Chapter 7: ESRD among Children, Adolescents, and Young Adults

- The number of children and adolescents beginning end-stage renal disease (ESRD) care is steadily decreasing from a high of 17.5 per million in 2004 to 13.8 per million population in 2016, representing a decrease of 21.1% (Figure 7.1.a).
- As of December 31, 2016, the point prevalence of children and adolescents, 0 to 21 years of age, with ESRD was 9,721, or 99.1 per million population (Figure 7.1.b).
- The one-year ESRD patient mortality decreased by 20.4% over the last decade, with the greatest improvement observed in the 0-4 year age group with a 35.0% decrease. (Figure 7.8.a & b).
- 20% of incident and 72% of prevalent children and adolescents with ESRD have kidney transplants, in 2016 (Figure 7.1.a & b).
- Short stature is common in children and adolescents with incident ESRD; this affects the majority of the youngest patients between the ages of 0 and 4 years (51.9%; Figure 7.4.a).
    - Since 1978, a total of 19,441 survivors of childhood onset ESRD transitioned into adulthood. 81% of these individuals were still alive as of December 31, 2016 (Figure 7.17).

Introduction

This chapter presents an overview of end-stage renal disease (ESRD) in children and adolescents. In this age group, ESRD is caused by congenital and acquired disorders which are largely distinct from the predominant etiologies of diabetes and hypertension reported in adults with ESRD. The majority of children with ESRD will depend on a spectrum of the available renal replacement therapies (RRT) throughout their lifetime including hemodialysis (HD), peritoneal dialysis (PD), and transplantation. Throughout the ESRD experience, children are at risk for growth failure, frequent hospitalizations, and significantly higher mortality than the general pediatric population. Hospitalizations are a particular burden to the ESRD population. These hospitalizations may be due to medical or surgical indications. In this 2018 chapter of the Annual Data Report (ADR), hospitalizations have been newly classified as surgical and medical to provide additional insight. A section on young adult survivors of childhood onset ESRD is provided in order to improve our understanding of this resilient population.

Pediatric chronic kidney disease (CKD) is addressed in a separate chapter of the 2018 ADR – Volume 1, Chapter 6: *CKD Among Children, Adolescents, and Young Adults*.

Methods

The findings presented in this chapter were drawn from multiple data sources, including from the Centers for Medicare & Medicaid Services (CMS), the Organ Procurement and Transplantation Network (OPTN), the Centers for Disease Control and Prevention (CDC), and the U.S. Census. Details of these are described in the *Data Sources* section of the *ESRD Analytical Methods* chapter.

The analytical methods used to generate the study cohorts, figures, and tables in this chapter can be found in the section on *Chapter 7* within the *Analytical Methods Used in the ESRD Volume* chapter. Downloadable Microsoft Excel and PowerPoint files containing the data and graphics for these figures and tables are available on the *USRDS website*.

Epidemiology of End-stage Renal Disease in Children

The number of children and adolescents beginning ESRD care is steadily decreasing from a high of 17.5 per million population (PMP) in 2004 to 13.8 PMP in 2016—a decline of 21.1% (Figure 7.1.a). The ESRD incidence varies by age group; in 2016 there were 204 cases in those aged 0-4 years, 139 aged 5-9, 202 aged 10-13, 295 aged 14-17, and 532 aged 18-21 years, for a total of 1,372 children with incident ESRD in 2016. Within these age-based cohorts, incidence rates in 2016 were 9.2 PMP per year for 0-4 year olds, 6.4 for 5-9 year olds, 11.0 for 10-13 year olds, 15.5 for those aged 14-17 years, and 29.0 PMP for those aged 18–21 years.

As of December 31, 2016, the point prevalence of children, 0 to 21 years of age, with ESRD was 9,721, or 99.1 PMP (Figure 7.1.b). Overall, the prevalence of ESRD in children in the U.S. has been generally stable for the most recent decade.

Incidence and Prevalence by ESRD Modality

Although PD is not frequently used in adults, its use is much greater in young children. However, children initiate ESRD therapy with HD more frequently than PD or transplantation. In 2016, 702 (51.2%) initiated therapy with HD, 353 (25.7%) with PD, and 275 (20.0%) with transplant.

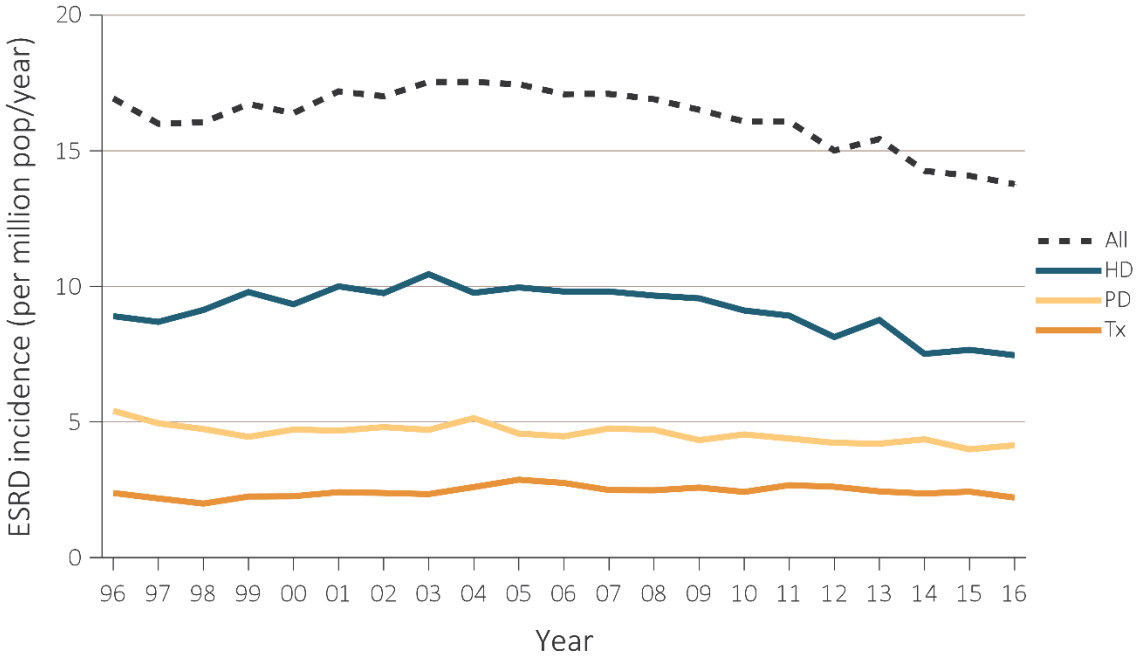
When examined by age, PD was the most common initial ESRD treatment modality for children aged 9 years and younger (Figure 7.2.a), and HD was the most common initial modality for patients aged 10 years and older. Similar relationships are shown by patient weight (which of course is highly correlated with age), with PD most commonly prescribed as the initial modality in children weighing less than 20 kilograms (kg) (Figure 7.2.b). For children less than 10kg: 9.0% for HD, 86.1% for PD and 4.9% for TX. For 10-<20 kg: 26.9% for HD, 47.3 for PD and 25.8% for TX (data not shown).

The modality at initiation varied greatly by race, with HD most commonly reported for those of Black/African American race (71.0%) compared to White (49.9%) and Other (43.0%) races (Figure 7.2.c). Examination of longitudinal changes in initial ESRD modality by race, the recent five-year window showed consistent HD use in Blacks/African Americans of 69.7%, Whites 48.4%, and Others 38.4%. The 21% overall decline in ESRD incidence was shown most remarkably in Black/African American children where the decline was twice as great, at 40%, decreasing from 33 per million to 20 per million.

Of the 9,619 children and adolescents under 22 years of age with prevalent ESRD as of December 31, 2016, kidney transplant was the most common ESRD modality (6,927, 72.0%), followed by HD (1,651, 17.2%) and PD (1,019, 10.6%) (Figure 7.1.b). This equates to a point prevalence PMP children of 17.5 for HD, 10.8 for PD, and 70.7 for transplant.

vol 2 Figure 7.1 (a, c) Incidence, and (b, d) December 31 point prevalence of ESRD among pediatric patients (aged 0–21 years) per million population per year, by modality and race, 1996-2016

(a) Incidence by modality



(b) Point prevalence by modality

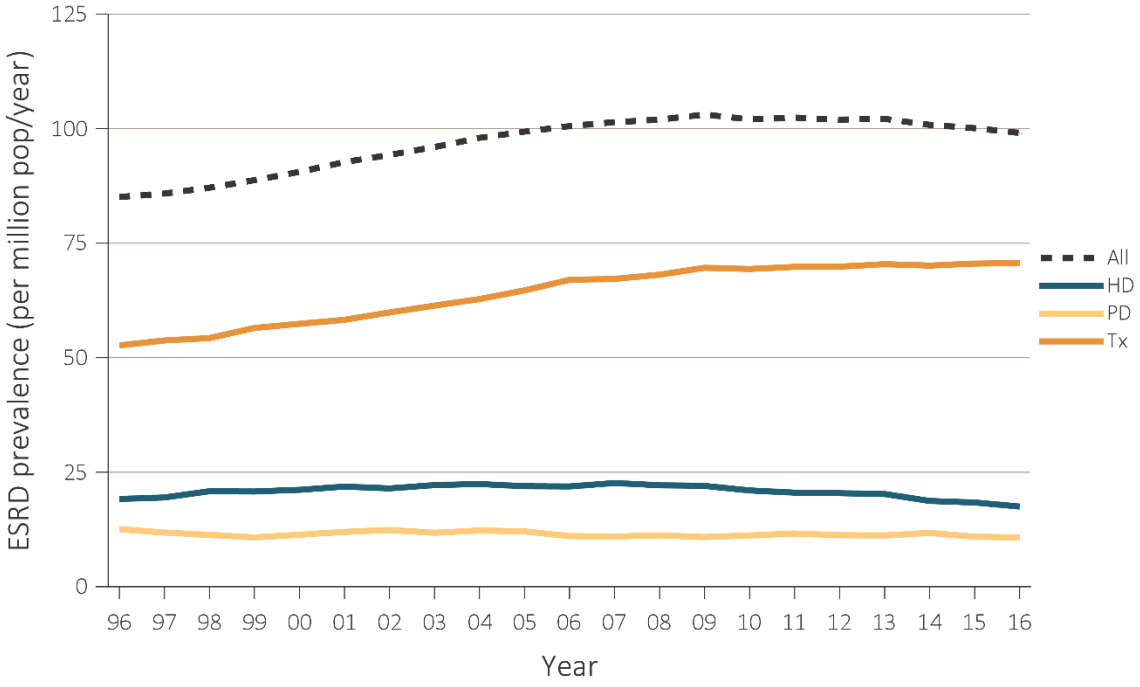
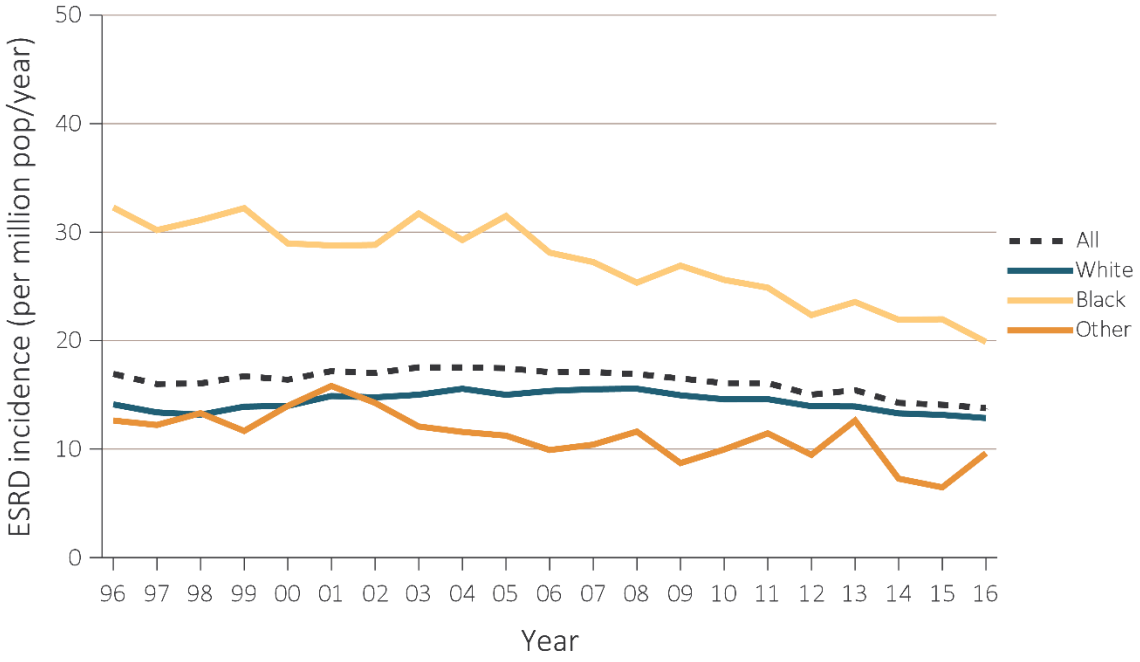


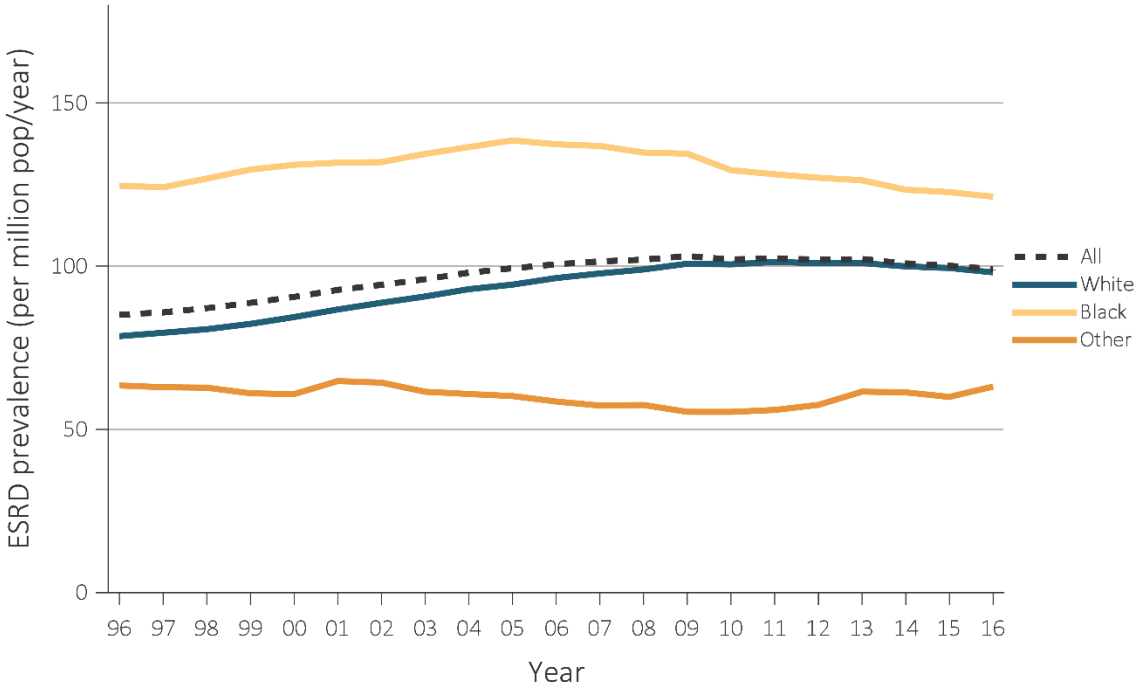
Figure 7.1 continued on next page.

vol 2 Figure 7.1 (a, c) Incidence, and (b, d) December 31 point prevalence of ESRD among pediatric patients (aged 0–21 years) per million population per year, by modality and race, 1996-2016 (continued)

(c) Incidence by race



(d) Point prevalence by race



Data Source: Special analyses, USRDS ESRD Database. Peritoneal dialysis consists of continuous ambulatory peritoneal dialysis and continuous cycling peritoneal dialysis. All consists of hemodialysis, peritoneal dialysis, uncertain dialysis, and transplant. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

vol 2 Figure 7.2 Cross-sectional distribution in pediatric ESRD modality at initiation, by patient (a) age, (b) weight, and (c) race, 1996-2016

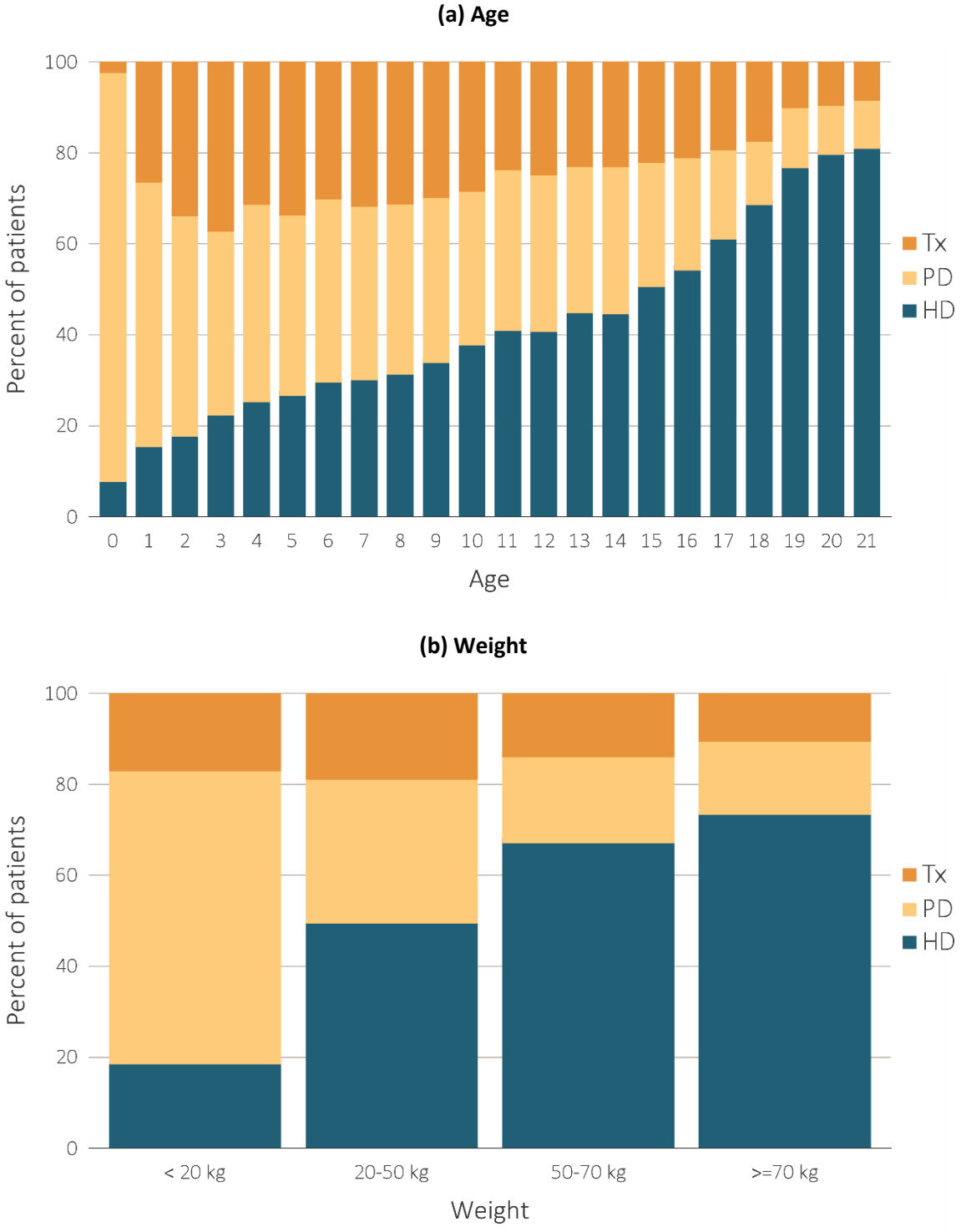
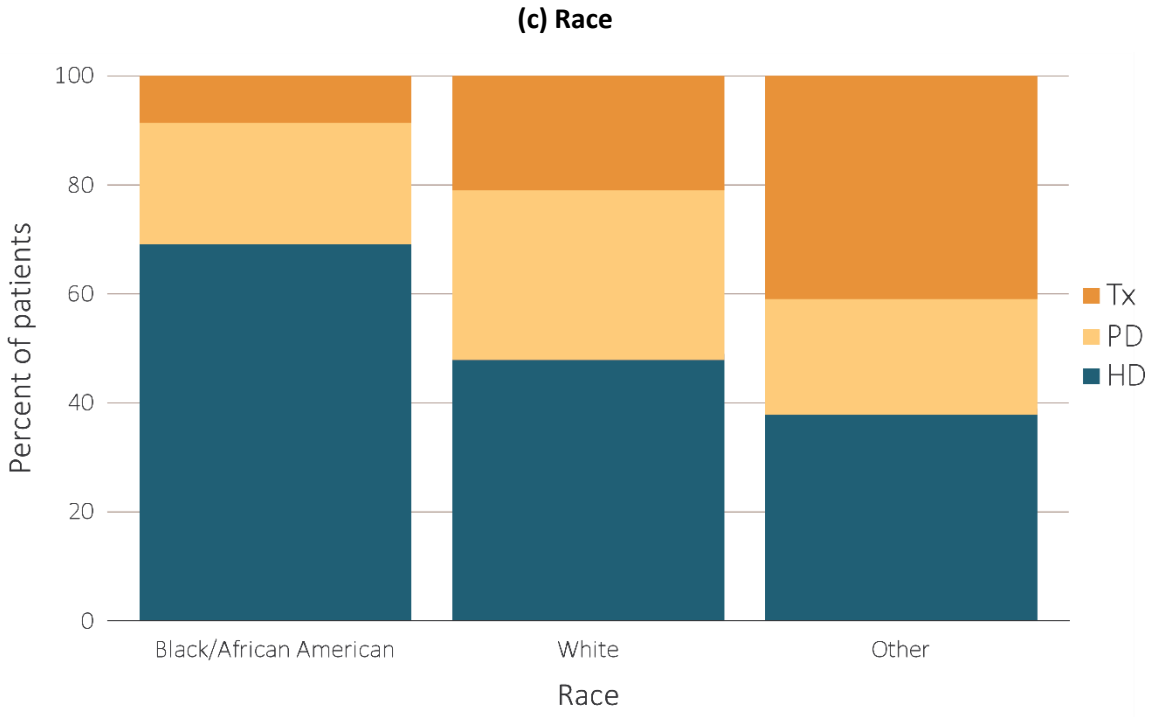


Figure 7.2 continued on next page.

vol 2 Figure 7.2 Cross-sectional distribution in pediatric ESRD modality at initiation, by patient (a) age, (b) weight, and (c) race, 1996-2016 (continued)



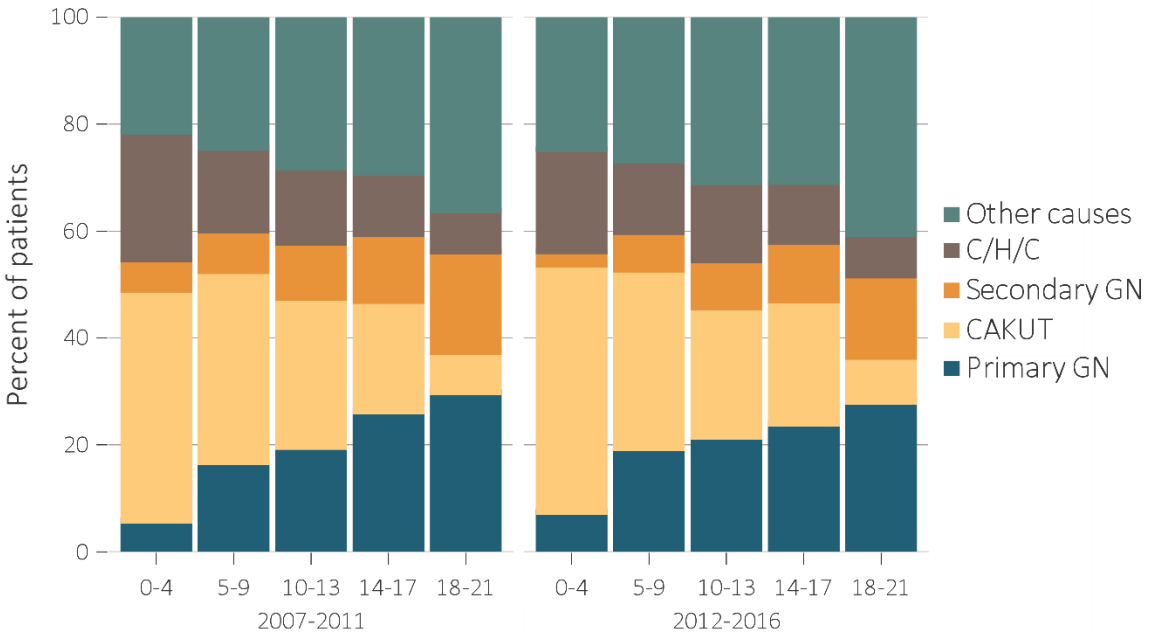
Data Source: Special analyses, USRDS ESRD Database. Includes incident ESRD patients in 1996-2016. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

Etiology

Table 7.1 shows that the leading causes of incident ESRD in children during 2012-2016 were primary glomerular disease (22.3%), CAKUT (congenital anomalies of the kidney and urinary tract; 21.9%), cystic/hereditary/congenital disorders (11.7%), and secondary glomerular disease/vasculitis (10.7%). The most common individual diagnoses associated with pediatric ESRD included focal glomerulosclerosis (828, 11.5%), renal hypoplasia/dysplasia (744, 10.4%), congenital obstructive uropathies (665, 9.3%), systemic lupus erythematosus (405, 5.6%), and unspecified with renal failure (503, 7.0%).

Figure 7.3 shows the distribution of the most common causes of ESRD by age and by year of onset of ESRD. CAKUT and congenital/hereditary/cystic disorders caused more ESRD in young children; primary and secondary glomerulonephritis and other etiologies became more common with advancing age. The distribution of ESRD etiology by age and year of onset of ESRD were consistent between incident years 2007-2011 and 2012-2016. The combined unspecified, uncertain, and missing reported ESRD etiologies accounted for over 1,000 incident cases between 2012 and 2016 (19.3%) (Tables 7.1 and 7.2).

vol 2 Figure 7.3 Distribution of reported incident pediatric ESRD patients by primary cause of ESRD, by age in 2007-2011 and 2012-2016



Data Source: Special analyses, USRDS ESRD Database. Abbreviations: CAKUT, congenital anomalies of the kidney and urinary tract; C/H/C, cystic/hereditary/congenital diseases; ESRD, end-stage renal disease; GN, glomerulonephritis.

vol 2 Table 7.1 Distribution of reported incident pediatric ESRD patients by primary cause of ESRD (aged 0-21 years), and by demographic characteristics, 2007-2011 (Period A) and 2012-2016 (Period B)

	Total patients		Percent incidence		Median age		Percent males		Percent White		Percent Black/ African American		Percent Other race	
Primary Disease Groups	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**
All ESRD, (reference)	8,154	7,176	100.0	100.0	16	16	56.3	56.9	66.1	66.2	24.6	23.5	9.3	10.3
CAKUT	1,682	1,574	20.6	21.9	11	11	70.1	68.7	75.6	74.8	17.8	18.9	6.5	6.2
Congenital obstructive uropathies	739	665	9.1	9.3	11	10	83.6	83.2	72.4	71.1	22.2	23.9	5.4	5.0
Renal hypoplasia, dysplasia, oligonephronia	749	744	9.2	10.4	9	9	63.0	59.0	76.4	75.7	16.6	17.3	7.1	7.0
Chronic pyelonephritis, reflux nephropathy	194	165	2.4	2.3	16	16	45.9	54.5	85.1	86.1	6.2	6.1	8.8	7.9
Cystic/Hereditary/Congenital Diseases	1,002	839	12.3	11.7	13	13	59.5	59.1	78.2	77.8	15.7	15.7	6.1	6.4
Polycystic kidneys, adult type (dominant)	49	45	.6	.6	18	18	53.1	35.6	77.6	84.4	20.4	11.1	2.0	4.4
Polycystic, infantile (recessive)	159	134	1.9	1.9	4	2	47.8	47.8	76.7	80.6	17.6	14.2	5.7	5.2
Medullary cystic disease, including nephronophthisis	118	107	1.4	1.5	13	12	43.2	43.9	86.4	77.6	6.8	13.1	6.8	9.3
Tuberous sclerosis	*	13	.1	.2	19	15	60.0	46.2	60.0	53.8	40.0	46.2	0	0
Hereditary nephritis, Alports syndrome	180	142	2.2	2.0	17	17	85.0	88.7	73.3	74.6	19.4	19.0	7.2	6.3
Cystinosis	60	38	.7	.5	13	11	51.7	57.9	93.3	86.8	6.7	7.9	0	5.3
Primary oxalosis	18	15	.2	.2	12	11	66.7	73.3	88.9	66.7	0	13.3	11.1	20.0
Congenital nephrotic syndrome	135	127	1.7	1.8	3	6	57.8	48.8	78.5	83.5	13.3	13.4	8.1	3.1
Drash syndrome, mesangial sclerosis	29	15	.4	.2	1	1	55.2	46.7	82.8	73.3	17.2	20.0	0	6.7
Other (congenital malformation syndromes)	226	188	2.8	2.6	13	16	60.2	66.0	81.0	79.8	11.5	12.2	7.5	8.0
Sickle cell disease/anemia	22	13	.3	.2	20	20	63.6	69.2	9.1	7.7	90.9	92.3	0	0
Primary Glomerular Disease	1,902	1,603	23.3	22.3	18	17	55.0	55.4	61.6	64.6	30.8	27.7	7.6	7.7
Glomerulonephritis (GN) (histologically not examined)	372	312	4.6	4.3	19	18	60.2	57.1	68.8	67.6	21.8	23.4	9.4	9.0
Focal glomerulosclerosis, focal sclerosing GN	989	828	12.1	11.5	17	17	56.0	55.9	53.6	60.5	40.7	34.3	5.7	5.2
Membranous nephropathy	39	44	.5	.6	17	19	51.3	72.7	43.6	59.1	46.2	36.4	10.3	4.5
Membranoproliferative GN type 1, diffuse MPGN	108	61	1.3	.9	17	17	45.4	45.9	66.7	72.1	22.2	16.4	11.1	11.5
Dense deposit disease, MPGN type 2	29	24	.4	.3	16	16	58.6	50.0	86.2	87.5	3.4	8.3	10.3	4.2
IgA nephropathy	194	169	2.4	2.4	19	19	62.4	60.9	74.7	75.1	14.9	8.3	10.3	16.6
IgM nephropathy	18	12	.2	.2	19	19	55.6	66.7	61.1	66.7	38.9	25.0	0	8.3
With lesion of rapidly progressive GN	64	45	.8	.6	16	16	25.0	35.6	76.6	68.9	12.5	20.0	10.9	11.1
Other proliferative GN	89	108	1.1	1.5	17	16	39.3	44.4	75.3	62.0	15.7	30.6	9.0	7.4
Secondary Glomerular Disease/Vasculitis	1,092	769	13.4	10.7	18	18	28.7	29.5	55.3	56.2	37.9	36.5	6.8	7.3
Lupus erythematosus, (SLE nephritis)	611	405	7.5	5.6	19	19	17.3	20.0	39.4	39.5	52.2	53.1	8.3	7.4

Table 7.1 continued on next page.

vol 2 Table 7.1 Distribution of reported incident pediatric ESRD patients by primary cause of ESRD (aged 0-21 years), and by demographic characteristics, 2007-2011 (Period A) and 2012-2016 (Period B) (continued)

	Total patients		Percent incidence		Median age		Percent males		Percent White		Percent Black/ African American		Percent Other race	
Primary Disease Groups	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**	**A**	**B**
Henoch-Schonlein (IgA Vasculitis)	34	26	.4	.4	17	15	58.8	42.3	88.2	80.8	5.9	7.7	5.9	11.5
Hemolytic uremic syndrome	136	98	1.7	1.4	9	9	40.4	37.8	81.6	77.6	14.0	16.3	4.4	6.1
Polyarteritis and other vasculitis	118	86	1.4	1.2	14	15	37.3	25.6	75.4	76.7	17.8	11.6	6.8	11.6
ANCA-associated vasculitis	65	83	.8	1.2	16	17	43.1	49.4	86.2	72.3	10.8	20.5	3.1	7.2
Goodpasture syndrome	55	35	.7	.5	19	19	36.4	54.3	89.1	97.1	5.5	0	5.5	2.9
Secondary GN, other	27	13	.3	.2	18	18	55.6	46.2	77.8	76.9	14.8	23.1	7.4	0
AIDS nephropathy	40	16	.5	.2	20	21	57.5	50.0	5.0	0	95.0	100.0	0	0
Tubulointerstitial Diseases	286	234	3.5	3.3	17	16	59.4	58.5	75.2	76.1	17.5	17.1	7.3	6.8
Chronic interstitial nephritis	81	86	1.0	1.2	17	17	58.0	53.5	75.3	77.9	17.3	15.1	7.4	7.0
Acute interstitial nephritis	*	21	.1	.3	20	17	55.6	52.4	55.6	66.7	44.4	28.6	0	4.8
Tubular necrosis	185	113	2.3	1.6	15	12	59.5	61.9	77.3	76.1	15.7	16.8	7.0	7.1
Transplant Complications	145	92	1.8	1.3	16	17	57.2	57.6	71.7	68.5	20.0	25.0	8.3	6.5
Kidney transplant complication	60	*	.7	.1	16	18	63.3	66.7	73.3	83.3	21.7	0	5.0	16.7
Other transplant complication	79	83	1.0	1.2	16	16	53.2	56.6	70.9	67.5	20.3	26.5	8.9	6.0
Diabetes	101	80	1.2	1.1	20	20	41.6	36.3	53.5	42.5	42.6	52.5	4.0	5.0
Diabetes with renal manifestations Type 2	47	39	.6	.5	20	20	38.3	38.5	59.6	43.6	38.3	51.3	2.1	5.1
Diabetes with renal manifestations Type 1	54	41	.7	.6	20	20	44.4	34.1	48.1	41.5	46.3	53.7	5.6	4.9
Neoplasms/Tumors	48	39	.6	.5	8	10	41.7	53.8	70.8	76.9	20.8	10.3	8.3	12.8
Renal tumor	39	28	.5	.4	7	5	41.0	53.6	71.8	71.4	25.6	10.7	2.6	17.9
Hypertensive/Large Vessel Disease	19	41	.2	.6	14	18	57.9	61.0	78.9	82.9	10.5	9.8	10.5	7.3
Renal artery stenosis	*	19	.1	.3	14	20	62.5	57.9	75.0	63.2	12.5	21.1	12.5	15.8
Renal artery occlusion	*	21	.1	.3	11	11	44.4	61.9	77.8	100.0	11.1	0	11.1	0
Miscellaneous Conditions	888	1,025	10.9	14.3	19	18	60.1	60.4	63.9	63.7	29.7	28.8	6.4	7.5
Acquired obstructive uropathy	50	104	.6	1.4	17	14	72.0	66.3	80.0	74.0	16.0	21.2	4.0	4.8
Nephrolithiasis	16	16	.2	.2	18	15	31.3	43.8	93.8	87.5	0	12.5	6.3	0
Traumatic or surgical loss of kidney(s)	15	34	.2	.5	9	15	66.7	55.9	73.3	70.6	13.3	17.6	13.3	11.8
Other renal disorders	246	311	3.0	4.3	15	14	54.5	55.9	77.6	74.3	13.8	14.8	8.5	10.9
Nephropathy caused by other agents	46	51	.6	.7	17	16	58.7	49.0	89.1	74.5	8.7	19.6	2.2	5.9
Unspecified with renal failure	507	503	6.2	7.0	20	20	62.9	63.8	52.1	53.1	42.6	41.0	5.3	6.0
Etiology Uncertain	689	342	8.4	4.8	16	16	59.1	54.7	73.7	70.2	18.9	19.9	7.4	9.9
Missing	300	538	3.7	7.5	15	15	63.7	59.9	20.7	40.9	7.0	9.9	72.3	49.3

Data Source: Special analyses, USRDS ESRD Database. Abbreviations: ANCA, anti-neutrophil cytoplasmic antibody; AIDS, acquired-immune deficiency syndrome; CAKUT, congenital anomalies of the kidney and urinary tract; congenital obstructive uropathy, combination of congenital ureteropelvic junction obstruction, congenital ureterovesical junction obstruction, and other congenital anomalies; ESRD, end-stage renal disease; GN glomerulonephritis; IgA, immunoglobulin A; IgM, immunoglobulin M; incl., including; MPGN, membranoproliferative glomerulonephritis; SLE, secondary lupus erythematosus. Diagnoses with 10 or fewer total patients for year categories are suppressed.*

vol 2 Table 7.2 Proportion of missing, unknown, and unspecified etiology of ESRD in children and adolescents, by age group, 2012-2016

	0-4	5-9	10-13	14-17	18-21	All
ESRD etiology missing, unknown, or unspecified	10.4%	13.8%	15.3%	17.9%	26.1%	19.3%

Data Source: Special analyses, USRDS ESRD Database. Abbreviation: ESRD, end-stage renal disease.

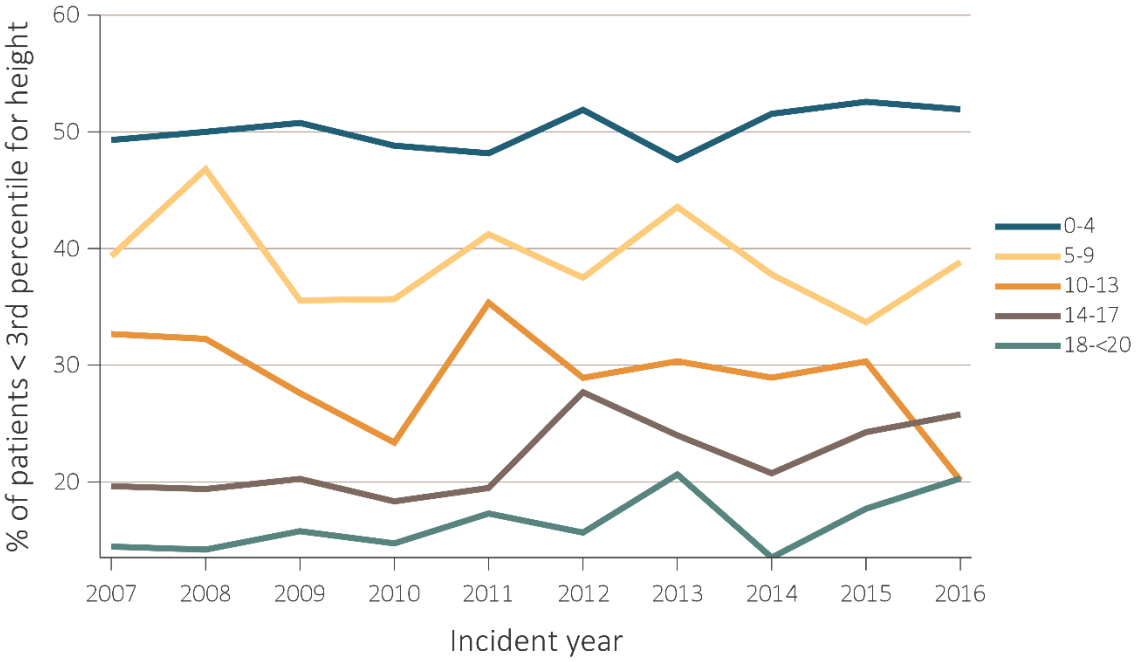
Growth

Children with ESRD are at risk for growth impairment, requiring intensive intervention to optimize growth. Using data reported in the CMS 2728 form from 2007-2016, pre-ESRD dietitian support was provided to 48.4% of children under 18 years of age and was highest among patients aged 5-9 years (55.9%), and lowest among patients aged 14-17 (42.8%). Over the past 10 years, the 0-4 age group consistently had the highest proportion of children with short stature, defined as height less than third percentile for age, at ESRD incidence (Figure 7.4.a). In 2016, the percentage of incident ESRD patients with short stature continued to be the highest in the youngest patients, 51.9% in the 0-4 age group, compared with 38.8% in the 5-9 age group, 20.1% in the 10-13 age group, 25.8% in the 14-17 age group, and 20.3% in the 18-<20 age group. Comparison of the 2007 and 2016 data demonstrates that the prevalence of short stature in the incident pediatric ESRD population has not improved over the past 10 years.

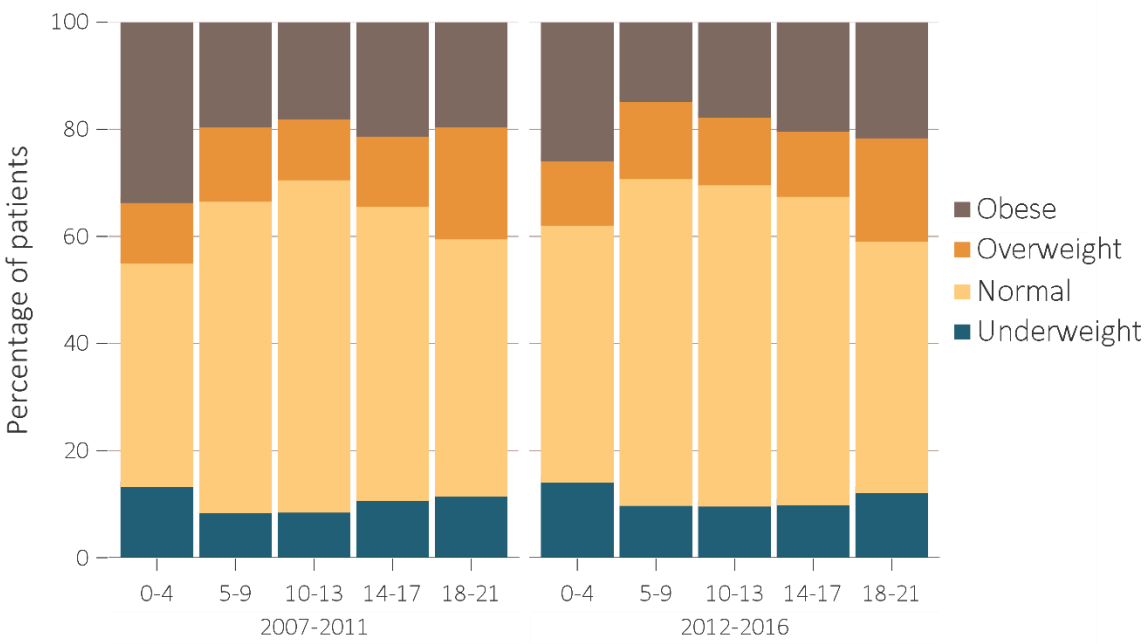
Weight status is based on age-based body mass index norms. Comparison between the periods 2007-2011 and 2012 – 2016 shows that the percent overweight and obese has been decreasing in the most recent period. The percent with unhealthy weight (underweight or obese) has been generally stable (Figure 7.4.b). In the most recent 5-year reporting period, 2012-2016, children with incident ESRD between 0-4 years of age had the largest proportion of unhealthy weight status, including underweight (14.5%) and obese (25.4%; Figure 7.4.b). This contrasts with the adult population where obese patients accounted for 41.6% of the incident population in 2016. In total, 55.1% of children aged 0-4 who were obese at ESRD initiation also had short stature, suggesting that nutritional support alone is insufficient to restore the majority of patients to an age-appropriate stature.

vol 2 Figure 7.4 Growth status at the time of ESRD initiation by (a) stature and (b) body mass index (BMI)

(a) Stature



(b) BMI



Data Source: Special analyses, USRDS ESRD Database. (a) Stature reported for age <20 per growth percentile guidelines. Percentiles for children greater or equal to 24 months of age and up to less than 20 years of age are calculated following Centers for Disease Control and Prevention (CDC) growth charts. Percentiles for children less than 24 months of age are calculated following World Health Organization (WHO) growth charts. Short stature is defined as height less than 3rd percentile for sex and age. (b) BMI categories are defined differently for patients younger than 18 (Underweight: BMI < 5th percentile; Normal: 5th percentile ≤ BMI < 85th percentile; Overweight: 85th percentile ≤ BMI < 95th percentile; and Obese: BMI ≥ 95th percentile) and patients 18 and older (Underweight: BMI < 18.5; Normal: 18.5 ≤ BMI < 25 percentile; Overweight: 25 ≤ BMI < 30; and Obese: BMI ≥ 30). Abbreviations: ESRD, end-stage renal disease; BMI, body mass index.

Hospitalizations in Children with Incident ESRD

This year we categorize hospitalization by surgical and non-surgical types. Surgery accounted for less than 20.0% of one-year hospitalizations in incident children (Figure 7.5.a). The adjusted all-cause hospitalization rates were highest in the youngest children, 0-4 years of age (Figure 7.5.a). During the 2011-2015 reporting years, the overall rate of hospitalization dropped by 1.8%, from 1,874 to 1,841 admissions per 1,000 patient-years. While they account for a minority of hospitalizations in children with incident ESRD, we report the one-year hospitalizations associated with cardiovascular disease (CVD) (2.2%) and infection (29.2%). This provides consistency with previous ADR pediatric chapters and aligns with two leading causes of ESRD-associated mortality in children. Other substantial causes of hospitalization in this population included hypertension (12.5%), complications of dialysis, including access complications (6.2%), complications of kidney transplant (5.2%), dehydration (2.0%), fever (unspecified) (1.8%), and hyperkalemia (1.6%).

vol 2 Figure 7.5 One-year adjusted all-cause hospitalizations in incident pediatric patients (aged 0-21 years), by (a) age and (b) modality, 2006-2010 and 2011-2015

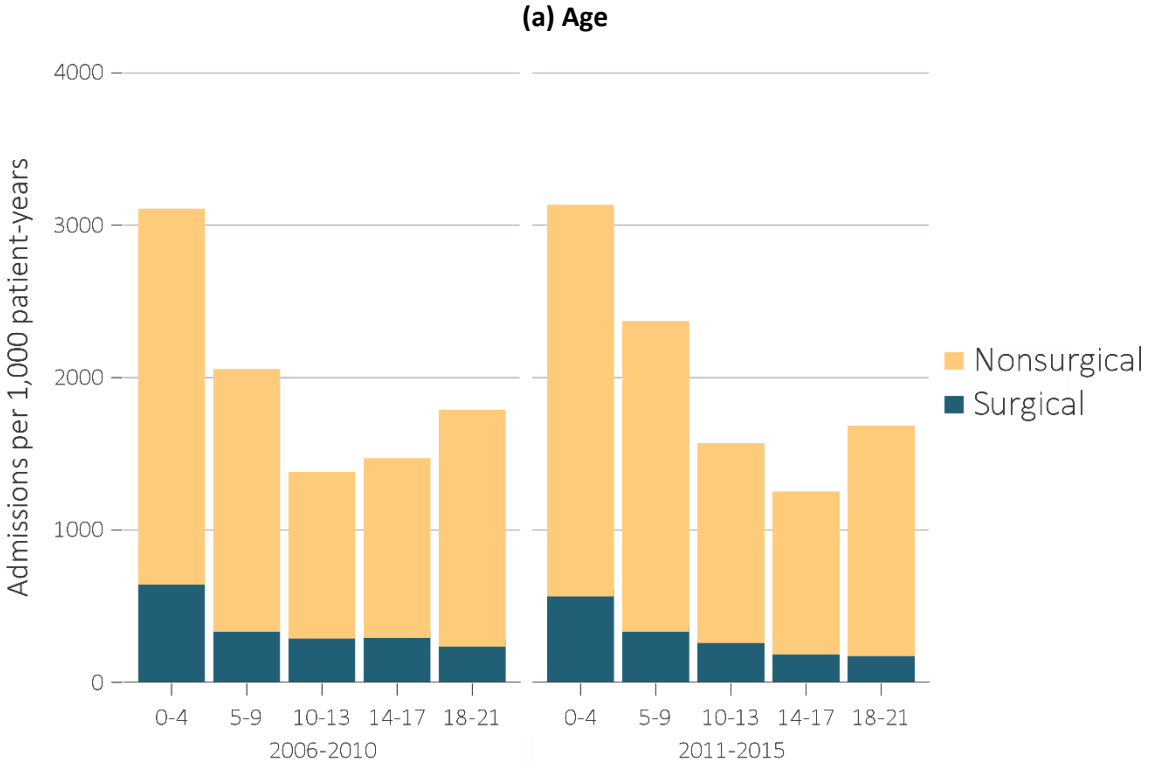
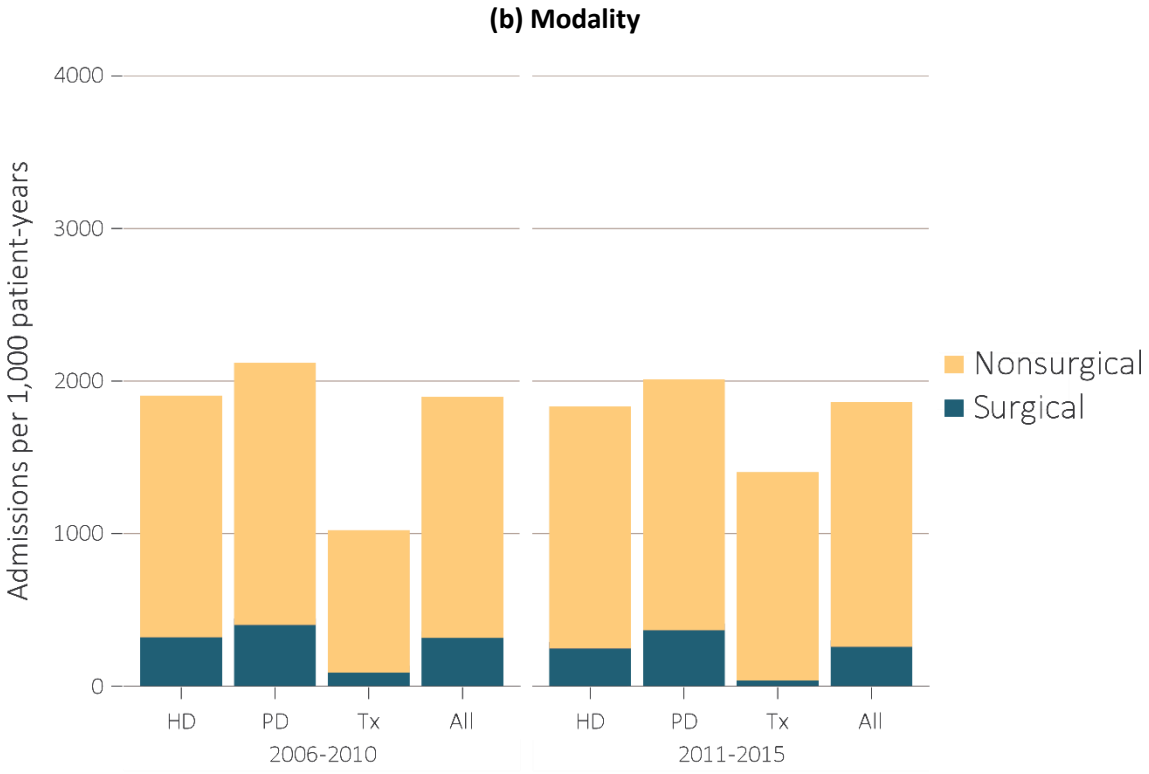


Figure 7.5 continued on next page.

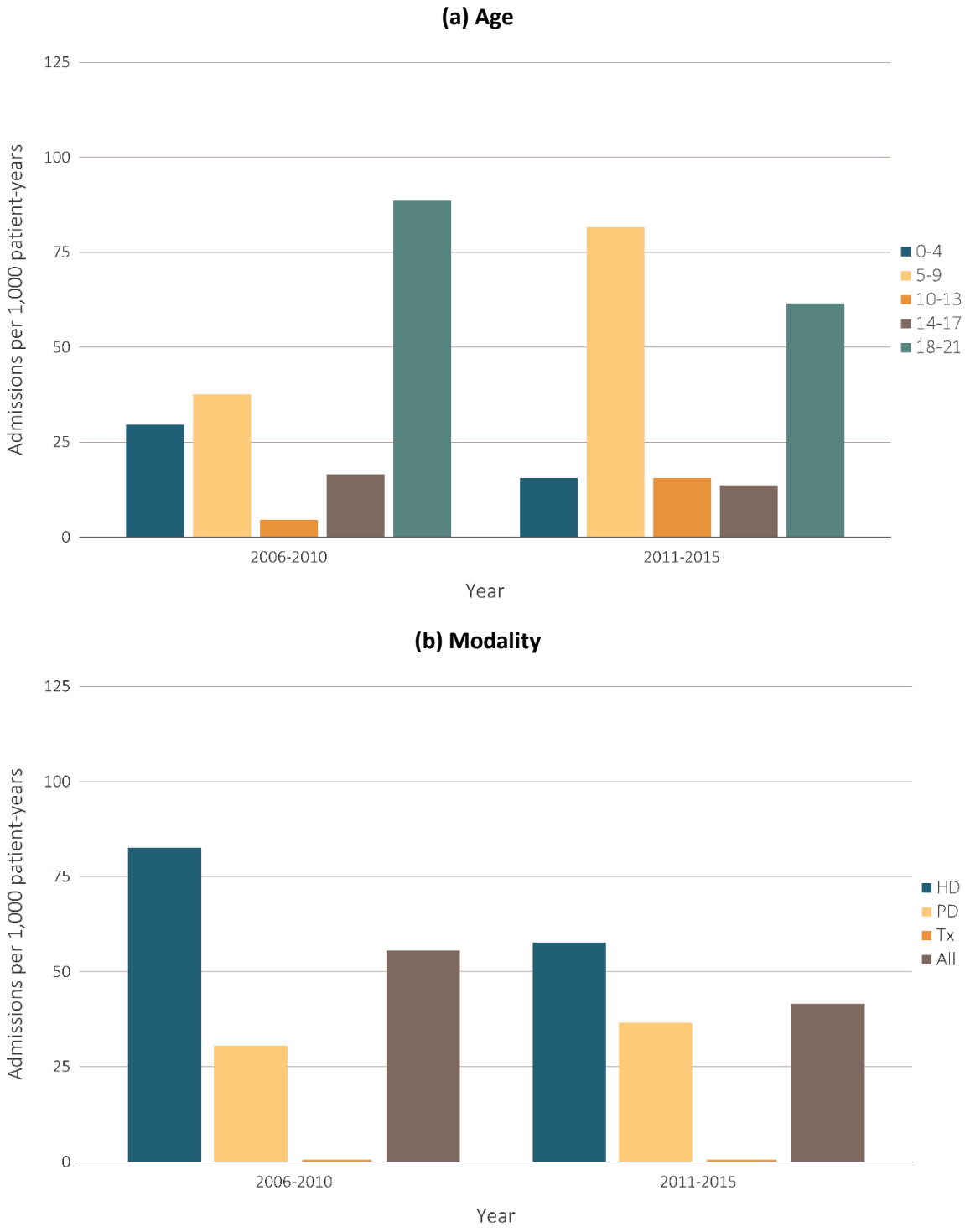
vol 2 Figure 7.5 One-year adjusted all-cause hospitalizations in incident pediatric patients (aged 0-21 years), by (a) age and (b) modality, 2006-2010 and 2011-2015 (continued)



Data Source: Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2006-2015, surviving the first 90 days after ESRD initiation and followed from day 90. (a) Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. (b) Adjusted for age, sex, race, primary cause of ESRD and Hispanic ethnicity. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

The first-year CVD hospitalization rates for children less than 22 years of age with incident ESRD were 55 per 1,000 patient-years from 2006-2010, and 41 from 2011-2015 (Figure 7.6.b), a decrease of 25.5%. The highest rates of CVD hospitalizations in incident patients were observed in children aged 5-9 and 18-21 years (Figure 7.6.a) and in children treated with dialysis (Figure 7.6.b). CVD hospitalizations decreased for ages 0-4, 14-17, and 18-21, while increasing for ages 5-9 and 10-13.

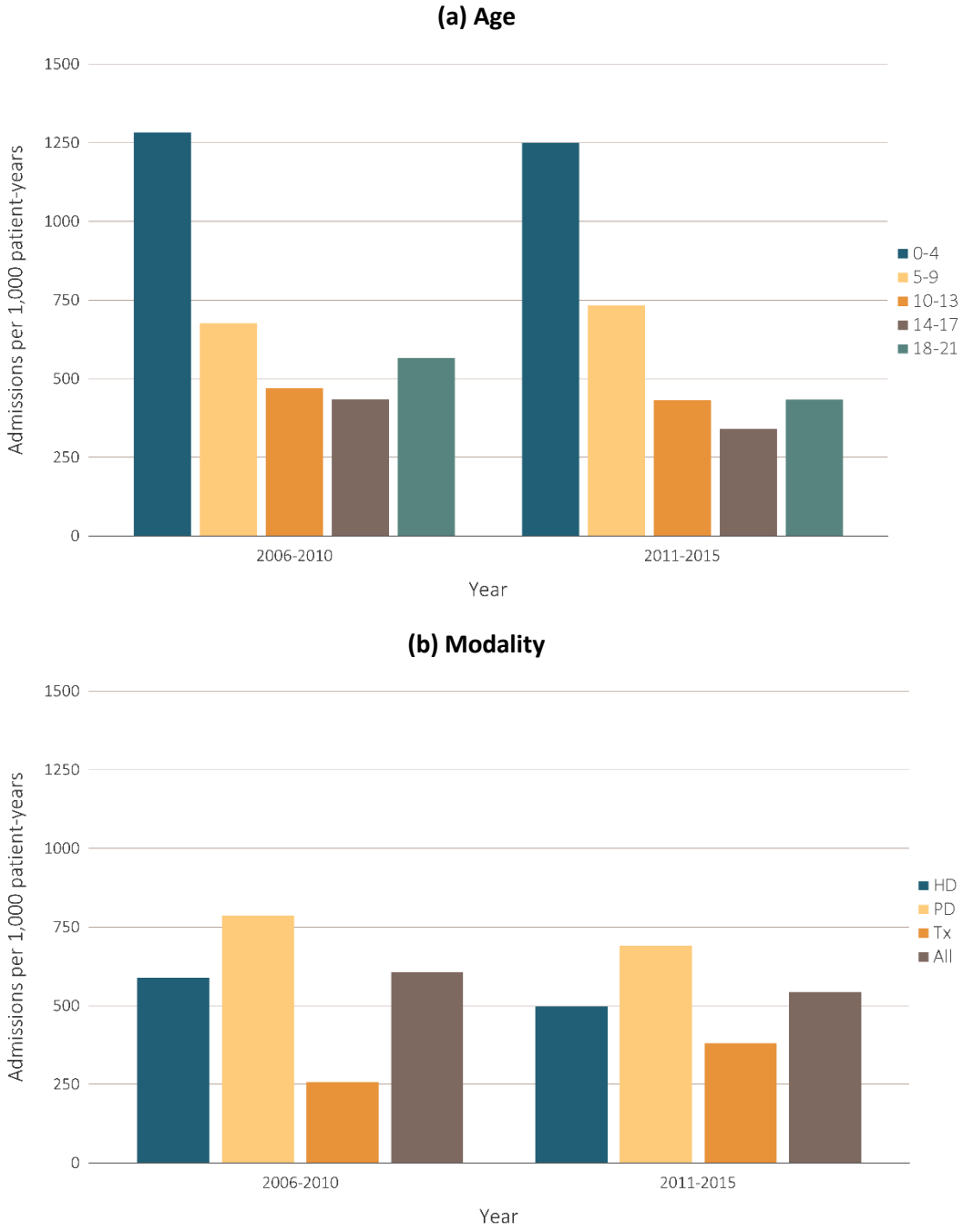
vol 2 Figure 7.6 One-year cardiovascular hospitalizations in incident pediatric patients (aged 0-21 years), by (a) age and (b) modality, 2006-2010 and 2011-2015



Data Source: Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2006-2015, surviving the first 90 days after ESRD initiation and followed from day 90. Reference population: incident ESRD patients aged 0-21, 2010-2011. (a) Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. (b) Adjusted for age, sex, race, primary cause of ESRD and Hispanic ethnicity. When examining cardiovascular associated hospitalizations, hypertension is not considered a cardiovascular diagnosis. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

The overall rate of hospitalization for infection in the first year of ESRD care was 537 admissions per 1,000 patient-years during 2011-2015, which was 10.4% lower than during 2006-2010 (Figure 7.7.b). These first-year infection-related hospitalizations in children increased by 49.2% in transplant patients, but decreased 15.5% and 12.2% in HD and PD patients in the most recent 5-year reporting window, respectively. In examining between-modality statistics, children on PD had the highest rates of infection-related hospitalizations, followed by HD and transplanted children (Figure 7.7.b).

vol 2 Figure 7.7 One-year adjusted hospitalizations for infection in incident pediatric patients (aged 0-21 years), by (a) age and (b) modality, 2006-2010 and 2011-2015



Data Source: Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2006-2015, surviving the first 90 days after ESRD initiation and followed from day 90. (a) Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. (b) Adjusted for age, sex, race, primary cause of ESRD and Hispanic ethnicity. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

Mortality

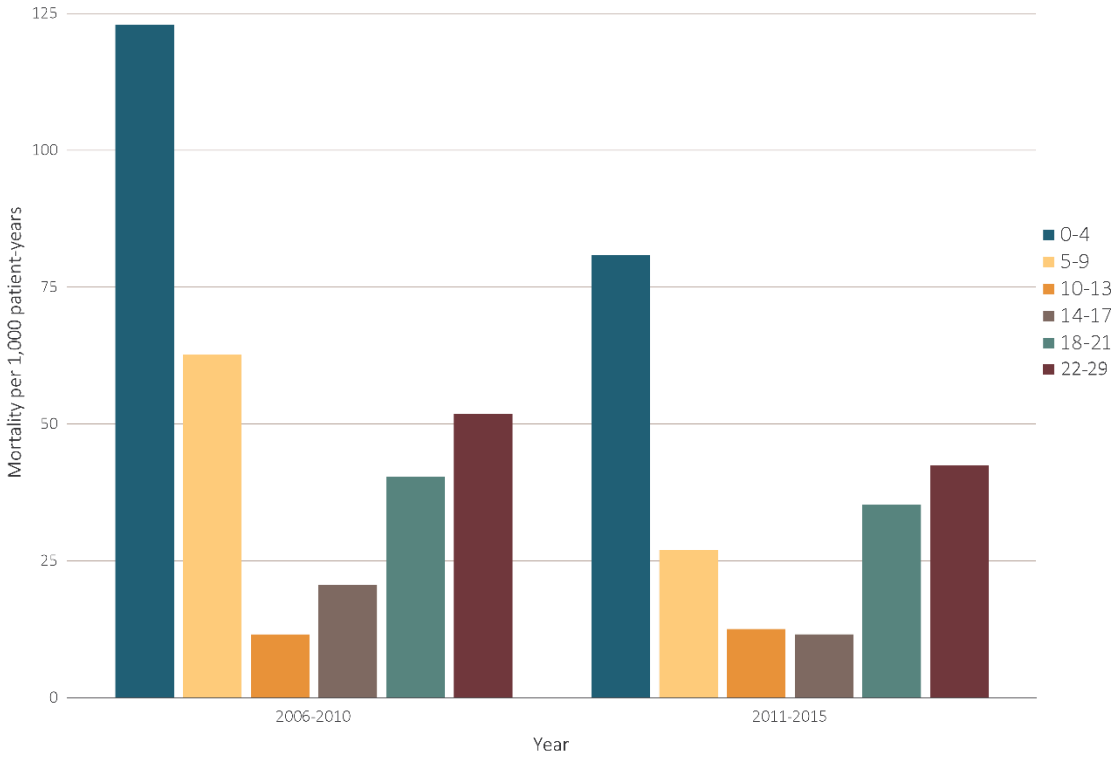
During 2011-2015, the one-year adjusted all-cause mortality rate was 39 per 1,000 patient-years, a decrease of 20.4% from the 49 per 1,000 patient-years seen in 2006-2010 (Figure 7.8.b). Reduced mortality was reported in almost all age categories, with the greatest reduced mortality by 35.0% in children ages 0-4 years (Figure 7.8.a). The improvement in the one-year mortality in the 0-4 age group was mostly in the infants less than 2 years of age at onset of ESRD (age <2 years: 39.9% vs age 2 to <5: 13.3% reduction in mortality).

When comparing the 2006-2010 and 2011-2015 periods, adjusted one-year all-cause mortality rates by modality showed decreases of 16.9% among HD patients, 35.5% among PD patients, and 30.8% among transplant patients (Figure 7.8.b). Despite the overall improvement in the adjusted one-year all cause-mortality from 2011-2015, a difference in mortality by modality remained, with HD- and PD-associated one-year all-cause mortality rates 5.4 and 2.2 times higher than for transplant patients. Across all modalities, the five most common causes of death reported on the Death Notification Form were predominantly attributed to cardiac arrest cause unknown, withdrawal from dialysis, sepsis, cerebrovascular accident including intracranial hemorrhage and pulmonary infection for children aged 0 to 21 years. The youngest children had similar reported causes when compared with older children and adolescents.

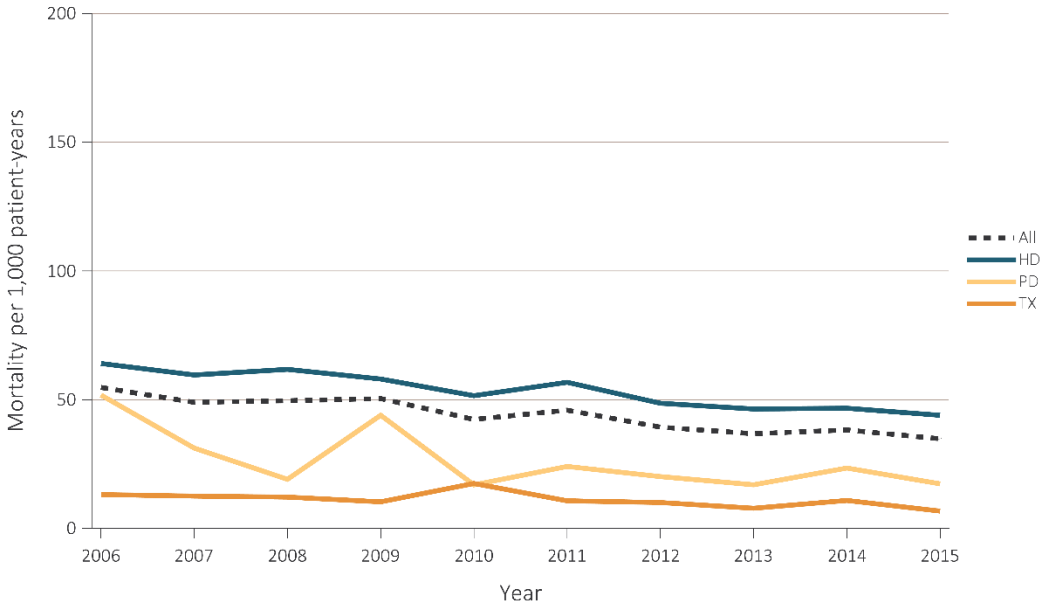
Assessment of expected remaining lifetime based on age and modality at ESRD incidence is presented in Table 7.3, and compared with published general population estimates from the U.S. Social Security Administration. Children treated with dialysis have a 40 to 55 year deficit in life expectancy compared to the general population while transplanted patients have an estimated 12 to 20 year deficit.

vol 2 Figure 7.8 One-year adjusted all-cause mortality in incident pediatric patients with ESRD by (a) age with comparison to young adults (aged 0-29 years), 2006-2010 and 2011-2015 and (b) modality, 2006-2015 (aged 0-21 years only)

(a) Age



(b) Modality



Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2016. (a) Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. (b) Adjusted for age, sex, race, primary cause of ESRD and Hispanic ethnicity. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

vol 2 Table 7.3 Expected remaining lifetime in years of prevalent patients by initial ESRD modality, 2015

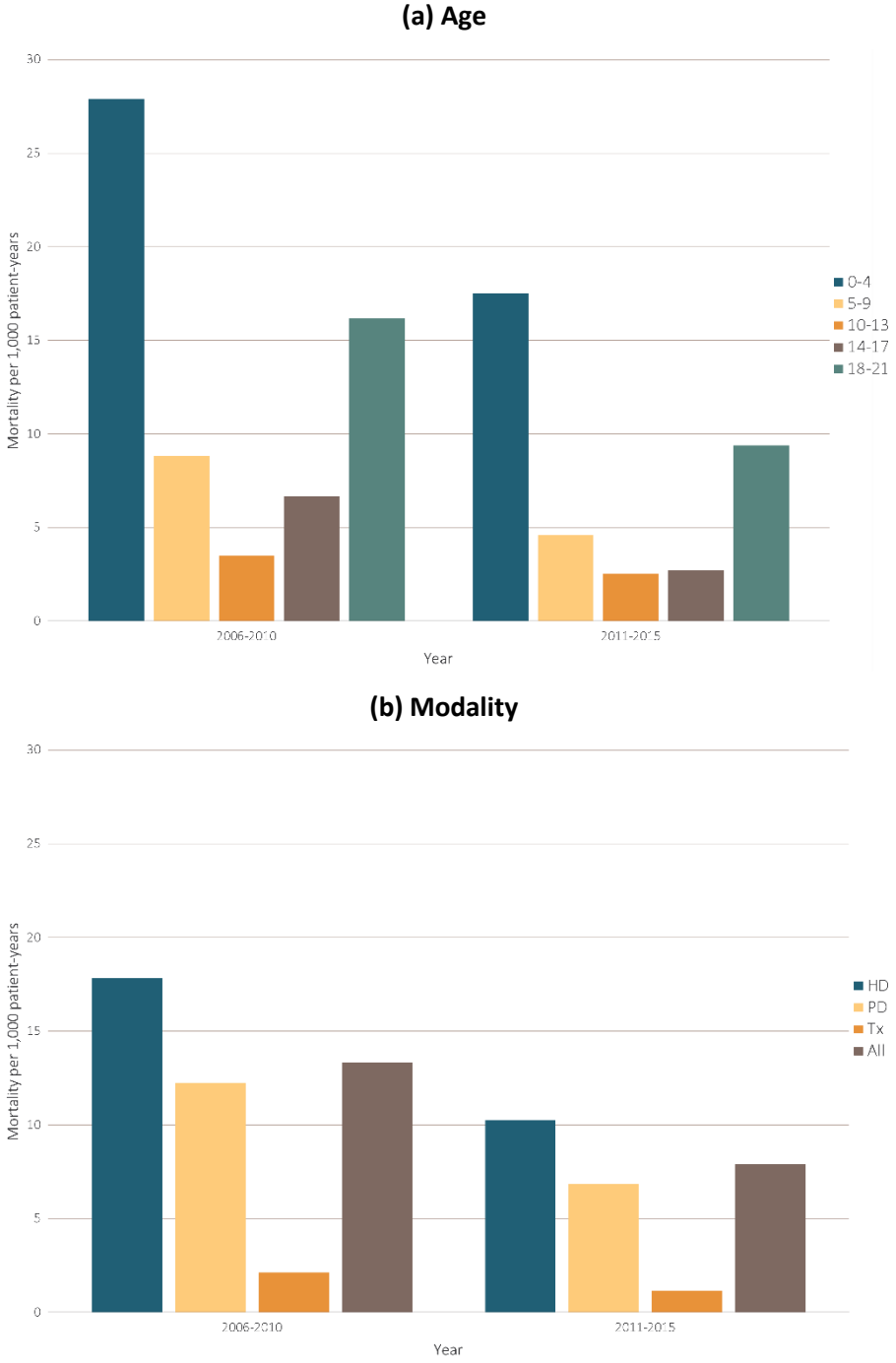
Age group	Dialysis patients	Transplant patients	General population
0-4	22.0	57.7	77.0
5-9	22.8	56.2	72.1
10-13	23.3	52.1	67.6
14-17	20.6	48.9	63.7
18-21	17.6	45.6	59.8
22-29	15.7	42.3	54.1

Data Source: Special analyses, USRDS ESRD Database, USA SSA (Social Security Administration) Period Life Table 2015. Includes period prevalent ESRD dialysis and transplant patients in 2015. Abbreviation: ESRD, end-stage renal disease.

During 2011-2015, the one-year adjusted CVD mortality rate was eight per 1,000 patient-years, a decrease of 38.5% from the 2006-2010 period (Figure 7.9.b). The adjusted one-year CVD mortality rate decreased across all age groups (Figure 7.9.a), but remained the highest in children aged 0-4 years.

When examining adjusted one-year CVD mortality across the periods from 2006-2010 and 2011-2015, mortality decreased in all ESRD treatment modality groups but continued to be highest in the dialysis groups, when compared to transplant (Figure 7.9.b).

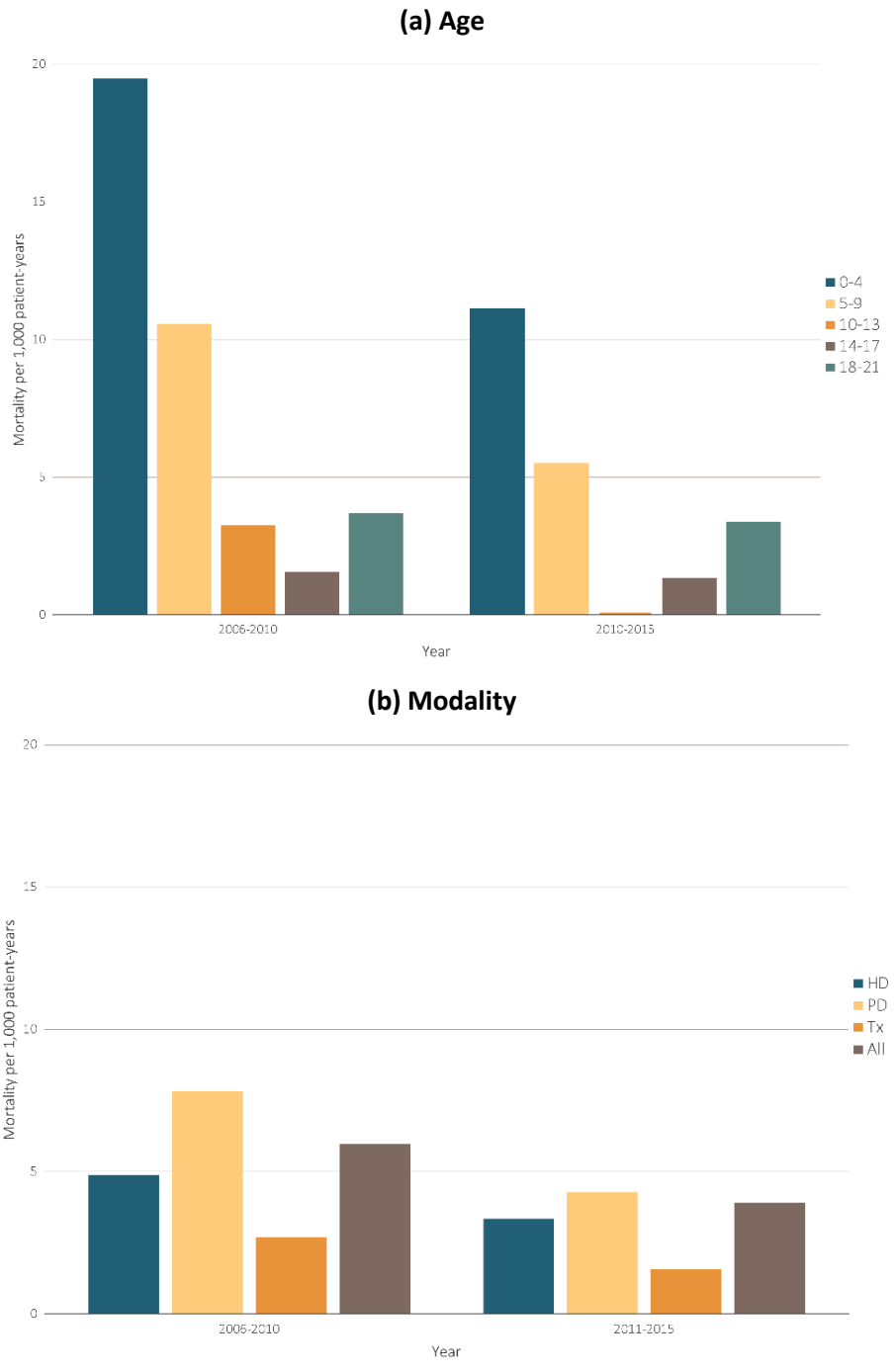
vol 2 Figure 7.9 One-year adjusted cardiovascular mortality in incident pediatric patients with ESRD (aged 0-21 years), by (a) age and (b) modality, 2006-2010 and 2011-2015



Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2016. (a) Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. (b) Adjusted for age, sex, race, primary cause of ESRD and Hispanic ethnicity. Reference population: incident ESRD patients aged 0-21, 2010-2011. When examining cardiovascular associated mortality, hypertension is not considered a cardiovascular diagnosis. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

During 2011-2015, the one-year adjusted infection-related mortality rate decreased from six to four per 1,000 patient-years when compared to the 2006-2010 period (Figure 7.10.b). This mortality rate decreased in those aged 0-4 years by 42.1% (Figure 7.10.a), followed with the same trend in other age groups. During 2011-2015, the modality associated mortality rate was quite low, ranging from two to four per 1,000 patient years in children with incident ESRD (Figure 7.10.b).

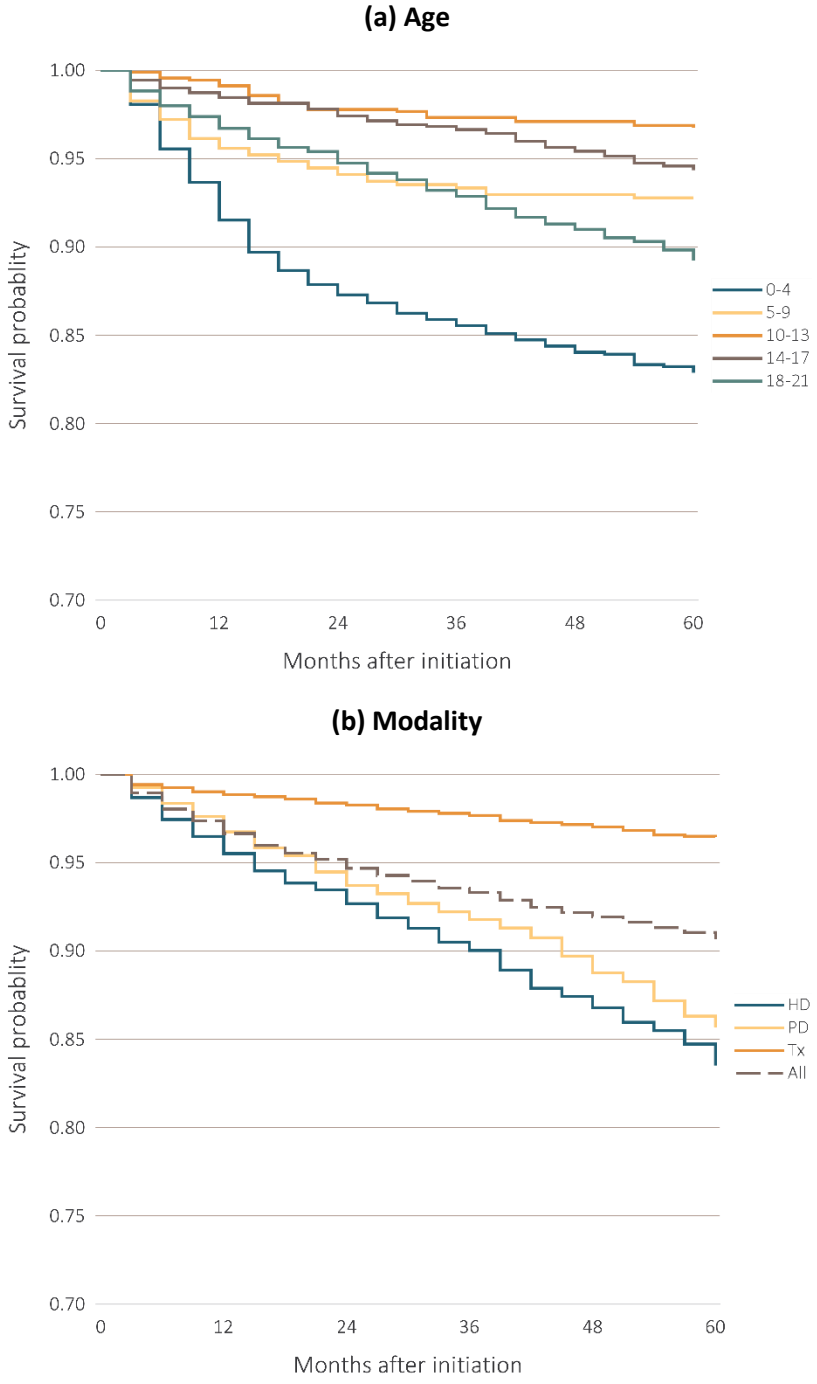
vol 2 Figure 7.10 One-year adjusted mortality due to infection in incident pediatric patients with ESRD (aged 0-21 years), by (a) age and (b) modality, 2006-2010 and 2011-2015



Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2016. (a) Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. (b) Adjusted for age, sex, race, primary cause of ESRD and Hispanic ethnicity. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

For patients beginning ESRD therapy during 2007-2011, the probability of five-year survival was 0.91 (Figure 7.11.b). The probability of surviving five years by age was the worst for the youngest and oldest subsets, including 0.83 for ages 0-4 and 0.89 for ages 18-21 years (Figure 7.11.a). Patients initiating ESRD care with transplantation had the highest probability of surviving five years, at 0.96, as compared to 0.84 with HD, and 0.86 with PD (Figure 7.11.b).

vol 2 Figure 7.11 Adjusted five-year survival in incident pediatric patients (aged 0-21 years) from day 1, by (a) age and (b) modality, 2007-2011



Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2016. (a) Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. (b) Adjusted for age, sex, race, primary cause of ESRD and Hispanic ethnicity. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

Vascular Access

The approach to vascular access in ESRD patients influences both immediate and future patient outcomes. Due to the consequences that central venous catheter (hereafter, catheter) use may have on future access, and because many pediatric patients will require multiple forms of vascular access during their lifetime, vascular access decisions are particularly important in pediatric patients. In this section, we will describe the vascular access practices in incident and prevalent HD patients.

Vascular access in pediatric ESRD patients is approached differently than in adult ESRD patients due to factors such as anatomical differences, short transplant waiting times, and high transplant rates in the initial year of ESRD. The technical challenge of AV fistula placement in small children and an expected short waiting time until a kidney transplant becomes available may influence the recommendations of initial vascular access for children who initiate therapy with HD. Since 2006, approximately 81.5% of incident pediatric ESRD patients have started HD with a catheter (ranging from 77.7% to 82.9%; Figure 7.12.a). The predominant catheter use was observed across all age groups of children and adolescents (Figure 7.12.b). Catheters with a maturing fistula and fistula alone became increasingly more common with advancing age of HD initiation, starting at age 8 years through adolescence.

vol 2 Figure 7.12 Vascular access type at initiation of incident pediatric hemodialysis patients (aged 0-21 years), by (a) year and (b) age, 2006-2016

(a) Year

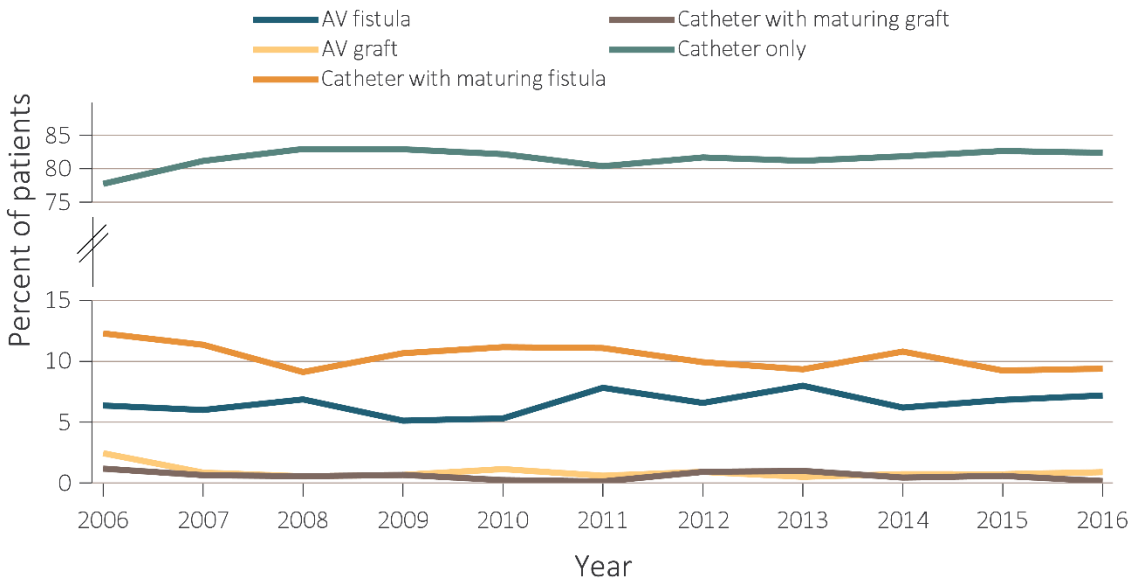
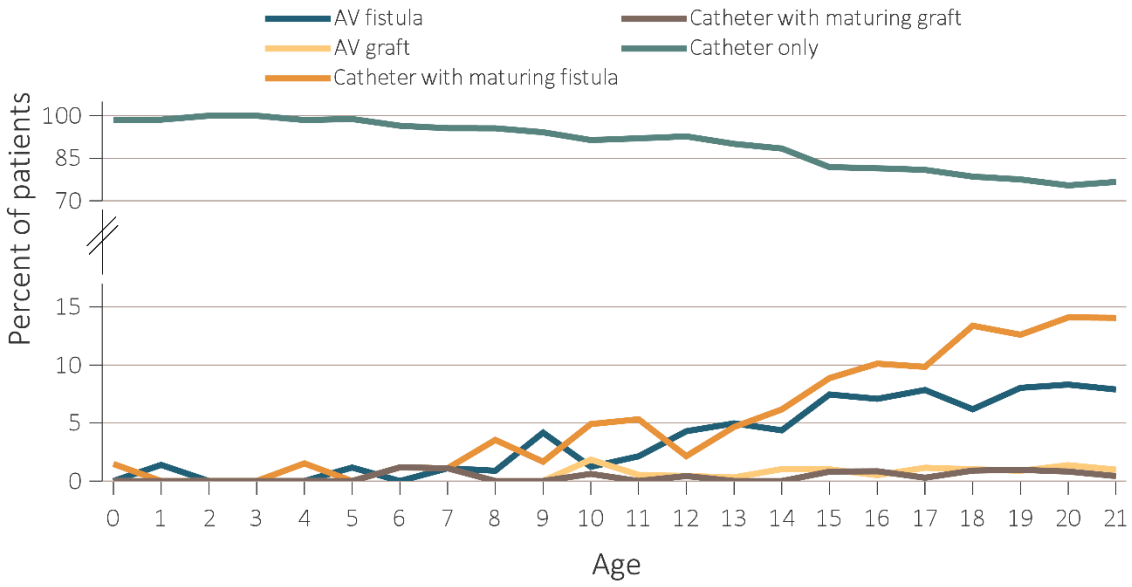


Figure 7.12 continued on next page.

vol 2 Figure 7.12 Vascular access type at initiation of incident pediatric hemodialysis patients (aged 0-21 years), by (a) year and (b) age, 2006-2016 (continued)

(b) Age (all years combined)



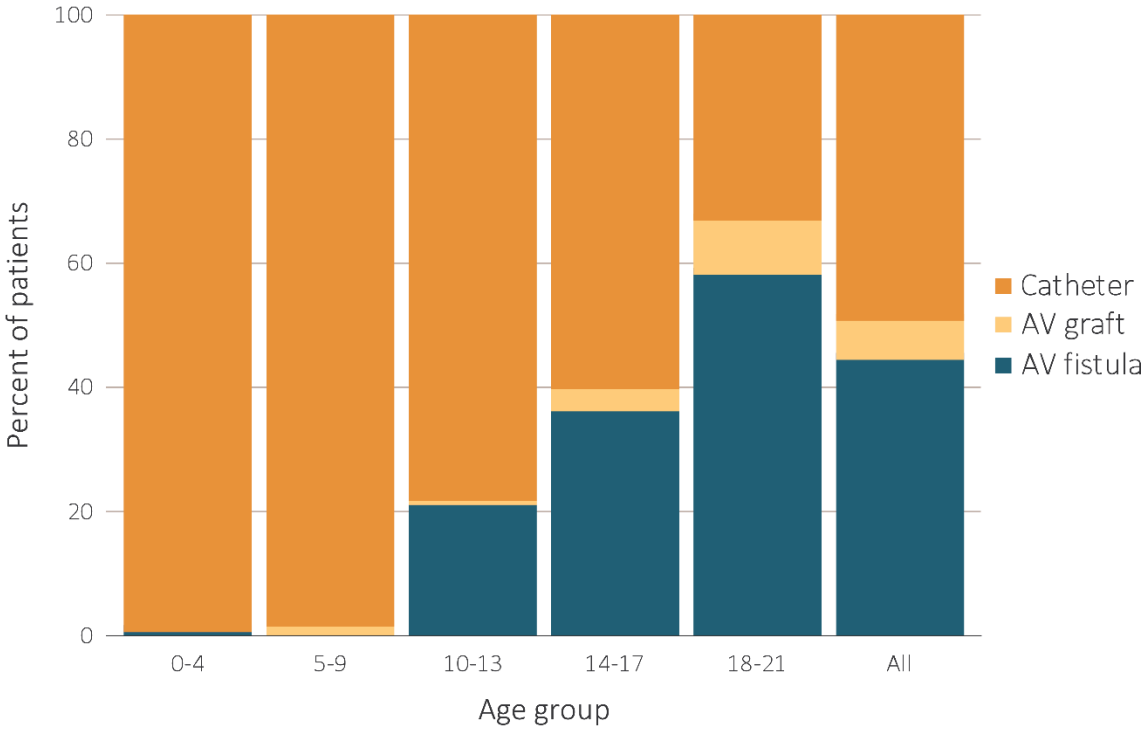
Data Source: Special analyses, USRDS ESRD Database. ESRD patients initiating hemodialysis in 2006-2015. Abbreviations: AV, arteriovenous; ESRD, end-stage renal disease.

When vascular access was examined in prevalent HD patients, there were higher rates of AV fistula and AV graft utilization in children aged 10-13 (22.3%), 14-17 (40.3%), and 18-21 (67.4%) than in children under age 10 (Figure 7.13).

A cross-sectional analysis of point prevalent ESRD patients aged 0-21 years in May 2017 showed that 51.3% of patients had an AV fistula or AV graft as their type of vascular access (Figure 7.13). Age strongly predicted the type of vascular access in use. There was a stepwise increase in the utilization of AV fistula or AV graft with increasing patient age, including 40.3% for those aged 14-17 and 67.4% for those aged 18-21 years.

When examining race and etiology of ESRD in age-adjusted analysis (see downloadable Volume 2, Chapter 7: Excel Web Data File), there were subtle differences in vascular access in the prevalent hemodialysis patients. Whites had higher use of catheters (52.0%) when compared to Blacks/African American (44.0%) and Other races (44.2%). Blacks/African Americans and Other races had a higher proportion of AV graft use (8.7% and 8.0%) when compared to Whites (4.5%). Overall, patients with primary glomerular disease as the etiology of ESRD had the highest proportion of surgical access in place (AV fistula 48.1% or AV graft 7.1%). In age-adjusted analysis, the highest rate of catheter use was in those with Other etiologies of ESRD (53.7%).

vol 2 Figure 7.13 Distribution of vascular access type in prevalent pediatric hemodialysis patients (aged 0-21 years* as of May 31, 2017)



*Data Source: Special analyses, CROWNWeb clinical extracts for May 2017. Hemodialysis patients initiating treatment for ESRD at least 90 days prior to May 1, 2017, *who were <22 years old as of May 1, 2017, and who were alive through May 31, 2017; Catheter=any catheter use; fistula and graft use shown are without the use of a catheter. Abbreviations: AV, arteriovenous; ESRD, end-stage renal disease.*

Trends in Pediatric Kidney Transplantation

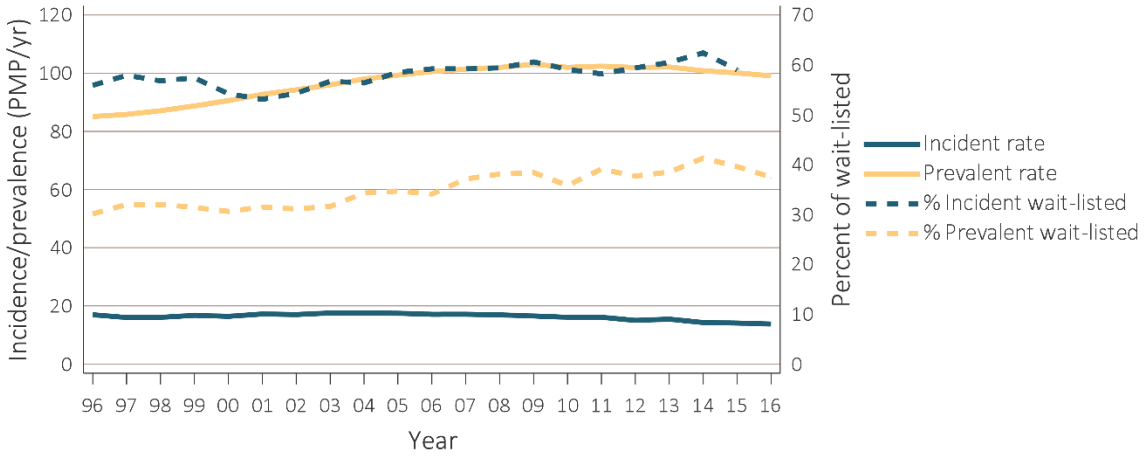
When examining race and etiology of ESRD in age-adjusted analysis, 36.3% of children received a kidney transplant within their first year of ESRD care, including 30.3% of children with weight greater than or equal to 10 kg (data not shown). In 2016 the rate of transplants was 34.9 per 100 dialysis patient-years—a stable trend since 2007 (Figure 7.14.a).

In 2016, 1,119 children were wait-listed for a kidney transplant, including 785 patients listed for the first time and 334 patients listed for repeat transplant. The number of patients awaiting a kidney transplant has ranged from 1,119 to 1,324 since 2004 (Figure 7.14.b). There has been a persistently low median waiting time for those listed for their first transplant over the most recent 10-year reporting period. In 2016, the median waiting time for first transplant was 12.94 months (Figure 7.16.a). Over the past 10 years, children receiving a repeat transplant have, on average, been on the waiting list at least 3-4 times longer than those awaiting their first transplant. See Figure 6.3 in Volume 2, Chapter 6, Transplantation, for trends from 1999-2015 in the percentage of incident patients aged 0-21 who were wait-listed or received a kidney transplant within one year of ESRD initiation.

In 2016, 1,020 children received a kidney transplant (Figure 7.14.c). Prior to 2005, pediatric transplants were most commonly from living donors. In 2016, living donors accounted for 35.7% of kidney transplants, a 17.7% decrease since 2009. Stratifying kidney transplants by age group, adolescents between age 18 and 21 have had a consistently low number of transplants annually compared with children less than 18, totaling less than 300 per year for adolescents and 750 per year in children (Figures 7.14.d and 7.14.e).

vol 2 Figure 7.14 Trends in pediatric transplantation (aged 0-21 years), by (a) ESRD incident and prevalent rates, and percent of patients wait-listed, (b) kidney transplant counts and waiting list times, (c) kidney transplant counts by donor type (aged 0-21 years), (d) kidney transplant counts, (aged 0-17 years), (e) and kidney transplant counts, (aged 18-21 years)

(a) ESRD incident rate, prevalent rate, and percent of patients wait-listed



(b) Kidney transplant counts and waiting list times

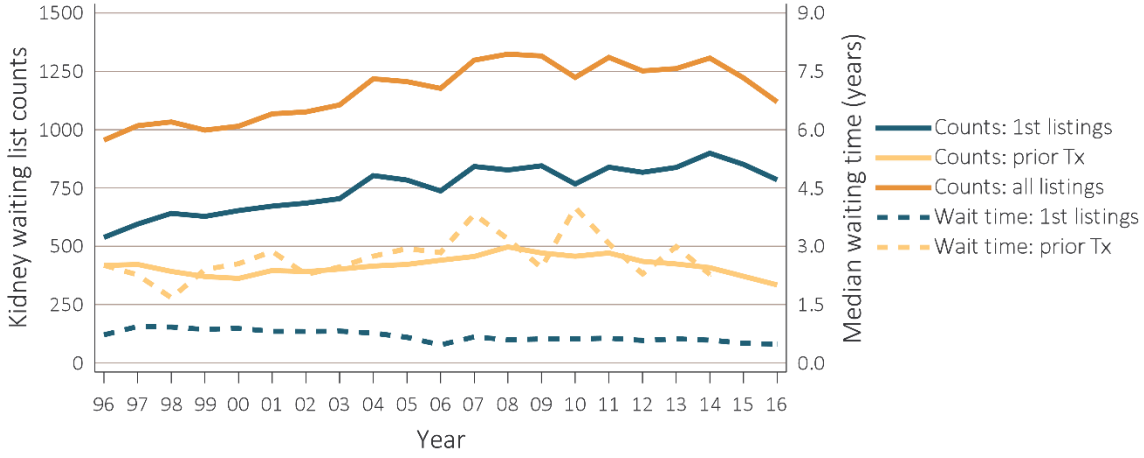
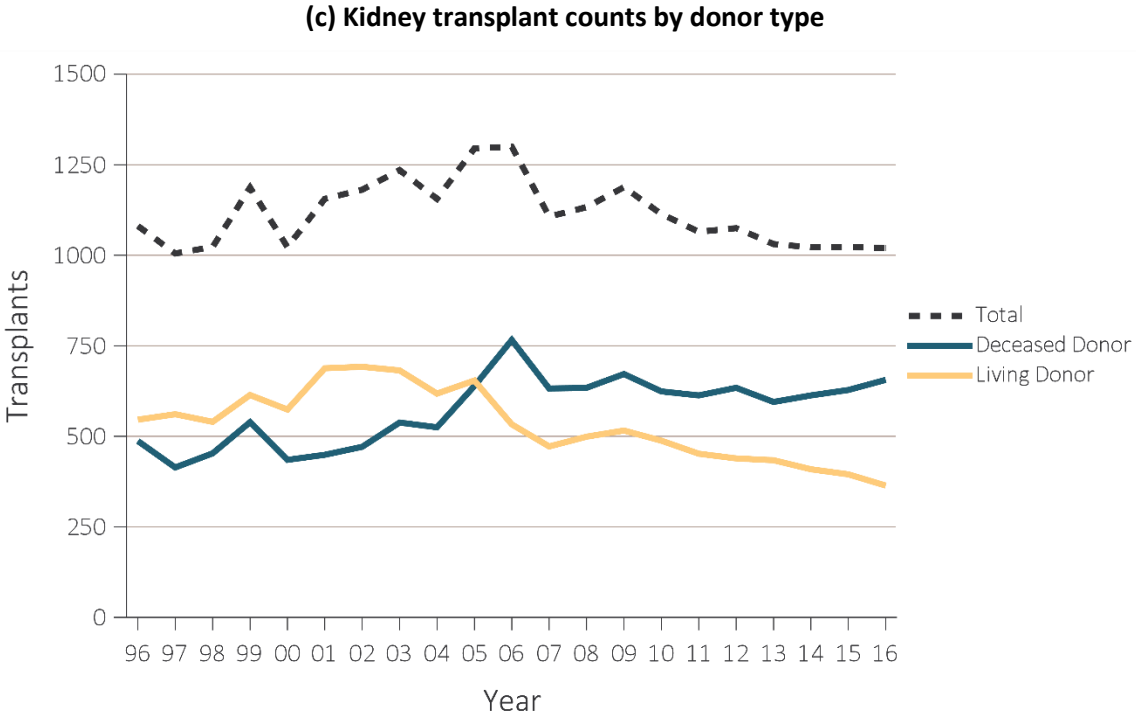


Figure 7.14 continued on next page.

vol 2 Figure 7.14 Trends in pediatric transplantation (aged 0-21 years), by (a) ESRD incident and prevalent rates, and percent of patients wait-listed, (b) kidney transplant counts and waiting list times, (c) kidney transplant counts by donor type, (d) kidney transplant counts, patients 0-17 years, (e) and kidney transplant counts, patients 18-21 years (continued)



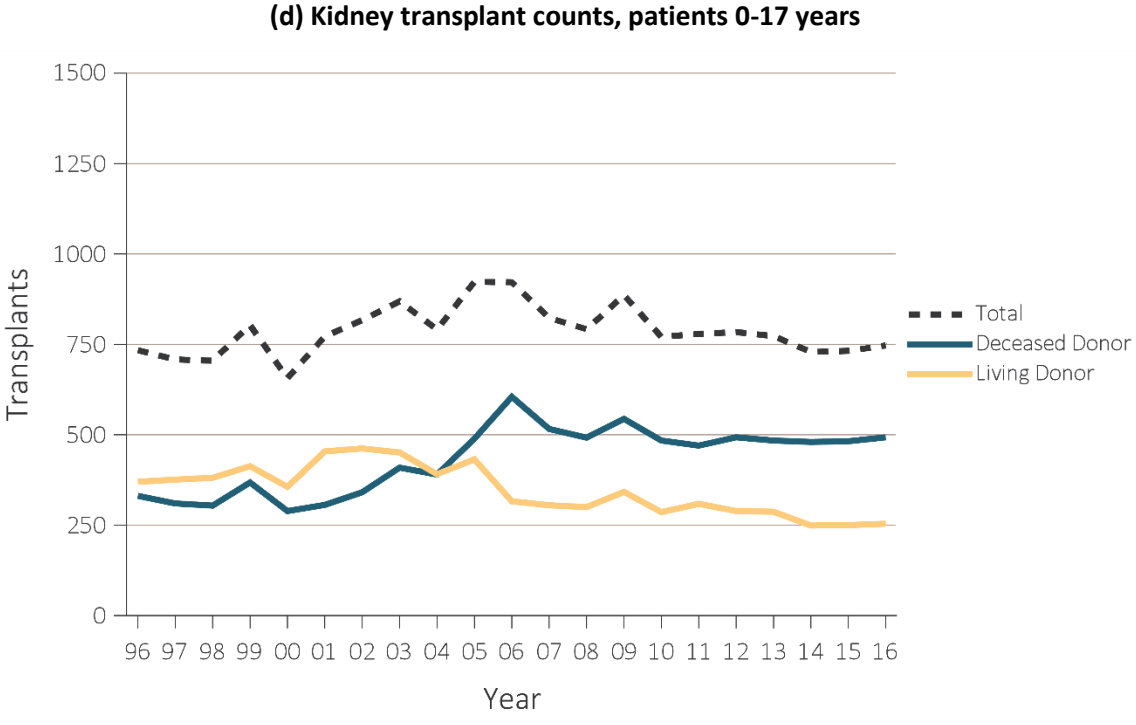
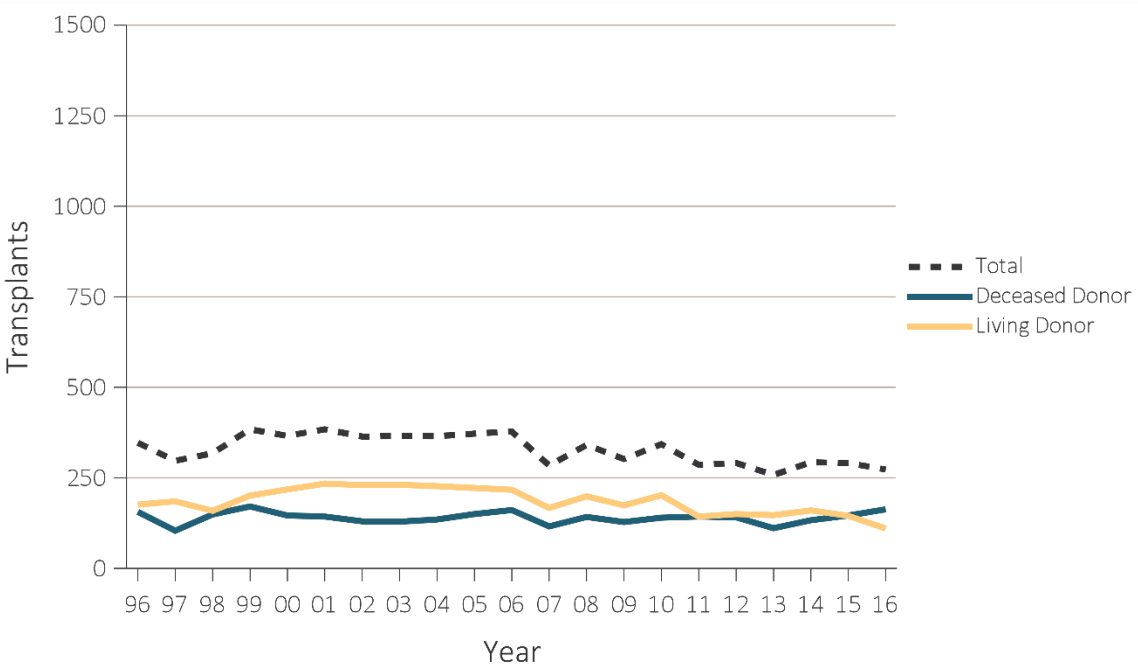


Figure 7.14 continued on next page.

vol 2 Figure 7.14 Trends in pediatric transplantation (aged 0-21 years), by (a) ESRD incident and prevalent rates, and percent of patients wait-listed, (b) kidney transplant counts and waiting list times, (c) kidney transplant counts by donor type, (d) kidney transplant counts, patients 0-17 years, (e) and kidney transplant counts, patients 18-21 years (continued)

(e) Kidney transplant counts, patients 18-21 years



Data Source: (a) Reference Tables E.4 and E.5(2). Incidence and December 31 point prevalence of ESRD among pediatric patients (aged 0-21 years) per million population per year, 1996-2016, percent of pediatric patients either wait-listed or receiving a kidney within one year of ESRD initiation date, 1996-2015 and percent of prevalent dialysis pediatric patients wait-listed for a kidney, 1996-2016. (b) Special analyses, USRDS ESRD Database. The waiting list count provides the number of pediatric candidates aged 0-21 years on the Organ Procurement and Transplantation Network kidney transplant waiting list on December 31 of each year for first and subsequent kidney alone or kidney plus pancreas transplantation. Candidates listed at more than one center on December 31 are counted only once. There are no data available for median waiting list time for patients with prior transplants listed after 2012. (c-e) Reference Tables E.8, E.8(2), E.8(3). This figure represents kidney alone and kidney plus pancreas transplant counts for all pediatric candidates. Abbreviations: ESRD, end-stage renal disease; PMP, per million population; Tx, transplant; yr, year.

Within this section we present details about annual transplant rates using three-year rolling averages to smooth the undue influence of fluctuations in the data in a single year. The rate of transplants relative to dialysis has remained between 30 and 38 per 100 dialysis years since 2016 (Figure 7.15.a). In 2016, patients aged 5-9 and 10-13 years had the highest average rates of transplants, 51.4 and 53.1 per 100 dialysis patient years respectively, and those aged 18-21 years had the lowest average rate at 20.6 (Figures 7.15.a and 7.15.b).

In 2016, males with ESRD were transplanted at average rates compared with females, at 36.0 versus 30.8 per 100 dialysis patient years. The average transplant rate remained lower in Black/African American dialysis patients compared with Whites, at 20.7 versus 37.0 per 100 dialysis patient years (Figures 7.15.c and 7.15.b). Analyses for Native and Asian Americans were not conducted due to the low number of transplants in these pediatric populations.

vol 2 Figure 7.15 Annual average rates of transplants in pediatric dialysis patients (aged 0-21 years), by (a) living donor by age, (b) deceased donor by age, (c) living donor by race, (d) deceased donor by race, 1998-2016

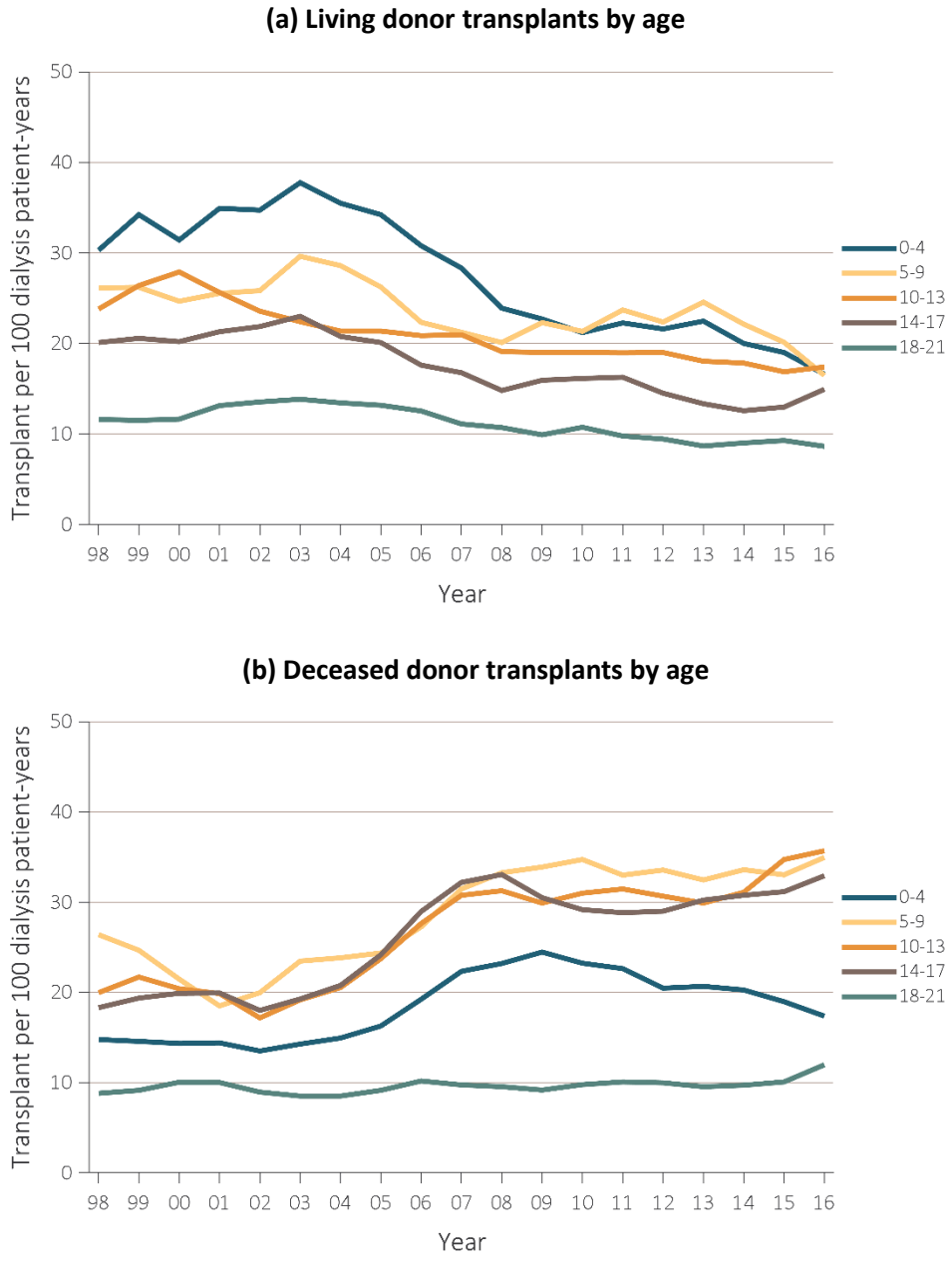
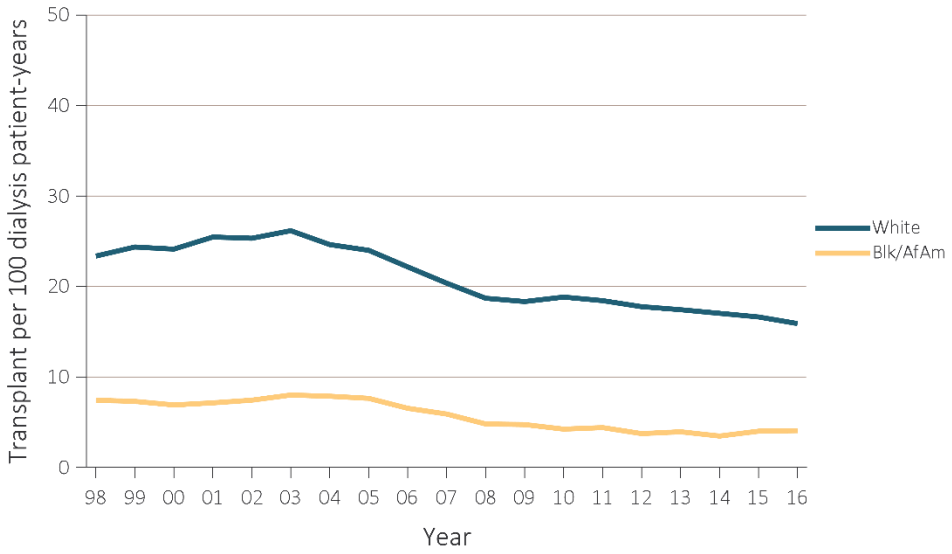


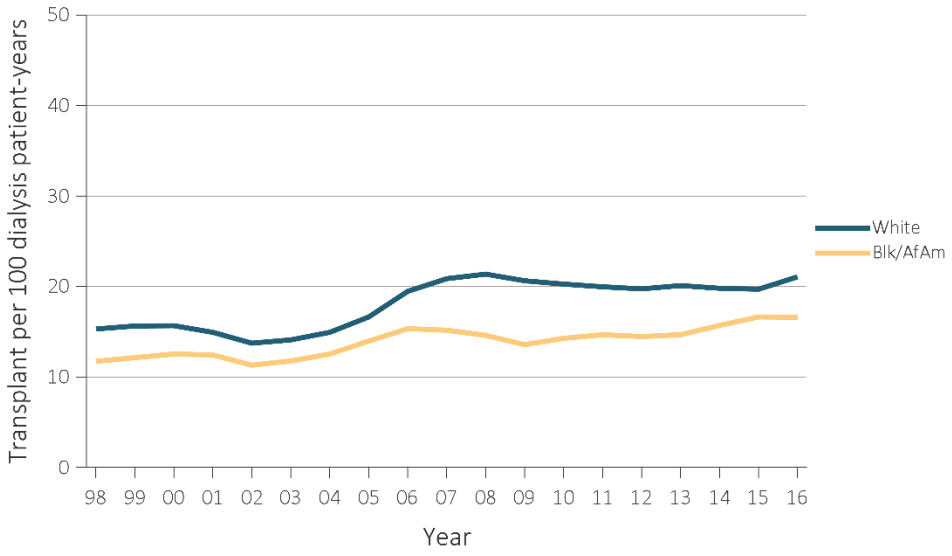
Figure 7.15 continued on next page.

vol 2 Figure 7.15 Annual average rates of transplants in pediatric dialysis patients (aged 0-21 years), by (a) living donor by age, (b) deceased donor by age, (c) living donor by race, (d) deceased donor by race, 1998-2016 (continued)

(c) Living donor transplants by race



(d) Deceased donor transplants by race



Data Source: Special analyses, USRDS ESRD Database. Includes transplant year between 1998–2016. Three-year rolling average rate is the mean among the rates of the current year and of the two years prior. Abbreviations: Blk/Af Am; Black/African American; ESRD, end-stage renal disease.

The trend in median time to first transplant for incident patients on dialysis has been improving. In 2002, the median time to first transplant peaked at 22.3 months then began to decline, with the most dramatic improvement occurring after 2005 (Figure 7.16.a). This coincided with the October 2005 change in the OPTN organ allocation policy, which gave priority to pediatric candidates for allografts from deceased donors aged less than 35 years. The goal of this policy change was to provide pediatric patients with high quality organs, reduce the delay in assignment of donor organs to all ages and reduce pediatric wait times. Since 2005, the median time from dialysis initiation to initial transplantation has continued to decrease, and was at its lowest in 2015, at 12.9 months. In 2015, the median time to transplant was shorter for HD patients (12.1 months) compared with PD patients (13.6 months).

The time to first transplant varied by age and ESRD etiology. In patients younger than 18 years of age, the median time from incident dialysis to transplant has been improving from 1996 to 2015 in most age groups. An exception was for those 0-4 years old (Figure 7.16.b). These youngest children have had stable waiting times, which may result from the surgical complexities in this age group. Since 1996, patients aged 18-21 years old have shown the largest improvement with time from dialysis initiation to initial transplant. In 2014, the median time for children 0-4 years old surpassed that of patients 18-21 years old. Patients with glomerulonephritis (GN) as the primary cause of their ESRD had the longest median time between dialysis and initial transplant, with a median of 14.1 months in 2015 (Figure 7.16.c). The longer dialysis to initial transplant time for GN patients may be related to manifestations of GN such as nephrotic syndrome or uncontrolled systemic vasculitis which require a time on dialysis to restore necessary health parameters to support a successful transplant.

In 1996, the median time between dialysis initiation and first transplant among Whites was a 34% shorter period than Blacks/African Americans (Figure 7.16.d). Since then, the median time for dialysis patients to first transplant has improved significantly for all patients, and the gap between races has narrowed substantially. Consequently, the most recent median times between dialysis initiation and first transplant are now similar between groups (Whites 12.5 and Blacks 13.8 months). With the resolution of the dialysis to first transplant-time gap between Black and White pediatric ESRD patients, improving the transplant disparity observed in dialysis-dependent Black children may be addressed through efforts to improve the listing rate in these children.

The median time between dialysis initiation and first transplant from a deceased donor has decreased steadily since 2010, such that the difference in median time between living- and deceased-donor organs was less than three months in 2015 (Figure 7.16.e).

Finally, Tables 7.4 and 7.5 display the one-, five- and ten-year kidney transplant outcomes between 1996 and 2015 for deceased- and living-donor transplants. During this time the deceased-donor one-year graft failure rate has decreased from 15.9% to 3.0%, five-year graft failure has improved from 43.6% to 23.8% and the ten-year graft failure has improved from 65.5% to 53.2% (Table 7.4). Living-donor transplants have achieved similar improvements with the one-, five- and ten-year graft failure rates in the most recent reporting year of 3.1%, 17.2%, and 39.4%, respectively. Comparison of these donor types continues to suggest a graft survival advantage for living-donor organs but the patient survival at one and five years exceeds 97% for both donor types.

vol 2 Figure 7.16 Median time from incident dialysis to first transplant, by (a) modality, (b) age, (c) primary cause of ESRD, (d) race, and (e) donor type, 1996-2015

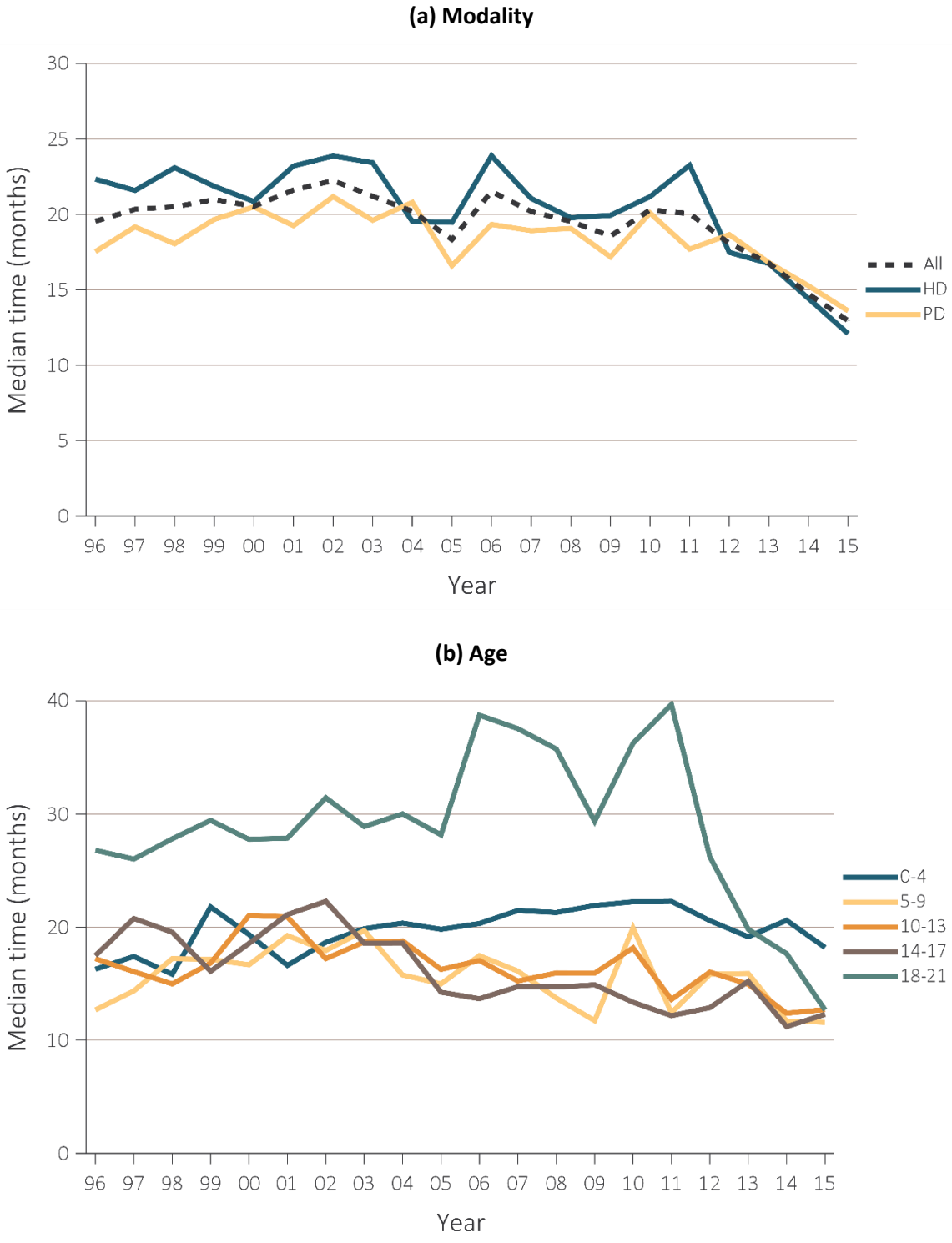


Figure 7.16 continued on next page.

vol 2 Figure 7.16 Median time from incident dialysis to first transplant, by (a) modality, (b) age, (c) primary cause of ESRD, (d) race, and (e) donor type, 1996-2015 (continued)

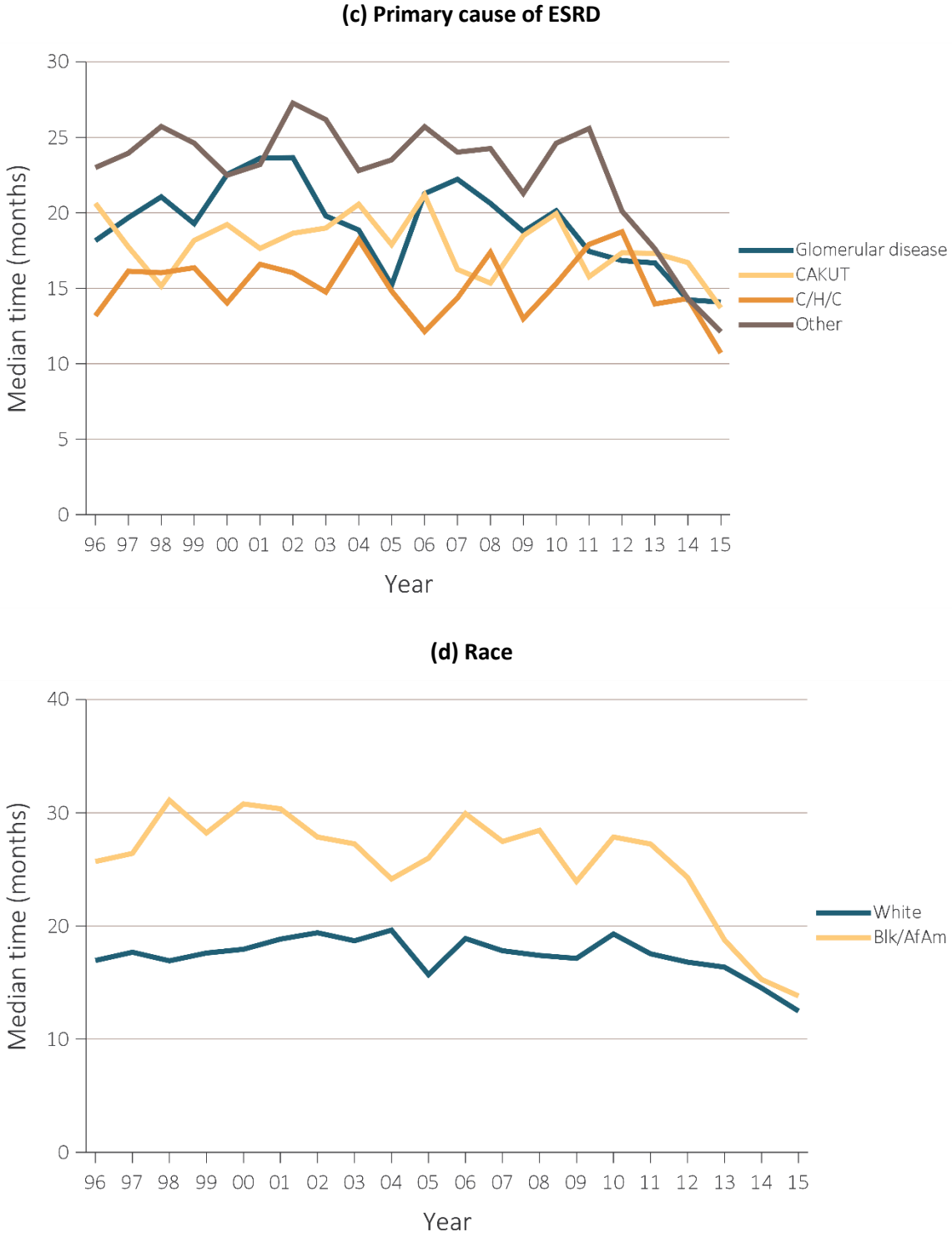
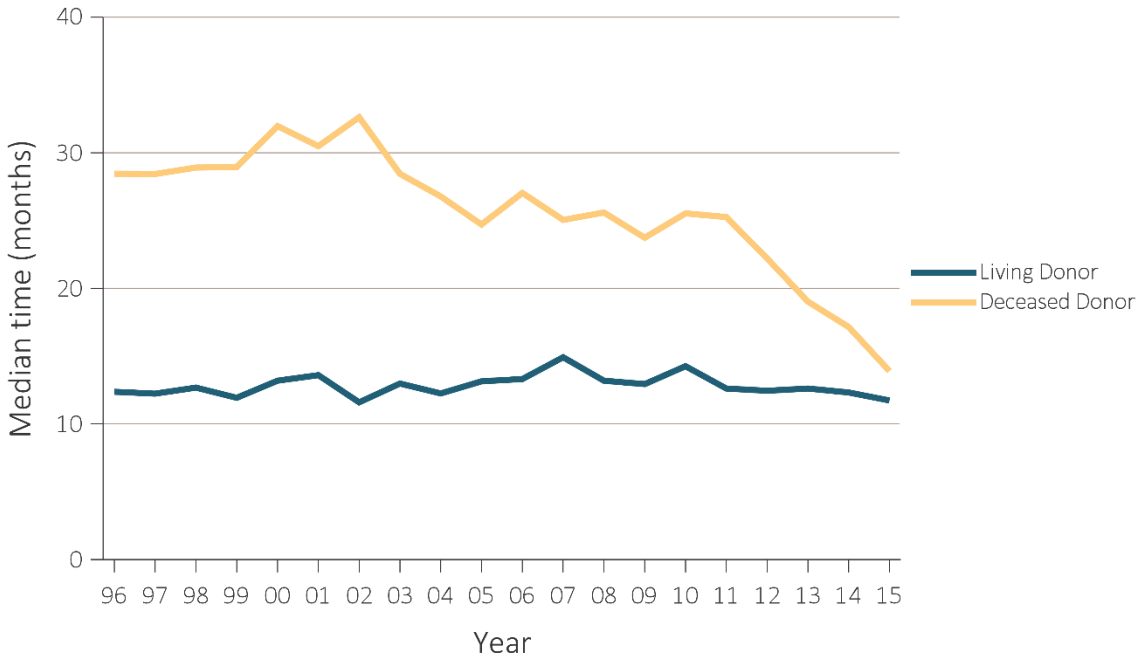


Figure 7.16 continued on next page.

vol 2 Figure 7.16 Median time from incident dialysis to first transplant, by (a) modality, (b) age, (c) primary cause of ESRD, (d) race, and (e) donor type, 1996-2015 (continued)

(e) Donor type



Data Source: Special analyses, USRDS ESRD Database. Sample restricted to children initiating ESRD care with dialysis. Time 0 is defined at the date of initiation of dialysis with the 60 day rule. Includes pediatric patients (aged 0-21 years) starting initiation of HD or PD in 1996-2015 and having the first transplant before 12/31/2017. Note that the percentage of unknown donor type is 1.32% in 1996, 1.00% in 1997, 0.44% in 1998, 0.54% in 1999, 0.22% in 2000, 0.10% in 2001, 0.30% in 2002, 0.10% in 2003, 0.10% in 2004, 0.22% in 2006, 0.13% in 2011, and 0% in 2005, 2007-2010, 2012-2015. Abbreviations: Blk/Af Am, Black/African American; CAKUT, congenital anomalies of the kidney and urinary tract; C/H/C, Cystic/Hereditary/Congenital disease; ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis.

vol 2 Table 7.4 Adjusted outcomes for deceased-donor kidney transplants in pediatric patients (aged 0-21 years) by year, 1996-2015

	One year post-transplant			Five years post-transplant			Ten years post-transplant		
Year	Probability of all-cause graft failure (%)	Probability of return to dialysis or repeat transplant (%)	Probability of death (%)	Probability of all-cause graft failure (%)	Probability of return to dialysis or repeat transplant (%)	Probability of death (%)	Probability of all-cause graft failure (%)	Probability of return to dialysis or repeat transplant (%)	Probability of death (%)
1996	15.9	13.7	2.0	43.6	40.5	8.6	65.5	62.4	15.9
1997	12.9	11.2	2.6	39.2	36.6	6.3	63.2	59.7	15.1
1998	14.8	13.4	2.0	38.4	36.3	6.1	57.8	55.7	11.2
1999	14.2	11.8	2.2	37.6	34.8	4.7	59.2	56.3	14.2
2000	11.7	9.9	1.4	41.0	38.6	5.3	59.9	56.6	11.3
2001	11.5	10.7	1.7	36.6	34.8	6.0	57.0	54.1	12.3
2002	10.2	9.0	0.9	35.7	33.1	3.7	52.0	48.6	7.1
2003	10.5	8.7	2.5	36.7	34.1	7.0	54.4	51.2	14.6
2004	8.7	6.7	1.7	37.7	35.0	4.9	59.4	56.6	8.8
2005	9.4	8.0	2.2	35.2	32.5	5.6	55.6	52.6	10.3
2006	9.0	7.9	1.4	32.9	31.1	3.8	53.2	50.9	8.2
2007	7.8	6.4	2.2	31.4	29.0	6.0			
2008	9.1	7.4	1.8	28.2	25.2	4.4			
2009	7.6	6.5	1.1	29.3	27.1	4.3			
2010	6.7	5.6	1.1	23.9	22.6	2.7			
2011	4.3	4.1	0.3	23.8	22.7	2.6			
2012	5.4	4.2	0.9						
2013	5.8	5.4	0.4						
2014	5.5	5.1	0.3						
2015	3.0	2.6	0.2						

Data Source: Reference Tables F.2, F.5, F.6, F.14, F.17, F.18, I.26, I.29, I.30. Probabilities for all-cause graft failure and return to dialysis or repeat transplant are adjusted for age, sex, race, primary cause of ESRD, and first versus subsequent transplant. All-cause graft failure includes repeat transplant, return to dialysis, and death. The death outcome is not censored at graft failure, and includes deaths that occur after repeat transplant or return to dialysis. Probabilities of death are adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. The reference population for all-cause graft failure and return to dialysis or repeat transplantation is all pediatric patients receiving a kidney alone transplant in 2011. The reference population for death is incident pediatric ESRD patients in 2011. Abbreviation: ESRD, end-stage renal disease.

vol 2 Table 7.5 Adjusted outcomes for living-donor kidney transplants in pediatric patients (aged 0-21 years) by year, 1996-2015

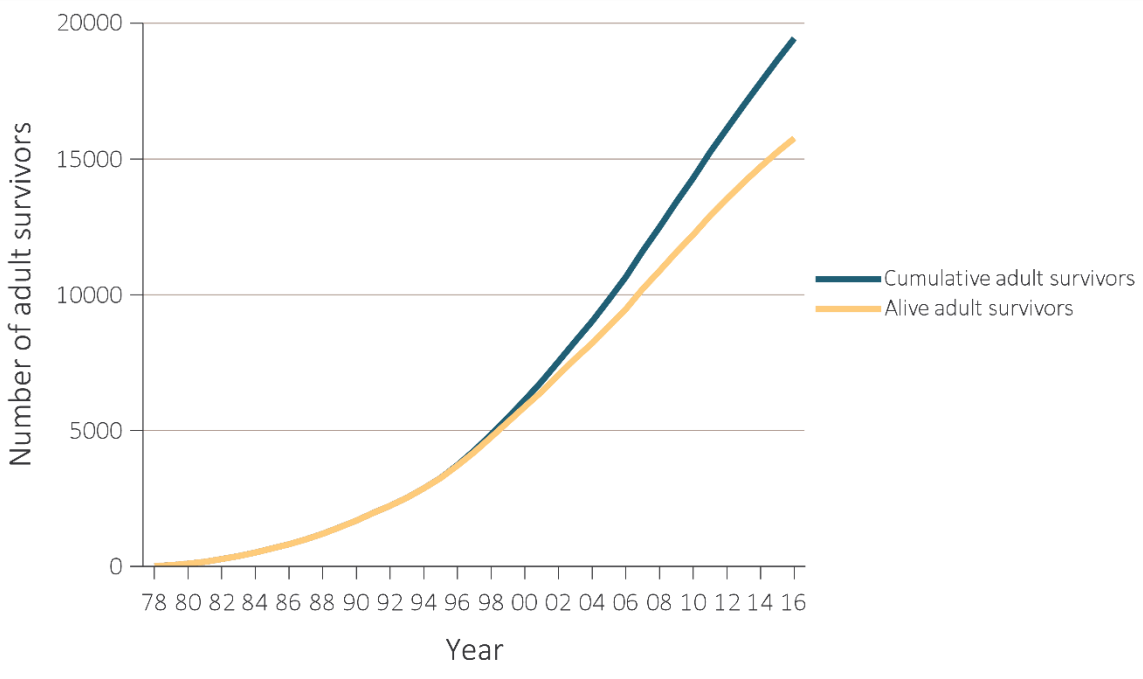
	One year post-transplant			Five years post-transplant			Ten years post-transplant		
Year	Probability of all-cause graft failure (%)	Probability of return to dialysis or repeat transplant (%)	Probability of death (%)	Probability of all-cause graft failure (%)	Probability of return to dialysis or repeat transplant (%)	Probability of death (%)	Probability of all-cause graft failure (%)	Probability of return to dialysis or repeat transplant (%)	Probability of death (%)
1996	9.2	8.0	1.8	30.1	28.0	5.9	51.1	49.1	12.0
1997	8.0	7.1	1.1	29.6	26.2	9.5	48.8	45.9	15.1
1998	7.1	6.5	0.8	25.3	24.1	2.5	48.5	46.3	9.8
1999	7.3	6.5	1.0	27.4	25.6	5.9	49.6	47.2	13.0
2000	8.3	7.7	1.6	28.4	26.6	7.3	51.2	48.2	14.7
2001	7.5	6.7	1.1	26.6	24.2	5.4	48.8	45.9	13.1
2002	6.4	5.5	1.6	25.6	23.6	7.1	42.0	39.8	13.1
2003	6.8	5.6	1.5	25.1	22.9	5.3	42.7	39.9	11.1
2004	5.9	4.9	1.0	25.8	23.3	3.9	43.7	41.0	6.2
2005	7.0	6.4	1.1	27.4	25.6	5.7	47.7	45.5	11.3
2006	3.9	3.7	0.3	20.8	19.4	2.4	39.4	37.3	6.0
2007	4.7	3.9	0.8	23.2	21.3	4.1			
2008	5.3	4.5	1.5	21.5	19.4	4.7			
2009	5.0	3.9	0.9	18.9	17.3	1.7			
2010	3.9	3.2	0.6	20.3	18.6	1.3			
2011	4.0	3.2	1.2	17.2	16.1	2.8			
2012	5.5	4.4	1.7						
2013	3.3	1.6	1.2						
2014	4.7	3.8	1.0						
2015	3.1	3.0	0.0						

Data Source: Reference Tables F.8, F.11, F.12, F.20, F.23, F.24, I.32, I.35, I.36. Probabilities for all-cause graft failure and return to dialysis or repeat transplant are adjusted for age, sex, race, primary cause of ESRD, and first versus subsequent transplant. All-cause graft failure includes repeat transplant, return to dialysis, and death. The death outcome is not censored at graft failure, and includes deaths that occur after repeat transplant or return to dialysis. Probabilities of death are adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. The reference population for all-cause graft failure and return to dialysis or repeat transplantation is all pediatric patients receiving a kidney alone transplant in 2011. The reference population for death is incident pediatric ESRD patients in 2011. Abbreviation: ESRD, end-stage renal disease.

Young Adults with Childhood Onset ESRD

In this section, adult survivors of childhood onset ESRD (survivors) are defined as individuals who initiated ESRD care before the age of 19 years and survived beyond their nineteenth birthday. As of December 31, 2016, the cumulative number of survivors between 1978 and 2016 is 19,441 in the United States with 15,765 (81.1%) still surviving on December 31, 2016. Prevalence trends in this cohort are shown in Figure 7.17.

vol 2 Figure 7.17 Prevalent adult survivors of childhood onset ESRD, 1978-2016



Data Source: Special analyses, USRDS ESRD Database. Survivorship cohort is defined as the patients with ESRD incidence in childhood who survive to adulthood by the end of each year and with ESRD onset year on and after 1978. Cumulative adult survivors include patients who reached adulthood but died by the end of each year. Alive adult survivors excludes patients who died during the year. Abbreviation: ESRD, end-stage renal disease.

Focusing on survivors with an ESRD initiation date between 1995 and 2016, a summary of the contemporary survivorship cohort is presented in Table 7.6. Survivors initiated ESRD care at any age between 0 and 18 years, with the majority entering as adolescents. The leading primary causes of ESRD were categorized as glomerular disease (39.7%), cystic/hereditary/congenital (11.4%), and other etiologies combined (48.9%). Hypertension was common at ESRD initiation. Cardiovascular disease and diabetes were present in less than 3% of the survivorship cohort at ESRD initiation.

The majority of survivors received at least one kidney transplant throughout their ESRD experience. The mean transplant number was 1.08 per patient and the maximum number of transplants was 5. The average length of time on ESRD modality for these survivors was 112.6 months for patients with a functioning graft, 52.5 months for patients on HD, and 28.0 months for patients on PD (Table 7.6).

vol 2 Table 7.6 Initiation characteristics and treatment modality of adult survivors of childhood onset ESRD, inclusive of patients initiating ESRD care between 1995 and 2016

Survivorship Cohort	All (N=13,981)	
	Frequency	Percent
Age of ESRD onset		
Less than 5	537	3.8%
5-9	1,287	9.2%
10-13	2,906	20.8%
14-18	9,251	66.2%
Sex		
Male	7,823	56.0%
Female	6,158	44.0%
Race		
White	9,526	68.1%
Black	3,533	25.3%
Other/Unknown	922	6.6%
Ethnicity		
Hispanic	3,580	25.6%
Non-Hispanic	10,354	74.1%
Unknown	47	0.3%
BMI Category		
Underweight	1,434	10.3%
Healthy Weight	7,994	57.2%
Overweight	2,109	15.1%
Obesity	2,444	17.5%
Cause of ESRD		
Glomerulonephritis / Secondary GN / Vasculitis	5,557	39.7%
Cystic / Hereditary / Congenital	1,589	11.4%
Other	6,835	48.9%
ESRD onset year		
1995-2004	8,244	59.0%
2005-2015	5,737	41.0%
Modality at initiation		
HD	7,251	51.9%
PD	4,160	29.8%
TX	2,514	18.0%
Cumulative time on HD (months)	52.5 (SD=52.3)	
Cumulative time on PD (months)	28.0 (SD=29.0)	
Cumulative time with functioning transplant (months)	112.6 (SD=66.6)	
Number of transplants	1.1 (SD=0.6)	
Co-existing conditions at ESRD incidence		
Heart Failure	276	2.0%
Coronary Artery and Cardiac Disease	302	2.2%
Other Vascular Disease	110	0.8%
Hypertension	6,048	43.3%
Diabetes	254	1.8%
Other	2,727	19.5%

Data Source: USRDS ESRD Database. Survivorship cohort is defined as the patients with ESRD incidence in childhood that survive to adulthood by the end of 2016 and with ESRD onset year after 1994 and with completed 2728 form information, including patients who reached adulthood but died by the end of 2016. Abbreviations: ESRD, end-stage renal disease; GN, glomerulonephritis; HD, hemodialysis; PD, peritoneal dialysis.

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