

Why am I so TIRED?

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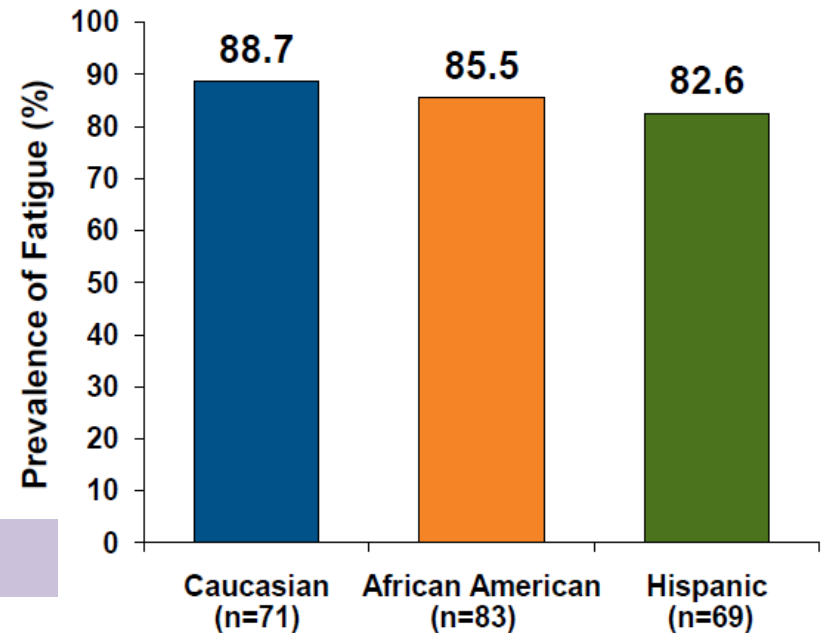
Disclosures

- LupusPRO, LIT: Survey tools for Lupus

Fatigue Is One of the Most Prevalent Clinical Manifestations of SLE

- Fatigue is prevalent across caucasians, African Americans, and Hispanics
- Severity may be related to psychosocial factors and/or disease activity

Prevalence of Fatigue Across Ethnic Groups (N=223)



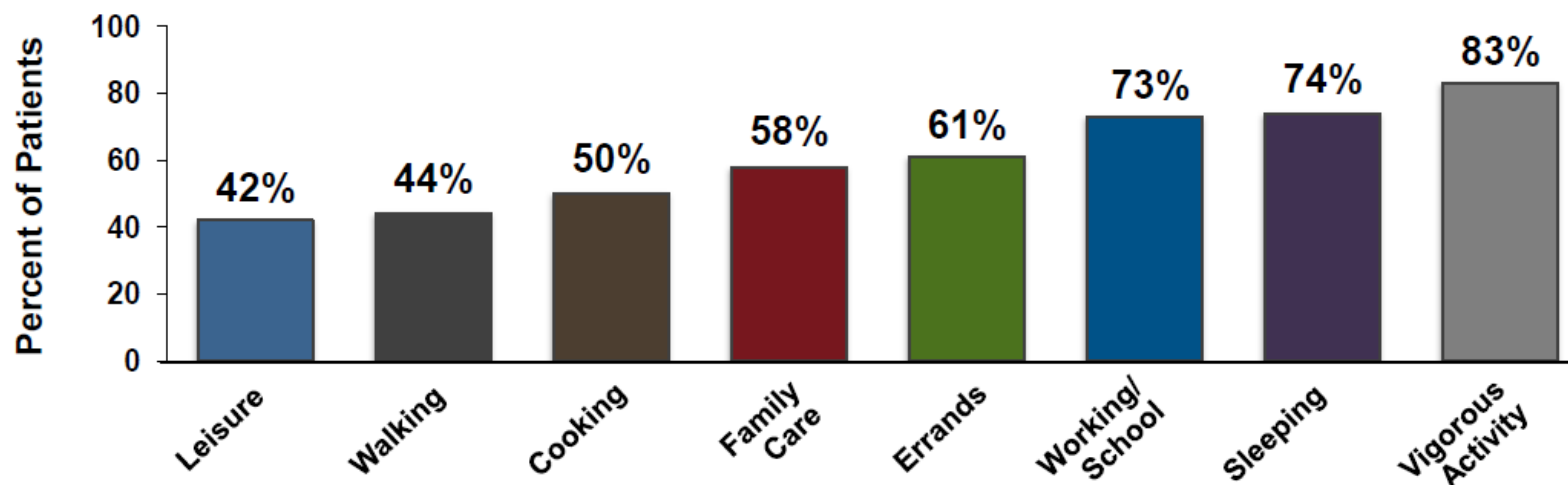
How common is fatigue by ethnicity?

A subanalysis of 223 patients participating in LUMINA, a prospective, multiethnic study of the outcome of SLE patients diagnosed ≤ 5 years prior to study entry, conducted jointly by the University of Alabama at Birmingham, the University of Texas-Houston Health Science Center, and the University of Texas Medical Branch at Galveston.

Patients With SLE Have Impaired Function Affecting Multiple Aspects of Daily Life

- In a telephone survey of 829 patients with SLE:
 - Nearly all patients (91%) had ≥ 1 valued life activity affected by SLE
 - Almost half (49%) were unable to perform ≥ 1 valued life activity

Some of the Valued Life Activities Affected by SLE (N=829)



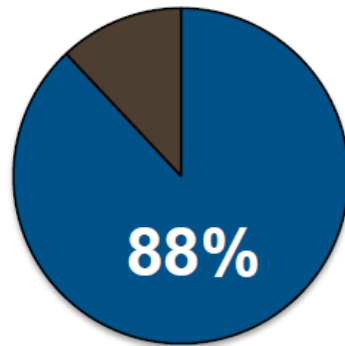
Prospective phone interview study of patients participating in the University of California at San Francisco Lupus Outcomes Studies. Valued life activity (VLA) disability was assessed using a scale rating the difficulty of performing 21 activities. Changes in VLA disability were assessed for 1 year from baseline. Affected VLAs were those with any level of difficulty or inability to perform. Mean age at baseline was 47.2 years, mean duration of SLE was 12.7 years, 91% were women, and 70% were white.

Physical Health

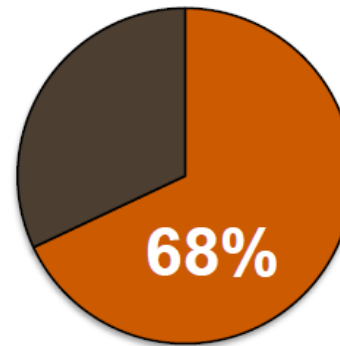
SLE Impacts Psychosocial Well-Being and Interpersonal Relationships¹

Depression is common and some patients are suicidal¹

88% reported mental health and well-being of their entire family was affected by lupus²



68% said lupus affects virtually every relationship they have^{3*}



- 80% reported that lupus negatively impacted their ability to fulfill various family roles²
 - Mother/father
 - Husband/wife
 - “Breadwinner”
- 88% reported that poor mental health impaired their ability to participate in activities they found enjoyable²

^{*}To some extent.

1. Boomsma MM, et al. *Arthritis Rheum*. 2002;47:196-201. 2. Hassett AL, et al. *Arthritis Care Res (Hoboken)*. 2012;64(9):1341-1348. 3. Gfk Custom Research North America. National Burden of Disease Survey. 2011.

Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus

Ten or less most prevalent unmet needs per domain ($N = 386$)

Item	Some need (%)	Moderate/high need (%)
Physical		
→ Tiredness ^a	81	54
Pain ^a	73	53
Sleeping problems ^a	70	40
Headaches	59	32
Skin rashes	51	29
Dry mouth	47	24

Focus on Patient Reported Outcomes



LupusPRO, MDHAQ (clinic).
SF-36 and others (Research)

Lupus Fellows

LEARN
at Rush

Research
-Clinical
Trials



Us 3

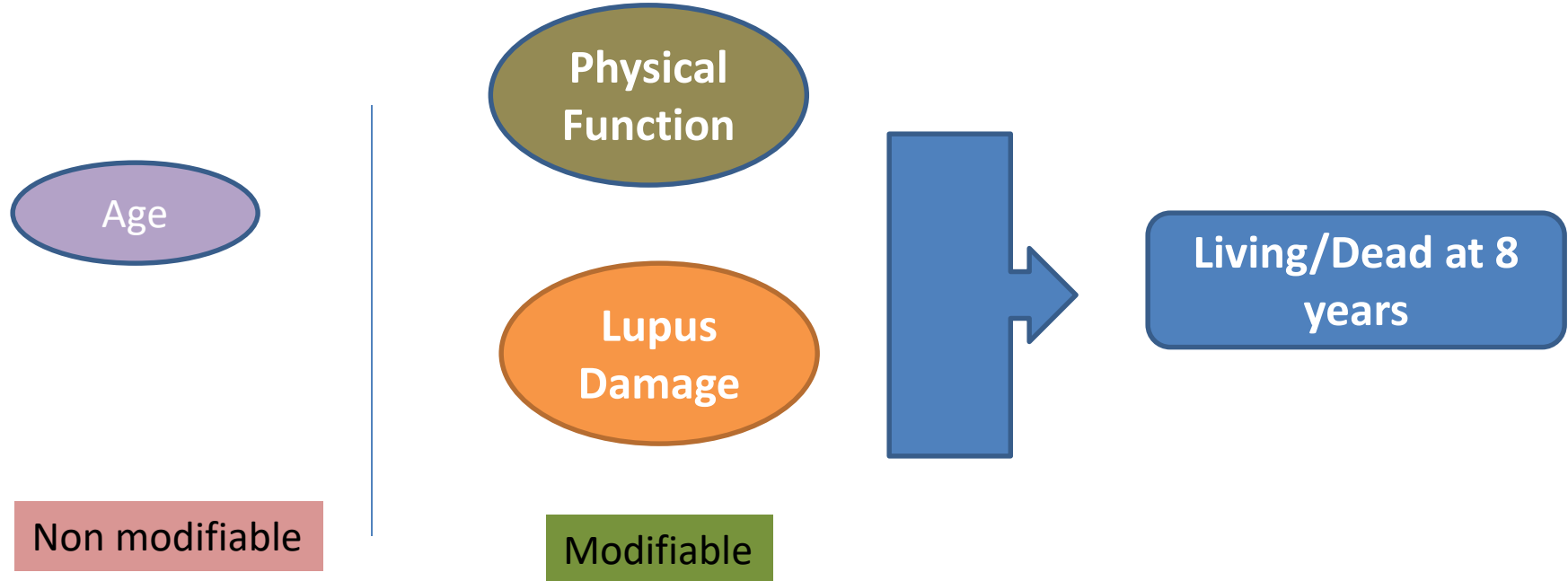
Rush Lupus Team

Clinical, Educational, Research and Social Work Community Health

Why do we care?

Collaborative study with University of California at San Francisco,
with 728 lupus patients, with 8 year follow up

71 deaths



After accounting for gender, poverty, duration of lupus, how active lupus was.

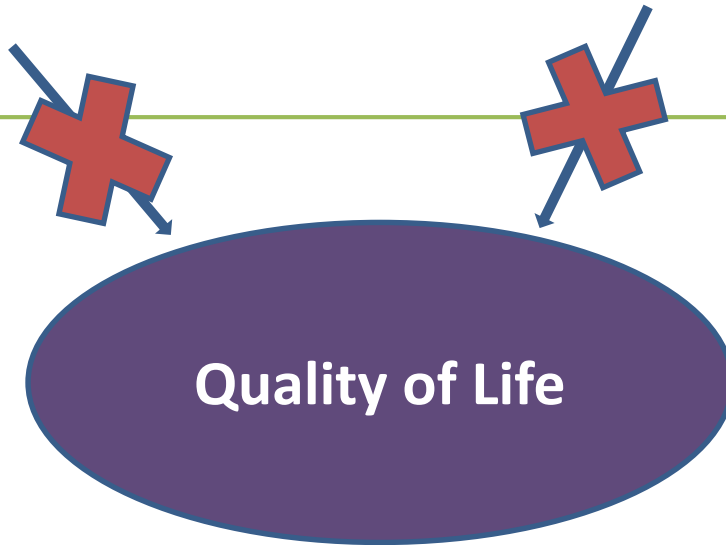
Poor relationship

DOCTOR'S REPORT CARD ON YOUR LUPUS

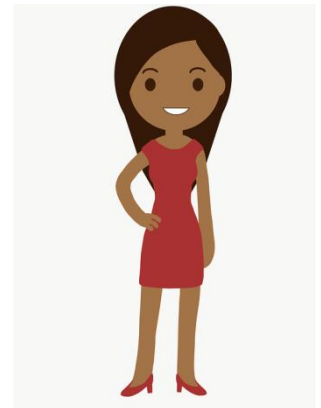
Active Lupus



Lupus Damage



PATIENT'S REPORT CARD ON YOUR LUPUS



Quality of Life in Lupus



	Lupus	Heart Failure	Depression
Physical Health		Same as Lupus	Better than Lupus
Emotional Health		Same as Lupus	Same as Lupus
Tiredness		Same as Lupus	Same as Lupus
Pain		Better than Lupus	Same as Lupus
General Health		Better than Lupus	Better than Lupus
Social Health		Better than Lupus	Same as Lupus
Age (years)	41	59	42
Number of patients	90	216	502

Worse quality of life in Lupus than high blood pressure, Diabetes and Heart attack patients.

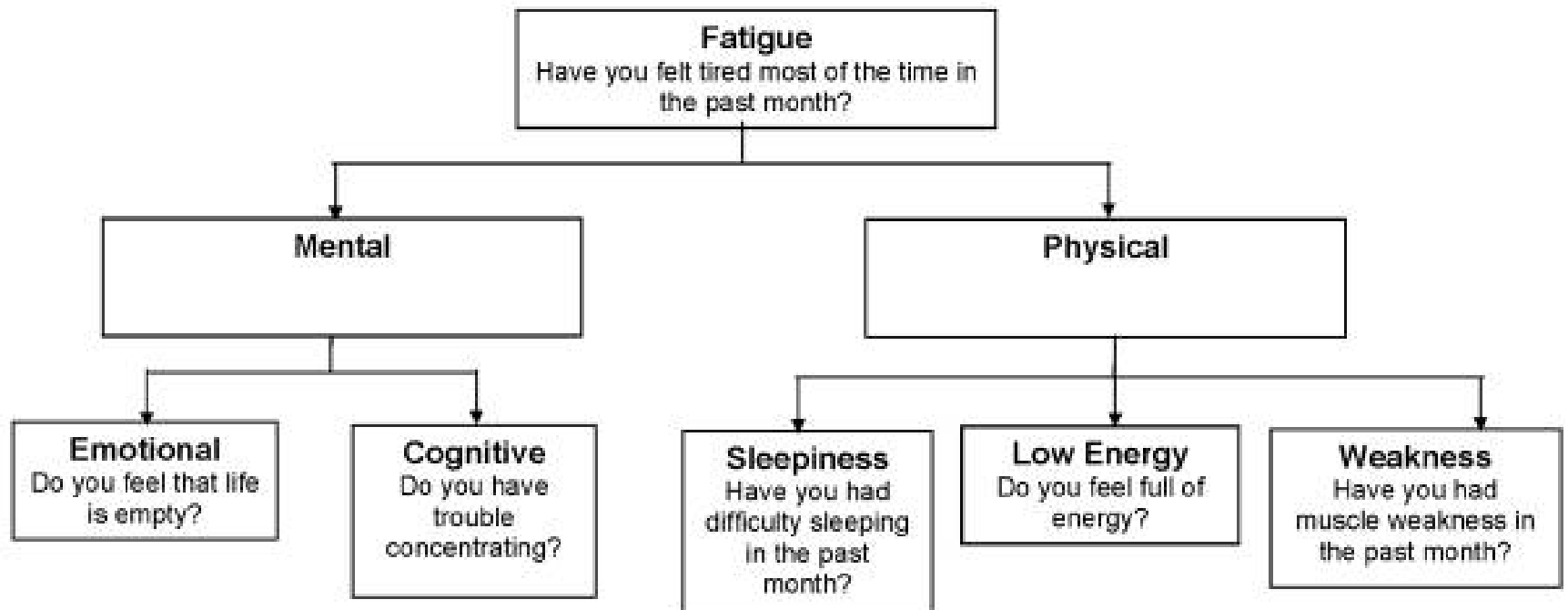
Jolly M. *J Rheumatol*. 2005;32(9):1706-1708.

Prevalence of persistent fatigue

LupusPRO

N 133

PRO Vitality Question	Responses	%
Tire easily during the day	Most or all of the time	33%
Unable to do usual activities due to tiredness	Most or all of the time	20%
Limited in kinds of tasks I could do because of tiredness	Most or all of the time	19%
Unable to do usual tasks for a long period of time due to tiredness	Most or all of the time	21%



Common Causes of Fatigue in Chronic Diseases

- Acceptance, Anxiety, Depression, Mourning the loss, Loss of control
- Coping
- Pain
- Sleep (OSA)
- Loss of Independence
- Social Support
- Poor Diet (Vit D, Iron, Calcium)/Dehydration/weight loss
- Other diseases e.g. Diabetes, Anemia, Thyroid, Infections, Cancer, heart disease
- Shift work
- Fibromyalgia
- Medications

Medicines that may add to fatigue

- Allergy meds
- BP meds, water pills
- Steroids
- Sleeping aides
- Mood disorder meds (Depression, Anxiety,
- Cholesterol lowering (Statins)

Medications that Can Cause Fatigue

Agent or Class	Fatigue Potential
ACE inhibitors (BP/Kidney)	Moderate
Amlodipine (Heart/BP)	Moderate
Anticonvulsants (Seizure)	Very high
Antineoplastic agents (Cancer)	Very high
Antiretrovirals (HIV)	Moderate
Beta-blockers (Heart/BP)	Moderate
Carvedilol (Heart)	Moderate
Clonidine (BP)	Moderate
Corticosteroids	Moderate
Disease-modifying drugs (Methotrexate, Azathioprine)	High
Dopaminergic agents (Parkinson, ADHD, Schizophrenia, Restless leg,)	Very high
Duloxetine (Fibromyalgia, Depression, OA)	High
Famciclovir (Herpes)	Moderate
Hydrochlorothiazide/metoprolol (Heart/BP)	Moderate
Hydrochlorothiazide/irbesartan (Heart/BP)	High
Irbesartan (BP/kidney)	Moderate
Metformin/rosiglitazone (Diabetes)	High
Opioid analgesics (Pain)	High
Pravastatin (Cholesterol)	Moderate
Skeletal muscle relaxant (MSK pain/spasm)	Moderate

+ Common Causes of Fatigue in Lupus

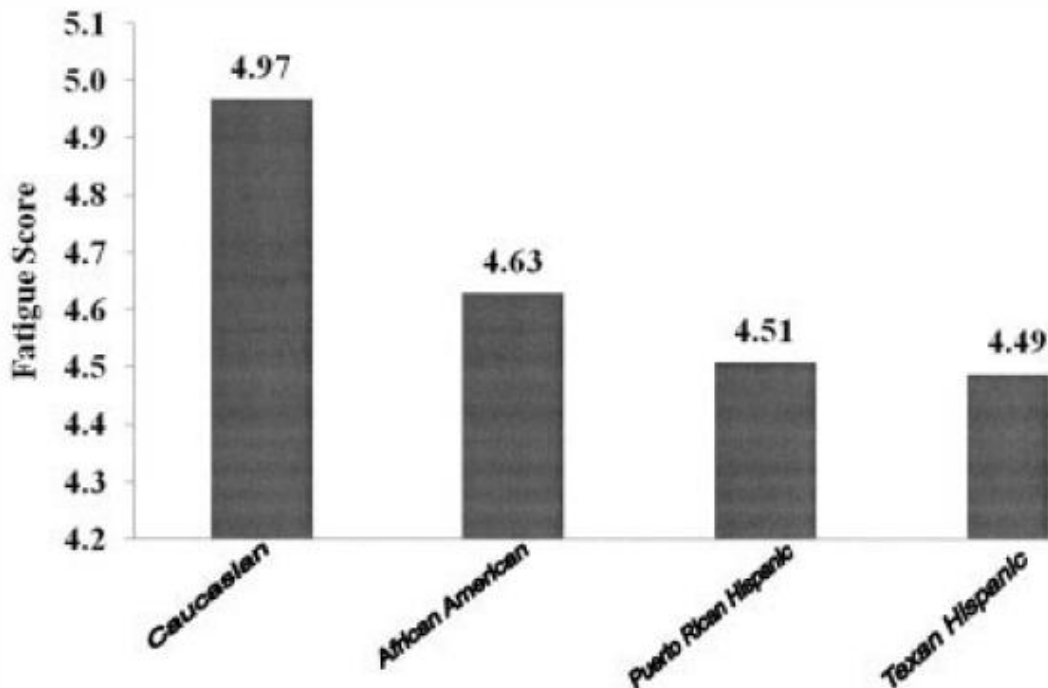
- Anemia
- Pain- Joints, Chest
- Inflammation-Active disease anywhere, uncontrolled/flare
- Damage: Kidney damage, Lung damage
- Sleep
- Depression, Anxiety
- Stress
- Fibromyalgia
- Medication side effects (including quick tapering of steroids)
- Multiple Health Problems
- Other: Vocation, Dating, Marriage, Intimacy, Pregnancy, Parenting, Financial burden, not being understood

Correlates of Fatigue in SLE

Active Disease or Damage not associated with Fatigue

About this study

Fatigue Severity by Ethnicity

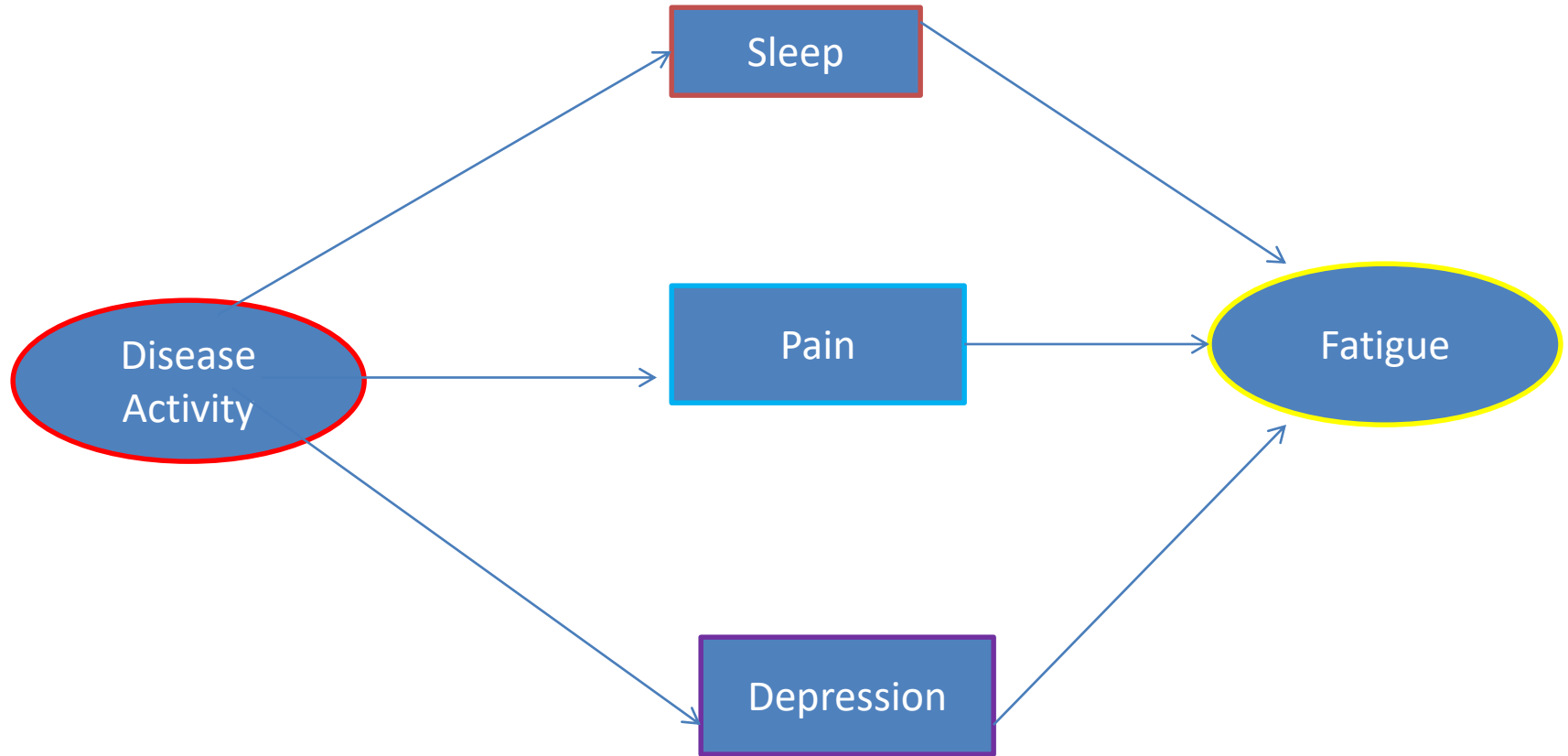


LUMINA

515 patients, 2,609 visits
91.7% of patients had fatigue.
Fibromyalgia was in 14%
Fatigue: White, Pain,
helplessness and Coping.

Figure 1. Distribution of the mean Fatigue Severity Scale scores as a function of ethnic group.

How Does Activity Cause Fatigue in Lupus?



Proposed Conceptual Model for Lupus Fatigue

Non Fibromyalgia patients
with SLE

What is Causing my Fatigue **Today**?

116 lupus patients at Rush. None with Fibromyalgia

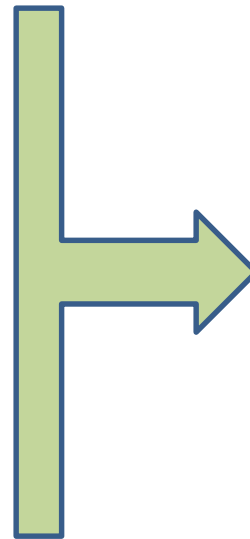
Stress



Depression



Pain



Fatigue

Adjusted for how active the disease is, physical health, sleep.

Azizoddin D, Gandhi N, Weinberg S, Sengupta M, Nicassio PM, Jolly M. Lupus.2018;28:163-173

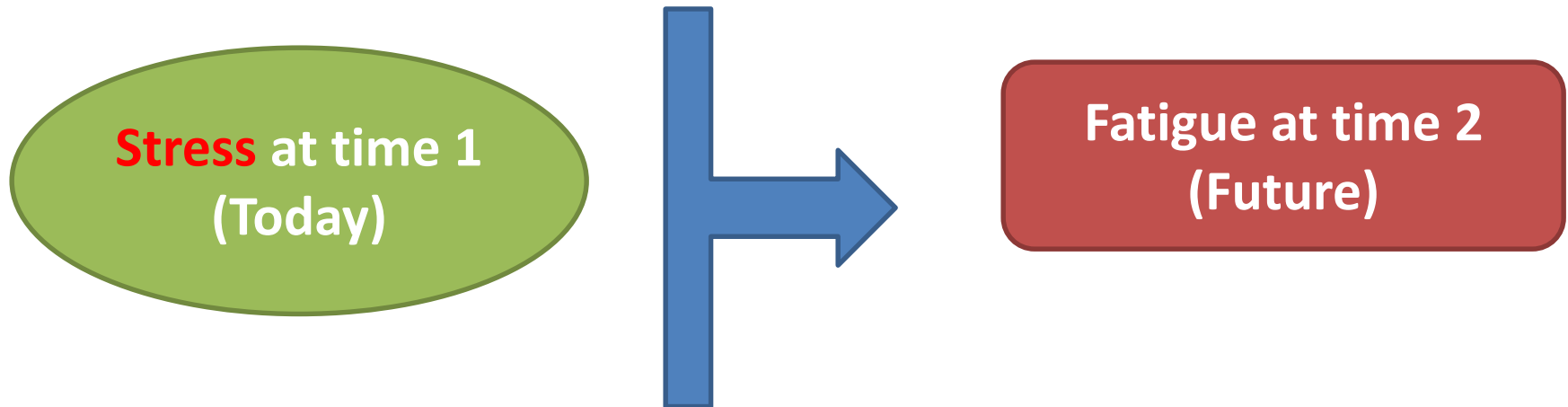
Azizoddin DR, **Jolly M**, Arora S, Yelin E, Katz P.

Arthritis Care Res (Hoboken). 2019 Aug 17. doi: 10.1002/acr.2405

Repeated in larger study

Will I remain Fatigued in Future?

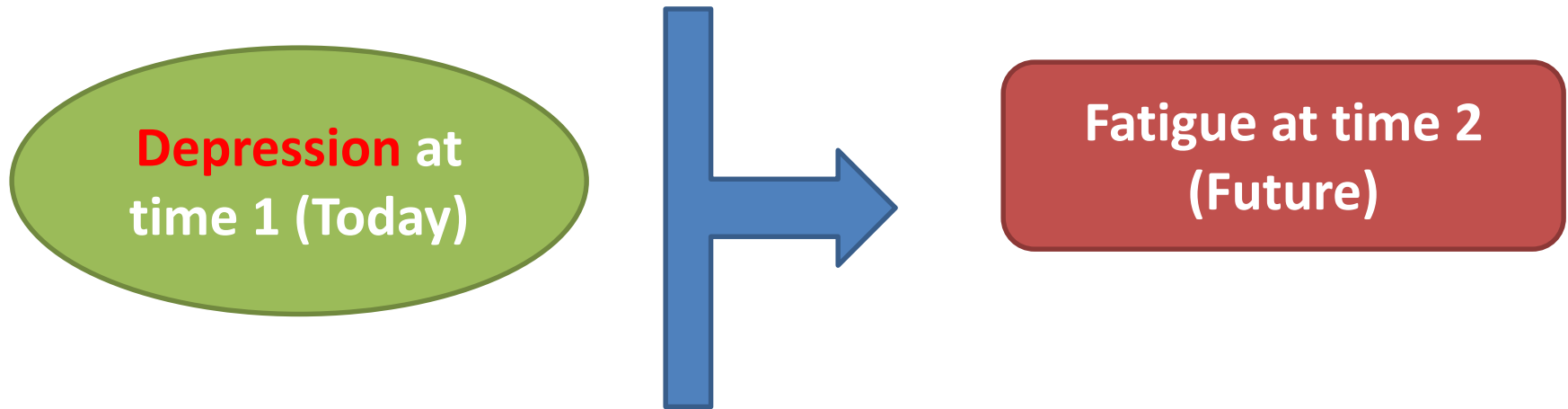
Collaborative study with University of California at San Francisco,
with 650 lupus patients, with 8 year follow up



Adjusted for age, gender, how active the disease is, how much damage, duration of lupus, pain, other medical conditions, fibromyalgia, and fatigue at time 1

Will I remain Fatigued in Future?

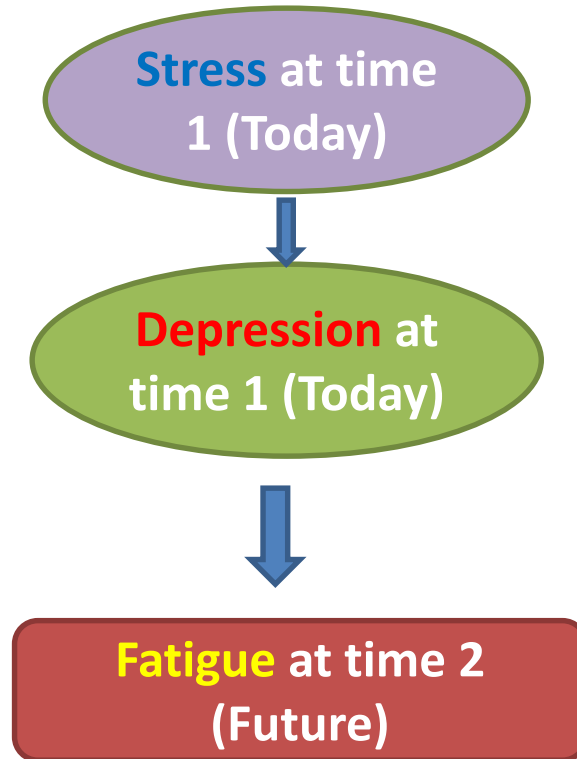
Collaborative study with University of California at San Francisco,
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Adjusted for age, gender, how active the disease is, how much damage, duration of lupus, pain, other medical conditions, fibromyalgia, and fatigue at time 1

Is it Stress or Depression causing Fatigue in Future?

Collaborative study with University of California at San Francisco, with 650 lupus patients, with 8 year follow up

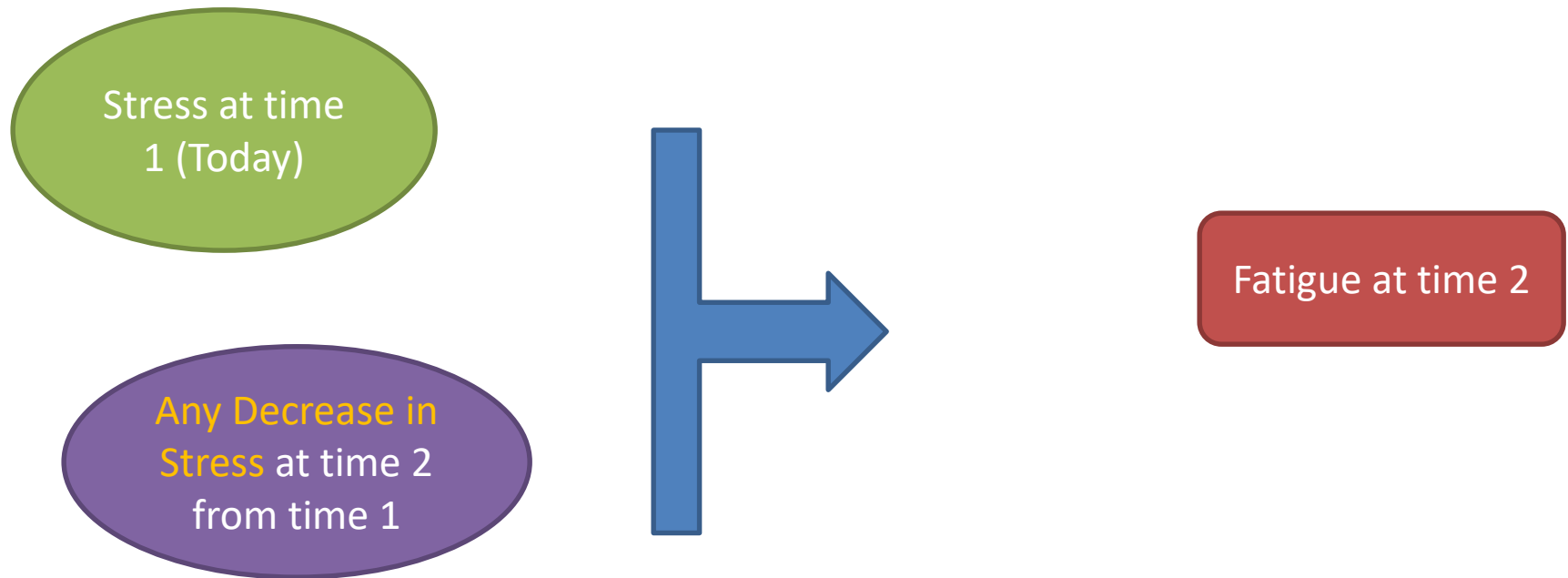


Adjusted for age, gender, how active the disease is, how much damage, duration of lupus, pain, other medical conditions, fibromyalgia, and fatigue at time 1

Azizoddin DR, **Jolly M**, Arora S, Yelin E, Katz P.
Arthritis Care Res (Hoboken). 2019 Aug 17. doi: 10.1002/acr.2405

What can I do to improve my Fatigue in Future?

Collaborative study with University of California at San Francisco, with 650 lupus patients, with 8 year follow up



Adjusted for age, gender, how active the disease is, how much damage, duration of lupus, pain, other medical conditions, fibromyalgia, and fatigue at time 1

Stress in Lupus

Stress is common in SLE

Nearly half report major life stress in the past 6 months¹

May lead to flares²⁻³ and cognitive impairments⁴

1.Kozora E et al . Lupus 2005;14:363-72.

2. Pawlak CR. Psychother Psychosom 2003;72:159-65.

3.Rousso E. Rheumatology international 2013;33:1367-70.

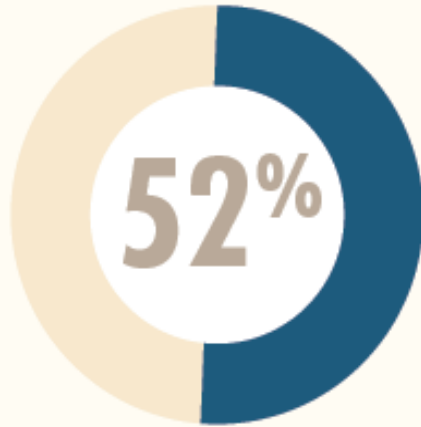
4.Peralta-Ramirez MI, Lupus 2006;15:858-64.

How common is persistent stress in Lupus?

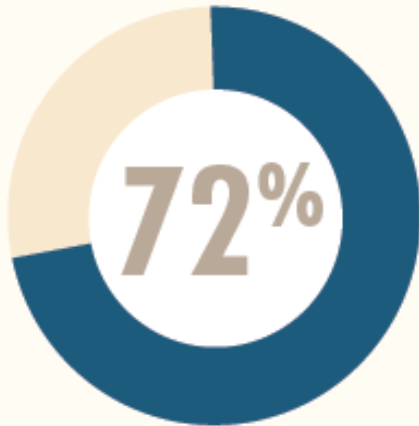
N=133, Rush Lupus Patients

PSS Question	Responses	%
Felt able to control the important things in my life	Almost never and never	27.6%
Felt confident about ability to handle personal problems	Almost never and never	16.4%
Felt things were going my way	Almost never and never	17.9%
How often felt difficulties piling up so high that you could not overcome them	Fairly Often and Very Often	25.6%

COMMUNICATION GAPS IN LUPUS CARE :WE ONLY SEE PART OF THE PICTURE



52% of patients report that they minimize their symptoms when they talk to physicians

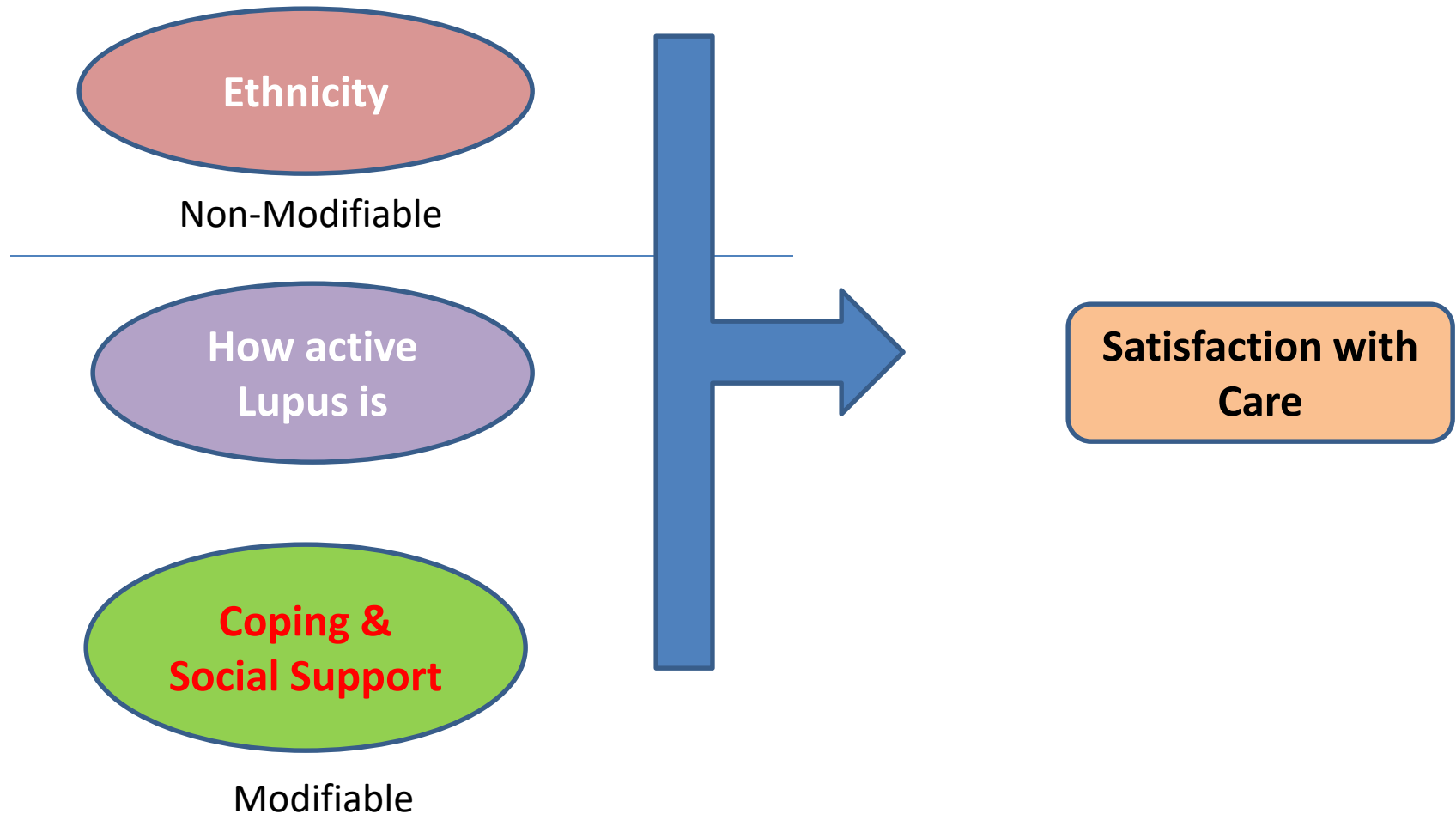


72% of physicians are unaware that patients tend to underreport their symptoms

- 87% of people with lupus said they downplay symptoms to avoid upsetting their families
- 48% (SLE) have difficulty **describing their symptoms** to MD
- 51 % (SLE) could **talk freely** with their MD

Patient Satisfaction

International Collaborative Study: Study on Outcomes in Lupus (SOUL): 1262 Lupus patients.



Changing Model of Care

- **Biomedical model:** Symptoms and functional problems are the product of underlying disease.

Assumptions:

Manage disease to control symptoms
Reliance on biomedical interventions alone
Health care team in charge of patient
Neglect of psychosocial factors



Bio-psychosocial Model: Psychological, Social, and Cultural Factors, in Addition to Disease, Affect Symptoms and Health Functioning

Assumptions:

Manage psychosocial dimensions of illness
Consider adjunctive/complementary treatments
Patient as self-manager
Emphasis on education and management skills
Mind-body integration

Partnership



Decrease Stress and Depression

A. Help Communication

1. Developed Surveys to help Communicate, Screen, Identify issues early and quickly, Referral
2. Increase Awareness about Lupus, medications among patients
3. Educate Physicians

B. Social Support, Coping

1. Through surveys screen and identify early, quickly, Referrals
2. Support Group (LEARN at Rush)
3. Community engagement in Support Groups, Educational Events
4. Psychology and SW services

Things that help

- Exclude Reversible Conditions
 - Thyroid
 - Anemia
 - Vitamin D
 - Medications
- Anti Inflammatory Diet
- Sleep Hygiene
- Stress, Depression
 - Exercise
 - Self Management
 - Support Groups
 - Cognitive Behavioral Therapy (Pain, fatigue, coping, support, sleep, dependence, depression, anxiety, stress)

Simple Suggestions

- Prioritize the task list. Hardest task in the morning.
- Schedule breaks
- Know your own comfort zone and communicate.
 - Spoon theory
- Don't overdo when feeling good
- Ask for help and be precise
- Discuss medicines with the doctor or pharmacist for side effects of fatigue











Butterflies in Las Vegas



LSI walk
2019









Thank you

Patients

Collaborators

Colleagues, Research and Clinical Staff

Rush Lupus Support Group (LEARN at Rush)

Trainees

Brewer Foundation

Lupus Society of Illinois