

Outcomes in Hospitalized Pediatric Patients With Systemic Lupus Erythematosus



WHAT'S KNOWN ON THIS SUBJECT: Systematic health disparities in adults with systemic lupus erythematosus are well documented and are likely driven by biologic as well as modifiable factors. Sociodemographic factors and health care delivery characteristics have been associated with poor outcomes.



WHAT THIS STUDY ADDS: In hospitalized children with systemic lupus erythematosus, race and ethnicity were associated with increased risk for ICU admissions, end-stage renal disease, and death. Identification of sociodemographic factors associated with outcomes is important to address the needs of these vulnerable patients.

abstract

OBJECTIVE: Disparities in outcomes among adults with systemic lupus erythematosus (SLE) have been documented. We investigated associations between sociodemographic factors and volume of annual inpatient hospital admissions with hospitalization characteristics and poor outcomes among patients with childhood-onset SLE.

METHODS: By using the Pediatric Health Information System, we analyzed admissions for patients aged 3 to <18 years at index admission with ≥ 1 *International Classification of Diseases, Ninth Revision* code for SLE from January 2006 to September 2011. Summary statistics and univariable analyses were used to examine demographic characteristics of hospital admissions, readmissions, and lengths of stay. We used multivariable logistic regression analyses, controlling for patient gender, age, race, ethnicity, insurance type, hospital volume, US census region, and severity of illness, to examine risk factors for poor outcomes.

RESULTS: A total of 10 724 admissions occurred among 2775 patients over the study period. Hispanic patients had longer lengths of stay, more readmissions, and higher in-hospital mortality. In multivariable analysis, African American race was significantly associated with ICU admission. African American race and Hispanic ethnicity were associated with end-stage renal disease and death. Volume of patients with SLE per hospital and hospital location were not significantly associated with outcomes.

CONCLUSIONS: In this cohort of hospitalized children with SLE, race and ethnicity were associated with outcomes. Further studies are needed to elucidate the relationship between sociodemographic factors and poor outcomes in patients with childhood-onset SLE. *Pediatrics* 2014;133:e106–e113

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KEY WORDS

end-stage renal disease, mortality, outcomes, systemic lupus erythematosus

ABBREVIATIONS

ESRD—end-stage renal disease

ICD-9—*International Classification of Diseases, Ninth Revision*

LOS—lengths of stay

PHIS—Pediatric Health Information System

SLE—systemic lupus erythematosus

Dr Son conceptualized and designed the study, drafted the initial manuscript, and interpreted the data; Mr Johnson performed the initial and revised data analyses, and reviewed and revised the manuscript; Dr Hersh interpreted the data and reviewed and revised the manuscript; Dr Lo performed a record review of pertinent records, interpreted the data, and reviewed and revised the manuscript; and Dr Costenbader contributed to the design of the study, interpreted the data, and reviewed and revised the manuscript critically for content. All authors approved the final manuscript as submitted.

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Childhood-onset systemic lupus erythematosus (SLE) is an uncommon disease with potentially devastating effects mediated via 2 mechanisms: the attack of visceral organs (including the brain and kidneys) by the immune system and therapeutic regimens that are dominated by corticosteroids and other powerful immunosuppressive medications. Children with SLE tend to have more severe disease at presentation and more disease activity over time compared with their adult counterparts.^{1–4} Hersh et al⁵ reported that childhood onset of SLE is a predictor of mortality among adult patients with SLE.

Disparities in the incidence, severity, and outcomes of adults with SLE are well characterized; women, minorities, those lacking medical insurance, and those with lower socioeconomic status are at increased risk for developing the disease and for poor outcomes.^{6–11} Fewer studies have examined socio-demographic disparities among children with SLE. The Lupus in Minorities: Nature Versus Nurture cohort consists of African American, white, Texan Hispanic, and Puerto Rican Hispanic subjects. Comparison of its youngest participants, aged 13 to 18 years at diagnosis, with their adult counterparts showed that Lupus in Minorities: Nature Versus Nurture participants with childhood-onset SLE were more likely to have renal and neurologic manifestations and renal damage compared with the adult SLE group, as well as a twofold higher mortality rate.² As in adults with SLE, it is likely that the poor outcomes described in certain populations of childhood-onset SLE patients are driven by biologic as well as modifiable factors that are difficult to disentangle.

By using the US Pediatric Health Information System (PHIS) database, we examined the association of socio-demographic features and volume of

admissions per hospital with outcomes, including ICU admissions, end-stage renal disease (ESRD), and in-hospital mortality.

METHODS

Data Source

The PHIS is a database contributed to by >40 freestanding US pediatric hospitals and is administered by the Children's Health Association.¹² Data are updated quarterly and were available for inclusion between January 1, 2006, and September 30, 2011. Anonymous patient identifiers allow for tracking of patients across admissions within the same hospital.

Data Collection

We searched the PHIS for all inpatient discharges with an *International Classification of Diseases, Ninth Revision* (ICD-9) code for SLE (710.0) for patients aged 3 to <18 years from hospitals that contributed full data for the entire study period. The index admission was defined as the first admission with a code for SLE. All subsequent admissions after the index admission date were included. The follow-up time was determined by subtracting the admission date of the first admission from the discharge date of the last admission per patient. Admissions lasting <48 hours with a pharmaceutical code for cyclophosphamide were considered infusion admissions. Patient information was recorded, including age at first admission; race (white, African American, Asian, Native American, or other); ethnicity (Hispanic, non-Hispanic, or other); medical insurance (private, government, self-pay, or no charge/other); hospital and ICU admissions; lengths of stay (LOS); pertinent diagnoses based on ICD-9 coding; All Patient Refined–Diagnosis Related Groups Severity of Illness index, version 25 (3M-Corp, Minneapolis, MN); and

deaths. We classified hospitals according to the volume of inpatient admissions per year, in quartiles.

Secondary ICD-9 codes were examined to determine the frequency of SLE renal disease, including glomerulonephritis, nephrosis, renal failure (ICD-9 codes 580–585 with all subcodes included), and dialysis therapy (ICD-9 codes V56.0 and V56.2).

Validation of Diagnoses

To assess the accuracy of coding for SLE by using the ICD-9 code 710.0, one of the study authors (M.S.L.) reviewed the medical records of patients at our institution (Boston Children's Hospital) identified in the query. We defined the positive predictive value of having a diagnosis of SLE as the number of patients with confirmed SLE per the 1997 American College of Rheumatology criteria for SLE, which have been validated in children,¹³ over the total number of patients identified.

Data Analyses

Continuous variables (eg, age at admission, LOS) were summarized by mean \pm SD or median (first quartile – third quartile) as appropriate. Frequencies and percentages were presented for discrete variables (eg, gender, ethnicity). Demographic characteristics of hospital admissions and readmission, proportions of patients with renal disease according to study region, severity of illness indices for ICU admissions, and admissions for cyclophosphamide administration were examined by using the Pearson χ^2 test. Differences in LOS among the highest and lowest quartiles of hospital volume were analyzed by using the Wilcoxon rank-sum test. Characteristics of all admissions were summarized according to race/ethnicity and then compared by using the Wilcoxon rank-sum test and Pearson's χ^2 test. Less frequent subgroups under race, ethnicity, and

insurance were combined to facilitate analysis. We constructed a multivariable logistic regression model controlling for patient gender, age, race, ethnicity, insurance type, hospital volume, severity of illness, and US Census Bureau regions (Northeast, South, Midwest, and West) as identified in the index admission to examine risk factors for adverse outcomes. We defined ICU admissions, ESRD, and in-hospital mortality as outcomes of interest. Due to the low number of deaths during the study period, ESRD and in-hospital mortality were analyzed as a combined outcome, adjusting for severity of illness.

Data were analyzed by using SAS version 9.1 (SAS Institute, Inc, Cary, NC). Two-tailed *P* values <.05 were considered statistically significant.

Institutional review board approval was obtained for utilization of the PHIS and for medical record review at Boston Children's Hospital.

RESULTS

Demographic and Disease Characteristics

We identified 10 724 admissions among 2775 patients from 43 participating hospitals over the study period (Table 1). Fifteen hospitals from the South contributed 4521 admissions (42.2%), 10 hospitals from the West contributed 2611 admissions (24.4%), 12 hospitals from the Midwest contributed 2412 admissions (22.5%), and 6 PHIS hospitals from the Northeast contributed 1180 admissions (11.0%). Eighty-two percent (*n* = 2277) of patients were female. The mean age at the time of the index admission was 14.2 ± 2.9 years. A total of 1100 patients were white (39.6%) and 982 patients were African American (35.4%); 5.3% (*n* = 148) were Asian. African-American patients were overrepresented in the

TABLE 1 Demographic Characteristics of Study Cohort

Characteristic	Patients With ≥1 Admission (<i>n</i> = 2775)	Admissions (<i>N</i> = 10 724)
Female, <i>n</i> (%)	2277 (82.1)	8799 (82.1)
Age at index admission, mean ± SD, y		
3–8	6.2 ± 1.5	6.2 ± 1.4
8–13	11.1 ± 1.4	11.1 ± 1.4
13–18	15.7 ± 1.4	15.7 ± 1.4
>18 ^a	—	19.1 ± 1.0
Race, <i>n</i> (%) [*]		
White	1100 (39.6)	3320 (31.0)
African American	982 (35.4)	4679 (43.6)
Asian	148 (5.3)	543 (5.1)
American Indian/Pacific Islander	62 (2.2)	218 (2.0)
Other/unknown	355 (12.8)	1461 (13.6)
Ethnicity, <i>n</i> (%)		
Hispanic or Latino	737 (26.6)	2617 (24.4)
Not Hispanic or Latino	936 (33.7)	4449 (41.5)
Other/unknown	1102 (39.7)	3658 (34.1)
Medical insurance type, <i>n</i> (%)		
Government	1477 (53.2)	6477 (60.4)
Private	886 (31.9)	2958 (27.6)
Self-pay	74 (2.7)	197 (1.8)
Other ^b /unknown	279 (10.1)	711 (6.6)
Location of PHIS hospitals, <i>n</i> (%)		
South	1112 (40.1)	4521 (42.2)
West	658 (23.7)	2611 (24.4)
Midwest	633 (22.8)	2412 (22.5)
Northeast	372 (13.4)	1180 (11.0)

^a Study sample limited to those aged 3 to <18 years at index admission.

^b Includes no charge and other.

* Multiple responses per patient.

SLE population (*P* < .001), constituting 43.6% of patients admitted with SLE, compared with 21.1% of patients overall in the PHIS. More than one-quarter of patients (*n* = 737 [26.6%]) were Hispanic. Eighty-five percent of patients (*n* = 2363) had insurance, with more than one-half supported by public insurance inclusive of Medicare, Medicaid, Title V, and other government sources (*n* = 1477 [53.2%]). Nearly 32% of patients (*n* = 886) had private insurance.

More than one-half of patients (*n* = 1515 [54.6%]) were assigned ≥1 ICD-9 code for renal disease at least once during the study period. A total of 160 patients (5.8%) developed ESRD, and 98 patients (3.5%) received dialysis at least once during the study period. The South had a larger proportion of SLE patients with renal disease, compared with other US regions combined (19.8% vs 15.4%, *P* < .001).

Validation of SLE Diagnoses

We determined that 65 of 72 patients (positive predictive value: 90%) hospitalized at our institution met American College of Rheumatology criteria for the diagnosis of SLE. Two of the patients who were assigned codes for SLE but did not meet clinical criteria were ages 3 and 4 years with neonatal lupus who were admitted for cardiac procedures. Two other patients had diagnoses of mixed connective tissue disease. Two diagnoses of SLE had been conferred by outside providers, which we were unable to confirm at our institution. The last patient had been evaluated for SLE but had an alternative diagnosis (celiac disease).

Admission Characteristics and Hospital Volume

We divided the hospitals into quartiles according to volume to evaluate LOS, readmissions, ICU stays, and mortality.

The mean LOS for all admissions was 5.2 ± 10.7 days. The average follow-up time per patient was 351.8 ± 507.1 days. The range of SLE admissions for high-volume hospitals was 327 to 952 admissions, whereas the range of admissions for low-volume hospitals was 15 to 136 admissions. The hospitals with the highest SLE volume had shorter LOS compared with the lowest-volume hospitals (median of 2 days [minimum = 1, maximum = 366] vs median of 3 days [minimum = 1, maximum = 61], $P < .001$), although readmissions per patient were more frequent in the highest SLE volume hospitals (median of 2 readmissions [minimum = 1, maximum = 84] vs median of 2 readmissions [minimum = 1, maximum = 21], $P = .001$) (Table 2). The high-volume hospitals had a significantly higher proportion of admissions for cyclophosphamide infusions compared with the low-volume hospitals (1207 [22.8%] of 5289 total discharges vs 93 [11.1%] of 836 total discharges, $P < .0001$). Ten percent of all admissions ($n = 1118$) included an ICU stay in 745 patients. A larger proportion of children with SLE at low-volume hospitals were admitted to an ICU, compared with high-volume hospitals, a finding that approached statistical significance ($n = 99$ [11.8%] vs $n = 515$

[9.7%], $P = .06$). Interestingly, a larger proportion of cases were classified as major and as extreme severity of illness in the lowest volume hospitals compared with the highest volume hospitals. However, there was no significant difference in ICU LOS, nor was there a difference in severity of illness indices among ICU admissions ($P = .15$) between the highest and lowest SLE volume hospitals. Lastly, readmissions, ICU admissions, and in-hospital mortality did not differ significantly between patients with renal disease at the highest and lowest SLE volume hospitals.

Overall in-hospital mortality was low at all hospitals at 1.5% ($n = 41$), and hospital volume was not significantly associated with mortality in univariable analysis (Table 2). Five of the patients (11%) who died during the study period had ESRD.

Admission characteristics were assessed according to race and ethnicity. Hispanic patients, compared with non-Hispanic patients, had longer LOS, more readmissions, and higher in-hospital mortality (Table 3).

Outcomes

We investigated the association of sociodemographic factors, insurance

type, and hospital volume with outcomes, adjusting for severity of illness in a multivariable analysis. African American patients were more likely to have an admission to the ICU during the study period (Table 4). African American and Hispanic patients were significantly more likely to develop ESRD or die during the study period (Fig 1).

DISCUSSION

By using the PHIS database, we described the demographic features and predictors of poor outcomes in a large hospitalized cohort of children with SLE over a 5.5-year period. We found that demographic features were associated with hospitalization characteristics as well as outcomes. Specifically, Hispanic children had longer LOS, more readmissions, longer ICU stays, higher severity of illness indices, and higher in-hospital mortality compared with non-Hispanic children. In multivariable analysis, African American race was associated with ICU admission. Furthermore, we found that African American race and Hispanic ethnicity were associated with developing ESRD or dying. Hospital characteristics recorded at index admission, including location and volume of SLE patients, were not associated with outcomes.

Although pediatric SLE patients have been less thoroughly studied than adults with SLE, some studies show that sociodemographic disparities influence the outcomes of these younger subjects. Levy et al¹⁴ found that Asian and African American patients were more likely to have severe disease compared with white patients. Hiraki et al¹⁵ evaluated outcomes among US children with lupus nephritis—associated ESRD from 1995 to 2006. They found that age, race, ethnicity, insurance, and geographic region were associated with significant variation in 5-year wait-listing for kidney transplantation, undergoing kidney

TABLE 2 Characteristics of All Admissions

Characteristic	Among All Hospitals (<i>N</i> = 10 724)	Highest Quartile SLE Volume Hospitals (<i>n</i> = 5289)	Lowest Quartile SLE Volume Hospitals (<i>n</i> = 836)	<i>P</i> ^a
LOS, median (min, max), d	2 (1, 366)	2 (1, 366)	3 (1, 61)	<.001
Readmissions per patient, median (min, max)	1 (1, 84)	2 (1, 84)	2 (1, 21)	.001
In-hospital mortality, <i>n</i> (%)	41 (0.4)	17 (0.3)	1 (0.1)	.50
ICU admissions, <i>n</i> (%)	1118 (10.4)	515 (9.7)	99 (11.8)	.06
LOS in ICU, median (min, max), d	9 (1, 366)	10 (1, 366)	9 (1, 61)	.19
Severity of illness index, <i>n</i> (%)				<.001
Not applicable	10 (0.1)	5 (0.1)	1 (0.1)	
Minor	2348 (21.9)	1314 (24.8)	132 (15.8)	
Moderate	4302 (40.1)	2224 (42.0)	325 (38.9)	
Major	3192 (29.8)	1357 (25.7)	292 (34.9)	
Extreme	872 (8.1)	389 (7.4)	86 (10.3)	

Hospital volume was divided into quartiles of inpatient SLE admissions per year: max, maximum; min, minimum.

^a *P* values are based on Wilcoxon rank-sum test for LOS and Pearson's χ^2 test for frequencies (percentages); all comparisons are top quartile to bottom quartile.

TABLE 3 Characteristics of All Admissions According to Ethnicity

Characteristic	Hispanic (n = 2617)	Non-Hispanic (n = 4449)	P ^a
LOS, median (min, max), d	3 (1, 366)	2 (1, 169)	<.001
Readmissions per patient, median (min, max)	2 (1, 60)	2 (1, 45)	.004
In-hospital mortality, n (%)	15 (0.6)	9 (0.2)	.001
ICU admissions, n (%)	275 (10.5)	475 (10.7)	.82
LOS in ICU, median (min, max), d	10 (1, 366)	8 (1, 169)	.001
Severity of illness index, n (%)			.003
Not applicable	1 (<0.1)	7 (0.2)	
Minor	624 (23.8)	890 (20.0)	
Moderate	1008 (38.5)	1809 (40.7)	
Major	772 (29.5)	1369 (30.8)	
Extreme	212 (8.1)	374 (8.3)	

max, maximum; min, minimum.

^a P values are based on Wilcoxon rank-sum test for continuous variables and Pearson's χ^2 test for frequencies (percentages).

transplantation, and mortality. Mortality was almost double among African American children compared with white children.

As in the study by Hiraki et al,¹⁵ our study identified sociodemographic

disparities in SLE outcomes in the form of fixed variables (race and ethnicity). Assessment of modifiable factors such as educational level of caregivers, social support, and other psychosocial factors is beyond the scope of the PHIS.

TABLE 4 Patient Characteristics Associated With ICU Admission (n = 2775)

Factor	Adjusted for Severity of Illness		Multivariable ^a	
	Odds Ratio	95% CI	Odds Ratio	95% CI
Gender				
Female	1.0	Ref	1.0	Ref
Male	1.10	0.87–1.39	1.10	0.76–1.59
Age at index admission, y				
13–18	1.0	Ref	1.0	Ref
8–13	0.95	0.77–1.18	1.56	0.77–3.18
3–8	1.89	1.26–2.84	0.91	0.65–1.26
Race ^b				
White	1.0	Ref	1.0	Ref
African American	1.25	1.01–1.53	1.55	1.05–2.29
Asian	1.05	0.69–1.60	1.74	0.91–3.32
American Indian/Pacific Islander	0.10	0.02–0.43	0.07	0.01–0.50
Ethnicity				
Non-Hispanic	1.0	Ref	1.0	Ref
Hispanic	1.23	0.96–1.57	2.07	1.40–3.05
Medical insurance type				
Private	1.0	Ref	1.0	Ref
Government	0.88	0.72–1.08	0.68	0.50–0.92
Self-pay	0.66	0.35–1.23	0.52	0.21–1.29
Hospital volume of SLE				
Quartile 4 (highest)	1.0	Ref	1.0	Ref
Quartile 3	0.99	0.79–1.23	1.04	0.70–1.54
Quartile 2	1.01	0.79–1.29	1.39	0.90–2.13
Quartile 1 (lowest)	0.99	0.72–1.36	1.67	1.04–2.68
Location of PHIS hospital				
South	1.0	Ref	1.0	Ref
Midwest	0.76	0.60–0.96	0.93	0.61–1.43
West	0.69	0.55–0.88	0.81	0.52–1.26
Northeast	0.77	0.58–1.03	0.81	0.50–1.32

CI, confidence interval.

^a Other/unknown variables of ethnicity (n = 1102), race (n = 483), and medical insurance type (n = 338).

^b P < .05 when adjusted for severity of illness.

The significant disparities seen in adult patients with SLE are likely underpinned by both biologic vulnerabilities in female subjects and specific racial/ethnic groups, as well as modifiable factors.¹⁶ Likewise, our findings help to identify specific populations that require further study but do not address all potential contributors to disease severity and poor outcomes in children with SLE.

Volume of SLE patients per hospital has been associated with variation in clinical outcomes in adult studies of SLE. Ward¹⁷ demonstrated that the risk of mortality was lower in SLE patients admitted to hospitals with a higher volume of SLE admissions in California. In our cohort, we found that hospitals with the highest volume of SLE admissions had shorter LOS, likely due to frequent admissions for cyclophosphamide infusions. Lower-volume hospitals had more ICU admissions and higher severity of illness indices across all admissions. It is possible that catchment areas of the low-volume hospitals were larger with patients transferred from non-PHIS hospitals for higher levels of care (ie, ICU). However, severity of illness indices in ICU admissions did not differ between the highest and lowest SLE volume hospitals, corresponding with the findings that ICU LOS and in-hospital mortality rates were not associated with SLE volume.

To assess the accuracy of ICD-9 coding for SLE, we reviewed cases identified by our query at Boston Children's Hospital (access to personal health information from other centers was not possible for privacy reasons). The positive predictive value of selection criteria for this SLE cohort at 90% is comparable to that described in other large database cohorts of adult patients with SLE. For example, Chibnik et al¹⁸ developed a strategy to identify patients with lupus nephritis based on a combination

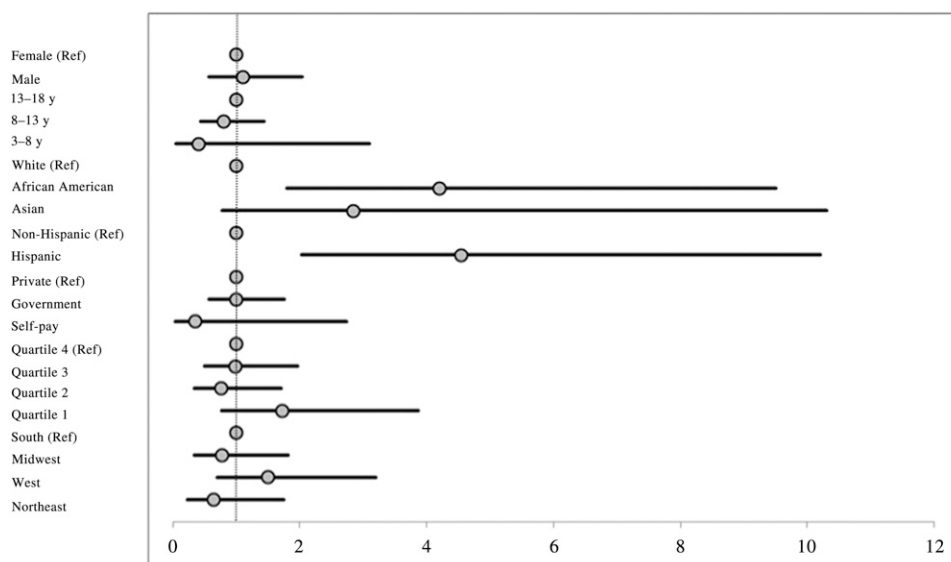


FIGURE 1

In multivariable analysis controlling for severity of illness, African American patients (odds ratio: 4.15 [95% confidence interval: 1.81–9.50]) and Hispanic patients (odds ratio: 4.55 [95% confidence interval: 2.03–10.22]) were at higher risk for ESRD or death during the study period.

of ICD-9 SLE and renal disease codes plus nephrologist encounter claims, which had a positive predictive value of 88%. Although our strategy was simpler, coding for SLE in our cohort seemed reliable, which may be due in part to the presence of at least 1 pediatric rheumatologist at each of the PHIS hospitals.

Slightly more than one-half of the patients in our cohort were assigned diagnostic codes for renal disease, which is within the range of most previous descriptions of SLE renal disease.¹⁹ However, we found a higher percentage compared with a recent study of children with SLE enrolled in the US Medicaid program, in which 37% of patients with SLE had lupus nephritis.²⁰ In that study, which was not restricted to inpatients, ≥ 2 ICD-9 codes for glomerulonephritis, proteinuria, or renal failure each recorded >30 days apart were required for inclusion. Possible explanations for the difference include the more stringent criteria in the study by Hiraki et al¹⁵ or the fact that the Medicaid database encompasses outpatient data as well, thus broadening the SLE population to

those without severe disease (including nephritis).

Few patients in our cohort developed renal failure or required dialysis during the study period. In fact, the number of SLE patients with ESRD in our cohort was low at 5.8% compared with other studies that evaluated children with SLE and lupus nephritis, in which 7.5% to 9% developed ESRD.^{21,22} However, our study had a shorter follow-up time with ~ 1 year per patient, which likely underestimated the true incidence of ESRD. It was not possible to estimate SLE duration for this cohort because admissions are not flagged for new (ie, first-time) diagnoses.

The strengths of our study include the assembly of a relatively large cohort of children with an uncommon disease. Of the rheumatic diseases, SLE is more likely to be associated with hospitalizations given the severity of disease and frequent need for intravenous treatments. As such, the PHIS database is a useful resource to describe the demographic characteristics of the population. The ability of the PHIS to track patients across admissions allowed us to analyze risk of readmission

as well as outcomes over a 5.5-year period.

Our analysis of the association of outcomes with index admission characteristics may be limited by characteristics that change over the study period, such as insurance. Berry et al²³ found that from 2003 to 2008, an increasing number of PHIS admissions per patient was associated with a change in insurance from commercial to public coverage. This finding is likely relevant to our population because chronic diseases are associated with more frequent admissions. As such, an impact of insurance type on outcomes may have been present, but not detected, in our study. However, the primary demographic predictors of outcome, such as race and ethnicity, would not change over the study period. In addition, patients are tracked within 1 hospital, not between hospitals; therefore, neither hospital volume nor location should change.

Excluding children <3 years old may have decreased the number of children in the youngest age bracket. However, neonatal lupus does not have a distinct ICD-9 code, and in the validation set of

patients admitted to our hospital, a few patients aged <3 years were admitted with the diagnosis of SLE but had neonatal lupus. Thus, we chose to exclude children aged <3 years who may have had neonatal lupus rather than SLE.

As with all database studies, our findings are limited by human error in terms of data collection and entry. Identification of a PHIS cohort relies on the accuracy of coding with ICD-9 codes. Race and ethnicity are known to be problematic in administrative databases²⁴ because the data are not collected and documented in standard manners across institutions and because substantial heterogeneity exists within the accepted broad race and ethnicity classifications. These difficulties are reflected in our results, in which 12.8% of patients were classified

as other/unknown race and nearly 40% as other/unknown ethnicity. However, the racial and ethnic representation in our population is similar to that in other reported cohorts of children with SLE.^{2,20} Reliability of coding for severity of illness by using the All Patient Refined–Diagnosis Related Groups is also somewhat user dependent, although clear guidelines exist. The PHIS tracks patients across admissions within the same hospital but is not able to track information for patients who are transferred to other PHIS or non-PHIS hospitals. As such, data from patients transferred to other hospitals cannot be accounted for. Similarly, data on patients who died at non-PHIS hospitals or at home would not have been captured. Lastly, the PHIS does not record parameters of health status (eg,

SLE activity and damage indices) or quality of life surveys. Despite these limitations, the PHIS database has been an excellent data source for studying other uncommon conditions.^{25,26}

CONCLUSIONS

The identification of race and ethnicity as predictors of admission characteristics, ESRD, and death in children with SLE is an important step in addressing the medical needs of this vulnerable population.

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