Body Image in Lupus?

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What is Systemic Lupus Erythematosus (SLE)

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

Effects of any war
During the launch of a war Day 1= Acute Inflammation/Flare

Great Explosive Impact: Life changing effects at onset

But brave it all for survival.

Don’t have luxury to think deeper about effects but safety/moving on and survival is the top concern

Next phase: Tiredness Exhaustion Sleep issues

Saftey and survival are still the top concerns. No time yet to even recognize any further effects

Protein is being used as bullets to wage the war
Some serious physical injuries come during the early phases.
Focus still is safety and survival.

Irrational attacks that do not make sense.
Still top focus is on safety and survival.

Next phase: Assessment of Damage. Obvious at first glance is only external damage.
One may not have the luxury of time/resources to do a full assessment (even just external) and address it while the war is still ongoing.
Focus is still on safety and survival.

Damage: Unseen, Unevaluated, Unaddressed

This may be while the war is still on, but weeks to months to years later. Or after the war has ended.
Now one may not be still safe/promised survival, but functioning may get affected without acknowledging it.

Anxiety, Depression, Stress, Sleep, PTSD
Next Phase: War (Acute inflammation/flare) has ended, so time for damage assessment. Casualties of war: Survival (overall or specific organs). If made it then, what organs damaged irreversibly, and how bad, and what needs to be done next...

Damage on Innocent people that were not direct part of the war

FAMILIES disrupted, health

Un- and under recognized Collateral impact (from acute/flare and damage) that exists and perpetuates among the troops and their loved ones.
This is Lupus.

And this 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
• Specially 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.
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 negative 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
Visible Disfigurements

- Hair loss: Patchy/ diffusely
- Rashes: Face, ears, body, hands
- Loss of teeth
- Joint disfigurements
- Hair (facial), acne, striae, cushingoid
- Raynauds, skin ulcers
- Weight
Looking Beyond the Ordinary: Genital Lupus

MEENAKSHI JYALI and PURVI PATIL
Steroid Effects

Disease Manifests as symptoms
Irreversible disruption of health

Rashes

Concern for what it may herald
Appearance
Body image
Impact Mood
Social functioning
QoL/well-being

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Rashes

Concerned for what it may herald
Appearance
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QoL/well-being
"Concealing the evidence": the importance of appearance concerns for patients with systemic lupus erythematosus

Young Women Dating Social Relationships Education/Profession Marriage/Homemaker Children

Physical Health Dating Social Relationships Emotional Health Education/Profession Marriage/Homemaker Children

Body Image in Patients with Systemic Lupus Erythematosus


<table>
<thead>
<tr>
<th></th>
<th>Lupus</th>
<th>no Lupus</th>
<th>Is it Different</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lymphoedema</td>
<td>87</td>
<td>746</td>
<td></td>
</tr>
<tr>
<td>Body Image</td>
<td>0.8 (Lower)</td>
<td>1.7</td>
<td>Yes</td>
</tr>
<tr>
<td>Health Status</td>
<td>0.6 (Lower)</td>
<td>0.8</td>
<td>Yes</td>
</tr>
</tbody>
</table>

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

Body Image in Patients with Systemic Lupus Erythematosus

Monatashi Jolly, A. Simon Pickard, Rachel A. Miklooti, A. Jenessa Cermuja, Winsten Seguin, Thomas E. Cash, Joel A. Black

N=87 N=78

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?

<table>
<thead>
<tr>
<th>All lupus patients (115)</th>
<th>Lupus patients without Fibromyalgia (98)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How Active Lupus is</td>
<td>not associated</td>
</tr>
<tr>
<td>Ongoing active Rash</td>
<td>not associated</td>
</tr>
<tr>
<td>Ongoing active Hair Loss</td>
<td>not associated</td>
</tr>
<tr>
<td>Ongoing active Arthritis</td>
<td>not associated</td>
</tr>
<tr>
<td>Having a discoid Rash</td>
<td>not associated</td>
</tr>
<tr>
<td>Having ever had a butterfly rash</td>
<td>worse Body Image</td>
</tr>
<tr>
<td>Physical health</td>
<td>not associated</td>
</tr>
<tr>
<td>Sleep</td>
<td>not associated</td>
</tr>
<tr>
<td>Tiredness</td>
<td>not associated</td>
</tr>
<tr>
<td>Depression</td>
<td>worse Body Image</td>
</tr>
<tr>
<td>Pain</td>
<td>not associated</td>
</tr>
<tr>
<td>Stressed</td>
<td>worse Body Image</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>not associated</td>
</tr>
<tr>
<td>Prednisone use</td>
<td>not associated</td>
</tr>
</tbody>
</table>

Can Body Image be Modified?

Intervention Design

- Depression
- Coping
- Function
- Hair
- Cutaneous
- BMI
- Function

Behavioral Intervention

Disease Damage

Appearance enhancement Training

Disease activity

Ongoing usual care

The Body Image Workbook

As Eight-Step Program for Learning to Like Your Looks

THOMAS E. 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

• BI is modifiable.
• Intervention was beneficial
• Effects were retained 3 months after the study
• Lead to improvements in depression and possibly self esteem.
• Web based intervention: Cost effective

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

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

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
**LupusPRO**

Includes Disease specific Domains in Gender Neutral Language. Developed from ethnically heterogenous SLE patients (male/female).

**Conceptual Model of LupusPRO**

- Lupus symptoms
- Lupus medication
- Physical health
- Mental health
- Pain
- Vitality
- Sleep
- Procreation
- Cognition
- Body image


**Partnership**

Thank you

- **Step 1: Discovering your personal BI.** Discover your BI strengths and weaknesses. Self discoveries to allow setting specific goals for change.
  - Used examples and self tests (BI evaluation test, BI thoughts test, BI distress test, appearance importance test, BI coping test, BI QOL test). Scored. Translating your self discoveries into goals for change. Help sheet for change.

- **Step 2: Understanding the origins of your BI story.** Historical influences, Cultural socialization (media messages), interpersonal experiences, physical characteristics and changes, personality traits —BI attitudes (evaluation and investment).
  - To understand how the story of their own personal BI evolved. Self discovery help sheets (pre SLE to post SLE). Help sheets for change. Expressive writing for 3 days.

- **Step 3: Mindfulness and acceptance of your BI experiences.** Building of skills to accept and neutralise their negative BI emotions.
  - Consequences: TIDE. T Type of emotion | Intensity | Duration. E Effects on your behavior. Private diary of daily body image experiences. One week.
• **Step 4: Seeing beneath the surface of your private body talk.** Exploring privately held beliefs, silent assumptions about BI, how they dictate your discontent. Ten taxing assumptions (Modified). Conversing with inner assumptions and development of a new inner voice. Help sheets for change.


• **Step 7: Erasing your BI rituals.** Building ladder of success for erasing rituals.

• **Step 8: Treating your body well.** Taking affirmative actions. Writing of wrongs “Dear body of mine” letter. Achieving and Pleasing with positive physical activities. Having good times with sensate activities and appearance oriented activities.