

Expert opinion: Learning from lupus

By Edward H. Yelin, PhD

We all know that systemic lupus erythematosus disproportionately impacts women and racial and ethnic minorities. We also know that people of lower socioeconomic status are often diagnosed later and have poorer outcomes after diagnosis. The same groups that are genetically at greater risk for SLE, namely women and minorities, are also more likely to be poor and uninsured. Add to this the complex and chronic nature of SLE and you have a perfect storm – a situation where those already at a great disadvantage are *more* likely to be sick and *less* likely to get the care they need.

While genetics plays an important role in the onset of SLE, once diagnosed, the progression of the disease appears to be more heavily influenced by race/ethnicity and socioeconomic status. For this reason, SLE provides a revealing window into our healthcare system, highlighting health disparities and the related issues of cultural competency, coordination of care, and access to care.

Utilizing lupus to examine access to care, cultural competence and more

The differences in disease progression based on race/ethnicity and socioeconomic status have led to a number of efforts to explain these disparities in outcomes, including the American College of Rheumatology's Lupus Initiative, which is aimed at addressing these disparities through trainee and provider education. The evidence points to several factors, beginning with delayed diagnosis and treatment. Under the best of circumstances, diagnosis of SLE is complex and may take several years from the onset of symptoms. Furthermore, because the poor and uninsured are unlikely to see a primary care physician for well-care, SLE may go undiagnosed and untreated for years.

Once diagnosed, access to specialists with experience treating SLE is crucial for good outcomes. But these providers often don't accept Medicaid, forcing the disadvantaged to travel longer distances for care, if they don't give up. Even those with private insurance may not have the necessary access to care due to the limitations of some managed care programs.

Compounding the issue of access to care is the lack of coordination of care between providers even within the same clinic. Lack of coordination of care and the high demands of SLE treatment are challenging for any patient, but are especially burdensome on those who lack the resources and support systems needed for good disease management. The situation is further aggravated by language barriers and poor communication due to cultural and background differences, or compromised cognitive function commonly related to the disease.

Once we get past the more obvious issues of access to care and coordination of care, examining SLE also instructs us about other factors related to race/ethnicity and socioeconomic status that impact disease progression. As with many other autoimmune diseases, stress is believed to impact lupus disease activity, possibly triggering and prolonging flares. For the disadvantaged, stress may play a major role in poor outcomes. Being unemployed, or living paycheck-to-paycheck, is a major stressor. Housing, child-care, good nutrition, and transportation may be taken for granted by those with greater resources, but for others, these can be daily challenges. The disadvantaged often work longer hours with fewer benefits; taking time off to visit doctors may not always be possible. The disadvantaged generally have more stressful lives, higher rates of depression, and fewer resources and support systems to deal with these stressors.

In addition to managing stress, nutrition is a factor in disease self-management. But more disadvantaged patients may not be able to afford wholesome foods for optimum health. They are more likely to consume a diet of low-quality processed foods, typically high in sugar and trans-fats. An unbalanced diet combined with stress may be one answer to why the disadvantaged have accelerated disease progression and poorer outcomes.

Good self-management is crucial. This includes proper nutrition, managing stress and mental health, and regular visits to a primary care physician, rheumatologist, and other specialists as needed.

For more information, visit <http://thelupusinitiative.org/>. ▲

In summary: Lessons learned from lupus

Understanding disparities and other issues common in SLE management has broad implications for our healthcare system at large. And examining the multiple facets of SLE can have broad applicability in medical education. As a starting point for that learning, we know that the following can be associated with improved outcomes in SLE:

- Having access to the right providers. This means having good insurance that allows access to health care providers with experience in treating complex, chronic diseases like SLE.
- These healthcare providers should also be skilled communicators with patients of varied backgrounds and cultures.
- Coordination of care is crucial to ensure that lupus patients have the full complement of resources needed. Access to care and coordination of care provide the support that patients need for good self-management, which underpins it all.
- Good self-management is crucial. This includes proper nutrition, managing stress and mental health, and regular visits to a primary care physician, rheumatologist, and other specialists as needed.

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What's happening Tuesday?

The 2012 ACR Town Hall Meeting on Tuesday, November 13, at 1:30 PM in Ballroom A at the Washington Convention Center!

ACR members are encouraged to come and find out about the College's activities and initiatives.

We'd love to hear what you want to learn more about. You can:

- Email ACR President, James O'Dell, MD at odell@rheumatology.org
- Post a question on our Facebook page at www.facebook.com/rheumatology
- Tweet your questions/comments to @ACRrheum using the hashtag #ACR2012
- Ask us in person during the Town Hall meeting

Following the ACR Town Hall, the annual Business Meeting will confirm incoming ACR Leadership, including the 76th ACR President.



NOW THAT YOU KNOW what's happening Tuesday, we look forward to seeing you there!