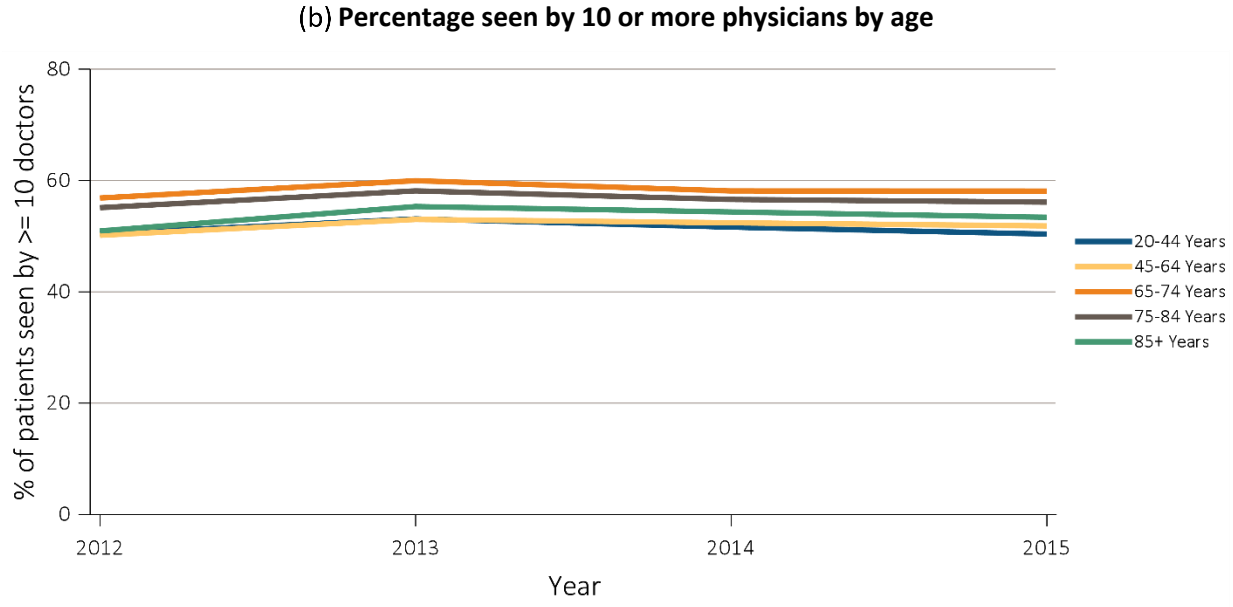



*Figure 12.7 continued on next page.*

**vol 2 Figure 12.7 Percentage of Medicare beneficiaries with ESRD seen by 10 or more physicians in the last 90 days of life, overall, and by age, race, ethnicity, sex, and modality, 2012-2015 (continued)**



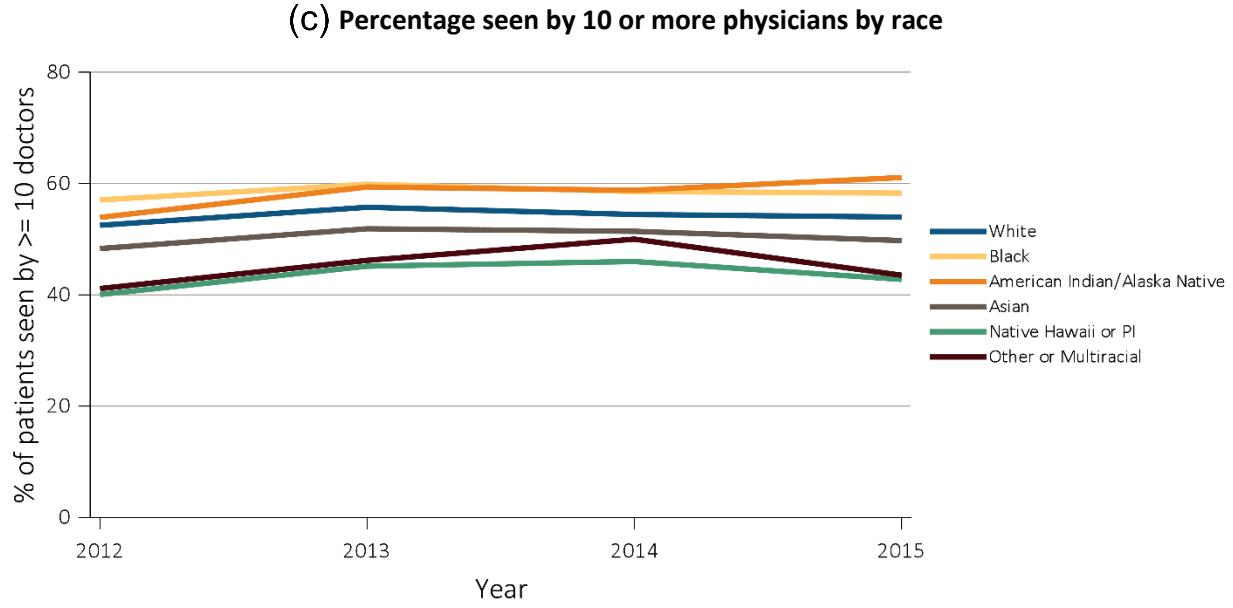




*Figure 12.7 continued on next page.*

**vol 2 Figure 12.7 Percentage of Medicare beneficiaries with ESRD seen by 10 or more physicians in the last 90 days of life, overall, and by age, race, ethnicity, sex, and modality, 2012-2015 (continued)**

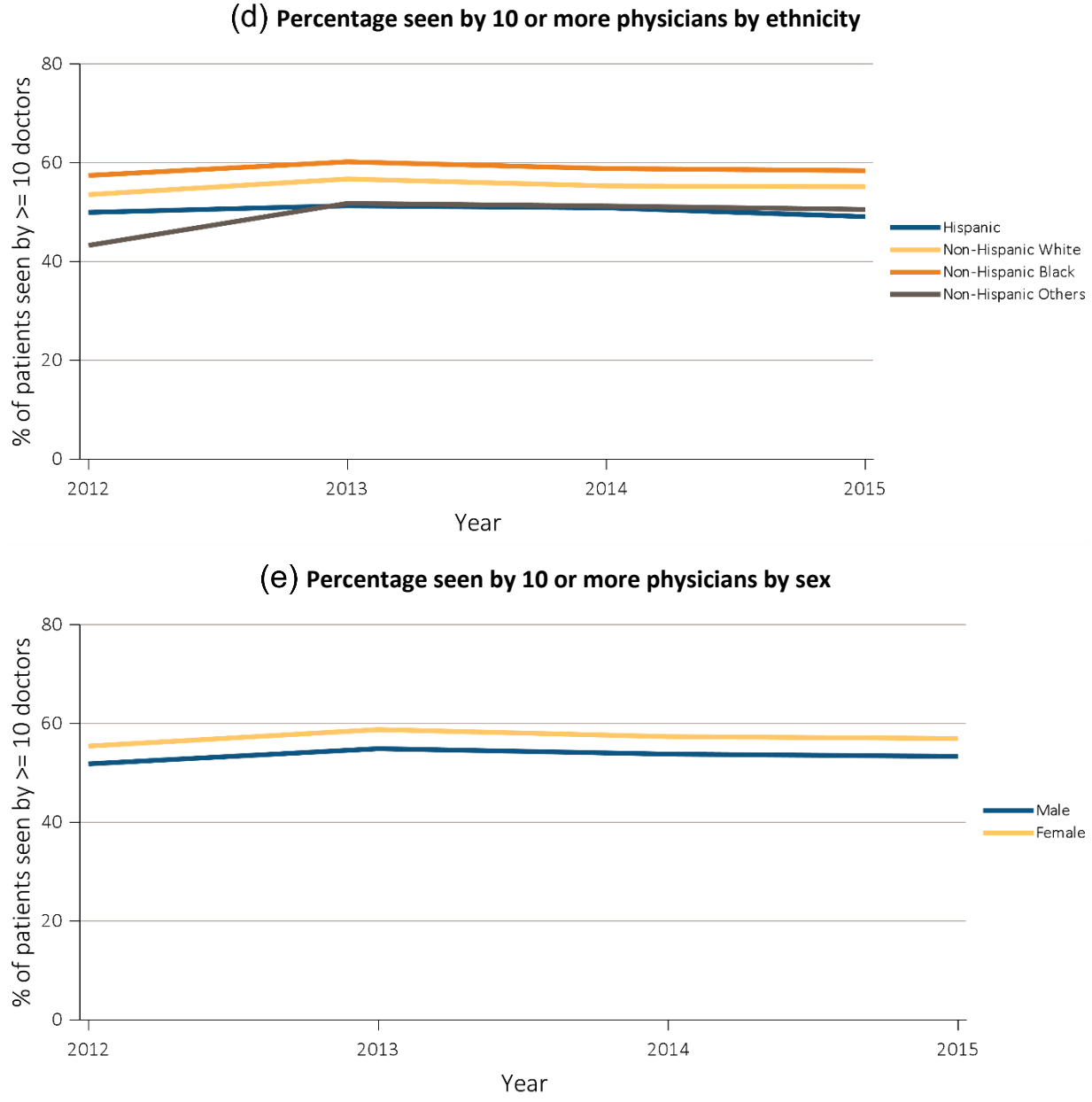
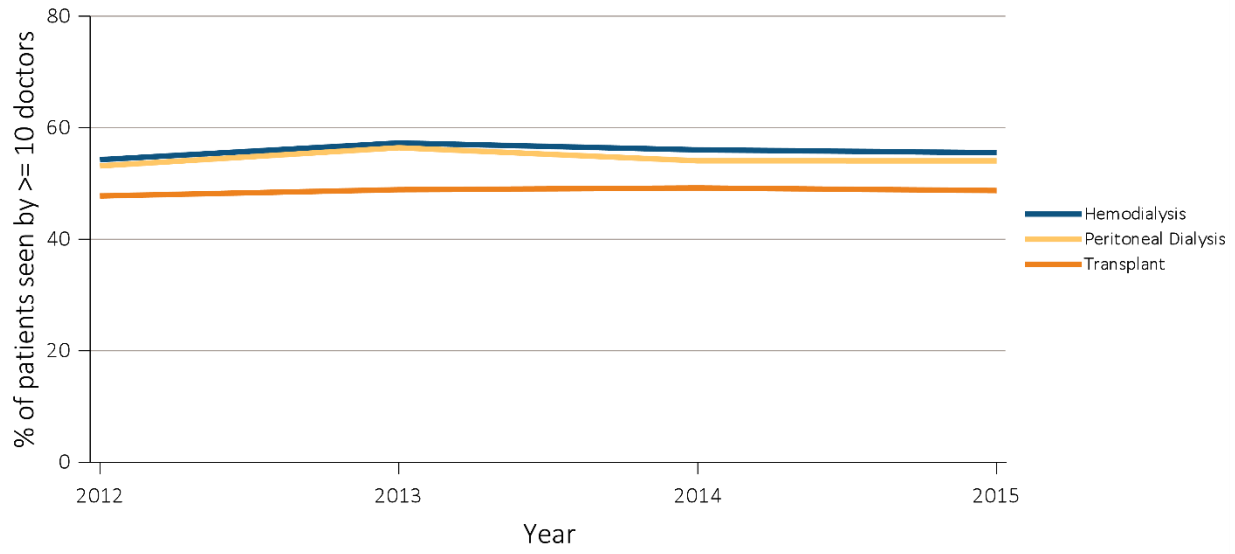


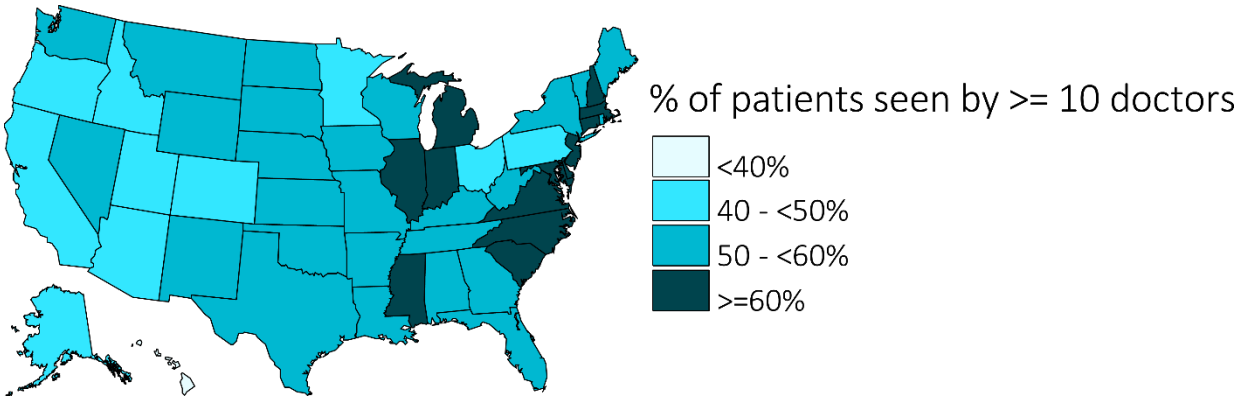

*Figure 12.7 continued on next page.*

**vol 2 Figure 12.7 Percentage of Medicare beneficiaries with ESRD seen by 10 or more physicians in the last 90 days of life, overall, and by age, race, ethnicity, sex, and modality, 2012-2015 (continued)**

(f) **Percentage seen by 10 or more physicians by modality**




(g) **Percentage seen by 10 or more physicians by state of residence**




*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 who died between 2012 and 2015. Abbreviation: ESRD, end-stage renal disease.*

### *Percentage of patients seen by ≥5 medical specialties in last 90 days of life*

The percentage of patients who were seen by 5 or more medical specialties in the last 90 days of life declined from 65% in 2012 to 62% in 2015. Percentages varied by demographic characteristics, modality, and state of residence. The top 3 medical specialties delivering care at the end of life for fee-for-service Medicare beneficiaries with ESRD were Internal Medicine, Nephrology, and Radiology (Table 12.2).

**vol 2 Figure 12.8 Percentage of Medicare beneficiaries with ESRD seen by 5 or more medical specialties in the last 90 days of life, overall, and by age, race, ethnicity, sex, and modality, 2012-2015**

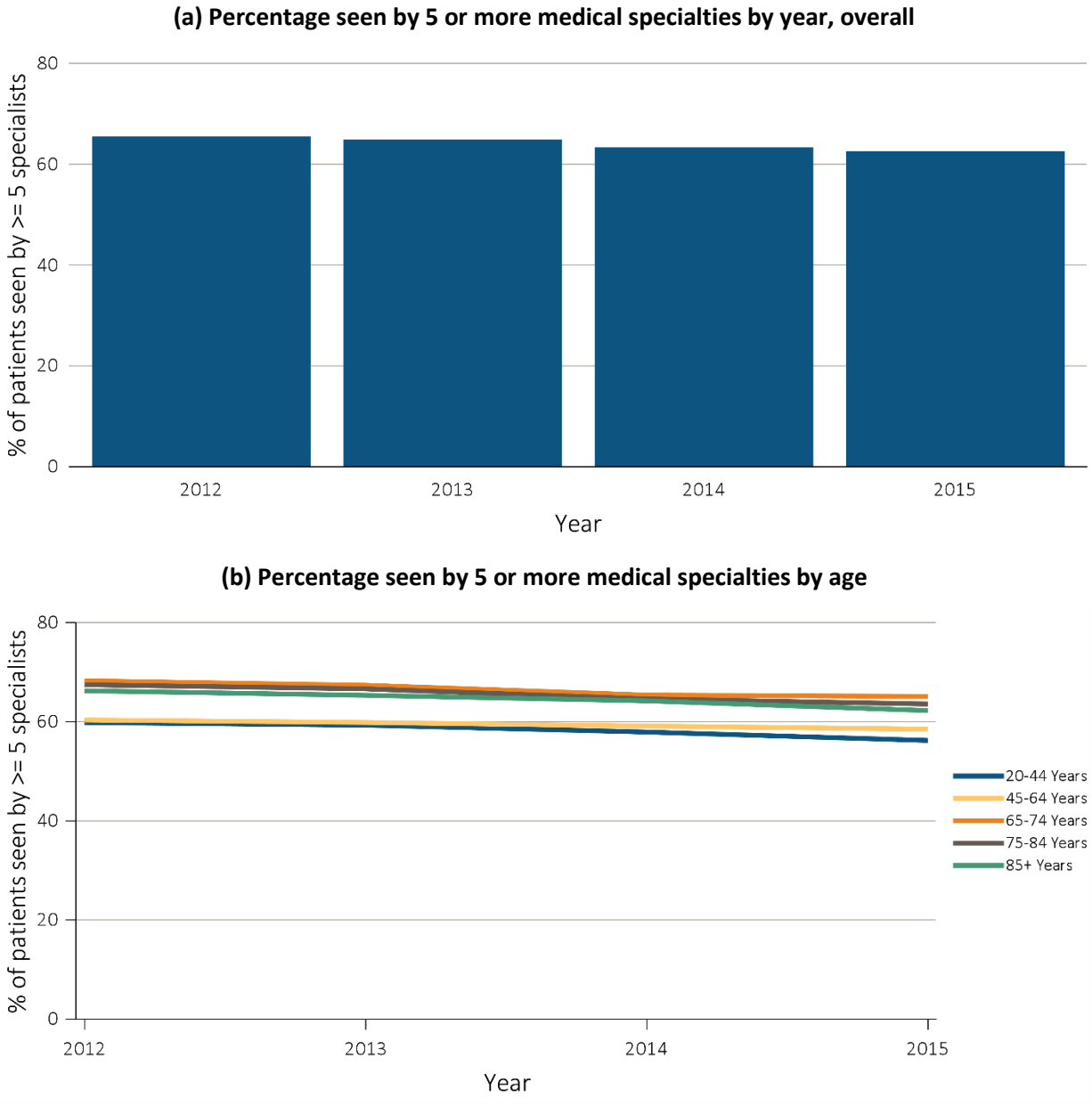
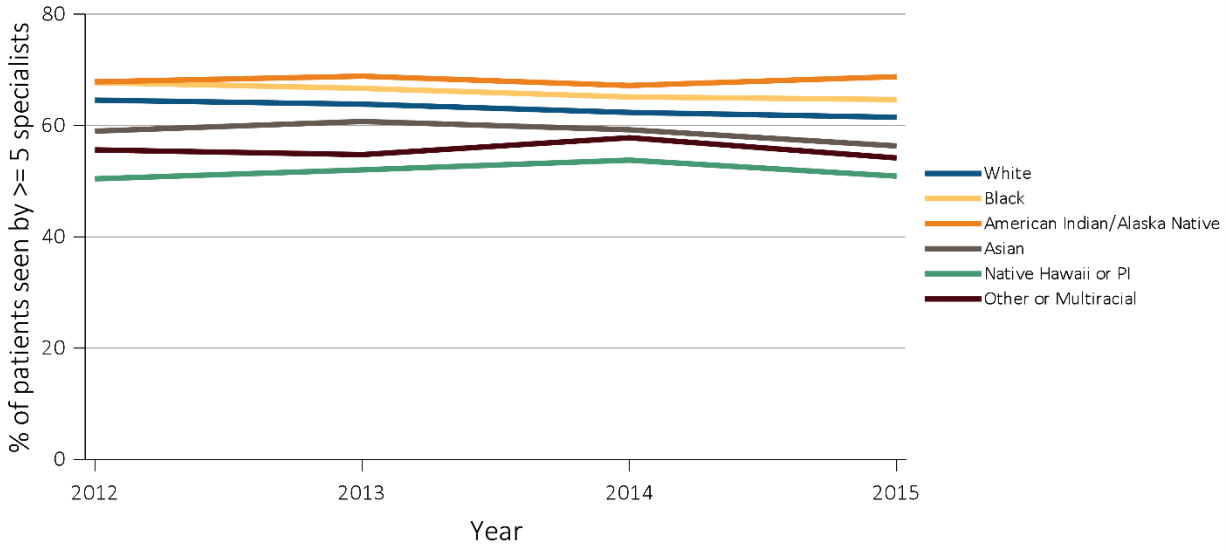



*Figure 12.8 continued on next page.*

**vol 2 Figure 12.8 Percentage of Medicare beneficiaries with ESRD seen by 5 or more medical specialties in the last 90 days of life, overall, and by age, race, ethnicity, sex, and modality, 2012-2015 (continued)**

**(c) Percentage seen by 5 or more medical specialties by race**




**(d) Percentage seen by 5 or more medical specialties by ethnicity**

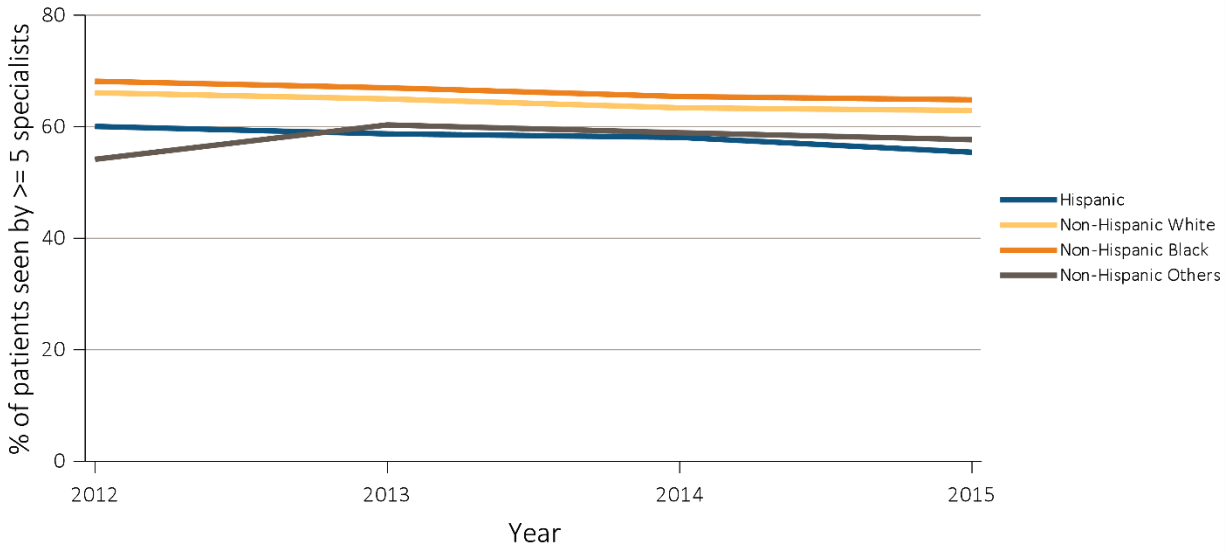
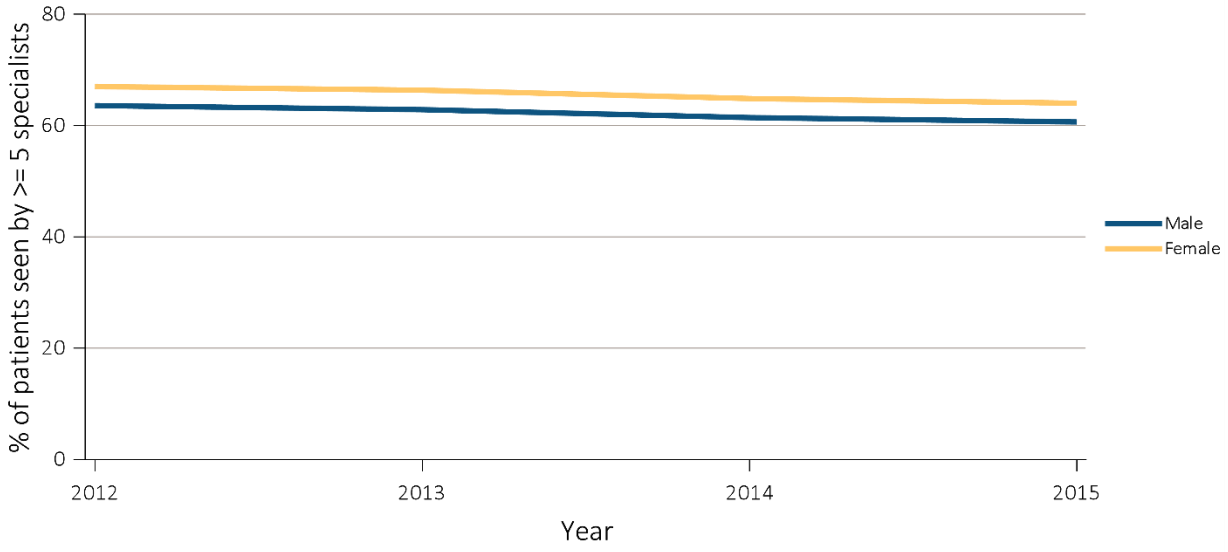



*Figure 12.8 continued on next page.*

**vol 2 Figure 12.8 Percentage of Medicare beneficiaries with ESRD seen by 5 or more medical specialties in the last 90 days of life, overall, and by age, race, ethnicity, sex, and modality, 2012-2015 (continued)**

**(e) Percentage seen by 5 or more medical specialties by sex**




**(f) Percentage seen by 5 or more medical specialties by modality**

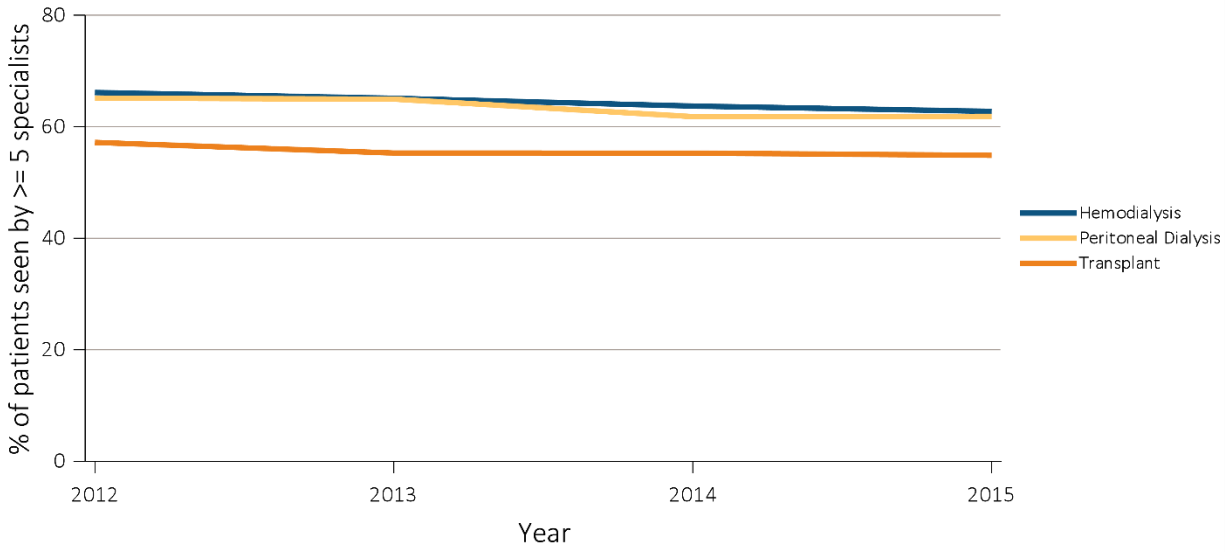
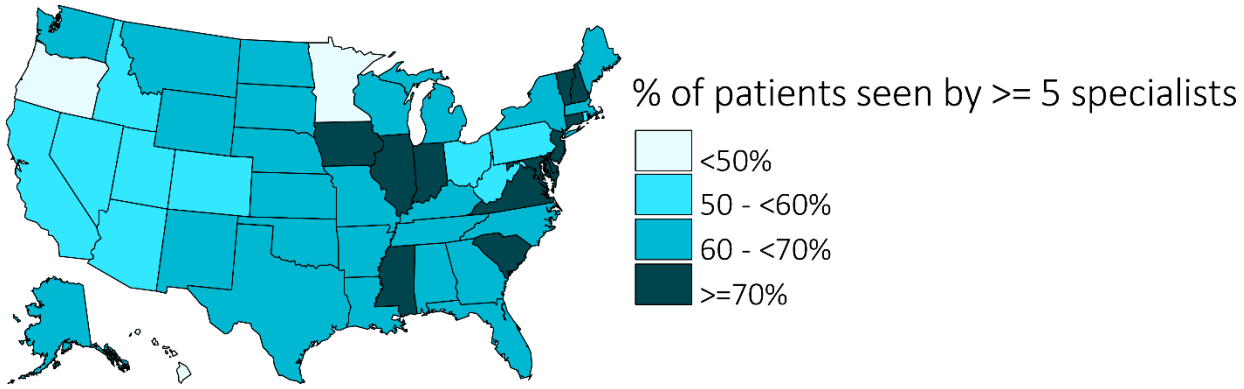



*Figure 12.8 continued on next page.*

**vol 2 Figure 12.8 Percentage of Medicare beneficiaries with ESRD seen by 5 or more medical specialties in the last 90 days of life, overall, and by age, race, ethnicity, sex, and modality, 2012-2015 (continued)**

**(g) Percentage seen by 5 or more medical specialties by state of residence**




*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 who died between 2012 and 2015. Abbreviation: ESRD, end-stage renal disease.*

**vol 2 Table 12.2 Percent of patients seen by a specialist and median number of visits in the last 90 days of life, from 2012 to 2015**

| Specialty | % of patients seen by specialist | Mean number of visits in last 90 days |
|---|---|---|
| **Nephrology** | 67% | 14.8 |
| **Diagnostic radiology** | 66% | 13.3 |
| **Internal medicine** | 63% | 17.0 |
| **Emergency medicine** | 59% | 4.5 |
| **Cardiology** | 55% | 8.6 |
| **Family practice** | 33% | 6.6 |
| **Pulmonary disease** | 31% | 8.9 |
| **Anesthesiology** | 27% | 4.5 |
| **General surgery** | 25% | 5.0 |
| **Pathology** | 25% | 3.6 |

*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 who died between 2012 and 2015. Abbreviation: ESRD, end-stage renal disease.*

## Dialysis Discontinuation before Death

The percentage of patients with either HD or PD listed on the CMS 2746 as their most recent modality, and who were reported as having discontinued dialysis treatments before death, ranged from 19% in 2000 to 23% in 2015, peaking at 25% in 2011 (Figure 12.8). The frequency of dialysis discontinuation before death varied by demographic characteristics, modality, and by state of residence. Discontinuation was nearly 4 times as common among decedents 85+ years as among decedents 20-44 years. Whites were more likely than other races to discontinue dialysis, as were women. By region, discontinuation rates were twice as high in the Northwest as in the Southeast.

**vol 2 Figure 12.9 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2015**

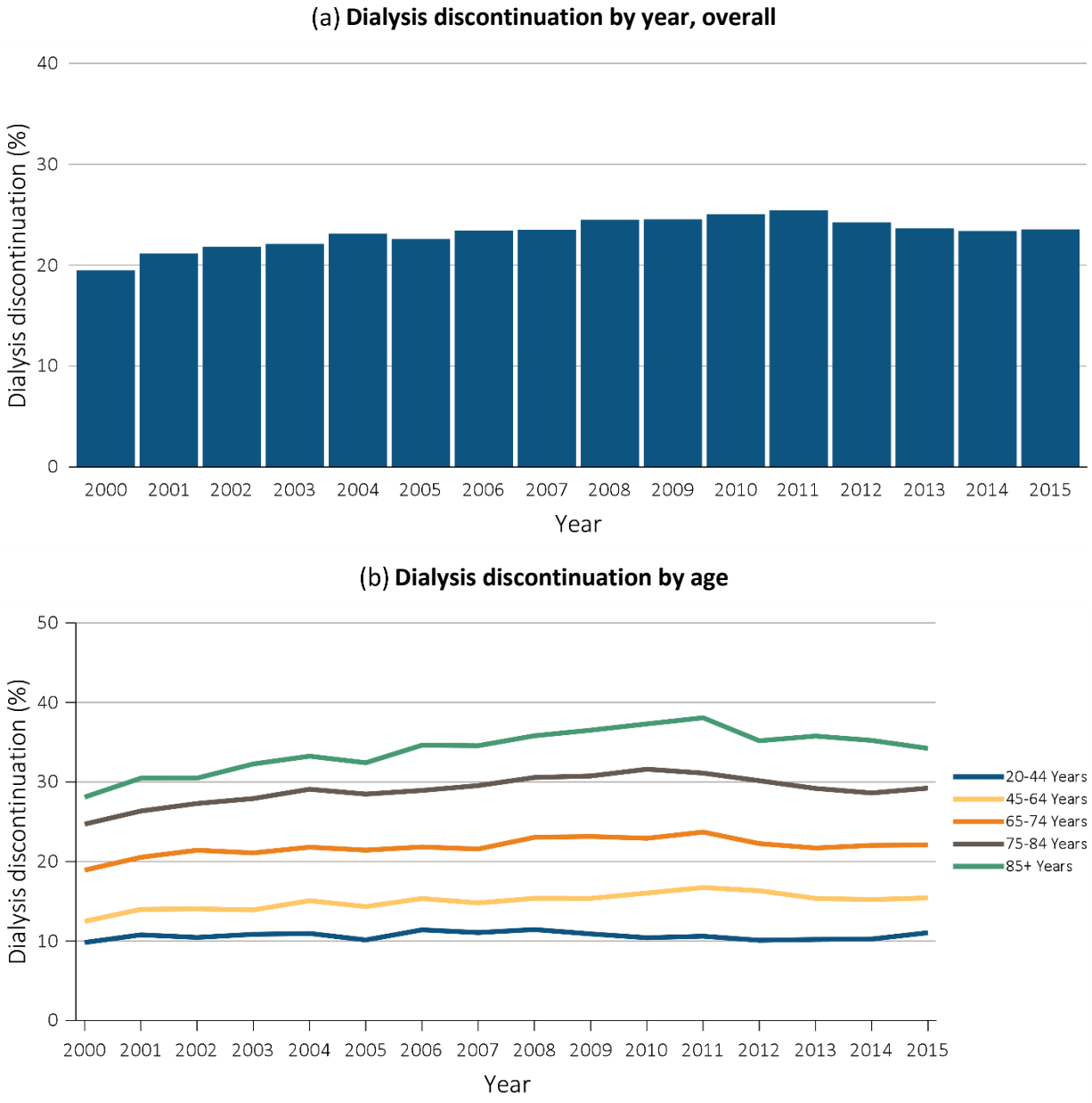



*Figure 12.9 continued on next page.*

**vol 2 Figure 12.9 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2015 (continued)**

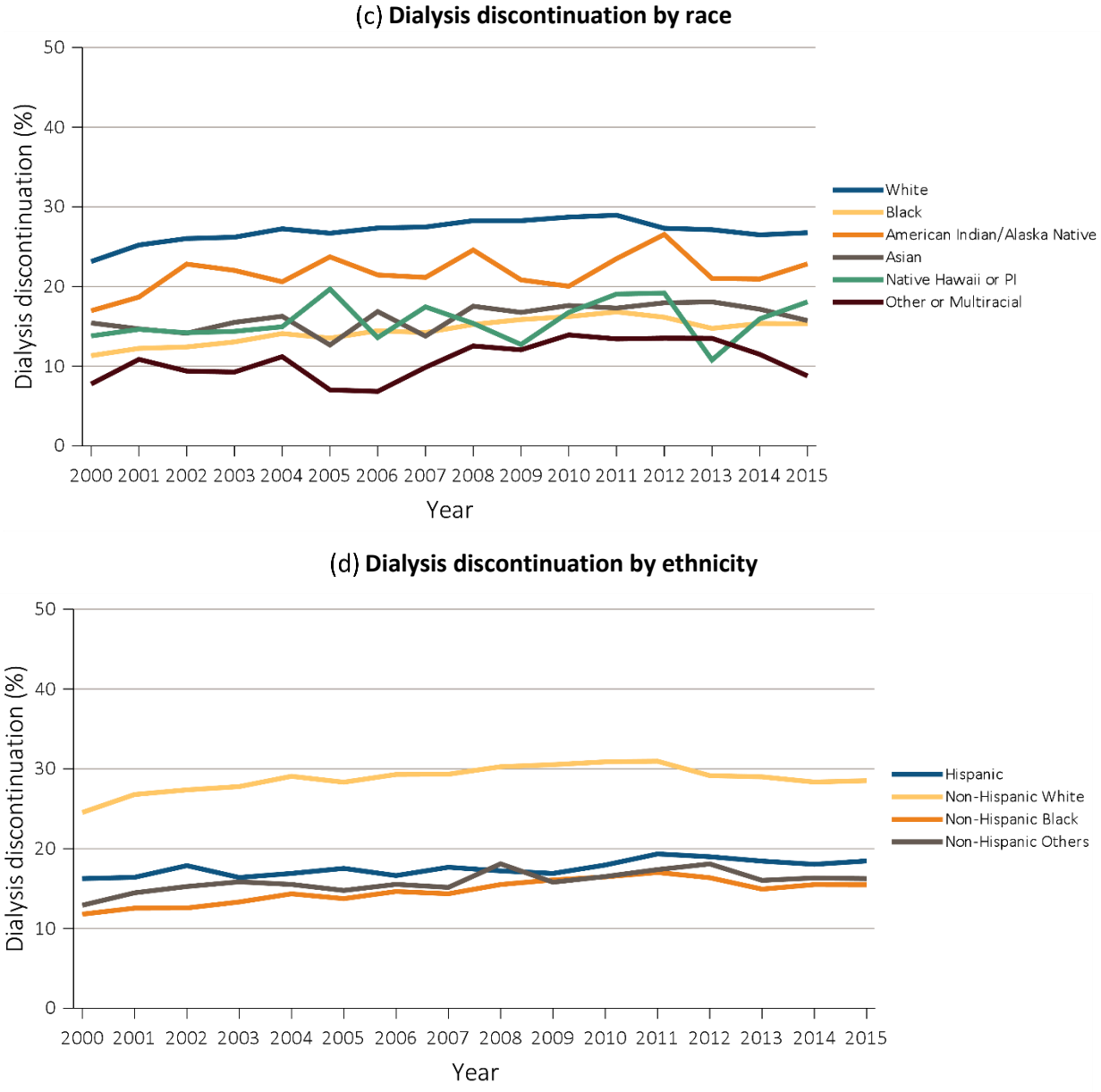



*Figure 12.9 continued on next page.*

**vol 2 Figure 12.9 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2015 (continued)**

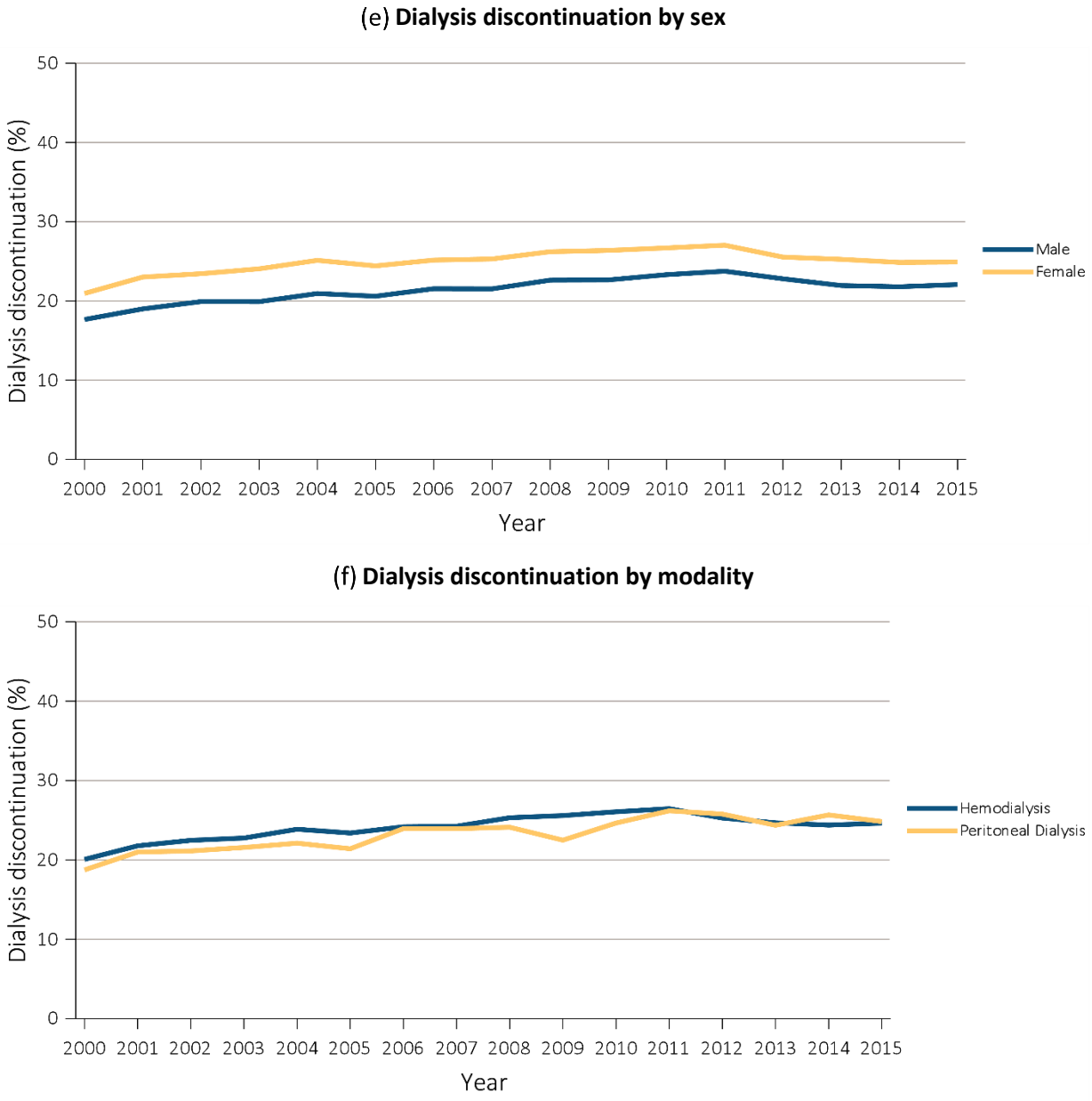
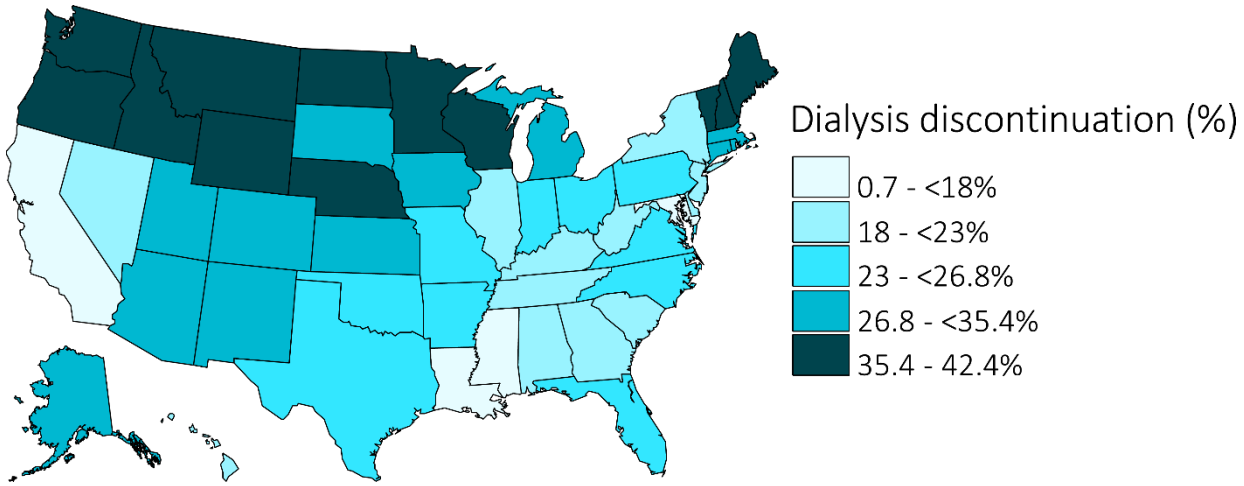



*Figure 12.9 continued on next page.*

**vol 2 Figure 12.9 Dialysis discontinuation before death among decedents overall, and by age, race, ethnicity, sex, and modality, 2000-2015 (continued)**

(g) **Dialysis discontinuation by state of residence**




*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) whose last modality was listed as dialysis. Abbreviation: ESRD, end-stage renal disease.*

## Patterns of Hospice Utilization before Death

The percentage of decedents with ESRD receiving hospice services at the time of death based on Medicare claims ranged from 11% in 2000 to 26% in 2015 (Figure 12.9). By comparison, rates of hospice use at death among the wider population of fee-for-service Medicare beneficiaries ranged from 21.6% in 2000 to 50.4% in 2015 (Teno et al., 2018). Among the overall population of fee-for-service Medicare beneficiaries, use of hospice services at the time of death varied by demographic characteristics, modality, and by state of residence. In addition, 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. For those who discontinued dialysis, the percentage receiving hospice at the time of death based on Medicare claims increased from 36% in 2000 to 62% in 2015. For those who did not discontinue dialysis treatments before death, the percentage receiving hospice services at the time of death increased from 5% in 2000 to 16% in 2015. Age at death was again a major predictor of hospice use with those 85 years and over using hospice (40%) at 4 times the rate of the youngest decedents (10%). Hospice was also much more common among White decedents than other races. There was also a two-fold difference in hospice use across the states, with generally higher rates in the central portions of the country.

**vol 2 Figure 12.10 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, 2000-2015**

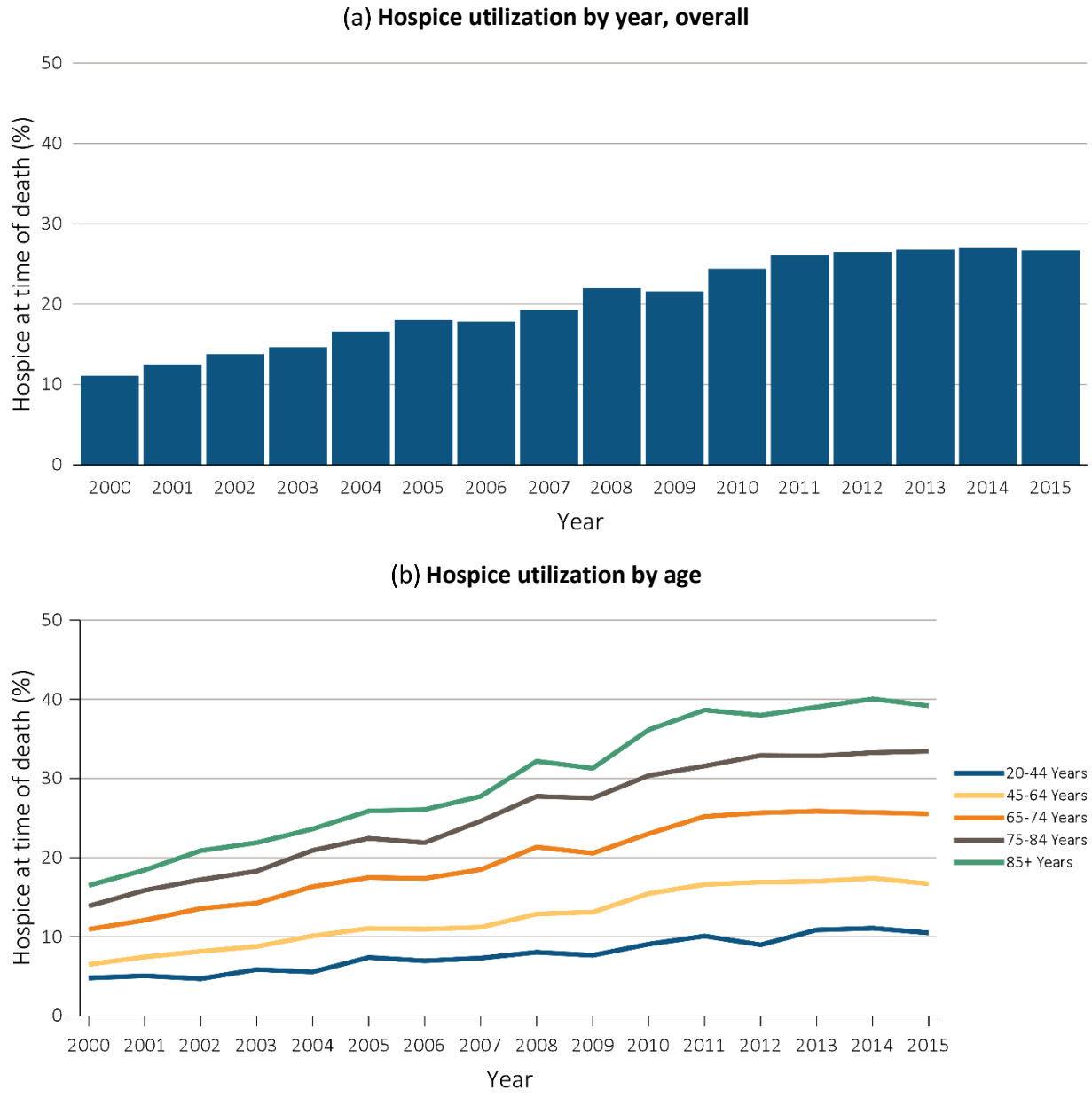



*Figure 12.10 continued on next page.*

**vol 2 Figure 12.10 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, 2000-2015 (continued)**

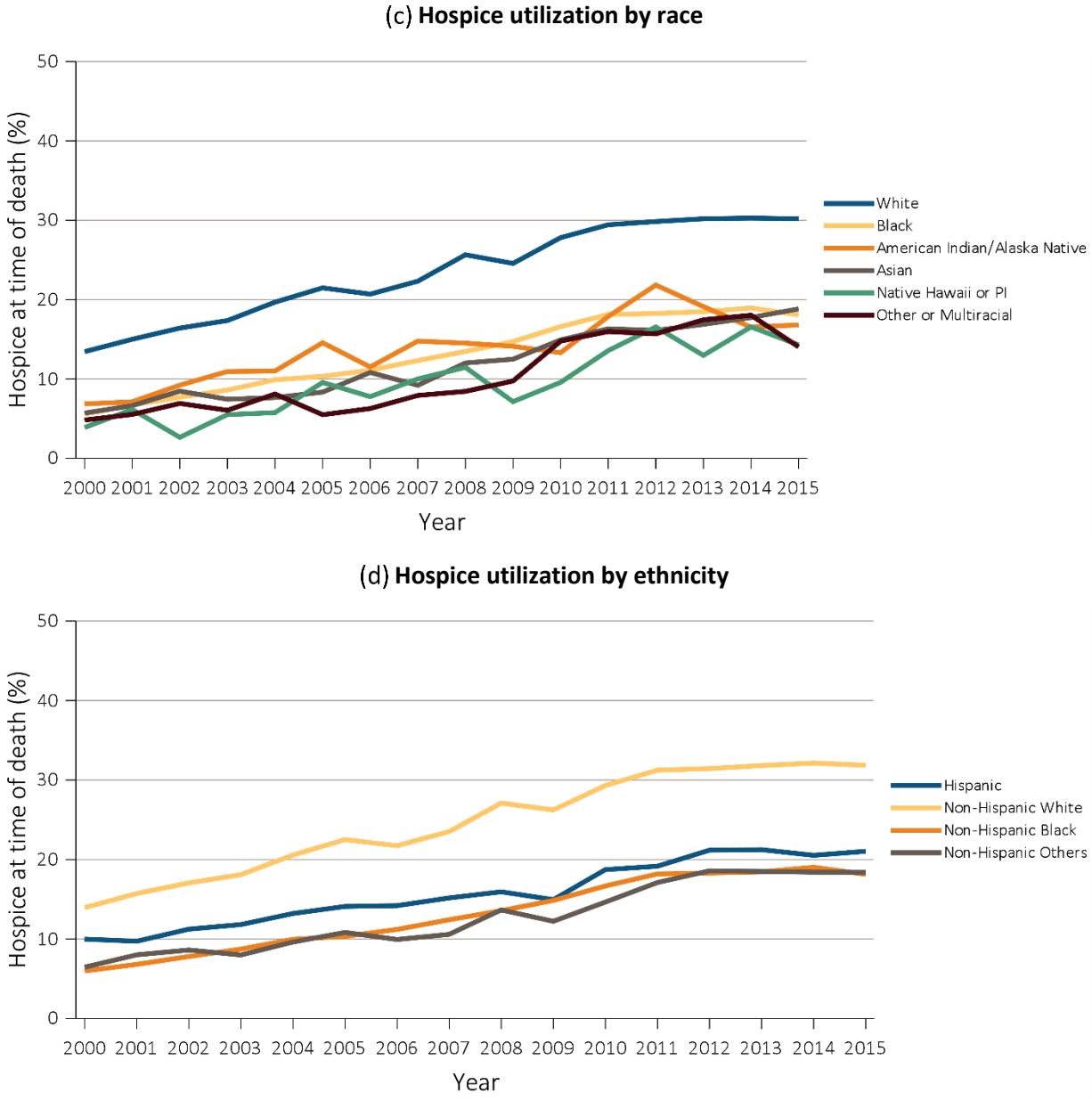
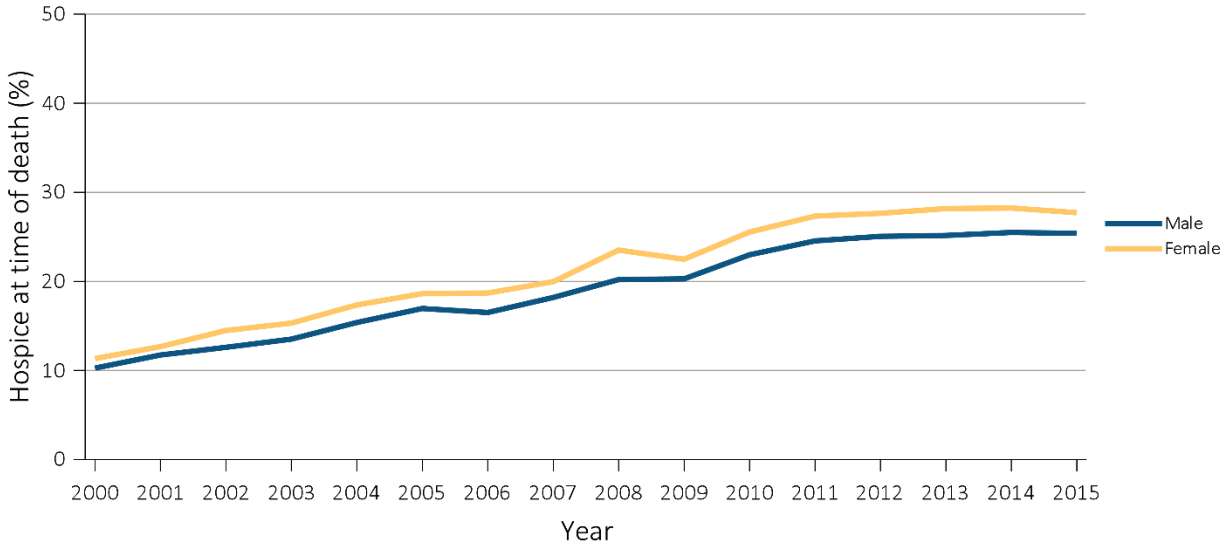



*Figure 12.10 continued on next page.*

**vol 2 Figure 12.10 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, 2000-2015 (continued)**

(e) **Hospice utilization by sex**




(f) **Hospice utilization by modality**

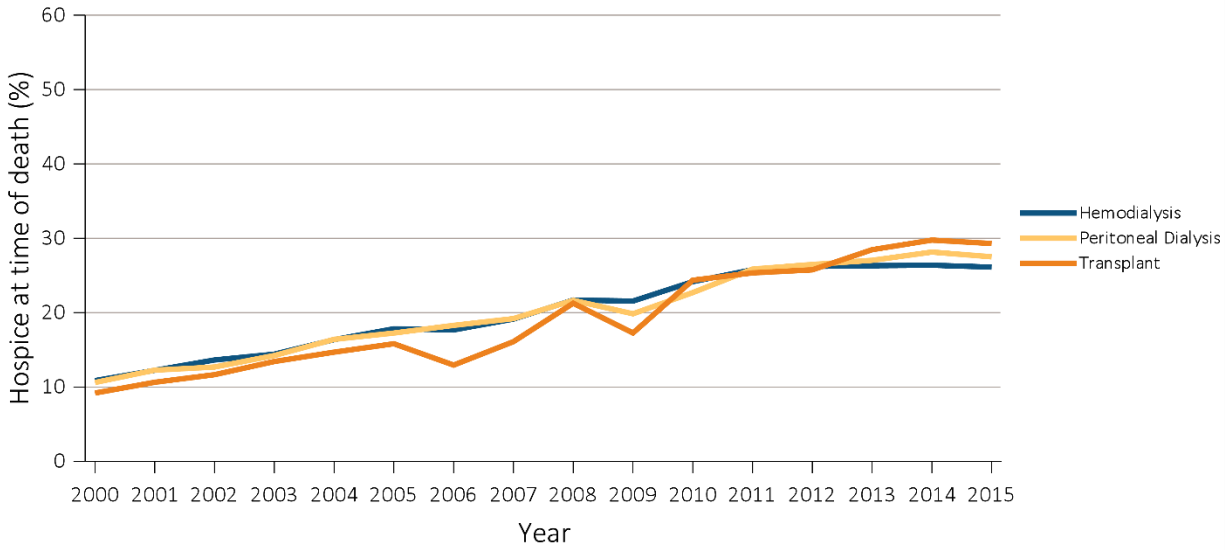
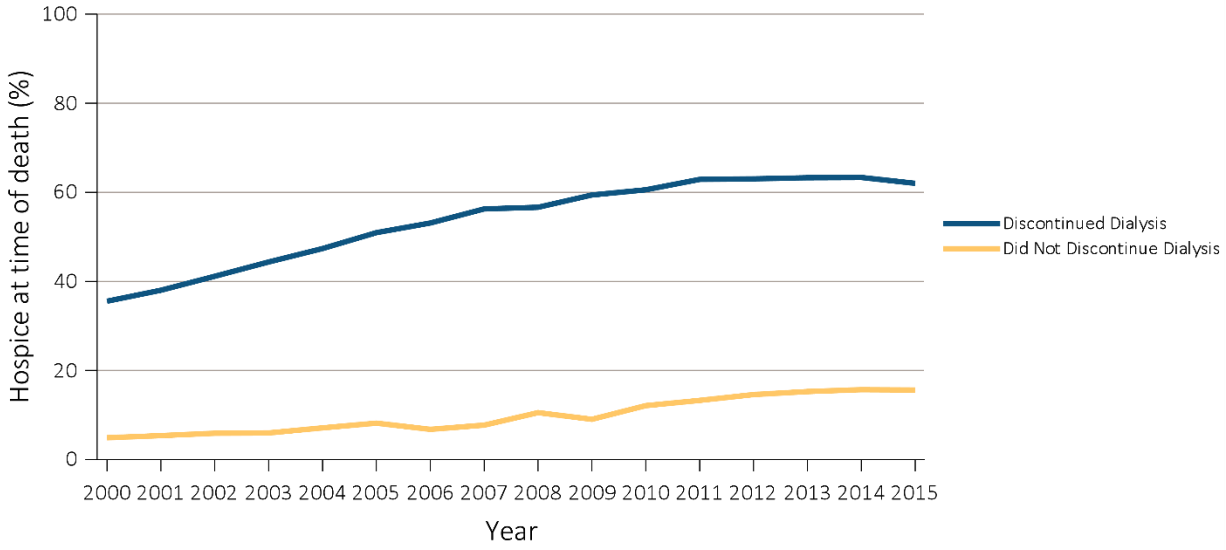


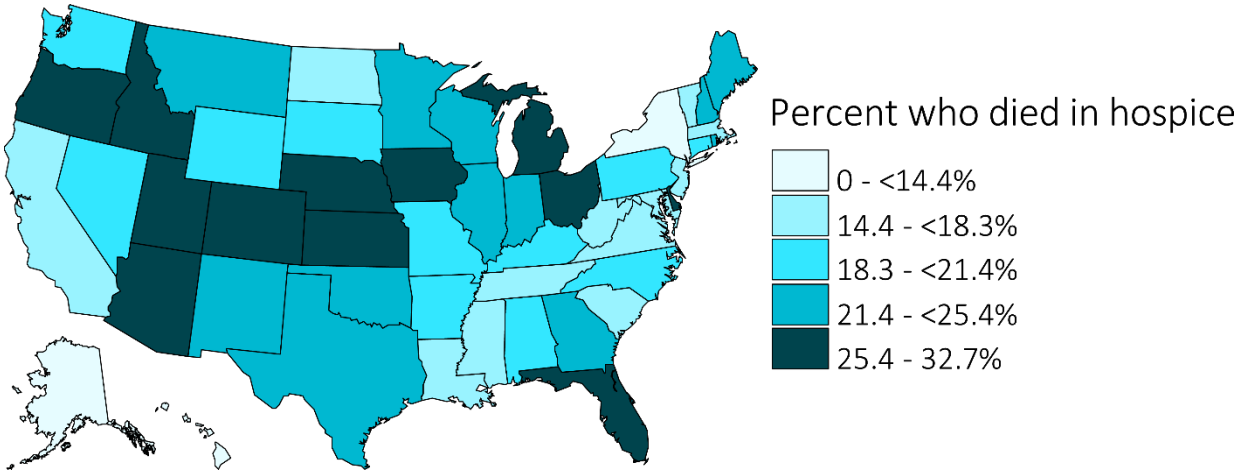

*Figure 12.10 continued on next page.*

**vol 2 Figure 12.10 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, 2000-2015 (continued)**

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




(h) **Hospice Utilization by state of residence**




*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 (HCFASAF=S) on or after the date of death or Discharge Status from hospice=40, 41, or 42. Abbreviation: ESRD, end-stage renal disease.*

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

For patients with ESRD who died in 2015, median per person costs under Medicare Parts A and B were $103,932 (IQR $65,345, $159,451) over the last year of life, $19,734 (IQR, $9,217, $34,979) over the last 30 days of life, and $7,687 (IQR, $1,866, $14,822) over the last seven days of life. Median costs during each of these time frames were progressively lower for patients with a longer time interval between the first claim for hospice and death, and were higher for those who received two or fewer days of hospice than for those who were not referred to hospice (Figure 12.15).

**vol 2 Figure 12.11 Costs in the (a) last 30 days of life, and (b) last 7 days of life in relation to timing of hospice care, 2000-2015**

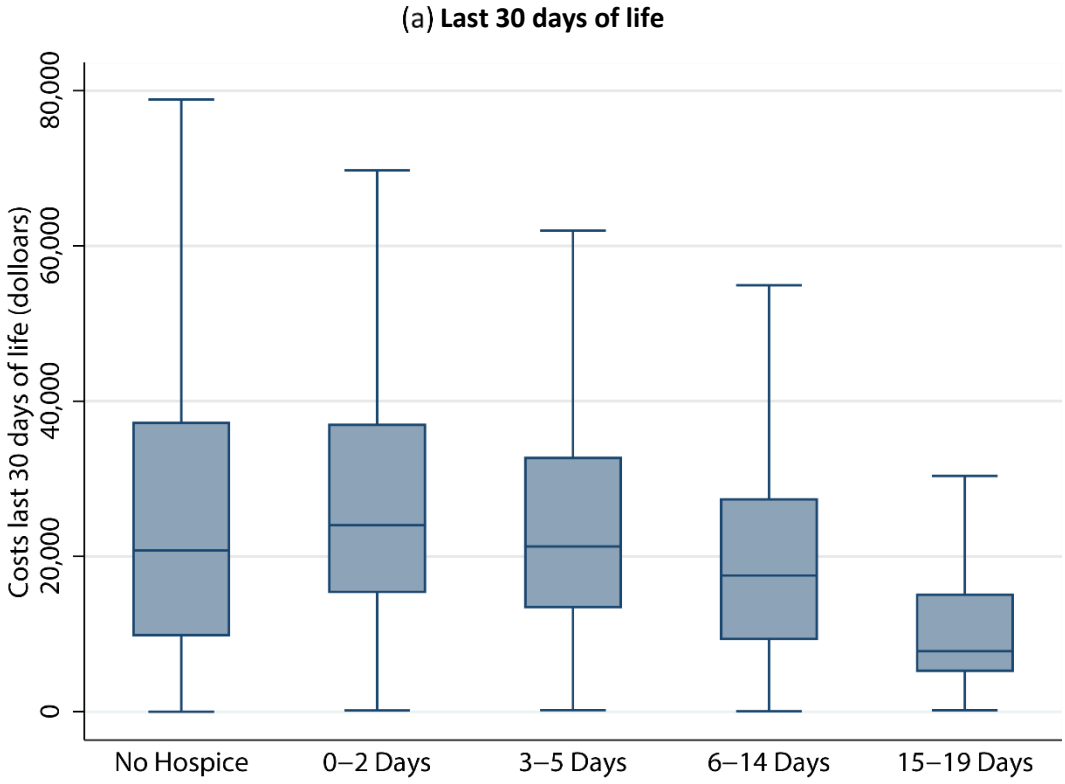
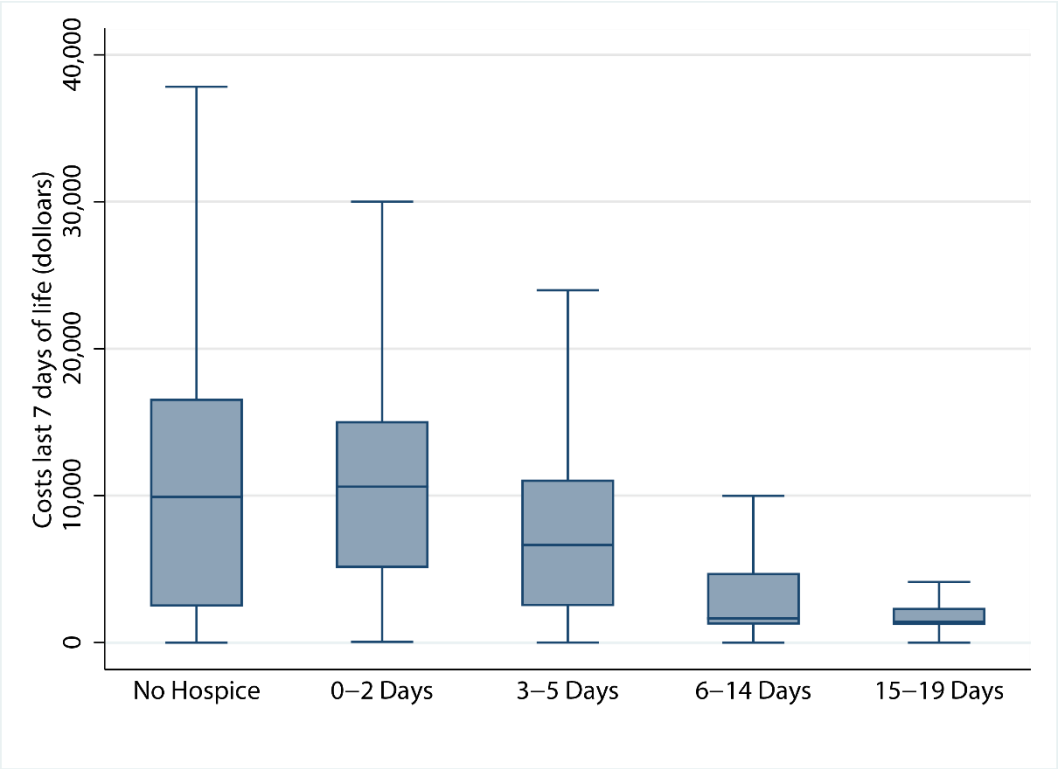



*Figure 12.11 continued on next page.*

**vol 2 Figure 12.11 Costs in the (a) last 30 days of life, and (b) last 7 days of life in relation to timing of hospice care, 2000-2015 (continued)**

(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=S) 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 ≥ the first quartile minus 1.5 times the interquartile range at the bottom to the highest value of the distribution that is ≤ 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.*

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Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 2013;309(5):470-477.

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