

Chapter 1: Incidence, Prevalence, Patient Characteristics, and Treatment Modalities

Incidence

- The number of incident (newly reported) ESRD cases in 2013 was 117,162; the unadjusted incidence rate was 363 per million/year.
- The adjusted incidence rate of ESRD in the United States rose sharply in the 1980s and 1990s, leveled off in the early 2000s, and has declined slightly since its peak in 2006.
- In 2013, the adjusted ESRD incidence rate ratios for Black/African Americans, Native Americans, and Asians/Pacific Islanders, compared with Whites, were 3.0, 1.1 and 1.2; the rate ratio for Hispanics versus Non-Hispanics was 1.4.

Prevalence

- On December 31, 2013, there were 661,648 prevalent cases of ESRD; the unadjusted prevalence (proportion) was 2,034 per million in the U.S. population.
- While the number of ESRD incident cases plateaued in 2010, the number of ESRD prevalent cases continues to rise by about 21,000 cases per year.
- Compared to Whites, ESRD prevalence is about 3.7 times greater in Blacks, 1.4 times greater in Native Americans, and 1.5 times greater in Asians.

Characteristics of Incident ESRD Cases

- Up to 38% of incident ESRD cases in 2013 received little or no pre-ESRD nephrology care.
- Mean eGFR at initiation of dialysis in 2013 increased steadily from 1996 until 2009, but has been stable or decreased slightly from 2010 to 2013

Treatment Modalities

- In 2013, 88.2% of all incident cases began renal replacement therapy with hemodialysis, 9.0% started with peritoneal dialysis, and 2.6% received a preemptive kidney transplant.
- On December 31, 2013, 63.7% of all prevalent ESRD cases were receiving hemodialysis therapy, 6.8% were being treated with peritoneal dialysis, and 29.2% had a functioning kidney transplant.

Introduction

The focus of this chapter is the incidence and prevalence of end-stage renal disease (ESRD) in the U.S. population. Incidence refers to the occurrence or detection of new (incident) cases of ESRD during a given period. Incidence is expressed in this chapter as a count (number of incident cases) and as a rate (number of new cases in one year, divided by the amount of person-years at risk, which is approximated by the mid-year census for the population in that year). Rates are then expressed

as per million population per year. For example, if 3,000 incident ESRD cases occurred in 2013 in a population of 10,000,000 adults, the incidence rate would be 0.000300 per year or 300 per million per year. Incidence rates are used to describe the occurrence of disease in populations, to identify risk factors for ESRD in etiologic studies, and to evaluate the impact of interventions for reducing ESRD risk in primary-prevention studies.

Prevalence refers to the presence of existing ESRD cases at a point in time (point prevalence) or during a specific

period (period prevalence; not used in this chapter); it is expressed in this chapter as a count (number of prevalent cases) and as a proportion (number of prevalent cases, divided by the size of the population from which those cases were identified); prevalence at the end of each year is then expressed as per million population. Note that prevalence is not a rate; it is a proportion. Prevalence is used to describe the existing burden of disease in populations, to quantify the need for and to allocate health care resources.

Although prevalence is easier to estimate than incidence, prevalence findings are more difficult to interpret because the prevalence of a condition depends on both the incidence rate of that condition and how long ESRD patients live with the condition before recovering or dying. For example, if something favorable is done to improve survival among ESRD patients without changing the incidence rate, the prevalence of ESRD will increase. On the other hand, if something favorable is done to reduce the ESRD incidence rate without changing the survival of ESRD patients, the prevalence of ESRD will decrease.

This chapter examines trends in ESRD incidence and prevalence, patient characteristics, and treatment modalities from 1996 through 2013. While the prevalence of ESRD continues to rise, the trend over the past decade indicates that ESRD incidence has plateaued after increasing for many years. If these incidence and prevalence trends continue in the coming years, this would be good news indeed, as it implies likely improvements in prevention of ESRD as well as longer survival among patients who have reached ESRD.

PRIMARY CAUSE OF ESRD: A CAUTIONARY NOTE

The “primary cause of renal failure,” as assessed by individual physicians and reported on Form CMS-2728, has been used for many years in nephrology to compare populations and assess temporal trends. In the ADR, it allows us to estimate the ESRD incidence rate and prevalence for different disease subtypes, i.e., those with the primary cause listed as diabetes, hypertension, glomerulonephritis, or cystic kidney disease. It should be noted, however, that this approach is not the same as stratifying on comorbidity status, e.g., in this chapter we are not estimating adjusted incidence rates of ESRD among diabetics or non-diabetics in the U.S. population. Furthermore, the reliability of clinician assigned “primary-cause” of ESRD has not been well established; and because causation cannot be definitively established for all patients on the basis of clinical judgment or testing,

and also because many patients arrive at ESRD without benefit of prior nephrology care, the validity of these etiologic subtypes of ESRD remains a challenge.

ADJUSTMENT OF INCIDENCE RATES AND PREVALENCE

When comparing the incidence rate or prevalence of ESRD between different groups or years, the magnitude of the difference might be distorted (biased) if the groups or years differ in the distribution of one or more risk factors for ESRD. To control for those risk factors (potential confounders or covariates) in this chapter, we stratify on them in each group or year and calculate a weighted average of the stratum-specific rate or prevalence estimates, where the weights are the numbers of persons in each stratum of a standard population. This method is called standardization or “direct adjustment.” To control for the potential confounders when comparing groups or years, we standardize all sets of rates or prevalences to the same standard population. In the 2015 ADR, standardization is used to adjust for age, sex, and race or ethnicity; and the standard population is the total U.S. population in 2011 (the same as in the 2014 ADR). Each standardized rate or prevalence for any specific group or year is interpreted as the rate or prevalence expected if that group or year had exhibited the covariate distribution of the standard population.

The major limitation of this adjustment method is that we are controlling for only a few demographic variables in this chapter. We are not controlling for other major ESRD risk factors such as CKD stage, diabetes status, hypertension status, or cardiovascular burden. Therefore, interpreting comparisons of incidence rates or prevalences between groups or years should be done with caution.

ANALYTICAL METHODS

See the ESRD Analytical Methods chapter for an explanation of analytical methods used to generate the figures and tables in this chapter.

Incidence of ESRD: Counts, Rates, and Trends

OVERALL INCIDENCE RATE

The number of incident (newly reported) ESRD cases in 2013 was 117,162 (Figure 1.1). The unadjusted incidence rate in 2013 was 363 per million/year. After a year-by-year rise in ESRD incidence over two decades from 1980 through 2000, it has been roughly stable from 2000 to 2013. The size of the incident dialysis

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