p = 0.81), or neurologic involvement (Co n = 46 (10%); non-Co n = 50 (13%), p = 0.21).

Conclusions In this single academic centre study, ethnic minority patients were underrepresented in the observational research cohort, mirroring what is described in clinical trial participation. While disease severity (represented by renal and neurologic involvement) did not appear to differ, the higher death rate, and death rate at an early age among nonparticipants suggests underrepresentation of high-risk vulnerable patients in our observational cohort. Observational cohorts represent an important source of real-world data; without representative participation we are lacking data on those lupus patients with the highest prevalence and worst outcomes. Better engagement of ethnic minority and vulnerable patients in research will be key to improve understanding of lupus.

Racial Discrimination Among Systemic Lupus Erythematosus (SLE) and Control Participants in the Social Factors, Epigenomics and Lupus in African American Women (SELA) Study: Preliminary Description and Exploratory Analysis

Jessica T Browder, Bethany J Wolf, Sam Lim, Quinnette King, Lori Ann Ueberroth, Diane L Kamen, Paula S Ramos, Florida State University, USA; Medical University of South Carolina, USA; Emory University, USA

Background African American women are disproportionately affected by SLE, but remain underrepresented in research studies. To further knowledge about the diversity of this health disparity group, the goal of this study was to investigate sociodemographic, behavioral, clinical characteristics, and their impact on SLE disease outcomes, in African American women from South Carolina.

Methods Adult self-reported African American women meeting the 1997 ACR revised or 2012 SLICC classification criteria for SLE, or controls without any known connective tissue disease, were recruited for the Social Factors, Epigenomics and Lupus in African American Women (SELA) study. SLE activity was self-reported using the Systemic Lupus Activity Questionnaire (SLAQ), and damage was self-reported using the Brief Index of Lupus Damage (BILD). Racial discrimination was measured using the Experiences of Discrimination (EOD) measure. A Welch two sample t-test was computed for the associations between EOD and SLAQ, and Wilcoxon rank sum tests with continuity correction was computed for the associations between EOD and BILD.

Results This preliminary study included 50 female African Americans, including 28 with SLE. In total, 74% of participants had a college degree, 53% had private health insurance, and 45% were employed. The majority were non-smokers (86%), rarely or never drank (76%), and exercised at least weekly (57%). Hypertension (51%), asthma (25%) and depression (18%) were the most prevalent comorbidities. Among those with SLE, the mean ± SD age of diagnosis was 29 ± 7 years, disease duration at the SELA visit was 22 ± 9 years, and mean SLE activity score was 9.8 ± 5.7. Most patients (86%) had a damage score of 2 or more, with the remaining 14% having damage to 1 organ or system, and overall mean damage score was 3.4 ± 2.2. Half (53%) of all participants reported experiencing racial discrimination. In an exploratory analysis, there was no association between racial discrimination and presence of SLE, level of SLE activity, nor damage. Participant engagement with SELA aims is high, evidenced by 81% of participants wishing to be included in this study’s progress, 71% wanting to provide feedback and research suggestions, and all requesting to receive their genetic ancestry estimates.

Conclusions The preliminary results of this exploratory analysis are distinct from those of the Black Women’s Experiences of Lupus in African American communities, continued recruitment into this ongoing study will enhance our knowledge about SLE in diverse African Americans.

Clinical Research in SLE

A Pilot Study to Implement the Type 1 & 2 SLE Model into Clinical Care

Amanda M Eudy, Jennifer L Rogers, Kai Sun, Rebecca E Sadun, David S Pisetsky, Mithu Maheswaranathan, Jayanth Doss, Lisa G Criscione-Schreiber, Megan EB Cloose, Department of Medicine, Duke University School of Medicine; Medical Research Service, Durham VA Medical Center

Background The Type 1 & 2 SLE Model was developed to better explain the signs, symptoms, and management goals of systemic lupus erythematosus (SLE) to patients. We assembled tools to discuss the Type 1 & 2 SLE Model, collectively called SLE@Duke, including patient-reported outcome (PRO) measures, physician global assessments (PGAs) for Type 1 and 2 SLE activity, and a patient handout. In this pilot study, we aimed to implement SLE@Duke into rheumatology care with the goal of increasing the frequency of discussion of the Type 1 & 2 SLE Model.

Methods We conducted a 4-week study in Duke Rheumatology Clinics. Providers received training on SLE@Duke that reviewed each of the tools, summarized approaches to treating Type 2 SLE, and scored case examples of PGAs. During the intervention period, patients with SLE received a questionnaire at check-in that included the Systemic Lupus Activity Questionnaire and the American College of Rheumatology Fibromyalgia Severity Score. After each visit, patients completed an anonymous satisfaction survey. Providers completed baseline and follow-up surveys on their satisfaction with care and acceptability, appropriateness, and feasibility of SLE@Duke. Clinic notes of patients seen during the intervention period and 4-weeks prior to the intervention were reviewed. Providers were invited to participate in interviews about their experience after the intervention period.

Results Sixteen of 25 eligible providers participated (3 APPs, 8 faculty, 5 fellows); 67 patients with SLE were seen (36 pre-intervention and 31 intervention). At follow-up, provider surveys showed high scores for acceptability (4.0/5), appropriateness (4.1/5), and feasibility (4.2/5) of SLE@Duke (table 1). All providers agreed or completely agreed the intervention seemed possible; there was an increase in the proportion who felt the intervention was easy to use (50% to 83%), Type 1 & Type 2 PGAs were documented in 87% of notes. The discussion of Type 2 SLE symptoms increased from 44% to 74% of patients (p = 0.02). Importantly, there was not an increase in the proportion who felt the intervention was easy to use (50% to 83%), Type 1 & Type 2 PGAs were documented in 87% of notes. The discussion of Type 2 SLE symptoms increased from 44% to 74% of patients (p = 0.02).

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