# 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 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