Depression stress and anxiety in SLE

Martha Rodríguez, MD
Assistant Professor of Clinical Pediatrics
Indiana University School of Medicine
Section of Pediatric Rheumatology
Riley Hospital for Children at Indiana University Health
Depression in chronic disease

- Chronic disease has a detrimental impact on an individual’s mental health.
- We have learned that the relationship between chronic physical disease and mental illness is bidirectional.
Depression in chronic disease

• The Healthy People 2020 report from the United States (US) Department of Health and Human Services states that “mental health disorders have a serious impact on physical health and are associated with the prevalence, progression, and outcome of some of today’s most pressing chronic diseases.”
Systemic lupus erythematosus

- Systemic lupus erythematosus (SLE) is a multisystem, autoimmune disease in which the immune system mistakenly attacks the body.
- SLE has frequent psychological comorbidities, of which depression and anxiety are two common manifestations.
The Impact of Lupus on the Body

Central and Peripheral Nervous System
- Seizures, Psychosis, Headaches, Cognitive Dysfunction
- Neuropathies, **Depression**
- Low Grade Fever

Heart, Lungs
- Pericarditis, Myocarditis, Endocarditis, Pleuritis, Pneumonitis

Kidneys
- Edema, Hypertension, Proteinuria, Cell Casts, Renal Failure

Reproductive System
- Pregnancy Complications, Miscarriages, Menstrual Cycle Irregularities

Blood
- Anemia, Thrombocytopenia, Leukopenia, Thrombosis, Circulating Autoantibodies and Immune Complexes

Eyes and Mucous Membranes
- Ulcers in the Eyes, Nose, Mouth or Vagina, Sjögren’s Syndrome

Gastrointestinal
- Nausea, Vomiting, Diarrhea, Weight Changes

Musculoskeletal
- Extreme Fatigue, Arthralgia, Myalgia, Arthritis, Myositis

Skin
- Butterfly Rash, Cutaneous Lesions, Photosensitivity, Alopecia, Vasculitis, Raynaud’s Phenomenon
• It has been reported that there were 2 times higher prevalence of depression in SLE patients compared to the general population.
• Approximately one-third of all people with lupus experience depression and anxiety.

Depression and SLE

• There is evidence that youth with SLE have disproportionately higher rates of suicidal ideation compared to healthy controls with reported rates of suicidal ideation ranging between 14-34%

Etiology

- Organic: autoantibody mediated vascular or neuronal injury seems to play a major role.
Etiology

- Hereditary predisposition
- Environmental factors
- Auto-antibodies
- Proinflammatory cytokines
- Iatrogenic (Medications)

Disrupted BBB

- Antibodies in intrathecal space
- ? Autoimmune damage
- DEPRESSION
Predictors of depression

• Appearance concerns.
• Inadequate pain/disease control.
• Work and activity limitations.
• Social isolation.
• Uncertainty about the future.
• Difficulty with family relationships.
Symptoms of Depression

- sadness
- anxiety
- guilt
- anger
- mood swings
- feelings of helplessness or hopelessness
- irritability

- frequent self-criticism
- impaired memory & concentration
- indecisiveness
- confusion
- thoughts of death and suicide

- crying
- withdrawal from others
- neglect responsibilities
- changes in personal appearance
- moving more slowly
- being agitated or unable to settle

- chronic fatigue
- lack of energy
- sleeping too much or too little
- weight gain or loss
- loss of motivation
- substance abuse
- unexplained aches and pains
## Diagnosis

### Patient Health Questionnaire-9 (PHQ-9)

**Over the last 2 weeks, how often have you been bothered by any of the following problems?**

*Use “✓” to indicate your answer*

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed, or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Trouble falling or staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Thoughts that you would be better off dead or of hurting yourself in some way</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
# PHQ-9 Interpretation

<table>
<thead>
<tr>
<th>Total Score</th>
<th>Depression Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>None</td>
</tr>
<tr>
<td>5-9</td>
<td>Mild</td>
</tr>
<tr>
<td>10-14</td>
<td>Moderate</td>
</tr>
<tr>
<td>15-19</td>
<td>Moderately Severe</td>
</tr>
<tr>
<td>20-27</td>
<td>Severe</td>
</tr>
</tbody>
</table>
### GAD-7

Over the last 2 weeks, how often have you been bothered by the following problems?

<table>
<thead>
<tr>
<th>Problem</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling nervous, anxious or on edge</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Not being able to stop or control worrying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Worrying too much about different things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Trouble relaxing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Being so restless that it is hard to sit still</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Becoming easily annoyed or irritable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling afraid as if something awful might happen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

If you checked off any problems, how **difficult** have these problems made it for you to do your work, take care of things at home, or get along with other people?

- Not difficult at all
- Somewhat difficult
- Very difficult
- Extremely difficult

Total Score = Add Columns
GAD 7 interpretation

<table>
<thead>
<tr>
<th>Total Score</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;10</td>
<td>Probable diagnosis of GAD; confirm by further evaluation</td>
</tr>
<tr>
<td>5</td>
<td>Mild anxiety</td>
</tr>
<tr>
<td>10</td>
<td>Moderate anxiety</td>
</tr>
<tr>
<td>15</td>
<td>Severe anxiety</td>
</tr>
</tbody>
</table>
Diagnosis

Figure 2. Comparison of Likert Scale Responses for Level of Comfort with Mental Health Providers Among Youth and their Parents

- Psychiatrist
  - Youth: 2.14
  - Parents: 2.49

- Counselor/therapist in your community
  - Youth: 2.21
  - Parents: 2.81

- School counselor/therapist
  - Youth: 1.63
  - Parents: 2.50

- Psychologist in your community
  - Youth: 2.03
  - Parents: 2.69

- Psychologist at Rheumatologist office
  - Youth: 2.21
  - Parents: 2.91

- Social worker at Rheumatologist Office
  - Youth: 1.78
  - Parents: 2.69

- Rheumatologist
  - Youth: 2.84
  - Parents: 3.54

- Primary care provider (PCP)
  - Youth: 2.47
  - Parents: 3.36

- Social worker at PCP Office
  - Youth: 1.49
  - Parents: 2.27

Mean Likert Score (0=Very Uncomfortable, 4=Very Comfortable)

- Youth
- Parents
Barriers for Mental Health Screening Perceived by Pediatric Rheumatologists

- Limited staff resources to screen.
- Limited time/space during the encounter.
- Limited staff resources to follow up results of screening.
- Lack of institutional support.
- Provider lack of knowledge about mental health.
- Patient willingness to be screened.
- Parent willingness to have child screened.

(Knight, 2016)

Up to 75% of symptomatic patients with SLE had not had mental health evaluation.
Complications

• Increased incidence of cardiovascular diseases.
• Myocardial infarction.
• Suicidal ideation.
• Physical disability.
• Decreased quality of life.
• Higher risk of premature mortality.
• Poorer disease control.
Relation between disease stress and depression
How do you combat a lupus depression?
Stages of grief with a diagnosis

• Aim for Acceptance of Your Lupus Diagnosis

Stage 1 – Denial and isolation:
Stage 2 – Anger “Why me?”
Stage 3 – Bargaining
Stage 4 – Depression
Stage 5 – Acceptance
Stage 1 – Denial and isolation:

• No, not me!
• This can’t be happening to me.
• A mistake has been made in the diagnosis.
• Is a type of shock absorber.
• Denial lets us cope with only what we can handle.
Stage 2 – Anger “Why me?”

- Feelings of anger, rage, jealousy and hatred.
- The person's anger is directed outward. It can extend from the immediate family, to medical professionals, to friends as well as to God.
- It is important to remember that underneath the anger is pain.
Stage 3 – Bargaining

• Patients may bargain about things like pain, whether physical or emotional.

• Guilt comes along with bargaining. People often go down the path of "What if.." or "If I only...", finding fault in themselves and things they have done.
Stage 4 – Depression

• Depression replaces the anger and the attempts at bargaining.
• Does not advise trying to cheer up or calm the individual steeped in depression.
• It is necessary to support the individual with compassion and understanding
Stage 5 – Acceptance

• It is about accepting the new reality.
• In this stage the patient ceases his or her fight against fate/diagnosis.
Talk With Your Doctor About Depression and Lupus

- Your doctor can assess, diagnose, and help you decide what kind of treatment is best.
Coping Strategies

• Trust in Divine Help
• Trust in Medical Help
• Conscious Way of Living
• Positive Attitudes. Positive self-talk
• Distraction
• Relaxation
• Seeking for social support
Keep Self-Talk Positive, Avoid Negative Self-Talk

• “What you tell yourself is more important than what others say about you” Grusd.

• List the people and things in your life for which you are grateful.

• Replace negative, self-defeating inner language with truthful, productive thoughts, such as: “I feel lousy, but I have many blessings

• Use imagery (thinking about positive experiences you have had)
Surround Yourself With Supportive People

• It’s important to surround yourself with positive people who are willing to be supportive -- even if this means making some new friends

• **LupusConnect** 24/7 Access to support and community

• Lupus support groups in Indiana
Surround Yourself With Supportive People

- Online
  Monday, October 29, 7:00-8:00 PM

Process for registering
Facilitators: Kayla Lockwood and Samantha Walker
Email: lupusinonline@gmail.com
Surround Yourself With Supportive People

• For more information on support groups, visit Find Help or for questions regarding any of our monthly meetings, please call 800.948.8806 or send an email to Debbie Campbell.
Find ways to reduce pain

• Yoga
• Tai Chi
• Pilates
• Acupuncture
• Biofeedback
• Meditation
• Chiropractic care
• Exercise
Natural therapies

- Acupressure
- Hot and cold therapy
- Massage therapy
- Mind-body therapies
Improve your sleep habits

• Get seven to eight hours of sleep in a 24-hour period.
• Do aerobic exercise every day, such as brisk walking—or whatever you can manage.
• Avoid caffeine, nicotine, and alcohol several hours before bedtime.
• Establish a regular relaxing bedtime routine
Improve your sleep habits

• Know which medications keep you from sleeping and take those early in the day.
• Have a good mattress, comfortable bed linens, the right room temperature, and the right amount of darkness.
• Limiting daytime naps to 30 minutes.
Discover the values of volunteerism

• Volunteerism can provide real emotional benefits. Helping with a charitable cause that is meaningful to you can create social, supportive connections. Helping others can have a positive impact on your sense of well-being.
Strive to accept the new “you.”

- Pace yourself, and don’t feel badly about delegating some of your responsibilities.
- Ask for help, and accept help graciously.
- Focus on what you have and what you can do, rather than on what you don't have and can’t do.
Negative coping strategies

- Negative self-talk
- **Negative daily mood** and more daily **stressful events** significantly predicted increased reports of **fatigue, stiffness, pain** and **cutting back on daily activities**.
Negative coping strategies

• Lack of social support network
• Emotion-based focusing (when patients focus on the negative aspects of the symptoms and avoiding active coping while internalizing negative feelings).
Negative coping strategies

- Rumination is the focused attention on the symptoms of one's distress, and on its possible causes and consequences, as opposed to its solutions.
- Catastrophizing is an irrational thought believing that something is far worse than it actually is.
Psychological interventions

• Antidepressant medications
• Anti-anxiety medications
• Psychotherapy: can help you learn to understand your feelings, your illness, and your relationships, and to cope more effectively with stress
• Cognitive behavioral therapy
Cognitive Behavioral Therapy

- The most successful psychological interventions for improving pain in patients with chronic diseases.
- Incorporate normalization of the patient’s experience through education regarding the condition and its impact, training in specific strategies, managing disease-related and other stressors, providing guidance on developing and implementing a long-term plan for self-managing the condition.
Things to work on

• More disease-specific knowledge.
• Self-management strategies.
• Meaningful social support.
Things to work on

• SLE may limit some of the things you can do, but it doesn’t have to control your life. Keep a positive attitude!!!

• Don’t dwell. How often do you think about your symptoms? The amount of time you spend thinking about your symptoms has a lot to do with how much discomfort you feel. Try to focus your energy on how to ease your symptoms.
Things to work on

• **Think about pain differently.** Think of pain as your body’s message to do something different. For example, if your pain is worse after sitting for a period of time, your body may be telling you to get up and move around.
Things to work on

• **Shift your focus.** One way to take your mind off your symptoms is to focus on something else, like an enjoyable activity. Doing things that make you laugh, listening to your favorite music, talking to a friend.

• This can help your body release feel-good chemicals that will ease your symptoms.
Never Give Up!