The Interface of Health and Culture: Lupus

PAMELA H. FOSTER, MD, MPH

PROFESSOR, COMMUNITY MEDICINE/POPULATION HEALTH & DEPUTY DIRECTOR, INSTITUTE FOR RURAL HEALTH RESEARCH, UNIVERSITY OF ALABAMA SCHOOL OF MEDICINE, TUSCALOOSA CAMPUS

"Of all the forms of inequality, injustice in health care is the most shocking and inhumane"

Martin Luther King, Jr. (1960s)

Agenda

- Evolution of Health Disparities and Cultural Competency
  - Definitions/Overview
  - Seminal Studies – Georgetown Study
- Exploring cultural competency/cultural humility
- HD and Lupus
- Summary/Q & A

Nomenclature/Definitions

- **Health Disparities (HD)** – differences in health indices between certain ethnic/racial groups and the majority population (Caucasian)

- **Health Inequalities /Health Inequities (HI)** – broader definition than health disparities, denotes more than identifying differences but takes into account underlying causes which are a result of social injustices or inequalities

Most Common Ethnic/Racial Populations used in HD/HI

African Americans*

Latinos

Native Americans/Alaska natives

Asian/Pacific Islanders

Priority Diseases – HD/HI

Cancer

Cardiovascular Disease

Diabetes

HIV/AIDS

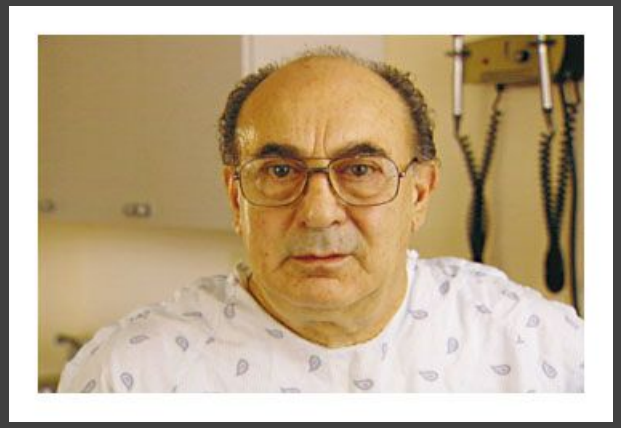
Immunizations

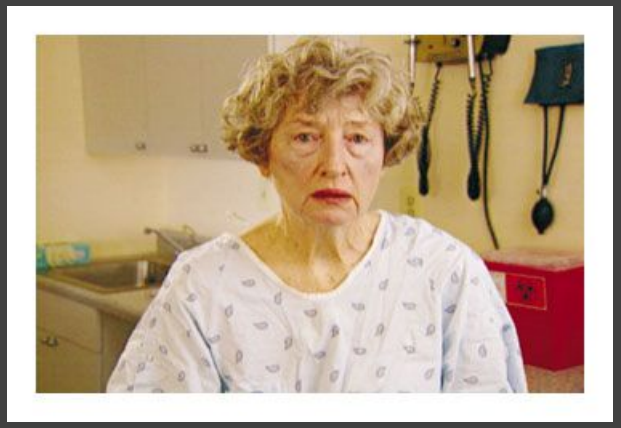
Infant Mortality

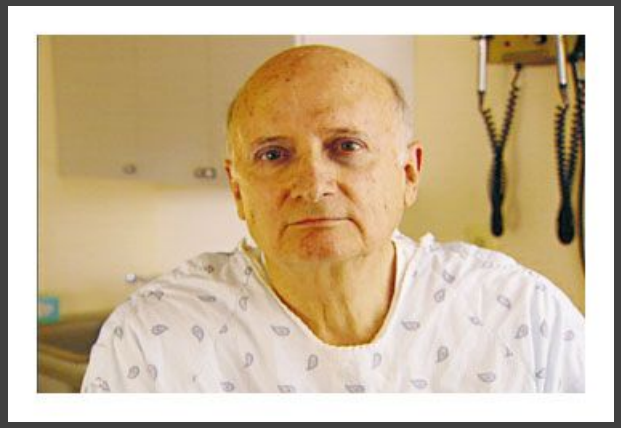
- **Using simulated cases and actors, 720 primary care physicians were interviewed on their practice in prescribing cardiac therapies**

New England Journal of Medicine, The Georgetown Study, February 25, 1999

“Patients” experiencing symptoms of heart disease, from Schulman et al. (1999)







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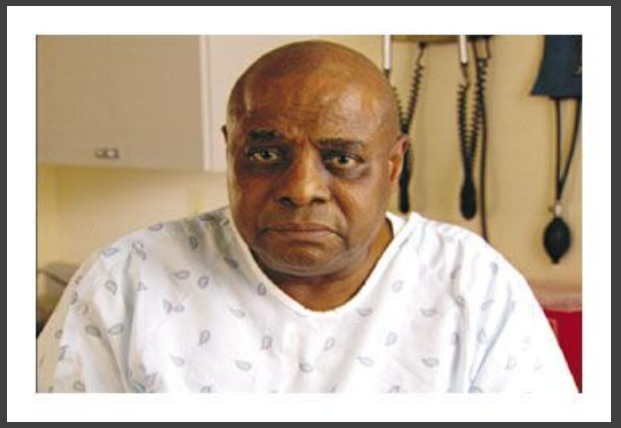

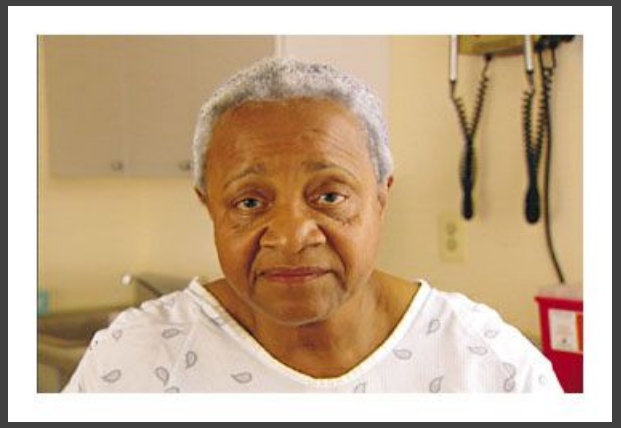

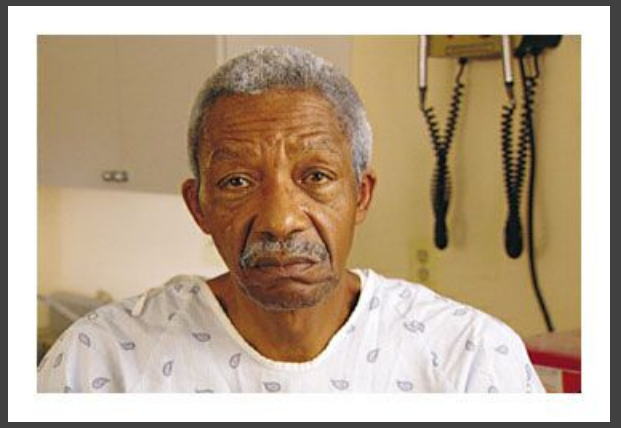

Results – Georgetown Study

The study participants prescribed aggressive cardiac care 60% less often to Blacks and women (i.e., cardiac cauterization, coronary angiography or coronary bypass surgery)

Possible Explanations for results of study

- **Racial Differences**
  - **Suggests Clinician-patient interactions – hint of racism of physicians who were mainly white either overt, probably subtle with their non-white patients**
- **Gender Differences**
  - **Sexism of physicians who were mainly male**
  - **Non-recognition of females and cardiovascular disease**
  - **Lack of women in early cardiovascular clinical trials**

Cultural Competency

"As a culturally competent manager, I am capable of interacting positively with people who do not look like, talk like, think like, believe like, act like, or live like me!"

Multnomah County Health Department, Oregon

Cultural Competency

"A culturally competent system of care acknowledges and incorporates, at all levels, the importance of culture, the assessment of cross-cultural relations, vigilance towards the dynamics that results from cultural differences, the expansion of cultural knowledge and the adaptation of services to meet culturally unique needs."

(Cross, Baron, Dennis & Isaacs, 1989)

Definitions of Cultural Competence

- Interpersonal Cultural Competence

–The ability of individual health care professionals to establish effective interpersonal and working relationships with patients (and each other) that supercede cultural differences1

- Health System Cultural Competence

–The ability of health care providers and organizations to understand and respond effectively to the cultural and linguistic needs brought by patients to the health care encounter2

1Cooper & Roter, Unequal Treatment, IOM, 2003 2Office of Minority Health 2001

Cultural Humility

" Cultural humility incorporates a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and no paternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations."

Teravalon M and Murray-Garcia J, 1997

Reaction to 2015 Kelly Report on Health Disparities

"The significance of lupus in the African American community can no longer be ignored, and it is clear there is much work to do to improve health equity among those who suffer from the disease."

Sandra C. Raymond, President and CEO of the Lupus Foundation of America, 2015

Disproportionate Affect

- Recent studies indicate that lupus affects 1 in 537 young African American women and that these women have higher mortality rates – up to three times the incidence of mortality than that of Caucasians.
- In recent years, there has been an erosion of funding at the NIH and other vital federal agencies. Without adequate and robust funding for biomedical research, progress into discovering, developing, and delivering new medications to people with lupus will continue to be delayed.
- The result will have a devastating impact on all people with lupus, especially members of the African American community who are at greatest risk for the disease.

Disproportionate Affect

- Additionally, we must conduct research to truly understand specific physical, social, emotional, and other challenges that can be overwhelming for medically underserved, minority populations including *provider bias which could affect outcomes*.

Disadvantaged Neighborhood Residence as Predictor of SLE Retention of Care*

- Among 397 SLE patients, 91% were female, 56% White, 39% Black, and 5% Hispanic. Notably, 51% of Black versus 5% of White SLE patients resided in the most disadvantaged ADI neighborhood quartile.
- Overall, 60% met visit-defined retention and 27% met complement lab-defined retention in 2015. Retention was 59% lower for patients in the most disadvantaged neighborhood quartile (adjusted OR 0.41, CI 0.18, 0.93).
- Future interventions could geo-target disadvantaged neighborhoods and design retention programs with vulnerable populations to improve retention in care and reduce SLE outcome disparities.

*Bartels, C.M., Rosenthal, A., Wang, X. *et al.* Investigating lupus retention in care to inform interventions for disparities reduction: an observational cohort study. *Arthritis Res Ther* **22,** 35 (2020).

Why Lupus Registries?

- The data allows researchers to dig into data to specifically *define* and analyze incidence, prevalence and mortality rates based on criteria such as age, race, etc. and *address* strategies to mitigate disparities and improve overall outcomes for those with lupus
- Recent study in 2019 reviewed Georgia Lupus Registry:

  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

Georgia Lupus Registry

- Blacks had significantly greater cumulative morality than whites and were significantly younger at death at both incident and prevalent cases (51.8 vs. 64.4 years and 52.3 vs. 65 years)
- Black females with prevalent SLE were 3 times more likely to die than were Black females in the general population.
- Blacks were also younger at death than whites for both incident and prevalent cases

The Future

As a result of article, the Lupus Foundation of America, The American College of Rheumatology and the CDC are *working together* to encourage early detection and treatment, enhance the self-management skills of those with lupus, and improve health care provider's ability to make accurate diagnoses.

Summary/Q & A Period

Q & A

Thank you!