



FULL TEXT ARTICLE

Understanding Lupus Disparities Through a Social Determinants of Health Framework

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Limitations in the ability to assemble large cohorts of patients with lupus from previously underrepresented groups have inhibited better understanding of many unanswered questions. The Georgians Organized Against Lupus (GOAL) Research Cohort is designed to overcome many of these limitations and is a rich and diverse repository of clinical, biological, sociodemographic, psychosocial, and health services data, and biologic material. Studies with the GOAL cohort will improve the understanding of how various factors interact and may lead to interventions on an individual and systems and societal level and help to mitigate the significant disparities that continue to exist in lupus.

Key points

- Limitations in the ability to assemble large cohorts of patients with lupus from previously underrepresented groups have been a significant barrier to better understanding many unanswered questions.
- Including social determinants in the health disparities framework provides a more comprehensive understanding of the reasons why communities of color experience disparities in disease burden and outcome.
- The GOAL research cohort is a repository of diverse data and biologic material that will improve the understanding of how social determinants impact lupus.

Disparities in lupus

As recently as the early 1950s, systemic lupus erythematosus (SLE) was felt to have a strong predilection for females of childbearing age, be associated with some drugs, and have a genetic component. At the time, there was relatively little attention to race, with the distribution of disease in the population being felt to be proportionate to the population under care at that time, which were mostly females with light hair, fair skin, and an inability to tan.^{1, 2} The first major population-based study of SLE in the United States, published

in 1970, uncovered the striking racial/ethnic disparities in disease distribution that are acknowledged today.³ Subsequently, there has also been increased recognition of the disparities in the onset, acuity, and outcomes from different ethnic groups. Patients from racial minorities are more likely to suffer from multiple comorbidities; they have a higher prevalence of depression, cardiovascular disease (CVD), and diabetes, and worse health-related quality of life (HRQL) than whites.^{4 5 6 7 8 9 10}

The Legacy of Lupus in Minorities: Nature versus Nurture

In 1994, Dr. Graciela Alarcón from the University of Alabama at Birmingham (UAB) led a study to better understand the relationship of ethnicity to SLE outcomes. Patients of Hispanic, African American, and Caucasian ancestry were recruited from 3 sites: UAB, the University of Texas Health Science Center at Houston, and the University of Puerto Rico. The study, aptly named LUPus in MINorities: NATURE versus Nurture (LUMINA), was comprised of 234 African Americans, 220 Hispanic, and 181 Caucasian patients. Over the years, LUMINA has contributed extensively to the SLE disparities literature through numerous articles, abstracts, and other publications. LUMINA highlighted many disparities (and associated factors) disproportionately afflicting Hispanics and African Americans with SLE compared with their Caucasian counterparts, including more renal involvement (ancestral genes ± socioeconomic factors), increased disease activity (ethnicity early but not later in the disease), diminished survival (poverty), and more adverse pregnancy outcomes (socioeconomic factors).¹¹

The LUMINA study was a harbinger of growing evidence suggesting that most health problems occur long before people get to their health care provider, with medical care contributing only partially to the overall health status of the population. Thus, given the nature of disparities, interventions are needed within and outside the health care system. Effective efforts to improve health and reduce gaps in health need to pay greater attention to addressing the nonmedical determinants of health. A critical mass of relevant knowledge has accumulated, documenting associations, exploring pathways and biological mechanisms, and providing a previously unavailable scientific foundation for appreciating the role of social factors in health. US public health leaders and researchers have increasingly recognized that the dramatic health problems people face cannot be successfully addressed by medical care alone.

Social determinants of health

Historically, many public health efforts have focused primarily on individual behaviors. Social determinants of health (SDH) are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. Including social determinants in the health disparities framework provides a more comprehensive understanding of the reasons why low-income communities and communities of color experience disproportionately higher rates of disease, health care utilization, and death. These conditions shape people's options, choice, and behavior, which can then in turn impact outcomes. Studies of social determinants have been relatively lacking and are imperative in SLE, where the disease disproportionately impacts minority communities, and biologic factors cannot fully explain or address health disparities.

The Georgia Lupus Registry

Limitations in the ability to assemble large population-based cohorts of patients with systemic and/or cutaneous lupus with validated diagnoses and with significant representation from previously under-represented sociodemographic groups have been a significant barrier to better understanding the true clinical burden of lupus, as well as the many unanswered questions related to treatment, health care access, and natural history. Furthermore, it is also challenging and expensive to follow such a group over time and collect clinical and biologic data, acknowledging the interaction of social and biologic factors.

The Georgia Lupus Registry (GLR) is 1 of 5 recently completed US Centers for Disease Control and Prevention (CDC)-funded population-based lupus registries designed to minimize many of these limitations.¹² In 2002, the CDC Arthritis Program supplied funding for the Georgia Department of Public Health (GA DPH) to conduct surveillance of SLE in 2 counties (Fulton and DeKalb) within the Atlanta metropolitan area with large African American populations. To avoid biased ascertainment and under-reporting as a result of recruiting large numbers of community patients, the GA DPH as a public health authority used its public health surveillance exemption to the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule (45 CFR, 164.512[b]) to obtain protected health information without written consent of the patient. The GA DPH contracted with Emory University as its designated agent to provide lupus expertise and manage the project. The primary sources of potential cases included hospitals, rheumatologists, nephrologists, and dermatologists in and around the catchment area. Administrative databases were queried for billing codes for lupus and related conditions. Secondary sources included laboratories, renal and cutaneous pathology, and queries in other population databases.

In addition to obtaining more accurate incidence and prevalence rates of SLE, the GLR has contributed to the understanding of disparities in SLE, including persistent and significant disparities in end-stage renal disease and mortality in African Americans compared with whites.¹³ · ¹⁴ Relative to SLE, research on cutaneous lupus erythematosus has been sparse, with little known about the epidemiology in minority populations. The GLR produced minimum estimates of the incidence of chronic cutaneous lupus erythematosus (CCLE) and found similar disparities as seen for SLE.¹⁵

The Georgians Organized Against Lupus Cohort

The Georgians Organized Against Lupus (GOAL) Cohort is a population-based lupus cohort supported by the CDC of over 1000 individuals with lupus derived, in large part, from the GLR. Institutional review board approvals allowed patients identified in the GLR to be contacted directly and offered the opportunity to consent to be prospectively followed in the GOAL cohort, primarily through regular surveys utilizing patient-reported instruments and receiving other research opportunities, including the collection of related biospecimens. To minimize survival bias and to compensate for attrition, SLE patients with less than 5 years of disease are continually recruited from diverse hospitals and community rheumatologists and through Lupus Foundation of America, Georgia Chapter (LFA-GA) advertisements. CCLE participants have been enrolled from multiple sources, including the GLR, Grady Hospital, and Emory University dermatology clinics, referrals by community practices, and self-referrals facilitated by LFA-GA advertisements.

Consecutive annual sets of surveys have been administered to the GOAL cohort participants since 2012. All participants completed a self-report questionnaire to return via mail or completed via Internet or phone. In order to maximize participation, participants in the GOAL cohort who received care at Grady Memorial Hospital were recruited to complete the survey during their regularly scheduled clinic visit. Grady Hospital provides care for Atlanta's indigent and underinsured populations and has the only clinic dedicated to lupus care in the area. This was particularly helpful in capturing the most vulnerable patients, who are often socially disadvantaged and have difficulty completing surveys remotely.

Coordinating different questionnaire modalities and timelines for mailing and processing of returned surveys was accomplished through a sophisticated project management and database system developed for the GOAL cohort. The system generates paper-based or Internet-accessible surveys unique to each designated recipient. For clinic visits, the system generates Web-based case report forms. For participants who request it, phone interview-assisted surveys are given by the research coordinators using a standardized script and responses.

Social determinants of health in the Georgians Organized Against Lupus cohort

The GOAL research cohort is a rich and diverse repository of clinical, biological, sociodemographic, psychosocial, and health services data as well as biologic material ([Fig. 1 \(fig1\)](#)) that will improve the understanding of how various factors interact and may lead to interventions, on an individual as well as systems and societal level, that will help to mitigate the significant disparities that continue to exist in lupus.

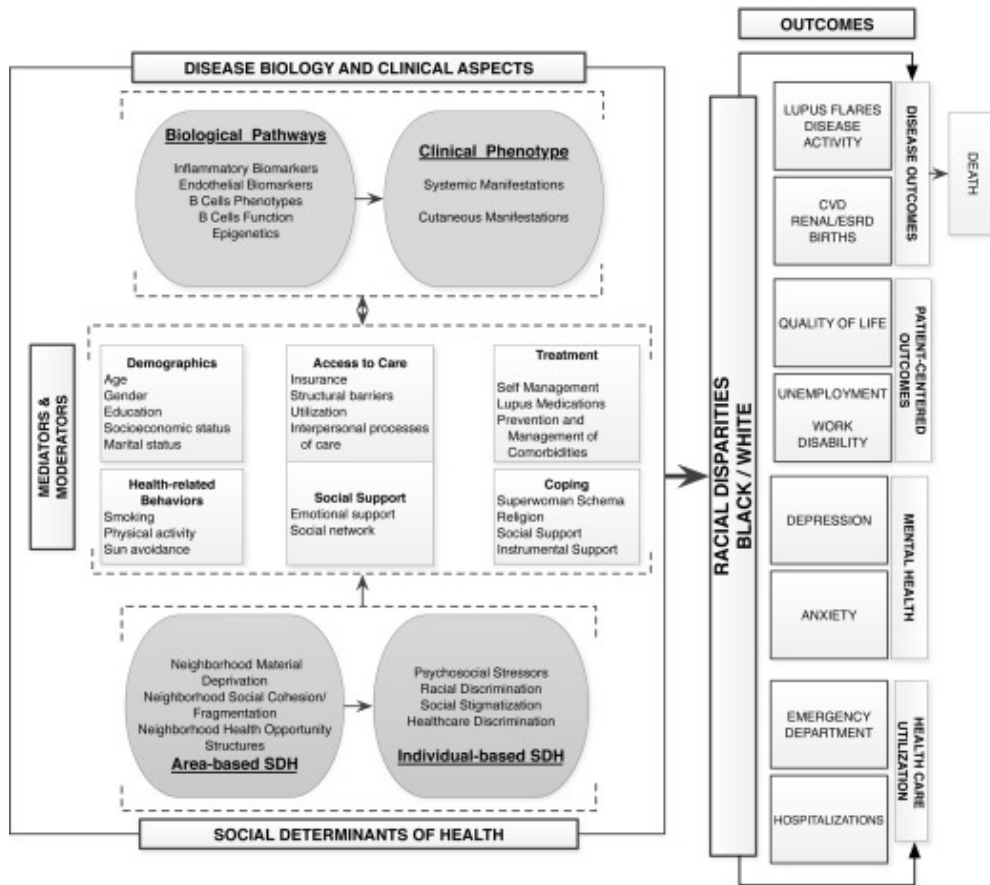


Fig. 1 Overall conceptual model of the GOAL cohort.

Surveys have covered the domains of natural history, treatment, health care access and gaps, and disparities using validated instruments whenever possible (Table 1 (tbl1)). Sociodemographic information was obtained, including employment, income, education, insurance, household composition, and relationship status. The surveys also included a detailed psychosocial battery, with measures of discrimination, other psychosocial stressors, and current mental health (eg, depression) and other social determinants that can potentially explain black/white disparities in this population.

Table 1 Summary of measures and self-reported instruments

Major Domain	Category	Measure
Natural History	CVD	Incident and prevalent CVD
	ESRD	Incident ESRD
	Cancer	Incident cancer and cancer types

Major Domain	Category	Measure
	Birth outcomes	Pregnancy risk factors, procedures, delivery method, maternal morbidity, newborn weight, abnormal conditions, birth defects, parent demographics
	Mortality	Death, cause(s) of death
	Violent death	Suicide and other violent deaths
	Disease severity	SLE disease activity, SLE organ damage, comorbidities, skin activity/chronicity
	Mental health	Depression, anxiety, anger, psychosocial illness impact, applied cognition, abilities, global health-mental, psychological distress
	Physical health	Physical function, bodily pain, pain interference, fatigue, sleep disturbance, global health-physical
	Social health	Social roles and activities, social isolation
	Skin-specific QoL	Emotions, functioning, symptoms, body image, photosensitivity
	Employment and work	Employment, disability, work productivity impairment
	Immune phenotypes and autoantibodies	Laboratory assays
	Inflammatory and endothelial markers	Laboratory assays
	Epigenetics	Laboratory assays
	Banked biospecimens	Laboratory assays
Treatment	Medications	Medications to treat lupus
	Opioids and pain medications	Prescription pain medication misuse, appeal of substance use, severity of substance use
	Self-management	Symptoms management self-efficacy, communication with physicians
	Alternative therapies	Complementary alternative medicine
	Treatment adherence	Medication management self-efficacy, treatment adherence

Major Domain	Category	Measure
Health care	Access	Insurance, copayments
	Utilization	ED visits, hospitalizations
	Quality of care	Physician-patient interactions Quality of skin lupus care Health care experiences ESRD treatment-quality indicators
Disparities themes	Demographics	Age, sex, race, socioeconomic status, education
	Geographic and neighborhood factors	Material deprivation, social cohesion/fragmentation, neighborhood opportunity structures
	Social stressors and barriers	Discrimination, stigma (disease-related), neighborhood domains, financial strain, childhood trauma, self-perceived stress, experiences of prison
	Social support	Emotional, Informational, Instrumental
	Health-related behaviors	Smoking, drinking, physical activity, eating habits, sleep disorders, preventive care Coping mechanisms, social isolation, religion, spirituality

Abbreviations: CVD, cardiovascular disease; ED, emergency department; ESRD, end-stage renal disease; QoL, quality of life.

Biospecimens from consenting GOAL participants have been collected and various immune and inflammatory assays have been analyzed to better understand the immune pathways across lupus phenotypes and the intersection between social determinants of health and biologic processes. DNA, RNA, and aliquots of serum and plasma are banked.

GOAL participants, as well as those in the GLR, have been matched with state and national databases, including the Georgia Hospital Discharge Database, National Death Index, Georgia Comprehensive Cancer Registry, US. Renal Data System, and Georgia Birth Records. Furthermore, all participants' addresses have been geocoded and linked to census information (tract and block group levels) and other area-based databases for socioeconomic, neighborhood, and other information.

Contributions

These data provide powerful opportunities to explore the impact of social determinants in lupus and have yielded the following

- A self-management program benefits low-income African American women with SLE. ¹⁶

- African Americans suffer higher rates of unemployment after lupus diagnosis. ¹⁷
- Unfair treatment may contribute to worse disease outcomes among African American women with SLE. ¹⁸
- Increasing frequency of racial discrimination was associated with greater SLE activity and damage in African American women. ¹⁹
- Vicarious racism, or secondhand exposure to racism, was found to be associated with SLE activity after adjusting for socioeconomic and health-related covariates. ²⁰
- There is a high burden of cognitive symptoms and perceived stress in SLE. ²¹
- Depressive symptoms are associated with low treatment adherence in African Americans with SLE. ²²
- There is a significant association between organ damage and depression in African American women, with social support being protective of depression. ²³
- The prevalence of depressive symptoms is high in a predominantly black cohort with primary CLE. ²⁴
- Depression, which is highly prevalent in African American patients with SLE, may have a negative impact on physician-patient interactions. ²⁵
- African American women with SLE were more likely to experience a 12-month period of infertility, and at younger ages, but as likely as comparison women without SLE to have met their desired family size. ²⁶

Summary

The GOAL research cohort was born out of the efforts of the GLR to create a population-based prospective cohort of validated SLE and cutaneous lupus patients, representing real-world lupus in an area where half of the population is African American or black. It is also an example of the power that can be harnessed by leveraging public health partnerships between federal, state, and academic institutions.

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Disclosure

The authors have nothing to disclose.

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