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Gaining Perspective on MS Care Priorities: Shared Decision-Making in Practice

Announcer Introduction:

You're listening to *NeuroFrontiers* on ReachMD, and this episode is sponsored by Novartis. Here's your host, Dr. Paul Doghramji.

Dr. Doghramji:

Welcome to *NeuroFrontiers* on ReachMD. I'm Dr. Paul Doghramji, and joining me to discuss how we can better incorporate shared decision-making in practice with our multiple sclerosis patients is Dr. Vikram Bhise. Dr. Bhise is Chief of Division of Child Neurology and Developmental Disabilities, as well as an Associate Professor for the Department of Pediatrics and Neurology at the Robert Wood Johnson Medical School at Rutgers University. Dr. Bhise, thanks for being here today.

Dr. Bhise:

Thank you for having me.

Dr. Doghramji:

So to start us off, Dr. Bhise, what are some of the key considerations that factor into your selection of a treatment plan for patients with multiple sclerosis?

Dr. Bhise:

There's quite a few. And even trying to narrow them down sometimes gets hard. You almost forget all the elements that go into making a decision. From the physician's perspective, one of the things we consider a lot is disease severity, trying to figure out is this an individual that's presenting with a very severe case or a very mild case and how that can go into their treatment paradigm. We also think a lot about timing, if someone's coming to us early or late and how they're going to do with routine imaging and bloodwork and getting them onto a schedule.

We're trying to figure the best therapy for people while also minimizing complications. And from the patient perspective, on the other hand, they're really focused a lot on safety. They do want something effective, but they want to be safe through all of this.

We also talk a lot about acute versus chronic care; how we do things differently when there's an urgent situation or brand-new symptoms versus preventing disease, which is a different aspect. A lot of other factors will weigh in on how we come up with our treatment plan, how we might have to modify it. It could have to do with access. For example, where people live, do they live near or far to the therapies that they might need? Do they have a lot of support? Do they have the finances? Are there services available in the area? Some of it might come down to their personal beliefs, their tolerance for risk. And for women in particular, if they're planning on having kids in the future.

Dr. Doghramji:

Now to get a better sense of how you balance those considerations with what matters most to our patients, I'd like to take a look at this through the lens of a patient. Can you briefly introduce us to a patient you've recently seen in practice?

Dr. Bhise:

We had someone we saw recently, a teenager coming from another country, not speaking the language and not as of yet having been set up with insurance. She came to a nearby institution and got excellent care there, but her MRI showed a very concerning feature, very aggressive-looking MS lesions. And we knew that we didn't have a lot of time. We needed to help this person get started on therapy very quickly. So we had to work with the institution to make sure that she was able to see us quickly, get started on medication, and had to also make sure we had time to discuss with the family how we're going to approach this. What are the best options? Why

we're going to recommend more aggressive medicines? And what are the concerns that they might have for side effects? So far, she's been doing great. We were able to start the therapy and work it through. We were able to help them with some of their insurance needs and set them up with services. But it can definitely be a big challenge.

Dr. Doghramji:

And how did you go about learning what goals of treatment this patient had and what challenges they were facing?

Dr. Bhise:

It's really about listening to the families and discussing with them carefully about what's important to them. You know, we certainly have our standard talking points, our basic discussion with families. But then after that, we will often open it up to discussion. We will say, 'Did you have any questions? What was concerning about what I said? What's important to you there?'

And at the heart, all patients, all families really want to go back to the way they were. That's what you really want when you feel sick. And you're trying to figure out a way to help them get back to that. But different people will bring different things to the table. And that's very important.

So I deal with both kids and adults. We did a study looking at the quality of life and transition needs in teenagers and young adults. And it was very interesting because adults, for example, can have a lot of cognitive complaints, fatigue, difficulty thinking. And that could be very detrimental to holding a job. That could prevent them from working entirely. But for a teenager, if they have a limp, that would be way more important to them than having a lot of fatigue.

So the things that are important to an individual can be very different based on their age, their background, and a number of other factors. And really getting to the heart of that is important. So we start with our basic talking points. But then you start really delving into the patient and their family. We ask people directly, what do you want? What are the things that are important to you? And how can we help you get to those?

And just listening to their questions, gives you a lot of information about what they really want to achieve here. And then you always make sure that they have time to ask about these questions. You open it up, you listen, you never let them feel pressured.

And then I also like to get a good sense of what's their social circumstances. You know, they might tell you that certain things are important, but they may have limitations or they may have great resources. So you ask about their family. You ask about where do they live. What can they manage? And what other commitments do they have that might conflict with their time that they need to undergo treatments and other parts of the management plan? And you put that all together to create the best treatment plan that you can for the patient and their family.

Dr. Doghramji:

For those just tuning in, you're listening to *NeuroFrontiers* on ReachMD. I'm Dr. Paul Doghramji, and I'm speaking with Dr. Vikram Bhise, who's sharing a patient case in multiple sclerosis care that demonstrates how we can incorporate shared decision-making in practice.

So Dr. Bhise, now that we know a little bit more about this patient's unique challenges and goals, how did you balance their priorities with your own?

Dr. Bhise:

There's really going to be no other option here. It's just part and parcel of what we do. You're always going to be balancing priorities, you're always going to be advocating for the patient to try to get the best treatment and listening to their concerns about what they can and they can't do. You never want to be in that situation where they're not telling you that they're not taking their medicine. So we always work with giving our recommendations, and then really asking the family how they feel about this? And what are the concerns that they have? And as families start asking you questions, it'll start revealing to some of the other issues that might not be at the forefront that might be gnawing at the back of their minds. But as you work through those, it really helps people understand the pertinent issues in making these decisions.

And then I like to give them time. Some families might say, 'I know exactly what I want to do.' And others might say, 'You know, why don't you make this part of the decision for me, I'll trust what you say.' But others are conflicted. And that's totally reasonable. But I'll tell them, 'Look, we don't have a lot of time to make some of these decisions, especially the initial treatment.' And I'll say, you know, 'Take this amount of time.' I'll give them reading material, resources for websites, and other information. And I'll say, 'Put that together, come up with your questions, come up with some ideas. And let's talk again in short order.' And we'll work together. We'll put all that information together to come up with the best plan for a patient in their family.

Dr. Doghramji:

And what kind of impact did that approach have on this patient's experience?

Dr. Bhise:

So fortunately, she's doing well and with my last meeting with her, she said everything's going good. Her mom is very happy. I don't know that we're always in the practice of saying, 'How did our approach go with you?' But in general, when we do get feedback, it seems to be supportive.

In that same study that I mentioned that we looked at quality of life and transition needs in teenagers, one of the things that they were generally very happy with was the medical aspects of the care. But there was also a lot of anxiety, fear that was still always lurking in the background, and they may not even always bring that to the office visit. And it may be an element to still work with, even if people are saying things are going great.

But working through all these things, working with families, discussing carefully, understand their concerns, I'd like to think that increases their follow-through, increases their chances of success, and helps you cut off problems before they start. Reducing side effects of medicines, having them communicate with you early, I think it all works together, and it increases the connection between the physician and the family, makes it stronger and makes the families feel more confident.

Dr. Doghramji:

Well thank you for walking us through that patient case, Dr. Bhise. Now we're almost out of time for today. But before we close, are there any final thoughts or takeaways you'd like to leave with our audience?

Dr. Bhise:

Shared decision-making is essential in the care of multiple sclerosis. It's part and parcel of everything we do. Some things are a bit standard with what we do. But also, there are elements of this that are clearly unique with every patient, with every family member. And we should always be looking at these small elements to help us really gauge which direction we're going to go and fine tune it to make it work for the family. We want to be open to challenges in the field, we want to make patients comfortable hearing difficult information. So having that shared process really establishes the trust and helps people reach the goals they need, I believe.

Dr. Doghramji:

Well you've certainly given us a lot to think about when it comes to implementing shared decision-making in practice. And I want to thank my guest, Dr. Vikram Bhise, for joining me to share this patient case of multiple sclerosis care. Dr. Bhise, it was great having you on the program.

Dr. Bhise:

Thank you for having me.

Announcer Close

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