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

Incidence

- The number of incident (newly reported) ESRD cases in 2014 was 120,688; the unadjusted (crude) incidence rate was 370 per million/year (Table 1.1). Since 2011, both the number of incident cases and the unadjusted incidence rate have begun rising again (Figure 1.1).
- The age-gender-race-ethnicity adjusted incidence rate of ESRD in the United States rose sharply in the 1990s, leveled off in the early 2000s, and has declined slightly since its peak in 2006 (Figure 1.1).
- In 2014, the adjusted ESRD incidence rate ratios for Blacks/African Americans, Native Americans, and Asians/Pacific Islanders, compared with Whites, were 3.1, 1.2, and 1.2, respectively; the rate ratio for Hispanics versus non-Hispanics was 1.3 (Figures 1.5 and 1.6).

Prevalence

- On December 31, 2014, there were 678,383 prevalent cases of ESRD; the unadjusted prevalence (crude proportion) was 2,067 per million in the U.S. population (Table 1.3).
- 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 (Figure 1.11).
- Compared to Whites, ESRD prevalence in 2014 was about 3.7 times greater in Blacks, 1.4 times greater in Native Americans, and 1.5 times greater in Asians (Figure 1.14).

Treatment modalities

- In 2014, 87.9% of all incident cases began renal replacement therapy with hemodialysis, 9.3% started with peritoneal dialysis, and 2.6% received a pre-emptive kidney transplant (Figure 1.2).
- On December 31, 2014, 63.1% of all prevalent ESRD cases were receiving hemodialysis therapy, 6.9% were being treated with peritoneal dialysis, and 29.6% had a functioning kidney transplant (Figure 1.11). Among hemodialysis cases, 88.0% used in-center hemodialysis, and 1.8% used home hemodialysis (Figure 1.19).

Characteristics of incident ESRD cases

- Up to 38% of incident ESRD cases in 2014 received little or no pre-ESRD nephrology care (Table 1.7).
- Mean eGFR at initiation of dialysis in 2014 was 10.2 ml/min/1.73m^2. The percent of incident ESRD cases starting with eGFR at ≥10 ml/min/1.73 m^2 rose from 13% in 1996 to 43% in 2010, but had decreased to 39% in 2014 (Table 1.22).

Introduction

The focus of this chapter is the incidence and prevalence of end-stage renal disease (ESRD) in the U.S. population. It should be noted that the terms ESRD incidence and prevalence, as used throughout the ADR, refer to treated cases of ESRD, i.e., patients started *or* currently on renal replacement therapy (dialysis or transplantation); they do not refer exclusively to disease occurrence (biological constructs). Although ESRD is often equated with treatment (i.e., renal replacement therapy with dialysis or transplantation) and usually commences in Stage 5 CKD (GFR <15 ml/min), it should be noted

that some patients with eGFR <15 may not receive (or choose to forego) dialysis or transplantation. In addition, there are a number of "ESRD treated" patients on renal replacement therapy who are initiated on dialysis at an eGFR greater than 15. In short, the definition of ESRD incidence and prevalence used throughout the USRDS is a treatment-based definition, not a purely physiological or biological construct. Thus, although the terms "incident ESRD" and "prevalent ESRD" are used throughout this chapter, they should always be interpreted as "treated ESRD."

Incidence refers to the occurrence or detection of new (incident) cases of a disease during a given period. In this chapter, ESRD incidence is expressed as a count (number of incident cases in one year) and as a rate (number of incident cases in one year, divided by person-years at risk, which is approximated by the mid-year census for the population in that year). Incidence rates are expressed as per million population per year. They are used to describe the occurrence or burden of new cases of ESRD in the population, 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 (prevalent) cases of a disease at a point in time (point prevalence) or during a specific period (period prevalence). In this chapter, ESRD (point) prevalence is expressed 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). ESRD prevalences at the end of each year are expressed per million population. It should be noted that ESRD prevalence depends on both the incidence rate of ESRD and the duration of the disease from the start of renal replacement therapy to death.

Both incidence rates and prevalences in this chapter are presented without adjustment for other factors (i.e., crude measures) and with adjustment for age, gender, and race by using a method known as "standardization." This method involves stratification of the population by those three variables and calculation of a weighted average of stratum-specific rates or prevalences, where the weights are the numbers of persons in strata of a "standard population," which, since the 2014 ADR, has been the U.S. population in 2011. Each standardized (adjusted) incidence rate or prevalence for a specific group or year is interpreted as the expected (crude) rate or prevalence if that group or year had exhibited the age-gender-race distribution of the standard population. Since we are not adjusting for other major ESRD risk factors such as diabetes, hypertension, or cardiovascular disease, interpreting comparisons of incidence rates or prevalences between groups or years should be done with caution.

Primary cause of ESRD: A cautionary note

The "primary cause of renal failure," as assessed by individual physicians and reported on the CMS 2728 form, 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 subtypes of chronic kidney disease, 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. For example, in this chapter we are not estimating adjusted incidence rates of ESRD among diabetics and non-diabetics because we do not have data on laboratory-based diabetes status in the total U.S. population by strata of age, gender, and race. In Reference Table A.11, however, incidence rates of ESRD are estimated for self-reported diabetics in the U.S. population. Those estimates should be interpreted with caution as many persons with diabetes either do not report their condition or are not aware that they have diabetes.

Another issue is that the reliability of clinician-assigned "primary-cause" of ESRD has not been well established. Because causation for some diagnoses cannot be definitively established on the basis of clinical judgment or testing, and because many patients arrive at ESRD without benefit of prior nephrology care, establishing the validity of these etiologic subtypes of ESRD remains a challenge. In diabetics with CKD, for example, kidney biopsies are rarely performed. Moreover, though authorities such as KDIGO provide guidance for assigning a diagnosis of diabetic CKD (diabetes as the primary cause), it is