

## Who Should Look After Patients with Mild Lupus?



I have several patients with systemic lupus erythematosus (SLE) in my family practice. This is in itself an anomaly, given that lupus occurs in about one in 2000 people in the general population. Most North American primary care practices are smaller than 2000 people, so each primary care physician would be expected to have few if any patients with lupus. Mine were referred to me from the same clinic that is described in this issue of *The Journal*<sup>1</sup> and most of them continue to attend that clinic. One patient is a young nurse who has emerged relatively intact from severe lupus nephritis complicated by disabling steroid myopathy. She continues to require anticoagulation and a small daily dose of prednisone and is followed regularly at the Lupus Clinic. Her threshold, and mine, for seeking advice from the clinic about new symptoms or management of intercurrent illness is extremely low. Another patient, an older woman, has a malar rash, photosensitivity, and positive antinuclear antibodies and anti-DNA, but no other symptoms or signs. She has declined to go back to the clinic and she continues to feel well. These 2 patients illustrate a key issue raised in this month's *Journal*<sup>1</sup>: who should monitor patients with mild disease? The first patient now has relatively quiescent disease, but I would never call her lupus mild. I know that she has major organ damage and that her chances for another serious flare are substantial. The second patient has never had symptoms beyond a rash over several years, and her risk for major organ involvement is relatively lower.

What is meant by mild disease? The American College of Rheumatology (ACR) guidelines for referral and management of SLE in adults refer to patients with mild and stable disease as "those without major organ involvement and/or co-morbidity"<sup>2</sup>. The study group in the article by Urowitz, *et al*<sup>1</sup> had a high proportion of patients with renal and central nervous system involvement, suggesting a relatively severe spectrum of disease, but also a high proportion of patients (more than three-quarters) who would not have been included in the ACR meaning of stable and mild disease, if

that meaning includes those with a history of major organ involvement. A SLEDAI score (SLE Disease Activity Index) of 0 on 2 consecutive visits may reflect remission in a relapsing and remitting condition, but does not necessarily reflect a lack of previous severe disease with major organ involvement. In the case of my 2 patients, the first does not fit the ACR guideline description of mild disease but the second probably does. Of note, my first patient might have met inclusion criteria for the study by Urowitz, *et al*, but the second, who only visited the clinic once, would not have met criteria because a minimum of 3 clinic visits was required. That sort of selection effect, and the centripetal referral patterns and more severe spectrum of disease found at an academic tertiary referral center, may limit the applicability of the findings of this article to all lupus patients in the community. This would be the case if more severely affected patients were more likely to relapse than those mildly affected. Within the study, lupus patients with renal involvement were especially likely to relapse after 2 visits with a SLEDAI of 0.

In the Urowitz, *et al* study, the intervention rate was high, even among those with a continuing SLEDAI of 0 on the third consecutive visit. What is a significant intervention, one that a rheumatologist would be qualified to make, but not a primary care physician? The most frequent intervention in the study group was to decrease medications, a step that could be outlined in a referral letter from the rheumatologist at the time that a mild and stable patient was referred back to the primary care physician. Increasing or adding new medications, as occurred in a quarter of study patients, is of more concern, especially if the medications were antimalarials or immunosuppressives, since many primary care physicians lack confidence in initiating and monitoring these agents<sup>3</sup>.

Can primary care physicians recognize a relapse or complication of SLE that requires intervention? The ACR guidelines call on primary care physicians to monitor mild

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disease and laboratory toxicities and to refer back to the lupus care specialist if there is an increase in disease activity or complication. Given the low exposure of primary care physicians to patients with lupus and the protean manifestations that could signal a flare or complication, it is likely that lupus care specialists would be more attuned to this possibility than would most primary care physicians. Does that mean that primary care physicians should not follow such patients?

To answer that question, it is important to look to the role of primary care physicians and to the logistics involved if all lupus patients without major organ involvement and/or comorbidity require regular followup from a lupus care specialist. The first implication is that those specialists and clinics will be flooded if many such patients exist in the community. Lupus care specialists would then find themselves attending to those at low risk for serious consequences of lupus, perhaps to the detriment of those in more need of subspecialty care. This would be an inefficient and probably undesirable use of scarce resources. A second implication speaks to the role of the primary care physician in longitudinal care, prevention, counselling, and care coordination. Lupus care specialists who wish to follow all their patients with mild and stable disease may find those patients presenting with mild intercurrent illnesses, chronic diseases, and a myriad of other health needs, all unrelated to lupus. This effect would further exacerbate demands on the time of lupus care specialists and fragment the care of such patients. The third implication would be for patients, many of whom have limited access to rheumatologists without a great deal of travel and inconvenience. This is the case in Ontario<sup>4</sup> and is likely true for most jurisdictions in the world.

What can we conclude from the study by Urowitz, *et al*?<sup>1</sup> Most lupus patients cared for in tertiary care settings have had major organ involvement and many relapse after remission. Such patients require close followup by a lupus care specialist, as recommended in the ACR guidelines. The study does not allow us to draw conclusions about the mild and stable patients described in the guidelines since few study patients fell into that group.

Who then should monitor SLE patients with mild disease? In the case of those in remission but with a history of severe disease, such as my first patient, the answer is a lupus care specialist if at all practicable. Patients who have never had major organ involvement or serious co-morbidity are at lower risk but still require ongoing monitoring. This

situation corresponds to my second patient. As with other management decisions, I like to elicit patient preferences, especially when the course of action is not clearly indicated by existing evidence. If my second patient preferred regular followup at the Lupus Clinic, I would be fully supportive of that choice. If she preferred to follow up with me, that would also be a reasonable course of action. For me and for the many primary care physicians with only one or 2 such patients, a written guide sent at the time a patient is returned to primary care would be ideal. The investigations to be done at specific intervals, the major signs and symptoms to watch for, and the findings indicating a need for referral back to the lupus care specialist would be key elements of such a guide.

Who should monitor SLE patients with mild disease? Let's work together, taking into account patient preferences and circumstances. This may take more effort on our part than automatic followup with a lupus care specialist, but it's sensible, practical, and consistent with the imperative to direct care where it is most needed.

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