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Gaining Perspective on Lupus Nephritis: Shared Decision-Making in Practice

Announcer:

You're listening to *Living Rheum* on ReachMD. Here's your host, Dr. Charles Turck.

Dr. Turck:

Welcome to *Living Rheum* on ReachMD. I'm Dr. Charles Turck, and joining me today to discuss how we can better incorporate care coordination and shared decision-making into our clinical approach to lupus nephritis are Drs. Robin Dore and Gates Colbert. Dr. Dore is a board-certified rheumatologist in private practice in Tustin, California. She's also a Clinical Professor of Medicine at the David Geffen School of Medicine at UCLA. Dr. Dore, welcome to the program.

Dr. Dore:

Thank you very much.

Dr. Turck:

And Dr. Colbert is a nephrologist and certified hypertension specialist. He's a practicing physician with the Kidney and Hypertension Associates of Dallas located at Baylor University Medical Center. He's also an Assistant Clinical Professor at Texas A&M College of Medicine in Dallas. Dr. Colbert, it's great to have you with us.

Dr. Colbert:

Yes, thank you so much. Good to be here.

Dr. Turck:

Starting with you, Dr. Dore, can you tell us what you prioritize when caring for patients with lupus nephritis?

Dr. Dore:

In treating patients with lupus nephritis, my main goal is to, if they have normal kidney function to maintain that function. If they have a reduced kidney function to try to return that to normal and then to keep it normal as time progresses. I certainly want to prevent further kidney damage. Another goal is to try to reduce or get the patients off prednisone, which has been shown to cause multiple long-term side effects, including diabetes, glaucoma, cataracts, osteoporosis, etc. and increase the cardiovascular mortality in patients with lupus.

My other goal is to educate the patient so that they understand what the goals of therapy are and to work with a team of nephrologists and if the woman is of child-bearing age to work with a reproductive medicine specialist in order to try to preserve her ovarian function and often bringing in the, of course, the primary care provider so we're all working together with the same common goals for the patient and try to maintain the patient's normal renal function and prevent further disease progression.

Dr. Turck:

And how about you, Dr. Colbert? From your vantage point as a nephrologist, what do you prioritize?

Dr. Colbert:

So as a kidney doctor, I feel that my main priority is to maintain kidney function and avoid a patient moving towards transplant or dialysis needs. So we need to put a patient on a regimen of medications and treatment plan that's going to preserve their GFR, potentially get back some that has been lost, but really to try to slow and even prevent further GFR loss over time.

Another thing that I really think is important is looking at the protein in the urine. We know that protein in the urine can cause further problems over time as it leads to more scarring and more GFR dropout. So if we can lower the protein through medication treatments,

we know that we're going to be helping our patient avoid further kidney loss over time. So we really got to focus in on that.

And then additionally, we need to have a connection with our patients to really to understand what their values are, what is their goals out of treatment, what are their fears and concerns about side effects or anything that medication may change from their lifestyle standpoint and really try to tie that all together so that we as clinicians and prescribers understand where they're coming from so we can guide them the best to have success over time.

Dr. Turck:

Now when it comes to our patients' priorities, Dr. Colbert, how do you go about balancing their unique goals and preferences with your own as a clinician?

Dr. Colbert:

Sure. So I think the first thing you have to do is really ask your patients what are their goals, what are they looking for in the future? Do they value their kidney function? Is it their lifestyle? Is it certain medication that they like or dislike in terms of side effects? You really want to understand what is the patient's perspective with their disease and what their treatment plan would look like because that's the best way to get on the same page of you as a clinician and the patient working together to treat this disease because unfortunately it is a chronic condition and we do not have a cure today for lupus nephritis. We can really push it down and try to control it very, very well. But unfortunately, there is no cure. So this is going to be a long-term group thinking with our patients on how we can best treat them. We want to educate them on their expectations as well. And one way that you might do that is talking about the data. We're putting you on this drug plan or we're trying these medications because we have great studies that show that they have effects and can really modify and improve the outcomes for each patient long-term. And so if a patient has that interest and can really absorb that information, I think that's very, very helpful so they understand why you're prescribing certain medications and certain regimens. And also, I think it's important to lay out that treatment plan over time and say we're putting you on these medicines, this is when you take them, and we may change that over time, or we may taper that or maybe we stay on this for months and years ahead until something new is invented or comes about. So I think just trying to get on the same page with your patients is extremely important.

Dr. Turck:

And with all that in mind, Dr. Dore, what kinds of team structures and care coordination are needed to help us do well by these patients?

Dr. Dore:

It really varies from patient to patient once you have your basic structure. One of the primary important things to me is the fact that the nephrologist has the same goals that I do and that we work together, that there is easy discussion whether it is by text or email, or the phone, or in a system like Kaiser where the chart can be easily shared. I'm in my little office so I have to go out of my way to make certain that the whole team is communicating.

Often the patients don't feel, usually they don't feel any problem with their kidneys. If they have other aspects of lupus besides lupus nephritis, they will feel joint pain or they will have a rash or they will know that their hair is thinning and those will be extremely important to them, which of course, it is. But since they can't feel their kidney function deteriorating, it's up to me to make certain that if they have normal kidney function that I am monitoring their protein/creatinine ratio; I'm looking for protein in the urine, I'm looking to make certain that their GFR is remaining stable and then I can talk to them and tell them, well your kidney function is not as good as it was so I want to make certain that I send you to a nephrologist who will work together with us to try to either improve or preserve their renal function.

Dr. Turck:

For those just tuning in, you're listening to *Living Rheum* on ReachMD. I'm Dr. Charles Turck, and I'm speaking with Drs. Robin Dore and Gates Colbert about coordinating care for our patients with lupus nephritis.

So Dr. Dore, we talked earlier about the importance of having team structures and care coordination in place to help our patients. But what are some of the challenges that can keep us from putting those in practice?

Dr. Dore:

Often it is a problem with again the patients not understanding how that care coordination is important but sometimes we actually need to bring in other people as part of the team. My daughter was at Cook County in medical school, and she had a young woman, a 27-years-old African American with lupus nephritis and kidney failure and she didn't understand because she felt OK that this kidney failure could kill her. She was afraid and her family was afraid of the side effects of medications. We actually had to bring the minister in to talk to the family to help them realize that although she was young, she could pass away from this condition, and so the minister actually became part of our care coordination team because he was able to help her understand the importance of taking the medication. So often in medicine, we look at other healthcare professionals as being important, but we have to also understand the role that the family plays in patients continuing their medication and other family extenders in order to make the patients understand the disease and to

continue to be compliant. And again make certain that all of the healthcare professionals that are providing care for these patients are working to educate the patient, make certain that they understand the goals that many aspects of lupus are not things that they can feel or see, and the importance of regular follow-up, coming to the doctor's appointment, having a laboratory test performed so we can best take care of them and maintain our treatment goals.

Dr. Turck:

Well great insights, Dr. Dore. And now we're almost out of time for today, but before we close, I'd like to hear each of your thoughts on how we can overcome these challenges. Starting with you, Dr. Colbert, what strategies have you found to be effective?

Dr. Colbert:

And I fully agree with the comments we had from Dr. Dore. Connecting the team and connecting the patient into that, I think of it as two-fold. We've got to connect with our patients both in terms of educating them, finding out their values, finding out what their goals are, what their fears are, and what they want to future to look like for their health and for their families so if you can really get that bond with your patient, I think that goes a long way.

Additionally, we have to work as a team with our other clinicians and prescribers and really try to do holistic care for the patient. I think it's important to have a couple rheumatologists that you know by name that you can share values with on how to treat patients and what you think has been an effective team strategy. I don't like when we just refer to rheumatology or just a specialty that's faceless. I think we really need to get back to connecting with individual clinicians so that we can make sure that we're all doing what's best for the patient, and we can coordinate that care.

Additionally, I always recommend that my patients have a primary care physician as well. A lot of our patients when they come to specialists, they can tend to try to have a specialist control everything, but I really think that having a team with a primary care physician or clinician is extremely important for their overall health so they can fill in the things that we may be missing as a specialist.

Dr. Turck:

Well, thank you, Dr. Colbert. And Dr. Dore, do you have any final thoughts on the matter?

Dr. Dore:

I just agree with the comments about the primary care provider in that often they're the ones that I'm looking to to control possible side effects of the medicine, to look at the patient's lipids, to look at their blood sugar, to make certain that the medicines that we're prescribing to treat their lupus nephritis are not having other adverse effects, and helping the patient understand, as was mentioned, that we need to have the primary care provider involved in that team approach. So I will try to take care of the lupus and determine with a nephrologist what our treatment goal is, but also explain to the patient that these are the things that I'm going to take care of, these are things the nephrologist will take care of, and then these are the coordination that we hope and that your primary care doctor will deal with. So again, it's all what's best for the patient and that our goal is reached, the patient's goal is reached, and that we can all work together for what's best for the patient and their overall health.

Dr. Turck:

Well with those strategies in mind, I want to thank my guests, Drs. Robin Dore and Gates Colbert, for sharing their insights on incorporating shared decision-making and care coordination into our treatment approach to lupus nephritis. Dr. Dore, Dr. Colbert, it was great having you both on the program.

Dr. Dore:

Thank you for having us.

Dr. Colbert:

Thank you so much.

Announcer:

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