Pediatric Rheumatology

BRIEF REPORT Open Access

Characterizing lupus in African American children in Southern United States

Taylor B. Winstead[1], Spencer Hagwood[1], Cynthia Karlson[2] and Anita Dhanrajani[3,4*]

Abstract

Objective To characterize the clinical, demographic, and socioeconomic profile of childhood systemic lupus erythematous (cSLE) in the Black Belt of the Southern United States in comparison to the current literature of predominantly Caucasian cohorts.

Methods This is a cross-sectional study characterizing patients with cSLE from two centers in the Southeastern United States– University of Mississippi Medical Center (UMMC) and University of Alabama at Birmingham (UAB). Demographic, social, and clinical data was retrospectively collected by medical chart review for prevalent and incident cSLE patients via electronic medical records for UMMC and the Childhood arthritis and rheumatology research alliance (CARRA) registry database for UAB. The data was combined and analyzed using SPSS statistical software.

Results Of the 45 patients,82.2%were female, 82.2% were of AA ethnicity, and 66.7% had Medicaid insurance. Mean age at diagnosis was 13.5 years (+/- 2.8). Mean American College of Rheumatology (ACR) score at diagnosis was 5.1 (+/- 1.27), the Systemic Lupus International Collaborating Clinics (SLICC score) was 8.4 (+/- 2.5). Average baseline Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) was 13.06 (+/- 9.3), SLEDAI at 6 months and 1 year respectively was 7.4 and 4.7. Average distance traveled to see a rheumatologist was 74.83 miles compared to a national average of 42.8 miles. 37/45 patients (82%) belonged to medium-high or high Social Vulnerability Index (SVI) group based on zip code.

Conclusion Compared to previously described multiethnic cohorts of cSLE, this predominantly AA patient population in the Southern United States has significantly higher disease activity and greater damage accrual. Social risk factors for this population include a higher SVI, longer distance from an academic pediatric rheumatology center, and having Medicaid insurance. The effect of these factors on disparity of disease outcomes needs to be further explored with larger cohorts.

Significance and innovations

• There is limited literature on childhood systemic lupus erythematosus (cSLE) in Black patients from the Southern United States. This descriptive cohort focuses on patients from two states in the geographical Black Belt of the United States, a region that has not been previously explored in this context.

• This study examines the potential association between adverse socioeconomic factors and disparities in outcomes in cSLE, an area that remains understudied.

*Correspondence:
Anita Dhanrajani
Anita.dhanrajani@lcmchealth.org

Full list of author information is available at the end of the article

Introduction

Systemic Lupus erythematosus (SLE) is a chronic autoimmune disorder that presents with variable clinical manifestations often leading to devastating health consequences. About 10–20% of SLE occurs in children younger than 18 years of age and is referred to as childhood SLE (cSLE) [1]. The worldwide prevalence of cSLE ranges from 3.3 to 9.7 per 100,000 children [2]. cSLE is reportedly more severe than adult SLE with higher incidence of major organ involvement such as lupus nephritis, hematologic manifestations, and neuropsychiatric features [1]. The incidence of cSLE is higher in females and certain ethnic groups such as African American, Asians, Hispanics, and Native Americans [3]. African American (AA) ethnicity is a known predisposing factor for childhood onset systemic lupus erythematosus (cSLE) and a predictor of poor outcomes. In addition to race/ethnicity, income and geographical location are known drivers of health care disparities in cSLE [4]. Mississippi is a part of the historic "black belt" which is a geopolitical term for counties with a predominant black population. The black belt stretches across 12 counties in southern central Alabama, Georgia, and Mississippi [5]. According to 2018 census data, 42% of the pediatric population in Mississippi is African American compared to the national average of 14%. In 2017, 27% of children in Mississippi were living in poverty [6]. Anecdotally, cSLE has been observed to be more severe with poorer outcomes, however, there is no literature describing this or exploring the effects of sociodemographic factors that may contribute to these outcomes. The overall goal of this study is to describe a small cohort of cSLE patients from two Southern states with respect to their clinical and socioeconomic profile with the intent to expand this into a larger database registry from several states in the Black Belt.

Patients and methods

Institutional review board approval was obtained from the University of Mississippi medical center (UMMC-IRB-2022-21).

Cohort description

We performed a cross-sectional study within two academic medical centers in the Southeastern United States-University of Mississippi Medical Center (UMMC) and University of Alabama at Birmingham (UAB) between August 2019 to July 2021. Our study cohort included all patients diagnosed with cSLE or cSLE related condition at the age of ≤ 18 years within the past 24 months who had regular scheduled clinic visits with a pediatric rheumatologist at UMMC or UAB. The Systemic Lupus Internal Collaborating Clinics (SLICC) classification criteria were utilized to classify patients with cSLE for this study. cSLE related conditions included acute or chronic cutaneous lupus, mixed connective tissue disease, sjogren's syndrome, anti-phospholipid antibody syndrome, or probable SLE (at least 3 SLICC criteria). Exclusion criteria included age > 21 years at time of study enrollment or insufficient clinical and/or demographic data.

Data collection

Demographic, social, and clinical data were retrieved by retrospective medical chart review for UMMC cohort. Similar data was collected via the Childhood Arthritis and Rheumatology Research Alliance (CARRA) registry for the UAB cohort. This data included age, sex, self-reported ethnicity, insurance type, American College of Rheumatology/Systemic Lupus Internal Collaborating Clinics (ACR/SLICC) criteria at diagnosis, and Systemic Lupus Erythematosus Disease Activity Index (SLEDAI-2 K) score within first three months of diagnosis. Pertinent laboratory features were retrieved at diagnosis and subsequent follow up visits to assess disease activity, including Complete Blood count (CBC), Erythrocyte sedimentation rate (ESR), C reactive protein (CRP), Complete metabolic profile, anti-nuclear antibody (ANA) and Extractable nuclear antigens (ENAs), complement 3, complement 4, anti-phospholipid antibody profile and a urinalysis including quantified proteinuria. Data was entered in the REDCap database for UMMC.

Statistical analysis

Clinical and demographic data was described using descriptive statistics. The mean and standard deviation were recorded for each endpoint. Unpaired t-test and chi square test were used to compare outcomes in this cohort to those reported in the literature. Data from both cohorts was combined and analyzed using SPSS (V.28).

Results

Baseline demographics and social characteristics: (Table 1)

Of the 45 patients enrolled in the study, comprising 26 from UMMC and 19 from UAB, 37/45 (82.2%) were female, 37/45 (82.2%) were of African American ethnicity, and mean age at diagnosis of SLE for the cohort was 13.5 years (+/- 2.8 Standard deviation). 37/45 patients (82%) belonged to medium-high or high Social Vulnerability Index group based on zip code, mean SVI score was 0.74, and 30/45 (66.7%) had Medicaid insurance. Average distance traveled to see a pediatric rheumatologist was 74.83 miles.

Disease severity measures: (Table 2)

cSLE disease activity was measured using validated criteria including ACR score at diagnosis, SLICC score at diagnosis, SLEDAI score at diagnosis, 6 months, and 1 year, and SLICC/ACR damage index at 1 year. Mean

Table 1 Socio-demographics

Socio-Demographics	Study cohort ($n=45$)	1000 faces of lupus cohort ($n=213$)	Chi-square test	Unpaired t-test
Female sex	37 (82)	176 (83)	0.26, $p=0.6$	
African American ethnicity	37 (82)	22 (11)	87.29, $p<0.00001$	
SVI > 2*	38 (84)	NA		
Age at diagnosis (years)	13.5 (2.8)	12.5 (3)		$P=0.04$

*SVI: Social Vulnerability Index

Table 2 Disease activity measures

Clinical Features	Study cohort ($n=45$)	1000 faces of lupus cohort ($n=213$)	Chi-square test	Unpaired t-test
ACR criteria	5.1 (1.27)	NA		
SLEDAI at baseline	13.06 (9.3)	3.1 (2.1)		$p<0.0001$
SLEDAI at 6 months	7.4 (6.81)	NA		
SLEDAI at 1 year	4.7 (3.94)	NA		
SDI > 0*	23 (51)	32 (16)	25.79, $p<0.00001$	
SDI > 2*	20 (44)	14 (7)	42.82, $p<0.00001$	
Renal Involvement	14 (31)	72 (36)	0.12, $p=0.72$	
Neurologic Involvement	9 (20)	26 (13)	1.92, $p=0.16$	

*SDI: SLICC Damage Index

ACR score at diagnosis was 5.1 (+/- 1.27), SLICC score was 8.4 (+/- 2.5). Average baseline SLEDAI was 13.06 (+/- 9.3), SLEDAI at 6 months and 1 year respectively was 7.4 and 4.7. 20/45 (44%) had SLICC/ACR damage index > 2. 14/45 (31%) had renal involvement at diagnosis, and 9/45 (20%) had neurologic involvement at diagnosis.

Comparison to published cohorts

Average baseline SLEDAI compared to a multiethnic Canadian cohort with 10% black population, was significantly higher: 13.06 versus 3.1 ($p<0.0001$, t = 10.99). 23/45 had SDI > 0 (51.11%) versus 16% reported in the literature ($p<0.00001$, chi-square 25.79). 20/45 (44.4%) had SDI >/= 2 compared to 7% reported in the literature ($p<0.00001$, chi-square 42.82).

Discussion

This is a small cohort of cSLE patients with focus on their sociodemographic profile and exploring a possible relation to disease activity and severity. While previous studies have described the clinical profile of cSLE, the cohorts consisted largely of Caucasian patients from other regions. There is currently no other literature describing cSLE in the Southern United States despite the mortality for lupus being the highest in the nation. According to US death trend data between 1968 and 2013, there was a relatively smaller decrease in SLE-related death among African Americans (13.3%) than in Caucasians (33.3%), suggesting an increase in racial disparities over time [7]. Racial disparities among African American patients with lupus have shown to be multi-factorial in nature in previous studies [4]. Structural, social, and individual determinants of health have all proven to play a role in the impact of lupus on health outcomes. The 2015 County Health Rankings (CHR) data showed that the overall relative contribution of socioeconomic factors to health outcomes was as high as 47% [8]. The LUMINA cohort study found that African American ethnicities, poor social support and lack of health insurance were some of the factors that predicted high level of disease activity [9]. Research has also shown that geography plays a role in access to treatment. A Medicaid data review showed that patients with lupus nephritis who lived in the Northeast were more likely to receive immunosuppressants than patients living in the South due decreased access to ambulatory care [10]. Our study consisted of significant number of patients with known drivers of racial disparities including African American ethnicity, medium to high social vulnerability index, Medicaid insurance, and travel burden. The travel burden to see a pediatric rheumatologist for our study cohort was much higher than the national average (74.83 vs. ~ 42.8 miles) [11]. Not only did our study describe the negative socio-economic factors faced by cSLE patients living in the Southern US, but we also proved our hypothesis that cSLE is more severe in the "Black Belt" region of the US. Compared to a Canadian cohort, the mean SLEDAI at baseline was significantly higher (13.06 vs. 3.1, $p<0.00001$) in our study cohort. The proportion of patients with SLICC damage index scores greater than 2 was also significantly higher than Canadian cohort, respectively (44% vs. 7%, $p<0.000001$) [12]. Although this study showed more severe disease in the setting of negative socioeconomics, we are limited by the descriptive nature and small sample size of this study. More studies with larger cohorts are needed to further

explore the relationship between health care disparities and severity of disease in cSLE.

Conclusion

In conclusion, this study highlights the heightened severity of cSLE among patients experiencing multiple health disparities in the "Black Belt" region of the United States, emphasizing the critical need for further research to mitigate healthcare disparities in this underserved population.

Acknowledgements
Childhood Arthritis and Rheumatology Research Alliance (CARRA) registry.

Author contributions
Taylor B Winstead made substantial contributions to the design of the work, acquisition of data and substantial revisions to the manuscriptSpencer Hagwood made substantial contributions to the acquisition of data and substantial revisions to the manuscriptCynthia Karlson made substantial contributions to the design of the work, data analysis and subtantial revisions to the manuscriptAnita Dhanrajani made substantial contributions to the design of the work, data acquisition and analysis and drafting of the manuscript.

Funding
This study was funded by the Intradepartmental Discovery Support Program (IDSP) with the University of Mississippi Medical Center (UMMC).

Data availability
No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
The study was approved by Institutional research board for University of Mississippi Medical Center (UMMC-IRB-2022-21) with waiver of consent.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Author details
[1]School of Medicine, The University of Mississippi Medical Center, Jackson, MS, USA
[2]Department of Pediatric Psychology, The University of Mississippi Medical Center, Jackson, MS, USA
[3]Department of Pediatrics, Division of Rheumatology, The University of Mississippi Medical Center, Jackson, MS, USA
[4]Department of Pediatrics, Section Rheumatology, Tulane University Medicine, 200 Henry Clay Avenue, New Orleans, LA 70115, USA

Received: 15 January 2025 / Accepted: 18 March 2025
Published online: 07 April 2025

References

1. Mina R, Brunner HI. Pediatric lupus - are there differences in presentation, genetics, response to therapy, and damage accrual compared with adult lupus? Rheum Dis Clin North Am. 2010;36(1):53–80, vii-viii.
2. Levy DM, Kamphuis S. Systemic lupus erythematosus in children and adolescents. Pediatr Clin North Am. 2012;59(2):345–64.
3. Hiraki LT, Benseler SM, Tyrrell PN, et al. Ethnic differences in pediatric systemic lupus erythematosus. J Rheumatol. 2009;36:2539–46.
4. Hasan B, Fike A, Hasni S. Health disparities in systemic lupus erythematosus-a narrative review. Clin Rheumatol. 2022;41(11):3299–311.
5. Black belt in the American South. Wikipedia. Wikimedia Foundation. 2021. Available from: Black Belt in the American South - Wikipedia.
6. 2020 Mississippi KIDS COUNT FactBook. Children's Foundation of Mississippi. Available from: 2020 Mississippi KIDS COUNT Factbook - Children's Foundation of Mississippi.
7. Chae DH, Martz CD, Fuller-Rowell TE, Spears EC. Racial discrimination, disease activity, and organ damage: the black women's experiences living with lupus (BeWELL) study. Am J Epidemiol. 2019;188(8):1434–43.
8. Buie J, McMillan E, Kirby J, et al. Disparities in lupus and the role of social determinants of health: current state of knowledge and directions for future research. ACR Open Rheumatol. 2023;5(9):454–64.
9. Alarcón GS, Calvo-Alen J, McGwin G Jr, et al. Systemic lupus erythematosus in a multiethnic cohort: LUMINA XXXV. Predictive factors of high disease activity over time. Ann Rheum Dis. 2006;65:1168–74.
10. Yazdany J, Feldman CH, Liu J, et al. Quality of care for incident lupus nephritis among medicaid beneficiaries in the United States. Arthritis Care Res (Hoboken). 2014;66:617–24.
11. Distance to provider dashboard by State by the American Board of Pediatrics. Distance to Provider Dashboard by State| Tableau Public.
12. Levy DM, Peschken CA, Tucker LB, et al. Influence of ethnicity on childhood-onset systemic lupus erythematosus: results from a multiethnic multicenter Canadian cohort. Arthritis Care Res (Hoboken). 2013;65(1):152–60. https://doi.org/10.1002/acr.21779

Publisher's note