Chapter 8: ESRD Among Children, Adolescents, and Young Adults

- The number of children beginning end-stage renal disease (ESRD) care decreased by 6% in 2014, totaling 1,398 (Figure 8.1.a).
- 9,721 children were being treated for ESRD on December 31, 2014 (Figure 8.1.b).
- Peritoneal dialysis is the most common initial ESRD treatment modality in children younger than 9 years and those who weigh less than 20 kg (Figure 8.2).
- The most common initial ESRD treatment modality among children overall continues to be hemodialysis (50.4%) (Figure 8.1.a). However, among the prevalent pediatric population, 70% are living with a functioning kidney transplant.
- Since 2006, 81% of incident pediatric ESRD patients have started hemodialysis with a central venous catheter without a maturing fistula or graft (Figure 8.11.a).
- 36% of children received a kidney transplant within the first year of ESRD care during 2010-2014 (Table 8.1).
- The total number of children wait-listed for kidney transplant was 1,321 in 2014 (Figure 8.13.b).
- Since 2006, deceased donor transplants have become more common in children than living donor transplants (Figure 8.13.c).
- All-cause hospitalization rates increased 24.4%, totaling 2 per patient year among children with incident ESRD (Figure 8.4.b).
- The five-year patient survival probability was 0.90 for children initiating ESRD care between 2005-2009 (Figure 8.10.b).
- The five-year patient survival probability was 0.80 for young adults (ages 22-29) initiating ESRD care between 2005-2009 (Figure 8.19).

Introduction

Pediatric end-stage renal disease (ESRD) affects children of all ages. The majority of these children will depend on renal replacement therapies over many decades. Consequently, children with incident ESRD often traverse the entire ESRD modality continuum of hemodialysis, peritoneal dialysis, and transplantation. These children are subjected to frequent hospitalizations and have a risk of mortality far exceeding that of the general pediatric population in the United States. Children with ESRD are quite different in disease etiology, transplant opportunities, morbidity, and mortality when compared to adults with ESRD. Consequently, this chapter of the Annual Data Report (ADR) focuses on pediatric ESRD. This chapter also includes a section on young adults in order to improve our understanding of the issues surrounding transitions and outcomes in these patients.

Methods

This chapter uses multiple data sources, including data 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 data sources are described in the Data Sources section of the *ESRD Analytical Methods* chapter.

The categories of ESRD etiology have been updated this year to include the widely accepted Congenital Anomalies of the Kidney and Urinary Tract (CAKUT). In addition, with this 2016 pediatric chapter the ICD-9 codes included for cardiovascular hospitalization were reorganized to reflect the spectrum of cardiovascular diseases in children and exclude diagnoses such as hypertension, hemorrhage NOS, and esophageal varices. More details are provided in the *ESRD Analytical Methods* chapter.

See the section on Chapter 8 in the *ESRD Analytical Methods* chapter for an explanation of analytical methods used to generate the study cohorts, figures, and tables in this chapter.

Epidemiology of End-Stage Renal Disease in Children

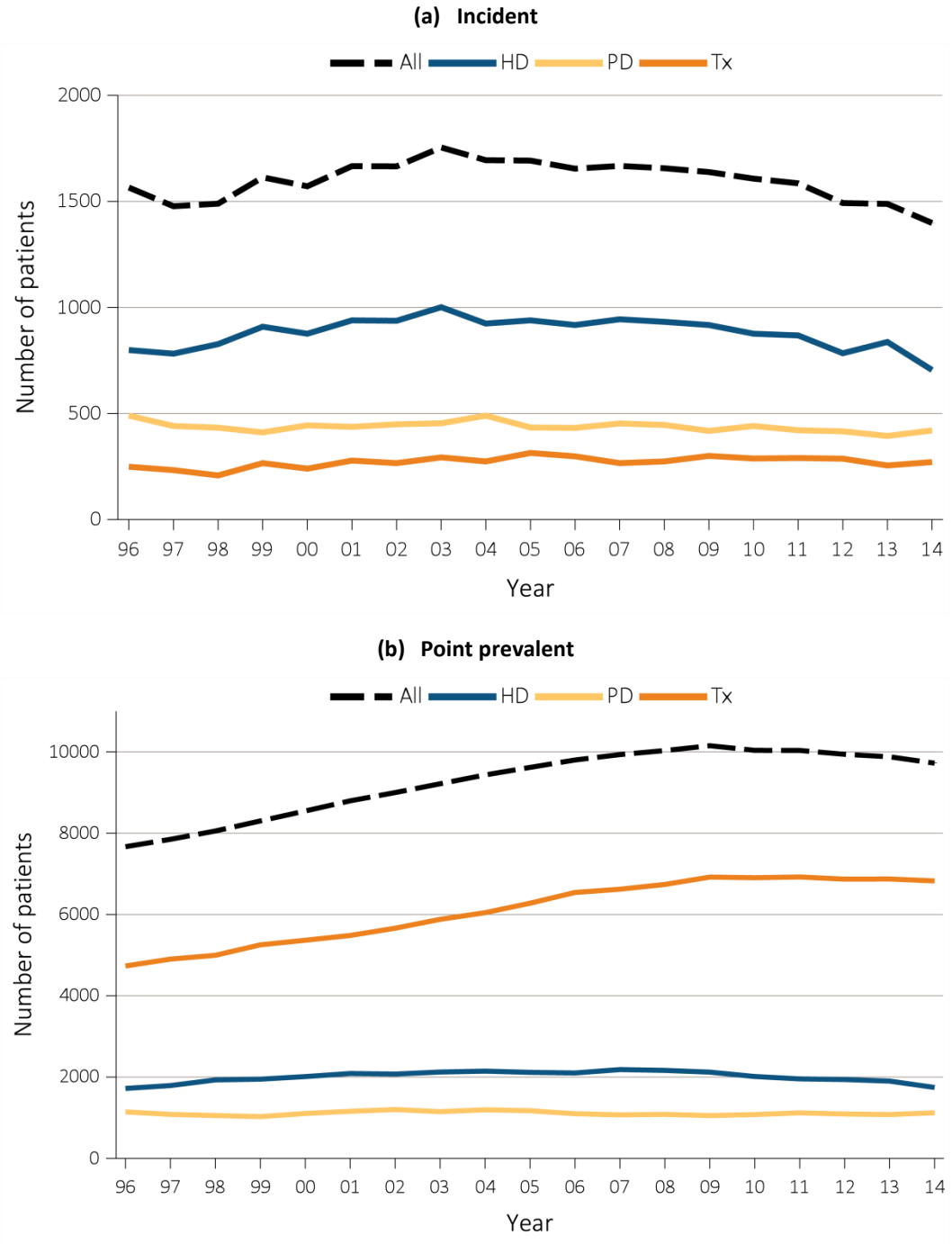
The incidence of ESRD in children has been decreasing annually in the United States between 2008 and 2014 (Figure 8.1.a). In 2014, a total of 1,398 children had new onset ESRD, which was 6% less than in 2013. By age, the number of incident cases ranged from a low of 152 in the 5-9 age group to 555 in the 18-21 age group. Children ages 18-21 years old account for 40% of the incident pediatric ESRD population. In terms of rates, incidence ranges from 6.8 per million for the 5-9 age group to 30.6 per million in the 18-21 age group. Similarly, as of December 31, 2014, the point prevalence of children with ESRD was 9,721, which represents a 1.6% decrease from the previous year (Figure 8.1.b). Prevalence counts do not account for the large number of pediatric patients who have aged into adulthood.

Incidence and Prevalence by ESRD Modality

From the earliest reporting year, in aggregate, children have initiated ESRD therapy with hemodialysis more frequently than peritoneal dialysis or transplantation. Data from 2014 demonstrate the same pattern with 705 (50.4%) initiating with hemodialysis, 420 (30.0%) peritoneal dialysis, and 271 (19.4%) transplant (Figure 8.1.a). This equates to an incidence rate per million per year (per million/year) of 7.5 in hemodialysis, 4.4 in peritoneal dialysis, 2.3 in transplant, and total ESRD incidence of 14.2 per million children per year.

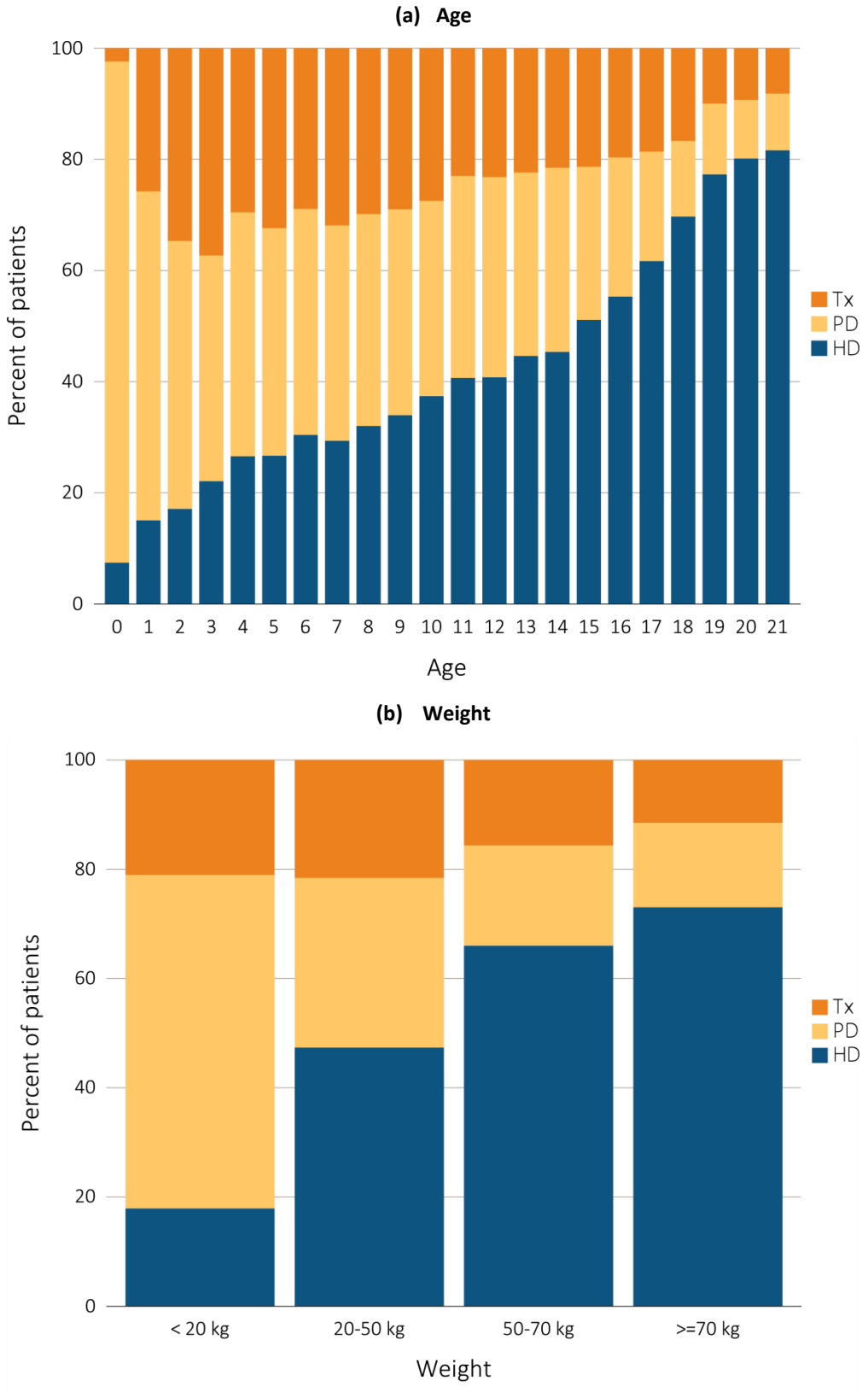
When examined by age, peritoneal dialysis is the most common initial ESRD treatment modality for children aged 9 years and younger (Figure 8.2.a). Hemodialysis becomes the most common initial modality for patients aged 9.5 years and older. Similarly, initial ESRD treatment modality is associated with patient weight. Peritoneal dialysis is most commonly the initial modality in small children weighing less than 20 kilograms (kg). Hemodialysis is the least common initiating modality in small children and increases in frequency with increasing patient weight (Figure 8.2.b). Kidney transplantation accounts for less than 40% of initial modality across all pediatric ages and weights but is the predominant prevalent ESRD treatment modality used in children. Of the 9,721 children and adolescents between the ages of 0 and 21 years with prevalent ESRD as of December 31, 2014, kidney transplant was the most common modality (6,825[70.2%]), followed by hemodialysis (1,745 [18.0%]) and peritoneal dialysis (1,122 [11.5%]) (Figure 8.1.b). Over 80% of prevalent children ages 5-13 have a kidney transplant. This equates to a point prevalence per million population of 18.5 for hemodialysis, 11.7 for peritoneal dialysis, and 69.8 for transplant.

vol 2 Figure 8.1 Number of (a) incident and (b) December 31 point prevalent ESRD pediatric patients (aged 0–21 years), by modality, 1996-2014



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 8.2 Cross-sectional trends in pediatric ESRD modality at initiation, by patient (a) age and (b) weight, 1996-2014



Data Source: Special analyses, USRDS ESRD Database. Includes incident ESRD patients in the years 1996-2014. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

Etiology

The underlying etiologies of ESRD are generated from the ESRD Medical Evidence form (CMS 2728) and summarized in Table 8.1. Patients have been classified using the updated format (see the section on Chapter 8 in *ESRD Analytical Methods* chapter for details). The leading causes of ESRD in children during 2010-2014 are as follows: primary glomerular disease (25.3%), CAKUT (congenital anomalies of the kidney and urinary tract) (24.1%), cystic/hereditary/congenital disorders (14.3%), and secondary glomerular disease (12.4%). The most common individual diagnoses associated with pediatric ESRD include renal hypoplasia/dysplasia (N=728), congenital obstructive uropathies (N=541), focal glomerular sclerosis (N=901), and systemic lupus erythematosus (N=489).

Figure 8.3 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 cause more ESRD in young children and primary and secondary glomerulonephritis and other etiologies become more common with advancing age. The distribution of ESRD etiology by age and year of onset of ESRD were consistent between incident years 2005-2009 and 2010-2014.

vol 2 Table 8.1 Distribution of reported incident pediatric ESRD patients by primary cause of ESRD (aged 0-21 years), and by demographic characteristics, 2005-2009 (period A) and 2010-2014 (period B)

	Total patients		% Incident		Median age		% Males		% White		% Black/ African American		% Other race		% Transplant first year		% Died first year	
Primary disease groups	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B
All ESRD, (reference)	8307	7570	100	100	16	16	56.6	56.4	65.4	66.0	25.3	24.1	9.3	9.9	37.4	36.0	3.6	2.7
Diabetes	103	93	1.4	1.4	20	20	43.7	40.9	52.4	40.9	42.7	54.8	4.9	4.3	14.6	10.8	8.7	5.4
Diabetes with renal manifestations Type 2	45	45	0.6	0.7	20	20	40	42.2	53.3	42.2	40	53.3	6.7	4.4	11.1	8.9	8.9	6.7
Diabetes with renal manifestations Type 1	58	48	0.8	0.7	20	20	46.6	39.6	51.7	39.6	44.8	56.3	3.4	4.2	17.2	12.5	8.6	4.2
Primary glomerular disease	1977	1702	26.4	25.3	18	18	55.5	55	61.3	64.3	32.1	28	6.6	7.7	32.2	30	1.6	1.6
Glomerulonephritis (GN) (histologically not examined)	398	303	5.3	4.5	19	19	63.3	59.7	67.8	69.3	24.4	20.1	7.8	10.6	23.4	20.5	2.5	1.3
Focal glomerulosclerosis, focal sclerosing GN	1018	901	13.6	13.4	17	17	55	55.8	52.2	58.8	42.9	35.7	4.9	5.4	35.4	29.1	1.7	1.8
Membranous nephropathy	50	36	0.7	0.5	18	19	50	69.4	54	52.8	40	41.7	6	5.6	28	44.4	0	0
Membranoproliferative GN type 1, diffuse MPGN	92	86	1.2	1.3	17	17	44.6	45.3	75	67.4	16.3	22.1	8.7	10.5	45.7	43	0	2.3
Dense deposit disease, MPGN type 2	31	28	0.4	0.4	16	15	51.6	50	100	75	0	10.7	0	14.3	32.3	7.1	3.2	0
IgA nephropathy, Berger's disease (proven by immunofluorescence)	212	204	2.8	3	19	19	63.7	59.8	72.2	77	17.5	10.3	10.4	12.7	35.8	40.7	0	2
IgM nephropathy (proven by immunofluorescence)	15	16	0.2	0.2	19	19	53.3	62.5	66.7	68.8	26.7	25	6.7	6.3	26.7	18.8	0	0
With lesion of rapidly progressive GN	61	54	0.8	0.8	16	16	37.7	20.4	72.1	74.1	13.1	20.4	14.8	5.6	11.5	27.8	1.6	1.9
Other proliferative GN	100	74	1.3	1.1	16	17	38	41.9	76	66.2	17	27	7	6.8	30	41.9	2	1.4
CAKUT	1694	1620	22.6	24.1	12	11	69.3	69.6	77.6	74.4	16.4	19.1	6	6.4	49.8	49.6	2.6	1.8
Congenital obstruction of ureteropelvic junction	54	50	0.7	0.7	13	15	79.6	74	72.2	72	22.2	22	5.6	6	44.4	46	1.9	2
Congenital obstruction of uretrovesical junction	56	50	0.7	0.7	14	14	85.7	82	76.8	72	21.4	18	1.8	10	50	44	0	2
Other Congenital obstructive uropathy	515	541	6.9	8	12	11	82.1	82.1	73.8	71	20.8	23.1	5.4	5.9	44.1	49.5	2.7	0.7
Renal hypoplasia, dysplasia, oligonephronia	753	728	10	10.8	10	10	62.7	61	77.6	75.3	15.8	18	6.6	6.7	51.4	50.1	3.1	2.3
Prune belly syndrome	92	77	1.2	1.1	8	5	97.8	98.7	80.4	63.6	17.4	29.9	2.2	6.5	57.6	46.8	2.2	1.3
Chronic pyelonephritis, reflux nephropathy	224	174	3	2.6	16	17	43.8	48.9	87.1	87.9	5.4	6.3	7.6	5.7	55.4	51.1	1.8	2.9
Secondary glomerular disease/Vasculitis	1081	834	14.4	12.4	18	18	31.9	27.6	51.2	54.3	40.9	39.1	7.9	6.6	12.8	13.8	6.9	3
Lupus erythematosus, (SLE nephritis)	649	489	8.7	7.3	19	19	20.5	19	38.8	38.2	50.8	54	10.3	7.8	6.5	4.9	8.3	2.9
Henoch-Schonlein syndrome	30	30	0.4	0.4	17	14	56.7	53.3	93.3	83.3	3.3	10	3.3	6.7	43.3	40	0	3.3
Hemolytic uremic syndrome	154	109	2.1	1.6	8	11	46.8	34.9	79.2	80.7	16.9	12.8	3.9	6.4	29.9	40.4	4.5	0.9
Polyarteritis and other vasculitis	41	44	0.5	0.7	15	15	48.8	25	63.4	86.4	24.4	9.1	12.2	4.5	12.2	22.7	0	2.3
Wegeners granulomatosis	59	59	0.8	0.9	16	17	44.1	47.5	84.7	76.3	11.9	16.9	3.4	6.8	28.8	16.9	0	1.7
Goodpasture syndrome	50	53	0.7	0.8	20	19	46	39.6	88	98.1	8	0	4	1.9	12	17	2	3.8
Secondary GN, other	26	18	0.3	0.3	18	19	65.4	27.8	76.9	77.8	19.2	16.7	3.8	5.6	26.9	33.3	7.7	0
AIDS nephropathy	63	26	0.8	0.4	19	20	54	57.7	11.1	3.8	87.3	96.2	1.6	0	1.6	0	15.9	15.4

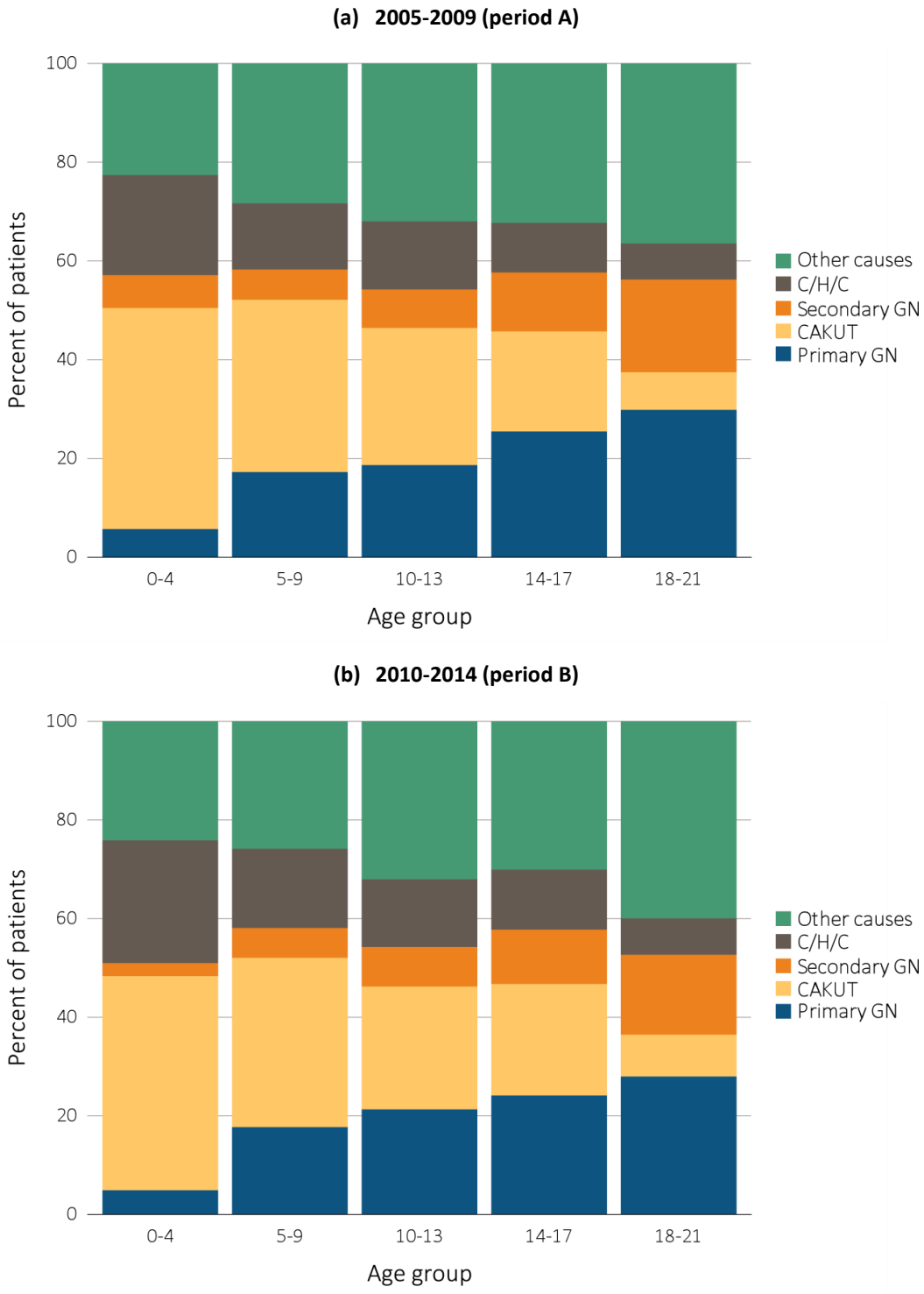
Table 8.1 continued on next page.

vol 2 Table 8.1 Distribution of reported incident pediatric ESRD patients by primary cause of ESRD (aged 0-21 years), and by demographic characteristics, 2005-2009 (period A) and 2010-2014 (period B) *(continued)*

	Total patients		% Incident		Median age		% Males		% White		% Black/ African American		% Other race		% Transplant first year		% Died first year	
Primary disease groups	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B
Interstitial nephritis/Pyelonephritis	338	281	4.5	4.2	17	16	54.7	55.2	76.9	76.9	18.3	14.2	4.7	8.9	29.3	31	6.8	8.2
Nephropathy caused by other agents	47	39	0.6	0.6	17	15	53.2	56.4	87.2	82.1	12.8	7.7	0	10.3	40.4	30.8	17	5.1
Nephrolithiasis	21	16	0.3	0.2	18	14	42.9	25	85.7	81.3	9.5	12.5	4.8	6.3	57.1	68.8	0	12.5
Chronic interstitial nephritis	80	73	1.1	1.1	17	17	60	53.4	76.3	76.7	20	13.7	3.8	9.6	50	45.2	2.5	4.1
Tubular necrosis (no recovery)	167	138	2.2	2.1	15	14	55.1	57.2	75.4	75.4	18.6	15.9	6	8.7	15.6	18.1	7.2	10.9
Hypertensive/Large vessel disease	16	15	0.2	0.2	14	14	56.3	53.3	81.3	86.7	6.3	13.3	12.5	0	43.8	26.7	6.3	0
Cystic/Hereditary/Congenital diseases	910	959	12.1	14.3	14	13	58.8	59.2	78.2	76.9	16.9	15.8	4.8	7.3	54.4	47	4	3.3
Polycystic kidneys, adult type (dominant)	49	48	0.7	0.7	19	18	44.9	45.8	77.6	79.2	20.4	18.8	2	2.1	44.9	43.8	2	2.1
Polycystic, infantile (recessive)	141	152	1.9	2.3	7	1	52.5	46.1	80.1	75.7	16.3	17.1	3.5	7.2	48.9	40.1	12.1	6.6
Medullary cystic disease, including nephronophthisis	102	115	1.4	1.7	13	12	38.2	46.1	87.3	80.9	5.9	11.3	6.9	7.8	71.6	67.8	0	1.7
Hereditary nephritis, Alport syndrome	185	165	2.5	2.5	17	17	86.5	85.5	69.7	78.2	23.8	15.2	6.5	6.7	50.3	48.5	0	0
Cystinosis	68	43	0.9	0.6	13	12	47.1	60.5	95.6	83.7	4.4	11.6	0	4.7	79.4	67.4	0	0
Primary oxalosis	19	16	0.3	0.2	6	7	52.6	81.3	78.9	75	10.5	0	10.5	25	63.2	56.3	5.3	6.3
Congenital nephrotic syndrome	123	138	1.6	2.1	2	3	56.9	52.2	80.5	81.2	14.6	12.3	4.9	6.5	58.5	39.1	5.7	3.6
Drash syndrome, mesangial sclerosis	18	31	0.2	0.5	1	1	61.1	48.4	77.8	80.6	16.7	16.1	5.6	3.2	44.4	25.8	5.6	3.2
Other (congenital malformation syndromes)	168	222	2.2	3.3	15	13	56	62.2	84.5	77.9	10.1	12.2	5.4	9.9	52.4	46.8	2.4	4.5
Sickle cell disease/anemia	26	19	0.3	0.3	19	20	69.2	68.4	7.7	0	88.5	100	3.8	0	11.5	15.8	19.2	10.5
Neoplasms/Tumors	50	51	0.7	0.8	8	10	46	45.1	70	76.5	18	13.7	12	9.8	16	21.6	28	9.8
Renal tumor	37	41	0.5	0.6	5	5	45.9	41.5	67.6	73.2	21.6	17.1	10.8	9.8	16.2	22	21.6	9.8
Transplant complications	148	84	2	1.2	16	17	55.4	56	77	69	14.9	21.4	8.1	9.5	46.6	26.2	14.2	14.3
Other transplant complication	94	73	1.3	1.1	15	16	56.4	56.2	76.6	68.5	16	23.3	7.4	8.2	37.2	23.3	20.2	15.1
Kidney transplant complication	48	*	0.6	0.1	16	19	56.3	50	77.1	83.3	14.6	0	8.3	16.7	62.5	50	0	0
Miscellaneous conditions	812	849	10.8	12.6	19	19	62.4	60.1	60.5	60.4	33.7	32.2	5.8	7.4	30.4	24.3	3.4	2.7
Acquired obstructive uropathy	54	42	0.7	0.6	17	16	77.8	69	75.9	78.6	18.5	14.3	5.6	7.1	40.7	35.7	0	0
Unspecified with renal failure	495	517	6.6	7.7	20	20	62.4	63.1	50.1	50.1	45.1	44.9	4.8	5	17.8	11.8	2	2.9
Traumatic or surgical loss of kidney(s)	15	11	0.2	0.2	9	12	66.7	54.5	80	54.5	13.3	18.2	6.7	27.3	53.3	9.1	13.3	18.2
Other renal disorders	244	272	3.3	4	15	14	59.4	52.9	76.6	77.9	15.6	11.8	7.8	10.3	52.9	46	5.3	2.2
Etiology uncertain	942	714	12.6	10.6	16	16	58	55.5	68.9	69	18	17.1	13.1	13.9	34.7	33.1	1.6	1.4
Missing	236	368	3.1	5.5	14	15	64.8	62	9.7	36.7	4.7	12.5	85.6	50.8	94.9	73.1	0.8	2.4

Data Source: Special analyses, USRDS ESRD Database. Abbreviations: AIDS, acquired-immune deficiency syndrome; CAKUT, congenital anomalies of the kidney and urinary tract; congenital obstructive uropathy, combination of congenital ureteropelvic junction obstruction, congenital uretrovesical junction obstruction, and other congenital anomalies; ESRD, end-stage renal disease; GN glomerulonephritis; IgA immunoglobulin A; IgM, immunoglobulin M; incl., including; MPGN, membranoproliferative glomerulonephritis; SBE, sub-acute bacterial endocarditis. Diagnoses with 10 or fewer total patients for year categories are suppressed.

vol 2 Figure 8.3 Distribution of reported incident pediatric ESRD patients by primary cause of ESRD, by age (a) 2005-2009 (period A) and (b) 2010-2014 (period B)



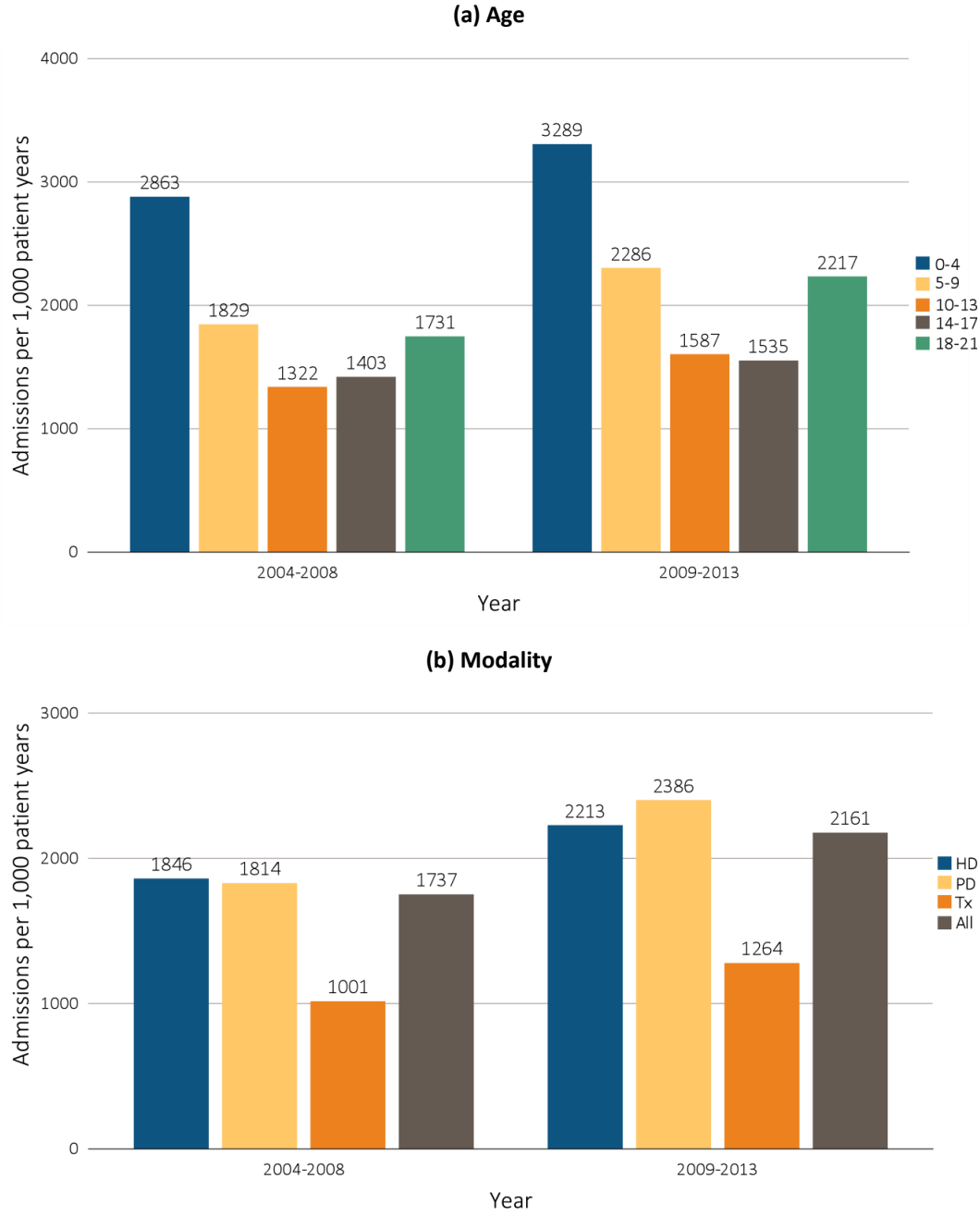
Data Source: Special analyses, USRDS ESRD Database. Abbreviations: CAKUT, congenital anomalies of the kidney and urinary tract; C/H/C, cystic/hereditary/congenital diseases; ESRD, end-stage renal disease; GN, glomerulonephritis.

Hospitalizations in Children With Incident ESRD

The one-year adjusted all-cause hospitalization rates by age (Figure 8.4.a) from 2004-2008 and 2009-2013 were highest in the youngest segment of children with incident ESRD (0-4 years of age). The rates of hospitalization rose in each incident age group during the 2009-2013 time frame compared with the prior four-year period. The one-year adjusted all-cause hospitalization rates in all incident children on renal

replacement therapy (Figure 8.4.b) rose 24.4% from 1,737 to 2,161 admissions per 1,000 patient years. The one-year adjusted all-cause hospitalization rates rose for all modalities in incident patients as follows: hemodialysis by 19.9%, peritoneal dialysis by 31.5%, and transplant by 26.3% from one period to the next.

vol 2 Figure 8.4 One-year adjusted all-cause hospitalization rates in incident pediatric patients (aged 0-21 years), by (a) age and (b) modality, 2004-2008 and 2009-2013

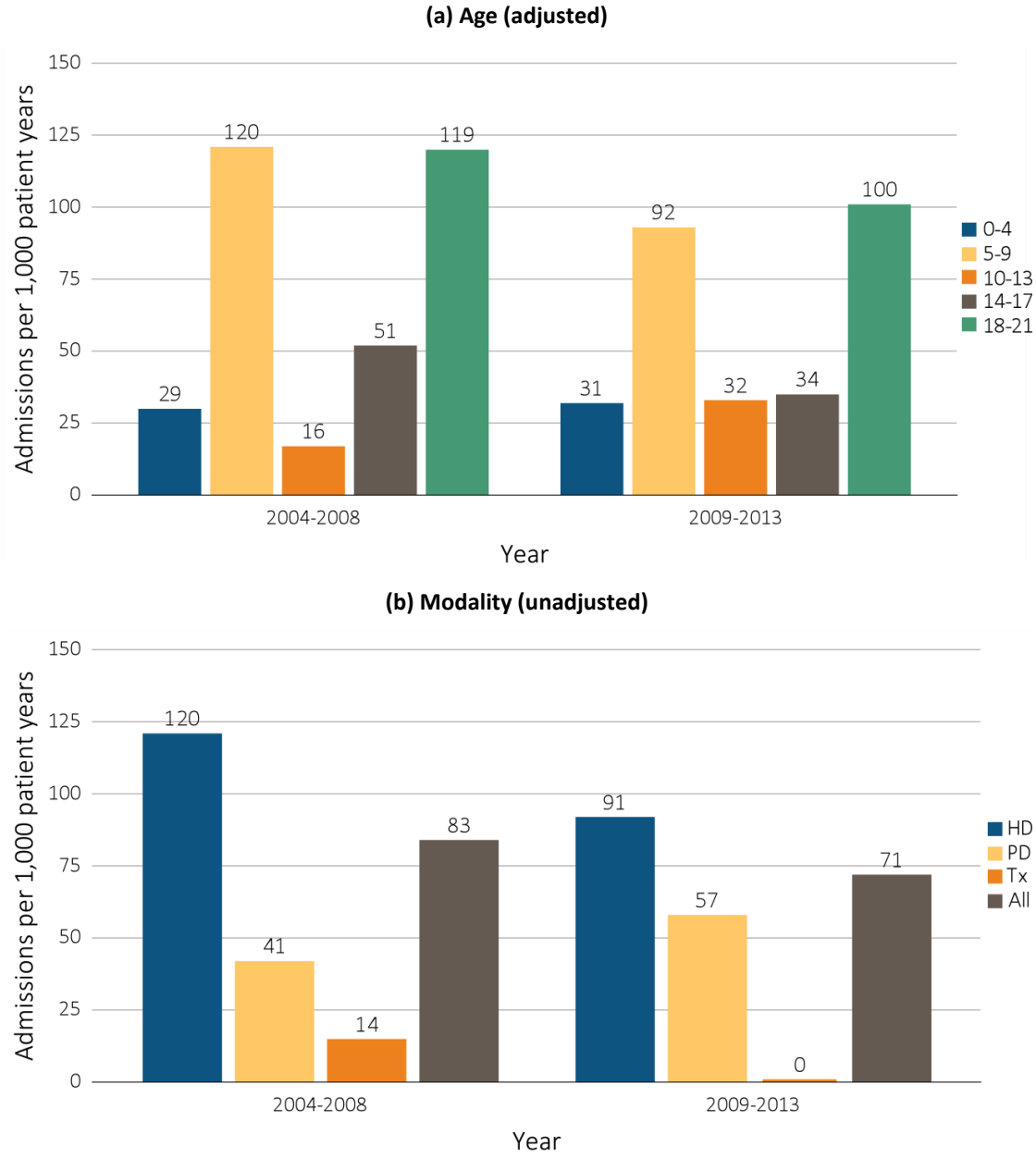


Data Source: Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2004-2013, surviving the first 90 days after ESRD initiation and followed from day 90. Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

While accounting for a minority of hospitalizations in children with incident ESRD, we report the cardiovascular disease and infection associated hospitalizations for consistency with previous ADR pediatric chapters and to align with two leading causes of ESRD associated mortality in children. Using

the newly defined cardiovascular diagnosis codes (for definition of terms, see the section on Chapter 8 in the *ESRD Analytical Methods* chapter), cardiovascular hospitalizations are substantially different in frequency with the increased precision in case definition. In total, the one-year cardiovascular hospitalization rates per 1,000 patient-years for children less than 22 years of age with incident ESRD was 85 from 2004-2008 and 71 from 2009-2013 (Figure 8.5.b). The highest rates of cardiovascular hospitalizations in incident patients were observed in children aged 5-9 and 18-21 years (Figure 8.5.a) and in children treated with hemodialysis (Figure 8.5.b).

vol 2 Figure 8.5 One-year cardiovascular hospitalization rates in incident pediatric patients (aged 0-21 years), by (a) age and (b) modality, 2004-2008 and 2009-2013

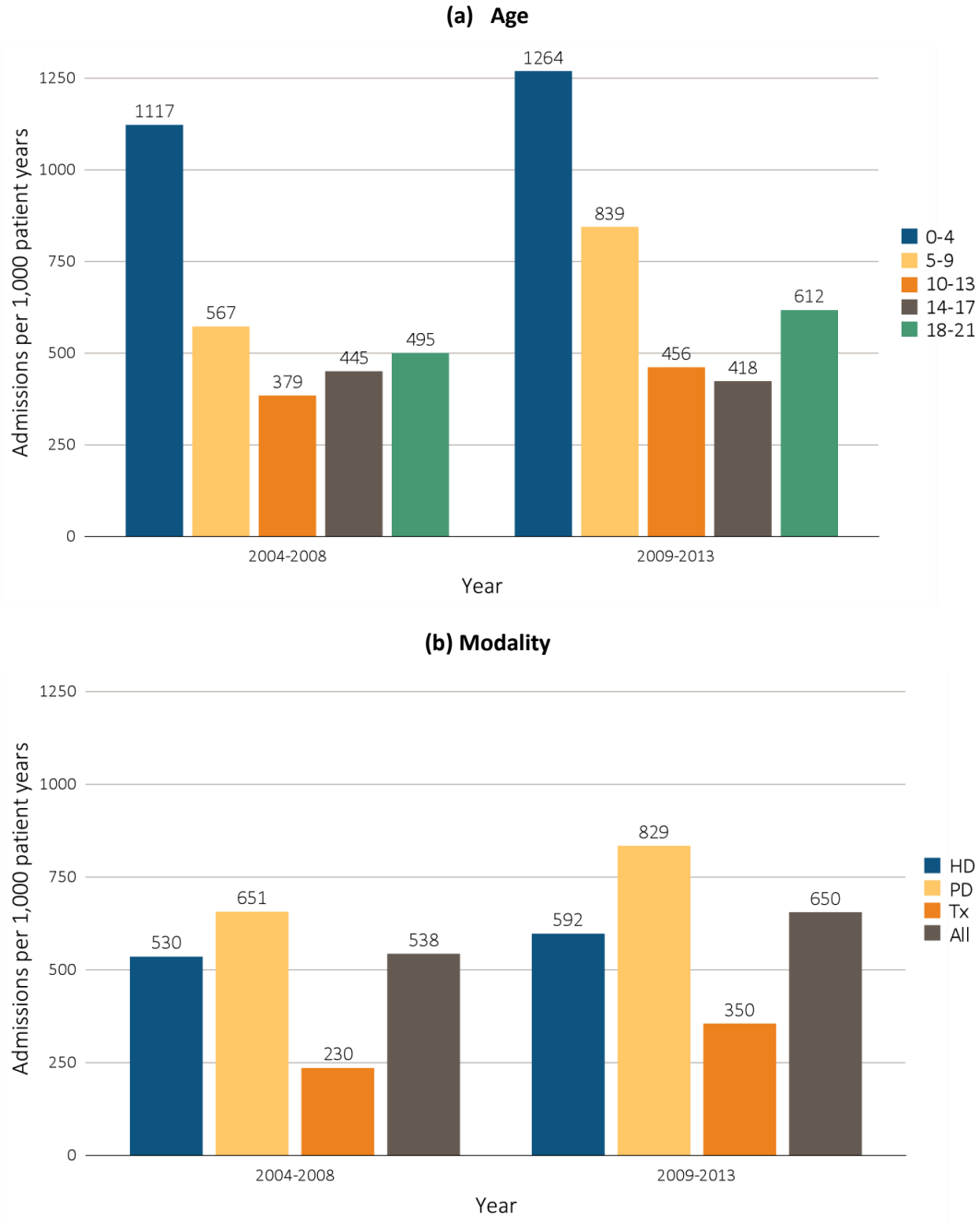


Data Source: Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2004-2013, surviving the first 90 days after ESRD initiation and followed from day 90. Reference population: incident ESRD patients aged 0-21, 2010-2011. (a) Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. (b) Unadjusted. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

The overall rate of hospitalization for infection was 650 admissions per 1,000 patient years during 2009-2013, which is 20.8% higher than during 2004-2008 (Figure 8.6.b). The rates of infection-related hospitalizations

rose by 13.2% in children aged 0-4 years, 48.0% in those aged 5-9 years, 20.3% in those aged 10-13 years, and 23.6% in those aged 18-21 years (Figure 8.6.a). Children between 14-17 years of age represented the only improvement in infection-related hospitalizations, decreasing 6.1% during the most recent time period (2009-2013) compared with 2004-2008. In examining modality, children on peritoneal dialysis had the highest rate of infection-related hospitalizations during 2004-2008 and 2009-2013 (Figure 8.6.b). However, during this time period there was an increase in infection-related hospitalization rates in each modality of renal replacement therapy (hemodialysis 11.7%, peritoneal dialysis 27.3%, transplantation 52.2%).

vol 2 Figure 8.6 One-year adjusted hospitalization rates for infection in incident pediatric patients (aged 0-21 years), by (a) age and (b) modality, 2004-2008 and 2009-2013



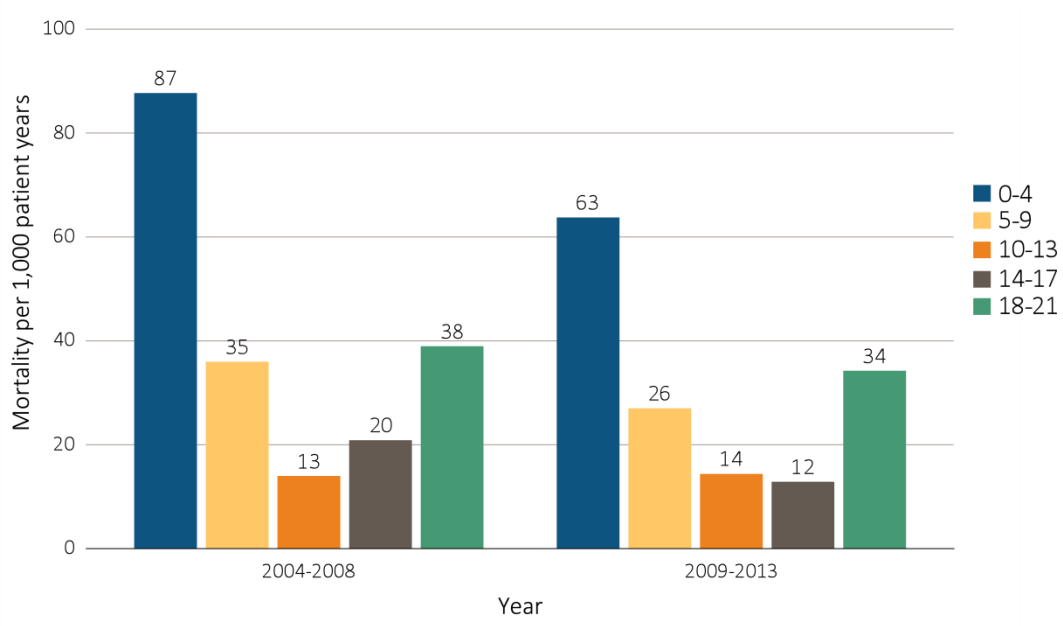
Data Source: Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2004-2013, surviving the first 90 days after ESRD initiation and followed from day 90. Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

Mortality

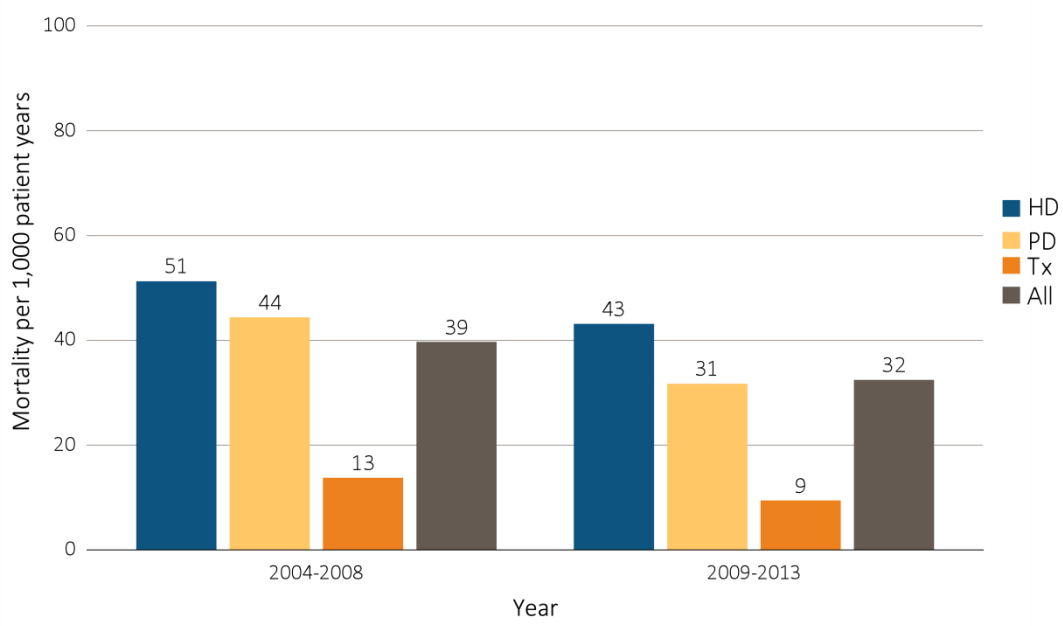
During 2009-2013, the one-year adjusted all-cause mortality rate was 32 per 1,000 patient years, which represents a decrease of 17.9% from the 39 per 1,000 patient years rate in 2004-2008 (Figure 8.7.b). The adjusted one-year all-cause mortality rates decreased in all age categories except for those aged 10-13 years (Figure 8.7.a). Adjusted one-year all-cause mortality rates by modality from 2004-2008 and 2009-2013 show decreases of 15.7% among hemodialysis patients, 29.5% among peritoneal dialysis patients, and 30.8% among transplant patients (Figure 8.7.b). Transplant-associated mortality continues to remain low.

vol 2 Figure 8.7 One-year adjusted all-cause mortality rates in incident pediatric patients with ESRD (aged 0-21 years), by (a) age and (b) modality, 2004-2008 and 2009-2013

(a) Age



(b) Modality

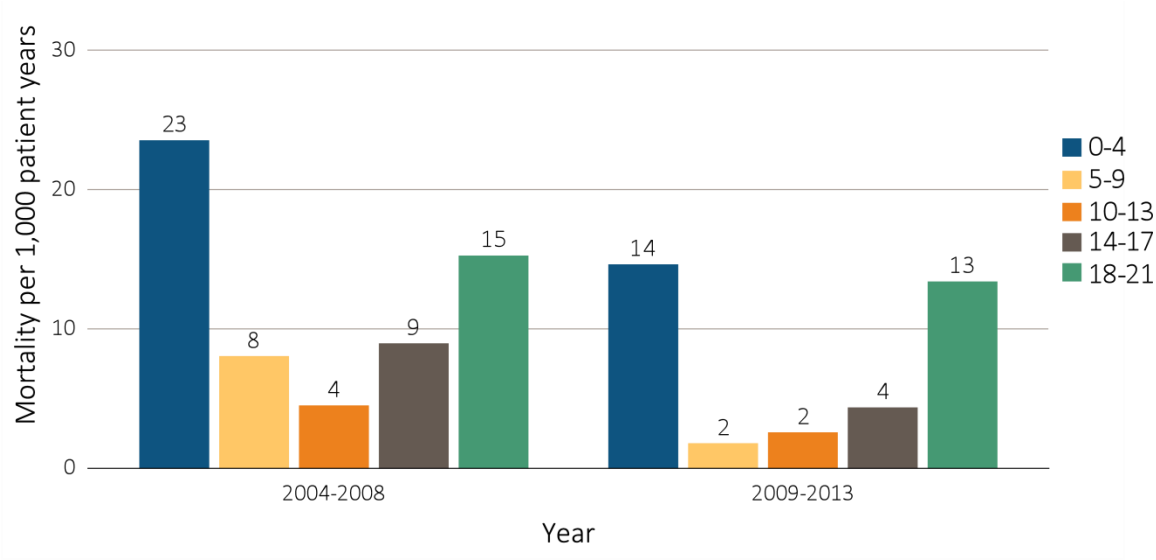


Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2014. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

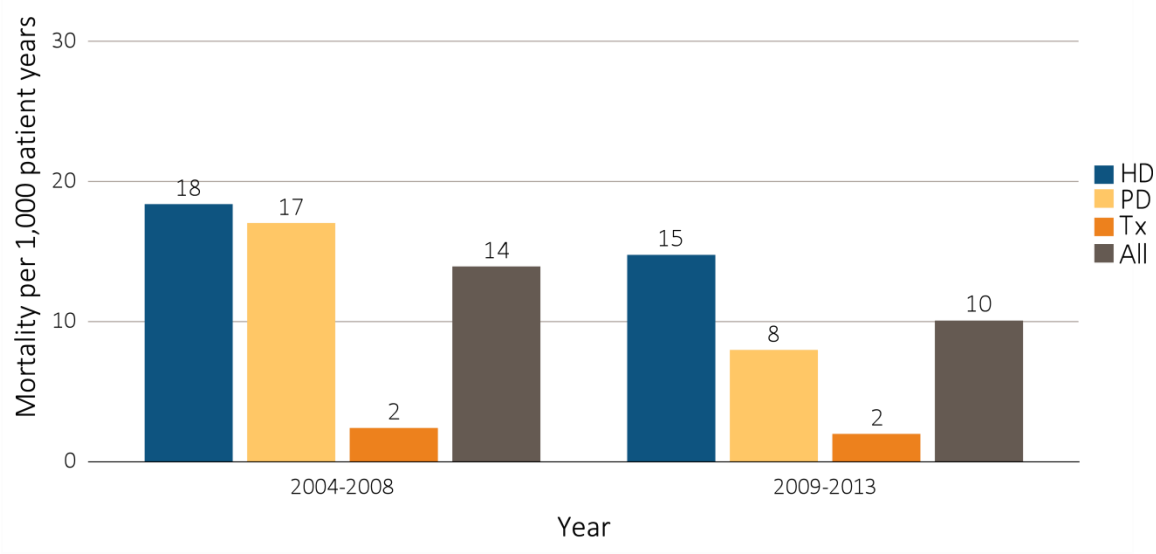
During 2009-2013, the one-year adjusted cardiovascular mortality rate was 10 per 1,000 patient years, which was a decrease of 28.6% from the 2004-2008 period (Figure 8.8.b). The adjusted one-year cardiovascular mortality rate decreased across all age groups: 0-4 years by 39.1%, 5-9 years by 75%, 10-13 years by 50%, 14-17 years by 55.6%, and 18-21 years by 13.3% (Figure 8.8.a). Compared to other pediatric age groups, children aged 0-4 years continued to have the highest adjusted one-year cardiovascular mortality. Examining adjusted one-year cardiovascular mortality across the periods 2004-2008 and 2009-2013 by modality, the rate decreased by 16.7% in hemodialysis, 52.9% in peritoneal dialysis, and was unchanged and quite low in transplant patients (Figure 8.8.b).

vol 2 Figure 8.8 One-year adjusted cardiovascular mortality rates in incident pediatric patients with ESRD (aged 0-21 years), by (a) age and (b) modality, 2004-2008 and 2009-2013

(a) Age



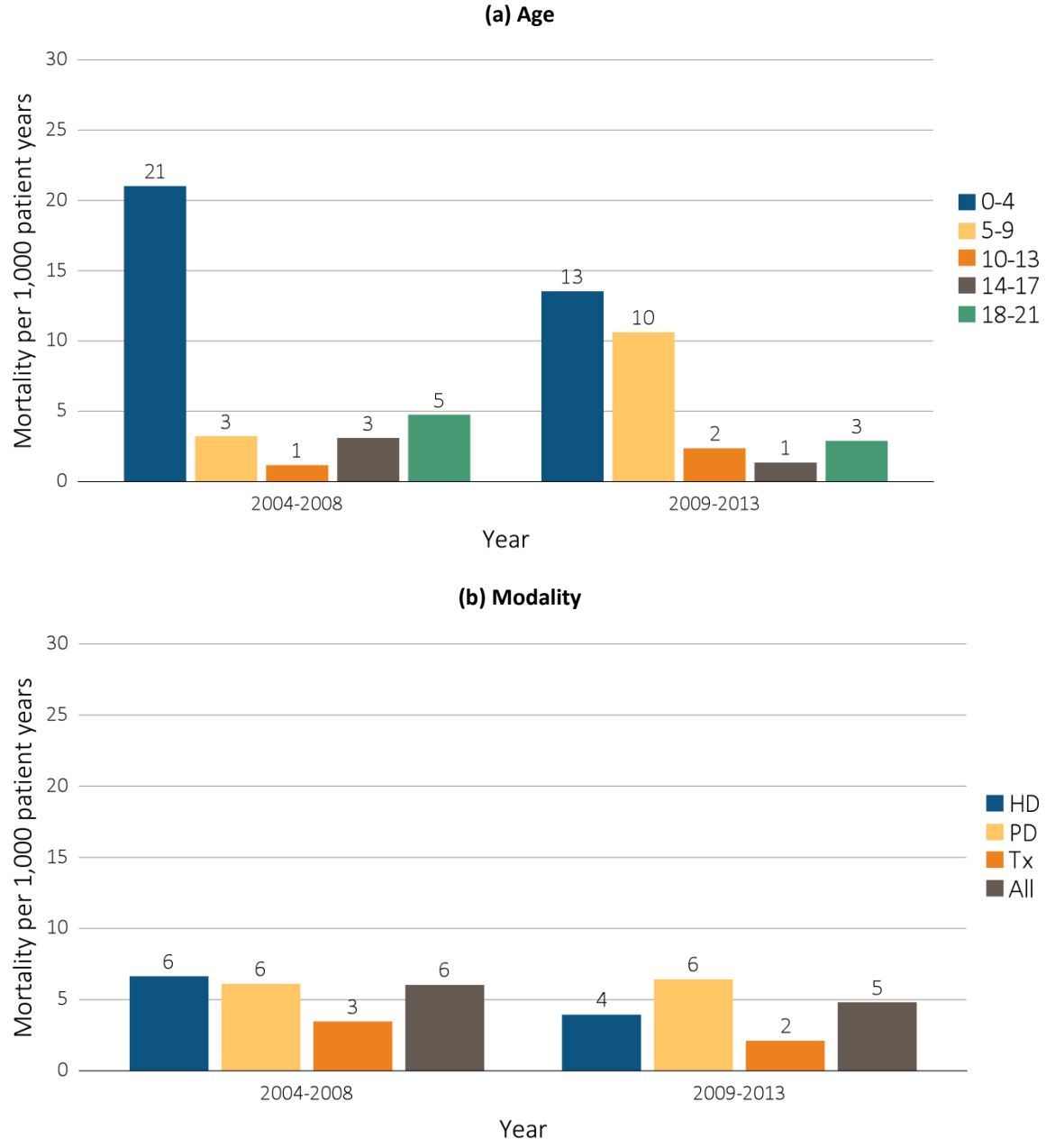
(b) Modality



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, 2014. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

During 2009-2013, the one-year adjusted infection-related mortality rate decreased from 6 to 5 per 1,000 patient years when compared to the 2004-2008 period (Figure 8.9.b). The adjusted one-year infection-related mortality rate decreased in those aged 0-4 years by 38.1% (Figure 8.9.a). There was a rise in the rate of infection-related mortality in children aged 5-9 years, but the overall rates remained low in the remaining groups. Those 0-4 years of age continued to have the highest adjusted one-year infection-related mortality rate. By modality, the one-year infection-related mortality rate ranges from 2 to 6 per 1,000 patient years in children with incident ESRD during 2009-2013 (Figure 8.9.b). Overall cardiovascular mortality rates continue to exceed infection-related mortality rates in children with ESRD.

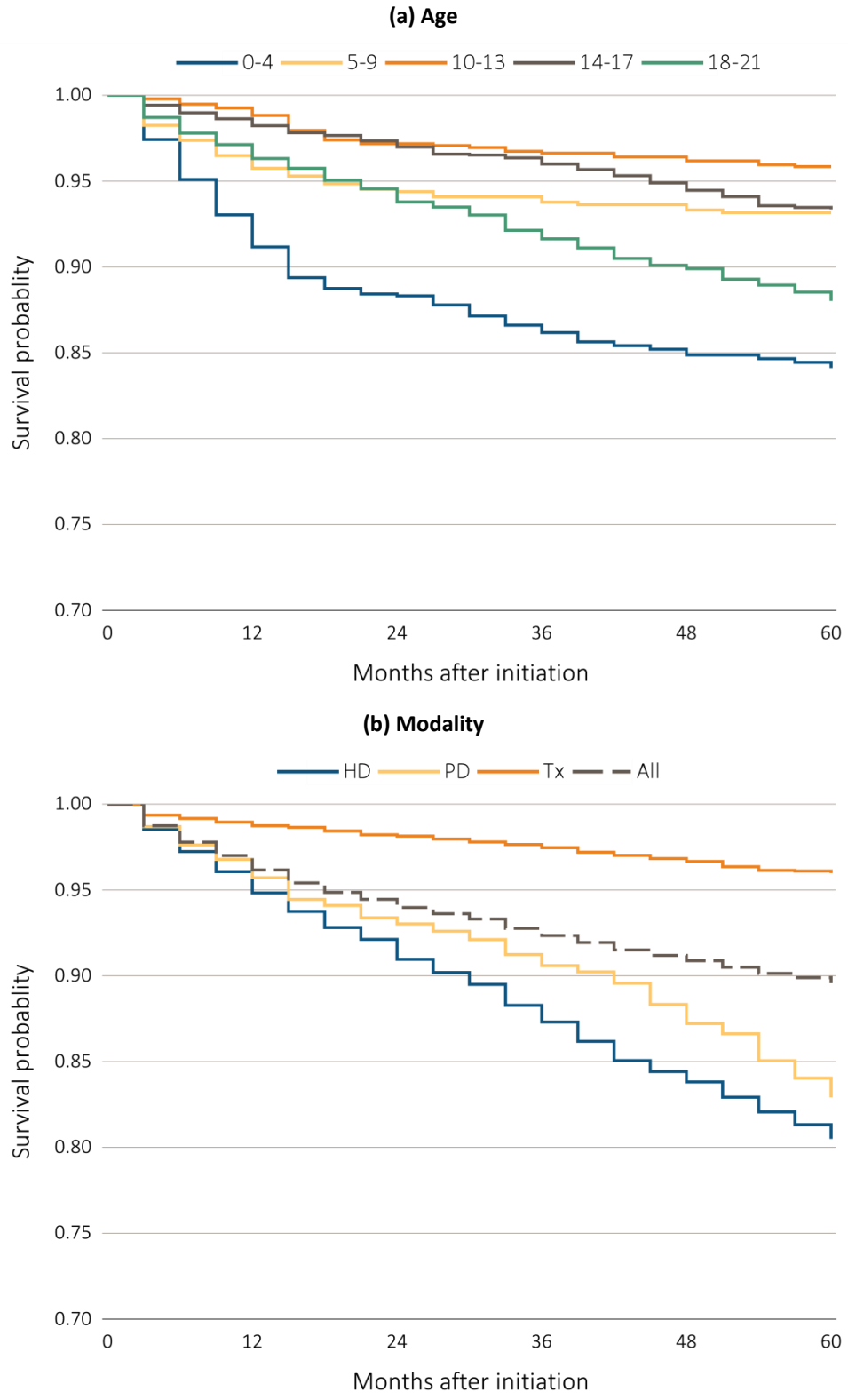
vol 2 Figure 8.9 One-year adjusted rates of mortality due to infection in incident pediatric patients with ESRD (aged 0-21 years), by (a) age and (b) modality, 2004-2008 and 2009-2013



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, 2014. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. 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 2005-2009, the probability of five-year survival was 0.90 (Figure 8.10.b). The probability of surviving five years by age was 0.84 for ages 0-4, 0.93 for ages 5-9, 0.96 for ages 10-13, 0.93 for ages 14-17, and 0.88 for ages 18-21 years (Figure 8.10.a). Mortality is most common in the initial year of ESRD care for children 0-4 years of age. Patients initiating ESRD care with transplantation had the highest probability of surviving five years, with a probability of 0.96, as compared to 0.81 with hemodialysis, and 0.83 with peritoneal dialysis (Figure 8.10.b).

vol 2 Figure 8.10 Adjusted five-year survival in incident pediatric patients (aged 0-21 years) from day 1, by (a) age and (b) modality, 2005-2009



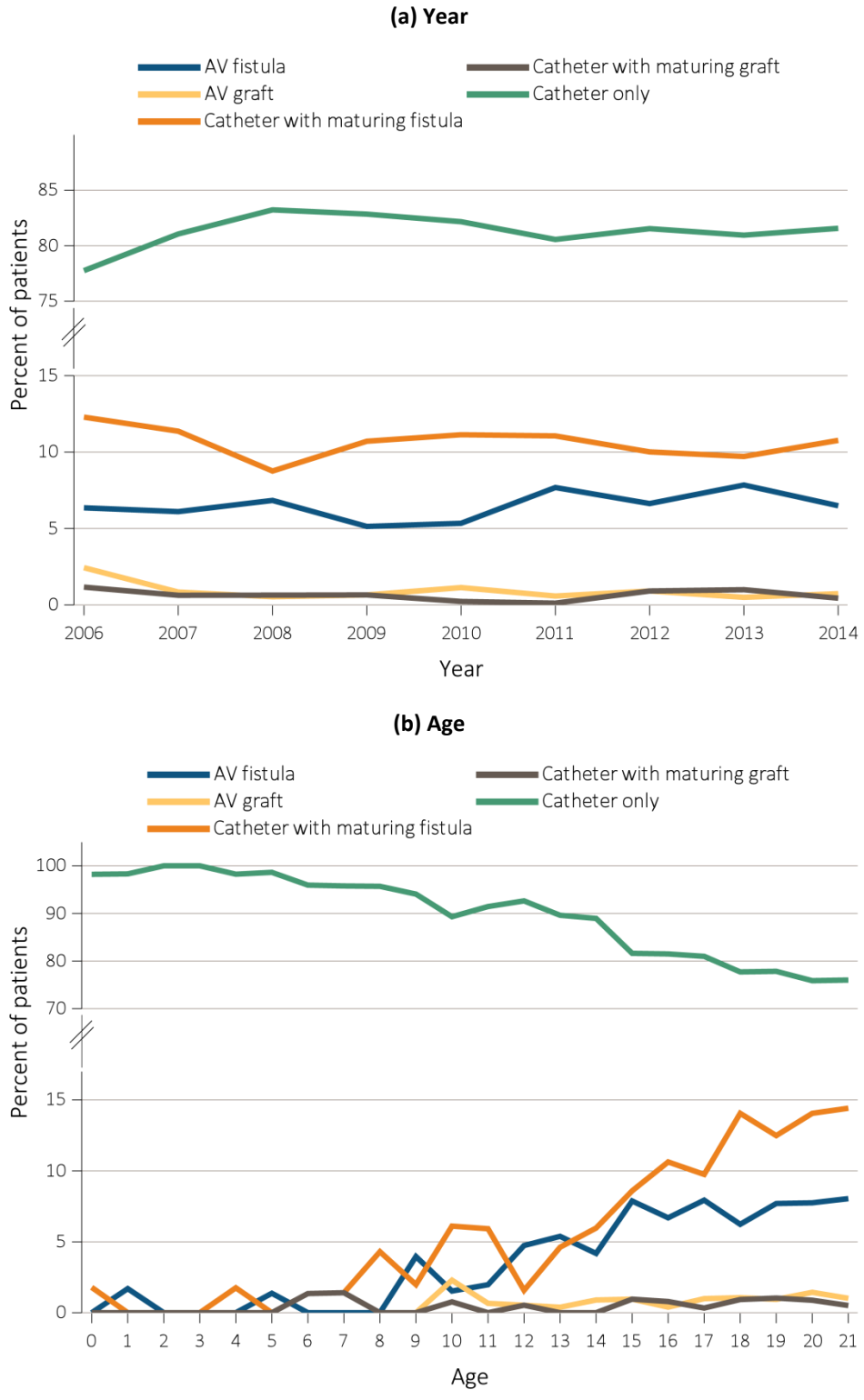
Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2014. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

Vascular Access

The decisions and approach to vascular access in ESRD patients impact both immediate and future patient outcomes. Due to the potential short- and long-term consequences that central venous catheter (hereafter, catheter) use can 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 hemodialysis patients. Vascular access in pediatric ESRD patients is approached differently than vascular access in adult ESRD patients due to factors such as anatomical differences, transplant waiting times, and transplant rates. The technical challenge of accessing vessels in small children and an expected short waiting time until a kidney transplant becomes available may influence the vascular access experience in children with ESRD. Since 2006, approximately 81% of incident pediatric ESRD patients have started hemodialysis with a catheter (ranging from 77.8% to 83.2%) (Figure 8.11.a). The initiation of hemodialysis with a catheter is observed in the majority of children and adolescents between the ages of 0 and 21 years (Figure 8.11.b). Beginning at age 8 years of age, catheters with a maturing fistula and fistula alone become increasingly more common with advancing age of hemodialysis initiation.

The trends in initial vascular access remain stable despite concerted efforts, such as the Fistula First Breakthrough Initiative, to increase the utilization of arteriovenous (AV) fistulas in pediatric patients. The explanation for this dichotomy may stem from an expected short waiting time for children on the transplant list.

vol 2 Figure 8.11 Vascular access type at initiation of incident pediatric hemodialysis patients (aged 0-21 years) by (a) year and (b) age, 2006-2014

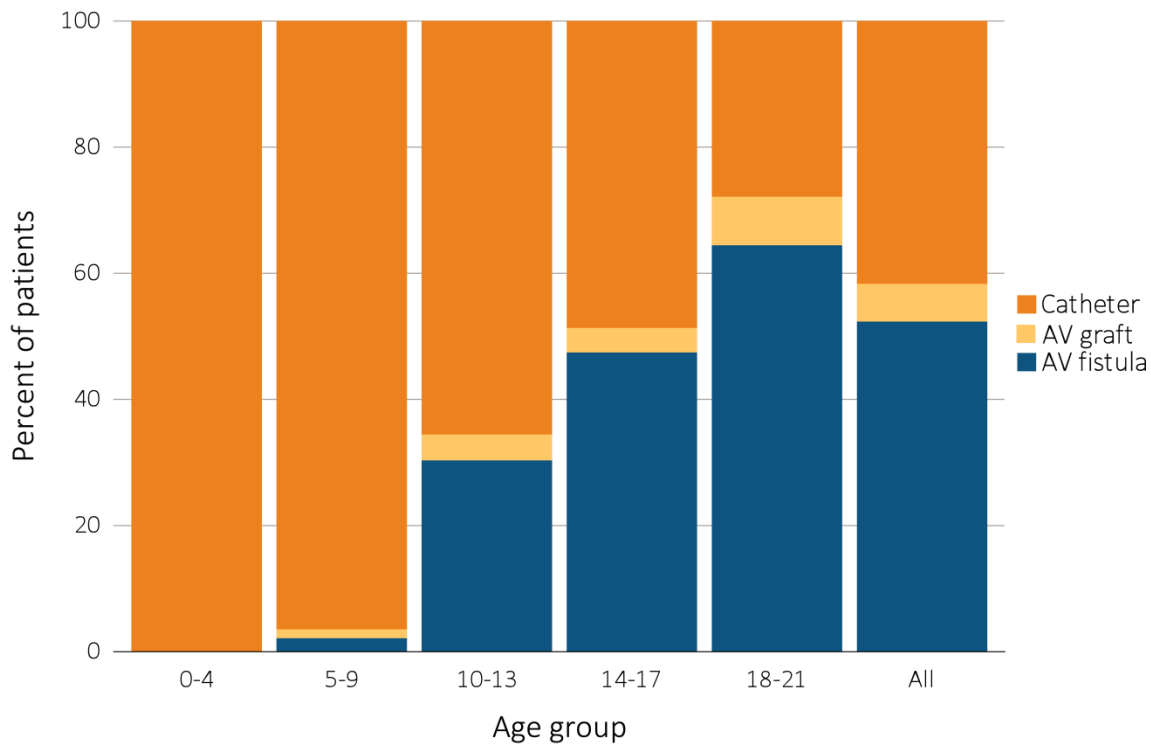


Data Source: Special analyses, USRDS ESRD Database. ESRD patients initiating hemodialysis in 2006-2014. Abbreviations: AV, arteriovenous; ESRD, end-stage renal disease.

When vascular access is examined in prevalent hemodialysis patients, there are higher rates of AV fistula and AV graft utilization in children aged 10-13 (35%), 14-17 (52%), and 18-21 (73%) than in children under age 10. (Figure 8.12).

A cross-sectional analysis of point prevalent ESRD patients aged 0-21 years in December 2015 shows that 58.9% of patients had AV fistula or AV graft as their type of vascular access (Figure 8.12). Age continues to strongly predict the type of vascular access in use. There is a stepwise increase in the utilization of AV fistula or AV graft for vascular access that parallels the increase in patient age, with the highest rates in older children, including 51.9% for those aged 14-17 and 72.7% for those aged 18-21 years. Also, when examining race and etiology of ESRD (figures not shown), there were subtle differences in vascular access in the prevalent patients in unadjusted analysis. Blacks/African Americans (hereafter, Blacks) had a higher proportion of AV graft use (8.8%) when compared to other races (white 4.3%, and other 5.7%). Whites and Blacks had lower use of central venous catheters only when compared to other races (41.7%, 39.7%, vs. 44.3%, respectively). Overall, patients with primary and secondary glomerulonephritis as the etiology of ESRD had a higher proportion of surgical access in place (AV fistula 57% or graft 21%) when compared to all other etiologies (AV fistula 51% or graft 5%) in unadjusted analysis.

vol 2 Figure 8.12 Distribution of vascular access type in prevalent pediatric hemodialysis patients (aged 0-21 years* as of December 31, 2015), 2015



*Data Source: Special analyses, USRDS ESRD Database. Hemodialysis patients initiating treatment for ESRD at least 90 days prior to December 1, 2015, *who were <22 years old as December 1, 2015, and who were alive through December 31, 2015; 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

Overall, 36.0% of children received a kidney transplant within the first year of ESRD care during 2010-2014 (Table 8.1), including 37.5% of children with weight greater than 10 kg. In 2014 the rate of transplants was 32.1 per 100 dialysis patient years, which has remained stable since 2007 (Figure 8.13.a).

A total of 1,321 children were wait-listed for a kidney transplant in 2014, including 896 patients listed for the first time and 425 patients listed for repeat transplant. The number of patients awaiting a kidney transplant has ranged from 1,233 to 1,391 since 2004 (Figure 8.13.b). Since 1997, there has been a decrease in the median waiting time for those listed for their first transplant with a flattening of the curve in 2005, which coincides with the change in the OPTN organ allocation policy. The median waiting time for patients receiving their first kidney transplant has ranged between 150-220 days. Over the same time period, 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.

A total of 1,018 children received a kidney transplant in 2014 (Figure 8.13.c). Kidney grafts in pediatric transplant recipients were most commonly from living donors prior to 2005. There has been a decline in the number of pediatric patients receiving living donor kidneys since 2009. In 2014, living donors accounted for 40.0% of kidney transplants, which is a 2.1% decrease from 2013 and a 21% decrease since 2009.

vol 2 Figure 8.13 Trends in pediatric transplantation (aged 0-21 years), by (a) ESRD incident and kidney transplant rates, (b) pediatric patient transplant counts and kidney transplant waiting list times, and (c) kidney transplant counts, (d) kidney transplant counts, patients 0-17 years, (e) kidney transplant counts, patients 18-21 years, 1996-2014

(a) ESRD incident and kidney transplant rates

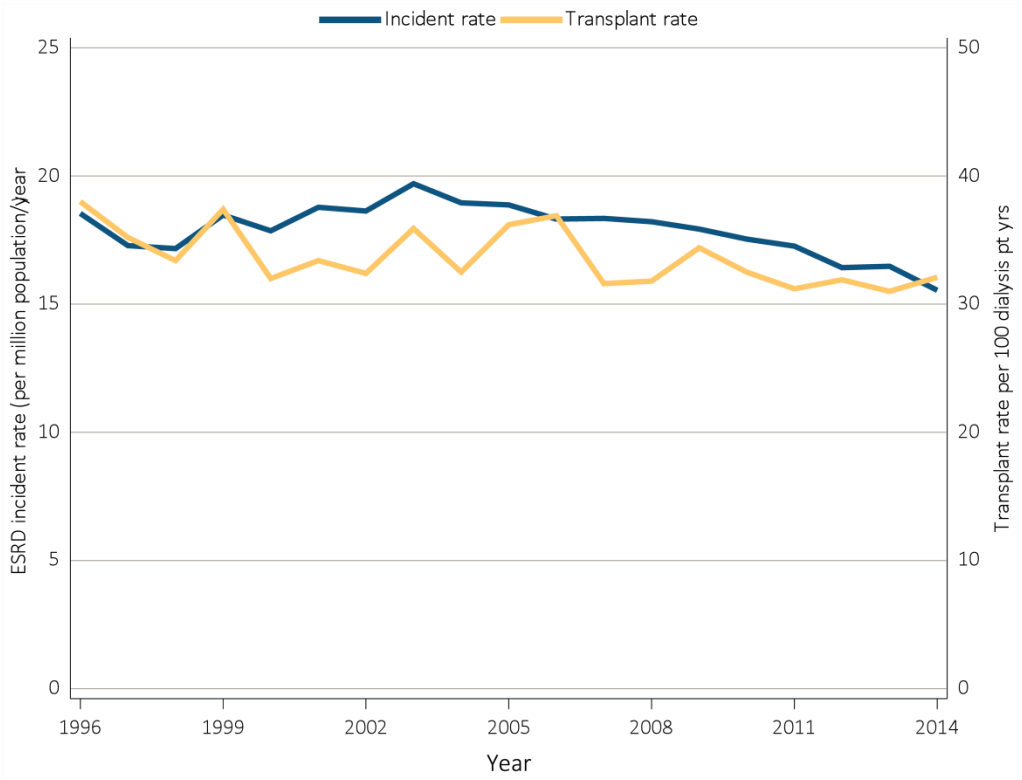
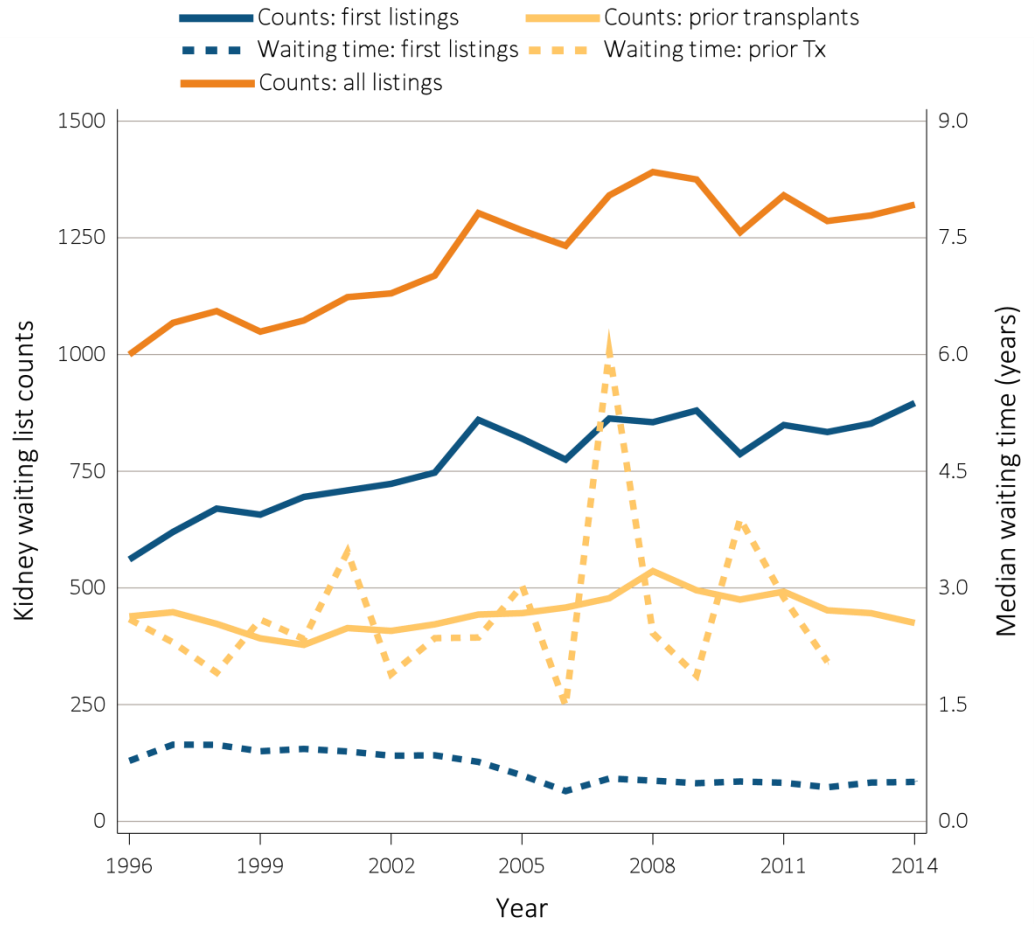


Figure 8.13 continued on next page.

vol 2 Figure 8.13 Trends in pediatric transplantation (aged 0-21 years), by (a) ESRD incident and kidney transplant rates, (b) pediatric patient transplant counts and kidney transplant waiting list times, and (c) kidney transplant counts, (d) kidney transplant counts, patients 0-17 years, (e) kidney transplant counts, patients 18-21 years, 1996-2014 *(continued)*

(b) pediatric patient transplant counts and kidney transplant waiting list times



(c) kidney transplant counts

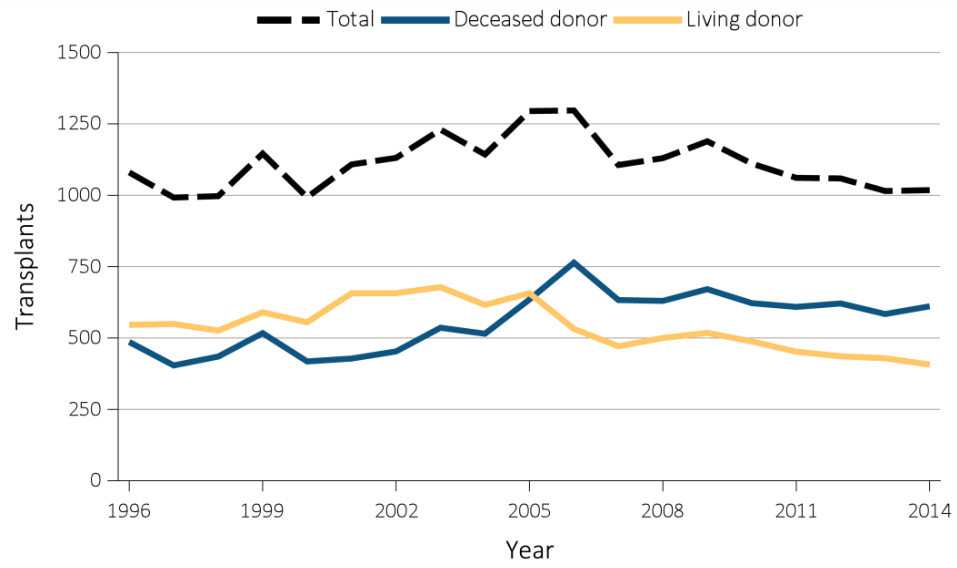
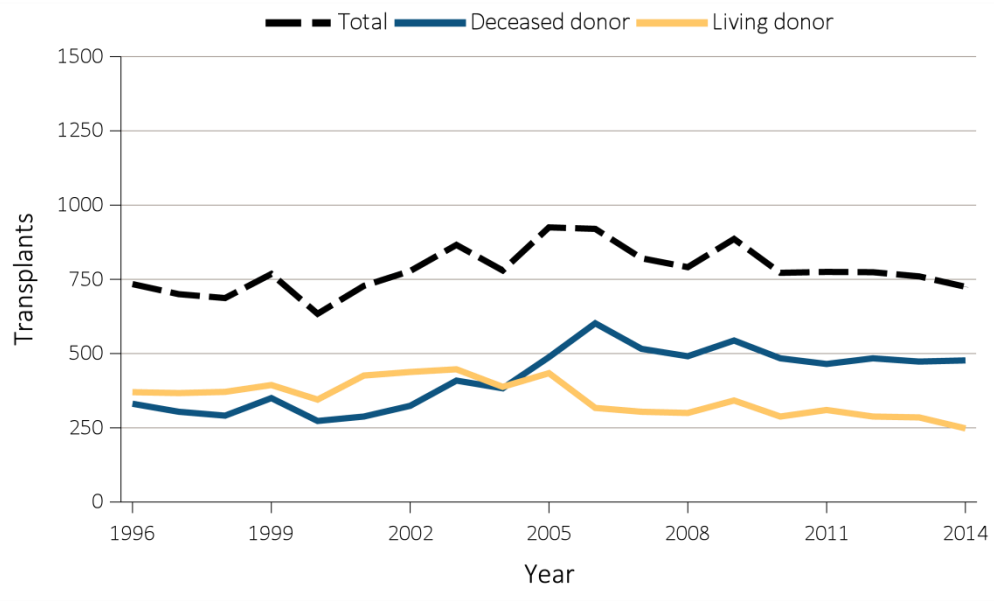


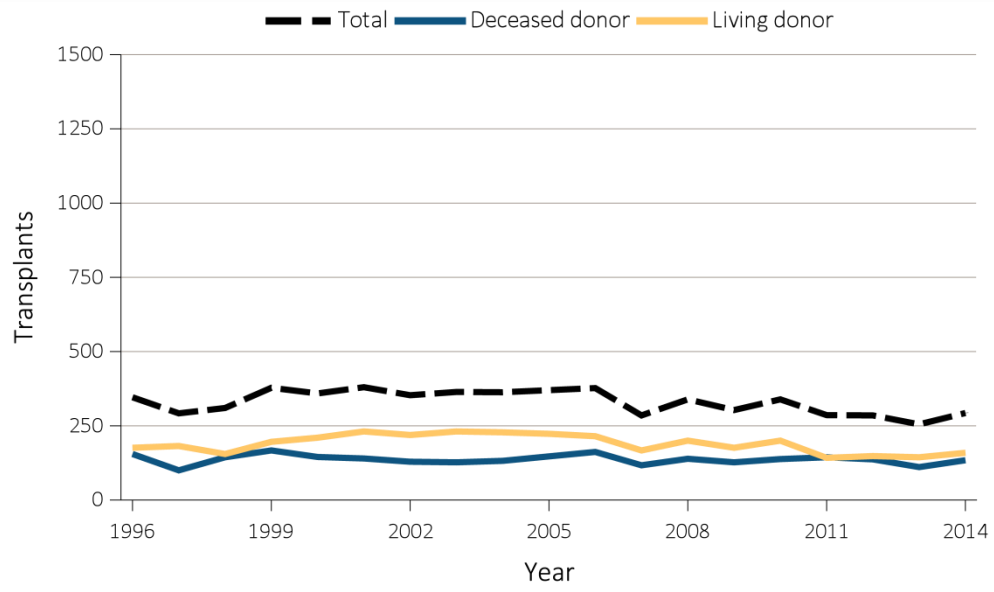
Figure 8.13 continued on next page.

vol 2 Figure 8.13 Trends in pediatric transplantation (aged 0-21 years), by (a) ESRD incident and kidney transplant rates, (b) pediatric patient transplant counts and kidney transplant waiting list times, and (c) kidney transplant counts, (d) kidney transplant counts, patients 0-17 years, (e) kidney transplant counts, patients 18-21 years, 1996-2014 *(continued)*

(d) kidney transplant counts, patients 0-17 years



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

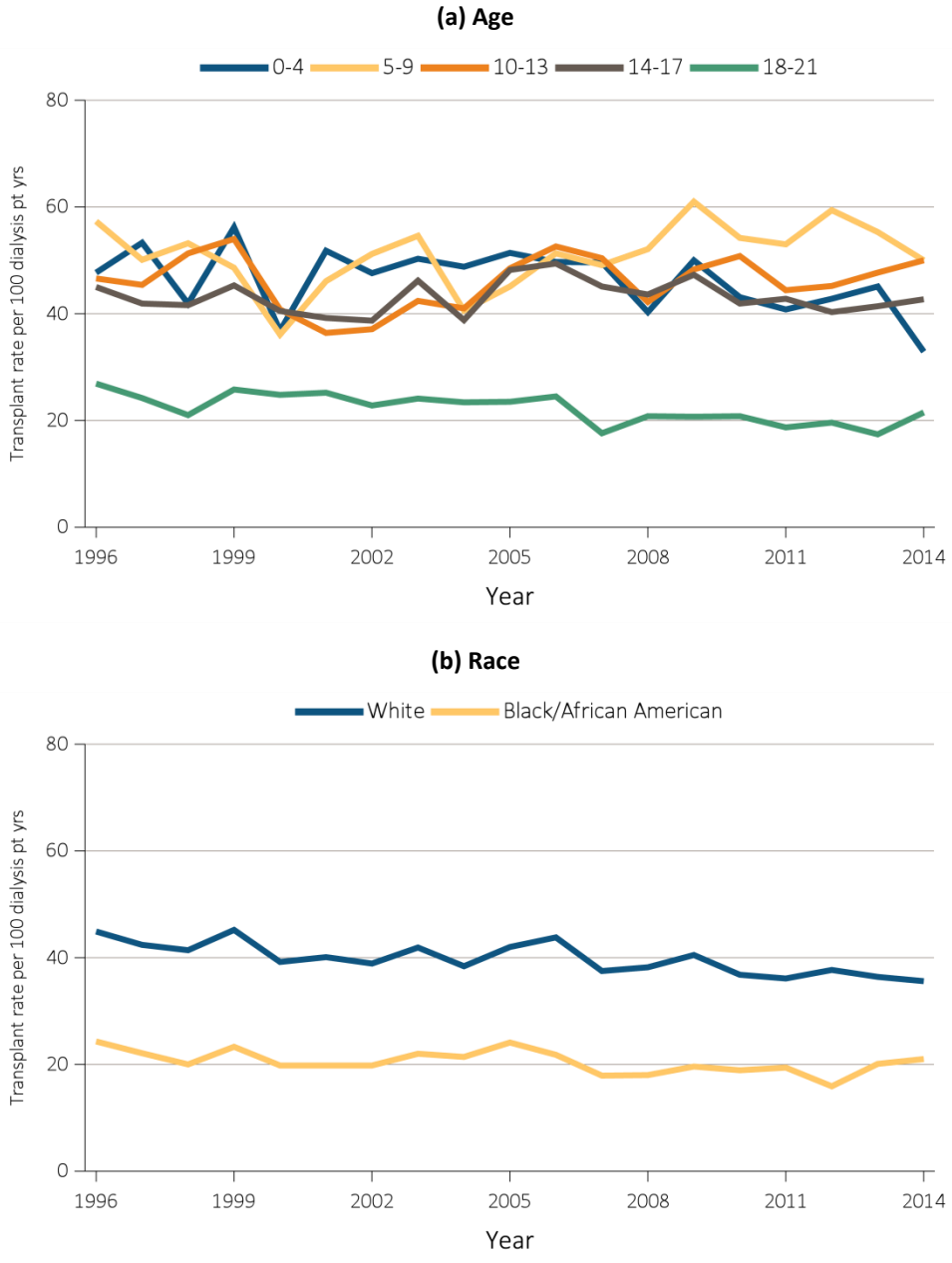


Data Source: (a) Reference Tables A1, E9, and M1. The rate of ESRD per million among the U.S. population aged 0-21 years and the rate of transplantation in dialysis patients aged 0-21 years at the time of transplant, 1996–2014. (b) Special analyses, USRDS ESRD Database. The waiting list count provides 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)(d)(e) Reference Tables E8, E8(2), E8(3) . This figure represents kidney alone and kidney plus pancreas transplant counts for all pediatric candidates. Abbreviations: ESRD, end-stage renal disease; pt, patient; Tx, transplant; yrs, years.

Overall, the transplant rates in each of the age groups have remained stable during 1996-2014. In 2014, patients 5-9 and 10-13 years old had the highest rates of transplantation at 50.0 transplants per 100 dialysis patient years and those 18-21 years old had the lowest transplant rate at 21.5 transplants per 100 dialysis patient years (Figure 8.14.a).

In 2014, males with ESRD were transplanted at a higher rate than females with ESRD, 34.3 versus 30.2 per 100 dialysis patient years, respectively. The transplant rate remains lower in Black dialysis patients compared with White dialysis patients (21.0 vs 35.6 per 100 dialysis patient years) (Figure 8.14.b). Analyses for Native and Asian Americans were excluded due to the low number of transplants.

vol 2 Figure 8.14 Annual rates of live and deceased donor transplants in pediatric dialysis patients (aged 0-21 years), by (a) age and (b) race, 1996-2014



Data Source: Special analyses, USRDS ESRD Database. Includes transplant year between 1996–2014. Abbreviations: ESRD, end-stage renal disease; pt, patient; yrs, years.

The median waiting time to transplant for incident patients on dialysis has been improving over time. In 2002, the median waiting time peaked at 1.83 years and began to decline, with the most dramatic improvement occurring after 2005 (Figure 8.15.a), which coincides with the change in the OPTN organ allocation policy. Since 2005, the median waiting time for incident dialysis patients has continued to

decrease and was at its lowest in 2013 at 1.04 years. Since 2007, the waiting times for incident patients on dialysis have been similar for hemodialysis and peritoneal dialysis. In 2013, the median waiting time to transplant for hemodialysis patients was 1.01 years, and for peritoneal dialysis patients it was 1.06 years.

Kidney transplant waiting times vary by age and ESRD etiology. In patients younger than 18 years old, who were given priority on the waiting list, the median time for incident dialysis to transplant has been improving from 1996 to 2013 in all age groups, with the exception of those 0-4 years old (Figure 8.15.b). Children aged 0-4 years have had stable waiting times, which may reflect the surgical complexities in this age group. Since 1996, patients aged 18-21 years old have shown the largest improvement with waiting times. In 2013, the median waiting time for children 0-4 years old surpassed that of patients 18-21 years old. Patients with secondary glomerulonephritis as the cause of their ESRD had the longest median waiting time to first transplant, with a median of 1.32 years in 2013 (Figure 8.15.c).

In 1996, White patients were on the waiting list on average 35% shorter than Black patients awaiting a transplant (Figure 8.15.d). Since then, the average time on the transplant list has improved significantly for all patients, and the gap between races has narrowed substantially. Consequently, median waiting times are now similar between groups (Whites 1.00 and Blacks 1.05 years). With the resolution of the waiting 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.

vol 2 Figure 8.15 Median waiting time from incident hemodialysis or peritoneal dialysis to first transplant, by (a) modality, (b) age, (c) primary cause of ESRD, and (d) race, 1996-2013

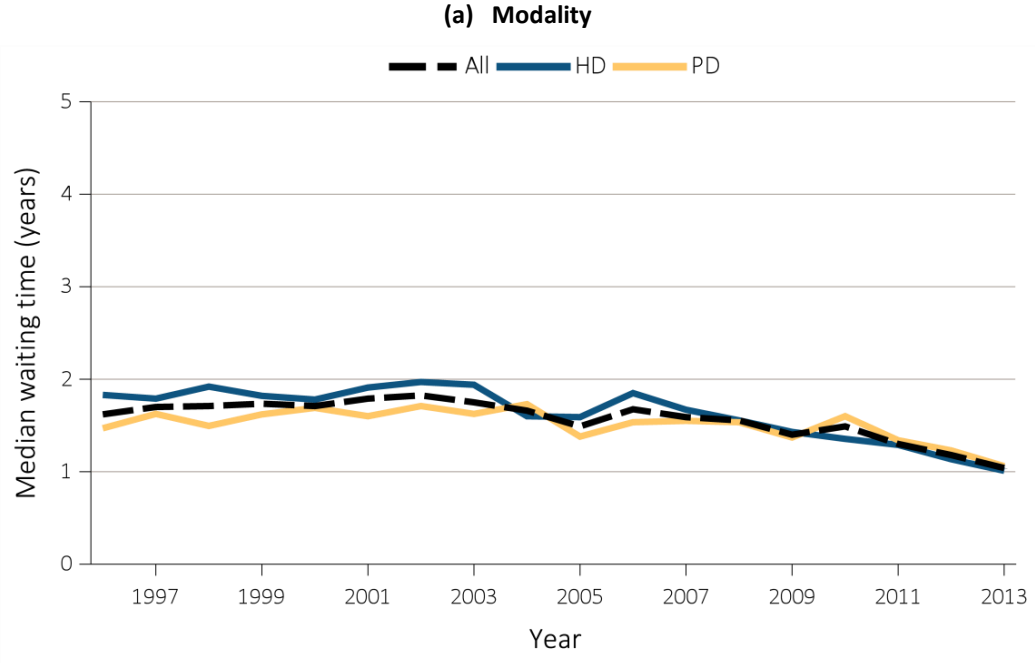
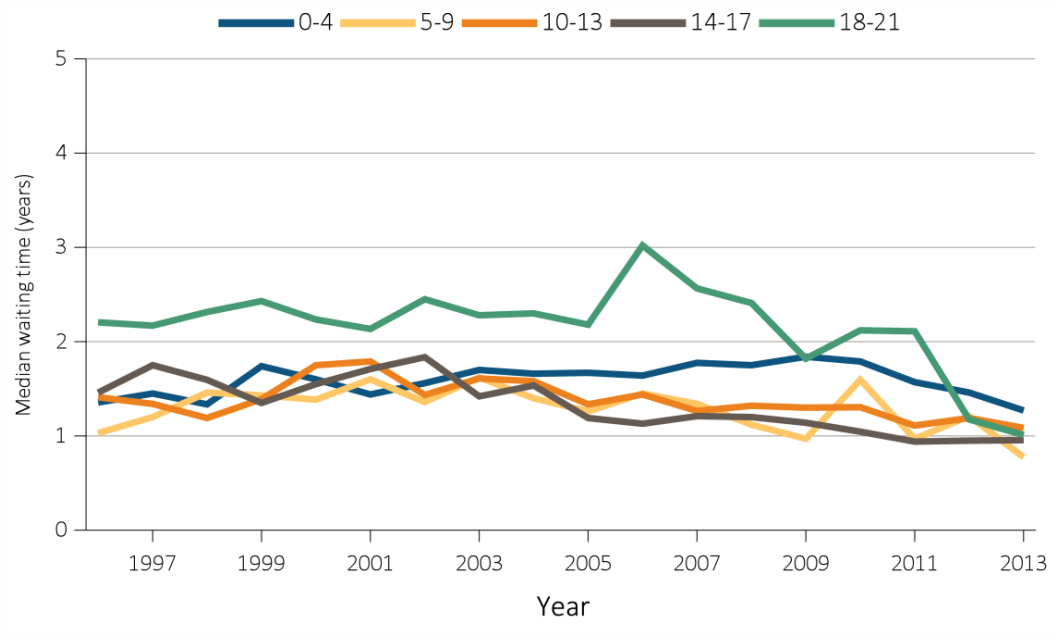


Figure 8.15 continued on next page.

vol 2 Figure 8.15 Median waiting time from incident hemodialysis or peritoneal dialysis to first transplant, by (a) modality, (b) age, (c) primary cause of ESRD, and (d) race, 1996-2013 *(continued)*

(b) Age



(c) Primary cause of ESRD

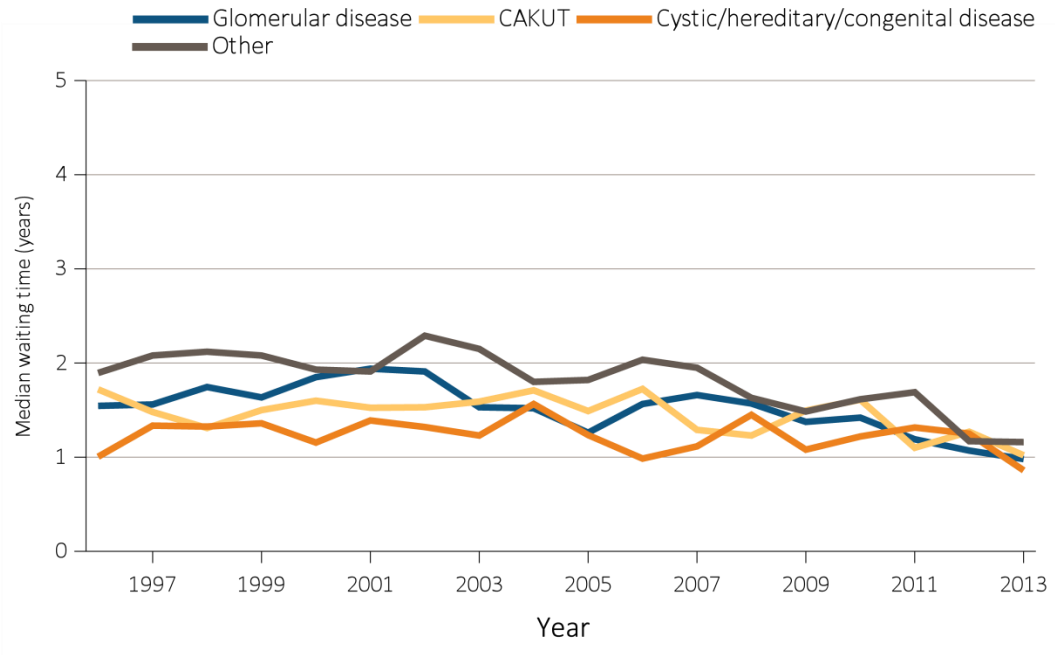
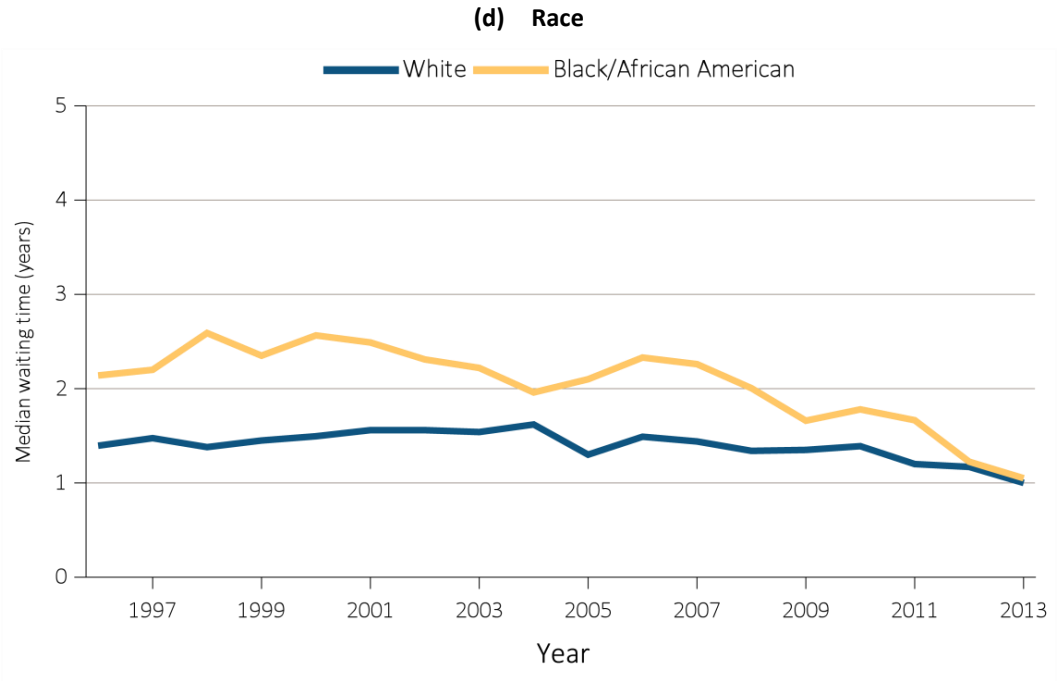


Figure 8.15 continued on next page.

vol 2 Figure 8.15 Median waiting time from incident hemodialysis or peritoneal dialysis to first transplant, by (a) modality, (b) age, (c) primary cause of ESRD, and (d) race, 1996-2013 *(continued)*



Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant with the 60-day rule. Includes pediatric patients (aged 0-21 years) starting initiation of HD or PD in 1996-2013 and having the first transplant before 12/31/2015. Abbreviations: CAKUT, congenital anomalies of the kidney and urinary tract; ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis.

Table 8.2 displays the ten-year kidney transplant outcomes. The ten-year outcomes improved with decreasing probability of all-cause graft loss and death for both deceased and living kidney transplants. Recipients of living donor kidneys have lower probability of returning to dialysis or retransplantation (0.42 in 2004), when compared to recipients of deceased donor kidneys (0.55 in 2004). The probability of death was higher for recipients of living donor kidney transplants than for deceased donor transplants until 2004, when the probability of death dropped to 0.06 for living donor recipients versus 0.08 for deceased donor recipients. The ten-year outcomes show significantly better all-cause graft failure outcomes for patients receiving living donor kidney transplants (0.45 in 2004) when compared to deceased donor kidney transplants (0.58 in 2004).

vol 2 Table 8.2 Adjusted ten-year outcomes for kidney transplants in pediatric patients (aged 0-21 years), by donor type and year, 1996-2004

	Adjusted ten-year outcomes					
	Deceased			Living		
Year	All-cause graft failure	Return to dialysis or retransplant	Death	All-cause graft failure	Return to dialysis or retransplant	Death
1996	0.62	0.58	0.11	0.51	0.49	0.15
1997	0.61	0.56	0.13	0.50	0.47	0.16
1998	0.57	0.54	0.10	0.50	0.47	0.10
1999	0.58	0.55	0.11	0.51	0.48	0.14
2000	0.57	0.54	0.10	0.52	0.49	0.16
2001	0.56	0.53	0.11	0.49	0.46	0.14
2002	0.50	0.47	0.06	0.43	0.41	0.15
2003	0.53	0.49	0.11	0.44	0.41	0.12
2004	0.58	0.55	0.08	0.45	0.42	0.06

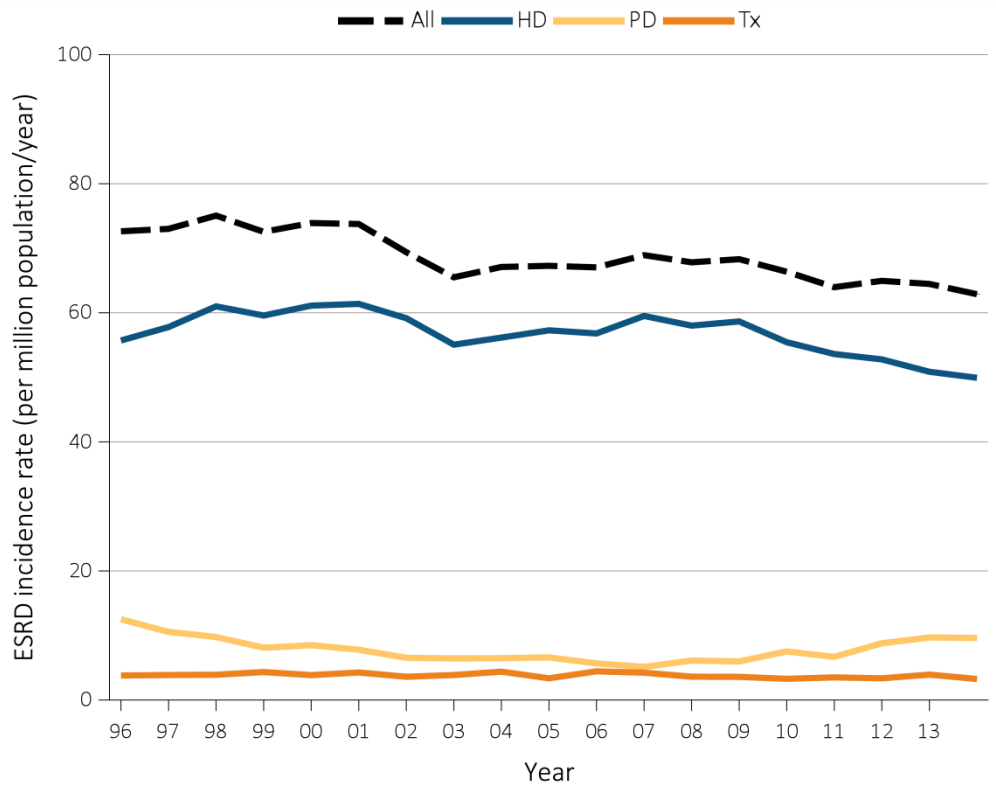
Data Source: Deceased: Reference Tables F6, F18, I30. Live: Reference Tables F12, F24, I36. Probabilities for all-cause graft failure and return to dialysis or repeat transplant are adjusted for age, sex, race, primary cause of ESRD, and first versus subsequent transplant. All-cause graft failure includes 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

As a result of improvements in the care of pediatric patients with ESRD, a larger percentage of these children are surviving into adulthood. The transition of these patients into adulthood represents a truly unique process and has resulted in the development of specific transition programs to improve health care for these individuals. In the USRDS ADR, the young adult age group is defined as those 22-29 years old. Cardiovascular disease remains the leading cause of mortality in this cohort, similar to children and older adults with ESRD. This section highlights the young adult population focusing on modality and the cardiovascular disease trends in this population.

The overall incident rate of ESRD in the young adult cohort has been slowly decreasing (Figure 8.16). In 1996, the rate was 72.6 per million/year in the young adult census population, while in 2014 the ESRD incident rate was 62.9 per million/year. In 2014, the rates of incident hemodialysis, peritoneal dialysis, and transplant were 49.9, 9.6, and 3.3 patients per million/year, respectively. Since 2008, there has been a trend in increased utilization of peritoneal dialysis as the incident ESRD modality. The point prevalence of young adults with ESRD (figure not shown) was 445.2 patients per million population in 2014. The use of ESRD modality within this 2014 point prevalent population included 206.1 hemodialysis, 43.4 peritoneal dialysis, and 194.3 transplant patients per million population, respectively.

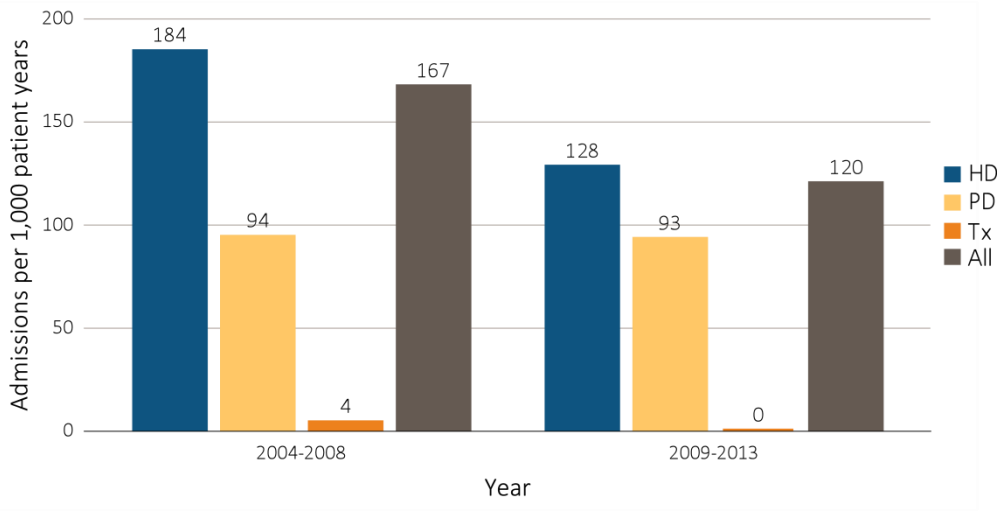
vol 2 Figure 8.16 Trends in incident rates of ESRD in young adults (aged 22-29 years), by modality, 1996-2014



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

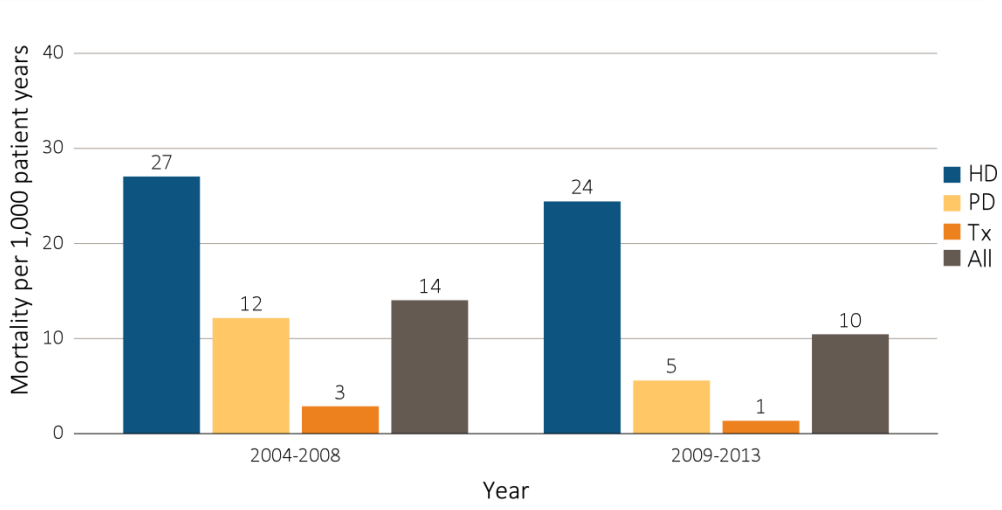
Cardiovascular health has been improving in the young adult ESRD population. The overall cardiovascular hospitalization rate during 2009-2013 was 124 admissions per 1,000 patient years, which is lower than the rate during 2004-2008 (Figure 8.17). The rate of cardiovascular hospitalizations remained highest in those on hemodialysis compared with other ESRD modalities. However, there was a 31.1% decline in cardiovascular hospitalization rates in hemodialysis patients in the most recent reporting years. Between 2009-2014, the one-year adjusted cardiovascular mortality was 10 per 1,000 patient years, which was a decrease of 28.6% from the 2004-2008 period (Figure 8.18). The adjusted one-year cardiovascular mortality rate decreased across all modalities.

vol 2 Figure 8.17 One-year unadjusted cardiovascular hospitalization rates in young adults with incident ESRD (aged 22-29 years), by modality, 2004-2008 and 2009-2013



Data Source: Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2004-2013, surviving the first 90 days after ESRD initiation and followed from day 90. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

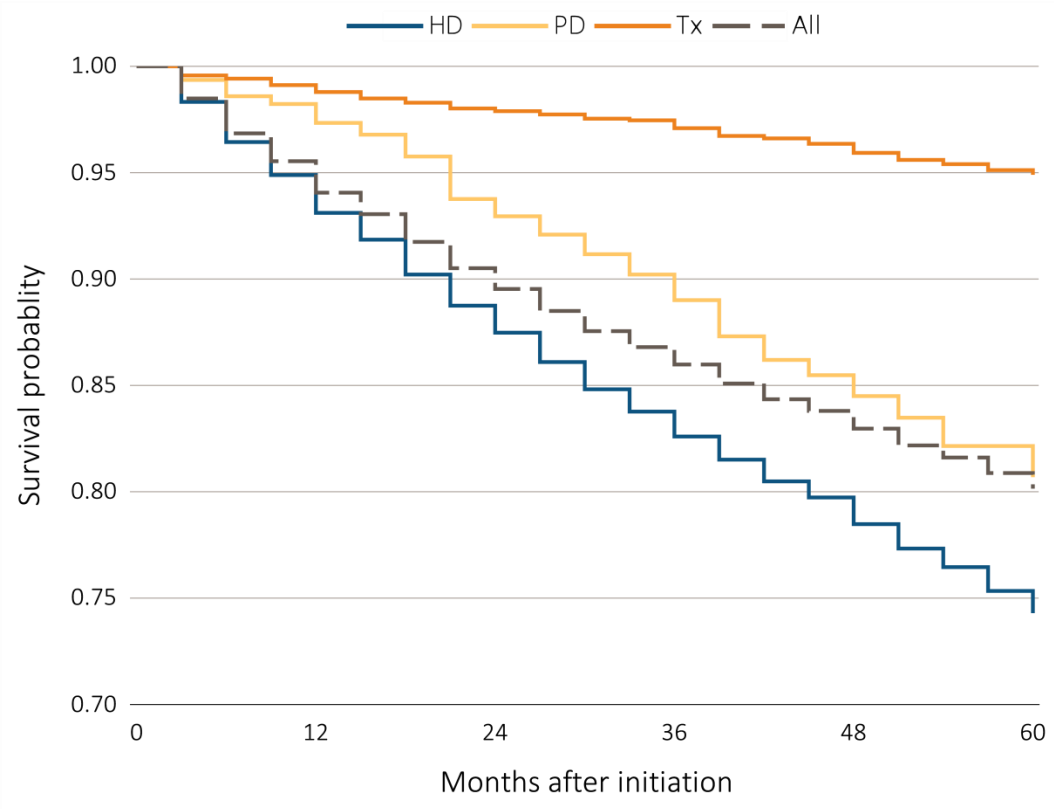
vol 2 Figure 8.18 One-year adjusted cardiovascular mortality rates in young adults with incident ESRD (aged 22-29 years), by modality, 2004-2008 and 2009-2013



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, 2014. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 22-29, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

For young adults beginning ESRD therapy during the period 2005-2009, the probability of five-year survival was 0.80, which is lower than the 0.90 five-year survival in patients aged 0-21 years (Figure 8.19). Young adult transplant patients had the highest probability of surviving five years with 0.95, as compared to 0.74 in hemodialysis patients, and 0.81 in peritoneal dialysis patients.

vol 2 Figure 8.19 Adjusted five-year survival probability of young adults with incident ESRD (aged 22-29 years), by modality and months after initiation, 2005–2009



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, 2014. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 22-29, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.