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LUPUS NEPHRITIS MORTALITY BY SEX, AGE, GEOGRAPHIC REGION, URBANIZATION, AND RACE/ETHNICITY: A NATIONWIDE POPULATION-BASED STUDY

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Background Kidney involvement is common in lupus. Lupus and kidney diseases incur poor outcomes in people from racial/ethnic minority groups. Previous studies have utilized the national registry of patients with end-stage renal disease (ESRD) to examine mortality in lupus nephritis. However, the ESRD database may not have lupus nephritis patients who may have died of infections or other complications prior to developing ESRD. There are a few population-based studies, but they are limited to small regions with a small sample size. There are no nationwide population-based studies on causes of death in all, unselected, patients with lupus nephritis across the entire U.S. population.

Objective Assess the impact of demographic and geographic determinants on lupus nephritis mortality.

Methods We performed an ecologic study using United States population-based data from the Center for Disease Control and Prevention using Multiple-Cause-of-Death datafiles. We obtained data on lupus nephritis deaths using ICD-10 codes for SLE + a renal condition that could occur in patients with SLE, overall and by sex, three age groups, four census regions, six urban-rural codes, and 5 race/ethnic groups. We calculated age-standardized mortality rate (ASMR), and performed logistic regression analysis including interactions to assess any effect modification.

Results From 1999 through 2019, 8,899 deaths were attributed to lupus nephritis. The top 10 underlying cause of death recorded among 8,899 lupus nephritis deaths were SLE (62.5%), ischemic heart disease (9.7%), kidney conditions (5.5%), infections (3.3%), neoplasms (2.2%), cerebrovascular disease (1.4%), diabetes mellitus without organ complications (1.0%), chronic lower respiratory disease (0.9%), accidents/poisoning (0.8%), and chronic liver disease (0.8%). Lupus nephritis ASMRs were significantly higher in females than males (2.16 [95% confidence interval, 2.11 to 2.21] vs 0.41 [0.38 to 0.43] per million persons), in ≥ 65 -year age group followed by 45–64 and ≤ 44 -years age groups, and in South census region followed by the West, and Midwest/Northeast regions. Lupus nephritis ASMRs were higher in large central metro areas (inner cities) than in all other regions and in black persons than in other race/ethnicities. Non-Hispanic black persons had the highest lupus nephritis ASMR (4.28 [4.13 to 4.42]), followed by American Indian/Alaska Natives (1.90 [1.50 to 2.38]), Hispanics (1.56 [1.46 to 1.65]), Asian/Pacific Islanders (1.42 [1.28 to 1.56]), and non-Hispanic white persons (0.70 [0.67 to 0.72]). Multivariable logistic regression analysis showed that the adjusted odds of lupus nephritis deaths were the highest in large central metro (inner cities) and the lowest in large fringe metro (suburbs), and in non-Hispanic black persons than in all other race/ethnic groups. Furthermore, significant interactions between urbanization and race/ethnicity modified the risk of renal lupus mortality. The largest disparity was seen in Hispanic persons in inner cities who had a 15.1-times the odds of death compared to white persons.

Black persons had 4.6 to 4.9 times the odds of death from renal lupus compared to white persons, regardless of their rural-urban region. White persons experienced the highest odds of death in nonmetro, black persons and Hispanic persons in inner cities, Asian/Pacific Islanders in medium metro, and American Indians/Alaska Natives in small metro and non-metro areas.

Conclusions We report substantial differences in lupus nephritis mortality rates by sex, age, geographic region, urbanization level, and race/ethnicity. This study suggests strong, independent and interactive, association between urban-rural residence and race/ethnicity on lupus nephritis mortality. Urbanization modified the impact of race/ethnicity on the risk of death from lupus nephritis. These findings demand research and policy planning to address healthcare access and sociodemographic factors in the highest renal lupus mortality risk groups, such as Hispanic persons in large central metro, white persons in nonmetro, Asian/Pacific Islanders in medium metro, and American Indian/Alaska Natives in small metro and non-metro areas. The high renal lupus mortality in black persons across all regions warrants prospective analyses of individual/biologic factors as well as differential healthcare in this subpopulation.

Achieving Equity in Lupus Care & Outcomes

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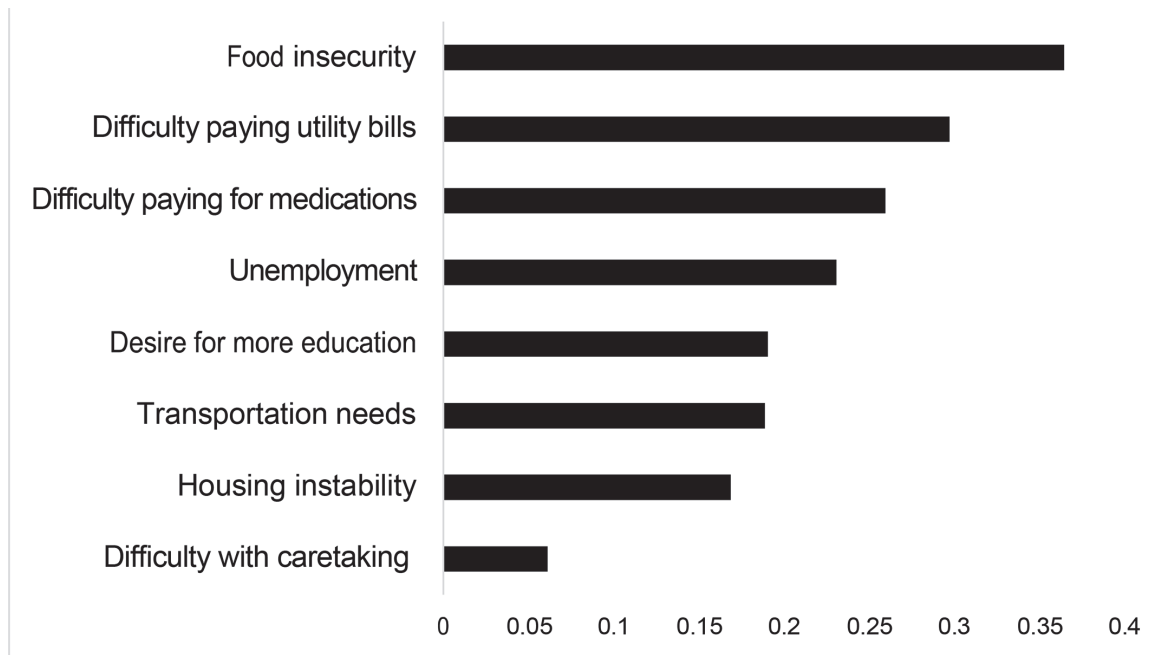
RHEUMATOLOGY-BASED SOCIAL DETERMINANTS OF HEALTH SCREENING TO UNCOVER AND ADDRESS NEEDS

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Background Social determinants of health (SDoH) contribute to inequities in rheumatic disease care and outcomes especially among individuals with rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE). Most SDoH screening occurs in primary care where resources may exist to meet related needs. Individuals with systemic rheumatic conditions receive extensive care in the subspecialty setting where SDoH are infrequently documented and infrastructure to address needs is often lacking. We implemented SDoH screening in 9 rheumatology clinics to determine feasibility, associated factors, and the ability to address SDoH in a subspecialty setting.

Methods We implemented an electronic health record-based SDoH questionnaire at e-check in, or on arrival with an iPad, at 3 hospital-based adult rheumatology clinics and 6 satellite clinics. We focused on patients with ≥ 1 ICD-10 codes for systemic rheumatic conditions with manifestations of inflammatory arthritis (e.g., RA and SLE). Patients screened within the year in primary care were not rescreened, however our team responded to incompletely addressed needs. Patients who indicated SDoH needs received resource sheets in their primary language and those requesting assistance received outreach from the rheumatology-based community resource specialist (rCRS). Rheumatologists and primary care physicians were



Abstract 102 Figure 1 Percentage of rheumatology patients with specific SDoH needs among those indicating any need (N=1,143)

Abstract 102 Table 1 Characteristics of patients screened and odds ratios (OR, 95% CI) for presence of one or more SDoH need vs. no needs from multivariable logistic regression models

Characteristics ⁺	Overall screened (N=7,146)	≥1 SDoH need (N=1,143)	No SDoH needs (N=6,003)	OR [#] (95% CI)
Age – mean (SD)	58 (16)	54 (15)	58 (16)	0.98 (0.98-0.99)
Female – N (%)	5,518 (77)	932 (17)	4,586 (83)	1.11 (0.93–1.32) Reference=Male
Race - N (%)				
White	5,836 (82)	736 (13)	5,100 (87)	Reference
Black/African American	379 (5)	139 (37)	240 (63)	3.21 (2.54-4.07)
Asian	309 (4)	45 (15)	264 (85)	0.98 (0.70–1.39)
More than one race	84 (1)	34 (40)	50 (60)	3.10 (1.93-4.97)
Other/Missing ⁺⁺	538 (8)	189 (35)	349 (65)	1.69 (1.29-2.22)
Ethnicity – N (%)				
Non-Hispanic	6,125 (86)	886 (14)	5,239 (86)	Reference
Hispanic	484 (7)	204 (42)	280 (58)	1.64 (1.23-2.20)
Unknown/Other	537 (8)	53 (10)	484 (90)	0.63 (0.46-0.85)
Primary Language – N (%)				
English	6,864 (96)	1,011 (15)	5,853 (85)	Reference
Spanish	162 (2)	96 (59)	66 (41)	2.69 (1.78-4.06)
Other/Declined	120 (2)	36 (30)	84 (70)	2.21 (1.43-3.41)
Insurance - N (%)				
Commercial	4,599 (64)	602 (13)	3,997 (87)	Reference
Medicaid	455 (6)	228 (50)	227 (50)	4.04 (3.25-5.04)
Medicare	2,061 (29)	303 (15)	1,758 (85)	1.67 (1.39-2.00)
Other/Missing	31 (0.4)	10 (32)	21 (68)	2.41 (1.07-5.43)
Rheumatic Condition* - N(%)				
Osteoarthritis	754 (11)	106 (14)	648 (86)	Reference
Rheumatoid arthritis	3,640 (51)	577 (16)	3,063 (84)	1.15 (0.90–1.45)

SLE and Connective Tissue Diseases	1,089 (15)	218 (20)	871 (80)	1.23 (0.94–1.62)
Other inflammatory arthritis	1,056 (15)	142 (13)	914 (87)	1.03 (0.78–1.38)
Vasculitis, Myositis, Behcet's, PMR	183 (3)	21 (11)	162 (89)	0.83 (0.49–1.41)
Crystalline arthritis	111 (2)	11 (10)	100 (90)	0.79 (0.40–1.57)
Other	313 (4)	68 (22)	245 (78)	1.34 (0.93–1.92)
Social Vulnerability Index** – N (%)				
Quartile 1- Least vulnerable	2,138 (35)	240 (11)	1,898 (89)	Reference
Quartile 2	1,775 (29)	207 (12)	1,568 (88)	1.45 (0.43–4.82)
Quartile 3	1,363 (22)	279 (20)	1,084 (80)	2.63 (0.83–8.28)
Quartile 4- Most vulnerable	811 (13)	290 (36)	521 (64)	4.92 (1.43-16.92)

[#]Primary multivariable logistic regression model includes age, gender, race, ethnicity, primary language, insurance, and rheumatic condition. Odds ratios (ORs) for the social vulnerability index are from a separate multilevel, multivariable logistic regression model adjusted for age, gender, race, and ethnicity.

⁺Overall percentages are by column, SDoH percentages are by row within overall characteristic-specific Ns; all categories except rheumatic condition demonstrate statistically significant differences (p<0.01) between ≥1 SDoH need vs. no need using descriptive statistics

⁺⁺Other includes Native Hawaiian and other Pacific Islander and American Indian/Alaska Native due to small sample size and individuals who indicated Other or declined to answer

^{*}Mutually exclusive categories for analyses (i.e., if a person had a systemic rheumatic condition and osteoarthritis, they were identified as having the systemic rheumatic condition)

^{**}Social vulnerability index quartiles restricted to addresses in MA (N=6,087) and uses MA-based references

Abstract 102 Table 2 Rheumatology-based Community Resource Specialist (rCRS) Activities to Address Social Determinants of Health (SDoH) Needs

SDoH Need	# Reached by rCRS*	Categories of Services Provided by rCRS
Food insecurity	81	<ul style="list-style-type: none"> • Determination of eligibility for state and federal programs • Assistance with SNAP and patient assistance program applications • Assistance with packaged meal delivery application to community-based organization • Connection with local food pantries
Difficulty paying utility bills	76	<ul style="list-style-type: none"> • Facilitation of access to utility payment assistance programs (e.g., Low Income Home Energy Assistance Program) • Review of finances and monthly bills to plan payments
Difficulty paying for medications	72	<ul style="list-style-type: none"> • Connection with organizations such as GoodRx and NeedyMeds for copayment assistance • Connection with multihospital-based specialty pharmacy program staff members • Connection with pharmaceutical company patient assistance programs when indicated • Aid in determining whether certain over the counter medications could be more affordable with prescriptions and conveying this to providers
Transportation needs	49	<ul style="list-style-type: none"> • Assistance with PT-1 applications • Connections with local public transportation ADA services • Providing information on other transportation assistance programs including Age Strong Commission Shuttle, The RIDE/RIDE Flex and planning ways to help them get to rheumatology or other subspecialty appointments
Housing instability	34	<ul style="list-style-type: none"> • Consultation with Harvard Center for Health Law and Policy Innovation housing legal expert for guidance regarding tenants' rights in MA • Aid with CHAMP, RAFT and Section 8 housing applications • Providing contact information for organizations providing volunteer legal services • Obtaining housing letters from rheumatologists and primary care providers
Unemployment	38	<ul style="list-style-type: none"> • Connection with local hiring offices in their respective towns and with job listing websites
Desire for more education	39	<ul style="list-style-type: none"> • Investigating training programs based on patients' needs and loan/payment assistant programs for these programs
Difficulty with child/family-caretaking responsibilities	17	<ul style="list-style-type: none"> • Referrals to elder services/Council on Aging • Assistance with SSDI application • Research into local early education resources (e.g., HeadStart, YMCA, private preschools) and providing them to patients

*Patients who indicated having ≥ 1 SDoH need and asked for assistance addressing needs were referred to the rCRS

Table 2. Rheumatology-based Community Resource Specialist (rCRS) Activities to Address**Social Determinants of Health (SDoH) Needs**

SDoH Need	# Reached by rCRS*	Categories of Services Provided by rCRS
Food insecurity	81	<ul style="list-style-type: none"> • Determination of eligibility for state and federal programs • Assistance with SNAP and patient assistance program applications • Assistance with packaged meal delivery application to community-based organization • Connection with local food pantries
Difficulty paying utility bills	76	<ul style="list-style-type: none"> • Facilitated access to utility payment assistance programs (e.g., Low Income Home Energy Assistance Program) • Reviewed finances and monthly bills to plan payments
Difficulty paying for medications	72	<ul style="list-style-type: none"> • Connected patients with organizations such as GoodRx and NeedyMeds • Introduced patients to multihospital-based specialty pharmacy program members • Connected patients with pharmaceutical company patient assistance programs when indicated • Helped determine whether certain over the counter medications could be more affordable with prescriptions and conveyed this to providers
Transportation needs	49	<ul style="list-style-type: none"> • Assistance with PT-1 applications • Connections with local public transportation ADA services • Provided patients with information on other transportation assistance programs including Age Strong Commission Shuttle, The RIDE/RIDE Flex and planned ways to help them get to rheumatology or other subspecialty appointments
Housing instability	34	<ul style="list-style-type: none"> • Consulted with Harvard Center for Health Law and Policy Innovation housing legal expert for guidance regarding tenants' rights in MA • Helped patients with CHAMP, RAFT and Section 8 housing applications • Provided contact information for organizations providing volunteer legal services • Obtained housing letters from rheumatologists and primary care providers
Unemployment	38	<ul style="list-style-type: none"> • Connected patients with local hiring offices in their respective towns and with job listing websites
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informed of their patients' needs and actions taken to address them. We assessed prevalence of SDoH needs, used multivariable logistic regression to examine factors associated with ≥ 1 SDoH need (vs. 0), and used multilevel, multivariable logistic regression to examine the association between census tract social vulnerability index (SVI) quartile and presence of needs, adjusting for demographics. We categorized actions taken by the rCRS.

Results From 6/23/22–4/18/23, 7,146 adults (≥ 18 years) completed the SDoH questionnaire. 6,309 (88%) were associated with rheumatology visits, 837 (12%) with primary care and re-reviewed in rheumatology. There were 2,015 SDoH needs among 1,143 (16%) patients; 120 others requested resources without specifying needs. SDoH needs varied by demographic factors and insurance status (table 1). 417 (36% of patients with needs) indicated food insecurity, 340 (30%) had difficulty paying utility bills, 297 (26%) had difficulty paying for medications (figure 1). We observed significantly higher odds of ≥ 1 SDoH need vs. no needs among Black (vs. White) and Hispanic (vs. non-Hispanic) individuals, Medicaid, and Medicare beneficiaries (vs. Commercially insured) and Spanish speakers (vs. English) (table 1). We did not observe statistically significant differences in burden of needs by rheumatic condition. While SDoH needs were present among individuals in all neighborhoods, living in the most vulnerable SVI quartile (vs. the least) was associated with 4.92 times higher odds (95% CI 1.43–16.92) of SDoH needs. The rCRS connected patients to varied resources to address needs (table 3).

Conclusions Screening and addressing SDoH in rheumatology clinics is feasible and has revealed a significant burden of needs not being met elsewhere. While needs were concentrated among individuals living in more vulnerable neighborhoods and among historically marginalized populations, they were not limited to these groups suggesting the importance of inclusive screening and connections to resources to improve care for all patients.

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A NOVEL, COMMUNITY-ENGAGED APPROACH TO ENCOURAGE DIVERSE PATIENT PARTICIPATION IN LUPUS CLINICAL TRIALS

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Background Efforts to encourage and increase diverse patient participation in lupus clinical trials (LCTs) require novel approaches to address complex patient and provider level barriers. To address these unmet needs, the American College of Rheumatology (ACR) developed the Training to Increase Minority Enrollment in Lupus Clinical Trials with CommunityY Engagement (TIMELY) program. TIMELY seeks to engage and improve how healthcare providers (providers) and community health workers (CHWs) discuss LCTs with diverse patients living with lupus. The TIMELY program uses a two-stage approach to engage providers and CHWs.

Providers and CHWs received access to tailored online education, followed by interactive roundtable discussions that include the principal investigators of the project and their research teams. In addition to discussing diverse patient

participation in LCTs, the roundtables seek to connect interdisciplinary providers with each other and CHWs with providers. Engaged, connected providers and CHWs can then bridge the gap between traditional clinical care and community-based health resources to overcome patient and provider level barriers to diverse patient participation in LCTs.

Methods The TIMELY program was implemented with providers and CHWs in congruent geographic areas, New York and North Carolina, to address both provider and patient level barriers to LCT participation. Provider and CHW participants, in tandem, completed an online education (providers – The ACR's Materials to Increase Minority Involvement in Clinical Trials (MIMICT) continuing medical education (CME) course; CHWs – the CHW Lupus Clinical Trials Training (LuCTT) program) and participated in roundtable discussions. We analyzed site-level roundtable reports and providers' and CHWs' post-roundtable open-ended responses to assess the extent to which the TIMELY roundtable approach engages and connects providers and CHWs.

Conclusion Overall, providers and CHWs demonstrated high engagement and connection during the roundtables. The provider roundtables included dermatologists, nephrologists, rheumatologists, and primary care providers. The CHW roundtables included CHWs from both New York and North Carolina. The small group and more informal nature of the roundtables created a setting in which providers and CHWs were able to meet, engage in discussion with, and connect with each other. Indeed, one provider noted, 'I like the variety of interdisciplinary teams that were involved and being able to place faces with names. Now that I have met other specialists, I'm more prone to reach out when I have questions.' Similarly, a CHW shared, 'It was informative and [I] also like that it was participants from other states involved and that health care professionals were involved.' TIMELY-trained providers and CHWs are currently utilizing knowledge and connections made to address barriers to LCT participation among diverse patients in their communities.

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DEMOGRAPHIC AND CLINICAL FACTORS THAT CONTRIBUTE TO CLINICAL STUDY ENROLLMENT IN SYSTEMIC LUPUS ERYTHEMATOSUS

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Lay Summary Participation in clinical trials is part of treatment for many patients with chronic diseases. However, patients with systemic lupus erythematosus (SLE), especially those of African American and Hispanic descent, have been reluctant to participate in clinical trials. Here, we describe patients' decisions to participate in a study that plans to enroll 200 patients in an engagement program modeled after the Lupus Research Alliance Patient Advocates for Lupus Studies (PALS) program. These data suggest that lupus patients' intention to participate in clinical research is influenced by severity of disease, patient factors, and the study design. It is difficult to tell