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# End-Stage Renal Disease due to Lupus Nephritis among Children in the U.S., 1995–2006

Linda T. Hiraki, MD, MS<sup>1,2</sup>, Bing Lu, PhD<sup>2</sup>, Steven R. Alexander, MD<sup>3</sup>, Tamara Shaykevich<sup>2</sup>, Graciela S. Alarcón, MD, MPH<sup>4</sup>, Daniel H. Solomon, MD, MPH<sup>2</sup>, Wolfgang Winkelmayer, MD, ScD<sup>5</sup>, and Karen H. Costenbader, MD, MPH<sup>2</sup>

<sup>1</sup> Harvard School of Public Health, Boston MA

<sup>2</sup> Division of Rheumatology, Immunology and Allergy, Brigham and Women's Hospital, PBB-B3, 75 Francis Street, Boston, MA

<sup>3</sup> Division of Nephrology, Department of Pediatrics, Stanford University School of Medicine, Stanford, CA

<sup>4</sup> Division of Clinical Immunology and Rheumatology, The University of Alabama at Birmingham, Birmingham, Alabama

<sup>5</sup> Division of Nephrology, Department of Medicine, Stanford University School of Medicine, Stanford, CA

# Abstract

**Purpose**—Little is known about the sociodemographic correlates of kidney transplantation and survival among U.S. children with lupus nephritis-associated ESRD. We aimed to identify predictors of listing for kidney transplantation (wait-listing), kidney transplantation, and mortality among children with lupus nephritis-associated ESRD.

**Methods**—Children aged 5–18 years with new onset lupus nephritis-associated ESRD were identified in the U.S. Renal Data System (1995–2006). We investigated demographic and clinical characteristics, causes of death and predictors of wait-listing, kidney transplantation, and mortality during the first 5 years of ESRD. Cox proportional hazards models were used.

**Results**—583 children had incident lupus nephritis-associated ESRD. Mean age at ESRD onset was 16.2 years (SD 2.4); 51% were African American and 24% Hispanic. Within 5 years 292 (49%) were wait-listed, 193 (33%) received a kidney transplant and 131 (22%) died. Main causes of death were cardiopulmonary (31%) and infectious (16%). Children in the Northeast and West (vs. South) were more than twice as likely to be wait-listed (P<0.001, P<0.001) and over 50% more likely to be transplanted (P<0.04). There were fewer kidney transplants among older vs. younger (OR 0.59, P=0.009), African American vs. white (OR 0.48, P<0.001), Hispanic vs. non-Hispanic (OR 0.63, P=0.03) children, and those with Medicaid vs. private insurance (OR 0.7, P=0.03). Mortality was almost double among African American vs. white children (OR 1.83, P<0.001).

**Conclusions**—Among U.S. children with lupus nephritis-associated ESRD age, race, ethnicity, insurance and geographic region were associated with significant variation in 5-year wait-listing for kidney transplant, kidney transplantation and mortality.

Corresponding author: Linda Hiraki, MD, MS, Section of Clinical Sciences, Division of Rheumatology, Immunology and Allergy, Brigham and Women's Hospital, PBB-B3, 75 Francis Street, Boston, MA, USA, Telephone: (617) 732-5325, Fax: (617) 731-9032, Ihiraki@hsph.harvard.edu.

**Disclaimer:** Data for this analysis was provided by United States Renal Data System (USRDS), but the analysis and conclusions are those of the authors and do not represent the USRDS or National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

# Keywords

Systemic Lupus Erythematosus; Pediatric Rheumatology; Nephritis; Survival; End Stage Renal Disease; Children; Disparities; Outcomes

#### Introduction

Systemic lupus erythematosus (SLE) in childhood accounts for 15–20% of all cases of SLE, and nephritis affects 20 to 75% of pediatric SLE patients<sup>1–5</sup>. Lupus nephritis in childhood usually presents after age 10 and presentation before age 5 is rare<sup>2, 6</sup>. Prior studies suggest that childhood lupus is more abrupt in onset than adult lupus and that children are more likely to have renal and central nervous system involvement<sup>1–4, 7–9</sup>. Lupus nephritis is more common and more severe among African American and Hispanic than among white adult and pediatric SLE patients in the U.S. <sup>6, 10–14</sup>. Similarly, racial and ethnic disparities, or inequities in access to and receipt of kidney transplantation according to sociodemographic factors resulting in adverse health outcomes, have been documented among adults and children with end-stage renal disease (ESRD) in the US, with lower rates among African Americans and Hispanics<sup>15–19</sup>.

Compared with adults with lupus, children receive more intensive drug therapy and accrue more organ damage, often related to steroid toxicity <sup>4</sup>, <sup>8</sup>, <sup>20</sup>, <sup>21</sup>. Among children with lupus nephritis, recent five-year renal survival rates have ranged from 77 to 93%, and overall five-year patient survival is between 78 and 97% <sup>6</sup>, <sup>22–24</sup>. Information on the outcomes of pediatric patients with ESRD due to lupus nephritis remains sparse and based on few studies involving small patient samples<sup>6</sup>. Many of these early pediatric studies of lupus nephritis-associated ESRD have noted high morbidity and mortality rates<sup>4</sup>, <sup>8</sup>, <sup>24</sup>. For example, McCurdy et al reported that among 10 children with ESRD due to lupus nephritis who did not receive kidney transplants, 5 died after a mean of 3.4 years on dialysis <sup>24</sup>.

For adult patients with lupus nephritis-associated ESRD, kidney transplantation has proven benefits, including improved survival and quality of life <sup>25–28</sup>. Early evaluation for kidney transplantation and placement on the waiting list for a kidney allograft are beneficial, although rates of graft failure and mortality increase with prolonged wait times <sup>29, 30</sup>. It is assumed that kidney transplantation is also beneficial for pediatric patients with lupus nephritis-associated ESRD, although past studies have been small<sup>11, 26</sup>. Much of the knowledge regarding predictors and outcomes among pediatric lupus nephritis-associated ESRD patients has been extrapolated from adult data and transplant studies and there is little available information on the sociodemographic predictors of waiting list access, kidney transplantation and mortality in this population.

In this study, we examined baseline demographic and clinical characteristics of children with ESRD due to lupus nephritis, and investigated potential sociodemographic and clinical predictors of wait-listing for and receipt of a kidney transplant and overall mortality from 1995 to 2006.

#### Methods

#### **Study Population**

The United States Renal Data System (USRDS) is the national registry of patients with ESRD. Since Medicare is mandated to pay for the health-care of these patients regardless of age, the Medicare claims of these patients form the backbone of the registry. The claims information is supplemented by data that have to be reported to the Centers for Medicare

and Medicaid Services (CMS) by providers on special forms, including the Medical Evidence Report (CMS-2728) and the ESRD Death Notification (CMS-2746). The USRDS database includes approximately 94% of the patients in the U.S who receive renal replacement therapy as dialysis or kidney transplantation, and in 2006 included information on 1.6 million individuals with ESRD since 1988<sup>31</sup>. For each new patient at enrollment, the attending nephrologist is required to complete the Medical Evidence Report. It serves to establish Medicare eligibility for those who were not previously Medicare eligible, reclassify previously eligible Medicare beneficiaries as ESRD patients and provide demographic and diagnostic information, including the etiology of ESRD on all new ESRD patients according to ICD-9-codes. The date of first service is derived from the earliest of dialysis start dates reported on the medical evidence form for chronic kidney failure; the date of kidney transplant as reported on a CMS or Organ Procurement Transplant Network transplant form, the Medical Evidence Report, a hospital inpatient claim, or the date of the first Medicare dialysis claim. Patients who were transiently dialyzed for acute renal failure, or who died before being enrolled in the database or who refuse renal replacement therapy, may not be included. From the USRDS, we identified all individuals ages 5 to 18 years with SLE (International Classification of Diseases, Ninth revision, ICD-9 code 710.0) identified as the cause of ESRD on the Medical Evidence Report at USRDS enrollment from January 1, 1995 to December 31, 2006. We were interested in ESRD onset, which occurs later than SLE diagnosis. To capture all pediatric cases of lupus nephritis-associated ESRD, we included children entered into USRDS at 18 years of age or younger

#### **Patient Characteristics**

Based on the Medical Evidence Report, the USRDS contains information concerning patient demographics, including age at initiation of renal replacement therapy, sex, race (white, African American, Asian, or Native American), and Hispanic ethnicity. Region of residence at the time of initiation of ESRD treatment is categorized into Northeast, Midwest, South or West. The USRDS Medical Evidence Report also includes the individual's body mass index (BMI, kg/m<sup>2</sup>), diagnoses of hypertension or diabetes mellitus at enrollment, and certain laboratory measurements. Type of medical insurance prior to onset of ESRD is also recorded (private, Medicaid, Medicare, other or none), as is receipt of an erythropoiesis-stimulating agent prior to onset of ESRD, and type of initial renal therapy received (hemodialysis, peritoneal dialysis or pre-emptive kidney transplant).

#### **Study Outcomes**

The outcomes of interest were time from ESRD to (1) being added to the wait-list for kidney transplantation, (2) receiving a kidney transplant, and (3) mortality from any cause, all standard definitions in the USRDS. In addition, we distinguished between kidney transplantation from a living versus a deceased donor, a living-related versus a living-unrelated donor. Cause of death was also available from the USRDS, as reported in the Death Notification form.

#### Statistical Analysis

Baseline characteristics were tabulated by race category and Hispanic ethnicity. Outcome variables wait-listing for kidney transplant, receipt of a kidney transplant, and overall mortality were approached using time-to-event analyses. Follow-up was censored at the earlier of 5-years after initiation of renal replacement therapy or end of database (12/31/2006). Predictors of the study outcomes were identified using age and sex adjusted Cox proportional hazards models, and multivariable adjusted models additionally adjusting for race, ethnicity, U.S. region of residence, and type of medical insurance. Tests for the proportionality hazards assumption were completed using interaction terms between each of the covariates and time. The relationships between age and the outcomes of interest were

explored with quartiles of age. Age was included in the final models both as a binary predictor (median split greater than or equal to 16 years and less than 16 years) and as a continuous covariate in multivariable-adjusted models investigating other predictors. In additional multivariable Cox models, we investigated the effects of additional adjustment for clinical characteristics including type of initial ESRD therapy, albumin and hemoglobin levels, presence of hypertension and diabetes, treatment with erythropoiesis-stimulating agents prior to ESRD, and BMI.

Data were obtained through a data use agreement with the USRDS and our results are presented according to their policies. (Table cell counts of fewer than 11 individuals have been suppressed.) The Partners' Healthcare Institutional Review Board deemed this protocol as exempt from human studies research approval.

# Results

We identified 583 children (ages 5–18 years) who initiated renal replacement therapy between 1995 and 2006 and whose underlying renal disease was reported as lupus nephritis. Mean age at onset of ESRD was 16.2 years (standard deviation, SD: 2.4 years). Table 1 presents the sociodemographic and clinical characteristics of the total population and stratified by race and ethnicity. African American children comprised almost half of the cohort and Native American children comprised a small percentage (2.4%). No individuals were missing data on date of birth or date of first service for ESRD, and no individuals were missing data on ethnicity.

Mean age at onset of ESRD was similar across racial groups. Females comprised the majority of cases in all races and ethnicities. More Asians and whites had private medical insurance at the time of ESRD onset than did those in other racial groups. Correspondingly, higher proportions of African Americans, Hispanics and Native Americans (not shown due to small numbers) were enrolled in Medicaid or did not have medical insurance. The geographic distribution of the cases by race and ethnicity was also uneven: the largest proportion of African American children resided in the South and that of white children resided in the West. Hispanic children with ESRD due to lupus nephritis mainly resided in the West and South.

Mean BMI was 23.2 kg/m<sup>2</sup> for the total cohort (SD:  $6.2 \text{ kg/m}^2$ ), with the highest BMI observed among Native American children (25 kg/m<sup>2</sup>, SD:  $7.5 \text{ kg/m}^2$ ) and lowest among Asian children (22.5 kg/m<sup>2</sup>, SD:  $6.4 \text{ kg/m}^2$ ). Within 5 years of ESRD onset, 292 (49%) children were placed on the waiting list for kidney transplant, 193 (33%) received a kidney transplant and 131 (22%) died. Mean age at kidney transplantation was 18.2 years (SD: 3.4 years) and at death was 19.5 years (SD: 3.5 years). Causes of death in this cohort were predominantly cardiopulmonary (31%) (Table 2).

In multivariable Cox proportional hazards models adjusting for sociodemographic factors, we found that region of residence was the only important predictor of increased rate of waitlisting for kidney transplant (Table 3). Children living in the U.S. Midwest, Northeast and West were up to twice as likely to be wait-listed as children living in the South. Residence in the West and Northeast, compared to the South, was also associated with increased rates of undergoing kidney transplantation (Table 4).

We found that children who were older than 16 years experienced almost half the rate of kidney transplantation compared with children less than or equal to 16 years of age (Table 4). Race and ethnicity were also important predictors of kidney transplantation. Five year rates of kidney transplantation among African American children were half that of white children, even after adjustment for U.S. region of residence and type of medical insurance.

Hispanic compared with non-Hispanic children also had 37% lower rates of kidney transplantation in multivariable models. We also observed 30% lower rates of transplantation among children with Medicaid insurance compared to those with private insurance (Table 4).

In our analyses of mortality, we observed that race was the most important factor. African American children had almost double the risk of death compared to white children, even after multivariable adjustment (Table 5). Mortality did not differ between Hispanic and non-Hispanic children. Additional multivariable analyses including clinical factors (type of initial ESRD therapy, albumin and hemoglobin levels, presence of hypertension and diabetes, treatment with erythropoiesis-stimulating agents prior to ESRD, and BMI) did not significantly change our estimates for any of these three outcomes, and hence clinical factors did not appear to be independent predictors of outcomes in these children.

Among the transplanted children, 61% received a deceased donor kidney transplant and 39% a living donor transplant (90% related, 10% unrelated). There was a higher proportion of deceased donor transplants among children aged 16 years and younger (71%) compared with children over 16 years of age (45%), and among African American (71%) and Asian (70%) children compared with white recipients (51%). Fifty-eight percent of Hispanic children had a deceased donor transplant. We also observed an increasing proportion of deceased donor kidney transplants over time by calendar year era, from 55% in 1995 to 1997, to 71% in 2004 to 2006. The proportion of deceased donor kidney transplants did not differ by region of residence.

# Discussion

ESRD is a devastating potential consequence of lupus nephritis and disparities in ESRD outcomes and in lupus nephritis across race and ethnicity are well documented in the literature. However, there is a scarcity of recent data on children with lupus nephritis-associated ESRD. We examined baseline demographic and clinical characteristics of children with ESRD due to lupus nephritis, and investigated potential sociodemographic and clinical predictors of wait-listing for and receipt of a kidney transplant and overall mortality. We found significant variations in waitlisting for kidney transplantation, receipt of a kidney transplant, and overall mortality by age, race, ethnicity, U.S. region of residence and type of medical insurance.

Clinical factors including type of initial ESRD therapy, albumin and hemoglobin levels, presence of hypertension and diabetes, treatment with erythropoiesis-stimulating agents prior to ESRD, and BMI, did not appear to be significant in our multivariable models. We found that children residing in the South were less likely to be wait-listed for kidney transplant than were children residing in other regions of the U.S. Children with lupus nephritis-associated ESRD were also more likely to be transplanted if they resided in the West and Northeast compared to the South. We also observed striking differences in rates of transplantation among different racial and ethnic groups, with African American and Hispanic children having lower rates of transplantation than white and non-Hispanic children. Overall survival among African American children was much lower when compared with that of white children.

The mean ages of ESRD onset and transplant in this lupus nephritis cohort are consistent with past data from pediatric lupus nephritis transplant cohorts that reported an older age at transplant among patients with SLE compared with children whose kidneys failed for other causes and then received a kidney transplant <sup>32, 33</sup>. The female to male ratio of 3.8:1 in this cohort is lower than ratios reported in pediatric lupus nephritis cohorts ranging from 4.5 to

7.8:1<sup>2, 24, 34</sup>. This difference highlights the need to investigate sex differences in risk of developing ESRD among pediatric SLE nephritis patients. Causes of death among the 131 who died included cardiopulmonary in 31% and infectious in 16%. This is consistent with cardiovascular complications being the most common cause of death among children with all cause ESRD<sup>31</sup>.

Our finding of decreased waitlisting rates in the Southern region of the U.S. is in agreement with a previous study that included pediatric ESRD patients regardless of their underlying kidney disease in which increased likelihood of activation on kidney transplant wait-lists was observed in the Northeast and Midwest regions of the U.S. compared with the South <sup>17</sup>. For SLE patients in the U.S., decreased rates of wait-listing for kidney transplant is likely related to decreased kidney transplantation rates in the South, although differences in patient disease severity may also be involved. Similar regional variation in treatment practices has been observed for adult ESRD patients, and the observed heterogeneity was not explained by differences in patient clinical characteristics<sup>35, 36</sup>.

We also observed decreased five year rates of kidney transplantation among African American and Hispanic children compared with white children that remained statistically significant after adjustment for U.S. region of residence and type of medical insurance. Kidney transplantation rates in the U.S. are known to be significantly lower among disadvantaged groups, in particular among African Americans, women, and individuals of low socioeconomic status (SES), inadequate insurance, and rural residence <sup>15–19, 37</sup>. A lower rate of wait-listing for kidney transplantation and receipt of a transplant among African Americans with all causes of ESRD has also been documented in adults and children <sup>16, 17</sup>.

Some possible explanations for sociodemographic variation in kidney transplantation rates proposed by past studies include a human leukocyte antigen (HLA)-based allocation strategy that limits access for minority racial and ethnic ESRD patients <sup>15, 16</sup>; barriers in the completion of the complicated renal transplantation evaluation process for socioeconomically disadvantaged patients; delayed referral to a nephrologist, and restricted access to a high volume transplant center. All of these factors are demonstrated predictors of time to transplant listing and receipt of a transplant<sup>18, 19, 38–41</sup>. Furthermore, physicians' perceptions that minority patients may prefer not to undergo kidney transplantation, or that medical non-adherence (more common in socioeconomically disadvantaged populations) deems these patients less appropriate transplant candidates, may contribute to differences transplant rates <sup>42, 43</sup>.

Our finding of decreased overall survival among African American children compared with white children with lupus nephritis ESRD is in remarkable contrast to the overall ESRD population where African Americans enjoy a marked survival advantage over whites who have otherwise similar characteristics<sup>44</sup>. Racial differences in severity of underlying SLE could explain some of the disparities in survival<sup>16</sup>. Furthermore, our findings are consistent with studies demonstrating decreased survival among non-white SLE populations<sup>14, 45</sup>, a phenomenon that does not hold true for other non-SLE associated causes of ESRD. In our analyses, adjustment for regional variation and medical insurance attenuated the increase in mortality only slightly (from an over 2-fold increase to an 83% increase in African Americans compared to whites), and adjustment for the clinical characteristics available at ESRD onset, including laboratory parameters, comorbidities, BMI and initial ESRD therapy, did not further affect this increased risk.

Prior smaller studies have compared outcomes among pediatric SLE associated ESRD to those with other causes of ESRD. A study of 94 SLE patients in the North American Pediatric Renal Trials and Cooperative Studies (NAPRTCS) found no difference in patient

survival at 3 years (89% vs. 95% in SLE vs. controls)<sup>33</sup>. The United Network for Organ Sharing (UNOS) study that included 254 pediatric SLE ESRD patients who had received kidney transplants found that over a median follow-up of 4.2 years, mortality was 1.8 times higher in those with SLE than those with other causes of ESRD<sup>32</sup>. African American race, transplantation of an organ from a deceased donor, and transplantation before 1993 were all related to increased risk of mortality. The UNOS study also found that children with lupus-associated ESRD had a longer duration of dialysis therapy before transplantation, similar to reports in adults <sup>11, 26</sup>.

In the current study, we found that initial ESRD therapy varied according to race, with a higher proportion of African American children receiving hemodialysis and fewer being placed initially on peritoneal dialysis compared with white children. This phenomenon has been reported for adults and children with all causes of ESRD in the U.S. in recent years; the rate of hemodialysis initiation among African Americans rather than peritoneal dialysis is nearly four times that reported for whites<sup>31</sup>. A study of children enrolled in the USRDS in 2000 found that African American race was strongly associated with the use of hemodialysis, speculating that family, patient, or provider preferences could account for the racial difference in choice of therapy<sup>46</sup>.

Kidney transplantation from a living-related donor confers superior outcomes for pediatric recipients, compared to deceased donor transplantation<sup>47</sup>. The small number of living donor transplants precluded a detailed analysis of survival comparing living-related and living-unrelated donor transplantation. Among all those transplanted in our cohort, we observed an increase in the proportion of deceased donor transplants with increasing calendar year. This is in keeping with trends observed in pediatric kidney transplantation since the 2005 implementation of the revised allocation policy (Share 35) that conferred preferential allocation of allografts from young deceased donors (less than 35 years old) to pediatric patients less than 18 years of age<sup>48</sup>. This policy change resulted in an overall increase in the number of pediatric kidney transplants per quarter and a reduced wait time for a deceased donor kidney, as well as marginally significant increase in overall HLA mismatching of recipients under 18 years of age<sup>47, 49</sup>. Since type of kidney transplant (living vs. deceased donor) has implications for transplant kidney survival, the impact of this change in allocation upon future re-transplantation rates is still unclear.

Our study has several strengths. This is the largest study of pediatric lupus nephritisassociated ESRD reported to date. The USRDS contains data from patients across the U.S. and includes almost all incident cases receiving Medicare-reimbursed renal replacement therapy. We analyzed and reported on data collected over ten years on a pediatric subset of this population, for whom there were few published studies to date. We used well documented and validated outcomes: wait-listing, kidney transplantation and mortality <sup>50</sup>.

The limitations of our study are that USRDS data are not available on acute renal failure or rates of recovered renal function for 1995 to 2006. Date and age of SLE onset, kidney biopsy results, measures of lupus disease activity and damage in other organ systems are also not available. Since these are all important predictors of disease outcomes and mortality, and are also related to race, ethnicity and socioeconomic status, their inclusion would improve the interpretability of our findings. Our study is also limited by small numbers of Asian and Native American SLE patients which impacts the ability to detect significant associations in these populations.

Our study sheds new light on several well described differences in outcomes among pediatric lupus-associated ESRD patients. Our results suggest that important disparities in access to care and in outcomes exist according to region of residence, age, race, ethnicity

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Sociodemographic and Clinical Characteristics of U.S. Children with Lupus Associated ESRD

			Race*		Et	Ethnicity*
Mean (standard deviation) or Count (%)	Total (n=583)	White <sup>*</sup> (n=219)	African American <sup>*</sup> (n=287) Asian <sup>*</sup> (n=46)	Asian <sup>*</sup> (n=46)	Hispanic (n= 142)	Non Hispanic (n=441)
Age at onset of ESRD (years)	16.2 (2.4)	16.1 (2.3)	16.1 (2.5)	16.0 (2.3)	16 (2.4)	16.1 (2.4)
Female	442 (76)	167 (76)	218 (76)	39 (85)	107 (73)	335 (76)
Medical insurance prior to $\mathbf{ESRD}^{\beta}$						
Private	224 (39)	99 (46)	87 (34)	27 (60)	52 (37)	172 (40)
Medicaid	285 (50)	90 (41)	163 (58)	14 (31)	68 (48)	217 (50)
No insurance **	52 (9)	22(10)	26 (9)	ı	20 (14)	32 (7)
Medicare	14 (2)				I	12 (3)
Geographic Area of U.S. residence $^{\dot{ au}}$						
Northeast	82 (14)	28 (13)	43 (15)		18 (13)	64 (15)
South	247 (43)	64 (29)	161 (56)	13 (32)	41 (30)	206 (47)
Midwest	97 (17)	30 (14)	53 (19)		ı	91 (21)
West	146 (25)	96 (44)	30 (10)	16 (39)	71 (52)	75 (17)
Body Mass Index (kg/m <sup>2</sup> )	23.2 (6.2)	23.0 (6.0)	23.4 (6.1)	22.5 (6.4)	22.7 (5.8)	23.4 (6.3)
Presence of Diabetes	12 (2)					
Presence of Hypertension	347 (60)	125 (57)	174 (61)	26 (57)	84 (59)	263 (60)
Use of an erythropoesis-stimulating agent prior to ESRD $\ddagger$	prior to ESRD $\ddagger$					
Yes	185 (33)	68 (33)	90 (32)	17 (40)	42 (31)	143 (33)
No	359 (64)	130 (63)	183 (64)	26 (60)	88 (65)	271 (63)
Unknown	21 (4)	I	11 (4)		I	15 (4)
Initial therapy $^{\%}$						
Hemodialysis	438 (75)	150 (68)	230 (80)	34 (74)	101 (71)	337 (76)
<b>Peritoneal dialysis</b>	116 (20)	55 (25)	44 (15)	11 (24)	32 (23)	84 (19)

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\*\* Medical insurance data missing on 8 subjects. Includes employer group health insurance, Dept. of Veterans' Administration

 $^{\dagger}Four$  U.S. regions according to US Census bureau state codes, missing on 5 subjects.

 ${}^{T}_{}$ Data on use of an erythropoesis-stimulating agent missing on 14 subjects.

Tre-emptive kidney transplantation in <11 subjects (breakdown not shown due to small numbers) and initial type of kidney replacement therapy missing for 25 subjects.

-Cell counts of fewer than 11 individuals have been suppressed.

Causes of 5 year Mortality (n=131) among U.S. Children with Lupus Associated ESRD

Cause of Mortality	Frequency (n)	Percent (%)
Cardiopulmonary*	40	31
Infectious <sup>**</sup>	21	16
Neurologic <sup>†</sup>	13	10
Hemorrhagic $^{\not \pm}$	13	10
Other <sup>¶</sup>	21	16
Renal <sup>§</sup>	-	-
Unknown	19	15
Total	131	100

\* Includes pericarditis/cardiac tamponade, cardiomyopathy, cardiac arrhythmia, cardiac arrest, valvular heart disease, pulmonary edema and embolus.

\*\* Includes septicemia due to vascular access, peritonitis, pulmonary infections and other infections.

 $^\dagger$  Includes cerebro-vascular accident, ischemic brain damage and seizures.

 $\ddagger$ Includes hemorrhage from vascular access, surgery, other hemorrhage and gastro-intestinal hemorrhage.

<sup>¶</sup>Includes mesenteric infarction/ischemic bowel, liver failure, pancreatitis, bone marrow depression, accident unrelated to treatment, and other identified cause of death.

<sup>§</sup>Includes withdrawal from dialysis/uremia and hyperkalemia.

-Cell counts of fewer than 11 individuals have been suppressed.

Sociodemographic Determinants of Wait-Listing (n=579)<sup>\*</sup> for Kidney Transplantation among U.S. Children with Lupus Associated ESRD

Sociodemographic factor (n)	Age <sup>**</sup> and Sex Adjusted (95% $CI^{\ddagger}$ )	Multivariable <sup>†</sup> Adjusted (95% CI <sup>≠</sup> )
Age**		
= 16 years (317)</td <td>1.0 (ref.)</td> <td>1.0 (ref.)</td>	1.0 (ref.)	1.0 (ref.)
> 16 years (262)	0.89 (0.69, 1.13)	0.96 (0.74, 1.23)
Sex		
Female (442)	1.0 (ref.)	1.0 (ref.)
Male (141)	1.09 (0.82, 1.45)	1.13 (0.85, 1.51)
Race		
White (219)	1.0 (ref.)	1.0 (ref.)
African American (287)	0.87 (0.67, 1.13)	1.24 (0.88, 1.75)
Asian (46)	0.86 (0.54, 1.37)	1.21 (0.71, 2.03)
Native American (14)	0.44 (0.16, 1.21)	0.45 (0.16, 1.23)
Ethnicity		
Non-Hispanic (441)	1.0 (ref.)	1.0 (ref.)
Hispanic (142)	1.22 (0.93, 1.60)	1.37 (0.94, 2.00)
US Region of Residence		
South (247)	1.0 (ref.)	1.0 (ref.)
West (146)	2.11 (1.56, 2.85)	2.11 (1.52, 2.54)
Midwest (97)	1.40 (0.97, 2.02)	1.54 (1.06, 2.25)
Northeast (82)	2.06 (1.45, 2.94)	2.07 (1.44, 2.98)
Medical Insurance		
Private (224)	1.0 (ref.)	1.0 (ref.)
Medicaid (285)	1.0 (0.77, 1.29)	1.02 (0.78, 1.33)
Medicare (14)	0.74 (0.33, 1.69)	0.92 (0.57, 1.50)
No insurance (52)	0.89 (0.56, 1.43)	0.61 (0.27, 1.39)
Unknown (25)	2.30 (1.07, 4.96)	2.61 (1.18, 5.80)

\*Waiting list access among all dialysis patients (n=579), excluding pre-emptively transplanted.

\*\* Age as a predictor, defined by median split ≤ 16 years and >16 years. Age as a covariate for adjustment in the multivariable-adjusted models was included as continuous age in years.

<sup>†</sup>Multivariable models adjusted for race, ethnicity, US region of residence and medical insurance. Race data missing on 17 subjects. Medical insurance data missing on 8 subjects. Region data missing on 5 subjects.

 $^{\ddagger}$ 95% Confidence interval by Wald method.

Sociodemographic Determinants of Kidney Transplantation (n=579)<sup>\*</sup> among U.S. Children with Lupus Associated ESRD

Sociodemographic factor (n)	Age <sup>**</sup> and Sex Adjusted (95% $CI^{\ddagger}$ )	Multivariable <sup>†</sup> Adjusted (95% CI <sup>≠</sup> )
Age**		
= 16 years (317)</td <td>1.0 (ref.)</td> <td>1.0 (ref.)</td>	1.0 (ref.)	1.0 (ref.)
> 16 years (262)	0.56 (0.41, 0.76)	0.59 (0.43, 0.81)
Sex		
Female (442)	1.0 (ref.)	1.0 (ref.)
Male (141)	0.86 (0.59, 1.24)	0.90 (0.62, 1.32)
Race		
White (219)	1.0 (ref.)	1.0 (ref.)
African American (287)	0.53 (0.38, 0.73)	0.48 (0.32, 0.71)
Asian (46)	0.97 (0.59, 1.60)	0.80 (0.47, 1.38)
Native American (14)	0.67 (0.21, 2.14)	0.73 (0.22, 2.35)
Ethnicity		
Non-Hispanic (441)	1.0 (ref.)	1.0 (ref.)
Hispanic (142)	0.95 (0.67, 1.33)	0.63 (0.41, 0.96)
US Region of Residence		
South (247)	1.0 (ref.)	1.0 (ref.)
West (146)	1.98 (1.36, 2.89)	1.54 (1.03, 2.31)
Midwest (97)	1.39 (0.88, 2.17)	1.13 (0.71, 1.81)
Northeast (82)	2.17 (1.43, 3.28)	1.94 (1.28, 2.95)
Medical Insurance		
Private (224)	1.0 (ref.)	1.0 (ref.)
Medicaid (285)	0.65 (0.47, 0.89)	0.70 (0.51, 0.97)
Medicare (14)	1.29 (0.59, 2.79)	0.55 (0.28, 1.07)
No insurance (52)	0.47 (0.25, 0.92)	1.20 (0.55, 2.61)
Unknown (25)	0.67 (0.21, 2.13)	0.74 (0.23, 2.40)

\*Waiting list access among all dialysis patients (n=579), excluding pre-emptively transplanted.

\*\* Age as a predictor, defined by median split ≤ 16 years and >16 years. Age as a covariate for adjustment in the multivariable-adjusted models was included as continuous age in years.

<sup>†</sup>Multivariable models adjusted for race, ethnicity, US region of residence and medical insurance. Race data missing on 17 subjects. Medical insurance data missing on 8 subjects. Region data missing on 5 subjects.

 $^{\ddagger}$ 95% Confidence interval by Wald method.

Sociodemographic Determinants of Overall Mortality (n=583) among U.S. Children with Lupus Associated ESRD

Sociodemographic factor (n)	Age <sup>*</sup> and Sex Adjusted (95% $CI^{\ddagger}$ )	Multivariable <sup>†</sup> Adjusted (95% CI <sup>‡</sup> )
Age*		
= 16 years (317)</th <th>1.0 (ref.)</th> <th>1.0 (ref.)</th>	1.0 (ref.)	1.0 (ref.)
> 16 years (262)	1.40 (0.96, 2.03)	1.36 (0.93, 2.00)
Sex		
Female (442)	1.0 (ref.)	1.0 (ref.)
Male (141)	1.40 (0.93, 2.10)	1.35 (0.89, 2.04)
Race		
White (219)	1.0 (ref.)	1.0 (ref.)
African American (287)	2.05 (1.31, 3.21)	1.83 (1.03, 3.24)
Asian (46)	1.51 (0.68, 3.32)	1.44 (0.61, 3.43)
Native American (14)	2.27 (0.79, 6.52)	2.22 (0.75, 6.61)
Ethnicity		
Non-Hispanic (441)	1.0 (ref.)	1.0 (ref.)
Hispanic (142)	0.66 (0.40, 1.06)	0.76 (0.39, 1.49)
US Region of Residence		
South (247)	1.0 (ref.)	1.0 (ref.)
West (146)	0.75 (0.47, 1.19)	0.62 (0.33, 1.16)
Midwest (97)	0.67 (0.39, 1.17)	0.69 (0.39, 1.23)
Northeast (82)	0.56 (0.30, 1.05)	0.62 (0.33, 1.16)
Medical Insurance		
Private (224)	1.0 (ref.)	1.0 (ref.)
Medicaid (285)	1.38 (0.91, 2.08)	1.27 (0.83, 1.94)
Medicare (14)	1.19 (0.37, 3.88)	1.22 (0.37, 4.01)
No insurance (52)	1.52 (0.79, 2.93)	1.42 (0.73, 2.78)
Unknown (25)	0.66 (0.09, 4.83)	0.73 (0.10, 5.41)

\* Age as a predictor, defined by median split 16 years and >16 years. Age as a covariate for adjustment in the multivariable-adjusted models was included as continuous age in years.

<sup>†</sup>Multivariable models adjusted for race, ethnicity, US region of residence and medical insurance. Race data missing on 17 subjects. Medical insurance data missing on 8 subjects. Region data missing on 5 subjects.

 $^{\ddagger}$ 95% Confidence interval by Wald method.