Racial Differences in Patient-provider Communication, Patient Self-efficacy, and Their Associations With Systemic Lupus Erythematosus–related Damage: A Cross-sectional Survey

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ABSTRACT. *Objective.* Despite significant racial disparities in systemic lupus erythematosus (SLE) outcomes, few studies have examined how disparities may be perpetuated in clinical encounters. We aimed to explore associations between areas of clinical encounters — patient-provider communication and patient self-efficacy — with SLE-related damage, in order to identify potential areas for intervention to reduce SLE outcome disparities.
Methods. We collected cross-sectional data from a tertiary SLE clinic including patient-provider communication, general self-efficacy, self-efficacy for managing medications and treatments, patient-reported health status, and clinical information. We compared racial groups and used logistic regression to assess race-stratified association of patient-provider communication and patient self-efficacy with having SLE-related damage.
Results. Among 121 patients (37% White, 63% African American), African Americans were younger, more likely to be on Medicaid, and less likely to be college educated, married, or living with a partner or spouse. African Americans reported less fatigue and better social function, took more complex SLE medication regimens, had lower fibromyalgia (FM) scores, and had higher SLE disease activity and SLE-related damage scores. African Americans reported similar self-efficacy compared to White patients, but they reported more hurried communication with providers, which was reflected in their perception that providers used words that were difficult to understand. Perceiving providers use difficult words and lower general self-efficacy were associated with having SLE-related damage among African American but not White patients.
Conclusion. African Americans had more severe SLE and perceived more hurried communication with providers. Both worse communication and lower self-efficacy were associated with having SLE-related damage among African American but not White patients, suggesting that these factors should be investigated as potential interventions to reduce SLE racial disparities.

Key Indexing Terms: health communication, healthcare disparities, self-efficacy, systemic lupus erythematosus

Systemic lupus erythematosus (SLE) and SLE-related damage are more common, severe, and deadly in underrepresented racial minority groups compared to White people.[1,2,3,4] An array of factors affects racial disparities in SLE outcomes, including socioeconomic status, community, and disease characteristics.

Few studies have examined factors contributing to racial disparities that are modifiable within the clinical encounter, rendering each encounter a potential missed opportunity for the physician to make a positive impact. Examining the clinical encounter is important because of high rates of racial mismatch between patients with SLE and providers. In the United States, although African Americans comprise nearly 40% of patients with SLE,[1] they represent only 0.8% of adult rheumatologists.[5] When patient-provider racial mismatch is present, patients may experience apprehension about being negatively stereotyped, an emotion labeled "stereotypic threat." Stereotypic threat has been shown to impair patient-provider communication and decrease patient self-efficacy, or an individual's sense of personal control over a certain behavior.[6] These in turn can undermine patient-centered care, medication adherence, and clinical outcomes.[7] Evidence suggests that more patient-centered communication is associated with better patient self-efficacy.[8] Therefore, both patient self-efficacy and patient-provider communication are potential modifiable factors that may improve the clinical encounter, if addressed appropriately. However, whether they

are associated with known racial outcome disparities in SLE has not been examined. The present study was guided by a conceptual model on healthcare disparities adapted from the work of Canino, *et al*, which described outcome disparities as the result of a complex interaction between the patient, the health system, and the clinic, where patients and providers interface (Figure 1).[9] We aimed to examine differences between African American and White patients with SLE in a tertiary SLE clinic, with a focus on patient self-efficacy and patient-rated communication with providers, both of which are modifiable factors in the clinical encounter that are negatively affected by patient-provider racial mismatch. Additionally, we examined factors associated with having SLE-related damage and explored racial disparities in the relationships between self-efficacy and communication with SLE-related damage.

METHODS

Study setting and population. We recruited consecutive eligible patients from a tertiary academic SLE clinic staffed by 6 attending rheumatologists, none of whom are African American. Patients were included if they were age ≥ 18 years, fluent in English, self-identified as African American or White, met American College of Rheumatology (ACR) 1997 or Systemic Lupus International Collaborating Clinics (SLICC) 2010 SLE criteria,[10,11] and were actively receiving treatment for SLE. We did not include patients of other racial and ethnic minorities because they represent < 5% of our SLE population. Patients were excluded if they were a new patient to the clinic or had significant cognitive impairment preventing them from completing the questionnaire or understanding informed consent. All participants provided written consent. The study was approved by the institutional review board at Duke University (IRB study # Pro00100861).

Data collection. Cross-sectional data were obtained through a self-administered questionnaire in clinic and medical records were reviewed by a rheumatologist. The following information was collected informed by our conceptual model (Figure 1).

Patient-provider communication. We used the Interpersonal Processes of Care (IPC) survey (https://cadc.ucsf.edu/interpersonal-processes-care-ipc), which has 29 items on a 5-point Likert scale, to assess 7 domains of patient-provider interaction: hurried communication; elicited concerns, responded; explained results, medications; patient-centered decision making; compassionate, respectful; discrimination; and disrespectful office staff. Scores for each domain range from 1 to 5, with higher scores indicating greater perception of that domain. A score of 1 is optimal for hurried communication, discrimination, and disrespectful office staff, whereas a score of 5 is optimal for the other domains.

Patient self-efficacy. We used Patient Reported Outcomes Measurement Information System (PROMIS) short forms to measure both general self-efficacy (4-item) and self-efficacy for managing medications and treatments (8-item). Raw scores were uploaded to the scoring service,[12] where *t*-scores were obtained. A *t*-score of 50 correlates to the reference population mean, with a 5-point difference (half SD) considered a clinically significant difference.[13,14]

Patient-reported health status. We used the PROMIS-29 short form, a validated instrument in SLE,[15,16] to measure patient-reported physical function, anxiety, depression, fatigue, sleep disturbance, social function, and pain interference. We chose to use PROMIS measures because they not only allow us to compare patient groups, but also compare patient groups to the reference population. Patients also completed the 2011 ACR FM Criteria questionnaire.[17]

SLE disease activity and damage. To measure SLE disease activity, we utilized the validated patient-reported Systemic Lupus Activity Questionnaire[18] and the provider-derived SLE Disease Activity Index (SLEDAI).[19] Each provider completed clinical SLEDAI assessments at the time of the clinic visit, and the full SLEDAI scores were calculated when laboratory results from the visit became available. We ascertained the SLICC Damage Index (SDI)[20] through chart review to derive SLE-related damage scores at the time of the study. We chose to use the SDI as the main outcome of interest because it estimates permanent damage from SLE that is cumulative over time, and therefore is the most clinically significant outcome not subject to short-term fluctuations.
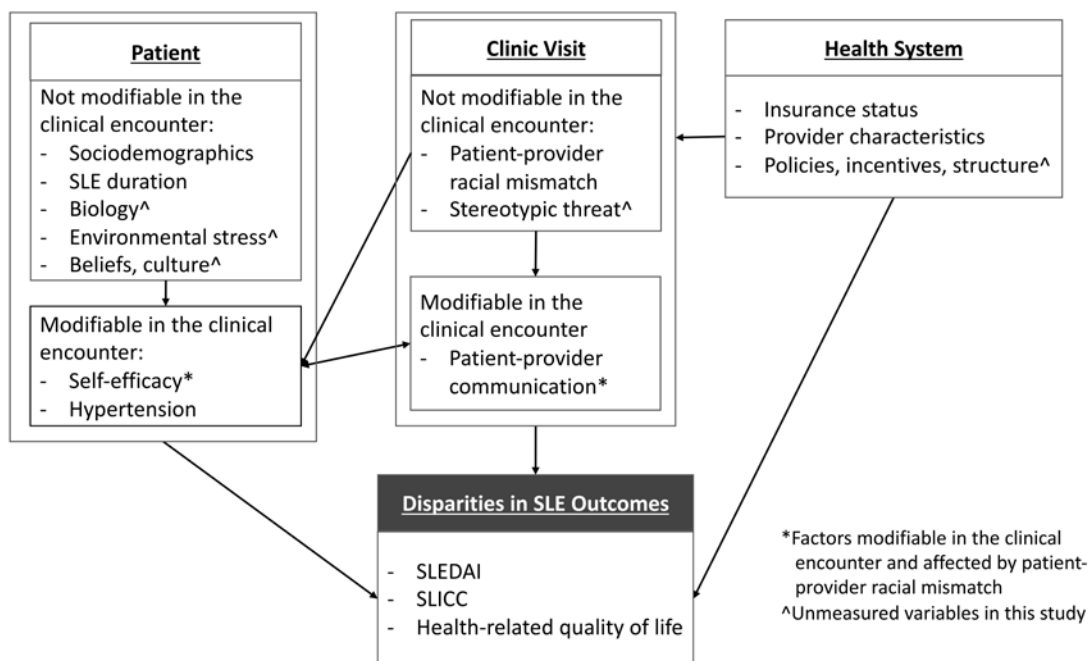

Figure 1. Conceptual model of SLE outcome disparities. SLE: systemic lupus erythematosus; SLEDAI: Systemic Lupus Erythematosus Disease Activity Index; SLICC: Systemic Lupus International Collaborating Clinics.

Health records review. We collected the following variables from chart review: insurance status, disease duration, Charlson Comorbidity Index score,[21] and medications. We calculated a medication regimen complexity index according to standard methods based on route and frequency of administration, with a higher score indicating a more complex regimen.[22]

Statistics. We summarized categorical variables with percentages and continuous variables with either mean (SD) or median (IQR), depending upon distribution. We compared demographics, patient-reported outcomes, and clinical factors between White and African American patients, using chi-square or Fisher exact tests for categorical variables, and *t* tests or Wilcoxon rank-sum tests for continuous variables. We used logistic regression models to examine factors associated with having any SLE-related damage (SDI ≥ 1). In the univariable model, we considered a number of candidate variables previously shown to be associated with SLE-related damage including age, disease duration, prednisone use, hydroxychloroquine (HCQ) use, and hypertension. However, due to the small sample size, we limited the univariable logistic regression models to 5 variables. We did not include prednisone and HCQ use in the logistic regression analysis due to sparse data. To explore associations of self-efficacy and patient-provider communication with SLE-related damage, we *a priori* decided to include general self-efficacy and a domain of patient-provider communication in the analysis. For the patient-provider communication domain, we used scores of "difficult words" (reflected through answers to the question, "How often did doctors use words that were hard to understand?"), a subdomain of hurried communication, which differed most significantly between White and African American patients. We then ran separate multivariable logistic regression models for general self-efficacy and difficult words for the entire cohort as well as stratified by race. We did not adjust for hypertension in the multivariable logistic regression models of White patients due to sparse data. Statistical analyses were performed using Stata (version 14.2; StataCorp).

RESULTS

One hundred and thirty patients were approached; 121 patients completed the questionnaires (37% White, 63% African American). Median age was 44 years, 95% were female, 51% had college or above education, 41% were on disability, 44% were married, and 17% were on Medicaid. Compared to White patients, African Americans were younger, more likely to be on Medicaid, and less likely to be college educated, married, or live with a partner or spouse (Table 1).

Table 2 compares patient-reported and clinical outcomes between racial groups. Overall, median scores were the maximum

Table 1. Comparing demographics between White and African American patients.

	Total, n = 121	White, n = 45	African American, n = 76	P
Age, yrs, median [IQR]	44 [34–53]	**46 [38–60]**	**41 [32–50]**	**0.006**
≥ College education, %	51	**71**	**39**	**0.001**
Disability, %	41	**27**	**49**	**0.02**
Unemployed, %	22	22	22	1.0
Marital status, %				**< 0.001**
Single	31	**16**	**41**	
Married	44	**62**	**33**	
Divorced	21	**13**	**26**	
Widowed	3	**9**	**0**	
Medicaid, %	17	**7**	**24**	**0.02**

Values in bold are statistically significant.

achievable scores for 5 out of 7 domains of patient-provider interaction as measured by the IPC survey. The only domains with less-than-optimal median scores were "patient-centered decision making" (median 4.5, best score 5), "explained results, medications" (median 4.5, best score 5), and "hurried communication" (median 1.3, best score 1). African American patients rated more "hurried communication" with their providers compared to White patients (median 1.3 vs 1, *P* = 0.01). Worse scores in this domain were primarily driven by responses to the question, "How often did doctors use words that were hard to understand?" (median 2 vs 1, *P* = 0.03). There were no racial differences in the scores for other questions within this domain and all other domains of the IPC survey.

Scores for general self-efficacy and self-efficacy in managing medications and treatments were close to the reference population mean of 50, and there were no significant differences in the scores between racial groups. Comparing patient-reported health status to the reference population mean, our cohort of patients had similar degrees of anxiety (median 52) and social function (median 48), but less depression (median 41), lower physical function (median 41), more pain interference (median 56), and more sleep disturbance (median 56). Between racial groups, African Americans had less fatigue (54 vs 59, *P* = 0.005) and better social function (52 vs 44, *P* = 0.004) compared to White patients. There were no racial differences in the scores of the rest of the PROMIS-29 domains.

On average, patients in this cohort had been diagnosed with SLE for 15 years and took 2 SLE medications. There were no racial differences in length of SLE diagnosis. However, African Americans took a higher number of SLE medications, had a more complex SLE medication regimen, and were more likely to be prescribed mycophenolate and prednisone. African Americans also had higher scores on the SDI and the SLEDAI, but lower FM severity scores.

Table 3 presents the univariable logistic regression models examining factors associated with having any SLE-related damage. SLE-related damage was associated with older age, higher scores in difficult words (reflected in responses to the question, "How often did doctors use words that were hard to understand?"), and having hypertension. There was a trend for SLE-related damage to be associated with lower general self-efficacy, but there was no relationship with disease duration.

Table 4 presents the multivariable logistic regression models exploring the association of difficult words with SLE-related damage for the entire cohort. We found that older age, perceiving providers use more difficult words, and having hypertension were independently associated with having SLE-related damage. When the analysis was stratified by race, SLE-related damage was associated with older age among Whites, while among African Americans, it was associated with difficult words. Similar results were obtained from logistic regression models examining the association of general self-efficacy and SLE-related damage (Table 5). In race-stratified analysis, SLE-related damage was associated with general self-efficacy only among African American but not White patients.

Table 2. Comparing patient-reported and clinical characteristics between White and African American patients.

	Total, n = 121	White, n = 45	African American, n = 76	P
IPC				
Hurried communication[a]	1.3 [1–1.8]	**1 [1–1.5]**	**1.3 [1–1.8]**	0.01
Difficult words[a,b]	1 [1–2]	**1 [1–2]**	**2 [1–2]**	0.03
Discrimination[a]	1 [1–1]	1 [1–1]	1 [1–1]	0.2
Disrespectful office staff[a]	1 [1–1]	1 [1–1]	1 [1–1]	0.9
Elicited concerns[c]	5 [4.3–5]	4.8 [4–5]	5 [4.3–5]	0.5
Explained results, medications[c]	4.5 [3.8–5]	4.5 [3.5–5]	4.8 [4–5]	0.3
Patient-centered decision making[c]	4.5 [3.5–5]	4.3 [3.5–5]	4.5 [3.3–5]	0.9
Compassionate, respectful[c]	5 [4.2–5]	5 [4.2–5]	5 [4.2–5]	0.6
PROMIS				
General self-efficacy[d]	51 [44–65]	52 [44–65]	50 [44–59]	0.6
Self-efficacy in managing treatments[d]	48 [42–56]	52 [43–61]	47 [42–54]	0.1
Social function[d]	48 [42–57]	**44 [38–52]**	**52 [44–64]**	0.004
Physical function[d]	41 [36–49]	41 [36–49]	42 [37–49]	0.6
Anxiety[d]	52 [40–58]	51 [40–56]	52 [40–59]	0.5
Depression[d]	41 [41–54]	41 [41–54]	41 [41–55]	0.7
Fatigue[d], mean (SD)	56 (11)	**59 (10)**	**54 (11)**	0.005
Sleep disturbance[d]	56 [54–59]	56 [53–60]	56 [54–58]	0.5
Pain interference[d]	56 [50–62]	58 [50–61]	56 [50–62]	1.0
SLE duration, yrs	15 [8–21]	14 [7–18]	15 [9–22]	0.3
No. SLE medications	2 [1–3]	**2 [1–2]**	**2 [2–3]**	0.003
SLE medication complexity	7 [3–9]	**5 [3–8]**	**8 [5–11]**	0.005
Prescribed MMF, %	35	**18**	**45**	0.003
Prescribed prednisone, %	43	**2**	**55**	0.002
SDI	2 [0–3]	**1 [0–2]**	**2 [1–4]**	0.03
SLEDAI	2 [0–5]	**0.5 [0–4]**	**2 [0–6]**	0.04
SLAQ	9 [5–14]	10 [5–14]	8 [5–13]	0.4
FM symptom severity score, mean (SD)	3.6 (2.5)	**4.3 (2.3)**	**3.3 (2.5)**	0.02
Charlson Comorbidity Index	2 [1–3]	2 [1–2]	2 [1–3]	0.8

Values are expressed in median [IQR] unless otherwise indicated. Values in bold are statistically significant. IPC scores range from 1 to 5. [a] Lower score is better. [b] Subdomains of Hurried communication, as reflected by responses to the question, "How often did doctors use words that were hard to understand?" Score ranges from 1 to 5, with higher scores indicating perceiving providers use more difficult words. [c] Higher score is better. [d] PROMIS short forms: 50 is reference population mean, 5 is clinically significant difference; higher scores are better for self-efficacy, social function, and physical function, but lower scores are better for anxiety, depression, fatigue, sleep disturbance, and pain interference. FM: fibromyalgia; IPC: Interpersonal Processes of Care survey; MMF: myco-phenolate mofetil; PROMIS: Patient Reported Outcome Measurement Information System; SLAQ: Systemic Lupus Activity Questionnaire; SLE: systemic lupus erythematosus; SLEDAI: Systemic Lupus Erythematosus Disease Activity Index; SDI: Systemic Lupus International Collaborating Clinics (SLICC) Damage Index.

DISCUSSION

In this cohort of patients from a tertiary SLE clinic, our findings that African Americans have more disadvantaged socioeconomic backgrounds and more active, severe SLE is consistent with known racial disparities in SLE.[23,24,25] We have also corroborated several factors known to be associated with increased damage in SLE in our univariate analysis, including older age and having hypertension.[26] Interestingly, SLE disease duration was not significantly associated with SLE-related damage scores, perhaps due to the uniformly long disease duration in this cohort. Potential modifiable factors in the clinical encounter to reduce racial disparities in SLE outcomes have not been well studied, and our analysis helps fill the gap by examining racial differences in patient self-efficacy and perceived interactions with providers. Self-efficacy is modifiable and plays a critical role in a patient's self-management and communication with providers.[27,28,29] Conversely, better patient-provider communication also has the potential to positively affect a patient's health-related self-efficacy.[8]

We found that overall scores for both general self-efficacy and self-efficacy in managing medications and treatments in our cohort were similar to those of the PROMIS reference population. Self-efficacy has been reported to be lower in African American compared to White patient populations in other diseases,[30,31] but we found no significant racial differences in our patients with SLE. Given the many known social, structural, and disease-related disadvantages faced by African Americans, they may require comparatively higher levels of self-efficacy in order to achieve disease outcome equity with White patients. Therefore, one possible interpretation of the observed similar

Table 3. Factors associated with having SLE-related damage (SDI ≥ 1) based on results of univariable logistic regression models.

	OR	95% CI	P
Age, per 1-yr increase	**1.05**	**1.01–1.08**	**0.01**
Difficult words[a], per 1-unit increase	**2.13**	**1.10–4.14**	**0.03**
General self-efficacy[b], per 5-unit increase	0.83	0.68–1.00	0.06
Disease duration, per 1-yr increase	1.04	0.99–1.09	0.1
Hypertension	**2.76**	**1.18–6.46**	**0.02**

[a] Subdomains of hurried communication, as reflected by responses to the question, "How often did doctors use words that were hard to understand?" Score ranges from 1 to 5, with higher scores indicating perceiving providers use more difficult words. [b] Measured using PROMIS short form: 50 is the reference population mean, a score difference of 5 is clinically significant; higher score is better. PROMIS: Patient Reported Outcome Measurement Information System; SDI: Systemic Lupus International Collaborating Clinics (SLICC) Damage Index; SLE: systemic lupus erythematosus.

levels of self-efficacy between races is that self-efficacy among African Americans is lower than required to overcome additional disadvantages faced by them. More investigation is needed on how race and self-efficacy interact, and this interaction's attendant effects on patient self-management skills and disease outcomes.

Despite having a high rate of patient-provider racial discordance in our SLE clinic, scores for patient-rated interactions with providers were substantially higher in our cohort than scores reported by Drenkard, *et al* using the same IPC survey.[32] The higher scores we observed can be partly explained by differences in clinical setting: while our study evaluated patients seeking care in a tertiary SLE clinic, the Drenkard study also included a large proportion of patients being cared for in community settings.[32] Despite having high scores in our patient population, the patient-provider communication domains receiving the poorest ratings were "patient-centered decision making" and "explained results, medications," suggesting room for improvement in these dimensions of care. Interestingly, there were no differences between African American and White patients in 6 of 7 domains of the IPC-29, but African American patients perceived more hurried communication with providers, particularly the use of difficult vocabulary. Below-basic health literacy skills are more common among African Americans compared to Whites, and ways in which health literacy affects the quality of perceived patient-provider communication should be investigated.[33] Future research is also needed to identify ways to improve this area of communication, as effective patient-provider communication is crucial for patient satisfaction, trust, involvement in treatment decision, and ultimately, the achievement of disease control.[34]

Our exploratory findings show interesting racial differences in the relationships of age, communication, and self-efficacy with SLE-related damage. Previous studies have reported links between these factors and SLE outcomes but have not investigated modifications of these relationships by race.[23,35,36] We found that younger age was associated with less SLE-related damage among Whites but not African American patients. One possible explanation may be that African Americans are more likely to have both earlier onset and more severe SLE; therefore, age does not affect damage in African American patients as much as among White patients with SLE. We hypothesize that

Table 4. Factors associated with having SLE-related damage (SDI ≥ 1) for the entire cohort and stratified by race based on results of multivariable logistic regression models, exploring association of "hard words" with SLE-related damage.

	All, n = 121			White, n = 45			African American, n = 76		
	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P
Age, per 1-yr increase	**1.05**	**1.00–1.09**	**0.03**	**1.17**	**1.06–1.28**	**0.001**	1.02	0.96–1.08	0.50
Difficult words[a], per 1-unit increase	**2.47**	**1.23–4.96**	**0.01**	1.56	0.47–5.23	0.47	**2.72**	**1.03–7.12**	**0.042**
Hypertension	**2.96**	**1.17–7.51**	**0.02**	–	–	–	0.94	0.28–3.12	0.92

Values in bold are statistically significant. [a] Subdomains of hurried communication, as reflected by responses to the question, "How often did doctors use words that were hard to understand?" Score ranges from 1 to 5, with higher scores indicating perceiving providers use more difficult words. SDI: Systemic Lupus International Collaborating Clinics (SLICC) Damage Index; SLE: systemic lupus erythematosus.

Table 5. Factors associated with having SLE-related damage (SDI ≥ 1) for the entire cohort and stratified by race based on results of multivariable logistic regression models, exploring association of general self-efficacy with SLE-related damage.

	All, n = 121			White, n = 45			African American, n = 76		
	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P
Age, per 1-yr increase	**1.04**	**1.02–1.14**	**0.03**	**1.17**	**1.07–1.28**	**0.001**	1.01	0.96–1.07	0.74
General self-efficacy[a], per 5-unit increase	**0.88**	**0.64–0.98**	**0.03**	0.87	0.62–1.23	0.43	**0.73**	**0.53–0.99**	**0.046**
Hypertension	**2.56**	**1.05–6.24**	**0.04**	–	–	–	0.80	0.25–2.53	0.70

Values in bold are statistically significant. [a] Measured using PROMIS short form: 50 is the reference population mean, a score difference of 5 is clinically significant difference; higher score is better. SDI: Systemic Lupus International Collaborating Clinics (SLICC) Damage Index; SLE: systemic lupus erythematosus.

the social, structural, and disease-related disadvantages among African American patients cumulatively have a larger effect than that of age on SLE-related damage.

We also found that perceiving that providers use more difficult words and lower general self-efficacy were independently associated with higher SLE-related damage scores among African American but not White patients, after adjusting for age and hypertension. While our findings need to be confirmed in a larger sample size, the association of damage with these modifiable factors in our data points to interventions to improve patient-provider communication and patient self-efficacy as a possible path forward to better outcomes among African Americans.

There are several limitations to this study. First, statistical power is limited by the small sample size and sparse data. We considered a number of candidate adjustment variables but were only able to include 5 in the univariable logistic models. Second, our analysis is cross-sectional and is unable to demonstrate causation and may be affected by reverse causality. For example, having more SLE-related damage may negatively affect patient self-efficacy and medication complexity. Further, having more comorbidities and taking more medications may in turn affect the choice of words used by providers. However, our findings are hypothesis-generating and should be examined in a longitudinal study. Third, patients were recruited from a single tertiary care SLE clinic, and therefore our findings may not be generalizable to patients with SLE cared for in community practices. Fourth, patients who completed surveys may represent a self-selected group who have better self-efficacy and patient-provider relationship than ones who declined to participate. However, this would likely result in a conservative bias, and with a 93% participation rate, we feel that selection bias should be minimal. Additionally, as surveys were administered in clinic, social desirability may have skewed patient answers toward more positive responses, and small variability in some of the IPC domains diminish chances of identifying a difference between races. Last, the SDI was calculated based on chart review and may have inaccuracies; however, bias introduced here should be small and similar between racial groups, as the SDI based on medical record review has been shown to have good correlation with gold standard prospective direct scoring.[37]

In conclusion, our data support and elaborate upon known racial disparities in SLE. While levels of communication and self-efficacy were similar between African American and White patients with SLE, perceiving providers use more difficult words and lower self-efficacy were associated with having SLE-related damage among African American but not White patients. Our data suggest that interventions targeting these modifiable factors may have the potential to reduce healthcare disparities in SLE.

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