Review

An ecological approach to understanding and addressing health inequities of systemic lupus erythematosus

Lupus
2023, Vol. 32(5) 612–624

DOI: 10.1177/09612033231164637
journals.sagepub.com/home/lup
SAGE

Mallet R Reid[1], Ashley N Danguecan[2], Isabella Colindres[3], Denasja Witherspoon, Tamar B Rubinstein[4], Cristina Drenkard[5], Andrea M Knight[2] and Natoshia R Cunningham[1]

Abstract

Systemic Lupus Erythematosus (SLE) is a complex chronic autoimmune disease disproportionally afflicting women and, in particular, American Indian/Alaska Native, Black, and Hispanic women. These groups of women have significantly worse SLE-related health outcomes which are partially attributable to their exposure to marginalizing and interconnecting social issues like racism, sexism, economic inequality, and more. Although these groups of women have higher rates of SLE and though it is well known that they are at risk of exposure to marginalizing social phenomena, relatively little SLE literature explicitly links and addresses the relationship between marginalizing social issues and poor SLE-health outcomes among these women. Therefore, we developed a community-engaged partnership with two childhood-SLE diagnosed women of color to identify their perspectives on which systemic issues impacted on their SLE health-related outcomes. Afterward, we used Cochrane guidelines to conduct a rapid review associated with these identified issues and original SLE research. Then, we adapted an ecological model to illustrate the connection between systems issues and SLE health outcomes. Finally, we provided recommendations for ways to research and clinically mitigate SLE health inequities.

Keywords

Systemic lupus erythematous, health inequities, ecological, community engagement

Date received: 25 August 2022; accepted: 3 March 2023

Systemic Lupus Erythematosus (SLE) is a chronic systemic autoimmune condition causing inflammation and affecting skin, joints, and multiple organ systems in the body.[1] In North America, diagnoses of SLE are highest among American Indian/Alaskan Native (AI/AN) women (271 per 100,000) followed by Black women (230.9 per 100,000), Hispanic women (Latinas; 120.7 per 100,000), then White and Asian/Pacific Islander women, each with a prevalence of ~84 per 100,000.[2] Yet, although AI/AN, Black, and Hispanic women have a heightened prevalence of SLE, their group-level health outcomes are consistently poorer than White and Asian women.[2] This issue is not unique to SLE as a substantial body of research has demonstrated these groups of women of color often have worse health outcomes than others largely due to various forms of inequality (e.g., racism and sexism).[3]

These SLE health inequities (health problems stemming from socially unjust systems) are worrisome. In the US, SLE is the 10th leading cause of death for all women aged 15-to-24 years-old, yet it is the fifth leading cause of death for Black women and Latinas of the same age.[4] Further, AI/AN women, Black women, and Latinas have the highest SLE-related mortality rates of any group.[2] In Canada, AI/AN's had a 2-fold risk for mortality compared with Whites,

[1]Department of Family Medicine, College of Human Medicine, Michigan State University, Grand Rapids, MI, USA
[2]Division of Rheumatology, The Hospital for Sick Children, Toronto, ON, Canada
[3]Population Health, University of Washington, Seattle, WA, USA
[4]Albert Einstein College of Medicine, Children's Hospital at Montefiore, New York, NY, USA
[5]School of Medicine, Emory University, Atlanta, GA, USA

Corresponding author:
Mallet R Reid, Department of Family Medicine, College of Human Medicine, Michigan State University, 15 Michigan Street NE, Grand Rapids, MI 49503, USA.
Email: reidmall@msu.edu

and on average, AI/AN people with SLE died ~15 years sooner than White people.[2] Further, even when controlling for other variables, Black women and Latinas have higher incidences of lupus nephritis compared to White women.[5,6] Addressing these SLE health inequities requires explicitly investigating the systemic issues producing them and adjusting research and clinical interventions accordingly.[7–9]

An ecological framework to address health inequities in SLE

Ecological frameworks illustrate relationships between structural and individual-level phenomena,[10,11] thus offering an appropriate lens to conceptualize SLE health inequities. We draw from Bronfenbrenner's developmental ecological model,[12] with our model (Figure 1) illustrating how macrosystem elements (societal ideologies), and mesosystem elements (economic forces, social policies, and community structures), influence microsystem (family), and individual outcomes.[9,11,13] We adapted this model to focus on macrosystem elements of structural racism, sexism, and ableism and mesosystem elements of economic inequality, social welfare policy, and neighborhood disadvantage.

In addition to using an ecological model to visualize macro- and meso-level phenomenon, we invoke an intersectional perspective wherever possible to suggest when macro- and meso-level phenomenon might interlock to produce unique and worse health outcomes for those under investigation. Intersectionality is an antisubordination framework that explores the effects of interlocking sociostructural phenomenon on individual-level experiences,[14] and is compatible with ecological analyses.

Methods

Following tenants of community-engaged research which encourages partnership with people experiencing the issue under study and ensuring their insights shape research,[15,16] we engaged in a discussion with two of our co-authors (IC and DW; both women of color diagnosed with childhood-onset SLE) regarding the topic of this review. Together, we situated the focus of the review on macro- and meso-level system's issues related to SLE, as relatively little research examines these issues whereas micro- and individual-level factors are widely studied. Collaboratively, we identified various macro- and meso-level issues influencing their wellbeing. They identified each of the topics discussed below and shared how they were affected by them. Additionally, IC and DW allowed several quotes to be used to frame the review's various topics. Notably, despite lacking literature in some topic areas (e.g., sexism and ableism), we elected to include these topics because they were important to our co-authors.

Next, using Cochrane Rapid Reviews guidelines[17] we conducted a rapid review of the topics across PubMed and PsycINFO, using reproducible search terms to investigate relevant scholarship published in the last 15 years (Table 1 and Figure 2). A total of 62 original research articles were found and were used throughout the sections below. When the available literature was limited regarding broader systems issues (e.g., ableism), we pulled literature from micro-level proxies (e.g., illness-related stigma) and linked these micro-level items with the macro-level phenomena. Michigan State University's IRB office deemed this project IRB exempt.

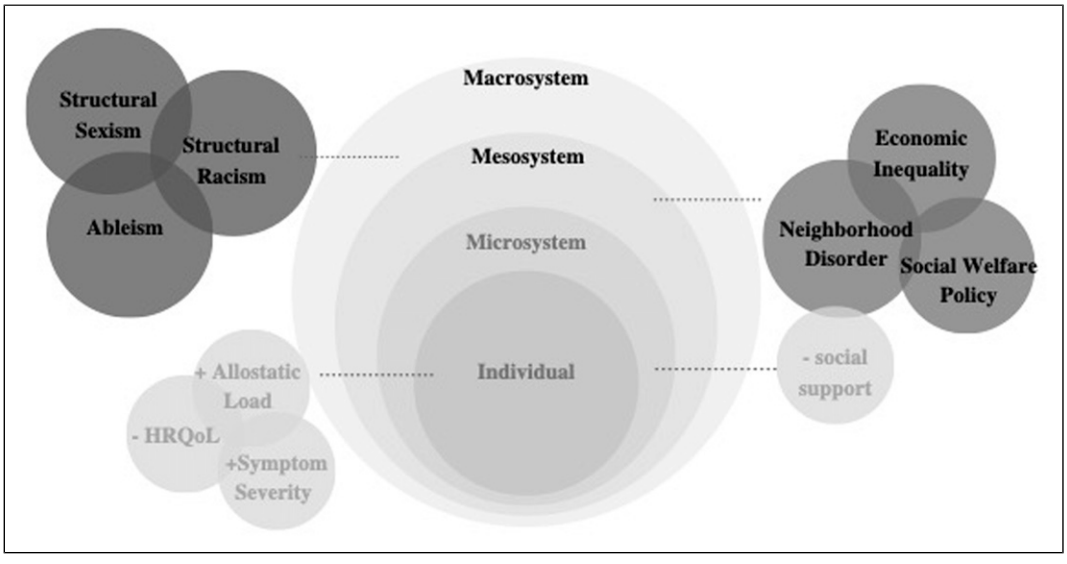

Figure 1. Ecological Illustration of SLE Health Inequities.

Table 1. Literature review search strings.

Search #	Keywords	Concept
1	"Systemic Lupus Erythematosus" OR "Lupus Erythematosus, Systemic"[Majr]	SLE
2	Health inequality[TIAB] OR health inequalities[TIAB] OR health inequities[TIAB] OR health inequity[TIAB] OR health disparities[TIAB] OR health disparity[TIAB] OR healthcare disparities[MH] OR health care disparities[TIAB] OR healthcare disparities[TIAB] OR health-care disparities[TIAB] OR health care disparity[TIAB] OR healthcare disparity[TIAB] OR health-care disparity[TIAB] OR health status disparities[MH] OR delivery of health care[MH:noexp] OR disparities[TIAB] OR social class[MH] OR social class[TIAB] OR social determinants of health[MH] OR social determinants of health[TIAB] OR social disparities[TIAB] OR social disparity[TIAB] OR social factors[TIAB] OR social inequities[TIAB] OR social inequity[TIAB]	Gen. Health ineq.
3	Racism OR racist OR racial discrimination[TIAB] OR racial disparities[TIAB] OR racial disparity[TIAB] OR racial equality[TIAB] OR racial equity[TIAB] OR racial inequities[TIAB] OR racial inequity[TIAB] OR racial prejudice[TIAB] OR racial segregation[TIAB] OR racism[MH]	Racism
4	Sexism OR "gender discrimination" OR sexism[MH] OR "gender inequity" OR "gender inequities"	Sexism
5	Disabled OR disability OR ableism OR health services for persons with disabilities[MH] OR "Disabled Persons"[Mesh] OR "Social Discrimination"[Mesh]	Ableism
6	Poverty OR "economic inequality" OR welfare OR socioeconomic factor[TIAB] OR socioeconomic factors [MH] OR socioeconomic factors[TIAB] OR socioeconomically disadvantaged[TIAB]	SES
7	"Affordable care act" OR medicaid OR medically underserved area[MH] OR medically uninsured[MH] OR uninsured[TIAB] OR underinsured[TIAB] OR medicare OR "Medicare"[Mesh] OR "Medicaid"[Mesh]	Policy
8	Neighborhood OR ghetto OR "section 8" OR "affordable housing" OR "residence characteristics"[Mesh] OR "neighborhood characteristics"[Mesh] OR "physical environment" OR "built environment" OR "social environment"	Neigh. dis.
9	#2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8	Inequ. combo
10	#1 AND #9	All factors

[a]We used the same search strings across databases and did not count duplicate articles in our review.
[b]Results are combined across databases.
[c]After identifying a relevant study, we examined the study's references for relevant articles. Note: most of the relevant studies were often the first or second to explore the topic.

Macrosystem

Structural racism

> *"I have to deal with all these other problems all the time, like worrying if my mom will make it back from the grocery store without being shot… a lot of the time it's made like I'm just dealing with [racism] inside of my head and I'm treated like society shouldn't have an effec… meds and controlling my feelings don't make everything else stop affecting me."*

Racism is a social system whereby a group creates a social hierarchy based on skin color; and in much of the world, lighter skin color (particularly White skin color) is deemed preferential and sits atop the skin-color power hierarchy.[7] Structural racism refers to the way society fosters racism through inequitable, mutually reinforcing systems to harm subordinate groups.[18–20] Structural racism generates and sustains health inequities for non-White people in numerous ways. Some of the most well-known instances of structural racism include Redlining, a US housing policy/procedure implemented in the 20th century that situated non-White individuals in environments low in beneficial social resources and high in exposure to environmental toxins, which subsequently heightened their risk of diseases like cancer and asthma; preferential hiring of White over non-White people which reduces non-White people's economic mobility and sustains their impoverishment; and limited funding of schools that primarily serve students of color in comparison to schools serving predominantly White students which has been linked with higher rates of high-school dropout rates and an increased likelihood of involvement in the juvenile justice system.[21] Structural racism's various effects have been implicated in heightened rates of stress among non-Whites which has led scholars to link structural racism with biomarkers of disease, including increased allostatic load, inflammatory markers, and hormonal dysregulation.[18–20]

Our rapid review found 29 articles related to race and health inequities. These articles predominantly focused on Black women and, to a lesser extent, Latinas. Findings showed these groups have heightened rates of, and risk for, worse health outcomes including pregnancy complication,[22] disease activity and damage accrual,[23–27] worse quality of life,[28,29] multiorgan disease,[30–32] and mortality.[33–35] They are also at heightened risk for cardiovascular events and

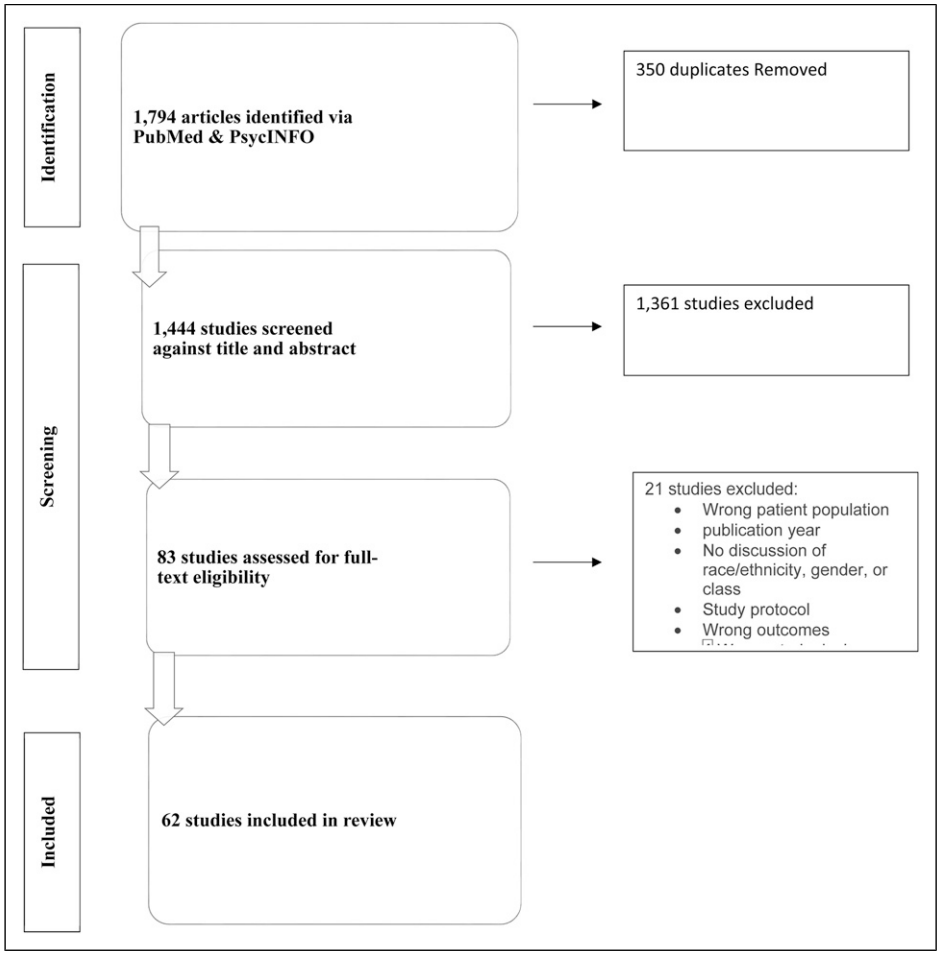

Figure 2. Identification of Articles.

cardiovascular-related death.[36] Black patients are less likely to adhere to SLE medication regiments,[37] an issue linked with structural racism via lack of health system trust and structural impediments to adherence.[38] Additionally, in a study comparing Black to White people with SLE, Sun et al.[39,40] found Black people more likely to perceive worse provider-patient communication, with Sun et al., asserting that Black people perceived more hurried communication with providers and felt providers used vocabulary during treatments that was too difficult to understand. Sun et al. suggest that below-basic health literacy skills may be to blame for the difference in clinical experiences. Instead, we argue that issues linked with systemic racism like limited educational opportunities, health system mistrust, and a lack of culturally tailored health information mediated by low health literacy is to blame.[41,42]

Although the studies above did not explicitly examine racism in relation to the outcomes they reported, some recent SLE studies have. First, Black women observing race-related discrimination had heightened disease activity, and personally experiencing race-based discrimination was related to increased SLE damage.[43–47] Second, Black people with SLE were more likely to face health care mistreatment that they attributed to racism.[48] Third, Black youth with SLE are less likely than Whites to be assessed for depression, reducing their overall health-related quality of life (HRQoL).[49,50] Finally, a recent study found that non-White people are underrepresented in SLE clinical trials,[51,52] an issue maintaining a lack of insight into race-specific SLE health issues.[52]

Structural sexism

> *"I feel stressed because [as a female] I have to really focus on how I phrase things with my doctors, and they may not give me the help I need unless I phrase things just right, so it doesn't sound like it's just all in my mind… people just listen to girls less."*

Structural sexism, defined as systematic gender inequality in power and resources, negatively influences the health and medical treatment of women.[53] For instance, although women generally live longer than men, they are more likely to experience chronic illness and disability due

to increased exposure to violence, trauma, and economic inequality.[54] Additionally, women are less likely than men to receive the most effective and advanced health care treatments,[55,56] are underrepresented in health studies,[57] and are more likely to have their medical issues trivialized or misdiagnosed.[54] Despite more women than men being diagnosed with SLE, our rapid review found no articles associated with structural sexism, nor proxies suitable to link with sexism. Moreover, AI/AN, Black, and Hispanic women with SLE have worse health outcomes than White women, and from an intersectional perspective, these worse outcomes are attributable to the ways racism and sexism interact to produce harmful outcomes for these women.[3] However, our review did not reveal any examinations into these crosshatching phenomena.

Ableism

> *"I'm unhealthy, and that means I'm not normal."*
>
> *"I'm sometimes afraid to even tell people I have lupus because I don't want to be treated differently or looked at differently… sometimes I don't tell a crush for a while because I worry, they won't want to date a person who isn't normal."*

Ableism is an ideology submitting that disabilities (e.g., illnesses like SLE) make a person abnormal and/or less capable compared to those without such conditions.[58] Our rapid review found two studies conceptually related to ableism and SLE. These studies investigated an individual-level proxy of ableism known as illness-related stigma (perceived experiences of discrimination linked to one's illness).[59,60] Studies found that when some SLE symptoms express themselves, people can face a lack of social support and ostracization from family and friends.[61] Sadly, some with SLE report hiding their rashes because they were bullied for having them.[62] Others share that less visible symptoms (i.e., fatigue) have been trivialized in ways that led to increased depression symptoms, loss of friends, and/or divorce.[61] Additionally, AI/AN, Black, and Hispanic people are more likely to experience SLE-related disability than Whites.[2,63] Yet, our review found no studies examining how racism, sexism, or how racism and sexism combine with ableism to uniquely affect different groups.

Mesosystem

Economic inequality

"It's more than not being able to afford things… everything around me feels darker and dirtier. I can't escape from stress or work or school, and it just makes me tired all the time."

Economic inequality is the unequal distribution of income and opportunity.[18] Poverty and socioeconomic status (SES) are the proxies for economic inequality often investigated in SLE research, and 15 identified articles were proximally related to economic inequality. Poverty influences mortality by increasing damage accrual, and impoverished people with SLE live about 14 years less than wealthier people and that.[33,64–68] In fact, the lower one's income, the worse one's SLE-related physical functioning.[69] Low SES also predicts of depression,[70–73] difficulty adhering to treatment,[74] and negative health outcomes independent of access to health care.[75] When people leave poverty they experience rapid normalization of damage accrual.[64,67]

It is well established that AI/AN, Black, and Latino people are consistently located at the bottom of the economic inequality gradient, with women from these groups situated lower than men.[18,76] Moreover, survey data illustrates Black and AI/AN women with disabilities experience the highest poverty levels of any group in North America.[59] Yet, our review found no studies specifically focused on these groups' experiences with economic inequality.

Neighborhood disadvantage

"The different places I've lived almost feel like they have different moods to them. Some places had me feeling stressed a lot because I never felt safe…"

Eight articles were related to SLE and neighborhood disadvantage. Life in disadvantaged neighborhoods (neighborhoods severely lacking in resources and high in environmental and social stressors) is associated with depression,[77] anxiety,[78] impaired cognitive functioning,[79] and increased prevalence of physical illness and mortality.[80] Recent findings illustrate that, when compared to racially integrated tracts, those with SLE who live in moderately and highly segregated census tracts face heightened risk of depression via increased exposure to neighborhood disadvantage.[81] Neighborhood disadvantage also contributes to SLE damage and mortality because living in an area with a high proportion of impoverished people heightens damage accrual.[2]

Furthermore, those living in disadvantaged neighborhoods are more likely to have higher re-hospitalization rates for SLE-related issues, and are less likely to consistently engage in care.[82,83] Given Black people are one of the groups most likely to be situated in disadvantaged neighborhoods due to Redlining,[18] it is unsurprising Black people in disadvantaged neighborhoods are those most likely to be re-hospitalized for SLE-related issues, are more difficult to retain in care.[82,83]

Social welfare policy

"It's weird to see that my friend with a different condition can't explore other options because their insurance won't cover it. It's like their health can't improve just because of their insurance."

Eight articles were related to social welfare policy, all focused on Medicaid. Social welfare policy, of which Medicaid is a product, is a subset of social policy including programs and policies meant to stabilize and/or improve the wellbeing of a population by targeting vulnerable groups.[84] When Medicaid expansion states were examined individually, people with SLE showed lower rates of preventable hospitalizations compared to non-Medicaid expansion states.[85] Another Medicaid study found people report a range of service use barriers, including long distances to health care providers and limited access to primary care physicians.[34,86] However, this study did not break findings down by identity rendering it difficult to determine which groups were more likely to report barriers. Interestingly, approximately 25% of people with Medicaid with SLE were re-admitted to a hospital within 30 days of leaving.[82] Yet, like the study above, there were no discussions of differences in re-admissions by identity nor comparisons of re-admissions by insurance status (i.e. Medicaid vs private vs no insurance).

Limitations

Although we examine several macro- and meso-level issues, we acknowledge we did not explore all the important issues, as we focused on those identified by our co-authors with an SLE diagnosis. Additional issues include (at the macrolevel) the health effects of colonization, ethnocentrism, patriarchy, and capitalism and at the meso-level historical trauma, rural and urban resource disparities, hospital/institutional policies, and more. Further, although word limits prevent us from a deeper exploration of the topic, one must note that the issues mentioned above likely drive many of the disparate outcomes afflicting marginalized groups brought on by the COVID-19 pandemic and must be considered in relation to studies examining COVID-19's effects. We also we did not cover the role of specific individual factors (biology, genetics) in relation to macro- and meso-level issues, as this was beyond the scope of our study. We acknowledge that a deeper understanding of the individual biologic and genetic factors (which are not synonymous with race/ethnicity) influencing the heterogeneity of SLE disease is important. Despite these limitations, this review illustrates that the health inequalities present among people with SLE are indelibly related to structural issues which influence society and societal experiences. We now make recommendations that enable clinicians and researchers to begin addressing these inequities.

Intervening

Clinical practice

Resources and tools designed to address social issues exist to aid physicians and their teams in addressing health inequities.[87] For example, a health equity champion on the medical team enables a clinic to address health equity concerns. The champion can be a physician assistant, social worker, or medical assistant who shares health equity information with the clinical team with the goal of identifying and addressing the social issues mentioned above. Clinics should also use community health workers (CHWs). CHWs are members of the community who are paid to work with health systems and who share characteristics with the population served (e.g., medical diagnosis).[88] Additionally, tools like the Patient-Centered Medical Home, a community-focused care model, can help physicians learn about and access resources dedicated to addressing structural issues. Further, physicians should engage in health equity training educate their students and residents. A mutual, open dialog with students and residents about health inequities can help seasoned and incoming practitioners improve practice.[89,90]

Research

A first step toward addressing inequities would be to adopt a lens that focuses a researcher's eye on broader societal structures and their effects on individual-level phenomena. Intersectionality is such a lens.[91] Intersectionality considers how structural forces influence different outcomes for people depending on a person's social identities.[92] Further, Intersectionality theory stresses social justice action as the keystone for research, practice, and programmatic intervention, meaning research should be conducted in a way such that findings either enable people to address inequities or make clearer how inequities are being perpetrated.[91]

Next, including disenfranchised groups in the research process is an additional step toward addressing health inequities. Community Engaged Research (CEnR) and Participatory Research orientations like Community-Based Participatory Research (CBPR) and Patient-Engaged Research (PER) are such orientations.[39,93–97] These orientations explicitly acknowledge that structural issues affect well-being and assert that researchers must act against these inequitable circumstances by partnering with those affected in at every stage of the research and dissemination process.[93,94,98] Researchers and participants work together to co-create research questions and cooperate during the research process. These orientations have been linked to increases in health equity, perceived social support, and to elevated participation and engagement of marginalized people in research.[99–101] Further, consciously making efforts to include disenfranchised groups of people in the research process may address the lack of inclusion of people of color in clinical trials.[102]

Additionally, our review found that most race-related investigations focused on Black and White people. Fewer investigations focused on Latino/health outcomes, and no

Table 2. Summary of recommendations for addressing macrosystem and mesosystem social issues contributing to health inequities.

Recommendation	Steps	Issue of focus[a]
Clinical practice		
1. Expand medical team to address social determinants of health	-Assign a person as a health inequities and equity "champion" who can provide relevant information to staff rounds.	R S A EI
	-Integrate Community Health Worker's whose goal is to address social determinants of health.	R EI
2. Use tools designed to enhance and inform ability to address health inequities	-Use toolkits designed to enhance one's ability to address these issues (MAP-IT, HealthPeople.gov, PCMH).	R EI ND
	-Use websites dedicated to informing how social welfare policy impacts health inequities (HIAs).	SP
3. Be mindful of and actively work against biases in medical practice by increasing knowledge and diversity activity.	-Learn about and remain conscious of identity-related bias in treatment.	S R EI
	-Establish community partnerships with people of color in clinic and member organizations (e.g., join health equity/ inequities groups for educational and intervention purposes.	R R S A
	-Recruit diverse students/residents/employees and ensure leadership positions are occupied by diverse groups of people.	R S A
	-Expand scope of reading to include literature by diverse authors on subjects related to interests.	R S A
Research		
1. Use research orientations suited to capturing context and addressing root issues of inequities.	-Community Engaged Research (CEnR) improves health promotion and health research, builds partnerships, engenders trust between investigators and participants, is mindful of power dynamics, and encourages investigators to recognize the expertise within those experiencing the issue of investigation.	R S A EI
	-Community-Based Participatory Research (CBPR) involves participant involvement in *every* step of the research process and can influence policy, culturally sensitive instrument development, external validity, long-term trust, and more.	R S A EI
	-Patient-Engaged Research (PER) is a form of engagement that is couched in the medical-model. Though other approaches are couched in the social/ecological-model PER is suited to capture context and encourage active participation in studies and treatment.	R S
	-Participatory Action Research (PAR) is another method of engagement designed to address structural issues.	R EI ND
2. Use research methods and interventions suited to capturing context and addressing root issues of inequities	-Utilize statistical methods that capture context including: Qualitative research, multilevel modeling, geographic information systems, network analysis, cluster analysis, and program evaluation.	ND R EI
3. Define race, ethnicity, and gender in ways that are contextually appropriate for the sample under study	-Acknowledge the sociopolitical nature of race, ethnicity, and gender.	R S
	-Accurately operationalize race, ethnicity, and gender in measures in order to capture identities accurately.	R S
	-Provide data on race, ethnicity, and whenever possible, gender for *all* participants to enrich knowledge.	R S
	-In discussion sections, include how the context of the sample as it relates to race, ethnicity, and/or gender may impact findings.	R S
	-Evaluate manuscripts for clear definitions of race and context for their sample.	R
	-Report within-group heterogeneity among sample populations.	R

(continued)

Table 2. (continued)

Recommendation	Steps	Issue of focus[a]
4. Intentionally conduct/link research on/with macro/meso-level topics and properly locate the problems driving disparities within these structures	-Research on sexism, ableism, and other macro-level issues (e.g., heterosexism) and on institutional policies, health care team structures, funding requirements, and other meso-level issues is warranted.	R S A
	-How we define a problem influences the solutions used to fix it. Therefore, link observed health disparities with the macro- and/or meso-level issues that are driving them.	R S A
5. Require the use of system centered language (SCL) in publications.	-When writing about health inequities, frame results using systems-centered language to properly situate observed inequities in their social contexts (e.g., disenfranchised people rather than vulnerable people).	R S A
	-Review other's manuscripts for the use of appropriate SCL and person-first language.	R S A
6. Include more AI/AN people and Latino/as in studies to boost relevance of findings	-Utilize CBPR and other techniques designed to incorporate these oft-neglected groups into studies.	R

[a]R: structural racism; S: structural sexism; A: ableism; EI: economic inequality; ND: neighborhood disadvantage; SP: social welfare policy. Each issue of focus is assigned according to the stated goals and philosophies of the steps suggested.

articles explicitly focused on AI/AN populations, despite AI/AN people having the worst SLE health outcomes. There may be less investigated for both of these groups as they are largely, albeit inconsistently,[103] considered an ethnicity. Indeed, these groups are less often researched in many health-related fields when compared to White and Black populations (particularly AI/AN people),[103–105] and this systemic exclusion maintains health inequities. Therefore, we recommend developing lines of research levering multiple sites specifically focused on AI/AN and Latino/a people (particularly women) SLE health inequities.

We also note traditional analytic approaches (e.g., ANOVA and regression) can fail to capture context, and other analytical methods are better suited for capturing social context.[95,106] We encourage a greater use of mixed methods approaches and qualitative research as they more naturally contextualize research.[107] Other useful statistical methods include multilevel modeling, geographic information systems, network analysis, and cluster analysis. Such methods allow researchers to broaden their lens and describe how social forces influence people's wellbeing.[95]

Finally, there are several small steps researchers can take to enhance health equity. Researchers should investigate means by which rheumatologists and other clinicians can address health inequities without adding undue burden to their clinical activities. This may include more culturally appropriate questionnaires, or the adaption of clinic treatment techniques that enhance patient–provider trust (i.e., motivational interviewing). Research should investigate how structural sexism might influence the health inequities of women with SLE by examining the effects of gender (and race and gender bias) on women and women of color in the clinic. Next, certain terms like "Hispanic," "Caucasian," and "African-American" do not always accurately operationalize group identities, yet much of the literature reviewed used these terms to describe their sample.[108] Problematically, using the incorrect term to describe a sample may hinder accurate interpretation of results.[108] More suggestions are made in Table 2 and references to resources and literature associated with suggestions are provided.

Conclusion

Macro- and meso-level issues meaningfully contribute to people's wellbeing. However, research about the impact of these issues on people with SLE remains underdeveloped. In all, efforts from clinicians and researchers are critical for reducing health inequities among those with SLE, and it is important to probe these broader structural issues if we are to reduce health inequities.

Positionality statement

As in all research, it is helpful to understand our positionality and, therefore, our lens on what was investigated. The primary author is a Chicano male and a fourth year PhD student in Psychology focused on addressing health disparities using feminist and intersectional approaches. The second author is a Filipino-Canadian psychologist who studies cognitive and mental health co-morbidities and disparities in childhood-onset lupus. The third author is an undergraduate Latina studying public health who hopes to

work in health care after graduation and who is diagnosed with SLE. The fourth author is a high-school aged Black female who aspires to study law and was diagnosed with SLE in middle school. The fifth author is a white female pediatric rheumatologist who studies disease and mental health outcomes in childhood-onset lupus. The sixth author the sixth author is a female Latina rheumatologist and epidemiologist focused on the study of lupus outcomes among minority populations. The seventh author is a Black female pediatric rheumatologist who studies mental health outcomes for children and adolescents with childhood-onset lupus and other pediatric rheumatologic diseases. The final author (NRC) is a white female first-generation scholar and pediatric psychologist who studies how to improve health- and mental health-related outcomes in individuals with childhood-onset lupus.

Acknowledgments

The authors wish to thank the Guppy Tank Review of Michigan State's Department of Family Medicine for offering invaluable feedback on early drafts of the paper. Our thanks also to Samantha Ely for technical assistance throughout the paper-writing process.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Several members of this research team (NRC, AND, TBR, AMK, IC, DW) are supported by the Childhood Arthritis and Rheumatology Research Alliance Transdisciplinary Research Grant, *A remotely delivered CBT intervention for youth with cSLE: A multi-site patient-engaged investigation,* awarded to the senior author (NRC). The senior author (NRC) is also supported by an National Institutes of Health K23 award, AT009458.

ORCID iDs

Mallet R Reid https://orcid.org/0000-0001-5529-2483
Tamar B Rubinstein https://orcid.org/0000-0001-8170-9377
Cristina Drenkard https://orcid.org/0000-0002-6832-7291

References

1. Danchenko N, Satia JA and Anthony MS. Epidemiology of systemic lupus erythematosus: a comparison of worldwide disease burden. *Lupus* 2006; 15: 308–318. DOI: 10.1191/0961203306lu2305xx.
2. Peschken CA. Health disparities in systemic lupus erythematosus. *Rheum Dis Clin North Am* 2020; 46: 673–683. DOI: 10.1016/j.rdc.2020.07.010.
3. Bowleg L. The problem with the phrase women and minorities: intersectionality-an important theoretical framework for public health. *Am J Public Health* 2012; 102: 1267–1273. DOI: 10.2105/AJPH.2012.300750.
4. Yen EY and Singh RR. Brief report: lupus—an unrecognized leading cause of death in young females: a population-based study using nationwide death certificates, 2000–2015. *Arthritis Rheumatol* 2018; 70: 1251–1255. DOI: 10.1002/art.40512.
5. Hiraki LT, Benseler SM, Tyrrell PN, et al. Ethnic differences in pediatric systemic lupus erythematosus. *J Rheumatol* 2009; 36: 2539–2546. DOI: 10.3899/jrheum.081141.
6. Hiraki LT, Feldman CH, Liu J, et al. Prevalence, incidence, and demographics of systemic lupus erythematosus and lupus nephritis from 2000 to 2004 among children in the US medicaid beneficiary population. *Arthritis Rheum* 2012; 64: 2669–2676. DOI: 10.1002/art.34472.
7. Yearby R. Race based medicine, colorblind disease: how racism in medicine harms us all. *Am J Bioeth* 2021; 21: 19–27. DOI: 10.1080/15265161.2020.1851811.
8. Yearby R. Racial disparities in health status and access to healthcare: the continuation of inequality in the United States due to structural racism. *Am J Econ Sociol* 2018; 77: 1113–1152. DOI: 10.1111/ajes.12230.
9. McLaren L and Hawe P. Ecological perspectives in health research. *J Epidemiol Community Health* 2005; 59: 6–14. DOI: 10.1136/jech.2003.018044.
10. Krieger N. Methods for the scientific study of discrimination and health: an ecosocial approach. *Am J Public Health* 2012; 102(5): 936–944. DOI: 10.2105/AJPH.2011.300544.
11. Hawe P. The contribution of social ecological thinking to community psychology: origins, practice, and research. *APA handbook of community psychology: theoretical foundations, core concepts, and emerging challenges*, Washington, DC: American Psychological Association, 2017; 1: 87–105.
12. Bronfenbrenner U and Morris PA. The ecology of developmental processes. In: Lerner RM (ed). *Handbook of child psychology: theoretical models of human development*, New York, NY: John Wiley, 1998; 1: 993–1028.
13. Krieger N. A glossary for social epidemiology. *J Epidemiol Community Health* 2001; 55: 693–700. DOI: 10.1136/jech.55.10.693.
14. Crenshaw K. Mapping the margins: intersectionality, identity politics, and violence against women of color. *Stanford Law Rev* 1991; 43: 1241–1299. DOI: 10.2307/1229039.
15. Frank L, Basch E, Selby JV, et al. The PCORI perspective on patient-centered outcomes research. *JAMA* 2014; 312: 1513–1514.
16. National Institutes of Health [NIH]. *Principles of community engagement*. 2nd ed. xviii, Washington, DC: Washington Department of Health and Human Services, 2011, p. 193.
17. Garritty C, Gartlehner G, Nussbaumer-Streit B, et al. Cochrane rapid reviews methods group offers evidence-

informed guidance to conduct rapid reviews. *J Clin Epidemiol* 2021; 130: 13–22.
18. Bailey ZD, Krieger N, Agénor M, et al. Structural racism and health inequities in the USA: evidence and interventions. *Lancet* 2017; 389: 1453–1463. DOI: 10.1016/S0140-6736(17)30569-X.
19. Metzl JM and Roberts DE. Structural competency meets structural racism: race, politics, and the structure of medical knowledge. *The social medicine reader*. 3rd ed. Durham, CA: Duke University Press, 2019; II: 170–187.
20. Asonye U, Apping N, Lopez LV, et al. Health disparities in Black patients with severe mental illness and the role of structural racism. *Psychiatr Ann* 2020; 50: 483–488. DOI: 10.3928/00485713-20201007-01.
21. Williams DR and Mohammed SA. Racism and health I: pathways and scientific evidence. *American Behavioral Scientist* 2013; 57: 1152–1173.
22. Clowse ME and Grotegut C. Racial and ethnic disparities in the pregnancies of women with systemic lupus erythematosus. *Arthritis Care Res (Hoboken)* 2016; 68: 1567–1572. DOI: 10.1002/acr.22847.
23. Nee R, Jindal RM, Little D, et al. Racial differences and income disparities are associated with poor outcomes in kidney transplant recipients with lupus nephritis. *Transplantation* 2013; 95: 1471–1478. DOI: 10.1097/TP.0b013e318292520e.
24. Alarcón GS. Multiethnic lupus cohorts: what have they taught us? *Reumatol Clin* 2011; 7: 3–6. DOI: 10.1016/j.reuma.2010.11.001.
25. Mok MY and Li WL. Do Asian patients have worse lupus? *Lupus* 2010; 19: 1384–1390. DOI: 10.1177/0961203310375832.
26. Lim SS and Drenkard C. Understanding lupus disparities through a social determinants of health framework: the Georgians organized against lupus research cohort. *Rheum Dis Clin North Am* 2020; 46: 613–621: DOI: 10.1016/j.rdc.2020.07.002.
27. Lim SS, Helmick CG, Bao G, et al. Racial disparities in mortality associated with systemic lupus erythematosus - Fulton and DeKalb counties, Georgia, 2002–2016. *MMWR Morb Mortal Wkly Rep* 2019; 68: 419–422. DOI: 10.15585/mmwr.mm6818a4.
28. Barnado A, Wheless L, Meyer AK, et al. Quality of life in patients with systemic lupus erythematosus (SLE) compared with related controls within a unique African American population. *Lupus* 2012; 21: 563–569. DOI: 10.1177/0961203311426154.
29. Elera-Fitzcarrald C, Alva M, Gamboa-Cardenas R, et al. Factors associated with health-related quality of life in Peruvian patients with systemic lupus erythematosus. *Lupus* 2018; 27: 913–919. DOI: 10.1177/0961203317751062.
30. Aguirre A, Izadi Z, Trupin L, et al. Race, ethnicity, and disparities in risk of end-organ lupus manifestations following SLE diagnosis in a multiethnic cohort. *Arthritis Care Res (Hoboken)* 2022; 75(1): 34–43. DOI: 10.1002/acr.24892.
31. Chang JC, Sears C, Torres V, et al. Racial disparities in renal outcomes over time among hospitalized children with systemic lupus erythematosus. *Arthritis Rheumatol* 2022; 74(8): 1430–1439. DOI: 10.1002/art.42127.
32. Kuan WP, Li EK and Tam LS. Lupus organ damage: what is damaged in Asian patients? *Lupus* 2010; 19: 1436–1441. DOI: 10.1177/0961203310370050.
33. Falasinnu T, Chaichian Y, Palaniappan L, et al. Unraveling race, socioeconomic factors, and geographical context in the heterogeneity of lupus mortality in the United States. *ACR Open Rheumatol* 2019; 1: 164–172. DOI: 10.1002/acr2.1024.
34. Gómez-Puerta JA, Barbhaiya M, Guan H, et al. Racial/ethnic variation in all-cause mortality among United States Medicaid recipients with systemic lupus erythematosus: a Hispanic and Asian paradox. *Arthritis Rheumatol* 2015; 67: 752–760. DOI: 10.1002/art.38981.
35. González LA, Toloza SM and Alarcón GS. Impact of race and ethnicity in the course and outcome of systemic lupus erythematosus. *Rheum Dis Clin North Am* 2014; 40: 433–454. vii-viii. DOI: 10.1016/j.rdc.2014.04.001.
36. Scalzi LV, Hollenbeak CS and Wang L. Racial disparities in age at time of cardiovascular events and cardiovascular-related death in patients with systemic lupus erythematosus. *Arthritis Rheum* 2010; 62: 2767–2775. DOI: 10.1002/art.27551.
37. Sun K, Eudy AM, Criscione-Schreiber LG, et al. Racial disparities in medication adherence between African American and Caucasian patients with systemic lupus erythematosus and their associated factors. *ACR Open Rheumatol* 2020; 2: 430–437. DOI: 10.1002/acr2.11160.
38. Pugh M, Perrin PB, Rybarczyk B, et al. Racism, mental health, healthcare provider trust, and medication adherence among black patients in safety-net primary care. *J Clin Psychol Med Settings* 2021; 28: 181–190.
39. Borgia RE and Alarcón GS. Community-engaged research to address health disparities in systemic lupus erythematosus. *Arthritis Care Res (Hoboken)* 2021; 73: 305–307. DOI: 10.1002/acr.24432.
40. Sun K, Eudy AM, Criscione-Schreiber LG, et al. Racial differences in patient-provider communication, patient self-efficacy, and their associations with systemic lupus erythematosus-related damage: a cross-sectional survey. *J Rheumatol* 2021; 48: 1022–1028. DOI: 10.3899/jrheum.200682.
41. Bhattacharya G. Contextualizing disparity reduction in rural health care: a call to action. *J Fam Soc Work* 2013; 16: 86–100. DOI: 10.1080/10522158.2012.736079.
42. Goodman MS, Gaskin DJ, Si X, et al. Self-reported segregation experience throughout the life course and its association with adequate health literacy. *Health Place* 2012; 18: 1115–1121. DOI: 10.1016/j.healthplace.2012.04.010.

43. Martz CD, Allen AM, Fuller-Rowell TE, et al. Vicarious racism stress and disease activity: the Black women's experiences living with lupus (BeWELL) study. *J Racial Ethn Health Disparities* 2019; 6: 1044–1051. DOI: 10.1007/s40615-019-00606-8.
44. Spears EC, Allen AM, Chung KW, et al. Anticipatory racism stress, smoking and disease activity: the Black women's experiences living with lupus (BeWELL) study. *J Behav Med* 2021; 44(6): 760–771. DOI: 10.1007/s10865-021-00235-9.
45. Chae DH, Drenkard CM, Lewis TT, et al. Discrimination and cumulative disease damage among African American women with systemic lupus erythematosus. *Am J Public Health* 2015; 105: 2099–2107. DOI: 10.2105/ajph.2015.302727.
46. Chae DH, Martz CD, Fuller-Rowell TE, et al. Racial discrimination, disease activity, and organ damage: the Black women's experiences living with lupus (BeWELL) study. *Am J Epidemiol* 2019; 188: 1434–1443. DOI: 10.1093/aje/kwz105.
47. Chae DH, Drenkard CM, Lewis TT, et al. Racial discrimination and disease damage among African American women with systemic lupus erythematosus. *Arthritis Res Ther* 2014; 16: A13. DOI: 10.1186/ar4629.
48. Vina ER, Hausmann LR, Utset TO, et al. Perceptions of racism in healthcare among patients with systemic lupus erythematosus: a cross-sectional study. *Lupus Sci Med* 2015; 2: e000110.
49. Knight AM, Xie M and Mandell DS. Disparities in psychiatric diagnosis and treatment for youth with systemic lupus erythematosus: analysis of a national US Medicaid sample. *J Rheumatol* 2016; 43: 1427–1433. DOI: 10.3899/jrheum.150967.
50. Reid MR, Fabricius J, Danguecan A, et al. Anxiety and depression in childhood rheumatologic conditions: a topical review. *Indian J Rheumatol* 2021; 11: 237–252. DOI: 10.4103/injr.injr_127_20.
51. Sheikh SZ, Englund TR, Burriss SW, et al. EMBRACE: one small story in lupus-one giant challenge in clinical trials. *ACR Open Rheumatol* 2022; 4(9): 747–752. DOI: 10.1002/acr2.11477.
52. Sheikh SZ, Wanty NI, Stephens J, et al. The state of lupus clinical trials: minority participation needed. *J Clin Med* 2019; 8: 1245. DOI: 10.3390/jcm8081245.
53. Homan P. Structural sexism and health in the United States: a new perspective on health inequality and the gender system. *Am Sociol Rev* 2019; 84: 486–516. DOI: 10.1177/0003122419848723.
54. Tasca C, Rapetti M, Carta MG, et al. Women and hysteria in the history of mental health. *Clin Pract Epidemiol Ment Health* 2012; 8: 110–119.
55. Arber S, McKinlay J, Adams A, et al. Patient characteristics and inequalities in doctors' diagnostic and management strategies relating to CHD: a video-simulation experiment. *Soc Sci Med* 2006; 62: 103–115.
56. Chapman EN, Kaatz A and Carnes M. Physicians and implicit bias: how doctors may unwittingly perpetuate health care disparities. *J Gen Intern Med* 2013; 28: 1504–1510. DOI: 10.1007/s11606-013-2441-1.
57. Dusenbery M. *Doing harm; the truth about how bad medicine and lazy science leave women dismissed, misdiagnosed, and sick*. New York, NY: HarperCollins, 2018.
58. Jun H. *Social justice, multicultural counseling, and practice: beyond a conventional approach*. Berlin, Germany: Springer, 2018.
59. Maroto M, Pettinicchio D and Patterson AC. Hierarchies of categorical disadvantage: economic insecurity at the intersection of disability, gender, and race. *Gend Soc* 2019; 33: 64–93.
60. Freedman VA, Wolf DA and Spillman BC. Disability-free life expectancy over 30 years: a growing female disadvantage in the US population. *Am J Public Health* 2016; 106: 1079–1085.
61. Sutanto B, Singh-Grewal D, McNeil HP, et al. Experiences and perspectives of adults living with systemic lupus erythematosus: thematic synthesis of qualitative studies. *Arthritis Care Res* 2013; 65: 1752–1765.
62. Pettersson S, Lövgren M, Eriksson LE, et al. An exploration of patient-reported symptoms in systemic lupus erythematosus and the relationship to health-related quality of life. *Scand J Rheumatol* 2012; 41: 383–390.
63. Courtney-Long EA, Romano SD, Carroll DD, et al. Socioeconomic factors at the intersection of race and ethnicity influencing health risks for people with disabilities. *J Racial Ethn Health Disparities* 2017; 4: 213–222.
64. Yelin E, Yazdany J and Trupin L. Relationship between poverty and mortality in systemic lupus erythematosus. *Arthritis Care Res (Hoboken)* 2018; 70: 1101–1106. DOI: 10.1002/acr.23428.
65. Durán S, Apte M and Alarcón GS. Poverty, not ethnicity, accounts for the differential mortality rates among lupus patients of various ethnic groups. *J Natl Med Assoc* 2007; 99: 1196–1198.
66. Yelin E, Tonner C, Trupin L, et al. Longitudinal study of the impact of incident organ manifestations and increased disease activity on work loss among persons with systemic lupus erythematosus. *Arthritis Care Res (Hoboken)* 2012; 64: 169–175. DOI: 10.1002/acr.20669.
67. Yelin E, Trupin L, Bunde J, et al. Poverty, neighborhoods, persistent stress, and systemic lupus erythematosus outcomes: a qualitative study of the patients' perspective. *Arthritis Care Res (Hoboken)* 2019; 71: 398–405. DOI: 10.1002/acr.23599.
68. Yelin E, Trupin L and Yazdany J. A prospective study of the impact of current poverty, history of poverty, and exiting poverty on accumulation of disease damage in systemic lupus erythematosus. *Arthritis Rheumatol* 2017; 69: 1612–1622. DOI: 10.1002/art.40134.
69. Hoge C, Bowling CB, Lim SS, et al. Association of poverty income ratio with physical functioning in a cohort of patients

with systemic lupus erythematosus. *J Rheumatol* 2020; 47: 983–990. DOI: 10.3899/jrheum.190991
70. Nery FG, Borba EF, Hatch JP, et al. Major depressive disorder and disease activity in systemic lupus erythematosus. *Compr Psychiatry* 2007; 48: 14–19. DOI: 10.1016/j.comppsych.2006.04.002.
71. Schattner E, Shahar G, Lerman S, et al. Depression in systemic lupus erythematosus: the key role of illness intrusiveness and concealment of symptoms. *Psychiatry (Washington, DC)* 2010; 73: 329–340. DOI: 10.1521/psyc.2010.73.4.329.
72. Shen B, Tan W, Feng G, et al. The correlations of disease activity, socioeconomic status, quality of life, and depression/anxiety in Chinese patients with systemic lupus erythematosus. *Clin Dev Immunol* 2013; 2013: 270878. DOI: 10.1155/2013/270878.
73. van Exel E, Jacobs J, Korswagen LA, et al. Depression in systemic lupus erythematosus, dependent on or independent of severity of disease. *Lupus* 2013; 22: 1462–1469. DOI: 10.1177/0961203313508443.
74. Garcia-Gonzalez A, Richardson M, Garcia Popa-Lisseanu M, et al. Treatment adherence in patients with rheumatoid arthritis and systemic lupus erythematosus. *Clin Rheumatol* 2008; 27: 883–889. DOI: 10.1007/s10067-007-0816-6.
75. Sagy I, Cohen Y, Nahum Y, et al. Lower socioeconomic status worsens outcome of patients with systemic lupus erythematosus independently of access to healthcare. *Lupus* 2022; 31: 532–540: DOI: 10.1177/09612033221084518.
76. United States Census Bureau. *Poverty 2018 and 2019*. Suitland, MA: United States Census Bureau, 2020.
77. Ross CE. Neighborhood disadvantage and adult depression. *J Health Soc Behav* 2000; 41: 177–187. DOI: 10.2307/2676304.
78. Ross CE and Mirowsky J. Neighborhood disorder, subjective alienation, and distress. *J Health Soc Behav* 2009; 50: 49–64. DOI: 10.1177/002214650905000104.
79. Wight RG, Aneshensel CS, Miller-Martinez D, et al. Urban neighborhood context, educational attainment, and cognitive function among older adults. *Am J Epidemiol* 2006; 163: 1071–1078. DOI: 10.1093/aje/kwj176.
80. Phelan JC and Link BG. Controlling disease and creating disparities: a fundamental cause perspective. *J Gerontol B Psychol Sci Soc Sci* 2005; 60: 27–33. Spec No 2. DOI: 10.1093/geronb/60.special_issue_2.s27.
81. Martz CD, Hunter EA, Kramer MR, et al. Pathways linking census tract typologies with subjective neighborhood disorder and depressive symptoms in the black women's experiences living with lupus (BeWELL) study. *Health Place* 2021; 70: 102587. DOI: 10.1016/j.healthplace.2021.102587.
82. Bartels CM, Chodara A, Chen Y, et al. One quarter of Medicare hospitalizations in patients with systemic lupus erythematosus readmitted within thirty days. *Semin Arthritis Rheum* 2021; 51: 477–485. DOI: 10.1016/j.semarthrit.2021.02.006.
83. Bartels CM, Rosenthal A, Wang X, et al. Investigating lupus retention in care to inform interventions for disparities reduction: an observational cohort study. *Arthritis Res Ther* 2020; 22: 35. DOI: 10.1186/s13075-020-2123-4.
84. Barker RL. *The social work dictionary*. 6th ed. Washington, DC: NASW Press, 2014.
85. Brown EA, Dismuke-Greer CE, Ramakrishnan V, et al. Impact of the affordable care act Medicaid expansion on access to care and hospitalization charges for lupus patients. *Arthritis Care Res (Hoboken)* 2020; 72: 208–215. DOI: 10.1002/acr.24080.
86. Gillis JZ, Yazdany J, Trupin L, et al. Medicaid and access to care among persons with systemic lupus erythematosus. *Arthritis Rheumatol* 2007; 57: 601–607. DOI: 10.1002/art.22671.
87. Kaufman AMD. Theory vs practice: should primary care practice take on social determinants of health now? yes. *Ann Fam Med* 2016; 14: 100–101. DOI: 10.1370/afm.1915.
88. Johnson D, Saavedra P, Sun E, et al. Community health workers and Medicaid managed care in New Mexico. *J Community Health* 2012; 37: 563–571. DOI: 10.1007/s10900-011-9484-1.
89. Hofmeister S and Soprych A. Teaching resident physicians the power of implicit bias and how it impacts patient care utilizing patients who have experienced incarceration as a model. *Int J Psychiatry Med* 2017; 52: 345–354. DOI: 10.1177/0091217417738935.
90. McCleary-Gaddy AT and Scales R. Addressing mental illness stigma, implicit bias, and stereotypes in medical school. *Acad Psychiatry* 2019; 43: 512–515. DOI: 10.1007/s40596-019-01081-3.
91. Buchanan NT and Wiklund LO. Why clinical science must change or die: integrating intersectionality and social justice. *Women Therap* 2020; 43: 309–329.
92. Overstreet NM, Rosenthal L and Case KA. Intersectionality as a radical framework for transforming our disciplines, social issues, and the world. *J Soc Issues* 2020; 76: 779–795.
93. Wallerstein N. *Community-based participatory research for health: advancing social and health equity*. 3rd ed. Hoboken, NJ: Jossey-Bass and Pfeiffer Imprints, Wiley, 2017: p. 1. Online Resource.
94. Control and Prevention (U.S). *Principles of community engagement*. 2nd ed. New York, NY: Control and Prevention (U.S), 2011.
95. Luke DA. Getting the big picture in community science: methods that capture context. *Am J Community Psychol* 2005; 35: 185–200. DOI: 10.1007/s10464-005-3397-z.
96. Miller RL. *The practice of program evaluation in community psychology: intersections and opportunities for stimulating social change*. In: Bond MA, et al. (eds). Washington, DC: American Psychological Association, 2017, pp. 107–121.

97. Largent EA, Lynch HF and McCoy MS. Patient-engaged research: choosing the "right" patients to avoid pitfalls. *Hastings Center Report* 2018; 48: 26–34. DOI: 10.1002/hast.898.
98. Chudyk AM, Waldman C, Horrill T, et al. Models and frameworks of patient engagement in health services research: a scoping review protocol. *Res Involv Engagem* 2018; 4: 28. DOI: 10.1186/s40900-018-0111-5.
99. Braveman PA. Swimming against the tide: challenges in pursuing health equity today. *Academic medicine* 2019; 94: 170–171. DOI: 10.1097/ACM.0000000000002529.
100. Wallerstein N and Duran B. The theoretical, historical and practice roots of CBPR. *Community-based participatory research for health: advancing social and health equity*, Hoboken, NJ: Wiley, 2017: 17–29.
101. Wallerstein N and Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *Am J Public Health* 2010; 100: S40–S46. DOI: 10.2105/AJPH.2009.184036.
102. Sneed RS, Mason M, Williams JN, et al. Using critical race theory to understand trial participation among black individuals with systemic lupus erythematosus: a qualitative study of patients and caregivers. *Arthritis Care Res* 2021; 73: 1387–1395.
103. Gone JP and Trimble JE. American Indian and Alaska Native mental health: diverse perspectives on enduring disparities. *Annu Rev Clin Psychol* 2012; 8: 131–160.
104. Gone JP, Hartmann WE, Pomerville A, et al. The impact of historical trauma on health outcomes for indigenous populations in the USA and Canada: a systematic review. *Am Psychol* 2019; 74: 20–35. DOI: 10.1037/amp0000338.
105. Fernández CR, Silva D, Mancias P, et al. Hispanic identity and its inclusion in the race discrimination discourse in the United States. *Academic Medicine* 2021; 96: 788–791.
106. Braveman P. Health disparities and health equity: concepts and measurement. *Annu Rev Public Health* 2006; 27: 167–194. DOI: 10.1146/annurev.publhealth.27.021405.102103.
107. Lincoln YS and Guba EG. *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications, 1985.
108. Wadsworth LP, Morgan LP, Hayes-Skelton SA, et al. Ways to boost your research rigor through increasing your cultural competence (part 1 of 2). *Behav Ther (NY)* 2016; 39: 76–82.