

Health Disparities in SLE

- Those we can address as health professionals
- Those we can address as citizens
- Those that are immutable



the
upus
initiative
Eliminating Health Disparities in Lupus

Eliminating health disparities • Cultural competence • Genetic and non-genetic factors • Health equity • Signs and symptoms of disease onset • Complex disease • Social determinants • Interdisciplinary care • Early diagnosis • Dermatologic • Early diagnosis • Cardiovascular • Pulmonary • Neurologic • Reproductive • Signs and symptoms of disease onset • Complex disease • Dermatologic • Early diagnosis • Genetic factors • Pulmonary • Renal • Dermatologic • Psychosocial • Cardiovascular • Renal • Cultural competence • Genetic and non-genetic factors • Health equity • Signs and symptoms of disease onset • Cardiovascular • Reproductive • Renal

Objectives

- Define health disparities
- Describe health disparities in lupus
 - Health outcomes
 - Healthcare delivery
- Explore factors associated with lupus health disparities
- Discuss ways to reduce health disparities



Definition of Health Disparities

- *Health* disparities are the differences in the incidence, prevalence, mortality, and burden of disease and other adverse health conditions that exist among specific population groups in the United States
- *Healthcare* disparities refer to differences in access to or availability of facilities and services

National Institutes of Health



Disparities in Lupus Prevalence

- Black women are 3 times more likely to develop lupus than White women
 - Affects up to 1 in 250 Black women in the United States
- Hispanic, Asian, and Native American populations are also more likely to develop lupus
- Women are 9 times more likely to develop lupus than men

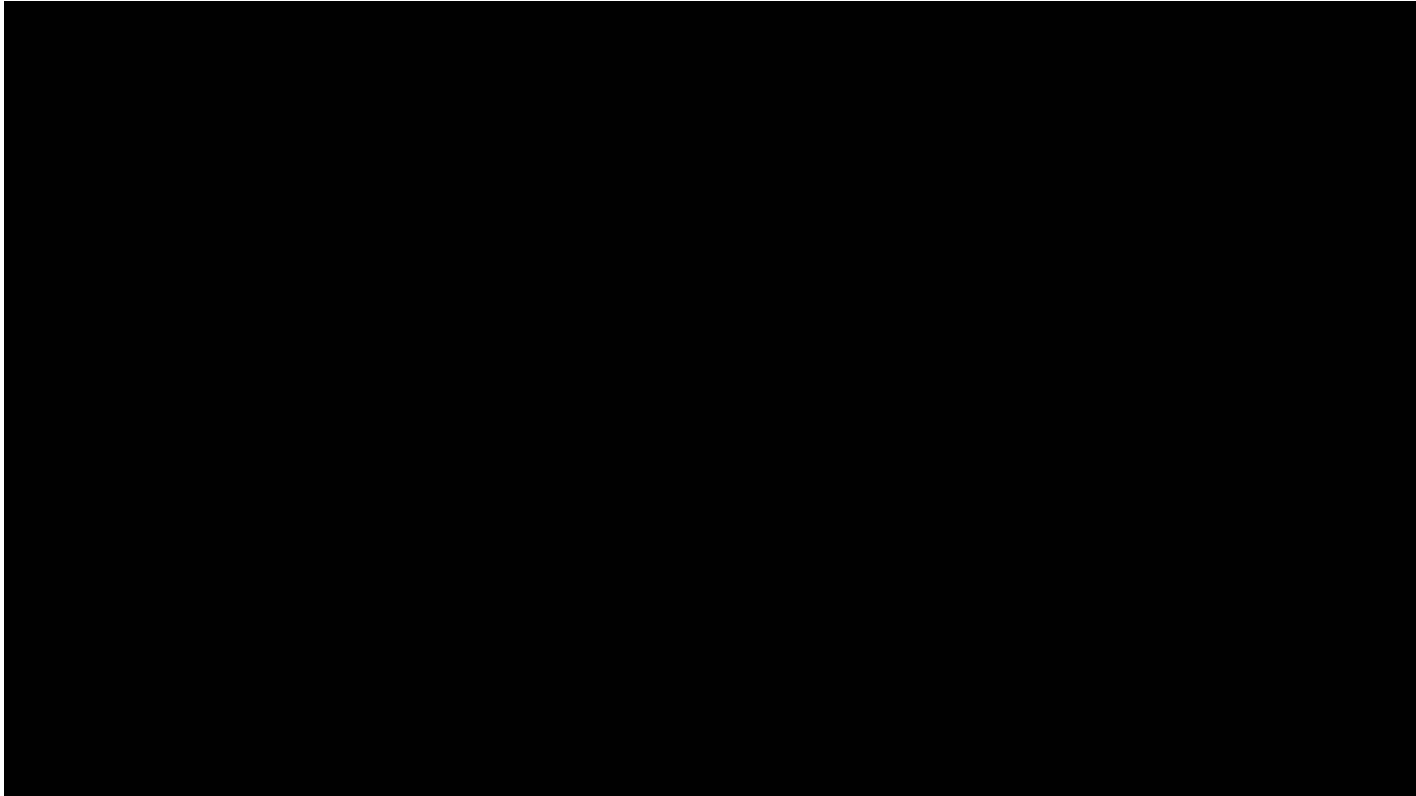


Video of Dr. Graciela Alarcón and Dr. David Wofsy

The University of Alabama at Birmingham

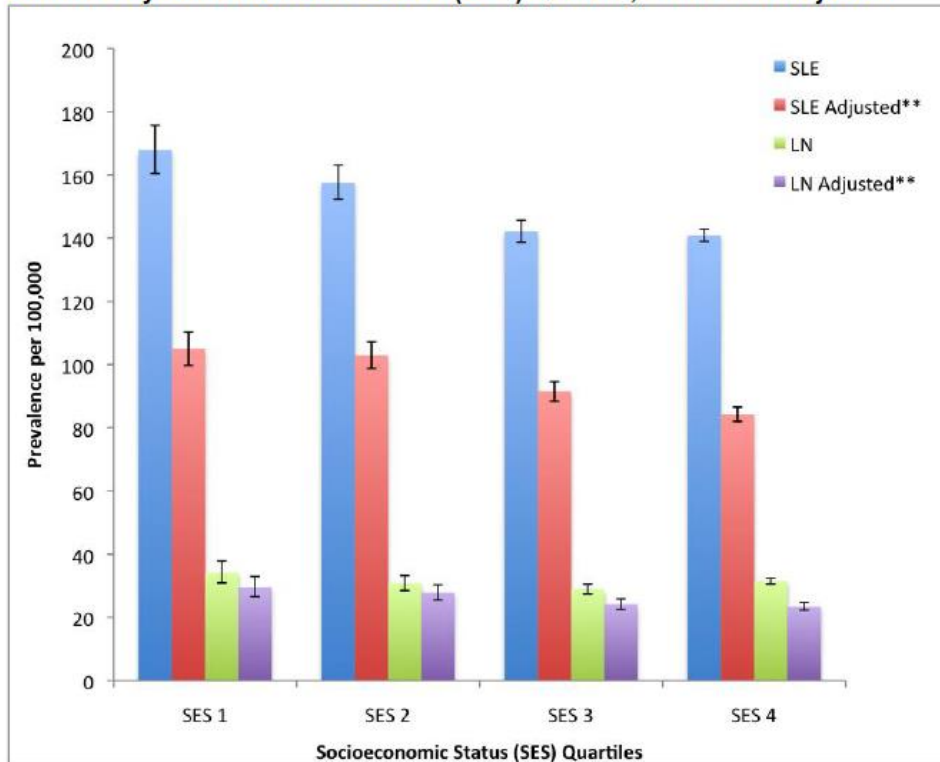
University of California, San Francisco
School of Medicine





Disparities in Lupus Prevalence

Prevalence of Systemic Lupus Erythematosus (SLE) and Lupus Nephritis (LN) Stratified by Socioeconomic Status (SES) Quartile, Crude and Adjusted*



*SES 1 (LOWEST): ≤ -1.62 , SES 2: >1.62 and ≤ -0.72 , SES 3: >0.72 and ≤ 0.26 , SES 4 (HIGHEST): >0.26 **Adjusted by age group, sex and race/ethnicity

- Among Medicaid enrollees across the United States from 2000–2004, the prevalence of both lupus and LN was highest in the ZIP code areas of lowest SES, even after adjusting for multiple other factors, including age and race/ethnicity
- It is not clear whether area-level factors, such as environmental exposures, affect development of SLE or, alternatively, if people affected with SLE lose their incomes and have to move to lower SES areas



Disparities in Lupus Disease Burden

Specific racial/ethnic minorities are more likely to develop lupus at a younger age and to have more severe symptoms at onset

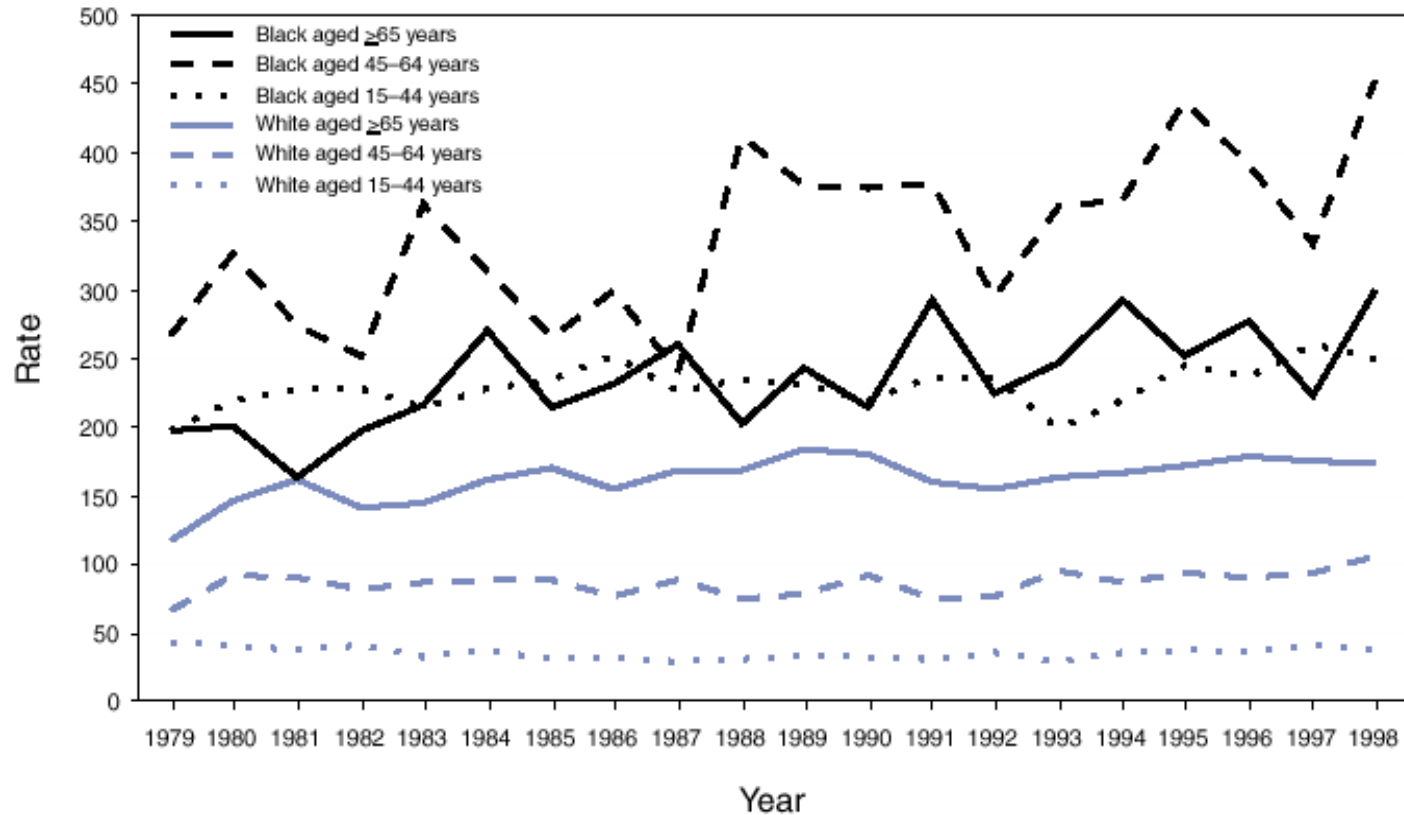


Disparities in Lupus Outcomes—Mortality

Specific racial/ethnic minorities with lupus have mortality rates at least 3 times as high as White individuals



Unadjusted SLE Death Rates for White and Black Women in the United States, According to the Centers for Disease Control and Prevention



* Per 10 million population.



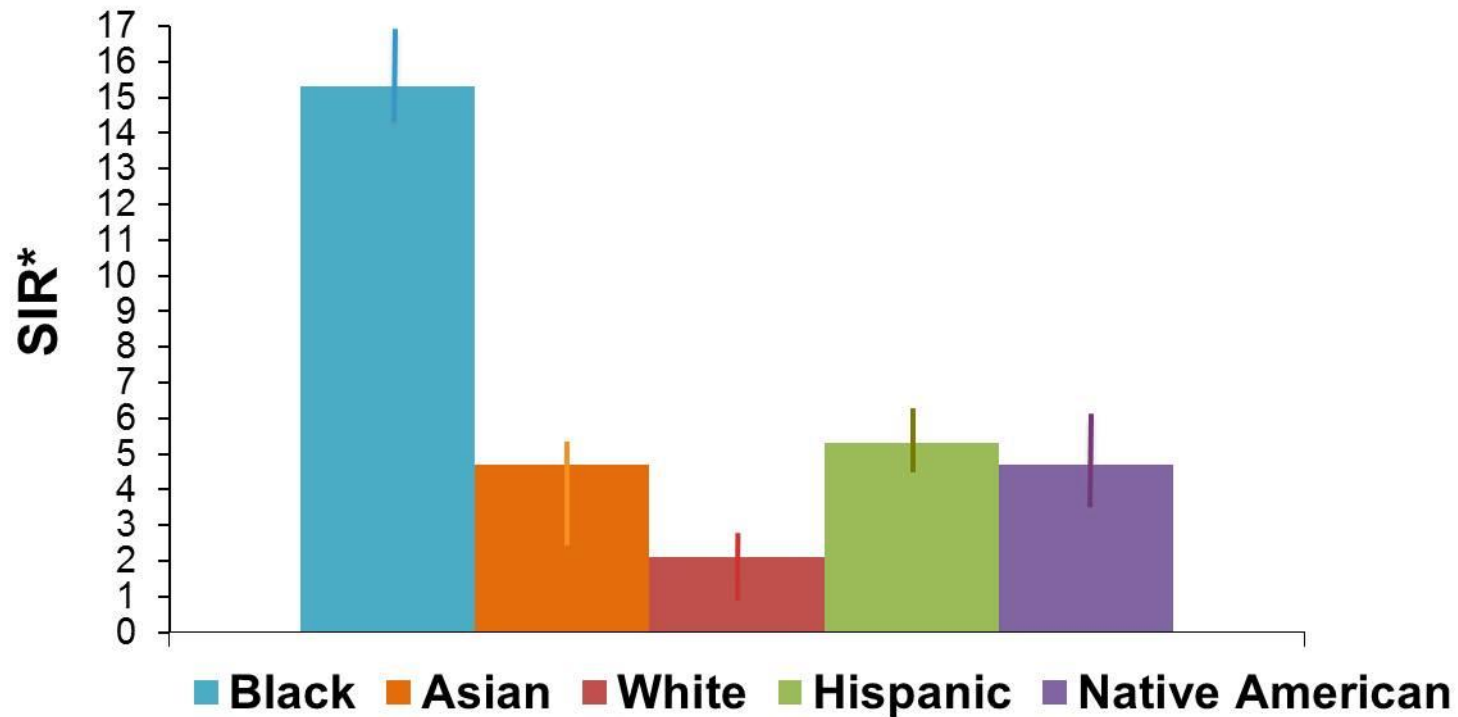
Disparities in Lupus Outcomes—Mortality

- Poverty is also associated with higher mortality in lupus
- It is challenging to disentangle the effects of poverty from race/ethnicity
- In some studies, accounting for poverty diminishes or eliminates racial/ethnic disparities in lupus mortality



Disparities in Lupus Outcomes—Renal

Standardized Incidence Rates, End-Stage Renal Disease Due to Lupus Nephritis, United States, 2001–2006

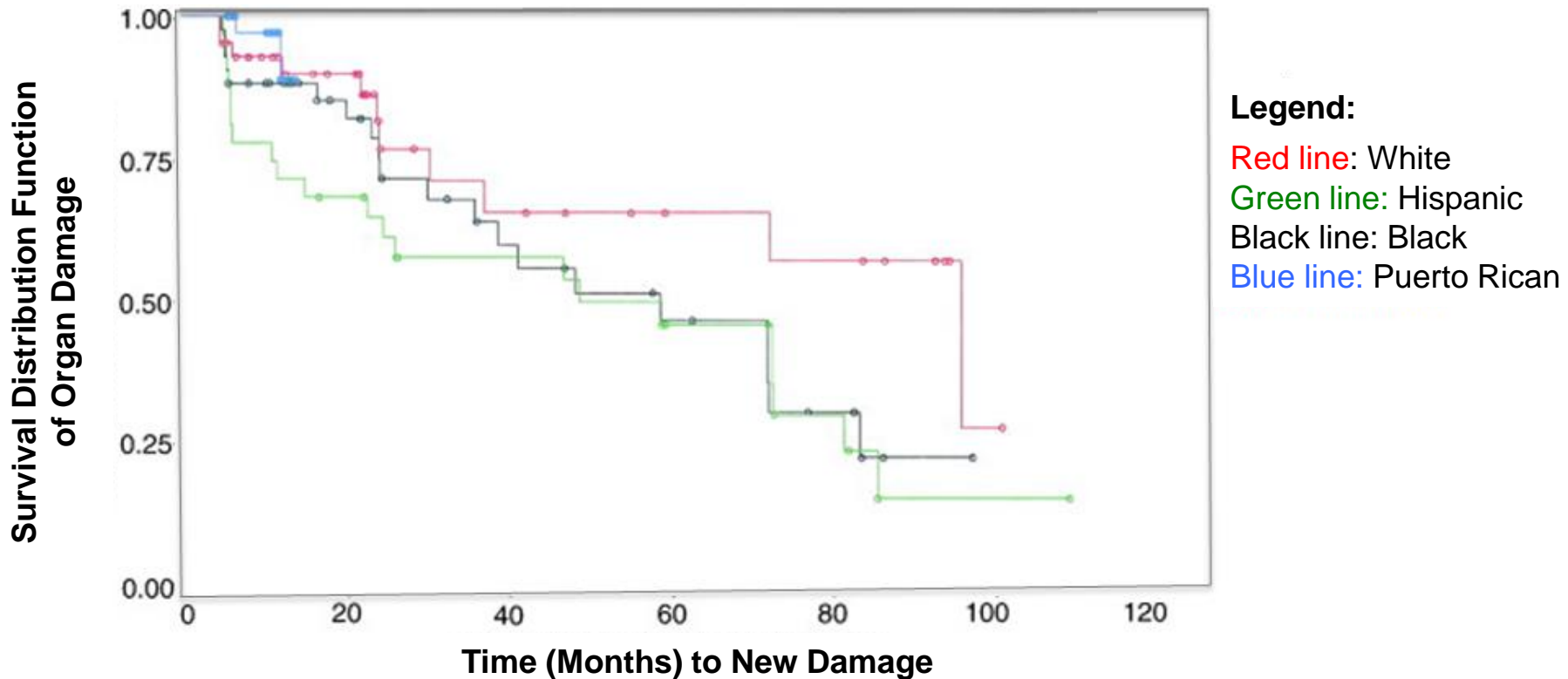


* Standardized incidence rate: end-stage renal disease cases/million person-years.



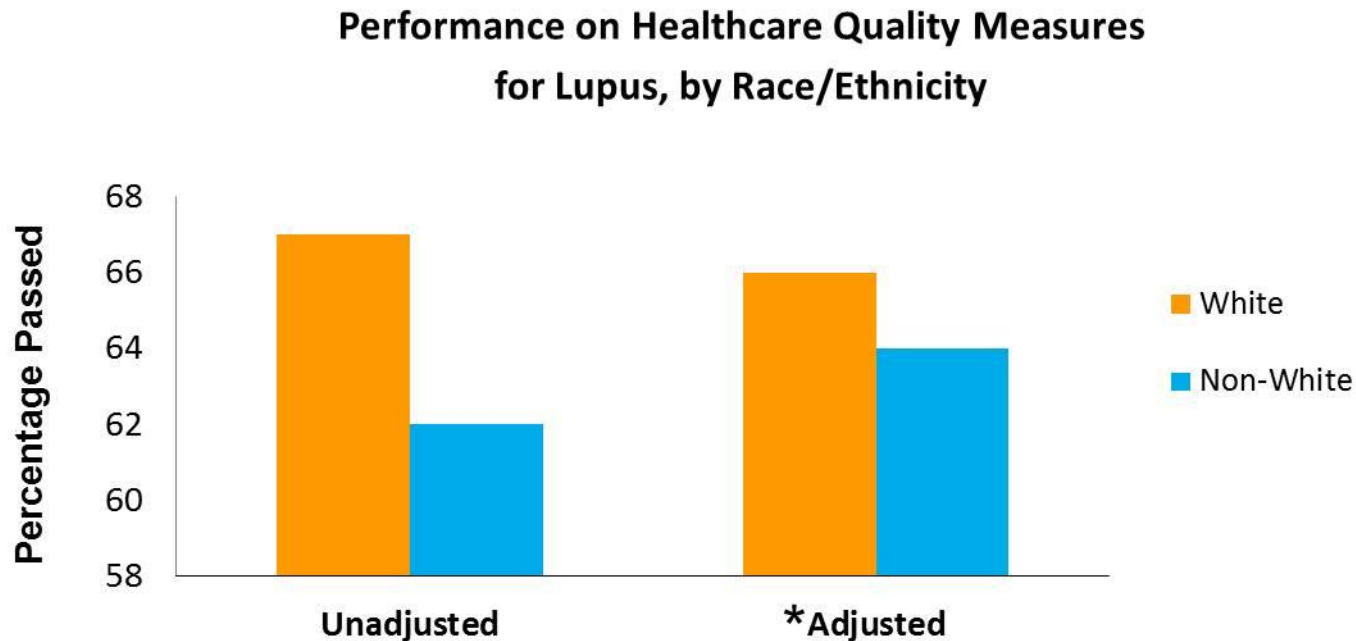
Disparities in Lupus Outcomes—Damage

Racial/ethnic minorities develop damage earlier



Disparities in Healthcare

Racial/ethnic minorities are less likely to receive recommended healthcare for lupus

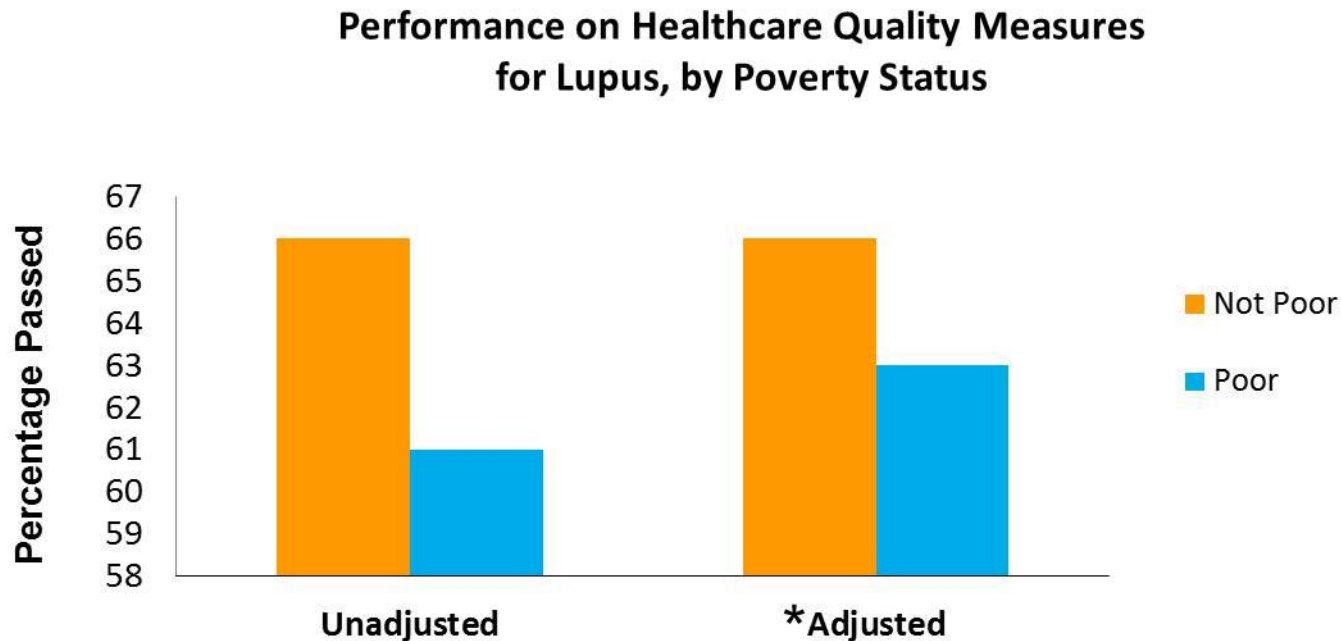


*Adjusted for age, poverty, disease duration, healthcare utilization, and health insurance.



Disparities in Healthcare (cont.)

Low-income individuals are less likely to receive recommended healthcare for lupus



*Adjusted for age, race/ethnicity, disease duration, healthcare utilization, and health insurance.

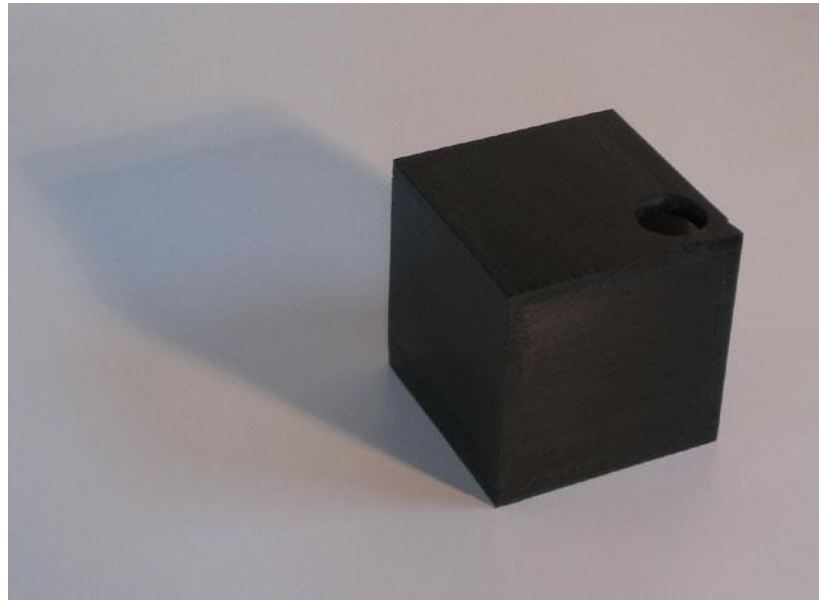


Disparities in Healthcare

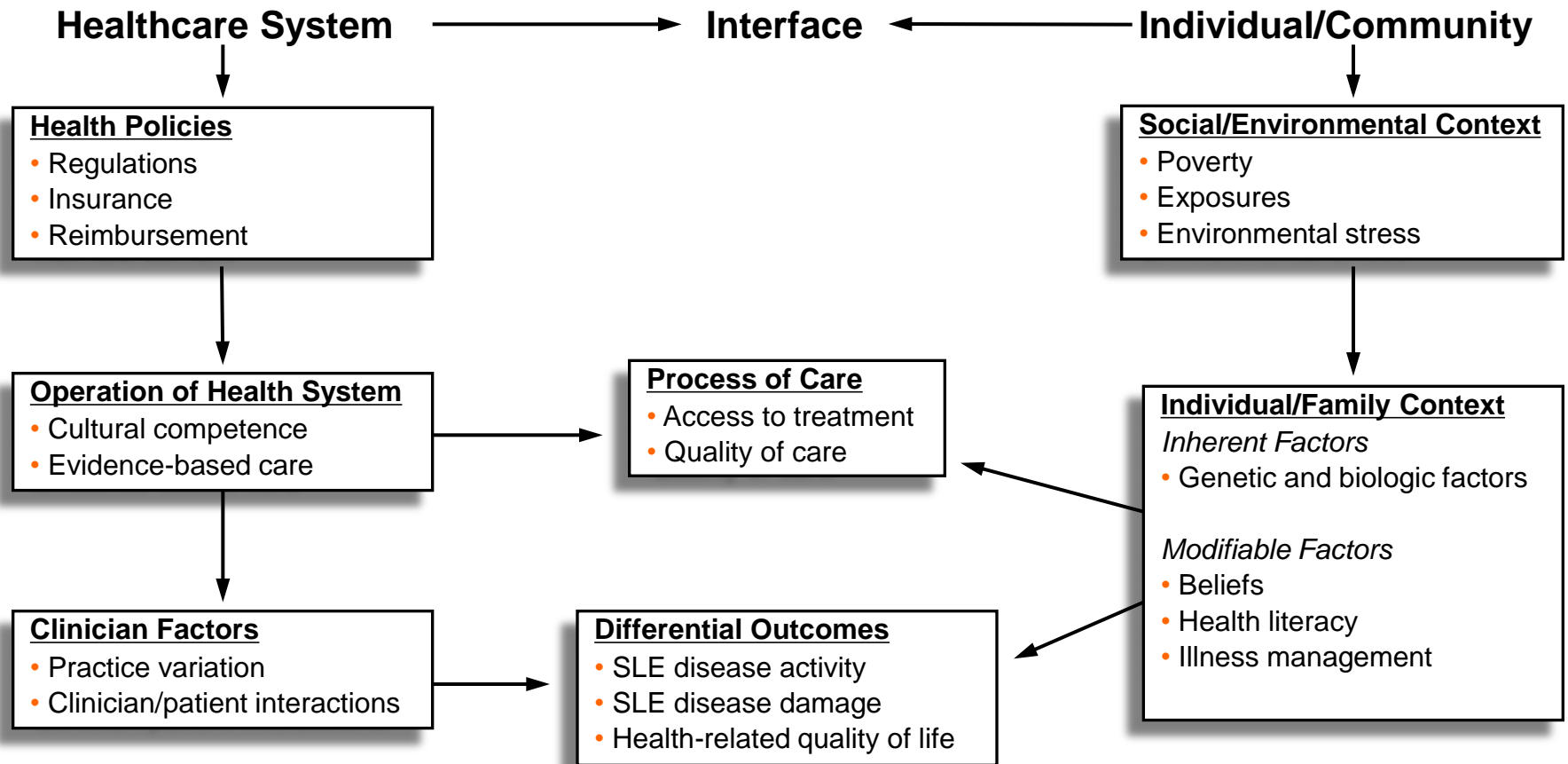
- Differences in healthcare quality for lupus among racial/ethnic minorities and those living in poverty may reflect poorer access to healthcare
 - Controlling for the presence and type of health insurance eliminated differences in quality of care for minorities and low-income individuals



What Underlies These Disparities?



Causes of Health Disparities—A Framework



Understanding Lupus Health Disparities

“The reality is that to get to the root cause of disparities, it is not going to be just one factor. For example, poor health literacy perpetuates health disparities, as does a lack of access to care, a lack of access to a regular provider, and a lack of access to a medical home. No single factor can be considered to be the root cause of disparities.”

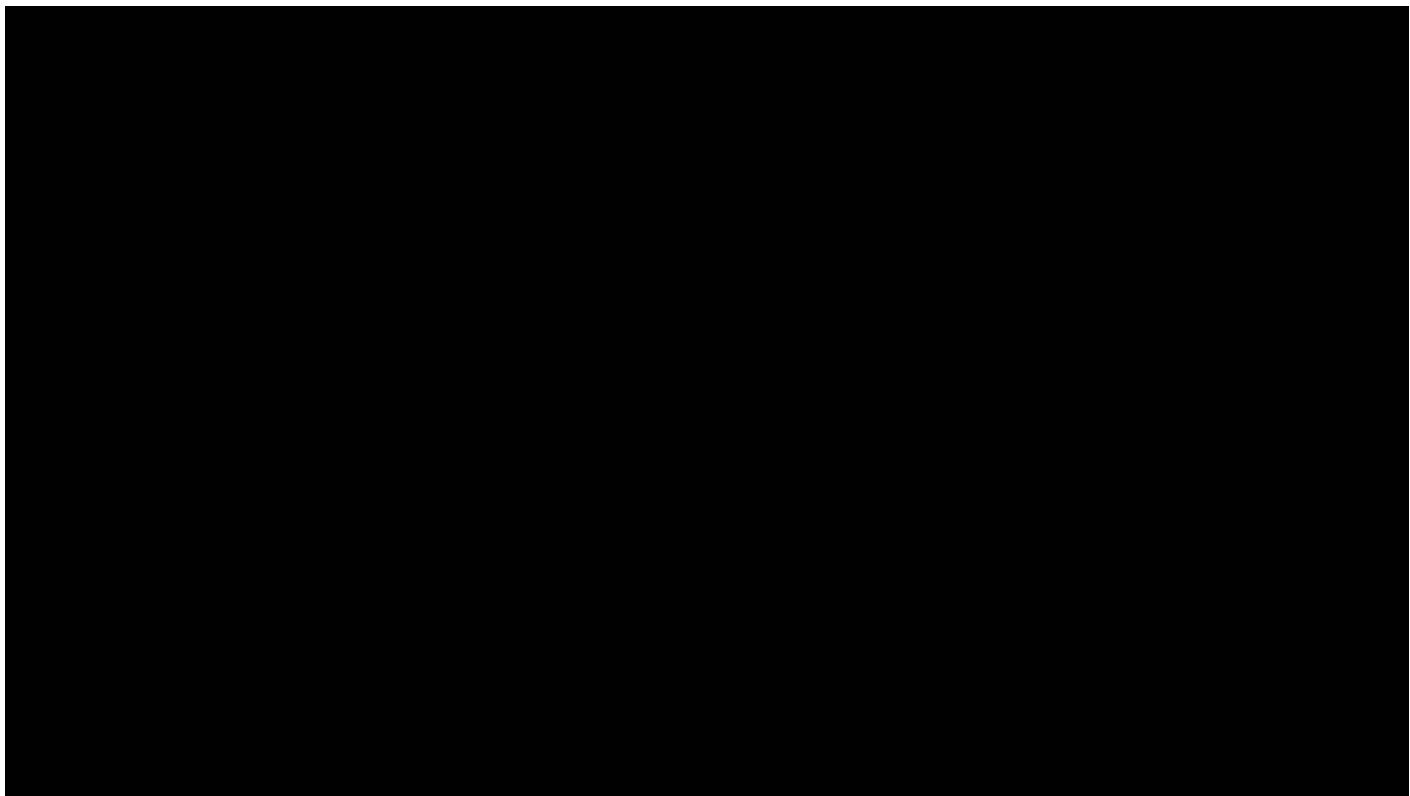
Anne Beal, Institute of Medicine



Video of Dr. Graciela Alarcón

The University of Alabama at Birmingham





The Role of Genetics in Disparities

- Genome-wide association studies (GWAS) have identified more than 30 genetic risk loci for lupus
- Studies have found susceptibility genes that are common in multiple racial/ethnic groups
 - Research is ongoing to understand differences in genetic risk factors across populations
 - Such information may one day allow more targeted, personalized treatment strategies that reduce disparate health outcomes



The Role of Genetics in Disparities

- Women are more likely to develop lupus than men across all ages
 - Lupus is increased among men with Klinefelter's syndrome (XXY), suggesting genetic susceptibility and a role of X chromosome specifically
 - Several genes on X chromosome are associated with SLE in genome-wide association studies. Incomplete X inactivation may lead to increased “gene dosage” among those with 2 Xs
 - High female-to-male ratio in SLE incidence peaks during the childbearing years, suggesting that factors related to reproductive hormones play a role



Social Determinants of Health Disparities

- Biologic mechanisms that contribute to health disparities are influenced by a complex interplay of socioeconomic, cultural, and environmental factors
- Socioeconomic disparities in lupus incidence and outcomes strongly suggest that factors beyond genetics or innate biology underlie health disparities



Poverty and Outcomes in Lupus

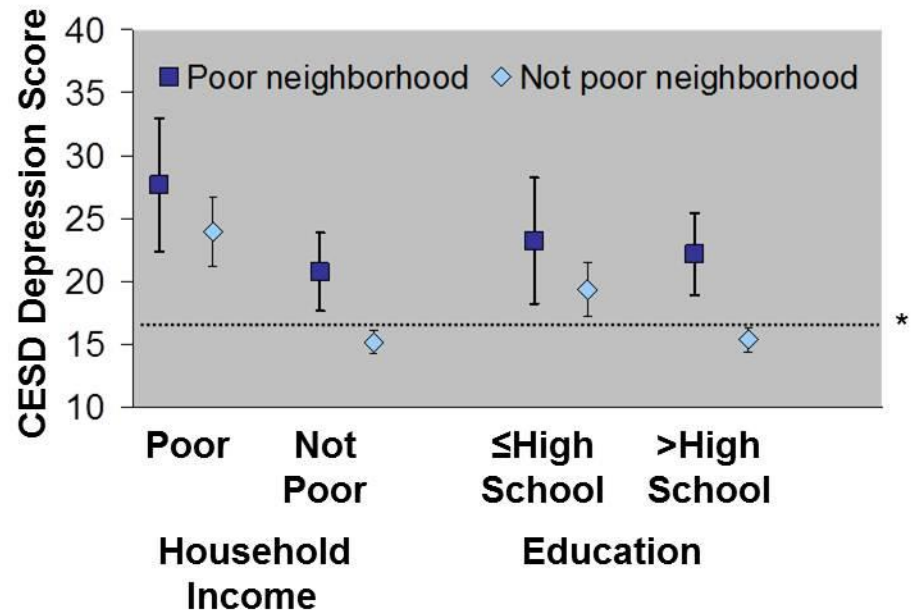
- Poverty is associated with a variety of poor outcomes in lupus
 - Higher mortality
 - Greater disease activity
 - More disease-related damage
 - Poorer physical function
 - Worse health-related quality of life
 - Higher rates of depression after disease onset



Poverty and Outcomes in Lupus

- *The neighborhood effect:* personal poverty and living in a poor neighborhood both lead to worse lupus outcomes
- Mechanisms unclear, but hypotheses include:
 - Lack of resources for a healthy life (eg, healthy food, healthcare)
 - Fewer supportive social networks
 - Stressors, such as violence

Personal and Community Poverty and Depression in Lupus



*Indicative of clinically significant depressive symptoms.



The Role of Environmental Factors

- Differential exposures among racial/ethnic minorities and the poor may contribute to health disparities
- Examples include:
 - Smoking is associated with worse lupus outcomes and is more prevalent among minorities and the poor
 - Poverty is associated with poor diet, which can lead to comorbidities, such as obesity or hypertension, which are associated with poorer lupus outcomes



The Role of Healthcare—Access

- Low-income individuals with lupus are less likely to see a lupus specialist (rheumatologist) for healthcare
- Low-income individuals enrolled in the Medicaid program travel significantly farther to see a physician for lupus, suggesting geographic barriers to care



The Role of Healthcare—Trust

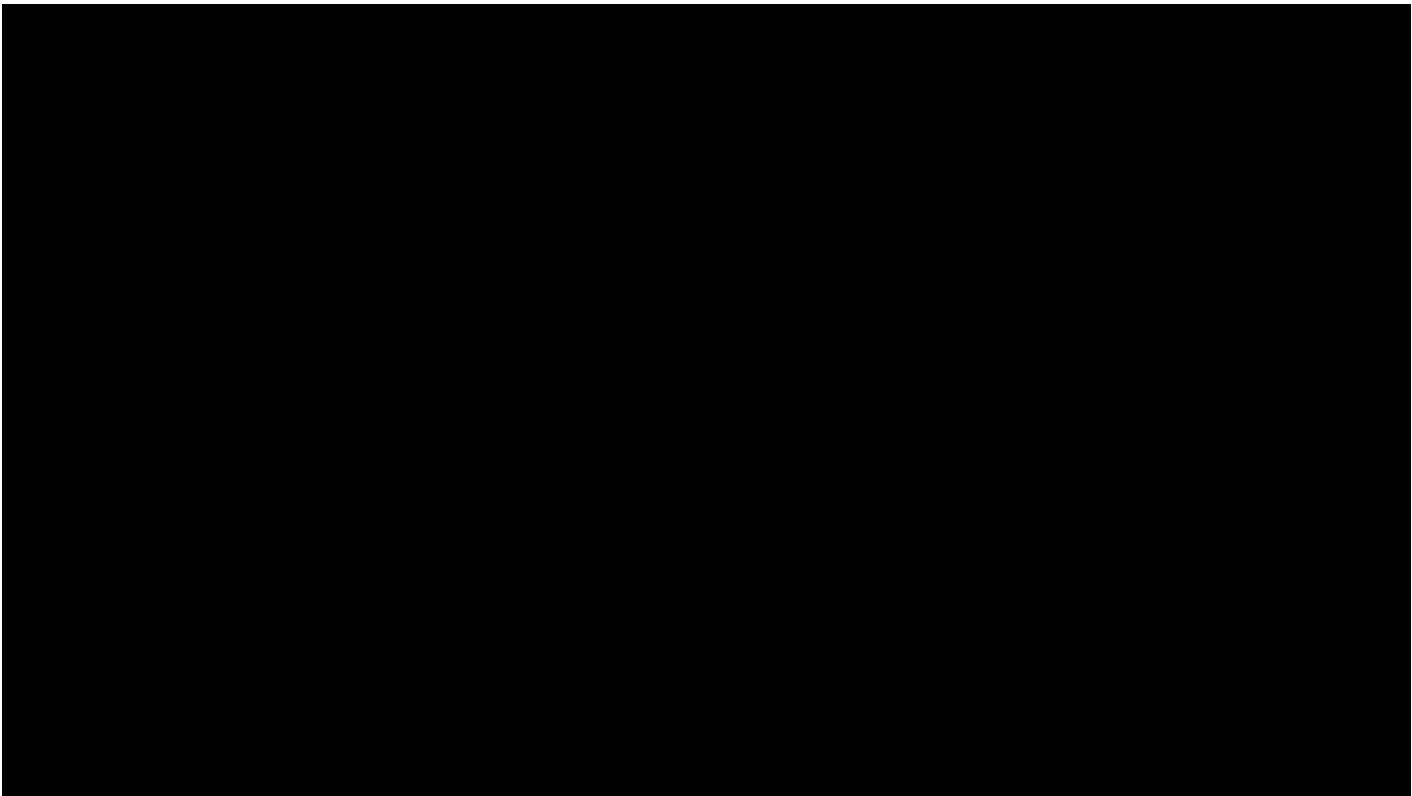
- Blacks with lupus were less willing to receive potent immunosuppressive medications for renal disease than Whites
- This racial/ethnic difference was mediated by less trust in physicians and lower perceived medication effectiveness



Video of Dr. Graciela Alarcón

The University of Alabama at Birmingham





The Role of Healthcare—Delivery

Disparities in healthcare quality may arise from:

- Insurance coverage and type*
- Inadequate cultural competency of providers
- Poor patient-provider communication
- Bias and discrimination
- Patient preference for less-aggressive treatment*
- Poor adherence*
- Language barriers
- Lack of participation in clinical trials*
- Inadequate diversity of the healthcare workforce

**These factors have been documented as sources of disparities in healthcare quality in studies of lupus*



Reducing Health Disparities in Lupus

Health disparities in lupus have complex causes and therefore require broad and multidisciplinary solutions at the individual, community, healthcare system, and population levels



Reducing Health Disparities in Lupus

- *Educate* – improve awareness of the disease among providers and the public
- *Collect data* – promote consistent, reliable, and longitudinal data collection to identify the nature and extent of lupus disparities
- *Intervene* – develop and target initiatives to improve health and healthcare for lupus and measure changes over time

Reducing Health Disparities in Lupus

- *Access* – expand access to appropriate healthcare for lupus
- *Train* – train healthcare providers regarding the impact of health disparities and the relevance of cultural and linguistic competency
- *Engage* – meaningfully engage communities to develop strategies to mitigate negative social determinants of health

*“Knowing is not enough; we must apply.
Willing is not enough; we must do.”*

— Goethe



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