

# Rush Lupus Clinic Team



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# Rush Lupus Research Team



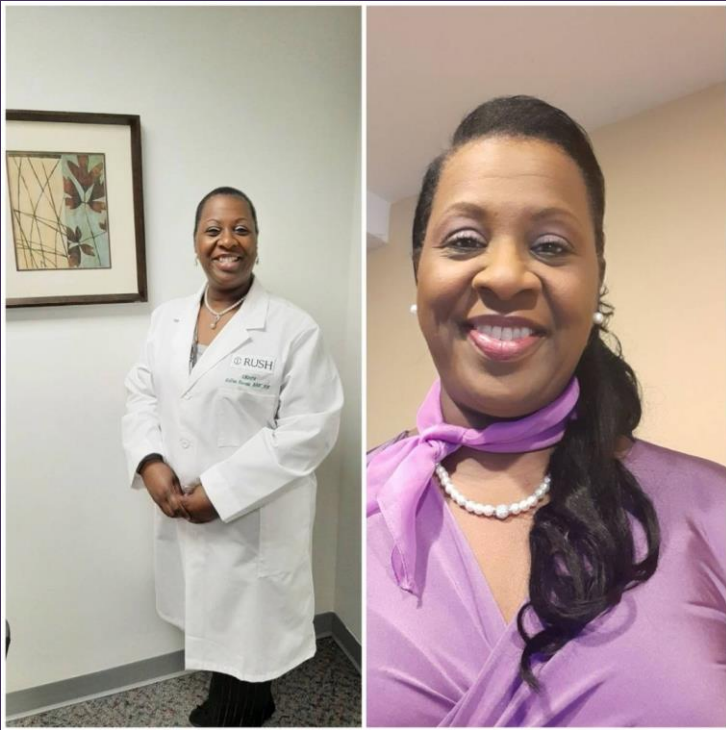
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# LEARN at Rush

## Lupus Erythematosus Awareness and Resource Networks



Leader:  
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Rush Lupus Clinic-Research –Education-Patient Support Team



# Body Image in Lupus?

Meenakshi Jolly, MD  
Professor of Medicine  
Director, Rush Lupus Clinic  
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# What is Systemic Lupus Erythematosus (SLE)

- Young women
- Ethnic Minority
- Disease of the immune system
- Many organs
- Fight/**War**
  - **against own**

# This is Lupus.

And the war is unpredictable,  
recurring, life long and starts at a  
younger age...

# What is Bio-Psychosocial Model of Health

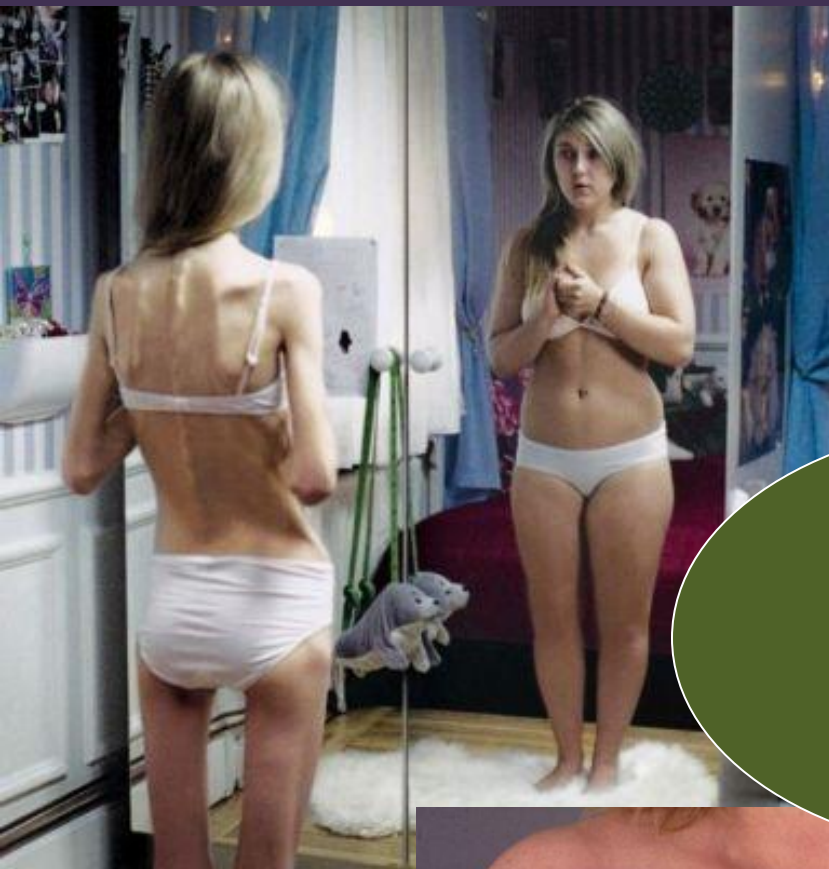
- Treat the person as whole not just numbers or symptoms
- Especially important for chronic diseases like Lupus
- At Rush Lupus Center that is what we believe in. Empower the patient.
- Involve other specialties-
  - Social work, Psychology, Support groups, Allied Health personnel eg PT
  - Other specialists



# What is Body Image?

- Defined as the mental picture of one's body, and includes an assessment about :
  - Physical self
  - Appearance
  - State of health
  - Wholeness
  - Functioning
  - Sexuality

- The way we experience our body is highly subjective
- Product of our perceptions, thoughts, and feelings about:
  - Body size
  - Competence
  - Function
- Body image is most strongly influenced by the patient's overall health rating
- Having a presentable skin surface is important for Body Image.



Eating disorders

**BODY IMAGE**



Psoriasis/Burns



Cancers, post surgery

# Why study BI?

**Connected** with various aspects of **OUR functioning**, AND  
influenced by OUR assessment of **overall health**

Related to

**Psycho-social wellbeing**

Coping

Depression

**Social Function**

**Sexual Function**

**Continuation of Care**

**Quality of life**

# Need in SLE?

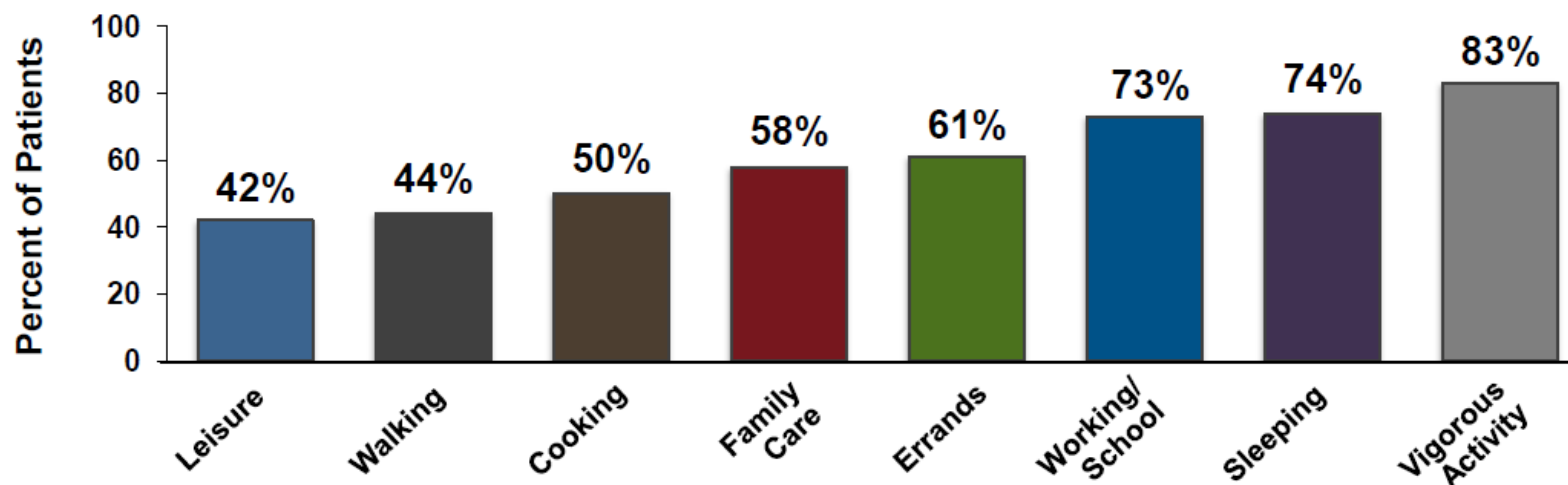
- Disfigurement and disease affecting the skin or scalp may lead to **embarrassment, humiliation, or other unpleasant experiences, self esteem and depression** (Koo 2002).
- Demonstrable need:
  - 82% of SLE patients identify, “changes in body appearance” as **“an area of unmet need”** towards attaining optimal health and quality of life (Moses 2004)
- Little written/known about body image concerns in SLE
  - Despite the fact that women are more likely than men to experience BI concerns
  - SLE is a disease of predominantly young females
  - SLE has the potential for significant disfigurement



# 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  $\geq 1$  valued life activity affected by SLE
  - Almost half (49%) were unable to perform  $\geq 1$  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.

# Visible Disfigurements

- Hair loss: Patchy/ diffuse
- Rashes: Face, ears, body, hands
- Loss of teeth
- Joint disfigurements
- Hair (facial), acne, striae, cushingoid
- Raynauds, skin ulcers
- Weight





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CASE REPORT

# Looking Beyond the Ordinary: Genital Lupus

MEENAKSHI JOLLY<sup>1</sup> AND PURVI PATEL<sup>2</sup>



# Disease Manifests as symptoms

Discernible disruption of health

## Rashes



Concern for what it may herald



Appearance



Body image



Impact Mood  
Social functioning



QoL/well-being

What are some of the comments you have heard from others (or perceived yourself) regarding your body?

How did it make you feel?

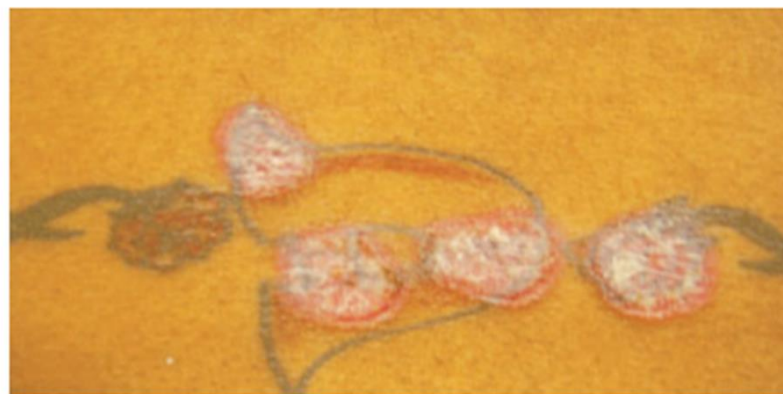
What did you do in response to the comment?



# STEROID EFFECTS







**Figure 1.** Appearance of discoid lesions superimposed on a tattoo in a patient with Koebner phenomenon.

Jolly M. Arthritis Care & Research. 2005; 53(4): 627

Jolly, Meenakshi et al. JCR: Journal of Clinical Rheumatology. 2007(1): 49



# ‘Concealing the evidence’: the importance of appearance concerns for patients with systemic lupus erythematosus

2006

ED Hale<sup>1\*</sup>, GJ Treharne<sup>2,1</sup>, Y Norton<sup>3</sup>, AC Lyons<sup>4</sup>, KMJ Douglas<sup>1</sup>, N Erb<sup>1</sup> and GD Kitas<sup>1,2,5</sup>

| <i>Theme</i>  | <i>Subthemes</i>                                      | <i>Example extracts from quotes</i>   |
|---|---|---|
| 1) Becoming publicly self-conscious and attempts to manage appearance | i) Visibility of the changed physical body in society | ‘I’d only got to walk through the town and people stopped and just literally looked at me.’ (Alison)  |
|   | ii) Cosmetic concealment                              | ‘... if my face is that bad I won’t go because you can’t cover it up.’ (Jessica)<br>‘... but you can still see it because like I said the make-up’s lighter on the white patches than the dark...’ (Alison)<br>‘... then I have a sun block and then I put a foundation on and then I put another screen on and then I put make-up on so in the summer I’ve usually got loads of make-up on.’ (Grace) |
|   | iii) Clothing to cover-up                             | ‘... you were focusing on the cardigan you weren’t focusing on me...’ (Claire)<br>‘... I usually like to wear a blouse and a skirt and a top because then I’ve got my arms covered...’ (Grace)  |
| 2) Social and physical isolation                                      | i) Social withdrawal                                  | ‘... now I find it hard... to talk, to converse with people because I haven’t been about...’ (Maud)<br>‘... when I can’t go out the house and I think “Well is it because I don’t want to see people or I don’t want them to see me?”’ (Sally)  |
|   | ii) Family activities                                 | ‘... so I can’t enjoy my holidays with the children...’ (Alison)  |
| 3) Understanding SLE*   | i) Society’s knowledge of SLE*                        | ‘... it is so difficult for anybody else to understand how it’s affecting you...’ (Claire)  |
|   | ii) Disease information and explanation               | ‘We’ve picked leaflets up out of the hospital but nobody has ever said. ‘Sit there and we’ll explain what it is.’’ (Jessica)  |

**Young**



**Women**

**S  
L  
E**

**Physical Health**

**Emotional Health**

**Pain  
Tiredness  
Sleep**

**skin**

Dating

Social  
Relationships

Education/  
Profession

Marriage/  
Homemaker

Children

**B  
O  
D  
Y  
  
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M  
A  
G  
E**



# Body Image in Patients with Systemic Lupus Erythematosus

Meenakshi Jolly • A. Simon Pickard •

Rachel A. Mikolaitis • Jessica Cornejo •

Winston Sequeira • Thomas F. Cash • Joel A. Block

|                  | Lupus       | no Lupus | Is it Different |
|------------------|-------------|----------|-----------------|
| Number of people | 87          | 78       |                 |
| Body Image       | 0.8 (Lower) | 1.7      | Yes             |
| Health Status    | 0.6 (Lower) | 0.8      | Yes             |

|                        |                   |
|------------------------|-------------------|
| Greater Age            | Worse Body Image  |
| Better Health          | Better Body Image |
| Greater Skin Damage    | Worse Body Image  |
| Greater Pain           | Worse Body Image  |
| More Tired             | Worse Body Image  |
| Less Social Active     | Worse Body Image  |
| Worse Emotional Health | Worse Body Image  |



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N=87

|                                       |                  |
|---------------------------------------|------------------|
| How active Lupus Is                   | No Association   |
| Greater Damage you have from Lupus    | Worse Body Image |
| Use of Prednisone                     | No Association   |
| Having Fibromyalgia                   | No Association   |
| Being Depressed                       | Worse Body Image |
| Your Body Mass Index (Weight, height) | No Association   |

When you put everything together that you find to be associated with Body Image

Greater age

Worse Body Image

Poor Health

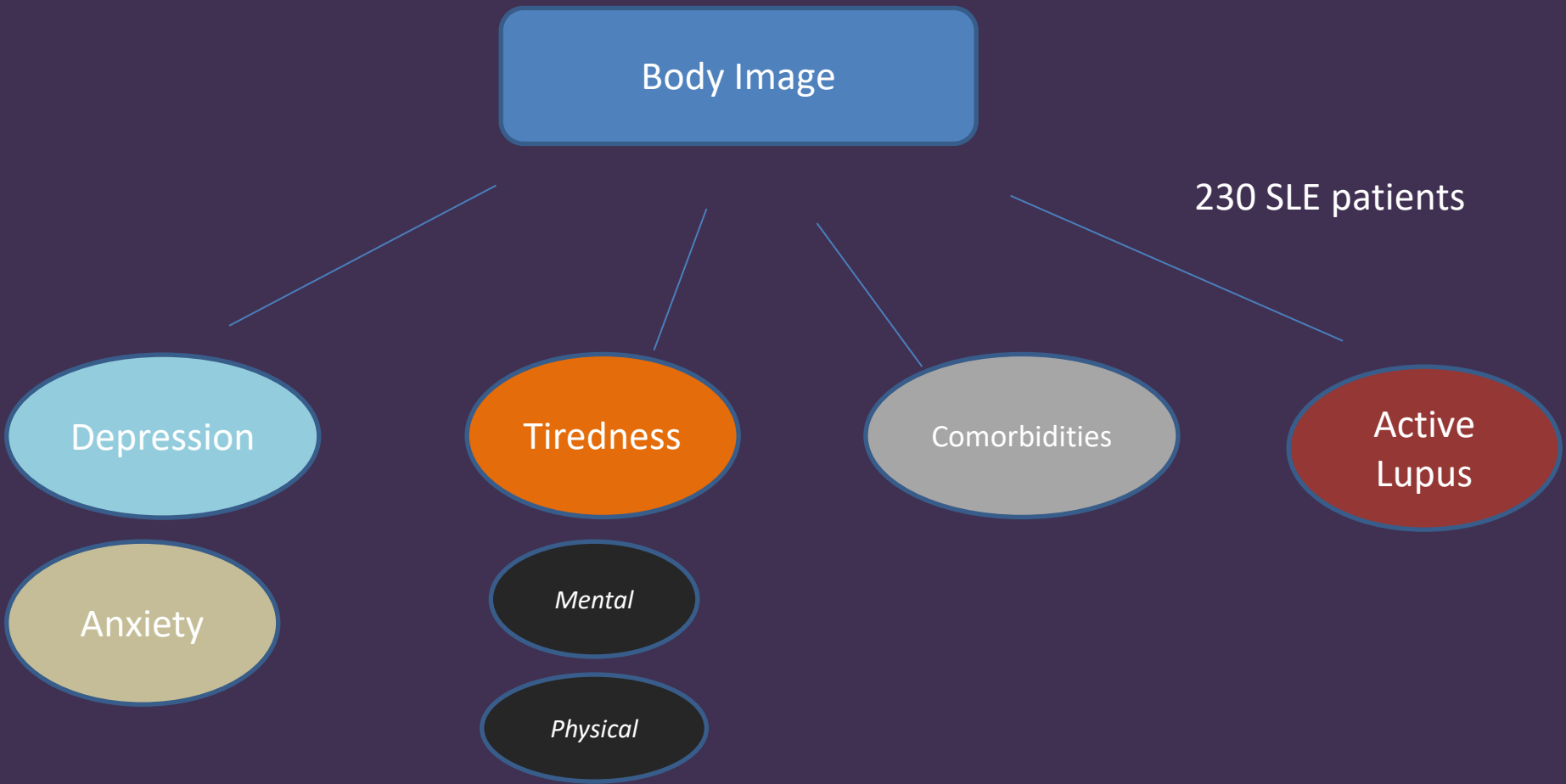
Worse Body Image

So, not just appearance!!!

What about Stress, sleep, Pain.....etc etc

# Body image in lupus: Is it disease activity, physical function, depression, pain, fatigue, sleep, fibromyalgia or stress?

|   | All lupus patients (115) | Lupus patients without Fibromyalgia (98) |
|---|--------------------------|--|
| How Active Lupus is                     | not associated           | not associated                           |
| Ongoing active Rash                     | not associated           | not associated                           |
| Ongoing active Hair Loss                | not associated           | not associated                           |
| Ongoing active Arthritis                | not associated           | not associated                           |
| Having had a discoid Rash Ever          | not associated           | not associated                           |
| <b>Having ever had a butterfly rash</b> | <b>worse Body Image</b>  | <b>worse Body Image</b>                  |
| Physical health                         | not associated           | not associated                           |
| Sleep                                   | not associated           | not associated                           |
| Tiredness                               | not associated           | not associated                           |
| <b>Depression</b>                       | <b>worse body image</b>  | <b>worse body image</b>                  |
| Pain                                    | not associated           | not associated                           |
| <b>Stressed</b>                         | <b>worse Body Image</b>  | <b>worse Body Image</b>                  |
| Fibromyalgia                            | not associated           |  |
| Prednisone use                          | not associated           | not associated                           |



# Body Image, Depression Symptoms, and Health-Related Quality of Life in Black Women With Systemic Lupus Erythematosus

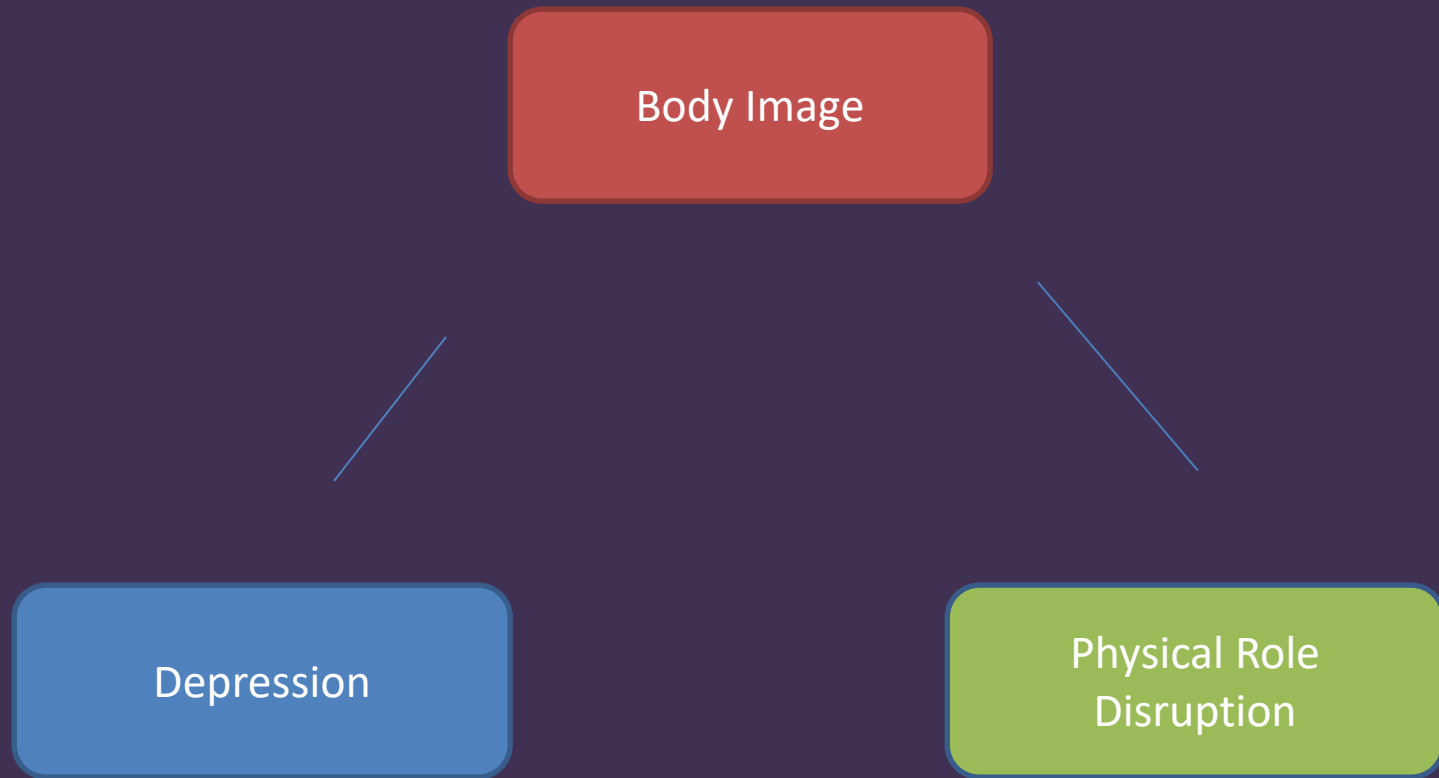
Madeline M. Jones & Laura P. Kimble

Using social media advertising, recruited 43 Black women with self-reported SLE to complete a web-based survey

**TABLE 1 DEMOGRAPHIC AND CLINICAL CHARACTERISTICS (N = 43)**

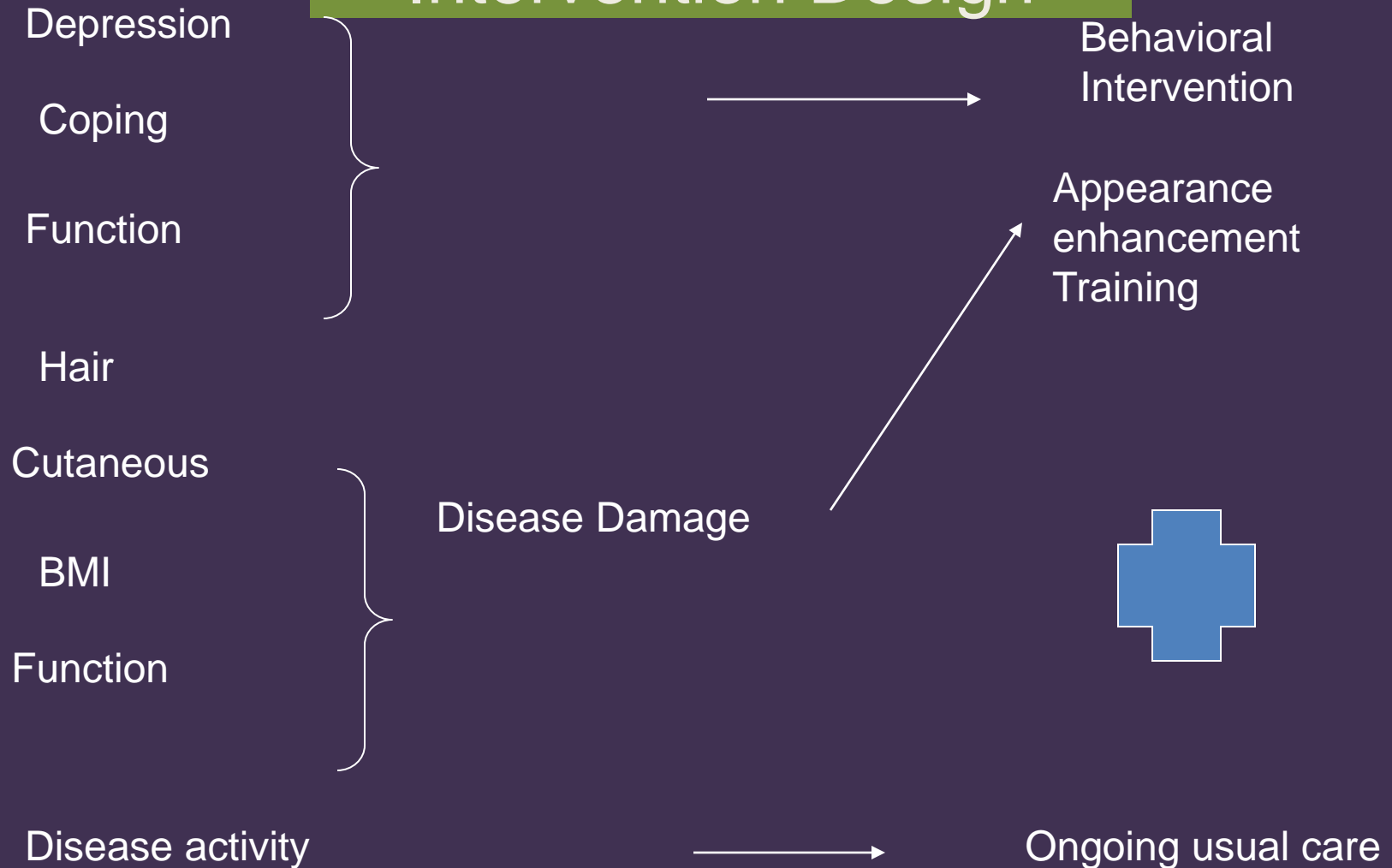
| Variable               | Mean (SD)  | Observed Range |
|------------------------|------------|----------------|
| Age, years             | 33.5 (6.9) | 23–56          |
| Years since diagnosis  | 5.9 (4.0)  | 1–26           |
| BMI, kg/m <sup>2</sup> | 23.1 (5.2) | 15.2–44.3      |
|                        | <i>n</i>   | %              |
| Ethnicity              |            |                |
| Hispanic or Latina     | 9          | 20.9           |
| Oral steroid use       |            |                |
| Yes                    | 22         | 51.2           |
| No                     | 20         | 46.5           |
| Hydroxychloroquine use |            |                |
| Yes                    | 19         | 44.2           |
| No                     | 23         | 53.5           |





# Can Body Image be Modified?

## Intervention Design



A NEW HARBINGER SELF-HELP WORKBOOK

# The Body Image Workbook

SECOND EDITION



An  
Eight-Step  
Program for  
Learning to  
Like Your  
Looks



THOMAS F. CASH, PH.D.



Kristin Flynn Peters, PhD

# Makeup kit



Look Good Feel Better,  
Modified





- Intervention or Usual Care (10 vs 5)
- Intervention:
  - Once a week, 2 hrs., for 10 wks.
  - Education
  - Cognitive behavioral therapy using - Cash Protocol, Modified
  - Appearance Enhancement Skills **Training-personalized and educated-Look Good Feel Better, Modified**

**Body Image Improved  
in Intervention group**

**Body Image Improvements  
retained at 18 & 24 weeks in  
Intervention group**

**Improvement in  
Depression over time in  
Intervention group**



**BEFORE**



**AFTER**



**BEFORE**



**AFTER**



**BEFORE**



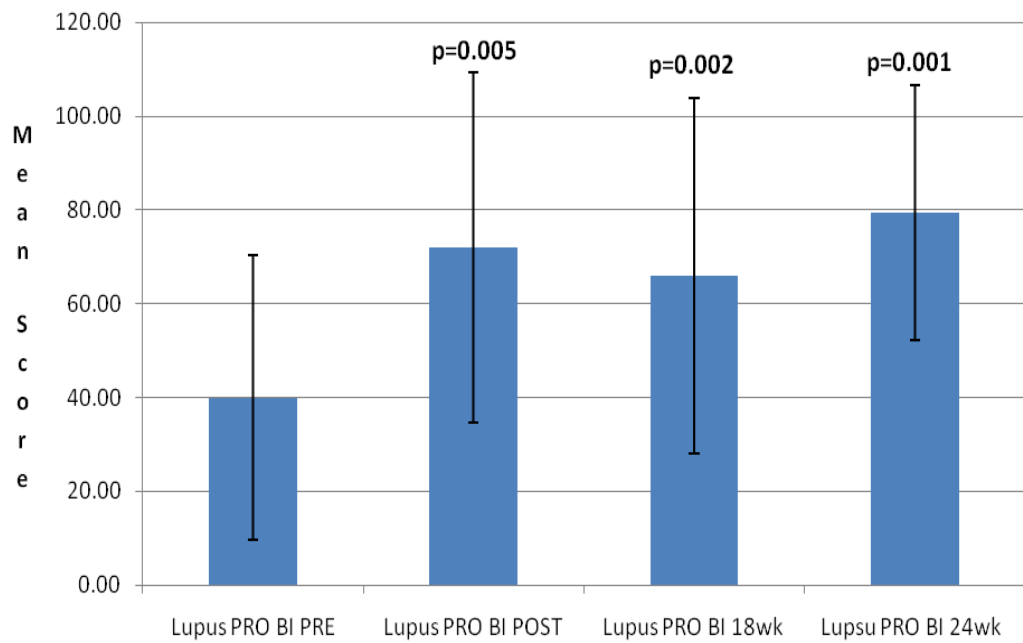
**AFTER**



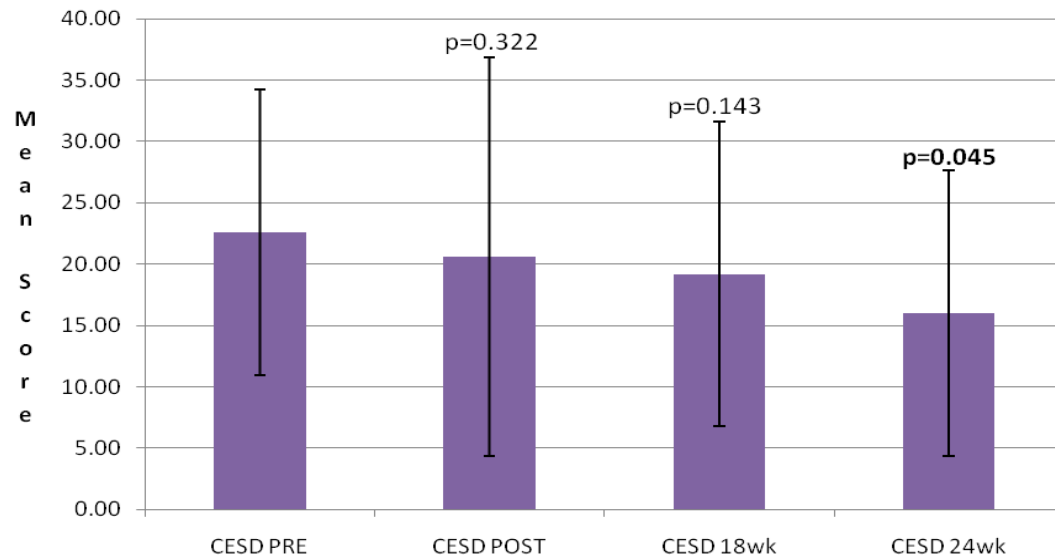
**BEFORE**



**AFTER**





\* P-Values are all compared against the PRE score



\* P-Values are all compared against the PRE score

# Body image mediates the impact of pain on depressive symptoms in patients with systemic lupus erythematosus

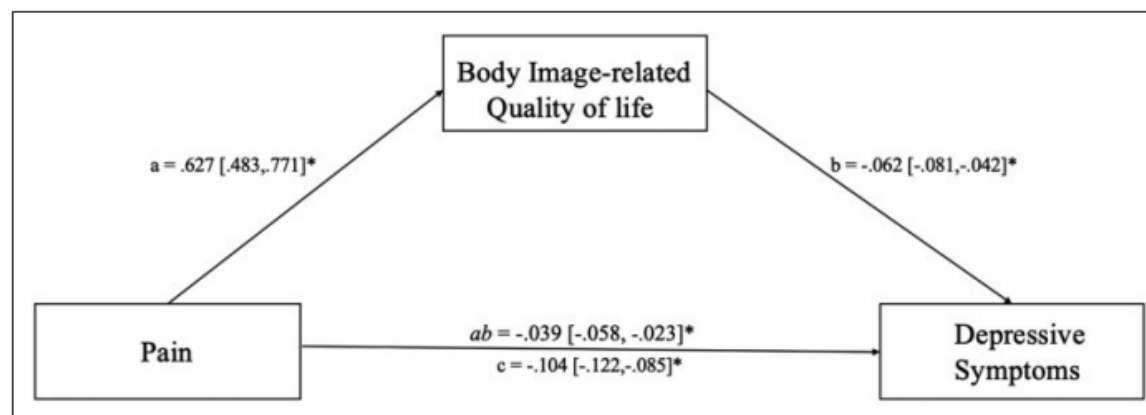
S Gholizadeh <sup>1,2</sup>, D R Azizoddin <sup>2</sup>, S D Mills<sup>3</sup>, G Zamora<sup>4</sup>, H M K Potemra<sup>5</sup>, A E Hirz<sup>6</sup>, D J Wallace<sup>7</sup>, M H Weisman<sup>7</sup>, and P M Nicassio<sup>8</sup>

135 SLE  
patients  
California

R sq 51%

## Race/Ethnicity<sup>a</sup>

|                            |           |
|----------------------------|-----------|
| White                      | 61 (45.2) |
| Hispanic                   | 28 (20.7) |
| African American/Black     | 19 (14.1) |
| Asian/Pacific Islander     | 22 (16.3) |
| Other Mixed Race/Ethnicity | 5 (3.7)   |



**Figure 1** Mediation model. Standardized regression coefficients controlling for age, sex, and disease severity [95% confidence interval]; indirect effect of pain on depressive symptoms represented by path  $ab$ ;  $*p < 0.001$ .

# Prevalence and biopsychosocial factors associated with depressive symptoms among patients living with systemic lupus erythematosus in clinical settings in urban Thailand

Nirunya Narupan<sup>1,2</sup>, Acharaporn Seeherunwong<sup>2\*</sup> and Walailak Pumpuang<sup>2</sup>

185 Thai SLE patients

Severe Pain

Tiredness

Prednisolone of  $\geq 15$  mg day

Low Body Image

Low Social Support

Depression



# LupusPRO and Lupus Impact Tracker

- To help communication, Identify concerns
- Help Track health concerns, including body image.
- Lupus Impact Tracker is only 10 questions
- LupusPRO has 43 questions and used Internationally

# ABC sequence of my body image experience

- **Activators**
  - Triggering events and situations
- **Beliefs**
  - Thoughts and interpretations about my appearance and myself
- **Consequences (Emotional TIDE)**
  - Types of emotions (anxiety, self consciousness, despair, angry)
  - Intensity of emotions (0-10)
  - Duration of episode
  - Effects of the episode on my behavior

# Partnership



Thank you