In 2019, 134,608 individuals were newly diagnosed with end-stage renal disease (ESRD), representing an increase of 2.7% from the previous year and 15.8% from a decade ago (Figure 1.1). However, the adjusted incidence fell from a peak of 431 per million population (pmp) in 2006 to 386 pmp in 2019.

In 2019, 85% of those with incident ESRD initiated in-center hemodialysis (HD) (Figure 1.2). This represents a decrease from 91% in 2009. Over the past decade, the percentage initiating kidney replacement therapy with peritoneal dialysis (PD) nearly doubled, from 6% to 11%. The percentage who received a preemptive kidney transplant remained unchanged over the decade at about 3%.

Adjusted ESRD incidence increased as age increased: among individuals aged 0-17 years, the adjusted incidence in 2019 was 12 pmp; among individuals aged 65-74 years, 1,307 pmp; and among individuals aged ≥75 years 1,587 pmp (Figure 1.4).

Between 2009 and 2019, adjusted ESRD incidence in Black individuals decreased by 17.5%, in Native American individuals by 14.1%, in Hispanic individuals by 12.1%, in Asian individuals by 5.2%, and in White individuals by 2.4% (Figure 1.4). However, in all individuals except for Whites, adjusted incidence increased between 2018 and 2019.

The prevalent count of individuals with ESRD reached 809,103 in 2019, an increase of 41.0% from 2009 (Figure 1.5). Adjusted ESRD prevalence also increased to an all-time high of 2302 cases pmp in 2019.

At the end of 2019, 492,096 individuals were receiving in-center HD, up 1.7% from 2018 and 34.5% from 2009 (Figure 1.6). There were 12,243 patients performing home HD at year’s end, an increase of 20.1% over the preceding year. The number of individuals receiving PD increased to 62,275, representing 8.5% growth in a single year.

Adjusted ESRD prevalence in Black individuals was far higher, at 6423 pmp, than in other racial and ethnic groups; adjusted prevalence in Black individuals was 78.6% higher than in the next-highest group, Native Americans, and more than fourfold higher than in White individuals (Figure 1.8).

The percentage of patients with prevalent ESRD who had a functioning kidney transplant was highest among White (36%) and lowest among Native Hawaiian and Pacific Islander (18%) individuals. Conversely, White individuals had the lowest percentage receiving in-center HD (54%), and Native Hawaiian and Pacific Islander individuals had the highest (73%) (Figure 1.10).

White (73%), Asian (72%), and Native American (72%) individuals were much more likely to have received pre-ESRD care compared with Black (64%), Native Hawaiian/Pacific Islander (62%), and Hispanic (61%) individuals (Figure 1.11).

In 2019, 39% of patients had an estimated glomerular filtration rate (eGFR) ≥10 mL/min/1.73 m² at ESRD onset (Figure 1.14). The mean eGFR at initiation of kidney replacement therapy was 9.6 mL/min/1.73m² (Table 1.3). Overall, 60.6% of incident patients with ESRD had diabetes mellitus (DM), 28.4% heart failure (HF), and 20.8% other cardiac disease (Figure 1.18). Fully 77.5% of Native American individuals had DM, compared with 57.8% of White individuals.

Cardiovascular disease (CVD) was present in 77.3% of patients receiving HD, 66.4% of patients receiving PD, and 54.8% of patients with a kidney transplant.
We next report on the prevalence of nephrology care before the onset of ESRD and its correlates among patients with incident ESRD. These correlates include eGFR at the time of initiation of kidney replacement therapy (with a focus on how eGFR at initiation differs by strata of age, sex, and race/ethnicity) as well as other biochemical parameters reported on the ESRD Medical Evidence Report, which is completed at the time that kidney replacement therapy is initiated. Finally, we show data on comorbid conditions among patients with ESRD.

Methods

Throughout this chapter, we rely heavily on the enumeration of incident and prevalent ESRD patients and their kidney replacement therapy history in the USRDS database. Estimates of incidence are primarily informed by validated submissions of the ESRD Medical Evidence Report (form CMS 2728), which by rule must be submitted whenever a patient is newly treated for ESRD. This form establishes the date of ESRD onset, which might more properly be termed the date of initiation of kidney replacement therapy because the USRDS tracks treated ESRD and not ESRD overall (the latter encompassing use of conservative care).

The unadjusted incidence of ESRD is derived by dividing the annual number of patients with incident ESRD by the size of the U.S. population, as reported by the U.S. Census Bureau (Centers for Disease Control and Prevention, 2019). The adjusted incidence of ESRD is standardized to the age, sex, race, and Hispanic ethnicity distribution of the 2015 U.S. population. Considering the gradual aging of the population, adjustment for age is relatively influential.

The prevalence of ESRD is derived in the same manner; adjustment factors are the same as for incidence. The mixture of dialysis modalities and presence of a functioning kidney transplant in the prevalent ESRD population reflects the treatment history constructed by the USRDS. Of note, home HD in the ESRD database reflects an uncertain mixture of patients dialyzing in private residences and in skilled nursing facilities.

Receipt of from a nephrologist or dietician prior to ESRD as well as eGFR and hemoglobin level at initiation of kidney replacement therapy are ascertained from the ESRD Medical Evidence Report. Using the Chronic Kidney Disease Epidemiology Collaboration (CKD-EPI) equation (Levey et al., 2009), GFR is estimated from the serum creatinine measurement that must be recorded on the Medical Evidence Report.
Figure 1.1 Incidence of ESRD

Data Source: USRDS ESRD Database. All U.S. ESRD incident patients were included for Incident Count; unknown sex and either or unknown race/ethnicity were excluded for Incidence Rate (adjusted and unadjusted). Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.
In 2019, 134,608 individuals were newly registered as having treated ESRD, which represented an increase of 2.7% from the previous year and 15.8% from a decade ago (Figure 1.1). However, the adjusted incidence fell from a peak of 431 cases pmp in 2006 to 386 cases pmp in 2017, or by 10.4%; the rate remained virtually unchanged between 2017 and 2019. From 2012 onwards, year-over-year adjusted percent change has oscillated between approximately -2% and +2%. Much of the apparent discordance between trends in unadjusted and adjusted ESRD incidence can be explained by the aging of the U.S. population.

Data Source: USRDS ESRD Database. All U.S. ESRD incident patients were included for Incident Count; unknown sex and other or unknown race/ethnicity were excluded for Incidence Rate (adjusted and unadjusted). Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

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Data Source: USRDS ESRD Database. All U.S. ESRD incident patients were included for Incident Count; unknown sex and other or unknown race/ethnicity were excluded for Incidence Rate (adjusted and unadjusted). Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

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In 2019, 134,608 individuals were newly registered as having treated ESRD, which represented an increase of 2.7% from the previous year and 15.8% from a decade ago (Figure 1.1). However, the adjusted incidence fell from a peak of 431 cases pmp in 2006 to 386 cases pmp in 2017, or by 10.4%; the rate remained virtually unchanged between 2017 and 2019. From 2012 onwards, year-over-year adjusted percent change has oscillated between approximately -2% and +2%. Much of the apparent discordance between trends in unadjusted and adjusted ESRD incidence can be explained by the aging of the U.S. population.

Data Source: USRDS ESRD Database. All U.S. ESRD incident patients were included for Incident Count; unknown sex and other or unknown race/ethnicity were excluded for Incidence Rate (adjusted and unadjusted). Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.
Figure 1.2 Incident ESRD by modality

Annual incident counts by initial modality of kidney replacement therapy and the percentage starting on each modality are shown in Figure 1.2. In 2019, 114,432 individuals initiated in-center HD, representing 85.1% of individuals with incident ESRD. This percentage decreased from 91.1% in 2009. Over the past decade, the percentage who initiated PD nearly doubled, increasing from 6.2% to 11.5% (total count, 15,433 in 2019). The percentage who received a preemptive kidney transplant remained essentially unchanged over the decade at about 3% (total count, 4022 in 2019). Although individuals initiating home HD in 2019 represented <1% of the total ESRD incident count, the percentage initiating home HD nevertheless increased by more than one third (34.5%) between 2018 and 2019.
ESRD incidence from 2018 to 2019 is shown in Figure 1.3 by Health Service Areas (HSAs). Higher adjusted ESRD incidence was apparent in several areas, including southeastern Ohio and West Virginia; the coastal plains of South Carolina and southern Georgia; the border of Illinois and Indiana; the southern Mississippi River Valley; western Arkansas and eastern Oklahoma; much of southern Texas, from Houston to El Paso; sparse areas in the western Dakotas; the Four Corners region in the Southwest; and the Central Valley in California. Relatively low ESRD incidence was apparent in New England; much of Minnesota, Wisconsin, and the Upper Peninsula of Michigan; the Rocky Mountains; and much of the Pacific Northwest.

Data Source: USRDS ESRD Database. U.S. ESRD patients, unknown sex, and other and unknown race/ethnicity excluded. Adjusted incidence rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.
Table 1.1 Incidence of ESRD and distribution of modality at incidence by ESRD network

<table>
<thead>
<tr>
<th>Network</th>
<th>All ESRD</th>
<th>In-Center Hemodialysis</th>
<th>Home Hemodialysis</th>
<th>Peritoneal Dialysis</th>
<th>Preemptive Transplant</th>
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<tbody>
<tr>
<td></td>
<td>N</td>
<td>Unadjusted Incidence Rate</td>
<td>Adjusted Incidence Rate</td>
<td>N</td>
<td>% of Network</td>
</tr>
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<td>1 CT, MA, ME, NH, RI, VT</td>
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<td>288.3</td>
<td>17,624</td>
<td>86.2</td>
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<tr>
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<td>90.0</td>
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<td>23,378</td>
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<td>563,116</td>
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Data Source: USRDS ESRD Database. U.S. and US territories ESRD patients. Persons with “Uncertain Dialysis” type were included in the total count of incident ESRD cases but are not represented separately. Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

There is substantial variability in ESRD incidence and distribution of kidney replacement therapy modalities utilized in patients with incident ESRD across ESRD Networks (Table 1.2). In 2019, adjusted ESRD incidence ranged from a low of 288.3 pmp in New England to a high of 437.0 pmp in Texas, a one-and-half-fold difference. Although in-center HD was the most common modality among patients with incident ESRD across all Networks, utilization of other therapies varied widely. The percentage of patients who initiated PD varied by more than two-and-a-half fold across networks, from 5.4% in New York to 13.8% in Northern California, Hawaii, and the U.S. Pacific Territories. Similarly, the percentage of patients who received a preemptive kidney transplant varied by two-and-half-fold by network, from 1.7% in Southern California and the Alabama/Mississippi/Tennessee region to 4.2% in New England. The percentage of patients who initiated home HD varied even more dramatically, from 0.1% in many areas of the country to 0.6% in Delaware and Pennsylvania and 0.7% in Illinois, although it is important to note that home HD sometimes represents individuals who receive hemodialysis in a skilled nursing facility (SNF).
Adjusted ESRD incidence from 2000-2018 is displayed in Figure 1.4, stratified by age, sex, and race/ethnicity. Adjusted ESRD incidence was higher among older age groups. Among individuals aged 0-17 years, the adjusted incidence of ESRD in 2019 was 12 pmp but was 1307 pmp among individuals aged 65-74 years and 1587 pmp among individuals aged ≥75 years. In the decade between 2009 and 2019, adjusted ESRD incidence declined by 13.1% among individuals aged 65-74 years and by 17.5% among individuals aged ≥75 years. Among the youngest individuals, adjusted incidence decreased by 14.3%. In contrast, adjusted incidence was virtually unchanged over this period in individuals aged 18-44 years.

Between 2009 and 2019, adjusted ESRD incidence in Black individuals decreased by 17.5%, in Native American individuals by 14.1%, in Hispanic individuals by 12.1%, in Asian individuals by 5.2%, and in White individuals by 2.4%. However, between 2018 and 2019, adjusted incidence increased in all race groups except Whites.

Men have always had a higher incidence of ESRD than women, and despite declines in adjusted incidence in men and women since 2009, the relative difference continues to increase: adjusted ESRD incidence was 57.8% higher among men in 2009 but 63.9% higher in 2019.
The number of individuals with prevalent ESRD reached 809,103 in 2019, an increase of 41.0% from 2009. After adjustments for age, sex, and race/ethnicity, adjusted ESRD prevalence also increased to an all-time high of 2302 pmp in 2019, representing an increase of 1.4% from 2018. Year-over-year increases in adjusted ESRD prevalence have been at or below 2% since 2009.
At the end of 2019, 492,096 individuals were receiving in-center HD, up 1.7% from 2018 and 34.5% from 2009. There were 12,243 patients receiving home HD at year’s end, an increase of 20.1% over the preceding year. The number of patients receiving PD increased to 62,275, representing 8.5% growth in a single year. Finally, the number of prevalent patients with a functioning kidney transplant increased from 229,181 in 2018 to 239,413 in 2019, a year-over-year increase of 4.5% and an increase of 34.3% from the previous decade. Overall, 61.1% of patients with ESRD received in-center HD, down from 63.9% in 2009; patients receiving PD increased from 5.3% of the prevalent ESRD population in 2009 to 7.7% in 2019. Individuals living with a functioning kidney transplant have consistently represented approximately 30% of the prevalent ESRD population over the decade.
The map of adjusted ESRD prevalence by HSA (Figure 1.7) shows that contiguous areas with elevated prevalence in 2018-2019 included the coastal plains of South Carolina and southern Georgia; the shores of Lake Michigan, from Gary, Indiana to Chicago to Milwaukee; the Mississippi River Valley from roughly St. Louis to Memphis; southern Texas; the western Dakotas; and the Central Valley of California.
<table>
<thead>
<tr>
<th>ESRD Network</th>
<th>N</th>
<th>Adjusted Prevalence Rate</th>
<th>Unadjusted Prevalence Rate</th>
<th>% of Network</th>
<th>% of Network</th>
<th>% of Network</th>
<th>% of Network</th>
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<td>558</td>
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<td>60.8</td>
<td>12,243</td>
<td>1.5</td>
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Data Source: USRDS ESRD Database. US and US territories ESRD patients. Persons with "Uncertain Dialysis" were included in the total count of prevalence ESRD cases but are not represented separately. Prevalence rates are calculated for US ESRD patients with unknown sex and other or unknown race/ethnicity dropped. Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

There was substantial variability in ESRD prevalence and utilization of kidney replacement therapy modalities across ESRD Networks (Table 1.2). In 2019, adjusted ESRD prevalence ranged from a low of 1,875.8 pmp in New England to a high of 2,566.1 pmp in Southern California. In-center HD was the most frequently utilized kidney replacement therapy across all Networks, although in five Networks spanning 21 states, fewer than 55% of patients utilized in-center HD.

Network-specific percentages of ESRD patients who received home HD varied between 0.5% and 2.0%, except for Illinois, where 4.6% of prevalent patients with ESRD utilized home HD. (This outlying value is likely attributable to a large population of skilled nursing facility residents utilizing on-site hemodialysis, which is indistinguishable from home dialysis in claims.) Network-specific percentages of ESRD patients who received PD varied by more than twofold, ranging from 3.9% in New York to 9.2% in many states across five Networks. Network-specific percentages of patients with a functioning kidney transplant varied between 24.1% (North and South Carolina, Georgia, and Southern California) and 39.3% (New England).
Figure 1.8 Adjusted prevalence of ESRD by patient characteristics

Data Source: USRDS ESRD Database. U.S. ESRD patients, unknown sex and other or unknown race/ethnicity excluded. Rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.
Figure 1.8 displays adjusted ESRD prevalence from 2000-2019 stratified by age and race/ethnicity. Adjusted ESRD prevalence was higher among older individuals, with 7473 cases pmp among individuals aged ≥75 years (an increase of 15.6% since 2009) and 7419 cases pmp among individuals aged 65-74 years in 2019 (an increase of 11.9% since 2009). Even among the youngest individuals (those aged 0-17 years), the adjusted prevalence of ESRD in 2019 was 7.9% higher than in 2009, at 82 cases pmp.

Adjusted ESRD prevalence in Black individuals increased by 0.6% between 2018 and 2019 but remained far higher, at 6423 cases pmp, than in other racial and ethnic groups. For example, adjusted prevalence in Black individuals was 78.6% higher than in the next-highest group, Native Americans (3596 cases pmp), and more than four-fold higher than in White individuals (1500 cases pmp). Between 2018 and 2019, adjusted prevalence increased by 2.1% in Asian, 1.6% in Native American, 1.6% in Hispanic, and 1.7% in White individuals.

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Figure 1.9 Modality at incidence of ESRD by patient characteristics

Data Source: USRDS ESRD Database. U.S. and U.S. territories ESRD patients. Persons with "Uncertain Dialysis" type were excluded.
The Executive Order on Advancing American Kidney Health envisions increased utilization of preemptive transplantation and home dialysis in patients with incident ESRD. Figure 1.9 displays the modality of kidney replacement therapy at incidence of ESRD in 2019. As age increased, the percentage initiating kidney replacement therapy with in-center HD increased, and the percentage initiating with PD or a preemptive kidney transplant decreased. There were no salient differences between men and women. Compared with Black individuals, a higher percentage of White individuals initiated kidney replacement therapy with PD or a preemptive kidney transplant. Individuals with glomerulonephritis (GN) or cystic kidney disease as their cause of ESRD more commonly initiated kidney replacement therapy with PD or a preemptive kidney transplant than did individuals with DM or HTN as their cause of ESRD.
Data Source: USRDS ESRD Database. U.S. and U.S. territories ESRD patients. Persons with "Uncertain Dialysis" type were excluded.
The distribution of kidney replacement therapy modality utilized in prevalent patients with ESRD in 2019 is shown in Figure 1.10 by age, sex, race/ethnicity, and cause of ESRD. The percentage with a functioning kidney transplant was lower among older individuals. For example, among pediatric patients, 74% had a functioning kidney transplant, compared with 33% of individuals aged 45-64 years (the largest single age group) and just 13% of individuals aged ≥75 years. Correspondingly, the percentage receiving in-center HD was higher among older individuals (e.g., 57% of individuals aged 45-64 years, 65% of individuals aged 65-74 years, and 79% of individuals aged ≥75 years). The percentage receiving PD was slightly lower among older individuals. About 2% of prevalent patients aged 18-64 years received home HD, compared with about 1% of those aged ≥65 years. There is little difference in modality use between men and women.

White patients had the highest percentage with a transplant (36%) and the lowest receiving in-center HD (54%); Native Hawaiian and Pacific Islander patients had the lowest percentage with a transplant (18%) and the highest receiving in-center HD (73%), followed closely by Native American (20% transplant and 72% in-center HD) and Black (21% transplant and 71% in-center HD) patients. Individuals with ESRD attributed to GN or cystic kidney disease were much more likely to have a functioning kidney transplant (and, correspondingly, much less likely to be receiving in-center HD) than individuals with DM or HTN as their ESRD cause.

Figure 1.11 Duration of pre-ESRD nephrology care among incident ESRD patients by patient characteristics

Receipt and duration of pre-ESRD nephrology care among patients with incident ESRD in 2019 is displayed in Figure 1.11. Overall, about 30% of patients had unknown or no nephrology care prior to ESRD. Children were most likely to have received pre-ESRD care (79%), and young adults (aged 18-44 years) were least likely (62%). White (73%), Asian (72%), and Native American (72%) individuals were much more likely to have received pre-ESRD nephrology care than were Black (64%), Native Hawaiian/Pacific Islander (62%), or Hispanic (61%) individuals. Among those with a known cause of ESRD, patients with cystic kidney disease as their cause of ESRD were most likely to have received care prior to ESRD and those with HTN least likely. Patients with cystic kidney disease and GN were particularly likely to receive pre-ESRD care extending for at least 12 months prior to ESRD (cystic kidney disease, 56%; GN, 42%).

Pre-ESRD care varied widely by ESRD Network and was highest in New England, at 82%, and lowest in Texas, at only 61%. The percentage of unemployed individuals who did not receive pre-ESRD care (43%) was substantially higher than the percentage of employed individuals or students who did not (24%). As expected, those without insurance or who were in the waiting period for Medicare eligibility were substantially less likely to receive care than those who were insured by a Medicare program.
The percentage of patients with incident ESRD who received at least 12 months of pre-ESRD nephrology care is depicted in Figure 1.12. Areas with the highest percentage included New England and upstate New York, the Upper Midwest, and parts of the Pacific Northwest. In the southern part of the U.S., there were relatively few areas where a high percentage of patients received at least 12 months of pre-ESRD nephrology care.

Data Source: USRDS ESRD Database. U.S. ESRD patients with a Medical Evidence Report (form CMS 2728).
The distribution of clinical characteristics and care in patients with incident ESRD in 2019 are displayed in Figure 1.13, stratified by duration of pre-ESRD nephrology care. Less than 1% of patients without any pre-ESRD nephrology care had received pre-ESRD care from a dietician, but unexpectedly, the percentage receiving dietician care did not increase as the duration of pre-ESRD nephrology care increased. Only about 2% of patients without pre-ESRD nephrology care had received an erythropoiesis-stimulating agent (ESA), whereas the corresponding percentage in patients with 0-6 months, 6-12 months, and >12 months of pre-ESRD nephrology care were 26%, 20%, and 21%, respectively. There was little difference in eGFR at ESRD onset; in contrast, there was a clear association between duration of pre-ESRD nephrology care and catheter use at ESRD onset.

More than one quarter of patients who initiated HD with >12 months of pre-ESRD nephrology care did so with an arteriovenous fistula or graft, compared with only 18% of patients with 6-12 months of pre-ESRD nephrology care, 10% of patients with 0-6 months of nephrology care, and 4.0% of patients with no known pre-ESRD nephrology care.

Data Source: USRDS ESRD Database. U.S. and U.S. territories ESRD patients with a Medical Evidence Report (form CMS 2728). eGFR calculated using the CKD-EPI equation for those aged ≥18 years and the Bedside Schwartz equation for those aged <18 years.
Figure 1.14 Estimated glomerular filtration rate among incident ESRD patients

Figure 1.14 shows the distribution of eGFR at ESRD onset from 2000-2019. After a substantial increase in the percentage of patients initiating kidney replacement therapy with an eGFR ≥10 ml/min/1.73m² between 2000 and 2010 from 23% to 43%, there has been little change in this percentage since 2010. In 2019, eGFR at onset of kidney replacement therapy was between 5 and 10 mL/min/1.73 m² in 48% of patients and was between 10 and 15 mL/min/1.73 m² in 28%; in only 11% of patients was eGFR ≥15 mL/min/1.73m².

Figure 1.15 Estimated glomerular filtration rate among incident ESRD patients by patient characteristics

Data Source: USRDS ESRD Database. U.S. and U.S. territories ESRD patients with a Medical Evidence Report (form CMS 2728). eGFR calculated using the CKD-EPI equation for those aged ≥18 years and the Bedside Schwartz equation for those aged <18 years.
Figure 1.15 displays the distribution of eGFR at initiation of kidney replacement therapy by age, sex, and race/ethnicity. Among pediatric patients, 44% had eGFR ≥15 mL/min/1.73 m² at initiation of kidney replacement therapy, which may be the result of high use of preemptive kidney transplantation in children. Among adults, the percentage whose eGFR was <10 mL/min/1.73 m² at initiation of kidney replacement therapy was lower among older individuals, driven almost entirely by a smaller percentage initiating at an eGFR <5 mL/min/1.73 m². Men (59%) were less likely than women (64%) to initiate kidney replacement therapy with eGFR of <10 mL/min/1.73 m². Approximately 21% of Black, 20% of Asian, and 22% of Native Hawaiian/Pacific Islander individuals had an eGFR <5 mL/min/1.73 m² at initiation of kidney replacement therapy, whereas the corresponding percentages were 9% for White and 11% for Native American individuals.

Data Source: USRDS ESRD Database, U.S. and U.S. territories with a Medical Evidence Report (form CMS 2728). eGFR calculated using the CKD-EPI equation for those aged ≥18 years and the Bedside Schwartz equation for those aged <18 years.
The percentage of incident ESRD patients in 2018-2019 with eGFR >10 mL/min/1.73 m² at onset of kidney replacement therapy is mapped by HSA in Figure 1.16. Many HSAs with high percentages of patients with eGFR >10 mL/min/1.73 m² were located north of the Ohio River, throughout the Upper Midwest, and in the middle of the country. HSAs with the lowest percentages of patients with estimated GFR >10 mL/min/1.73 m² were often in the southeast.
The percentage of incident ESRD patients in 2018-2019 with hemoglobin <9 g/dL is depicted in Figure 1.17. Many HSAs with the highest percentages of patients with hemoglobin <9 g/dL were located in the southern and southeastern U.S. Other areas with high percentages included western Massachusetts, eastern Virginia, the Detroit area, the corridor from Chicago to Milwaukee, southern Iowa and northern Missouri, and parts of the Pacific Northwest.

Data Source: USRDS ESRD Database. U.S. ESRD patients with a Medical Evidence Report (form CMS 2728)
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<th>Hemoglobin (g/dL)</th>
<th>ESA Use (%)</th>
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Data Source: USRDS ESRD Database. US and US territories ESRD patients with CMS form 2728, unknown sex and unknown or other race/ethnicity excluded.

Table 1.3 displays data from the ESRD Medical Evidence Report among patients with incident ESRD in 2019. Overall, the mean estimated GFR at initiation of kidney replacement therapy was 9.6 mL/min/1.73m². eGFR was higher among older than younger adults, among White and Native American than Black and Asian individuals, and (to a lesser extent) among men than women. Mean serum albumin concentration was low (3.3 g/dL), with little variation among subgroups, except in patients with cystic kidney disease as the primary cause of ESRD, who had a higher mean serum albumin concentration (3.9 g/dL). Pre-ESRD dietician care was uncommon, with only about 1 in 8 individuals receiving such care; more than half of pediatric patients and nearly 1 in 5 patients with cystic kidney disease were seen by a dietician. White and Asian individuals were more likely to see a dietician than Black, Asian, or native Hawaiian/Pacific Islander individuals. Mean hemoglobin level was 9.3 g/dL overall and was between 9.0 and 9.4 g/dL in every subgroup except for patients with cystic kidney disease as the cause of ESRD, who had higher hemoglobin (10.0 g/dL). Among children, 40.8% had received an ESA before ESRD onset; in adults, 12.6% to 18.2% received an ESA prior to ESRD. Asian (20.1%) and White (17.1%) individuals were more likely to receive an ESA than Black (13.5%) and Hispanic (13.9%) individuals.
Figure 1.18 Comorbid conditions of incident ESRD patients

The presence of major comorbid conditions, as documented on the Medical Evidence Report (form CMS 2728) for incident ESRD patients, is shown in Figure 1.18, overall and by age, sex, and race/ethnicity. Overall, 60.6% had DM, 28.4% HF, and 20.8% other cardiac disease. DM was present in nearly two thirds of individuals aged 45-74 years but was less common in younger and older individuals. The major manifestations of cardiovascular disease – HF, atherosclerotic heart disease, PVD, CVA/TIA, and other cardiac disease – were more common among older individuals, as would be expected. Comorbidities varied little by sex. Fully 77.5% of Native American individuals had DM, compared with 57.8% of White individuals. HF was more common in White (31.1%) and Black (29.1%) individuals than in Asian (20.3%), Hispanic (22.4%), Native American (23.3%), or Native Hawaiian/Pacific Islander (24.2%) individuals.
The unadjusted prevalence of common cardiovascular diseases was high. In 2019, CVD of any type was present in 77.3% of patients receiving HD, 66.4% of patients receiving PD, and 54.8% of patients with a kidney transplant. As expected, older individuals were more likely to have CVD than younger ones, regardless of kidney replacement therapy modality. The patterns by sex and race/ethnicity were heterogeneous.
Summary

Data presented in this chapter provide reasons for cautious optimism and also for concern. As the U.S. population continues to grow, age, and become more racially and ethnically diverse, there are more total cases of incident ESRD and a corresponding increase in the unadjusted incidence of ESRD. However, adjusted ESRD incidence increased by “only” about one quarter of one percent between 2018 and 2019. Indeed, 2019 was the third consecutive year in which adjusted ESRD incidence was below 390 cases pmp – a level not previously observed in at least two decades. However, despite overall progress, there remains substantial variation in the adjusted incidence of ESRD around the country. Some very large areas of the country have persistently high incidence, including Texas, with an adjusted incidence of 437 pmp, and Southern California, with an incidence of 418 pmp; many other areas have adjusted incidence exceeding 400 pmp. Alarming, some HSAs even demonstrate adjusted incidence of 600, 700, or even 800 pmp. Focused efforts in these areas will be key to accomplishing one of the primary objectives of the Executive Order on Advancing American Kidney Health, namely reducing the incidence of ESRD by 25% by 2030.

The growth in ESRD prevalence is a result, primarily, of patients with ESRD living longer. The near-uniform linear increase in the prevalent count (and corresponding increase in the adjusted prevalence) of ESRD is the result of consistent annual growth in prevalence of between 1-2% since 2009. That patients with ESRD are living longer is a welcome development, but the growth of the ESRD population nevertheless represents a burden on the U.S. healthcare system that can be abated only by decreasing ESRD incidence, liberating more patients from dialysis through kidney transplantation, and increasing the use of home-based dialysis modalities over in-center HD.

The high burden of ESRD among Black individuals is striking. For nearly two decades, there had been progress in closing this disparity, but it actually increased between 2018 and 2019. Over the past year, the adjusted incidence decreased by about 2% in White individuals and increased about 2.5% in Black individuals. Indeed, there was an increase in all non-White groups over this period, most strikingly (>4%) in Native American individuals. The disparity in adjusted ESRD incidence between White and non-White individuals is another important target for reducing the national incidence of ESRD during the next decade. A related disparity is in the use of kidney transplantation. White individuals were substantially more likely than individuals of other racial and ethnic groups to receive a preemptive kidney transplant (incident ESRD) and to be living with a functioning kidney transplant (prevalent ESRD).

Although in-center HD remains the most common form of kidney replacement therapy by a wide margin, its use in the prevalent ESRD population has slowly declined, from approximately 65% two decades ago to approximately 61% in 2019. Although the prevalent population receiving HD grew by <2% between 2018 and 2019, the prevalent count receiving PD increased by approximately 8.5% and receiving home HD by approximately 20%. Relatively faster growth of the home dialysis patient population is likely to continue in future years in light of the Executive Order (U.S. Department of Health and Human Services, 2019) and the recently finalized ESRD Treatment Choices payment model (Centers for Medicare & Medicaid Services, 2021), although the degree to which this growth can be sustained must be carefully monitored. A sustained shift to home-based dialysis would have profound consequences for the dialysis delivery system in the U.S., as there will be a need not only for more accessible home dialysis machines and related equipment but, more profoundly, for nurses trained in PD and home HD, nephrologists who are comfortable prescribing and managing these therapeutic modalities, and an overhaul in the “systems-based approach” to maintenance dialysis that has focused heavily on construction of brick-and-mortar in-center HD units over the past several decades (Wetmore & Collins, 2015).

Pre-ESRD nephrology care remains an area of concern. In every subgroup of incident ESRD patients defined by age, sex, race and ethnicity, less than half of individuals had seen a nephrologist for more than a year prior to requiring kidney replacement therapy – an astonishing figure given that CKD is a chronic disease that usually evolves over years or decades. Here, too, there are marked disparities by race. This is a notable shortcoming of the U.S. healthcare system because lack of pre-ESRD nephrology care is likely to result in poorer transitions to ESRD, including a higher risk of initiating dialysis in the hospital, a higher risk of initiating HD with a catheter, and lower likelihood of selecting a home dialysis modality. The new Kidney Care Choices payment models aim to build a bridge between advanced CKD and ESRD and may be effective in improving preparation for ESRD.

Nearly 4 in 10 individuals had an eGFR ≥10 mL/min/1.73 m² at onset of registered ESRD in 2019. A major clinical trial demonstrated that dialysis initiation at higher levels of eGFR did not reduce mortality or improve health-related quality of life (Cooper et al., 2010), and the year of this study’s publication appears to have marked the high water mark in terms of percentage of patients starting at eGFRs above 10 mL/min/1.73m². However, the increase in the percentage of patients starting ESRD treatment with eGFR <10 mL/min/1.73m² that followed the publication of this study was nowhere near as pronounced as the decline that preceded it. As a result, a far higher percentage...
patients started ESRD treatment a higher eGFR in 2019 than in 2009, despite good evidence that the shift towards higher eGFR was not beneficial. The USRDS will continue to track this metric to see whether the new ESRD payment models result in a lowering of eGFR at ESRD onset as intended. In addition, a greater understanding of the “bedside” decision-making process that prompts dialysis initiation, such as the role symptoms play in dialysis initiation and which treatments may help delay it, may be required to more fully understand why the mean eGFR has been relatively stable in recent years. The degree of variability in this very fundamental process of deciding when to initiate dialysis and the resulting large differences in the practice of starting patients early (Figure 1.16) suggests that this is an area in which there is substantial room for improvement. Delaying dialysis initiation has the potential to save money and improve patient care, yet there has been little progress in the last decade.

Treatment of anemia is an interesting aspect of pre-ESRD care. The mean hemoglobin among incident ESRD patients in 2019 was 9.3 g/dL, and the prevalence of hemoglobin <9 g/dL at onset of ESRD was over 40% in hundreds of HSAs around the U.S. Moreover, less than 1 in 6 incident ESRD patients had received ESAs prior to initiating kidney replacement therapy despite the large percentage of patients with low hemoglobin. Whether approaches to anemia treatment among patients not requiring kidney replacement therapy change may depend partly on whether hypoxia-inducible factor (HIF) stabilizers are shown to be beneficial in clinical practice.

The USRDS will continue to examine and present trends in ESRD incidence and prevalence; characteristics and treatments of patients with ESRD; and racial and ethnic disparities in ESRD in the 2022 ADR. However, 2019 may represent the end of a period of relative stability. It will be challenging to understand the combined impacts of the COVID-19 pandemic and upcoming changes in payment models in patients with advanced CKD and ESRD.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 1. Incidence, Prevalence, Patient Characteristics, and Treatment Modalities, located here: https://adr.usrds.org/2021/end-stage-renal-disease/1-incidence-prevalence-patient-characteristics-and-treatment-modalities

References

Home Dialysis

Highlights

- From 2009 to 2019, the percentage of incident dialysis patients performing home dialysis increased from 6.8% to 12.6% (Figure 2.1a).
- From 2009 to 2019, the percentage of patients performing home dialysis at 1 year after dialysis initiation increased from 10.5% to 18.2% (Figure 2.1a).
- From 2009 to 2019, the percentage of prevalent patients performing home dialysis increased from 8.9% to 13.1% (Figure 2.1a). Those 13.1% of patients in 2019 included 1.9% who performed home hemodialysis and 11.2% who performed peritoneal dialysis.
- In 2019, 45% of Medicare-certified dialysis facilities were not certified to offer either home dialysis modality; 8% were certified to offer at least 1 home dialysis modality but had no active patients; and 47% were certified to offer at least 1 home dialysis modality and had active patients (Figure 2.2).
- Among active home dialysis programs in 2019, 20% of programs had 1-5 patients and another 18% had 6-10 patients (Figure 2.3).
- Compared with patients performing peritoneal dialysis, patients performing home hemodialysis tended to be older, more likely male, and were more likely Black (Figure 2.4).
- For peritoneal dialysis, 85% of patients initiate the therapy during the first year of ESRD (Figure 2.5). For home hemodialysis, only 43% of patients initiate the therapy during the first year of ESRD.
- Between 2009 and 2019, utilization of automated peritoneal dialysis among patients performing peritoneal dialysis steadily increased, from 68% in 2009 to 86% in 2019 (Figure 2.7).
- For home hemodialysis in 2019, 39.1% of patients were prescribed at least 3.5 treatment sessions per week (i.e., every-other-day dialysis) and fewer than 5.0 sessions per week. Another 38.0% of patients were prescribed at least 5.0 and fewer than 6.0 sessions per week (Figure 2.8a).
- Medicare covered 3.8 home hemodialysis treatment sessions per week in 2019 (Figure 2.8d).
- With peritoneal dialysis, rates of hospitalization for catheter complications and peritonitis both declined between 2009 and 2019 (Figure 2.9). Likewise with home hemodialysis, the rate of hospitalization for vascular access complications declined during the same timeframe (Figure 2.10).
- Among patients who initiated home hemodialysis in 2017-2018, the 2-year cumulative incidence of conversion from home dialysis to in-facility hemodialysis was 25%. The corresponding incidence with peritoneal dialysis was 24% (Figure 2.11).
- Among patients who initiated home hemodialysis in 2017-2018, the 2-year cumulative incidence of kidney transplantation was 10%. The corresponding incidence with peritoneal dialysis was 11% (Figure 2.14).
- In 2019, the prevalence of kidney transplant waitlisting was 28% with home hemodialysis and 30% with peritoneal dialysis (Figure 2.15).

Introduction

For the first time, the USRDS presents a chapter devoted exclusively to home dialysis. We begin with a description of home dialysis utilization, overall and by modality, from 2009 to 2019. We display utilization at three points in time: at dialysis initiation; at 1 year after dialysis initiation; and among prevalent dialysis patients, on December 31 of each year. Utilization data are stratified by age, sex, race/ethnicity, and primary cause of ESRD. Among prevalent patients, we also stratify home dialysis utilization by payer type.

We next show the cross-classification of Medicare certification of facilities to offer home dialysis and actual delivery of home dialysis, overall and by modality in 2019. Among facilities with active home dialysis programs, we proceed to show distributions of the number of home dialysis patients per facility.

We subsequently describe the characteristics of incident and prevalent ESRD patients performing home dialysis. For patients who initiated home dialysis in 2019, we display distributions of time from ESRD diagnosis to home dialysis initiation, stratified by modality. In the subset of home dialysis patients who are Medicare fee-for-service (FFS) beneficiaries, we assess modality-specific distributions of the number of training sessions.
We display a variety of modality-specific factors describing the delivery of the home dialysis modalities. First, we show the utilization of automated peritoneal dialysis among prevalent peritoneal dialysis patients during each year from 2009 to 2019. Second, among home hemodialysis patients in 2019, we show distributions of prescribed treatment frequency, prescribed session duration, and cumulative prescribed treatment hours per week.

We display clinical outcomes among home dialysis patients, stratified by modality. First, we show rates of hospitalization for peritoneal dialysis catheter complications, peritonitis, and sepsis among Medicare FFS beneficiaries performing peritoneal dialysis. Second, we show rates of hospitalization for vascular access complications and sepsis among Medicare FFS beneficiaries performing home hemodialysis. Third, we display the cumulative incidence of conversion from home dialysis to in-facility hemodialysis among cohorts of patients who initiated home dialysis in 2009-2010, 2011-2012, 2013-2014, 2015-2016, and 2017-2018. We also assess the cumulative incidence of death and kidney transplantation after home dialysis initiation. Finally, we display trends in the percentage of prevalent home dialysis patients who were registered on the kidney transplant waitlist.

Methods
Throughout this chapter, home dialysis utilization was ascertained from the treatment history dataset that is routinely updated by the USRDS. This longitudinal dataset tracks each patient’s utilization of in-facility hemodialysis, home hemodialysis, continuous ambulatory peritoneal dialysis, and automated peritoneal dialysis, as well as kidney transplantation. In the context of this chapter, one important limitation of the treatment history dataset is that home treatment is defined as treatment that occurs outside of a dialysis facility. Therefore, intervals of home hemodialysis treatment do not distinguish between home hemodialysis in a private residence and home hemodialysis in a skilled nursing facility. In recent years, there has been relatively rapid expansion of the latter type of home hemodialysis. Although estimates of home hemodialysis utilization are not greatly affected by activity in the skilled nursing facility, estimates of the incidence of clinical outcomes can be greatly affected, as patients dialyzing in the skilled nursing facility tend to be elderly, have substantial comorbidity, and are highly likely to use a catheter for vascular access. In this chapter, we aimed to describe utilization of home hemodialysis in the private residence. To do so, we exclude all patients in facilities in which either of two conditions are satisfied: (1) ≥40 percent of the census on December 31 of a given year resided in a skilled nursing facility during that year; (2) the facility was located inside a long-term care facility. Both conditions were determined using Dialysis Facility Report data. By inspection, the first condition routinely identifies dialysis providers who specialize in providing dialysis in skilled nursing facilities.

In Figure 2.1a, home dialysis utilization is measured at dialysis initiation (i.e., on the date of ESRD diagnosis), at exactly 1 year after dialysis initiation (among patients undergoing dialysis at that time), and on December 31 of each year (among patients undergoing dialysis on that date). In Figure 2.2, data about home dialysis certification was ascertained from Dialysis Facility Compare, whereas data about home dialysis activity was ascertained from Dialysis Facility Reports. Figures 2.3 and 2.4 describe characteristics of home dialysis programs and patients on December 31, 2019. Figure 2.5 includes patients who initiated home dialysis in 2019, whereas Figure 2.6 includes Medicare FFS beneficiaries with at least 1 home dialysis training session in 2019. In Figure 2.7, utilization of automated peritoneal dialysis was measured among prevalent patients undergoing peritoneal dialysis on December 31 of each year. In Figures 2.8a, 2.8b, and 2.8c, home hemodialysis treatment intensity data were ascertained from dialysis facility admission and discharge records during 2019 in the End Stage Renal Disease Quality Reporting System (EQRS). In Figures 2.9 and 2.10, rates of hospitalization were estimated using Medicare Part A claims, with the cause of hospitalization defined by principal discharge diagnosis codes. Rates of all-cause hospitalization in Figure 2.12 were also estimated using Part A claims.

Figures 2.11, 2.13, and 2.14 include patients who initiated home hemodialysis or peritoneal dialysis between 2009 and 2018. In all analyses, patients were followed until the earliest of death, kidney transplantation, or December 31, 2019. In Figure 2.11, death and kidney transplantation were classified as competing risks in our examination of the cumulative incidence of conversion to in-facility hemodialysis. In Figures 2.13 and 2.14, incidence estimates were derived with and without classifying conversion to in-facility hemodialysis as a competing risk. Waitlisting prevalence in Figure 2.15 was estimated among prevalent home dialysis patients on December 31 of each year.
Figure 2.1a  Utilization of home dialysis, overall and by modality, stratified by ESRD status, 2009-2019

Overall

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage Among Incident Patients</th>
<th>Percentage At 1 Year After Dialysis Initiation</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2010</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>2011</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>2012</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>2013</td>
<td>8</td>
<td>20</td>
</tr>
<tr>
<td>2014</td>
<td>10</td>
<td></td>
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<tr>
<td>2015</td>
<td>12</td>
<td></td>
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<td>2016</td>
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<td></td>
</tr>
<tr>
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<td></td>
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<tr>
<td>2018</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>2019</td>
<td>20</td>
<td></td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD Database.
From 2009 to 2019, the percentage of incident dialysis patients performing home dialysis increased from 6.8% to 12.6% (Figure 2.1a). Growth was steady, although it slowed during the middle of the decade when peritoneal dialysate was in short supply. Home hemodialysis is a very small contributor to home dialysis utilization at dialysis initiation: in 2019, the percentage of incident dialysis patients performing home hemodialysis was only 0.3%. 
At 1 year after dialysis initiation, the percentage of patients performing home dialysis was higher than at dialysis initiation, due to adoption of home dialysis during the first year and to deaths among people who were older, frail, and less likely to elect home dialysis. Between 2009 and 2019, the percentage of patients performing home dialysis at 1 year after dialysis initiation increased from 10.5% to 18.2%. Those 18.2% of patients dialyzing at home in 2019 included 1.4% who performed home hemodialysis and 16.9% who performed peritoneal dialysis.

Among prevalent patients undergoing dialysis at the end of each calendar year, the percentage of patients performing dialysis was lower than among patients at 1 year after dialysis initiation, due to conversion of patients from home dialysis to in-facility hemodialysis and to the higher incidence of kidney transplantation among patients performing home dialysis. Nevertheless, between 2009 and 2019, the percentage of prevalent patients performing home dialysis increased from 8.9% to 13.1%, a relative increase of nearly 50%. Those 13.1% of patients dialyzing at home in 2019 included 1.9% who performed home hemodialysis and 11.2% who performed peritoneal dialysis.

In general, older age was associated with less utilization of home dialysis. Home hemodialysis utilization was higher in men than women, but peritoneal dialysis utilization did not exhibit that same tendency. Regarding race and ethnicity, White and Asian patients were more likely to dialyze at home than Black and Hispanic patients; the only exception to this pattern was utilization of home hemodialysis among Asian patients, which was more like utilization among Black and Hispanic patients than White patients. Patients whose primary cause of ESRD was glomerulonephritis or cystic kidney disease were more likely to dialyze at home than were patients whose primary cause was diabetes or hypertension.

Home dialysis utilization among prevalent patients varied among payers (Figure 2.1b). Highest utilization was observed among patients with Medicare as secondary payer; in that group, utilization reached 30.7% in 2019, with 3.9% due to home hemodialysis and 26.7% due to peritoneal dialysis. Patients with original Medicare (FFS) coverage, but without Medicaid coverage, exhibited intermediate home dialysis utilization, whereas patients with original Medicare and concurrent Medicaid coverage (i.e., “dual enrollment”) exhibited the lowest home dialysis utilization. It is likely that age and socioeconomic status explains much of the apparent variation.
Many facilities are certified to offer home dialysis, but there is no assurance that a certified facility has an active home therapies program. According to data in Dialysis Facility Compare and Dialysis Facility Reports, 45.1% of Medicare-certified dialysis facilities in 2019 were not certified to offer either home dialysis modality; 8.0% were certified to offer at least 1 home dialysis modality but had no active patients; and 46.8% were certified to offer at least 1 home dialysis modality and had active patients (Figure 2.2). Among facilities certified to offer home hemodialysis, 37% had no active patients. In contrast, among facilities certified to offer peritoneal dialysis, only 17% had no active patients.

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### Figure 2.2 Facility certification to offer home dialysis and delivery of home dialysis, by modality, 2019

Data source: Dialysis Facility Compare (January 2021) and Dialysis Facility Report (Fiscal Year 2021) data.

### Figure 2.3 Number of home dialysis patients per facility, by modality, 2019

Data source: USRDS ESRD Database.
Home dialysis program size may influence clinical outcomes, as staff can develop expertise in home dialysis patient care through routine exposure. Among active home dialysis programs in 2019, 20% of programs had between 1 and 5 patients and another 18% had between 6 and 10 patients (Figure 2.3). In sum, over half of programs had 15 or fewer patients. Home hemodialysis exhibited an even greater tendency toward small programs, with 82% of programs having 10 or fewer patients. On the other hand, 58% of peritoneal dialysis programs had 11 or more patients.

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Figure 2.4  Characteristics of home dialysis patients, by modality, 2019

Data source: USRDS ESRD Database.
The demographic and clinical characteristics of incident and prevalent ESRD patients performing home dialysis in 2019, overall and by modality, are displayed in Figure 2.4. Among incident ESRD patients performing home dialysis, more than half were aged 18-64 years, nearly 60% were male, and slightly more than half were White. These attributes were also apparent among prevalent ESRD patients performing home dialysis. Compared with patients performing peritoneal dialysis, patients performing home hemodialysis tended to be older, were more likely male, and were more likely Black.

Figure 2.5 Years between ESRD incidence and home dialysis initiation, by modality, 2019

Data source: USRDS ESRD Database.
The distribution of time from diagnosis of ESRD to home dialysis initiation among patients who initiated home dialysis in 2019 is displayed in Figure 2.5. The time at which home dialysis is initiated, relative to the diagnosis of ESRD, differs between home hemodialysis and peritoneal dialysis. For peritoneal dialysis, 85% of patients initiated the therapy during the first year of ESRD. Another 5% initiated peritoneal dialysis during the second year of ESRD. For home hemodialysis, only 43% of patients initiated the therapy during the first year of ESRD. Another 36% of patients initiated home hemodialysis between 1 and 5 years after the diagnosis of ESRD, and 10% initiated home hemodialysis more than 10 years after the diagnosis of ESRD.

Data source: USRDS ESRD Database.

Figure 2.6 Number of home dialysis training sessions, by modality, 2019

The number of home dialysis training sessions, by modality, is displayed in Figure 2.6. Home hemodialysis patients received a median of 16 sessions, while peritoneal dialysis patients received a median of 17 sessions. The percentage of patients receiving different numbers of sessions is shown.

Data source: Medicare Part B claims for outpatient dialysis.
Training regimens differed greatly between home hemodialysis and peritoneal dialysis. The cumulative number of training sessions among Medicare beneficiaries with at least 1 home dialysis training session in 2019 is displayed in Figure 2.6. For peritoneal dialysis, 26% of patients accumulated between 1 and 4 sessions, 46% accumulated between 5 and 8 sessions, and 21% accumulated between 9 and 12 sessions. For home hemodialysis, 31% of patients accumulated between 1 and 12 sessions (and may have discontinued training before initiating dialysis in the home setting), 48% of patients accumulated between 13 and 24 sessions, and 21% accumulated 25 or more sessions.

Data source: Medicare Part B claims for outpatient dialysis.

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**Figure 2.7** Automated peritoneal dialysis utilization among prevalent peritoneal dialysis patients, 2009-2019

Data source: USRDS ESRD Database.
Between 2009 and 2019, utilization of automated peritoneal dialysis among patients performing peritoneal dialysis steadily increased, from 67.8% in 2009 to 86.3% in 2019 (Figure 2.7). Utilization of automated peritoneal dialysis was nearly universal among patients aged ≤17 years.

The distribution of prescribed number of treatments per week among patients who performed home hemodialysis in 2019 is displayed in Figure 2.8a. Overall, 39.1% of patients were prescribed at least 3.5 treatment sessions per week (i.e., every-other-day dialysis) and fewer than 5.0 sessions per week. Another 38.0% of patients were prescribed at least 5.0 and fewer than 6.0 sessions per week; most patients in this category were prescribed 5 sessions per week, but one variant involves “5.5 sessions,” because of each 5-day interval including 4 treatment days and 1 off-day. Prescriptions involving no more than 3.0 sessions per week were more common among patients aged ≤17 and ≥80 years. Men were slightly more likely than women to be prescribed at least 5.0 sessions per week.

Data source: Centers for Medicare & Medicaid Services End Stage Renal Disease Quality Reporting System.
The distribution of prescribed number of treatment hours per session among patients who performed home hemodialysis in 2019 is displayed in Figure 2.8b. Overall, 18.2% of patients were prescribed sessions of <2.5 hours, 23.9% were prescribed sessions of 2.5 to 2.9 hours, and 27.6% were prescribed sessions of 3.0 to 3.4 hours. Only 4.0% of patients were prescribed sessions of ≥6.0 hours, a presumed marker of nocturnal hemodialysis. Among patients aged ≤17 years, 67.2% of patients were prescribed sessions of <3.0 hours. Men were more likely than women to be prescribed sessions of duration ≥3.5 hours. Relative to other subgroups defined by race and ethnicity, Black patients were more likely to be prescribed longer sessions.

**Figure 2.8c** Prescribed number of treatment hours per week among patients performing home hemodialysis, 2019

Data source: Centers for Medicare & Medicaid Services End Stage Renal Disease Quality Reporting System.
The distribution of prescribed number of treatment hours per week among patients who performed home hemodialysis in 2019 is displayed in Figure 2.8c. Overall, 19.3% of patients were prescribed between 10.0 and 11.9 hours per week, 26.7% were prescribed between 12.0 and 13.9 hours per week, 16.7% were prescribed between 14.0 and 15.9 hours per week, and 20.9% were prescribed ≥20.0 hours per week. Among patients aged ≤17 years, 93.4% of patients were prescribed <14.0 hours per week. Men were more likely than women to be prescribed ≥14.0 hours per week.

Regardless of the prescribed frequency of home hemodialysis, Medicare reimburses providers for additional sessions only if medical justification is provided. The number of Medicare-covered treatments per week among patients performing home hemodialysis in 2019 is displayed in Figure 2.8d. Overall, Medicare covered 3.8 sessions per week on average. There was very little variability among subgroups defined by age, sex, or race/ethnicity.

Data source: Medicare Part B claims for outpatient dialysis.
Figure 2.9 Rate of hospitalization with catheter complications, peritonitis, or sepsis among patients performing peritoneal dialysis, 2009-2019

Data source: USRDS ESRD Database and Medicare Part A claims for inpatient hospital care.

Figure 2.9 Rate of hospitalization with catheter complications, peritonitis, or sepsis among patients performing peritoneal dialysis, 2009-2019

Data source: USRDS ESRD Database and Medicare Part A claims for inpatient hospital care.
Rates of hospitalization due to peritoneal dialysis catheter complications, peritonitis, and sepsis among Medicare beneficiaries performing peritoneal dialysis are displayed in Figure 2.9. Overall, the rate of hospitalization due to catheter complications decreased between 2009 and 2019, from 23.8 admissions per 100 person-years in 2009 to 15.2 admissions per 100 person-years in 2019. Similarly, the rate of hospitalization due to peritonitis decreased from 15.1 admissions per 100 person-years in 2009 to 5.9 admissions per 100 person-years in 2019. However, the rate of hospitalization due to sepsis increased from 5.7 admissions per 100 person-years in 2009 to 11.6 admissions per 100 person-years in 2019.

Rates of hospitalization due to peritoneal dialysis catheter complications and peritonitis were relatively higher among patients aged 18-44 years, women, and Black patients. Rates of hospitalization due to sepsis were strongly associated with older age and higher among patients whose primary cause of ESRD was diabetes.
Figure 2.10  Rate of hospitalization with vascular access complications or sepsis among patients performing home hemodialysis, 2009-2019

Data source: USRDS ESRD Database and Medicare Part A claims for inpatient hospital care.
Rates of hospitalization due to vascular access complications and sepsis among Medicare beneficiaries performing home hemodialysis are displayed in Figure 2.10. Overall, the rate of hospitalization due to vascular access complications decreased between 2009 and 2019, from 22.6 admissions per 100 person-years in 2009 to 13.1 admissions per 100 person-years in 2019. However, the rate of hospitalization due to sepsis increased from 11.3 admissions per 100 person-years in 2009 to 17.8 admissions per 100 person-years in 2019.

Rates of hospitalization due to vascular access complications were higher among women and Black patients. Rates of hospitalization due to sepsis were strongly associated with older age and were higher among patients whose primary cause of ESRD was diabetes.

**Figure 2.11** Cumulative incidence of conversion from home dialysis to in-facility hemodialysis, by modality and year of home dialysis initiation

<table>
<thead>
<tr>
<th>Overall</th>
<th>Age</th>
<th>Sex</th>
<th>Race/Ethnicity</th>
<th>Primary Cause of ESRD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Hemodialysis</td>
<td>Peritoneal Dialysis</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Data source: USRDS ESRD Database. In subgroups defined by age, sex, race/ethnicity, and primary cause of ESRD, only patients who initiated home dialysis in 2017-2018 are included in the figure.*
The cumulative incidence of conversion from home dialysis to in-facility hemodialysis within 2 years, is displayed in Figure 2.11, with stratification by home dialysis modality and year of home dialysis initiation. Among patients who initiated home hemodialysis between 2011 and 2018, there was little evolution in the incidence of conversion to in-facility hemodialysis, with cumulative incidence of approximately 18% to 19% at 1 year and 25% to 27% at 2 years. Among patients who initiated home hemodialysis in 2017-2018, the cumulative incidence of conversion to in-facility hemodialysis was higher among patients aged 18-64 years, Black and Hispanic patients, and patients whose primary cause of ESRD was diabetes or hypertension.

Among patients who initiated peritoneal dialysis between 2011 and 2018, there was also little evolution in the incidence of conversion to in-facility hemodialysis, with cumulative incidence of approximately 14% to 15% at 1 year and 24% to 26% at 2 years. Among patients who initiated peritoneal dialysis in 2017-2018, the cumulative incidence of conversion to in-facility hemodialysis was lower among patients aged ≤17 years and ≥80 years. The cumulative incidence of conversion to in-facility hemodialysis was higher among Black patients and lower among Asian patients than among members of other race/ethnicity groups.
Figure 2.12 Rate of all-cause hospitalization during the 6 months preceding technique failure, by modality, 2009-2019

Data source: USRDS ESRD Database and Medicare Part A claims for inpatient hospital care.
Medical complications may lead to discontinuation of home dialysis, regardless of whether those complications are directly attributable to the home modalities. Rates of all-cause hospitalization during the 6 months preceding home dialysis technique failure are displayed in Figure 2.12. For home hemodialysis, the rate of hospitalization during the 6 months preceding conversion to in-facility hemodialysis declined only modestly between 2009 and 2019, from 278.7 admissions per 100 person-years in 2009 to 239.2 admissions per 100 person-years in 2019. Similarly for peritoneal dialysis, the rate of hospitalization during the last 6 months preceding conversion to in-facility hemodialysis decreased between 2009 and 2019, from 360.1 admissions per 100 person-years in 2009 to 315.6 admissions per 100 person-years in 2019. Despite these decreases, rates in 2019 remain far higher than rates of hospitalization among prevalent dialysis patients, as reported in Chapter 5 of this volume of the ADR. Among patients treated with peritoneal dialysis, rates of hospitalization were highest among women and among patients aged 18-44 years.

Figure 2.13  Cumulative incidence of death after home dialysis initiation, by modality, year of home dialysis initiation, and follow-up methodology

Data source: USRDS ESRD Database. In subgroups defined by age, sex, race/ethnicity, and primary cause of ESRD, only patients who initiated home dialysis in 2017-2018 are included in the figure.
The cumulative incidence of death among patients who initiated home dialysis between 2009 and 2018, with and without censoring at home dialysis discontinuation, is displayed in Figure 2.13. The cumulative incidence of death among patients who initiated home hemodialysis increased between the cohort of patients who initiated therapy in 2009-2010 and the cohort of patients who initiated therapy in 2013-2014. Among patients who initiated home hemodialysis in 2017-2018, the cumulative incidence of death was 20.5% at 1 year and 30.5% at 2 years if follow-up was not censored at home dialysis discontinuation. With censoring at home dialysis discontinuation, corresponding estimates of cumulative incidence were 18.9% at 1 year and 25.6% at 2 years.

The cumulative incidence of death among patients who initiated peritoneal dialysis decreased between the cohort of patients who initiated therapy in 2013-2014 and the cohort of patients who initiated therapy in 2017-2018. Among patients who initiated peritoneal dialysis in 2017-2018, the cumulative incidence of death was 10.0% at 1 year and 20.4% at 2 years if follow-up was not censored at home dialysis discontinuation. With censoring at home dialysis discontinuation, corresponding estimates of cumulative incidence were 9.1% at 1 year and 16.7% at 2 years.

Figure 2.13 Cumulative incidence of death after home dialysis initiation, by modality, year of home dialysis initiation, and follow-up methodology

Data source: USRDS ESRD Database. In subgroups defined by age, sex, race/ethnicity, and primary cause of ESRD, only patients who initiated home dialysis in 2017-2018 are included in the figure.
Figure 2.14  Cumulative incidence of kidney transplantation after home dialysis initiation, by modality, year of home dialysis initiation, and follow-up methodology

Data source: USRDS ESRD Database. In subgroups defined by age, sex, race/ethnicity, and primary cause of ESRD, only patients who initiated home dialysis in 2017-2018 are included in the figure.
The cumulative incidence of kidney transplantation among patients who initiated home dialysis between 2009 and 2018, with and without censoring at home dialysis discontinuation, is displayed in Figure 2.14. The cumulative incidence of transplantation among patients who initiated home hemodialysis was similar among cohorts of patients who initiated therapy after 2010. Among patients who initiated home hemodialysis in 2017-2018, the cumulative incidence of transplantation was 5.0% at 1 year and 10.0% at 2 years if follow-up was not censored at home dialysis discontinuation. With censoring at home dialysis discontinuation, corresponding estimates of cumulative incidence were 4.7% at 1 year and 8.7% at 2 years.

The cumulative incidence of transplantation among patients who initiated peritoneal dialysis decreased between the cohort of patients who initiated therapy in 2009-2010 and the cohort of patients who initiated therapy in 2013-2014 but then increased between the cohort of patients who initiated therapy in 2013-2014 and the cohort of patients who initiated therapy in 2017-2018. Among patients who initiated peritoneal dialysis in 2017-2018, the cumulative incidence of transplantation was 5.5% at 1 year and 11.2% at 2 years if follow-up was not censored at home dialysis discontinuation. With censoring at home dialysis discontinuation, corresponding estimates of cumulative incidence were 5.2% at 1 year and 10.1% at 2 years.

**Figure 2.15** Percentage of prevalent home dialysis patients registered on the kidney transplant wait list, by modality, 2009-2019

Overall Age Sex Race/Ethnicity Primary Cause of ESRD

- **Overall**
- **Home Hemodialysis**
- **Peritoneal Dialysis**

Data source: USRDS ESRD Database.
The prevalence of kidney transplant waitlisting among home hemodialysis patients remained between 36% and 38% from 2009 to 2014 but decreased thereafter, falling to only 28.1% in 2019. The prevalence of kidney transplant waitlisting among peritoneal dialysis patients remained between 34% and 36% from 2009 to 2014 but decreased thereafter, falling to 29.9% in 2019.

Figure 2.15  Percentage of prevalent home dialysis patients registered on the kidney transplant wait list, by modality, 2009-2019

Data source: USRDS ESRD Database.
White and Asian patients perform home dialysis more commonly than Black and Hispanic patients. The reasons for this are complex. Mastery of complex and strenuous processes of self-care. For decades, Medicare has not provided coverage for staff-assisted home dialysis, which is a predictable pattern that can be partly attributed to increasing comorbidity and frailty with advancing age, in addition to social factors. Despite this growth in home dialysis utilization, disparities remain. As age increases, home dialysis utilization decreases. On one hand, this is a predictable pattern that can be partly attributed to increasing comorbidity and frailty with advancing age, in addition to social factors, such as lower desire for employment or the absence of a capable care partner. However, home dialysis in the United States requires mastery of complex and strenuous processes of self-care. For decades, Medicare has not provided coverage for staff-assisted home dialysis, which might be instrumental in increasing home dialysis adoption among the elderly. Racial and ethnic disparities also remain. White and Asian patients perform home dialysis more commonly than Black and Hispanic patients. The reasons for this are complex. Socioeconomic conditions likely play a role, for impoverished people who lack sufficient space in their residence (or any stable residence at all) are less likely to dialyze at home. In fact, the reality of socioeconomic is most clearly demonstrated by the much higher utilization of home dialysis in patients with Medicare as secondary payer (i.e., those with private insurance as primary payer), relative to all other payer classes and lower utilization among those with Medicaid coverage. However, other biases may play important roles. Are Black and Hispanic patients routinely educated about home dialysis options? Is home dialysis discussed in Spanish with Hispanic patients who are more comfortable using this language? Are Black and Hispanic patients who are already dialyzing at home available to model home dialysis? Another potential issue is the local availability of home dialysis. Data in this chapter show that over half of all Medicare-certified facilities are either not certified to offer home dialysis or have no active program. Are there home dialysis "deserts" in areas characterized by poverty and unemployment? A potentially important impediment to continuous quality improvement in home dialysis delivery is the size of the typical program in the U.S. Over half of active home dialysis programs in 2019 had 15 or fewer patients, and only 36% had 26 or more patients. The situation is more extreme with home hemodialysis than with peritoneal dialysis. Over 60% of home hemodialysis programs had no more than 5 patients at the end of 2019. Many studies have demonstrated associations of patient volume with outcomes on home dialysis. Herein lies the tension as home dialysis expands. On one hand, it is plausible that home dialysis quality could be improved by creating centers of excellence that concentrate staff expertise. On the other hand, limiting the footprint of home dialysis in facilities may inadvertently limit exposure and access to home dialysis. Home hemodialysis and peritoneal dialysis are quite different in their application. Over half of patients who initiated home hemodialysis in 2019 had accumulated more than 1 year of kidney replacement therapy (typically, in-facility hemodialysis) upon initiation of home therapy. In contrast, 85% of patients who initiated peritoneal dialysis in 2019 were less than 1 year removed since the diagnosis of ESRD. This observation carries important implications for comparisons of outcomes between home modalities, as long-term dialysis itself may affect outcomes. Specific issues that frequently arise include among patients undergoing in-facility hemodialysis include loss of residual kidney function, progressive diastolic dysfunction, and worsening hyperparathyroidism. Data about the details of the peritoneal dialysis prescription are limited in federal datasets, including Medicare claims and EQRS. Automated peritoneal dialysis has become dominant, and through the lens of loop diuretic utilization displayed in Chapter 3, there appears to be increasing emphasis on preserving residual kidney function among patients performing peritoneal dialysis. Regarding home hemodialysis, an increasing volume of data about treatment frequency and session duration in the legacy CROWNWeb system provides better visibility into the nature of the therapy. In the U.S., due to the historical dominance of machines that utilize low dialysate flow rates, treatment frequency greater than 3 sessions per week is common. In 2019, most patients were prescribed either 4 or 5 sessions per week. Meanwhile, approximately 70% of patients dialedyz for less than 3.5 hours.
per session. This combination of increased frequency and relatively short sessions results in median treatment hours per week between 12 and 14 hours—just a few hours more than is typical of in-facility hemodialysis. Furthermore, nocturnal hemodialysis appears to be rarely prescribed in the home. This puts the U.S. in a unique position relative to international practice. The emphasis on increased treatment frequency in the U.S. should have positive effects on interdialytic fluid load, but the relative de-emphasis on treatment duration constrains potential clearance of middle molecules. How this translates into short-term and long-term outcomes, including the incidence of conversion to in-facility hemodialysis, is uncertain.

Trends in hospitalization outcomes with both peritoneal dialysis and home hemodialysis paint a mixed picture. With peritoneal dialysis, rates of hospitalization for peritoneal dialysis catheter complications and peritonitis decreased steadily between 2009 and 2019, and with home hemodialysis, the rate of hospitalization for vascular access complications also decreased during this time. However, in both groups, rates of hospitalization for sepsis increased. The key question is why the rate of hospitalization for sepsis has increased among both peritoneal dialysis and home hemodialysis patients. If hospitalizations were increasingly documented as being due to sepsis instead of peritoneal dialysis catheter complications, peritonitis, and vascular access complications, then the apparent in those 3 outcomes is partially an illusion. If the incidence of sepsis has truly increased, then a new problem has emerged. However, if hospitalizations were increasingly documented as being due to sepsis instead of other problems unrelated to home dialysis itself, then the apparent progress in reducing peritoneal dialysis catheter complications, peritonitis, and vascular access complications is likely real.

The incidence of conversion to in-facility hemodialysis and death on both home modalities has been quite stable among successive waves of patients initiating home dialysis between 2013 and 2018. Still, with the 2-year cumulative incidence of conversion to in-facility hemodialysis equal to approximately 25% for patients performing both home modalities, there is ample opportunity for improvement, which—if realized—would ultimately translate into higher population-wide utilization of home dialysis. Even if the incidence of home dialysis attrition has reached a transient plateau, the transition from home dialysis to in-facility hemodialysis is itself a potential target for quality improvement. Among patients utilizing both modalities, hospitalization rates during the last 6 months of home dialysis are extremely elevated relative to rates among prevalent dialysis patients. Further analysis is needed the causes of morbidity during this time, and whether that morbidity reflects problems with home dialysis, rather than more general problems that necessitate a change in dialysis setting.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 2. Home Dialysis, located here: https://adr.usrds.org/2021/end-stage-renal-disease/2-home-dialysis
Clinical Indicators and Preventive Care

Highlights

- Among patients receiving hemodialysis in 2019, 97% of patients each month achieved a single-pool Kt/V ≥1.2. Among patients receiving peritoneal dialysis in 2019, 93% achieved weekly Kt/V ≥1.7 each quarter (Figure 3.1a).
- During 2019, between 40% and 46% of hemodialysis patients had serum albumin ≥4.0 g/dL, whereas between 20% and 25% of peritoneal dialysis patients had serum albumin ≥4.0 g/dL (Figure 3.1b).
- In 2019, mean hemoglobin was 10.7 g/dL among hemodialysis patients and 10.9 g/dL among peritoneal dialysis patients (Figure 3.2).
- In 2019, 77% of hemodialysis patients and 59% of peritoneal dialysis patients received an erythropoiesis-stimulating agent (ESA) each month (Figure 3.3). For the first time, pegylated epoetin beta was the most commonly used ESA during hemodialysis.
- Among hemodialysis patients in 2019, mean monthly ESA doses were 46,600 U of epoetin alfa, 159 mcg of darbepoetin alfa, and 146 mcg of pegylated epoetin beta (Figure 3.4).
- In 2019, 64% of hemodialysis patients and 39% of peritoneal dialysis patients received iron each month (Figure 3.5a).
- Mean monthly intravenous (IV) iron doses were 201 mg with hemodialysis and 183 mg with peritoneal dialysis (Figure 3.5b).
- Over 71% of hemodialysis patients had serum ferritin ≥500 ng/mL (Figure 3.6).
- The monthly percentage of Medicare beneficiaries undergoing dialysis who received at least 1 blood transfusion decreased to 3.1% in the second half of 2019 (Figure 3.8b).
- In 2013, 17.6% of hemodialysis patients had ultrafiltration rates greater than 13.0 mL/hr/kg, but in 2019, that percentage had fallen to only 9.1% (Figure 3.9a).
- In 2019, the plurality of hemodialysis patients (36.5%) had session durations between 3.5 and 3.9 hours (Figure 3.9b). Nearly 89% of patients underwent between 9 and 13 hours of hemodialysis per week (Figure 3.9c).
- Utilization of nocturnal hemodialysis among Medicare fee-for-service (FFS) beneficiaries was low, at approximately 0.4% in 2019 (Figure 3.10).
- Utilization of loop diuretics among peritoneal dialysis patients increased to 37.2% in the fourth quarter of 2019 (Figure 3.11b).
- In 2019, 18% of hemodialysis patients had serum phosphorus of 5.5-6.4 mg/dL and 22% had serum phosphorus ≥6.5 mg/dL. Prevalence of hyperphosphatemia was slightly higher among peritoneal dialysis patients (Figure 3.13).
- In 2019, 62% of dialysis patients used a phosphate binder in each quarter. Among treated patients, 54% used sevelamer, 27% used calcium acetate, 2% used lanthanum carbonate, and 16% used iron-based phosphate binders (Figure 3.14a).
- By the fourth quarter of 2019, 33% of dialysis patients used a calcimimetic, and 31% of that share used etelcalcetide (Figure 3.14b).
- Over 75% of Medicare beneficiaries undergoing dialysis in 2019 received a seasonal influenza vaccination (Figure 3.15a) and nearly 19% received a pneumococcal vaccination (Figure 3.15b).

Introduction

In this chapter, we describe a wide array of quality and drug utilization measures pertaining to the care of dialysis patients. We begin with an overview of dialysis adequacy (Kt/V), serum albumin, and hemoglobin among patients undergoing dialysis in 2019, as well as ultrafiltration rates among patients undergoing hemodialysis. Here and elsewhere throughout the chapter, we describe laboratory and clinical data that were reported in the now-retired Consolidated Renal Operations in a Web-Enabled Network (CROWNWeb) system, which is today included in the End Stage Renal Disease Quality Reporting System (EQRS). The Medicare Improvements for Patients and Providers Act (MIPPA) of 2008 directed the Secretary of the Department of Health and Human Services to establish quality incentives for facilities providing dialysis services, thus launching the ESRD Quality Improvement Program (QIP). To support data collection required for implementation of the QIP, the Centers for Medicare and Medicaid Services (CMS) developed the CROWNWeb system. CROWNWeb was launched nationally in May 2012 and allowed dialysis facilities to electronically submit monthly laboratory and clinical data for patients under their care. New this year, data are stratified by primary cause of ESRD and duration of ESRD. Furthermore, we include pediatric patients (aged ≤17 years) among age strata.
We next describe measures pertaining to the treatment of anemia. We describe trends in hemoglobin from 2013 to 2019 and trends in ESA and iron utilization from 2016 to 2019. New this year, we present the data about IV iron dosing; we also present the joint distribution of serum ferritin and transferrin saturation to better characterize absolute and functional iron deficiency. We again describe the incidence of blood transfusions in Medicare FFS beneficiaries undergoing dialysis.

We supplement data about the distribution of ultrafiltration rates among patients undergoing hemodialysis from 2013 to 2019 with new data about session duration, cumulative treatment hours per week, and nocturnal hemodialysis utilization. To further elucidate the state of residual kidney function in patients performing peritoneal dialysis, we assess 24-hour urine volume and loop diuretic utilization.

Subsequently, we describe measures pertaining to the treatment of mineral and bone disease. We examine distributions of serum calcium and serum phosphorus. We examine trends in utilization of phosphate binders, calcimimetics, and vitamin D receptor activators (VDRAs) among dialysis patients enrolled in Medicare Parts B and D. Coverage of calcimimetics shifted from Part D to Part B in 2018, due to a transitional drug add-on payment adjustment (TDAPA) for dialysis facilities. We examine utilization of new agents, including iron-based phosphate binders and etelcalcetide.

Finally, we report several quality measures based on Medicare claims data. We examine trends in not only seasonal influenza vaccination, but also pneumococcal and herpes zoster vaccinations. We examine trends in the receipt of glycated hemoglobin tests, lipid tests, and diabetes eye examinations in patients with diabetes as the primary cause of ESRD. Finally, we assess nephrology visits per month among patients receiving in-center hemodialysis.

Methods

This chapter utilizes data from both the now-retired CROWNWeb system (today known as EQRS, the successor system) and Medicare claims. Analyses of albumin, calcium, dialysis adequacy (Kt/V), ESA utilization, ferritin, hemodialysis session duration, hemoglobin, iron utilization, phosphorus, transferrin saturation, ultrafiltration rate, and urine volume are based on data from CROWNWeb, which includes all patients receiving dialysis, not only those with Medicare FFS coverage.

The CROWNWeb system was launched in 2012, and essentially universal use of the system is evident by the beginning of 2013 based on the volume of data entered. Thus, many analyses extend from January 2013 to December 2019. However, there are exceptions. In the case of anemia treatment, because highly accurate reporting of pegylated epoetin beta administration begins in 2016, we limit analyses to the period from January 2016 to December 2019. In the case of residual kidney function among patients undergoing peritoneal dialysis, to construct parallel analyses of urine volume and loop diuretic utilization, we limit analyses to the period from January 2017 to December 2019.

For patients undergoing hemodialysis, we report data monthly, but for patients undergoing peritoneal dialysis, we report data quarterly. In the CROWNWeb system, clinical data about patients undergoing peritoneal dialysis could be reported monthly. However, most outpatient dialysis providers report these data during 1 month per quarter. In the case of patients undergoing peritoneal dialysis, reported measurements of Kt/V may reflect both dialysis and residual kidney function components; CROWNWeb data from 2019 indicate that approximately 90% of Kt/V measurements reflect both components. Regarding 24-hour urine volume among patients performing peritoneal dialysis, we summarize all nonzero values that are reported. However, it is likely that urine volume is not reported for all patients.

We report the percentage of patients receiving ESAs and iron during each month (or quarter). Nevertheless, individual patients’ receipt of these agents may be intermittent, such that utilization during a quarter is not indicative of utilization during each of the 3 calendar months in the quarter.

Analyses of blood transfusion incidence are based on Medicare claims data. Analyses of nocturnal in-facility hemodialysis utilization, seasonal influenza vaccination, pneumococcal vaccination, herpes zoster vaccination, diabetes management, and outpatient nephrology visits per month are also based on Medicare claims data. In the case of herpes zoster vaccination, claims arise under Medicare Part D. In all other cases, claims arise under Medicare Part B.

Finally, analyses of phosphate binders, calcimimetics, and VDRAs are based on Medicare Parts B and D claims. Phosphate binder utilization is ascertained exclusively from Part D claims, whereas vitamin D receptor activator utilization is ascertained exclusively from Part B claims. Until 2018, calcimimetics were covered under Medicare Part D. However, in 2018, calcimimetic coverage shifted to Part B, as part of outpatient dialysis facility billing. In these analyses, we report utilization during the quarter, as evidenced by any dispensation of medication. Analyses of vitamin D receptor activator utilization are limited to the period from 2017 to 2019 to ensure complete ascertainment of oral calcitriol administration.
Figure 3.1a  Prevalence of single-pool Kt/V ≥1.2 in hemodialysis patients and weekly standard Kt/V ≥1.7 in peritoneal dialysis patients, 2019

Data source: USRDS ESRD Database and CROWNWeb data, 2019.
During 2019, most patients received adequate dialysis, as defined by urea clearance (Figure 3.1a). Among patients receiving hemodialysis, between 96.7% and 97.2% of patients each month achieved a single-pool Kt/V ≥1.2. Among patients receiving peritoneal dialysis, between 92.7% and 93.3% achieved weekly Kt/V ≥1.7 each quarter. Although differences in prevalence of adequate clearance were small among subgroups, older patients, women, and Hispanic and Asian patients treated with hemodialysis were more likely to achieve adequate Kt/V. Women and Asian patients performing peritoneal dialysis were more likely to achieve adequate Kt/V.

![Figure 3.1b](image_url)

**Figure 3.1b** Distribution of serum albumin in patients receiving dialysis, 2019

<table>
<thead>
<tr>
<th>Overall Age</th>
<th>Sex</th>
<th>Race/Ethnicity</th>
<th>Primary Cause of ESRD</th>
<th>Duration of ESRD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hemodialysis</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD Database and CROWNWeb data, 2019.
During 2019, between 40% and 46% of hemodialysis patients each month had serum albumin ≥4.0 g/dL, between 41% and 45% had serum albumin between 3.5 and 4.0 g/dL, and between 13% and 16% had serum albumin <3.5 g/dL (Figure 3.1b). With advancing age, the prevalence of serum albumin <3.5 g/dL increased, from an average monthly prevalence of nearly 9% in those aged 18-44 years to an average monthly prevalence of over 20% in those aged ≥80 years. The prevalence of serum albumin <3.5 g/dL was modestly higher among women than men and among White than Black patients. Notably, the average monthly prevalence of serum albumin <3.5 g/dL was 22% among patients with less than 1 year since diagnosis of ESRD—much higher than among patients with more than 1 year since diagnosis of ESRD.

During 2019, between 20% and 25% of peritoneal dialysis patients each quarter had serum albumin ≥4.0 g/dL, between 44% and 45% had serum albumin between 3.5 and 4.0 g/dL, and between 31% and 36% had serum albumin <3.5 g/dL. Thus, the prevalence of hypoalbuminemia in peritoneal dialysis patients was approximately 2.4 times that of hemodialysis patients in 2019.
Figure 3.1c  Distribution of hemoglobin in patients receiving dialysis, 2019

Data source: USRDS ESRD Database and CROWNWeb data, 2019.
Among all hemodialysis patients, most of whom received ESAs and some of whom did not, an average of 8.0% had hemoglobin <9 g/dL each month in 2019, 15.5% had hemoglobin between 9 and 10 g/dL, 35.5% had hemoglobin between 10 and 11 g/dL, 28.7% had hemoglobin between 11 and 12 g/dL, and 13.3% had hemoglobin greater ≥12 g/dL (Figure 3.1c).

Among all peritoneal dialysis patients in 2018, an average of 8.0% each quarter had hemoglobin <9 g/dL, 15.8% had hemoglobin between 9 and 10 g/dL, 31.0% had hemoglobin between 10 and 11 g/dL, 25.2% had hemoglobin between 11 and 12 g/dL, and 20.0% had hemoglobin ≥12 g/dL. Thus, the prevalence of hemoglobin ≥12 g/dL was approximately 50% higher in peritoneal dialysis than in hemodialysis patients.

Among all hemodialysis patients in 2019, an average of 45.9% had an ultrafiltration rate <7 mL/hr/kg each month, 28.0% had an ultrafiltration rate between 7 and 10 mL/hr/kg, 17.1% had an ultrafiltration rate between 10 and 13 mL/hr/kg, and 9.1% had an ultrafiltration rate ≥13 mL/hr/kg (Figure 3.1d). The distribution of ultrafiltration rates shifted lower with increasing age and upward with increasing duration of ESRD.

---

**Figure 3.1d** Distribution of ultrafiltration rate in patients receiving hemodialysis, 2019

<table>
<thead>
<tr>
<th>Year and month</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>100</td>
</tr>
<tr>
<td>2019</td>
<td>75</td>
</tr>
<tr>
<td>0-2</td>
<td>25</td>
</tr>
<tr>
<td>3-4</td>
<td>0</td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD Database and CROWNWeb data, 2019.

Among all hemodialysis patients in 2019, an average of 45.9% had an ultrafiltration rate <7 mL/hr/kg each month, 28.0% had an ultrafiltration rate between 7 and 10 mL/hr/kg, 17.1% had an ultrafiltration rate between 10 and 13 mL/hr/kg, and 9.1% had an ultrafiltration rate ≥13 mL/hr/kg (Figure 3.1d). The distribution of ultrafiltration rates shifted lower with increasing age and upward with increasing duration of ESRD.
Figure 3.2  Mean hemoglobin in patients receiving dialysis, 2013-2019

Between 2013 and 2019, mean hemoglobin declined very slightly among patients on hemodialysis, from approximately 10.8 g/dL in early 2012 to 10.7 g/dL in late 2019 (Figure 3.2). During 2019, mean hemoglobin was approximately 0.25 g/dL higher in men than in women, but differences among subgroups defined by age and race/ethnicity were small. Patients whose primary cause of ESRD was cystic kidney disease had mean hemoglobin that was roughly 0.5 g/dL higher than patients with other primary causes of ESRD.

Among peritoneal dialysis patients, mean hemoglobin was nearly 10.9 g/dL during 2019. Mean hemoglobin increased with advancing age. Mean hemoglobin was approximately 0.25 g/dL higher in men than in women. Mean hemoglobin in White patients was over 11.0 g/dL in 2019, whereas mean hemoglobin in Black patients was 10.7 g/dL. Patients whose primary cause of ESRD was cystic kidney disease had mean hemoglobin that was roughly 0.6 g/dL higher than patients with other primary causes of ESRD.

Figure 3.3 Use of erythropoiesis-stimulating agents in patients receiving dialysis, 2016-2019

Data source: USRDS ESRD Database and CROWNWeb data, 2016-2019.
Utilization of ESAs between January 2016 and December 2019 is displayed in Figure 3.3. Between 74% and 78% of hemodialysis patients received an ESA every month. Since 2016, the percentage of patients receiving hemodialysis who were administered epoetin alfa has decreased from approximately 41% to 33%, albeit with relatively little evolution in 2019. The percentage of patients who were administered darbepoetin alfa fell to approximately 5% at the end of 2019, while the percentage of patients who were administered pegylated epoetin beta increased to more than 38% during the last quarter of 2019.

Among hemodialysis patients in 2019, average monthly utilization of any ESA was highest among patients aged <18 years, at approximately 90%. However, in adult patients, ESA utilization was lowest with age 18-44 years (75%) and highest with age ≥80 years (81%). ESA utilization was slightly higher among women than men and much lower among patients whose primary cause was cystic kidney disease (versus all other diseases).

Among peritoneal dialysis patients in 2019, average monthly utilization of any ESA was approximately 59%. The utilization trajectory of individual ESAs was similar among peritoneal dialysis patients as among hemodialysis patients. There were large differences in ESA utilization among subgroups defined by race and ethnicity, with utilization at 54% among White patients, 65% among Black patients, 62% among Hispanic patients, and 65% among Asian patients. ESA utilization increased with increasing duration of ESRD.

Data source: USRDS ESRD Database and CROWNWeb data, 2016-2019.
### Figure 3.4 Mean monthly dose of erythropoiesis-stimulating agents in patients receiving dialysis, 2016-2019

<table>
<thead>
<tr>
<th>Overall</th>
<th>Age</th>
<th>Sex</th>
<th>Race/Ethnicity</th>
<th>Primary Cause of ESRD</th>
<th>Duration of ESRD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>15k</td>
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<tr>
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<td>2016</td>
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<td>2018</td>
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<tr>
<td></td>
<td>2019</td>
<td></td>
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</tr>
</tbody>
</table>

**Data source:** USRDS ESRD Database and CROWNWeb data, 2016-2019.
Mean monthly ESA doses are displayed in Figure 3.4. Although there were month-to-month fluctuations, mean monthly ESA dose did not change appreciably between 2016 and 2019. Among hemodialysis patients in 2019, mean monthly epoetin alfa dose was 46,600 U, mean monthly darbepoetin alfa dose was 159 mcg, and mean monthly pegylated epoetin beta dose was 146 mcg. Among peritoneal dialysis patients in 2019, mean monthly epoetin alfa dose was 45,100 U, mean monthly darbepoetin alfa dose was 153 mcg, and mean monthly pegylated epoetin beta dose was 141 mcg.

Figure 3.5 Mean hemoglobin in patients receiving dialysis and using erythropoiesis-stimulating agents, 2016-2019

Data source: USRDS ESRD Database and CROWNWeb data, 2016-2019.
Mean hemoglobin in Figure 3.2 reflects an average of hemoglobin in the minority of patients who were not administered an ESA and the majority of patients who were administered an ESA. Mean hemoglobin among ESA-treated patients is displayed in Figure 3.5.

Among hemodialysis patients, mean hemoglobin remained between 10.4 and 10.5 g/dL from 2016 to 2019. Among peritoneal dialysis patients, mean hemoglobin remained around 10.3 g/dL from 2016 to 2019. In both modalities, patients aged 0-17 years and ≥80 years had relatively higher mean hemoglobin levels. Sex, race/ethnicity, primary cause of ESRD, and duration of ESRD had very little influence on hemoglobin levels.
Figure 3.6a Use of intravenous and oral iron in patients receiving dialysis, 2016-2019

Data source: USRDS ESRD Database and CROWNWeb data, 2016-2019.
IV and oral iron utilization—excluding iron-based phosphorus binders—is displayed in Figure 3.6a. Utilization was stable between 2016 and 2019. Among hemodialysis patients in 2019, approximately 64% of patients received iron each month, with more than 99% of iron-treated administered an IV formulation. Iron utilization was relatively higher among patients aged 0-17 years, and more than 10% of iron-treated patients in this age group used an oral formulation. Iron utilization decreased markedly with increasing duration of ESRD, with utilization at 79% among patients with less than 1 year since diagnosis of ESRD and only 54% among patients with more than 10 years since diagnosis of ESRD.

Among peritoneal dialysis patients, utilization of iron was lower. In 2019, monthly utilization of iron was 39%. In contrast to patients undergoing hemodialysis, almost 9% of iron-treated patients performing peritoneal dialysis in 2019 used an oral formulation, although the share has been decreasing in recent years.

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**Figure 3.6b** Mean monthly dose of intravenous iron in patients receiving dialysis, 2016-2019

<table>
<thead>
<tr>
<th>Year and month</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016</td>
<td>200</td>
</tr>
<tr>
<td>2017</td>
<td>200</td>
</tr>
<tr>
<td>2018</td>
<td>200</td>
</tr>
<tr>
<td>2019</td>
<td>200</td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD Database and CROWNWeb data, 2016-2019.
Mean monthly doses of IV iron between 2016 and 2019 were nearly constant, with mean doses of 201 mg among hemodialysis patients in 2019 and 183 mg among peritoneal dialysis patients in 2019. For both modalities, mean doses in the subgroup of patients with less than 1 year since diagnosis of ESRD were relatively larger.

Data source: USRDS ESRD Database and CROWNWeb data, 2016-2019.

Figure 3.6b  Mean monthly dose of intravenous iron in patients receiving dialysis, 2016-2019

Figure 3.7  Joint distribution of serum ferritin and transferrin saturation (TSAT) in patients receiving dialysis, 2013-2019

The joint distribution of serum ferritin and transferrin saturation (TSAT) has been stable in recent years (Figure 3.7). Among hemodialysis patients in 2019, 16.7% of patients had serum ferritin <500 ng/mL and TSAT <30%, whereas only 5.2% of patients had serum ferritin <500 ng/mL and TSAT ≥30%. In contrast, 41.4% of hemodialysis patients had serum ferritin ≥500 ng/mL and TSAT <30%, and 36.7% of patients had serum ferritin ≥500 ng/mL and TSAT ≥30%. Thus, 71.4% of patients had serum ferritin ≥500 ng/mL. Higher serum ferritin values were relatively less common among hemodialysis patients with less than 1 year since diagnosis of ESRD.

Among peritoneal dialysis patients in 2019, the joint distribution of serum ferritin and TSAT tended toward lower serum ferritin than the distribution among hemodialysis patients. Specifically, 24.0% of patients had serum ferritin <500 ng/mL and TSAT <30%, whereas 14.8% of patients had serum ferritin <500 ng/mL and TSAT ≥30%. In contrast, 23.2% of peritoneal dialysis patients had serum ferritin ≥500 ng/mL and TSAT <30%, and 37.9% of patients had serum ferritin ≥500 ng/mL and TSAT ≥30%.
An important measure of the quality of anemia treatment is the incidence of blood transfusion. Figure 3.8a displays the distribution of blood transfusions per patient per year in annual cohorts of Medicare beneficiaries receiving dialysis between 2009 and 2019. In 2009, 28.0% of dialysis patients received at least 1 blood transfusion during the year. That value peaked in 2012 and then steadily fell, reaching a new low of 22.5% in 2019. Transfusions were more likely among patients aged 0-17 years and slightly more likely among women than men.

Data source: USRDS ESRD Database and Medicare Parts A and B claims.

Figure 3.8b Monthly incidence of blood transfusion of Medicare beneficiaries receiving dialysis, 2009-2019

Data source: USRDS ESRD Database and Medicare Parts A and B claims.
The monthly percentage of Medicare beneficiaries receiving dialysis who received at least 1 blood transfusion is displayed in Figure 3.8b. That percentage peaked at an average of 4.6% of patients in January 2013. After that year, the percentage steadily decreased to 3.1% of patients per month during the fourth quarter of 2019. Women remained more likely to receive a blood transfusion in 2019, as did both White and Black patients (relative to Hispanic and Asian patients). Patients whose primary cause of ESRD was cystic kidney disease were relatively less likely to receive a blood transfusion. Interestingly, whereas the monthly incidence of blood transfusion was relatively higher among patients whose duration of ESRD was less than 1 year in 2009, these patients were almost equally likely to receive a blood transfusion in 2019.

Figure 3.9a Distribution of ultrafiltration rate in patients receiving hemodialysis, 2013-2019

<table>
<thead>
<tr>
<th>Overall Age</th>
<th>Sex</th>
<th>Race/Ethnicity</th>
<th>Primary Cause of ESRD</th>
<th>Duration of ESRD</th>
<th>Session Length</th>
</tr>
</thead>
</table>

The distribution of ultrafiltration rate among hemodialysis patients from 2013 to 2019 is displayed in Figure 3.9a. The distribution has steadily shifted toward lower rates. In 2013, 17.6% of patients had ultrafiltration rates greater than 13.0 mL/hr/kg, but in 2019, that percentage had fallen to only 9.1%. Meanwhile, the percentage of patients with an ultrafiltration rate less than 7.0 mL/hr/kg has increased from 36.3% in 2013 to 45.9% in 2019. Ultrafiltration rates remain higher in patients aged 18-44 years, with 17.0% of patients having rates greater than 13.0 mL/hr/kg; in contrast, only 7.1% of patients aged ≥80 years had ultrafiltration rates greater than 13.0 mL/hr/kg. Distributions of ultrafiltration rates also shifted upward with increasing duration of ESRD.

The distribution of treatment session duration among hemodialysis patients from 2013 to 2019 is displayed in Figure 3.9b. The plurality of patients (36.5%) had session durations between 3.5 and 3.9 hours. Approximately 5% of patients had session durations <3.0 hours and another 5% had session durations >4.5 hours. Session duration tended to be shorter in both pediatric and elderly patients. Meanwhile, session duration tended to be longer in Black patients and shorter in Asian patients. Session duration also tended to shorten with increasing duration of ESRD.

The distribution of cumulative treatment hours per week among hemodialysis patients from 2013 to 2019 is displayed in Figure 3.9c. Most patients underwent between 9 and 13 hours of hemodialysis per week, with 46.3% of patients in 2019 undergoing between 9 and 11 hours and 42.3% undergoing between 11 and 13 hours. The majority of patients aged 18-64 years underwent >11 hours of hemodialysis per week, whereas the majority of patients aged 65 years or older underwent <11 hours per week.

In 2017, Medicare introduced claims documentation for nocturnal hemodialysis in the facility. Figure 3.10 displays the percentage of patients undergoing in-facility hemodialysis who dialyzed at night. Overall, utilization of nocturnal hemodialysis is low, at approximately 0.4%. However, age is strongly associated with utilization: in 2019, about 0.8% of patients aged 18-44 years utilized nocturnal hemodialysis, whereas not even 0.1% of patients aged ≥80 years did so. Utilization was higher among men and Black patients. Furthermore, there was a clear gradient by duration of ESRD, with higher utilization among patients with a longer duration and very little utilization in the first year of dialysis treatment.
Figure 3.11a Distribution of 24-hour urine volume in patients performing peritoneal dialysis, among patients with recorded urine volume, 2017-2019


CROWNWeb data about the adequacy of peritoneal dialysis include measurements of 24-hour urine volume. Figure 3.11a displays mean 24-hour urine volume among patients with recorded, nonzero urine volume in 2017-2019. In 2019, mean volume was approximately 1L. Patients aged 18-64 years exhibited mean urine volume slightly more than 1 L, whereas elderly patients exhibited mean urine volume nearer to 900 mL. Mean urine volume was >200 mL higher among men than women and approximately 170 mL higher among White than Black patients. As the duration of ESRD increased, mean urine volume decreased, from approximately 1.1 L in patients with less than 1 year since diagnosis of ESRD to slightly more than 800 mL in patients with more than 5 years since diagnosis of ESRD.
Between 2017 and 2019, use of loop diuretics among Medicare beneficiaries performing peritoneal dialysis steadily increased, reaching 37.2% of all patients in the fourth quarter of 2019. Loop diuretic utilization increased sharply with advancing age and was approximately 10 percentage points higher among White patients than among Black patients. In contrast to age, loop diuretic utilization decreased with increasing duration of ESRD: over half of patients with less than 1 year since diagnosis of ESRD used a loop diuretic in 2019, whereas less than 20% of patients with more than 5 years since diagnosis of ESRD used a loop diuretic.
The distribution of serum calcium is displayed in Figure 3.12. The distribution was stable. Among hemodialysis patients in 2019, 12.7% had serum calcium <8.4 mg/dL, 84.7% had serum calcium between 8.4 and 10.2 mg/dL, and 2.6% had serum calcium >10.2 mg/dL. This distribution reflects a slight increase in the prevalence of hypocalcemia. Among peritoneal dialysis patients in 2019, 12.7% had serum calcium <8.4 mg/dL, 83.7% had serum calcium between 8.4 and 10.2 mg/dL, and 3.6% had serum calcium >10.2 mg/dL.
Figure 3.13 Distribution of serum phosphorus in patients receiving dialysis, 2013-2019

The distribution of serum phosphorus is displayed in Figure 3.13. Among hemodialysis patients in 2019, 7.8% had serum phosphorus <3.5 mg/dL, 21.4% had serum phosphorus between 3.5 and 4.5 mg/dL, 31.0% had serum phosphorus between 4.5 and 5.5 mg/dL, 17.9% had serum phosphorus between 5.5 and 6.5 mg/dL, and 21.9% had serum phosphorus ≥6.5 mg/dL. This distribution reflects the result of a long-term trend toward higher serum phosphorus levels. The prevalence of hyperphosphatemia (serum phosphorus ≥5.5 mg/dL) varied by age, with relatively higher prevalence in patients aged 18-44 years and relatively lower prevalence in patients aged ≥80 years. The prevalence of hyperphosphatemia increased with increasing duration of ESRD.

Among peritoneal dialysis patients in 2019, 5.2% had serum phosphorus <3.5 mg/dL, 19.5% had serum phosphorus between 3.5 and 4.5 mg/dL, 29.4% had serum phosphorus between 4.5 and 5.5 mg/dL, 21.3% had serum phosphorus between 5.5 and 6.5 mg/dL, and 24.6% had serum phosphorus ≥6.5 mg/dL. Therefore, the prevalence of hyperphosphatemia was higher with peritoneal dialysis than with hemodialysis.

### Figure 3.14a Utilization of phosphate binders in Medicare beneficiaries receiving dialysis, 2009-2019

<table>
<thead>
<tr>
<th>Year and quarter</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
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<td><strong>Calcium acetate</strong></td>
<td>0</td>
</tr>
<tr>
<td><strong>Sevelamer</strong></td>
<td>20</td>
</tr>
<tr>
<td><strong>Lanthanum</strong></td>
<td>40</td>
</tr>
<tr>
<td><strong>Iron-based agent</strong></td>
<td>60</td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD Database and Medicare Part D claims for prescription drugs.

Utilization of phosphate binders among dialysis patients enrolled in Medicare Parts B and D is displayed in Figure 3.14a. In this figure, utilization is defined by possession of at least 1 dispensed prescription during a quarter. Between 2009 and 2013, approximately 66% of dialysis patients used a phosphate binder each quarter. Utilization decreased modestly since 2013, with utilization at 61.5% in 2019. Phosphate binder utilization was less common among older patients. Utilization was similar in White and Black patients, but higher in Hispanic and Asian patients.

The mix of phosphate binders has evolved between 2009 and 2019. In 2009, 57% of phosphate binder use was attributed to sevelamer, 32% to calcium acetate, and nearly 11% to lanthanum carbonate. Iron-based phosphate binders first appeared in 2014. By 2019, 54% of phosphate binder use was attributed to sevelamer, 27% to calcium acetate, only 2% to lanthanum carbonate, and 16% to iron-based phosphate binders.
Utilization of calcimimetics among dialysis patients enrolled in Medicare Parts B and D is displayed in Figure 3.14b. In this figure, utilization is defined by possession of at least 1 dispensed prescription (or at least 1 administration, in the case of etelcalcetide) during a quarter. Between 2009 and 2019, calcimimetic utilization steadily increased, from 23% of dialysis patients in 2009 to almost 33% in 2019. Calcimimetic utilization was higher among patients aged 18-44 years and Black patients than among other subgroups. In addition, calcimimetic utilization increased greatly with increasing duration of ESRD: in 2019, 46% of patients with duration of ESRD between 5 and 10 years and 51% of patients with duration of ESRD greater than 10 years used a calcimimetic.

Etelcalcetide entered clinical practice in the United States in 2018. During the first quarter of 2018, 8.7% of calcimimetic use was attributed to etelcalcetide. By the fourth quarter of 2018, that percentage had increased to 22.2%, and by the fourth quarter of 2019, it had further increased to 31.2%.
Utilization of vitamin D receptor activators in Medicare beneficiaries receiving dialysis, 2017-2019

Overall Age Sex Race/Ethnicity Primary Cause of ESRD Duration of ESRD

<table>
<thead>
<tr>
<th>Year and quarter</th>
<th>Percentage</th>
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<td>2018</td>
<td>71%</td>
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<tr>
<td>2019</td>
<td>71%</td>
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</table>

Data source: USRDS ESRD Database and Medicare Part B claims for outpatient dialysis.

Utilization of VDRAs among dialysis patients enrolled in Medicare Parts B and D is displayed in Figure 3.14c. VDRAs are covered by Part B and administered by dialysis facilities. Historically, almost all dialysis patients who used a VDRA received IV administrations of calcitriol, doxercalciferol, or paricalcitol. More recently, an increasing number of dialysis patients have received oral calcitriol. In 2019, an average of 71% of dialysis patients were administered a VDRA each quarter. Among patients who were administered a VDRA, approximately 35% received oral calcitriol, 54% received intravenous doxercalciferol, and nearly 11% received intravenous paricalcitol.

Figure 3.15a Administration of seasonal influenza vaccination in Medicare beneficiaries receiving dialysis, 2009-2019

Overall Age Sex Race/Ethnicity Primary Cause of ESRD Duration of ESRD

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage</th>
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<tbody>
<tr>
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<td>80%</td>
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<tr>
<td>2019</td>
<td>81%</td>
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</tbody>
</table>

Data source: USRDS ESRD Database and Medicare Part B claims.
The percentage of Medicare beneficiaries receiving dialysis who were administered the seasonal influenza vaccine is displayed in Figure 3.15a. The analyzed period of vaccine administration extended from August 1 to December 31, in line with Dialysis Facility Report methodology; only vaccines administered in an outpatient setting can be ascertained from claims. In 2019, 75.7% of patients were administered the influenza vaccine in the outpatient setting, slightly below utilization in 2017 and 2018. Vaccine administration in 2019 was lower in patients aged 0-17 years (60.9%) and aged 18-44 years (71.1%) that in other age groups. Vaccine administration was also lower in Black (72.3%) than White (77.6%), Hispanic (77.9%), and Asian (79.0%) patients.

The percentage of Medicare beneficiaries receiving dialysis who were administered the pneumococcal vaccine is displayed in Figure 3.15b. Only vaccines administered in an outpatient setting can be ascertained from claims. In 2019, 18.8% of patients were administered the pneumococcal vaccine, extending a modest downward trend since utilization peaked at 21.4% in 2015.
The percentage of Medicare beneficiaries receiving dialysis who were administered the zoster vaccine is displayed in Figure 3.15c. Unlike the influenza and pneumococcal vaccines, which are covered by Medicare Part B, the zoster vaccine is covered by Medicare Part D. In recent years, utilization has increased. In 2019, 1.9% of all dialysis patients received the zoster vaccine. Utilization was relatively higher among elderly patients, White and Asian patients, and patients with shorter duration of ESRD.

Data source: USRDS ESRD Database and Medicare Part D claims for prescription drugs.

The percentage of Medicare beneficiaries receiving dialysis who were administered the zoster vaccine is displayed in Figure 3.15c. Unlike the influenza and pneumococcal vaccines, which are covered by Medicare Part B, the zoster vaccine is covered by Medicare Part D. In recent years, utilization has increased. In 2019, 1.9% of all dialysis patients received the zoster vaccine. Utilization was relatively higher among elderly patients, White and Asian patients, and patients with shorter duration of ESRD.

Data source: USRDS ESRD Database and Medicare Part D claims for prescription drugs.
The distribution of nephrology visits per month in Medicare beneficiaries receiving in-facility hemodialysis is displayed in Figure 3.17. The distribution was nearly static between 2009 and 2019. During 2019, 6.3% of patients saw a nephrology provider once per month, 22.7% of patients saw a nephrology provider 2 or 3 times per month, and 71.0% of patients saw a nephrology provider at least 4 times per month.

Data source: USRDS ESRD Database and Medicare Part B claims.
Summary

In 2019, 97% of patients undergoing hemodialysis and 93% of patients undergoing peritoneal dialysis achieved adequate urea clearance. However, as is now widely appreciated, adequate urea clearance does not ensure optimal patient outcomes. Less than half of patients achieved serum albumin ≥4.0 g/dL and more than 25% of hemodialysis patients had ultrafiltration rates ≥10 mL/hr/kg. Room for improvement remains.

Treatment of anemia now appears to have reached a steady state, except for continued evolution in the mix of specific agents that dialysis providers utilize. Between 2013 and 2019, mean hemoglobin has remained between 10.7 and 10.8 g/dL among hemodialysis patients and between 10.9 and 11.0 g/dL among peritoneal dialysis patients. In the subset of patients treated with an ESA, mean hemoglobin was lower than among those not receiving an ESA: between 10.4 and 10.5 g/dL among hemodialysis patients and approximately 10.3 g/dL among peritoneal dialysis patients. Still, slightly less than 1 in every 4 patients had hemoglobin <10 g/dL in 2019. At this level, patients may be more likely to experience symptoms like fatigue. During 2018 and 2019, the mixture of individual agents became increasingly concentrated on epoetin alfa and pegylated epoetin beta; by the end of 2019, only 5% of hemodialysis patients and 4% of peritoneal dialysis used darbepoetin alfa. In total, between 75% and 80% of hemodialysis patients and approximately 60% of peritoneal dialysis patients used an ESA in each month of 2019. Meanwhile, approximately 65% of hemodialysis patients and between 35% and 40% of peritoneal dialysis patients used iron in each month of 2019. IV formulations of iron have long been dominant in hemodialysis, but they now show increasing dominance in peritoneal dialysis, too. Despite the volume of treatment, more than 40% of hemodialysis patients and between 20% and 25% of peritoneal dialysis patients in 2019 exhibited relatively high serum ferritin (>500 ng/mL) and a low transferrin saturation (<30%), suggesting possible functional iron deficiency. In recent years, the trend toward decreasing utilization of blood transfusions among patients on dialysis has largely abated, with monthly incidence of transfusion stabilizing at just above 3%.

Ultimately, as the 2010s end, the challenge of treating anemia in patients undergoing dialysis remains on full display. According to the Food and Drug Administration, no randomized clinical trial has identified a hemoglobin target level, ESA dose, or dosing strategy that does not definitively increase risks of death, serious adverse cardiovascular reactions, or stroke. However, in synthesizing trial evidence, clinical practice has settled upon a target between 10 and 11 g/dL. This level leaves almost one-quarter of dialysis patients with hemoglobin levels <10 g/dL and approximately 8% of patients with hemoglobin levels <9 g/dL. ESAs and intravenous iron are widely administered, but transferrin saturation measurements <30% are still common. Transfusion incidence is no longer declining from one year to the next. Unfortunately, new treatment options remain elusive. FDA approval of roxadustat is no longer assured, leaving vadadustat and daprodustat as the next HIF stabilizers to be reviewed by the agency. Even so, both agents have been reported to be merely noninferior to existing ESAs with respect to cardiovascular safety.

New this year are increasingly detailed data about hemodialysis intensity and ultrafiltration rates in the facility setting. During the early part of the 2010s, there was strong emphasis on reducing ultrafiltration rates, but that process appears to have largely concluded. From 2017 to 2019, between 70% and 75% of hemodialysis patients had an ultrafiltration rate <10 mL/hr/kg, and the share with ultrafiltration rates exceeding 13 mL/hr/kg continued to decline. However, in dialysis patients aged 18-44 years, ultrafiltration rates seem to be stubbornly high, with more than 35% of patients in 2019 having ultrafiltration rates exceeding 10 mL/hr/kg. Regarding hemodialysis intensity, median session duration was between 3.5 and 3.9 hours in 2019. In young adult patients, there was a tendency toward longer sessions, suggesting that the relative high ultrafiltration rates in this group reflect higher ultrafiltration requirements rather than insufficient duration of dialysis sessions. Interestingly, between 2017 and 2019, there appeared to be gradual movement toward shorter dialysis sessions in patients with less than 1 year since diagnosis of ESRD. Ultimately, most hemodialysis patients accumulated between 9 and 13 treatment hours per week. In-facility nocturnal hemodialysis is a very small contribution to the menu of treatment options. We reported 24-hour urine volume among peritoneal dialysis patients for the first time. Among patients with reported nonzero volume, 24-hour urine volume was approximately 1000 mL, with higher levels among patients in their first year of ESRD and lower levels among patients later during ESRD. Between the beginning of 2017 and the end of 2019, loop diuretic utilization among peritoneal dialysis patients enrolled in Medicare Part D increased from 31% to 37%.

The treatment of mineral and bone disease in dialysis patients exhibited gradual changes, although the clinical significance of those changes is unclear. During 2019, the incidence of hypocalcemia increased slightly, from 12.2% of hemodialysis patients in January to 14.4% of hemodialysis patients in December. A qualitatively similar increase was also observed in the peritoneal dialysis patient population. One possibility is that expanding use of etelcalcetide, a potent calcimimetic, has slightly increased the prevalence of hypocalcemia in the population. From its introduction at the beginning of 2018 to the end of 2019, etelcalcetide utilization rapidly increased to more than 10% of all dialysis patients with Medicare FFS coverage, thus constituting nearly one third of all calcimimetic utilization in this population. Meanwhile, the distribution of serum phosphorus continued its long-term drift upward. In 2013, between 15% and 17% of hemodialysis patients had serum phosphorus ≥6.5 mg/dL, but in 2019 that percentage had increased to between 22% and 23%. This evolution may be attributed to multiple causes, possibly including skepticism about the cardiovascular efficacy of phosphate binders in patients undergoing dialysis. What is clear is that phosphate binder utilization has declined modestly between 2013 and 2019, from over 67% of patients in 2013
to a little more than 61% of patients in 2019. This decline is especially evident in patients aged ≥80 years. As phosphate binder utilization has decreased, the share of users who have received either ferric citrate or sucroferric oxyhydroxide has steadily climbed, reaching more than 1 in 6 users in 2019. These agents are branded and relatively costly, especially compared with the widely available generic formulations of sevelamer. In contrast to iron-based agents, utilization of lanthanum carbonate declined to less than 2% of dialysis patients enrolled in Medicare Part D.

Seasonal influenza vaccination rates maintained recent strength in 2019, with more than 75% of Medicare FFS beneficiaries undergoing dialysis having been vaccinated between August 1 and December 31. Vaccination coverage among pediatric patients has increased sharply in recent years. There is no disparity between White and Hispanic patients, but vaccination coverage remains approximately 5 percentage points lower among Black patients. Since 2015, the percentage of dialysis patients who have received a pneumococcal vaccine each year has been higher, although the percentage has declined some since its peak. Notably, more than 22% of dialysis patients with less than 1 year since diagnosis of ESRD received the pneumococcal vaccine in 2019, a level that slightly lower than the previous calendar year.

Finally, the distribution of nephrology visits per month among in-center hemodialysis patients with Medicare coverage exhibits remarkable stability, perhaps owing to stability in the number of relative value units (used as a basis for reimbursement) associated with 1, 2, 3, and 4 or more visits per month.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 3. Clinical Indicators and Preventative Care, located here: https://adr.usrds.org/2021/end-stage-renal-disease/3-clinical- indicators-and-preventive-care
Vascular Access

Highlights

- The percentage of patients initiating hemodialysis (HD) with a catheter (with or without a maturing fistula or graft) was virtually unchanged between 2009 (82.4%) and 2019 (81.8%) (Figure 4.1). The percentage of patients initiating HD with a catheter alone increased, from 64.9% to 67.8%.

- Patients who received nephrology care for more than 12 months prior to ESRD onset had the highest percentage of fistula use, at 28.6%; fistula use was only 5.4% among patients with no or unknown prior nephrology care (Figure 4.2).

- Among patients who initiated HD with a fistula in 2016-2018, cumulative incidence (not accounting for competing risks) of loss of primary unassisted patency at 1 year was 51.8%, of loss of primary assisted patency was 19.0%, and of loss of secondary patency was 3.3% (Figure 4.3a). These cumulative incidence estimates were slightly lower when accounting for competing risks, such as death and transplantation (Figure 4.3b).

- After initiation of HD in 2016-2018, the cumulative incidence of placement of a tunneled catheter within the first month was similar among patients with a fistula or a graft at approximately 9% (Figure 4.5a). The cumulative incidence of placement of a tunneled catheter at 1 year was 26.2% in graft users and 17.4% in fistula users not accounting for competing risks of death or transplantation. These cumulative incidence estimates were slightly lower when accounting for competing risks (Figure 4.5b).

- Among prevalent patients receiving HD in December 2019, more than 4 out of every 5 patients were using a fistula or graft (81.2%, of whom 64.5% were using a fistula and 16.7% a graft); 18.8% were using a catheter (Figure 4.6).

- Among patients who initiated HD in 2018 and remained on HD, nearly 70% were still using a catheter 3 months after HD initiation (Figure 4.8a). Only by 6 months after HD initiation were a majority of patients using an AV access. By 18 months after HD initiation, the percentage of patients using an arteriovenous (AV) access had increased to 83.6%.

- Among patients who initiated HD using a catheter in 2018, a majority were still using a catheter 6 months after HD initiation (Figure 4.8b). By 18 months, more than 80% were using an arteriovenous (AV) access.

- Among patients initiating HD in 2018, 80.8% of patients used a catheter, 16.2% a fistula, and 3.0% a graft at HD initiation (Figure 4.9a). By 18 months after HD initiation, only 64.3% remained on HD (with 42.4%, or about two thirds of those on HD, using an AV fistula), while 5.0% had transitioned to PD, 2.3% had received a kidney transplant, and one quarter had died.

Introduction

In this chapter, we describe vascular access among patients receiving HD. We first examine incident patients initiating HD, then describe trends in vascular access type (AV fistulas, AV grafts, and central venous catheters) in patients initiating HD from 2009-2019, then report access type in patients initiating HD in 2019 stratified by various patient characteristics.

Next, we show outcomes in the form of cumulative incidence curves in patients who initiate HD with an arteriovenous fistula, graft, or catheter. For each type of access, we show two types of cumulative incidence curves: one that does not account for the competing risk of death, and one that does. The concept of a competing risk approach and its utility are described in the Methods section below.

We then present curves showing the cumulative incidence of tunneled catheter placement among patients initiating HD with a fistula or graft, followed by an examination of vascular access in prevalent patients receiving HD. We report type of access in use as of December 2019 and display trends over time in vascular access use among prevalent patients receiving HD.

The chapter concludes by reporting change in vascular access type over 18 months following HD initiation in 2018. We first examine access in use at 3-month intervals among patients who remain on HD for up to 18 months. Because such an analysis does not account for other events such as death, change to PD, or receipt of a kidney transplant, we repeat this analysis considering all patients who initiate HD, reporting the percentage remaining on HD with a catheter, fistula, or graft in the context of other outcomes.
Methods

This chapter utilizes data primarily from the Centers for Medicare and Medicaid Services (CMS) ESRD Medical Evidence Report (form CMS 2728), Medicare claims, and the Consolidated Renal Operations in a Web-Enabled Network (CROWNWeb). There are several important methodological details to note, as described below.

The first is our use of different cohorts in analyses of vascular access use over time in patients who initiate HD in specific years. Some analyses were restricted to beneficiaries initiating HD with a catheter, or separately, a fistula when assessing outcomes. Access outcomes for grafts and fistulas are loss of primary unassisted patency, loss of primary assisted patency, and loss of secondary patency. Loss of primary unassisted patency was defined as use of any intervention that was required to maintain full function of the permanent access: angioplasty, surgery of any type (such as for an aneurysm or pseudoaneurysm), thrombectomy or thrombolysis, or creation of an entirely new access. Loss of primary assisted patency was defined as the need for surgery, thrombectomy or thrombolysis, or creation of an entirely new access (thus, this outcome does not include simple angioplasty, which is the most commonly performed procedure for maintaining patency). Loss of secondary patency was defined as the need to create an entirely new permanent access.

The second is our examination of vascular access outcomes by estimating cumulative incidence with and without consideration of competing risks; the two approaches are shown in paired figures. Cumulative incidence estimated by the Kaplan-Meier method, which does not involve explicit consideration of competing risks, answers the question, “What is the risk of an outcome if a patient (hypothetically) remained alive and on HD to the time point in question?” In contrast, in a competing risk framework, competing outcomes such as death, kidney transplant, and switch in dialysis modality, which may (and likely do) preclude the occurrence of the event of interest, are explicitly considered when estimating the cumulative incidence. Use of the competing risk method for cumulative incidence answers a slightly different question, specifically, “What is the risk of an outcome occurring prior to dying, receiving a kidney transplant, or switching modality, by the time point in question?” When estimating the cumulative incidence of an outcome at a given time point (e.g., 1 year), the competing risk method accounts for the reality that many patients will never reach that time point. The cumulative incidence estimate generated in a competing risk framework therefore generally estimates a lower risk of outcome events over time than the cumulative incidence estimate that is generated using the Kaplan-Meier framework. Detailed methods can be found in the ESRD Analytical Methods chapter.
Figure 4.1 shows temporal trends in type of vascular access used at HD initiation among patients with incident ESRD from 2009 to 2019. The use of any catheter (that is, a catheter with or without a maturing fistula or graft) at HD initiation was virtually unchanged over time (82.4% in 2009 and 81.8% in 2019). The percentage of patients with a catheter alone increased from 64.9% to 67.8%. Fistula use at HD initiation increased very slightly, from 14.4% to 15.2%, over this period. Use of a graft at HD initiation (3.0% in 2019) remained relatively unchanged. Thus, a smaller percentage of catheter users had a maturing fistula or graft in place at initiation in 2019 (14.0%) than in 2009 (17.5%). In general, these temporal patterns were consistent by age, sex, race, ethnicity, and insurance type.
Figure 4.2 Vascular access use at HD initiation by patient characteristics, 2019

Data source: ESRD Medical Evidence Report (CMS 2728). Incident patients with ESRD aged ≥18 years initiating HD between January 1 and December 31, 2019.
Figure 4.2 shows types of vascular access in use at HD initiation among patients with incident ESRD in 2019, overall and stratified by patient characteristics. Overall, patients most frequently used catheters (81.8%), followed by fistulas (15.2%) and grafts (3.0%) at the first outpatient HD treatment session. Furthermore, over two thirds (67.8%) of all patients initiated HD using a catheter without a maturing fistula or graft.

The youngest adults (those aged 18-44 years) had the highest percentage of catheter use (87.8%) and the lowest percentage of fistula (10.5%) or graft (1.7%) use at HD initiation; the percentage of fistula use was slightly higher among the older age groups (14.8% to 16.9%). A slightly higher percentage of men (16.6%) than women (13.1%) initiated with a fistula. Asian patients who initiated HD did so with a catheter less often than patients of other race/ethnicity groups (73.1%, versus >80% in other race/ethnicity groups) and used a fistula substantially more often (23.1%). Hispanic patients initiated with a catheter more frequently (85.4%) than patients of other race/ethnicity groups. The percentage of patients with cystic kidney disease as primary cause of ESRD who initiated HD using a fistula, 34.6%, was more than twice as high as the percentage among patients with other causes of ESRD.

In terms of comorbid conditions, the percentage of patients initiating HD using a fistula was lower among those with history of heart failure or an amputation (11.2% and 10.3%, respectively) than for those with other conditions. Those initiating HD with Medicare as a secondary payer (MSP) – a marker of coverage with private insurance serving as the primary payer – used a fistula more frequently (17.8%) than those with Medicare only (12.2%), dual Medicare and Medicaid coverage (10.6%), or Medicare Advantage (11.3%).

The most striking differences in vascular access type used at HD initiation were related to receipt of pre-ESRD nephrology care. Patients who received nephrology care for more than 12 months prior to ESRD onset had the highest percentage of fistula use, at 28.6%; fistula use decreased, in graded fashion, to only 5.4% among patients with no or unknown prior nephrology care. Of patients who initiated dialysis with an eGFR ≥15 mL/min/1.73m², 90.6% used a catheter, suggesting that they may have initiated dialysis abruptly, perhaps for symptoms attributed to ESRD.
Figure 4.3a  Cumulative incidence of loss of access patency after HD initiation with a fistula in 2016-2018

Data source: ESRD Medical Evidence Report (CMS 2728), CROWNWeb clinical extracts, and Medicare claims. Incident patients with ESRD, aged ≥18 years, and with Medicare fee-for-service (FFS) coverage initiating HD with a fistula in 2016-2018. Estimated using the Kaplan-Meier method, whereby death, kidney transplant, and change in modality or vascular access are treated as censoring events.

Data source: ESRD Medical Evidence Report (CMS 2728), CROWNWeb clinical extracts, and Medicare claims. Incident patients with ESRD, aged ≥18 years, and with Medicare fee-for-service (FFS) coverage initiating HD with a fistula in 2016-2018. Estimated using the Kaplan-Meier method, whereby death, kidney transplant, and change in modality or vascular access are treated as censoring events.
Figure 4.3a  Cumulative incidence of loss of access patency after HD initiation with a fistula in 2016-2018

Data source: ESRD Medical Evidence Report (CMS 2728), CROWNWeb clinical extracts, and Medicare claims. Incident patients with ESRD, aged ≥18 years, and with Medicare fee-for-service (FFS) coverage initiating HD with a fistula in 2016-2018. Estimated using the Kaplan-Meier method, whereby death, kidney transplant, and change in modality or vascular access are treated as censoring events.

Figure 4.3a  Cumulative incidence of loss of access patency after HD initiation with a fistula in 2016-2018

Data source: ESRD Medical Evidence Report (CMS 2728), CROWNWeb clinical extracts, and Medicare claims. Incident patients with ESRD, aged ≥18 years, and with Medicare fee-for-service (FFS) coverage initiating HD with a fistula in 2016-2018. Estimated using the Kaplan-Meier method, whereby death, kidney transplant, and change in modality or vascular access are treated as censoring events.
Among patients who initiated HD with a fistula in 2016-2018, cumulative incidence at 1 year was 51.8% for loss of primary unassisted patency, 19.0% for loss of primary assisted patency, and 3.3% for loss of secondary patency (Figure 4.3a; note that this figure does not account for competing risks). Corresponding estimates for 2-year cumulative incidence were 64.8%, 27.2%, and 5.0%. Loss of fistula patency of all types was substantially higher among patients aged ≥65 years and lower in patients aged 18-44 years. Women had a higher incidence of loss of fistula patency than men. By race/ethnicity, patterns varied by type of patency loss, and low numbers of patients (as reflected by relatively crude tracings in many cases) precludes drawing definitive conclusions for smaller race/ethnicity groups.

**Figure 4.3b** Cumulative incidence of loss of access patency after HD initiation with a fistula in 2016-2018, accounting for competing risks

Data source: ESRD Medical Evidence Report (CMS 2728), CROWNWeb clinical extracts, and Medicare claims. Incident patients with ESRD, aged ≥18 years, and with Medicare FFS coverage initiating HD with a fistula in 2016-2018. Estimated using the cumulative incidence function, whereby death, kidney transplant, and change in modality or vascular access are treated as competing risk events.

Figure 4.3b differs from Figure 4.3a by accounting for competing risks (such as death and transplantation). Overall, among patients who initiated HD with a fistula in 2016-2018, the cumulative incidence by 1 year was 40.9% for loss of primary unassisted patency, 14.7% for loss of primary assisted patency, and 2.6% for loss of secondary patency. Corresponding estimates of cumulative incidence by 2 years were 47.7%, 18.9%, and 3.4%. Overall patterns by age, sex, and race were similar to those shown in Figure 4.3a.
Among patients who initiated HD with a graft in 2016-2018, the cumulative incidence of loss of primary unassisted patency at 1 year was 69.2%, of loss of primary assisted patency was 46.9%, and of loss of secondary patency was 10.6%. Corresponding estimates for 2-year cumulative incidence were 86.3%, 64.1%, and 14.5%. Over the first 12 months, cumulative incidence of loss of primary unassisted patency was lowest among patients aged 18-44 years, but between the first and second years, cumulative incidence differed little by age group. Loss of primary assisted patency and loss of secondary patency differed little by age group. Men and women had similar incidence of all types of graft patency loss. By race/ethnicity, patterns of patency loss were somewhat variable, depending on the definition of patency; again, low numbers of patients precludes drawing definitive conclusions for some race groups.

Data source: ESRD Medical Evidence Report (CMS 2728), CROWNWeb clinical extracts, and Medicare claims. Incident patients with ESRD, aged ≥18 years, and with Medicare FFS coverage initiating HD with a graft in 2016-2018. Estimated using the Kaplan-Meier method, whereby death, kidney transplant, and change in modality or vascular access are treated as censoring events.

Figure 4.4b Cumulative incidence of loss of access patency after HD initiation with a graft in 2016-2018, accounting for competing risks

Data source: ESRD Medical Evidence Report (CMS 2728), CROWNWeb clinical extracts, and Medicare claims. Incident patients with ESRD, aged ≥18 years, and with Medicare FFS coverage initiating HD with a graft in 2016-2018. Estimated using the cumulative incidence function, whereby death, kidney transplant, and change in modality or vascular access are treated as competing risk events.
Figure 4.4b differs from Figure 4.4a by accounting for competing risks (such as death and transplantation). Overall, among patients who initiated HD with a graft in 2016-2018, the cumulative incidence by 1 year was 51.0% for loss of primary unassisted patency, 34.8% for loss of primary assisted patency, and 8.2% for loss of secondary patency. Corresponding estimates of cumulative incidence by 2 years were 58.4%, 42.6%, and 9.7%.

**Figure 4.5a** Cumulative incidence of tunneled catheter placement after HD initiation with a fistula or graft in 2016-2018

Data source: ESRD Medical Evidence Report (CMS 2728), CROWNWeb clinical extracts, and Medicare claims. Incident patients with ESRD, aged ≥18 years, and with Medicare FFS coverage initiating HD with a fistula or graft in 2016-2018. Estimated using the Kaplan-Meier method, whereby death, kidney transplant, and change in modality or vascular access are treated as censoring events.
Figure 4.5a Cumulative incidence of tunneled catheter placement after HD initiation with a fistula or graft in 2016-2018

Data source: ESRD Medical Evidence Report (CMS 2728), CROWNWeb clinical extracts, and Medicare claims. Incident patients with ESRD, aged ≥18 years, and with Medicare FFS coverage initiating HD with a fistula or graft in 2016-2018. Estimated using the Kaplan-Meier method, whereby death, kidney transplant, and change in modality or vascular access are treated as censoring events.
After initiation of HD in 2016-2018, the incidence of placement of a tunneled catheter within the first month was similar among patients with a fistula or a graft at approximately 9% (Figure 4.5a). Thereafter, the incidence is higher among patients with a graft. The cumulative incidence of placement of a tunneled catheter at 1 year was 26.2% in graft users versus 17.4% in fistula users. Corresponding estimates of cumulative incidence at 2 years were 39.0% and 23.3%. Among fistula users, patients aged 18-44 years had the lowest cumulative incidence of placement of a catheter; those aged ≥75 years had the highest. Among graft users, however, there was little difference in incidence of catheter placement by age. Women using a fistula had a higher incidence of catheter placement than men, but the incidence of catheter placement was similar between men and women who used grafts. Among fistula users, incidence of catheter placement was higher among White patients than patients of other races/ethnicities, but catheter placement varied little by race among graft users (although counts were low for some race/ethnicity groups, limiting conclusions).

Figure 4.5b  Cumulative incidence of tunneled catheter placement after HD initiation with a fistula or graft in 2016-2018, accounting for competing risks

Data source: ESRD Medical Evidence Report (CMS 2728), CROWNWeb clinical extracts, and Medicare claims. Incident patients with ESRD, aged ≥18 years, and with Medicare FFS coverage initiating HD with a fistula or graft in 2016-2018. Estimated using the cumulative incidence function, whereby death, kidney transplant, and change in modality or vascular access are treated as competing risk events.

Figure 4.5b differs from Figure 4.5a by accounting for competing risks. The cumulative incidence of placement of a tunneled catheter by 1 year after HD initiation with a fistula or graft in 2016-2018 was 23.4% in graft users and 16.3% in fistula users. Corresponding estimates of cumulative incidence by 2 years were 30.9% and 20.0%. Overall patterns by age and sex were similar to those depicted Figure 4.5a.
Figure 4.6 Distribution of type of vascular access in use among prevalent HD patients, December 2019

Data source: CROWNWeb clinical extracts. Prevalent patients with ESRD receiving HD on December 1, 2019.

Figure 4.6 Distribution of type of vascular access in use among prevalent HD patients, December 2019

Data source: CROWNWeb clinical extracts. Prevalent patients with ESRD receiving HD on December 1, 2019.
Figure 4.6 shows the distribution of vascular access types in use among prevalent patients receiving HD, overall and stratified by patient characteristics, in December 2019. Overall, more than 4 out of every 5 patients receiving HD were using a fistula or graft (81.2%, of whom 64.5% were using a fistula and 16.7% a graft); 18.8% were using a catheter.

Older patients were less likely to be using a fistula than younger patients (e.g., 60.8% among those aged ≥75 years versus 64.7% among those aged 18-44 years). Older patients were less likely to be using a fistula than younger patients (e.g., 60.8% among those aged ≥75 years vs. 64.7% among those aged 18-44 years) and more likely to be using a graft. A higher percentage of patients aged 18-44 years were using a catheter than older patients (22.2%, versus <19% among all others). Women were much less likely to be using a fistula than men (57.0% versus 70.0%); as such, they were more likely to be using a graft (21.7% versus 13.0%) or a catheter (21.3% versus 17.0%).

In terms of race/ethnicity, Black patients used a fistula least frequently (58.2%) and a graft most frequently (23.2%), whereas White patients used a catheter most frequently (20.4%). Native American patients had the highest use of a fistula (76.4%), and Asian patients had the lowest use of a catheter (14.7%). Patients with cystic kidney disease were more likely to be using a fistula, and less likely to be using a catheter, than patients with other causes of ESRD. A higher percentage of patients with Medicare as a secondary payer were using a catheter than patients with other known types of insurance coverage.
Figure 4.7 shows the percentage of patients using different vascular access types from 2012 to 2019. There has been relatively little change in patterns of vascular access use among prevalent HD population as a whole or within subgroups defined by demographic characteristics since CMS began collecting these data; catheter use increased from 17.9% in 2018 to 18.8% in 2019, while fistula use decreased from 65.5% to 64.5%.

Data source: CROWNWeb clinical extracts. Prevalent patients with ESRD receiving HD on December 1 of each year.
The distribution of vascular access types in use at 3-month time points among patients who initiated HD in 2018 and remained on HD for up to 18 months is shown in Figure 4.8a. Overall, nearly 70% of patients were still using a catheter 3 months after HD initiation. Only by 6 months after HD initiation were a majority of patients using an AV access. By 18 months after HD initiation, the percentage of patients using an AV access had increased to 83.6%.

At 18 months, the subgroups with the highest percentage of fistula use were patients who were aged 18-44 years, men, Native American, Hispanic, or Asian, whereas patients who were aged 18-44 years, women, or Black had the highest percentage of catheter use. Notably, although the distribution of access types was similar between men and women when initiating HD, by 18 months, women were using substantially more grafts (22.0%, versus 13.3% in men) and catheters (19.6%, versus 14.1% in men).
Figure 4.8b Change in vascular access type among patients remaining on HD over up to 18 months following HD initiation with a catheter in 2018

Overall Age Sex Race/Ethnicity

Figure 4.8b shows the distribution of vascular access types in use at 3-month time points over up to 18 months in patients who initiated HD using a catheter in 2018. Only patients remaining on HD were analyzed at each 3-month time point. Although a majority of patients were still using a catheter 6 months after HD initiation, by 18 months more than 80% of patients were using an AV access; this was similar to the percentage using an AV access in the overall HD population (Figure 4.6).

At 18 months, the subgroups with the highest percentage of fistula users were patients who were aged 18-44 years, men, Native American, Hispanic, or Asian. The groups with the highest percentage using a catheter were patients who were aged ≥75 years, women, and Black (who had a slightly higher percentage of catheter use than did White patients).
Figure 4.8c shows the distribution of vascular access types in use at 3-month time points over up to 18 months in patients who initiated HD using a fistula in 2018. Only patients remaining on HD were analyzed at each 3-month time point. By 3 months, use of a fistula decreased to 87.3% of patients, but the percentage then remained stable at roughly 90% for all subsequent time-points. Considered in another way, by 3 months, fistula failure requiring a catheter or graft placement had occurred in 12.6% of patients. Most patients not using a fistula at 3 months were using a catheter, but there was a gradual and modest shift from catheters to grafts over successive intervals between 6 and 18 months.

A similar pattern was observed across age groups. A consistently higher percentage of women used catheters and, especially, grafts, than men. Black patients were also more likely to switch to a graft over time than White patients, and by 18 months, 85.0% of Black, as compared with 91.4% of White and 92.9% of Asian, patients were using a fistula. By 18 months, only 1.5% of Asian patients were using a catheter, the lowest percentage of any group.
Figure 4.9a Change in vascular access type and other outcomes over the 18 months following HD initiation in 2018

Overall
- AV fistula
- AV graft
- Catheter
- Transplant
- Other/unknown
- Peritoneal dialysis
- Death

Data source: ESRD Medical Evidence Report (CMS 2728) and CROWNWeb clinical extracts. Incident patients with ESRD aged ≥18 years initiating HD between January 1 and December 31, 2018.

Figure 4.9a shows changes in vascular access type and other outcomes over 18 months among patients initiating HD in 2018. At initiation of HD, 80.8% of patients used a catheter, 16.2% a fistula, and 3.0% a graft. By 18 months after HD initiation, only 64.3% remained on HD (with 42.4%, or about two thirds of those on HD, using an AV fistula), while 5.0% had transitioned to PD, 2.3% had received a kidney transplant, and one quarter had died.

The percentage of patients alive and remaining on HD by 18 months after HD initiation decreased with increasing age, from 69.3% among those aged 18-44 years to 54.2% among those aged ≥75 years. Younger patients were more likely to transition to PD than older patients (e.g., 9.2% by 18 months among patients aged 18-44 years versus 2.6% among patients aged ≥75 years). At 18 months, the subgroups with the highest percentage using a fistula were patients who were aged 45-64 years and men; White individuals has the lowest fistula use. The groups with the highest percentage using a catheter were patients who were aged 18-44 years, women, or Black. The probability of death varied widely: among White patients, 31.0% had died at 18 months, as compared with 19.8% of Black, 18.6% of Native American, 16.7% of Asian, and 16.6% of Hispanic patients.
Figure 4.9b shows changes up to 18 months in vascular access type and other outcomes for patients initiating HD with a catheter in 2018. By 18 months, 61.2% of patients remained on HD (with 37.9% of the initial population using a fistula), while 5.3% had transitioned to PD, 2.0% had received a transplant, and 27.3% had died.

The percentage of patients alive and remaining on HD by 18 months after HD initiation with a catheter decreased with advancing age, from 67.8% among those aged 18-44 years to 49.8% among those aged ≥75 years. At 18 months, the highest percentages of patients using a fistula were in those who were aged 18-64 years and men. White individuals have the lowest fistula use. The highest percentages of catheter users were in patients who were aged 18-44 years, women, and Black. At 18 months, 34.1% of White, 21.7% of Black, 19.6% of Asian, 19.3% of Native American, and 18.0% of Hispanic patients had died.
Figure 4.9c shows changes in vascular access type and other outcomes for patients initiating HD with a fistula in 2018. By 18 months after initiation, 84.1% remained on HD, 2.1% had transitioned to PD, 4.1% had received a transplant, and 8.6% had died. Compared with those who started with a catheter (Figure 4.9b), less than half as many patients using a fistula switched to PD during follow-up (2.1% versus 5.3%), and less than one third as many had died (8.6% versus 27.3%). Over three quarters (77.5%) of the entire cohort was dialyzing using a fistula at 18 months.

The percentage of patients remaining on HD by 18 months after initiation decreased with increasing age, from 78.8% among those aged 18-44 years to 72.1% among those aged ≥75 years, largely due to the competing risk of death. At 18 months, the subgroups with the highest percentage using a fistula were patients who were aged 45-64 years and men. White individuals were least likely to use a fistula. Groups with highest percentage of catheter users were patients who were aged 18-44 years, women, or Black. By 18 months, 17.6% of White and 14.8% of Native American patients had died, compared with 9.6% of Black, 8.6% of Hispanic, and 7.1% of Asian patients.
Summary
Optimizing dialysis access remains a longstanding problem in the care of patients with ESRD. No progress was made over the decade of 2009-2019 in initiating maintenance dialysis with a permanent access; indeed, the percentage of patients who initiate HD with a developing fistula or graft has fallen. Given that development of ESRD typically takes years or even decades in most patients, this finding should be a grave disappointment to nephrologists, access surgeons, and of course, patients with kidney disease.

The U.S. has long lagged many other countries in use of permanent vascular access (Robinson et al., 2010). The Fistula First Initiative (Vassalotti et al., 2012) appears to have raised awareness of the importance of vascular access, leading to a gradual and substantial increase in the percentage of prevalent patients utilizing an AV fistula. Indeed, only one third of prevalent patients receiving HD in 2003 utilized a fistula, as opposed to >80% in 2019. However, approximately 80% of incident patients began HD utilizing a central venous catheter in 2019, and nearly two thirds of patients initiated HD with a catheter but no maturing AV fistula or graft. Even 3 months after dialysis initiation, >70% of HD patients are using a catheter. It is not until nearly 6 months that half of recent HD initiators are using a permanent vascular access. The duration of (predialysis) stage 5 CKD may last as little as 9 or fewer months (Ku et al., 2018; Wetmore et al., 2020); as such, nephrologists must make difficult decisions regarding the optimal timing of access placement in a relatively short period of time, especially given the many medically complex clinical priorities in patients with very advanced CKD.

Use of a permanent access at dialysis initiation is likely the result of numerous factors, many of which the nephrologist cannot directly control. Not unexpectedly, longer duration of predialysis nephrology care correlated with a higher likelihood of using a permanent access, suggesting that better access to and delivery of nephrology care might improve the rate of permanent access use at HD initiation. However, even in patients with a year or more of predialysis nephrology care, <30% of patients initiated HD with a functioning fistula. Further, recent evidence (Brown et al., 2017) suggests that patient-related factors may be responsible for much of the apparent benefit of initiating HD with a fistula, since even patients who initiated HD with a catheter after an apparently unsuccessful permanent access placement have better survival than patients who initiated HD with a catheter but with no permanent access having been attempted. Comorbidities and other patient-related factors, many of which are influenced by social determinants of health, may be at least as strongly associated with the adverse outcomes attributed to initiating HD with a catheter as the catheter itself.

Understanding whether and how catheters are associated with adverse outcomes is important for contextualizing patterns of mortality in the post-initiation period. Patients who initiate HD with a catheter die at a higher rate than patients initiating with a permanent access, evidenced by the fact that death is approximately 3 times as common at 18 months among patients who initiated HD with a catheter compared with an AV fistula. Thus, the sharp increase in prevalence of permanent access use at 1 year after dialysis initiation may reflect not only successful transition to permanent access for many patients but also a failure of more catheter users to survive the first year of dialysis.

The evolution of vascular access can be considered in one of two ways: among patients who remain alive and on HD over time or among all patients (those remaining on HD as well as those who experience competing events, such as change to PD, transplantation, or death). Considering only those who remain on dialysis, a higher percentage of White patients initiated HD with a fistula and used a fistula 18 months after initiation than Black patients. However, considering all outcomes, a higher percentage of Black than White patients used a fistula after 18 months. This difference appears to be driven mostly by the higher rate of mortality among White patients. Some of the apparent success of White patients (when competing risks are not considered) in terms of use of a permanent access may be because of the higher likelihood of death among catheter users rather than to higher rates of conversion to permanent accesses. Women and men initiate HD with generally similar distributions of access type (with men initiating slightly more frequently with AV fistulas), but over time (e.g., by 18 months after HD initiation), women use a graft or catheter more often than men. Because similar percentages of men and women transition to PD, receive a kidney transplant, or die, these competing events do not change their relative degree of successful fistula use.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 4. Vascular Access, located here: https://adr.usrds.org/2021/end-stage-renal-disease/4-vascular-access
References


End Stage Renal Disease: Chapter 5

Hospitalization

Highlights

- The overall adjusted rate of hospitalization in Medicare beneficiaries with ESRD decreased from 1.83 to 1.60 hospitalizations per person-year between 2009 and 2019 (Figure 5.1a). However, the lowest rate, 1.55, occurred in 2015. Similarly, the rate of combined hospitalization and observation stays was lowest in 2014 and 2015, at 1.81 per person-year.

- Beneficiaries in the youngest age group (18 to 44 years) had the highest rates of hospitalization, and there was surprisingly little difference in adjusted hospitalization rates across age groups among those aged ≥45 years (Figure 5.1b).

- Adjusted hospitalization and combined hospitalization and observation stay rates were consistently highest among White and lowest among Asian patients receiving hemodialysis (HD, Figure 5.1b) but were highest among Black patients treated with peritoneal dialysis (PD; Figure 5.1c).

- Hospitalization for cardiovascular causes was more common than hospitalization for infection among patients receiving HD (Figure 5.2a). However, infection-related hospitalizations were more common than cardiovascular hospitalizations among patients receiving PD and patients with a kidney transplant.

- Patients with Medicare fee-for-service (FFS) coverage had higher rates of hospitalization than Medicare Advantage beneficiaries (Figure 5.3).

- Hospitalization rate within the first 3 years after dialysis initiation improved for patients initiating HD and PD from 2008-2017 (Figure 5.4). As a result, the early period of higher hospitalization among patients initiating HD has diminished considerably.

- Among Medicare beneficiaries without CKD, 15.6% of hospital discharges in 2019 were followed by rehospitalization within 30 days (Figure 5.7). That percentage was 21.5% for discharges among beneficiaries with CKD and 32.0% for discharges among beneficiaries with ESRD.

- Among patients receiving dialysis, older patients were less likely to be readmitted within 30 days of hospital discharge but more likely to die in this period (Figure 5.9). Black beneficiaries were slightly more likely to be readmitted than their White counterparts, but White beneficiaries had the highest percentage of death without rehospitalization.

Introduction

The focus of this chapter is hospitalization in patients with ESRD covered by Medicare FFS. However, we also include Medicare Advantage beneficiaries in Figure 5.3. All patients in this chapter are aged ≥18 years. Hospitalization for patients aged <18 years are described in Chapter 8. Several changes in Centers for Medicare & Medicaid Services (CMS) rules surrounding observation hospital stays (which are considered outpatient services) in the last decade, including introduction of the Hospital Readmissions Reduction Program (HRPP) in October 2012 and the introduction and subsequent modification of the Two-Midnight rule (2013-2016), may affect hospitalization rates. Therefore, we also examine the combined metric of hospital admission or observation stay in many instances.

We begin by showing trends in the rates of hospitalization from 2009 to 2019. These trends are stratified by ESRD treatment modality and by age, sex, and race/ethnicity. Trends in rates of cause-specific hospitalization (e.g., cardiovascular, infection-related, vascular access-related) are then examined. Next, because other causes of hospitalization account for more than half of the total, we examine rates of hospitalization for other causes, including diabetes (DM), gastrointestinal bleeding, non-infectious lung disease, fracture, and cancer.

To demonstrate how hospitalization rates have changed by era, we create cohorts of patients who initiated dialysis in 2008, 2011, 2014, and 2017 and follow them for hospitalizations in subsequent years. We then present a map of Health Service Areas (HSAs) to illustrate, in fine detail, the geographic variation in hospitalization rates across the U.S.

Because emergency department encounters represent episodes of acute care that have the potential to lead to hospitalization, we present a figure showing trends in emergency department encounters over time. Finally, we examine rehospitalization and death within 30 days of hospital discharge over time and in 2019. These analyses are presented separately by ESRD treatment modality and examine differences by age and other patient characteristics.
Methods

Analyses in this chapter derive from data from CMS and rely on claims data from traditional FFS coverage (Medicare Parts A and B). Patients covered by Medicare Advantage and other sources such as employer group health plans or other commercial insurers are not included, except in Figure 5.3. Detailed methods are described in the Data Sources section of the ESRD Analytical Methods. For an explanation of the analytical methods used to generate cohorts, figures, and tables in this chapter, see the section on Chapter 4 in the ESRD Analytical Methods chapter.

Figure 5.1a All-cause hospitalization rates in adult ESRD patients, by treatment modality, 2009-2019

Figure 5.1a shows unadjusted and adjusted rates of hospitalization and observation stays in prevalent Medicare FFS beneficiaries with ESRD covered by Medicare Parts A and B from 2009-2019, overall and stratified by ESRD treatment modality. Beneficiaries receiving HD had the highest rate of hospitalization and of combined hospitalization and observation stays, and those with functioning kidney allografts had the lowest rates over the last decade. Adjusted hospitalization rates decreased from 2009 (1.83 per person-year) to 2019 (1.60 per person-year) among patients receiving treatment for ESRD, but the trends were not uniform. The rate of hospitalization in patients receiving HD and PD and with a kidney transplant declined until 2015. After 2015, hospitalization rate stabilized or rose slightly. Considering rates of hospitalization or observation stays together, declines were somewhat less pronounced, and rates more clearly increased after 2015 among patients receiving HD.
Figure 5.1b  All-cause hospitalization rates in adult hemodialysis patients, by demographic characteristics, 2009-2019

Data source: ESRD database. Yearly period prevalent HD patients 2009-2019 covered by Medicare FFS Parts A and B and aged ≥18 years. Age, sex, race/ethnicity, ESRD cause, and comorbidity were used in adjusted analyses.
Beneficiaries in the youngest age group (18 to 44 years) had the highest rates of hospitalization, and there was surprisingly little difference in adjusted hospitalization rates across age groups among those aged ≥45 years (Figure 5.1b). Over time, all groups experienced a decline in the first half of the decade followed by a slight increase in the second half to rates that remained below 2009 levels. Women were more likely to be hospitalized than men throughout the time period, and changes over time were similar among men and women. There was more variation in hospitalization rates across race groups than across age groups. Adjusted hospitalization and combined hospitalization and observation stay rates were consistently highest among White and lowest among Asian patients.

Figure 5.1c  All-cause hospitalization rates in adult peritoneal dialysis patients, by demographics, 2009-2019

As for beneficiaries receiving HD, the youngest adults on PD had hospitalization rates higher than even the oldest group (≥75 years), and there was relatively little variation in hospitalization by age (Figure 5.1c). Women had higher rates of hospitalization than did men, but changes in hospitalization rates between 2009 and 2019 was similar among men and women. As for HD, rates of hospitalization were lowest among Asian patients. However, in contrast to the pattern among beneficiaries receiving HD, Black patients receiving PD had slightly higher rates of hospitalization than White patients.
Although hospitalization rates were much lower among kidney transplant recipients than among patients treated with dialysis, patterns of hospitalization across age, sex, and race groups were similar to those observed in the dialysis population (Figure 5.1d). Specifically, hospitalization varied little by age, was higher among women than men, and was lowest among Asian individuals compared with members of other race groups.

Data source: ESRD database. Yearly period prevalent patients with a kidney transplant 2009-2019 covered by Medicare FFS Parts A and B and aged ≥18 years. Age, sex, race/ethnicity, ESRD cause, and comorbidity were used in adjusted analyses.

Data source: ESRD database. Yearly period prevalent patients 2009-2019 covered by Medicare FFS Parts A and B and aged ≥18 years. Age, sex, race/ethnicity, ESRD cause, and comorbidity were used in adjusted analyses.
Hospitalization for cardiovascular causes was more common than hospitalization for infection among patients receiving HD (Figure 5.2a). However, infection-related hospitalizations were more common than cardiovascular hospitalizations among patients receiving PD, even though peritonitis was not included, and among patients with a kidney transplant. For all modalities, rates of non-cardiovascular- and non-infection-related hospitalization were higher than cardiovascular- and infection-related hospitalization.
Among beneficiaries receiving HD, adjusted rates of hospitalization for cardiovascular causes decreased from 2009 to 2014 but then increased through 2019. Adjusted hospitalization rates for infection-related causes changed little over the decade, while rates for vascular access-related reasons decreased between 2009 and 2016 and then stabilized. Rates of hospitalization for all other causes decreased over the decade. Among beneficiaries receiving PD, the pattern of adjusted hospitalization rates for cardiovascular indications was similar to that among beneficiaries receiving HD. The rate of hospitalization for peritonitis decreased over the decade, while rates of hospitalization for other infections decreased between 2009 and 2014 and then stabilized. Rates of hospitalization for all other causes decreased consistently between 2011 and 2018 and then rose in 2019. Among beneficiaries with a kidney transplant, adjusted rates of cardiovascular- and infection-related hospitalizations were lower than for those for beneficiaries receiving dialysis and did not change meaningfully between 2009 and 2019. However, the rate of hospitalizations for other causes decreased over the decade.

Figure 5.2b shows rates of selected non-cardiovascular, non-infection related hospitalization from 2009-2019, overall and by ESRD treatment modality. No cause accounted for more than 0.1 hospitalization per person-year for any group. DM was the most common for all groups, beginning the decade at 0.09 per person year and decreasing to 0.07 in 2019 in the overall ESRD population. Non-infectious lung disease and gastrointestinal bleeding were the next most common causes for patients receiving dialysis, although hospitalization for lung disease occurred slightly more frequently for patients receiving HD, and gastrointestinal bleeding was slightly more common for those treated with PD for most of the period.

Data source: ESRD database. 2019 period prevalent dialysis patients covered by Medicare FFS Parts A and B, aged ≥18 years. Age, sex, race/ethnicity, ESRD cause, and comorbidity were used in adjusted analyses.
Data source: ESRD database for Medicare FFS cohort and Medicare MEDPAR database for Medicare Advantage cohort. Yearly period prevalent HD patients 2019 covered by Medicare FFS Parts A and B or Medicare Advantage, aged ≥18 years. Age, sex, race/ethnicity, ESRD cause, and comorbidity were used in adjusted analyses.
Among patients receiving HD, hospitalization rates were higher among Medicare FFS beneficiaries than among Medicare Advantage beneficiaries for all subgroups (Figure 5.3). Medicare FFS and Medicare Advantage beneficiaries aged 18-44 years had the highest overall adjusted rate of hospitalization in 2019, at 1.96 and 1.77 per person-year, respectively. Hospitalization rates were remarkably similar among other age groups among FFS beneficiaries, but the rate was higher among patients aged 45-64 years than among older Medicare Advantage beneficiaries. The higher rates of hospitalization in younger beneficiaries appears to have been driven by a slightly higher rate of infection-related hospitalization and by hospitalizations for causes other than cardiovascular or infection. Rates for cardiovascular causes were surprisingly similar across age groups. Vascular access infections were a rare cause of hospitalization but did occur among beneficiaries aged 18-44 years at approximately twice the adjusted rate as among beneficiaries aged ≥65 years. Women were hospitalized at a rate that was slightly higher than for men, a difference that was consistent across causes of hospitalization. White patients had the highest and Asian patients the lowest rates of hospitalization overall and for each cause. Hospitalization rates among Medicare FFS beneficiaries differed somewhat by primary cause of ESRD, with higher rates among those with ESRD caused by DM and glomerulonephritis than other causes. This difference was also evident for infection-related causes of hospitalization. Among Medicare FFS beneficiaries, overall hospitalization rates increased with increasing dialysis duration. This was also true for Medicare Advantage beneficiaries after a higher rate within the first year.

Figure 5.4 All-cause hospitalization rates in adult dialysis patients, by treatment modality and number of years after start of dialysis, incident year 2008, 2011, 2014, and 2017

Data source: ESRD database. 2008, 2011, 2014, and 2017 incident dialysis patients, covered by Medicare FFS Parts A and B and aged ≥18 years. Age, sex, race/ethnicity, ESRD cause, and comorbidity were used in adjusted analyses.
Data source: ESRD database. 2008, 2011, 2014, and 2017 incident dialysis patients, covered by Medicare FFS Parts A and B and aged ≥18 years. Age, sex, race/ethnicity, ESRD cause, and comorbidity were used in adjusted analyses.

Unadjusted and adjusted rates of all-cause hospitalization and observation stays among Medicare beneficiaries after initiating HD or PD for ESRD are shown in Figure 5.4 for 4 distinct incident cohorts: 2008, 2011, 2014, and 2017. The pattern of hospitalization after dialysis initiation differs by modality. In the earlier cohorts, patients initiating HD had a higher rate of hospitalization in the first year that gradually declined and stabilized at a lower rate after 3 to 4 years. In contrast, patients initiating PD had a lower initial hospitalization rate that increased over the first 3 years and then stabilized. Hospitalization rate within the first 3 years after dialysis initiation improved with successive cohorts (i.e., over time for patients on HD and PD, with the result that the early period of higher hospitalization among patients initiating HD diminished substantially. Hospitalization in the first few years after dialysis initiation also decreased among recent cohorts of patients starting PD resulting in a more pronounced period of lower hospitalization rates after dialysis initiation.

Adjusted rates of observation stays were considerably lower than hospitalization rates and followed a different pattern. Rates of observation stays increased between 2008 and 2019 regardless of dialysis duration or modality.
Figure 5.5 Health Service Area level map of hospitalization rate (admissions per person-year) in adult ESRD patients, by treatment modality, 2018-2019

Data source: ESRD database. Yearly period prevalent patients 2018-2019 covered by Medicare FFS Parts A and B and aged ≥18 years. Age, sex, race, ethnicity, and ESRD cause were used in adjusted analyses.

Figure 5.5 shows rates of all-cause hospitalization among beneficiaries with ESRD by U.S. HSA in 2018-2019. Rates of hospitalization ranged from 0.7–2.8 per person-year. Hospitalization rates were highest in portions of NY, PA, and WV, as well as southern IL and western MO, FL, and west-central TX. Rates were lowest in large rural areas of the south, central, and northwestern U.S.
There was a slight upward trend in the rate of emergency department (ED) encounters between 2009 and 2019 for all treatment modalities (Figure 5.6a). Compared with beneficiaries receiving HD, rates were more than 20% lower in beneficiaries treated with PD and more than 50% lower in beneficiaries with a kidney transplant.

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There was a slight upward trend in the rate of emergency department (ED) encounters between 2009 and 2019 for all treatment modalities (Figure 5.6a). Compared with beneficiaries receiving HD, rates were more than 20% lower in beneficiaries treated with PD and more than 50% lower in beneficiaries with a kidney transplant.

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Rates of ED encounters were substantially higher among beneficiaries aged 18-44 years than for all other age groups for patients treated with both dialysis modalities and among beneficiaries with a kidney transplant (Figure 5.6b. Similar to patterns of hospitalization, women had higher rates of ED encounters than men. Black patients consistently had the highest rates of ED encounters across all ESRD treatment modalities and Asian patients the lowest. In 2019, the rate of ED encounters was approximately twice as high among Black patients on HD or PD as among Asian patients.
Figure 5.7 Rehospitalization and death within 30 days of hospital discharge in older adults, by kidney disease status, 2019

Figure 5.7 shows the adjusted and unadjusted percentage of hospital discharges in 2019 followed by readmission or death within 30 days among Medicare beneficiaries aged ≥66 years without CKD, with CKD, and with ESRD. Considering adjusted rehospitalization without including observation stays (i.e., “true” rehospitalization, 15.6% of hospital discharges among beneficiaries without CKD, 21.5% of discharges among beneficiaries with CKD, and 32.0% of discharges among beneficiaries with ESRD were followed by rehospitalization within 30 days. Considering the competing risk of death, 5.1%, 6.5%, and 7.5% died without readmission, respectively. Although observation stays are not considered to be inpatient encounters, they may be used in place of hospitalization in some cases. When observation stays were included in the definition of rehospitalization, percentages of rehospitalizations increased slightly, but the pattern across CKD status was unchanged.
Figure 5.8 Percentage of all-cause hospitalizations resulting in hospital readmission or observation stays within 30 days of hospital discharge in adult ESRD patients, by treatment modality, 2009-2019

Figure 5.8 shows the unadjusted percentage of hospital discharges that were followed by rehospitalization within 30 days, by ESRD treatment modality, from 2009 to 2019. Rehospitalization rates were similar among patients receiving HD and PD and lower among those with a kidney transplant. Between 2009 and 2015, rehospitalization rates declined modestly among beneficiaries with ESRD for all treatment modalities and stabilized or increased thereafter. Including observation stays in the definition of rehospitalization increased the rehospitalization percentages only slightly. However, as observation stays increased over time, reductions in rehospitalization rates among patients receiving HD and PD were no longer evident when observation stays were included.
Figure 5.9 Rehospitalization and death within 30 days of hospital discharge in adult dialysis patients, by dialysis modality and demographic characteristics, 2019

Figure 5.9 shows the percentage of Medicare beneficiaries who were rehospitalized and/or who died within 30 days after hospital discharge by patient characteristics. Rehospitalization rates were similar among beneficiaries receiving HD and PD overall (35.0% and 33.3%) and across age categories, except that younger beneficiaries receiving HD, particularly those aged <45 years, had higher rates of rehospitalization than their counterparts on PD. Across age groups, rehospitalization rates were highest among beneficiaries aged 18-44 years and then declined with increasing age.

In beneficiaries receiving HD, death without rehospitalization also increased with increasing age, so that the percentage dying or being rehospitalized was similar for beneficiaries aged ≥45 years. In contrast, in beneficiaries receiving PD, the percentage dying or being rehospitalized increased with increasing age. Trends were broadly similar when observation stays were included in the definition of rehospitalization. Black beneficiaries were slightly more likely to be readmitted than their White counterparts, but White beneficiaries had the highest percentage of death without rehospitalization.
Summary
Hospitalization rates are no longer declining among patients with ESRD, as has been noted for the last 4 years. This stands in contrast to the broader population of Medicare FFS beneficiaries, in whom the hospital discharge rate has decreased from 292 to 266 discharges per 1000 beneficiaries between 2014 and 2018 (Centers for Medicare & Medicaid Services, 2020. The stabilization in overall hospitalization is mostly driven by small increases in cardiovascular- and infection-related hospitalizations, whereas hospitalizations for other causes are not increasing in recent years. Rates of observation stays are much lower than hospitalization rates, but they have been increasing over time. When hospitalizations and observation stays are considered together, rates have been nearly stable over the last decade.

Stable hospitalization rates in patients with Medicare FFS coverage may mask an increasingly complex subset of patients undergoing dialysis. As data in Chapter 9 indicate, Medicare Advantage enrollment has steadily increased among patients undergoing dialysis. To date, because of statutory restrictions, these patients must have been enrolled in a Medicare Advantage plan before the date of their ESRD diagnosis. If patients enrolled in Medicare Advantage are relatively healthy, then the remainder of patients enrolled in traditional FFS Medicare must have an increasing relative burden of comorbidity. Indeed, examination of hospitalization rates among beneficiaries with Medicare Advantage in this year’s ADR show lower rates than among beneficiaries with traditional FFS coverage, even after adjustment for demographic characteristics and burden of comorbidity. However, it should be noted that although we adjust for comorbid conditions, we are able to adjust only for the presence of these conditions and not for their severity.

There is surprisingly little variation in hospitalization rate by age among patients with ESRD. Among patients treated with HD, the youngest adult age group (those aged 18-44 years had rates of hospitalization that were higher than the oldest group, aged ≥75 years. Among patients treated with PD, rates of hospitalization were slightly higher among patients aged 18-44 years than among those aged ≥75 years. The reasons for the high rates of hospitalization among younger adults on dialysis are not clear. Examination of cause-specific hospitalization reveals that younger adults have higher rates of infection-related and non-cardiovascular, non-infection-related hospitalization than other age groups, whereas rates of cardiovascular-related hospitalizations are similar across age groups. As for hospitalization, rates of emergency department visits were highest in patients aged 18-44 years.

Rates of hospitalization over time after dialysis initiation differ among patients initiating HD and PD. Patients initiating HD typically have higher rates of hospitalization in the first few years, whereas patients initiating PD have lower rates of hospitalization immediately after dialysis initiation that rise over time. Although overall rates of hospitalization have not been declining in the last few years, hospitalization rates have declined among incident patients for those starting HD and PD. As a result, the high rates of hospitalization in the first few years of treatment with HD have been nearly eliminated in recent years. It is unclear why rates of hospitalization early in the course of dialysis treatment have declined over time, but there have also been improvements in early dialysis mortality (see ESRD Volume, Chapter 6. It is possible that the most recent improvements in early rates of hospitalization and death reflect a changing nature of dialysis initiation. Beginning in 2017, Medicare reimburses providers for outpatient dialysis for the treatment of acute kidney injury (AKI. As data in Volume 1 show, the number of Medicare FFS beneficiaries initiating outpatient dialysis for the treatment of AKI has increased steadily from 2017-2019. A substantial share of these patients are diagnosed with ESRD within 3 to 6 months of initiating outpatient dialysis, but some die before recovering kidney function or being diagnosed with ESRD. In this context, the date of transition from chronic kidney disease to ESRD reflects a clinical decision that recovery of kidney function will not occur rather than a hospitalization in which a patient is “crashing” into irreversible loss of kidney function. In other words, the first twelve months of dialysis, beginning in 2017, may be more like months 4 to 15 of dialysis in an earlier era. Onset of ESRD is likely to occur after the period of early risk has passed for some patients – and not at all for others who die before being diagnosed with ESRD and entering the USRDS database. This would be expected to result in a modest decrease in the apparent hospitalization rate in the first months after onset of ESRD.

Rates of readmission within 30 days of hospital discharge remain higher among patients on HD than among those not on dialysis. Rehospitalization rates were lower among older patients receiving HD, but death without rehospitalization increased with age such that combined rates of death or rehospitalization were similar across age groups except for the youngest group, which was highest. For patients on PD, rehospitalization rates varied little by age, but death within 30 days increased with age such that the combined rates of death or rehospitalization increased with age. These findings highlight the importance of considering the competing risk of death in high-risk populations.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 5. Hospitalization, located here: https://adr.usrds.org/2021/end-stage-renal-disease/5-hospitalization

Reference
End Stage Renal Disease: Chapter 6

Mortality

Highlights

- All-cause mortality declined further in 2019, reaching all-time lows for patients with ESRD and for those treated with all modalities of kidney replacement therapy. The overall reduction in mortality from 2009-2019 was 19.7% among all ESRD, 17.5% for those receiving maintenance hemodialysis (HD), 21.3% for those on peritoneal dialysis (PD), and 10.5% for kidney transplant recipients.
- Mortality in the first year after dialysis initiation decreased between 2005 and 2017 (Figure 6.4). Although mortality rates are high for those initiating HD and low for those initiating PD, early mortality (in the first year of dialysis) has declined substantially for both populations (27% for HD and 35.4% for PD) between 2005 and 2017.
- White patients receiving dialysis had substantially higher mortality than Black patients and members of other racial groups across all age groups (Figure 6.5).
- Arrhythmia/cardiac arrest accounted for 44.9% of deaths in 2019 among patients treated with HD with a known cause of death (Figure 6.6a). Over half of known deaths were related to cardiovascular disease (CVD) causes. When missing or unknown causes of death were included in the total, arrhythmia/cardiac arrest accounted for 34.7% of deaths, and CVD, collectively, was the cause of death in 42.5%. The distribution of cause of death in 2019 was similar for patients treated with PD.
- Between 2005 and 2015, median survival increased by approximately 9 months in patients initiating HD, reaching a new high of 48 months in 2015, and by 10 months for those initiating PD, reaching 55 months in 2015 (Figure 6.7).
- Individuals with ESRD have foreshortened lives compared to those without (Table 6.1). There is a >25-year projected lifespan difference between men receiving dialysis in 2019 (expectancy 11.1 years) and men in the general population in 2018 (expectancy 36.5 years); the difference was >30 years for women receiving dialysis.
- Adjusted mortality rates among Medicare beneficiaries were >10-fold higher for men and approximately 15-fold higher for women aged 66-74 years receiving dialysis than for individuals not receiving dialysis in 2019 (Table 6.2). Mortality rate among beneficiaries with a kidney transplant was similar to mortality among beneficiaries with cancer or with a history of cerebrovascular accident/transient ischemic attack.
- Between 2009 and 2019, adjusted mortality rates fell among beneficiaries receiving dialysis to a greater degree than among beneficiaries with other major medical conditions, but mortality among beneficiaries receiving dialysis was still far higher than among those with other conditions (Figure 6.8).
- Kidney transplant recipients with CVD had longer adjusted survival than patients receiving dialysis without CVD (Figure 6.9).

Introduction

In this chapter, we report findings related to mortality in patients with ESRD. We first describe trends in all-cause mortality in the decade between 2009 and 2019 and then illustrate geographic variation in mortality across the U.S. by Health Service Area (HSA). We next show changes in mortality rates over time in successive cohorts whose ESRD onset occurred in 2005, 2010, 2015, or 2017 and then describe mortality rates in patients with ESRD in 2019 by ESRD treatment modality, age, sex, and race/ethnicity.

Cause-specific mortality among patients with ESRD in 2019 is next illustrated using two pie charts, one of which includes individuals without a known cause of death and the other of which does not. Survival percentages by ESRD treatment modality and year of ESRD onset are then shown, followed by a display of the expected remaining years of life, in tabular format, for individuals with and without ESRD. Mortality rates are then contrasted between Medicare beneficiaries with ESRD and beneficiaries with other chronic diseases, such as cardiovascular conditions, diabetes or cancer. Finally, we examine mortality among Medicare beneficiaries with ESRD with and without CVD diagnoses and following cardiovascular procedures.
Methods
The analyses conducted for this chapter utilize several data sources, including the Centers for Medicare & Medicaid Services (CMS), data from the End Stage Renal Disease Quality Reporting System (EQRS), the Organ Procurement and Transplantation Network (OPTN), and the National Vital Statistics Report. Mortality analyses also use data from the 5% Medicare sample and U.S. Census mortality data. Cause of death in patients with ESRD was drawn from the CMS 2746 Death Notification Form. For an explanation of the analytical methods used to generate the study cohorts, figures, and tables contained in this chapter, see Chapter 6 within the ESRD Analytical Methods section.

Figure 6.1 All-cause mortality in adult ESRD patients, by treatment modality, 2009-2019

All-cause adjusted mortality in prevalent patients with ESRD decreased between 2009 and 2019 (Figure 6.1). In patients treated with HD, adjusted mortality decreased from 193.2 to 159.3 per thousand person-years. The decrease was slightly greater, in absolute and relative terms, among patients treated with PD, in whom mortality decreased from 171.5 to 134.9 per thousand person-years over this period (36.6%). Most of the decrease in mortality among patients receiving dialysis occurred during the first half of the decade. In recipients of a kidney transplant, the adjusted mortality rate decreased from 52.3 to 46.8 per thousand person-years between 2009 to 2019.

Data source: USRDS ESRD database. Yearly period prevalent ESRD patients 2009-2019. Age, sex, race/ethnicity, and ESRD cause were used in adjusted analyses.
Figure 6.2 Geographic variation of all-cause mortality (deaths per thousand person-years) in adult ESRD patients, by treatment modality, 2018-2019

Data source: USRDS ESRD database. Yearly period prevalent ESRD patients 2018-2019. Age, sex, race/ethnicity, and ESRD cause were used in adjusted analyses.

Among patients receiving HD, adjusted mortality rate was highest in the upper Midwestern parts of the U.S., ME, some areas in southern TX, parts of LA, and the Ohio River Valley (Figure 6.2). Mortality was lowest in the southwestern parts of the U.S. and along much of the Atlantic seaboard. Among patients receiving PD and with a kidney transplant, adjusted mortality rates were highly variable among even adjacent HSAs.
For both Black and White patients, mortality was lowest in the north and large areas of the Plains states, and highest in areas in the southeast, parts of the west coast, and the Ohio River valley (Figure 6.3). Geographic variation appeared greater among Black than among White patients with ESRD.

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Data source: USRDS ESRD database. Yearly period prevalent ESRD patients 2018-2019. Age, sex, race/ethnicity, and ESRD cause were used in adjusted analyses.

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Data source: USRDS ESRD database. Yearly incident ESRD patients 2005, 2010, 2015, and 2017. Age, sex, race/ethnicity, ESRD cause, and comorbidity were used in adjusted analyses.
Figure 6.4 shows all-cause mortality rate after initiation of dialysis for ESRD, by treatment modality, 2005, 2010, 2015 and 2017 using a traditional approach in which patients are censored upon receipt of a kidney transplant (i.e., considering only patients who remain on dialysis) and also in analyses without censoring upon receipt of a kidney transplant. Among those starting HD, the mortality rate decreased sharply between the first and second years after dialysis initiation for each cohort before steadily increasing over time. Over the first 3 years following dialysis initiation, mortality was highest for the cohort initiating HD in 2005 and lowest for the cohort initiating HD in 2017. Early mortality (in the first 2 years after dialysis initiation) declined dramatically, especially for the earlier cohorts (comparing those who initiated in 2005 to those starting HD in 2010). The same pattern was observed for early mortality when patients were not censored upon receipt of a kidney transplant. However, whereas mortality rose progressively after the second year on dialysis in the analysis that censored at transplantation, the rise was much less pronounced when patients were not censored at transplantation. This likely reflects the fact that censoring at the time of receipt of a kidney transplant tends to remove healthier individuals from the cohort. In addition, survival is better after a kidney transplant than during treatment with dialysis. Thus, censoring follow-up at the time of receipt of a kidney transplant constitutes informative censoring in epidemiological terms and would be expected to inflate mortality estimates progressively over time.

Among patients receiving PD, the pattern was different. The mortality rate was lowest in the first year and then increased steadily over time with censoring for kidney transplantation. As for HD, mortality in the first few years after dialysis initiation decreased in successive cohorts, and particularly between the 2005 and 2010 cohorts. Whereas mortality increased over time for all cohorts in the analysis with censoring at transplantation, the mortality rate did not increase appreciably after 3 years without censoring for transplantation.

Data source: USRDS ESRD database. Yearly incident ESRD patients 2005, 2010, 2015, and 2017. Age, sex, race/ethnicity, ESRD cause, and comorbidity were used in adjusted analyses.
White patients receiving dialysis had substantially higher mortality rates than Black patients and members of other racial groups across all age groups (Figure 6.5). For example, in patients receiving dialysis aged 65-74 years, the adjusted mortality rate in White patients (244 per thousand person-years) was more than 40% higher than that of Black patients (170.4 per thousand person-years). Among recipients of a kidney transplant, the difference in mortality between White and Black patients was most pronounced among patients aged ≥75 years. Differences in mortality by sex were less prominent than differences by race.
Figure 6.6a  Percentages of cause-specific mortality, with and without inclusion of missing and unknown causes of death, in patients with ESRD receiving hemodialysis, who died in 2019


Figure 6.6a shows causes of death for patients receiving HD who died in 2019 excluding (left) and including (right) missing and unknown causes. Arrhythmia/cardiac arrest (or sudden cardiac death, SCD), accounted for 44.9% of deaths among patients with a known cause, and over half of known deaths were related to cardiovascular causes. Sepsis was the cause of death in 6.5%, and withdrawal from dialysis was the attributed cause of death in 19.6%. The percentage of deaths attributed to withdrawal from dialysis appears to be relatively high because withdrawal from dialysis may be listed as the cause of death among patients whose death from another cause is imminent (i.e., who are withdrawn from dialysis because of imminent death). All other causes (i.e., cancer, other infection, all others) contributed 18.4%. Cause of death was missing or unknown for nearly one-quarter of patients who died in 2019 (22.7%). When these deaths were included in the total (at right), arrhythmia/cardiac arrest accounted for 34.7% of deaths, and CVD, collectively, was the cause of death in 42.5%.

Figure 6.6b  Percentages of cause-specific mortality, with and without inclusion of missing and unknown causes of death, in patients with ESRD receiving peritoneal dialysis, who died in 2019

Causes of death are shown for patients receiving PD who died in 2019 excluding (left) and including (right) missing and unknown causes (Figure 6.6.b.). Among deaths with a known cause, arrhythmia/cardiac arrest, was the cause in 40.7%, and 52.3% of all deaths were CVD-related. Sepsis was the cause of death in 9.4%, and withdrawal from dialysis was the attributed cause of death in 19.5%. All other causes (i.e., cancer, other infection, all others) contributed 18.1%. Approximately 1 in 5 patients who died (20.3%) had a missing or unknown cause of death. Including deaths with a missing or unknown cause, arrhythmia/cardiac arrest accounted for 32.4%; CVD, collectively, was the cause of death in 41.6%.


Causes of death are shown in Figure 6.6c for patients with a kidney transplant who died in 2019 excluding (left) and including (right) missing and unknown causes. Among deaths with a known cause, arrhythmia/cardiac arrest (SCD) accounted for 18.9%, and 32% were CVD-related. Sepsis was the cause of death in 12.5% and malignancy in 18%. However, almost 4 of 5 deaths (77.7%) among patients with kidney transplant were due to a missing or unknown cause. Therefore, it is unclear whether the distribution of known causes of death is representative of the overall distribution of causes.

Among patients receiving dialysis, survival improved in successive incident cohorts from 2005 to 2015 (Figure 6.7). For example, the median survival was approximately 39 months among patients initiating HD in 2005, 46 months among patients initiating HD in 2010, and 48 months for those initiating HD in 2015. In other words, in the span of a decade, patients initiating HD accrued an extra 9 months of median survival time. This “survival advantage” was slightly greater in patients initiating PD (10 months). For patients initiating HD and PD, the improvement appears to have occurred mostly between 2005 and 2010, with much less improvement between 2010 and 2015.

Survival was better among recipients of a living donor kidney transplant than those for those receiving a kidney transplant from a deceased donor. Among living donor kidney transplant recipients, mortality improved in each successive cohort; 5-year survival was 93% in patients whose ESRD onset occurred in 2015, compared with 89.8% and 91.5% in patients whose ESRD onset was in 2005 and 2010, respectively. Five-year survival among recipients of deceased donor kidney transplants also improved from 77.1% in 2005 to 82.7% in 2015.
Table 6.1 Expected remaining years of life in prevalent patients with ESRD and in the general population, by age, sex, and ESRD treatment modality

<table>
<thead>
<tr>
<th>Age</th>
<th>Female</th>
<th>Male</th>
<th>Female</th>
<th>Male</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>40-44</td>
<td>10.2</td>
<td>11.1</td>
<td>29.9</td>
<td>28.2</td>
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<td>36.5</td>
</tr>
<tr>
<td>45-49</td>
<td>9.1</td>
<td>9.6</td>
<td>26.0</td>
<td>24.3</td>
<td>35.8</td>
<td>32.1</td>
</tr>
<tr>
<td>50-54</td>
<td>7.8</td>
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<td>22.3</td>
<td>20.6</td>
<td>31.3</td>
<td>27.8</td>
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<td>55-59</td>
<td>6.8</td>
<td>6.9</td>
<td>18.9</td>
<td>17.3</td>
<td>26.9</td>
<td>23.8</td>
</tr>
<tr>
<td>60-64</td>
<td>5.9</td>
<td>5.8</td>
<td>15.7</td>
<td>14.3</td>
<td>22.8</td>
<td>20.0</td>
</tr>
<tr>
<td>65-69</td>
<td>5.0</td>
<td>4.9</td>
<td>12.7</td>
<td>11.7</td>
<td>18.8</td>
<td>16.4</td>
</tr>
<tr>
<td>70-74</td>
<td>4.3</td>
<td>4.1</td>
<td>10.3</td>
<td>9.5</td>
<td>15.0</td>
<td>13.0</td>
</tr>
<tr>
<td>75-79</td>
<td>3.7</td>
<td>3.5</td>
<td>8.3*</td>
<td>7.6*</td>
<td>11.5</td>
<td>9.9</td>
</tr>
<tr>
<td>80-84</td>
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<td>7.2</td>
</tr>
<tr>
<td>85+</td>
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<td>2.4</td>
<td></td>
<td></td>
<td>4.3</td>
<td>3.7</td>
</tr>
</tbody>
</table>

* This is for 75+.


Table 6.1 shows the expected remaining lifetime, in years, for the 2019 prevalent ESRD population and the 2018 general U.S. population. The table illustrates the markedly foreshortened projected lifespan for patients with ESRD relative to those without. In individuals aged 40-44 years, for example, there is a >25-year projected lifespan difference between men receiving dialysis (expectancy 11.1 years) and men in the general population (expectancy 36.5 years); the difference was >30 years for women receiving dialysis. As might be anticipated, the difference in expected remaining years of life decreases with increasing age. However, even men and women aged 80-84 years on dialysis have life expectancies that are 4.3 and 5.2 years shorter than their counterparts who are not receiving dialysis. Individuals with a kidney transplant live far longer than those receiving dialysis but still have a shorter life expectancy than those without ESRD.

Table 6.2 Mortality rates (per 1000 person-years) among older adults, by age, sex, 2019

<table>
<thead>
<tr>
<th>Age</th>
<th>Sex</th>
<th>ESRD</th>
<th>Medicare</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Unadjusted</td>
<td>Adjusted</td>
</tr>
<tr>
<td>66-74</td>
<td>Female</td>
<td>233.7</td>
<td>58.3</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>239.8</td>
<td>67.7</td>
</tr>
<tr>
<td>75+</td>
<td>Female</td>
<td>333.9</td>
<td>116.2</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>345.0</td>
<td>142.1</td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD database and Medicare 5% database. 2019 January 1 point prevalent ESRD patients and Medicare fee-for-service (FFS) beneficiaries without ESRD, all were aged ≥66 years, at least 1 year of Medicare coverage before January 1. Age, race/ethnicity, and sex were used for adjustment.

In 2019, adjusted mortality rates among Medicare FFS beneficiaries were >10-fold higher for men and approximately 15-fold higher for women aged 66-74 years receiving dialysis than for individuals not receiving dialysis (Table 6.2). Mortality rates were more than twice as high for dialysis patients in this age group than for those with heart failure and more than 3 times as high as for those with cancer. Even among beneficiaries aged ≥75 years, mortality rates in those receiving dialysis were more than 4 times those of beneficiaries without ESRD. Mortality rates in beneficiaries with a kidney transplant were similar to rates in beneficiaries with cancer or with a history of cerebrovascular accident/transient ischemic attack.
Figure 6.8 Mortality rates among older adults, 2009-2019

Figure 6.8 compares trends in mortality rates between 2009 and 2019 among Medicare beneficiaries aged ≥66 years with ESRD (receiving dialysis or with a kidney transplant) with those of beneficiaries with one of several medical conditions: diabetes (DM), acute myocardial infarction (AMI), heart failure (HF), cerebrovascular accident or transient ischemic attack (CVA/TIA), and cancer. Adjusted mortality rates fell among beneficiaries receiving dialysis to a greater degree than among beneficiaries with other major medical conditions, but the mortality rate among beneficiaries receiving dialysis was still far higher than among those with other conditions. In 2019, the mortality rate in beneficiaries treated with dialysis was twice as high as in those with HF, more than twice as high as in those with AMI, and 3 times as high as in those with cancer.

Data source: USRDS ESRD database and Medicare 5% database. 2009-2019 January 1 point prevalent ESRD patients and Medicare FFS beneficiaries without ESRD, all were aged ≥66 years, with at least 1 year of Medicare coverage before January 1. Age, race/ethnicity, and sex were used for adjustment. Cancer, DM (diabetes mellitus), HF (heart failure), CVA/TIA (cerebrovascular accident/transient ischemic attack), and AMI (acute myocardial infarction) represent patients with these respective conditions in general Medicare population.
Figure 6.9 displays the survival probability for patients receiving dialysis or with a functioning kidney transplant by the presence or absence of key CVD diagnoses. For all diagnoses, the survival benefit of transplantation outweighed the disadvantage of CVD, particularly over the second year. In other words, transplant recipients with each CVD diagnosis had similar adjusted survival probability over the first year and better survival in the second year than patients receiving dialysis who did not have that diagnosis. For example, the adjusted 2-year survival probability of patient with a kidney transplant with HF (81.1%) was comparable to the probability of surviving 20 months for a patient receiving dialysis who did not have HF.

Data source: USRDS ESRD Database. January 1, 2018 point prevalent patients with ESRD aged ≥18 years with Medicare FFS Parts A and B coverage. Adjustments were for age, sex, and race/ethnicity. Abbreviations: AMI, acute myocardial infarction; CAD, coronary artery disease; CVA/TIA, cerebrovascular accident/transient ischemic attack; HF, heart failure; PAD, peripheral artery disease; NVAF, nonvalvular atrial fibrillation.
Table 6.3 Two-year survival probability in adult patients with ESRD by cardiovascular disease status and treatment modality, 2018-2019

<table>
<thead>
<tr>
<th>Cardiovascular disease</th>
<th>Dialysis</th>
<th>Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unadjusted</td>
<td>Adjusted</td>
</tr>
<tr>
<td>CAD</td>
<td>60.4</td>
<td>75.8</td>
</tr>
<tr>
<td>AMI</td>
<td>52.9</td>
<td>71.5</td>
</tr>
<tr>
<td>HF</td>
<td>60.8</td>
<td>76.9</td>
</tr>
<tr>
<td>CVATIA</td>
<td>59.0</td>
<td>71.1</td>
</tr>
<tr>
<td>PAD</td>
<td>60.9</td>
<td>74.5</td>
</tr>
<tr>
<td>NVAF</td>
<td>55.4</td>
<td>72.3</td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD Database. January 1, 2018 point prevalent patients with ESRD aged ≥18 years with Medicare FFS Parts A and B coverage. Adjustments were for age, sex, and race/ethnicity. Abbreviations: AMI, acute myocardial infarction; CAD, coronary artery disease; CVA/TIA, cerebrovascular accident/transient ischemic attack; HF, heart failure; PAD, peripheral artery disease; NVAF, nonvalvular atrial fibrillation.

Table 6.3 lists the 2-year survival probabilities for patients receiving dialysis or with a functioning kidney transplant by the presence or absence of key CVD diagnoses. The difference in survival probability between patients with and without each CVD diagnosis was greater among patients receiving dialysis than among kidney transplant recipients. For all CVD diagnoses, the survival benefit of transplantation was larger than the disadvantage of CVD. At 2 years, the adjusted survival probability of kidney transplant recipients with each CVD diagnosis was greater than that of patients receiving dialysis without each CVD manifestation.

Figure 6.10 Unadjusted survival probability in adult patients with ESRD following a first cardiovascular procedure, by treatment modality, 2017-2019

The unadjusted survival probability following a first cardiovascular procedure in 2017-2019 is shown in Figure 6.10 for patients receiving HD, PD, or with a functioning kidney transplant. Unadjusted survival probability after each procedure was highest among patients with a kidney transplant and lowest among patients receiving PD. In the case of CABG, for example, the 2-year survival probability of a patients with kidney transplant (74.4%) was comparable to the 12-month survival probability of a patient receiving HD and the 10.5-month survival probability of a patient receiving PD.
Summary

Adjusted mortality rate fell by 17.5% among patients receiving HD and by 21.3% in patients receiving PD between 2009 and 2019. A large portion of this improved mortality appears to have been related to a substantial reduction in early mortality (e.g., within the first 2 years of dialysis initiation). This reduction in early mortality was mirrored by a reduction in in-hospital dialysis initiation and in hospitalization early in the course of ESRD (see Chapter 5, Hospitalization) and occurred despite continued high rates of catheter use at initiation of HD (see Chapter 4, Vascular Access). Although mortality rates have declined, ESRD remains a disease with extraordinarily high mortality. The difference in lifespan between age-matched individuals who do and do not receive dialysis is measured in decades rather than years. The mortality rate in patients with ESRD in 2019 was more than 3 times higher than in patients with cancer.

The data in this chapter continue to demonstrate large differences in survival between patients who receive a kidney transplant and those who remain dialysis-dependent. Of course, patient selection is a key driver of these differences. The data on long-term survival of patients on dialysis with and without censoring upon receipt of a kidney transplant supports the role of selecting healthier patients to receive transplanted kidneys in the observed mortality differences. However, comparisons of mortality between those on dialysis and with a kidney transplant within strata defined by age and the presence of cardiovascular disease reveal that survival is better for transplant recipients with cardiovascular conditions than among patients receiving dialysis of similar age without these conditions (Table 6.3). These results highlight the fact that transplant recipients represent a healthier cohort than those who remain dialysis dependent, although it is also probable that dialysis itself may confer some risk.

Increasing access to kidney transplantation is an important and well-recognized strategy to decrease mortality (and improve quality of life) among patients with ESRD – and one that is incentivized in new payment models starting in 2021. Nevertheless, because the number of patients on the waiting list for a kidney transplant continues to exceed the organ supply by a wide margin, many patients will continue to be supported with long-term dialysis. Therefore, it is essential that the nephrology community continue to seek effective cardioprotective strategies for anuric, long-term survivors on dialysis, especially given their high incidence of sudden death. It is astonishing that there is not greater clarity about optimal management of volume status and blood pressure, particularly among patients receiving HD, after more than 50 years of treating these patients. However new data from implantable loop recorders may provide important clues (Roy-Chaudhury et al., 2018). Clinically significant arrhythmias are common in patients receiving HD. Bradycardia is particularly common and follows a weekly pattern that is strongly associated with the intermittent schedule of dialysis therapy. Although home HD allows customization of therapy, it is far from a universal solution using currently available technology. Ultimately, it seems likely that major breakthroughs in clinical outcomes will require thoughtful re-examination of the usual intensity of HD (3 sessions, providing between 9 and 13 treatment hours per week) in the facility. In the interim, continued focus on vascular access health and infection control may lead to steady, incremental improvement in survival, as has been observed during the past decade.

One of the more interesting and challenging problems in dialysis is how to address regional variation in patient survival. Although there is variation from year to year, some regions have long exhibited relatively poor survival. Given the nature of HD and the geographic scope of major dialysis provider organizations, it seems unlikely that dialysis treatment-related factors can explain much of the regional variability in mortality. Rather, it is more likely that background factors in the community, including nutrition, pollution, poverty, and access to health care, play large roles in supporting or depressing patient survival. Although Medicaid is designed and administered by the states, the Medicare ESRD program has historically avoided local payment and policy initiatives, with regional quality improvement efforts the purview of the ESRD Networks. New payment models in which nephrology practices assume more responsibility for population health management and cost containment for patients with CKD and ESRD may facilitate regional customization of care delivery to address local needs.

Unfortunately, preliminary data indicate that the COVID-19 pandemic has reversed decades of progress in mortality among patients with ESRD (see this year’s COVID-19 supplement), exposing the underlying vulnerability of this population even in the face of recent improvements in survival. The full impact of the COVID-19 pandemic on non-COVID-related mortality among patients with ESRD has not yet been fully quantified, but the decreases in non-COVID hospitalization rates raise concern that patients may not have been willing or able to access care for their many comorbid conditions. The 2022 ADR will include COVID-related mortality using traditional data sources, allowing for analysis of cause-specific mortality and elucidation of the full impact of COVID-19 on mortality in patients with ESRD in 2020.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 6. Mortality, located here: https://adr.usrds.org/2021/end-stage-renal-disease/6-mortality

References

End Stage Renal Disease: Chapter 7

Transplantation

Highlights

- After a period of relative stability, the number of patients with ESRD added to the waitlist for a kidney transplant increased in 2018 and 2019, reaching an all-time high of 28,539 in 2019 (Figure 7.1).
- At the end of 2019, 78,690 patients were on the waitlist for a kidney transplant (Figure 7.2).
- Five percent of incident ESRD patients who initiated dialysis in 2019 had been waitlisted before the onset of ESRD (Figure 7.3). Although they remain low, rates of preemptive waitlisting (i.e., waitlisting before ESRD onset) increased between 2000 and 2019 and have almost doubled since 2005.
- The percentage of prevalent ESRD patients who were undergoing dialysis and on the waitlist for a kidney transplant reached 13.1% at the end of 2019 (Figure 7.4), continuing a decrease that began in 2014.
- Among patients with incident ESRD in 2018, 13.7% were waitlisted or received a kidney transplant within one year (Figure 7.5).
- The cumulative incidence of death at 6 months after ESRD onset (11.6%) was 4.3 times that of waitlisting (2.7%) (Figure 7.6). Thereafter, the cumulative incidence of death approached and remained approximately 3-fold higher than that of waitlisting.
- Almost one third of patients received a transplant within 1 year of being placed on the waitlist (32.9%), and the rate reached 51.8% by 5 years (Figure 7.7). The incidence of death was much lower in this select subset than in the non-waitlisted dialysis population.
- The adjusted rate of cardiovascular hospitalization among Medicare fee-for-service (FFS) beneficiaries who were on the waitlist for a kidney transplant increased steadily (by 22.6% overall) between 2015 and 2019, reaching a high of 422.5 hospitalizations per 1000 patient-years in 2019 (Figure 7.9).
- Among patients who were initially waitlisted in 2014, the median wait-time was 51.6 months, slightly lower than the corresponding estimate in the previous year (55.9 months) (Figure 7.10). The disparity in wait-time experienced by Black patients compared with White patients narrowed from almost 3 years among those waitlisted in 2009, but remained an astonishing 2.2 years for those listed in 2014.
- In 2019, the number of kidney transplants increased by 10.2% over 2018, continuing a steady rise that began in 2014 after several years of flat counts and reaching an all-time high of 24,502 (Figure 7.11).
- The number of patients with a functioning kidney transplant increased to 239,413 at the end of 2019, an increase of 4.5% since 2018 (Figure 7.18). The rate of growth has been greatest for patients aged 45-74 years.
- Total Medicare drug expenditures in the first year after kidney transplantation were $24,185 per person-year among Medicare beneficiaries with Part D coverage who received a kidney transplant between 2015 and 2018.

Introduction

In this chapter, we examine access and outcomes of kidney transplantation among patients with ESRD from the beginning of the transplant journey (waitlisting prior to ESRD) through to the end (outcomes after failed kidney transplant). We first examine wait listing for a kidney transplant, including the number of individuals added to the kidney transplant waitlist each year, the total number of patients on the kidney transplant waitlist, the timing of placement on the waitlist relative to dialysis initiation, and the percentage of dialysis patients on the kidney transplant waitlist. We then examine the waitlist itself, including its size and events that occur among patient on the waitlist, including time to receipt of a transplant among those who go on to receive a kidney transplant, as well as cardiovascular hospitalizations and deaths among waitlisted patients. Next, we examine counts and rates of kidney transplantation, characteristics of deceased donors, and outcomes among transplant recipients, including graft and patient survival. We also examine hospitalizations and costs of medications among transplant recipients, and new this year, we examine mortality and retransplantation rates after initiating dialysis following graft failure.
Methods

This chapter draws upon data from merging the USRDS database of patients with ESRD with the Organ Procurement and Transplantation Network (OPTN) database of waitlisted and transplanted patients.

In Figures 7.1 and 7.2, tallies of waitlisted patients are derived from those patients who have been diagnosed with ESRD before the date of waitlisting or are diagnosed with ESRD no later than December 31 of the year in which waitlisting occurs. The practical consequence of this is that waitlisting counts are lower in the Annual Data Report than waitlisting counts that are reported by the Scientific Registry of Transplant Recipients (SRTR), as listings that occur long before the diagnosis of ESRD are reflected only in the latter source. In Figure 7.3 and 7.4, only patients undergoing dialysis are included in the denominator of wait-list measures.

In Figure 7.5, patients are followed from the date of ESRD diagnosis to the earliest of waitlisting, transplant, death, or the end of the first year of ESRD. Death was considered as a competing risk, so the reported statistic is the cumulative incidence of waitlisting or receipt of a transplant. Nevertheless, patients who were waitlisted before the diagnosis of ESRD or received a preemptive kidney transplant were included in the estimate of cumulative incidence.

In Figure 7.9, the rate of cardiovascular hospitalization among waitlisted patients was limited to those with Medicare Parts A and B as primary payer, and cardiovascular-related admissions were ascertained from Medicare claims by inpatient facilities with a principal discharge diagnosis of cardiovascular morbidity, as described in Chapter 5 of the Annual Data Report.

Median wait-time for a kidney transplant, as displayed in Figure 7.10, was estimated using a cumulative incidence approach, with death considered as a competing risk. The cohort comprised patients with ESRD, as defined in Figures 7.1 and 7.2. Patients were followed from initial waitlisting until the earliest of transplant, waitlist removal, death, or December 31, 2019. Median time to kidney transplant was defined by the time at which the estimated cumulative incidence of transplant reached 50%.

In Figure 7.11 and elsewhere, kidney transplant rates were estimated as transplants in all dialysis patients, regardless of waitlisting, and without limitation on maximum age. This approach deviates from the approach used by the SRTR, which reports the transplant rate among waitlisted patients.

In Figures 7.15, 7.16, and 7.17, rates of kidney donation are based on a denominator of all deaths in patients aged <75 years, according to data from the Centers for Disease Control and Prevention.

In Figure 7.20, Medicare Part D enrollment was identified at the date of kidney transplant. In Figure 7.21, the cohort comprised all patients who carried Medicare Parts A, B, and D during the first year post-transplant, so that medication expenditures in both Parts B and D could be tallied.

In Figures 7.22, 7.23, and 7.24, patients are followed from the date of transplant until the outcome of interest, with censoring at December 31, 2019. For models of graft failure and the composite of return to dialysis or re-transplant, adjustment factors included age, sex, race/ethnicity, primary cause of ESRD, and first versus subsequent transplant. For models of death, adjustment factors included all the aforementioned factors, except for first versus subsequent transplant.

In Figure 7.25, patients were followed from the date of initiation of dialysis following graft failure for up to 3 years or until the earliest of receipt of a kidney transplant or death.
The number of ESRD patients who were added to the waitlist for a kidney transplant during each year from 1999 to 2019 is displayed in Figure 7.1. After an increase between 1999 and the mid 2000s, the number of patients added to the waitlist stabilized between 24,000 and 26,000 per year through 2017. However, that number began a sharp increase in 2018 and increased again in 2019 to a new high of 28,539. First-time listings increased by 16.2% between 2017 and 2019, reaching an all-time high of 24,904 patients, and subsequent listings increased by 9.6%.

The sharp increase in patients added to the waitlist from 2017 to 2019 occurred in all age groups except children, for whom the number actually decreased during this interval. Between 2017 and 2019, the number of Black patients who were added to the waitlist increased by 16.6%, whereas the corresponding increase in White patients was 11.2%. Between 2017 and 2019, the number of Hispanic or Latino patients who were added to the waitlist increased by 19.2%.
At the end of 2019, 78,690 patients with ESRD were on the waitlist for a kidney transplant (Figure 7.2). This number decreased only 1.2% since 2018 but by 11.3% since the all-time high in 2014. Between 2018 and 2019, the number of patients on the waitlist for a kidney transplant decreased slightly in all age groups except those aged 65-74 years. Between 2018 and 2019, the number of Black patients who were on the waitlist for a kidney transplant decreased 2.9%, whereas the corresponding decrease in White patients was only 1.6%, and the number of Hispanic patients actually increased by 1.2%.

The number of patients who were on the waitlist with active status decreased less than the total number on the list. The decrease from 51,808 to 51,228 between 2018 and 2019 was part of a small absolute drop since the peak in 2014-2015. The number of patients who were on the waitlist with inactive status decreased by 1.4% between 2018 and 2019 to 27,462 patients. That count is 20% lower than the all-time high of 34,697 patients in 2014 and is the lowest end-of-year count since 2009. The number of patients who were on the waitlist with inactive status decreased similarly across age groups. Between 2017 and 2018, the number of Black patients who were on the waitlist with inactive status decreased by 6.8%, whereas the corresponding decrease in White patients was only 1.0%, and the number of Hispanic and Asian patients on the waitlist with inactive status increased 2.4% and 9.4%, respectively.

Data source: USRDS ESRD database and OPTN waitlisting history.
Five percent of incident ESRD patients who initiated dialysis in 2019 had been waitlisted before the onset of ESRD (Figure 7.3). Rates of preemptive waitlisting (i.e., waitlisting before ESRD onset) increased between 2000 and 2019 and have approximately doubled since 2005. Preemptive waitlisting was more common among younger than older individuals. In patients aged 0-17 years who initiated dialysis in 2019, 13.7% had been preemptively wait-listed, whereas corresponding values were 8.9%, 6.8%, 4.9%, and 0.8% in patients aged 18-44, 45-64, 65-74, and ≥75 years, respectively. Asian patients were consistently more likely to be preemptively waitlisted than members of other races. In 2019, the prevalence of preemptive waitlisting among Asian patients was 7.9%, whereas in Black, White, and Hispanic patients, the prevalence of preemptive waitlisting was 4.2%, 5.5%, and 4.4%, respectively.
The percentage of prevalent ESRD patients who were undergoing dialysis and on the waitlist for a kidney transplant reached 13.1% at the end of 2019 (Figure 7.4), continuing a decrease that began in 2013, when the percentage was 17.6%. Between 2018 and 2019, decreases in the percentage of prevalent patients who received dialysis and were on the transplant waitlist were apparent in all subgroups defined by age, sex, and race/ethnicity.

The percentage of prevalent ESRD patients who were undergoing dialysis and on the waitlist for a kidney transplant reached 13.1% at the end of 2019 (Figure 7.4), continuing a decrease that began in 2013, when the percentage was 17.6%. Between 2018 and 2019, decreases in the percentage of prevalent patients who received dialysis and were on the transplant waitlist were apparent in all subgroups defined by age, sex, and race/ethnicity.

Figure 7.5 Percentage of incident ESRD patients who were waitlisted or received a kidney transplant within 1, 3, or 5 years

Data source: USRDS ESRD database and OPTN waitlisting history. The outcome of waitlisting or transplant includes preemptive transplant on the date of ESRD diagnosis.
Among patients with incident ESRD in 2018, 7.6% were waitlisted before ESRD onset or received a kidney transplant as their initial modality of ESRD treatment (Figure 7.5). Although this percentage remains low, it has increased steadily since 1999 when it was 4.0%. The percentage of patients preemptively waitlisted or receiving a preemptive transplant was highest among patients aged 0-17 years at ESRD onset at 33.5% and was progressively lower in older age groups. By race/ethnicity, Asian patients were most likely to be preemptively waitlisted or to receive a preemptive kidney transplant (10.5%), and Native American patients were least likely (3.5%).

Among patients with incident ESRD in 2018, 13.7% were waitlisted or received a kidney transplant within 1 year. There was a gradient across age groups, with 65.1% of those aged 0-17 waitlisted or receiving a transplant within 1 year, 30.6% of those aged 18-44 years, 18.0% of those aged 45-64 years, and lower percentages in older age groups. By race and ethnicity, the percentage waitlisted or receiving a transplant was highest in Asian patients (22.3%), intermediate in White patients (14.0%) and lowest in Native American patients (7.1%). Although this metric increased slightly from 13.2% among patients with incident ESRD in 2017, it has changed little since 1999. The largest increase was among patients aged 0-17 years, 65.1% of whom were waitlisted within 1 year compared with 59.8% of those initiating in 2017.

Among patients with incident ESRD in 2016, the percentage waitlisted or receiving a kidney transplant within 3 years was 18.6%. As expected, the percentage was highest among younger individuals, reaching 80.0% among patients aged 0-17 years. Hispanic patients were slightly more likely to be waitlisted or receive a transplant within 3 years (20.9%) than White (17.6%) or Black (17.3%) patients.

Overall, among patients with incident ESRD in 2014, 20.4% were waitlisted or received a transplant within 5 years. This percentage was only modestly higher than the percentage waitlisted or receiving a transplant within 3 years.

Data source: USRDS ESRD database and OPTN waitlisting history. The outcome of waitlisting or transplant includes preemptive transplant on the date of ESRD diagnosis.
Figure 7.6 Cumulative incidence of waitlisting and death up to three years after initiation of dialysis

Data source: USRDS ESRD database and OPTN waitlisting history.

Figure 7.6 shows the cumulative incidence of waitlisting or death over 3 years after onset of ESRD. The cumulative incidence of death at 6 months (11.6%) was 4.3 times that of waitlisting (2.7%). Thereafter, the cumulative incidence of death approached and remained approximately 3 times than that of waitlisting. As expected, the cumulative incidence of waitlisting decreased and cumulative incidence of death increased with age. The cumulative incidence of waitlisting exceeded that of death for those aged 0-17 and 18-44 years, whereas the cumulative incidence of death exceeded that of waitlisting for older age groups. Although men and women had a similar risk of death, women were less likely to be waitlisted than men. For example, the cumulative incidence of waitlisting among women was 7.0% at 18 months, and the corresponding percentage was 9.3% among men. After 3 years, the cumulative incidence was 9.9% among women and 13.1% among men. The cumulative incidence of waitlisting was lower among White patients than among other race/ethnicity groups, a phenomenon that was driven in large part by higher mortality among White patients. Among White patients, the cumulative incidence of waitlisting over 3 years was 9.7%, the corresponding cumulative incidence among Black, Hispanic, and Asian patients was 12.5%, 15.7%, and 18.2%, respectively. Almost half of White patients died over 3 years (46.9%) compared with about one third of Black patients (31.2%), and a little more than one quarter of Hispanic (27.4%) and Asian patients (27.1%).
Figure 7.7 Cumulative incidence of death or transplant after waitlisting

Figure 7.7 shows the cumulative incidence of receiving a kidney transplant and of dying at 1, 3, and 5 years among the subset of patients with ESRD who are placed on the waitlist for a kidney transplant. Almost one third received a transplant within 1 year (32.9%), and 51.8% had received a kidney transplant by 5 years. The incidence of death was much lower in this select subset than in the non-waitlisted dialysis population. Figure 7.8 provides additional information on outcomes within 5 years of registration on the kidney transplant waitlist.

Figure 7.8 Yearly distribution of living donor transplantation, deceased donor transplantation, death, and removal from the waitlist after initial waitlisting, 2010-2014

Data source: USRDS ESRD database and OPTN waitlisting history.
The yearly distribution of outcomes after initial waitlisting is displayed in Figure 7.8; the cohort comprised patients who were initially waitlisted between 2010 and 2014. At 1 year after waitlisting, 11.2% of patients had received a living donor transplant, 8.1% had received a deceased donor transplant, 2.4% had died, and 3.3% had been removed from the waitlist. At 3 years after waitlisting, 16.3% had received a living donor transplant, 19.9% had received a deceased donor transplant, 7.4% had died, and 13.8% had been removed from the waitlist. At 5 years after waitlisting, 17.6% had received a living donor transplant, 29.1% received a deceased donor transplant, 11.1% had died, and 22.5% had been removed from the waitlist, and 19.7% remained on the waitlist.

With increasing age, the cumulative probability of transplant increased less rapidly during follow-up, while the cumulative probability of death and of removal from the waitlist increased more rapidly. At 5 years after waitlisting, 88% of patients aged 0-17 years had received a transplant, whereas the corresponding probability was approximately 43.7% in patients aged 45-64 years. At 5 years after waitlisting, roughly 66% of patients with AB blood type had received a transplant, whereas less than 41% of patients with B and O blood types had received a transplant. PRA levels had little influence on 5-year probability of receiving a kidney transplant, although patients with PRA of 20% or higher were more likely to receive a deceased versus living donor transplant.

**Figure 7.9** Rate of cardiovascular hospitalization among Medicare beneficiaries who were waitlisted

Data source: USRDS ESRD database, OPTN waitlisting history, and Medicare claims. Waitlisted patients carried Medicare Parts A and B as primary payer.
The adjusted rate of cardiovascular hospitalization among Medicare FFS beneficiaries who were on the waitlist for a kidney transplant increased steadily (by 22.6% overall) between 2015 and 2019, reaching a high of 422.5 hospitalizations per 1000 patient-years in 2019 (Figure 7.9). Among adults, the year-over-year increase from 2018 to 2019 was largest for the patients aged 18-44 years at 9.5%. Although the rate of cardiovascular hospitalization increased between 2018 and 2019 among most subgroups, it decreased among Native American patients. Patients with diabetes had a rate of cardiovascular hospitalization that was 6.9% higher than those without in 2019.
The median wait-time for a kidney transplant is displayed in Figure 7.10 by year of initial waitlisting. Among patients who were initially waitlisted in 2014, the median wait-time was 51.6 months, slightly lower than the corresponding estimate in the previous year (55.9 months). Median wait-time was 6.6 months in patients aged 0-17 years, whereas in adult patients, median wait-time ranged between 42.3 and 59.5 months across age brackets without a clear gradient by age. The median wait-time was 63.8 months for Black patients who were initially waitlisted in 2014 but only 37.3 months for White patients. The disparity in wait-time experienced by Black patients compared with White patients narrowed from almost 3 years among those waitlisted in 2009 but remained an astonishing 2.2 years for those listed in 2014. Hispanic patients' median wait-time was similar to that of Black patients for those listed in 2009, but wait-time shortened slightly in recent years among Hispanic patients to 56.5 months for those waitlisted in 2014, 7.3 months shorter than the median time for Black patients. Median wait-time was over 5 years for patients with B or O blood types, approximately 3 years for patients with A blood type, and under 2 years for patients with AB blood type.
Figure 7.11  Count and rate of kidney transplants in patients undergoing dialysis

Data source: USRDS ESRD database and OPTN waitlisting history. Rate calculated among all dialysis patients, including patients not waitlisted.
In 2019, the number of kidney transplants increased by 10.2% over 2018, continuing a steady rise that began in 2014 after several years of flat counts and reaching an all-time high of 24,502 (Figure 7.11). Between 2018 and 2019, the number of kidney transplants in patients aged 18-44 years increased 9.1%, whereas corresponding increases in patients aged 45-64 years, 65-74 years, and ≥75 years were 9.2%, 15.9%, and 13.8%, respectively. The number of transplants increased 9.3% in White patients, 11.0% in Black patients, and 9.0% in Hispanic patients.

The number of deceased donor kidney transplants increased 11.8% between 2018 and 2019 to reach an all-time high of 17,586. The number of living donor kidney transplants increased 6.5%, also reaching an all-time high. The number of living donor kidney transplants increased among all age groups except children.

The rate of kidney transplantation among patients with ESRD declined between 2000 and 2014 due to growth in the ESRD population that was not matched by an increase in transplant events. However, transplant rates have been increasing since 2014, driven primarily by an increase in deceased donor transplantation with stable or only slightly increasing rates of living donor transplantation. This pattern was observed across most subgroups. However, the pattern differed among patients aged 0-17 years. In this group, the rate of deceased donor transplants increased throughout the last two decades. The rate of deceased donor transplants declined more among White patients than among Black patients until 2014, eliminating the racial disparity in deceased donor transplantation. However, rates of living donor transplantation remain lower among Black patients than among White patients, perpetuating an ongoing disparity in overall transplantation rate. Rates of living donor transplantation among Hispanic patients are intermediate between the rates for Black and White patients.
Characteristics of kidney transplant recipients are displayed in Figure 7.12. In 2019, 3.2% of recipients were aged 0-17 years, 27.1% were aged 18-44 years, 48.5% were aged 45-64 years, 19.0% were aged 65-74 years, and 2.2% were aged ≥75 years. This distribution represented a slightly older mix of transplant recipients relative to 2018. The percentage of recipients aged ≥65 years has tripled since 1999, while the percentage of recipients aged <45 years decreased by over 60%. The proportion of recipients who were White decreased over the last two decades, with corresponding increases in proportions of Black, Hispanic, and Asian recipients. The percentage of recipients whose cause of kidney disease was diabetes or hypertension has increased since 1999 and is approaching 50%.
Kidney transplantation rates among patients with ESRD in 2019 varied more than threefold among the states, from a minimum of 1.6 transplants per 100 patient-years in HI to a maximum of 7.3 transplants per 100 patient-years in UT (Figure 7.13). Many Mountain and Upper Midwest states had relatively high transplant rates. Rates among patients aged <75 years were higher than overall rates, but the patterns across states did not differ for this younger subset of patients with ESRD.
The number of paired donation transplants increased over the last decade, with a particularly sharp increase between 2017 and 2019, from 703 to 1119, thus reaching an all-time high (Figure 7.14). In turn, the percentage of living donor transplants arising from paired donation increased to 16.2 in 2019. The percentage of transplant centers performing paired donation transplants continues to increase steadily.

Data source: OPTN database.
Figure 7.15 shows the donation rate and the number of deceased kidney donors by decedent age, race, and sex. Donation rates increased in all age groups except those decedents aged ≥65 years. The donation rate increased almost 50% over the last decade among decedents aged 18-44 years. Donation rates were similar among White, Black, and Asian decedents in 2018, but rates increased among White and Asian decedents in 2019 and decreased among Black decedents. The donation rate is much lower for Native American decedents than for decedents in other race groups.

Data source: OPTN database.
Kidney donation rates in 2019 varied more than threefold among states, from a minimum of 4.0 events per 1,000 decedents in MT to a maximum of 15.0 events per 1,000 decedents in DE (Figure 7.16).
Kidney donation rates among decedents who experienced traumatic death are displayed in Figure 7.17. The unadjusted kidney donation rate in 2018 was 61 events per 1,000 decedents aged 0-17 years, 39 events per 1,000 decedents aged 18-44 years, and 18 events per 1,000 decedents aged 45-64 years. These rates have been relatively stable over time. In 2019, donation rates were highest for White decedents and lowest for American Indian or Alaska Native decedents.
The number of patients with a functioning kidney transplant increased to 239,413 at the end of 2019, an increase of 4.5% since 2018 (Figure 7.18). The rate of growth has been greatest for patients aged 45-74 years. The number of patients aged 65-74 years has exceeded the number aged 18-44 years since 2016, and in 2019, the largest population was patients aged 45-64 years.

The percentage of all ESRD patients with a functioning transplant was 29.6% at the end of 2019. Nearly three quarters of pediatric ESRD patients had a functioning transplant. Corresponding percentages were 41.8% in ESRD patients aged 18-44 years, 33.2% in patients aged
45-64 years, 26.7% in patients aged 65-74 years, and 12.8% in patients aged ≥75 years. Those percentages in the older age brackets represented new highs, reflecting the shift towards older age among transplant recipients (Figure 7.12).

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**Figure 7.19** Rate of all-cause, cardiovascular, and infection hospitalization during the first year after transplantation in Medicare beneficiaries, 2015-2018

Data source: USRDS ESRD database and Medicare claims. Patients carried Medicare Parts A and B as primary payer.
Rates of all-cause, cardiovascular-related, and infection-related hospitalization during the first year after kidney transplantation among Medicare FFS beneficiaries who received a transplant between 2015 and 2018 are displayed in Figure 7.19. The all-cause hospitalization rate was 1.3 admissions per person-year; rates of cardiovascular- and infection-related hospitalization were 0.1 and 0.3 admissions per person-year, respectively. Children had higher all-cause (1.8 per person-year) and infection-related (0.5 per person-year) hospitalization rates than any other age group but had very low rates of cardiovascular-related hospitalization (0.03 per person-year). In deceased donor transplant recipients, the all-cause hospitalization rate was 1.3 admissions per person-year, whereas in living donor transplant recipients, the rate was 1.0 admissions per person-year.
Half of transplant recipients in 2019 were enrolled in Medicare Part D (Figure 7.20). In the subset of recipients with Medicare FFS coverage, 71.6% were enrolled in Part D. Overall, Medicare Part D enrollment was more common among older patients than among younger ones, among Black patients than among patients of other race/ethnicity groups, and among deceased versus living donor transplant recipients.
Drug expenditures in Medicare Parts B and D during the first year after kidney transplantation among patients who received a transplant between 2015 and 2018 and were enrolled in Parts A, B, and D are displayed in Figure 7.21. Total drug expenditures were $24,185 per person-year. Immunosuppressant expenditures were $6599 per person-year and almost entirely accumulated in Part B, whereas cytomegalovirus (CMV) agent expenditures were $5580 per person-year and almost entirely accumulated in Part D. Hepatitis C virus (HCV) agents constituted approximately 11% of drug expenditures.

In deceased donor transplants, total drug expenditures were $25,012 per person-year, whereas in living donor transplants, expenditures were $20,171 per person-year. CMV and HCV agent expenditures were higher in deceased donor transplant recipients, as were expenditures for calcimimetics and vitamin D receptor activators. In contrast, complement inhibitor (e.g., eculizumab) expenditures were higher in living donor transplant recipients.
One-year, 5-year, and 10-year graft survival percentages are displayed in Figure 7.22. Living donor graft survival reached all-time highs in the most recent cohorts of transplant recipients. Adjusted 1-year graft survival among living donor transplant recipients in 2018 improved to 97.5%, adjusted 5-year graft survival among recipients in 2014 improved to 86.6%, and adjusted 10-year graft survival among recipients in 2009 improved to 65.5%.

Adjusted 1-year graft survival among deceased donor transplant recipients in 2018 was 92.7%, adjusted 5-year graft survival among recipients in 2014 was 77.6%, and adjusted 10-year graft survival among recipients in 2009 was 49.5%.
One-year, 5-year, and 10-year patient survival percentages are displayed in Figure 7.23. Adjusted 1-year patient survival among living donor transplant recipients in 2018 was 99.2%, adjusted 5-year patient survival among recipients in 2014 was 87.7%, and adjusted 10-year patient survival among recipients in 2009 was 61.0%.

Adjusted 1-year patient survival among deceased donor transplant recipients in 2018 improved to 95.5%, adjusted 5-year patient survival among recipients in 2014 was stable at 79.3%, and adjusted 10-year patient survival among recipients in 2013 improved to 49.5%.

Data source: USRDS ESRD database.

Figure 7.24 Adjusted rates of graft failure, and death with functioning graft within 3 years, 2008, 2012, 2016

Data source: USRDS ESRD database.
Figure 7.24 shows rates of overall graft failure and of death with a functioning graft within 3 years among incident transplant recipients in 2008, 2012, and 2016. The overall graft failure rate decreased from 5.8 per 100 patients with a functioning graft in 2008 to 4.3 per 100 patients in 2016. The rate of death with a functioning graft also decreased from 2.1 per 100 patients to 1.7 per 100 patients.

Figure 7.25  Cumulative incidence of death or retransplant after transplant failure during 2009-2016, within 3 years

![Graph showing cumulative incidence of death or retransplant after transplant failure between 2009 and 2016. Patients treated with peritoneal dialysis (PD) were more likely to receive a subsequent kidney transplant than to die at any time over the ensuing 3 years, whereas the opposite was true for patients treated with hemodialysis (HD). Patients <45 years of age treated with PD were more likely to receive a subsequent transplant at all time points. For those aged 45-64 years, the cumulative incidence of death or receipt of a transplanted kidney were similar over the first 2 years, but the risk of death was higher in the third year. Patients in older age groups were much more likely to die than receive a transplanted kidney. The pattern was similar among those treated with HD, except that the incidence of death was higher than that of transplant even in the first 2 years for patients aged 45-64 years. Black patients were less likely to die within 3 years of graft failure than White patients, but they were also less likely to receive a subsequent kidney transplant. The relative incidence of death versus transplant was higher among Black patients. Whereas White patients treated with HD were approximately twice as likely to die within 3 years as to receive a kidney transplant, Black patients were approximately 4 times as likely to die as to receive a transplant.]

Data source: USRDS ESRD database.
Summary

Additions to the waitlist increased sharply in 2018 and 2019 after a previous period of relative stability. This recent increase may be related in part to the Advancing American Kidney Health Executive Order (U.S. Department of Health and Human Services, 2019) and the introduction of new payment models that will incentivize waitlisting (Department of Health and Human Services, 2019). Although these models were not implemented in 2019, they were widely disseminated and discussed in that year. Nevertheless, these new models may not explain the increase in waitlisting that occurred in 2018. Despite the higher number of patients being placed on the waitlist for a kidney transplant, the total number of patients on the waitlist decreased from 2014 to 2019. This decrease appears to be driven by an increase in the rate of deceased donor transplantation, a smaller increase in living donor transplantation, and a decrease in the number of patients listed with inactive status.

Unfortunately, there has been little change in the last 3 years in the percentage of incident dialysis patients who were waitlisted prior to ESRD (5%) or in the percentage who are waitlisted or receive a kidney transplant within the first year after starting dialysis (approximately 13.7%). More alarmingly, the percentage of prevalent dialysis patients on the kidney transplant waiting list has declined since 2013 and was only 13.1% in 2019.

Although wait-times remain long, the median wait-time among ESRD patients who were initially waitlisted for a kidney transplant in 2014—the last year for which a median wait-time can be calculated—decreased slightly, relative to earlier cohorts of ESRD patients who were waitlisted. This hopeful development may be a result of the increasing transplantation rates among dialysis patients over the last few years. Nevertheless, efforts to increase the supply of living and deceased organ donors are urgently needed.

The number of kidney transplants performed in 2019 hit an all-time high of 24,502. The rate of kidney transplantation also increased for the last 5 years after a prolonged period in which the transplant rate declined because of higher growth in the dialysis population than in the number of transplants. Despite an increase in the number of paired donations, with more than half of centers participating in paired donation programs in 2019, the increase in transplantation was driven mainly by an increase in deceased donor transplants. Although transplant rates are higher among younger than older individuals, the number of older individuals receiving transplants is much higher because of the age distribution of the ESRD population. The number of transplants has increased most in the older age groups, and as a result, transplant recipients in recent years have been older than in the past on average. The steady increase in rates of cardiovascular hospitalizations among waitlisted patients between 2014 and 2019 may be a function of the aging of the transplant waiting list (reflecting the dialysis population itself).

Racial disparities in receipt of a transplanted kidney persist, but some metrics have improved. Although the transplantation rate among all dialysis patients remains higher for White than for Black patients, the difference has narrowed dramatically since 1999, mainly as a result of a larger decrease in the rate among White patients. However, the patterns of disparity for deceased donor and living donor transplantations are remarkably different. The disparity in access to deceased donor transplants has been completely eliminated for the last 4-5 years, beginning in 2014 when the Kidney Allocation System was changed to allow patients to begin to accrue waittime for deceased donor kidney transplantation beginning from the time of dialysis initiation (or preemptive waitlisting) rather than from the time of listing. However, Black patients with ESRD have better survival than their White counterparts and a lower burden of comorbidity and potential contraindications to transplantation (Ku et al., 2020). Thus, lower rates of waitlisting and similar rates of deceased donor kidney transplantation among Black patients compared with White patients likely represent disparity. In other words, differences in case mix suggest that rates of waitlisting and deceased donor transplantation should actually be higher among Black than among White patients.

In addition, a large disparity in receipt of living donor kidney transplants persists, with rates over 75% lower among Black than among White patients. Wait-times were also substantially longer for Black transplant recipients than for White recipients, which may partially reflect the disparity in living donor transplantation among Black patients. In this year’s ADR, we include a special supplement on racial/ethnic disparities in care and outcomes of patients with ESRD. In this supplement, we examine the contribution of social determinants of health to the lower wait-list access and lower living donor transplant rates among Black patients receiving dialysis.

Outcomes following receipt of a kidney transplant continue to improve for deceased donor transplants and remain excellent for living donor transplant recipients. Nevertheless, graft failure continues to occur, and we examined the incidence of death and receipt of a new kidney transplant after graft failure in this year’s ADR. Rates of death were much lower and rates of receipt of a new kidney transplant much higher among patients who were performed PD after graft failure than among those treated with HD. Unfortunately, racial disparities in access to a new kidney transplant were observed even though all members of this population had successfully navigated at least 1 kidney transplant. Although Black patients had lower mortality after graft failure, they also had lower rates of receipt of a new kidney transplant. After 3 years, the rate of receipt of a new kidney transplant among Black patients was approximately half that of White patients. Thus, there is a surprising level of racial disparity in access to transplantation even among patients who have already been followed in a kidney transplant clinic. This issue needs further exploration because disparities are presumably independent of referral for transplant evaluation. Insight into the causes of this disparity may have implications for first-time transplant candidates as well, who may face barriers both at the level of referral and in the transplant evaluation process.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 7. Transplantation, located here: https://adr.usrds.org/2021/end-stage-renal-disease/7-transplantation
References


ESRD among Children and Adolescents

Highlights

- The adjusted incidence of ESRD in children decreased from 12 per million population (pmp) in 2009 to 11 pmp in 2019, but the rate was relatively unchanged since 2014. Counts and adjusted prevalence of ESRD among children increased between 2009 and 2019, primarily due to an increase in the prevalence of kidney transplant recipients (Figure 8.1).

- The adjusted prevalence of ESRD in children remains higher in Black children than among children of other race/ethnicity groups (Figure 8.2).

- At onset of ESRD, treatment with peritoneal dialysis (PD) was less common among children who were older at dialysis initiation (Figure 8.3). White children were more than twice as likely to receive a kidney transplant as Black children (25.2% versus 10.5%). A substantially higher percentage of Black (55.4%), compared with White (34.5%) children initiated hemodialysis (HD). Hispanic children received a kidney transplant at ESRD onset less often than did White children (12.2% versus 25.2%) and initiated HD more often and PD less often than White children. Use of HD at the time of dialysis initiation was also more common for children with glomerulonephritis (GN) compared with children with congenital anomalies of the kidney and urinary tract (CAKUT) or cystic/hereditary/congenital diseases.

- Approximately 10% of children between the ages of 13-17 years of age received care from an adult nephrologist in 2019 (Figure 8.5). Receipt of care from an adult nephrologist was more common in children living in the most rural areas of the U.S.

- Adjusted rates of hospitalization for non-surgical causes were higher in children aged <6 years of age than in children 6-12 and 13-17 years of age (Figure 8.7). Hospitalization for non-surgical related causes was more common in children treated with HD compared with those treated with PD or kidney transplantation.

- Rates of hospitalization for infection in children in the year after ESRD onset increased among children <6 years of age. In contrast, rates decreased for children aged 6-17 years (Figure 8.8). Adjusted rates of hospitalization for infection among children treated with PD decreased over time.

- Non-surgical hospital admissions were more common than other types of hospitalization for all age groups, followed by non-access-related surgical admissions. Children receiving HD spent an average of 8 days in the hospital, children receiving PD an average of 14.2 days, and children with a kidney transplant an average of 7.7 days per person-year.

- Adjusted mortality in the first year of ESRD treatment was highest in children aged <1 year and decreased with age (Figure 8.10). Adjusted mortality in the first year of treatment for ESRD decreased since 2002, but remained highest for children treated with PD, followed by HD, and lowest for kidney transplant recipients.

- Five-year survival probability among incident pediatric patients with ESRD was 0.80 in children aged <1 year, 0.90 in children aged 1-5 years, and 0.96 in children aged ≥6 years (Figure 8.11). Survival probability at 5 years was lower for children receiving HD and highest in children who received a kidney transplant.

- Between 2010-2019, nearly 30% of deaths for children with ESRD were of unknown cause (Figure 8.12), with unknown cause of death particularly high (57.4%) among transplant recipients.

- Among children with prevalent ESRD who are on the waitlist for a kidney transplant, the percentage with a tunneled catheter was 80%, similar to the percentage with a tunneled catheter among children who were not yet on the kidney transplant waitlist (Figure 8.13).

- Among children with incident ESRD, the percentage receiving a preemptive kidney transplant was stable between 2009-2019 (Figure 8.14a). Preemptive waitlisting rates increased between 2009-2019 (Figure 8.14b). The median wait-time for a kidney-alone transplant for children increased from 156 days in 2009 to 196 days (Figure 8.14c).

- Deceased donor transplantation rates among children with ESRD increased between 2009-2019, while living donor transplantation rates decreased between (Figure 8.15).

- The median time to transplantation in children receiving dialysis was 22.5 months (Figure 8.16). This time was longest in children 0-5 years of age (29.8 months) and in Black children (30.2 months).

- The most prevalent type of kidney replacement modality in adult survivors of childhood ESRD was transplant, followed by HD (Figure 8.19).
Introduction
This chapter focuses on children with ESRD. We begin by reporting counts and rates of incident and prevalent ESRD in children, overall and by age, sex, and race/ethnicity, between 2009 and 2019, followed by distributions of treatment modality at ESRD onset and causes of ESRD in children. We next examine hospitalization, reporting per person per year rates of hospitalization by category (surgical dialysis access-related, surgical non-access-related, and non-surgical), hospitalization for infection over two eras (2004-2008 and 2014-2018), and hospital days per annum by category.

We then move to mortality, showing trends in first-year mortality among children with incident ESRD and 5-year survival probabilities in children by age and treatment modality. Causes of death in children with ESRD are reported for 2010-2019. Next, we illustrate the distribution of vascular access type used among children with prevalent HD in 2019.

Finally, we report details on transplantation and associated outcomes: preemptive kidney transplantation, waitlisting for a kidney transplant prior to ESRD onset, median waitlist time for a kidney-alone transplant, median waitlist time before kidney transplantation, and outcomes in children who received a kidney transplant and adult survivors of childhood-onset ESRD.

Methods
The analyses presented in this chapter utilize data from the Centers for Medicare & Medicaid Services (CMS), the Organ Procurement and Transplantation Network (OPTN), and the End Stage Renal Disease Quality Reporting System (EQRS) clinical extracts, all of which are used to create the ESRD Database. Details of these sources are described in the Data Sources section of the ESRD Analytic Methods. Again in this year’s ADR, we considered only children (age <18 years, as opposed to young adults up to age 22) for the analyses because regulations and policies regarding transplantation differ between children and adults. Because the pediatric ESRD population is small, many analyses in this chapter make use of cohorts of incident or prevalent patients that span more than a single year, and many outcomes are not shown for small race/ethnicity groups. Analyses that focus on stature and body mass index (BMI) use age-specific norms. Short stature is defined as having height below the 3rd percentile for age. Normal BMI is defined as having a z-score above -1.64 and ≤1.64 (or between the 5th and 95th percentile), with children with z-scores ≤-1.64 considered underweight and those with z-scores >1.64 considered obese (Ku et al., 2017). The analytical methods used in generation of the study cohorts and figures in this chapter can be found in the section on Chapter 8 within the Analytical Methods used in the ESRD Volume.
The number of children with incident ESRD decreased between 2009 and 2019 (Figure 8.1). The number of children starting HD was relatively stable over this period, while the number of children starting PD and receiving a kidney transplant as the initial treatment modality decreased. The number of children with prevalent ESRD increased between 2009 and 2019, driven mainly by a slight increase in the number of children with a functioning kidney transplant. The overall number of children with ESRD continues to grow.

The adjusted rate of incident ESRD decreased from 12 pmp in 2009 to 11 pmp in 2019. The incidence of HD was relatively stable over this period, while the incidence of PD and kidney transplant decreased. The adjusted prevalence of ESRD among children increased from 71 to 75 pmp, which was driven mostly by an increase in the prevalence of children with a functioning kidney transplant.
Figure 8.2 Counts and rates of incident and prevalent ESRD in children, by patient characteristics, 2009-2019

Data source: USRDS ESRD database. ESRD patients aged 0-17 years, 2009-2019.
Overall, the incidence of ESRD among children continues to decline while the prevalence of continues to increase (Figure 8.2). Adjusted ESRD incidence was highest among children aged <1 year and 13-17 years and lower for ages 1-12 years. Black children had the highest ESRD incidence, followed by Hispanic children. The incidence of ESRD was substantially higher among boys than girls.

The adjusted prevalence of ESRD increased with age. Black children had the highest prevalence of ESRD by a substantial margin compared with any other group. Asian children and children of other race/ethnic groups had the lowest prevalence of ESRD. The adjusted prevalence of ESRD was nearly 50% higher in boys than in girls.

**Figure 8.3** Distribution of treatment modality in children at ESRD onset, by patient characteristics, 2015-2019

<table>
<thead>
<tr>
<th>Age (Years)</th>
<th>Percentage</th>
<th>By Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>75</td>
<td></td>
</tr>
<tr>
<td>6-12</td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>13-17</td>
<td>25</td>
<td></td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD database. Incident patients with ESRD aged 0-17 years, 2015-2019. Abbreviations: CH/C: cystic/hereditary/congenital diseases; CAKUT, congenital anomalies of the kidney and urinary tract; GN, glomerulonephritis.
The distribution of modality at ESRD onset among children in 2015-2019 is shown by age, race/ethnicity, BMI, and cause of ESRD in Figure 8.3. Among children aged <1 year, 92.6% initiated PD. In the older age groups, approximately 1 in 5 received a preemptive kidney transplant, but the percentage initiating PD decreased and the percentage initiating HD increased with age. More than twice as many children aged 13-17 years initiated HD as PD. White children received a kidney transplant more than twice as often as Black children (25.2% versus 10.5%). A substantially higher percentage of Black children initiated HD compared with White children (55.4% versus 34.5%). For all children who were not White, HD was at least 3 times as common as preemptive transplant as the initial treatment modality (whereas it was only 1.4 times as common for White children). Underweight children received a kidney transplant less often than children in higher BMI categories, including obese children. Children with congenital causes of ESRD received a kidney transplant at ESRD onset much more often than did children with a primary or secondary GN. Children with GN also initiated HD much more often than children with non-GN causes of ESRD. These differences were likely driven primarily by differences in age of ESRD onset.
CAKUT was the most common cause of incident ESRD among children aged <1 year (54.9%) and became less common with advancing age (Figure 8.4). In contrast, primary and secondary GNs (combined) as the cause of incident ESRD increased from 4.7% of children aged <1 year to 35.8% of children aged 13-17 years.

Data source: USRDS ESRD database. ESRD incident patients aged 0-17 years, 2015-2019.
Table 8.1 Characteristics of children with incident ESRD, by primary cause of ESRD, 2015-2019

<table>
<thead>
<tr>
<th>Primary Cause of ESRD</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All Etiologies</strong></td>
<td>4,218</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Primary Glomerular Disease</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glomerulonephritis (GN) (histologically not examined)</td>
<td>206</td>
<td>4.9</td>
</tr>
<tr>
<td>Focal glomerulosclerosis, focal sclerosing GN</td>
<td>487</td>
<td>11.5</td>
</tr>
<tr>
<td>Membranous nephropathy</td>
<td>10</td>
<td>0.5</td>
</tr>
<tr>
<td>Membranoproliferative GN (MPGN) type 1, diffuse MPGN</td>
<td>16</td>
<td>0.4</td>
</tr>
<tr>
<td>Dense deposit disease, MPGN type 2</td>
<td>13</td>
<td>0.3</td>
</tr>
<tr>
<td>IgA nephropathy, Berger's disease (proven by immunofluorescence)</td>
<td>22</td>
<td>0.5</td>
</tr>
<tr>
<td>With lesion of rapidly progressive GN</td>
<td>33</td>
<td>0.8</td>
</tr>
<tr>
<td>Other proliferative GN</td>
<td>91</td>
<td>2.2</td>
</tr>
<tr>
<td><strong>Secondary Glomerular Disease</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lupus erythematosus (SLE nephritis)</td>
<td>111</td>
<td>2.6</td>
</tr>
<tr>
<td>Hemolytic uremic syndrome</td>
<td>75</td>
<td>1.8</td>
</tr>
<tr>
<td>Polyarteritis and other vasculitis</td>
<td>58</td>
<td>1.4</td>
</tr>
<tr>
<td>Associated vasculitis</td>
<td>72</td>
<td>1.7</td>
</tr>
<tr>
<td><strong>CAKUT</strong></td>
<td>1,244</td>
<td>29.5</td>
</tr>
<tr>
<td>Congenital obstructive uropathies</td>
<td>474</td>
<td>11.2</td>
</tr>
<tr>
<td>Renal hypoplasia, dysplasia, oligonephronia</td>
<td>643</td>
<td>15.2</td>
</tr>
<tr>
<td>Chronic pyelonephritis, reflux nephropathy</td>
<td>127</td>
<td>3.0</td>
</tr>
<tr>
<td><strong>Cystic/Hereditary/Congenital Diseases</strong></td>
<td>525</td>
<td>12.4</td>
</tr>
<tr>
<td>Polycystic kidneys, adult type (dominant)</td>
<td>16</td>
<td>0.4</td>
</tr>
<tr>
<td>Polycystic, infantile (recessive)</td>
<td>117</td>
<td>2.8</td>
</tr>
<tr>
<td>Medullary cystic disease, including nephronophthisis</td>
<td>78</td>
<td>1.8</td>
</tr>
<tr>
<td>Hereditary nephritis, Alport syndrome</td>
<td>53</td>
<td>1.3</td>
</tr>
<tr>
<td>Cystinosis</td>
<td>39</td>
<td>0.9</td>
</tr>
<tr>
<td>Primary oxalosis</td>
<td>16</td>
<td>0.4</td>
</tr>
<tr>
<td>Congenital nephrotic syndrome</td>
<td>93</td>
<td>2.2</td>
</tr>
<tr>
<td>Other (congenital malformation syndromes)</td>
<td>98</td>
<td>2.3</td>
</tr>
<tr>
<td><strong>Tubulointerstitial Diseases</strong></td>
<td>189</td>
<td>4.5</td>
</tr>
<tr>
<td>Chronic interstitial nephritis</td>
<td>85</td>
<td>2.0</td>
</tr>
<tr>
<td>Acute interstitial nephritis</td>
<td>17</td>
<td>0.4</td>
</tr>
<tr>
<td>Tubular necrosis</td>
<td>83</td>
<td>2.0</td>
</tr>
<tr>
<td><strong>Transplant Complications</strong></td>
<td>64</td>
<td>1.5</td>
</tr>
<tr>
<td>Other transplant complication</td>
<td>60</td>
<td>1.4</td>
</tr>
<tr>
<td><strong>Diabetes</strong></td>
<td>12</td>
<td>0.3</td>
</tr>
<tr>
<td><strong>Neoplasms/Tumors</strong></td>
<td>31</td>
<td>0.7</td>
</tr>
<tr>
<td>Renal tumor</td>
<td>29</td>
<td>0.7</td>
</tr>
<tr>
<td><strong>Hypertensive/Large Vessel Disease</strong></td>
<td>60</td>
<td>1.4</td>
</tr>
<tr>
<td>Renal artery stenosis</td>
<td>16</td>
<td>0.4</td>
</tr>
<tr>
<td>Renal artery occlusion</td>
<td>43</td>
<td>1.0</td>
</tr>
<tr>
<td><strong>Miscellaneous Conditions</strong></td>
<td>584</td>
<td>13.8</td>
</tr>
<tr>
<td>Acquired obstructive uropathy</td>
<td>182</td>
<td>4.3</td>
</tr>
<tr>
<td>Unspecified with renal failure</td>
<td>90</td>
<td>2.1</td>
</tr>
<tr>
<td>Traumatic or surgical loss of kidney(s)</td>
<td>47</td>
<td>1.1</td>
</tr>
<tr>
<td>Other renal disorders</td>
<td>231</td>
<td>5.5</td>
</tr>
<tr>
<td>Nephropathy caused by other agents</td>
<td>30</td>
<td>0.7</td>
</tr>
<tr>
<td><strong>Etiology Uncertain</strong></td>
<td>143</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Etiology Missing</strong></td>
<td>137</td>
<td>3.2</td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD database. ESRD incident patients aged 0-17 years, 2015-2019
A comprehensive list of causes of incident ESRD among children is presented in Table 8.1. CAKUT was the most common cause of ESRD, followed by primary glomerular disease. Focal segmental glomerular sclerosis was the most common of the primary GN, accounting for more than half of the total. Renal hypoplasia, dysplasia, or oligonephronia was the most common type of CAKUT. Diabetes, neoplasms and tumors, and hypertensive/large vessel disease were relatively uncommon causes of incident ESRD in children. Children with primary and secondary GN had a later onset of ESRD on average, whereas those with CAKUT had a younger onset. CAKUT was more common among White than non-White children, whereas GN was more common among Black and Hispanic than among White children.

### Table 8.1 Characteristics of children with incident ESRD, by primary cause of ESRD, 2015-2019

<table>
<thead>
<tr>
<th>Primary Cause of ESRD</th>
<th>&lt;1</th>
<th>1-5</th>
<th>6-12</th>
<th>13-17</th>
<th>Female</th>
<th>Male</th>
<th>White</th>
<th>Black</th>
<th>Hispanic</th>
<th>Asian</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Etiologies</td>
<td>11.5</td>
<td>14.9</td>
<td>28.0</td>
<td>45.5</td>
<td>42.7</td>
<td>57.3</td>
<td>45.9</td>
<td>19.9</td>
<td>27.1</td>
<td>3.9</td>
<td>3.2</td>
</tr>
<tr>
<td>Primary Glomerular Disease</td>
<td>2.1</td>
<td>15.2</td>
<td>27.8</td>
<td>54.0</td>
<td>49.6</td>
<td>50.4</td>
<td>36.2</td>
<td>27.4</td>
<td>28.8</td>
<td>5.3</td>
<td>3.4</td>
</tr>
<tr>
<td>Secondary Glomerular Disease</td>
<td>1.2</td>
<td>12.1</td>
<td>28.6</td>
<td>58.1</td>
<td>68.1</td>
<td>31.9</td>
<td>38.6</td>
<td>23.0</td>
<td>30.4</td>
<td>2.4</td>
<td>5.6</td>
</tr>
<tr>
<td>CAKUT</td>
<td>21.5</td>
<td>16.6</td>
<td>26.5</td>
<td>33.4</td>
<td>31.9</td>
<td>66.1</td>
<td>51.0</td>
<td>19.1</td>
<td>24.1</td>
<td>2.6</td>
<td>3.2</td>
</tr>
<tr>
<td>Cystic/Hereditary/Congenital Diseases</td>
<td>13.9</td>
<td>13.5</td>
<td>31.0</td>
<td>41.5</td>
<td>38.9</td>
<td>61.1</td>
<td>54.1</td>
<td>12.2</td>
<td>27.2</td>
<td>4.2</td>
<td>2.3</td>
</tr>
<tr>
<td>TubuloInterstitial Diseases</td>
<td>8.5</td>
<td>12.7</td>
<td>27.5</td>
<td>51.3</td>
<td>47.1</td>
<td>52.9</td>
<td>54.0</td>
<td>12.2</td>
<td>22.8</td>
<td>7.4</td>
<td>3.7</td>
</tr>
<tr>
<td>Transplant Complications</td>
<td>4.7</td>
<td>15.6</td>
<td>32.6</td>
<td>46.9</td>
<td>45.3</td>
<td>54.7</td>
<td>42.2</td>
<td>34.4</td>
<td>17.2</td>
<td>1.6</td>
<td>4.7</td>
</tr>
<tr>
<td>Diabetes</td>
<td>0.0</td>
<td>0.0</td>
<td>50.0</td>
<td>50.0</td>
<td>16.7</td>
<td>83.3</td>
<td>58.3</td>
<td>25.0</td>
<td>8.3</td>
<td>0.0</td>
<td>8.3</td>
</tr>
<tr>
<td>Neoplasms/Tumors</td>
<td>3.2</td>
<td>45.2</td>
<td>25.6</td>
<td>20.6</td>
<td>45.2</td>
<td>54.8</td>
<td>45.2</td>
<td>16.1</td>
<td>22.6</td>
<td>12.9</td>
<td>3.2</td>
</tr>
<tr>
<td>Hypertensive/Large Vessel Disease</td>
<td>26.7</td>
<td>13.3</td>
<td>21.7</td>
<td>38.3</td>
<td>45.0</td>
<td>55.0</td>
<td>50.0</td>
<td>11.7</td>
<td>38.3</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Miscellaneous Conditions</td>
<td>11.5</td>
<td>10.3</td>
<td>28.9</td>
<td>49.3</td>
<td>40.4</td>
<td>59.6</td>
<td>43.2</td>
<td>18.5</td>
<td>31.3</td>
<td>3.6</td>
<td>3.4</td>
</tr>
<tr>
<td>Etiology Uncertain</td>
<td>7.7</td>
<td>7.9</td>
<td>23.8</td>
<td>61.5</td>
<td>53.1</td>
<td>46.9</td>
<td>38.5</td>
<td>20.3</td>
<td>32.2</td>
<td>7.7</td>
<td>1.4</td>
</tr>
<tr>
<td>Etiology Missing</td>
<td>6.6</td>
<td>16.2</td>
<td>29.9</td>
<td>46.3</td>
<td>38.0</td>
<td>62.0</td>
<td>63.5</td>
<td>12.9</td>
<td>19.0</td>
<td>2.9</td>
<td>0.7</td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD database. ESRD incident patients aged 0-17 years, 2015-2019
Among children 13-17 years receiving dialysis in 2019, 9.7% received care from an adult nephrologist, whereas a very small percentage of younger children received care from adult nephrologists. Children residing in the most rural areas and children treated with HD were more likely to receive care from adult nephrologists than those in more urban areas and those treated with PD.

Data source: Linked Medicaid and USRDS ESRD database. 2019 period prevalent ESRD patients on dialysis, aged 0-17 years.
Figure 8.6 displays the mean hemoglobin level among children and adolescents from 2013-2019. The lack of variation over time and by patient characteristics is remarkable. Despite KDIGO guidelines that recommend maintaining hemoglobin between 11 and 12 g/dL (Kidney Disease: Improving Global Outcomes (KDIGO) Anemia Workgroup, 2012), the mean hemoglobin was routinely below 11 g/dL.
Figure 8.7 Rates of cause-specific hospitalization in children in the year after ESRD onset, by age, and treatment modality, 2014-2018

<table>
<thead>
<tr>
<th>Age (Years)</th>
<th>&lt;1</th>
<th>1-5</th>
<th>6-12</th>
<th>13-17</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>1.9</td>
<td>3.0</td>
<td>1.7</td>
<td>1.4</td>
</tr>
<tr>
<td>&lt;1</td>
<td>2.8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>3.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-12</td>
<td></td>
<td></td>
<td>1.7</td>
<td></td>
</tr>
<tr>
<td>13-17</td>
<td></td>
<td></td>
<td>1.4</td>
<td></td>
</tr>
</tbody>
</table>

Data source: USRDS ESRD database. Incident patients with ESRD aged 0-17 years, 2014-2018. Age, sex, race/ethnicity, and primary cause of ESRD were used in adjusted analyses. Reference: All children with ESRD in 2015.

Overall hospitalization rates were highest among children aged <6 years at 2.8-3.0 per person-year and declined with age thereafter to 1.4 per person-year among children aged 13-17 years (Figure 8.7). The rate of non-surgical hospitalization was over twice as high as the rate of surgical hospitalization overall and for all age groups. The rate of hospitalization for access-related surgical issues was low overall and lowest for children aged 13-17 years. Hospitalization rates were similar among children receiving PD and HD and lower among children with a kidney transplant.
Adjusted rates of hospitalization for infection increased among children aged <6 years between the 2004-2008 and 2014-2018 eras (about 1.1 per person-year in children 0-5 years in the later period) (Figure 8.8) but decreased in children 6 years of age or older. Adjusted hospitalization rates for infection decreased slightly in children receiving PD and remained relatively stable for children receiving HD and for transplant recipients.
Figure 8.9 Hospital days in children in the year after ESRD onset, by type of hospitalization, age, and treatment modality, 2014-2018

Children <6 years of age spent more days in the hospital per person-year than other age groups, regardless of whether the hospitalization was for surgical or non-surgical related issues (Figure 8.9). Hospital days decreased with age, regardless of whether the admission was surgical or non-surgical. Non-surgical admissions were most common for all age groups, followed by non-access-related surgical admissions.
admissions. Children receiving HD spent an average of 8 days in the hospital, children receiving PD an average of 14.2 days, and children with a kidney transplant an average of 7.7 days per person-year. Surgical admissions related to dialysis access were much more common in children receiving PD than in those receiving HD.

**Figure 8.10** First-year mortality rate in children with incident ESRD, by age and treatment modality, 2002-2019

Data source: USRDS ESRD database. Incident patients with ESRD aged 0-17 years, 2002-2019. Age, sex, race/ethnicity, and primary cause of ESRD were used in adjusted analyses. Reference: incident ESRD patients aged 0-17 years in 2013-2015.
Adjusted mortality in the first year of treatment for ESRD was highest in children aged <1 year and decreased with age. Mortality rates were much lower in 2017-2019 than in 2002-2004, particularly for the youngest age group, whose mortality rate declined to a level only slightly above other age groups in the most recent period. As would be expected, first-year mortality was lowest in children with a kidney transplant; mortality rates were similar for children initiating HD and PD between 2017-2019.

Data source: USRDS ESRD database. Incident patients with ESRD aged 0-17 years, 2002-2019. Age, sex, race/ethnicity, and primary cause of ESRD were used in adjusted analyses. Reference: incident ESRD patients aged 0-17 years in 2013-2015.

5-year survival probability among children with incident ESRD, by age and treatment modality, 2010-2014

Data source: USRDS ESRD database. Incident patients with ESRD aged 0-17 years, 2010-2014.
Adjusted 5-year survival probability was lowest in children aged <1 year at the time of ESRD onset, followed by children aged 1-5 years (Figure 8.11. At 5 years, survival probability was 0.80 in children aged <1 year, 0.90 in children aged 1-5 years, and 0.96 in children aged ≥6 years. Survival probability at 5 years was similar among children receiving HD and PD (HD, 0.84; PD, 0.87, but much lower than in children with a kidney transplant (0.93. The 5-year survival on dialysis was substantially higher than survival in the adult population (see Figure 6.7.

The most common cause of death in children with ESRD was a cardiovascular cause, followed by an infectious cause, but the causes of death differed by treatment modality (Figure 8.12). For example, children receiving PD died more commonly of infections than children receiving HD. A large proportion of the causes of death in children were of unknown cause (30%), and the cause was particularly likely to be unknown for children with a kidney transplant.
Children with prevalent ESRD most often used a catheter as their vascular access (Figure 8.13). The percentage receiving HD with a catheter was only slightly lower among children who were not wait-listed for a kidney transplant.

For each year between 2009 and 2019, between 1 in 4 and 1 in 5 children with incident ESRD received a preemptive kidney transplant (Figure 8.14a).
Among children initially treated with dialysis, the percentage who were waitlisted for a kidney transplant before the start of dialysis increased from 8.6% to 15% between 2009 and 2019 (Figure 8.14b). The percentage of children who were waitlisted or transplanted within the first year of ESRD, including by preemptive transplantation, was relatively stable around 50%, although in 2019 this percentage declined to only 46%.

The median time among children on the waitlist for a kidney-alone transplant increased from 156 days in 2009 to 196 days in 2019. Time on the waitlist has not decreased among children since the start of the new Kidney Allocation System (KAS) in December 2014.
The counts of deceased and living donor kidney transplants and counts of preemptive kidney transplants (living or deceased donor) among children are shown for 2009-2019 (Figure 8.14d). Note that in a few cases, the donor source is unclear. The total number of transplants was relatively stable over this period since 2010, with about two thirds of the kidney transplants being from a deceased donor source.

Data source: USRDS ESRD database. ESRD patients aged 0-17 years, 2009-2019.

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**Figure 8.15** Rates of kidney transplantation among children receiving dialysis for ESRD, overall and by donor source and race, 2009-2019

Data source: USRDS ESRD database. ESRD patients aged 0-17 years, 2009-2019.
The rate of kidney transplantation decreased slightly in the first half of the last decade and was lowest in 2014, before increasing after changes to the KAS were made in 2014 (Figure 8.15). The rate of receipt of a deceased donor kidney transplant in children receiving dialysis for ESRD increased slightly over the last decade. The rate of receipt of a deceased donor kidney transplant was roughly twice the rate of receipt of a living donor kidney in 2019. The transplantation rate was lowest among Black children (31 per 100 person-years in 2019) and highest among White children (54.8 per 100 person-years). These differences in the rate of kidney transplantation between Black and White children have not changed since 2010.
Figure 8.16  Time from dialysis initiation to 10%, 25%, and 50% incidence of kidney transplantation in children with incident ESRD, by patient characteristics

Data source: USRDS ESRD database. Incident ESRD patients aged 0-17 years, 2015-2018.

Figure 8.16  Time from dialysis initiation to 10%, 25%, and 50% incidence of kidney transplantation in children with incident ESRD, by patient characteristics

Data source: USRDS ESRD database. Incident ESRD patients aged 0-17 years, 2015-2018.
The time to reach 10%, 25%, and 50% incidence of kidney transplantation among children with incident ESRD was 5.5, 11.3, and 22.5 months, respectively (Figure 8.16). The time to 50% incidence of kidney transplantation was 30 months in children aged 0-5 years and between 19 and 20 months in children ≥6 years. The time to 50% incidence of kidney transplantation varied substantially by race/ethnicity: it was 30 months in Black children, 24 months in children of other races, and 19 months in White children. The time to 50% incidence of transplantation was similar in girls and boys. Time to 50% incidence was markedly longer (54 months) in children with ESRD due to causes other than cystic/hereditary/congenital diseases, CAKUT, and secondary GNs. Time to 50% incidence was similar among children receiving HD (22 months) and PD (24 months).

Figure 8.17 Adjusted one-, five-, and ten-year cumulative incidence of outcomes in children who received a deceased donor kidney transplant, 1999-2018

Data source: USRDS ESRD database. ESRD patients aged 0-17 years, 1999-2018. Incidence of all 3 outcomes are adjusted for race/ethnicity, sex, primary cause of ESRD, and first versus subsequent transplant, and standardized to the characteristics of children who received a deceased donor kidney transplant in 2015.
Figure 8.17  Adjusted one-, five-, and ten-year cumulative incidence of outcomes in children who received a deceased donor kidney transplant, 1999-2018

Data source: USRDS ESRD database. ESRD patients aged 0-17 years, 1999-2018. Incidence of all 3 outcomes are adjusted for race/ethnicity, sex, primary cause of ESRD, and first versus subsequent transplant, and standardized to the characteristics of children who received a deceased donor kidney transplant in 2015.

One-year, 5-year, and 10-year incidence of all-cause kidney transplant (graft) loss (including death) among children after a deceased donor kidney transplant decreased over time (Figure 8.17). The percentage with graft loss at 1 year decreased from 17.3% to 4.5% in the decade between 1999 and 2018; analogous values for 5-year percentages were 37.4% in 1999 and 20% in 2014 (the last year for which data can be reported). There were also decreases in rates of return to dialysis or retransplantation over time, but these were less dramatic in recent years: for example, the 1-year incidence of return to dialysis or retransplantation was relatively unchanged between 2014 and 2018, as was the 5-year rate between 2010 and 2013 (the last year for which rates were available). Rates of death have declined over time.
Figure 8.18  Adjusted one-, five-, and ten-year cumulative incidence of outcomes in children who received a living donor kidney transplant, 1999-2018

Data source: USRDS ESRD database. ESRD patients aged 0-17 years, 1999-2018. Incidence of all 3 outcomes are adjusted for race/ethnicity, sex, primary cause of ESRD, and first versus subsequent transplant, and standardized to the characteristics of children who received a living donor kidney transplant in 2015.
Figure 8.18  Adjusted one-, five-, and ten-year cumulative incidence of outcomes in children who received a living donor kidney transplant, 1999-2018

The percentage of children who experienced all-cause kidney transplant (graft) loss (including death) within 1, 5, and 10 years after a living donor kidney transplant has decreased over time (Figure 8.18). The percentage with graft loss within 1 year decreased from 7.1% to 2.7% in the decade between 1999 and 2018; analogous values for 5-year percentages were 25.9% in 2004 and 12.7% in 2014 (the last year that can be reported). There were also decreases in mortality over time.

Data source: USRDS ESRD database. ESRD patients aged 0-17 years, 1999-2018. Incidence of all 3 outcomes are adjusted for race/ethnicity, sex, primary cause of ESRD, and first versus subsequent transplant, and standardized to the characteristics of children who received a living donor kidney transplant in 2015.

Figure 8.19  Distribution of kidney replacement modality among prevalent adult survivors of ESRD onset in childhood, 1999-2019

In 2019, 24.1% of adults with childhood onset of ESRD were receiving HD, 3.8% were receiving PD, 43.2% had functioning of a first kidney transplant, and 29% had a functioning subsequent kidney transplant. The proportion with a functioning (first or subsequent) transplant increased gradually over the decade.

Data source: USRDS ESRD database. ESRD patients aged ≥18 years, 1999-2019.
Summary
The adjusted incidence of ESRD in children has been relatively unchanged since 2014. The adjusted rate of prevalent ESRD in children increased over the last decade by approximately 6%, due mainly to a 10% increase in prevalent kidney transplant recipients, but has remained relatively stable between 2018-2019.

There are substantial differences in ESRD incidence and in initial kidney replacement therapy (KRT) modality by race among children. Although rates can vary substantially by year, especially in smaller groups such as Asian children, the adjusted incidence was consistently higher in Black than in White children. As a result, there were also large differences in the prevalence of ESRD among race groups.

Treatment of ESRD also differed by race. A much higher percentage of Black, as compared with White, children initiated HD. The rate of receipt of a kidney transplant for White children on dialysis was more than double that of Black children. The time to 50% incidence of kidney transplantation among children treated with dialysis was also substantially longer for Black than for White children.

About 10% of children between 13-17 years of age receive their ESRD care from an adult nephrologist. Treatment by an adult nephrologist was more common in children living in rural areas as opposed to urban areas, and in children receiving HD as opposed to PD.

Because children receive a higher priority for kidney transplantation than adults, rates of transplantation are higher and waiting time much lower than for adults. However, the data in this chapter suggest that there is room for improvement. Only about 15% of children are preemptively waitlisted for a kidney transplant, and the median time to receipt of a kidney transplant has increased over time, although it remained stable over 2018-2019. Use of tunneled dialysis catheters in children with prevalent ESRD on HD who had not been waitlisted was just as high as in children who were waitlisted, which suggests that high rates of catheter use may not be solely because of an expectation of an impending kidney transplant. On the other hand, it may not be inappropriate that rates of catheter use are high because young children may be too small for vascular access, and median waiting time for a kidney transplant among children was only about 6.4 months.

Infection remains a major concern among children with ESRD. Adjusted hospitalization rates for infection increased more than 45% for children aged <1 year and nearly 37% in children aged 1-5 years between 2004-2008 and 2014-2018 (although rates decreased for children aged 6-17 years). However, children receiving PD had lower rates of infection in 2014-2018 compared with 2004-2008.

At 10 years of follow-up, the incidence of graft failure among children who received a deceased donor transplant was approximately 50%. The incidence of graft failure was lower in children who had received a living donor transplant (37%). In adults who survived childhood onset ESRD, most had a functioning kidney transplant. Among those who did not, HD was the most common modality of dialysis.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 8. ESRD among Children and Adolescents, located here: https://adr.usrdso.org/2021/end-stage-renal-disease/8-esrd-among-children-and-adolescents

References
End Stage Renal Disease: Chapter 9

Healthcare Expenditures for Persons with ESRD

Highlights

- Total Medicare-related expenditures for beneficiaries with ESRD rose to $51.0B in 2019 (Figure 9.1). Between 2009 and 2019, total expenditures increased 50% in nominal (non-inflation-adjusted) dollars but by only 13.3% after adjustment for inflation (current dollars). Inflation-adjusted expenditures for beneficiaries with Medicare fee-for service (FFS) as primary payer (MPP) only and those with dual Medicare MPP and Medicaid coverage declined slightly with adjustment for inflation.

- Expenditures were consistently highest for dually eligible, lowest for Medicare FFS only, and intermediate for Medicare Advantage (MA) beneficiaries (Figure 9.2).

- Medicare FFS expenditures for beneficiaries with ESRD increased without adjustment for inflation (from $28.0B in 2009 to $37.3B in 2019) but were relatively stable in inflation-adjusted dollars ($37.2B in 2009 vs. $37.3B in 2019). ESRD expenditures accounted for 7.1-7.2% of total Medicare expenditures throughout the decade considering adjustment for inflation (Figure 9.3).

- Among incident patients with ESRD, the percentage with non-Medicare coverage remained relatively constant (Figure 9.4a). The percentage with Medicare MPP (with Medicare only or with dual Medicare and Medicaid coverage) fell, from 44.2% in 2009 to 32.6% in 2019. Conversely, the percentage of patients with MA increased from 15.0% to 24.9%, representing an increase of 66% in relative terms.

- Point prevalent patients with ESRD had greater use of Medicare-only coverage than did incident patients (31.9% versus 23.3% in 2019, respectively) and greater use of dual Medicare and Medicaid (22.3% versus 9.3% in 2019, respectively) (Figure 9.4b).

- Inflation-adjusted inpatient spending decreased from $13.8B to $12.2B from 2009 to 2019, while outpatient spending increased 12% from $11.7B to $13.1B; outpatient spending surpassed inpatient spending in 2014 to become the largest category of costs (Figure 9.5).

- In inflation-adjusted dollars, per person per year (PPPY) inpatient spending decreased from $33,346 in 2009 to $25,082 in 2019, a drop of approximately 25% (Figure 9.6). Inflation-adjusted PPPY outpatient spending fell less than inpatient spending, from $30,738 in 2009 to $28,630 in 2019, thus becoming the largest category of spending from 2012 onward.

- Although overall outpatient costs increased almost 50% between 2009 and 2019 in nominal (not adjusted for inflation) dollars, the inflation-adjusted increase was approximately one quarter as great at 11.5% (Figure 9.7). This includes a $1.1B increase in dialysis-related costs between 2017 and 2019 that is likely due to transitional drug add-on payment adjustments (TDAPA) for calcimimetic drugs.

- Peritoneal dialysis (PD) was 22.7% less expensive than hemodialysis (HD) in 2009 and 14.3% less expensive in 2019 in inflation-adjusted terms (Figure 9.10).

Introduction

In 1972, Medicare eligibility was extended to persons with “irreversible kidney failure.” The Assistant Secretary for Health in the Department of Health, Education, and Welfare was informed in 1972 by his analysts that, once the ESRD program was in “steady-state,” approximately 20,000-30,000 patients would be receiving maintenance dialysis and that annual costs of the ESRD program would equilibrate at approximately $1B ($6.1B in 2019 dollars). However, at the end of 2019, there were over 550,000 patients receiving maintenance dialysis, representing approximately 1% of the U.S. Medicare FFS population and accounting for approximately 7.2% of Medicare FFS spending.

In this chapter, we report unadjusted and inflation-adjusted trends in Medicare-related spending for beneficiaries with ESRD between 2009 and 2019. We refer to unadjusted dollars as “unadjusted for inflation” or as “nominal” dollars, whereas inflation-adjusted dollars can be considered as current dollars (as the year on which inflation adjustment is based is 2019, or the most current year in this chapter) or constant dollars. We then examine trends in total Medicare and ESRD FFS spending as well as ESRD spending as a percentage of total Medicare spending. We next explore sources of coverage for the care of incident and prevalent patients with ESRD, followed by detailed analyses of Medicare ESRD FFS spending by type of service (inpatient, outpatient, physician/supplier, skilled nursing facility, home health agency, or hospice, and Part D). New for this year’s ADR, we examine expenditures for outpatient services covered by Medicare Part B. Categories include costs related to dialysis, injectable medications, radiology, pharmacy, ambulance, laboratory/pathology, and “other” services. Other outpatient services include clinical encounters, diagnostic tests, and physical and occupational therapy, among other things. Finally, we report Medicare ESRD FFS spending by cause of hospitalization and by ESRD treatment modality.
Methods

This chapter uses data primarily from the Centers for Medicare and Medicaid Services (CMS).

In this year’s ADR, we adjust for inflation in longitudinal analyses using the medical care index, a component of the Consumer Price Index (https://data.bls.gov/timeseries/CUUR0000SAM?output_view=data); costs are expressed in 2019 U.S. dollars. Analyses of total Medicare expenditures for beneficiaries with ESRD include those with MPP) who have Medicare only, MPP with dual Medicare and Medicaid eligibility, Medicare as a secondary payer (MSP), and those enrolled in MA. Medicare expenditures for MA plans are estimated using the total equivalent eligible MA months determined from the USRDS payer history files (PAYHIST) multiplied by the monthly payment rates for dialysis patients published by CMS (https://www.cms.gov/Medicare/Health-Plans/MedicareAdvtgSpecRateStats/Ratebooks-and-Supporting-Data.html). We applied an estimated monthly payment rate for MA beneficiaries with a functioning kidney transplant, i.e., a multiplier of 0.31 relative to the monthly dialysis payment rates (https://www.cms.gov/Medicare/Health-Plans/MedicareAdvtgSpecRateStats/Downloads/RTC-Dec2018.pdf). When reporting cost estimates for the “patient responsibility” category, we estimate the amount as the difference between Medicare allowable and Medicare paid amounts. Costs deemed to be the patient’s responsibility may be paid by the patient, reimbursed by a secondary insurer, or may remain uncollected.

Reported Medicare ESRD expenditures for specific events or services (e.g., hospitalizations, medications) include only beneficiaries covered by traditional FFS Medicare because Medicare expenditures can be calculated from the claims submitted for payment for healthcare services provided to individuals with FFS coverage but not for individuals enrolled in MA plans. (The Medicare program pays for services provided through MA plans on a risk-adjusted, per-capita basis and not by specific claims for services.) Therefore, Part C costs are deducted to examine FFS Medicare costs for these analyses. Medicare paid expenditures for period prevalent beneficiaries with ESRD with at least 1 Medicare claim in a year include Parts A, B, and D. Unless otherwise noted, total spending estimates include beneficiaries with MPP and MSP; per person per year (PPPY) spending includes those with MPP only. When presenting total Medicare FFS inpatient spending by primary cause of hospitalization, we use definitions for cause of hospitalization as in Chapter 5.

Figure 9.1 Inflation adjusted total spending for Medicare beneficiaries with ESRD, 2009-2019

Figure 9.1 displays Medicare spending for period prevalent beneficiaries with ESRD from 2009 to 2019 in unadjusted and inflation-adjusted dollars. Also shown are amounts designated as “patient responsibility” (i.e., the estimated difference between Medicare allowable and Medicare paid amounts). In unadjusted dollars, total “liabilities” (expenditures plus patient responsibilities) increased from $34.0B in 2009 to $51.0B in 2019. In inflation-adjusted dollars, however, total liabilities increased from $45.0B in 2009 to $51.0B in 2019 – 13.3% overall, or about 1.2% per annum. Even in inflation-adjusted dollars, expenditures for MA more than doubled, from $5.4B to $12.4B. Although unadjusted expenditures for both the MPP with Medicare only and MPP with dual Medicare and Medicaid categories increased over the decade, they both declined slightly with adjustment for inflation (from $18.3B to $17.8B for the former and from $16.9B to 16.5B for the latter). Expenditures for MSP increased from $0.5B to $0.8B, but these expenditures were low in absolute terms. Patient responsibility costs decreased slightly.
Figure 9.2  Inflation adjusted per person per year spending in Medicare fee-for-service vs. Medicare Advantage beneficiaries with ESRD, 2009-2019

Figure 9.2 shows PPPY spending for Medicare FFS-only beneficiaries, dually eligible beneficiaries with Medicare and Medicaid coverage, and Medicare Advantage enrollees with ESRD from 2009-2019. Expenditures were consistently highest for dually eligible beneficiaries, lowest for FFS only, and intermediate for MA beneficiaries. Unadjusted costs for all 3 groups increased from 2009-2019. However, the opposite was true with adjustment for inflation: expenditures for those with FFS only decreased from $81,211 to $66,603; for dually eligible beneficiaries from $111,060 to $92,686; and for MA beneficiaries from $91,646 to $79,316.

Figure 9.3  Inflation adjusted total and ESRD spending in Medicare fee-for-service, and ESRD spending as a percentage of total Medicare spending, 2009-2019

Figure 9.3 shows total expenditures and ESRD spending as a percentage of total Medicare spending from 2009-2019. The percentage of Medicare spending on ESRD remained relatively stable over the years.

Figure 9.3 shows trends in total Medicare and ESRD FFS spending (in billions of U.S. dollars), as well as the percentage of Medicare FFS spending attributable to ESRD, between 2009 and 2019, with and without adjustment for inflation. In unadjusted dollars, total FFS expenditures increased from $396.3B in 2009 to $522.4B in 2019. In inflation-adjusted dollars, however, expenditures did not increase ($525.9B in 2009 and $522.4B in 2019). (Over the same period, total U.S. gross domestic product increased from $14.4T to $21.3T, or 47.9% [https://fred.stlouisfed.org/series/GDP]). FFS expenditures for beneficiaries with ESRD followed a similar pattern as overall expenditures: they increased without adjustment for inflation (from $28.0B in 2009 to $37.3B in 2019) but were relatively stable in inflation-adjusted dollars ($37.2B in 2009 vs. $36.9B in 2019). ESRD expenditures accounted for 7.1-7.2% of total Medicare expenditures throughout the decade considering adjustment for inflation.

Figure 9.4a  Sources of medical coverage for patients with incident ESRD, 2009-2019, by treatment modality

Data Source: USRDS ESRD database. Incident ESRD patients in a year, 2009-2019. Percent refers to the percent of patients in each payer category, adding up to 100% for each year's cohort.
Figure 9.4a shows trends in sources of medical coverage between 2009 and 2019 for incident patients with ESRD, overall and by ESRD treatment modality (in-center HD, home HD, PD, or kidney transplant). Among incident patients with ESRD, the percentage with non-Medicare coverage remained relatively constant, while the percentage with MPP with Medicare only fell from 31.0% to 23.3%, a decrease of 24.8% in relative terms. The percentage with MPP with dual Medicare and Medicaid coverage also fell, from 13.2% to 9.3%. However, the percentage of patients with MA increased from 15.0% to 24.9%, representing an increase of 66% in relative terms. Trends among patients receiving in-center HD were similar to overall trends in sources of medical coverage. For the home-based therapies (home HD and PD), a substantially higher percentage of patients had MSP compared with patients receiving in-center HD, and a lower percentage had non-Medicare coverage. As was the case with in-center HD, the percentage of patients using home-based therapies covered by Medicare alone decreased over time. A much greater percentage of patients receiving a kidney transplant had MSP (28.6% in 2019) compared with patients receiving in-center HD (3.6%); the percentage covered by MA, however, was relatively low among those receiving kidney transplants (8.2% in 2019).
**Figure 9.4b** Sources of medical coverage for patients with prevalent ESRD, 2009-2019, by treatment modality

Data Source: USRDS ESRD database. Point prevalent ESRD patients on January 1 in a year, 2009-2019. Percent refers to the percent of patients in each payer category, adding up to 100% for each year’s cohort.

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**Figure 9.4b** Sources of medical coverage for patients with prevalent ESRD, 2009-2019, by treatment modality

Data Source: USRDS ESRD database. Point prevalent ESRD patients on January 1 in a year, 2009-2019. Percent refers to the percent of patients in each payer category, adding up to 100% for each year’s cohort.
Point prevalent patients with ESRD had greater use of Medicare-only coverage than did incident patients (31.9% versus 23.3% in 2019, respectively) and greater use of dual Medicare and Medicaid (22.3% versus 9.3% in 2019, respectively) (Figure 9.4b). Conversely, a much lower percentage were covered by a non-Medicare source (21.0% among point prevalent patients in 2019, compared with 37.0% among incident patients) or by Medicare Advantage (17.7% versus 24.9%). Higher percentages of patients utilizing home-based dialysis therapies had Medicare-only coverage and MSP compared with patients receiving in-center HD. Point prevalent patients with a kidney transplant were more than twice as likely to utilize non-Medicare coverage (32.9%) as patients receiving dialysis (13.8-16.1%).

Data Source: USRDS ESRD database. Point prevalent ESRD patients on January 1 in a year, 2009-2019. Percent refers to the percent of patients in each payer category, adding up to 100% for each year’s cohort.
Without adjustment for inflation, total inpatient spending for Medicare FFS beneficiaries with ESRD increased from $10.4B to $12.2B; outpatient spending increased from $8.9B to $13.1B (Figure 9.5). In inflation-adjusted dollars, however, inpatient spending decreased from $13.8B to $12.2B, while outpatient spending increased 12%, from $11.7B to $13.1B. Outpatient spending surpassed inpatient spending in 2014 to become the largest category of costs. Physician/supplier spending decreased from a peak of $7.1B, in inflation-adjusted dollars, in 2010 to $5.8B in 2019. Over the decade, there was little change in expenditures for skilled nursing facilities, home health agencies, or hospice. Part D spending more than doubled in inflation-adjusted dollars, from $2.3B in 2009 to $5.4B in 2017 and then decreased to $4.0B from 2017 to 2019 (likely because calcimimetics were moved from Part D to Part B, known as the "bundle" for patients receiving dialysis).

Figure 9.6 Inflation adjusted per person per year Medicare fee-for-service spending for beneficiaries with ESRD, by type of service, 2009-2019

Without adjustment for inflation, total inpatient spending for Medicare FFS beneficiaries with ESRD increased from $10.4B to $12.2B; outpatient spending increased from $8.9B to $13.1B (Figure 9.5). Inflation-adjusted dollars, however, inpatient spending decreased from $13.8B to $12.2B, while outpatient spending increased 12%, from $11.7B to $13.1B. Outpatient spending surpassed inpatient spending in 2014 to become the largest category of costs. Physician/supplier spending decreased from a peak of $7.1B, in inflation-adjusted dollars, in 2010 to $5.8B in 2019. Over the decade, there was little change in expenditures for skilled nursing facilities, home health agencies, or hospice. Part D spending more than doubled in inflation-adjusted dollars, from $2.3B in 2009 to $5.4B in 2017 and then decreased to $4.0B from 2017 to 2019 (likely because calcimimetics were moved from Part D to Part B, known as the "bundle" for patients receiving dialysis).

Figure 9.6 Inflation adjusted per person per year Medicare fee-for-service spending for beneficiaries with ESRD, by type of service, 2009-2019

Without adjustment for inflation, total inpatient spending for Medicare FFS beneficiaries with ESRD increased from $10.4B to $12.2B; outpatient spending increased from $8.9B to $13.1B (Figure 9.5). Inflation-adjusted dollars, however, inpatient spending decreased from $13.8B to $12.2B, while outpatient spending increased 12%, from $11.7B to $13.1B. Outpatient spending surpassed inpatient spending in 2014 to become the largest category of costs. Physician/supplier spending decreased from a peak of $7.1B, in inflation-adjusted dollars, in 2010 to $5.8B in 2019. Over the decade, there was little change in expenditures for skilled nursing facilities, home health agencies, or hospice. Part D spending more than doubled in inflation-adjusted dollars, from $2.3B in 2009 to $5.4B in 2017 and then decreased to $4.0B from 2017 to 2019 (likely because calcimimetics were moved from Part D to Part B, known as the "bundle" for patients receiving dialysis).
Without adjusting for inflation, PPPY inpatient spending in Medicare FFS beneficiaries with ESRD was just over $25,000 in 2009, decreased slightly until 2015, and then increased again to $25,082 in 2019, nearly identical to the amount in 2009 (Figure 9.6). Outpatient spending increased from $23,177 in 2009 to $28,630 in 2019. In inflation-adjusted dollars, however, PPPY inpatient spending decreased from $33,346 in 2009 to $25,082 in 2019, a drop of approximately 25%. Inflation-adjusted PPPY outpatient spending fell less than inpatient spending, from $30,738 in 2009 to $28,630, thus becoming the largest category of spending from 2012 onward. Inflation-adjusted PPPY physician/supplier expenditures decreased from $17,973 to $12,275 over the decade. PPPY annual expenditures changed little for skilled nursing facility, home health agency, or hospice care. Inflation-adjusted Part D expenditures began at $8135 per person per year in 2009, peaked at $12,581 per year in 2017, and then decreased to $8510 in 2019 (after calcimimetics were shifted to Part B for patients receiving dialysis).
New in this year’s ADR, Figure 9.7 displays outpatient (Part A) spending for Medicare FFS beneficiaries by category from 2009 to 2019. Categories include costs related to dialysis, injectable medications, and radiology, pharmacy, ambulance, laboratory/pathology, and “other” services. Other outpatient services include clinical encounters, diagnostic tests, and physical and occupational therapy among other things. In addition, medications typically administered in dialysis facilities and currently included in the ESRD “bundled” Prospective Payment System (PPS) since 2011 are included in the other outpatient category. (Note that prescription medications covered under Medicare Part D are not included in this figure.)

Although overall outpatient costs increased almost 50% between 2009 and 2019 in nominal (not adjusted for inflation) dollars, the inflation-adjusted increase was approximately one quarter as great at 12%. As expected, introduction of the ESRD PPS in 2011 resulted in a substantial shift in the distribution of outpatient expenditures, with some non-dialysis related costs becoming dialysis-related costs. However, overall inflation-adjusted outpatient costs increased only 3.4% in 2011. Since 2011, dialysis-related costs account for approximately 80% of total outpatient costs (78% in 2019). Inflation-adjusted dialysis-related costs increased by $0.6B, or 6.3% from 2017 to 2019, likely because calcimimetics were moved from Part D to Part B (known as the “bundle” for patients receiving dialysis) in 2017. Other outpatient costs make up the second-largest category (16% in 2019).
As for many other medical costs, inpatient spending for Medicare FFS beneficiaries with ESRD increased in nominal (not adjusted for inflation) and decreased in inflation-adjusted dollars (Figure 9.8). In 2019, inpatient spending accounted for $12.2B. Inflation-adjusted expenditures for infection-related hospitalizations decreased from $3.5B to $2.3B; expenditures for cardiovascular disease-related hospitalization also decreased, from $3.7B to $3.1B. Since 2015, cardiovascular and infection-related hospitalizations have accounted for <50% of inpatient costs for patients with ESRD. Therefore, we examined costs of hospitalization for diabetes, gastrointestinal causes, cancer, fractures, and non-infectious pulmonary causes. None of these causes accounted for more than 5% of total inpatient costs in any year; in 2019, diabetes hospitalizations accounted for 3.6%, gastrointestinal 2.0%, cancer 1.4%, fractures 2.2%, and non-infectious pulmonary causes 2.4%.
In nominal dollars (not adjusted for inflation), total expenditures for Medicare FFS beneficiaries with ESRD increased from $28.0B in 2009 to $37.3B in 2019 (Figure 9.9). Expenditures for HD, PD, and kidney transplant all increased individually as well. However, in inflation-adjusted dollars, total expenditures changed very little, from $37.2B in 2009 to $37.3B in 2019. Inflation-adjusted expenditures for beneficiaries receiving HD decreased slightly from $30.3B in 2009 to $29.0B in 2019. Expenditures for beneficiaries receiving PD increased 58.8% from $1.7B to $2.7B, while expenditures for beneficiaries with a kidney transplant increased by 20.6% from $3.4B to $4.1B.
Without accounting for inflation, PPPY spending (from 2009 to 2019) increased from $86,923 to $94,608 for HD, from $67,187 to $81,091 for PD, and from $33,584 to $38,863 for kidney transplant (Figure 9.10). In inflation-adjusted dollars, however, PPPY expenditures for beneficiaries receiving HD decreased from $115,283 in 2009 to $94,608 in 2019, or 17.9%. PPPY expenditures decreased from $89,108 to $81,091 for beneficiaries receiving PD and from $44,541 to $38,863 for beneficiaries with a kidney transplant. As a result, the difference in inflation-adjusted PPPY costs for beneficiaries receiving HD and PD narrowed from $26,175 in 2009 to $13,517 in 2019. In relative terms, PD was 22.7% less expensive than HD in 2009 and 14.3% less expensive in 2019.
Summary

Total inflation-adjusted Medicare expenditures for beneficiaries with ESRD (FFS plus MA) rose steadily over the decade from 2009 to 2019 by about 1.2% per annum, from $45.0B to $51.0B. The largest contributor to this growth was expenditures under the MA program, where spending increased by $7B because of a substantial increase in enrollment in MA. Inflation-adjusted MPP spending (for beneficiaries with Medicare-only and dual Medicare and Medicaid) decreased by $0.9B. Total FFS spending decreased $1.2B from $39.7B in 2009 to $38.5B in 2019. As a percentage of all FFS Medicare spending, spending for beneficiaries with ESRD remained relatively unchanged during this period at approximately 7.1%. Inflation-adjusted per person spending was lower in 2019 than in 2009 for beneficiaries treated with HD and PD, and for kidney transplant recipients.

There have been significant changes in sources of medical coverage among patients with ESRD over the last decade. In 2009, 44.2% of incident ESRD patients had Medicare as Primary Payer FFS coverage, and 15.0% had MA; in 2019 those percentages were 32.6% and 24.9%, respectively. Among prevalent patients, the percent with MA increased from 9.1% to 17.7% from 2009 to 2019. Additionally, in more recent years, a greater percentage of individuals who received a kidney transplant were covered by a non-Medicare source or had Medicare as Secondary Payer coverage. This suggests that well-insured patients have greater access to kidney transplantation. Whether this is an effect of insurance type itself or an indication that healthier patients are both more likely to have private insurance and to receive a kidney transplant cannot be determined from these data.

During the decade between 2009 and 2019, inflation-adjusted total expenditures for inpatient services for beneficiaries with ESRD declined ($13.8B to $12.2B) while those for outpatient services increased ($11.7B to $13.1B). Part D expenditures more than doubled between 2009 and 2019 before decreasing precipitously (by >25%) between 2017 and 2019, due mostly to a decrease in spending for calcimimetics and several other key drugs. In the cataloging of outpatient costs, these medications were not included when they were covered under Medicare Part D but were captured as dialysis-related outpatient costs in 2018 and 2019 when they were moved into the dialysis PPS bundled payment system under a transitional drug add-on payment adjustment (TDAPA). During this period, outpatient dialysis-related costs increased by $0.6B. Dialysis-related costs account for almost 80% of overall outpatient spending for patients receiving maintenance dialysis. Inpatient costs for hospitalizations due to infection and cardiovascular disease among beneficiaries with ESRD decreased from 2009-2019, accounting for 44.3% of total inflation-adjusted inpatient spending in 2019 compared with 52.2% in 2009. We examined expenditures for hospitalizations for other causes in this year’s ADR, but none accounted for more than 5% of overall hospitalization-related costs.

Expenditures by ESRD treatment modality are important to consider as governmental initiatives designed to increase kidney transplantation and to foster use of home-based dialysis modalities are implemented. Although HD remained the most expensive treatment for ESRD in 2019 at $94,608 per person annually (and kidney transplantation, as expected, the least expensive, at $38,863), PPPY spending for beneficiaries receiving PD, at $81,091 in 2019, decreased less in inflation-adjusted dollars than for those receiving HD. It is important to note that these estimates were not adjusted for comorbidities, dialysis duration, or other factors that might distinguish patients receiving HD from those receiving PD. However, these findings raise the possibility that growth in the PD population might cause a narrowing in the relative cost savings of PD over HD. If expansion of PD results in sicker, and therefore more costly, patients receiving PD, the relative cost advantage conferred by this modality over HD may continue to narrow. More complete efforts at risk-adjustment (beyond the scope of this ADR) would be required to make more informed predictions in this regard.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 9. Healthcare Expenditures for Persons with ESRD, located here: https://adr.usrds.org/2021/end-stage-renal-disease/9-healthcare-expenditures-for-persons-with-esrd
Prescription Drug Coverage in Patients with ESRD

Highlights

- Approximately 78% and 71% of fee-for-service (FFS) beneficiaries with and without ESRD, respectively, were enrolled in a Medicare Part D plan in 2019 (Figure 10.1).

- Qualification for the Low Income Subsidy (LIS) was nearly twice as common among Part D beneficiaries with ESRD (59.9%) as among beneficiaries without (30.3%). LIS qualification was more common for beneficiaries receiving hemodialysis (HD) than for those receiving peritoneal dialysis (PD) or with a kidney transplant (Figure 10.3).

- In beneficiaries with ESRD, LIS qualification was much more common among Black and Hispanic patients (nearly three quarters) than among White patients (under half) (Figure 10.3).

- Between 2009 and 2019, total Medicare Part D spending among beneficiaries with ESRD rose by approximately 65% in inflation-adjusted dollars (from $2.0 to $3.3 billion) and by approximately 44% in those without ESRD (from $48.5 to $69.7 billion). Beneficiaries with ESRD accounted for 4.7% of all Part D spending in 2019 (Figures 10.5 and 10.6).

- Per person per year (PPPY) Part D spending also increased in beneficiaries with ESRD until 2017, after which there was a large decrease (Figure 10.5), which was likely explained by the shift of payment for calcimimetics among beneficiaries receiving dialysis from Part D to Part B.

- In 2019, mean PPPY Medicare Part D spending was more than twice as high for beneficiaries with ESRD ($7794) as for those without ($3531) (Figure 10.8). The difference was even greater for median costs: $2919 for those with ESRD and $411 for those without, or 7-fold higher for those with ESRD. However, mean and median out-of-pocket costs were lower for beneficiaries with ESRD.

- In 2019, mean PPPY Medicare Part D insurance spending for patients with ESRD was 2.8 times higher and median spending was 4.7 times higher among those with the LIS than among those without the LIS (Figure 10.9).

- Overall out-of-pocket Part D costs continued to decrease for patients with ESRD, with and without the LIS (Figure 10.10), as the “donut hole” was phased out.

- Overall, Medicare Part D PPPY insurance spending on medications was higher in Black and Hispanic beneficiaries than among White beneficiaries with ESRD. (Figure 10.8) However, consideration of beneficiaries with and without the LIS separately demonstrates that Part D spending was relatively similar by race/ethnicity, or even higher in White, as compared with Black and Hispanic, beneficiaries among those with and without the LIS (Figure 10.9).

- Among those with ESRD, just over three quarters of total Part D expenditures in 2019 were for brand-name drugs, a fraction that is similar among those treated with hemodialysis (HD), peritoneal dialysis (PD), and with a kidney transplant (Figure 10.7).

- Beta blockers, statins, and antibiotics appeared among the top 4 most commonly used drugs across all ESRD treatment modalities in 2019, with more than half of beneficiaries receiving prescriptions for each of these drugs. (Table 10.2).

- The percentage of beneficiaries on HD prescribed angiotensin converting enzyme inhibitor (ACEI)/angiotensin receptor blocker (ARB) therapy and a potassium binder in 2019 (5.8%) was higher than the percentage of beneficiaries with CKD 4-5 (3.8%) with Part D coverage receiving these drugs. In both groups, the use of sodium polystyrene sulfonate decreased since 2015-2016, while use of patiromer and sodium zirconium cyclosilicate increased (Figure 10.13b and CKD Volume Figure 7.16b).

- Treatment of diabetes (DM) among beneficiaries with ESRD was extremely expensive in 2019. Insulin accounted for the largest percentage of Part D spending of any medication class among kidney transplant recipients and was behind only phosphorus binders among patients receiving dialysis. Dipeptidyl peptidase-4 inhibitors (DPP-4is) and/or glucagon-like peptide-1 receptor agonists (GLP-1RAs) were also in the top 15 most expensive drugs for all modalities (Table 10.3).

- Newer insulin analogs were by far the most frequently prescribed DM treatments among beneficiaries with ESRD and type 2 DM (Figure 10.14a). Transplant recipients were more likely to be treated with newer brand-name DM medication classes (newer insulin analogs, DPP-4is, and GLP-1RAs) in general than patients receiving dialysis.

- In 2019, 30.4% of beneficiaries on HD received an antidepressant during the year (Figure 10.17). The corresponding percentage for those on PD was 28.4% and for kidney transplant recipients was 26.1%. 

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Introduction

This chapter focuses on drug costs and utilization among Medicare FFS beneficiaries with Part D prescription drug coverage. The Part D prescription drug program and its implications for the analyses contained in this chapter are discussed more fully below. To help orient readers, the first table describes the Medicare Part D parameters for the defined standard benefit, and the first figure shows the sources of prescription drug coverage in Medicare beneficiaries with and without ESRD in 2019.

We begin with a focus on Part D enrollment and expenditures, showing trends over time in the percentage of Medicare beneficiaries with and without ESRD enrolled in Part D, then turn to the LIS by reporting the percentage of Medicare Part D beneficiaries with the LIS in 2019. Part D spending is then reported in figures showing the trends in total and Pppy Part D inflation-adjusted spending between 2009 and 2019. Next, insurance and out-of-pocket spending for Part D beneficiaries is illustrated on a Pppy basis, both overall and by LIS status. New this year, we examine spending for generic and brand-name medications separately. In addition, this year’s ADR includes box plots showing the median, 25th percentile, and 75th percentile in addition to mean costs because spending on medications is not normally distributed.

We then shift the focus to drug prescribing, with figures showing the 15 most commonly prescribed drugs and insurance spending attributed to the most expensive drugs. Finally, we highlight issues involving the prescribing of medications to treat cardiovascular disease, ESRD complications, type 2 DM, depression, and hepatitis C. Note, however, that we did not include metformin and sodium-glucose cotransporter-2 inhibitors (SGLT2is) in this chapter because these medications are contraindicated in kidney failure. However, these classes may have been used among patients with a functioning kidney transplant, and this may be a topic for future exploration.

Methods

In this chapter, we use data from the 100% ESRD population (receiving HD, PD, or with a functioning kidney transplant) and those without ESRD from the Medicare 5% random sample to describe enrollment in Medicare Part D prescription drug programs and associated costs and utilization of prescription medications. Reporting of costs and utilization of prescription medications is limited to FFS beneficiaries enrolled in stand-alone Part D programs and does not include prescription drug information from Medicare Advantage (MA) enrollees owing to the capitated Medicare reimbursement mechanisms used for medical and drug costs in these plans.

The general Medicare data include yearly point prevalent cohorts of Medicare FFS beneficiaries without ESRD on January 1 of the reported year. The ESRD data include yearly period prevalent cohorts of Medicare FFS beneficiaries receiving dialysis or with a functioning kidney transplant. In all cohorts, beneficiaries were included if they were alive, aged ≥18 years, and resided in the U.S. (50 States, District of Columbia, or Territories) at cohort entry. Modality was assessed on January 1 for prevalent patients and on day 90 after ESRD onset for incident patients.

We assessed enrollment in Medicare Part D and prescription drug utilization using the Medicare Enrollment Database and the Medicare Part D drug event files, which provide records of all prescriptions filled by beneficiaries enrolled in Part D. We assessed total costs to Medicare for each Part D enrollee for Part D-covered drugs, including the net amount paid by the Part D plan and the amount paid by the LIS, when applicable. Out-of-pocket expenses exclude premiums but include all copayments, coinsurance, deductible, or other patient payment amounts, as well as other third-party payments counting towards a beneficiary’s true out-of-pocket costs. Analyses of utilization of medications for the treatment of type 2 DM, and hepatitis C are limited to patients diagnosed with these conditions in a baseline period defined as the six months preceding the reported cohort year under investigation.

The Medicare Part D Prescription Drug Benefit

The optional Medicare Part D prescription drug benefit has been available to all beneficiaries since 2006. Part D benefits can be managed through a stand-alone prescription drug plan or through a MA prescription drug plan (MA-PD). Most MA plans include a Part D prescription drug plan. After 2006, the majority of Medicare enrollees obtained Part D coverage. The Part D program offers a substantial LIS benefit to enrollees with limited assets and income, including those dually enrolled in Medicare and Medicaid. The LIS provides full or partial waivers for many out-of-pocket cost-sharing requirements, including premiums, deductibles, and copayments, and provides full or partial coverage during the Part D coverage gap (commonly referred to as the “donut hole”). In 2019, beneficiaries with the standard benefit were responsible for a portion of drug costs during the coverage gap in 2019 (maximum of 37% of generic drug costs and 25% of brand-name drug costs), which will be reduced to 25% for both generic and brand drugs in 2020.

Some Medicare beneficiaries with ESRD are covered through MA programs with Medicare Part D coverage, but their medication use and associated costs are not captured in the data presented in this chapter. Medicare Part D is not the only source of drug coverage available to beneficiaries. Some may choose to obtain outpatient medication benefits through retiree drug subsidy plans or other creditable coverage plans.
such as employer group health plans, other private coverage, or Veterans Health Administration (VHA) benefits rather than through Medicare Part D plans. Some Medicare Part A and B enrollees remain uninsured for medication costs and pay for their outpatient prescription medications out-of-pocket. In addition, several medications used by Medicare beneficiaries with ESRD are covered in bundled payments under the ESRD Prospective Payment System (e.g. erythropoiesis stimulating agents [ESAs], intravenous [IV] iron, vitamin D analogs) and others are covered fully or in part under Medicare Part B (e.g. transplant immunosuppressive agents and calcimimetics, which have been covered for dialysis beneficiaries under a Transitional Drug Add-on Payment [TDAPA] since 2018). These costs are not captured in the Medicare Part D expenditures and enrollee out-of-pocket expenses reported here. Therefore, costs reported here are total costs to Medicare Part D for prescription drugs for FFS beneficiaries but are not the total costs of medications used by Medicare beneficiaries.

Table 10.1  Medicare Part D parameters for defined standard benefit, 2019

(a) Standard benefit design

<table>
<thead>
<tr>
<th>Plan cost-sharing tier and explanation</th>
<th>Total drug costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beneficiary pays 100% of total prescription costs up to the deductible.</td>
<td>$0-$415</td>
</tr>
<tr>
<td><strong>Deductible</strong></td>
<td>$415</td>
</tr>
<tr>
<td>After the deductible is met, the beneficiary pays 25% of total prescription costs up to the initial coverage limit.</td>
<td></td>
</tr>
<tr>
<td><strong>Initial coverage limit</strong></td>
<td>$3,820</td>
</tr>
<tr>
<td>The coverage gap (&quot;donut hole&quot;) begins at this point.</td>
<td></td>
</tr>
<tr>
<td><strong>Coverage gap (&quot;donut hole&quot;)</strong></td>
<td>$3,820-$7,654</td>
</tr>
<tr>
<td>Beneficiaries receive a 75% discount on brand-name drugs (5% paid by plan, 70% paid by manufacturer) and a 63% discount on generic drugs while in the coverage gap</td>
<td></td>
</tr>
<tr>
<td><strong>Catastrophic coverage threshold</strong></td>
<td>$7,654</td>
</tr>
<tr>
<td>Catastrophic coverage begins after beneficiary has spent $5,100 out-of-pocket</td>
<td></td>
</tr>
<tr>
<td><strong>Catastrophic coverage</strong></td>
<td>&gt;$7,654</td>
</tr>
<tr>
<td>Beneficiary pays the greater of $3.40 or 5% of the cost for generic or preferred multisource drugs and the greater of $8.50 or 5% for brand-name drugs during this phase.</td>
<td></td>
</tr>
</tbody>
</table>

(b) Breakdown of out-of-pocket costs prior to reaching the catastrophic coverage threshold

<table>
<thead>
<tr>
<th>2019 Example:</th>
<th>Out-of-pocket costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>$415 (deductible)</td>
<td>$415</td>
</tr>
<tr>
<td>+ (($3820 – $415) * 25%) (initial coverage)</td>
<td>$851</td>
</tr>
<tr>
<td>+ (($7654 – $3820) * 100%) (coverage gap)</td>
<td>$3,834</td>
</tr>
<tr>
<td>Total</td>
<td>$5,100</td>
</tr>
</tbody>
</table>

(maximum out-of-pocket costs prior to catastrophic coverage, excluding plan premium)

Data source: Adapted from https://q1medicare.com/PartD-The-2019-Medicare-Part-D-Outlook.php

By design, beneficiaries qualifying for the LIS have lower out-of-pocket drug costs than those who do not qualify. The LIS provides full or partial waivers for premiums, deductibles, and/or copayments. This includes full or partial coverage during the coverage gap, or "donut hole." (For beneficiaries without the LIS, Part D premiums varied widely in 2019, including premium surcharges for high-income beneficiaries.) Most plans have different cost-sharing tiers, but specific copayments and coinsurance rates vary widely among plans. Nearly all plans charge coinsurance for higher-cost and non-preferred drugs.

As shown in Table 10.1, the typical standard deductible for most enrollees in 2019 was $415 (although some plans charge no deductible). During the initial coverage period when prescription drug costs have exceeded the deductible but have not yet reached the initial coverage limit of $3820 in total drug costs, enrollees are responsible for 25% of drug costs, with the remainder covered by the plan.

Above $3820, but up to a maximum out-of-pocket threshold of $5100, enrollees enter a coverage gap, often referred to as the "donut hole." Additional costs to enrollees in the "donut hole" were further reduced in 2019. Enrollees pay a higher percentage of cost for generic drugs (37%) but continue to be responsible for only 25% of the cost of brand-name drugs. When total drug costs exceed the catastrophic coverage threshold ($7654 in 2019), enrollees’ share of drug costs is reduced to 5% or $3.40 per generic and $8.50 for brand-name drug prescription, whichever is greater.
Approximately 78% and 71% of FFS beneficiaries with and without ESRD, respectively, were enrolled in a Medicare Part D plan (Figure 10.1). Part D enrollment was higher for those receiving HD (82% of beneficiaries) compared with those receiving PD or with a kidney transplant (just over 70% in each). Among those with ESRD, older individuals were more likely to have Part D coverage but less likely to qualify for the LIS than younger beneficiaries. Black and Hispanic individuals were more likely to receive the LIS compared with Asian individuals and individuals of other races, and White individuals were least likely.
From 2009 to 2019, enrollment in Medicare Part D rose from 66.3% to 78.3% among beneficiaries with ESRD and from 53.8% to 71.3% among those without ESRD (Figure 10.2). Relative to other ESRD treatment modalities, beneficiaries receiving HD consistently had the highest percentage of Part D enrollees. Enrollment in Part D from 2009 to 2019 increased more for beneficiaries with a kidney transplant than for those receiving PD. The slightly larger increase in enrollment in 2012-2013, particularly among beneficiaries without ESRD, was ascribed to increased enrollment of retirees in employer-only Part D plans by the Kaiser Family Foundation (Cubanski & Neuman, 2015).

**Figure 10.3** Percentage of adults with the low-income subsidy (LIS), 2019

Data source: Medicare 5% sample and ESRD database. January 1, 2019 point prevalent (non-ESRD) and 2019 period prevalent (ESRD) Medicare FFS beneficiaries aged ≥18 years with Part D coverage.

Among Part D enrollees in 2019, LIS qualification was nearly twice as common among those with ESRD (59.9%) compared with those without ESRD (30.3%) (Figure 10.3). Among those with ESRD, LIS qualification was higher among beneficiaries receiving HD than those receiving PD or with a kidney transplant and higher among Black and Hispanic than among White patients. Among all race/ethnicity groups, younger beneficiaries were more likely to qualify for the LIS than older beneficiaries; this pattern was particularly pronounced among Whites patients.
Approximately 98% of beneficiaries receiving the LIS were automatically eligible for a full premium subsidy (Figure 10.4); among these, the majority had either a low copayment or none at all. Similar percentages of beneficiaries with ESRD (26.4%) and without ESRD (26.8%) received the highest level of subsidy—100% premium subsidy, no copayment. Beneficiaries with ESRD receiving PD or with a kidney transplant were more likely to have some level of required copayment compared with those receiving HD.

Data source: Medicare 5% sample and ESRD database. January 1, 2019 point prevalent (non-ESRD) and 2019 period prevalent (ESRD) Medicare FFS beneficiaries aged ≥18 years with Part D coverage.
Figure 10.5 Part D spending for covered prescription medications in adults, 2009-2019

Data source: Medicare 5% sample and ESRD database. Yearly January 1 point prevalent (non-ESRD) and yearly period prevalent (ESRD) Medicare FFS beneficiaries aged ≥18 years with Part D coverage. Costs are inflation-adjusted (to 2019 dollars).
Between 2009 and 2017, total inflation-adjusted Medicare Part D spending increased by approximately 130% in beneficiaries with ESRD (from $2.0 to $4.7 billion) and by approximately 40% in beneficiaries without ESRD ($48.5 to $66.3 billion) (Figure 10.5). In 2018 and 2019, total costs for Part D enrollees without ESRD continued to rise, whereas costs for enrollees with ESRD decreased precipitously.

Between 2009 and 2017, mean PPPY Part D spending in beneficiaries with ESRD increased 53% (from $7655 to $11,703) but then decreased by one third (to $7794), between 2017 and 2019. The substantial decrease in total and PPPY Part D costs among enrollees with ESRD is largely explained by the shift in payment for calcimimetics from Part D to Medicare Part B under the TDAPA program. In addition, generic versions of sevelamer carbonate entered the U.S. market in 2017. These two changes likely explain the large decrease in total Part D costs in 2018 and 2019 after years of steady increases among patients receiving dialysis and the relatively stable costs among transplant recipients. On a per person basis, Part D costs were higher for patients on HD than for those on PD from 2011 onward; the per person cost difference between the modalities was highest in 2016 and 2017, before decreasing in 2018 and 2019.

Because PPPY costs are not normally distributed, they are also shown in box plots in Figure 10.5. Median PPPY costs are depicted as a solid line within the boxes. The median PPPY Part D cost for enrollees with ESRD was $2919 in 2019, approximately 7-fold higher than the median cost for those without ESRD ($411).

Figure 10.6 illustrates that Medicare Part D inflation-adjusted spending increased slightly more among beneficiaries with ESRD than among those without ESRD between 2009 and 2019. In 2009, total Medicare Part D spending was $50.5 billion, in inflation-adjusted dollars, 2.0% of which was for beneficiaries with ESRD. By 2019, total Medicare Part D spending rose to $73.1 billion, 3.4% of which was for beneficiaries with ESRD. The increase in Part D spending among beneficiaries with ESRD was related to a slightly disproportionate rise in the number of beneficiaries with ESRD compared with those without ESRD and to higher PPPY costs. In 2017, the year before payment for calcimimetics for beneficiaries receiving dialysis was shifted from Part D to Part B under the TDAPA, beneficiaries with ESRD accounted for 6.6% of total Part D spending (Figure 10.5).
Figure 10.7 Part D spending for covered generic and brand-name medications in adults, 2019

Data source: Medicare 5% sample and ESRD database. January 1, 2019 point prevalent (non-ESRD) and 2019 period prevalent (ESRD) Medicare FFS beneficiaries aged ≥18 years with Part D coverage.

Figure 10.7 Part D spending for covered generic and brand-name medications in adults, 2019

Data source: Medicare 5% sample and ESRD database. January 1, 2019 point prevalent (non-ESRD) and 2019 period prevalent (ESRD) Medicare FFS beneficiaries aged ≥18 years with Part D coverage.
Figure 10.7 displays total and PPPY Medicare Part D expenditures for generic and brand-name drugs in 2019. Among enrollees without ESRD, 82% of total Medicare Part D expenditures were for brand-name products. Among those with ESRD, just over three quarters of expenditures were for brand-name drugs, a fraction that is similar among those treated with HD, PD and with a kidney transplant.

Because PPPY costs are not normally distributed, they are shown using box plots in the figure. Median PPPY costs are depicted as a solid line within the boxes, and mean costs are superimposed as square points. The mean PPPY cost for generic medications among enrollees with ESRD was $1877 in 2019, and for brand-name drugs was $5885. Corresponding means for individuals without ESRD were $637 for generics and $2893 for brand-name drugs. Median costs were much lower at $775 PPPY for generic and $1299 PPPY for brand-name drugs among those with ESRD and $166 for generic and $0 for brand-name drugs among enrollees without ESRD. Given that both the ESRD and non-ESRD populations have large numbers of expensive outliers, the large differences in median PPPY drug costs (>4.5-fold higher for generics and $1299 vs. $0 for brand-name drugs) among beneficiaries with ESRD compared with those without ESRD may better represent the differences in drug prescribing between these populations.

**Figure 10.8** Per person per year Part D insurance and out-of-pocket spending for covered prescription medications in adults, 2019

<table>
<thead>
<tr>
<th>Overall</th>
<th>Age</th>
<th>Sex</th>
<th>Race/Ethnicity</th>
</tr>
</thead>
</table>

Data source: Medicare 5% sample and ESRD database. January 1, 2019 point prevalent (non-ESRD) and 2019 period prevalent (ESRD) Medicare FFS beneficiaries aged ≥18 years with Part D coverage.
Figure 10.8 illustrates PPPY Medicare Part D insurance spending and enrollee out-of-pocket spending in 2019 overall and by demographic characteristics. Although mean insurance spending was 2.2 times higher for beneficiaries with ESRD and median spending was more than 7-fold higher than for those without ESRD, out-of-pocket costs were lower for those with ESRD. The mean out-of-pocket cost for enrollees with ESRD was $426 PPPY, whereas the mean among those without ESRD was $452. The corresponding medians were $97 and $168. Among beneficiaries with ESRD, out-of-pocket Part D costs were higher for those receiving PD or with a kidney transplant than for those receiving HD. Total Part D insurance costs were slightly higher for women than for men among beneficiaries receiving dialysis, but costs were similar for men and women with a functioning kidney transplant. Total Part D insurance costs decreased with age for all ESRD treatment modalities; however, out-of-pocket costs increased with age. Total Part D insurance costs were higher in Black, Hispanic, and Asian individuals relative to Whites and those of other racial/ethnic groups, whereas out-of-pocket costs were highest in White beneficiaries compared with members of other race/ethnicity groups.

Data source: Medicare 5% sample and ESRD database. January 1, 2019 point prevalent (non-ESRD) and 2019 period prevalent (ESRD) Medicare FFS beneficiaries aged ≥18 years with Part D coverage.
Figure 10.9  Per person per year Part D insurance and out-of-pocket spending for covered prescription medications in adults, by LIS status, 2019

Data source: Medicare 5% sample and ESRD database. January 1, 2019 point prevalent (non-ESRD) and 2019 period prevalent (ESRD) Medicare FFS beneficiaries aged ≥18 years with Part D coverage.

Figure 10.9  Per person per year Part D insurance and out-of-pocket spending for covered prescription medications in adults, by LIS status, 2019

Data source: Medicare 5% sample and ESRD database. January 1, 2019 point prevalent (non-ESRD) and 2019 period prevalent (ESRD) Medicare FFS beneficiaries aged ≥18 years with Part D coverage.
In 2019, mean PPPY Medicare Part D spending for beneficiaries with ESRD was 2.8 times higher and median spending was 4.7 times higher among those with the LIS than among those without the LIS (Figure 10.9). The ratio of LIS to non-LIS spending was similar between those receiving HD and PD. As expected, among beneficiaries with ESRD, out-of-pocket expenses were substantially lower for those with the LIS (mean $75, median $40) than for those without the LIS (mean $940, median $567).

Patterns by race/ethnicity observed in beneficiaries with and without the LIS differed considerably from what was observed when the whole population was examined without stratification (Figure 10.8). For example, whereas total PPPY insurance drug costs were higher for Black and Hispanic patients than for White patients overall, these costs were higher for White patients compared with Black and Hispanic patients for those with and without the LIS (Figure 10.9). This suggests that overall differences by race and ethnicity in prescription drug costs were related to differences in socioeconomic status. In the ESRD population, Part D insurance and out-of-pocket costs showed a reverse U-shaped distribution, with lower costs in the youngest and oldest age groups than for those aged 45-74 years.

**Figure 10.10** Per person per year out-of-pocket spending for Part D covered prescription medications in adults, 2009-2019

Data source: Medicare 5% sample and ESRD database. Yearly January 1 point prevalent (non-ESRD) and yearly period prevalent (ESRD) Medicare FFS beneficiaries aged ≥18 years with Part D coverage. Costs are inflation-adjusted (to 2019 dollars).

Figure 10.10 shows that inflation-adjusted out-of-pocket spending for Part D beneficiaries with ESRD declined between 2009 and 2019. The mean decreased by approximately 36% and the median by 15%, with a substantial portion of the reduction occurring between 2016 and 2019 as the “donut hole” was being phased out. Among enrollees with ESRD, the mean PPPY out-of-pocket spending was consistently lowest for those treated with HD. Mean spending was highest for patients receiving PD until 2017, after which it declined to a level similar to that of kidney transplant recipients.

Median out-of-pocket spending by beneficiaries with ESRD has been consistently lower than that of enrollees without ESRD, even though the mean was higher for those with ESRD between 2013 and 2017. The lower median out-of-pocket expenses for those with ESRD appear to be related to a larger percentage receiving the LIS. Among those receiving the LIS and among those not receiving the LIS, mean and median out-of-pocket costs were higher for patients with ESRD.
Table 10.2 Top 15 covered drug classes most commonly received by adults with ESRD, 2019

<table>
<thead>
<tr>
<th>Rank</th>
<th>Drug class</th>
<th>Hemodialysis %</th>
<th>Peritoneal Dialysis %</th>
<th>Transplant %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Phosphate binders</td>
<td>66.4</td>
<td>62.2</td>
<td>71.2</td>
</tr>
<tr>
<td>2</td>
<td>Beta blockers</td>
<td>61.7</td>
<td>61.1</td>
<td>61.8</td>
</tr>
<tr>
<td>3</td>
<td>Antibiotics</td>
<td>57.3</td>
<td>58.1</td>
<td>60.0</td>
</tr>
<tr>
<td>4</td>
<td>Statins</td>
<td>54.7</td>
<td>53.2</td>
<td>49.1</td>
</tr>
<tr>
<td>5</td>
<td>Opioids</td>
<td>44.9</td>
<td>46.3</td>
<td>45.8</td>
</tr>
<tr>
<td>6</td>
<td>Calcium channel blockers (DHP)</td>
<td>44.1</td>
<td>41.8</td>
<td>Proton pump inhibitors</td>
</tr>
<tr>
<td>7</td>
<td>Proton pump inhibitors</td>
<td>36.7</td>
<td>40.9</td>
<td>ACEi / ARBs</td>
</tr>
<tr>
<td>8</td>
<td>Statins</td>
<td>32.5</td>
<td>37.8</td>
<td>34.7</td>
</tr>
<tr>
<td>9</td>
<td>Insulin</td>
<td>29.4</td>
<td>32.9</td>
<td>31.5</td>
</tr>
<tr>
<td>10</td>
<td>Gabapentinoids</td>
<td>26.5</td>
<td>28.7</td>
<td>27.6</td>
</tr>
<tr>
<td>11</td>
<td>Loop diuretics</td>
<td>24.7</td>
<td>25.1</td>
<td>19.6</td>
</tr>
<tr>
<td>12</td>
<td>Loop diuretics</td>
<td>23.9</td>
<td>21.9</td>
<td>19.3</td>
</tr>
<tr>
<td>13</td>
<td>SSRI / SNRIs</td>
<td>21.4</td>
<td>20.4</td>
<td>18.9</td>
</tr>
<tr>
<td>14</td>
<td>Antiplatelets</td>
<td>19.9</td>
<td>19.5</td>
<td>16.6</td>
</tr>
<tr>
<td>15</td>
<td>Beta adrenergics</td>
<td>19.8</td>
<td>18.7</td>
<td>15.2</td>
</tr>
</tbody>
</table>


Table 10.2 shows the 15 most commonly prescribed drug classes in terms of percentage of Medicare Part D beneficiaries with at least 1 medication claim among those with ESRD in 2019. As was observed in 2018 (shown in the 2020 ADR), beta blockers, statins, and antibiotics appeared among the top 4 most commonly used drugs across recipients of all ESRD treatment modalities, with more than half receiving prescriptions for each of these drug classes. Phosphate binders were also in the top 3 for patients on dialysis. Opioid use decreased slightly across all treatment modalities in 2019 compared with 2018, but over one third of transplant recipients and almost 45% of those receiving HD were treated with opioids in 2019. Only about half of Part D beneficiaries with a kidney transplant had Part D claims for immunosuppressive medications because these agents are covered by Part B for the first 3 years following transplantation. Therefore, a substantial portion of prescriptions for kidney transplant immunosuppressive agents are not covered under the Part D program.
Table 10.3 Top 15 covered drug classes by Part D insurance spending in adults with ESRD, 2019

<table>
<thead>
<tr>
<th>Drug class</th>
<th>Hemodialysis</th>
<th>Peritoneal Dialysis</th>
<th>Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Insurance spending</td>
<td>Per Part D enrollee</td>
<td>Per drug class user</td>
</tr>
<tr>
<td>1   Phosphate binders</td>
<td>$902.6</td>
<td>$2,900</td>
<td>$4.140</td>
</tr>
<tr>
<td>2   Insulin</td>
<td>$270.4</td>
<td>$895</td>
<td>$2,690</td>
</tr>
<tr>
<td>3   Cancer and adjunctive agents</td>
<td>$178.3</td>
<td>$590</td>
<td>$15.339</td>
</tr>
<tr>
<td>4   Antiretrovirals</td>
<td>$110.2</td>
<td>$365</td>
<td>$23.389</td>
</tr>
<tr>
<td>5   Direct oral anticoagulants</td>
<td>$71.1</td>
<td>$235</td>
<td>$2,253</td>
</tr>
<tr>
<td>6   Pulmonary hypertens.</td>
<td>$55.4</td>
<td>$163</td>
<td>$38.926</td>
</tr>
<tr>
<td>7   Beta adrenergens</td>
<td>$55.2</td>
<td>$163</td>
<td>$896</td>
</tr>
<tr>
<td>8   Immunomodulators</td>
<td>$52.4</td>
<td>$174</td>
<td>$91.671</td>
</tr>
<tr>
<td>9   DPP-4 inhibitors</td>
<td>$49.0</td>
<td>$162</td>
<td>$3,280</td>
</tr>
<tr>
<td>10  Antibiotics</td>
<td>$42.6</td>
<td>$141</td>
<td>$228</td>
</tr>
<tr>
<td>11  Hepatitis agents</td>
<td>$36.8</td>
<td>$122</td>
<td>$15.924</td>
</tr>
<tr>
<td>12  Proteins</td>
<td>$32.5</td>
<td>$108</td>
<td>$4.994</td>
</tr>
<tr>
<td>13  Gabapent.</td>
<td>$27.2</td>
<td>$90</td>
<td>$345</td>
</tr>
<tr>
<td>14  Anti-inflammatory agents(excludes NSAIDs)</td>
<td>$26.0</td>
<td>$86</td>
<td>$28,032</td>
</tr>
<tr>
<td>15  Potassium binders</td>
<td>$25.2</td>
<td>$83</td>
<td>$1,398</td>
</tr>
<tr>
<td>Total insurance spending</td>
<td>$2,456.5</td>
<td>$8,136</td>
<td>$196.5</td>
</tr>
</tbody>
</table>


Table 10.3 shows the top 15 drug classes by insurance spending among Medicare Part D beneficiaries with ESRD by treatment modality. New this year, we include the cost per enrollee receiving each class of medication. The top 4 drug classes in 2019 were unchanged from 2018 for each modality (results for 2018 are shown in the 2020 ADR). Treatment of DM remained extremely expensive. Insulin accounted for the largest percentage of Part D spending of any medication class among kidney transplant recipients and was behind only phosphorus binders among patients receiving dialysis. DPP-4is and/or GLP-1RAs were also in the top 15 most expensive for all modalities. Treatment of DM with these 3 classes alone accounts for one quarter of all Part D costs for transplant recipients and 17.3% of costs among patients receiving PD.

Despite the stability of the top 4 categories, there were some noteworthy changes in spending by drug class in 2019. Across all modalities, cost of treatment for hepatitis decreased. For example, among Part D beneficiaries treated with HD, spending on these drugs decreased from $57.9 million in 2018 to $36.8 million in 2019. The cost per recipient of these drugs was high, however, ranging from $10,931 to $15,924. Costs for direct oral anticoagulants (DOACs) increased for enrollees across all modalities of ESRD therapy. For example, whereas DOACs were the 10th most expensive class in 2018 at $44.4 million, they moved into the 5th position in 2019, at $71.1 million. Calcimimetics fell out of the top 15 among Part D beneficiaries on HD and PD after the shift of these agents to Part B under TDAPA. However, calcimimetics remained the second-most expensive class among kidney transplant recipients at $71.5 million and >10% of total Part D expenditures for this population. Given the continuing reductions in prescription of opioid analgesics, these agents, which were the 15th most expensive among patients receiving HD in 2018, were no longer among the 15 most expensive classes in 2019. Instead, potassium binders entered the list at $25.3 million dollars and $1398 per recipient of this class of medication.
Figure 10.11 Percentage of adults with ESRD receiving medications for cardiovascular disease, 2019

Data source: ESRD database. January 1, 2019 point prevalent Medicare FFS beneficiaries aged ≥18 years with Part D coverage and the specific cardiovascular disease of interest. Abbreviations: ARNIs, angiotensin receptor neprilysin inhibitors; BBs, beta blockers; CCBs, calcium channel blockers; DHP, dihydropyridines; LLT, lipid-lowering therapy; MRAs, mineralocorticoid receptor antagonists; NVAF, nonvalvular atrial fibrillation; OACs, oral anticoagulants; RAASi, renin-angiotensin-aldosterone system inhibitors.
Figure 10.11 shows the percentage of Part D beneficiaries with ESRD and cardiovascular conditions receiving cardiovascular medications and combinations of agents. Among beneficiaries with CAD, about three quarters of patients treated with dialysis received a beta blocker during 2019, and the fraction treated with lipid lowering therapy was also about three quarters. The percentages were slightly higher among transplant recipients at >80% for each. Over half of patients received both of these medication classes. Less than half of dialysis patients and transplant recipients were treated with ACEi/ARBs, and most of these were also receiving beta blockers and/or lipid lowering therapy. Very few patients did not receive any of these 3 classes of medications (7.2% of dialysis patients and 3.8% of transplant recipients).

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Just over three quarters of those with heart failure (HF) were treated with beta blockers, but under half received renin-angiotensin-aldosterone system inhibitors, and <10% received mineralocorticoid receptor antagonists. Over half of Part D beneficiaries receiving dialysis with non-valvular atrial fibrillation and approximately two thirds of those with a kidney transplant received oral anticoagulation.
Sevelamer carbonate was the most commonly prescribed phosphate binder among Part D beneficiaries receiving dialysis in 2019 (Figure 10.12a). Although a higher percentage of patients on HD received most phosphate binders, the differences between those on HD and PD were small. Younger patients were more likely to receive phosphate binders than older patients. Patients with the LIS were more likely to receive all phosphate binders. This difference was particularly pronounced for sevelamer carbonate (47.3% among those on HD with the LIS vs. 29.6% among those without the LIS, for example). However, calcium carbonate could be used more often among patients without the LIS, but its use cannot be tracked as Part D plans do not typically cover over-the-counter drugs.
Figure 10.12b shows changes in use of phosphate binders among Part D beneficiaries receiving dialysis from 2015 to 2019. Use of calcium acetate, sevelamer, and lanthanum binders decreased. During the same period, use of iron-containing phosphate binders increased, with ferric citrate use reaching 5.4% and sucroferric oxyhydroxide 5.8% in 2019; use of iron-containing phosphate binders was higher in PD than in HD patients.

Figure 10.13a Percentage of adults with ESRD receiving potassium binders, 2015-2019

Data source: ESRD database. Yearly period prevalent Medicare FFS beneficiaries aged ≥18 years with Part D coverage.
Use of potassium binders generally increased from 2015 to 2019, particularly among Part D beneficiaries treated with HD (Figure 10.16a). For beneficiaries on HD and PD and those with a kidney transplant, use of patiromer steadily increased with a concomitant decrease in sodium polystyrene sulfonate. A small amount of sodium zirconium cyclosilicate use began in 2019. Younger patients, those with the LIS, and Hispanic patients were more likely to receive potassium binders than older patients, those without the LIS, and Black or White patients.
Figure 10.13b shows use of potassium binders among the subset of ESRD Part D beneficiaries receiving ACEis or ARBs from 2015 to 2019. The percentage of HD patients on ACEis or ARBs receiving potassium binders was 6.5% in 2019, only slightly higher than the overall percentage receiving potassium binders (5.8%; Figure 10.13a). Patterns of use by age, race/ethnicity, and LIS status were similar to patterns observed for the whole population.
Newer insulin analogs were by far the most frequently prescribed DM treatment among Part D beneficiaries with ESRD and type 2 DM (Figure 10.14a). Transplant recipients were more likely to be treated with newer insulins and with DM medications in general than patients receiving dialysis. Older patients were less likely to receive insulin but more likely to receive sulfonylureas and DPP-4is than younger patients. Patients eligible for the LIS were more likely to receive most DM treatments, including newer brand-name medications, than those without the LIS.
Figure 10.14b shows the percentage of Part D beneficiaries with ESRD and type 2 DM treated with DM medications each year from 2015 to 2019. Among patients undergoing HD, the percentage receiving newer insulin formulations was stable during this period at just under 40%. Use of DPP-4is and GLP-1RAs increased during this period, while the use of older insulin preparations decreased from 11.2% to 7.1% and of sulfonylureas from 10% to 8.2%. Patterns were similar for those on PD and with a kidney transplant except that the increase in use of GLP-1RAs was more pronounced, more than tripling from 2.5% in 2015 to 8.4% in 2019 among transplant recipients.

Figure 10.15a shows the per person per year Part D spending on diabetes medication in adults with ESRD and type 2 DM, 2015-2019. Costs are inflation-adjusted (to 2019 dollars).
The mean and median PPPY Medicare Part D insurance cost of DM medications among beneficiaries with ESRD and type 2 DM increased from 2015 to 2019 (Figure 10.15a). In 2019, the median Part D cost reached $2187 PPPY, and the mean was >$3500. Patient out-of-pocket costs changed little during this period. Per person Medicare Part D insurance costs were higher for younger individuals, consistent with greater use of newer insulins in younger patients. Out-of-pocket costs were higher for older patients, likely reflecting a lower percentage with the LIS (Figure 10.1). Insurance costs were higher and out-of-pocket costs lower for enrollees qualifying for the LIS.
Figure 10.15b Per person per year Part D insurance and out-of-pocket spending on diabetes medications, by users of each class, in adults with ESRD and type 2 diabetes, 2019

Data source: ESRD database. Yearly period prevalent Medicare FFS beneficiaries aged ≥18 years with Part D coverage. Abbreviations: DPP-4i, dipeptidyl peptidase 4 inhibitors; GLP-1RA, glucagon-like peptide-1 receptor agonists; INS, insulin; MEG, meglitinides; SU, sulfonylureas; TZD, thiazolidinediones.
Figure 10.16 examines the percentage of use of combinations of medications for DM among Part D beneficiaries with ESRD and type 2 DM who were treated with at least 1 such medication. Separately for each modality, the combinations used in ≥1% of patients in at least 1 year are shown. Combinations were examined in a mutually exclusive fashion. For example, a patient receiving the three-medication combination of sulfonylurea (SU), DPP-4i, and insulin (INS) would not be included in the SU+INS, DPP-4i+INS, or SU+DPP-4i categories. Furthermore, patients who were receiving monotherapy for DM are not presented.

Among patients treated with HD, the combinations involving the most expensive medications – DPP-4i plus insulin and GLP-1RA plus insulin – increased substantially from 2015 to 2019, and DPP-4i plus insulin surpassed sulfonylurea plus insulin after 2017. A similar pattern was evident for patients treated with PD except that the DPP-4i plus insulin combination was not more common than sulfonylurea plus insulin in 2019.
Figure 10.17  Percentage of adults with ESRD receiving antidepressant medications, 2015-2019

Data source: ESRD database. Yearly period prevalent Medicare FFS beneficiaries aged ≥18 years with Part D coverage.
Figure 10.18 shows the percentage of Part D beneficiaries with ESRD who received antiviral treatment each year from 2015 to 2019 by modality. There have been small increases in the percentage receiving antiviral treatment for all groups. In 2019, 30.4% of patients on HD received an antiviral during the year. The corresponding percentage for those on PD was 28.3% and for kidney transplant recipients was 26.1%. Selective serotonin reuptake inhibitors were the most commonly prescribed antidepressants for all groups. Women and White patients were more likely to be treated with antiviral than men and members of other races/ethnicities. Those receiving the LIS were slightly more likely to be treated, but the difference was smaller than for phosphate binders (Figure 10.12a).

Figure 10.18 Percentage of adults with ESRD and hepatitis C receiving antiviral treatment, 2015-2019

Data source: ESRD database. Yearly period prevalent Medicare FFS beneficiaries aged ≥18 years with Part D coverage.

Figure 10.18 shows the percentage of Part D beneficiaries with ESRD and a diagnosis of hepatitis C who received antiviral treatment each year from 2015 to 2019 by modality. Among patients receiving dialysis, antiviral treatment for hepatitis C peaked in 2016 and declined thereafter, reaching 6.6% (HD) and 6.7% (PD) in 2019. The percentage receiving treatment for hepatitis C decreased each year among patients with a kidney transplant to 9.5% in 2019, just over a quarter of the rate in 2015 (35.7%). Given that the first combination antiviral pill was approved by the U.S. Food and Drug Administration in 2014, these decreases could reflect a decreasing pool of previously untreated patients.

Patterns of treatment by age, sex, and race/ethnicity were not consistent across ESRD treatment modalities. Individuals with the LIS were slightly more likely to receive antiviral treatment.
Summary

Introduction of the Part D prescription drug benefit has resulted in profound changes for Medicare FFS beneficiaries. The benefit is heavily utilized: among beneficiaries with ESRD, fully 78% had Part D coverage as of 2019, up from approximately 66% in 2009. Further, the LIS was utilized in approximately 60% of Part D beneficiaries with ESRD. From the perspective of the research community, the existence of Part D allows for detailed study of Part D-covered drug prescribing patterns in Medicare beneficiaries with and without ESRD.

Between 2009 and 2019, total Medicare Part D spending increased by about 64% in inflation-adjusted dollars in beneficiaries with ESRD (to $3.3 billion) and approximately 44% in those without ESRD (to $67.3 billion). Over this period, the percentage of Medicare beneficiaries with ESRD who had Part D coverage increased, contributing to the relatively large overall increase in total Part D spending in beneficiaries with ESRD. Mean annual per person Part D spending on beneficiaries with ESRD increased by 53% (to $11,703) between 2009 and 2017 but then decreased by one third (to $7794), between 2017 and 2019. This decrease is likely primarily due to a shift of payment for calcimimetics (in patients receiving dialysis) from Medicare Part D to Part B under the TDAPA program and availability of generic sevelamer carbonate in 2017. Even with this shift, beneficiaries with ESRD accounted for a slightly higher share of total Part D spending in 2019 (4.8%) than in 2009 (4.0%). Despite the higher per person Part D costs for beneficiaries with ESRD, their mean and median out-of-pocket Part D costs were lower than for beneficiaries without ESRD in 2019 because more beneficiaries with ESRD qualified for the LIS.

Perhaps not surprisingly, beta blockers, statins, and antibiotics appeared among the 5 most commonly prescribed drugs across recipients of all ESRD treatment modalities, with more than half of beneficiaries receiving prescriptions for each of these drugs. Calcimimetics no longer appear on the list of most expensive Part D-covered medications among HD or PD patients, because of the shift in payment under the TDAPA. However, calcimimetics remained the second-most costly class of medications among kidney transplant recipients.

In this year’s ADR, we undertook a closer examination of treatment of type 2 DM among Part D beneficiaries with ESRD. The mean and median Medicare Part D cost of medications for the treatment of DM among patients with ESRD and type 2 DM increased from 2015 to 2019. In 2019, the median cost PPPY reached $2187, and the mean was >$3500. Overall, GLP-1RAs were most expensive in terms of Medicare Part D spending in 2019 (mean cost of $4918 per person, median $4475), followed by DPP-4is (mean $3359 per person, median $3397) and newer insulins (mean $3496 per person, median $2249). The high cost of treating DM is related to increased use of newer expensive insulin, DPP-4is, GLP-1RAs and of combinations of these medications. Although clinical trial data show a benefit of GLP-1RAs in reducing cardiovascular events, patients with ESRD were not included in these trials. Given the high percentage of patients with ESRD who also have DM, high quality evidence comparing the relative benefits of the many different regimens available to treat DM among patients with ESRD, including GLP-1RA, is needed (Kidney Disease: Improving Global Outcomes (KDIGO) Diabetes Workgroup, 2020).

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 10. Prescription Drug Coverage in Patients with ESRD, located here: https://adr.usrds.org/2021/end-stage-renal-disease/10-prescription-drug-coverage-in-patients-with-esrd

References

End Stage Renal Disease: Chapter 11

International Comparisons

Highlights

- The highest incidence of treated end stage renal disease (ESRD) in 2019 was observed in the Mexican state of Jalisco (570 per million population, or pmp), Taiwan (529 pmp), the Mexican state of Aguascalientes (483 pmp), and the U.S. (410 pmp) (Figure 11.1). Areas with an ESRD incidence <100 pmp were Switzerland (99 pmp), Finland (96 pmp), Russia (86 pmp), Serbia (82 pmp), Estonia (74 pmp), Bangladesh (64 pmp), Latvia (63 pmp), and Ukraine (40 pmp).

- The incidence of treated ESRD was particularly high in Asia: in addition to Taiwan, ESRD incidence ≥300 pmp was reported in Thailand (377 pmp), South Korea (360 pmp), Singapore (337 pmp), Indonesia (306 pmp), and Japan (306 pmp) (Figure 11.2). Thus, 6 of the top 9 countries or regions were in Asia.

- Countries or regions where more than half of all incident cases of treated ESRD were attributed to diabetes in 2019 were Singapore (67.5%), Qatar (63.9%), and Hong Kong (52.9%) (Figure 11.4a).

- The highest prevalence of treated ESRD in 2019 was observed in Taiwan (3679 pmp), Japan (2696 pmp), the U.S. (2465 pmp), Singapore (2327 pmp), South Korea (2100 pmp), Thailand (2063 pmp), Aguascalientes in Mexico (2020 pmp), and Portugal (2008 pmp) (Figure 11.9).

- Only in Norway (68%), the Netherlands (65%), Finland (62%), Scotland (61%), Sweden (60%), England/Wales/Northern Ireland (57%), Spain (55%), Ireland (55%), Denmark (54%), Latvia (54%), and Switzerland (54%) were more than half of prevalent patients with ESRD treated with a kidney transplant; in Japan, only 2% of prevalent patients were treated with a kidney transplant (Figure 11.13). Hong Kong (44%) was the only country or region in which more than 40% of patients on dialysis received PD.

- Only in Hong Kong were more than half of patients on dialysis receiving a home-based therapy in 2019 (69% PD, 3% home HD) (Figure 11.16). Areas where a quarter or more of patients received a home-based therapy were the Mexican states of Jalisco (46% PD, no home HD) and Aguascalientes (35% PD, no home HD), New Zealand (30% PD, 14% home HD), Denmark (20% PD, 7% home HD), Colombia (26% PD, no home HD), Australia (17% PD, 8% home HD), and Canada (20% PD, 5% home HD).

- The incidence of kidney transplantation was highest in the U.S. (75 pmp), Spain (73 pmp), and Jalisco in Mexico (72 pmp) (Figure 11.17a). Areas where the prevalence was ≤10 pmp were Russia, North Macedonia, Hong Kong, Bosnia and Herzegovina, Montenegro, Ukraine, Serbia, and Bangladesh.

- There was substantial geographic variation in use of deceased versus living donor kidneys for transplantation (Figure 11.19). In Poland, Estonia, the Dutch-speaking part of Belgium, the French-speaking part of Belgium, the Czech Republic, Spain, and Italy, ≥90% of kidney transplants were from deceased donors. Deceased donors made up ≤15% of donors in the Jalisco and Aguascalientes states of Mexico and Japan; in Bangladesh and Montenegro, no transplants originated from deceased donors.

- Countries or regions with the highest prevalence of individuals with a functioning kidney transplant in 2019 were Spain (748 pmp), Jalisco in Mexico (740 pmp), the U.S. (729 pmp), and Portugal (707 pmp) (Figure 11.20). Countries or regions where the prevalence was <100 pmp were Romania (98 pmp), Thailand (93 pmp), Russia (69 pmp), Japan (57 pmp), Ukraine (33 pmp), Bangladesh (6 pmp), and Montenegro (5 pmp).
Introduction

The focus of this chapter is international comparisons of treated ESRD incidence and prevalence. We first report incidence of treated ESRD by country or region in 2019 and the change in treated ESRD incidence around the world in the decade between 2009 and 2019. We next show rates of ESRD attributed to diabetes globally, followed by figures showing the incidence of treated ESRD by age and sex worldwide.

We then move to the prevalence of ESRD. In a fashion analogous to ESRD incidence, we show the prevalence of treated ESRD by country or region in 2019 as well as the change in prevalence of treated ESRD between 2009 and 2019. The prevalence of treated ESRD by age and sex, across countries or regions, is shown next.

The prevalence of dialysis worldwide and its change over time are then reported, followed by a display of the distribution of dialysis modalities employed worldwide. Finally, global rates and trends in kidney transplantation globally, kidney donor source, are shown.

Methods

The findings in this chapter are based on analyses of data collected and generously supplied by each participating country or region. Each entrant completes a standardized collection form (located on the USRDS website). For the 2021 Annual Data Report, 56 countries or regions participated. Every effort is made by the USRDS to contact individuals or authorities across the world who may have access to the relevant data, and we welcome new contributors each year.

Because methods of data collection vary considerably by country, readers should exercise caution when making direct cross-country comparisons. First, data collection can improve over time in countries or regions, especially for incidence of treated ESRD. Second, in the U.S. and some other countries, regulatory and reimbursement frameworks make nearly complete acquisition of data on treated ESRD possible, but this is not the case in many other countries or regions because regulatory and reimbursement frameworks differ considerably worldwide. Note that in the U.S. and other countries or regions, information is available only for treated ESRD; many individuals with ESRD do not undergo treatment (maintenance dialysis or kidney transplantation, also known as kidney replacement therapy). This could be either because conservative care is deliberately selected or because kidney replacement therapy is not available. In addition to variation in their ability to provide access to dialysis or kidney transplantation for ESRD, countries or regions also vary in the specific dialysis modalities utilized. Finally, countries vary in geographic, economic, cultural, historical, religious, and other societal ways that doubtless affect the treatment of kidney disease in myriad ways.

Note that data presented in this chapter are not adjusted or standardized in any way; age, sex, and race/ethnicity mixtures differ considerably between countries or regions. As such, this chapter is designed to provide only broad descriptive data about the landscape of treated ESRD around the world.

Data tables for the content presented in this chapter can be found in Reference Table N. A complete explanation of the analytical methods used to generate the study cohorts and figures in this chapter can be found in the Chapter 11 section of the ESRD Analytical Methods.

Data collection for this chapter is possible only through the generous efforts of individuals in many participating countries who contribute to the USRDS mission of kidney disease epidemiology. The USRDS gratefully acknowledges their contributions and welcomes additional data from other contributors (see the full acknowledgment at the end of the chapter).
Figure 11.1 displays the incidence of treated ESRD in 2019 for countries or regions that supplied data to the USRDS. Areas that had an incidence of ≥400 persons with ESRD per million population were the Mexican state of Jalisco (570 pmp), Taiwan (529 pmp), the Mexican state of Aguascalientes (483 pmp), and the U.S. (410 pmp). Areas with an ESRD incidence <100 pmp were Switzerland (99 pmp), Finland (96 pmp), Russia (86 pmp), Serbia (82 pmp), Estonia (74 pmp), Bangladesh (64 pmp), Latvia (63 pmp), and Ukraine (40 pmp).
Jalisco, Mexico (570 pmp), Taiwan (529 pmp), Aguascalientes, Mexico (483 pmp), and the U.S. (410 pmp) had the highest incidence of treated ESRD in 2019 (Figure 11.2). Many Asian countries or regions also had high incidence: in addition to Taiwan, ESRD incidence ≥300 pmp was reported in Thailand (377 pmp), South Korea (360 pmp), Singapore (337 pmp), Indonesia (306 pmp), and Japan (306 pmp). Thus, 6 of the top 9 countries or regions were in Asia.

Data source: Special analysis, USRDS ESRD Database. Data presented only for countries from which relevant information was available. The incidence is unadjusted. Data for Mexico includes Jalisco and Aguascalientes only. NOTE: Data collection methods vary across countries, requiring caution in making direct comparisons.
In 2019, relative to 2009, incidence of treated ESRD was nearly 5-fold higher in Bangladesh, more than 3-fold higher in Thailand and Indonesia, 2.5-fold higher in Russia, and more than 2-fold higher in Brazil and South Korea (Figure 11.3a). In the U.S., which is included for purposes of comparison, incidence increased approximately 11%.
Hungary (39.9 pmp), Thailand (24.4 pmp), and South Korea (19.4 pmp) had the largest average yearly increase in the incidence of treated ESRD (Figure 11.3b). Indonesia, Jalisco (Mexico), Singapore, Taiwan, and Malaysia also had average yearly increases ≥10 pmp. Incidence decreased in 11 countries or regions, most notably in Turkey (-7.1 pmp).
There was large variation in the percentage of treated ESRD attributed to diabetes globally (Figure 11.4a). Countries or regions where more than half of all incident cases of treated ESRD were attributed to diabetes in 2019 were Singapore (67.5%), Qatar (63.9%), and Hong Kong (52.9%). Countries or regions where <20% of incident cases were attributed to diabetes were in the Dutch-speaking region of Belgium, the Netherlands, Norway, Italy, mainland China, Thailand, Romania, and Iceland (the lowest, at a mere 7.7%).

Data source: Special analysis, USRDS ESRD Database. Data presented only for countries from which relevant information was available. NOTE: Data collection methods vary across countries, requiring caution in making direct comparisons.
Figure 11.4b Incidence of treated ESRD attributed to diabetes, by country or region, 2019

Jalisco, Mexico (274 pmp), Taiwan (253 pmp), Singapore (228 pmp), and the U.S. (191 pmp) had the highest incidence of treated ESRD attributed to diabetes in 2019 (Figure 11.4.b). Switzerland (20 pmp), Russia (19 pmp), Latvia (17 pmp), Estonia (16 pmp), mainland China (16 pmp), Ukraine (10 pmp), and Iceland (8 pmp) had the lowest.

Data source: Special analysis, USRDS ESRD Database. Data presented only for countries from which relevant information was available.
NOTE: Data collection methods vary across countries, requiring caution in making direct comparisons.
South Korea (10.0 pmp), Singapore (9.1 pmp), Malaysia (8.4 pmp), and Qatar (8.2 pmp) had the largest yearly increases in the incidence of treated ESRD attributable to diabetes between 2009 and 2019 (Figure 11.5). Incidence of treated ESRD attributable to diabetes decreased in Japan, Bosnia and Herzegovina, Hungary, Sweden, the Dutch-speaking region of Belgium, Italy, the state of Jalisco in Mexico, Iceland, and Austria.
The correlation between percentage change in the incidence of treated ESRD attributed to any cause and the percentage change attributed to diabetes appears to be strongest in Asia and Russia (with Qatar being an outlier; Figure 11.6). This suggests that diabetes drove the growth of incident (treated) ESRD most strongly in Asia.
Incidence of treated ESRD in 2019 is shown by 4 age groups in Figure 11.7. In most (although not all) developed countries in the West (e.g., the U.S., Canada, England/Wales/Northern Ireland, France, Iceland, Greece, Israel, Spain, Finland, Norway, Sweden, Austria, Italy, and Switzerland), the highest incidence of treated ESRD occurred in individuals aged ≥75 years; this was also the case in Japan. In some countries or regions, such as Aguascalientes in Mexico, Singapore, Argentina, New Zealand, Scotland, Romania, Hong Kong, Australia, Russia, Denmark, Montenegro, Estonia, Latvia, Ukraine, and Serbia, incidence was higher in individuals aged 64-75 years than in individuals aged ≥75 years.
In every country or region, the incidence of treated ESRD was higher in men than women (Figure 11.8). Note that in many countries or regions, the ratio was 2:1 or even higher.

Data source: Special analysis, USRDS ESRD Database. Data presented only for countries from which relevant information was available. NOTE: Data collection methods vary across countries, requiring caution in making direct comparisons.
The prevalence of treated ESRD varied by more than 30-fold across reporting countries or regions (Figure 11.9). Countries or regions with the highest prevalence of treated ESRD in 2019 were Taiwan (3679 pmp), Japan (2696 pmp), the U.S. (2465 pmp), Singapore (2327 pmp), South Korea (2100 pmp), Thailand (2063 pmp), Aguascalientes in Mexico (2020 pmp), and Portugal (2008 pmp). Thus, 5 of the 7 countries or regions where the prevalence exceeded 2000 pmp were in Asia. Countries or regions where the prevalence was <500 pmp were Russia, Montenegro, Ukraine, and Bangladesh.
The prevalence of treated ESRD was generally higher in individuals aged 65-74 and ≥75 years than among younger individuals (Figure 11.10). However, in some countries or regions (Scotland, New Zealand, Hong Kong, Estonia, Latvia, Russia, Montenegro, and Ukraine), the prevalence was higher among individuals aged 45-64 years than among those aged ≥75 years.
In all reporting countries or regions, the prevalence of ESRD was higher in men than in women (Figure 11.11). In many countries or regions, the prevalence was 50% higher (or more) in men than in women.
Figure 11.12a  Prevalence of treated ESRD in countries or regions with the largest percentage increase in prevalence, 2009 versus 2019

Indonesia had the largest percentage increase in prevalence of treated ESRD between 2009 and 2019 – staggeringly, treated prevalence grew from 28 pmp to 973 pmp; the rate was therefore 35 times as high in 2019 as in 2009. In Thailand, prevalence in 2019 was nearly 4-fold higher than in 2009. In Russia, Romania, Brazil, Colombia, and South Korea, prevalence roughly doubled over this period. By comparison, during this period, the percentage increased in the U.S. by about one third (35.4%).

Data source: Special analysis, USRDS ESRD Database. Data presented only for countries from which relevant information were available. (a) Ten countries having the highest percentage rise in 2018/19 versus that in 2009/10, plus the U.S. NOTE: Data collection methods vary across countries, requiring caution in making direct comparisons.
The 6 countries or regions with the largest average yearly increase in the prevalence of treated ESRD were in Asia: Thailand (156.8 pmp), South Korea (105.4 pmp), Taiwan (97.8 pmp), Singapore (82.0 pmp), Indonesia (81.3 pmp), and Malaysia (69.3 pmp) (Figure 11.12b); the U.S. ranked seventh (67.0 pmp). In contrast, the growth in Bangladesh was 0.8 pmp, and in Qatar, the change was nil. The only country or region in which prevalence decreased was Hungary.
Only in Norway (68%), the Netherlands (65%), Finland (62%), Sweden (60%), England/Wales/Northern Ireland (57%), Spain (55%), Ireland (55%), Denmark (54%), Latvia (54%), and Switzerland (54%) were more than half of prevalent patients with ESRD treated with a kidney transplant (Figure 11.13). In Japan, only 2% of prevalent patients were treated with a kidney transplant. Worldwide, HD was the predominant treatment modality for ESRD. Hong Kong (44%) was the only country or region in which more than 40% of patients on dialysis received PD; only 18% received in-center HD. Other areas where home-based therapies (PD and home HD) were relatively common, compared with in-center HD, were Aguascalientes and Jalisco in Mexico, Colombia, and New Zealand (all 18% or higher).
The prevalence of individuals receiving dialysis among the general population in 2019 was highest, by far, in Taiwan (3510 pmp) (Figure 11.14). Other countries or regions where the prevalence exceeded 1500 pmp were Japan (2639 pmp), Thailand (1969 pmp), Singapore (1926 pmp), the U.S. (1736 pmp), and South Korea (1692 pmp). The prevalence was <300 pmp in Iceland (241 pmp), Latvia (239 pmp), Ukraine (209 pmp), and Bangladesh (112 pmp).

Data source: Special analysis, USRDS ESRD Database. Data presented only for countries from which relevant information was available.

NOTE: Data collection methods vary across countries, requiring caution in making direct comparisons.
Indonesia had the largest increase in prevalence of patients receiving dialysis between 2009 and 2019: prevalence was nearly 35-fold higher. In Thailand, prevalence nearly quadrupled. In Russia the increase was nearly 2.5-fold, and in Romania and South Korea, prevalence roughly doubled. During this period, by comparison, the prevalence of dialysis treatment increased in the U.S. by 33%.
With the exception of Romania, all of the countries or regions in which the average yearly increase in the prevalence of dialysis between 2009 and 2019 exceeded 50.0 pmp were in Asia: Thailand (148.4 pmp), Taiwan (89.3 pmp), South Korea (86.5 pmp), Indonesia (83.9), Singapore (77.6 pmp), and Malaysia (70.5 pmp) (Figure 11.15b). The yearly change was 57.0 pmp in Romania and, for comparison, 45.4 pmp in the U.S.. The average yearly increase was ≤1.0 pmp in Iceland, Bangladesh, and Sweden, and there was a decrease in the Netherlands, Scotland, and Denmark.

Data source: Special analyses, USRDS ESRD Database. (b) Estimates derived from linear regression. NOTE: Data collection methods vary across countries, suggesting caution in making direct comparisons.
Only in Hong Kong were more than half of patients on dialysis receiving a home-based therapy as of 2019 (69% PD, 3% home HD) (Figure 11.16). Areas where a quarter or more of patients received a home-based therapy were the Mexican states of Jalisco (46% PD, no home HD) and Aguascalientes (35% PD, no home HD), New Zealand (30% PD, 14% home HD), Denmark (20% PD, 7% home HD), Colombia (26% PD, no home HD), Australia (17% PD, 8% home HD), and Canada (20% PD, 5% home HD). Areas where ≤5% of patients received a home-based therapy were Poland, Japan, Bangladesh, and North Macedonia.

Data source: Special analysis, USRDS ESRD Database. Data presented only for countries from which relevant information was available.

Denominator was calculated as the sum of patients receiving HD, PD, Home HD; does not include patients with other/unknown modality.

NOTE: Data collection methods vary across countries, requiring caution in making direct comparisons.
The incidence of kidney transplantation varied by 2 orders of magnitude among reporting countries or regions in 2019 (Figure 11.17a). Incidence of kidney transplantation was highest in the U.S. (75 pmp), Spain (73 pmp), and Jalisco in Mexico (72 pmp). Other areas were the incidence was ≥50 pmp were Scotland (56 pmp), Finland (56 pmp), England/Wales/Northern Ireland (54 pmp), France (54 pmp), the Netherlands (53 pmp), Aguascalientes in Mexico (52 pmp), Canada (51 pmp), Israel (50 pmp), and Portugal (50 pmp). Areas where the incidence was ≤10 pmp were Russia, North Macedonia, Hong Kong, Bosnia and Herzegovina, Montenegro, Ukraine, Serbia, and Bangladesh.
Figure 11.17b  Kidney transplantation in patients receiving dialysis, by country or region, 2019

Norway (154 per thousand), Finland (154 per thousand), the Netherlands (145 per thousand), and Scotland (144 per thousand) had the highest incidence of kidney transplantation among patients receiving dialysis in 2019 (Figure 11.17b). Areas where the incidence was ≤10 per thousand were Romania, Hong Kong, Bosnia and Herzegovina, Japan, Thailand, Taiwan, and Serbia.

Data source: Special analysis, USRDS ESRD Database. Data presented only for countries from which relevant information was available.
NOTE: Data collection methods vary across countries, requiring caution in making direct comparisons.
Figure 11.18a Incidence of kidney transplantation in countries or regions with the largest percentage increase in transplantation, 2009 versus 2019

Qatar had the largest percentage increase in the incidence of kidney transplantation between 2009 and 2019, increasing about 17-fold (Figure 11.18a). Incidence roughly doubled in Thailand and in Saudi Arabia. Countries or regions with a >50% increase were Turkey, South Korea, Israel, New Zealand, and Romania.

Data source: Special analysis, USRDS ESRD Database. (a) Ten countries having the highest percentage rise in kidney transplantation: 2018/19 versus that in 2009/10, plus the U.S. NOTE: Data collection methods vary across countries, requiring caution in making direct comparisons.
The countries or regions in which the average yearly increase in kidney transplantation was ≥2.0 pmp were Israel (2.8 pmp), Spain (2.5 pmp), Finland (2.0 pmp), Kuwait (2.0 pmp), and Scotland (2.0 pmp) (Figure 11.18b). Incidence of kidney transplantation decreased over this period in the Dutch-speaking part of Belgium, Portugal, Malaysia, the French-speaking part of Belgium, Hong Kong, Iceland, and Norway.
There was substantial geographic variation in use of deceased versus living donor kidneys for transplantation (Figure 11.19). In Poland, Estonia, the Dutch-speaking part of Belgium, the French-speaking part of Belgium, the Czech Republic, Spain, and Italy, ≥90% of kidney transplants were from deceased donors. Deceased donors made up ≤15% of donors in the Jalisco and Aguascalientes states of Mexico and Japan; in Bangladesh and Montenegro, no transplants originated from deceased donors.
Countries or regions with the highest prevalence of individuals with a functioning kidney transplant in 2019 were Spain (748 pmp), Jalisco in Mexico (740 pmp), the U.S. (729 pmp), and Portugal (707 pmp) (Figure 11.20). Countries or regions where the prevalence was <100 pmp were Romania (98 pmp), Thailand (93 pmp), Russia (69 pmp), Japan (57 pmp), Ukraine (33 pmp), Bangladesh (6 pmp), and Montenegro (5 pmp).
The Mexican state of Jalisco had the largest average yearly increase in the prevalence of individuals with a functioning kidney transplant between 2009 and 2019, at 29.8 pmp (Figure 11.21). Other countries or regions where the average yearly increase exceeded 15.0 pmp were Spain (28.7 pmp), England/Wales/Northern Ireland (20.6 pmp), the Netherlands (20.6 pmp), Scotland (20.2 pmp), Iceland (19.2 pmp), Portugal (19.1 pmp), South Korea (19.0 pmp), France (16.0 pmp), the U.S. (15.8 pmp), and Denmark (15.2 pmp). The annual prevalence of patients with a functioning kidney transplant decreased in Japan (-1.2 pmp), Malaysia (-1.2 pmp), Saudi Arabia (-5.3 pmp) and Kuwait (-23.4 pmp).
Summary
ESRD is an ever-increasing global threat to public health. Unfortunately, in the absence of comprehensive registry data on advanced non-dialysis-dependent CKD (e.g., stages 4 and 5) – data that few if any countries are likely to possess – the USRDS ADR can report only on treated ESRD. Treated ESRD refers to the provision of life-sustaining kidney replacement therapy, including in-center HD, home HD, PD and kidney transplantation.

Large numbers of individuals who reach ESRD likely have no access to kidney replacement therapy, particularly in developing countries or regions. As such, treated ESRD represents a substantial undertook of total ESRD. It is likely that the prevalent dialysis population could double, triple, or even quadruple if kidney replacement therapy were universally available (Liyanage et al., 2015). An additional reason that true ESRD counts are likely far higher than treated ESRD counts is the growing acceptance of the merits of utilizing conservative care, thereby forgoing initiation of dialysis, in appropriate candidates.

The most striking findings we report are the high and growing rates of incident treated ESRD, particularly in Asia. Of the 9 countries or regions with the highest incidence of treated ESRD in 2019, 6 were in Asia. Asian countries or regions were also overrepresented among the areas with the fastest increases in incidence of ESRD. Much of the growth in ESRD appears to be driven by diabetes; this seems to be case in Asia in particular. Asian countries or regions and developing parts of the world are also overrepresented in the growth of prevalent ESRD. Indeed, the 6 countries with the fastest annual change in ESRD prevalence were all in Asia. Collectively, these findings suggest that as countries around the world continue to develop economically and improve access to health care (and, specifically, to maintenance dialysis), the incidence and prevalence of treated ESRD are poised to grow substantially, particularly in Asia (Thomas et al., 2015). In developing countries or regions, many of which appear to have expanded access to maintenance dialysis, the increase in prevalent cases of dialysis is attributable mainly to growth in the incident population (Thomas et al., 2015). In developed countries or regions, most notably the U.S. and Taiwan, there has been substantial growth in the prevalent ESRD population (although ESRD incidence also remains high in many). Even areas in which there is universal access to ESRD care will struggle to provide healthcare for ever-aging populations with ESRD and multiple comorbid conditions.

In-center HD remains by far the most common treatment modality for ESRD globally; in only a small handful of countries or regions is transplantation used more commonly (as a percentage) than dialysis. Hong Kong was the only country or region in which >40% of individuals with ESRD received a home-based therapy; remarkably, >70% of patients on dialysis received a home-based therapy in Hong Kong. The states of Aguascalientes and Jalisco in Mexico, as well as Colombia, also have a relatively large proportion of individuals receiving home-based dialytic therapies. That relatively few developing countries or regions have successfully implemented widespread use of PD is important because the infrastructure requirements for in-center HD (the dialysis facility itself and its complex and expensive reverse osmosis system, plus systems of transportation to ferry patients to the dialysis facility) entail substantial costs that the healthcare systems in even affluent countries may not be able to support over the long term.

Unfortunately, the preferred treatment of ESRD, kidney transplantation, remains relatively uncommon. Although some countries or regions have fairly high rates of transplantation relative to their dialysis populations, rates are low in many Asian countries or regions where ESRD prevalence is either high or expected to grow substantially. Fortunately, kidney transplantation rates grew substantially between 2009 and 2019 in a few countries where the overall ESRD population is also growing, such as Qatar, Thailand, and Saudi Arabia. However, whether the growth in transplantation can keep pace with the growth of ESRD is far from certain.

Governments in countries and regions around the world, regardless of development status, will have to manage the immense economic and social costs of the growing ESRD population. Facilitating access to self-care dialysis modalities might be the best way to meet these immense future needs (Wetmore and Collins, 2015), coupled with efforts to increase access to kidney transplantation. Likewise, governments must improve access to CKD care in an attempt to blunt the anticipated rise in ESRD incidence.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 11. International Comparisons, located here: https://adr.usrds.org/2021/end-stage-renal-disease/11-international-comparisons
References


Acknowledgements

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Patient Experience: End-of-life Care for Patients with ESRD

Highlights

- A minority (17.3%) of patients enrolled in the USRDS Study of Treatment Preferences (USTATE) had a family member (inclusive of friends) who agreed to complete the family survey. Most participants did not want the study team to contact family members (51.3%) or indicated that they did not have anyone to list (10.4%).

- Most enrolled family members indicated that they had spoken with the patient about his/her treatment preferences (62.8%) and about situations that might reduce his/her quality of life so much that life would not be worth living (52.9%) (Figures 12.2, 12.3).

- Less than one-third of enrolled family members reported having had a conversation with the patient about stopping dialysis (27.3%) or receipt of hospice care (32.6%) if he/she were to become sicker or his/her goals changed (Figures 12.4, 12.5).

- Less than one third (32.0%) of enrolled family members indicated that they were extremely confident about the kind of care the patient would want to receive if he/she were very sick and unable to speak for him/herself. Level of confidence was highest for family members who indicated that the patient had documented them as a surrogate decision-maker and family members of patients who had documented his/her treatment preferences (Figure 12.6).

- Enrolled family members had relatively optimistic prognostic expectations for the patient (only 18.6% selected <5 years), but these were often less optimistic than those of the patient (Figures 12.7 & 12.8).

- Most (65.0%) family members thought the patient would prefer a focus on relieving pain and discomfort vs. life prolongation if he/she were to become very sick in the future and unable to speak for him/herself, but family members’ responses to this question often did not agree with those of the patient (Figure 12.9).

- Almost two thirds (64.4%) of family members thought that if he/she had to decide right now, the patient would definitely want to receive cardiopulmonary resuscitation (CPR), while only 24.4% thought that he/she would definitely want to be placed on a ventilator. There was more agreement between patient and family member responses to the question about CPR than to the question about placement on a ventilator (Figures 12.10, 12.11).

- Most (64.5%) family members thought the patient would prefer to die at home or at the home of a relative; patient and family member responses to this question were often different (Figure 12.12).

- Most family members thought the patient would prefer a patient-led (55.2%) or shared approach (36.6%) to decision-making about treatments to prolong life that might increase suffering, but family member responses to this question often did not agree with those of the patient (Figure 12.13).

Introduction and Methods

As part of the USRDS Special Study on Palliative and End-of-life Care, we conducted a survey—the USRDS Study of Treatment Preferences (USTATE)—among patients undergoing maintenance dialysis at non-profit dialysis facilities in the greater Seattle and Nashville areas from 2015-2018 (Bernacki et al., 2020; Johansen et al., 2021; O’Hare et al., 2019; Scherer et al., 2021). The paper survey—which included questions about a range of different domains related to palliative and end-of-life care—could be completed while patients were at the dialysis facility or returned at a later time. Patients who completed the survey were given the option of filling out the form themselves or having study staff do so based on their verbal responses. At the end of the survey, participants were asked to provide contact information for one or more family members (inclusive of friends) who could be invited to complete a parallel survey to elicit their involvement in the patient’s care and understanding and knowledge of his/her preferences and perspectives on topics related to end-of-life care. The family survey was administered by phone, and patient’s responses were recorded by staff administering the survey on a paper survey form. Patient and family member survey responses were then entered into a REDCap database by study staff members. Data entry for both the patient and family surveys was checked against copies of completed surveys by either the principal investigator or the study analyst. Enrolled patients provided written, and family members provided verbal, informed consent to participate in the survey, and all participants received a $20 gift card upon completion of the survey. This chapter focuses on the results of the family and patient surveys for USTATE participants with at least one enrolled family member.
Among 997 patients enrolled in USTATE (O'Hare, 2021), 511 (51.3%) indicated that they did not want the study team to contact a family member or friend, 104 (10.4%) indicated that they did not have anyone to list, and 382 (38.3%) provided contact information for one or more family members (Saeed et al., 2021). Listed family members of 210 patients either could not be contacted or chose not to participate in the study, and a total of 187 family members of 172 (17.3%) patients completed the family survey. Analyses presented here are based on the responses of only one family member per patient and patient-family member dyads include the 172 enrolled family members who were most involved in the patient’s care.

The mean age of the 172 USTATE patient participants with at least 1 enrolled family member was 61.0 (±14.6) years, 82 (47.7%) identified as women (no participants identified as non-binary), 95 (55.2%) identified as White, 50 (29.1%) identified as Black or African American, 27 (15.7%) identified with other racial groups (participants could select Asian, Native Hawaiian or other Pacific Islander, American Indian or Alaskan Native or enter a text response which could include identifying with more than one racial group) and 12 (7.0%) were Hispanic. The mean age of the 172 enrolled family members was 54.8 (±17.0) years, 136 (79.1%) identified as women (no family members identified as non-binary), 93 (54.1%) identified as White, 43 (25.0%) identified as Black or African American, 35 (20.9%) identified with other racial groups and 7 (4.1%) were Hispanic. A total of 67 (38.9%) of these family members were spouses or partners of the patient, 46 (26.7%) were children, 26 (15.0%) were siblings, 16 (9.3%) were parents, 9 (5.2%) were other relatives, and 8 (4.7%) were friends (Figure 12.1). A total of 102 (59.3%) family members lived with the patient and 154 (89.5%) indicated that they were the family member most involved with the patient's care. Most family members provided some care for the patient, including 56 (32.6%) who provided care "most of the time" and 57 (33.1%) who provided care "all of the time".

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**Figure 12.1 Relationship of family member with patient**

![Pie chart showing the relationship of family members with patients, with the largest segment representing spouses or partners, followed by children, siblings, parents, and other relatives or friends.]

Data source: USRDS Study of Treatment Preferences (USTATE).
Figure 12.2 Discussion about treatment preference

Data source: USRDS Study of Treatment Preferences (USTATE).

Figure 12.2 Discussion about treatment preference

Data source: USRDS Study of Treatment Preferences (USTATE).
Overall, 62.8% of family members indicated that they had spoken with the patient about treatments that he/she would or would not want were he/she to become very sick and unable to speak for him/herself (e.g., living will or advance directive) (Figure 12.2). In patients of all ages, most family members responded that they had spoken with the patient about this matter, ranging from 51.4% of family members of patients <45 years to 81.8% of family members of patients aged ≥75 years. The percentage of family members who said that they had discussed treatment preferences with the patient ranged from 61.4% of parents, children, or siblings to 70.6% of other relatives or friends. The percentage of family members who said that they had discussed treatment preferences with the patient ranged from a low of 53.5% for those of patients who responded >10 years to the prognosis question to 68.8% of those of patients who responded <5 years and 71.4% of those of patients who responded that they were not sure about prognosis. The percentage of family members who said they had discussed treatment preferences with the patient ranged from 43.6% of those who were unsure whether the patient had documented them as a surrogate decision-maker to 84.3% of those who indicated that the patient had done so. Prior discussion of treatment preferences was higher among family members of patients who showed more readiness to engage in advance care planning, ranging from 41.4% of family members of patients who had not thought about documenting their treatment preferences to 78.8% of those had done this.

**Figure 12.3** Discussion of situations that might make life not worth living

![Figure 12.3](image)

Data source: USRDS Study of Treatment Preferences (USTATE).

A total of 91 (52.9%) family members indicated that they had spoken with the patient about situations that might reduce his/her quality of life so much that life would not be worth living, ranging from 48% of family members of patients aged <45 years to 66.7% of family members of those aged ≥75 years (Figure 12.3). The percentage who had discussed this matter with the patient ranged from 50% of those who were a parent, child, or sibling of the patient to 58.8% of those who were other relatives or friends and from 45.1% of family members of patients with a prognostic expectation of >10 years to 81.3% of those with a prognostic expectation of <5 years. The percentage of family members who had discussed what would make life not worth living ranged from 34.9% of those who indicated they were not documented as the patient’s surrogate decision-maker to 71.4% of those who indicated that that they were.
Overall, 27.3% of family members reported having had a conversation with the patient about stopping dialysis were he/she to become sicker or his/her goals changed (Figure 12.4). These percentages varied relatively little by the age of the patient and ranged from 22.4% of spouses or partners to 31.8% of parents, children, or siblings of the patient. The percentage of family members who indicated they had discussed stopping dialysis with the patient also varied little by the patient’s prognostic expectation and was actually lower for patients who selected <5 years or 5-10 years than for those who selected >10 years or were not sure about prognosis. The percentage of family members who indicated that they had spoken with the patient about stopping dialysis ranged from 15.4% of those who were not sure if they were documented as the patient’s surrogate decision-maker to 31.4% of those who indicated that they were. Only 36.5% of family members of patients who indicated that he/she had spoken with someone about stopping dialysis indicated that they had spoken with the patient about this.
**Figure 12.5** Discussions about hospice

<table>
<thead>
<tr>
<th>Overall</th>
<th>Patient Age</th>
<th>Family Relationship</th>
<th>Patient Prognostic Expectation (years)</th>
<th>Surrogate</th>
<th>Patient Report of Discussion</th>
</tr>
</thead>
</table>

![Bar chart showing discussions about hospice by patient age and patient report of discussion.](chart)

Data source: USRDS Study of Treatment Preferences (USTATE).

**Figure 12.5** Discussions about hospice

<table>
<thead>
<tr>
<th>Overall</th>
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<th>Surrogate</th>
<th>Patient Report of Discussion</th>
</tr>
</thead>
</table>

![Bar chart showing discussions about hospice by patient report of discussion and patient prognostic expectation.](chart)

Data source: USRDS Study of Treatment Preferences (USTATE).
Overall, 32.6% of family members reported that they had spoken with the patient about hospice were he/she to become sicker or his/her goals changed (Figure 12.5). Percentages ranged from 24% of family members of patients aged <45 years to 39.4% of family members of patients aged ≥75 years. The percentage of family members who reported having spoken with the patient about hospice ranged from 29.9% of spouses or partners to 35.3% of other relatives or friends and from 29.6% of family members of patients whose prognostic expectation was >10 years to 37.9% of those whose prognostic expectation was 5-10 years. Percentages were highest for family members who indicated that the patient had documented them as a surrogate decision-maker (45.7%) and lowest for those who were not sure about this (20.5%). Only 48.8% of family members of patients who reported having had a conversation about hospice indicated that they had spoken with the patient about this.

**Figure 12.6** Family member's confidence in their knowledge of the patient’s serious illness preferences

Overall, 32.0% of family members indicated that they were extremely confident that they knew what kind of care the patient would want to receive if he/she were very sick and unable to speak for him/herself, 43.0% said they had quite a bit of confidence, and the remainder indicated that they were somewhat, a little, or not at all confident (Figure 12.6). The percentage of family members who were extremely confident in their knowledge of what kind of care the patient would want ranged from 28.0% of family members of patients <45 years to 40.0% of family members of patients aged 65-74 years and from 11.8% of other relatives or friends to 37.5% of parents, children, or siblings. The percentage of family members who were extremely confident did not vary greatly by how patients responded to the prognosis question but ranged from 25.6% of family members who were not sure if they were documented as the patient’s surrogate decision-maker to 40% of those who indicated that they were. The percentage of family members who were extremely confident in their knowledge of the patient’s treatment preferences also varied based on the patient’s readiness to document treatment preferences ranging from 25.6% of family members of patients who had thought about or discussed but not documented his/her treatment preferences to 37.5% of family members of patients who had documented his/her preferences.

Data source: USRDS Study of Treatment Preferences (USTATE).
When asked how long they thought people of a similar age and health conditions to the patient could expect to live, 18.6% of family members responded <5 years, 22.7% 5-10 years, and 33.1% >10 years while 24.4% were uncertain and 1.1% did not provide a response (Figure 12.7). As expected, the prognostic expectations of family members of younger patients were generally more optimistic than those of
older patients with 14.9% of family members of patients <45 years selecting <5 years and 33.8% selecting >10 years (vs. 24.2% and 15.2%, respectively of family members of patients aged ≥75 years). The percentage who were uncertain about prognosis ranged from 16% of family members of patients <45 years of age to 30% of family members of patients aged 65-74 years. Family members who identified as White had the least optimistic, and those who identified as Black had the most optimistic, prognostic expectations. The percentage of family members who responded that they were uncertain about prognosis was lowest for those who identified as White and highest for those who identified with other race groups. Compared with female family members, male family members were more likely to respond >10 years to the prognosis question and more likely to indicate that they were uncertain about prognosis. Friends or other relatives were much more likely than those who were more closely related to the patient to respond <5 years and much less likely to respond >10 years. Children, parents, and siblings were more likely than other groups to respond that they were uncertain about prognosis.

Figure 12.8 Comparison of the prognostic expectations of patients and family members

Overall, there was poor agreement between how patients and family members responded to the prognosis question (Figure 12.8). Among family members of the 16 patients who responded <5 years, 37.5% provided the same response as the patient, 25.0% responded 5-10 years, 25.0% responded >10 years, and 12.5% were uncertain. Among family members of the 71 patients who selected >10 years, 47.9% provided the same response, 14.1% responded <5 years, 16.9% responded 5-10 years, and 19.7% were uncertain. Among family members of the 56 patients who indicated they were not sure about prognosis, 33.9% provided the same response, 16.1% responded <5 years, 30.4% responded 5-10 years and 19.6% responded >10 years (percent agreement 38.2%, kappa 0.15, p<0.001). Among patient-family
member dyads with non-missing responses to the prognosis question, 46.5% of dyads included at least 1 member who responded that they were not sure, 27.1% provided a numeric response that was the same response as the patient, 17.1% provided a numeric response that was less optimistic than that of the patient, and 9.4% provided a more optimistic response. The percentage of dyads in which patients and family members provided the same numeric response to the prognosis question was highest, and the percentage where one or more family members indicated that they were uncertain about prognosis was lowest for dyads where the patient was <45 years old. Patients and family members were more likely to have provided the same numeric response to the prognosis question in dyads in which the family member identified as Black or other vs. White race. Male family members were more likely than those who were female to belong to dyads that included at least 1 member who was unsure about prognosis. Responses to the prognosis question were more closely aligned for spouses or partners than for parents, children, or siblings and other relatives or friends, whereas the responses of members of the latter group were least aligned with those of the patient and less optimistic.

Figure 12.9  Family member's values around patient's life prolongation

When asked what they thought the patient would value most if seriously ill and unable to speak for him/herself, 27.3% of family members chose extending life even if that meant having more pain and discomfort, 50.6% chose relieving pain and discomfort as much as possible, even if that meant not living as long, and 22.1% were not sure (Figure 12.9). In all age groups, more family members selected relieving pain and discomfort than extending life, ranging from 40% vs. 36.0% of family members of patients aged <45 years to 66.7% vs. 12.1% of family
members of patients aged ≥75 years. The percentage of family members who selected extending life was lower among spouses or partners (19.4%) than among parents, children, or siblings (33.0%) and other relatives or friends (29.4%). The percentage of family members who were uncertain of what the patient would value ranged from 25.4% of spouses or partners to 17.7% of other relatives or friends. The percentage of family members who selected extending life ranged from 12.5% of those for whom the patient responded <5 years to the prognosis question to 37.9% of family members of patients who responded 5-10 years. The percentage who selected relieving pain and discomfort ranged from 42.9% of those who indicated that they were not documented as the patient’s surrogate decision-maker to 60% of those who indicated that they were. The percentage who were not sure about the patient’s values ranged from 15.7% of those who indicated that they were documented as the patient’s surrogate decision-maker to 30.2% of those who indicated that they were not. Only 35.3% of family members of patients who indicated a preference for extending life also thought this is what the patient would prefer, with 38.2% indicating that they thought the patient would prioritize relief of pain and discomfort and 26.5% indicating they were not sure. Overall, 62.0% of family members of patients who indicated they would value relief of pain and discomfort also listed this as a priority, but 21.5% indicated that they thought the patient would prioritize life prolongation, and 16.5% were not sure (percent agreement 44.8%, kappa statistic 0.13, p=0.006).

Figure 12.10  Family member’s thought on patient’s preferences for cardiopulmonary resuscitation (CPR)

Data source: USRDS Study of Treatment Preferences (USTATE).
Overall, 64.0% of family members reported that if the patient had to decide right now, he/she would definitely want to receive CPR if his/her heart were to stop beating and 19.2% thought that he/she probably would want this, whereas 2.9% thought that he/she probably would not want this, 8.1% thought that he/she definitely would not want this, and 5.8% were not sure (Figure 12.10). Family members of younger patients were far more likely than those of older patients to indicate that they thought the patient would definitely want to receive CPR, ranging from 92.0% of family members of patients aged <45 years to 42.4% of family members of patients aged ≥75 years. The percentage of family members indicating that the patient would definitely want to receive CPR ranged from 31.3% of family members of patients who responded <5 years to the prognosis question to 74.7% of family members of patients who responded >10 years. Family members who indicated that the patient had documented them as a surrogate decision-maker were less likely than other family members to indicate that the patient would definitely want to receive CPR and more likely to indicate that he/she would definitely not want this. Among family members of patients who indicated that they would definitely want to receive CPR, 78% provided the same response, less than 5% thought they would probably or definitely not want CPR, and 5.6% were not sure. However, among family members of the 13 patients who indicated that they definitely would not want to receive CPR, only 46.2% provided the same response, and 53.9% thought the patient would probably or definitely want to receive CPR.

Data source: USRDS Study of Treatment Preferences (USTATE).
Overall, 24.4% of family members indicated that if the patient had to decide right now, they thought that he/she would definitely want to be put on a breathing machine (ventilator or respirator) if he/she were to become so sick that he/she could not breath on their own, and 24.4% thought the patient would probably want this, whereas 15.1% thought that he/she probably would not want this, 20.9% thought that he/she definitely would not want this, and 15.1% were not sure (Figure 12.11). The percentage of family members who indicated that the patient...
would definitely want to be put on a breathing machine ranged from 9% of family members of patients aged ≥75 years to 40% of family members of patients aged <45 years old. The percentage of family members who indicated that the patient would definitely want to be put on a breathing machine ranged from 14.9% of spouses or partners to 35.3% of other relatives and friends and from 6.3% of family members of patients who responded <5 years to the prognosis question to 28.6% of family members of patients who responded >10 years. The percentage of family members who indicated that the patient would definitely want to be put on a breathing machine ranged from 17.1% of those who said the patient had listed them as a surrogate decision-maker to 31.8% of those who indicated that this was not the case. Among family members of patients who indicated that he/she would definitely want to be placed on a breathing machine, 35.0% provided the same response, 13.3% thought the patient would probably not want to be put on a breathing machine, 11.7% thought he/she would definitely not want this and 16.7% were not sure. Among family members of patients who said he/she would definitely not want to be put on a breathing machine, 37.0% provided the same response, a similar number (37.1%) thought the patient would probably or definitely want this and 11.4% were not sure.

**Figure 12.12** Family member's thought on patient's preferred place of death

Overall, 64.5% of family members indicated that they thought the patient would prefer to die at home or in the home of a relative, 23.3% indicated he/she would prefer to die in a hospital, nursing home, or other location, and 12.2% did not respond to this question (Figure 12.12). The percentage of family members who responded that the patient would prefer to die at home or the home of a relative ranged from 48% of family members of patients aged <45 years to 66.7% of family members of patients aged ≥75 years and from 62.7% of spouses or partners to 70.6% of other relatives or friends. The percentage of family members who indicated the patient would want to die at home or the home of a relative ranged from 62.0% of family members of patients who responded >10 years to the prognosis question to 81.3% of those of patients who responded <5 years to the prognosis question. The percentage of family members who indicated that they thought the patient would prefer to die at home or in the home of a relative ranged from 53.9% of those who were not sure if the patient had documented them as a surrogate decision-maker to 69.8% of those who indicated that this was not the case. Overall, 64.8% of family members of
patients who indicated that they preferred to die at home or at the home of a relative provided the same response to the question about preferred place of death, 19.4% indicated that the patient would prefer to die somewhere other than their own home or that of a relative. Almost two thirds (66.0%) of family members of patients who indicated that they preferred to die somewhere other than their own home or that of a relative indicated that they thought the patient would prefer to die at home.

Figure 12.13 Family member’s thought about patient’s preferred decision role

When asked about what role they thought the patient would want to have in decision-making if he/she were to become very sick and had to make a decision about whether to accept treatments to prolong his/her life that might increase suffering, 55.2% selected a patient-led approach, 36.6% selected a shared approach, 4.7% selected a physician-led approach and 3.5% did not respond to the question (Figure 12.13). Regardless of the age of the patient and of his/her relationship to the patient, most family members thought the patient would prefer a patient-led or shared approach. The percentage who preferred a physician-led approach ranged from 0% of family members of patients aged <45 years to 9.1% of family members of patients aged ≥75 years. Regardless of the patient’s prognostic expectation, most family members thought the patient would prefer a patient-led approach, and a small minority indicated that he/she would prefer a physician-led approach. Those who indicated that they were documented as the patient’s surrogate decision-maker were more likely than other groups to indicate that the patient would prefer a shared approach to decision-making. Regardless of their relationship to the patient, very few family members indicated that the patient would prefer a physician-led approach. The percentage of family members who indicated that the patient would prefer a patient-led approach ranged from 38.5% of family members of patients who had documented their treatment preferences to 62.4% of family members of patients who had not thought about this. Although a minority of family members indicated that they thought that the patient would prefer a physician-led approach, the percentage was highest for patients who indicated that they had documented their treatment preferences. Among patients who preferred a patient-led decisional role, 62.4% of family members also chose this option, with most others choosing a shared decisional role. Among patients who preferred a shared approach, 46.9% of family members also selected this option, with most others choosing a patient-led approach. Among the 13 patients who preferred a physician-led role, all but one family member indicated that they thought the patient would prefer a patient-led or shared decisional role.
Summary
The USTATE family survey adds to a relatively small number of studies that have examined the roles, expectations, and knowledge of family members pertaining to the serious illness preferences of people who receive maintenance dialysis (Hines et al., 1999; Miura et al., 2006; Song et al., 2017; Song et al., 2015; Song et al., 2009; Song et al., 2012). Most USTATE participants were unwilling or unable to identify a family member to participate in the study and only 17.3% ultimately had one or more family members who enrolled in the study. As one might expect, many of these family members had a relatively high level of involvement in the patient’s care, making some of our results especially remarkable.

Most enrolled family members had spoken with the patient about his/her treatment preferences and the kinds of situations that might make life not worth living but most had not spoken with the patient about hospice or stopping dialysis were he/she to become sicker or his/her goals changed and were not extremely confident about the kind of care the patient would want to receive if very sick and unable to speak for him/herself. Family members who indicated that the patient had documented them as a surrogate decision-maker and family members of patients who indicated that they had documented his/her treatment preferences had the highest levels of confidence.

Similar to enrolled patients, family members had relatively optimistic responses to the prognosis question, with fewer than 1 in 5 choosing <5 years, but family member responses to this question were often not the same as those of the patient and tended to be less optimistic. Although most family members thought the patient would prefer a plan of care focusing on relief of pain and discomfort vs. life prolongation if he/she were to become very sick in the future and unable to speak for him/herself, their responses to this question also often differed from those of the patient. The majority of family members thought the patient would definitely want to receive CPR, but only a minority thought the patient would definitely want to be placed on a ventilator. Family member responses to the question about CPR tended to be more aligned with those of the patient than for the question about mechanical ventilation. Although most family members thought the patient would prefer to die in his/her own home or the home of a relative, responses to this question were also poorly aligned with those of the patient. Most family members of patients who indicated that they wanted to die somewhere other than home did not seem aware of this preference. Family members also appeared to have a limited understanding of the patient’s preferred decisional role.

For more information, see the USRDS Annual Data Report website, Volume 2 End Stage Renal Disease, Chapter 12. Patient Experience: End-of-life Care for Patients with ESRD, located here: https://adr.usrds.org/2021/end-stage-renal-disease/12-patient-experience-end-of-life-care-for-patients-with-esrd

References


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COVID-19

Highlights

- Among Medicare beneficiaries, the weekly incidence of COVID-19 testing steadily increased during 2020, reaching >3.5% of CKD patients, >5.5% of dialysis patients, and 2.5% of transplant patients in November and December (Figure 13.1).

- Among Medicare beneficiaries with CKD, the weekly incidence of diagnosed COVID-19 was between 0.1% and 0.2% from April to early October 2020, and then increased to 0.5% in December (Figure 13.2a). Among those undergoing dialysis, weekly incidence oscillated between 0.3% and 0.6% from April to early November, and then increased to almost 1.0% in December.

- Among Medicare beneficiaries in February 2020, the cumulative incidence of COVID-19 diagnosis by the end of 2020 was 7.7% in beneficiaries with CKD, 15.8% in beneficiaries undergoing dialysis, and 9.4% in beneficiaries with a kidney transplant (Figure 13.2b).

- For Medicare beneficiaries with CKD, states with the highest cumulative incidence of COVID-19 diagnosis by the end of 2020 were Mississippi (9.9%), South Dakota (10.1%), New York (10.2%), Louisiana (11.3%), and New Jersey (11.6%) (Figure 13.3).

- The correlation between the incidence of COVID-19 diagnosis among Medicare beneficiaries undergoing dialysis and the incidence of COVID-19 in the general population was 0.85, suggesting a strong influence of community transmission on disease incidence among dialysis patients (Figure 13.4).

- Dialysis patients diagnosed with COVID-19 in 2020 were more likely to have been exposed to a skilled nursing facility and less likely to have been performing home dialysis, compared with dialysis patients not diagnosed with COVID-19 (Figure 13.5).

- Over 24% of dialysis facilities had a cumulative incidence of COVID-19 diagnosis exceeding 20.0% of patients by the end of 2020 (Figure 13.6).

- Among patients performing dialysis in the home setting, telehealth utilization during nephrology visits was ≥20% in April and May 2020 but fell thereafter, reaching 9% in October (Figure 13.7).

- Among Medicare beneficiaries with CKD, Black beneficiaries had substantially higher incidence of COVID-19 hospitalization than White beneficiaries during the spring wave and modestly higher incidence during the summer wave (Figure 13.8). Among those undergoing dialysis, Black patients exhibited higher incidence than White patients during the spring and summer waves but not the winter wave.

- Among Medicare beneficiaries undergoing dialysis, the percentage of patients hospitalized with COVID-19 who were treated with mechanical ventilation decreased from an early peak of approximately 26% to a steady state between 10% and 15% (Figure 13.9a). The percentage of patients receiving intensive care remained between 25% and 30% for much of the year (Figure 13.9b).

- Among beneficiaries with CKD, mortality during COVID-19 hospitalization was approximately 40% during the first wave of the pandemic but decreased thereafter, reaching an average of 18% from July to December (Figure 13.10).

- Between epidemiologic week 13 of 2020 and epidemiologic week 8 of 2021, the number of prevalent dialysis patients fell from 567,303 to 555,264, an unprecedented decline of over 2% (Figure 13.11).

- Among patients undergoing dialysis, mortality was consistently elevated, relative to recent historical norms, between epidemiologic week 12 of 2020 and week 10 of 2021. Among patients with a kidney transplant, excess mortality was persistent through the second quarter of 2021 (Figure 13.12a).

- The cumulative number of deaths among dialysis patients in 2020 was 18% higher than in 2019, while the cumulative number of deaths among transplant patients in 2020 was 41% higher than in 2019 (Figure 13.12b).

- During the winter 2020 wave of the pandemic, the weekly percentage of dialysis patient deaths due to COVID-19 peaked at 19.9% (Figure 13.13).

- The weekly number of incident ESRD patients who initiated dialysis was far below historical norms during the spring 2020 wave of the pandemic (Figure 13.14).

- Kidney transplantation among prevalent dialysis patients was severely disrupted during the spring 2020 wave of the pandemic (Figure 13.17).

- During the spring 2020 wave, more than 40% of COVID-19 hospitalizations among Medicare beneficiaries with CKD involved AKI. That percentage gradually declined to slightly more than 30% by the end of 2020 (Figure 13.18).
Introduction

This year, we offer a more expansive view of the impact of the COVID-19 pandemic during 2020 on patients with CKD (aged ≥66 years) and patients with ESRD (aged ≥18 years). In many analyses, we rely on Medicare claims to identify process and clinical outcomes, so cohorts are limited to people with Medicare fee-for-service coverage. Furthermore, throughout the chapter, we track outcomes during the epidemiologic weeks of 2020. Each epidemiologic week begins on a Sunday and ends on a Saturday.

We begin by displaying the weekly incidence of COVID-19 testing, when covered by Medicare Part B, among patients with CKD, patients undergoing dialysis, and patients with a functioning kidney transplant. Subsequently, we display the weekly incidence of diagnosed COVID-19 infection in any setting, including inpatient, outpatient, and ambulatory. We also show the weekly incidence of diagnosed COVID-19 infection among patients with a billed COVID-19 test as an approximation of the widely used test positivity rate.

Among Medicare beneficiaries with CKD, undergoing dialysis, or with a functioning kidney transplant in week 6 of 2020 (beginning on February 2), we estimate the cumulative incidence of diagnosed COVID-19 infection by December 31, 2020, in overall and by state.

We display the characteristics of dialysis patients with versus without diagnosed COVID-19 infection in 2020. We also display the distribution of the cumulative incidence of COVID-19 infection among outpatients receiving maintenance dialysis among prevalent patients in week 6 of 2020 with follow-up during the remainder of the year. On a monthly basis, we assess the delivery of outpatient nephrology visits via telehealth.

Next, we display the weekly incidence of COVID-19 hospitalization among patients with CKD, undergoing dialysis, or with a functioning kidney transplant. Among those who were hospitalized, we assess weekly percentages of patients needing mechanical ventilation or intensive care. We also assess the weekly distribution of discharge status following COVID-19 hospitalization. Finally, we assess the weekly incidence of all-cause emergency department visits among patients with CKD, undergoing dialysis, or with a functioning kidney transplant.

We show the weekly incidence of death among all patients with ESRD, regardless of Medicare coverage, stratified by kidney replacement therapy (i.e., dialysis or kidney transplant). These data are displayed from week 1 of 2018 to week 26 of 2021. In 2020 and 2021, we show the percentage of deaths due primarily to COVID-19 among patients receiving maintenance dialysis.

Next, we show the weekly number of incident ESRD patients initiating dialysis from week 1 of 2018 to week 13 of 2021. Among these patients, we show mean estimated glomerular filtration rate (eGFR) and the distribution of dialysis modality. We also show the weekly incidence of kidney transplantation among prevalent dialysis patients from week 1 of 2018 to week 26 of 2021.

Finally, we show the weekly percentage of COVID-19 hospitalizations accompanied by a diagnosis of acute kidney injury among Medicare fee-for-service beneficiaries aged ≥20 years, as well as the monthly number of beneficiaries undergoing outpatient dialysis for the treatment of acute kidney injury.

Methods

In Figures 13.1, 13.2a, and 13.2b, cohorts of Medicare fee-for-service beneficiaries with CKD, undergoing dialysis, and with a functioning kidney transplant were identified during each epidemiologic week of 2020, beginning with week 6. Epidemiologic weeks extend from Sunday to Saturday. Weekly cohorts of beneficiaries with CKD were identified using a 5% sample of Medicare claims; beneficiaries were aged ≥66 years and had at least one inpatient or two outpatient claims with diagnosis codes indicating CKD during the one-year interval preceding the first day of the epidemiologic week. Weekly cohorts of beneficiaries undergoing dialysis or with a functioning kidney transplant were identified using a 100% sample of Medicare claims; all beneficiaries were ≥18 years of age; those undergoing dialysis had at least one outpatient dialysis session during the 4-week interval preceding the first day of the epidemiologic week; and those with a transplant had at least one physician claim with ICD-10 diagnosis code Z94.0 (“kidney transplant status”) during the 13-week interval preceding the first day of the epidemiologic week. COVID-19 testing was ascertained from outpatient facility claims and physician claims, whereas diagnosed COVID-19 infections were ascertained from all Medicare Parts A and B claims with ICD-10 diagnosis codes B97.29 or U07.1. Analyses of the cumulative incidence of diagnosed COVID-19 infection in Figures 13.3 and 13.6 were estimated in the cohort of prevalent patients during epidemiologic week 6 of 2020; these patients were followed until December 31, 2020. COVID-19 hospitalizations were ascertained from Medicare Part A claims with diagnosis codes B97.29 or U07.1; in most cases, code U07.1 was used as the principal discharge diagnosis. Due to incomplete data when the admission date was in late 2020 and the discharge date was in early 2021, we tracked hospitalization through only epidemiologic week 50. In Figure 13.4, data on COVID-19 rates in the general population were obtained from the CDC (Centers for Disease Control and Prevention, 2021).
Among ESRD patients, all-cause mortality was ascertained from death data in the ESRD Quality Reporting System, which collects ESRD Death Notifications and death records in the Medicare Enrollment Database. Weekly cohorts included all prevalent dialysis and transplant patients, regardless of Medicare coverage. The primary cause of death in dialysis patients was ascertained from ESRD Death Notifications. In Figures 13.14, 13.15, and 13.16, incident ESRD patients initiating dialysis, eGFR at dialysis initiation, and initial dialysis modality were ascertained from ESRD Medical Evidence Reports. Kidney transplant events in Figure 13.17 were ascertained from the ESRD Quality Reporting System.

Several figures in this supplement display incidence of events. Incidence estimates can be readily downloaded within each of those figures. For those readers who are interested in further detail, including cumulative event counts, the following file includes numerator and denominator values underlying incidence estimates: COVID-19 Supplemental Data.

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**Figure 13.1** COVID-19 testing among Medicare beneficiaries with CKD or ESRD, 2020

<table>
<thead>
<tr>
<th>Overall</th>
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<tbody>
<tr>
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<td>Transplant</td>
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</table>

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
Figure 13.1 COVID-19 testing among Medicare beneficiaries with CKD or ESRD, 2020

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
The weekly incidence of COVID-19 testing among Medicare beneficiaries with CKD or ESRD is displayed in Figure 13.1. Among beneficiaries with CKD, testing in claims emerged in week 11, and weekly testing incidence exceeded 1% of prevalent patients for the first time in week 20 (May 10-May 16). Testing incidence continued to increase through the end of July, stabilized at 2% of patients per week through the end of September, and subsequently increased through the rest of the year. Testing was more likely among beneficiaries aged 85 years or older and among women, likely partially due to testing in nursing homes.

Among beneficiaries undergoing dialysis, testing incidence exceeded 1% of patients for the first time in week 17 (April 19-April 25) and continued to increase to approximately 4% per week by the end of July. Testing incidence stabilized through the end of September, before increasing to roughly 5% of patients per week during late November and December. Testing incidence was higher among older beneficiaries. Among beneficiaries with a kidney transplant, testing incidence exceeded 1% for the first time in week 19 (May 3-May 9), before climbing to 2% per week by late July. Although testing incidence increased further later in the year, weekly incidence never exceeded 3% of patients per week. Age, sex, and race/ethnicity were not associated with testing incidence among transplant recipients.

Figure 13.2a  Weekly incidence of diagnosed COVID-19 among Medicare beneficiaries with CKD or ESRD, 2020

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
Figure 13.2a Weekly incidence of diagnosed COVID-19 among Medicare beneficiaries with CKD or ESRD, 2020

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
The weekly incidence of diagnosed COVID-19 among Medicare beneficiaries with CKD or ESRD is displayed in Figure 13.2a. Among beneficiaries with CKD, weekly incidence was between 0.1% and 0.2% from April to early October. During the rest of the year, weekly incidence steadily increased to over 0.5% in week 49 (November 29-December 5). Patients aged 85 years or older had noticeably higher weekly incidence of COVID-19 diagnosis during all of 2020, as did patients of non-White race/ethnicity through the end of September.

Among beneficiaries undergoing dialysis, weekly incidence of COVID-19 diagnosis oscillated between 0.3% and 0.6% from April to early November and subsequently escalated to approximately 1.0% in December. Older age was associated with higher incidence during the spring and again during the winter. Black race and Hispanic ethnicity were associated with higher incidence from April to September; Black patients had highest incidence during the spring, whereas Hispanic patients had highest incidence during the summer. At the end of 2020, Black patients had the lowest weekly incidence of COVID-19 diagnosis. Among patients with a kidney transplant, weekly incidence essentially mirrored trends among beneficiaries with CKD.

**Figure 13.2b** Cumulative incidence of diagnosed COVID-19 among Medicare beneficiaries with CKD or ESRD, 2020

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
Figure 13.2b  Cumulative incidence of diagnosed COVID-19 among Medicare beneficiaries with CKD or ESRD, 2020

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
The cumulative incidence of diagnosed COVID-19 among Medicare beneficiaries with CKD or ESRD is displayed in Figure 13.2b. In this figure, cohorts of patients with CKD or ESRD as of the beginning of epidemiologic week 6 (February 2) are followed during the remainder of 2020; the cumulative incidence of diagnosed COVID-19 is reported at the end of each calendar month.

The CKD cohort included 175,856 Medicare beneficiaries, among whom 13,565 people were diagnosed with COVID-19 by December 31, 2020. The cumulative incidence of COVID-19 diagnosis increased linearly between the ends of March and October, and then increased more rapidly during the last two months of the year, reaching 7.7% by the end of December. Cumulative incidence was higher in people aged 80 years or older, as well as in Black beneficiaries (9.7% by December 31, compared with 7.5% in Whites).

The dialysis cohort included 302,128 Medicare beneficiaries, among whom 47,860 people were diagnosed with COVID-19 by December 31, 2020. The cumulative incidence of COVID-19 diagnosis increased linearly between the ends of March and October, and then increased more rapidly during the last two months of the year, reaching 15.8% by the end of December. The cumulative incidence was lower in people aged 18-44 years than in other age groups. The cumulative incidence of COVID-19 diagnosis on December 31, 2020, was 14.0% in White patients, but 16.6% in Black patients and 18.7% in those of other race/ethnicity.

Finally, the transplant cohort included 58,860 Medicare beneficiaries, among whom 5,542 people were diagnosed with COVID-19 by December 31, 2020. The cumulative incidence of COVID-19 diagnosis increased linearly between the ends of March and October, and like in the CKD and dialysis cohorts, increased more rapidly during the last two months of the year, reaching 9.4% by the end of December. The cumulative incidence of COVID-19 diagnosis on December 31, 2020 was 7.8% in White patients, 11.0% in Black patients, and 12.0% in those of other race/ethnicity.

Figure 13.3  Cumulative incidence of diagnosed COVID-19 by December 31, 2020, among Medicare beneficiaries with CKD or ESRD, by state

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population. Cumulative incidence was estimated among prevalent patients in epidemiologic week 6 of 2020.
The cumulative incidence of diagnosed COVID-19, as of December 31, 2020, among Medicare beneficiaries with CKD or ESRD on February 2, 2020, is displayed in Figure 13.3. Among beneficiaries with CKD, in whom the national cumulative incidence was 7.7%, states with the highest cumulative incidence were Mississippi (9.9%), South Dakota (10.1%), New York (10.2%), Louisiana (11.3%), and New Jersey (11.6%). Among beneficiaries undergoing dialysis, in whom the national cumulative incidence was 15.8%, states with the highest cumulative incidence of COVID-19 were Mississippi (19.6%), District of Columbia (19.9%), South Dakota (20.3%), New York (22.0%), and New Jersey (22.4%). Finally, among beneficiaries with a kidney transplant, in whom the national cumulative incidence was 9.4%, states with the highest cumulative incidence were Connecticut (12.0%), New York (12.7%), North Dakota (13.4%), New Jersey (14.2%), and South Dakota (15.0%).
Figure 13.4  Weekly incidence of diagnosed COVID-19 among Medicare beneficiaries undergoing dialysis and in the general population, 2020

Figure 13.4 displays the weekly incidence of diagnosed COVID-19 among Medicare beneficiaries undergoing dialysis and in the general population. From week 12 (March 15-March 21) to the end of the year, the correlation of weekly incidence between these groups was 0.85, signaling a strong relationship between transmission of the virus in the community and the incidence of COVID-19 diagnosis among dialysis patients. However, the magnitude of the relative incidence changed throughout 2020. In March and early April, the ratio of incidence was between 8 and 10—that is, diagnosed rates of infection among patients undergoing dialysis were 8 to 10 times those in the general population. During the course of 2020, that ratio gradually declined, reaching a plateau slightly above 2 in November and December.

Figure 13.5  Characteristics of Medicare beneficiaries undergoing dialysis with versus without diagnosed COVID-19, 2020

Data source: 100% sample of Medicare population.

Data source: For ESRD, 100% sample of Medicare population. For general population, CDC: https://covid.cdc.gov/covid-data-tracker/#trends_dailycases.
Characteristics of Medicare beneficiaries undergoing dialysis in 2020, stratified by COVID-19 diagnosis status, are displayed in Figure 13.5. Patients with COVID-19 were slightly more likely to be elderly, more likely to be Black or Hispanic, and more likely to have diabetes and heart failure than were patients who were not diagnosed with COVID-19 in 2020. In other words, patients diagnosed with COVID-19 were more likely to have been exposed to a skilled nursing facility and less likely to have been performing home dialysis. Specifically, among those diagnosed with COVID-19, 21.3% received in-facility hemodialysis and had a recent history of skilled nursing facility care compared with 5.3% of those without COVID-19, and 3.6% received hemodialysis in a skilled nursing facility (vs 1.0% in those without COVID-19). Only 6.6% of patients diagnosed with COVID-19 performed home dialysis compared with 12.6% of those not diagnosed with COVID-19.

![Figure 13.6](image)

There was considerable variation in the cumulative incidence of COVID-19 diagnosis, as of December 31, 2020 within outpatient dialysis facilities with at least 25 patients on February 2, 2020 (Figure 13.6). More than 25% of facilities had a cumulative incidence among prevalent patients between 10.1% and 15.0%, and another 22.6% of facilities had a cumulative incidence between 15.1% and 20.0%. Over 24% of facilities had a cumulative incidence that exceeded 20.0%.

Data source: 100% sample of Medicare population. Cumulative incidence was estimated among prevalent patients in epidemiologic week 6 of 2020.
Figure 13.7  Telehealth delivery of outpatient nephrology visits among Medicare beneficiaries undergoing dialysis, 2020

Figure 13.7 displays utilization of telehealth for outpatient nephrology visits among Medicare beneficiaries undergoing dialysis. Among patients undergoing dialysis in a facility, telehealth utilization quickly increased to 9.3% in April 2020 and 8.9% in May 2020 but subsequently decreased to between 3.5% and 4.0% during the period from September to December. Among patients performing dialysis in the home setting, telehealth utilization increased much more, reaching 22.2% in April 2020 and 19.9% in May 2020. Utilization fell thereafter, reaching 8.8% in October 2020. As COVID-19 incidence increased in November and December, utilization of telehealth also rebounded.

Data source: 100% sample of Medicare population.

Figure 13.8  Incidence of COVID-19 hospitalization among Medicare beneficiaries with CKD or ESRD, 2020

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
Figure 13.8 Incidence of COVID-19 hospitalization among Medicare beneficiaries with CKD or ESRD, 2020

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
The weekly incidence of COVID-19 hospitalization among Medicare beneficiaries with CKD or ESRD is displayed in Figure 13.8. Among beneficiaries with CKD, weekly incidence increased to a first peak of 4 admissions per 1000 patients in week 15 (April 5-April 11) and declined through the middle of June. Weekly incidence reached a second peak of 0.9 admissions per 1000 patients in week 30 (July 19-July 25) and declined again through early October. After week 42 (October 11-October 17), weekly incidence increased linearly, reaching 2.3 admissions per 1000 patients in each of weeks 49 and 50. At the time of peaks, weekly incidence of COVID-19 hospitalization was relatively higher among patients aged 85 years or older. Black patients had substantially higher incidence of COVID-19 hospitalization than White patients during the spring wave and modestly higher incidence during the summer wave.

Among beneficiaries undergoing dialysis, the weekly incidence of COVID-19 hospitalization increased to a first peak of 4.2 admissions per 1000 patients in week 15 (April 5-April 11) and declined through the middle of June, reaching a temporary nadir of 1.3 admissions per 1000 patients. Weekly incidence reached a second peak of 3.0 admissions per 1000 patients in week 29 (July 12-July 18) and declined again through early October. During the remainder of 2020, weekly incidence of COVID-19 hospitalization steadily increased, reaching 6.0 admissions per 1000 patients in week 50. Except during the summer wave, older age was associated with higher incidence of COVID-19 hospitalization. Black patients exhibited higher incidence than White patients during the spring and summer waves but not the winter wave. Patients of other race/ethnicity—including both Hispanic and Asian patients—exhibited the highest incidence during the summer wave.

Among patients with a kidney transplant, the weekly incidence of COVID-19 hospitalization increased to a first peak of 1.7 admissions per 1000 patients in week 15 (April 5-April 11) and declined through the middle of June, reaching a temporary nadir of 0.6 admissions in June. Weekly incidence reached a second peak of 1.6 admissions per 1000 patients in week 28 (July 5-July 11) and declined again, but only until early September. After that time, the weekly incidence of COVID-19 hospitalization rapidly increased, reaching a peak of 3.2 admissions per 1000 patients in week 49 (November 29-December 5). Non-White patients exhibited higher incidence during the spring and summer waves, and to a lesser degree, during the winter wave.

Figure 13.9a  Mechanical ventilation during COVID-19 hospitalization among Medicare beneficiaries with CKD or ESRD, 2020

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
Figure 13.9a displays the percentage of COVID-19 hospitalizations during which patients received mechanical ventilation. Among Medicare beneficiaries with CKD, the percentage of hospitalized patients receiving mechanical ventilation decreased from an early peak of 31% to a steady state of between 10% and 15%, with a tendency toward 10% during December. Among beneficiaries undergoing dialysis, the percentage of hospitalized patients treated with mechanical ventilation decreased from an early peak of approximately 26% to a steady state between 10% and 15%. Finally, among beneficiaries with a kidney transplant, the percentage of hospitalized patients receiving mechanical ventilation decreased from an early peak of approximately 40% to a steady state near 20%.
Figure 13.9b  Intensive care unit utilization during COVID-19 hospitalization among Medicare beneficiaries with CKD or ESRD, 2020

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
Figure 13.9b displays the percentage of COVID-19 hospitalizations during which patients received intensive care. Among Medicare beneficiaries with CKD, the percentage of hospitalized patients receiving intensive care remained between 20% and 30% for much of the year. Among beneficiaries undergoing dialysis, the percentage of hospitalized patients receiving intensive care remained between 25% and 30% for much of the year. Finally, among beneficiaries with a kidney transplant, the percentage of hospitalized patients receiving intensive care remained between 30% and 40% for much of the year.

Figure 13.10 Discharge status after COVID-19 hospitalization among Medicare beneficiaries with CKD or ESRD, 2020

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
Figure 13.10 Discharge status after COVID-19 hospitalization among Medicare beneficiaries with CKD or ESRD, 2020

The weekly distribution of discharge status after COVID-19 hospitalization in Medicare beneficiaries with CKD or ESRD is displayed in Figure 13.10. Among beneficiaries with CKD, in-hospital mortality was approximately 40% during the first wave of the pandemic but decreased thereafter, reaching an average of 18% from July to December. As the year elapsed, live discharges (excluding those to hospice) shifted from predominantly to a skilled nursing facility to predominantly to home and home health. Among beneficiaries undergoing dialysis, in-hospital mortality decreased from approximately 30% during the first wave of the pandemic to an average of 16% from July to December. During the second half of the year, live discharges also shifted to predominantly discharges to home and home health. Beneficiaries undergoing dialysis were less likely to be discharged to hospice care. Finally, among beneficiaries with a kidney transplant, in-hospital mortality during the second half of 2020 was approximately 17%. Meanwhile, approximately 60% of hospitalized patients were discharged to home or home health.

Data source: For CKD, 5% sample of Medicare population; for ESRD, 100% sample of Medicare population.
Figure 13.11 Number of prevalent ESRD patients, 2018-2021

Data source: End Stage Renal Disease Quality Reporting System (EQRS).
The number of prevalent ESRD patients, stratified by dialysis or transplant status, is displayed in Figure 13.11. During 2018 and 2019, the number of dialysis patients steadily climbed, reaching 565,676 at the beginning of epidemiologic week 52 (December 22) of 2019. That increase continued through the first 13 weeks of 2020, with the census reaching 567,303 at the beginning of epidemiologic week 13 (March 22). Thereafter, the number of dialysis patients decreased, primarily during a first period of decline in the spring of 2020 and a second decline in the winter of 2020-2021. By the beginning of epidemiologic week 8 (February 21) of 2021, the number of dialysis patients had reached a nadir of 555,264, a drop of over 2% since the beginning of the pandemic. During the second quarter of 2021, the number of dialysis patients increased by roughly 5000. In contrast to the dialysis patient population, the number of patients with a kidney transplant generally increased during the pandemic, although at a slower rate than in 2018 and 2019. At the beginning of epidemiologic week 13 of 2020, there were 221,681 transplant recipients. That number decreased slightly during the early spring before resuming growth in May 2020. By epidemiologic week 13 of 2021, there were 225,462 transplant recipients, an increase of only 1.7% from one year earlier.

**Figure 13.12a** All-cause mortality rate among patients with ESRD, 2018-2021

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<tr>
<th>Epidemiologic week</th>
<th>Deaths per 1000 patients</th>
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<tr>
<td>2018</td>
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<tr>
<td>2021</td>
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</table>

Data source: End Stage Renal Disease Quality Reporting System (EQRS).
Weekly rates of all-cause mortality among all patients with ESRD in 2018-2021 are displayed in Figure 13.12a. Among patients undergoing dialysis, mortality was consistently elevated, relative to recent historical norms, between week 12 of 2020 and week 10 of 2021. The spring 2020 wave peaked at 4.2 deaths per 1000 patients in week 15 (April 5-April 11), approximately 40% above historical norms; the summer wave peaked at 3.4 deaths per 1000 patients in week 31 (July 26-August 1), approximately 20% above historical norms; and the winter wave peaked at 4.7 deaths per 1000 patients in week 1 of 2021 (January 3-January 9), approximately 30% above historical norms.

Among patients with a kidney transplant, the spring wave peaked at nearly 1.0 deaths per 1000 patients in week 17 (April 19-April 25), approximately 67% above historical norms. The weekly rate then receded to between 0.7 and 0.8 deaths per 1000 patients throughout the summer, a level that was approximately 50% above than historical norms. During the winter wave, the weekly rate of all-cause mortality surged to 1.2 deaths per 1000 patients, a level that was approximately 100% above historical norms. By the end of the first quarter of 2021, excess mortality was greatly attenuated but nevertheless apparent.
Figure 13.12b  Cumulative number of all-cause deaths among patients with ESRD, 2018-2021

Data source: End Stage Renal Disease Quality Reporting System (EQRS).
The cumulative number of deaths among people with ESRD in 2018, 2019, 2020, and 2021 (through epidemiologic week 26) is displayed in Figure 13.12b. These death counts reflect data in the End Stage Quality Reporting System, so as to facilitate rapid identification of deaths in 2020 and 2021. For the sake of comparability, counts from 2018 and 2019 were derived with identical methodology. Therefore, those counts do not match official counts of cumulative deaths in the Reference Tables.

Among dialysis patients, the cumulative number of deaths was 82,561 during the first 52 weeks of 2018 and 83,797 during the first 52 weeks of 2019. During the early part of 2020, the cumulative number of deaths tracked prior years, aside from growth due to the steadily increasing size of the dialysis patient population. However, beginning in March, the cumulative number of deaths deviated from historical trends. By the end of the year, there were 98,897 deaths, an increase of 18% from 2019. The cumulative number of deaths during the first half of 2021 followed the track of deaths in 2020.

Among transplant recipients, the cumulative number of deaths was 5,516 during the first 52 weeks of 2018 and 5,914 during the first 52 weeks of 2019. During the early part of 2020, the cumulative number of deaths tracked that of prior years, aside from growth due to the steadily increasing size of the transplant patient population. However, beginning in March, the cumulative number of deaths deviated from historical trends. By the end of the year, there were 8,335 deaths, an increase of 41% from 2019. The cumulative number of deaths during the first half of 2021 was even higher than during the same period in 2020, with 4559 deaths by the end of epidemiologic week 26, an increase of almost 19% from the first half of 2020.

**Figure 13.13** Percentage of deaths due primarily to COVID-19 among patients undergoing dialysis, 2020-2021

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<th>Year and epidemiologic week</th>
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Data source: End Stage Renal Disease Quality Reporting System (EQRS).

Figure 13.13 displays the percentage of deaths among dialysis patients due primarily to COVID-19, according to submissions of the ESRD Death Notification form. During the spring wave, the percentage of deaths due primarily to COVID-19 peaked at 11.8% in week 18 (April 26-May 2); during the summer wave, that percentage peaked at 10.0% in week 31 (July 26-August 2); and during the winter wave, that percentage peaked at 19.9% in week 1 of 2021 (January 3-January 9). During the first half of 2021, the percentage of deaths due primarily to COVID-19 steadily declined.
The weekly number of incident ESRD patients who initiated dialysis declined sharply during the first wave of the pandemic (Figure 13.14). In week 15 (April 5-April 11), the number of incident ESRD patients who initiated dialysis was 2030, approximately 30% below historical norms. The apparent deficit of patients initiating dialysis gradually closed during the second quarter of 2020, with weekly numbers of incident ESRD patients in line with historical norms during the second half of 2020 and the first quarter of 2021. This pattern was evident for members of all subgroups defined by age, sex, and race/ethnicity.

On a cumulative basis, the number of incident ESRD patients who initiated dialysis was 135,567 during the first 52 weeks of 2018, 139,704 during the first 52 weeks of 2019, and 134,329 during the first 52 weeks of 2020. Thus, the cumulative number of incident ESRD patients who initiated dialysis fell between 2019 and 2020, but the magnitude of the decline was nearly fully attributable to the deficit of patients during the second quarter of 2020. During the first 13 weeks of 2021, the number of incident ESRD patients who initiated dialysis was 36,205, slightly above comparable counts in 2018 and 2020, but still below the count in 2019.
Mean estimated glomerular filtration rate (eGFR) at dialysis initiation declined below historical norms during the first wave of the pandemic (Figure 13.15). Between weeks 15 (April 5-April 11) and 23 (May 31-June 6), mean eGFR was approximately 0.25 mL/min/1.73 m² lower than historical norms. During December 2020, January 2021, and February 2021, mean eGFR was approximately 0.2 mL/min/1.73 m² lower than historical norms.

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Data source: End Stage Renal Disease Quality Reporting System (EQRS).
During the first 11 weeks of 2020, the average weekly percentage of incident ESRD patients initiating home dialysis was 12.3% (Figure 13.16). Between weeks 12 (March 15-March 21) and 17 (April 19-April 25), that percentage consistently exceeded 14%, with a peak of 16.5% during week 16 (April 12-April 18). From August to December 2020, the average weekly percentage of incident ESRD patients initiating home dialysis was 14.1%. However, home dialysis utilization returned to a level nearer 12% for much of the first quarter of 2021, except for a small increase at the end of the quarter.

Weekly and cumulative numbers of kidney transplants among prevalent ESRD patients undergoing dialysis in 2018, 2019, 2020, and 2021 (through epidemiologic week 26) are displayed in Figure 13.17. The weekly number of kidney transplants averaged 263 in 2018 and 290 in 2019. In 2020, the average weekly number of kidney transplants dipped to 279, entirely due to a decline in kidney transplantation during the second quarter of the year. In fact, during the second half of 2020, the average weekly number of kidney transplants was 294—just a fraction of one percentage point lower than during the same period of 2019. During the first half of 2021, the average weekly number of kidney transplants reached 303, more than 6% higher than the pre-pandemic high during the same period of 2019.

On a cumulative basis, the number of kidney transplants was 13,683 in 2018, 15,082 in 2019, and 14,529 in 2020. During the first 26 weeks of 2021, there were 7865 kidney transplants, an increase of 14% from the same period of 2020 and an increase of 6% even from the same period of 2019.
The percentage of COVID-19 hospitalizations involving acute kidney injury (AKI) among Medicare beneficiaries is displayed in Figure 13.18. During the spring wave, more than 40% of hospitalizations involved AKI. That percentage gradually declined to slightly more than 30% by the end of 2020. Among COVID-19 hospitalizations, AKI was more common among older patients and Black patients.
The estimated number of patients undergoing outpatient dialysis for the treatment of AKI was 3820 in January 2020 and between 3300 and 3400 patients per month from February to April 2020. By May, that count fell to less than 2900 patients, a level that was sustained until a small increase during the fourth quarter of 2020. Thus, the pandemic interrupted what had been steady growth in the number of Medicare beneficiaries undergoing outpatient dialysis for the treatment of AKI between 2017 and 2019, as shown in Figure 4.13 of the CKD volume of this ADR.
Summary
The COVID-19 pandemic has changed all parts of the world, and in general, the data in this chapter of the ADR paint a vivid picture of the impact of COVID-19 on patients with ESRD. Nevertheless, with calendar year 2020 fully concluded, several overall observations merit detailed discussion.

First, although many incidence curves throughout this chapter rise and fall at predictable times in the spring, summer, and winter, following the course of the virus throughout the United States, one curve that is noticeably divergent is the incidence of COVID-19 testing. During the first wave of the pandemic, billed testing was stubbornly low. Among people with CKD, weekly incidence of COVID-19 testing did not exceed 1% until week 20 (May 10-May 16). Among people undergoing dialysis—most of whom could not shelter at home during early lockdowns—weekly incidence of COVID-19 testing did not exceed 1% until week 17 (April 19-April 25). The inability to manufacture, distribute, and deploy COVID-19 tests during the early part of the pandemic surely impeded effects at infection control.

Second, the gradient of risk for diagnosed COVID-19 infection and COVID-19 hospitalization generally had persons with non-dialysis-dependent CKD at lowest risk, those with a functioning kidney transplant at modestly higher risk, and patients undergoing dialysis at highest risk. The transplant patient population exhibited some evolution in its relative profile, as it appeared to be at higher risk, relative to people with CKD, during most of the first half of 2020, but at very similar risk during the winter wave. For dialysis patients, the weekly incidence of diagnosed COVID-19 infection was consistently between 2 and 3 times higher than the weekly incidence among people with CKD. Associations with COVID-19 hospitalization were similar, although transplant patients had persistently higher risk of hospitalization, relative to people with CKD, even late in 2020. During the course of the pandemic, there has been much discussion of prioritizing specific populations for interventions aimed at reducing COVID-19-related risks; residents of skilled nursing facilities and immunocompromised people are just two examples of many. The data in this chapter, particularly those comparing incidence of diagnosed COVID-19 infection among dialysis patients and in the general population, provide further support to the concept that people with reduced kidney function—culminating in the absence of kidney function—should have been highly prioritized for testing and vaccination, regardless of age.

Third, dialysis facilities made many efforts to control COVID-19 during 2020, including use of routine symptom assessment, universal masking of patients and staff, and cohorting of patients who were COVID-19-positive in specific facilities or specific shifts within facilities. However, the value of those (necessary) efforts must be understood in the context of disease transmission within the broader community. The correlation of weekly incidence of diagnosed COVID-19 infection among dialysis patients in the general population, was 0.85 during 2020, thus revealing community transmission of the virus to be a sort of tidal wave that overwhelmed all efforts at protecting dialysis patients from risk encountered inside the dialysis facility. State-level variability in the cumulative incidence of COVID-19 infection is particularly interesting. High incidence in New York and New Jersey can be understood through the overwhelming nature of the first wave of the pandemic, but the presence of states like North Dakota, South Dakota, and Mississippi among the states with highest cumulative incidence of COVID-19 infection likely speaks to the collateral effects of laissez-faire infection control policies on disease burden in small, vulnerable populations.

Fourth, telehealth utilization among dialysis patients, albeit strictly in the confines of outpatient nephrology visits, was not overwhelming, particularly for in-facility hemodialysis patients. In April 2020, only 9.3% of in-facility hemodialysis patients and 22.2% of home dialysis patients utilized telehealth to see their nephrologist. From that point, utilization decreased steadily, reaching a nadir in October, before rebounding some during the winter wave. This is an interesting observation, considering that some have questioned the value of frequent physician visits in the outpatient dialysis facility. It appears that nephrology providers gravitated toward continued contact with their patients in the facilities. The practical value of this contact is obvious, not only for in-facility hemodialysis, but also for both home modalities. Visual examination of the vascular access or PD catheter is never so straightforward as it is in person. Home dialysis patients who otherwise took advantage of their dialysis setting to shelter might have genuinely desired contact with their nephrologist. How telehealth for dialysis patients evolves is an open question, as are the outcomes of those who substitute telehealth for in-person interaction with healthcare professionals.

Fifth, the mortality impact of COVID-19 on patients with ESRD cannot be overstated. Excess mortality among dialysis patients was apparent for at least 51 consecutive weeks, beginning with week 12 of 2020 (March 15-March 21). In patients with a kidney transplant, excess mortality persisted even through the second quarter of 2021, possibly related to lower vaccine efficacy in this population. The net effect of persistent excess mortality has been an unprecedented decline in the size of the dialysis patient population. For a segment of health care that has been built around a steadily increasing census (and treatment volume), this shock will reverberate for years. How the financial consequences of a decline in treatment volume ultimately translate into investments in improved patient care remain to be seen, as dialysis providers are truly in the early stages of adjusting to this change in course.

Finally, from the narrow perspective of public health surveillance, the data throughout this chapter suggest that the Medicare claims environment can provide excellent visibility into evolving outcomes among people with CKD or ESRD. In general, trajectories of incidence throughout this chapter have high face validity, even if some testing was not billed and not all COVID-19 infections were diagnosed. Going forward, the power of these data should be harnessed to track outcomes and inform public policy in real time, rather than retrospectively, as we have done here.

For more information, see the USRDS Annual Data Report website, Supplements, Chapter 13. COVID-19, located here: https://adr.usrds.org/2021/supplements-covid-19-disparities/13-covid-19-supplement
References

Racial and Ethnic Disparities

Highlights

- Applying the new CKD-EPI creatinine-based equation refitted without a race variable resulted in a lower estimate of the prevalence of CKD stages 3-5 (i.e., eGFR <60 ml/min/1.73m²) in the U.S. of 5.3%, compared with 6.4% with the 2009 equation. The prevalence of stage 3-5 CKD decreased from 7.7% to 5.8% among White individuals and increased from 6.4% to 9.3% among Black individuals.

- The percentage of Black Medicare beneficiaries in the highest category (most deprivation) of neighborhood Social Deprivation Index (SDI; 58.6%) was more than 2.5 times as high as the percentage of White beneficiaries (21.5%). The percentage of Hispanic beneficiaries (65.1%) was 3 times that of White beneficiaries. Only 10.5% of Hispanic and 15.5% of Black beneficiaries lived in neighborhoods in the lowest range of SDI scores (least deprivation).

- Black and Hispanic patients were not less likely to receive angiotensin converting enzyme inhibitors (ACEIs) or angiotensin receptor blockers (ARBs), potassium binders, phosphorus binders, or sodium-glucose cotransporter-2 inhibitors (SGLT2is) than White beneficiaries. Hispanic patients were actually more likely to receive all of these medications.

- Black beneficiaries with CKD had higher rates of nephrology visits than White beneficiaries at every stage of CKD.

- Medicare beneficiaries with a higher neighborhood SDI score (more deprivation) were more likely to experience acute kidney injury (AKI) than those living in neighborhoods with less deprivation.

- The rate of ESRD was higher among individuals living in areas with worse SDI scores regardless of race/ethnicity. However, racial/ethnic differences in the rate of ESRD persisted within SDI categories.

- Hispanic individuals in all age groups were more likely to have ESRD caused by diabetes (DM) than White or Black individuals. Black individuals in all age groups were more likely to have ESRD caused by hypertension than White or Hispanic individuals.

- Although White patients were more likely to be dialyzing at home than Black or Hispanic patients within each stratum of neighborhood SDI, differences across levels of SDI were larger than differences among race groups within SDI categories.

- Among all race/ethnicity groups, those living in neighborhoods with higher SDI scores (higher deprivation) were substantially less likely to have been preemptively waitlisted for a kidney transplant. Nevertheless, White patients were more likely to be waitlisted than Black or Hispanic patients from neighborhoods with SDI scores in the same range.

- Within all race/ethnicity groups, patients living in neighborhoods with high SDI scores (more deprivation) had much lower rates of receipt of a living donor kidney transplant. However, large disparities by race/ethnicity persist within and across strata of neighborhood SDI.

Introduction

Racial and ethnic disparities in access to medical care and health outcomes persist in the U.S. Unfortunately, patients with kidney disease experience particularly large and well documented disparities. For example, the incidence of ESRD in 2019 was higher among Black individuals than among other racial groups and was more than 3 times that of the White population (ESRD Volume, Figure 1.4). Black patients with ESRD are less likely to be placed on the waiting list for a kidney transplant and less likely to receive one than their White counterparts. Although these issues have been well studied and have improved in some cases, recent clinical and societal events have highlighted the continued presence of significant racial and ethnic disparities in treatment of patients with CKD and ESRD. Specifically, the routine practice of including Black race as a factor in estimation of glomerular filtration rate (GFR) has been in the spotlight as an example of potentially harmful consideration of race in clinical medicine – that is, as a practice that might introduce or worsen disparities. Further, the COVID-19 pandemic resulted in dramatically higher rates of infection, hospitalization, and death among Black and Hispanic patients than among White patients, uncovering major vulnerability that had been under-recognized, perhaps because of the lower overall mortality of Black and Hispanic patients receiving maintenance dialysis compared with White patients.
Considering the ongoing disparities faced by patients with CKD and these recent developments, this year’s ADR includes a special supplement on racial and ethnic disparities. This chapter does not replace race and ethnicity stratified data on key metrics (e.g., incidence and prevalence of CKD and ESRD, rates of kidney transplantation), which are presented throughout the ADR in the relevant chapters. Rather, we have attempted in this supplement to delve further into potential reasons for worse outcomes among Black and Hispanic patients throughout the spectrum of kidney disease, including CKD, AKI, ESRD, and transplantation. Two areas of particular focus are processes of care and social determinants of health, and we examine the extent to which these might contribute to racial and ethnic disparities.

In response to a national call for reevaluation of the use of race in clinical algorithms, the National Kidney Foundation (NKF) and the American Society of Nephrology (ASN) established a joint task force to reassess inclusion of race in the estimation of GFR in the U.S. and implications of this strategy on diagnosis and management of patients with or at risk for kidney disease (Delgado et al., 2021). After 10 months of intense investigation and deliberation, the task force put forth a recommendation that hospitals and laboratories in the U.S. should immediately transition to use of a new refitted GFR estimating equation that does not include race (Delgado et al., 2021; Inker et al., 2021). This chapter includes an examination of how application of this new equation affects estimates of the prevalence of CKD among Black and non-Black individuals in the U.S. and how CKD stage is reclassified in these groups.

We then examine use of International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) diagnostic codes related to social determinants of health (SDOH; Z codes). Finding little utilization of these codes, we turn to the Social Deprivation Index (SDI) (Robert Graham Center, 2021), which was developed to quantify levels of disadvantage across small areas, evaluate their associations with health outcomes, and address health inequities. The SDI is a composite measure incorporating seven demographic characteristics collected in the American Community Survey (ACS): percentage of residents living in poverty, percentage with less than 12 years of education, percentage of single parent households, percentage living in rented housing units, percentage living in overcrowded housing units, percentage of households without a car, and percentage of adults under 65 years of age who are non-employed. A disadvantage of the SDI is that, unlike Z codes, it estimates SDOH at the level of an individual’s neighborhood rather than at the individual patient level. However, unlike Z codes, which appear to be grossly underutilized, a neighborhood SDI score can be calculated for each patient, allowing examination of the association of SDOH with outcomes that is potentially less biased (but also less direct). We then examine differences in processes of care and outcomes by race and ethnicity across the spectrum of kidney disease and the extent to which SDOH is associated with outcomes independent of race and ethnicity.

Methods
To address racial and ethnic disparities in all phases of CKD, this chapter includes data from several sources. We begin with an examination of the prevalence of CKD stages 3-5 (eGFR <60 ml/min/1.73m²) in the U.S. population using data from the National Health and Nutrition Examination Survey (NHANES) from 2015-2018. In this population, we estimate GFR using the CKD-EPI creatinine-based equation that is in use by most laboratories and health care systems in the U.S. and includes an adjustment term for Black race (Levey et al., 2009). We then estimate GFR using the new CKD-EPI creatinine-based equation that was refitted without a term for Black race (Inker et al., 2021). We compare the prevalence of CKD stages 3-5 according to these two methods and examine reclassification across CKD stages 3-5 using the new equation overall and among strata defined by age, sex, and race/ethnicity.

A key goal of this chapter is to examine how processes of care and outcomes differ by social determinants of health, the conditions of an individual’s living, learning, and working environments that affect health risks and outcomes (Centers for Disease Control and Prevention, 2020). We examine use of “Z” codes within Medicare claims data among individuals with CKD and ESRD. Z codes are ICD-10 CM encounter reason codes (Z55-Z65) that can be used to document SDOH data (Centers for Medicare & Medicaid Services, 2021). The main Z code categories and their descriptions are listed below.
We examine SDI distribution by race among patients with CKD and ESRD and then examine outcomes by race and SDI. Although this chapter focuses primarily on disparities faced by Black individuals, we also consider Hispanic ethnicity for some outcomes for which a large enough population was available. (However, for several analyses in the CKD population, in particular, the sample was not large enough to allow this, particularly for stratifications within race groups.) In the ESRD population where sample size is less of a concern, we examine the country of origin among Hispanic patients with ESRD overall and by region to better understand the diversity within this ethnic group.

Because use of Z codes is extremely rare, we use a neighborhood-level social deprivation index to examine associations between SDOH and outcomes. Specifically, we use the U.S. SDI, developed by the Robert Graham Center, the policy institute affiliated with the American Academy of Family Physicians (Phillips et al., 2016; Robert Graham Center, 2021), at the ZIP code Tabulation Area (ZCTA) level (United States Census Bureau, 2020). The domains of the SDI are listed below.

- Income: Percentage of the population with income less than 100% of the federal poverty limit
- Education: Percentage of the population aged ≥25 years with less than 12 years of education
- Employment: Percentage of the population aged ≤65 years that is non-employed
- Housing: Percentage of the population living in renter-occupied housing units
- Housing: Percentage of the population living in crowded housing units
- Household characteristics: Percentage of single-parent households with dependents <18 years of age
- Transportation: Percentage of the population with no car

We examine SDI distribution by race among patients with CKD and ESRD and then examine outcomes by race and SDI. Although this chapter focuses primarily on disparities faced by Black individuals, we also consider Hispanic ethnicity for some outcomes for which a large enough population was available. (However, for several analyses in the CKD population, in particular, the sample was not large enough to allow this, particularly for stratifications within race groups.) In the ESRD population where sample size is less of a concern, we examine the country of origin among Hispanic patients with ESRD overall and by region to better understand the diversity within this ethnic group.
Figure 14.1a Prevalence of CKD using the original versus the newly recommended CKD-EPI creatinine-based equations for estimated GFR, by CKD stage and demographic characteristics

Data source: 2015-2018 NHANES data. Participants aged ≥18 years of White, Black, or Hispanic race/ethnicity. CKD-EPIcr: the original CKD-EPIcr equation; CKD-EPIcr_R: the newly recommended equation. *All Stages: CKD stages 3-5 together.

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White, By CKD Stage

Black, By CKD Stage

Data source: 2015-2018 NHANES data. Participants aged ≥18 years of White, Black, or Hispanic race/ethnicity. CKD-EPIcr: the original CKD-EPIcr equation; CKD-EPIcr_R: the newly recommended equation. *All Stages: CKD stages 3-5 together.
Figure 14.1a shows the prevalence of eGFR <60 ml/min/1.73m² using the CKD-EPI creatinine-based equation (Levey et al., 2009) and using the newly refitted CKD-EPI creatinine-based equation without a term for Black race (Inker et al., 2021) among White, Black, and Hispanic participants in the NHANES from 2015-2018. Using the newly refitted CKD-EPI equation resulted in a lower prevalence of CKD stages 3-5 of 5.3%, compared with 6.4% with the 2009 equation. As expected, most of the difference was in the prevalence of CKD stage 3, which was 4.9% with the new equation compared with 5.9% with the traditional equation.

Use of the new equation decreased the prevalence of CKD from 7.7% to 5.8% among White individuals and from 2.9% to 2.4% among Hispanic individuals but increased the prevalence from 6.4% to 9.3% among Black individuals. Applying the new equation reduced the prevalence of CKD by 19.3% among men and 15.5% among women.
Figure 14.1b  Prevalence of CKD using the original versus the newly recommended CKD-EPI creatinine-based equations for estimated GFR, by demographic combinations

Data source: 2015-2018 NHANES data. Participants aged ≥18 years of White, Black, or Hispanic race/ethnicity. CKD-EPIcr: the original CKD-EPIcr equation; CKD-EPIcr_R: the newly recommended equation. *All Stages: CKD stage 3-5 together.
Table 14.1 Reclassification among CKD stages using the original versus the newly recommended CKD-EPI creatinine-based equations for eGFR, by demographic characteristics

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Data source: 2015-2018 NHANES data. Participants aged ≥18 years of White, Black, or Hispanic race/ethnicity.

Figure 14.1b examines changes in prevalence of CKD in subgroups defined by race/ethnicity in combination with age and sex. The magnitude of the increase in CKD prevalence using the new equation among Black individuals was greater among men than among women. Although the absolute increase in prevalence of CKD among younger Black individuals using the new equation was smaller than the increase among older individuals, the relative increase among younger Black individuals was 69% compared with a 36.0% increase among older Black individuals.
Table 14.1 shows reclassification of individuals among CKD stages when converting from the 2009 CKD-EPI equation with a coefficient for Black race to the newly recommended CKD-EPI creatinine-based equation. At all stages, a substantial percentage of White and Hispanic individuals are reclassified into a less severe stage of CKD using the new equation, whereas smaller percentages of Black individuals are reclassified into more severe stages of CKD. For example, approximately one third of White individuals with CKD stage 3a according to the older equation are classified as having an eGFR >60 ml/min/1.73m² with the new equation, and one third of patients with CKD stage 3b are reclassified as having stage 3a. By contrast, approximately 18% of Black individuals with CKD stage 3a, 15% of those with stage 3b, and 15% of those with stage 4 are reclassified as stage 3b, 4, and 5, respectively.

Data source: Medicare 5% random sample database (for CKD cohort) and USRDS ESRD database (for dialysis cohort). CKD cohort: December 31, 2019 point prevalent Medicare fee-for-service (FFS) beneficiaries with Parts A and B, aged ≥ 66 years, with diagnosis of CKD stages 3-5, and of White, Black, or Hispanic race/ethnicity. Dialysis cohort: 2019 period prevalent dialysis patients, covered by Medicare FFS Parts A and B and of White, Black, or Hispanic race/ethnicity.
Figure 14.2a Percentage of patients with claims including Medicare Social Determinants of Health codes in older CKD and dialysis patients, by race/ethnicity, 2019

Data source: Medicare 5% random sample database (for CKD cohort) and USRDS ESRD database (for dialysis cohort). CKD cohort: December 31, 2019 point prevalent Medicare fee-for-service (FFS) beneficiaries with Parts A and B, aged ≥ 66 years, with diagnosis of CKD stages 3-5, and of White, Black, or Hispanic race/ethnicity. Dialysis cohort: 2019 period prevalent dialysis patients, covered by Medicare FFS Parts A and B and of White, Black, or Hispanic race/ethnicity.
Figure 14.2a presents the frequency of use of Medicare “Z” codes that can be used to document data on SDOH by race among older Medicare beneficiaries with CKD and ESRD. No Z code was used among more than 1% of beneficiaries aged ≥66 years with CKD or ESRD. Problems related to housing and economic circumstances (Z59), problems related to the social environment (Z60), and other problems related to primary support group (Z63) were the most commonly used codes. Problems related to housing and economic circumstances include homelessness, inadequate or unstable housing, extreme poverty, and low income among other specific circumstances. These codes were used more frequently in encounters with Black patients, particularly for beneficiaries with ESRD (1.06% for Black patients vs. 0.81% for White patients). However, the code for problems related to the social environment (Z60), which can include problems with living alone, social exclusion and rejection, and being the target of adverse discrimination and persecution, was used slightly more commonly among White beneficiaries with ESRD (0.85% vs. 0.67% among Black beneficiaries). Problems related to primary support group (Z63), which includes separation and divorce, death of a family member, and alcoholism or addiction in the family, among other problems, was also used slightly more commonly among White beneficiaries.

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Figure 14.2b Percentage of patients with Medicare claims with Social Determinants of Health codes in older CKD and dialysis patients, by Medicare/Medicaid dual eligible status, 2019

Dual eligibility for Medicare and Medicaid is often used as a proxy for low socioeconomic status. Figure 14.2b examines the frequency of Medicare “Z” codes that can be used to document data on SDOH by dual eligible status. All Z codes are used more often among dually eligible beneficiaries, but these codes are rarely used even in this population.

Data source: Medicare 5% random sample database (for CKD cohort) and USRDS ESRD database (for dialysis cohort). CKD cohort: December 31, 2019 point prevalent beneficiaries covered by Medicare FFS for Parts A and B, aged 266 years, with diagnosis of CKD stages 3-5, and of White, Black, or Hispanic race/ethnicity. Dialysis cohort: 2019 period prevalent dialysis patients covered by Medicare FFS Parts A and B and of White, Black, or Hispanic ethnicity.
Figure 14.2c  Distribution of Social Deprivation Index score in older patients with CKD, by race/ethnicity, Medicare/Medicaid dual eligible, and CKD stage, 2019

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Medicare/Medicaid Dual Eligible</th>
<th>CKD Stage</th>
</tr>
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<tr>
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Figure 14.2c  Distribution of Social Deprivation Index score in older patients with CKD, by race/ethnicity, Medicare/Medicaid dual eligible, and CKD stage, 2019

<table>
<thead>
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<th>Medicare/Medicaid Dual Eligible</th>
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<tr>
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<td>[Diagram showing distribution]</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>[Diagram showing distribution]</td>
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</tr>
</tbody>
</table>

The SDI is a composite measure incorporating seven demographic characteristics of neighborhoods collected in the American Community Survey (ACS): percentage of the population living in poverty, percentage with less than 12 years of education, percentage of single parent households, percentage living in rented housing units, percentage living in overcrowded housing units, percentage of households without a car, and percentage of adults under 65 years of age who are non-employed. Figure 14.2c shows the percentage of older beneficiaries with CKD who have SDI scores in the lower (less deprivation), middle, and upper third of the range (which is 0-100) by race/ethnicity, Medicare and Medicaid dual eligibility status, and CKD stage. The percentage in the highest SDI category was more than 2.5 times as high among Black beneficiaries and 3 times higher among Hispanic beneficiaries (58.6% and 65.1%, respectively) as among White beneficiaries (21.5%). Only 10.5% of Hispanic and 15.5% of Black beneficiaries lived in neighborhoods in the lowest range of SDI scores (least deprivation). Almost half of dually eligible beneficiaries had SDI scores in the highest category. The percentage with highest SDI scores increased with advancing CKD stage.

Figure 14.3 shows use of key medications among patients with CKD by race/ethnicity. Black and Hispanic patients were not less likely to be prescribed ACEis or ARBs, potassium blockers, phosphorus binders, or SGLT2is than White beneficiaries. Hispanic patients were actually more likely to receive all of these medications. The high percentage of Black (60.8%) and Hispanic (87.1%) patients receiving the Part D Low Income Subsidy (LIS) compared with White patients (26.2%) may account for the lack of racial/ethnic disparities in receipt of these medications (Figure 7.3 in the CKD Volume of this year’s ADR).
Figure 14.4a  Rate of outpatient nephrology encounters among older patients with CKD, by race/ethnicity and CKD stage, 2019

Figure 14.4a shows rates of outpatient nephrology visits by race/ethnicity and CKD stage among Medicare FFS beneficiaries aged ≥66 years. The rates of nephrology visits were 0.7-1.0 per person-year among beneficiaries with stage 3 CKD, 2.0-2.4 per person-year for those with stage 4 CKD, and 1.9-2.4 per person-year for stage 5 CKD. Black beneficiaries with CKD had higher rates of nephrology visits than White beneficiaries at every stage of CKD. Hispanic beneficiaries with stage 3 and stage 5 CKD also had higher rates of nephrology visits than White beneficiaries in the same stages; rates were similar among Hispanic and White beneficiaries with stage 4 CKD.

Figure 14.4b  Rate of outpatient nephrology encounters among older patients with CKD, by demographics, Social Deprivation Index, and CKD stage, 2019

Data source: Medicare 5% random sample database. January 1, 2019 point prevalent beneficiaries covered by Medicare FFS Parts A and B, aged ≥66 years, with diagnosis of CKD stages 3-5, and of White, Black, or Hispanic race/ethnicity.
Figure 14.4b shows the rate of nephrology visits by CKD stage stratified by race and by age, sex, and neighborhood SDI within each race/ethnicity group. Among Black and White beneficiaries with stage 3 CKD, the association of neighborhood SDI with visit rate was small and inconsistent. Among Hispanic beneficiaries, those living in neighborhoods with higher SDI scores (more deprivation) actually saw nephrologists more frequently than those living in neighborhoods with lower SDI scores. Among beneficiaries with stages 4 and 5 CKD, the pattern of association between SDI and rate of nephrology visits was not consistent across race/ethnicity groups.

Figure 14.5a Adjusted one year probability of developing ESRD or death in older patients with CKD, by race/ethnicity and Social Deprivation Index, 2019

Data source: Medicare 5% random sample database. January 1, 2019 point prevalent beneficiaries covered by Medicare FFS Parts A and B, aged ≥66 years, with diagnosis of CKD stages 3-5, and of White, Black, or Hispanic race/ethnicity. ESRD and death were treated as competing events for each other. Age, sex, comorbidity, and CKD stage were used in adjusted analyses. Abbreviation: SDI, Social Deprivation Index.

Figure 14.5a shows the 1-year risk of death and ESRD among Medicare FFS beneficiaries aged ≥66 years with CKD by SDI within race/ethnicity groups. The risk of ESRD was higher among Black and Hispanic than among White beneficiaries regardless of SDI, which was not strongly associated with risk of ESRD. The risk of death was slightly higher among Black and White beneficiaries living in neighborhoods with higher SDI scores, but the higher mortality among White beneficiaries was present regardless of neighborhood SDI score.
Figure 14.5b shows the 1-year risk of death and ESRD among Medicare FFS beneficiaries aged ≥66 years with CKD by race/ethnicity with and without adjustment for demographic factors, comorbidity, and SDI. Among beneficiaries with stage 3 CKD, the unadjusted risk of death and ESRD were similar among racial/ethnic groups. However, after adjustment, mortality was highest among White and lowest among Hispanic beneficiaries, and risk of ESRD was low for all groups. For those with more advanced CKD, higher mortality among White beneficiaries was evident even in unadjusted analyses and was more prominent after adjustment. The adjusted risk of ESRD was approximately 25-50% higher among Black and Hispanic beneficiaries than among White beneficiaries with stage 4 or 5 CKD.

Data source: Medicare 5% random sample database. January 1, 2019 point prevalent beneficiaries covered by Medicare FFS Parts A and B, aged ≥66 years, with diagnosis of CKD stages 3-5, and of White, Black, or Hispanic race/ethnicity. ESRD and death were treated as competing events for each other. Age, sex, comorbidity, SDI, and Medicare/Medicaid dual eligibility were used in adjusted analyses.
Figure 14.6a shows the percentage of point prevalent beneficiaries with stages 3-5 CKD on January 1 of each year from 2016-2019 who were hospitalized with AKI requiring dialysis in the year by race/ethnicity and SDI. White beneficiaries were less likely to develop dialysis-requiring AKI than Black or Hispanic beneficiaries. Those with a higher neighborhood SDI score (more deprivation) were more likely to experience AKI than those living in neighborhoods with less deprivation. The association with SDI is more apparent among Black and Hispanic than among White individuals. For example, Hispanic beneficiaries with the highest SDI scores were 1.5 times as likely to have a AKI hospitalization than those with the lowest scores.

Data source: Medicare 5% random sample database. January 1 point prevalent beneficiaries 2016-2019, covered by Medicare FFS Parts A and B, aged ≥66 years, with diagnosis of CKD stages 3-5, and of White, Black, or Hispanic race/ethnicity. Age, sex, comorbidity, SDI, and Medicare/Medicaid dual eligibility were used in adjusted analyses.

Figure 14.6b Percentage of AKI hospitalizations requiring dialysis in older patients with CKDs, by race/ethnicity and CKD stage, 2016-2019

Figure 14.6b shows that Black individuals aged ≥66 years with CKD were consistently more likely to experience hospitalization with AKI requiring dialysis within 1 year than White beneficiaries even after adjusting for SDI. Hispanic beneficiaries with CKD stage 3 and stage 4 were also more likely to experience hospitalization with AKI requiring dialysis than White beneficiaries, but this was not true for those with stage 5 CKD.
The overall probability of death or ESRD within 6 months after a hospitalization with AKI requiring dialysis was very high for all race/ethnicity groups and varied little by SDI score. However, the risk of death within 6 months differed by race/ethnicity and neighborhood SDI. The probability of death was higher among White than among Black or Hispanic individuals. There was little difference in the risk of death across categories of SDI score among White beneficiaries, whereas the risk of mortality was higher among Black and Hispanic beneficiaries living in neighborhoods with higher SDI scores. Conversely, and likely because of the competing risk of death, Black and Hispanic individuals from neighborhoods with lower SDI scores (less deprivation) were more likely to reach ESRD within 6 months than those living in areas with higher SDI scores.
Figure 14.7b Six-month probability of developing ESRD or death after AKI hospitalization requiring dialysis in older patients with CKD, by race/ethnicity and CKD stage, 2016-2019

Data source: Medicare 5% random sample database. January 1 point prevalent beneficiaries 2016-2019, covered by Medicare FFS Parts A and B, aged ≥66 years, with diagnosis of CKD stages 3-5 who had an AKI hospitalization requiring dialysis and were of White, Black, or Hispanic race/ethnicity. ESRD and death were treated as competing events for each other. Age, sex, comorbidity, SDI, and Medicare/Medicaid dual eligibility were used in adjusted analyses.

Figure 14.7b shows that White beneficiaries had a higher risk of death and lower risk of ESRD within 6 months following a hospitalization with AKI requiring dialysis than Black beneficiaries even after adjusting for demographic characteristics, comorbidity, and SDI.

Figure 14.8 ESRD rate by race/ethnicity and Social Deprivation Index, 2019

Data source: USRDS ESRD database. 2019 incident ESRD patients and 2019 US population, aged ≥18 years, and of White, Black, or Hispanic race/ethnicity. Age and sex were used for adjusted analysis. Abbreviation: SDI, Social Deprivation Index.
Figure 14.8 shows the rate of ESRD by race/ethnicity and by SDI score. For all race/ethnicity groups, the rate of ESRD was higher among individuals living in areas with worse SDI scores. However, racial/ethnic differences in the rate of ESRD persisted within SDI categories. The rate of ESRD among Black individuals in the lowest SDI category was 3.5 times as high as among White individuals in the lowest SDI category and was more than twice as high as Hispanic individuals in this category.

Figure 14.9a  Country or area of origin of Hispanic incident ESRD patients, 2016-2019

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<td>Mexico</td>
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<tr>
<td>Dominican Republic</td>
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<tr>
<td>Guatemala</td>
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<tr>
<td>Other</td>
<td>2%</td>
</tr>
<tr>
<td>Unknown</td>
<td>1%</td>
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</table>

Data source: USRDS ESRD database. 2016-2019 Hispanic incident ESRD patients, aged ≥18 years.

Figure 14.9a shows the country or area of origin among incident ESRD patients of Hispanic ethnicity. Forty-four percent were from the (mainland) U.S. (i.e., not immigrants). Among those who were immigrants, the most common country of origin was Mexico. Ten percent indicated that they were from or were living in Puerto Rico.
Figure 14.9b shows the distribution of country or area of origin of Hispanic individuals initiating treatment for ESRD by census region, age, and sex. The percentage from mainland U.S. and the largest non-mainland U.S. point of origin differed substantially by census region. In the South, more than half of Hispanic individuals were from mainland U.S., whereas that percentage was only 28.9% in the Northeast. The largest non-mainland U.S. point of origin was Mexico in the Midwest, South, and West, with approximately half of all Hispanic patients in the West from Mexico. However, in the Northeast, a relatively small percentage of Hispanic patients was from Mexico, and one quarter was from Puerto Rico.

Data source: USRDS ESRD database. 2016-2019 Hispanic incident ESRD patients, aged ≥18 years.
Figure 14.10 Percentage of patients initiating dialysis in the hospital, by race/ethnicity and Social Deprivation Index, stratified by age, 2019

Data source: USRDS ESRD database. 2019 incident ESRD patients with dialysis as the initial treatment modality, covered by Medicare FFS Parts A and B, aged ≥18 years, and of White, Black, or Hispanic race/ethnicity. Age, sex, cause of ESRD, comorbidity, and SDI were used in adjusted analyses. Abbreviation: SDI, Social Deprivation Index.
Figure 14.10 shows the percentage of patients initiating dialysis in the hospital in 2019. Older patients were more likely to initiate dialysis in the hospital than younger ones. Differences by race/ethnicity were smaller than differences across age groups, and the pattern varied by age. Younger Hispanic patients were less likely than White or Black patients to initiate dialysis in the hospital, but older Hispanic patients were more likely than their White or Black counterparts to do so. Across all age groups, patients living in neighborhoods with higher SDI scores were more likely to initiate dialysis in the hospital than those living in neighborhoods with lower scores.

Figure 14.11a Percentage of patients initiating hemodialysis with a catheter, by Social Deprivation Index, 2019

Data source: USRDS ESRD database. 2019 incident ESRD patients with HD as the initial treatment modality, aged ≥18 years, and of White, Black, or Hispanic race/ethnicity. Age, sex, cause of ESRD, comorbidity, and race/ethnicity were used in adjusted analyses. Abbreviation: SDI, Social Deprivation Index.

Patients' neighborhood SDI score was not associated with the likelihood of initiating HD with a catheter. Catheter use was high for all groups.
Initiation of HD using a catheter occurred in a similarly high percentage of White, Black, and Hispanic patients with and without adjustment for demographic characteristics, comorbidity, and SDI.

Data source: USRDS ESRD database. 2019 incident ESRD patients with HD as the initial treatment modality, aged ≥18 years, and of White, Black, or Hispanic race/ethnicity. Age, sex, cause of ESRD, comorbidity, and SDI were used in adjusted analyses.
Figure 14.13a shows the primary cause of ESRD by age and race/ethnicity. Hispanic individuals in all age groups were more likely to have ESRD caused by DM than White or Black individuals. Black individuals in all age groups were more likely to have ESRD caused by hypertension than White or Hispanic individuals. Glomerulonephritis was more likely to be the cause of ESRD among younger individuals than older ones. Patterns across race/ethnicity groups were not consistent across age groups.

Data source: USRDS ESRD database. 2018 incident ESRD patients with dialysis as the initial treatment modality, aged ≥18 years, and of White, Black, or Hispanic race/ethnicity. Age, sex, cause of ESRD, and comorbidity were used in adjusted analyses. Abbreviation: SDI, Social Deprivation Index.
Figure 14.13a Percentage of patients on home dialysis in the first year of ESRD, by race/ethnicity and Social Deprivation Index, 2018

Figure 14.13a shows the percentage of incident dialysis patients starting dialysis at home and receiving dialysis at home after 1 year by race and SDI. Patients in all race/ethnicity groups living in neighborhoods with higher SDI were less likely to dialyze at home initially and after 1 year. Although White patients were more likely to be dialyzing at home than Black or Hispanic patients within each stratum of neighborhood SDI, differences across levels of SDI were larger than differences among race groups within SDI categories.

Data source: USRDS ESRD database. 2018 incident ESRD patients with dialysis as the initial treatment modality, aged ≥18 years, and of White, Black, or Hispanic race/ethnicity. Age, sex, cause of ESRD, and comorbidity were used in adjusted analyses. Abbreviation: SDI, Social Deprivation Index.
Figure 14.13b Percentage of patients receiving home dialysis in the first year of ESRD, 2018

Figure 14.13b shows that a higher percentage of White beneficiaries initiated home dialysis treatment and dialyzed at home after 1 year compared with Black or Hispanic beneficiaries, even after adjustment for demographic characteristics, comorbidity, and neighborhood-level variables including the percentage of the population living in crowded housing units.

Figure 14.14a Percentage of preemptive wait listing or transplantation in incident ESRD patients, by race/ethnicity and Social Deprivation Index, 2019

Data source: USRDS ESRD database. 2019 incident ESRD patients, aged ≥18 years, and of White, Black, or Hispanic race/ethnicity. Age, sex, cause of ESRD, and comorbidity were used in adjusted analyses. Abbreviation: SDI, Social Deprivation Index.
Figure 14.14a shows the percentage of incident dialysis patients who had been placed on the waitlist for a kidney transplant prior to dialysis initiation (i.e., preemptively waitlisted) by race/ethnicity and by SDI. Among all race/ethnicity groups, those living in neighborhoods with higher SDI scores (higher deprivation) were substantially less likely to have been preemptively waitlisted for a kidney transplant. Nevertheless, White patients were more likely to be waitlisted than Black or Hispanic patients from neighborhoods with SDI scores in the same range.

Data source: USRDS ESRD database. 2019 incident ESRD patients, aged ≥18 years, and of White, Black, or Hispanic race/ethnicity. Age, sex, cause of ESRD, comorbidity, and SDI were used in adjusted analyses.

Figure 14.14b shows that White patients remain substantially more likely to be placed on the waitlist for a kidney transplant prior to starting dialysis than Black or Hispanic patients even after adjusting for demographic characteristics, comorbidity, and SDI.
Figure 14.15a shows the rate of receipt of a living donor kidney transplant by race/ethnicity and SDI among patients on dialysis. Within all race/ethnicity groups, patients living in neighborhoods with high SDI scores (more deprivation) had much lower rates of receipt of a living donor kidney transplant. However, large disparities by race/ethnicity persisted within and across strata of neighborhood SDI. For example, Black patients living in neighborhoods in the lowest SDI category (least deprivation) had lower rates of receipt of a living donor kidney transplant than White patients living in neighborhoods with the highest SDI scores.
Figure 14.15b shows the rate of receipt of a living donor kidney transplant by race/ethnicity among patients receiving dialysis with and without adjustment for demographic characteristics, comorbidity, and SDI. Despite the large differences in rate of receipt of a living donor kidney transplant across categories of neighborhood SDI (Figure 14.15a), adjustment for SDI made little difference in the degree of disparity across race/ethnicity groups.
Summary
The aims of this chapter were to examine racial/ethnic disparities in outcomes across the spectrum of CKD and ESRD in more detail than in other parts of the ADR. We focused initially on the disconnect between the large differences in ESRD incidence between race/ethnicity groups and the lack of difference in rates of early stages of CKD in the overall U.S. population. We examined the possibility that the current method of estimation of GFR may underestimate the rate of early CKD among Black individuals; that Black and Hispanic individuals have less access to care for CKD or higher rates of AKI; and that social determinants of health may play a role. We also examined the potential role of social determinants of health in access to home dialysis and kidney transplantation among patients with ESRD.

Potential impact of the new eGFR equation on estimates of CKD

Although the biological rationale for including coefficients for characteristics associated with non-GFR determinants of serum creatinine concentration (e.g., age, sex, body weight) seems apparent, the reasons for including race are more questionable. It may be problematic to rely on a correction factor without completely understanding what information is being captured. Specifically, there is an underappreciation of the ancestral and social diversity within the Black community in the U.S. (which is also true for other racial and ethnic groups). Furthermore, as a growing number of individuals in the U.S. identify as being of mixed racial background, the complexity of using race in the practice of medicine is increasing. Race is increasingly being recognized as a social construct rather than a biological one, making its inclusion in GFR estimation increasingly problematic. For these reasons, the joint NKF-ASN taskforce recently recommended adoption of a new eGFR equation that does not include an adjustment for Black race (Delgado et al., 2021; Inker et al., 2021).

We used data from the NHANES to examine the distribution of eGFR among Black, White, and Hispanic individuals using the CKD-EPI equation currently employed by most healthcare systems (Levey et al., 2009) and using the newly derived equation that is based on serum creatinine that does not include a coefficient for Black race (Inker et al., 2021). Use of the new equation systematically lowered the estimated prevalence of CKD among White and Hispanic individuals and increased the estimated prevalence among Black individuals. Thus, although there appeared to be little difference in the prevalence of CKD between Black and White individuals using the older equation (7.7% of White and 6.4% of Black individuals with eGFR <60 ml/min/1.73m² based on NHANES participants from 2015-2018), Black individuals have a higher prevalence of CKD according to the new estimating equation (9.3% vs. 5.8% of White individuals). In other words, Black individuals are estimated to have a 60% higher rate of stage 3-5 CKD than White individuals using the new equation. Use of an estimating equation that leads to a higher eGFR among Black patients may be masking disparities in CKD prevalence earlier in the course of disease.

Access to care during CKD

We did not observe disparities in rates of outpatient nephrology visits or receipt of medications to treat CKD or its complications, including ACEi/ARBs, potassium or phosphorus binders, or SGLT2i, by race/ethnicity. Rates of nephrology visits also differed little by level of neighborhood deprivation. These results suggest that Medicare coverage, including Part D and the LIS, appear to provide comparable access to care for CKD across race/ethnicity groups and across levels of neighborhood deprivation. However, it is important to note that these analyses were limited to individuals aged ≥66 years with Medicare FFS coverage. An important contributor to the disparity in ESRD incidence among Black and Hispanic individuals appears to be related to higher rates of hypertension and DM (as evidenced by the causes of ESRD in Figure 14.12), which often begin at a younger age among Black and Hispanic than among White individuals. Barriers to access to care prior to Medicare eligibility likely contribute to the higher rates and earlier onset of DM and hypertension among Black and Hispanic individuals as well as to the higher risk of subsequent CKD and ESRD. The likelihood that disparities are much greater before Medicare eligibility is supported by a recent study published in JAMA Internal Medicine, which reported that racial and ethnic healthcare disparities in the general population decreased substantially after the age of Medicare eligibility, even in the era after implementation of the Affordable Care Act (Wallace et al., 2021).

Social determinants of health

Race may serve as a proxy measure for social, environmental, and structural factors that have important effects on health. ICD-10-CM includes SDOH-related encounter reason codes (Z55-Z65) that can be used to document SDOH data (Centers for Medicare & Medicaid Services, 2021). These codes were created to identify individuals’ social risk factors and unmet needs to inform healthcare delivery and services and ultimately to improve quality of care, care coordination, and experience of care. Collecting data on SDOH and the associations among SDOH and receipt of healthcare and services and health outcomes could help identify opportunities to address barriers to high quality of care. However, SDOH-related Z codes are rarely documented among Medicare beneficiaries with (or without) CKD (Mathew et al., 2020), limiting our ability to study the role of SDOH in racial and ethnic disparities in this population.
Because Z-codes were coded so infrequently, we turned to the U.S. Social Deprivation Index, developed by the Robert Graham Center, the policy institute affiliated with the American Academy of Family Physicians (Phillips et al., 2016; Robert Graham Center, 2021), at the ZIP code Tabulation Area (ZCTA) level (United States Census Bureau, 2020). Although we found little association between SDI and receipt of medical care (medications and nephrology visits) among patients with CKD, there were strong associations between patients’ neighborhood SDI and access to home dialysis and kidney transplantation. Patients living in neighborhoods with high SDI scores were much less likely to dialyze at home, to be waitlisted for a kidney transplant prior to initiating dialysis, or to receive a living donor kidney transplant. Addressing barriers related to SDI may be critical to successfully increasing utilization of home dialysis.

Considering kidney transplantation, implementation of the new Kidney Allocation System in December 2014 essentially eliminated disparities in access to deceased donor transplantation among Black patients with ESRD (see Figure 7.11 in the ESRD Volume of this year’s ADR). Thus, lower rates of preemptive transplantation and living donor kidney transplantation are now the key drivers of the ongoing overall disparity in access to transplantation among Black patients. These disparities are particularly significant because outcomes are superior for preemptive and living donor kidney transplants compared with deceased donor kidney transplants after ESRD onset.

It is important to note some limitations of these analyses. First, SDI is a measure at the ZCTA level and does not represent an individual’s SDOH. Although there is overlap, patient-level and community-level approaches for assessing patient social risks are not equivalent (Cottrell et al., 2020). Second, we examined associations of SDI with outcomes using the lower, middle, and upper thirds of the total range of scores as has been done in other analyses of associations with health outcomes. These groups each include a fairly wide range of SDI scores, and it is likely that scores with these subgroups vary by race/ethnicity (i.e., that the mean neighborhood SDI among White individuals with SDI 1-33 is lower than the mean among Black individuals with SDI 1-33). Both of these approximations have the potential to introduce “noise” into analyses of the associations between SDOH and outcomes and would be expected to lessen the extent to which SDOH are associated with outcomes and the extent to which SDOH may account for racial disparities. Therefore, although it appears as though addressing SDOH would not eliminate racial and ethnic disparities in access to preemptive and living transplantation or barriers to home dialysis, it is likely that these barriers are more important than our analyses suggest. Efforts to mitigate barriers posed by SDOH should be a high priority.

Conversely, we should not ignore the large disparities that remain unexplained after accounting for demographic characteristics, comorbidity, and SDI. Although rates of nephrology visits and receipt of some key medications used in treatment of patients with CKD did not differ meaningfully by race/ethnicity, there are many aspects of access to and processes of care that cannot be examined through claims data. Therefore, the nephrology community must critically examine healthcare delivery using other data sources to look for evidence of potential racism in the delivery of healthcare and be willing to address any racism that is discovered.


References


### Healthy People 2030 CKD Objectives

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<th>Indicator</th>
<th>Target</th>
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<td>Increase the proportion of people on Medicare who get follow-up care 3 months after kidney injury</td>
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<td>CKD-03</td>
<td>Increase the proportion of people on Medicare with chronic kidney disease who get recommended tests</td>
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<td>CKD-04</td>
<td>Reduce the rate of new cases of end-stage kidney disease</td>
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<td>CKD-07</td>
<td>Reduce the proportion of adult dialysis patients who rely on catheters for dialysis</td>
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<td>CKD-08</td>
<td>Increase the proportion of people who get a kidney transplant within 3 years of end-stage kidney disease treatment</td>
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<td>CKD-09</td>
<td>Reduce the death rate for people on dialysis</td>
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<td>D-05</td>
<td>Increase the proportion of adults with diabetes who get a yearly urinary albumin test</td>
<td>66.4%</td>
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Data Source: https://health.gov/healthypeople/objectives-and-data/browse-objectives/chronic-kidney-disease

Abbreviations: CKD, chronic kidney disease; HP2030, Healthy People 2030; PMP, per million population; PY, patient-years
### CKD-03: Increase the proportion of people on Medicare who get follow-up care 3 months after kidney injury

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Data Source: Special analyses, Medicare 5% sample. Medicare patients aged 65 & older with a hospitalized AKI event in a given year. Abbreviations: AKI, acute kidney injury; CKD, chronic kidney disease.
**CKD-4: Increase the proportion of people on Medicare with chronic kidney disease who get recommended tests**

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Data Source: Special analyses, Medicare 5% sample. Medicare patients aged 65 & older with CKD. Abbreviations: CKD, chronic kidney disease.
## CKD-07: Reduce the rate of new cases of end-stage kidney disease

**Reference year used for adjustment: 2015**

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Data Source: USRDS ESRD Database, incident ESRD patients. Adjustments: overall rates adjusted for age, sex, and race/ethnicity; rates by age adjusted for sex and race/ethnicity; rates by sex adjusted for age and race/ethnicity; rates by race/ethnicity adjusted for age and sex. Reference population: 2015 U.S. population. *Values for cells with 10 or fewer individuals are suppressed. Abbreviations: CKD, chronic kidney disease; ESRD, end-stage renal disease.
## CKD-08: Reduce the proportion of adult dialysis patients who rely on catheters for dialysis

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Data Source: Special analyses, CROWNWeb. Prevalent patients receiving hemodialysis with a valid CMS ESRD Medical Evidence Form; vascular access type determined from CROWNWeb. Abbreviations: CKD, chronic kidney disease; ESRD, end-stage renal disease; CMS, Centers for Medicare and Medicaid Services.
**CKD-09: Increase the proportion of people who get a kidney transplant within 3 years of end-stage kidney disease treatment**

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Data Source: Special analyses, USRDS ESRD Database. Individuals with incident ESRD younger than age 70. Abbreviations: CKD, chronic kidney disease; ESRD, end-stage renal disease.
CKD-10: Reduce the death rate for people on dialysis

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Data Source: Special analyses, USRDS ESRD Database. Period prevalent patients receiving dialysis. *Values for cells with 10 or fewer patients are suppressed. Abbreviations: CKD, chronic kidney disease; ESRD, end-stage renal disease.
**D-05: Increase the proportion of adults with diabetes who get a yearly urinary albumin test**

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Data Source: Special analyses, Medicare 5% sample. Medicare beneficiaries aged 65 & older with diabetes mellitus.
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Data Sources for ESRD Volume, 2021 USRDS ADR

Introduction

The ESRD Analytical Methods chapter describes the data, analytical approaches, and statistical methods for ESRD Volume of the Annual Data Report (ADR). For this ADR, we report on data through December 31, 2019. Many of the analyses depend heavily on Medicare Claims data. Therefore, careful construction of appropriate denominators based on Medicare enrollment and primary payer status is required.

Data Sources

The United States Renal Data System (USRDS) maintains a database of the medical and demographic characteristics of all patients with end-stage renal disease (ESRD). These data include information on ESRD incidence, prevalence, morbidity, mortality, and related biochemical laboratory results. Also incorporated are Medicare fee-for-service claims for care received in inpatient (IP), outpatient (OP, including dialysis), skilled nursing facility (SN), home health agency (HH), and hospice (HS) settings. This information is complemented by details of physician/supplier services (PS), treatment histories (useful for modality determination), payer histories (essential for determining denominators for Medicare claims data as shown below), modality events, and provider characteristics.

History of CMS Data Collection

This section summarizes the history of federally organized data collection for ESRD patients in the U.S.

In October 1972, patients with ESRD became eligible for health insurance coverage through the Medicare Program (Public Law 92-603, expansion of the Social Security Act [U.S. Government Publishing Office, 1972]). Soon after, the development of computer systems to manage the data generated from the new ESRD program began.

In 1977, the Health Care Financing Administration (HCFA) was established to oversee Medicare’s financing and claims processing. To organize and assure quality of medical care, collect data, and adjudicate patient grievances, HCFA created 18 regional ESRD Networks.

In June of 1978, Public Law 95-292 facilitated significant improvements to ensure cost-effective quality of care in the ESRD program. The ESRD Program Management and Information System (PMMIS) was established to provide medical and cost information for ESRD program analysis, policy development, and epidemiologic research (Rettig and Levinsky, 1991; CMS Fact Sheet, 2012). Data were compiled from Medicare claims and ESRD-specific data forms: the Medical Evidence form (CMS 2728), the Death Notification form (CMS 2746), and the Facility Survey form (CMS 2744). Initially there was no mandatory compliance for data collection, so early data was quite incomplete. In 1981, reporting on the incidence of ESRD was mandated as a requirement for Medicare certification, and a new Medical Evidence form was introduced.

Throughout the 1980s, efforts continued to create a comprehensive ESRD registry with reporting beyond that which the PMMIS provided. The Omnibus Budget Reconciliation Act of 1986 called for the Department of Health and Human Services to establish a “national end-stage renal disease registry”. A Request for Proposals was issued for the development of the United States Renal Data System (USRDS). NIDDK awarded the contract in May 1988 to the Urban Institute, with a subcontract to the University of Michigan, and the first USRDS Annual Data Report on the ESRD population was released in 1989.

In 1995, HCFA transitioned PMMIS to the Renal Beneficiary and Utilization System (REBUS). Also in 1995, non-Medicare patients were included in the database as the ESRD Medical Evidence form (CMS 2728) was made mandatory for all ESRD patients.

In 2001, HCFA was renamed the Centers for Medicare & Medicaid Services.

In 2003, the REBUS database was converted into an Oracle relational database known as the Renal Management Information System (REMIS), and the Standard Information Management System (SIMS) database of the ESRD networks was also established. SIMS collected the CMS Medical Evidence, Death Notification, and Facility Survey forms, and included information to track patient movement in and out of ESRD facilities and their transitions from one treatment modality to another. Integrating SIMS events data into the USRDS Database improved the tracking of patients beyond treatment initiation. SIMS was replaced by CROWNWeb in 2012.

CROWNWeb

The Consolidated Renal Operations in a Web-Enabled Network (CROWNWeb) is a web-based data collection system that captures clinical and administrative data from Medicare-certified dialysis facilities for all ESRD patients in the United States. This system was implemented nationally in May 2012. In addition to replacing the existing patient tracking functionality of SIMS, CROWNWeb collects new data to support calculation of clinical measures (e.g., Kt/V, hemoglobin, and calcium) and integrates these data with the REMIS system.

CMS Medicare Enrollment Database (EDB)

The Medicare EDB is the designated repository of all Medicare beneficiary enrollment and entitlement data, including current and historical information on beneficiary residence, Medicare as secondary payer, employer group health plan status, and Health Insurance Claim/Beneficiary Identification Code cross-referencing.

ESRD Medical Evidence Report (CMS 2728)

The CMS ESRD Medical Evidence Report form (CMS 2728) is used to register patients at the onset of ESRD and must be submitted by dialysis facilities or transplant centers within 45 days of treatment initiation. The form establishes Medicare eligibility for individuals previously not enrolled in Medicare, reclassifies existing beneficiaries as patients with ESRD, and provides demographic and diagnostic information on all new ESRD patients regardless of Medicare entitlement. The CMS, USRDS, and renal research communities rely on the form to ascertain patient demographics, primary cause of ESRD, comorbidities, and biochemical test results at the time of ESRD initiation.

Prior to 1995, providers were required to file the Medical Evidence form only for Medicare-eligible patients. Since the 1995 revision, however, providers have been required to complete the form for all new patients with ESRD regardless of Medicare eligibility status. The revised 1995 form included new fields for comorbid conditions, employment status, expanded race categories, ethnicity, and
biochemical data at ESRD initiation.

The third major revision of the Medical Evidence form, in May 2005, remedied several shortcomings of the 1995 form and its earlier versions. It included new data collection methods and new variables. The revision allows users to specify whether the Medicare registration is initial (new ESRD patient), a re-entitlement (reinstating Medicare entitlement after a lapse due to no claims being filed for 12 or more months or a functioning graft for 36 or more months), or supplemental (updating missing or incorrect information). This clarifies the intended use of the form without recourse to the "First Regular Dialysis Start Date," and helps chronicle the historical sequence of multiple forms completed for the same patient. Data fields for duration of nephrologist and dietitian care, as well as access type, were added, indicating their respective time intervals relative to ESRD onset. Laboratory values for hematocrit, creatinine clearance, blood urea nitrogen (BUN), and urea clearance were no longer collected. Added laboratory values were hemoglobin A1c (HbA1c) and lipid profiles (total cholesterol, low-density lipoprotein, high-density lipoprotein, and triglycerides).

Additional fields relate to whether patients have been informed of transplant options, and if not, why not, and discussed donor type. Effective in October 2015, CMS updated the 2728 form with ICD-10-CM codes to reflect "primary cause of renal failure" (Field 15). ICD-10-CM codes provide more diagnosis and procedure detail as compared to ICD-9-CM codes, resulting in a better understanding of the patient's health. In addition, CMS implemented options of "<6 months" for Fields 18a-c, "Prior to ESRD therapy".

The Medical Evidence form is the only reliable source of information about the cause of a patient's ESRD. Because the list of causal diseases has been revised, the USRDS stores the diagnosis codes from each version so that detail is not lost through conversion of one set of codes to another.

Most ESRD patients have only one Medical Evidence form completed during his or her entire ESRD treatment period. Multiple forms may be submitted, however, especially for transplant patients. Medicare entitlement for transplant patients with a functioning graft ends after three years if ESRD was the sole qualification for Medicare eligibility. If such a patient experiences kidney transplant failure and returns to dialysis, a second Medical Evidence Report must be filed to reestablish Medicare eligibility. A patient who discontinue dialysis for more than 12 months also loses Medicare ESRD benefits. If such a patient returns to dialysis or undergoes kidney transplant, a second Medical Evidence form must be filed to reestablish Medicare eligibility.

All versions of the CMS 2728 form (2015, 2005, 1995, 1987) are provided in the USRDS Core SAF dataset and are available on the USRDS website in the USRDS Researcher's Guide, Appendix D: Data Collection Forms.

ESRD Death Notification Form (CMS 2746)

The ESRD Death Notification form (CMS 2746) is used to report the death of a patient with ESRD. According to CMS policy, this form must be submitted by dialysis or transplant providers within 30 days of a patient's death. It provides the date and causes of death (primary and secondary), reasons for discontinuation of renal replacement therapy, if applicable, and evidence of hospice care prior to death. It is the primary source of death information for the USRDS ESRD database, identifying more than 90% of deaths. The USRDS also utilizes several supplemental data sources for ascertaining death (see the Death Date Determination section below for more details). The USRDS has not used the National Death Index data due to the prohibitive cost of obtaining it for the entire U.S. dialysis population.

Annual Facility Survey (CMS 2744)

In addition to the CMS ESRD databases, independent ESRD patient counts are available from the CMS Annual Facility Survey (AFS; CMS 2744). Every facility approved by Medicare to provide services to ESRD patients must provide the information requested in the AFS. It is also the facility's responsibility to provide patient and treatment counts to its local ESRD Network upon termination of operations. Facilities certified as only providing inpatient services are not requested to complete a survey. The AFS reports the counts of patients being treated at the end of the year, new ESRD patients starting treatment during the year, and patients who died during the year. Both Medicare and non-Medicare end-of-year patients are counted. While AFS files do not contain patient-specific demographic and diagnosis data, they provide independent patient counts used to complement the CMS patient-specific records. In addition, CMS 2744 includes facility level information such as ownership, services offered, number of stations, and detailed staffing data. Upon publication of the 2005 AFS, CMS stopped posting data from these surveys on the internet. From 2007 to 2011, the USRDS extracted the relevant facility survey data directly from the SIMS database. Since 2012, the USRDS has received the facility survey data directly from CROWNWeb.

Organ Procurement and Transplantation Network (OPTN) database

In the early 1980s, CMS began collecting data on all Medicare-paid kidney transplants in the PPMIS data system. In 1984, the National Organ Transplant Act established the Organ Procurement and Transplantation Network (OPTN) to collect data and maintain a registry for organ matching and transplantation. The United Network for Organ Sharing (UNOS) was awarded the OPTN contract in 1988 to provide a national system for allocating donor organs and to maintain a centralized data depository for all organ transplants, not just those paid for by Medicare. The OPTN and CMS collection efforts were consolidated in 1994; only OPTN continued to collect data on transplant donors and recipients. In addition, transplants are also identified from Medical Evidence forms that indicate transplant as the initial modality, from CROWNWeb transplant events, and from institutional inpatient claims.

Medicare ESRD Claims Files

The CMS ESRD Claims Standard Analysis Files (SAFs) contain data from final action claims for medical services provided to Medicare beneficiaries with ESRD, in which all adjustments have been resolved.

To compile institutional claims, the USRDS uses the following 100% SAFs:

- Inpatient (IP)
- Outpatient (OP)
- Skilled Nursing Facility (SN)
- Home Health Agency (HH)
- Hospice (HS)
For non-institutional claims, the USRDS uses the following 100% SAFs:

- Physician/Supplier (PS)
- Durable Medical Equipment (DME)

CMS SAFs are updated each quarter through June of the following year, when the annual files are finalized. Datasets for the current year are created six months into the year, and updated quarterly until they are finalized at 18 months, after which files are frozen and will not include late arriving claims. The data lag for the ascertainment of death and graft loss is about nine months. The annual files used in the ADR are approximately 98% complete. The USRDS 2021 SAFs include all claims up to December 31, 2019.

Medicare Prescription Drug Event File (PDE)

In December 2003, Congress passed the Medicare Prescription Drug, Improvement, and Modernization Act (MMA), amending the Social Security Act by adding the Part D prescription benefit under Title XVIII. With this new Part D coverage, health plans must submit a summary record called the prescription drug event (PDE) to CMS whenever a Medicare beneficiary fills a prescription. Each drug is identified by a National Drug Code (NDC). The prescription record also contains dosage information, drug costs above and below the out-of-pocket threshold, other true out-of-pocket (TrOOP) amounts, plan paid amounts, and low-income cost sharing subsidy amounts. The USRDS 2021 ADR includes 2006-2019 PDE data.

The Medicare Provider Analysis and Review (MedPAR) data

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 hemodialysis patients who were covered by Medicare Advantage plans in 2019 and to compare these rates with those among the Medicare FFS population.

The ESRD Quality Reporting System (EQRS) data

The ESRD Quality Reporting System (EQRS, formerly CROWNWeb/REMS) is a national registry for ESRD patients in the U.S. 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 supplement of this year’s ADR.

Database Definitions

ESRD is defined as chronic kidney disease requiring renal replacement treatment — dialysis or transplant — to sustain life. It is not the same as acute kidney injury (acute renal failure), from which patients are expected to recover within weeks or months. Kidney disease providers must complete a Medical Evidence form for all ESRD patients, which registers them in the CMS ESRD database via CROWNWeb and allows them to apply for Medicare if they were not previously eligible.

Identifying patients with ESRD

A person is identified as having ESRD when a physician certifies the disease on the Medical Evidence form, when there is other evidence of chronic dialysis that meets the criteria of ESRD, or upon registering as a candidate for kidney transplant through the OPTN. The identification of ESRD patients does not rely on the International Classification of Diseases (ICD) codes for ESRD. Patients with acute kidney injury who receive dialysis for days or weeks, but who subsequently recover kidney function, are excluded from the database if their Medical Evidence forms have not been submitted. Patients who die soon after kidney failure without receiving dialysis often are not included in the CMS ESRD database.

ESRD First Service Date

The ESRD first service date is the single most important data element in the USRDS database; each patient must, at a minimum, have a valid first service date. This date is used to determine the incident year of each patient and the first year in which the patient is counted as prevalent.

In most cases, the first service date is derived by identifying the earliest date of any of the following potential indicators:

- the start of dialysis for presumed ESRD as reported on the Medical Evidence form;
- the first CROWNWeb event;
- a kidney transplant as reported on a CMS or OPTN transplant worksheet/form, a kidney transplant as reported on CROWNWeb transplant, or a Medical Evidence form

Death Date Determination

After the ESRD first service date, the date of death is the next most critical piece of information in the USRDS database. Death dates are obtained from several sources: the CMS Medicare Enrollment Database (EDB), CMS forms 2746 and 2728, the OPTN transplant follow-up worksheet/form, and/or the CROWNWeb database. Because multiple sources report death information for the same patient, an individual may have several reported dates. For these patients, the accepted death date is based on the hierarchical order below:

1. CMS 2746 Death Notification form
2. CMS EDB
3. CMS Patient List
4. CROWNWeb events
5. OPTN Transplant follow-up data and transplant data
**Date of Kidney Transplantation**

Transplant events can be identified from the OPTN data, Medical Evidence forms indicating kidney transplant as the initial modality, and/or CROWNWeb transplant events. Each transplant event found in the Transplant file of the USRDS Core SAF dataset is a unique event. To resolve any conflicts among the data sources and to create a complete list of unique transplant events, the USRDS has adopted the following procedures:

- Before 1988, all transplant events found in CMS PMMIS/REBUS/REMIS Transplant files are used.
- Between 1988 and 1993, all transplant events found in OPTN Files are used, and additional transplant events from the CMS PMMIS/REBUS/REMIS are recorded.
- Additionally, transplant events reported on the Medical Evidence form are used, as are transplants found in the CROWNWeb patient events data.

**Kidney Graft Failure**

We assume a (kidney) graft failure date is correct as reported in the OPTN transplant follow-up or REMIS identification file unless death or a new transplant occurs before this date. A graft failure date may not be recorded in either file, however. In this case, we use the earliest of the following events:

- date of death
- date of subsequent transplant
- date of return to regular dialysis, indicated by a continuous period of dialysis billing records covering a minimum of 60 days, or
- date of return to dialysis reported on the Medical Evidence form, or the date of graft nephrectomy from the OPTN follow-up record or a Medicare claim.

**Medicare and Non-Medicare Patients**

Beneficiaries who are enrolled in Medicare due to their age are representative of the U.S. population aged 65 and older, as 98% of individuals are eligible for Medicare. Those who are younger than 65 tend to have more serious health conditions than do others their age in the general population given that they become entitled to Medicare due to disability or ESRD.

Most patients with ESRD under age 65 are eligible to apply for Medicare as their primary insurance payer at the start of their third month following the start of ESRD treatment. Some, however, may not immediately enroll in Medicare if they have private insurance such as employer group health plans. For a person with private insurance, that insurance is the primary payer for the first 30 months of ESRD treatment, after which Medicare becomes primary. The patient may choose to enroll in Medicare at the start of ESRD or may wait to enroll until the 30-month coordination of coverage period is completed. These patients will have first service dates established by Medical Evidence forms or CROWNWeb events, but no dialysis claims or hospitalization events in the CMS claims database. All ESRD patients, regardless of their Medicare Eligibility status, are included in the CROWNWeb system.

The USRDS recognizes that non-Medicare patients are “true” ESRD patients and should be included in patient counts for incidence, prevalence, and treatment modality, as well as in mortality and transplant rate calculations. Calculations of hospitalization statistics or any outcomes derived from Medicare claims (e.g., any specific diagnostic or therapeutic code), however, should not include these patients because of the small number of claims available in the first 30-33 months after their first ESRD service date. It is important to understand that a fraction of the patients in the USRDS database does not have Medicare as their primary payer at any given time. For this reason, the ADR analyses construct a denominator cohort using the PAYHIST file.

**Integration of the CROWNWeb and CMS Claims Databases**

The USRDS uses all available data to create a treatment history for each patient in the database, including all modality events, their duration, and the kidney disease providers involved in each patient’s care. We use this history to identify incident and prevalent cohorts and to determine censoring points and outcomes for observational studies.

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<td>Dialysis after Transplant</td>
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<td>Failed (at Dialysis Facility)</td>
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<td>Transfer Out for a Transplant</td>
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<td>Death</td>
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The CROWNWeb event database is the primary source of the modality sequence file, and dialysis claims are used as a way of confirming placements and resolving problem cases. See Table I above for a list of CROWNWeb events.

As described in previous sections, we use all available sources to determine first service dates, deaths, transplants, and graft failures.

For patients who do not appear in the CROWNWeb events file, whose only event is “New ESRD Patient”, or who have gaps in facility assignment, the Medicare dialysis claims file is used.

For “Transfer Out” and “Transfer Out for a Transplant” events followed by gaps of seven days or more, claims falling in those gaps are included, unless the “Transfer Out for a Transplant” event has a corresponding transplant or transplant failure event within 30 days. Claims data are also included for the periods after “Transplant Failure” events and “Discontinued Dialysis” modality if the periods are longer than seven days. Because the claims data capture the modality “Center Self-Hemodialysis” more accurately than the CROWNWeb data, any CROWNWeb dialysis event that falls into a “Center Self-Hemodialysis” period as determined by claims is
recoded as “Center Self-Hemodialysis.”

Events that are implausible are removed. These include events that occur before a patient’s first service date, those falling between “Transplant” and “Transplant Failure,” “Transfer Out for a Transplant” events that occur 60 days or less after the corresponding “Transplant,” and events occurring after “Death.”

**Lost to Follow-Up Methodology**

Gaps frequently exist in the CROWNWeb and the billing data upon which modality periods are based. The USRDS assumes that a modality continues until death or the next modality-determining event. A patient with a functioning transplant is assumed to maintain it unless a new CROWNWeb event, claim event, or death date is encountered in the data. A dialysis modality, in contrast, is assumed to continue for only 365 days from the date of the last claim, in the absence of a new CROWNWeb event, a transplant date, a death date, or dialysis claims. After this period, the patient is declared lost to follow-up, until the occurrence of a new CROWNWeb event, dialysis claim, or transplant event.

Patients are considered lost to follow-up beginning 365 days after a “Transplant Failure” event or “Discontinued Dialysis” modality with no subsequent events. Patients for whom the only event is a first service date, and who do not exist in any other files, are also treated as lost to follow-up, beginning one year after the first service date. A number of different events can result in the lack of dialysis data, and eventual reclassification of a patient as lost to follow-up, including:
- recovery of renal function
- no longer a resident of the United States
- the patient has died, but this was not reported to the Social Security Administration or to CMS

**Serum Albumin Data**

The Medical Evidence form reports patient albumin levels along with the test’s lower limit, which indicates the testing method, namely brom cresol purple or brom cresol green (with lower limits of 3.2 and 3.5 g/dL, respectively). For all figures in the ADR that present serum albumin data from the Medical Evidence form, the USRDS ESRD database includes only those incident patients who had both an albumin value and an albumin lower limit of 3.2 or 3.5 g/dL.

**Modalities**

USRDS and CMS have worked extensively on methods of categorizing patients by ESRD treatment modality. The initial modality for a patient is determined using an algorithm based on a hierarchy of data sources. The data sources are evaluated in the following order: CROWNWeb data, Medical Evidence form, claims data, and transplant data. The modality indicated in CROWNWeb and the Medical Evidence form may be temporary, as patients often change to a new modality during the first 90 days of treatment, it can be difficult to track modality during this time.

Patients aged 65 years and older or those with disabilities have Medicare claims in the first 90 days that contain revenue codes designating modality. Most patients younger than age 65 and in employer group health plans (EGHP), however, have no such early claims. Thus, modality may not be determined until Medicare becomes the primary payer at day 91 or, for EGHP patients, at 30-33 months after the ESRD first service date. These limitations influence our ability to determine a patient’s modality at any one point in time.

Of note are the patients categorized as having an unstable modality (i.e., on a modality for fewer than 60 consecutive days) in the first 90 days of treatment. Because these patients tend to have higher death and hospitalization rates, interpretations of modality-specific outcomes from their data should be viewed with caution. These patients are not considered as being either stable hemodialysis (HD) or stable peritoneal dialysis (PD) patients in analyses of patients with stable modality (e.g., hospitalization rates in the ADR). When the 60-day stable modality rule is used, these patients are included in the “all ESRD” category, which provides a more complete view of outcomes with the least biasing of the data.

**60-Day Stable Modality Rule: Treatment History File**

The 60-day stable modality rule requires that a modality continue for at least 60 days before it is considered a primary or switched modality. The rule is used to construct a second modality sequence, or treatment history, for each patient and assigns the patient a modality only if it is a stable or established modality. The hospitalization statistics shown by modality and the vascular access analyses in the ADR use the 60-day rule to define a stable modality. Most of the other data reported in the ADR do not use this rule.

**90-Day Rule: Outcomes Analyses**

This rule defines each patient’s start date for data analyses as day 91 of ESRD, and is used primarily to calculate hospitalization rates.

**Recovered Renal Function (RRF)**

A new modality event — recovered renal function (RRF) — was introduced in the 2007 ADR. Prior to the 2016 ADR, this event required the recovery of function to occur within 180 days of the first service date and to persist for at least 90 days. Starting with the 2016 ADR, every indication of RRF is now considered valid. The RRF event is similar to the lost to follow-up event in that such patients will not be included in the prevalent populations for outcomes analyses.

However, as with lost to follow-up events, we retain these patients in the modality sequence so that subsequent renal failure episodes can be tracked closely and in a timely manner.

ESRD treatment modalities may be categorized in different ways within the analyses in each chapter, they are defined in the chapter-specific analytical methods sections that follow this section.

**Payers**
For analyses using claims data, it is important to know whether Medicare is the primary payer (MPP) for the beneficiary, since claims are only filed with Medicare for those beneficiaries. Information on payers is obtained primarily from the EDB. We also examine Medicare outpatient claims to find beneficiaries with at least three consecutive months of dialysis treatment covered by Medicare. Regardless of their status in the EDB, these patients are designated as having MPP coverage. From these two data sources, we construct a Payer Sequence file to provide payer history, identifying Medicare eligibility status and other payers. The construction of this file is similar to that of the Treatment History file. Payer status is maintained for each ESRD patient from the ESRD first service date until death or December 31, 2019.

Payer status information prior to the start of ESRD (ESRD first service date) is available from the back-casted Payer Sequence file. The Pre-ESRD Payer Sequence file is similar to the standard ESRD Payer Service file, except it begins at the first evidence of Medicare enrollment from the EDB, rather than ESRD first service date. The Pre-ESRD payer sequence ends the day before the ESRD first service date.

Constructing denominators based on payer history is essential for analyses using Medicare claims-defined outcomes — that is, for any outcome using a specific diagnostic or procedure code. ICD diagnosis codes are used for all claims, while ICD procedure codes are used for inpatient claims. Healthcare Common Procedure Coding System (HCPCS) codes are used in the Physician/Supplier claims and the revenue portion of the institutional claims.

Only a minority of patients who receive dialysis have Medicare primary payer status when they start dialysis, although this increases to about 60% of patients after several months. Prior ADRs and some medical journal articles have suggested using the 90-day window after dialysis start rule to assume Medicare primary payer eligibility, but this is only a guideline. Both the percent of patients with Medicare coverage at incidence and the average time from initiation of dialysis to Medicare coverage for those not covered at incidence have changed over time. Because of this, using actual payer status and dates, as described above, is much more precise and is therefore the recommended method.

Payer data are used to categorize a patient during a given period of time as MPP (established in the SAF PAYHIST), Medicare as secondary payer (MSP) with an employer group health plan (EGHP), MSP non-EGHP, Medicare Advantage (Medicare + Choice), Medicare or Medicaid only, or a combination of payers; see the Researcher's Guide to the USRDS Database for more information.

Race and Ethnicity

Data on patient race and ethnicity are obtained from the Medical Evidence form, the REMIS patient identification file the CROWNWeb patient list. The Medical Evidence form asks patient race and Hispanic ethnicity in two separate questions, so they can be treated independently or combined.

Patient ethnicity became a required field on the 1995 revision of the Medical Evidence form, but because the form did not go into effect until midway through 1995, data for that year are incomplete. Therefore, information on Hispanic patients is presented starting in 1996. The non-Hispanic category includes all non-Hispanics, but does not include those of unknown ethnicity, which is a separate category.

In the 2021 ADR, we present data using combined categories defined by race and ethnicity. Hispanic individuals are considered as a separate category, and other race groups include non-Hispanic individuals within those groups (e.g., 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 categories have been previously presented in the ESRD volume that serves to better align race and ethnicity categories in the CKD and ESRD volumes. In addition, this strategy facilitates comparisons among Hispanic and non-Hispanic individuals in different race groups. In other words, rather than simply displaying Hispanic and 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/ethnicity categories whenever possible, but in many instances, stable estimates of outcomes cannot be generated for smaller race/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/ethnicity in analyses using Medicaid data because race/ethnicity is missing entirely or for the majority of beneficiaries in many states in the Medicaid database. Therefore, it is not possible to examine race/ethnicity groups that are representative of the U.S. population in these groups.

Volume 2, Chapter 1: Incidence, Prevalence, Patient Characteristics, and Treatment Modalities

This chapter addresses the incidence and prevalence of ESRD, along with patient characteristics and the distribution of kidney replacement therapies, including dialysis modalities.

Throughout this chapter, we rely heavily on the enumeration of incident and prevalent ESRD patients and their kidney replacement therapy history in the USRDS database. Estimates of incidence are primarily informed by validated submissions of the ESRD Medical Evidence Report (form CMS-2726), which must be submitted whenever a patient is newly diagnosed with ESRD. This form typically establishes the date of ESRD onset.

USRDS assigns a unique identification (USRDS ID) number that facilitates longitudinal follow-up of each patient in the USRDS database, including follow-up of associated treatment therapies, hospitalizations, outpatient encounters, and other healthcare events. Linkage across databases and assignment of USRDS IDs must be performed annually. New claims and other data must be linked to correct individuals already in the database, new patients must be identified, and USRDS IDs must ultimately be assigned. Key patient attributes and identifiers, such as names, date of birth, sex, date of death, Social Security Number (SSN), and Health Insurance Claim/Beneficiary Identification Code (HIC/BIC), have typically been used to uniquely identify each ESRD patient. Small differences, errors, or missing values for patient identifiers complicate this process, and matching rules must therefore be developed and applied. Overly stringent criteria may result in inclusion of some individuals more than once, whereas overly loose criteria risk combing different individuals into one record.
The Centers for Medicare & Medicaid Services (CMS) recently discontinued use of SSN as its primary form of identification of beneficiaries to better protect beneficiary privacy and financial information. By design, SSNs will be less reliably included in CMS databases going forward. USRDS has developed a new patient matching process that incorporated the Medicare Beneficiary Identifier (MBI) and does not require SSN, as long as there is sufficient matching of other identifiers. This change has identified some additional incident and prevalent cases of ESRD, particularly in recent years, compared with the prior matching process. These newly identified individuals differ from the general ESRD population in that they are younger, are more likely to be Hispanic or Latino, and are concentrated in western states. These individuals may have been excluded from the database because of missing SSN and Medicare HIC/BIC but are likely true cases of ESRD. We provide this explanation because discerning readers may note slightly higher ESRD incidence and prevalence counts and rates in this year’s ADR than in prior years, particularly between 2013 and 2017.

Figure 1.1 displays number of incident ESRD patients, adjusted and unadjusted incidence per million people, and percent change, from 1999 to 2019. Patients with incident ESRD included those who initiated maintenance dialysis for the treatment of ESRD and those who received a preemptive kidney transplant (without prior dialysis treatment). Unadjusted incidence per million people is derived by dividing the annual number of patients with incident ESRD by the size of the United States population, as reported by the US Census Bureau. Adjusted incidence per million people is derived similarly and adjusted for age, sex, race, and Hispanic ethnicity. Considering the gradual aging of the US population, adjustment for age is more influential than adjustment for all other factors. The reference population for adjusted rates is the United States population in 2015.

Figure 1.2 displays the number of patients with incident ESRD, stratified by modality, in each year from 2000 to 2019. The initial modality (in-center hemodialysis, home hemodialysis, peritoneal dialysis, kidney transplant) is identified in the USRDS treatment history dataset. At ESRD onset, the most important source of information about treatment modality is the ESRD Medical Evidence Report. However, other sources, including transplant records in the Organ Procurement and Transplantation Network (OPTN), provide additional information.

Figure 1.6 displays the number of patients with prevalent ESRD, stratified by modality, in each year from 1990 to 2019. Prevalence and modality were ascertained on December 31 of each year. Modality is identified in the USRDS treatment history dataset. The reference population for adjusted prevalence is the United States population in 2015.

Figure 1.7 displays the adjusted and unadjusted prevalence of ESRD per million people, by Health Service Area. Here, prevalence during 2018 and 2019 is pooled. Table 1.1 displays the number of patients with incident ESRD, unadjusted incidence per million people, adjusted incidence per million people, and the distribution of initial modalities, stratified by initial ESRD Network, among patients with incident ESRD in 2019. Initial ESRD Network was identified from the USRDS residence history. Adjusted incidence was derived in the same manner as in Figure 1.1, with the United States population in 2015 as the reference.

Figure 1.8 displays the adjusted prevalence of ESRD in strata defined by age and race/ethnicity in each year from 2000 to 2019. Prevalence and modality were ascertained on December 31 of each year. Modality is identified in the USRDS treatment history dataset.

Figure 1.9 shows the distribution of incident modality among patients with incident ESRD in 2019, stratified by age, race/ethnicity, sex, and primary cause of ESRD. Identification of initial modality in both figures employed the same methodology as in Figure 1.2.

Figure 1.10 shows the distribution of modality among patients alive and with ESRD on December 31, 2019, stratified by age, race/ethnicity, sex, and primary cause of ESRD.

Figure 1.11 displays the duration of pre-ESRD nephrology care among patients with incident ESRD in 2019, stratified by age, race/ethnicity, sex, primary cause of ESRD, ESRD Network, employment status, and insurance status. Pre-ESRD nephrology care, employment status, and insurance status were ascertained from the ESRD Medical Evidence Report.

Figure 1.12 displays the number of patients with prevalent ESRD, stratified by modality, in each year from 1990 to 2019. Prevalence of ESRD was based on the number of patients alive and with ESRD on December 31 of each year; patients with ESRD include those receiving dialysis and those with a functioning kidney transplant. Unadjusted prevalence per million people is derived by dividing the patients alive and with ESRD on December 31 by the size of the United States population, as reported by the U.S. Census Bureau. Adjusted prevalence per million people is derived similarly, and adjusted for age, sex, race, and Hispanic ethnicity. The reference population for adjusted prevalence is the United States population in 2015.

Figure 1.13 displays the adjusted and unadjusted prevalence of ESRD per million people, by Health Service Area. Here, prevalence during 2018 and 2019 is pooled. Table 1.2 displays the number of patients with prevalent ESRD, unadjusted prevalence per million people, adjusted prevalence per million people, and the distribution of modalities, stratified by ESRD Network, among patients alive and with ESRD on December 31, 2019. ESRD Network was identified from the USRDS treatment history dataset. The reference population for adjusted prevalence is the United States population in 2015.

Figure 1.14 shows the distribution of estimated GFR among patients with ESRD in each year from 2000 to 2019. GFR greater than 10 mL/min/1.73 m² at ESRD onset.
Figure 1.17 shows the percentage of patients with incident ESRD in 2018 and 2019, by Health Service Area, who had hemoglobin less than 9 g/dL at ESRD onset, overall and stratified by ESA use prior to initiation of renal replacement therapy; hemoglobin was ascertained from the ESRD Medical Evidence Report.

Table 1.3 displays mean values of laboratory measurements, all ascertained from the ESRD Medical Evidence Report, among patients with incident ESRD in 2019, stratified by age, race/ethnicity, sex, and primary cause of ESRD.

Figure 1.18 shows select comorbid conditions from the Medical Evidence form for incident ESRD patients in 2019, overall and by age, sex and race/ethnicity.

Figure 1.19 displays prevalence of common cardiovascular diseases in prevalent patients in 2019, by modality. The cohort includes point prevalent patients with ESRD receiving HD or PD, or with a functioning kidney transplant aged 18 and older on January 1, 2019, who were continuously enrolled in Medicare Parts A and B, and with Medicare as primary payer from January 1, 2019 to December 31, 2019, resided in the 50 U.S. states, the District of Columbia, or the U.S. territories, and whose first ESRD service date was at least 90 days prior to January 1, 2019.

Cardiovascular disease (CVD) of interest examined in this figure includes heart failure (HF), coronary artery disease (CAD), acute myocardial infarction (AMI), peripheral artery disease (PAD), cerebrovascular accident/transient ischemic attack (CVA/TIA), and atrial fibrillation (AF). Patients with any CVD are identified if they had at least one of the six general categories of CVD including CAD, HF, CVA/TIA, dysrhythmia, peripheral vascular disease (PVD), or other cardiac disease. Refer to the section Identification of Chronic Kidney Disease and Major Comorbidities in the DATA SOURCES for CKD Volume, 2021 USRDS ADR for the complete methodology and relevant ICD-10-CM codes used to identify HF, CAD, CVA/TIA, dysrhythmia, PVD, other cardiac disease, or diabetes. The codes and algorithms used to identify AMI, PAD, and AF are presented in the Excel file Codes and Algorithm for CVD and Procedure.

The prevalence of any CVD and each cardiovascular disease is calculated by treatment modality (HD, PD, transplant). Overall, and stratifications based on age, sex, race/ethnicity and presence of diabetes are shown.

Volume 2, Chapter 2: Home Dialysis

Throughout this chapter, home dialysis utilization was ascertained from the treatment history dataset that is routinely updated by the USRDS. This longitudinal dataset tracks each patient’s utilization of in-facility hemodialysis, home hemodialysis, continuous ambulatory peritoneal dialysis, and automated peritoneal dialysis, as well as kidney transplantation. In the context of this chapter, one important limitation of the treatment history dataset is that home treatment is defined as treatment that occurs outside of a dialysis facility. Therefore, intervals of home hemodialysis treatment do not distinguish between home hemodialysis in a private residence and home hemodialysis in a skilled nursing facility. In recent years, there has been relatively rapid expansion of the latter type of home hemodialysis. Although estimates of home hemodialysis utilization are not greatly affected by activity in the skilled nursing facility, estimates of the incidence of clinical outcomes can be greatly affected, as patients dialyzing in the skilled nursing facility tend to be elderly, have substantial comorbidity, and are highly likely to use a catheter for vascular access. In this chapter, we aimed to describe utilization of home hemodialysis in the private residence. To do so, we exclude all patients in facilities in which either one of two conditions are satisfied: (1) ≥40 percent of the census on December 31 of a given year resided in a skilled nursing facility during that year; (2) the facility was located inside a long-term care facility. Both conditions were determined using Dialysis Facility Report data. By inspection, the first condition routinely identifies dialysis providers who specialize in providing dialysis in skilled nursing facilities.

In Figure 2.1a, home dialysis utilization was measured at dialysis initiation (i.e., on the date of ESRD diagnosis), at exactly 1 year after dialysis initiation (among patients undergoing dialysis at that time), and on December 31 of each year (among patients undergoing dialysis on that date). In the first case, patients were grouped into annual cohorts based on the date of dialysis initiation. In the second case, patients were grouped into annual cohorts based on the date exactly 1 year after dialysis initiation. In the third case, patients were grouped into annual cohorts based on prevalent status as of December 31 of each year from 2009 to 2019. Home dialysis was defined by either home hemodialysis or peritoneal dialysis. Utilization estimates were stratified by age, sex, race/ethnicity, and primary cause of ESRD, but were not adjusted. In Figure 2.1b, home dialysis utilization was measured on December 31 of each year, as in the third case of Figure 2.1a. Payer status was ascertained from the payer history dataset that is routinely updated by the USRDS. Payer status was defined on December 31 of each year, in accordance with date upon which the dialysis modality was ascertained.

In Figure 2.2, data about home dialysis certification was ascertained from Dialysis Facility Compare, whereas data about home dialysis activity was ascertained from Dialysis Facility Reports. The January 2021 release of Dialysis Facility Compare data, which describes outcomes in dialysis facilities through December 31, 2019, was used to identify home dialysis certification.

In Figure 2.3, the number of home dialysis patients in each facility with an active home dialysis program was measured on December 31, 2019. Figure 2.4 describes characteristics of prevalent patients performing home dialysis on December 31, 2019. In Figure 2.5, the number of years between ESRD incidence and home dialysis initiation was calculated as the difference between the date of ESRD diagnosis and the date of first-ever home dialysis initiation; the cohort was limited to patients who initiated home dialysis in 2019.

Figure 2.6 includes Medicare fee-for-service beneficiaries with at least one home dialysis training session in 2019. Home dialysis training sessions were identified from Medicare claims submitted by outpatient dialysis facilities with condition code 73. The cumulative number of training sessions during 2019 was tallied for each patient, and the distribution of the cumulative number of training sessions was estimated.

In Figure 2.7, utilization of automated peritoneal dialysis was measured among prevalent patients undergoing peritoneal dialysis on December 31 of each year from 2009 to 2019.

In Figures 2.8a, 2.8b, and 2.8c, home hemodialysis treatment intensity data were ascertained from dialysis facility admission and discharge records during 2019 in the End Stage Renal Disease Quality Reporting System (EQRS). Each record in EQRS spans an interval of time and includes designations of dialysis modality, setting, prescribed number of sessions per week, and prescribed...
number of minutes per session. All home hemodialysis records that overlapped with any part of 2019 were included in the figures. Distributions of treatment intensity were estimated by time-weighted averages of home hemodialysis records. In Figure 2.8d, the Medicare-covered number of treatments per week was estimated among patients performing home hemodialysis in 2019 and concurrently carrying Medicare Part B coverage as primary payer. Covered treatments were ascertained from Medicare claims submitted by outpatient dialysis facilities.

In Figures 2.9 and 2.10, annual cohorts included all intervals of time during the year in which patients performed either peritoneal dialysis (Figure 2.9) or home hemodialysis (Figure 2.10) and concurrently carried Medicare Part B coverage as primary payer. Rates of hospitalization were estimated using Medicare Part A claims, with the cause of hospitalization defined by principal discharge diagnosis codes. For peritoneal dialysis catheter complications and vascular access complications, ICD-9-CM diagnosis codes were 996.1, 996.56, 996.62, 996.68, 996.73, 996.74, 999.31, 999.32, and 999.33, whereas ICD-10-CM diagnosis codes were T80.21, T82.4, T82.510, T82.511, T82.520, T82.521, T82.530, T82.531, T82.550, T82.591, T82.7, T82.858, T82.868, T85.511, T85.621, T85.631, T85.691, and T85.71. For peritonitis, ICD-9-CM diagnosis codes were 008.x, 567.x, or 999.39, whereas ICD-10-CM diagnosis codes were A04.x, K65.x, or T80.29. For sepsis, the ICD-9-CM diagnosis code was 038.x, whereas the ICD-10-CM diagnosis code was A41.x.

Figures 2.11 includes patients who initiated home hemodialysis or peritoneal dialysis between 2009 and 2018. In all analyses, patients were followed until the earliest of death, kidney transplantation, or December 31, 2019. Both death and kidney transplantation were classified as competing risks in estimation of the cumulative incidence of conversion to in-facility hemodialysis. Conversion was defined by at least 60 days of in-facility hemodialysis.

In Figure 2.12, annual cohorts included patients who had converted from home dialysis to in-facility hemodialysis in each year from 2009 to 2019, as defined in Figure 2.11. Only those patients who had accumulated at least 6 months of home dialysis treatment at the time of conversion and who carried Medicare as the primary payer during the last 6 months of home dialysis treatment were retained. Hospitalizations were ascertained from Medicare Part A claims.

In Figures 2.13 and 2.14, cohorts were the same as those in Figure 2.11. Death and kidney transplantation incidence estimates were derived with and without classifying conversion to in-facility hemodialysis as a competing risk.

In Figure 2.15, the prevalence of kidney transplant waitlist registration was estimated among prevalent home dialysis patients on December 31 of each year. Annual cohorts were restricted to patients aged less than 80 years on December 31 of each year.

Volume 2, Chapter 3: Clinical Indicators and Preventive Care

This chapter utilizes data from both the Consolidated Renal Operations in a Web-enabled Network (CROWNWeb) database and Medicare claims. Whenever possible, figures are based on analyses of the CROWNWeb database, which includes data about all patients undergoing dialysis, not only those with Medicare fee-for-service coverage. For analyses that are based on CROWNWeb data, monthly cohorts of patients undergoing dialysis are constructed between January 2013 and December 2019. For each month, all prevalent patients undergoing dialysis on the first day of the month are identified, according to the USRDS treatment history. Patients are required to remain on dialysis for the entirety of the month. In addition, patients are required to have a dialysis adequacy record in the CROWNWeb database during the given month. Only those patients whose dialysis modality (hemodialysis or peritoneal dialysis) on the first day of the month matches the modality on the dialysis adequacy record in the CROWNWeb database is included for analysis. In figures, outcomes are reported monthly among patients on hemodialysis, whereas outcomes are reported quarterly among patients on peritoneal dialysis. Technically, outcomes are recorded on a monthly basis even among patients on peritoneal dialysis, but in CROWNWeb, biochemical data may be recorded as infrequently as once per quarter in patients on peritoneal dialysis. If biochemical data are recorded during multiple months within a single quarter, then the mean value is calculated and included in the figure.

Figure 3.1a displays the percentage of hemodialysis patients in 2019 with single-pool Kt/V ≥1.2 and the percentage of peritoneal dialysis patients in 2019 with weekly Kt/V ≥1.7. In the case of peritoneal dialysis, weekly Kt/V may reflect both dialysis and residual Kt/V. The CROWNWeb database does not separate these components but does indicate whether residual Kt/V was included in the estimation of weekly Kt/V. According to CROWNWeb data in 2019, approximately 90% of Kt/V measurements reflect both components. Figure 3.1b displays the distribution of serum albumin among hemodialysis and peritoneal dialysis patients in 2019. Figure 3.1c displays the prevalence of hemoglobin among hemodialysis and peritoneal dialysis patients in 2019. Finally, Figure 3.1d displays the distribution of ultrafiltration rate among hemodialysis patients in 2019; the ultrafiltration rate is calculated from pre- treatment weight, post-treatment weight, and session duration data recorded on the same day as blood urea nitrogen measurements.

Figure 3.2 displays mean hemoglobin among hemodialysis and peritoneal dialysis patients between January 2013 and December 2019. Figure 3.3 displays the utilization of erythropoiesis-stimulating agents among hemodialysis and peritoneal dialysis patients between January 2016 and December 2019. In Figure 3.4, mean monthly doses of epoetin alfa, darbepoetin alfa, and pegylated epoetin beta are displayed, again between January 2016 and December 2019. Quantities reflect cumulative monthly doses in the outpatient setting, without consideration of the number of hospitalized days during the given month. Figure 3.5 displays mean hemoglobin among hemodialysis and peritoneal dialysis patients who were treated with an ESA between January 2016 and December 2019.

Figure 3.6 displays blood transfusion incidence between 2009 and 2019. In Figure 3.6a, annual cohorts include patients undergoing dialysis on January 1 of the given year and with Medicare fee-for-service coverage. Patients are followed from January 1 until the earlier of death or December 31 of the given year. During follow-up, the number of blood transfusions are derived. Each blood transfusion is identified from Medicare claims: (1) inpatient facility claims with revenue center codes 0380, 0381, 0382, 0389, 0554
dialysis, for each year from 2009 to 2019. In each year, the January cohort, as defined in Figure 3.8b, is followed from January 1 to G9142, and Q2033-Q2039. Figure 3.15b displays pneumococcal vaccination utilization among Medicare beneficiaries receiving 90470, 90630, 90653-90658, 90660-90664, 90666-90668, 90672-90674, 90682, 90685-90688, 90724, 90756, G0008, G9141, Volume 2, Chapter 4: Vascular Access

Figure 3.15a displays seasonal influenza vaccination utilization among Medicare beneficiaries receiving dialysis, for each year from 2009 to 2019. Cohort construction followed the approach of Figure 3.8a. In Figure 3.8b, the distribution of cumulative treatment hours per week is displayed; for each patient, the number of treatment hours per week was estimated under the assumption that the patient dialedyzed three times per week.

Figure 3.10 displays the utilization of nocturnal hemodialysis among patients undergoing in-facility hemodialysis and carrying Medicare fee-for-service coverage during each month from January 2017 to December 2019. Utilization of nocturnal hemodialysis was ascertained from Medicare claims submitted by outpatient dialysis facilities with modifier code UJ.

Figure 3.11a displays mean 24-hour urine volume among patients performing peritoneal dialysis during each quarter between January 2017 and December 2019. Urine volume was summarized among patients with a recorded nonzero value, so the figure should be interpreted as mean 24-hour urine volume among patients with reported urine output. Figure 3.11b displays loop diuretic utilization among patients performing peritoneal dialysis during each quarter between January 2017 and December 2019. Cohorts were limited to patients with Medicare Part D coverage. Loop diuretic utilization was defined as at least one fill of qualifying medication during a quarter.

Figures 3.12 and 3.13 show distributions of serum calcium and serum phosphorus, respectively, among hemodialysis and peritoneal dialysis patients between January 2013 and December 2019. These figures are based on CROWNWeb data and utilize the same cohort construction as in Figure 3.2.

Figure 3.14a shows phosphate binder utilization among patients undergoing dialysis between January 2009 and December 2019. Each quarterly cohort includes patients who underwent dialysis, carried Medicare fee-for-service coverage, and were enrolled in Medicare Part D during the entirety of the quarter. Phosphate binder utilization is categorized by agent: calcium acetate, sevelamer (hydrochloride or carbonate), lanthanum carbonate, or iron-based agent (either ferric citrate or sucroferric oxyhydroxide).

Figure 3.14b shows calcimimetic utilization among patients undergoing dialysis between January 2009 and December 2019. The cohort construction is the same as in Figure 3.14a. Calcimimetic utilization is categorized by agent: cinacalcet hydrochloride or etelcalcetide. The former agent is ascertained from Medicare Part D claims in 2009-2017. In 2018 and 2019, both agents are ascertained from outpatient dialysis facility claims.

Figure 3.14c displays vitamin D receptor activator (VDRA) utilization between January 2017 and December 2019. The cohort construction is the same as in Figure 3.14a. VDRA utilization is categorized by agent and/or route of administration: oral calcitriol, intravenous calcitriol, doxercalciferol, and paricalcitol. The figure spans only 2017-2019 because identification of oral calcitriol requires querying outpatient dialysis facility claims for National Drug Code (NDC) values; at present, the USRDS database includes claims with such detail only in 2017-2019.

Figure 3.15a displays seasonal influenza vaccination utilization among Medicare beneficiaries receiving dialysis, for each year from 2009 to 2019. In each year, the August cohort, as defined in Figure 3.8b, is followed from August 1 to the earlier of death or December 31 of the given year. During follow-up, influenza vaccination is ascertained from Medicare claims with HCPCS codes 90470, 90630, 90653-90658, 90660-90664, 90666-90668, 90672-90674, 90682, 90685-90688, 90724, 90756, G0008, G9141, G9142, and Q2033-Q2039. Figure 3.15b displays pneumococcal vaccination utilization among Medicare beneficiaries receiving dialysis, for each year from 2009 to 2019. In each year, the January cohort, as defined in Figure 3.8b, is followed from January 1 to the earlier of death or December 31 of the given year. During follow-up, influenza vaccination is ascertained from Medicare claims with HCPCS codes 90669, 90670, 90732, and G0009. Finally, Figure 3.15c displays herpes zoster vaccination utilization among Medicare beneficiaries receiving dialysis, for each year from 2009 to 2019. Cohort construction followed the approach of Figure 3.15b and added a requirement of Medicare Part D coverage. Herpes zoster vaccination was ascertained from Part D claims.

Figure 3.16 displays utilization of glycedated hemoglobin tests, lipid tests, and diabetes eye examinations among Medicare beneficiaries receiving dialysis and with diabetes as the primary cause of ESRD, for each year from 2009 to 2018. The cohort construction and follow-up are the same as in Figure 3.8a. All tests and examinations are ascertained from Medicare claims submitted by outpatient facilities, physicians, and suppliers (e.g., clinical laboratories). Glycated hemoglobin tests are defined by HCPCS codes 83036 and 83037; lipid tests are defined by HCPCS codes 80061, 82465, 82470, 83695, 83700-83705, 83715-83721, and 84478; and diabetes eye examinations are defined by HCPCS codes 2022F, 2024F, 2026F, 3072F, 67028, 67030, 67031, 67036, 67038-67043, 67101, 67105, 67107, 67108, 67110, 67112, 67113, 67121, 67141, 67145, 67208, 67210, 67218, 67220, 67221, 67227, 67228, 92002, 92004, 92012, 92014, 92018, 92019, 92225, 92226, 92230, 92235, 92240, 92250, 92260, S0620, S0621, S0625, and S3000.

Figure 3.17 displays the distribution of the number of outpatient nephrology visits per month in Medicare beneficiaries undergoing in-center hemodialysis between January 2009 and December 2019. We use the same cohort construction as in Figure 3.8b. For each patient, we queried Medicare claims submitted by physicians for the monthly capitlated payment (MCP) for in-center hemodialysis patient care, as indicated by Current Procedural Terminology (CPT) codes 90960 (4 or more visits), 90961 (2 or 3 visits), and 90962 (1 visit).
This chapter uses the ESRD database. Across all figures, we include only patients with ESRD receiving hemodialysis (HD) who were 18 years or older and who resided in the 50 states, the District of Columbia, or the U.S. territories. Patients with missing vascular access data were excluded.

Figures 4.1-4.2 present data derived from the Medical Evidence Report (CMS 2728) for incident patients with ESRD who initiated HD during the reported years. Age was calculated as of the date on which regular, chronic dialysis began.

Figures 4.3-4.5 present data derived from the Medical Evidence Report, the Consolidated Renal Operations in a Web-Enabled Network (CROWNWeb) clinical extracts, and Medicare claims. These figures present the cumulative incidence of various vascular access outcomes. Starting from the date of the first outpatient HD session after ESRD incidence, patients were followed until the earliest of the following: the event of interest, change in vascular access for more than 30 days, change to peritoneal dialysis or kidney transplant, death, loss of Medicare coverage, December 31, 2019, or after two years of follow-up. Vascular access type was identified using data from the Medical Evidence form at HD initiation and CROWNWeb clinical data during follow-up.

Cumulative incidence was estimated two ways: using one minus the Kaplan-Meier method (in Figures 4.3a, 4.4a, and 4.5a) and using the cumulative incidence function approach (in Figures 4.3b, 4.4b, and 4.5b). In the latter approach, we accounted for death, kidney transplant, and change in modality or vascular access as competing risk events.

Figures 4.3-4.4 present the cumulative incidence of three vascular access patency outcomes (loss of primary unassisted patency, loss of primary assisted patency, and loss of secondary patency) over two years of follow-up among patients with incident ESRD and who had fee-for-service Medicare coverage and who initiated HD with an arteriovenous (AV) fistula (Figures 4.3a-b) or AV graft (Figures 4.4a-b) in 2016-2018. Results are presented overall and stratified by age, sex, and race/ethnicity.

Loss of primary unassisted patency was identified as the earliest occurring of the following interventions: angioplasty, surgery for an anatomical complication, thrombectomy, thrombolysis, or creation of a new AV access. Loss of primary assisted patency was defined in a similar manner to loss of primary unassisted patency, except did not include angioplasty, which is the easiest and most common procedure for maintaining patency. Loss of secondary patency was defined as the creation of a new AV access. Interventions related to patency were identified on the basis of a Medicare Part A or Part B claim with a Healthcare Common Procedure Coding System (HCPCS) or Current Procedural Terminology (CPT) code, as follows. Angioplasty was identified using HCPCS/CPT codes G0392, G0393, 35475**, 35476**, 36902, 36903, 36905, 36906, 36907, 37025*, 37026*, 75960*, 75962*, 75964*, or 75978*.

Surgery for an anatomical complication was identified using CPT codes 36832, 36833, 36834, 36835, 36836, 36838, 36839, 36890, 36904, 36905, 36906, 37184*, 37185*, 37186*, 37187*, or 37188*. Thrombectomy was identified using CPT codes 37211, 37212, or 37213, with the additional requirement of occurring on the same day as an angioplasty. New AV access creation was identified using CPT codes 36818, 36819, 36820, 36821, 36825, or 36830.

For codes listed above with an asterisk (*), one of the CPT codes 36147, 36148, 93990, 90940, or 75791 was required to have occurred within 2 days before or including the day of the thrombectomy, surgery for anatomical complication, or angioplasty intervention. Similarly, for codes listed above with two asterisks (**), one of CPT codes 36147, 36148, 93990, 90940, 75791, or 75710 was required to have occurred within 2 days before or including the day of a thrombectomy intervention.

Figures 4.5a-b present the cumulative incidence of placement of a tunneled catheter over two years of follow-up among patients with incident ESRD who had fee-for-service Medicare coverage and who initiated HD with an AV fistula or AV graft. Placement of a tunneled catheter was identified on the basis of a Medicare Part A or Part B claim with a CPT code of 36558, 36565, or 36581.

Figures 4.6-4.7 present vascular access use among prevalent patients receiving HD. CROWNWeb clinical data were used to determine vascular access use among patients dialyzing on December 1 of the reported year. Catheter use includes any catheter, whereas AV fistula and AV graft use excludes the use of a central venous catheter.

Figures 4.8-4.9 include incident patients with ESRD who initiated HD in 2018. Data were derived from the Medical Evidence Report at HD initiation and from CROWNWeb at subsequent time points. Patients with a maturing AV fistula or AV graft with a catheter in place were classified as having a catheter. In Figures 4.8a-c, percentages of vascular access types are illustrated among patients who were alive and remained on HD up to each time point 3 to 18 months after initiation. Thus, the denominator shrinks with each subsequent time point as patients change modality, receive a transplant, or die.

Conversely, in Figure 4.9a-c, all patients who initiated HD in 2018 are included at each subsequent time point, and percentages for vascular access type as well as other outcomes (modality change, transplant, death) are displayed.

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Data Sources and Inclusion and Exclusion of Patients

Data sources for analyses in this chapter are the ESRD database (for ESRD Medicare fee-for-service [FFS] cohorts), CMS MedPar data (for ESRD Medicare Advantage [MA] cohorts), and the 5% Medicare random sample database (for general Medicare FFS cohorts). For details about data sources of the ESRD database, see “Data Sources” section.

Patients included in analyses in this chapter are placed into yearly ESRD cohorts. For each year, unless specified otherwise, the cohort includes point prevalent patients as of January 1 and incident patients throughout the year. We refer to these cohorts as yearly period cohorts and henceforth simply call them period cohorts. For point prevalent cohorts, we require patients to have been on ESRD for at least 90 days as of January 1, with Medicare as the primary payer for both Part A and Part B (Medicare FFS or MA). For hemodialysis, peritoneal dialysis, and transplant treatment modality specific cohorts, we also require patients to have been on the modality for at least 80 days. For transplant patients, we also require them to be in the first 3 years after receipt of a kidney transplant because many patients lose their Medicare eligibility after 3 years of transplant. Patients who remain in Medicare beyond 3 years after being transplanted are mainly older patients who are not representative of the transplant population as a whole. For incident patients, we have the same requirements on day 91 of ESRD. The cohort year is determined based on day 91 for incident patients. In this chapter, only patients aged 18 years or older are included.
The start date of the analysis period was January 1 for prevalent patients and day 91 for incident patients.

The analysis period is defined differently for different cohorts. Specifically,
- ESRD cohort: from start date to the earliest of death, loss to follow-up, recovery of kidney function, loss of Medicare coverage (including MA/FFS switch), 3 years after transplant for transplant recipients, and end of the year.
- Hemodialysis cohort: from start date to the earliest of death, loss to follow-up, recovery of kidney function, loss of Medicare coverage (including MA/FFS switch), 3 days before transplant, and end of the year.
- Peritoneal dialysis cohort: from start date to the earliest of death, loss to follow-up, recovery of kidney function, loss of Medicare coverage (including MA/FFS switch), 3 days before transplant, and end of the year.
- Transplant cohort: from start date to the earliest of death, loss to follow-up, graft failure, loss of Medicare coverage (including MA/FFS switch), 3 years after transplant, and end of the year.

For incident cohorts, analysis periods may vary; see specific figures for details. Figures that contain general Medicare non-ESRD beneficiaries used point prevalent cohorts, with inclusion criteria described in Chapter 3 of the CKD volume.

Analyses of rehospitalization are based on hospitalizations among members of study cohorts described above. Only acute hospitalizations resulting in live discharge are included in the analysis.

In this year's analyses, race is combined into one variable with ethnicity (we call this race/ethnicity), meaning that it is recorded as non-Hispanic White, non-Hispanic Black, Hispanic, Native American, Asian, and Other. When we say White and Black in this chapter, we mean non-Hispanic White and non-Hispanic Black. In most analyses, due to sample size limitations, we combined Native American, Asian, and Other into one group, which we then referred to as "Other".

Outcomes

Outcomes in this chapter include hospitalization, observation stay not leading to hospital admission, emergency department (ED) encounter without leading to hospital admission, and readmission, observation stay, and death within 30 days after hospital discharge. With the exception of events occurring within 30 days after hospital discharge, all events in the analysis period are total events (i.e., multiple events are allowed in the analysis period). Events within 30 days after hospital discharge are described as a percentage of hospital discharges. (i.e., only count the event happened or not; see details for specific figures).

Hospitalizations and readmissions are derived from Medicare inpatient claims. Only acute hospitalizations are included. Inpatient claims are processed first, and all overlapping as well as certain adjacent hospitalizations are combined. Specifically, hospitalizations with an admission on the same day or the day after a previous discharge are combined only when there is a discharge transfer code or indication of an interim claim. In the case of two hospitalizations combined into one, the principal diagnosis and procedure codes are retained from the first of the two hospitalizations, with the combined hospitalization extending from the first admission date to the last discharge date. Observation stays and ED encounters are derived from outpatient claims using revenue center code 0762 with type-of-bill not equal to 72 for observation stay and revenue center codes 0450-0459 or 0981 with type-of-bill not equal to 72 for ED visits.

Statistical Analyses

Event rates for hospital admissions, observation stays, and ED encounters within the analysis period are calculated as the total number of events in the analysis period divided by the time at risk, per person-year. Time at risk is calculated as length of the analysis period minus days in which patients are in the hospital. If a hospitalization crosses the beginning date or end date of the analysis period, only the portion in the analysis period is included in the time at risk calculation. For readmissions, observation stays, and death within 30 days after a live discharge from the hospital, we calculate percentages of discharges that result in a readmission, observation stay, or death.

For adjusted analyses, a model-based method (Liu et al., 2006) is used with adjustment for patient age, sex, race/ethnicity, primary cause of ESRD and some are adjusted for comorbidity also. To reduce the dimension of analyses, instead of individual comorbidities, a comorbidity index/score [Liu et al., 2010] was used. The score is weighted sum of comorbidities of atherosclerotic heart disease, congestive heart failure, cerebrovascular accident or transient ischemic attack, peripheral vascular disease, dysrhythmia, other cardiovascular disease, diabetes, chronic obstructive pulmonary disease, gastrointestinal disease, liver disease, and cancer. Based on how the index was developed, the score can be treated as a continuous variable in the model. For figures illustrating changes over time, the reference population is the 2015 ESRD population; while figures that only include data from 2019 use the 2019 ESRD population for adjustment, unless otherwise indicated. Unless specified otherwise, these analyses employ Poisson regression models.

To show fine geographic patterns of hospitalization rates, we use a Conditional Autoregressive Bayesian spatial model (Waller et al., 1997) to estimate Health Service Area (HSA) level hospitalization rate. By borrowing information from neighbors, this complex Bayesian model can stabilize the estimates for small areas, showing fine geographic patterns adjusted for patient characteristics.

Hospitalizations, Observation Stays, and ED encounters

Figure 5.1 (5.1a-5.1d) shows the trends in adjusted and unadjusted hospitalization rates over period 2009-2019 among prevalent Medicare FFS beneficiaries with ESRD, overall and by age, sex, race/ethnicity and modality, with and without including observation stays. For adjusted rates, age, sex, race/ethnicity, ESRD cause, and comorbidity were adjusted for.

Figure 5.2 shows the trend of adjusted and unadjusted cause-specific hospitalization rates over Period 2009-2019 among prevalent Medicare beneficiaries with ESRD by modality. Causes include cardiovascular disease (CVD), infection, and non-CVD and non-infection (it is further split to cancer, diabetes, non-infectious lung disease, GI bleeding, fracture, and other). Cause also includes vascular access for hemodialysis patients and peritonitis for peritoneal dialysis patients. All causes, except vascular access, are determined by the primary diagnosis code in inpatient claims based on the corresponding International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) or ICD-10-CM diagnosis codes listed in Excel file "Codes for Cause of Hospitalization – ESRD Volume". Vascular access related hospitalization is determined by corresponding diagnosis-related group (DRG) codes, ICD-9-10 procedure codes, and ICD-9/10 primary diagnosis codes. Algorithms for determining vascular access hospitalization are also listed in Excel file "Codes for Cause of Hospitalization – ESRD Volume”. To avoid double counting, if a
hospitalization is defined as a vascular access hospitalization by DRG code and procedure code and a non-vascular access hospitalization by primary diagnosis, we classify this hospitalization as a vascular access hospitalization. For adjusted rates, age, sex, race/ethnicity, ESRD cause, and comorbidity were adjusted for.

Figure 5.3 shows all-cause and cause-specific hospitalization rate in 2019 among adult hemodialysis patients by age, sex, race/ethnicity, primary cause of ESRD, and vintage on ESRD, separated by patients covered by Medicare FFS and patients covered by Medicare Advantage. Hospitalizations for patients covered by Medicare FFS are derived from Medicare inpatient claims; while hospitalization for patients covered by Medicare Advantage are derived from Medicare MedPAR data. Although MedPAR data contains hospital stays covered under Medicare Advantage, these claims are not comprehensive. The interpretation of the results should be with caution. Causes include cardiovascular, any infection, and vascular access infection. Vascular access infection is determined by corresponding ICD-9-CM and ICD-10-CM diagnosis codes listed in Excel file “Codes for Cause of Hospitalization – ESRD Volume” at the primary position in claims. For adjusted rates, age, sex, race/ethnicity, ESRD cause, and comorbidity were adjusted for.

Figure 5.4 shows adjusted and unadjusted rates of hospitalization and observation stays among incident hemodialysis and peritoneal dialysis cohorts in 2008, 2011, 2014, and 2017 over each year after dialysis initiation for up to 12 years. For the first year of ESRD, the analysis period is day 91 to day 365 from onset of ESRD, for the second year it is day 366 to day 730 for the second year, and so on. For event rate calculations in the second year and beyond, only patients who are followed into that year are included. Due to small sample sizes, the rates for peritoneal dialysis cohorts may not be stable for later follow-up years. For adjusted rates, age, sex, race/ethnicity, ESRD cause, and comorbidity were adjusted for.

Figure 5.5 shows the geographic variation of hospitalization rate 2018-2019 by modality using a Health Service Area (HSA) level map. The rate for each HSA is estimated by a Conditional Autoregressive Bayesian spatial model (Waller et al., 1997). For adjusted rates, age, sex, race/ethnicity, and ESRD cause were adjusted for.

Figure 5.6 (5.6a and 5.6b) shows the trend in rates of ED encounters among prevalent ESRD patients over period 2009-2019 by modality and further by patient age, sex, and race/ethnicity. ED encounters include only those that did not lead to a hospital admission in the analysis period.

**Readmission Rates**

The unit of analyses for readmission is live hospital discharges in the analysis period (not patients). We refer to these hospitalizations as index hospitalizations. Outcomes of interest are readmissions, observation stays, and deaths within 30 days after discharge. Different index hospitalizations are included for different outcomes. For analyses examining readmissions and observation stays only, we require follow-up for at least 30 days after discharge in the analysis period. In analyses that include death within 30 days, we also include those hospitalizations for which follow-up was less than 30 days because of death within 30 days.

Figure 5.7 shows the percentages of 30-day readmission or death after discharge, with and without including observation stays not leading to a hospitalization, among point prevalent patients with ESRD on January 1, 2019 and among general (non-ESRD) Medicare beneficiaries with CKD and ESRD vintage. ESRD was determined by medical claims in 2018. All were required to be aged 66 years or older at January 1, 2019 and covered by Medicare Parts A and B for the whole of 2018. The outcomes were categorized as readmitted within 30 days and died within the 30 days without readmission. Some patients could be readmitted and discharged alive, then died within 30 days of discharge of the initial hospitalization. These deaths were not counted for the first hospitalization because death happened after live discharge of the rehospitalization, which became a new index hospitalization, and death was counted as the outcome of the new index hospitalization. This methodology is necessary to avoid double counting deaths. Outcomes are categorized in the same way in Figure 5.9. These analyses include hospitalizations with live discharge dates between January 1 and December 1, 2019, allowing assessment of outcomes for 30 days after discharge. Variables used for adjustment are age, sex, and race/ethnicity. The reference population is the 2019 general Medicare enrollees in the 5% random sample.

Figure 5.8 shows trends in the percentage of hospital discharges followed by a readmission with/without including observation stays within 30 days over the period 2009-2019 among yearly prevalent ESRD patients, by treatment modality (hemodialysis, peritoneal dialysis, and transplant).

Figures 5.9 shows readmission or death within 30 days after hospital discharge, by age, sex, and race/ethnicity groups, among 2019 prevalent hemodialysis and 2019 prevalent peritoneal dialysis patients, separately, with and without including observation stays.

**Reference**


**Volume 2, Chapter 6: Mortality**

The analyses in this chapter use the USRDS ESRD database and Medicare 5% fee-for-service random sample database. The USRDS ESRD database includes data from different data sources. For details, see the “Data Sources” section.

The study population in this chapter is ESRD patients in the U.S. For comparison, some analyses also include general Medicare beneficiaries without ESRD. Unless otherwise specified, cohorts underlying the analyses in this chapter include only patients living in the 50 states, the District of Columbia, or territories. Study cohorts for most of analyses are yearly period prevalent cohorts; study cohort for some figures are incident cohorts. Yearly period prevalent ESRD cohorts include point prevalent ESRD patients on January 1 of the year and incident ESRD patients during the year. For general Medicare beneficiary cohorts, only point prevalent cohorts are included. Some analyses are performed by patient modality, including dialysis (including hemodialysis, peritoneal
dialysis, and unknown dialysis), hemodialysis, peritoneal dialysis, and transplant. Modality is defined based on the modality on the first day in the cohort. In this chapter, only patients aged 18 years or older are included.

The analysis period is defined differently for different cohorts:

- **ESRD:** from the first day in the cohort to the earliest date of death, kidney function recovery, loss to follow-up, or end of study period, which is usually the end of the year.
- **Dialysis,** hemodialysis, and peritoneal dialysis: from the first day in the cohort to the earliest date of death, kidney function recovery, loss to follow-up, the day before receipt of a kidney transplant, or end of study period.
- **Transplant:** from the first day in the cohort to the earliest date of death, loss to follow-up, or end of study period.
- **Non-ESRD** Medicare cohort: from January 1 to the earliest date of death, loss of Medicare coverage, ESRD, or end of the year.

The outcome in this chapter is death. Death information for patients with ESRD is derived from the ESRD death notification form (CMS-2746), supplemented by the CMS enrollment database, CROWNWeb data, OPTN transplant data, and other sources. Cause of death is derived only from CMS-2746, and cause of death is missing among patients without this form. The date of death for Medicare non-ESRD beneficiaries is provided in the Master Beneficiary Summary File, which is part of the Medicare 5% database.

In this year’s analyses, race is combined into one variable with ethnicity (we call this race/ethnicity), meaning that it is recorded as non-Hispanic White, non-Hispanic Black, Hispanic, Native American, Asian, and Other. When we say White and Black in this chapter, we mean non-Hispanic White and non-Hispanic Black. In most analyses, due to sample size limitations, we combined Native American, Asian, and Other into one group, which we then referred to as “Other”.

The unadjusted death rate is calculated as the number of events divided by total follow-up time, and adjusted death rates are calculated using the model-based method (Liu et al., 2006), adjusted for patient age, sex, race/ethnicity, and primary cause of ESRD. Comorbidities were also adjusted for some selected figures. The model may be a Poisson regression model for prevalent cohorts or a Cox proportional hazard regression model for incident cohorts. Survival probability is based on the Kaplan-Meier method for unadjusted survival and Cox regression models for adjusted survival. To avoid too many variables for the adjustment, the Liu comorbidity score was used (Liu et al., 2010). This comorbidity score was developed specifically for analyses among ESRD patients and it can be used as a continuous variable for most of analyses.

To show geographic variation in death rates, HSA-level maps are created. A Conditional Autoregressive Bayesian spatial model is used to model the geographic pattern of death rate and at the same time to adjust for patient characteristics (Waller et al., 1997). The Bayesian spatial model can model geographic pattern and also stabilize estimates for small areas.

Figure 6.1 shows trends in adjusted and unadjusted all-cause mortality in prevalent patients with ESRD between 2009 and 2019 overall and by modality. Adjusted mortality rates are adjusted for patient age, sex, race/ethnicity, and primary cause of ESRD with the 2015 cohort as the reference.

Figures 6.2 and 6.3 show the geographic variation of adjusted and unadjusted all-cause mortality of prevalent ESRD patients by modality and by race/ethnicity (non-Hispanic White and non-Hispanic Black only due to small sample sizes) in the period 2018-2019 using HSA-level maps. Because of large differences of mortality rates among modality groups and race/ethnicity groups, different mapping rate-ranges were used for different cohorts to make sure the maps can show clear geographic patterns for each cohort.

Figure 6.4 shows adjusted and unadjusted all-cause mortality among incident dialysis patients followed for each year after the first service date for cohorts of incident patients in 2005, 2010, 2015, and 2017 by modality with censoring at transplant and not censoring at transplant. The interpretation of these figures differs. With censoring at transplant, the death rate in the figure shows the rate over the course of ESRD without transplantation (if no transplant had happened), whereas the death rate over the course of ESRD with possible transplantation is shown in Figure “Not Censor at Transplant”. The rates are based on the predicted cumulative hazard for patient groups in each cohort from a Cox model. The reference cohort is the 2015 incident ESRD cohort and the adjustment also included comorbidity.

Figure 6.5 shows deaths per 1,000 person-years by modality and by age and race/ethnicity or age and sex among 2019 period prevalent ESRD patients. Age and race/ethnicity subgroups are adjusted for sex and primary cause of ESRD. Age and sex subgroups are adjusted for race/ethnicity, and primary cause of ESRD.

Figure 6.6 shows the percentage of each cause of death among those who died in 2019 by modality with and without missing/unknown cause included — dialysis patients (6.6a), peritoneal dialysis (6.6b), and transplant patients (6.6c). The cause of death is derived from the ESRD death notification form CMS-2746 and grouped by codes listed in Excel file "Cause of Death – ESRD Volume".

Figure 6.7 shows adjusted survival over five-years from onset of ESRD by modality (hemodialysis, peritoneal dialysis, deceased donor transplant, and living donor transplant) and incident year. Adjustment is performed using the model-based method and Cox regression models. The reference cohort is the 2015 incident ESRD cohort and the adjustment also included comorbidity.

Table 6.1 presents expected remaining lifetime in years for the 2018 general U.S. population and for 2019 period prevalent dialysis and transplant patients. For dialysis and transplant patients, expected lifetime is calculated using the death rates from a Poisson regression model, assuming a constant mortality rate within each 5-years age group and calculating the area under this piecewise exponential survival curve. For this estimation, the younger the patients are, the more 5-years periods are used, and therefore, the large the possible cumulative error. Therefore, this year we only reported the expected remaining lifetime for groups aged 40 or older. Data for the general population are obtained from National Vital Statistics Report, United States Life Tables, 2018, "Table A. Expectation of life, by age, race, Hispanic origin, race for the non-Hispanic population, and sex: United States, 2018."

Table 6.2 shows adjusted and unadjusted all-cause mortality in the 2019 January 1 point prevalent dialysis, transplant, and general Medicare non-ESRD populations (all and those with the comorbidities of cancer, diabetes mellitus, heart failure, cerebrovascular accident or transient ischemic attack, and acute myocardial infarction) by age and sex. Patients can be in more than one comorbidity category. To make the ESRD cohorts and Non-ESRD cohorts comparable, we require all patients to be 66 or older on January 1, 2019, covered by Medicare Parts A and B, and not in a Medicare Advantage plan in the whole year of 2018. The dialysis and transplant cohorts are from the ESRD database, and the general Medicare non-ESRD cohorts are from the Medicare 5% database.
Figure 6.8 shows adjusted and unadjusted all-cause mortality of similar cohorts overall (not by age and sex) over the period 2009-2019. Follow-up for patients receiving dialysis begins on January 1 of the year and continues to the earliest of death, loss to follow-up, recovery of kidney function, the day before receipt of a kidney transplant, or the end of the year; from January 1 of the year to the earliest of death, loss to follow-up, or end of the year for transplant patients; and from January 1 of the year to the earliest of death, loss of Medicare coverage or enrollment of a Medicare Advantage plan, onset of ESRD, or end of the year for general Medicare non-ESRD beneficiaries. Adjusted mortality is adjusted for race/ethnicity only with the 2019 general Medicare population as the reference population for Table 6.2 and adjusted for age, sex and race/ethnicity for Figure 6.8 with 2015 Medicare patients serving as the reference population.

Figure 6.9 displays the adjusted and unadjusted survival probability, by the presence or absence of key CVD diagnoses, for point prevalent ESRD patients. The cohort includes point prevalent patients with ESRD receiving dialysis (including HD, PD, and unknown dialysis) or with a functioning kidney transplant on January 1, 2018 who were 18 years or older; resided in the 50 U.S. states, the District of Columbia, or the U.S. territories; had first ESRD service date prior to July 1, 2017; and were continuously enrolled in Medicare Parts A and B, and with Medicare as primary payer from July 1, 2017 to December 31, 2017 and on January 1, 2018. Patients are followed from January 1, 2018 to the earliest date of death, loss to follow-up, or December 31, 2019. For patients receiving dialysis, time to death is also censored at the date of transplant or recovery of kidney function.

Cardiovascular disease examined in this figure includes heart failure (HF), coronary artery disease (CAD), acute myocardial infarction (AMI), peripheral artery disease (PAD), cerebrovascular accident/transient ischemic attack (CVA/TIA), and non-valvular atrial fibrillation (NVAF). Various types of claims, codes, and algorithms were used to identify beneficiaries with the disease of interest in 2017. Specifically, patients with each disease are those whose Medicare claims indicate the diagnosis in 2017 using the standard claims-based method described in the section Identification of Chronic Kidney Disease and Major Comorbidities in the DATA SOURCES for CKD Volume, 2021 USRDS ADR. Patients with HF, CAD, CVA/TIA, or PAD are also identified if their latest Medical Evidence form on or before the index date reports the corresponding comorbid condition. Additionally, patients with PAD are also identified using relevant procedure codes on at least one Medicare claim in 2017. Finally, patients with NVAF are those whose Medicare claims indicate the diagnosis of AF using the standard claims-based method without diagnosis of mitral stenosis or undergoing a heart valve procedure in 2017. Refer to the Excel file Codes and Algorithm for CVD and Procedure for codes and algorithm to identify patients with the cardiovascular disease of interest using Medicare claims.

Unadjusted survival probability is estimated using the Kaplan-Meier method. Adjusted survival probability is calculated using the model-based method (Liu et al., 2006) with Cox proportional hazards modeling and adjusted for age, sex, and race/ethnicity. The combined cohort of point prevalent dialysis and transplant patients on January 1, 2018 is used as the reference population. Results are presented by ESRD treatment modality and the presence or absence of CVD diagnosis.

Table 6.3 shows the numeric values for unadjusted and adjusted two-year survival probability by ESRD treatment modality and the presence or absence of CVD diagnosis.

Figure 6.10 shows the unadjusted survival probability following a first cardiovascular procedure in 2017-2019 for patients receiving HD, PD, or with a functioning kidney transplant. Cardiovascular procedures include coronary artery bypass graft (CABG), percutaneous coronary interventions (PCI), placement of implantable cardioverter defibrillator/cardiac resynchronization therapy defibrillator (ICD/CRT-D), and carotid artery stenting and carotid endarterectomy (CAS/CEA). To form the study cohort for each cardiovascular procedure of interest, Medicare claims from January 1, 2017 through December 31, 2019 are searched for the qualifying codes for each cardiovascular procedure using the method described in the Excel file Codes and Algorithm for CVD and Procedure. The date of the first claim with a relevant code and qualifying for the procedure is considered as the index date. To be retained in the analysis cohort, on the index date, the patient must have been aged 18 and older; received dialysis (HD or PD), or with a functioning kidney transplant; resided in the 50 U.S. states, the District of Columbia, or the U.S. territories. In addition, we require patients to be enrolled in Medicare Parts A and B with Medicare as primary payer, and their first ESRD service date must be at least 90 days prior to the index date.

Patients are followed from the index date to the earliest date of death, loss to follow-up, 2 years after the index date, or December 31, 2019. For dialysis patients, time to death is also censored at the date of transplant or recovery of kidney function. Unadjusted survival probability is estimated using the Kaplan-Meier method. Results are presented separately for each procedure by treatment modality.

Reference

Volume 2, Chapter 7: Transplantation

Figure 7.1 shows the number of ESRD-certified patients added to the kidney or simultaneous kidney-pancreas transplant waiting list during each year from 1999 to 2019, stratified by first-ever versus subsequent addition to the waiting list. In this analysis, a waiting list addition is counted only if the patient is certified to have ESRD by December 31 of the given year. The practical consequence of this is that wait-listing counts are lower in the Annual Data Report than wait-listing counts that are reported by the Scientific Registry of Transplant Recipients (SRTR), as listings that occur long before the diagnosis of ESRD are reflected only in SRTR. The data source for this figure is Reference Table E.1.

Figure 7.2 shows the number of patients with prevalent ESRD that are on the kidney transplant waiting list on December 31 of each year from 1999 to 2019, stratified by active versus inactive status. The data source for this figure is Reference Table E.3.
Patients are required to carry Medicare fee-for-service coverage and to be enrolled in Medicare Part D during all of follow-up. Patients are followed from the date of transplant to the earliest of graft failure, one year after the transplant procedure, or December 31, 2019. Estimates are derived from a competing-risks analysis, in which death is classified as a competing event.

Figure 7.6 displays the cumulative incidence of death or wait-listing up to three years after initiation of dialysis, overall, and by age, sex and race/ethnicity.

Figure 7.7 shows the cumulative incidence of transplant or death, at 1, 3 and 5 years after wait-listing.

Figure 7.8 shows the distribution of outcomes, at one-year intervals, among patients who were initially wait-listed in 2010-2014. The denominator reflects the same methodology as in Figure 7.1. Patients are followed from the initial wait-listing until December 31, 2019. Outcomes include living donor kidney transplant, deceased donor kidney transplant, death, removal from the waiting list, and continued registration on the waiting list. After a patient receives a transplant or is removed from the waiting list, status in this analysis no longer changes. Patients are stratified by age, race, and percent panel-reactive antibody (PRA) at wait-listing.

Figure 7.9 shows the rate of cardiovascular hospitalization among ESRD-certified Medicare beneficiaries who were wait-listed between January 1, 2015, and December 31, 2019. During each year, all wait-listed patient-years concurrent with Medicare fee-for-service coverage are identified. During that time, hospitalizations are identified from Medicare claims submitted by inpatient facilities. Cardiovascular hospitalizations are defined by claims with qualifying principal discharge diagnosis codes.

Figure 7.10 shows the median waiting time (in months) from wait-listing to kidney transplant for candidates for kidney-alone transplants (i.e., the time after wait-listing at which 50% of these candidates had received a kidney transplant). Candidates listed at more than one transplant center on December 31 are counted only once. Cumulative incidence was estimated with death as a competing risk. Median waiting time is calculated for all candidates initially on the waiting list during each year from 2009 to 2014. The data source for this figure is Reference Table E.2.

Figure 7.11 shows the number and rate of kidney transplants among patients undergoing dialysis during each year from 1999 to 2019. Counts and rates are shown for all transplant, deceased donor transplants alone, and living donor transplants alone. The denominator of each transplant rate includes all patient-years on dialysis within the given year, according to the USRDS treatment history. Patients are stratified by overall, age, sex, race/ethnicity, and primary cause of ESRD.

Figure 7.12 shows the distribution of patient characteristics among kidney transplant recipients during each year from 1999 to 2019.

Figure 7.13 shows transplant rates in each state among all dialysis patients and dialysis patients < 75 years of age during 2019, using the same methodology as in Figure 7.11. The location of record is ascertained from the USRDS residence history.

Information about the occurrence of paired donation is ascertained from transplant records in the Organ Procurement and Transplantation Network (OPTN) database; a kidney paired donation transplant is defined as any living donor kidney transplant for which the donor type was recorded as "non-biological, unrelated: paired donation."

Figures 7.15, 7.16, and 7.17 display counts and unadjusted rates of deceased donation among all deaths in the United States population aged less than 75 years, stratified by age, sex, and race, between 2009 and 2019. Donors had at least one kidney recovered. Data on the deceased donors are obtained from OPTN data, and data on the annual number of deaths in the U.S. population are obtained from the Centers for Disease Control and Prevention. Traumatic deaths are defined by cause of death being motor vehicle accident, homicide, or suicide.

Figure 7.18 displays the number and percent of patients with a functioning kidney transplant among prevalent ESRD patients on December 31 of each year from 1999 to 2019, according to the USRDS treatment history. Patients are displayed overall, and by age.

Figure 7.19 shows rates of all-cause, cardiovascular, and infection-related hospitalization during the first year after transplant among Medicare beneficiaries who received a kidney transplant between January 1, 2015, and December 31, 2018. Patients are followed from the date of kidney transplant until the earliest of graft failure, one year after the transplant procedure, or December 31, 2019. Patients are required to carry Medicare fee-for-service coverage during all of follow-up.

Figure 7.20 displays Medicare Part D enrollment among patients who received a kidney transplant in 2019. Two denominators are used: (1) all kidney transplant recipients in 2019 and (2) all kidney transplant recipients in 2019 who carried Medicare fee-for-service coverage. Medicare Part D enrollment is identified on the date of transplant. Figure 7.21 shows medication expenditures during the first year after transplant among patients who received a kidney transplant between January 1, 2015, and December 31, 2018. Patients are followed from the date of transplant to the earliest of graft failure, one year after the transplant procedure, or December 31, 2019. Patients are required to carry Medicare fee-for-service coverage and to be enrolled in Medicare Part D during all of follow-up. Medicare expenditures are ascertained from both Part B claims and Part D claims. In Part B claims, medications are ascertained and categorized on the basis of Healthcare Common Procedure Coding System (HCPCS) codes beginning with ‘J,’ whereas in Part D claims, medications are categorized on the basis of National Drug Codes mapped to Medi-Span Generic Product Identifier codes.

Figure 7.22 displays one-, five-, and ten-year graft survival for recipients who received a kidney transplant during 1999-2018, stratified by source of transplant (deceased donor, living donor). To ensure adequate follow-up duration, one-year graft survival estimates are displayed in 1999-2018 (with follow-up through December 31, 2019), whereas five-year and ten-year graft survival estimates are displayed in 1999-2014 and 1999-2009, respectively.
Figure 7.23 displays one-, five-, and ten-year patient survival for recipients who received a kidney transplant during 1999-2018. In both Figures 7.22 and 7.23, data are reported as survival probabilities derived from Cox proportional hazards regression. All-cause graft failure is defined as any graft failure, including repeat transplant, return to dialysis, and death. In adjusted models of graft failure, adjustment factors include age, sex, race, ethnicity, primary cause of ESRD, and first versus subsequent transplant. In adjusted models of death, first versus subsequent transplant is not included among the adjustment factors.

Figure 7.24 shows rates of overall graft failure and of death with a functioning graft within 3 years among recipients who received a kidney transplant in 2008, 2012, and 2016, using the same definition of graft failure as in Figure 7.22. Death with functional graft is defined as death without any graft failure. All rates are adjusted for age, sex, race/ethnicity.

Figure 7.25 shows the cumulative incidence of death and receipt of a new kidney transplant within 3 years after graft failure between 2009 and 2016, by two types of return modality (hemodialysis and peritoneal dialysis). For cumulative incidence of a new kidney transplant after graft failure, death is considered as a competing risk. Cumulative incidences of both events are adjusted for age, sex, race/ethnicity. Age stratified cumulative incidences of both events are adjusted for sex, race/ethnicity. Race/ethnicity stratified cumulative incidences of both events are adjusted for age and sex.

Volume 2, Chapter 8: ESRD Among Children, Adolescents, and Young Adults

The methods for creating most figures are similar to the methods used throughout other chapters in this volume.

After reviewing the age, height, and weight of patients using data from the Medical Evidence Report (CMS 2729) and CROWNWeb, a data cleaning process was deemed necessary for this chapter. Patients aged 0-4 with extreme values of weight or height (i.e., a z-score of greater than 4 for height or greater than 8 for weight) are excluded, as these values are considered to be a data error. Children residing outside of the 50 states, the District of Columbia, or the U.S. territories are also excluded.

Figure 8.1 displays counts, unadjusted rates, and adjusted rates of ESRD incidence and ESRD prevalence, overall and by kidney replacement therapy, among US children from 2009 to 2019.

Figure 8.2 displays these measures of ESRD incidence and ESRD prevalence from 2009 to 2019 stratified by age, sex, and race/ethnicity. For a detailed discussion of methods regarding this section, refer to the discussion of methods regarding Chapter 1: Incidence, Prevalence, Patient Characteristics, and Treatment Modalities. Data sources are the same, except for the data cleaning described above.

Figure 8.3 shows mean hemoglobin among children with prevalent ESRD in 2015-2019, by age, race/ethnicity, body mass index (BMI), and cause of ESRD. BMI is categorized by the z-score:

- Underweight: BMI <5th percentile (BMI z-score <-1.64)
- Normal: 5th percentile ≤ BMI <95th percentile (-1.64 ≤ BMI z-score ≤1.64)
- Obese: BMI ≥95th percentile (BMI z-score >1.64)

Note that Overweight is not considered because with fluid overload, this can be misclassified (Ku et al., 2017).

Figure 8.4 displays the distribution of the primary cause of ESRD, stratified by age, among children with incident ESRD in 2015-2019.

Table 8.1 displays the number of children with incident ESRD in 2015-2019, stratified by categories and specific primary causes of ESRD, along with the distributions of age, sex, and race/ethnicity among those patients. The underlying primary causes of ESRD are ascertained from the ESRD Medical Evidence Report. Categories of the primary cause of ESRD consist of primary glomerular disease; secondary glomerular disease; congenital anomalies of the kidney and urinary tract (CAKUT); cystic, hereditary, and congenital diseases; tubulointerstitial disease; transplant complications; diabetes; neoplasms and tumors; hypertensive and large vessel disease; miscellaneous conditions; uncertain etiology; and unknown (i.e., missing) etiology. Some specific primary causes of ESRD are not displayed in the table, due to patient counts of 10 or fewer, thus resulting in apparent discordance between counts of patients in categories and sums of counts in the specific primary causes of ESRD that constitute those categories. Refer to the sections about methods for Reference Tables A: Incidence and B: Prevalence for conversion of the primary cause of ESRD categories used in the 2015 ESRD Medical Evidence Report to the corresponding categories used in the 2005 Medical Evidence Report.

Figure 8.5 shows the percentage of children with ESRD being cared by pediatric nephrologists, adult nephrologists, or Other physicians by age, incidence/prevalence, dialysis modality, and urban/rural status in 2019. Physician specialty is identified by their NPI on their ESRD service monthly claims (CPT codes 90951-90959) and the NPI profile publicly available on CMS website.

Figure 8.6 shows mean hemoglobin among children with prevalent ESRD receiving dialysis. For each month from January 2013 to December 2019, we identify all patients aged <18 years who are undergoing dialysis on the first day of the month. For each such patient, we ascertain the monthly hemoglobin measurement in the Consolidated Renal Operations in a Web-Enabled Network (CROWNWeb) database.

Figures 8.7-8.8 present adjusted and unadjusted admission rates in the first year of ESRD, by age, and modality, for incident patients younger than 18 years with incident ESRD in 2014-2018 (Figure 8.7) and in two periods 2004-2008 and 2014-2018 (Figure 8.8).

Patients are divided into four age groups (age <1, 1-5, 6-12, and 13-17) and three modality groups (HD, PD, and transplant). For Figure 8.7, we divide hospitalizations into three categories: access-related surgical, non-access-related surgical, and nonsurgical. Surgical hospitalization is defined using diagnosis related group (DRG) codes. Hospitalizations with surgical DRGs are defined as surgical hospitalizations. Surgical hospitalizations are further split into access-related and nonaccess-related using the same method as in Chapter 5. Since patients who are younger than 65 and not disabled cannot enroll in Medicare until 90 days after ESRD initiation, the 90-day rule is applied. Patients are required to survive the first 90 days after initiation and are followed for admissions for up to one year after day 90. Data cleaning and counting of admissions and time at risk for admissions generally follow methods.
described for Volume 2 Chapter 5. Censoring occurs at death, loss to follow-up, recovery of kidney function, end of payer status, December 31, 2019, or at one year. Censoring also occurs three days prior to transplant for dialysis patients, and three years after the transplant date for transplant recipients. Rates are adjusted for age sex, race/ethnicity, and primary cause of ESRD. Adjusted rates are calculated using the model-based adjustment method with Poisson regression model. The reference population is incident ESRD patients aged 0-17 years in 2015. We use the same principal ICD-9-CM and ICD-10-CM diagnosis codes used to define infectious hospitalizations in Volume 2 Chapter 5. Cardiovascular hospitalization is not analyzed because it is rare in children.

Figure 8.9 shows hospital days in children in the year after ESRD onset, by type of hospitalization, age, and treatment modality, 2014-2018, corresponding to hospitalizations in Figure 8.7.

Figures 8.10 presents adjusted all-cause mortality in the first year of ESRD, by age (ages<1, 1-5, 6-12, and 13-17) and modality (hemodialysis, peritoneal dialysis, and transplant), for 2002-2019 incident patients younger than 18 years old, in 3-year cohorts. Rates are adjusted for age sex, race/ethnicity, and primary cause of ESRD. Adjusted rates are calculated using the model-based adjustment method with Poisson regression model. The reference population is incident ESRD patients aged 0-17 years in the period 2013-2015.

Figure 8.11 shows five-year adjusted survival rates for 2010-2014 incident ESRD patients aged<1, 1-5, 6-12, and 13-17 years) and modality (hemodialysis, peritoneal dialysis, and transplant).

Figures 8.12 shows the percentage of cause-specific death by modality (hemodialysis, peritoneal dialysis, and transplant) among patients who died during 2010-2019 and were<18 years old when they died. Causes of death are cardiovascular, infectious, cancer, dialysis withdraw, other, and unknown. The cause is defined using codes in the death notification form (CMS-2746) with cardiovascular: 23, 24-32, 36, 37; infection: 33, 34, 45-48, 51, 52, 61-65, 70, 71; cancer: 82, 83; dialysis withdraw: 104.

Figure 8.13 presents vascular access use among prevalent children receiving HD for ESRD, separately by kidney transplant waitlist status (i.e., waitlisted or not). CROWNWeb clinical data are used to determine vascular access use among children dialyzing on December 1, 2019. Catheter use includes any catheter, whereas arterovenous fistula and graft use excludes the use of a central venous catheter. Children with missing vascular access data are excluded from the figure. Waitlist status was defined using data from the Organ Procurement and Transplantation Network (OPTN); waitlisted patients include those on the kidney or simultaneous kidney-pancreas transplant waiting list on December 1, 2019.

Figure 8.14 presents an overview of kidney transplantation among children. Figure 8.14a shows the percentage of children with incident ESRD who received a preemptive kidney transplant during each year from 2009 to 2019. Figure 8.14b shows, first, the percentage of patients who were preemptively waitlisted (i.e., waitlisted before ESRD onset) among children with incident ESRD who initiated dialysis during each year from 2009 to 2019; and second, the percentage of patients who were either waitlisted or received a kidney transplant during the first year of ESRD among children with incident ESRD during each year from 2009 to 2019. Refer to the discussion of methods for Volume 2 Chapter 7 (Transplantation) for details about estimation of the latter percentage. Figure 8.14c shows median waitlist time for a kidney-alone transplant among children with ESRD. Details about estimation are likewise described in the discussion of methods for Volume 2 Chapter 7. Figure 8.14d displays counts of kidney transplants among children with ESRD during each year from 2009 to 2019. Preemptive transplants are defined by kidney transplantation on the date of ESRD onset.

Figure 8.15 displays the number of kidney transplants per 100 dialysis patient-years among children with ESRD. For each year from 2009 to 2019, all patient-days coinciding with dialysis treatment during the year are included in the denominator of the rate estimate. Transplant rates by donor source are additive; that is, rates of deceased donor transplants and living donor transplants sum to the overall transplant rate. In contrast, transplant rates by race/ethnicity are estimated within patient subgroups defined by White, Black, or other race/ethnicity.

Figure 8.16 displays the estimated duration of time from initiation of dialysis to 10%, 25%, and 50% cumulative incidence of kidney transplant, among children who were diagnosed with ESRD and initiated dialysis between January 1, 2015, and December 31, 2018. Patients are followed from the date of ESRD onset to the earliest of kidney transplant, death, or December 31, 2019. Estimated duration to 10%, 25%, and 50% cumulative incidence of transplant is extracted from a competing-risks analysis in which death is classified as a competing event. Figure 8.17 shows adjusted estimates of one-year, five-year, and ten-year cumulative incidence of post-transplant events among children who received a deceased donor kidney transplant between January 1, 1999, and December 31, 2018. The events, which are analyzed separately, consist of graft failure, return to dialysis or re-transplantation, and death. Graft failure includes return to dialysis, re-transplantation, and death. Patients are followed from the kidney transplant date to the earliest of return to dialysis, re-transplantation, death, or December 31, 2019 to access the occurrence of each outcome. Displayed statistics are reported as adjusted probabilities of each outcome occurring and are computed using Cox proportional hazards regression. Probabilities of each outcome are adjusted for race/ethnicity (White, Black, Hispanic, Other), sex, primary cause of ESRD, and first versus subsequent transplant. Probabilities are standardized to the characteristics of children who received a deceased donor kidney transplant in 2015.

Figure 8.18 shows corresponding adjusted estimates of post-transplant events among children who received a living donor kidney transplant using the same methods described above for Figure 8.17. Probabilities are standardized to the characteristics of children who received a living donor kidney transplant in 2015.

Figure 8.19 shows the distribution of kidney replacement therapies on December 31 of each year from 1999 to 2019 among prevalent adult patients (age ≥18 years) who were diagnosed with ESRD during childhood. Patients with a functioning transplant on December 31 of a given year are stratified according to whether the transplant was a first-ever or subsequent transplant.

Volume 2, Chapter 9: Healthcare Expenditures for Persons with ESRD

For the 2021 ADR, we report Medicare expenditures primarily for those ESRD beneficiaries covered by Medicare fee-for-service (FFS) for their Medicare Part A, B, and D benefits except for Figure 9.1 and Figure 9.2, which include ESRD beneficiaries with Medicare Advantage (MA) and Figure 9.3, which includes general Medicare FFS beneficiaries.
Except for Figure 9.4a (incident ESRD) and 9.4b (point prevalent ESRD), the ESRD study population includes period prevalent Medicare FFS beneficiaries with at least one Medicare claim in each reported year. Calculation of ESRD costs includes costs from Medicare Parts A, B, and D, and time at risk is described in Reference Table K (Healthcare Expenditures for ESRD). We produce per person per year (PPPY) costs by dividing the total cost by total person-years at risk during the follow-up period in each year. Unless otherwise noted, total spending includes Medicare as primary payer (MPP) and Medicare as secondary payer (MSP); PPPY spending includes MPP only. In this year’s ADR, we adjust for inflation in longitudinal analyses using the medical care index, a component of the Consumer Price Index (https://data.bls.gov/timeseries/CUUR0000SA7?output_view=tabular;data); costs are expressed in 2019 U.S. dollars.

Figure 9.1 displays Medicare paid amounts for period prevalent ESRD patients from 2009-2019, as well as patient responsibility, which are estimated as the difference between Medicare allowable and Medicare paid amounts. Patient responsibility may be paid by the patient, by a secondary insurer, or may be uncollected. As in the 2020 ADR, we report Medicare paid amounts by MPP – Medicare only, MPP – dual Medicare/Medicaid, and MSP. Medicare expenditures can be calculated from the claims submitted for payment for health care provided to these individuals, but not for those enrolled in MA (managed care) plans. The Medicare program pays for services provided through MA plans on a risk-adjusted, per-capita basis and not by specific claims for services. Medicare expenditures for MA plans are estimated using the total equivalent eligible MA months (determined from the USRDS payer history files) multiplied by the monthly payment rates for dialysis patients published by CMS (https://www.cms.gov/Medicare/Health-Plans/MedicareAdvvtSpecRateStats/Ratebooks-and-Supporting-Data). Also as in the 2020 ADR, we apply an estimated monthly payment rate for MA beneficiaries with a functioning kidney transplant, i.e., a multiplier of 0.31 relative to the monthly dialysis payment rates (Table 5-41 and Table 5-66 of Report to Congress: Medicare Advantage Risk Adjustment - December 2018. Accessed at https://www.cms.gov/Medicare/Health-Plans/MedicareAdvvtSpecRateStats/Downloads/RTC-Dec2018.pdf). New in this year’s ADR, we report PPPY spending among Medicare FFS separately for those with MPP only and those with dual Medicare/Medicaid eligibility as well as for MA beneficiaries in Figure 9.2.

In Figure 9.3, total Medicare costs from each year are abstracted from the Medicare Trustees Report, Table II.B.1, which is available at 2020 Medicare Trustees Report (cms.gov). Part C costs are deducted to show the FFS Medicare costs. Medicare paid cost for period prevalent ESRD with at least one Medicare claim in a year include Parts A, B, and D.

Figures 9.4a-9.4b present trends from 2009 to 2019 in the distribution of sources of medical coverage among incident and January 1 point prevalent ESRD patients. Sources of medical coverage are determined from USRDS payer history files. The percentage of patients in each payer category sum to 100% for each annual cohort.

Figure 9.5 shows total ESRD Medicare FFS expenditures by type of service, 2009-2019. The analysis includes period prevalent patients, specifically, all ESRD patients with at least one Medicare claim. Medicare paid costs include Parts A, B, and D. Total spending includes MPP and MSP beneficiaries. Medicare spending is abstracted from Reference Table K: Healthcare Expenditures for ESRD, Table K.1.

Figure 9.6 shows trends in Medicare FFS PPPY spending by type of service, 2009-2019. The analysis includes period prevalent patients, specifically, all ESRD patients with at least one Medicare claim. Medicare paid cost including Parts A, B, and D. PPPY spending includes beneficiaries with MPP only. Medicare spending is abstracted from Reference Table K: Healthcare Expenditures for ESRD, Table K.1.

New in this year’s ADR, Figure 9.7 presents total Medicare FFS outpatient spending for beneficiaries receiving maintenance dialysis by types of services, 2009-2019. Types of services include dialysis related (sum of outpatient hemodialysis, peritoneal dialysis, and other dialysis), outpatient other injectables which are not bundled, radiology, pharmacy, ambulance, laboratory/pathology, and other outpatient services. Medicare spending is abstracted from Reference Table K: Healthcare Expenditures for ESRD, Table K.1. Medicare paid costs include Parts A, B, and D. Total spending includes MPP and MSP beneficiaries.

Figure 9.8 presents total Medicare FFS inpatient spending by primary cause of hospitalization during 2009-2019. Primary causes of hospitalization are defined in the same way for Volume 2 Chapter 5 which include cardiovascular, infection, diabetes, gastrointestinal, cancer, fracture, non-infectious pulmonary, and other. Medicare paid costs include Parts A, B, and D. Total spending includes MPP and MSP beneficiaries.

Figure 9.9 describes total Medicare ESRD expenditures by modality for period prevalent ESRD patients with at least one Medicare claim in a year, 2009-2019; Medicare paid costs include Parts A, B, and D; spending includes MPP and MSP beneficiaries. Spending for the total dialysis population includes those with unknown dialysis type. Data sources are Reference Table K, Healthcare Expenditures for ESRD, Table K.1.

Medicare paid costs include Parts A, B, and D. Total spending includes MPP and MSP beneficiaries.

Figure 9.10 shows the total Medicare ESRD expenditures PPPY by modality. The analysis includes period prevalent ESRD patients with at least one Medicare claim in a year, 2009-2019 and is restricted to patients with MPP only. Medicare paid costs include Parts A, B, and D. Data sources are Reference Table K, Healthcare Expenditures for ESRD, Table K.7, K.8, and K.9.

Volume 2, Chapter 10: Prescription Drug Coverage in Patients with ESRD

This chapter uses administrative claims data for the ESRD fee-for-service Medicare population using data primarily from the CMS ESRD 100% SAFs. For comparative purposes, this chapter also uses claims data for the non-ESRD fee-for-service Medicare population derived from the CMS 5% general Medicare SAFs.

Period prevalent cohorts of patients with ESRD are included in most analyses in this chapter, unless noted otherwise. These cohorts include point prevalent patients who were alive and enrolled in Medicare Parts A and B on January 1 of the reported year, with ESRD onset at least 90 days earlier, and incident patients who were alive and enrolled in Medicare Parts A and B 90 days after ESRD onset from January 1 and through December 31 of the reported year. Treatment modality is defined on January 1 for point prevalent patients and on day 90 after ESRD onset for incident patients. The general Medicare population in this chapter uses point prevalent cohorts of beneficiaries enrolled in Medicare Parts A and B and without ESRD on January 1 of the reported year. The creation of the non-ESRD cohorts is described in full detail in the analytic methods for Volume 1, Chapter 7 (Prescription Drug Coverage in Patients with CKD).
In both the ESRD and non-ESRD populations, analyses are limited to beneficiaries who were 18 years or older and who resided in the 50 states, the District of Columbia, or the U.S. territories at cohort entry. Initial analyses (Figures 10.1-10.2) include all Medicare fee-for-service beneficiaries meeting the criteria described above, while subsequent analyses (Figures 10.3-10.18 and Tables 10.2-10.3) are limited to the subset of beneficiaries with Medicare Part D coverage. In the ESRD cohorts, Part D coverage is required on January 1 for point prevalent patients and at day 90 after ESRD onset for incident patients. Throughout the chapter, analyses are conducted separately for beneficiaries with and without ESRD. Among those with ESRD, additional analyses are also generally performed separately by treatment modality (HD, PD, and kidney transplant).

In many analyses in this chapter, we report on Part D-related spending. The Part D benefit expenditure for a prescription drug event (PDE) is the sum of the amount of cost sharing for the drug that is paid by the Part D LIS (LIS amount) and the net amount that the Part D plan pays for the PDE (covered Part D plan paid amount). Out-of-pocket spending is the sum of the amounts the patient pays without being reimbursed by a third party (patient payment amount), which includes all copayments, coinsurance, deductible, or other patient payment amounts. This latter payment category includes the amount paid by other third-party payers that reduced the beneficiary’s liability for the PDE (other true out-of-pocket amount). Examples of this are payments by qualified state pharmacy assistance programs or charities.


In some analyses in this chapter, we report data on use and spending for specific drug classes of interest. These drug classes were identified by matching Part D PDE claims to a therapeutic class according to the Medi-Span Generic Productor Identifier (GPI) classification system.

Table 10.1 is an adaptation of data presented in the "2019 Medicare Part D Outlook" section of the www.medicare.com website and does not include USRDS analyses.

Figures 10.1 summarizes prescription drug insurance coverage for fee-for-service Medicare beneficiaries by source, showing results overall and by age and race/ethnicity categories. The sources of coverage across the calendar year are combined into mutually exclusive and exhaustive categories in a hierarchical manner. Enrollment in a Part D plan is determined by the first digit of the Part D Plan Contract Number variable (one for each month) being "E" (an employer direct plan), a valid value starting in 2007), "H" (a managed care organization other than a regional preferred provider organization (PPO)), "R" (a regional PPO), or "S" (a stand-alone prescription drug plan). A beneficiary is considered to be enrolled in a Part D plan if he or she was enrolled for one month or more of the analysis year. Those in a Part D plan who received a low-income subsidy (LIS) in at least one month, as determined by monthly Cost Sharing Group Code values “01” through “08,” are classified as “Part D with LIS”, and as “Part D without LIS” otherwise. Among beneficiaries not enrolled in a Part D plan, those with at least one month with a Part D Retiree Drug Subsidy Indictor value of “Y” (yes) are classified as “Retiree Drug Subsidy,” meaning they enrolled in an employer-sponsored prescription drug plan that qualified for Part D’s retiree drug subsidy. Beneficiaries meeting none of the situations described above are classified as “No known or other creditable coverage.”

Figure 10.2 shows the percentage of fee-for-service beneficiaries with Part D coverage between 2009 and 2019.

Figure 10.3 shows the percentage receiving a LIS (overall, by race/ethnicity, and by age within race/ethnicity categories) among fee-for-service beneficiaries who were enrolled in a Part D plan for at least one month in 2019.

Figure 10.4 is limited to those enrolled in a Part D plan with LIS and shows the different types of LIS, as determined by the values of the Cost Sharing Group Code. In each of Figures 10.2-10.4, Part D and LIS enrollment are defined as described for Figure 10.1.

Data on Medicare spending and beneficiary out-of-pocket spending for Part D benefits are presented in Figures 10.5-10.10. Values in these figures are presented in terms of total and/or per person per year spending. Figure 10.7, which is new to this year’s ADR, presents spending data separately for generic and brand-name prescription drugs. Spending is presented overall and stratified by sex, age, and race/ethnicity categories in Figure 10.8, and additionally stratified by LIS status in Figure 10.9. Out-of-pocket spending from 2009-2019 is presented overall and by LIS status in Figure 10.10.

Per person per year spending is calculated by dividing the total spending by the total observed beneficiary-years of follow-up in each year. In previous versions of the ADR, only mean values were reported for per person per year spending. However, spending data are typically right skewed, and so quartile values on the upper end of the distribution can have an influence on the mean. Therefore, to provide a fuller picture of the spending distribution, in this year’s ADR we report per person per year spending using both means and box plots. Mean values are displayed using either lines or squares. Each box plots displays information on five values: the minimum (bottom of lower whisker), first quartile (bottom of the box), median (line in the middle of the box), upper quartile (top of the box), and maximum (top of the upper whisker) of the distribution. It should be noted that the minimum and maximum box plot values exclude any potential outliers, which are numbers that are smaller (larger) than 1.5 times the interquartile range below the first (above the third) quartile. As noted above, these outliers will usually occur on the upper end of the distribution for the spending data presented in this chapter.

Using Part D PDE claims from 2019, drug classes are ranked two ways: by the percentage of beneficiaries who filled at least one prescription for a given class, and by the total Medicare spending for a given class. The top 15 drug classes for each ranking method, along with percentages of patients with at least one prescription and the total Medicare spending in each class, are shown in Tables 10.2 and 10.3, respectively. In addition to showing total spending for each class, Table 10.3 also shows spending per Part D enrollee and per drug class user for each of the 15 drug classes, as well as total spending for all covered medications. The per enrollee and per drug class user spending values, which are new to this year’s ADR, can be used to differentiate costly drug classes in terms of being inexpensive drugs used by a large number of enrollees (e.g., antibiotics) versus very expensive drugs used by a minority of enrollees (e.g., antiretrovirals). Only data from Medicare fee-for-service Part D beneficiaries with ESRD are included in these tables.

Figure 10.11 presents the percentage of Medicare fee-for-service beneficiaries with ESRD who received medications for cardiovascular disease in 2019. The cohort includes point prevalent patients with ESRD receiving dialysis (HD, PD, or unknown...
Cardiovascular diseases of interest include acute myocardial infarction (AMI), cerebrovascular accident/transient ischemic attack (CVA/TIA), coronary artery disease (CAD), heart failure (HF), nonvalvular atrial fibrillation (NVAF), and peripheral artery disease (PAD). Most CVDs (AMI, CVA/TIA, CAD, and HF) were defined based on having a relevant diagnosis code on at least one inpatient or two outpatient claims in 2019. PAD was defined based on having a relevant diagnosis code on at least one inpatient or two outpatient claims in 2019 or having a relevant procedure code on at least one inpatient or outpatient claim in 2019. The codes and algorithms used to identify these diseases are presented in the Excel file Codes and Algorithm for CVD and Procedure. Beneficiaries with NVAF in 2019 were identified by excluding beneficiaries with AF who underwent a heart valve procedure or had mitral stenosis in 2019. Refer to the worksheets AF and NVAF Exclusion in the Excel file Codes and Algorithm for CVD and Procedure for codes and algorithm to identify beneficiaries with NVAF.

For each cardiovascular disease of interest, three drugs or drug classes were selected for assessment based on their relevant indications:

- **AMI**: Beta blockers (BBs), lipid-lowering therapy (LLT), angiotensin converting enzyme inhibitors/angiotensin II receptor blockers (ACEI/ARBs)
- **CAD**: BBs, LLT, ACEI/ARBs
- **CVA/TIA**: Oral anticoagulants (OACs), P2Y12 inhibitors, LLT
- **HF**: BBs, Renin-angiotensin-aldosterone system inhibitors (RAASI) including ACEI/ARBs and angiotensin receptor neprilysin inhibitors (ARNIs), and mineralocorticoid receptor antagonists (MRAs)
- **PAD**: LLT, P2Y12 inhibitors, cilostazol
- **NVAF**: OACs, BBs, non-dihydropyridine calcium channel blockers (Non-DHP CCBs; diltiazem/verapamil)

Part D PDE claims for 2019 were searched for each drug class. A beneficiary was defined as having been prescribed a medication in a given drug class if he/she had a claim for at least one filled or refilled medication in the drug classes during 2019. The denominators were the total numbers of beneficiaries with each cardiovascular disease of interest in each modality, and the numerators were the numbers of beneficiaries having a medication in each relevant drug class and their various combinations of drug classes within that modality. Results are presented separately by treatment modality.

Figures 10.12a-b report on the percentage of Part D beneficiaries with ESRD on dialysis who used phosphate binders. These figures show data for the percentages of beneficiaries with at least one PDE claim for six different phosphate binder medications (calcium acetate, ferric citrate, lanthanum carbonate, sevelamer carbonate, sevelamer hydrochloride, and sucroferric oxyhydroxide) in the reported year. Results are presented separately by treatment modality. Figure 10.12a reports data for year 2019 overall and stratified by age, race/ethnicity, LIS status, and the combination of race/ethnicity and LIS status. Figure 10.12b reports data for years 2015-2019.

Figures 10.13a-b report on the percentage of Part D beneficiaries with ESRD who used potassium binders. These figures show data for the percentages of beneficiaries with at least one PDE claim for three different potassium binder medications (sodium polystyrene sulfonate, patiromer, and sodium zirconium cyclosilicate) in the reported year. Data are also presented for use of any of the three potassium binders. Results are presented separately by treatment modality. Figure 10.13a reports data overall for years 2015-2019 and then stratified by age, race/ethnicity, HF status, LIS status, and the combination of race/ethnicity and LIS status for year 2019 only. Figure 10.13b reports the same information as Figure 10.13a except is further limited to beneficiaries who had Part D coverage for at least 180 days before January 1 of the reported year and received ≥1 prescription for an ACEI/ARB medication during that period. HF status was identified based on having a relevant ICD-9-CM or ICD-10-CM diagnosis code on at least one inpatient or two outpatient claims during the 6 months prior to the start of the reported year. Refer to the section Identification of Chronic Kidney Disease and Major Comorbidities in the CKD volume Analytical Methods for the complete methodology and relevant diagnosis codes used to identify HF.

Figures 10.14-10.16 present analyses related to use of and spending for different classes of diabetes medications. These analyses only include Part D beneficiaries with ESRD and type 2 diabetes. Type 2 diabetes was identified based on having a relevant ICD-9-CM or ICD-10-CM diagnosis code on at least one inpatient or two outpatient claims during the 6 months prior to the start of the reported year. Refer to the section Identification of Chronic Kidney Disease and Major Comorbidities in the CKD volume Analytical Methods for the complete methodology and relevant diagnosis codes used to identify type 2 diabetes. All codes used for identifying the diabetes comorbidity, except those related to type 1 diabetes, were used to identify type 2 diabetes.

Diabetes medication classes of interest included insulin (INS), sulfonylureas (SU), dipeptidyl peptidase 4 inhibitors (DPP-4i), glucagon-like peptide-1 receptor agonists (GLP-1RA), thiazolidinediones (TZD), meglitinides (MEG), and other diabetes medications. The other diabetes medications class includes alpha-glucosidase inhibitors, amylin mimetics, bile acid sequestrants, and dopamine-2 agonists. In Figures 10.14 and 10.15b, INS was further sub-categorized as newer INS analogs and older INS. Since metformin and sodium-glucose co-transporter-2 (SGLT2) inhibitors are contraindicated in patients with ESRD receiving dialysis, these two drugs were not assessed in Figures 10.14-10.16.

Figures 10.14a-b present the percentage of beneficiaries who used each medication class, defined as having at least one PDE claim for that class during follow-up in the reported year. Results are presented separately by treatment modality. In Figure 10.14a, results are presented overall and stratified by age, race/ethnicity, heart failure (HF) status, LIS status, and the combination of race/ethnicity and LIS status.

Figures 10.15a-b present per person per year Medicare and out-of-pocket spending for all diabetes medications prescribed during follow-up in the reported year. In Figure 10.15a, spending is reported for all diabetes medications combined. Results are presented overall for years 2015-2019 and stratified by age, race/ethnicity, HF status, LIS status, and the combination of race/ethnicity and LIS status. Stratified results are only presented for 2019. In Figure 10.15b, spending in 2019 is reported separately for each class of diabetes medications, both overall and stratified by LIS status. HF status was defined in the same manner as described in Figure 10.13a.

Figure 10.16 presents the percentage of Part D beneficiaries who used combinations of diabetes medications for years 2015-2019. Only beneficiaries who had a prescription for ≥1 diabetes medication were included in each respective year. Combination use was...
defined as having at least 2 continuous calendar months with pill supply for multiple diabetes medications. Combination use was explored separately within each treatment modality for all possible mutually exclusive combinations involving two, three, or four diabetes medications. Figure 10.15 presents results only for the combinations in each modality that had a prevalence ≥1% in at least one of the reported years. Thus, for patients on HD, we reported data on four combinations of two drugs (SU + INS, DPP-4i + INS, SU + DPP-4i, and GLP-1RA + INS). For patients on PD, we reported data on four combinations of two drugs (SU + INS, DPP-4i + INS, SU + DPP-4i, and GLP-1RA + INS) and one combination of three drugs (SU + DPP-4i + INS). Lastly, for patients with a kidney transplant, we reported data on four combinations of two drugs (SU + INS, DPP-4i + INS, SU + DPP-4i, and GLP-1RA + INS) and one combination of three drugs (SU + DPP-4i + INS).

Figure 10.17 presents results on the percentage of Part D beneficiaries with ESRD who used antidepressant medications. Five classes of interest included selective serotonin reuptake inhibitors (SSRIs), serotonin-norepinephrine reuptake inhibitor (SNRIs), tricyclic antidepressants (TCAs), atypical antidepressants, and other antidepressants. The other antidepressants class includes monoamine oxidase inhibitors, maprotiline, esketamine, nefazodone, and vilazodone. Use was defined as having at least one PDE claim for a given medication class during follow-up in the reported year. Results were also presented for use of any one of the five antidepressant classes. Results were presented separately by treatment modality. Overall results were presented for years 2015-2019 and stratified results were presented by age, sex, race/ethnicity, LIS status, and the combination of race/ethnicity and LIS status for year 2019.

Figure 10.18 presents results on the percentage of use of antiviral treatments for hepatitis C. This analysis only includes Part D beneficiaries with ESRD who were diagnosed with hepatitis C. Hepatitis C was identified based on having a relevant ICD-9-CM (070.41, 070.44, 070.51, 070.54, 070.70, 070.71) or ICD-10-CM (B17.10, B17.11, B18.2, B19.20, B19.21) code on at least one inpatient or two outpatient claims during the 6 months prior to the start of the reported year. Antiviral use was defined as having at least one PDE claim for a single agent (daclatasvir, peginterferon alfa-2a, peginterferon alfa-2b, ribavirin, simprevir, or sofosbuvir) or a combination agent (elbasvir-grazoprevir, glecaprevir-pibrentasvir, ledipasvir-sofosbuvir, ombitasvir-paritaprevir-ritonavir, sofosbuvir-velpatasvir, ombitasvir-paritaprevir-ritonavir-dasabuvir) for hepatitis C during follow-up in the reported year. Results were presented separately by treatment modality. Overall results were presented for years 2015-2019 and stratified results were presented by age, sex, race/ethnicity, LIS status, and the combination of race/ethnicity and LIS status for year 2019.

Volume 2, Chapter 11: International Comparisons

Data Collection

Representatives from each country were provided a data-collection form spreadsheet (located on the USRDS website) to complete for years 2015 through 2019. Countries were asked to report patient count data for each year, if available, for the entire population, by sex (male, female), and by five different age categories (0-19, 20-44, 45-64, 65-74, 75+) for: (1) the country’s or region’s general population, (2) patients new to ESRD during the year, (3) patients new to ESRD during the year for whom diabetes was the primary cause of ESRD, (4) the point prevalent count of ESRD patients living on December 31 of the given year, (5) total number of patients with a functioning kidney transplant on December 31 of the given year, (6) total number of kidney transplants performed during the year, by type of donor (deceased, living, other), and (7) the number of dialysis patients, HD patients, CAPD/APD/IPD patients, and home HD patients on December 31 of the given year. Prevalence is reported for all patients at the end of the calendar year (December 31, 2019), except where otherwise noted. The data were imported into SAS from Microsoft Excel and data quality checks were performed, with follow-up with the registries, as needed.

Simple linear regression is used throughout the chapter for ease of interpretation in describing country or region level trends in incidence, prevalence, and transplantation rates among the international ESRD population. Though linear regression assumes a linear trend in the outcome of interest over time, results should be interpreted with caution, as the true country or region level data do not always adhere to this assumption. To be included in linear regression models, country or region needed to have reported relevant data for either 2009 or 2010, at least five of the years from 2011-2017, and for either 2018 or 2019. Additionally, percent change from 2009/10 to 2018/19 is also used to reflect trends in incidence, prevalence, and transplantation rates over time. To be included in this calculation, a country or region needed to have reported relevant data for 10 years overall, and at least one of the first two years (2009 and 2010) and one of the last two years (2018 and 2019).

The incidence rate for Figures 11.1, 11.2, 11.7, and 11.8 is calculated as the number of patients new to ESRD during the year divided by the total population for that year, multiplied by one million. For age-specific and sex-specific categories, the incidence rate was calculated as the count in each category divided by the total population in the respective category, multiplied by one million.

Figure 11.3a presents the countries or regions with the highest percent increase in incidence rate from 2009-10 to 2018-19. The percent change in incidence rate is calculated as the percent difference between the average incidence rate in 2018 and 2019 and the average in 2009 and 2010. Figure 11.3b presents the average yearly change in the incidence rate (per million population) for each country or region from 2009-2019, based on a univariate linear regression model.

Note that ascertainment of primary ESRD cause may have changed over the reporting period in some countries and thus potentially contributes to observed changes in the percentage of patients with diabetes as cause of ESRD in incident patients.

Figure 11.4a presents the percentage of incident ESRD patients with diabetes as the primary cause. The denominator is the total number of patients new to ESRD. Figure 11.4b presents the incidence rate of treated ESRD due to diabetes as the assigned primary ESRD cause, by country or region, for 2019. The incidence rate is calculated as the number of patients new to ESRD during the year, where diabetes was the designated primary cause of ESRD, divided by the total population for that year, multiplied by one million.

Figure 11.5 presents the average yearly change in incidence rate (per million population) of treated ESRD due to diabetes for each country or region from 2009-2019, based on a univariate linear regression model.

Figure 11.6 presents three regional scatter plots showing the country or region level correlation of the percent change in ESRD incidence with the percent change in ESRD incidence due to diabetes from 2009-10 to 2018-19. Percent change is calculated as the percent difference between the average incidence of treated ESRD or treated ESRD due to diabetes in 2018 and 2019 and the average in 2009 and 2010.
The prevalence for Figures 11.9 to 11.11 is calculated as the total number of ESRD patients receiving renal replacement therapy divided by the total population for that year, multiplied by one million. For the age-specific or sex-specific category, the prevalence is calculated as the count in each category divided by the total population in the respective category, multiplied by one million. Figure 11.12a presents the ten countries or region with the highest percent increase in prevalence of ESRD from 2009-10 to 2018-19. The percent change in prevalence of ESRD is calculated as the percent difference between the average prevalence of ESRD in 2018 and 2019 and the average in 2009 and 2010. Figure 11.12b presents the average yearly change in the prevalence of ESRD (per million population) for each country or region from 2009-2019, based on a univariate linear regression model. Figure 11.13 presents each country’s or region’s distribution of the type of renal replacement therapy modality for prevalent patients. The denominator is calculated as the sum of patients receiving HD, PD, Home HD, or kidney transplantation.

The prevalence of patients receiving dialysis for Figure 11.14 is the total number of ESRD patients on dialysis divided by the total population for that year, multiplied by one million.

Figure 11.15a presents the ten countries or region with the highest percent increase in prevalence of dialysis from 2009-10 to 2018-19. The percent change in prevalence of dialysis is calculated as the percent difference between the average prevalence of dialysis in 2018 and 2019 and the average in 2009 and 2010. Figure 11.15b presents the average yearly change in the prevalence of dialysis (per million population) for each country or region from 2009-2019, based on a univariate linear regression model.

Figure 11.16 presents the percent distribution of the type of renal replacement therapy modality. The denominator is calculated as the sum of patients receiving HD, PD, Home HD, and does not include patients with other/unknown modality.

The incidence kidney transplant rate is shown two ways: the transplant rate in Figure 11.17a is calculated as the total number of kidney transplants divided by the population total, multiplied by one million, and the rate in Figure 11.17b is calculated as the total number of kidney transplants divided by the prevalent number of dialysis patients, multiplied by 1,000.

Figure 11.18a presents the ten countries or regions with the highest percent increase in the kidney transplantation rate from 2009-10 to 2018-19. The percent change in kidney transplantation rate is calculated as the percent difference between the average transplantation rate in 2018 and 2019 and the average in 2009 and 2010. Figure 11.18b presents the average yearly change in the kidney transplantation rate (per million population) for each country or region from 2009-2019, based on a univariate linear regression model.

Figure 11.19 presents the percentage of kidney transplantations by kidney donor type (deceased, living, unknown). The denominator is calculated as the sum of deceased, living, and unknown donors.

The prevalence in Figure 11.20 is calculated as the total number of patients with a functioning kidney transplant divided by the total population for that year, multiplied by one million. Figure 11.21 presents the average yearly change in the prevalence of ESRD patients with a functioning kidney transplant (per million population) for each country or region from 2009-2019, based on a univariate linear regression model.

To contribute data from your country’s registry, please contact www.usrds.org.

Supplement, Chapter 13: COVID

In Figure 13.1 and Figure 13.2a, cohorts of Medicare fee-for-service beneficiaries with CKD, undergoing dialysis, and with a functioning kidney transplant were identified during each epidemiologic week of 2020, beginning with week 6. Epidemiologic weeks extend from Sunday to Saturday. Weekly cohorts of beneficiaries with CKD were identified using a 5% sample of Medicare claims; beneficiaries were aged ≥66 years and had at least one inpatient or two outpatient claims with diagnosis codes indicating CKD during the one-year interval preceding the first day of the epidemiologic week. Weekly cohorts of beneficiaries undergoing dialysis or with a functioning kidney transplant were identified using a 100% sample of Medicare claims; all beneficiaries were ≥18 years; those undergoing dialysis had at least one outpatient dialysis session during the 4-week interval preceding the first day of the epidemiologic week; and those with a transplant had at least one physician claim with ICD-10 diagnosis code Z94.0 (“kidney transplant status”) during the 13-week interval preceding the first day of the epidemiologic week. In Figure 13.1, COVID-19 testing was ascertained from outpatient facility claims and physician claims with HCPCS codes 86328, 86408, 86413, 86769, 87426, 87428, 87535, 87636, 87637, 87811, U0001, U0002, U0003, and U0004. In Figure 13.2a, COVID-19 infection was ascertained from all Medicare Parts A and B claims with ICD-10-CM diagnosis codes B97.29 and U07.1. Importantly, after a patient experienced a diagnosed COVID-19 infection, that patient was excluded from all subsequent weekly cohorts.

In Figure 13.2b, the cumulative incidence of diagnosed COVID-19 infection was estimated in the cohort of prevalent patients during epidemiologic week 6 of 2020; these patients were followed until December 31, 2020. As in Figure 13.2a, COVID-19 infection was ascertained from all Medicare Parts A and B claims with ICD-10-CM diagnosis codes B97.29 and U07.1.

Figure 13.3 follows the same methodologic approach as in Figure 13.2b, but with cumulative incidence estimated in each state.

Figure 13.4 displays the weekly incidence of diagnosed COVID-19 infection among Medicare beneficiaries undergoing dialysis and in the general population of the United States. The data pertaining to the dialysis patient population is the same data as in Figure 13.2a, whereas the data pertaining to the general population was ascertained from the Centers for Disease Control and Prevention ongoing accounting of COVID-19 cases in the United States.

Figure 13.5 displays the characteristics of dialysis patients with and without a diagnosed COVID-19 infection in 2020. The cohort included patients with at least one epidemiologic week of follow-up during the year. For patients with a diagnosed COVID-19 infection, characteristics, including dialysis modality, were ascertained in the epidemiologic week of the infection. For patients without a diagnosed COVID-19 infection, characteristics, including dialysis modality, were ascertained during the first epidemiologic week at risk during 2020.

Figure 13.6 displays the distribution of the cumulative incidence of diagnosed COVID-19 infection among outpatient dialysis facilities. The methodologic approach in this figure followed the approach in Figure 13.2b, with the cohort of dialysis patients at risk being
ascertained during epidemiologic week 6. Only those facilities with at least 25 patients carrying Medicare fee-for-service coverage were included in the analysis. Figure 13.7 displays telehealth utilization among dialysis patients with Medicare coverage, but only in the context of telehealth utilization during outpatient nephrology visits. Telehealth was identified from modifier code 95.

Figure 13.8 displays the weekly incidence of COVID-19 hospitalization during 2020. Cohort construction was identical to that in Figure 13.2a, except that patients were not included from subsequent weekly cohorts following a first COVID-19 hospitalization. Hospitalizations were defined by Medicare Part A claims submitted by inpatient facilities with diagnosis codes B97.29 and U07.1; in most cases, code U07.1 was used as the principal discharge diagnosis. Due to incomplete data when the admission date was in late 2020 and the discharge date was in early 2021, we tracked hospitalization through only epidemiologic week 50.

Figures 13.9a and 13.9b display percentages of COVID-19 hospitalizations with mechanical ventilation and ICU utilization, respectively. Mechanical ventilation was ascertained from ICD-10-CM procedure codes included in the claim submitted by the hospital; those codes were 5A1935Z, 5A1945Z, and 5A1955Z. ICU utilization was ascertained from revenue center codes included in the claim submitted by the hospital; those codes were 0200, 0201, 0202, 0203, 0204, 0207, 0208, and 0209. Figure 13.10 displays the distribution of discharge status among COVID-19 hospitalizations.

In Figure 13.11, weekly numbers of prevalent patients undergoing dialysis or with a kidney transplant are displayed. Counts were estimated at the beginning of each epidemiologic week from week 1 of 2018 to week 26 of 2021. Counts were based on data in the ESRD Quality Reporting System (EQRS), as extracted by the Centers for Medicare & Medicaid Services in August 2021. Weekly cohorts included all patients, regardless of Medicare coverage.

Figure 13.12a displays the weekly incidence of all-cause death among prevalent patients undergoing dialysis or with a kidney transplant. Weekly cohorts are the same as those in Figure 13.11. Deaths were ascertained from the EQRS, which collects ESRD Death Notifications and death records in the Medicare Enrollment Database. Figure 13.12b displays the cumulative number of deaths, week by week, in 2018, 2019, 2020, and 2021. The deaths that are tabulated in Figure 13.12b are the same deaths as in the numerator of the incidence estimates in Figure 13.12a.

In Figure 13.13, the primary cause of death among dialysis patients was ascertained from ESRD Death Notifications. Thus, the percentage of deaths due primarily to COVID-19 was estimated among the subset of patients with death reported by the ESRD Death Notification.

In Figures 13.14, 13.15, and 13.16, incident ESRD patients initiating dialysis, estimated glomerular filtration rate at dialysis initiation, and initial dialysis modality were ascertained from ESRD Medical Evidence Reports. In Figure 13.17, kidney transplant events were ascertained from the EQRS.

Figure 13.18 displays the percentage of COVID-19 hospitalizations with acute kidney injury. All COVID-19 hospitalizations in Medicare Part A were included in the analysis, with the exception of those occurring among patients with ESRD. Acute kidney injury was defined in the same manner as in Chapter 4 of the CKD volume of the Annual Data Report. Figure 13.19 displays the estimated number of Medicare beneficiaries undergoing outpatient dialysis for the treatment of acute kidney injury during each month of 2020. A crude number of patients undergoing such treatment was ascertained from a 5% sample of Medicare claims, and that number was multiplied by 20.

**Supplement, Chapter 14: Racial and Ethnic Disparities**

The analyses in this chapter use the 2015-2018 National Health and Nutrition Examination Survey (NHANES) database, Medicare 5% fee-for-service random sample database, and United States Renal Data System (USRDS) End Stage Renal Disease (ESRD) database. The USRDS ESRD database includes data from different data sources. For details, see the Data Sources section.

For most analyses, the study cohort is either a chronic kidney disease (CKD) cohort or an ESRD cohort. For CKD cohorts, only patients with CKD stage 3-5 are included. For both CKD and ESRD cohorts, only patients with race/ethnicity of White, Black, or Hispanic are included.

This chapter compares medical services and clinical outcomes among race/ethnicity groups and neighborhood Social Deprivation Index (SDI; Butler, 2012; Robert Graham Center, 2021) groups. The SDI score was developed to quantify levels of disadvantage across small areas, evaluate their associations with health outcomes, and address health inequities. The Zip Code Tabulation Areas (ZCTA) level SDI score from the Robert Graham Center website (Robert Graham Center, 2021) was used, unless specified differently. In our database, living address zip code is available for each patient. We converted the zip code to ZCTA code and linked the SDI score to each patient based on the ZCAT code. The SDI is a composite measure of seven demographic characteristics collected in the American Community Survey (ACS): percent living in poverty, percent with less than 12 years of education, percent single parent household, percent living in rented housing unit, percent living in overcrowded housing unit, percent of households without a car, and percent non-employed adults under 65 years of age. SDI score has the range 1-100; larger score means larger disparity.

In this chapter, study cohort and analytical method vary based on the study outcomes and are described accordingly for each figure/table.

All the adjusted analyses in this chapter were model-based (Liu 2006) and many of them were adjusted for patient age, sex, comorbidity and SDI score. For the CKD cohort, dual eligible status and CKD stage were additionally adjusted for in models, while for the ESRD cohort, primary cause of ESRD was additionally adjusted for. To reduce the dimension of analyses, instead of individual comorbidities, a comorbidity index/score [Liu et al., 2010] was used. The score is a weighted sum of comorbidities of atherosclerotic heart disease, congestive heart failure, cerebrovascular accident or transient ischemic attack, peripheral vascular disease, dysrhythmia, other cardiovascular disease, diabetes, chronic obstructive pulmonary disease, gastrointestinal disease, liver disease, and cancer. Based on the way the index was developed, the score was treated as a continuous variable in models. Exploratory analysis showed that, with a proper link function, SDI score shows its linear relationship with the “outcomes” in the interval of 1-75. For score being greater than 75, its effect is flat. Therefore, in all models, we treated SDI score as a continuous variable trimmed at 75 (if SDI score is greater than 75, we treated it as 75).

Figures 14.1s show the prevalence of CKD by CKD stage and further by race/ethnicity, age, and sex (Figure 14.1a) and then by age and sex within each race/ethnicity groups (Figure 14.1b) for adults aged ≥18 years old based on the 2015-2018 NHANES data using the original CKD-EPI creatinine-based equations (CKD-EPIcr) and the newly NKF-ASN recommended CKD-EPI creatinine-based equations (CKD-EPIcr_R) for estimated GFR (eGFR). The CKD-EPIcr equation contains race as a variable, while the CKD-EPIcr_R equation does not (see equations below).
In both cases, CKD stages are defined as follows:

- **Stage 3**: 30 mL/min/1.73m^2 ≤ eGFR < 60 mL/min/1.73m^2
- **Stage 4**: 15 mL/min/1.73m^2 ≤ eGFR < 30 mL/min/1.73m^2
- **Stage 5**: eGFR < 15 mL/min/1.73m^2

Prevalence is calculated using sample survey weights.

Table 14.1 shows reclassification among CKD stages overall and by race/ethnicity, age, and sex for adults aged ≥18 years based on the 2015-2018 NHANES data using the two different estimating equations for eGFR described for Figure 14.1. CKD stages are defined as follows:

- **Stage 3**: 30 mL/min/1.73m^2 ≤ eGFR < 60 mL/min/1.73m^2
  - o **Stage 3a**: 45 mL/min/1.73m^2 ≤ eGFR < 60 mL/min/1.73m^2
  - o **Stage 3b**: 30 mL/min/1.73m^2 ≤ eGFR < 45 mL/min/1.73m^2
- **Stage 4**: 15 mL/min/1.73m^2 ≤ eGFR < 30 mL/min/1.73m^2
- **Stage 5**: eGFR < 15 mL/min/1.73m^2

Prevalence is calculated using sample survey weights.

Figures 14.2a and 14.2b present percentage of patients had claim with Medicare Social Determinants of Health (SDOH) diagnosis codes by race/ethnicity (Figure 14.2a) and by Medicare/Medicaid dual eligible status (Figure 14.2b) in the 2019 CKD and dialysis cohorts. The CKD cohort is the December 31, 2019 point prevalent Medicare beneficiaries covered by Medicare fee-for-service for both A and B, aged 66 years and older, with diagnosis of CKD stages 3-5, and race/ethnicity of White, Black, or Hispanic. The dialysis cohort is the 2019 period prevalent dialysis patients covered by Medicare fee-for-service for both A and B, and race/ethnicity of White, Black, or Hispanic. SDOH refers to the conditions of an individual’s living, learning, and working environments that affect one’s health risks and outcomes. Collection of SDOH information can empower providers to address health disparities. There are 9 ICD-10-CM Z-code categories with some sub-codes in each category to record those conditions (see the table below).

SDI is another tool to describe social disparities that is associated with healthcare received and health outcomes.

Figure 14.2c shows the distribution of SDI groups by race/ethnicity, Medicare/Medicaid dual eligible status, and CKD stages.

Figure 14.3 shows the use of key medications among patients with CKD by race/ethnicity. The cohort is the same as that for Figure 4.2a except that patients also had Medicare Part D coverage here. Medications include angiotensin-converting enzyme inhibitors or angiotensin receptor blockers (ACEI/ARBs, potassium binders, phosphorus binders, and sodium-glucose cotransporter-2 inhibitors (SGLT 2)). The use of medication was derived from Medicare Part D claims in 2019 using the corresponding National Drug codes.

The study cohort for Figures 14.4-14.5 is the January 1, 2019 point prevalent Medicare beneficiaries who were covered by Medicare fee-for-service for Parts A and B on January 1, 2019, aged 66 years and older, with diagnosis of CKD stages 3-5, and race/ethnicity of White, Black, or Hispanic. In 2019, the beneficiaries were followed from January 1, 2019 to the earliest date of death, ESRD, loss of Medicare coverage, or December 31, 2019. For 14.4, patients were followed upon to one week prior to ESRD date, instead of ESRD date. All “outcomes” are defined in the follow-up period. Similar cohort was used for Figures 14.6. Instead of one year cohort, four years cohorts (2016-2019) were used due to low event rate.

Figures 14.4a show rates of outpatient nephrology visits by race/ethnicity and CKD stage (Figure 14.4a) and, within race/ethnicity groups, by age, sex and SDI groups (Figure 14.4b). Outpatient nephrology visits were identified by special code (39) from physician claims and rate was calculated as visits per-person year.

Figure 14.5a shows adjusted 1-year probabilities of death and ESRD by SDI within race/ethnicity groups, adjusted for patient age, sex, comorbidity, and CKD stage. Figure 14.5b shows the adjusted 1-year probabilities of death and ESRD by race/ethnicity group within CKD stage groups, adjusted for patient age, sex, comorbidity, SDI score, and Medicare/Medicaid dual eligible status for CKD stage groups, and additionally adjusted for CKD stage for “All” patients. Cox proportional hazard regression models were used for adjusted probability calculation. Unadjusted 1-year probabilities of death and ESRD was also calculated by race/ethnicity group within CKD stage groups based on the Kaplan-Meier estimate (Figure 14.5b).

Figures 14.6a & 14.6b show the percentage of patients had AKI hospitalization requiring dialysis presented in a similar way as Figures 14.5a & 14.5b. AKI hospitalizations were defined as hospitalization with primary diagnosis ICD-10 codes N01, N107, N171, N172, N178, and N179, and “requiring dialysis” was identified based on ICD-10 procedure codes 3E1M39Z, 5A1D00Z, 5A1D60Z, 5A1D70Z, 5A1D80Z, 5A1D90Z in the AKI hospitalization claim. The adjusted percentages were calculated based on the logistic models using the same covariates in the multivariable models for Figures 14.6a & 14.6b.

Similar to Figures 14.5a & 14.5b, Figures 14.7a & 14.7b show the 6-month probability of death and ESRD among patients who had AKI hospitalization requiring dialysis which was defined for Figures 14.6a & 14.6b. Patients were followed from the first AKI hospitalization requiring dialysis till the earliest date of death, ESRD, loss of Medicare coverage, the 2nd AKI hospitalization requiring dialysis, 8 months after the first AKI hospitalization requiring dialysis, and end of 2019. The adjusted and unadjusted probability were calculated the same way as used for Figures 14.5a & 14.5b.

Figure 14.8 shows the ESRD rate (per million) by SDI groups within race/ethnicity groups in year 2019 calculated based on the 2019 US population and 2019 incident ESRD patients aged 18 years or older. The population data was from the US Census Bureau website and incident ESRD patients were derived from the USRDS ESRD data source. The county level SDI score from the Robert Graham Center website (Robert Graham Center, 2021) was used. A Poisson regression model was used to get the adjusted rates, adjusting for age, gender, and SDI groups (for all patients).

Figures 14.9a show the percentage of patients’ country of origin of Hispanic incident ESRD patients (14.9a), and by census region and demographics (14.9b) for years 2016-2019. The cohort is 2016-2019 Hispanic incident ESRD patients who were 18 or older at the ESRD initiation. Countries of United States, Mexico, Puerto Rico, El Salvador, Cuba, Dominican Republic, Guatemala, along with Other country, and Unknown country of origin were presented in the figures.
Figure 14.10 presents the percentage of patients initiated dialysis in hospital among dialysis patients, by race/ethnicity and SDI groups within age groups in year 2019. The cohort is 2019 incident dialysis patients with Medicare Part A & B coverage and aged 18 or older at initiation. "Initiating dialysis in hospital" was identified by the inpatient claims covering the ESRD date. A logistic model was used to get the adjusted percentages, adjusting for age, gender, comorbidity, and primary cause of ESRD.

Figures 14.11s present the percentage of patients initiated dialysis with catheter among hemodialysis patients by SDI group (14.11a) and race/ethnicity group (14.11b) in year 2019. The cohort is the 2019 incident hemodialysis patients aged 18 or older at the ESRD initiation. Catheter use was from the ESRD Medical Evidence form (CMS-2728). The adjusted percentages were obtained the same way as used for Figures 14.10.

Figure 14.12 shows the primary cause of ESRD overall and by race/ethnicity within age groups for the 2019 incident ESRD patients. The cohort is 2019 incident ESRD patients who were 18 or older at the ESRD initiation and the primary cause of ESRD was from ESRD Medical Evidence form. Causes were categorized as diabetes, hypertension, glomerulonephritis, and other.

Figures 14.13s present the percentage of patients on home dialysis in the first year of ESRD by race/ethnicity (14.13a), and by SDI group within race/ethnicity groups (14.13a). Two cohorts are included. One is the 2018 incident dialysis patients aged 18 years or older at dialysis initiation; another one is a subcohort, in which everyone survived the first year. Percentages of patients with home dialysis were assessed at initiation (for both cohort) and at one-year after initiation (for the subcohort only). Logistic models were used to get the adjusted percentages, adjusting for age, gender, comorbidity, primary cause of ESRD, and zip code level variables like percent population living in crowded housing units, percent no car, percent of rental, and percent drop out high school, which are elements of SfD.

Figures 14.14s show the percentages of preemptive wait listing or transplantation in incident ESRD patients by race/ethnicity (14.14b) and by SDI within race/ethnicity groups (14.14a) in year 2019. The cohort is 2019 incident ESRD patients who were 18 or older at the ESRD initiation. The logistic model was used to get the adjusted percentages, adjusting for the usual covariates described earlier in this chapter.

Figures 14.15s show the rates (per 100 patient-year) of receipt of a living donor kidney transplant in dialysis patients by race/ethnicity (14.15b) and by SDI groups within race/ethnicity groups (14.15b). The cohort is 2019 point prevalent dialysis patients who were 18 or older on January 1, 2019. Patients were followed from January 1, 2019 to the earliest date of death, transplant date, or December 31, 2019. The Poisson model was used to get the adjusted rates, adjusting for the usual covariates described earlier in this chapter.

Reference


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