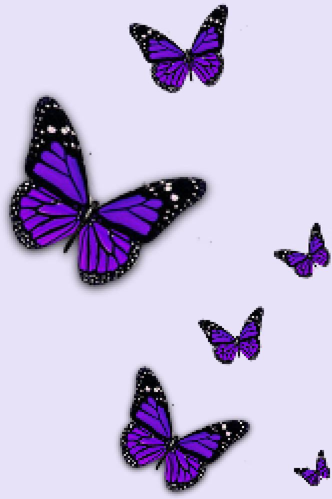
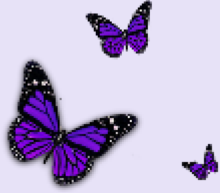


Treating the Diverse Patient: A Holistic Approach to Care

Ashira D Blazer, MD
Assistant Professor of Medicine
Hospital for Special Surgery

Instructor Disclosures and Funding

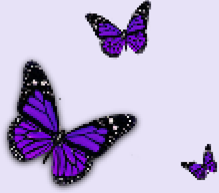


- HSS educational activities are carried out in a manner that serves the educational component of our Mission.
- As faculty we are committed to providing transparency in any relevant external relationships prior to giving an academic presentation.

- I have these relevant financial relationships to disclose:

Company	Nature of Relationship
GSK	Medical Educators Network, Disparities
Novartis	Consultant: Diversity, Equity, and Inclusion

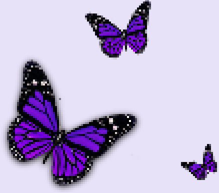
- Grant Support:
  - K23AI163359 (NIH/NIAID)

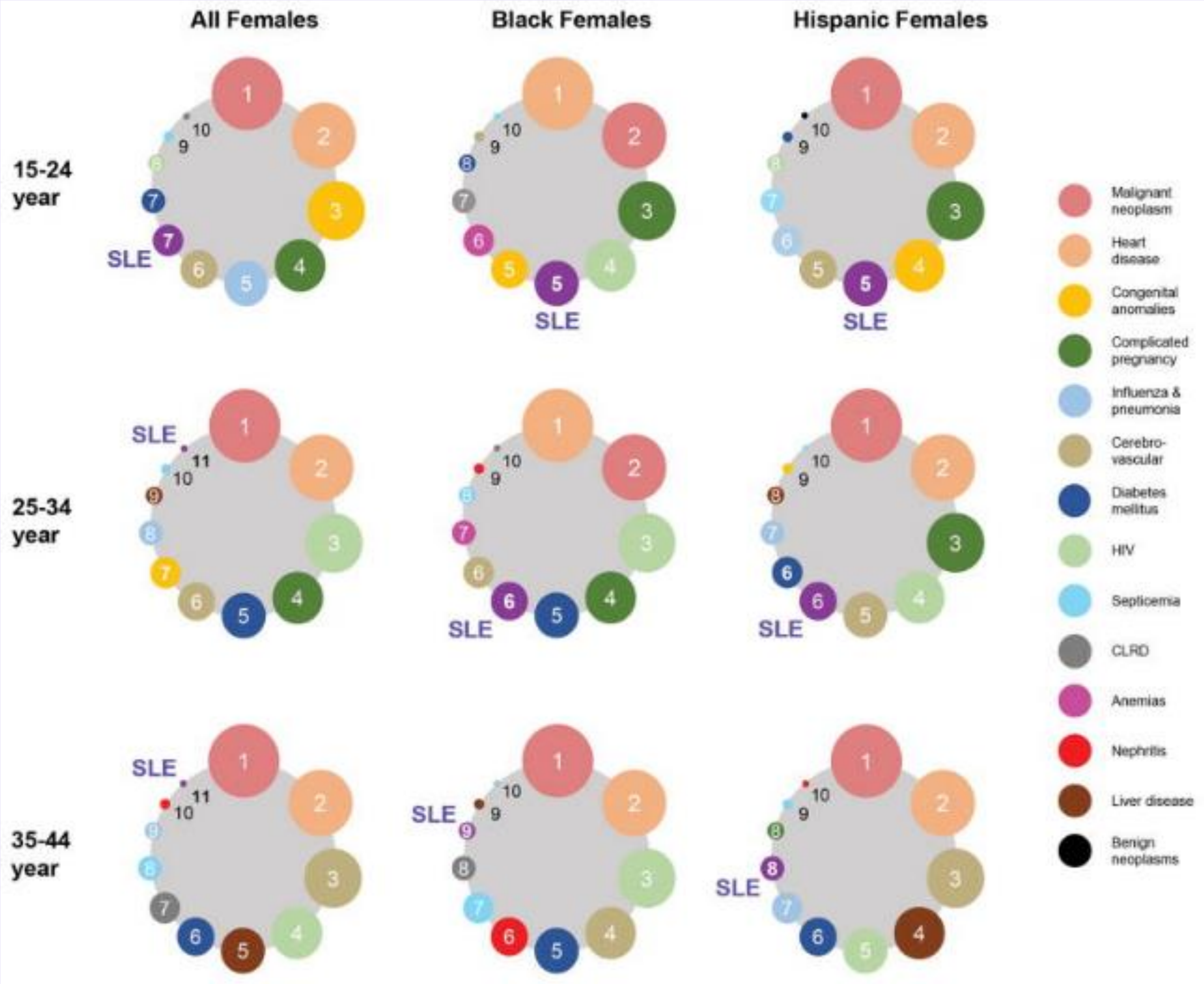


Learning Objectives

- Understand the social and structural factors that worsen outcomes for minoritized SLE patients
- Learn to create a holistic care plan for the diverse SLE patient
- Learn about emerging solutions to improve disparities in SLE

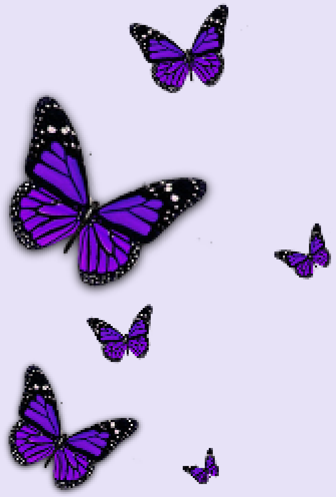
SLE is a Major Cause of Morbidity and Mortality Especially in Minority Women

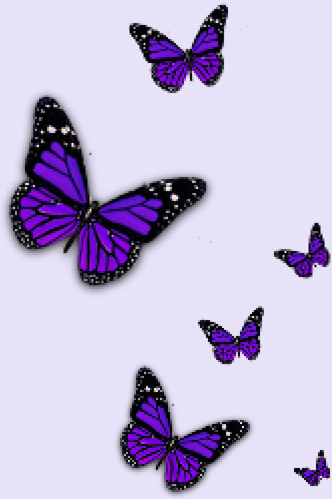




Leading Causes of Deaths for Females of Reproductive Age by Race/Ethnicity and Age

(Yen and Singh 2018)

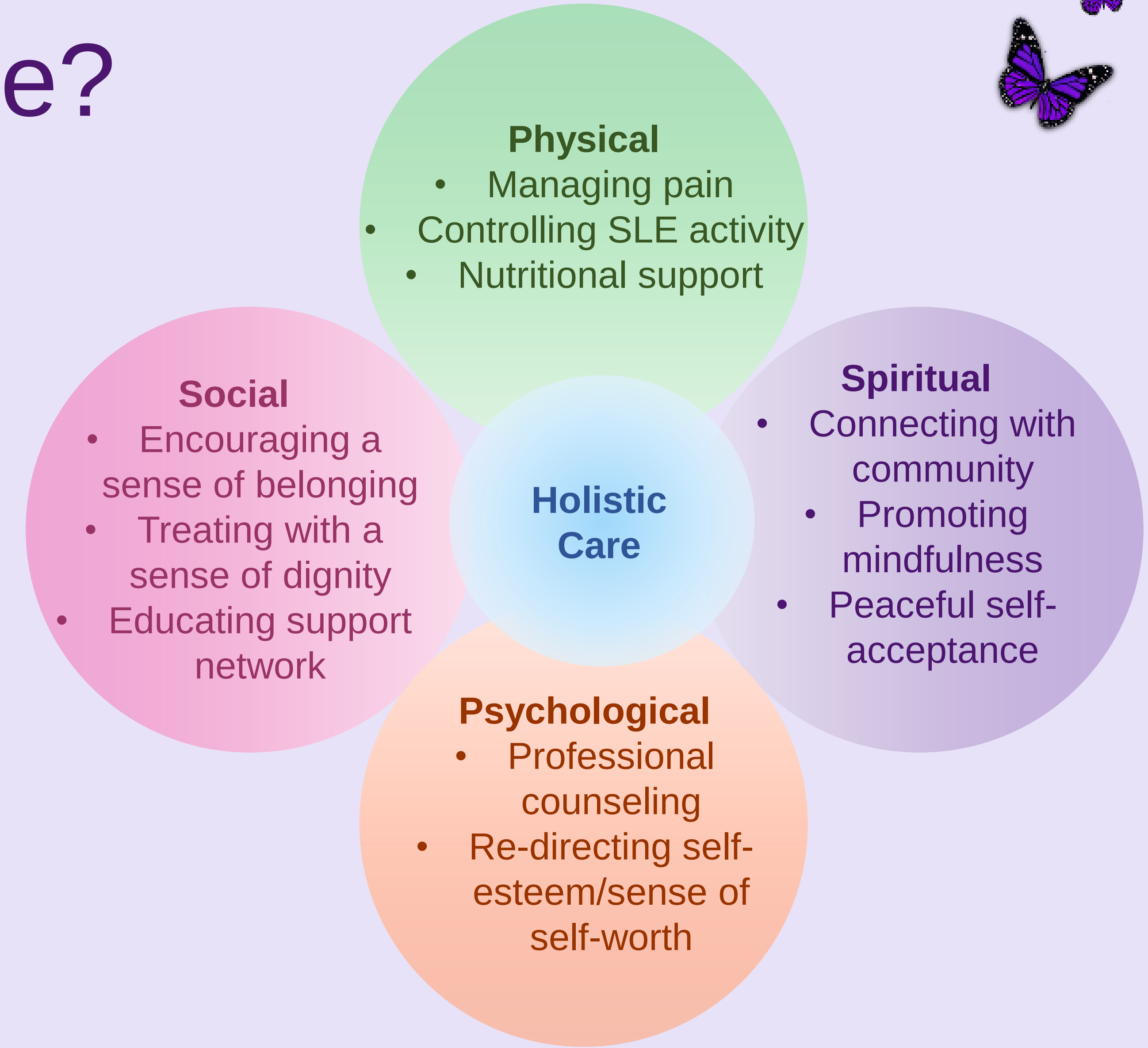




Key Concept: When we measure racial differences in medicine, we are largely measuring the effects of racism→ I.E. Race becomes biology

What is Holistic Care?

- Providing comprehensive care to address multiple dimensions:
  - Physical
  - Social
  - Psychological
  - Spiritual
- Focuses on the “wholeness” of the patient
- Takes into consideration the patient’s social, cultural, and family context



Physical
- Managing pain
- Controlling SLE activity
- Nutritional support

Social
- Encouraging a sense of belonging
- Treating with a sense of dignity
- Educating support network

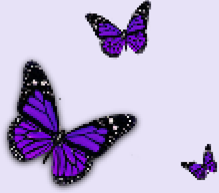
Holistic Care

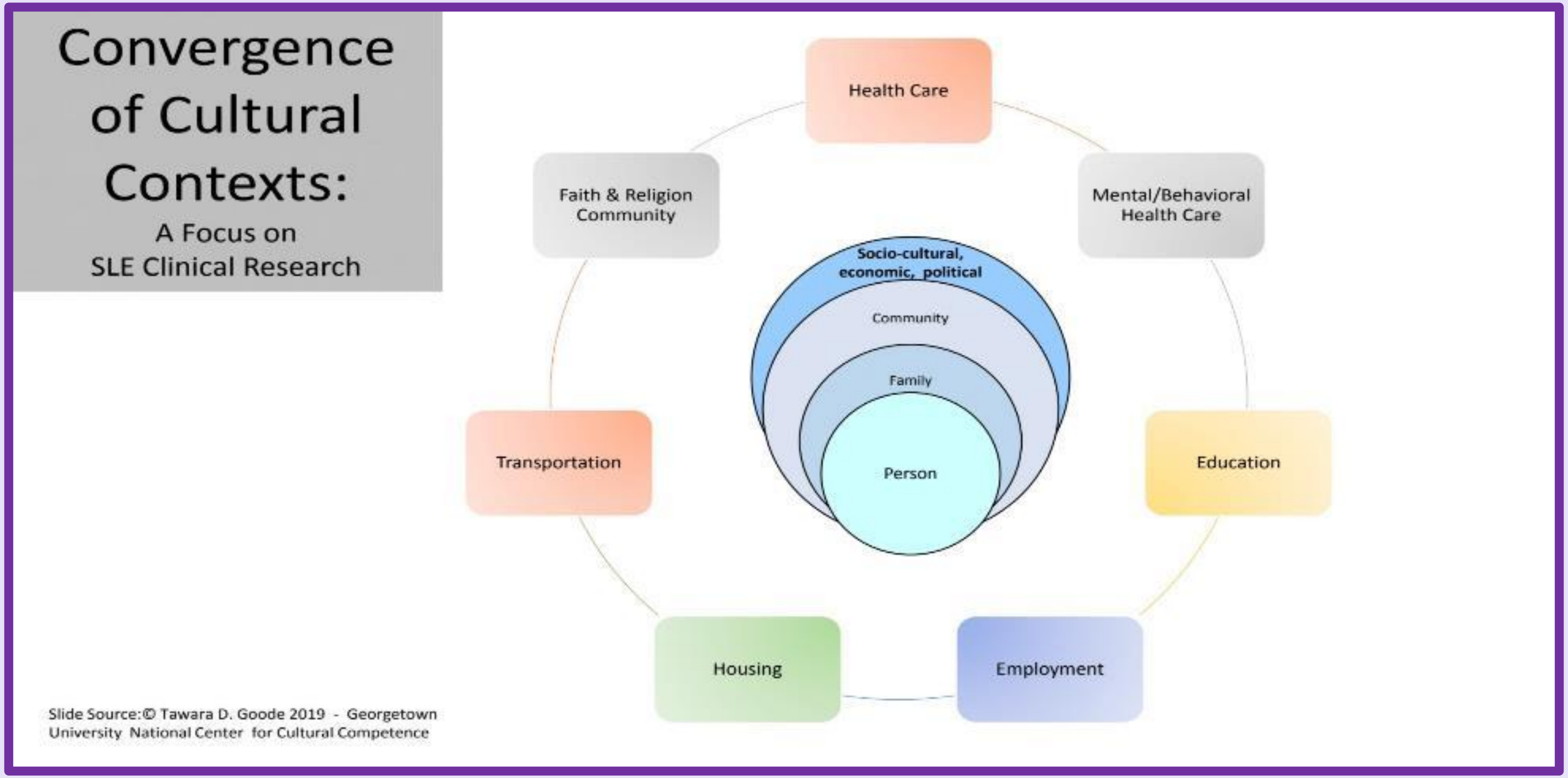
Spiritual
- Connecting with community
- Promoting mindfulness
- Peaceful self-acceptance

Psychological
- Professional counseling
- Re-directing self-esteem/sense of self-worth

Jasemi M, et al. Indian J Palliat Care. 2017 Jan-Mar;23(1):71-80

We All Experience the World Through Culture: This Impacts Care





Convergence of Cultural Contexts:

A Focus on
SLE Clinical Research

Health Care

Mental/Behavioral Health Care

Education

Employment

Housing

Transportation

Faith & Religion Community

Socio-cultural, economic, political

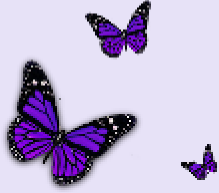
Community

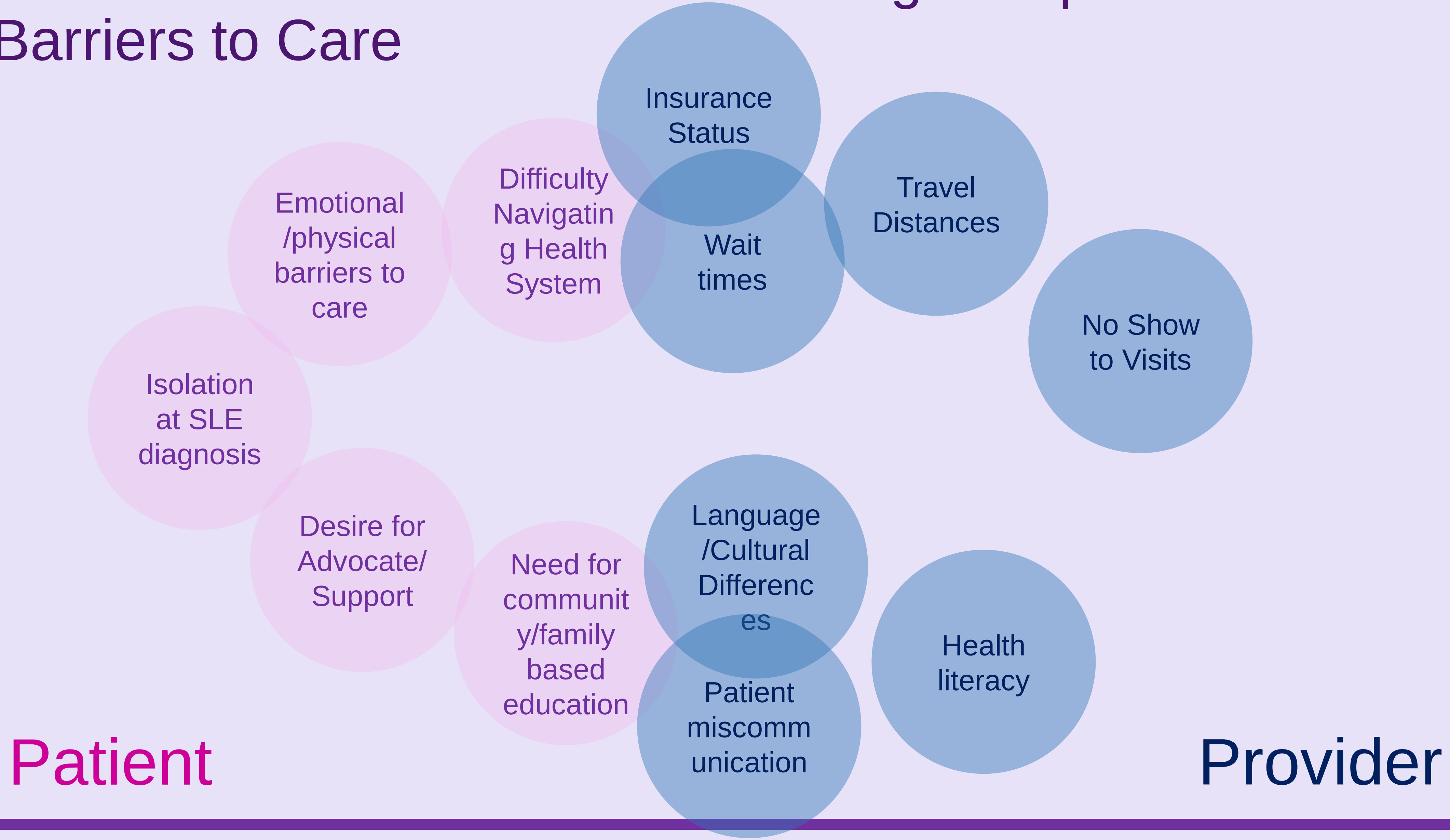
Family

Person

Slide Source:© Tawara D. Goode 2019 - Georgetown University National Center for Cultural Competence

Patient and Providers have Differing Perspectives on Barriers to Care





Emotional /physical barriers to care

Difficulty Navigating Health System

Isolation at SLE diagnosis

Desire for Advocate/ Support

Need for community/family based education

Insurance Status

Wait times

Travel Distances

No Show to Visits

Language /Cultural Differences

Patient miscommunication

Health literacy

Patient

Provider

Feldman et al. J Clin Rheumatol 2013; 19(7):361-6.

Self-Reported Experiential Racism Associates with Decreased Health Services Utilization

- Meta analysis of 70 studies reporting quantitative associations between self-reported racism and healthcare service utilization
- Experiencing racism associated with
  - Negative patient experiences (OR = 0.35 CI: [0.24-0.52])
  - Delay in seeking healthcare (OR = 0.43 CI: [0.36-0.52])
  - Treatment uptake/adherence (OR = 0.70 CI: [0.54-0.91])

(Ben, Cormack et al. 2017)

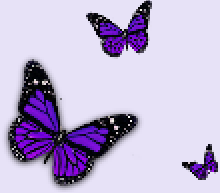
Hurried Provider Communication Associates with SLICC Damage Accrual in African American SLE Patients

- Single-center cross sectional study of provider communication, self efficacy for medication management, and patient-reported health status across race and ethnicity
- 121 participants (36% White, 64% African American)

	All (n=121)		White		African American	
Variable	OR	95% CI	OR	95% CI	OR	95% CI
Age (per 1 year)	**1.05**	**1.0-1.1**	**1.2**	**1.1-1.3**	1.0	0.9-1.1
Hurried Communication	**2.47**	**1.2-4.9**	1.6	0.5-5.2	**2.7**	**1.1-7.1**
Hypertension	**2.96**	**1.2-7.5**	-	-	0.9	0.3-3.1

Table adapted from (Sun, Eudy et al. 2021)

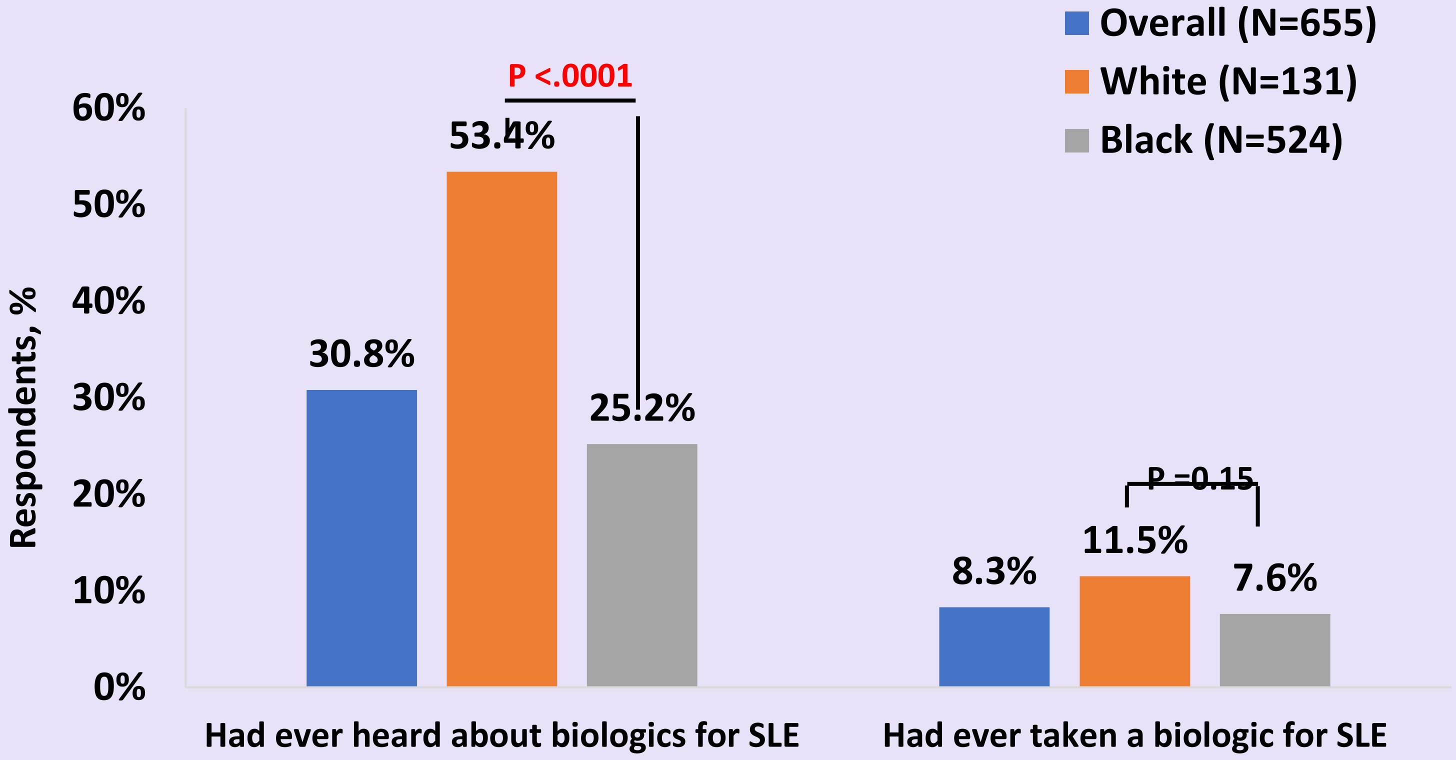
Communicating Treatment Options: SLE Patients of Color are Less Aware of Biologics



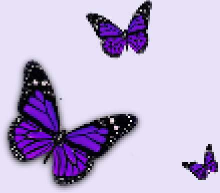
SLE disproportionately impacts *women of color*

However, providers were less likely to ensure patients of color were aware of all treatment options--including novel biologic therapies.

Cross-sectional Survey of Patients with SLE, 2014-2015



Lim SS, et al. *Lupus Science & Medicine* 2019;6:e000322.



Polling Question

- Which of the following are barriers to SLE diagnosis?
  A. SLE presents with different symptoms that may change over time, which makes diagnosis more difficult
  B. SLE does not have validated diagnostic criteria, so rely on physicians to make diagnosis
  C. SLE may co-present with other autoimmune diseases, so symptoms must be attributed to the correct disease state
  D. SLE disproportionately affects demographics with less healthcare access
  E. All of the above

Several Barriers to SLE Diagnosis may be Compounded by Bias

Diagnosis

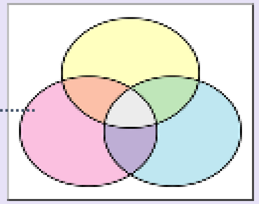
SLE diagnostic criteria are variable and created for research. A physician’s diagnosis is the gold standard.

Access to Care

SLE disproportionately affects demographics with less healthcare access

Symptom Variability

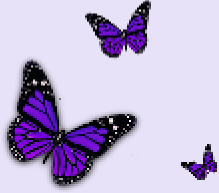
SLE symptoms vary from patient to patient, and within the same patient over time



Co-Presentation

Autoimmune diseases may present in combination. SLE commonly overlaps with rheumatoid arthritis, Sjogren’s syndrome, or fibromyalgia.

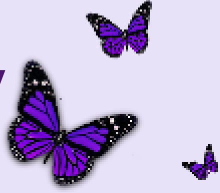
Time to SLE Diagnosis in Delayed in Ethnic Minorities



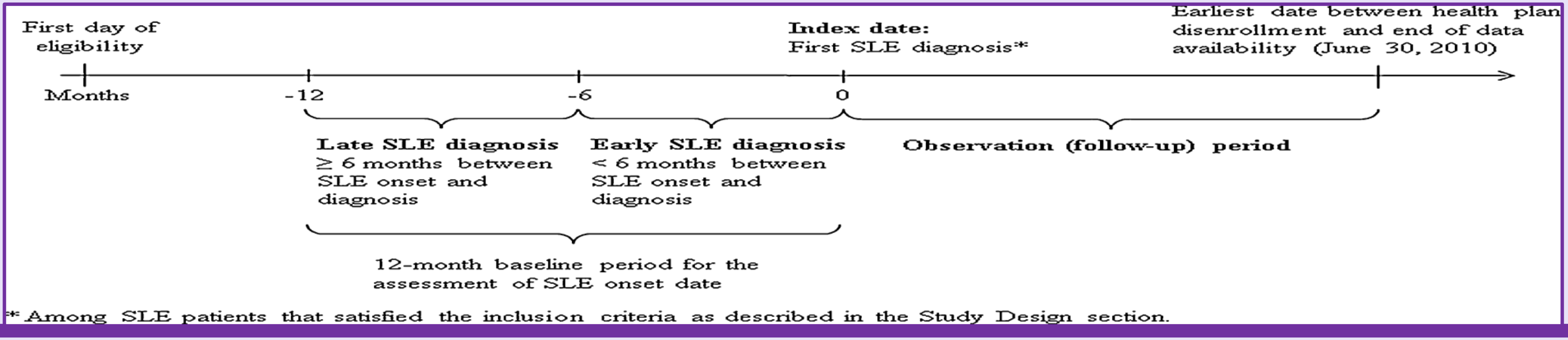
- UCSF CLUES cohort data (196 SLE patients) found that a longer time to SLE diagnosis associated with:
  - African American or Asian race
  - Lower educational attainment
  - Lower socioeconomic status
- Minorities tended to wait over 1 year to receive a diagnosis
- Asian and African American SLE patients were less likely to see a specialist within 3 months (92% of European Americans compared to 64% of AA and 66% of Asian Americans)

https://acrabstracts.org/abstract/diagnostic-delays-and-disparities-in-access-to-care-in-systemic-lupus-erythematosus/

SLE Patients Who are Diagnosed Early Experience Fewer Flares



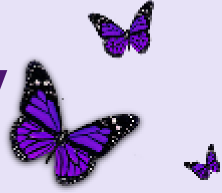
SLE flares	Patients with early SLE diagnosis (*N* = **4,166**)		Patients with late SLE diagnosis (*N* = 4,166)		Rate ratio (95 % CI)	*p* value
	Number of SLE flares	Incidence rate^a (per person-year)	Number of SLE flares	Incidence rate^a (per person-year)		
Any severity	34,136	3.57	37,072	3.75	0.95 (0.94–0.97)	\0.0001
Mild	29,837	3.12	32,615	3.30	0.95 (0.93–0.96)	\0.0001
Moderate	10,316	1.08	11,090	1.12	0.96 (0.94–0.99)	0.0047
Severe	1,677	0.18	1,994	0.20	0.87 (0.82–0.93)	\0.0001



* Among SLE patients that satisfied the inclusion criteria as described in the Study Design section.

Oglesby, et al doi.org/10.1007/s40258-014-0085-x

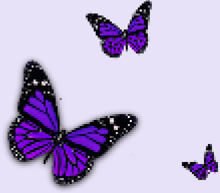
SLE Patients Who are Diagnosed Early Exhibit Fewer Comorbidities



d			
Characteristics	Patients with early SLE diagnosis (N = 4,166)	Patients with late SLE diagnosis (N = 4,166)	p value[a]
SLE-related baseline comorbidities excluded from the CCI[c], n (%)			
Rheumatic disease	2,408 (57.8)	3,500 (84.0)	0.0001
Chronic pulmonary disease	483 (11.6)	681 (16.3)	0.0001
Renal disease	305 (7.3)	411 (9.9)	0.0001
Congestive heart failure	290 (7.0)	386 (9.3)	0.0001
Cerebrovascular disease	233 (5.6)	321 (7.7)	0.0001
Peripheral vascular disease	89 (2.1)	129 (3.1)	0.0060
Acute myocardial infarction	73 (1.8)	94 (2.3)	0.0958
Other SLE-related comorbidities,[c] n (%)			
Hypertension	1,233 (29.6)	1,404 (33.7)	0.0001
Hypothyroidism	560 (13.4)	617 (14.8)	0.0739
Hypercholesterolemia	272 (6.5)	352 (8.4)	0.0009
Osteopenia/osteoporosis	246 (5.9)	586 (14.1)	0.0001

Oglesby, et al doi.org/10.1007/s40258-014-0085-x

Strategies to Assess Communication & Trust Between Patient and Care Team



Patient interviews and surveys suggest the *quality of the communication and relationship with their care team* is a major contributor to treatment plan uptake

Am I being Listened to?	Do I Understand my Health?	Do I Feel Validated?	Do I Feel Respected?	Does my Doctor Show Empathy?
SLE Patients who engage treatment plans give their care teams significantly higher ratings for listening skills	Poor provider communication of clinical findings and treatment expectations create frustration, distrust, and a lack of understanding of treatment importance	Clinician dismissal of patient symptoms and treatment side effects contributes to distrust and a cynical view of treatment effectiveness, leading to less treatment uptake	Perceiving fewer “compassionate respectful” interactions with care teams, especially among Black patients with SLE, associates with less treatment uptake	Feeling cared about by their clinicians is frequently cited as being extremely important to SLE patients and reported more often in those who follow their care plan.

Leung J, et al. *Rheumatol Adv Pract*. 2021;5(1). Sloan M, et al. *Rheumatology*. 2021; keab534; Sun K, et al. *ACR Open Rheumatol*. 2020;2(7):430-437.

Community-Based SLE Support Groups Can Improve Self Efficacy

the lupus initiative
Eliminating Health Disparities in Lupus

HSS

LUPUS™
FOUNDATION OF AMERICA

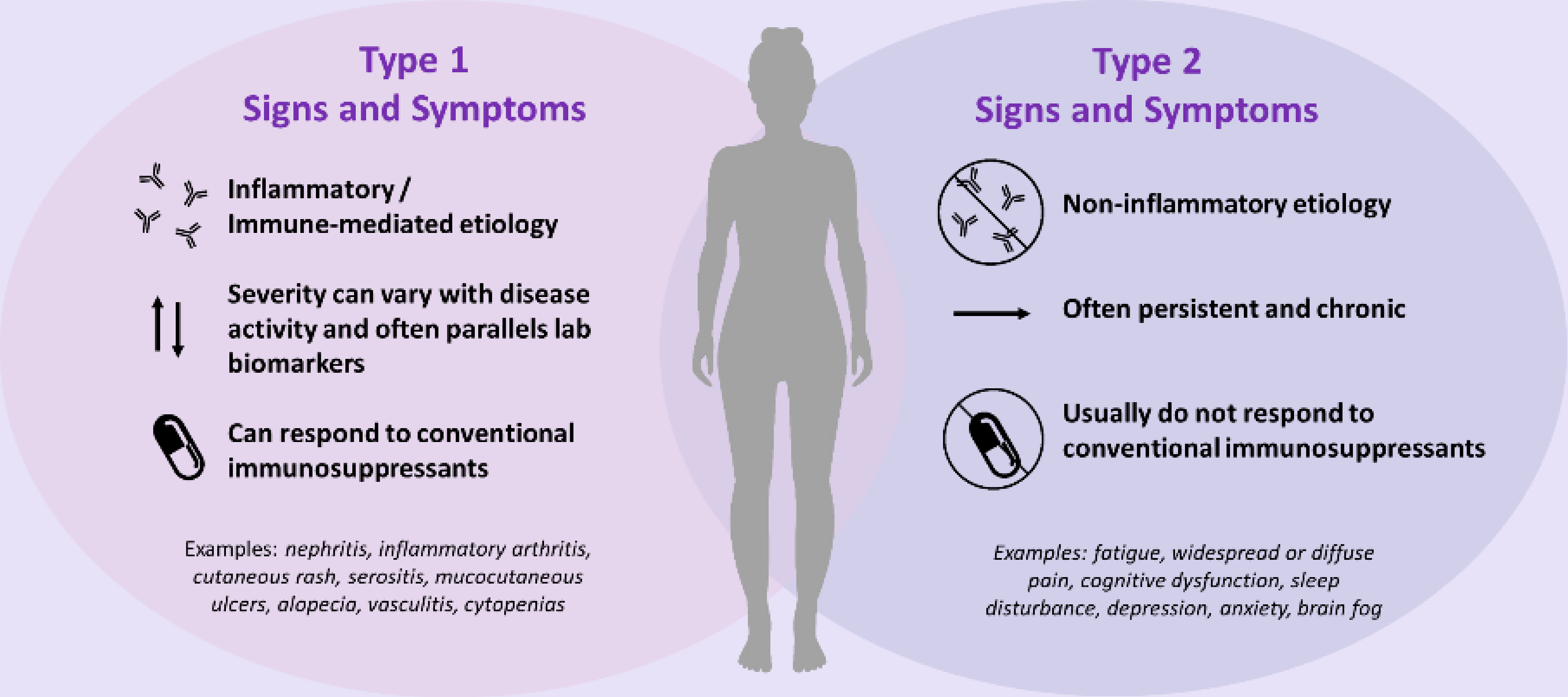
LUPUS IN COLOR
EDUCATE.INSPIRE.ENCOURAGE.INSPIRE
#LUPUSINCOLOR

- LANtern (Lupus Asian Network
- SLE Workshop (monthly education)
- Lupus Line: telephone peer counseling
- Charla de Lupus (Lupus Chat): Peer health education in Spanish
- Teen and Parent Lupus Chat Groups

Seeking Solutions: Integrating Physician Care Plan and Patient Preferences with Shared Decision-Making

Shared Decision-Making (SDM)

A *collaborative process* that allows patients and their providers to *make health care decisions together*, taking into account the best *scientific evidence* available as well as the *patient's values and preferences*



Type 1 Signs and Symptoms

- **Inflammatory / Immune-mediated etiology**
- **Severity can vary with disease activity and often parallels lab biomarkers**
- **Can respond to conventional immunosuppressants**

Examples: *nephritis, inflammatory arthritis, cutaneous rash, serositis, mucocutaneous ulcers, alopecia, vasculitis, cytopenias*

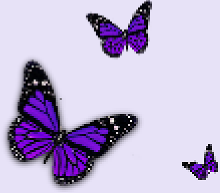
Type 2 Signs and Symptoms

- **Non-inflammatory etiology**
- **Often persistent and chronic**
- **Usually do not respond to conventional immunosuppressants**

Examples: fatigue, widespread or diffuse pain, cognitive dysfunction, sleep disturbance, depression, anxiety, brain fog

Pisetsky DS, et al. Arthritis Care Res. 2019;71(6):735-741

Our Patients Are Using Complementary/Alternative Medicine



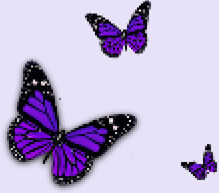
- A cohort study: 707 SLE patients
  - Canada
  - United States
  - United Kingdom
- 49.8% of patients reported using alternative medicine
- Characteristics of alternative medicine users:
  - Younger
  - Better educated
  - **Poorer self-rated health status**
  - **No difference in SLE disease activity (SLAM)**

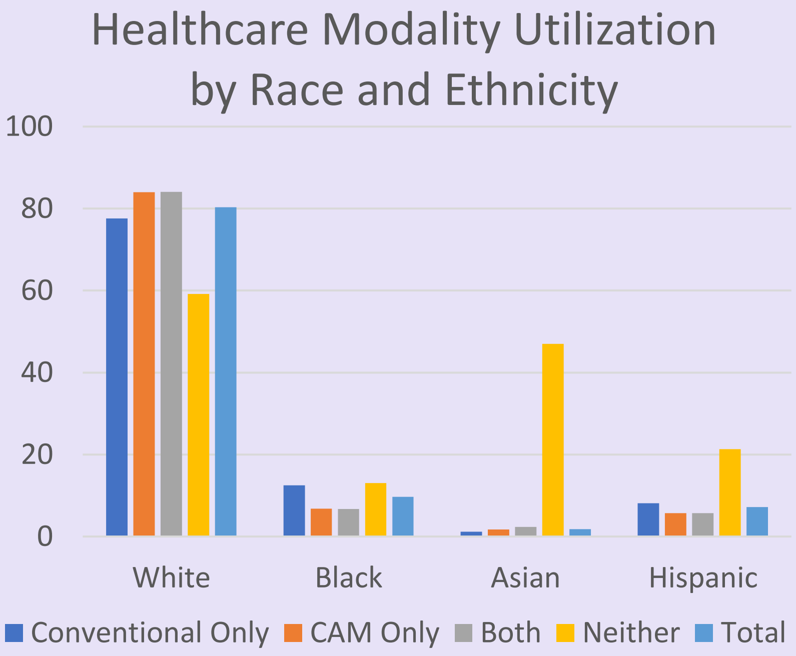
	Canada (n = 229)	**United States (n = 267)**	**United Kingdom (n = 211)**
Relaxation techniques	51 (22.3)	71 (26.6)	45 (21.3)
Massage	36 (15.7)	52 (19.5)	40 (19)
Herbal medicine	28 (12.2)	28 (10.5)	32 (15.2)
Lifestyle diets	26 (11.4)	41 (15.4)	27 (12.8)
Self-help groups	21 (9.2)	29 (10.9)	10 (4.7)
Imagery	18 (7.9)	26 (9.7)	7 (3.3)
Folk remedies	18 (7.9)	10 (3.7)	4 (1.9)
Spiritual healing	16 (7)	39 (14.6)	14 (6.6)
Chiropractic	15 (6.6)	13 (4.9)	4 (1.9)
Megavitamin therapy	14 (6.1)	14 (5.2)	10 (4.7)
Homeopathy	14 (6.1)	6 (2.2)	13 (6.2)
Energy healing	11 (4.8)	6 (2.2)	6 (2.8)
Commercial weight loss	8 (3.5)	18 (6.7)	14 (6.6)
Biofeedback	8 (3.5)	10 (3.7)	0 (0)
Acupuncture	7 (3.1)	3 (1.1)	8 (3.8)
Hypnosis	3 (1.3)	3 (1.1)	3 (1.4)
Other	10 (4.4)	8 (3)	13 (6.2)
Total	**116 (50.7)**	**134 (50.2)**	**102 (48.3)**

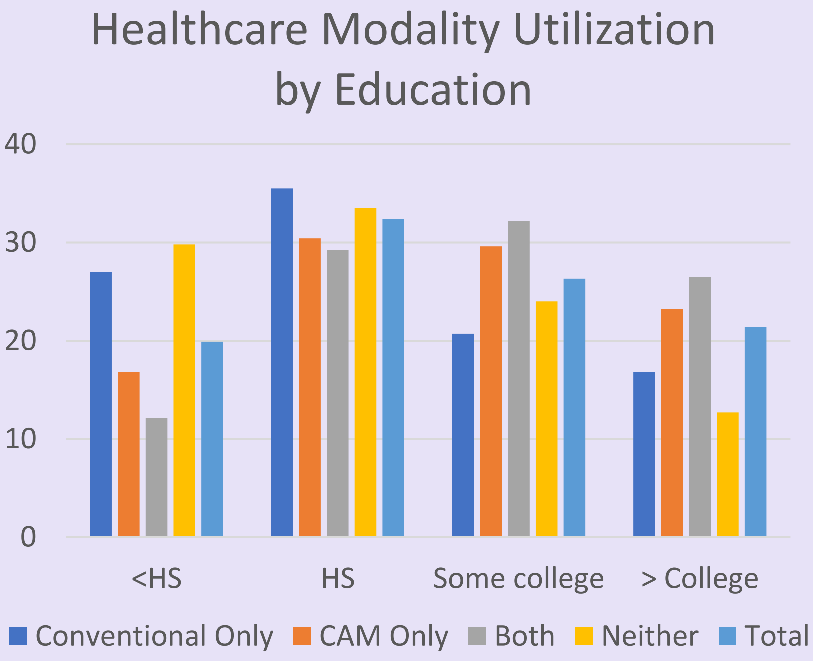
* The total refers to all patients using at least 1 alternative therapy. Values are the number (%) of patients. SLE = systemic lupus erythematosus.

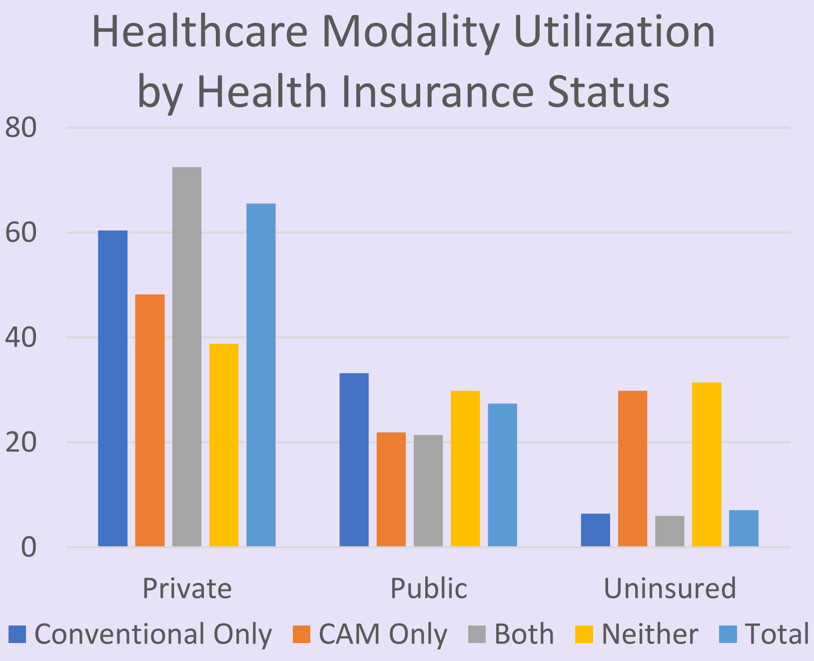
Moore AD, et al. Arthritis Rheum. 2000 Jun;43(6):1410-8

Race/Ethnicity, Education, and Health Insurance Status Influence CAM Use




Healthcare Modality Utilization by Race and Ethnicity


Healthcare Modality Utilization by Education


Healthcare Modality Utilization by Health Insurance Status

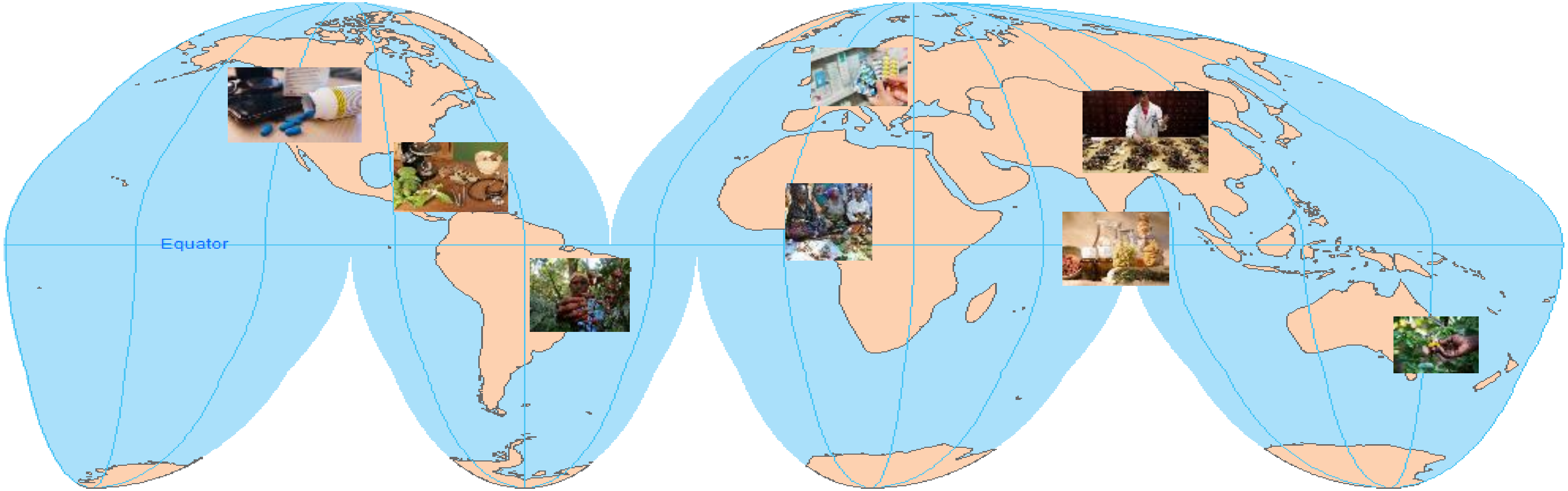
OR: Neither Treatment Modality vs White
Black: 2.44*
Asian: 3.26*
Hispanic: 3.91***

OR: Conventional Alone vs Both
HS degree or equivalent: 1.71***
<High school degree: 2.43***

OR: CAM alone vs Both
Public insurance 1.99
Uninsured: 7.77***
OR: Neither Treatment vs Both
Public insurance 1.44
Uninsured: 4.06*

Hoerster KD, et al. Prev Med. 2012 Jan;54(1):13-7.

The World Health Organization is Recognizing and Classifying Traditional Medicine



Concept: When we dismiss a patient’s complementary care plan, we risk dismissing their culture

Strategies to Incorporate CAM Into the Treatment Plan

- Keep an open mind to allow patients to freely communicate their CAM strategies
- Educate yourself on basic evidence-based CAM modalities
  - Acupuncture
  - Supplements
  - Dietary strategies
  - Exercise
  - Mindfulness practices
- Familiarize yourself with local complementary medicine practitioners

Antimalarials (hydroxychloroquine) were originally derived from the bark of the Peru-native Cinchona tree

Acupuncture is an Evidence-Based Treatment for Type-2 SLE Symptoms

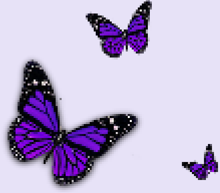
- Meta-analysis of 29 RCTs
  - Acupuncture decreased OA pain scores 0.57 SDs compared to controls
- Meta analysis of 12 RCTs
  - Acupuncture was significantly better than sham acupuncture or placebo for relieving fibromyalgia pain and improving PRO quality of life scores
- Insurance covers for headache, nausea, back pain, stress/anxiety, arthritis pain

Evidence-Based Nutrition as Adjunct to SLE Therapy Plan

	Vitamin D	Omega 3 FA	Curcumin	Anti-oxidants (C/E
Dietary Sources	Salmon, egg yolks, mushrooms, milk	Mackerel, salmon, walnuts, flax/chia seed	Turmeric, curry powder, mango ginger	Dark chocolate, pecans, blueberries, kale, beans
Evidence Level	Observational trails 5 RCTs	2 RCTs 24 weeks (52pts and 60pts)	Iranian study of refractory LN 3-month RCT 24 patients	Observational trails (Japanese 241 women X4 years & Hong Kong 39 women X 12 weeks)
Benefit	• Decreased PRO fatigue scores • ↑serum vit D = ↓SLEDAI • Bone health w/Ca^{2+}	• Sig reduction in SLAM-R at week 24 • Improved FMD (endothelial function) at 12 and 24 weeks • Improved BILAG	500mg turmeric TID with SOC associated with decreased proteinuria and lower SBP **small sample size	• ↑Intake associated with ↓SLE activity • 500mg vit C/800mg vit E improved oxidative stress (MDA levels) but not FMD

Greco CM, et al. Curr Rheumatol Rep. 2013 Nov;15(11):378.

Evidence-Based Mind/Body Practices for SLE

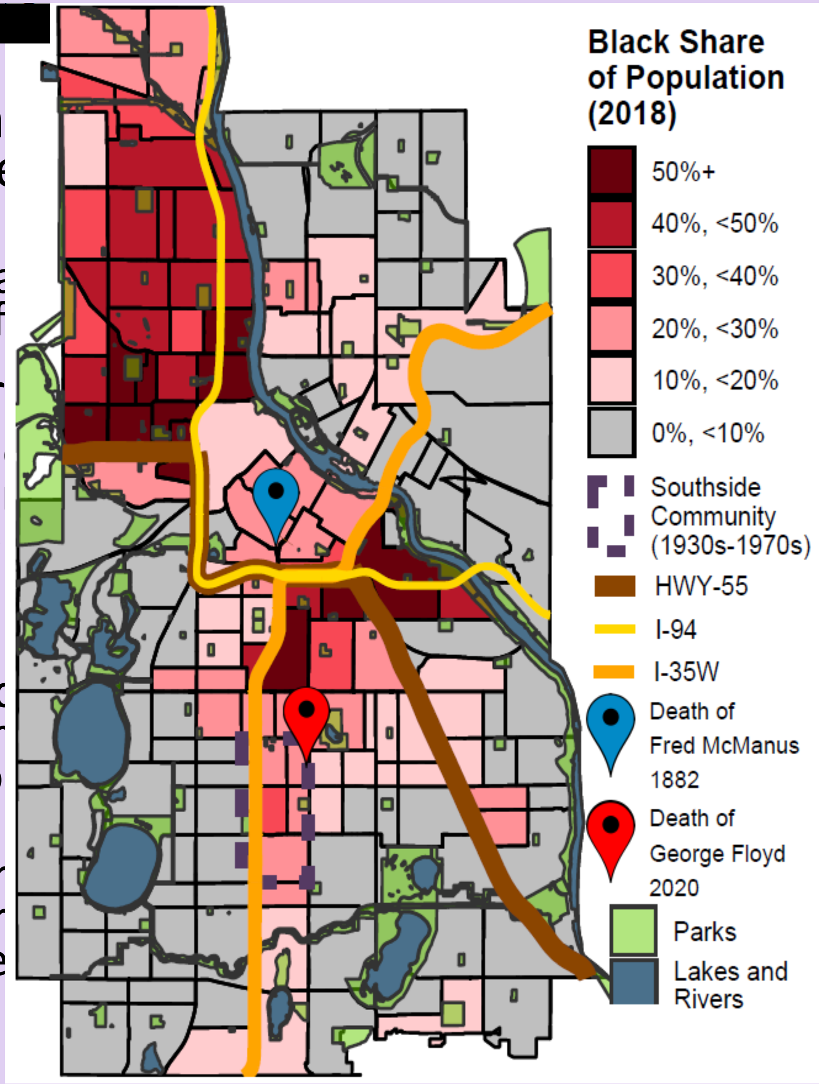


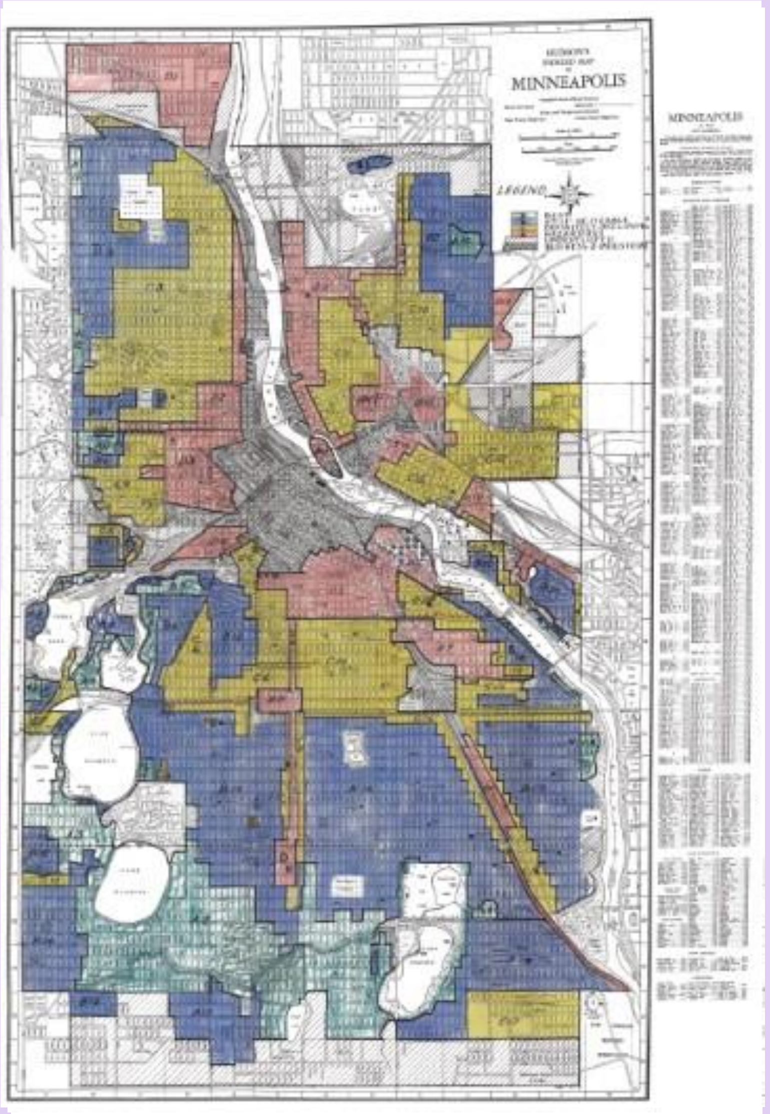
	Group Psychoeducation	Cognitive Behavioral Therapy	Mindfulness Based Stress Reduction	Tai chi
Modality	8-week group psychoeducational course: The Chronic Disease self-management Program	Psychological intervention with strong evidence for depression and anxiety	Mindfulness is the cultivation of conscious awareness and attention in the moment with no judgement	Traditional Chinese mind/body practice combining meditation, breathing, and gentle movements
Evidence Level	Uncontrolled pilot study, 17 low-income SLE patients	RCT of 45 SLE patients reporting high stress 10 weekly group CBT vs usual care	26 SLE patients randomized to MBSR or a waitlist. Evaluated pre-post, and 6 months	RCT of 226 adults with fibromyalgia. 24 weeks Tai chi or supervised exercise
Benefit	• 60% reported significant physical and cognitive improvement • Increased self-efficacy for managing SLE	• Reduced stress perceptions • Reduced depressive symptoms • CBT+ Biofeedback= reduced pain/improved body awareness	• Improved quality of life perception • Decreased pain scores • Decreased SLE-related shame	• All exercise improved fibromyalgia impact questionnaire (FIQR) • Tai Chi > exercise • Once weekly = twice weekly Tai Chi

Greco CM, et al. Curr Rheumatol Rep. 2013 Nov;15(11):378; Taub R, et al. *J. Clin. Med.* **2021**, *10*, 4450; Wang C, etg al. *BMJ.* 2018;360:k851.

Neighborhood Segregation and the Legacy of Redlining Impacts Health Outcomes

- Under the New Deal, the Nationa
FHA, which regulated mortgage te
access to homeownership.
  - FHA underwriting manual made ra
home's neighborhood an explicit f
- In the late 1930's, HOLC created r
  - **Best**: "where good mortgage lend
make their maximum loans . . . pe
  - **Still Desirable**: "neighborhoods w
a tendency to hold commitments
65% of appraisal.
  - **Definitely Declining**: characterized
lower grade population." "Good m
conservative in . . . C areas and ho
ratio for the A and B areas."
  - **Hazardous**: "characterized by detr
degree, undesirable population or
"refuse to make loans in these are

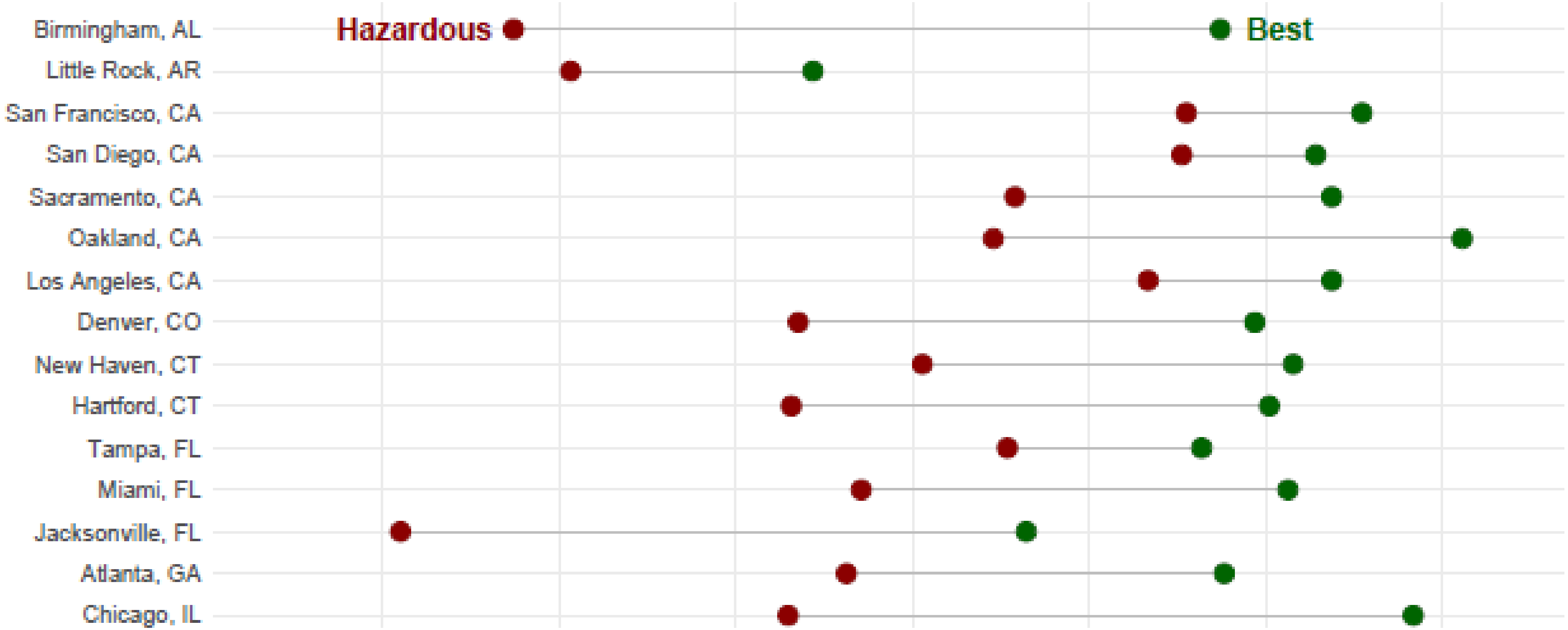


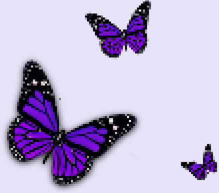


Adapted from presentation: Raymond Givens MD

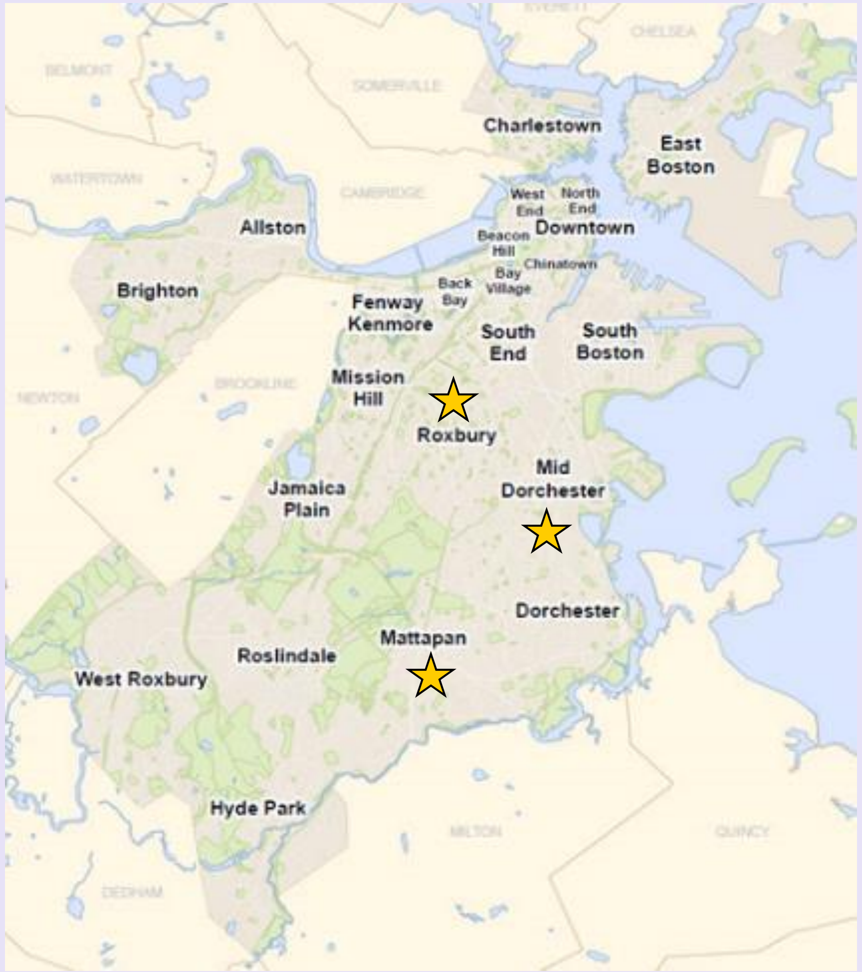
Adapted from presentation: Raymond Givens MD

Life Expectancy Deficits for Redlined Neighborhoods



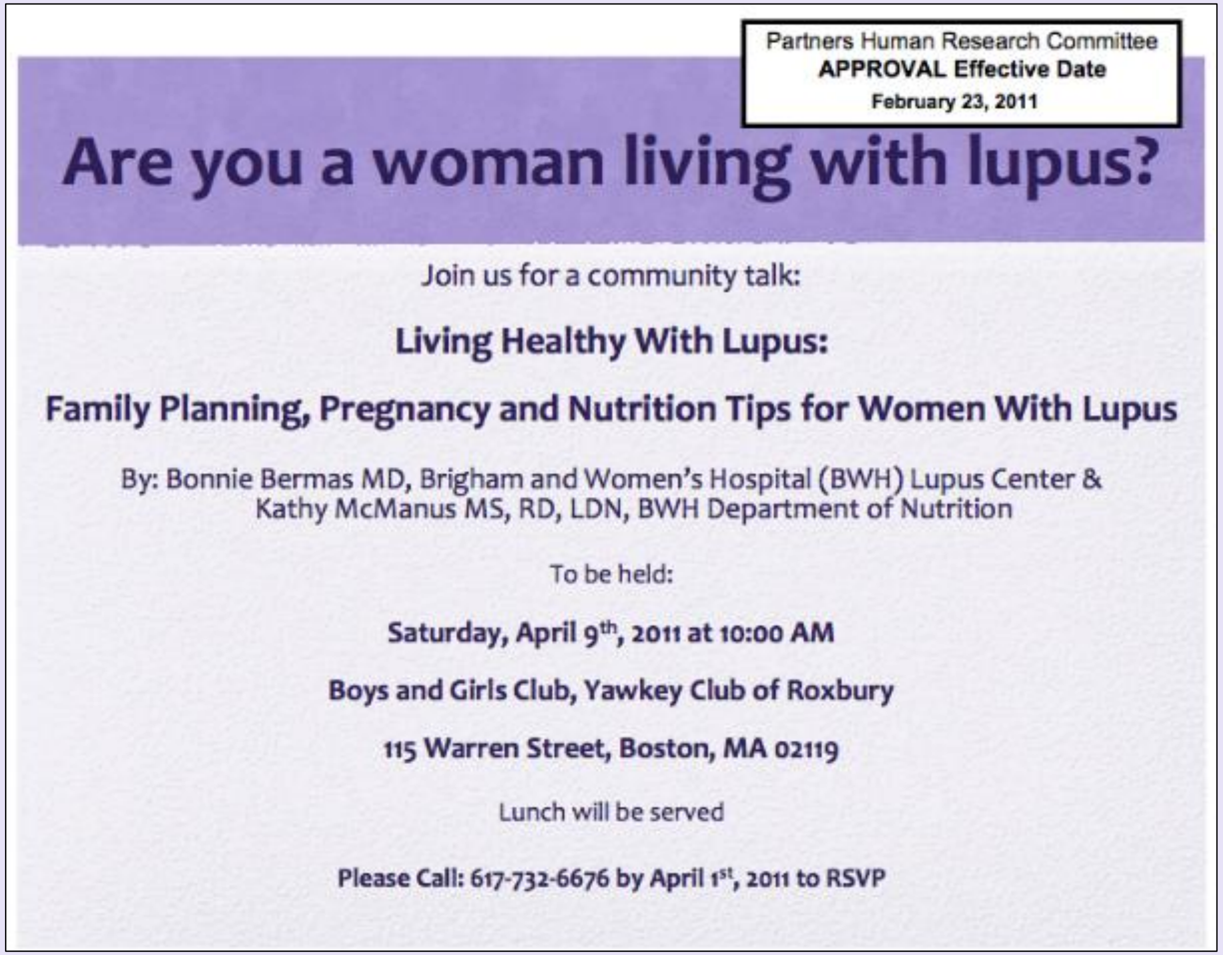


Patient perspectives



- Recruited 29 women with SLE living in federally-defined medically underserved areas (MUAs) to participate in two educational seminars and focus groups
- MUA: few health providers, high infant mortality, high poverty and high elderly population
- Predominantly African-American, urban communities
- 70% of households low-moderate income level

Feldman et al. Lupus 2013; 22(1): 52-62



Partners Human Research Committee
APPROVAL Effective Date
February 23, 2011

Are you a woman living with lupus?

Join us for a community talk:

Living Healthy With Lupus:

Family Planning, Pregnancy and Nutrition Tips for Women With Lupus

By: Bonnie Bermas MD, Brigham and Women's Hospital (BWH) Lupus Center &
Kathy McManus MS, RD, LDN, BWH Department of Nutrition

To be held:

Saturday, April 9th, 2011 at 10:00 AM

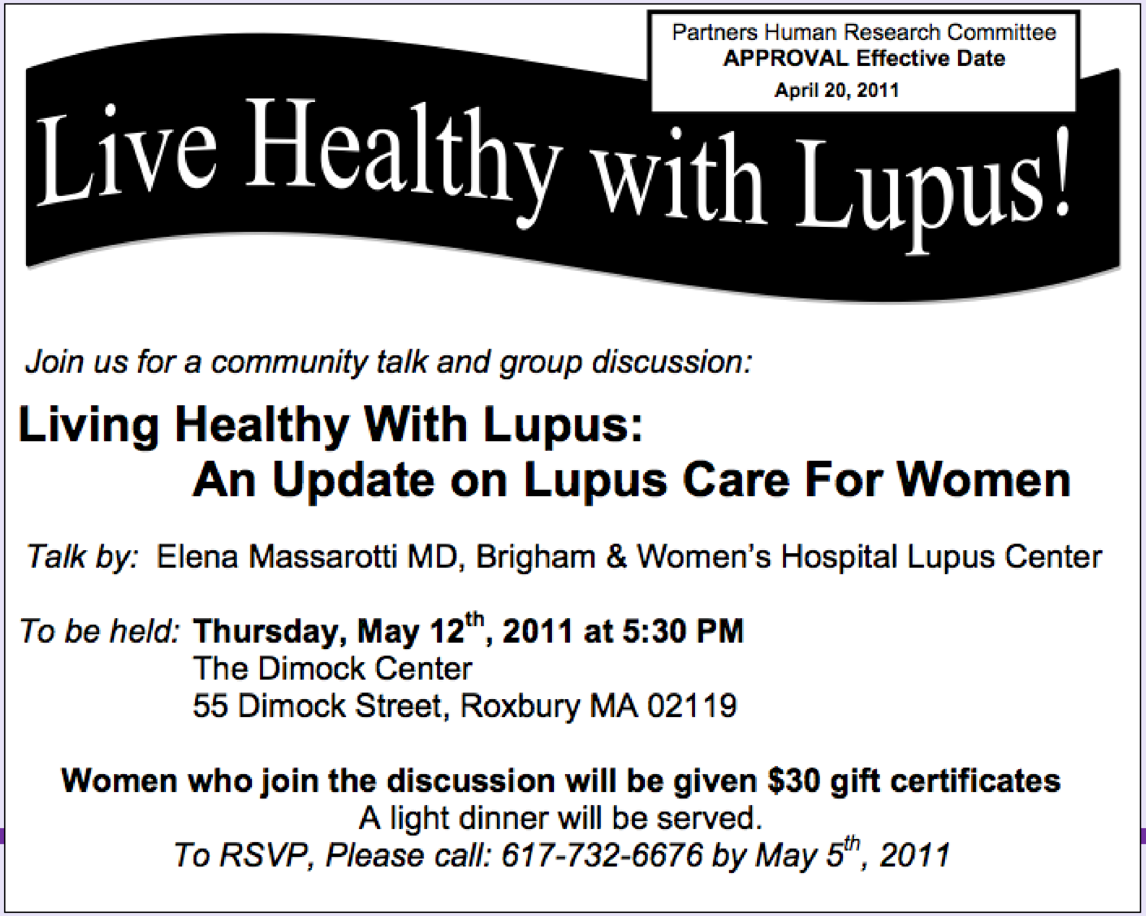
Boys and Girls Club, Yawkey Club of Roxbury

115 Warren Street, Boston, MA 02119

Lunch will be served

Please Call: 617-732-6676 by April 1st, 2011 to RSVP

BOYS & GIRLS CLUBS
OF BOSTON



Partners Human Research Committee
APPROVAL Effective Date
April 20, 2011

Live Healthy with Lupus!

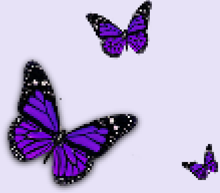
Join us for a community talk and group discussion:

Living Healthy With Lupus:
An Update on Lupus Care For Women

Talk by: Elena Massarotti MD, Brigham & Women's Hospital Lupus Center

To be held: **Thursday, May 12th, 2011 at 5:30 PM**
The Dimock Center
55 Dimock Street, Roxbury MA 02119

Women who join the discussion will be given $30 gift certificates
A light dinner will be served.
To RSVP, Please call: 617-732-6676 by May 5th, 2011

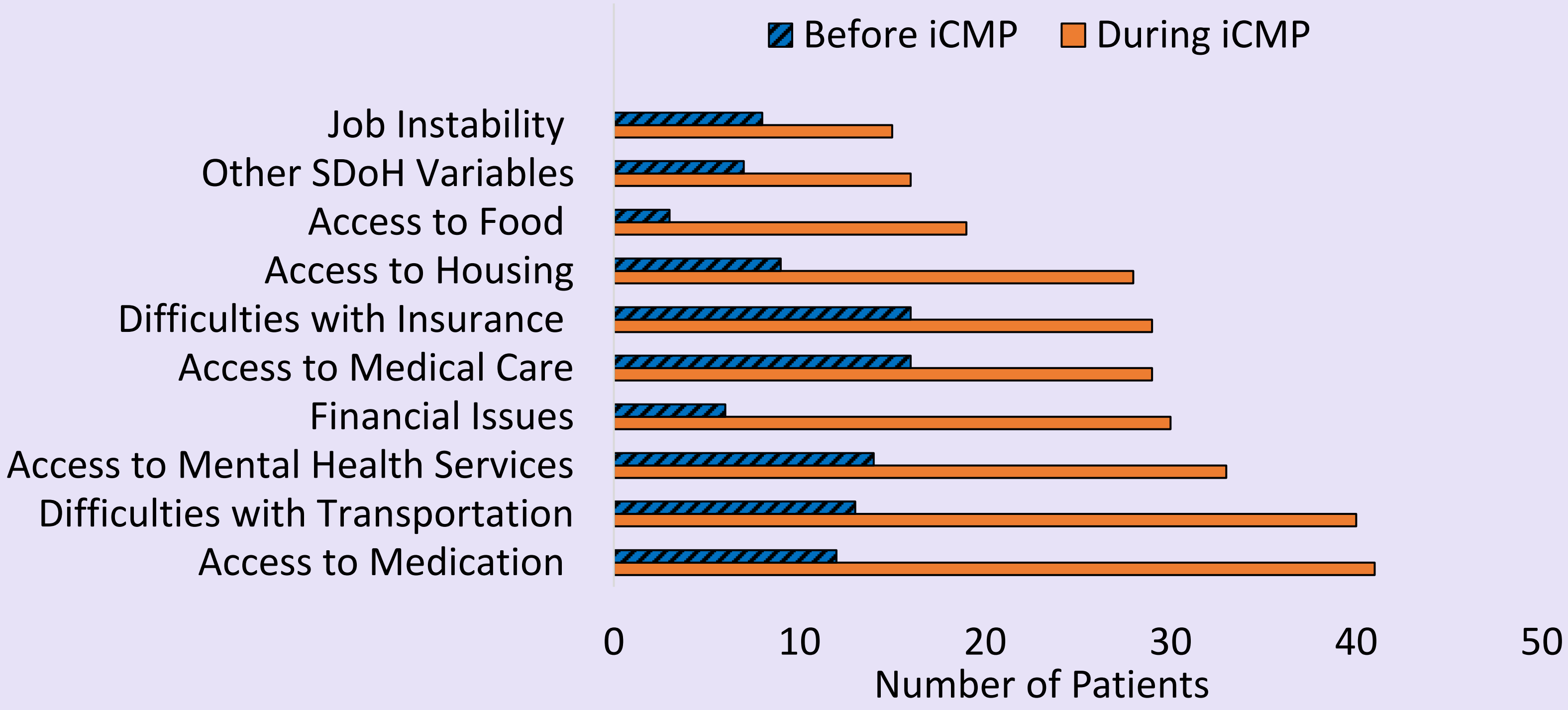


Integrated Care Management Program (iCMP)

- Started in 2006 – enrolls the top 2% of medically and psychosocially complex patients within the Partners Healthcare system
- Uses an algorithm that factors in age, comorbidities, acute care utilization
- Matches patients with a nurse care coordinator in primary care practice
- Nurse conducts needs assessments and matches patients with resources, provides appointment reminders, triages urgent medical issues
- Among Medicare patients, found $125/mo savings among those enrolled vs. non-enrolled and relative risk of ED visits and hospitalizations decreased as length of enrollment in the program increased, also reduced mortality

Hsu et al. Health Affairs 2017

SDoH in High-Risk Lupus Patients

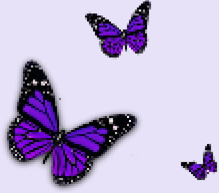


57% with >1 SDoH need pre-iCMP; 95% with >1 need during iCMP

81% had SDoH need addressed by iCMP nurse

Taber, K. et al. ACR Open 2021

Lupus Patients in iCMP Showed Reductions in Acute Care Use



- **ED visits**: 0.14/person-month during iCMP vs. 0.20/person-month pre-iCMP (IRR 0.66, 95% CI 0.48-0.92, p=0.01)
- **Outpatient no-shows**: 0.09/person-month during iCMP vs. 0.14/person-month pre-iCMP (IRR 0.74, 95% CI 0.57-0.97, p=0.03)
- In adjusted analyses (age, sex, race, ethnicity, number of comorbidities, year, and clustering by patient), **37% reduction in the rate of ED visits** during iCMP vs. pre-iCMP (p=0.003), and a trend towards reduced hospitalizations (IRR 0.88, 95% CI 0.65-1.19, p=0.39) and fewer missed appointments (IRR 0.80, 95% CI 0.62-1.04, p=0.097)

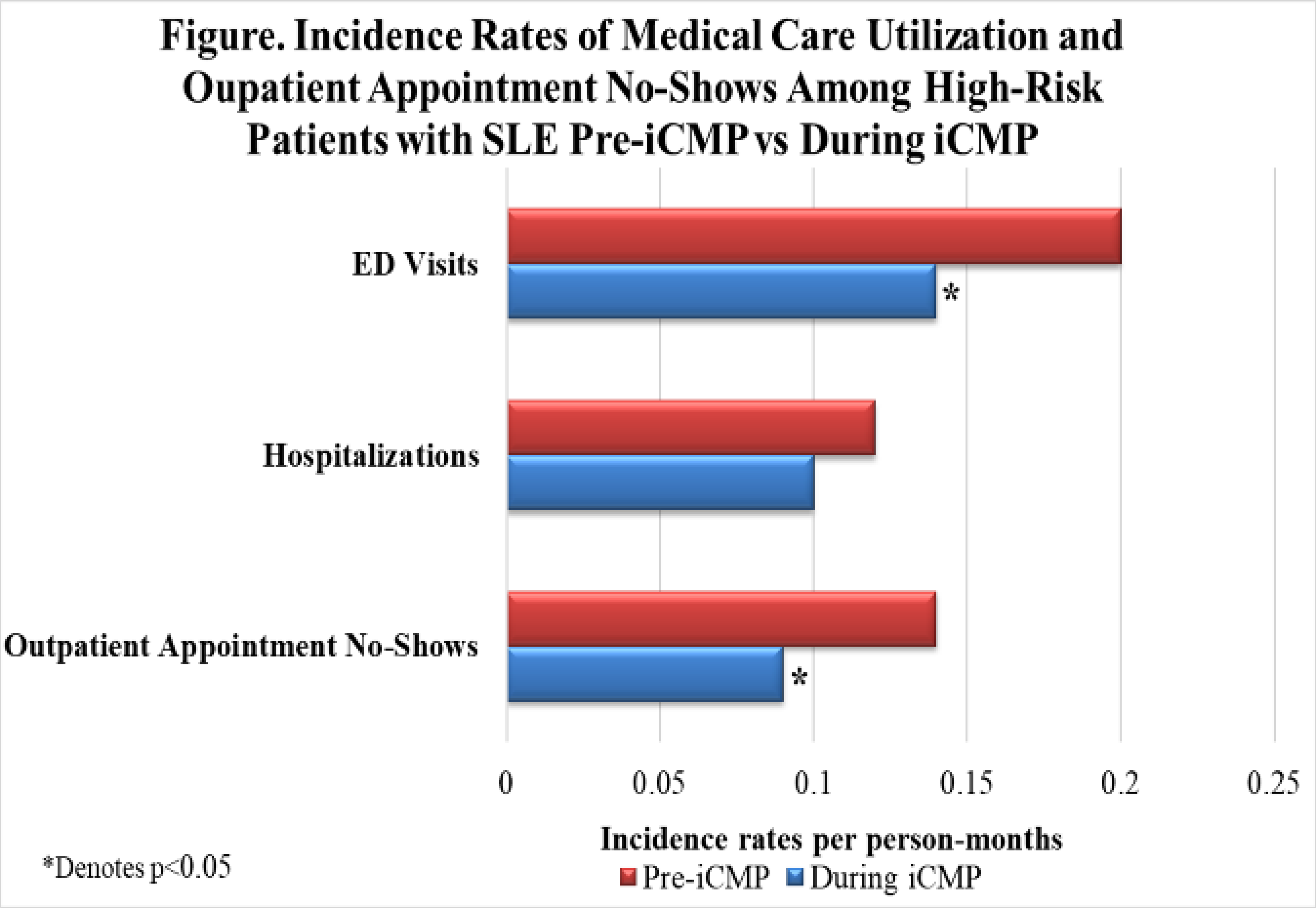


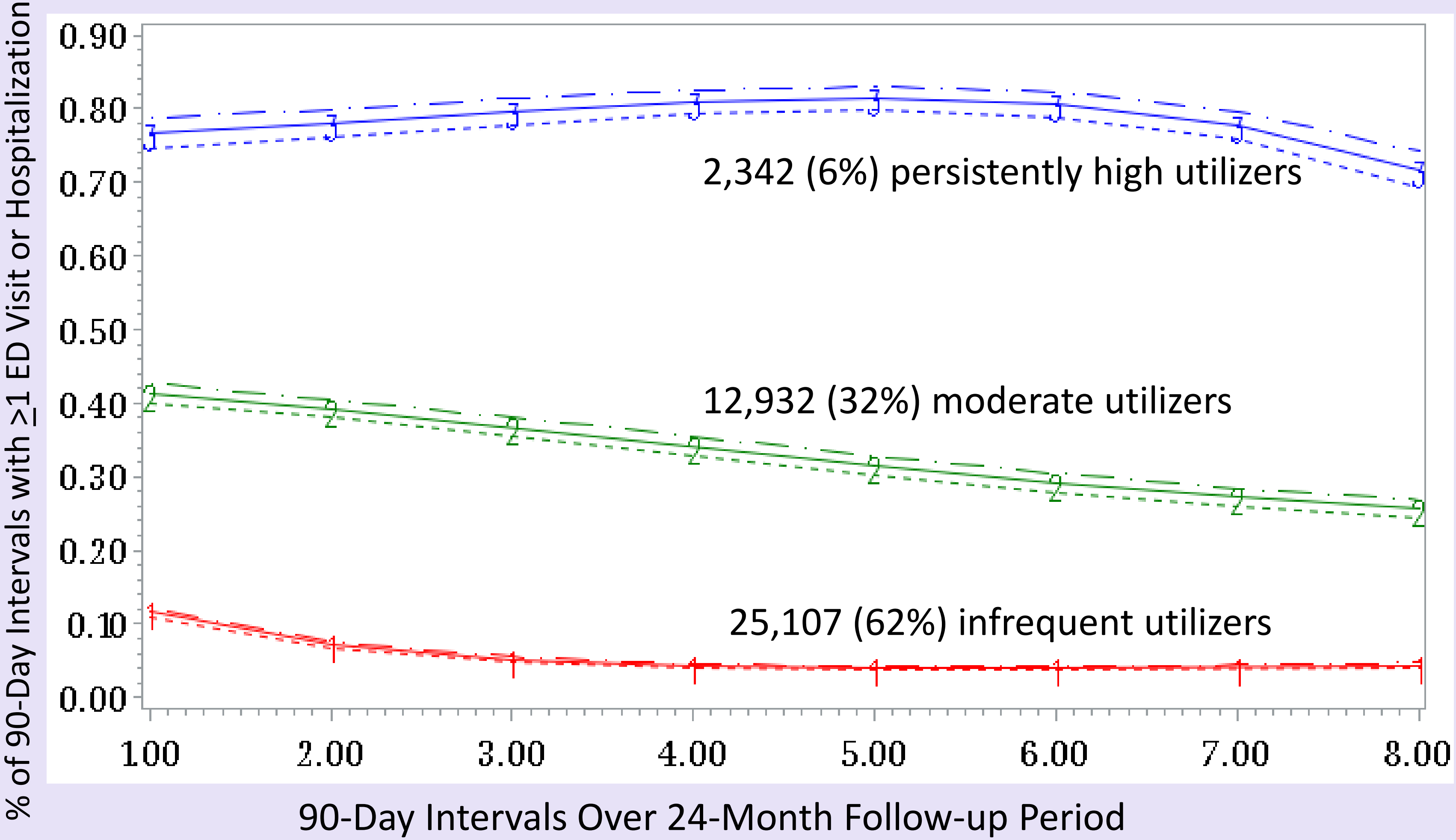
Figure. Incidence Rates of Medical Care Utilization and Oupatient Appointment No-Shows Among High-Risk Patients with SLE Pre-iCMP vs During iCMP

*Denotes p<0.05

Williams et al. ACR Open 2022

Acute Care Use Is Associated with SLE Morbidity and Mortality

- Persistently high use associated with higher mortality, more severe SLE, Black race, chronic pain, depression and cardiovascular disease
- Male sex, older age and hydroxychloroquine use associated with less frequent acute care use



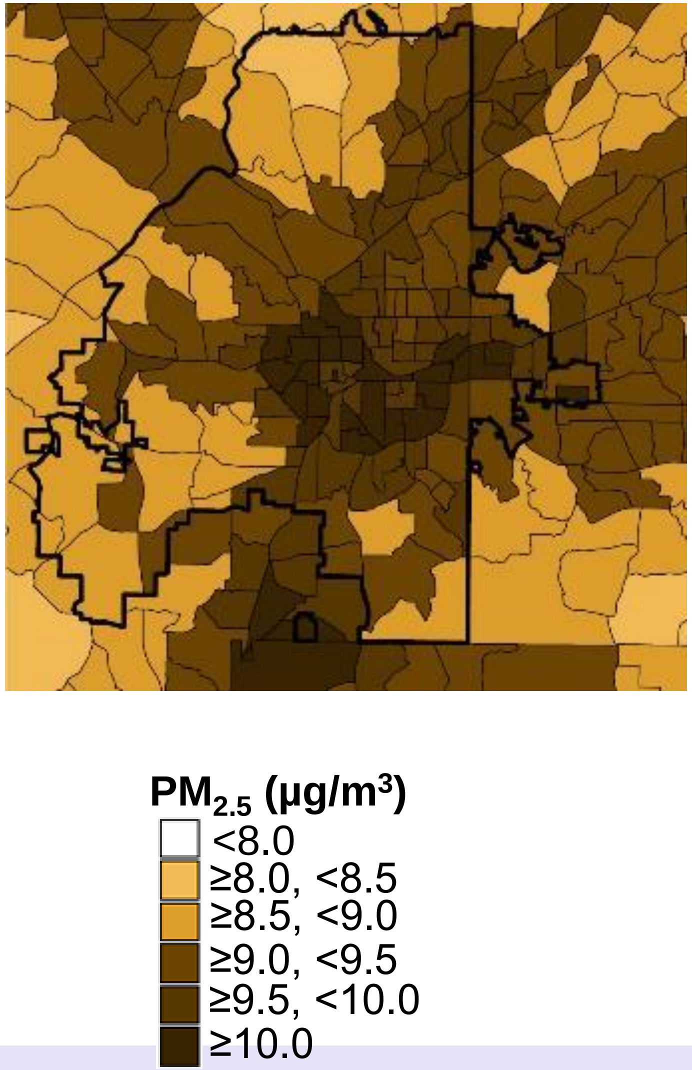
2,342 (6%) persistently high utilizers

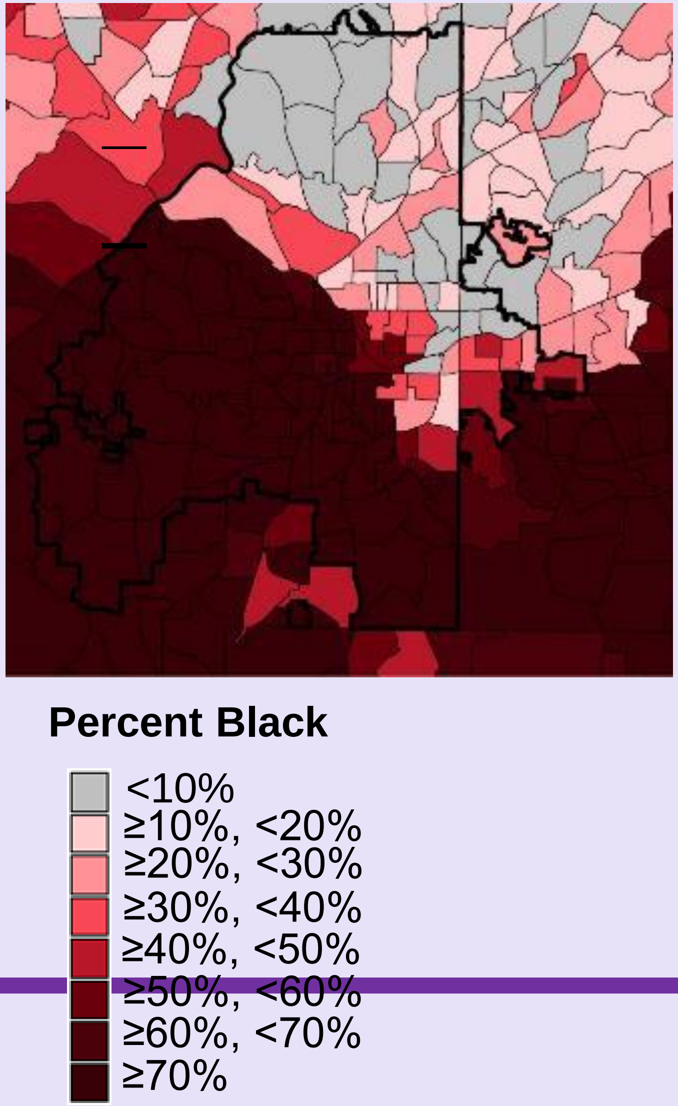
12,932 (32%) moderate utilizers

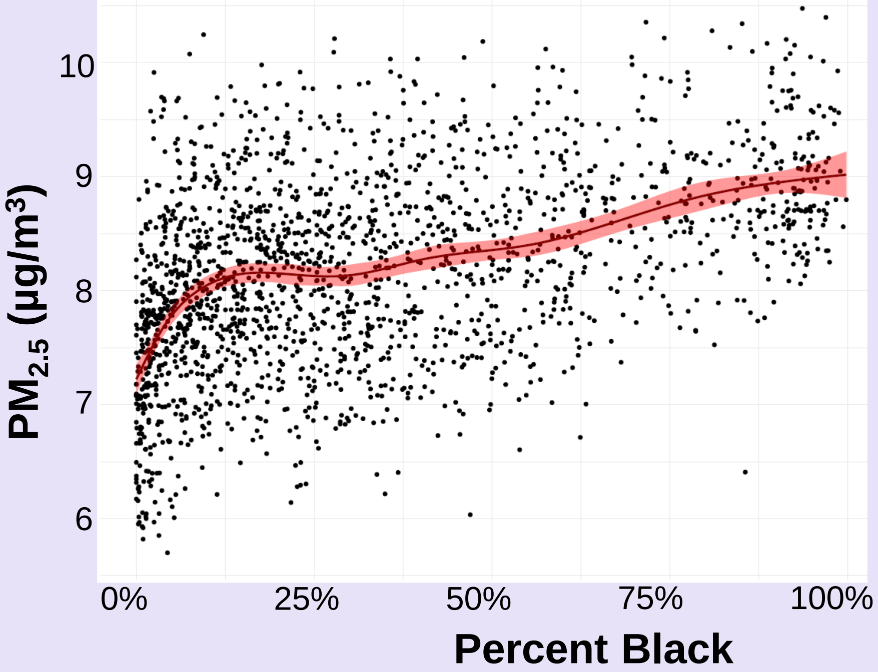
25,107 (62%) infrequent utilizers

Feldman et al. Seminars in Arthritis Rheum 2020

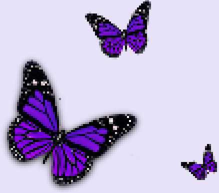
Racial Segregation Results in Adverse Environmental Exposures for Minorities: Atlanta Georgia and $PM_{2.5}$







Environmental Pollutants are Emerging Risk Factors for the Development of SLE and Asthma

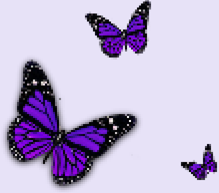


- Chronic PM2.5 exposure results in increased circulating neutrophils and new onset nephritis in SLE-susceptible NZBW mice
- Epidemiologic data draws associations between PM2.5 exposure, asthma risk, SLE prevalence, and autoantibody production
- Every 10-$\mu g/m^3$ increase in $PM_{2.5}$ is associated with a 20% increment in risk of asthma
- Environmental exposures may impart their effects through epigenetic modifications that alter gene expression

The Gap

- Minority Communities suffer disproportionately from chronic illness, such as asthma and SLE, yet the Western healthcare system is not culturally congruent with the patients it serves

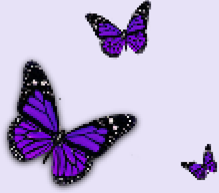
- Frontline communities most affected by environmental pollutants and with least access to healthcare are largely uninformed about chronic diseases



What is Breath is Lyfe?

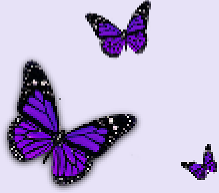
Breath Is Lyfe is an art, music and spoken word movement that brings awareness to the environmental injustices, their causes, and how to take action in our communities.

Breath is Lyfe: Our Goals



- Bring attention to the association between environmental pollution and chronic disease
  - Asthma
  - Systemic lupus erythematosus
- Communicate health information in the language of the people
  - Visual Art
  - Spoken word
  - Dance
- Teach the community about respiratory and immune health
- Provide assistance to chronic illness sufferers
  - Tips for disease control
  - Mind/body techniques such as deep breathing
  - Dissemination of educational materials and resources

The Breath is Lyfe Team is Designed to Impart Scientific Knowledge to Frontline Communities

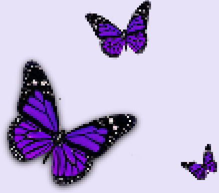


Sunni Patterson	**Cherelle Blazer**	**Ashira Blazer**	**Bionca McCants**
Arts & Culture	**Environmental**	**Medical**	**Mental Health**
Internationally acclaimed poet	Senior director of International Policy, Sierra Club	Assistant Professor of Rheumatology, HSS	Certified psychologist/Group Facilitator
Uses art, poetry, and ancestoral rememberance to promote dialog and spiritual awareness	Educates frontline communities on environmental justice and grass roots organizing	Educates front-line communities on SLE and its relation to social stressors	Facilitates group discussions centered on community mental health


EATH IS
LYFE

The Breath is Lyfe Annual March for the Ancestors: Algiers New Orleans

Reaching Patients of All Backgrounds Requires a Multi-Layered Approach



- **Study**: We must understand the scope of the problem through both qualitative and quantitative research
- **Listen**: We must educate ourselves to understand the unique challenges our patients face
  - Focus groups: Community partnerships→ Lupus Conversations Modules Drs. Feldman and Ramsey-Goldman
  - Online platforms: EMPOWER study sponsored by the OMRF Dr. Joan Merrill
- **Educate**: Provide physicians and trainees with comprehensive education on cultural competence and bias. Dr. Irene Blanco: Medical education equity initiatives
- **Partner**: Understand that discovery in SLE is a two-way communication. We must ensure our patients have agency as advocates, educators, researchers, and true academic partners. Dr. Jillian Rose: Lupus Line
- **Diversify**: Focus on recruitment, equity, and inclusion for diverse rheumatology providers across the field (clinical care and research). Dr. Grace Wright: AWIR outreach

Thank You!!