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US Renal Data System 2020 Annual Data Report: Epidemiology of Kidney Disease in the United States

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The US Renal Data System (USRDS) *Annual Data Report* (ADR) is an authoritative source of data about the chronic kidney disease (CKD) and kidney failure populations in the United States. Herein, we will refer to the latter using the Centers for Medicare & Medicaid Services (CMS) term, end-stage renal disease (ESRD). Supported by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health and the CMS, the USRDS Coordinating Center is operated by the Chronic Disease Research Group within the Hennepin Healthcare Research Institute in Minneapolis, Minnesota.

The 2020 ADR contains the most current US surveillance data on incidence, prevalence, and outcomes of CKD, acute kidney injury (AKI), and ESRD. According to recent data from the National Health and Nutrition Examination Survey, the prevalence of CKD among adults in the United States has been relatively stable at just under 15% for the last 15 years. At the same time, the number of individuals with key risk factors such as older age, diabetes, and hypertension has increased. Thus, stable rates of CKD reflect lower rates among individuals with these risk factors. Rates of hospitalizations during which AKI occurs have been rising in the Medicare population, but the rate of AKI requiring dialysis has been stable over the past decade.

Turning to ESRD, the unadjusted incidence has risen over the last 20 years and continues to increase. However, it has risen more slowly in recent years, and its adjusted incidence has declined from a peak in 2006. By contrast, the adjusted prevalence of ESRD has steadily increased, primarily owing to declining mortality among patients with ESRD. ESRD prevalence in the United States remains one of the highest in the world at 2,242 cases per million population in 2018. The rate of kidney transplantation among patients receiving dialysis increased in 2018 to 3.6 per 100 person-years, continuing a trend that started in 2014 after years of steady decline. At the end of 2018, there were 554,038 patients

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undergoing dialysis and 229,887 patients with a functioning kidney transplant in the United States. These data do not capture patients with ESRD who chose to forego dialysis or transplantation and were being managed using conservative means, a strategy that has garnered increasing attention in recent years.

Racial disparities in rates of CKD and ESRD and in access to kidney transplantation have been widely appreciated and remain evident in the 2020 ADR. However, there is evidence of some progress. The incidence of ESRD among Black individuals decreased by 20% between 2008 and 2018, narrowing the gap between Black and White patients somewhat. Nevertheless, the incidence remained more than 2.5 times higher among Black individuals in 2018. The rate of deceased donor kidney transplantation increased among Black patients receiving dialysis and now equals that among White patients. However, the rate of living donor transplantation among Black patients still lagged substantially.

This year's ADR also incorporates new information, including a chapter focusing on patients' preferences about end-of-life care and a supplemental chapter describing the early impact of coronavirus disease 2019 (COVID-19) on the ESRD population. Information about patients' prognostic expectations and end-of-life treatment preferences was drawn from participants in the USRDS Study of Treatment Preferences. Just over 40% of patients were uncertain of their prognosis, and over half of the remainder anticipated surviving for 10 years or longer despite a statistically estimated survival of less than 10 years among prevalent dialysis patients over 44 years of age. Patients' prognostic expectations may have influenced their engagement in end-of-life preparations and discussions as well as their preferences for end-of-life care. Those with more optimistic expectations were less likely to have documented a surrogate decision maker or considered end-of-life preferences, whereas they were more likely to prioritize life prolongation over relief of discomfort and to favor receipt of cardiopulmonary resuscitation. These findings suggest missed opportunities to discuss expected prognosis and goals of care with patients receiving dialysis.

Timely analyses on COVID-19 in the ESRD population were possible using data in the CMS Renal Management Information System extracts. During the first half of 2020, there were 11,200 COVID-19 hospitalizations among Medicare beneficiaries undergoing dialysis. Compared with the same periods in 2017-2019, all-cause mortality among all patients receiving dialysis in 2020 was 37% higher from March 29 to April 25 and 16% higher from April 26 to July 4. Among patients with a functioning kidney transplant, corresponding estimates of excess mortality were 61% and 25%. Between mid-March and mid-May, the number of ESRD patients with incident ESRD was 20% lower than average cumulative counts during the same period in 2017-2019. Thus, the impact of COVID-19 on the ESRD population in the United States was profound during the first half of 2020.

The ADR is published at the USRDS website (www.usrds.org) and as a supplement to *AJKD*. This year, the ADR available at the USRDS website is presented in a new, interactive format. The report was designed with the data at the center so that tables and figures are juxtaposed with brief explanatory text. In most cases, figures can be customized by the reader to display data stratified by patient characteristics and/or to show unadjusted values or values adjusted for patient demographic characteristics or for inflation. As a result, some

figures have many more possible configurations in the online ADR than can be reproduced in the journal supplement version. Therefore, the investigative team has curated the content for presentation in *AJKD*, sifting through the material presented in each figure to select the versions that display the most noteworthy findings. Readers who wish to view alternative or additional displays may visit the interactive ADR at <https://adr.usrds.org/2020>.

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