Coping with Chronic Illness: Living a Life with Lupus

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POLLING SLIDE – “Who is today’s audience?”

- I am diagnosed with lupus
- I am a healthcare provider
- I am interested in lupus
- I am a mental health provider
- I may have lupus – I do not have a lupus diagnosis
- I have a loved one with lupus
- No vote
Agenda

- Nature of chronic illness
  - Dealing with uncertainty
  - Stress-illness cycle
  - Impact on caregivers
- Anxiety, Depression and Stress
  - How to identify them
  - Their prevalence in populations of patients with lupus
- Ways to cope
The Nature of Chronic Illness

- The fear that comes with not knowing
  - May be fine for a while, then have flares
- Lifestyle changes
  - Giving up loved activities
  - Adapting to physical limitations
  - LOTS of time in the hospital
    - Missing school/work
- Day-to-day living is HARD
  - Patients with chronic pain showed decreases in work and social functioning; 3-15x more likely to have anxiety or depression
The Nature of Chronic Illness

- Many medications
- Complicated regimen
  - Side effects
    - Steroids can lead to
      - facial swelling
      - weight gain
      - increased acne
      - hair growth
      - mood swings
The connection between emotions and illness

- Over time, these stresses and changes can rob patients of the emotional energy that’s needed to keep moving
- Lack of progress in recovery, or symptoms getting worse can trigger negative thoughts
  - Why me? I’m never going to get better, etc.….  
  - Increased anxiety and sadness – can lead to depression
POLLING SLIDE – “For those of you in the audience who have lupus, have you had these negative thoughts about your illness (why me, this isn’t fair, etc)?

- Yes
- No
- No vote
Polling Slide: “For those of you who answered yes to the previous question, how do you think those thoughts have affected your behavior? (Feel free to choose more than one answer)

- Having negative thoughts about my illness has led to me skipping my medication
- Having negative thoughts about my illness has made me anxious about my future
- Having negative thoughts about my illness has made me feel depressed and/or hopeless
- I don’t think having these negative thoughts has affected my behavior
- No vote
Thoughts, Feelings, and Behaviors: Their Connection
The connection between your emotions and your illness

- Feeling bad can often lead to poor eating habits, lack of exercise, isolating yourself, etc…
  - All of these things can worsen one’s physical condition
  - They may make it hard to get to doctor’s appointments

- Three things people may feel:
  - Depressed
  - Anxious
  - Stressed
The Need to Act Quickly if You’re Feeling Sad

- In studies of patients recently diagnosed with a chronic illness, the highest risk of depressive symptoms occurred during the first two years.
“Sad” vs “Depressed”

- How do we know when we’re depressed?
  - difficulty concentrating, remembering details, and making decisions
  - fatigue and decreased energy
  - feelings of guilt, worthlessness, and/or helplessness
  - feelings hopeless
  - Trouble sleeping OR sleeping too much
  - irritability, restlessness
  - loss of interest in activities or hobbies that you once enjoyed
  - overeating or appetite loss
  - persistent sad, anxious, or "empty" feelings
  - Not just every now and then – really gets in the way of your functioning
“Worry” vs “Anxiety”

- How do we know when we’re anxious?
  - Feelings of nervousness or dread
  - Trouble concentrating
  - Feeling tense and jumpy
  - Anticipating the worst
  - Irritability
  - Restlessness
  - Watching for signs of danger
  - Feeling like your mind’s gone blank
  - Physical symptoms (pounding heart, sweating, stomach or headaches, etc.)
  - **Not just every now and then – really gets in the way of your functioning**
Lupus, Depression, and Anxiety

- Depression is the most frequently documented psychiatric problem in patients with lupus
  - Point prevalence rates between 10.8% and 39.6%
  - Depressive disorders occur in almost 44% of hospitalized patients with active lupus, and symptoms are significantly associated with CNS involvement (Nery et al., 2007)
- Depression has been shown to be a strong predictor of medication non-adherence in lupus (Julian et al., 2009)
Lupus, Depression, and Anxiety

- As many as 46% of lupus patients may suffer from an anxiety disorder (Nery et al., 2008)
- Depression and anxiety are often related to the changes in physical appearance and limitations in physical abilities that come along with lupus (Auerbach & Beckerman, 2011)
- The more chronic the symptoms, the more likely symptoms will ensue
Negative Reinforcement Cycle of Non-Adherence

**Emotions**
- Fear
- Sadness
- Frustration

**Thoughts**
- I am afraid of dying
- I don’t want to be sick, I want to be normal
- I hate to take these medicines

**Behaviors**
**AVOIDANCE**
- Skipping pills
- Missing appointments
- Not communicating with your doctors

**Short-term consequences**
- Temporary relief
  - Avoidance of negative emotions
  - Stop thinking about the disease; “pretend” I am not sick

**Long-term consequences**
- Progression of the disease
- Loss of quality of life (hospitalization, missed work/school/time with loved ones)
Stress is Common

- Lupus patients may feel a loss of control and uncertainty about their future

- Why care about stress?
  - Can increase perceptions of pain
  - Stress-illness cycle
Stress-Illness Cycle

- Stressor
- Reaction to Stress
- Increased Sensitivity to Stress
- Wear and Tear on Body and Organ Systems
- Reduced Optimum Health
Why and how does stress lead to illness?

- Stress raises the levels of hormones like cortisol and adrenaline and boosts nervous system activity
  - affects your health and leads to further anxiety and more stress
- Stress affects your immune system: weakens it
- Stress affects your metabolism adversely
  - excessive weight gain or loss
- It affects hormonal levels of estrogen and progesterone
- Affects brain neurotransmitters
  - Can cause loneliness, depression and other mental disorders
- Can increase acidity in the gastrointestinal system
- Can raise the level of toxins in your blood and causes skin diseases and conditions like acne
- Causes a buildup of pressure which leads to headaches and migraines
- Prolonged stress can lead to heart attacks and strokes that affect the quality of your life and even cause death
Stress Isn’t Always Bad

● All stress is not bad; in fact, a small amount of it at the right time is good

● Examples:
  - when you feel a surge of adrenaline before a competition
  - when you’re threatened in any way, the surge of hormones that rushes through your system raises your self-protective instincts and keeps you from harm and danger

● The key to making the most of stress is to not let it become a chronic issue in your life
  - no use worrying about the things you cannot control

● If things are within your control, try to be proactive and find a solution instead of worrying and stressing yourself out

● Prevent and minimize stress
  - follow a diet rich in nutrients and vitamins
  - Get good sleep
  - exercise regularly
The Impact on Caregivers

- Parents and family members of patients with chronic illness also experience stress and mental health issues.
- Study that found 80% of parents saying that their child’s condition has affected their work lives:
  - 90% said it affected their mental health.
  - 70% said it affected their marriage.
  - Reduces ability of parent(s) to be social, engage in activities outside of the house.
- High levels of anxiety, overprotection, excessive feelings of responsibility, guilt, depression in caregivers:
  - Hopelessness, frustration, isolation from the community.
Impact on Social Life

- Support from close friends can buffer the impact of stressors
  - Adjustment to disease
  - Coping with difficult medical treatment
- Patients who report high levels of BOTH family and friend support exhibit lower levels of behavior problems than those with support from only one source
Another Contributor of Stress: Illness Representation

- The significance of having lupus
- Disease course
- Symptoms and severity
- Controllability of the disease
- Treatment
Illness representation makes a difference

Illness representations may influence the coping strategies that people employ, and may influence self-management, health outcomes, and quality of life (Han et al, 2006; Nicholas et al, 2007)

- In other health conditions, positive illness representation and coping (“I am able to manage my illness”) correlated with less:
  - disease activity
  - disability
  - mood disturbance
  - pain and psychological distress
Coping with chronic illness

- Coping: making regular cognitive and behavioral efforts to manage your disease, prevent disability, and enhance health-related quality of life (Nicassio, 2008)

- Types:
  - Passive (avoidance, denial)
  - Active (problem solving, seeking support)
  - Meaning-based (acceptance, finding benefits, spiritual mechanisms)
Balance

Focus is on enhancing the self and personal growth as ways to maximize quality of life and manage disease.
Reduce Stress By Increasing Healthy Living

- Set a routine
- Exercise
- Eat healthy
- Relax
- Sleep
- Manage your time and pace yourself
- Be social/active
Additional Points to Consider

- Patient education
  - Absolutely critical for long-term management
  - Broad overview of illness, treatments, and general management issues
    - Doctor-patient relationship
- Cognitive Behavior Therapy (CBT)
  - Has established empirical efficacy for chronic illness
  - Development of self-efficacy, pain management, stress management, mood regulation, problem solving, personal growth (Greco et al., 2004; Karlson et al., 2004)
- Exercise
  - Physical endurance, cardiovascular health, mood regulation
- Development and maintenance of effective social support network and mechanisms
  - Important for self-esteem, stress resistance, enhancement of coping
What to do

- Stay connected (#1): Establish and maintain quality relationships with friends and family
  - support groups composed of other people experiencing similar challenges
    - will not only aid your own well-being, but also provide rewarding opportunities for you to help others

- Take care of yourself
  - Don’t allow worries about your illness to get in the way of eating properly, getting rest and exercise, and having fun
  - RELAXATION

- Maintain a daily routine of work, errands, household chores, and hobbies as much as possible
  - This will provide you with a feeling of stability amid the chaos and uncertainty of your illness
Diaphragmatic Breathing

- To check how you are breathing:
- Rest one hand on your upper chest and the other over your belly
- Breathe normally for a minute or so
- Notice which hand rises when you first inhale
Polling Slide: “Which hand was moving during this exercise?”

- The hand on my chest.
- The hand on my stomach.
- Both hands.
- No vote
Diaphragmatic Breathing

- Find a comfortable upright position. Relax your neck and shoulders, and close your eyes if you’re comfortable.
Using Diaphragmatic Breathing as Mindfulness

- Adding in the exercise of counting your breath
- Allows you to put all of your focus into breathing from your diaphragm
  - clears your mind of stressors/difficult thoughts or feelings
Progressive Muscle Relaxation

- Start with your legs. Tighten all the muscles of your legs. Tense the muscles further. Hold onto this tension. Feel how tight and tensed the muscles in your legs are right now. Squeeze the muscles harder, tighter... Continue to hold this tension. Feel the muscles wanting to give up this tension. Hold it for a few moments more... and now relax. Let all the tension go. Feel the muscles in your legs going limp, loose, and relaxed. Notice how relaxed the muscles feel now. Feel the difference between tension and relaxation. Enjoy the pleasant feeling of relaxation in your legs.

- Now focus on the muscles in your arms. Tighten your shoulders, upper arms, lower arms, and hands. Squeeze your hands into tight fists. Tense the muscles in your arms and hands as tightly as you can. Squeeze harder.... harder..... hold the tension in your arms, shoulders, and hands. Feel the tension in these muscles. Hold it for a few moments more.... and now release. Let the muscles of your shoulders, arms, and hands relax and go limp. Feel the relaxation as your shoulders lower into a comfortable position and your hands relax at your sides. Allow the muscles in your arms to relax completely.

- Focus on your breathing. Slow, even, regular breaths. Breathe in relaxation.... and breathe out tension..... in relaxation....and out tension.... Continue to breathe slowly and rhythmically.

- Tighten the muscles of your back now. Feel your back tightening, pulling your shoulders back and tensing the muscles along your spine. Arch your back slightly as you tighten these muscles. Hold.... and relax. Let all the tension go. Feel your back comfortably relaxing into a good and healthy posture.

- Turn your attention now to the muscles of your chest and stomach. Tighten and tense these muscles. Tighten them further...hold this tension.... and release. Relax those muscles.

- Finally, tighten the muscles of your face. Scrunch your eyes shut tightly, wrinkle your nose, and tighten your cheeks and chin. Hold this tension in your face.... and relax. Release all the tension. Feel how relaxed your face is.

- Notice all of the muscles in your body.... notice how relaxed your muscles feel. Allow any last bits of tension to drain away. Notice your calm breathing.... your relaxed muscles.... Enjoy the relaxation for a few moments....

- When you are ready to return to your usual level of alertness and awareness, slowly begin to re-awaken your body. Wiggle your toes and fingers. Swing your arms gently. Shrug your shoulders. Stretch if you like.
For additional questions or further information, please feel free to contact me!

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References

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