

Socioeconomic Status, Health Care, and Outcomes in Systemic Lupus Erythematosus



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KEYWORDS

• Poverty • Socioeconomic status • Systemic lupus erythematosus • Outcomes

KEY POINTS

- Individuals with systemic lupus erythematosus (SLE) who are poor face unmet financial, physical, and psychosocial needs that exacerbate worse long-term outcomes such as disease damage and quality of life.
- The most severe negative outcomes are among individuals with SLE who are poor and who live in areas of concentrated poverty.
- Among individuals with SLE, permanent exit from poverty is associated with less adverse outcomes compared with individuals who remain in poverty. Interventions that target the individual's poverty may result in better SLE outcomes.
- Research exposing health inequities galvanizes health care providers to advocate for efforts to reduce disparities among the poor with SLE within medicine. Ending poverty among persons with SLE demands a greater societal commitment.

Research on the effect of lower socioeconomic status (SES) on health care and outcomes among persons with systemic lupus erythematosus (SLE) has been expanding over the last decade, joining the considerable work done on the effect of race and ethnicity in the onset, pathogenesis, and outcomes of this condition. There is overlap in the literature, primarily because the prevalence of SLE is higher and more severe among members of racial and ethnic minorities, including persons of African and Asian backgrounds as well as Hispanics from any racial background. However, much research has established that, once SLE onset—which may be driven by genetic factors such as continent of origin—has occurred, differences in health care and outcomes among persons with SLE are driven sharply by the SES of the individual.^{1,2}

In this article, the authors review the evidence that compares the health care and outcomes of persons with SLE from lower socioeconomic backgrounds with that of

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the more affluent. Had this article been written a decade ago, the research reviewed would have been limited to a handful of studies showing the extent to which low SES was associated with access to and utilization of health care and outcomes. Recent studies have started to elucidate some of the mechanisms underlying these relationships, giving rise to some initial attempts to intervene to reduce the disparities by actions of health care providers and in community demonstration projects. This article provides an overview of what has been established in the authors' understanding of the relationship between SES and SLE and what is beginning to be done to overcome the effects of low SES.

THE FOUNDATION FOR UNDERSTANDING SOCIOECONOMIC STATUS AND SYSTEMIC LUPUS ERYTHEMATOSUS

The literature on SES and SLE builds on almost 2 centuries of work on SES, morbidity, and mortality. Beginning with the anecdotal observations of Frederick Engels on the geography of despair in Manchester, England³ but then continuing with the systematic cumulation of data by John Snow on the prevalence of environmental threats to the longevity of the poor⁴ and of Charles Booth on the confluence of personal and neighborhood adversity on a range of outcomes including, but not limited to death,⁵ the Victorians began the quest to understand why low SES translates into illness and its sequelae. Although the Victorians were the first to make these observations, historical epidemiologists have established that the adverse health outcomes did not just arise in the industrial era. In one such study, Smith⁶ observed that in the main cemetery in Glasgow Scotland in which all who died in that city were buried for close to a millennium, the length of life as documented on gravestones was highly correlated with the height of the gravestone, a proxy for wealth, for several centuries preceding the industrial revolution. Adverse outcomes of low SES have been the historical norm.

However, it is in the last several decades that we have begun to understand why. The foundational work again came from the United Kingdom. Marmot and colleagues^{7,8} used data encompassing the entire British civil service to establish that with each step up the socioeconomic ladder, rates of morbidity of almost every condition and of mortality were lower. Because the British had established universal coverage half a century before this research was conducted, health care probably did not account for very much of the health disparities, although the authors acknowledge that there may be quality of care differences. In addition, they noted that the usual explanation other than health care is that persons of lower SES have more adverse health behaviors, for example, higher rates of smoking and heavy alcohol usage and greater levels of obesity; but this too did not account for the more adverse outcomes of those of lower SES.⁹ If not due to health care and health behaviors, they hypothesized and then proved that the differences in health arose from the conditions of life in work and community, what we now call the social determinants of health.¹⁰ These include poverty; the stresses associated with poverty, including, but not limited to, unemployment, underemployment, and poor working conditions; and the adverse conditions in the neighborhoods in which persons of low SES live.¹¹ This is the foundation for the studies of low SES and SLE to which we now turn.

POVERTY AND SYSTEMIC LUPUS ERYTHEMATOSUS

SLE disproportionately affects members of minority groups and the poor.¹² In US Medicaid data from 2000 to 2004, the prevalence of SLE was highest among the lowest quartile of area-level SES, independent of age, sex, or race/ethnicity (104.9 per 100,000, 95% confidence interval [CI] 99.8–110.3).¹³ Although poverty is officially

defined in countries such as the United States by a combination of income and household size, being poor is multidimensional and extends beyond lack of economic means alone. The concept of poverty also includes unmet social, physical, and political needs as important contributing factors to the impact of poverty on functioning in society. As a result of one or more of these factors, individuals with SLE of low SES have worse long-term disease outcomes¹² and poorer quality of life than those of higher SES.¹⁴

LONG-TERM OUTCOMES IN THE DISADVANTAGED WITH SYSTEMIC LUPUS ERYTHEMATOSUS

In addition to the impact of personal SES or frank poverty, there are effects of living in areas of concentrated poverty (areas in which a high proportion of the residents meet criteria for personal poverty) that may make the effect of personal poverty worse. In such areas, there may be limited access to basic human needs such as food, health, and medical care. There are potential adverse effects of toxic environmental exposures ranging from traffic to factories, prejudice and crime. Further, living in such areas may result in discrimination in housing, making it difficult to move to safer areas even when money is available to do so. With negative effects of living in areas of concentrated poverty, those with SLE living under such conditions may experience stigmatization and further marginalization. Residents of these areas report higher levels of perceived stress. The marginalization and fear associated with crime in the neighborhood may lead residents to spend more time within their households, curtailing their ability to take advantage of the social networks they have and limiting the reach of their network.¹⁵

Personal poverty alone but especially in combination with living in areas of concentrated poverty may result in higher levels of organ damage. Greater organ damage portends increased long-term disability and mortality in SLE. It is estimated that those who are poor with SLE live 14 fewer years than their nonpoor counterparts.¹⁶ Recent studies suggest an intricate relationship among poverty, damage, and mortality.¹⁷ Low income is directly associated with SLE damage in proportion to the degree of economic deprivation. With each lower level of income, the degree of organ damage increases. Similarly, there is a dose effect of living in poverty such that those who are persistently poor accrue more organ damage than those who are intermittently poor.¹⁵

Living in a state of concentrated poverty exaggerates personal poverty in those with SLE. Individuals living in areas of concentrated poverty experience higher levels of damage than those who are poor but not living in areas of concentrated poverty and the nonpoor regardless of where they live. Although many individual and community characteristics beyond poverty affect the level of organ damage, even after taking a wide array of those factors into account, the effect of personal and community poverty on organ damage remains profound. Examples of factors include degree of cognitive impairment; depression; health behaviors such as smoking, exercise, and diet; and the extent and quality of health care. The strong effect of living in concentrated poverty on SLE damage can be mitigated by exiting poverty. Exiting poverty permanently puts one on a more benign course of organ damage so that within a year or so, those who have left poverty have a disease course much like those who were never poor,¹⁸ which suggests that the effects of being poor are mutable and not inherent in the people who are poor but rather by the fact of their current low incomes. It also suggests that programs to alleviate poverty and blunt the effects of living in areas of concentrated poverty may help persons with SLE avoid higher levels of disease damage.

BARRIERS TO IMPROVING LONG-TERM OUTCOMES AMONG POOR WITH SYSTEMIC LUPUS ERYTHEMATOSUS: DIRECT, INDIRECT, AND INTANGIBLE COSTS

The chronic multisystem course of SLE, often with cycles of flares and quiescence, yields high patient costs. Direct SLE-associated expenditures include hospitalizations, outpatient follow-up, medications, and transportation. Indirect costs due to disability from SLE sequelae include losses in productivity and employment. A litany of intangible humanistic costs affect quality of life in SLE. Each of these 3 types of costs is exacerbated in poverty with long-term adverse outcomes in SLE.

Direct Costs: Systemic Lupus Erythematosus is Expensive for the Poor

Cost for medical care, including medications, is high in SLE. Estimates for mean annual direct cost for US patients with SLE ranged from \$13,735 to 20,926 (USD 2009), with costs for SLE nephritis exceeding 2 to 3 times those estimates. Expenses are distributed among inpatient (14%–50%), outpatient (24%–56%), and medication costs (19%–30%).¹⁹ Although they fluctuate, costs persist over time, which can especially burden the poor and uninsured. Even in a universal health care setting in Canada, there were higher direct medical costs over time in those with a lower SES.¹⁴ The reason for this disparity despite universal health care is unclear. One possibility is that those who are poor incur greater hospital costs, given they have more severe disease and often compromised access to outpatient care.

Access to care is a known challenge in SLE.²⁰ In the United States, despite Medicaid services, those with income levels less than \$40,000 have fewer visits to a rheumatologist and travel a greater distance to access their care teams.^{21,22} Poor patients living with SLE experience greater avoidable hospitalizations. Avoidable hospitalizations are preventable by prompt and appropriate treatments. In addition, a proportion of the direct cost for poor patients with SLE care may be associated with hospital readmissions. Based on administrative data, there are more frequent 30-day hospital readmissions among those who already tend to have lower SES and live in poverty: those of the youngest age, nonwhite racial/ethnic (African American and Hispanic), and publicly insured groups.^{12,23}

Processes of care, such as care quality, are factors in the direct cost equation. Those who live in poverty report lower ratings of health plan interactions, such as health care utilization and technical quality of care, and experience worse patient-reported damage.²⁴ It is possible that in the setting of lesser quality of available care, some patients will need repeat visits to emergency departments or hospitals, which associate with more frequent admissions and utilization, driving up costs.

These examples suggest that patients with lower SES experience health inequities at a health care systems and delivery level.²⁵ Because those who experience poverty do not necessarily report inadequate patient-provider communication, there may be potential protective value in strengthening trust between a patient and their care team. There is ample evidence to support improvements in health care delivery for positive engagement of the poor toward improved long-term outcomes in SLE.

Indirect Costs: Education and Employment Are Disrupted

SLE affects patients during key years of productivity, when disruption of education and career are likely. High rates of career changes, interruptions, or complete work loss is a global problem among patients with SLE, with 20% to 50% reporting work

loss after initial diagnosis.^{26–28} The estimated annual loss in indirect costs for patients with SLE in the United States was \$8659 (USD 2004).²⁹ In a multiethnic study, poverty and severe disease were among factors that predicted self-reported disability.³⁰ Patients who are already poor are less likely to be working at the time of diagnosis.²⁷ Unemployed individuals with SLE tend to be either receiving Medicare/Medicaid or are uninsured.³¹ Because exit from poverty implies the ability to earn a living wage, discerning how to improve life for those with SLE of lower SES via job security is critical.

Studies among adults with childhood-onset SLE (cSLE) demonstrate that although patients often complete their education, they do not maintain consistent employment in adulthood.³² In addition, individuals with cSLE who grow up in an environment with low household income frequently report disability.³³ Patterns of low SES and high disability increase vulnerability for adults with cSLE and identify them as a special subgroup that need resources that point them toward career success.

High and recurrent direct costs of care have dire consequences for those living in poverty with SLE. Worse disability increases risks of health care loss, especially for those not eligible for Social Security Disability Insurance (SSDI) because SSDI beneficiaries are entitled to Medicare benefits 2 years after being approved for SSDI benefits. Loss of health insurance and means to support all but basic needs may lead to inability to make regularly scheduled appointments or obtain medications. These individuals become higher utilizers of emergent care services at risk of greater direct costs.³⁴ The extreme challenge of living in poverty with SLE extends past the individual level to the community and beyond: patients may rely on family or friends to pay for or provide housing and/or may need assistance from government-provided Supplemental Security Income and Supplemental Nutrition Assistance Program (formerly referred to as food stamps) to survive.³⁵ Career rehabilitation resources should be available to individuals with SLE living in poverty.

Humanistic Costs: Depression and Stress Affect Quality of Life

Direct and indirect costs of SLE do not operate in isolation. The humanistic costs of SLE—quality of life, mental health, social, and societal support—affect each other and play a role in indirect and direct costs.³⁶ Intangible costs are magnified by poverty: worse quality of life is common among those with SLE who have a low SES³⁷ and is associated with SLE-related disability as mediated by depression and perceived stress.³⁸

Major depression or depressive symptoms are estimated to occur in 24% and 39% of patients with SLE, respectively,³⁹ with a negative impact on organ-related damage and quality of life.⁴⁰ Although poverty is not always one of the primary factors in this relationship,⁴¹ it can play a role. For example, both individual and neighborhood SES are associated with greater depression.¹⁸ One distinction between prevalent and incident depression is that individuals with a lower SES are more likely to have a high burden of depression at baseline. In addition, women who perceive high financial strain over time are at risk for new onset depression.¹⁴ The degree to which depression affects poor individuals with SLE merits a dedicated focus for health improvement.

Stress has long been thought to drive disease onset and flares in SLE.⁴² Recent data support an increased risk of incident SLE among those with a history of trauma in childhood or adulthood.^{43,44} Exposure to adverse childhood experiences (ACEs) such as abuse, neglect, and household challenges before age 18 years can negatively affect adult health in a dose-response manner.⁴⁵ Individuals with a higher burden of ACEs reported worse SLE disease activity, damage, depression, and health status.⁴⁶ Depression and posttraumatic stress disorder play a significant role in coping with

stressors in SLE.⁴⁷ Those living in poverty with SLE are vulnerable to early, chronic stress. A focus on the types as well as the timing, duration, and concentration of stress in those with SLE who live in poverty will help to better understand humanistic costs via stress and poverty. This knowledge can guide targeted programs to promote resilience among those with low SES.

MODIFIABLE FACTORS IN POVERTY AND SYSTEMIC LUPUS ERYTHEMATOSUS

The past 2 decades make clear the argument that poverty negatively influences important objective and subjective health outcomes in SLE such as organ damage and quality of life. Health care systems and teams should target modifiable factors both internal and external to health care to facilitate an improved life course in low income patients with SLE.

Interventions Internal to Health Care

Improve access to systemic lupus erythematosus care

Comprehensive medical homes for rheumatologic conditions and especially for SLE replete with mental health services, physical therapy, social work, and primary care could remove some barriers to access for patients who are living in poverty. Mental health care is of utmost import for this population, and greater efforts to secure timely visits for depression and other conditions are justified. Same day clinic visits for rheumatology and other specialists such as nephrology can minimize costs. Because individuals with SLE of lower SES travel greater distances from their rheumatology care,²² mobile clinics, home visits, or rideshares could remove geographic barriers between patients and their care teams. A rideshare intervention for Medicaid patients in 2 urban, low-income academic primary care clinics failed to demonstrate improved no-show rates.⁴⁸ Therefore, needs assessments specific to low-income patients with SLE and transportation concerns could identify factors impeding travel to visits, such as work obligations. Telemedicine visits at home or at community centers could permit patients with responsibilities such as childcare to attend visits. Telehealth is well suited to effect change for poor patients with SLE. Finally, patient navigators with specialized training in assisting those with low income could help SLE patients as they move through the health care system.

Improve technical quality of care

The poor have more severe disease and are high utilizers of primary, community and academic care services. Technical quality of care relies on dissemination and use of the most up-to-date SLE and preventive care guidelines. Low-income patients may not interact principally with a rheumatologist during their visits for their SLE.²¹ There is a need for leading rheumatology bodies to develop SLE medical education modules and toolkits to address standards of care for those living in poverty and to provide current information for trainees, emergency physicians, primary care physicians, and hospitalists. For example, a partnership between the American College of Rheumatology and the Lupus Initiative has made important strides in awareness about disparities among minorities with SLE by creating education tools for community practitioners.⁴⁹ Additional work can expand to address poverty specifically and promote these efforts to rheumatologists nationwide for dissemination among community stakeholders.

Improve interpersonal quality of care

In some instances, the poor have reflected positively on the patient-provider dyad.²⁴ In contrast, some patients have negative experiences with care teams. Negative

perceptions can be heightened when low-income patients are depressed and have high disease activity.⁵⁰ Because perceptions can change behaviors, materials sensitive to SES should be used to educate care teams about how to build positive relationships with individuals living with poverty and SLE. An important tool is shared decision-making, which strengthens the patient-provider bond by promoting self-efficacy around a common goal of the SLE care plan.

Interventions External to Health Care

Provide educational/vocational resources

Because education and navigating a job search are skills relevant to employment and, ideally, release from poverty, services that assist with educational and vocational programs are invaluable. An adolescent employment readiness center at Children's National Hospital facilitated academic and career counseling to teenagers.⁵¹ Because of profound disruption of education and employment for this population, strategies on how to minimize gaps in work and enable those with SLE to continue to be gainfully employed should be rigorously explored and tested.

Promote independence with social health

Peer support programs have long been used in other diseases to build community and understanding of symptoms and treatment goals. Several academic-community partnerships curated and tested SLE awareness programs for Latino⁵² and African American⁵³ communities. In addition, a peer-mentor-based project designed to build independence as well as improve outcomes and quality of life for African American women with SLE is underway.⁵⁴ Tailoring programs to specifically address the needs of those who are living in poverty is essential.

Champion resilience

The multifactorial stresses of living in poverty require individual, community, and systemic action to improve disease outcomes and quality of life. At the individual level, successful programs will help patients manage stress and support resilience to improve negative effects on quality of life. One patient-centered pilot, the Chronic Disease Self-Management Program, positively affected self-management behaviors and decreased health care utilization among low-income patients with SLE.⁵⁵ Systemic shifts to develop and use trauma-informed care modules are also underway.⁵⁶ Stress and ACEs differentiate the life course and heighten risk for poor outcomes in SLE. Strategies on how to prevent or repair effects of ACEs are needed, particularly in the context of poverty. In addition, disadvantaged communities need representation in research: conscious efforts must be made to provide infrastructure to include these groups so that there can be accurate exploration of how poverty, mental health, and stress can be mitigated in patients with SLE.

SUMMARY

In the last several decades, a series of studies have moved from recognizing that individuals with SLE living in poverty have worse outcomes to beginning to evaluate the mechanisms of why those patterns exist. We can expect the next decade to yield a greater focus on the mechanisms described with additional insight into how poverty affects coping with SLE. Deeper understanding of how poverty affects direct, indirect, and humanistic costs can inform which modifiable factors might be successful targets for interventions to minimize disparities in this vulnerable group of patients. Motivation to eliminate poverty and minimize adverse stressors should come from within and outside of the health care sphere.

DISCLOSURE

The authors have nothing to disclose.

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