Health Disparities in SLE in the United States
WELCOME
Before we get started…

ABOUT THIS PROJECT
• The presentation is designed to be easily incorporated into medical school lectures on a variety of topics; they are tailor-made for the classroom setting, and easy to digest
• The PowerPoint presentation is designed for medical students M3 and M4

DRUGS AND DOSES
When prescribing medications, the physician is advised to check the product information sheet accompanying each drug to verify conditions of use and to identify any changes in drug dosage schedule of contra-indications.

USE OF PROFESSIONAL JUDGMENT
This activity, including all educational links, is intended to be used as a tool to assess the base knowledge of the learner. The information presented relates to basic principles of diagnosis and therapy, and is meant in no way to substitute for an individual patient assessment based upon the healthcare provider’s examination of the patient and consideration of laboratory data and other factors unique to the patient.

ACR DISCLOSURE STATEMENT
The American College of Rheumatology is an independent, professional organization that does not endorse specific procedures or products of any pharmaceutical/biotech concern.

SUPPORT
The project described is, in part, supported by the Centers for Disease Control and Prevention under Cooperative Agreement Number NU58 DP006138. Its contents are solely the responsibility of its developers/authors. Points of view or opinions do not, therefore, necessarily represent official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

FACULTY REPORTED DISCLOSURES
[To be filled in once we get disclosures]
Learning Objectives

• Understand the health disparities in lupus incidence, prevalence, severity, and long-term morbidity and mortality by age, race/ethnicity, sex, and social determinants of health status

• Discuss the disparities in health outcomes and healthcare delivery in lupus

• Recognize the factors associated with health disparities in lupus

• Identify ways to reduce health disparities in lupus
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 and Incidence

- 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

Disparities in Lupus Disease Burden

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

• Black females with incident lupus were 4-6 years younger than their White counterparts

Disparities in Lupus Prevalence

- U.S. Medicaid enrollees from 2000-2004
- Lupus and Lupus Nephritis prevalence highest in the ZIP code areas of lowest SES, even after adjusting for age, race/ethnicity and others
- Unclear whether area level factors, such as environmental exposures, affect development of SLE or, alternatively, if people affected with SLE lose their incomes and must move to lower SES areas

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), crude and adjusted by age group, sex and race/ethnicity

Unadjusted SLE Death Rates for White and Black Women: U.S. Centers for Disease Control and Prevention

Disparities in Lupus Outcomes—Mortality

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

• Among Black women, death rates were highest and increased most (69.7%) among those aged 45-64 years from 1979 to 1998

• Compared with White individuals with SLE, the cumulative SLE mortality was significantly higher among black individuals, with deaths occurring sooner after diagnosis and at a mean age approximately 13 years younger.


Unadjusted and Adjusted hospital mortality in hospitalized SLE By Race

Higher Death Rates for Racial/Ethnic minorities

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—End stage Kidney Disease (ESKD)

Standardized Incidence Rates, End stage Kidney Disease due to Lupus Nephritis, United States, 2001–2006

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


Disparities in Lupus Outcomes—Infections

Using the Medicaid data for the years 2000–2006, people with SLE were identified

- There were 9,078 serious infections in 5,078 SLE patients and 3,494 infections in 1,825 patients with lupus nephritis
- In multivariable-adjusted models, increased risks of infection were seen in:
  - Black individuals as compared to White individuals:
    - Hazard Ratio, 1.14 [95% confidence interval, 1.06–1.21]
  - Men as compared to women:
    - Hazard Ratio, 1.33 [95% confidence interval, 1.20–1.47]


Disparities in Lupus Outcomes—Health care utilization for Hospitalization with Infections

- 1998-2016 US National Inpatient Sample data used to examine outcomes of serious infection hospitalizations in SLE
- Rates of pneumonia, sepsis/bacteremia, urinary tract infection (UTI), skin and soft tissue infections (SSTIs), and opportunistic infections (OIs) all increased in SLE patients over time
- In multivariable-adjusted models, compared to White SLE patients, Black SLE patients hospitalized for serious infection had significantly higher odds of:
  - higher hospital charges
  - a longer hospital stay
  - discharge to a non-home facility (nursing home or a long-term facility)

Disparities in Lupus Outcomes—Damage

Racial/ethnic minorities develop damage earlier

Legend:
Red line: White
Teal line: Hispanic
Gray line: Black
Purple line: Puerto Rican

Disparities in Healthcare

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

Performance on Healthcare Quality Measures for Lupus, by Race/Ethnicity

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

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

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

Disparities in Healthcare related to fragmented care

- 4,276 SLE patients
- Blacks experienced more care fragmentation compared to white
  - odds ratio [OR] 1.66, 95% confidence interval [CI], 1.44-1.97
- Fragmented care associated with increased risk of
  - Infections: OR 1.57, 95% CI 1.30-1.88
  - cardiovascular disease: OR 1.51, 95% CI 1.23-1.86
  - end-stage renal disease: OR 1.34, 95% CI 1.05-1.70
  - Nephritis: OR 1.28, 95% CI 1.07-1.54
  - Stroke: OR 1.28, 95% CI 1.01-1.62

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 and other factors (age, race/ethnicity, disease duration healthcare utilization) eliminated differences in quality of care for minorities and low-income individuals

What Underlies These Disparities?
Causes of Health Disparities—A Framework

“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
The Role of Genetics in Disparities

- Genome-wide association studies (GWAS) have identified more than > 100 genetic risk loci for lupus
- Thirty-four novel variants identified in a recent study.
- New loci included the immune checkpoint receptor CTLA4, the TNF receptor-associated factor TRAF3 and the type I interferon gene cluster on 9p21
- 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

Deng Y, Tsao BP. Nat Rev Rheumatol. 2010;6(12):683-692;
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
  - TLR7 is located on the X chromosome and is likely an important gene leading to increased SLE susceptibility
  - 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

- **CDC**: Social determinants of health (SDOH) are conditions in the places where people live, learn, work, and play that affect a wide range of health and quality-of-life risks and outcomes.

- 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.

CDC Definition of SDOH: https://www.cdc.gov/socialdeterminants/index.htm
Poverty and 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, including physical function and depression symptoms.

- Mechanisms unclear, but hypotheses include:
  - Lack of resources for a healthy life (e.g., healthy food, healthcare)
  - Fewer supportive social networks
  - Stressors, such as violence, safe living conditions, psychological safety and well-being, psychological stress


*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
  - Racism at personal, societal and institutional levels can lead to psychological stress, anxiety, depression, all of which increase the risk of lupus flares and poor 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.
- Access to pharmacy and to transportation to get to a physician are more limited in low-income individuals that can interfere with healthcare access.

Black individuals with lupus were less willing to receive potent immunosuppressive medications for kidney disease than White individuals living with lupus.

This racial/ethnic difference was mediated by less trust in physicians and lower perceived medication effectiveness.

Blacks in the U.S. are more likely to perceive racism in healthcare.

Higher perceived racism in Blacks in the U.S. is associated with higher levels of depression in SLE.

Structural racism and Implicit bias in healthcare teams and systems can erode the trust of racial minorities in healthcare systems.
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

- **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, which can then prevent and/or help early and more effective treatment of serious infections in people with low socio-economic status and/or racial/ethnic minorities

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

— Goethe
Visit: https://thelupusinitiative.org/

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