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DOI:

[10.1016/S2665-9913\(23\)00296-5](https://doi.org/10.1016/S2665-9913(23)00296-5)

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*Document Version*

Publisher's PDF, also known as Version of record

*Citation for published version (Harvard):*

Sandoval-Heglund, D, Roberts, E, Park, J, Dall'Era, M, Lanata, C, Barbour, K, Greenlund, KJ, Gordon, C, Katz, P & Yazdany, J 2023, 'Economic insecurities and patient-reported outcomes in patients with systemic lupus erythematosus in the USA: a cross-sectional analysis of data from the California Lupus Epidemiology Study', *The Lancet Rheumatology*. [https://doi.org/10.1016/S2665-9913\(23\)00296-5](https://doi.org/10.1016/S2665-9913(23)00296-5)

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# Economic insecurities and patient-reported outcomes in patients with systemic lupus erythematosus in the USA: a cross-sectional analysis of data from the California Lupus Epidemiology Study

Donavon Sandoval-Heglund\*, Eric Roberts\*, Joonsuk Park, Maria Dall'Era, Cristina Lanata, Kamil E Barbour, Kurt J Greenlund, Caroline Gordon, Patricia P Katz†, Jinoos Yazdany†



## Summary

**Background** Social determinants of health are consistently associated with systemic lupus erythematosus (SLE) outcomes. However, social determinants of health are typically measured with conventional socioeconomic status factors such as income or education. We assessed the association of economic insecurities (ie, food, housing, health care, and financial insecurity) with patient-reported outcomes in a cohort of patients with SLE.

**Methods** In this cross-sectional analysis, data were derived from the California Lupus Epidemiology Study based in the San Francisco Bay Area, CA, USA. Participants were recruited between Feb 25, 2015, and Jan 10, 2018, from rheumatology clinics. Inclusion criteria were Bay Area residency; oral fluency in English, Spanish, Cantonese, or Mandarin; 18 years or older; ability to provide informed consent; and a physician confirmed SLE diagnosis. Food, housing, health care, and financial economic insecurities were assessed by validated screening tools. Patient-reported outcomes were obtained using PROMIS, Quality of Life in Neurological Disorders (known as Neuro-QoL) Cognitive Function short form, Patient Health Questionnaire (PHQ)-8, and General Anxiety Disorder (GAD)-7 instruments. Poverty was defined as household income of 125% or less of the federal poverty limit. Lower education was defined as less than college-graduate education. The association of economic insecurities with patient-reported outcomes was assessed by multivariable linear regression models adjusting for demographics, SLE disease characteristics, and comorbidities. We tested for interactions of insecurities with poverty and education.

**Findings** The final cohort included 252 participants. Mean age was 49.7 (SD 13.4) years, 228 (90%) of 252 were women and 24 (10%) were men. 80 (32%) individuals self-identified as Asian, 26 (10%) as Black, 101 (40%) as White, eight (3%) as mixed race, and 37 (15%) as other race; 59 (23%) self-identified as Hispanic. 135 (54%) individuals had at least one insecurity. Insecurities were highly prevalent, and more common in those with poverty and lower education. Adjusted multivariate analyses revealed that participants with any insecurity had significantly worse scores across all measured patient-reported outcomes. For physical function, no insecurity had an adjusted mean score of 48.9 (95% CI 47.5–50.3) and any insecurity had 45.7 (44.3–47.0;  $p=0.0017$ ). For pain interference, no insecurity was 52.0 (50.5–53.5) and any insecurity was 54.4 (53.0–55.8;  $p=0.031$ ). For fatigue, no insecurity was 50.5 (48.8–52.3) and any insecurity was 54.9 (53.3–56.5;  $p=0.0005$ ). For sleep disturbance, no insecurity was 49.9 (48.3–51.6) and any insecurity was 52.9 (51.4–54.5;  $p=0.012$ ). For cognitive function, no insecurity was 49.3 (47.7–50.9) and any insecurity was 45.6 (44.1–47.0;  $p=0.0011$ ). For PHQ-8, no insecurity was 4.4 (3.6–5.1) and any insecurity was 6.1 (5.4–6.8;  $p=0.0013$ ). For GAD-7, no insecurity was 3.3 (2.6–4.1) and any insecurity was 5.2 (4.5–5.9;  $p=0.0008$ ). Individuals with more insecurities had worse patient-reported outcomes. There were no statistically significant interactions between insecurities and poverty or education.

**Interpretation** Having any economic insecurity was associated with worse outcomes for people with SLE regardless of poverty or education. The findings of this study provide insight into the relationship between economic insecurities and SLE outcomes and underscore the need to assess whether interventions that directly address these insecurities can reduce health disparities in SLE.

**Funding** US Centers for Disease Control, Rheumatology Research Foundation, and National Institute of Arthritis and Musculoskeletal and Skin Diseases.

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## Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease with a prevalence of approximately 73 per 100 000 person-years in North America.<sup>1</sup> Research

suggests a genetic component to SLE onset but that the course and severity of SLE are often driven by social determinants of health,<sup>2</sup> defined as the “conditions in

Lancet Rheumatology 2023

Published Online  
December 20, 2023  
[https://doi.org/10.1016/S2665-9913\(23\)00296-5](https://doi.org/10.1016/S2665-9913(23)00296-5)

See Online/Comment  
[https://doi.org/10.1016/S2665-9913\(23\)00323-5](https://doi.org/10.1016/S2665-9913(23)00323-5)

\*Joint first authors

†Joint senior authors

University of California San Francisco, School of Medicine, San Francisco, CA, USA (D Sandoval-Heglund BA); University of California San Francisco, Department of Medicine, Division of Rheumatology, San Francisco, CA, USA (E Roberts PhD, J Park MS, M Dall'Era MD, Prof P P Katz PhD, Prof J Yazdany MD MPH); National Human Genome Research Institute, National Institutes of Health, Bethesda, MD, USA (C Lanata MD); Centers for Disease Control and Prevention, Division of Population Health, Atlanta, GA, USA (K E Barbour PhD, K J Greenlund PhD); Rheumatology Research Group, Institute of Inflammation and Ageing, University of Birmingham, Birmingham, UK (C Gordon MD); University of California San Francisco, Institute for Health Policy Studies, San Francisco, CA, USA (Prof P P Katz)

Correspondence to Prof Patricia Katz, University of California San Francisco, Department of Medicine, Division of Rheumatology, San Francisco, CA 94101, USA [patti.katz@ucsf.edu](mailto:patti.katz@ucsf.edu)

**Research in context****Evidence before this study**

We searched PubMed for observational studies of systemic lupus erythematosus (SLE) from July 1, 2008, to July 31, 2023, using the search terms “poverty”, “socioeconomic”, and “systemic lupus erythematosus”. Pre-existing literature on the relationship between socioeconomic factors and SLE outcomes consisted of cross-sectional analyses of varying SLE cohorts including the California Lupus Surveillance Project, California Lupus Epidemiology Study, and Lupus Outcomes Study. These studies show that low income, low educational attainment, and inadequate or no health insurance are among the social determinants of health associated with poorer SLE outcomes. However, there are additional social determinants of health, including economic insecurities, that might affect SLE patient-reported outcomes above and beyond income, education, and health insurance. A qualitative study revealed the self-reported impact of economic insecurities related to food, housing, medical care, and finances on patients’ management of SLE.

**Added value of this study**

Economic insecurities related to food, housing, medical care, and finances, contribute to poor SLE outcomes, even after

accounting for factors such as having health insurance, health literacy, poverty, and education. These results increase our understanding of the relationship between social determinants of health and SLE outcomes, and identify economic insecurities as an area for further investigation.

**Implications of all the available evidence**

Economic insecurity is an emerging concept in research examining social determinants of health and their relationship to disease outcomes. In this study, we show that economic insecurity regarding food, housing, health care, and finances is associated with worse outcomes for people with SLE regardless of poverty, education, health literacy, or health insurance status. Findings provide further insight into the relationship between economic insecurity and SLE outcomes and warrant further research into the mechanisms underpinning this association. From a clinical perspective, our study underscores the need to study whether interventions that directly address economic insecurities can reduce health disparities in SLE.

which people are born, grow, live, work, and age”.<sup>3</sup> Although social determinants of health encompass a wide range of social risk factors, only a select few have been examined in SLE, such as income, education level, and health insurance status. These factors have been associated with disease activity, damage accrual, and mortality.<sup>4,5</sup>

After accounting for social determinants of health like poverty, education, and health insurance status, there are still variations in SLE outcomes that could be related to additional social determinants of health. Recently, some researchers have investigated the concept of economic insecurity, including difficulty paying for food, medications, or housing and found strong associations with several chronic disease outcomes.<sup>3</sup> These measures might be particularly salient in the case of a complex chronic disease like SLE, which requires significant personal costs even among patients with health insurance.<sup>6</sup> Indeed, a qualitative study reported that low-income and non-low-income respondents had similar experiences accessing care and having a treatment plan, and that both groups were affected by traditional stressors for people with SLE (eg, sun exposure and daily hassles).<sup>7</sup> However, the groups differed in their experience of economic insecurity, with low-income respondents reporting more concerns about housing, food, and medical costs. In addition to these chronic stressors, low-income respondents highlighted how these concerns caused them to relegate dealing with their SLE to times of severe illness or distress, rather than chronic disease management that focused on prevention of disease exacerbations.

We built on this work by assessing the relationship between measures of economic insecurity and SLE patient-reported outcomes in the California Lupus Epidemiology Study (CLUES). Our analyses were guided by the comprehensive social determinants of health conceptual framework developed by WHO, in which material circumstances such as housing and financial means to buy food are viewed as intermediary determinants of health outcomes, separate from, but causally related to, structural social determinants of health such as education and income.<sup>8</sup> In the WHO framework, these intermediary factors constitute an important mechanism through which socioeconomic position generates health inequities.

In this study, we examined the hypothesis that such intermediary social determinants of health, which we conceptualise here as economic insecurity, are associated with worse patient-reported outcomes in patients with SLE even after accounting for conventional measures of socioeconomic status. CLUES offers a unique opportunity to understand how economic insecurity might exert an effect beyond health insurance as all participants in the cohort have access to care through private insurance, universal health insurance in San Francisco, or the Medicaid expansion in California.<sup>9</sup> We also evaluated whether poverty or education modified the association between economic insecurity and SLE outcomes, hypothesising that economic insecurity might exacerbate the negative effect of low income and low educational attainment on patient-reported outcomes.

## Methods

### Study design and participants

In this cross-sectional analysis, we used data from CLUES, a cohort of racially and ethnically diverse participants with SLE that were recruited from the California Lupus Surveillance Project<sup>10</sup> with additional recruitment from academic and community rheumatology clinics throughout the nine San Francisco Bay Area counties between Feb 25, 2015, and Jan 10, 2018. All study procedures were approved by the UCSF Institutional Review Board, and all participants provided written informed consent.

CLUES procedures involved an in-person research clinic visit, including collection and review of medical records beforehand; a history and physical examination conducted by a physician specialising in SLE; collection of biospecimens; and completion of a structured interview administered by an experienced research assistant. Follow-up interviews were conducted annually and all data for these analyses are from the year 5 interviews (Feb 1, 2020, to March 31, 2021), the first year in which information regarding economic insecurities was collected.

Inclusion criteria were San Francisco Bay Area residency; age 18 years or older; oral fluency in English, Spanish, Cantonese, or Mandarin; and ability to provide informed consent.

All SLE diagnoses were confirmed by study physicians based upon one of the following definitions used in previous California Lupus Surveillance Project and CLUES studies:<sup>10</sup> (1) meeting four or more of the 11 American College of Rheumatology (ACR) revised criteria for the classification of SLE as defined in 1982 and updated in 1997,<sup>11</sup> (2) meeting three ACR criteria plus a documented rheumatologist's diagnosis of SLE, or (3) a confirmed diagnosis of lupus nephritis, defined as fulfilling the ACR renal classification criterion (>0.5 g of proteinuria per day or 3+ protein on urine dipstick analysis) or having evidence of lupus nephritis on kidney biopsy.

### Procedures

We assessed the effect of economic insecurities on seven patient-reported outcomes. Four Patient Reported Outcomes Measurement Information System (PROMIS) short forms were administered in CLUES to assess symptoms relevant to SLE: physical function, pain interference, fatigue, and sleep disturbance.<sup>12</sup> Minimally meaningful differences for these PROMIS scores have been estimated at around 2 points in patients with SLE.<sup>13</sup> The Quality of Life in Neurological Disorders (Neuro-QoL) Cognitive Function short form was used to assess cognitive symptoms that are commonly reported in patients with SLE.<sup>14</sup> All PROMIS and Neuro-QoL scales were scored as recommended and converted to T-scores with a population mean of 50 and SD of 10, using PROMIS scoring documentation.

We also examined the collected measures of depression and anxiety. The Patient Health Questionnaire (PHQ)-8 is an eight-item measure of depressive symptoms; scores greater than 10 correspond with clinical diagnoses of depression.<sup>15</sup> The Generalized Anxiety Disorder (GAD)-7 is a validated seven-item screen for generalised anxiety disorder and can assess the severity of anxiety symptoms.<sup>16</sup> For pain interference, fatigue, sleep disturbance, depression, and anxiety, higher scores reflect worse health outcomes, whereas higher scores for physical function and cognitive function reflect better health outcomes.

All measures were available through PROMIS and NeuroQoL in English and Spanish but not Cantonese or Mandarin as these patients had already been lost to follow-up at the time of administration.

Our primary predictors were insecurities related to food, housing, general financial status, and ability to afford care for SLE. Housing insecurity was assessed with the 2013 Behavioral Risk Factor Surveillance System question "How often in the past 12 months would you say you were worried or stressed about having enough money to pay your rent/mortgage?"<sup>17</sup> Answer options were "never", "rarely", "sometimes", "usually", or "always", with sometimes or always considered housing insecurity.

A validated brief assessment that asked how often the following statements were true assessed food insecurity: "Within the past 12 months we worried whether our food would run out before we got money to buy more," and "Within the past 12 months the food we bought just didn't last and we didn't have money to get more."<sup>18</sup> Participants who answered either "always true" or "sometimes true" to either or both statements were classified as food insecure.

Financial insecurity was assessed with three questions:<sup>19</sup> "In the next two months, how likely is it that you and your family will experience actual hardships, such as inadequate housing, food, or medical attention?", "In the next two months, how likely is it that you and your family will have to reduce your standard of living to the bare necessities in life?", and "How difficult is it for you to live on your total household income right now?". Participants rated their likelihood of experiencing actual hardships, having to reduce their standard of living to the bare necessities in the next two months, and their current difficulty living on their household income. Participants were characterised as financially insecure if they answered, "likely" or "somewhat" to any of the three items.

Inability to afford SLE care was assessed with the question, "How worried are you now that you may not be able to afford the care you need for your lupus in the next one to two years?" Response options were "not at all worried," "somewhat worried," and "very worried". Participants were classified as SLE care insecure if they responded "somewhat" or "very worried".

### Statistical analysis

Covariates for multivariable regression analyses included demographic and SLE-specific variables. Basic

demographic characteristics such as age, self-identified sex, and self-identified race and ethnicity were drawn from the baseline interview. Covariates for social determinants of health included poverty status (household income <125% federal poverty level based on household size for poverty or  $\geq$ 125% for no poverty), and education (college-graduate education or higher for high education or no college-graduate education for low education) collected in year 5 and health literacy (dichotomised as limited or not limited, on the basis of Chew and colleagues)<sup>20,21</sup> collected at baseline. Number of major comorbid conditions (including cardiovascular disease, asthma, cancer, and diabetes), obesity (defined as baseline BMI  $\geq$ 30), and SLE-specific clinical data, including SLE disease duration, moderate or high dose oral glucocorticoid use (prednisone or equivalent glucocorticoid  $\geq$ 7.5 mg per day for high and <7.5 mg per day for moderate), immunosuppressive medication use (yes or no), and hydroxychloroquine use (yes or no) collected from year 5 were also used as covariates. At year 4, accumulated SLE damage was assessed by the Brief Index of Lupus Damage (BILD), a validated patient-reported proxy for the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SDI). Higher BILD scores indicate worse disease damage.

We characterised the demographic and clinical characteristics of our cohort using mean (SD), median (IQR), or frequencies and proportions. The distribution of economic insecurities was calculated three ways: (1) binary indicator of any insecurity, (2) count of the number of insecurities experienced, and (3) stratification of our binary indicator by poverty and education. Testing for differences in the distribution of patient-reported outcomes across these categories was done using independent-sample *t* tests or one-way analyses of variance with Tukey post-hoc means tests. Missingness for all analytical variables was coded to 0 (eg, no insecurity; appendix p 2). Listwise deletion was performed for three observations for PROMIS Fatigue and one observation for other patient-reported outcomes.

Interactions between economic insecurities, poverty, and education were operationalised using the cross-classification of our binary insecurity measure with our binary measures for poverty and education. Unadjusted differences in patient-reported outcomes by group were examined with analyses of variance with Tukey post-hoc means tests.

Differences in patient-reported outcomes were then examined in multivariable linear regression models, controlling for age; sex; race and ethnicity; poverty status; education; marital status; obesity; disease duration; disease damage (via BILD); comorbidities; and use of oral steroid, immunosuppressives, and hydroxychloroquine, and marginal adjusted means were calculated. To examine whether there was an interaction between insecurities and poverty status, the cross-classified measures of binary

insecurity with binary poverty status were added to another set of regression analyses. We conducted a sensitivity analysis stratifying annual household income as less than US \$60 000 per year or \$60 000 and greater per year. A similar strategy was used to examine the interaction between insecurities and education. Sensitivity analyses assessed associations between individual insecurities and outcomes using both unadjusted and adjusted models.

To ensure the appropriateness of models, we did regression diagnostics for influential data, normality of residuals, homoscedasticity of residuals, multicollinearity, and non-linearity. All variance inflation factors were less than 3, indicating a lack of multicollinearity.

All analyses used Stata SE version 17.0 software. A *p* value of 0.05 or less was considered statistically significant. Our study conforms to the STROBE checklist for observational studies.

#### Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or the decision to submit this manuscript for publication. KEB and KJG, both employees of the funder, reviewed drafts of the manuscript.

#### Results

CLUEs included 431 participants at baseline. Annual follow-up interview retention averaged 86%; however, between baseline and year 5, 179 participants were lost to follow-up (including 14 deaths and all Mandarin-speaking and Cantonese-speaking participants, due to loss of a language-concordant interviewer), leaving 252 participants for these analyses. The mean age of the cohort at year 5 was 49.7 (SD 13.4) years, with a mean SLE duration of 22.4 (10.7) years (table 1). 228 (90%) of 252 were women and 24 (10%) were men. 80 (32%) self-identified as Asian, 26 (10%) as Black, 101 (40%) as White, 8 (3%) as mixed race, and 37 (15%) as other race; 59 (23%) individuals self-identified as Hispanic. 29 (12%) participants reported household incomes below poverty, and 39 (16%) reported less than college education. Individuals who had been lost to follow-up before year 5 were older than those with follow-up at year 5 (mean 48.2 years [SD 15.2] for those lost to follow-up before year 5 vs 45.4 years [13.4] for those not lost to follow-up) and more commonly had incomes below poverty (42 [24%] of 179 individuals lost to follow-up before year 5 vs 33 [13%] of 252 individuals with follow-up at year 5), but there were no significant differences at baseline in sex, race, comorbid conditions, SLE disease activity or damage, or patient-reported outcomes (appendix p 3). Housing insecurity was reported by 57 (23%) of 252 participants, food insecurity by 43 (17%), financial insecurity by 53 (21%), and worry about paying for SLE care by 106 (42%; table 2). 135 (54%) respondents reported experiencing at least one insecurity, and 72 (29%) reported two or more.

See Online for appendix

	All participants (n=252)
<b>Sociodemographic characteristics</b>	
Age, years	49.7 (13.4)
Female	228 (90%)
Male	24 (10%)
Race	
Asian	80 (32%)
Black	26 (10%)
White	101 (40%)
Mixed	8 (3%)
Other	37 (15%)
Hispanic ethnicity	59 (23%)
Income	
Below poverty	29 (12%)
Unknown	17 (7%)
Education	
Less than high school	12 (5%)
High school degree	27 (11%)
Some college	38 (15%)
Associate degree, trade school	36 (14%)
College or university degree	78 (31%)
Postgraduate or professional	60 (24%)
Unknown	1 (<1%)
Married	143 (57%)
<b>Patient-reported outcomes</b>	
PROMIS Physical Function	47.2 (9.8)
PROMIS Pain Interference	53.3 (9.7)
PROMIS Fatigue	52.9 (10.6)
PROMIS Sleep Disturbance	51.2 (9.2)
NeuroQoL Cognitive Function	47.3 (9.7)
PHQ-8 (depressive symptoms)	
Mean (SD)	5.3 (4.5)
Median (IQR)	5 (2-8)
GAD-7 (anxiety)	
Mean (SD)	4.3 (4.4)
Median (IQR)	3 (1-6)

(Table 1 continues in next column)

	All participants (n=252)
(Continued from previous column)	
<b>General health characteristics</b>	
Number of comorbid conditions	
Mean (SD)	2.0 (1.7)
Median (IQR)	2 (1-3)
Obesity (BMI ≥30)	25 (63)
<b>SLE-related characteristics</b>	
SLE disease duration (years)	22.4 (10.7)
SLE disease damage (BILD)	
Mean (SD)	2.5 (2.4)
Median (IQR)	1 (0-3)
<b>Medications</b>	
High-dose glucocorticoids (≥7.5 mg per day)	35 (14%)
Hydroxychloroquine	163 (65%)
Immunosuppressives	129 (51%)
Data are n (%) or mean (SD) unless otherwise specified. Patients reported race and ethnicity as separate variables. BILD=Brief Index of Lupus Damage. GAD-7=General Anxiety Disorder-7. PHQ-8=Patient Health Questionnaire-8. PROMIS=Patient-reported Outcomes Measurement Information System. SLE=systemic lupus erythematosus.	

**Table 1: Baseline characteristics**

Insecurities were significantly more common among individuals with poverty-level income and lower education (table 2). Worry about paying for SLE care did not differ by poverty status (table 2).

Unadjusted analyses examining the relationships between economic insecurities and patient-reported outcomes revealed significant differences between those with and without any economic insecurity and by the number of insecurities for all patient-reported outcomes. In all cases, economic insecurities were significantly associated with worse self-reported health outcomes. Across patient-reported outcomes, the magnitude of the differences between none and any insecurity generally exceeded minimally meaningful

	Total (n=252)	Poverty		p value*	Lower education (<college degree)		p value*
		No (n=206)	Yes (n=29)		No (n=138)	Yes (n=113)	
<b>Insecurities</b>							
Housing	57 (23%)	39 (19%)	12 (41%)	0.011	16 (12%)	41 (36%)	<0.0001
Financial	53 (21%)	32 (16%)	16 (55%)	<0.0001	15 (11%)	38 (34%)	<0.0001
Food	43 (17%)	25 (12%)	13 (45%)	<0.0001	12 (9%)	31 (27%)	<0.0001
SLE care	106 (42%)	82 (40%)	14 (48%)	0.49	43 (31%)	63 (56%)	<0.0001
Any of the above	135 (54%)	100 (49%)	23 (79%)	0.0031	54 (39%)	81 (72%)	<0.0001
Number of insecurities				0.0002			<0.0001
0	117 (46%)	106 (52%)	6 (21%)		84 (61%)	32 (28%)	
1	63 (25%)	53 (26%)	6 (21%)		33 (24%)	30 (27%)	
≥2	72 (29%)	47 (23%)	17 (59%)		21 (15%)	51 (45%)	
Data are n (%) unless otherwise specified. 17 individuals did not provide income data. One individual did not provide education information. SLE=systemic lupus erythematosus. *p-values are from $\chi^2$ analyses.							

**Table 2: Frequency of reports of economic insecurities, total and by income and education**

differences for each scale (table 3). When considering the number of insecurities, differences were even larger. Examining the mean scores based on the number of insecurities, there appeared to be a stepwise effect, with the worst outcomes for the group with two or more economic insecurities (table 3). By contrast, the only statistically significant differences by poverty status were for physical function and pain interference. Results of sensitivity analyses using income instead of

	Physical function*	Cognitive function*	Pain interference†	Fatigue†	Sleep disturbance†	Depression†	Anxiety†
<b>Any insecurity</b>							
No (n=117)	50.4 (0.7)	50.2 (8.9)	50.7 (9.2)	49.5 (10.0)	49.4 (9.0)	3.9 (4.0)	2.9 (3.6)
Yes (n=135)	44.4 (8.9)	44.8 (8.8)	55.5 (9.5)	55.8 (10.2)	53.3 (9.1)	6.5 (4.6)	5.5 (4.7)
p value	<0.0001	<0.0001	<0.0001	<0.0001	0.0008	<0.0001	<0.0001
<b>Number of insecurities</b>							
0 (n=117)	50.4 (0.7)	50.2 (8.9)	50.7 (9.2)	49.5 (10.0)	49.4 (9.0)	3.9 (4.0)	2.9 (3.6)
1 (n=63)	46.1 (9.3)‡	‡46.0 (9.9)	‡54.6 (9.5)	‡55.1 (10.8)	52.6 (9.2)	‡6.2 (4.6)	‡4.7 (4.1)
≥2 (n=72)	42.9 (8.4)‡	‡43.8 (7.8)	‡56.3 (9.6)	‡56.3 (9.7)	‡54.0 (9.0)	‡6.8 (4.6)	‡6.2 (5.1)
p value	<0.0001	<0.0001	0.0002	<0.0001	0.0024	<0.0001	<0.0001
<b>Poverty§</b>							
No (n=206)	48.0 (9.7)	47.8 (9.3)	52.7 (9.5)	52.3 (10.7)	51.2 (8.9)	5.1 (4.4)	4.2 (4.3)
Yes (n=29)	42.1 (8.6)	44.8 (9.6)	57.0 (10.1)	55.3 (10.6)	52.2 (11.3)	6.2 (5.5)	5.2 (4.9)
p value	0.0024	0.097	0.025	0.17	0.59	0.24	0.26
<b>Lower education (&lt;college degree)¶</b>							
No (n=138)	49.5 (9.5)	48.3 (9.2)	51.4 (9.5)	51.6 (10.6)	50.6 (8.4)	4.7 (4.2)	3.7 (4.1)
Yes (n=113)	44.3 (9.3)	46.0 (9.3)	55.6 (9.4)	54.6 (10.4)	52.8 (10.0)	6.1 (4.8)	5.0 (4.7)
p value	<0.0001	0.042	0.0005	0.026	0.056	0.012	0.020
<b>Any insecurity and income§</b>							
No insecurity and no poverty (n=111)	50.9 (9.5)	50.4 (8.8)	50.3 (8.9)	49.1 (9.9)	49.7 (8.8)	3.7 (3.6)	2.9 (3.6)
No insecurity and poverty (n=6)	41.9 (10.6)	45.9 (10.7)	58.6 (11.5)	56.4 (10.2)	45.3 (13.2)	8.2 (8.3)	2.8 (3.8)
Any insecurity and no poverty (n=112)	‡44.9 (9.0)	‡44.9 (8.7)	‡55.3 (9.5)	‡55.9 (10.1)	‡53.2 (8.8)	‡6.7 (4.6)	‡5.5 (4.6)
Any insecurity and poverty (n=23)	‡42.1 (8.2)	‡44.5 (9.6)	‡56.7 (10.0)	55.0 (10.9)	54.0 (10.4)	5.6 (4.6)	‡5.8 (5.1)
p value	<0.0001	<0.0001	<0.0001	<0.0001	0.0018	<0.0001	<0.0001
<b>Any insecurity and education¶</b>							
No insecurity and higher education (n=84)	51.8 (9.2)	50.6 (9.1)	49.6 (8.9)	49.1 (9.9)	49.9 (8.5)	3.8 (3.8)	3.0 (3.7)
No insecurity and lower education (n=32)	‡46.5 (10.1)	48.9 (8.7)	53.8 (9.4)	50.7 (10.6)	48.5 (10.5)	4.3 (4.8)	2.8 (3.4)
Any insecurity and higher education (n=54)	‡45.8 (9.0)	‡44.8 (8.3)	‡54.2 (9.7)	‡55.3 (10.7)	51.6 (8.4)	‡6.1 (4.5)	‡4.9 (4.4)
Any insecurity and lower education (n=81)	‡43.4 (8.9)	..	‡56.4 (9.4)	‡56.0 (9.9)	‡54.5 (9.4)	‡6.8 (4.7)	‡5.9 (4.9)
p value	<0.0001	..	<0.0001	<0.0001	0.0020	<0.0001	<0.0001

Data are mean (SD). Differences in group means were tested with t-tests or analyses of variance. \*Higher scores reflect better outcomes. †Higher scores reflect worse outcomes. ‡Significantly different from "No insecurity, income>poverty/high education" group based on post-hoc means test. §17 individuals did not provide income data. ¶One individual did not provide education information.

**Table 3: Unadjusted differences in patient-reported outcomes by insecurities, income, and education**

poverty status (appendix p 5) were not substantially different. Significant differences in outcome by education were also identified, with the lower education group having worse scores on all patient-reported outcomes. Nearly all patient-reported outcomes were significantly worse for participants with any individual insecurity (appendix p 6).

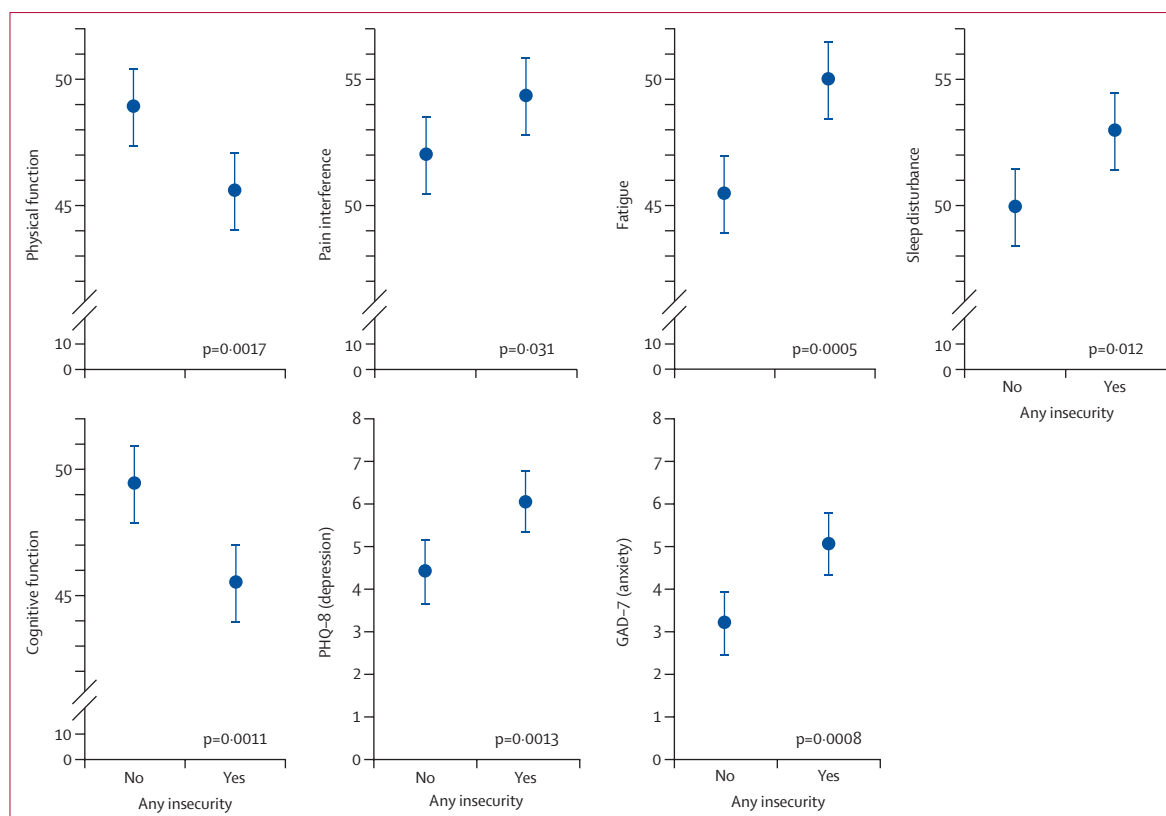
In unadjusted models of the insecurity by poverty groups, overall significant differences between groups were seen for each patient-reported outcome (table 3). In each case, there were significant differences between one or both insecurity groups (either insecurity and no poverty or insecurity and poverty) and the no insecurity and no poverty group (table 3). Similar results were noted for the insecurity by education analysis (table 3).

After adjustment for covariables, including poverty status, education, and health literacy, individuals with any insecurity had significantly worse scores on all patient-reported outcomes (figure 1). The magnitude of

between-group differences ranged from 2 points to 4 points; although smaller than in the unadjusted models, these are still meaningful differences (appendix p 4). Differences by the number of insecurities showed significantly worse scores for individuals with one insecurity, or at least two insecurities compared with individuals with no insecurities (figure 2). There was no clear association between individual economic insecurities and patient-reported outcomes in adjusted analyses (appendix p 6), although housing and financial insecurity were associated with worse physical functioning and anxiety symptoms. We did not find interactions between insecurities and either poverty status or education.

### Discussion

In this study of the relationship between economic insecurities—an important emerging concept in the social determinants of health literature—and patient-reported outcomes in a diverse group of individuals with



**Figure 1: Adjusted marginal means from multivariable analysis by any insecurity**

Points are adjusted means and error bars are 95% CIs. Data were calculated from multivariable linear regression analyses controlling for age, sex, race and ethnicity, marital status, education, income, health literacy, comorbid conditions, obesity, disease duration, disease damage, high glucocorticoid use, immunosuppressive use, and hydroxychloroquine use. p values were derived from multivariable linear regression, compared with the no insecurities group. GAD-7=Generalized Anxiety Disorder questionnaire. PHQ-8=Patient Health Questionnaire.

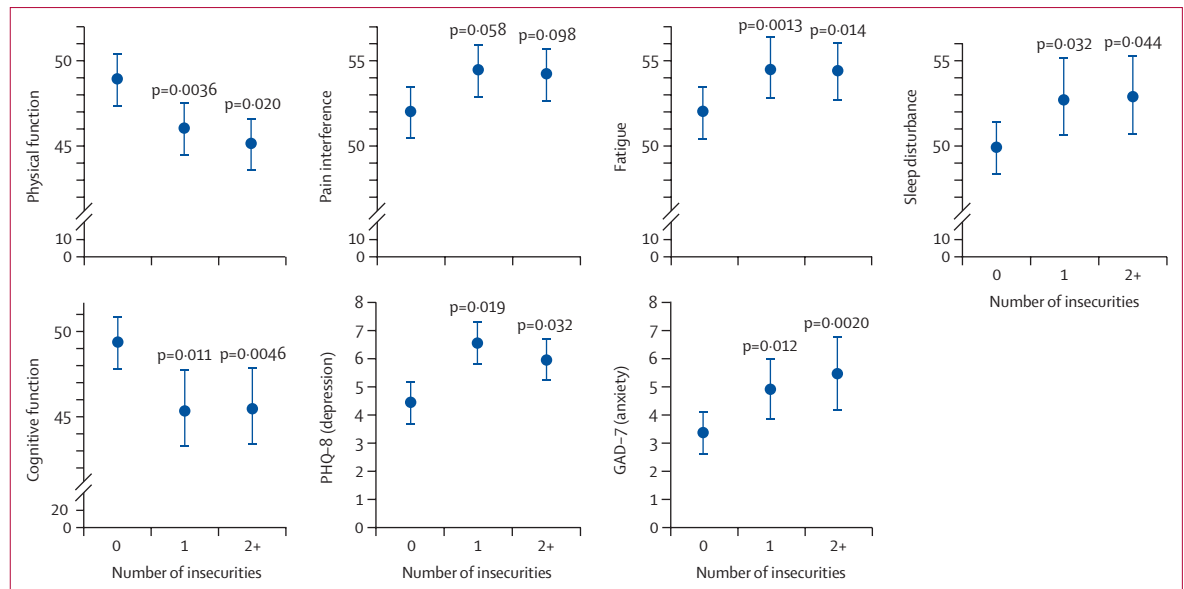
SLE, we found that economic insecurities were highly prevalent, with over half of participants reporting at least one insecurity, such as concern about paying for food, housing, or SLE medical care. The presence of any insecurity was associated with worse patient-reported outcomes across a broad range of domains. These relationships were observed even after accounting for sociodemographic factors, poverty status, education, health literacy, comorbidities, SLE disease damage, and SLE medications.

This study expands the growing knowledge base regarding the relationship between social determinants of health and outcomes in SLE, a condition with substantial health disparities. Previous studies have shown that more commonly considered social determinants of health, such as poverty, lower educational attainment, or health insurance coverage, are associated with worse outcomes in SLE. Within a broader social determinants of health framework, we build on this previous work by examining several additional social determinants of health related to economic insecurity. We found that economic insecurities were not limited to individuals below the poverty boundary; almost half of those with incomes above the poverty boundary reported

at least one insecurity. Additionally, we did not find that a specific type of insecurity drove the association with outcomes; instead, we saw the strongest effects among those with the highest number of insecurities of any type. These results held after controlling for poverty, education level, health literacy, and a host of clinical indicators, indicating that economic insecurities are a unique risk factor for poor health outcomes in patients with SLE.

Building on a previous qualitative study,<sup>22</sup> we hypothesised that economic insecurities would exacerbate the harmful effects of poverty and that higher education would ameliorate the effects of economic insecurities. We did not find support for either hypothesis: there was no significant direct effect of poverty on most of the patient-reported outcomes examined. Although our sample size precluded examination of more granular income brackets and results need to be replicated in larger samples, we found that differences in outcomes were primarily due to insecurities, suggesting that traditional income thresholds do not adequately capture the total effect of low socioeconomic status. Our study was conducted in the San Francisco Bay Area which has a high cost of living and might explain why economic insecurities





**Figure 2: Adjusted marginal means from multivariable analysis by number of insecurities**

Points are adjusted means and error bars are 95% CIs. Data were calculated from multivariable linear regression analyses controlling for age, sex, race and ethnicity, marital status, education, income, health literacy, comorbid conditions, obesity, disease duration, disease damage, high glucocorticoid use, immunosuppressive use, and hydroxychloroquine use. p values were derived from multivariable linear regression, compared with the no insecurities group. PHQ-8=Patient Health Questionnaire. GAD-7=Generalized Anxiety Disorder questionnaire.

have a stronger relationship with outcomes than poverty and educational achievement. There are probably factors at the macro, meso, and micro level that could affect economic insecurity including the housing supply, physical access to food, neighborhood characteristics, accessibility of transportation, and disability status.<sup>23,24</sup>

However, strong direct effects for education were identified, consistent with the existing literature.<sup>22</sup> The pattern of results for education when tested with any insecurity suggests that the effect of education was confounded by economic insecurities rather than an interaction between the two. Respondents in Yelin and colleagues'<sup>5</sup> study narrated how social connections, a form of social support, via higher education helped them navigate the health-care system. More direct measures of social support might modify the harmful effects of economic insecurities and should be the subject of future investigations. In addition, work remains to establish the contexts in which economic insecurities have the strongest (or any) effect.<sup>5,23,24</sup>

The pattern of economic insecurities seen in this study is consistent with that observed in other chronic diseases, such as diabetes. For example, in a study of the relationship between economic insecurities and diabetes in the USA, 19% of the study cohort reported food insecurity in 2015 (compared with 17% in CLUES).<sup>25</sup> For context, the total prevalence of adults living in households with food insecurity in the USA was markedly lower at 10% in 2021.<sup>26</sup> Additionally, the association we found between insecurities and outcomes is consistent with findings from studies

examining economic insecurities and diabetes management. For example, for people with diabetes having food insecurity was associated with increased HbA<sub>1c</sub> and worse depression and anxiety symptoms.<sup>25,27</sup>

There are several mechanisms that might explain the association of social determinants of health with SLE outcomes. We found evidence for an additive effect of insecurities suggesting that studying interventions across the broad domains examined might be needed to improve health outcomes in patients with SLE. For example, housing and financial insecurity can create difficulties with obtaining, storing, and regularly taking medications or accessing health care for chronic conditions such as SLE.<sup>28</sup> Additionally, economic insecurities might be associated with both depression and anxiety symptoms via chronic stress. For example, in the context of diabetes, researchers observed that food insecurity increased stress and depression thereby worsening diabetes outcomes through impaired self-care practices.<sup>29</sup> Whether the effects of these insecurities on psychological outcomes was modified in the presence of SLE warrants further study.

This study has limitations. We could not examine additional factors that might affect economic insecurities such as disability status, accessibility of transportation, physical access to food, housing supply, and neighborhood characteristics.<sup>23,24</sup> Our measures of financial insecurity and SLE care insecurity asked about anticipated needs rather than an inability to pay for medications as others have.<sup>25</sup> These measures are not fully equivalent, but we believe that they still reflect the psychological aspect of

these concerns and probably reflect, at least partially, an inability to pay for food, housing, or medications. Our measures also assessed insecurities over varying time frames. A portion of the original CLUES sample was lost to follow-up; participants lost to follow-up were more likely to be below the poverty level, which might affect the internal and external validity of the study. As we collected our primary exposure (ie, economic insecurities) at year 5, we were unable to perform sensitivity analyses on the participants lost to follow-up as both exposure and outcome data (ie, patient-reported outcomes) were missing. Our cohort was based in California; the unique demographics and sociopolitical context of the area limits the generalisability of our findings outside this region. Our cohort was also relatively highly educated; in a cohort with greater diversity in educational attainment, our results could have differed. Other limitations of our study include unmeasured confounding, possible exposure–confounder feedback, and potential residual confounding secondary to measurement errors in confounders such as education and disease duration.

The study also has significant strengths, including our cohort's universal access to health care via regional policy.<sup>9</sup> Access to care is crucial for proper management of SLE but access is not the same as the ability to afford proper care for a complex chronic disease like SLE, particularly in the US health-care system in which individuals with health insurance can still have substantial personal costs. This unique characteristic of the CLUES cohort removed confounding between those with and without insurance and allowed us to examine the effect of economic insecurities beyond access to care. In fact, our analyses found that SLE care insecurity did not correspond with poverty status. One potential reason for these findings is that Medicaid, the US insurance programme for those with low incomes, provides a drug low-income subsidy so that payment for expensive medications including biologics, is only a few dollars a month, unlike for individuals with other types of insurance where drug costs can be high.

Overall, this study provides one of the most comprehensive examinations of the relationship between an important subset of social determinants of health—economic insecurities—and SLE outcomes. Our findings suggest that economic insecurities are highly prevalent and impactful exposures for those living with SLE. Having any of the examined insecurities was associated with worse outcomes across a breadth of domains. Importantly, many of these economic insecurities are modifiable with the appropriate interventions, such as long-term rent subsidies, child tax credits, and food programmes.<sup>30</sup> Studies examining the effects and cost-effectiveness of interventions that address economic insecurity are needed given the striking health disparities in SLE. Increased recognition of the importance of these social exposures and knowledge of available resources to provide to patients experiencing economic insecurity,

might have potential to improve outcomes for those with SLE.

#### Contributors

DS-H, ER, PPK, and JY conceptualised the study. DS-H, ER, PPK, and JY wrote the original draft. DS-H, ER, MD'E, CL, KEB, KJG, CG, PPK, and JY reviewed and edited the paper. PPK designed the methodology. PPK, MD'E, and JY were involved in participant recruitment and data collection for CLUES. JP and PPK did the formal analysis, had direct access to the data, and verified the underlying data reported in the manuscript. MD'E, CL, PK, and JY acquired funding. All authors had full access to the data in the study and had final responsibility to submit for publication.

#### Declaration of interests

CG declares consulting fees from Amgen, UCB, Astra Zeneca, and Alumis. PPK declares grant support for this manuscript from the US Centers for Disease Control (CDC; grant numbers CDC U01DP006701 and U48DP006374). JY declares grant support for this manuscript from the National Institute of Arthritis and Musculoskeletal and Skin Diseases (grant numbers NIH/NIAMS K24 AR074534 and NIH/NIAMS P30 AR070155) and the US CDC (grant number CDC U01DP006701); research grants from Gilead, Astra Zeneca, and Bristol Myers Squibb Foundation; consulting fees from Astra Zeneca, Aurinia, Pfizer, and Adelphi Values; and is the research lead for the Rheumatology Informatics System for Effectiveness registry for the American College of Rheumatology. All other authors declare no competing interests.

#### Data sharing

Deidentified participant data that underlie these analyses and data codebooks will be made available to academic researchers upon request to the corresponding author and in accordance with institutional data sharing guidelines, which will require a formal signed data access agreement. Study questionnaires used to collect data will also be available. Data will be available beginning at the time of publication and ending 36 months following Article publication. Requestors must submit a formal request, including a proposal for analysis and variables requested. Proposals for new analyses and requests for data for meta-analyses will be considered. Requests will be reviewed by the CLUES executive committee. Costs for any data preparation will be the responsibility of the requestor. Datasets might be conveyed by email or other secure transmission method.

#### Acknowledgments

This study was funded by grants from the US Centers for Disease Control and Prevention (grant numbers U01DP006701 and U48DP006374), a grant from the Rheumatology Research Foundation, and grants from the National Institute of Arthritis and Musculoskeletal and Skin Diseases (grant numbers P30-AR-070155 and K24AR074534). JY's research programme is also supported by the Alice Betts Endowed Chair and the Robert L Kroc Chair for Arthritis Research, and Russell/Engleman Rheumatology Research Center, housed within the Division of Rheumatology at University of California San Francisco and supports research, training, and patient care. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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