Why am I so TIRED?

Meenakshi Jolly, MD, MS
Professor of Medicine and Behavioral Sciences

Director, Rush Lupus Clinic
Associate Program Director,
Fellowship Training Program
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

How common is fatigue by ethnicity?

Prevalence of Fatigue Across Ethnic Groups (N=223)

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Prevalence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian (n=71)</td>
<td>88.7</td>
</tr>
<tr>
<td>African American(n=83)</td>
<td>85.5</td>
</tr>
<tr>
<td>Hispanic (n=69)</td>
<td>82.6</td>
</tr>
</tbody>
</table>

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.

LUMINA=LUpus in Minorities: NAture Versus Nurture.
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)

- Leisure: 42%
- Walking: 44%
- Cooking: 50%
- Family Care: 58%
- Errands: 61%
- Working/School: 73%
- Sleeping: 74%
- Vigorous Activity: 83%

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 Relationships

Depression is common and some patients are suicidal

- 88% reported mental health and well-being of their entire family was affected by lupus
- 68% said lupus affects virtually every relationship they have

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

*To some extent.
Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus

<table>
<thead>
<tr>
<th>Item</th>
<th>Some need (%)</th>
<th>Moderate/high need (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tiredness^a</td>
<td>81</td>
<td>54</td>
</tr>
<tr>
<td>Pain^a</td>
<td>73</td>
<td>53</td>
</tr>
<tr>
<td>Sleeping problems^a</td>
<td>70</td>
<td>40</td>
</tr>
<tr>
<td>Headaches</td>
<td>59</td>
<td>32</td>
</tr>
<tr>
<td>Skin rashes</td>
<td>51</td>
<td>29</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>47</td>
<td>24</td>
</tr>
</tbody>
</table>
Focus on Patient Reported Outcomes

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

Quality of Life

PATIENT’s REPORT CARD ON YOUR LUPUS

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

## Prevalence of persistent fatigue

### PRO Vitality Question

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

LupusPRO  
N 133
Fatigue
Have you felt tired most of the time in the past month?

Mental

- Emotional
  Do you feel that life is empty?

- Cognitive
  Do you have trouble concentrating?

Physical

- Sleepiness
  Have you had difficulty sleeping in the past month?

- Low Energy
  Do you feel full of energy?

- Weakness
  Have you had muscle weakness in the past month?
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)
<table>
<thead>
<tr>
<th>Agent or Class</th>
<th>Fatigue Potential</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACE inhibitors (BP/Kidney)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Amlodipine (Heart/BP)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Anticonvulsants (Seizure)</td>
<td>Very high</td>
</tr>
<tr>
<td>Antineoplastic agents (Cancer)</td>
<td>Very high</td>
</tr>
<tr>
<td>Antiretrovirals (HIV)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Beta-blockers (Heart/BP)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Carvedilol (Heart)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Clonidine (BP)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Corticosteroids</td>
<td>Moderate</td>
</tr>
<tr>
<td>Disease-modifying drugs (Methotrexate, Azathioprine)</td>
<td>High</td>
</tr>
<tr>
<td>Dopaminergic agents (Parkinson, ADHD, Schizophrenia, Restless leg,)</td>
<td>Very high</td>
</tr>
<tr>
<td>Duloxetine (Fibromyalgia, Depression, OA)</td>
<td>High</td>
</tr>
<tr>
<td>Famciclovir (Herpes)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Hydrochlorothiazide/metoprolol (Heart/BP)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Hydrochlorothiazide/irbesartan (Heart/BP)</td>
<td>High</td>
</tr>
<tr>
<td>Irbesartan (BP/kidney)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Metformin/rosiglitazone (Diabetes)</td>
<td>High</td>
</tr>
<tr>
<td>Opioid analgesics (Pain)</td>
<td>High</td>
</tr>
<tr>
<td>Pravastatin (Cholesterol)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Skeletal muscle relaxant (MSK pain/spasm)</td>
<td>Moderate</td>
</tr>
</tbody>
</table>
+ 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

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

LUMINA
515 patients, 2,609 visits

Active Disease or Damage not associated with Fatigue

Fatigue Severity by Ethnicity

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

Sleep

Pain

Depression

Fatigue

Proposed Conceptual Model for Lupus Fatigue

How Does Activity Cause Fatigue in Lupus?

Non Fibromyalgia patients with SLE
What is Causing my Fatigue Today?

- Stress (1st)
- Depression (2nd)
- Pain (3rd)

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

116 lupus patients at Rush. None with Fibromyalgia


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

Stress at time 1 (Today) → Fatigue at time 2 (Future)

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, with 650 lupus patients, with 8 year follow up

Depression at time 1 (Today) → Fatigue at time 2 (Future)

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

Stress at time 1 (Today) → Depression at time 1 (Today) → Fatigue at time 2 (Future)

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

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

Stress at time 1 (Today)

Any Decrease in Stress at time 2 from time 1

Fatigue at time 2

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 months\(^1\)
May lead to flares\(^2-3\) and cognitive impairments\(^4\)

How common is persistent stress in Lupus?

N=133, Rush Lupus Patients

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

\(^1\)Kozora E et al. Lupus 2005;14:363-72.
\(^3\)Roussou E. Rheumatology international 2013;33:1367-70.
\(^4\)Peralta-Ramirez MI, Lupus 2006;15:858-64.
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.

GFK Roper Survey
Patient Satisfaction

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

- Ethnicity
- How active Lupus is
- Coping & Social Support
- Satisfaction with Care

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
LEARN at Rush
Lupus Erythematosus Awareness and Resource Networks

Leader: LaShon Gurrola
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