Patient Care at the Intersection of Rheumatology & Neurology

Transcript

Laura Cappelli, MD: From a practical standpoint, there really aren't enough neurologists or rheumatologists to care for the patients [who] have autoimmune disease.

Michael Kornberg, MD: You just have to have very good communication between rheumatologists and neurologists.

Meghna Rao (Host): Welcome back to season 2 of the *Rheumatology Advisor* podcast, Rheum Advisor on Air. I'm Meghna Rao, the senior editor of *Rheumatology Advisor* and the host of this podcast.

In this series, we will be joined by expert clinicians and researchers to discuss emerging and compelling topics in rheumatology. These perspectives may be related to the management of rheumatic disease, guideline updates, patient care, data from conferences and scientific meetings, and much more.

So, let's dive in!

Meghna: Rheumatologists and neurologists are known to manage and collaborate between their specialties in the care of patients with shared diagnoses, such as disorders of the central nervous system, like giant cell arthritis and neuropsychiatric lupus.

Now, in this episode, I'm joined with experts in the field to talk more about this cross-specialty partnership, the concerns within practices, strategies for process improvements, and so on.

But first, let me introduce my co-host for today, Lizette Borreli, my colleague and the editor of *Neurology Advisor*. Hey there, Liz!

Lizette Borreli (Host): Hi, Meghna. I just want to say thank you for having me on as your co-host today here on Rheum Advisor on Air.

Meghna: Absolutely, it's great to have you here. So, should we get right into it?

Lizette: Let's do it!

Meghna: Okay. So, our expert guests for today are Dr Michael Kornberg, assistant professor of neurology at Johns Hopkins School of Medicine in Baltimore and Dr Laura Cappelli, assistant professor of medicine in the Division of Rheumatology also at the Johns Hopkins School of Medicine.

Hello, and a warm welcome to the both of you.

Dr Kornberg: Thank you for having us.

Dr Cappelli: Yes, it's great to be here; very excited to talk to my colleague about this important topic.

Lizette: That's terrific! Meghna and I are thrilled to have you both here, and let's begin.

I'll start with you, Dr Kornberg – how would you define the term "neurorheumatology" and what exactly does it mean for neurologists and rheumatologists when it comes to patient care?

Dr Kornberg: Yeah, well, I think this is a great question to start off with because I don't think there is a single definition of what neurorheumatology means. I think in the strictest sense [it's] what Meghna mentioned a few moments ago, [it's] the intersection of neurology and rheumatology when it comes to neurologic complications from rheumatologic conditions. So, lupus, vasculitis, nervous system involvement of sarcoidosis, [and] things like that.

But in my practice, there are several other ways in which I have to think about rheumatology or interact with rheumatologists so patients that have 1 autoimmune disease are at greater risk [for] others and so people with multiple sclerosis or neuromyelitis optica will oftentimes have other rheumatologic conditions, and it's very important to coordinate therapies for those conditions. Then there [are] also a number of rheumatologic conditions that have neurologic symptoms that aren't directly related to the inflammation associated with those diseases, like cognitive fog in patients with lupus.

So, there's really a very big umbrella in terms of the overlap between neurology and rheumatology.

Meghna: Dr Cappelli, just piggybacking off what Dr Kornberg said, let's talk about some of the barriers in the care of patients with rheumatic disease, specifically with regard to dealing with neurologic manifestations, right? So take, for example, a patient with neuropsychiatric lupus, a condition that has been reported among 40% of patients with SLE, which is a significant number.

Dr Cappelli: I think there are several issues that can make caring for these patients complicated and sometimes difficult, even when you have great colleagues from the neurology side.

From a practical standpoint, there really aren't enough neurologists or rheumatologists to care for the patients [who] have autoimmune disease. So, sometimes when we're concerned for a particular neurologic manifestation, it's hard to get the patient in in a timely fashion to a neurologist because they're so busy and are dealing with so many different types of issues.

It's also, I think, difficult on both sides to, one, find neurologists who are comfortable with autoimmune diseases in the community and comfortable managing them and to find rheumatologists who are also very comfortable with a neurologic exam and determining what kind of issues are going on. So, all of these things together can definitely get in the way of providing the best care for the patient.

There's certainly also issues with accessing certain kind of testing in a timely fashion, skin biopsies for small-fiber neuropathy comes to mind. A lot of our patients have autoimmune-mediated small-fiber neuropathy, and there's not as much awareness about this as other conditions, getting [electromyograms] (EMGs) for myositis, [and] those sorts of things. So, there are a lot of practical issues that we have to overcome to provide the best care for these patients.

Dr Kornberg: Yeah, I think, she's exactly right. It's a question of access and comfort, which is probably the biggest barrier. I think we'll probably spend some time talking about how to overcome that. But there are lots of challenges.

So, even in an academic setting where Laura and I practice, I don't think we do that as well as we could or should, in terms of having a multidisciplinary-team approach to these patients [who] have neurologic and rheumatologic manifestations. But, as Laura mentioned, most people don't get their medical care in an academic setting; they're in community settings, where it's an even bigger challenge. I think that the best models that I've seen have been, like the Kaiser system, which has a really concerted, multidisciplinary clinic setting. But that's hard to achieve.

Meghna: Dr Cappelli, alluding to what you said before, would you be able to tell us about other conditions in rheumatology that involve neurologic or extraneurologic manifestations? I'm thinking, possibly something that is less commonly known or expected in your specialty and/or maybe undertreated for the same reason.

Dr Cappelli: I think our patients get undertreated for a variety of neurologic conditions associated with their autoimmune disease, because, primarily, there are probably 2 reasons for this. One, like Michael was saying, the comfort of rheumatologists in assessing and evaluating neurologic conditions. But also, sometimes, the symptoms can seem unusual or seem nonspecific at first, when the patient first presents, and might not be taken as seriously by some.

A great example is one that I mentioned previously, that of small-fiber neuropathy. When you think of small-fiber neuropathy with diabetes, you think of a classic stocking-and-glove distribution and that is not how patients with autoimmune small-fiber neuropathy present usually. They can have a very odd distribution involving all parts of the body, even the face.

Dr [Julius] Birnbaum, when he was here, and Dr [Michelle] Petri, who had focused on this in lupus, have shown all sorts of patterns of involvement for those sensory changes. So, if you're not aware of this and that it might look different than your classic patient who has a neuropathy from thyroid disease or diabetes or other conditions, then you might not know when to send the patient for testing or how to manage the patient with medications, which rheumatologists really can do and can do on their own or in conjunction with neurologists.

I think some manifestations that are also not appreciated are some of the effects on the autonomic nervous system that we are coming to understand even more in rheumatic diseases, such as scleroderma and [Sjögren] syndrome. That area is probably even more difficult to decide who, in terms of specialists, can take ownership – I don't know if Michael agrees with this – but sometimes cardiovascular physicians are involved if there are autonomic neuropathies vs neurologists and the rheumatologists. I think there are several issues that probably get underdiagnosed for our patients.

Dr Kornberg: I absolutely agree with that, and I think it is most challenging with some of these, for lack of a better word, “soft” symptoms, [which] no one has dedicated expertise in. So, the autonomic symptoms is a great example because just depending on where patients live and what providers are available in their area, a symptom might fall under the umbrella of different specialists. I agree. That's a big problem even at an academic center.

Lizette: As the editor for [*Neurology*] *Advisor*, something that I've come across in my research are studies that talk about the presence of peripheral neuropathy seen in patients with lupus and Sjögren syndrome.

Dr Kornberg: Yeah, and I think, in addition to the neuropathy, particularly the small-fiber neuropathy, something that I've had a lot of referrals for, and I'd love to hear Laura's thoughts on this too, is in patients [who] have rheumatologic conditions, I often see it in people with lupus. So, Dr Petri, who Laura mentioned, is, kind of, a legendary rheumatologist at Johns Hopkins, describes type 1 and type 2 symptoms. The type 2 symptoms being the ones that are just harder to pin pathophysiologically; so that's the brain fog and some of the nonspecific pain. We see that a lot in neurologic conditions as well, and they're very, very common. I see so many patients with lupus get referred because of cognitive issues and their lupus is well-controlled, and there's not really a good explanation beyond some vague vasculopathy that we see in these patients.

The treatment approach is much different, right? Immunomodulatory therapies are not successful. So, having a good sense of, not just treating inflammation, but also how you manage symptoms, which can be cognitive [rehabilitation] or cognitive behavioral therapy, I think is something that is missed oftentimes, also.

Meghna: I attended the [American College of Rheumatology] (ACR) Winter Symposium just a couple of days ago, and there were some talks about the management of patients with neuromyelitis optica spectrum disorder as well. So, I think these conditions seem to be getting more attention; maybe we'll see some official guidelines in the future, right?

Dr Cappelli: Yeah, I hope so. I think there are a lot of rheumatologists who are interested in this area because they realize how much these conditions [affect] their patients. I don't know about Michael, but I know it's frustrating for me when we don't have great treatments or even great ways to diagnose the things that our patients are dealing with. So hopefully, we will continue to move forward in these areas of need.

Lizette: So, Dr Kornberg and Dr Cappelli, we kind of alluded to this before, but to summarize, what are some practical approaches clinicians can take to improve the standard-of-care in this complex patient population?

Dr Kornberg: I mean, from my perspective, communication is the biggest practical approach to improve management. You just have to have very good communication between rheumatologists and neurologists, which works best when there is a system in place that is designed to promote that. So, multidisciplinary settings really work the best in my view.

Along those lines, something that Laura has been a big part of at Johns Hopkins, specifically has been for immune checkpoint inhibitor-related autoimmune adverse events, which [has] a huge overlap of rheumatology and neurology. It's basically this community of a small group of physicians from different specialties that have the same kind of interest in this overlap. When issues come up where there's overlap, there's a clear line of communication to coordinate care; I think [it's] probably the most important practical step.

Dr Cappelli: Yeah, I agree with that, and I would add that, I think both specialties have a lot to teach each other. And so, at ACR, I know we love to have neurologists come and give talks about some of the issues and vice versa. But continuing to increase the knowledge about each other's specialties is ultimately going to help improve care for patients.

Meghna: Yeah, absolutely. I think communication is key to any kind of collaboration and partnership. But, shifting things to, specifically, clinical practice. Dr Kornberg, maybe we can start with you. How are patients with rheumatic and neurologic disease typically referred to your practice? And maybe, could you outline how this process can be better streamlined?

Dr Kornberg: Yes. So, these patients who get referred to me, they're typically either referred by a rheumatologist or by a primary care physician. Oftentimes, when they're referred by a primary care physician, it's someone [who] has a wide constellation of symptoms and that the primary care doctor might not be certain whether they fall under rheumatology or neurology.

How they can be streamlined? So, not to “beat a dead horse,” but when these are coming from rheumatologists, it's very helpful to have established relationships with the rheumatologist so that we can communicate all the information that's going to lead to the initial evaluation being as useful as possible for the patient.

Part of that is setting up these multidisciplinary structures, where you have rheumatologists and neurologists that have a relationship with each other to streamline that. I think that's probably the [best] way.

Dr Cappelli: I think it's always helpful to know what would make their visit for the referral, whatever the specialty is, but especially for neurology, most helpful for the patients. If there's testing that needs to be done ahead of time, that's not done in conjunction with a neurology visit, it's useful to know what all that testing is and vice versa if [n]eurologists are referring patients to rheumatology. All of those things help expedite the care of the patient.

Meghna: As a follow-up to this entire discussion, maybe Dr Kornberg, again, we could start with you, what would you want a rheumatologist to know about referring a patient to a neurologist such as yourself?

Dr Kornberg: Number 1 is, which Laura just mentioned is, it's very helpful to have a clear question. So, if a patient is being referred to me, I want to have a clear sense of what information the rheumatologist is looking for and exactly what I'm evaluating. It's very helpful to know the state of the activity of someone's rheumatologic condition.

So, if a patient being sent with lupus has tenuous disease and the classic manifestations of their lupus are not fully controlled, I have a much different mindset evaluating neurologic symptoms relative to someone who has been very stable with regard to their lupus for many years. The pathophysiology, the source of their neurologic complaints, and therefore, what to do about them, is very different in those 2 patient populations.

Meghna: I think this could be valuable information because rheumatologists mostly rely on physical exams vs lab tests for initial diagnoses and routine follow-up, as Dr Cappelli can attest to.

So, Dr Cappelli, from your perspective, what should rheumatologists know to help strengthen this partnership between the 2 specialties?

Dr Cappelli: I think that rheumatologists can strengthen the relationship by making sure that they are aware of all of the associated neurologic conditions with the different diseases that we treat and doing a little bit of management upfront.

If you suspect somebody has a small-fiber neuropathy and it's giving them pain, it's very reasonable to start some gabapentin and start titrating that while you're going to refer someone to neurology for a further evaluation. If you are suspecting some other process, a larger nerve process, it's reasonable

to put that EMG nerve conduction study order in and try to help facilitate that for the patient.

I think just listening to the patients and taking their concerns seriously, even if the symptoms don't sound clearly localizing to a particular neurologic problem that you're thinking about. Because sometimes patients are presenting in their own way, and symptoms that might not sound classic for a particular issue might actually be the start of that issue. And documenting a great neurologic exam in their notes and doing it regularly so they're comfortable will all probably help them take care of the patients and have a good relationship with the neurologist to whom they're referring patients.

Lizette: So, a few years ago, this is something I've come across in my research, Children's Mercy Hospital in Kansas City actually created a neurology-rheumatology combined clinic to assess the rheumatologic and neurologic aspects of rare pediatric diseases. This is done under the supervision of 3 physicians, typically 1 neurologist and 2 rheumatologists. Now, together, this group of clinicians created a unified plan of care for the patients.

Knowing this, what initiatives would you encourage your fellow colleagues to take to make this more common throughout the United States?

Dr Kornberg: Well, I'd say I wouldn't just encourage colleagues; I think that at [Johns] Hopkins, we have room for improvement in this regard. [W]e all just need to recognize the importance of it. And that's why I was excited to do this podcast because I think that it’s underappreciated and underserved in the sense of giving good coordinated care to people with rheumatologic and neurologic conditions.

So, the program you just described, I think, is exactly the way that this should be done, and it's challenging. Oftentimes, in places, there are just not enough rheumatologists and neurologists around to make this happen really well. But in an ideal world, we recognize the importance and the clinical need for these patients, and we set up very similar centers.

So, at Johns Hopkins, what I've found is that this works well in certain very small niches, like sarcoidosis, where the neurologist who specializes in sarcoidosis and the pulmonologists have a very close, tight knit group.

But I think even a simple place to start is just having joint clinical conferences. So, even if you can't have the infrastructure of having a multidisciplinary clinic, like you just described, having even a once-a-month joint conference where the rheumatologists and neurologists at an institution or in a community can get together to discuss some of these patients that have kind of [overlapping] symptoms, I think, is a great place to start. There's a lot of room for improvement all over, I think.

Dr Cappelli: I think another place where this has been done very well at Johns Hopkins is in the Myositis Center with rheumatology, neurology, and

even pulmonology for the interstitial lung disease. But if you think back to the story of how that came to be, it wasn't without a lot of effort and a lot of people being very dedicated to make it happen. I think the spirit of collaboration and not feeling territorial about things is incredibly important to successful collaborative clinics.

The point about conferences that Michael made, I think, is an excellent one. The education should be happening in parallel in both communities, and happening not just in parallel, but also happening together.

Michael mentioned earlier that I lead a group of physicians who are interested in immune-related adverse events from immune checkpoint inhibitors. We have organized that as a virtual consulting group, and certainly, patients get referred to physicians as it's needed, but just having a group of people who are interested in the same thing and can communicate on difficult cases, I think enhances the care, and also, really, for the clinicians, enhances their enjoyment of the care because they're learning something from their colleagues.

Dr Kornberg: I guess I'll just piggyback on that because I think 1 silver lining of the pandemic we're in now is that our infrastructure for having virtual environments is actually much stronger now. And so, it should be easier to create these multidisciplinary groups because we're better at establishing these relationships when we're not all physically in the same place.

Lizette: Thank you both, Dr Kornberg and Dr Cappelli, for shedding a light on, really, the importance of enhancing the relationship between rheumatologists and neurologists. It's important to continue this dialogue to improve the standard-of-care for this patient population.

Meghna: We will continue to follow the great work in your respective fields, Dr Kornberg [and] Dr Cappelli, and thank you so much, again, for joining us on this episode.

Dr Kornberg: Yeah, thank you for having us.

Dr Cappelli: Thank you; it was great to talk to all of you about this.

Meghna: Please stay tuned for more episodes in this series. For more information on *Rheumatology Advisor* and this podcast, you can reach out to us at editor@rheumatologyadvisor.com.

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