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US Renal Data System 2021 Annual Data Report: Epidemiology of Kidney Disease in the United States

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The 2021 US Renal Data System *Annual Data Report* (ADR) is again presented in an interactive format, which we introduced with the 2020 ADR. However, the content has been improved, restructured, and expanded. Building on the supplemental chapter on COVID-19 (coronavirus disease 2019) introduced in the 2020 ADR, we continue the ADR's critical surveillance mission by including an updated COVID-19 chapter that presents many outcomes through the end of 2020 and some through the second quarter of 2021. We utilize quarterly claims data from payment year 2020 to describe COVID testing and cases, incidence of COVID-related acute kidney injury (AKI), utilization of therapeutic interventions (eg, hospitalization, intensive care unit care, mechanical ventilation), post-discharge outcomes in COVID survivors, and the impact of COVID-19 on the size of the end-stage renal disease (ESRD) population.

The 2021 ADR includes a new chapter focused on racial and ethnic disparities in health care delivery and outcomes in the chronic kidney disease (CKD) and ESRD populations. This chapter does not replace material presented elsewhere in the ADR reporting incidence, prevalence, and outcome data by race and ethnicity. Rather, this chapter examines possible contributors to the observed disparities with an emphasis on social determinants of health and access to care. This chapter examines disparities in the context of CKD, AKI, dialysis, and kidney transplantation, spanning the continuum of kidney disease.

We have also included a new chapter on home dialysis. Many other chapters in the ESRD volume present outcomes by modality, but this chapter delves into greater detail and presents information not previously captured in the ADR. For example, we examine characteristics of patients performing home dialysis, the way in which home dialysis is delivered, complications experienced by patients performing home dialysis, and switches between home modalities and in-facility hemodialysis.

We have eliminated the chapters dedicated to cardiovascular disease, dispersing much of their content into the relevant remaining chapters. For example, data on cardiovascular events is presented in the hospitalization chapters, and medication utilization among patients with cardiovascular conditions is reported in the prescription drug chapters.

Data Sources

This year's ADR also includes new or reintroduced sources of data:

1. **Optum de-identified Clinformatics Data Mart database:** Reintroduced in the 2021 ADR, this database provides paid medical and prescription claims and enrollment information for participants in commercial insurance plans and Medicare Advantage plans of a large US managed-care health insurance company. Included plan members are enrolled in both a medical and a prescription plan, and the sample represents all areas of the country. In the CKD volume, Optum data from 2019 are used in estimating CKD prevalence and assessing the burden of illness and hospitalizations in CKD patients.
2. **CMS Medicaid T-MSIS Analytical Files:** The Centers for Medicare & Medicaid Services (CMS) Transformed Medicaid Statistical Information System (T-MSIS) analytical file contains information on Medicaid beneficiaries and CHIP (Children's Health Insurance Program) enrollees. The information includes enrollment records, service utilization, claims, and management care. New in this year's ADR, the USRDS requested the T-MSIS files for beneficiaries with advanced CKD and AKI diagnosis/procedure codes in 2018-2019. These data are used in various chapters in the CKD volume.
3. **EQRS data:** The ESRD Quality Reporting System (EQRS) replaces and updates the legacy CROWNWeb/REMIS. EQRS is a national registry for ESRD patients in the United States. EQRS captures clinical and administrative data for all ESRD patients, including the CMS-2728 Medical Evidence Report, CMS-2746 ESRD Death Notification, ESRD treatment modalities, and inpatient stays. Recently acquired EQRS data include information through the second quarter of 2021. These data are used to track COVID-19 among ESRD patients and are presented in the COVID-19 chapter of this year's ADR.
4. **MedPAR data:** New in this year's ADR, Medicare Provider Analysis and Review (MedPAR) data contains inpatient and Skilled Nursing Facility (SNF) stay records for Medicare beneficiaries from the National Claims History (NCH). We use MedPAR data to estimate rates

of all-cause and cause-specific hospitalization among adult patients receiving dialysis who were covered by Medicare Advantage plans in 2019 and to compare these rates with those among the Medicare fee-for-service (FFS) population.

Period of Transition

The need to process and finalize medical claims introduces an unavoidable lag between enrollees' receipt of clinical care and availability of claims data. Thus, 2019 is the most recent year for which data are available for most analyses in the 2021 ADR. We note that data for 2019—and trends over the decade leading up to 2019—are likely to form an important "baseline" upon which to examine substantial clinical and policy changes that began in 2020. Most notably, preliminary data have already shown that the COVID-19 pandemic led to substantial mortality in the ESRD population[1] and a simultaneous decline in rates of incident ESRD[2] (see the COVID-19 chapter for updated data). Together, these events brought about the first substantial shrinkage in the ESRD population.[3] Initiation of in-facility hemodialysis declined to a greater extent than initiation of peritoneal dialysis, leading to an increase in the percentage of new ESRD patients starting peritoneal dialysis that was not accompanied by an increase in new peritoneal dialysis starts.[2]

On July 10, 2019, the White House and the Department of Health and Human Services unveiled the Advancing American Kidney Health (AAKH) initiative with the objectives of preventing kidney failure and improving access to person-centered care and transplantation among patients with ESRD.[4] The Executive Order announcing the initiative set forth ambitious targets for increasing the use of home dialysis therapies and kidney transplantation, directed Medicare to develop and test payment models to create incentives aligned with these objectives, and introduced revisions (which were finalized in December 2020) to the performance outcome measures for organ procurement organizations. Although the Kidney Care Choices models were delayed until January 2022, ESRD Treatment Choices (ETC) launched in January 2021. Although CMS and its contractors will perform formal monitoring of the impact of these programs, the USRDS will also present changes in care of patients with CKD and ESRD in upcoming ADRs as the nephrology community enters the post-COVID, AAKH era. Data from this year's ADR—and from 2019 in particular—will serve as a reference point for assessments of the impact of these policy initiatives.

Given the upheavals that will become apparent in 2020 and the changes in provision and reimbursement of care of dialysis patients that occurred in the last decade, 2019—the year corresponding to the most recent data in this ADR—may be an appropriate end point to summarize recent progress. Providers have been preparing for or operating under an evolving bundled payment system and the Quality Improvement Program (QIP) that came with it since 2011. As providers adapted to these large changes in reimbursement and searched for financial efficiencies, there have been a number of changes in dialysis patient care that have had clear financial consequences. Examples include the transition from epoetin alfa to pegylated epoetin beta as the leading agent for the treatment of anemia; the steady growth of iron-based phosphate binders despite the concurrent arrival of inexpensive, generic sevelamer; rapid uptake of etelcalcetide while transitional add-on payments to Medicare reimbursement for dialysis were available; and introduction of oral calcitriol as a substitute for intravenous vitamin D receptor activators. To date, the effects of these changes on patient outcomes are not clear. The supply and cost of labor (including nurses and technicians) may be the next big driver of evolution of care delivery in the coming decade.

Based on the data in this year's ADR, the last decade was marked by substantial improvement in several important metrics and clinical outcomes among individuals with CKD and ESRD. Among others, these include:

- **CKD outcomes**
  - A 22% reduction in adjusted all-cause mortality among Medicare FFS beneficiaries ≥66 years of age with CKD, which was more than twice as large as the reduction in mortality observed among beneficiaries without CKD.
  - A 29% reduction in the adjusted rate of all-cause hospitalization among Medicare FFS beneficiaries aged 66 years or older with CKD.
  - A 14% reduction in readmission after hospital discharge among older Medicare FFS beneficiaries with CKD.
- **ESRD outcomes**
  - An increase in the percentage of older Medicare beneficiaries with prior CKD initiating dialysis outside of the hospital since 2014, reaching almost 60%.
  - A 8% reduction in adjusted ESRD incidence to 386 per million population in 2019.
  - A 25% reduction in the percentage of patients initiating dialysis with eGFR ≥15 mL/min/1.73 m^2.
  - An 85% increase in the percentage of incident dialysis patients starting home dialysis, and a 73% increase in the percentage of patients performing home dialysis one year after dialysis initiation.
  - A 61% reduction in the rate of hospitalization for peritonitis and a 36% reduction in the rate of hospitalization for catheter complications among patients performing peritoneal dialysis.
  - A 13% reduction in adjusted rate of all-cause hospitalization among prevalent hemodialysis patients, a 14% reduction among prevalent peritoneal dialysis patients, and an 11% reduction among kidney transplant recipients. Reductions in the rate of all-cause hospitalization in the first year after dialysis initiation were even larger, at 18% for patients treated with hemodialysis and 20% among those performing peritoneal dialysis.

- A 17.5% reduction in adjusted all-cause mortality among patients on hemodialysis and a 21% reduction among patients performing peritoneal dialysis.
- An increase in the rate of kidney transplantation that began in the second half of the decade—a reversal that followed a period of decline during the first half of the decade.

These developments should be celebrated. However, progress on several of these metrics slowed or stalled during the second half of the decade. This was true for rates of hospitalization among patients with CKD, receiving maintenance dialysis, and with a functioning kidney transplant. The downward trajectory of mortality among patients receiving maintenance dialysis also flattened after about 2014, and there has been no further reduction in early dialysis initiation in the last few years. Furthermore, important metrics—such as rates of AKI among patients with CKD and rates of catheter use among incident hemodialysis patients—have not improved.

The extensive characterization of changes over the last decade and of the state of health care utilization and outcomes in the CKD and ESRD populations in 2019 presented in this year's ADR will form the backdrop upon which the effects of the COVID-19 pandemic and new payment models can be reported in subsequent ADRs.

Notes About Race and Ethnicity

In the 2021 ADR, we present data in the CKD and ESRD volumes using combined categories defined by race and ethnicity. Hispanic individuals are considered as a separate category (that includes Hispanics of all races). Other race groups include non-Hispanic individuals within those groups (eg, non-Hispanic White, non-Hispanic Black). This strategy is consistent with race and ethnicity categories available within Medicare claims data but represents a change from how race and ethnicity have been previously presented in the ESRD volume. This change serves to better align race and ethnicity categories in the CKD and ESRD volumes. In addition, this strategy facilitates direct comparisons among Hispanic and non-Hispanic individuals in different race groups that were not possible previously for those with ESRD. In other words, rather than simply displaying data for Hispanic individuals alongside data for a multiracial group of non-Hispanic individuals, figures display Hispanic, non-Hispanic White, non-Hispanic Black, and often other race groups as separate categories. However, to avoid using abbreviations in figure tabs and to streamline descriptions of findings, we do not include "non-Hispanic" in the names of each race category. We present data for Hispanic individuals and individuals of smaller race and ethnicity categories whenever possible, but in many instances, stable estimates of outcomes cannot be generated for smaller race and ethnicity categories. This occurs most often among children and for some relatively rare outcomes among patients with CKD. In addition, we do not stratify by race and ethnicity in analyses using Medicaid data because race and ethnicity information is missing entirely in many states and is missing for the majority of beneficiaries in many other states. Therefore, it is not possible to examine race and ethnicity groups that are representative of the US population using Medicaid data.

In 2017, the USRDS reported incidence and prevalence of ESRD for individuals in the Native Hawaiian or Pacific Islander (NHPI) race group separately (from Asians) for the first time.[5] The extraordinarily high rates in this population caused concern[6] and spurred further evaluation,[7,8] which has identified considerable uncertainty about the true rates in this population. Differences in availability of information about multiracial individuals in the USRDS and the US Census are a major source of this uncertainty. Over half of individuals who identify as NHPI in the US Census also selected at least one other race category.[9] Thus, rate calculations that include only individuals designated solely as NHPI in the US Census in the denominator will overestimate the incidence and prevalence of ESRD in this population.

However, including all individuals who designate NHPI in the denominator (including multiracial individuals) will almost certainly underestimate the prevalence because the USRDS (effectively) designates individuals as belonging in only one race category. Although the Medical Evidence Report (form CMS 2728) allows individuals to choose more than one race, fewer than 1% of individuals have more than one race category designated in the USRDS, and no one who started dialysis after 2012 has more than one category. (This situation is the result of data entry into and retrieval and processing of data from CROWNWeb, the ultimate source of race data for the ESRD population in the USRDS.) Thus, the single race category in the USRDS is unlikely to be capturing all NHPI who self-report more than one race. Because there is no way to ascertain the true rates of ESRD in the NHPI population at present, and because the possible range is extremely wide, we do not report incidence and prevalence of ESRD for this race group in the text of the 2020 ADR. However, we do report outcomes among this race group when sample size allows stable estimates.

We calculated incidence and prevalence rates for other race groups using all individuals in the US Census who designated that race (including multiracial individuals) in the denominator for each group. This strategy results in a small decrease in rates because few individuals in these race groups designate more than one race. The problem of incomplete data on race in the USRDS is one that needs further exploration as the number of multiracial individuals in the United States has increased over time. Specifically, the 2020 Census reports a 276% increase in the multiracial population of the United States since 2010.[10]

Readers who wish to view alternative or additional displays may visit the online ADR at adr.usrds.org/2021.

Article Information

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