

## FEATURED EXPERT

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Lupus Center

**Director of Rheumatology Clinical Trials**Columbia University Medical Center  
New York, New York

Anca D. Askanase, MD, MPH, is a member of the Columbia University Medical Center Rheumatology faculty, where she is the founder and clinical director of Columbia's new Lupus Center and the director of rheumatology clinical trials. Dr Askanase is an internationally renowned clinician, diagnostician, and researcher with more than 15 years specializing in complex SLE. Dr Askanase trained as a rheumatologist at New York University, where she remained for more than 15 years on the faculty directing clinical trials, training fellows and residents, and treating challenging cases of SLE at the school's prestigious hospitals.

\*Data from the 2011 National Burden of Lupus survey was funded and developed by GSK. This survey included 957 people in the lupus community—502 people who reported being diagnosed with SLE, 204 supporters (family members or friends) of people with lupus and 251 rheumatologists.

**This promotional program was developed in conjunction with and sponsored by GSK, based on an interview with Anca D. Askanase, MD, MPH.**

**Dr Askanase received a fee for participation in this program.**

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## TOPIC HIGHLIGHTS

- SLE has a considerable impact on patients, including their psychosocial well-being, interpersonal relationships, quality of life, productivity, and healthcare utilization.<sup>1-6</sup>
- Due to the complexity of SLE management, healthcare providers may need to coordinate additional patient care and support from a multidisciplinary team.<sup>7</sup>
- Survey data revealed a serious gap between what patients experience and what they are willing to share with others, including their rheumatologists.\*
- Facilitating positive physician-patient interactions is an important part of SLE management. Such interactions are associated with patients being more satisfied with their management plan, feeling that their SLE is well controlled, expressing more favorable perception of current health, and having more hopefulness about their future health.<sup>8</sup>
- To facilitate effective communication about SLE, it is important that patients be able to help physicians distinguish coincidental but unrelated symptoms from the symptoms of a flare.<sup>7</sup>
- The American College of Rheumatology (ACR) guidelines recommend lifelong monitoring of disease activity and chronic comorbidities.<sup>7,9</sup>
- A range of clinical issues must be considered when managing patients with SLE, including fatigue, neuropsychiatric syndromes, cardiovascular disease, nephritis, and osteoporosis. Damage to major organ systems accrues over time and there is an increased mortality risk.<sup>10-21</sup>



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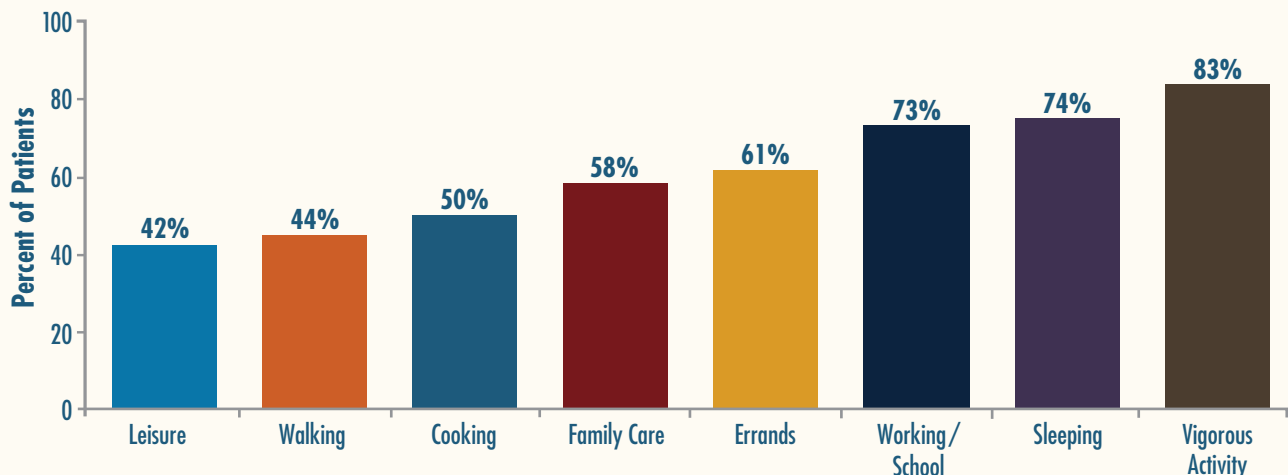
New York, New York

### What are initial concerns of patients when first diagnosed with SLE? Over time, how do these concerns change from disease symptoms to other issues such as disease progression?

In my professional experience, I have found that receiving a diagnosis of SLE can be very emotionally challenging for patients. After I have reviewed symptoms, laboratory findings, and the final diagnosis with each patient, we discuss their questions and concerns. Patients are often worried about the impact the disease will have on their daily lives, potential management challenges, and mortality risk.

SLE has a considerable impact on patients, including their psychosocial well-being and interpersonal relationships.<sup>1</sup> In the recent UNVEIL survey of 827 patients with lupus and their caregivers, 85% of patients reported depression, 90% of patients reported anxiety, and more than 94% of 253 caregivers reported increased anxiety and stress.<sup>22</sup> The majority of patients with the disease report a periodic or permanent effect on daily activities, and patients with SLE have impaired function affecting multiple aspects of daily life (Figure 1).<sup>1,2,22</sup> In a clinical study of 829 patients, nearly all (91%) had  $\geq 1$  valued life activity affected by SLE, and almost half (49%) were unable to perform  $\geq 1$  valued life activity.<sup>2</sup>

**Figure 1: Some Valued Life Activities Affected by SLE<sup>2</sup>**



Prospective study of 829 patients with SLE participating in the University of California at San Francisco Lupus Outcomes Studies. Valued Life Activities (VLA) disability was assessed during annual telephone interview 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 non-Hispanic.<sup>2</sup>

In fact, SLE adversely affects all aspects of health-related quality of life. In a prospective study of 186 patients with SLE enrolled in the Lupus Atherosclerosis Prevention Study at Johns Hopkins University School of Medicine from 2002 to 2005, patients with SLE scored lower in all domains of the SF-36 (Short Form-36) compared to controls. These quality-of-life ratings did not improve over time.<sup>3</sup> A 2011 survey showed that patients with SLE also have higher rates of work absenteeism and lost wages compared to the general population.<sup>4\*</sup>

Patients may also face challenges in diagnosis and disease management. More than 60% of patients report initial misdiagnosis, with 55% of them seeing 4 or more different healthcare providers before a correct diagnosis was made.<sup>22</sup> According to a survey, the average hospital stay for severe lupus flares was 10.5 days.<sup>22</sup>

Organ damage and mortality risk are important points to review with patients and are often central to their concerns, so in my clinical practice I present evidence-based information on these issues. I explain to patients that they can accrue organ damage even with low or moderate disease activity as SLE progresses, and that one-third to one-half of patients experience permanent organ damage within 5 years of diagnosis.<sup>19,20</sup> This early organ damage is associated with a reduced 10-year survival rate.<sup>23</sup>

### **What expectations and concerns do patients typically have regarding management of SLE? What expectations do patients typically have of their healthcare providers in helping them manage their disease?**

Patients are often anxious about being diagnosed with this unpredictable, chronic illness that has the potential to cause disability and mortality. Many patients initially hope that their disease will be limited and that they will be able to return to full productivity, but that is not always possible. Psychological support is required, and patients need to develop coping skills; in my practice, I refer patients to social workers and formal or informal support groups.<sup>7</sup>

Because SLE is a complex disease that requires lifelong self-management, it is important to create individualized plans that provide appropriate education and support for patients and their families. Patients must learn to monitor their disease and help healthcare providers distinguish flares from unrelated symptoms.<sup>7</sup> Active patient involvement is an essential part of the decision-making process. Shared decision-making between the patient and healthcare provider is a key consideration in patient care. A strong physician-patient relationship that encourages communication, routine physical examinations, and laboratory testing are all important aspects of successful disease management.<sup>24</sup> Due to the complexity of SLE management, healthcare providers may need to coordinate additional patient care and support from cardiologists, counselors, dermatologists, nephrologists, orthopedic surgeons, ophthalmologists, physical/occupational therapists, rheumatologists, social workers, and other clinicians.<sup>7</sup>

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**What data exist regarding patients being totally forthcoming in sharing their feelings and concerns about SLE with their healthcare providers? What is the potential impact of healthcare providers not being aware of underlying, unreported disease symptoms?**

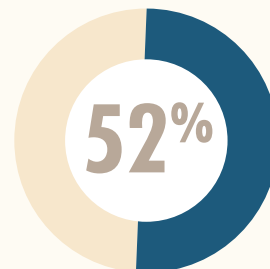
A GfK Roper North America survey\* of 957 members of the lupus community, including patients, family members and/or friends, and rheumatologists, revealed a serious gap between what patients experience and what they are willing to share with others, including their rheumatologists. The survey was funded and developed by GSK. Data from the survey indicated communication gaps about symptoms between doctors and patients; in the survey, 52% of patients with lupus reported they minimize their symptoms when speaking to their physicians. However, 72% of physicians disagreed that patients tend to underreport their symptoms (Figure 2). In fact, 53% of doctors who participated in the survey believed that patients were open and honest with them about their symptoms.

I have seen these challenges reflected in my clinical practice. It is critical that patients and physicians understand the importance of clear communication because it has implications for disease management. For example, patients may not mention low-level disease symptoms as they may consider it a normal part of living with SLE. However, low-level disease activity can still cause organ damage and may represent a missed opportunity for identifying a flare and instituting early intervention.

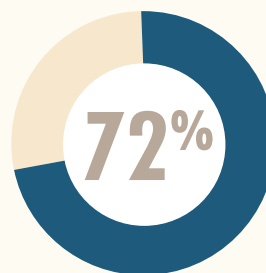
**How can healthcare providers enhance communication with patients regarding SLE issues such as disease symptoms, impact of SLE on patients, and realistic disease management goals?**

To facilitate effective communication about SLE, it is important that patients be able to help physicians distinguish coincidental but unrelated symptoms from the symptoms of a flare.<sup>7</sup> Because living with such a variable disease can be frustrating, it is important to empower patients to take charge of

**Figure 2: Communication Gaps in Lupus Care**



of patients report that they minimize their symptoms when they talk to physicians



of physicians are unaware that patients tend to underreport their symptoms

health-related factors that they can control, such as eating a balanced diet to minimize cardiovascular risk, maintain bone health, and prevent anemia; getting exercise as tolerated; using broad-spectrum sunscreen protection; getting sufficient sleep, including naps when needed; ensuring stress management; cessation of smoking; and receiving appropriate vaccinations.<sup>25-28</sup> I find it can be helpful to recommend appropriate patient programs and symptom tracking tools, like lupus questionnaires, the GSK Lupus Checklist/customizable lupus journal ([www.usinlupus.com](http://www.usinlupus.com)), and the My Lupus Log Android app.

**Why is it important for healthcare providers to carefully monitor and measure SLE disease activity and to continuously communicate this information to their patients?**

The ACR guidelines recommend lifelong monitoring of disease activity and chronic comorbidities.<sup>7,9</sup> The guidelines suggest that patients with very mild stable disease receive follow-up visits every

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3-6 months, with monitoring that includes assessment of disease activity, laboratory tests, identification of new or existing kidney disease, and presence of SLE manifestations.<sup>7</sup> The European League Against Rheumatism recommends that clinicians conduct clinical and laboratory assessments every 6-12 months in patients with no disease activity, organ damage, or comorbidity, and that follow-up should regularly include: review of disease activity, organ damage, and quality of life; laboratory assessments; identification of new or existing kidney disease; review of cardiovascular risk factors; assessment of osteoporosis and calcium and vitamin D intake; reinforcement of smoking cessation and exercise; cancer and infectious diseases screening; identification of mucocutaneous lesions; and review of neuropsychological symptoms.<sup>9</sup>

Although these recommendations provide guidance on the timing of follow-up appointments, more frequent monitoring may allow earlier detection of "silent variables."<sup>29</sup> In a retrospective analysis, 1 in 4 patients seen over 2 years had at least one "solitary silent variable," detectable only through routine laboratory assessments (N=515) (Figure 3). These data support following patients with mild or inactive disease at 3- to 4-month intervals.<sup>29</sup> In my clinical practice, I feel that frequent monitoring of serological activity is critical. I currently use routine blood tests and urinalysis, and I hope that, in the

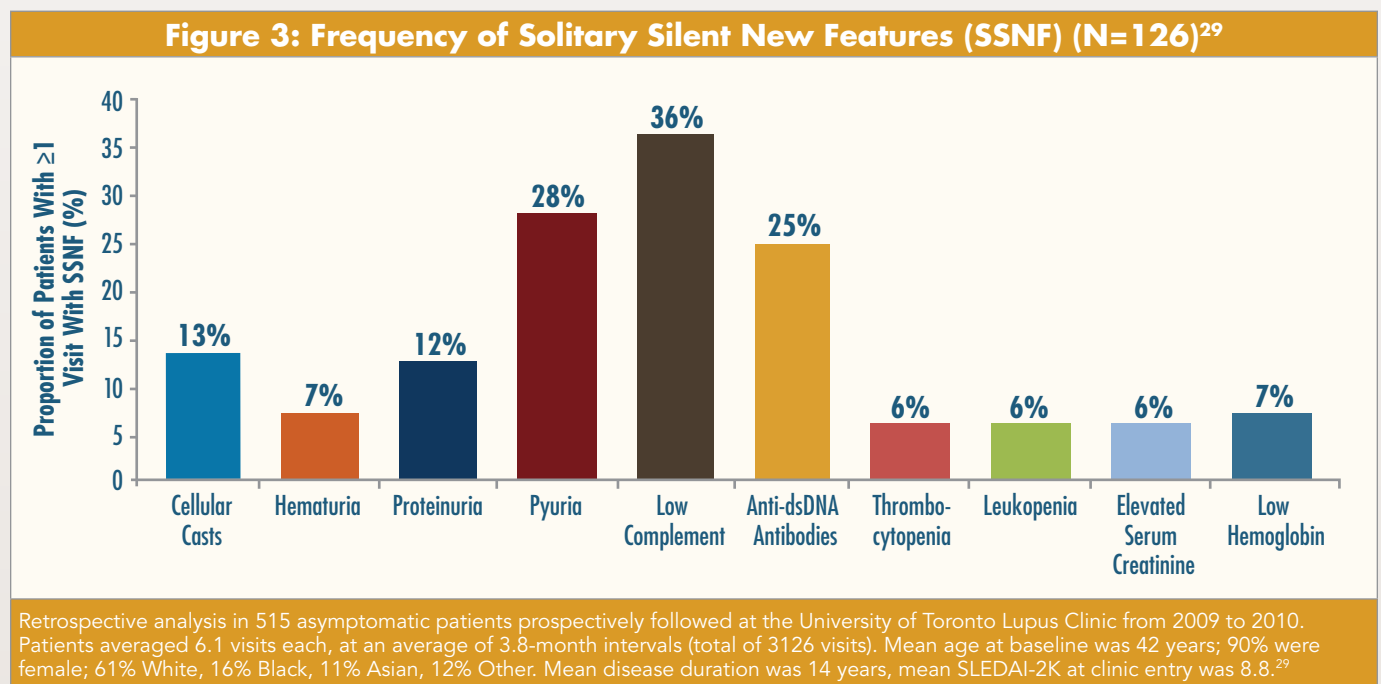
coming years, better biomarkers will become available for more accurate disease monitoring.

**It's not uncommon for patients with SLE to be seen by more than one healthcare provider. What are important considerations for healthcare providers in taking over care of a patient with SLE from another clinician?**

Facilitating positive physician-patient interactions is an important part of SLE management (Table 1).

| Table 1: Positive Physician-Patient Interactions <sup>8</sup> |
|---|
| Involve patient in lupus management plan                      |
| Set clear goals with patient                                  |
| Be an active listener   |
| Help patient understand lupus                                 |
| Encourage patient to ask questions                            |

Such interactions are associated with patients being more satisfied with their management plan, feeling that their SLE is well controlled, expressing more favorable perception of current health, and having more hopefulness about their future health. Setting individual goals with patients is a particularly key consideration in these interactions.<sup>8</sup>



Ongoing partnership between the patient, physician, and the entire healthcare team is needed to effectively manage SLE.<sup>24</sup> In my clinical practice, I find the multidisciplinary team to be crucial for patient care. Because SLE can involve multiple organ systems, different specialist providers may have roles on the multidisciplinary team, including rheumatologists, dermatologists, neurologists/psychiatrists, ophthalmologists, cardiologists, nephrologists, maternal-fetal specialists, orthopedic/musculoskeletal specialists, infectious disease specialists, psychologists, and social workers/counselors.<sup>7,30,31</sup> Therefore, I find that, in addition to developing a strong partnership with the patient, good communication with other healthcare professionals is critical in the management of patients with SLE, particularly if I am taking over the care of a patient from another clinician.

### **What additional clinical issues associated with SLE disease progression should be taken into account by healthcare providers when managing patients with SLE?**

In my professional experience, there is a range of clinical issues that clinicians must consider for their patients with SLE. Fatigue is one of the most prevalent and, from the patient's perspective, one of the most devastating clinical manifestations of SLE. Increasing fatigue is associated with increased helplessness and decreased mental and physical function. Although it is a nonspecific, subjective symptom, the severity of fatigue may be related to psychosocial factors and/or disease activity, so it is important to discuss fatigue with patients.

Neuropsychiatric syndromes\* affect 37% to 80% of patients with SLE.<sup>11-15</sup> The most common manifestations include cognitive dysfunction,<sup>†</sup> headache, depression, and anxiety.<sup>11</sup> Less common manifestations include seizures, psychosis, and movement disorders.<sup>11</sup> Compared with expected rates in the general population, the rate of cardiovascular events is higher overall in patients with SLE.<sup>16</sup> Additionally, nephritis impacts over 50% of patients as SLE progresses.<sup>17</sup> Osteoporosis is another major concern for patients with SLE, and fracture risk is estimated to be significantly higher than in the general population.<sup>18</sup>

Organ damage is a crucial consideration; one-third to one-half of patients with SLE accrue permanent organ damage within 5 years of diagnosis.<sup>19,20</sup> Organ damage is one of the most important correlates with mortality, and early organ damage is associated with reduced 10-year survival rate.<sup>32</sup> In a prospective cohort study, 25% of patients with early damage (measured by initial SDI [Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index]  $\geq 1$  at the time of initial assessment) died within 10 years, compared to 7.3% of patients with no early damage defined as SDI=0 ( $P=0.0002$ ).<sup>23</sup> Despite improved survival rates overall, SLE remains a chronic disease with higher than expected mortality rates.<sup>21</sup> Survival rates have significantly improved in patients diagnosed between 1980 and 1992 compared with patients diagnosed between 1950 and 1979.<sup>21</sup>

\*Definition of neuropsychiatric lupus included headache, per American College of Rheumatology criteria. Not all manifestations observed in SLE patients may be attributed to SLE.

†Cognitive dysfunction included difficulties in attention, concentration, memory, and visual perception.

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