Palliative Care for the Rheumatologist: When Does the End Begin…And Why Does It Matter?

By Alexandra Saltman, B.A. (Hons), MD, FRCPC

How often, if ever, would you refer a patient with a life-limiting rheumatologic condition to specialized palliative care services?

Would you do so if your patient had uncontrolled symptoms; if he or she had spiritual, psychological or social distress stemming from their illness; or if he or she had a short prognosis, and required assistance with advance care planning?

How comfortable would you be in identifying patients in your practice who might benefit from a palliative approach to care? And how would you introduce this approach to your patient?

When we think of palliative care, we often think about care for a dying patient in the last days, weeks or months of life. But palliative care in 2019 has come to encompass much more than that limited definition. The so-called "third wave" of palliative care seeks to integrate a palliative approach to care alongside disease-specific treatment, as part of a continuum of care. This approach aims to improve quality of life for patients with life-limiting illnesses, through the prevention and relief of suffering, the control of symptoms, and the management of physical, psychosocial and spiritual distress.

Such an approach is supported by a growing body of evidence that demonstrates improved patient satisfaction with care, decreased symptom burden and, in some cases, better survival, when a palliative approach to care is integrated early in a patient's disease trajectory.[1,2,3,4,5,6,7]

The last several decades have brought major advances in the treatment of systemic rheumatic diseases that have led to reduced morbidity and mortality for many of our patients. However, a patient population remains – those with systemic vasculitis, systemic sclerosis, inflammatory myositis, and severe courses of systemic lupus erythematosus and rheumatoid arthritis – who still suffer from life-limiting diseases with high symptom burdens and, often, poor prognoses. Nonetheless, these patients hardly ever have access to palliative care, and there is little data on their palliative care needs.[8,9,10,11,12]

At the same time, recent advances in oncology have created a second population of patients at the intersection of these two fields. By "awakening the immune system," new targeted therapies to treat metastatic cancer – namely, immune checkpoint inhibitors – have led to the development of de novo autoimmune diseases, so called rheumatic immune-related adverse events, in about one third of patients. This phenomenon has created another population of patients with both rheumatologic and palliative care needs.

From my earliest clinical experiences, I gravitated toward caring for patients suffering from complex, chronic disease. I was drawn to the natural areas of overlap between rheumatology and palliative care—in their shared emphasis on pain and symptom management, quality-of-life interventions, longitudinal relationships with patients and families, and complex, chronic disease management. But, I encountered few, if any, opportunities for these patients to access palliative services during my training, notwithstanding that the nature of their illnesses and treatments often made symptom management, and end-of-life care planning, uniquely challenging for their treating physicians. And so, it was for these reasons that I set out to position myself to practice dually as a rheumatologist and a palliative care physician.

By completing advanced clinical training in both specialities, through the Royal College certified Rheumatology Subspecialty Program at the University of Toronto, followed by a University Health Network Clinical Fellowship in Palliative Medicine, I have set out to create a niche at the intersection of these two specialties.

To pilot this model of chronic, integrated, subspecialty palliative care in rheumatology, I have launched two new clinics at Mount Sinai Hospital in Toronto:

(1) Advanced Pain and Symptom Management in Rheumatology Clinic, focusing on complex symptom management, palliative planning and end-of-life care for patients diagnosed with complex,

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Update from Dr. Sylvie Ouellette in New Brunswick

Now that we are down to two full-time members, meetings in the Rheumatology Division at The Moncton Hospital are best described as dates. Dr. Peter Docherty has kindly popped out of retirement, two-to-three days per week, to help with the clinical load. We remain hopeful that we will be able to recruit a new full-time member, and would love to tell anyone who might be interested about what a great place to live, work, and raise a family Moncton can be.

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chronic and life-limiting systemic rheumatic diseases; and

(2) **Rheumatology and Immuno-Oncology Clinic,** focusing on the management of patients with immune-related adverse events secondary to immune checkpoint inhibitor therapy for advanced malignancies, other immunotherapy-related autoimmune complications, and cancer-associated arthropathies.

I would welcome referrals to either clinic for an in-person consultation (or via telemedicine, if geographically distant and clinically appropriate), either faxed to 416-586-8766, to my attention, or emailed to *alexandra.saltman@sinaihealthsystem.ca.*

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