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Access to Care and the Incidence of Endstage Renal Disease Due to Systemic Lupus Erythematosus

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Abstract

Objective—Persons with low socioeconomic status have an increased risk of endstage renal disease (ESRD) due to systemic lupus erythematosus (SLE), possibly because of limited access to care. We examined if the incidence of ESRD due to SLE was higher in geographic areas with poorer access to care.

Methods—In this population-based ecological study, we tested associations between the incidence of ESRD due to SLE and the proportion of hospitalizations with no insurance, Medicaid or managed care insurance, residence in a primary care-provider shortage area or rural area, and rate of hospitalizations for ambulatory care-sensitive conditions, by ZIP code in California in 1999–2004.

Results—The incidence of ESRD due to SLE was higher in ZIP codes with higher proportions of hospitalizations with no insurance ($r = 0.22$, $p < 0.0001$) or Medicaid ($r = 0.21$, $p < 0.0001$), and in ZIP codes with higher rates of hospitalizations for ambulatory care-sensitive conditions ($r = 0.23$, $p < 0.0001$). In multivariate analyses, incidences were higher in ZIP codes with higher proportions of hospitalizations with Medicaid ($p < 0.0001$) and higher rates of hospitalizations for ambulatory care-sensitive conditions ($p = 0.06$), independent of the socioeconomic status of the ZIP code residents.

Conclusion—The incidence of ESRD due to SLE is higher in areas with higher proportions of residents who have public insurance and higher rates of avoidable hospitalizations, suggesting that limited access to care may contribute to this complication of SLE.

Key Indexing Terms

ACCESS TO CARE; ENDSTAGE RENAL DISEASE; SOCIOECONOMIC STATUS; SYSTEMIC LUPUS ERYTHEMATOSUS

Endstage renal disease (ESRD) requiring treatment with dialysis or renal transplant develops in 4%–17% of patients within 10 years of the diagnosis of lupus nephritis[1–7]. ESRD may develop in patients whose lupus nephritis is treatment-resistant, or when treatment recommendations are not followed. ESRD may also develop because some patients have limited access to medical care and appropriate treatment. Patients in the United States with ESRD due to systemic lupus erythematosus (SLE) who have public insurance or no medical insurance develop ESRD at younger ages than patients with private medical insurance, suggesting that limited access to care shortens the time to ESRD[8]. Also, persons of low

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socioeconomic status (SES) have an increased risk of ESRD due to SLE. In a recent national study, the incidence of ESRD due to SLE was 1.2 to 1.6 times higher among those living in the poorest 25% of neighborhoods in the US than in the wealthiest 25% of neighborhoods9. However, it is not known if the association between the incidence of ESRD and SES is also reflected in similar associations with measures of access to care. Barriers to care may be financial, including factors such as lack of medical insurance; organizational, including limited availability of providers; and behavioral, including uncertainty on the part of patients about when and how to engage with healthcare providers10. In this population-based ecological study, we examined the association of the incidence of ESRD due to SLE and measures of access to care in local areas in California in 1999–2004. We hypothesized that area-based measures of poor access to care would be directly correlated with the local incidence of ESRD due to SLE.

MATERIALS AND METHODS

Study design

This study used an ecological design because area-based measures of SES, access to care, and incidence of ESRD were available, whereas patient-based measures of SES were not available. We studied California because it is the most populous state and because population-based data on hospitalizations in California were available. These hospitalization data provided information on medical insurance coverage and the frequency of hospitalizations for ambulatory care-sensitive conditions, which were used as measures of access to care. We used ZIP codes as the area because this was the smallest geographic unit reported in all data sources.

The study was exempted from human subjects review by the National Institutes of Health Office of Human Subjects Research.

Dependent variable

The incidence of ESRD due to SLE in each ZIP code was the outcome. Data on incident cases of ESRD were abstracted from the United States Renal Data System (USRDS), a national population-based registry with near-universal coverage[11]. Patients are enrolled in this registry by their attending nephrologists after being certified as needing chronic renal replacement therapy. The registry includes patient demographic information, the primary renal disease causing ESRD, the type of renal replacement therapy, and patient outcomes, but does not include information on clinical features or treatment before the onset of ESRD. We tabulated the number of patients with incident treated ESRD due to SLE from January 1, 1999, to June 30, 2004, who resided in California. We limited the analysis to patients age 20 years or older, because measures of access may have different associations with risk of ESRD in children. We used data from these patients (N = 702; mean age 40.6 years ± SD 13.9; 80.5% women; 55.7% white, 24.9% black, 17.1% Asian) to compute incidences by ZIP code, which were then standardized to the age (10-year age groups), sex, and race distribution of the California population in 2000.

Independent variables

The SES of residents of each ZIP code was estimated using a previously validated composite measure of economic and educational indicators based on US census data9,[12]. The SES score is the sum of 7 z scores, each z score indicating the number of standard deviations above or below the national average each ZIP code lies on one of 7 census indicators. A ZIP code at the national average for all indicators would have an SES score of 0, while those with high positive scores would be substantially above the mean and those with large negative scores would be below the mean on most indicators. For example, residents of ZIP codes with an SES score of 6.43 (the 80th percentile of ZIP codes in California) had a median household income of

$66,873, 12% had incomes below 200% of the federal poverty level, and 42.8% were college graduates. Residents of ZIP codes with an SES score of −1.11 (the 20th percentile of ZIP codes in California) had a median household income of $34,315, 35% had incomes below 200% of the federal poverty level, and 12.9% were college graduates, based on US 2000 census data.

We examined 6 measures of access to care in each ZIP code: proportion of hospitalizations in which patients had no medical insurance; proportion of hospitalizations with Medicaid (a publicly funded insurance program for people with low income); proportion of hospitalizations with managed care insurance (insurance plans with administrative control over primary care services, often emphasizing coordination of care and disease prevention); rate of hospitalizations for ambulatory care-sensitive conditions; rural location; and designation as a primary care shortage area.

Data on the 3 insurance measures were based on hospital discharge data from the California Office of Statewide Health Planning and Development. This office mandates that all acute-care nonfederal hospitals in California report discharge abstracts on each hospitalization. The discharge abstracts include patient demographic characteristics, ZIP code, principal diagnosis (defined as the condition chiefly responsible for the hospitalization), up to 24 additional diagnoses, and disposition. Discharge abstracts are prepared from medical and billing records by trained abstractors. Data are subjected to extensive reliability checks, and reabstraction studies that compared these discharge abstracts with original medical records have found the specificities for diagnoses were 0.98 to 1.00, and sensitivities were 0.88 to 1.0013،14. We pooled hospital discharge data from 2001 to 2004, and divided the number of hospitalizations among patients age 20 years and older with no insurance, Medicaid, or managed care insurance by the total number of hospitalizations among these patients, by ZIP code, to obtain the proportion of hospitalizations covered by each type of insurance. Data from 1999 and 2000 could not be included because only partial (3-digit) ZIP codes were provided during these years.

We also used the hospital discharge data to estimate rates of hospitalizations for ambulatory care-sensitive conditions. Ambulatory care-sensitive hospitalizations are hospitalizations for conditions that in most cases could have been prevented or successfully treated in the outpatient setting if appropriate monitoring and care had been provided15،16.We used the definition of Weissman and colleagues, which considered hospitalizations with a principal discharge diagnosis of one of 12 specific conditions (such as congestive heart failure, diabetes mellitus out of control, hypokalemia, and malignant hypertension) to be for ambulatory care-sensitive conditions[15]. We pooled data on all hospitalizations from 2001 to 2004 among patients age 20 and older, and computed rates of hospitalizations for ambulatory care-sensitive conditions (per million per year) for each ZIP code. High rates of hospitalizations for ambulatory care-sensitive conditions have been widely accepted as indicators of inadequate access to primary care17.

We used the US Department of Agriculture Rural-Urban Commuting Area database to classify each ZIP code as rural (code 9 or 10) or urban (codes 1–8)[18]. Lastly, we used the Health Professional Shortage Area database of the US Department of Health and Human Services Health Resources and Services Administration to identify census tracts in California that had been designated as primary care shortage areas19. The criteria for this designation include a population to primary care physician ratio of 3500:1 or higher, and barriers to accessing care in neighboring areas. We mapped these census tracts to ZIP codes, and classified ZIP codes as primary care shortage areas if they had this designation at any time from 1999 to 2004.

Statistical analysis

Because the incidence data were highly skewed, with many ZIP codes having incidences of 0, we used Spearman correlations (for univariate analysis) and median regression (for

multivariate analysis) to examine associations between incidence and measures of access to care. Median regression differs from ordinary least-squares regression in that the model tests the associations with the conditional median rather than the conditional mean. It is robust to extreme values of the dependent variable, and does not require specific assumptions about the distribution of the model's error term. Regression models were weighted by the population in each ZIP code so that more populous ZIP codes contributed more to the associations than less populated ZIP codes. We used Wilcoxon rank-sum tests to compare incidences between rural and urban ZIP codes and between those that were in primary care shortage areas and those that were not. Analyses were performed using SAS programs (version 9.1; SAS Inc., Cary, NC, USA). All hypothesis tests were 2-tailed, and p values < 0.05 were considered statistically significant.

Because ESRD due to SLE is a rare condition, the incidence may be 0 in a sparsely populated ZIP code simply by chance, rather than reflecting good access to care. Including these ZIP codes might obscure true associations with measures of access to care. Therefore, we also analyzed associations between incidences and measures of access to care among ZIP codes with populations of 4000 or more. The criterion of 4000 was chosen based on a receiver-operating characteristic curve analysis as a level that maximized the specificity (0.50) of the association between ZIP code population size and incidences greater than 0, while retaining high sensitivity (0.975). ZIP codes with populations less than 4000 comprised 50% of ZIP codes with an incidence of ESRD due to SLE of 0, but only 2.5% of the ZIP codes with an incidence greater than 0.

RESULTS

Among 1681 ZIP codes, the mean population was 13,515 (median 9715; 25th percentile 1179; 75th percentile 22,857). SES scores ranged from −17.1 to 18.0 (median 1.8), indicating inclusion of both very poor and very wealthy areas. The proportion of hospitalizations with no medical insurance ranged from 0% to 50% among ZIP codes (median 1.5%; mean 2%), the proportion with Medicaid ranged from 0% to 100% (median 12.6%; mean 17%), and the proportion with managed care insurance ranged from 0% to 83% (median 23.3%; mean 24.5%). Annual rates of hospitalizations for ambulatory care-sensitive conditions among ZIP codes ranged from 0 to 200,000 hospitalizations per million (median 5162 hospitalizations per million). Two hundred forty-two (14.5%) ZIP codes were rural, and 169 (10%) were designated as primary care shortage areas at some time during the study years.

The average annual incidence of ESRD due to SLE was 7.3 per million persons, with a range from 0 to 1871 per million among ZIP codes (median 0 per million; 75th percentile 1.9 per million). Among all ZIP codes, the incidence was higher in ZIP codes with lower SES scores, and was higher among ZIP codes with higher proportions of hospitalizations with no insurance, Medicare, and managed care insurance (Table 1). In addition, incidences were higher in ZIP codes with higher rates of hospitalizations for ambulatory care-sensitive conditions. These associations indicate that the incidence of ESRD due to SLE is related to area-based measures of access to care. However, there was no significant difference in incidences between rural and urban ZIP codes (12.0 per million vs 6.6 per million, respectively; $p = 0.52$) or between ZIP codes that were primary care shortage areas and those that were not (23.0 per million and 5.6 per million; $p = 0.32$).

Results were similar among ZIP codes with populations of 4000 or more, except that in this analysis, the incidence of ESRD due to SLE was not associated with the proportion of hospitalizations with managed care insurance (Table 1). Among ZIP codes with populations of 4000 or more, there were also no significant differences in incidences between rural and urban ZIP codes (30.0 per million vs 8.1 per million, respectively; $p = 0.35$) or between ZIP

codes that were primary care shortage areas or not (24.0 per million vs 7.0 per million; p = 0.23).

In the multivariate analysis that included data for all ZIP codes, the incidence of ESRD due to SLE was strongly associated with the proportion of hospitalizations with Medicaid; the incidence was estimated to be 13.1 per million higher if Medicaid was the type of insurance for all hospitalizations than if no hospitalizations had Medicaid as the type of insurance (Table 2). The proportions of hospitalizations with managed care insurance and no insurance were not associated with the incidence of ESRD due to SLE. The incidence was marginally higher among ZIP codes with higher rates of hospitalizations for ambulatory care-sensitive conditions, even after adjusting for the insurance measures. Adjusting for measures of access to care reversed the association between the SES score and the incidence of ESRD due to SLE. In an unadjusted analysis, each 1-point increment in SES score (indicating wealthier ZIP codes) was associated with a decrease in the median incidence by 0.2 per million ($p < 0.0001$); whereas in the adjusted analysis, each 1-point increase in SES score was associated with a slight increase in median incidence of 0.06 per million ($p = 0.05$).

The proportion of hospitalizations with Medicaid insurance was also the most important correlate of variations in the incidence of ESRD due to SLE among ZIP codes with a population of 4000 or more (Table 2). In this subset of ZIP codes, the other insurance measures and rates of hospitalizations for ambulatory care-sensitive conditions were not associated with the incidence of ESRD. Adjusting for measures of access to care also reduced the association between the SES score and the incidence of ESRD due to SLE in this analysis. In an unadjusted analysis, each 1-point increment in SES score was associated with a decrease in the median incidence by 0.25 per million ($p < 0.0001$), while in the adjusted analysis, each 1-point increment in SES score was associated with a minimal increase in median incidence of 0.04 per million ($p = 0.37$).

DISCUSSION

Despite improvements in the treatment of lupus nephritis and advances in the management of associated conditions such as hypertension, the incidence of ESRD due to SLE has not decreased over the past 15 years[20,21]. One possible explanation for this paradox is that not all patients are receiving appropriate treatment, or are receiving treatment too late in the course of lupus nephritis to have its full benefit[4,22]. ESRD due to SLE is more common among people who live in poorer areas, suggesting, but only indirectly, that the risk of ESRD may be related to poorer access to care[9]. This study indicates that the incidence of ESRD due to SLE is linked to small-area variations in measures of access to care, particularly with higher prevalences of Medicaid coverage and hospitalizations for ambulatory care-sensitive conditions. These associations with measures of access to care were present over and above those of socioeconomic status.

Gaining access to medical care is a coordinated process that depends on several interdependent components, including a patient's ability to recognize the need for evaluation and followup care, to locate and travel to a provider, and to pay for or have insurance to cover the costs of care10. Financial barriers, including both the absence of medical insurance and restrictions related to the type of insurance, are often considered among the most important barriers, because these may influence decisions to seek treatment in the first place, and influence the distance needed to travel to obtain care. Areas with Medicaid insurance for a higher proportion of hospitalizations had higher incidences of ESRD due to SLE, suggesting that the coverage afforded by Medicaid was not sufficient to allow access to the types of care or quality of care available to residents of areas with a lower prevalence of Medicaid insurance. In 2001, only 50% of primary care physicians in California accepted new patients who had Medicaid

insurance, and access to specialists was much lower among patients with Medicaid than among the general population23. Patients with SLE who have Medicaid insurance have been reported to be as likely as those with other types of insurance to have seen a rheumatologist or to identify a rheumatologist as the primary provider of their SLE-related care, but patients with Medicaid see generalists more often and use hospital emergency departments as sources of care[24,25]. ZIP codes with higher proportions of hospitalizations with no insurance or managed care coverage were also associated with higher incidences of ESRD due to SLE in univariate analyses, but were not associated after adjusting for the prevalence of Medicaid-covered hospitalizations. The proportion of hospitalizations with Medicaid was correlated with the proportion of hospitalizations with no insurance ($r = 0.44$, $p < 0.0001$) and inversely correlated with the proportion of hospitalizations with managed care insurance ($r = -0.34$, $p < 0.0001$). The variation in Medicaid-covered hospitalizations among ZIP codes likely accounted for the variation in these measures in the multivariate analysis.

The rate of hospitalizations for ambulatory care-sensitive conditions is a measure that integrates many aspects of access to care, because it can represent the presence of financial or organizational barriers to care as well as limitations in patient's knowledge and motivation to seek care at appropriate times[17]. Incidences of ESRD due to SLE tended to be higher in ZIP codes with higher rates of hospitalizations for ambulatory care-sensitive conditions, even after adjusting for insurance characteristics, suggesting that organizational and educational/ behavioral barriers may also contribute to progression to ESRD among patients with lupus nephritis. The incidence of ESRD due to SLE was not associated with rural location or residence in a primary care shortage area, despite the finding in previous studies that areas with lower densities of physicians have higher rates of all-cause ESRD[26]. The most common causes of ESRD are diabetes mellitus and hypertension; ESRD due to these conditions is largely preventable, and therefore may be more closely linked to the availability of primary care providers than ESRD due to SLE. Patients with uncommon conditions such as SLE may also be more willing to travel long distances to obtain care, thereby minimizing associations with geographic barriers to care[25].

The few previous studies that examined associations between barriers to care and health outcomes in patients with SLE reported mixed associations. Having no medical insurance or Medicaid was associated with poorer physical and mental health status, but was not associated with the severity of permanent organ damage, in a cross-sectional study of 200 patients by Karlson and colleagues[27]. Patients who reported greater satisfaction with their access to care had higher levels of permanent organ damage in a cross-sectional British study[28].We previously reported that organizational barriers to care were significantly associated with worse physical functioning, and that absence of medical insurance was associated with more severe organ damage, in a cross-sectional study of 100 patients in California[29]. In contrast, poor adherence to treatment has been consistently associated with an increased risk of renal damage in patients with SLE[30,32]. Financial and organizational barriers have a major influence on medication adherence and patients' ability to keep appointments, and the effects of barriers to care on health outcomes may be mediated by factors such as adherence and helplessness[27, 33].

The strengths of this study include the large population-based sample and testing of several different measures of access to care. We also repeated the analysis using only ZIP codes with large populations to exclude the possibility that associations with measures of access to care had been obscured by the low incidence of ESRD due to SLE. This analysis did not reveal any new associations. However, the study has some limitations. We could include only one purely organizational barrier to care (residence in a primary care shortage area), as measures of access to specialists, wait times for appointments, distance traveled to appointments, and other measures of ease of obtaining care were not available. However, rural location was used as a

surrogate measure of distance traveled to receive care, and hospitalizations for ambulatory care-sensitive conditions encompass organizational as well as financial barriers. Although the incidences of ESRD due to SLE were adjusted for age, sex, and race, there were too few patients to test if associations were similar among patient subgroups. Lastly, the study was ecological, and associations present at the group level may not be present at the patient level. Cohort studies that examine the risk of ESRD in relation to measured barriers to care are needed to test this association further.

At the population level, measures of limited financial access to care were associated with higher incidences of ESRD due to SLE. Limitations in access to care may be one factor that explains the observation that the incidence of ESRD due to SLE has not decreased despite advances in the treatment of patients with lupus nephritis. Efforts to decrease rates of ESRD should include measures to ensure access to care before complications such as ESRD occur.

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Table 1

Correlations between ZIP code-based measures of access to care and the incidence of endstage renal disease due to SLE in California, 1999–2004.

	All ZIP Codes		ZIP Codes with Population ≥ 4000	
	r	p	r	p
SES score*	−0.05	0.02	−0.14	< 0.0001
Proportion of hospitalizations with no insurance	0.22	< 0.0001	0.16	< 0.0001
Proportion of hospitalizations with Medicaid	0.21	< 0.0001	0.24	< 0.0001
Proportion of hospitalizations with managed care insurance	0.13	< 0.0001	−0.02	0.55
Rate of hospitalizations for ambulatory care-sensitive conditions	0.23	< 0.0001	0.10	0.002

* SES: socioeconomic status; higher scores indicate wealthier areas.

Table 2

Association of measures of access to care and the incidence of endstage renal disease due to SLE; multivariate median regression analysis.

	All Zip Codes		ZIP Codes with Population ≥ 4000	
	Change in Median Incidence* (95% CI)	p	Change in Median Incidence* (95% CI)	p
SES score†	0.06 (0, 0.11)	0.05	0.04 (−0.05, 0.13)	0.37
Proportion of hospitalizations with no insurance	15.8 (−15.7, 47.4)	0.33	19.9 (−29.2, 69.1)	0.43
Proportion of hospitalizations with Medicaid	13.1 (9.4, 16.9)	< 0.0001	12.4 (7.3, 17.6)	< 0.0001
Proportion of hospitalizations with managed care insurance	2.1 (−0.5, 4.8)	0.12	1.7 (−2.4, 5.9)	0.41
Rate of hospitalizations for ambulatory care-sensitive conditions	68.3 (−2.4, 139.1)	0.06	53.3 (−58.5, 165.2)	0.94

*Changes in median incidence (new cases per million), per 1-unit increase in the level of the independent variable.

†SES: socioeconomic status; higher scores indicate wealthier areas.