Transcript Details

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Tracking Transition Readiness & Quality of Life Among Pediatric MS Patients

Dr. Caudle:
Pediatric multiple sclerosis, or MS for short, is defined as the onset of symptoms before the age of 18, and it occurs in more than 8,000 children in the United States alone. Although its presentation is not much different in children versus adults, there is little data regarding the quality of life for pediatric patients. So what do pediatric patients and their families need to know about navigating this disease?

Welcome to *NeuroFrontiers* on ReachMD. I'm Dr. Jennifer Caudle, your host, and joining me to talk about pediatric MS is Dr. Vikram Bhise, Associate Professor of Pediatrics and Neurology at Rutgers Robert Wood Johnson Medical School. Dr. Bhise also presented data on this topic at the 2021 Consortium of Multiple Sclerosis Centers Annual Meeting.

Dr. Bhise, thank you for joining me today.

Dr. Bhise:
Thank you for having me.

Dr. Caudle:
So let's just jump right in. I imagine that when a pediatric patient is first diagnosed with MS, there is a bit of fear or uncertainty among them and their families. So what are some of their biggest concerns, and how do you address them?

Dr. Bhise:
You're absolutely right and it's immediately overwhelming for patients and their families. Even just the starting point of trying to explain what multiple sclerosis is and what it means to family can take a significant amount of time. They're worried if there's going to be disability. "Am I going to be in a wheelchair tomorrow?" "Am I going to die?" Sometimes they're thinking, "My gosh, is this cancer?" So there's a lot of questions running around in people's minds, and what you really need to do is just sit down with people and spend some time answering as many of their questions as you can and saying, "It's okay to ask these questions. It's okay to ask them again." And give them the time that they need to get through all this information.

Dr. Caudle:
You know, I'm sure some of those concerns are only exacerbated for these patients as they transition in adulthood, which, as I understand it, is what your presentation at the 2021 CMSC Annual Meeting was all about, so let's zero in on that for a little bit. Dr. Bhise, what was your goal of this research, and how did you go about conducting it?

Dr. Bhise:
We wanted to understand what were the transition needs of the pediatric-onset MS population. We wanted to know what did they need to get to the next steps in life, what makes them successful, and for the people that reach those areas, what made them successful if they felt that they had reached a good point in their life. We did this by a qualitative methodology. It's not as well-known to many

people. The qualitative method, it's a little different than our quantitative methods, but it's a well-established strategy. We found patients between ages 15 and 26 years, and we used an adaptive interview guide. We had a series of interviews with these families over the course of a couple years, and we looked for specific concepts in what they were discussing and then used those concepts to bring out broader themes, and once we reached thematic saturation, once we no longer found new themes, we went back and looked at our data and collected those themes into action points and to talking points that we could give to our audience.

Dr. Caudle:
For those of you who are just tuning in, you're listening to *NeuroFrontiers* on ReachMD. I'm your host, Dr. Jennifer Caudle, and I'm speaking with Dr. Vikram Bhise about his presentation at the 2021 Consortium of Multiple Sclerosis Centers Annual Meeting that focused on the quality of life of pediatric patients with MS.

So, Dr. Bhise, now that we have an understanding of the methods you used to conduct this research, let's focus a bit on the results. What did you find, and did any key themes emerge?

Dr. Bhise:
Yes, we definitely found quite a few things related to several themes. One of the early ones was that people needed time to accept their diagnosis and adjust to a life with MS, and that was no surprise. We asked what it was that we could do, and they actually felt that it wasn't a specific intervention. It was really just the time to come to terms with the diagnosis, so really, a lot of the teenagers just wanted our patience. They did feel that there was an identity change. They felt that who they were changes because of this diagnosis a bit. And at first they might have misidentified their body as the enemy, but as time went on, they changed those ideas and would even get positive ways of looking at things using some of the disability to say, "Hey, maybe I can find better things in my life and find new goals and look for new things that are important in my life."

And we asked, you know, "What do you want to hear at the beginning?" and they actually appreciated a lot of the positive spins that we try to put as physicians, but they said, "You know, you also need to tell us all the negative stuff up front," and they're ready to hear it. They also focused a lot more when it came to the quality of life on the visible symptoms. So MS has a lot of invisible symptoms so to speak. People can be overwhelmed by cognitive problems and fatigue, and if you're an adult with MS and you're tired all day, you're not going to be able to hold a job very well, and if you can't think quite well, you're not going to be able to focus at that job, but for teenagers and young adults, it was much more about what other people could see. So if you had a limp that everyone could see, that was much more important than having fatigue to them in terms of their quality of life. Trust was an issue. "Do I tell my friends?" "Do I tell my employer?" But people that felt that they had a lot of control in their life really felt that that helped them with the motivation to develop the positive outlook, and in turn, those who had the positive outlook also felt that they had greater control in their life, so it was a back and forth there.

The teenagers did have to mature early, and we tried to gauge when they were ready to hear these messages. They said if you told them about these things too early, if you tried to talk about transition and their needs too early, they weren't ready for it, but you didn't want to wait too long either, so we suspected that there's a sweet point in the middle that you could really connect with them. And one of the most striking things we found is that we weren't surprised that they didn't know everything about transition, but in fact, they didn't have any of the language they needed. They didn't know the words. They didn't know what a 504 plan was. They really had nothing about that. And what was happening was that the parents were taking a lot of the work handling that, and the kids loved it—the teenagers loved it—but in turn it left them a little bit unprepared when they became young adults. So, we learned that there was a shared responsibility there as well and that kind of gave us a global look at the transition needs and the qualitative aspects in that.

Dr. Caudle:
That's so interesting. I think that our listeners are going to find that to be extremely valuable. And building on that, what are some key takeaways or calls to action then that you may want colleagues to learn from these findings?

Dr. Bhise:
So, one of them is to focus on visible symptoms when talking with the teenagers and young adults with MS, especially in terms of their quality of life. Dedicating a specific transition visit, so not taking away from your regular medical visits but actually saying, "Hey, let's do another visit," and when you walk in the door, you say, "Let's talk about transition today." So instead of talking about MRI studies and

bloodwork and other stuff, we're just going to focus on this one thing to make sure that we have it handled. And it may not even be answered all in one visit. It might be more than one visit, and that's fine.

We developed a series of topics or questions to go through with families, and I like to go through every one of those one by one and say, "Hey, did you think about this?" "Did you think about where to go for a local ER if your kid is going to be in a college far away from you?" "Have you spoken to the Office of Disability?" "Have you spoken to the Office of Finances at the new college?" "If you're going to go into the workforce, have you decided about whether you're going to tell your job?" And then really making sure that there's a strong family support since it was the overwhelming thing that a lot of teenagers and young adults said was critical to their success, that if they actually lacked that double-checking about that and seeing what you can do to help plan for their transition.

Dr. Caudle:
Now before we close, Dr. Bhise, do you have any final thoughts you want to share with our listeners on how we can better care for our patients with pediatric MS?

Dr. Bhise:
I think valuing transition as an important care for medical practitioners should not be relegated to the end. It should stay as part of our regular care topics. I think just getting somebody medically well, you know, just getting them on the right medicine is not enough. I think we also want the people we care for to succeed in their life. The illness has oftentimes set them back, so we really want to focus on their success overall, so we want to have a time to think about transition, make sure people are ready for the next steps and have things planned out. Considering even a full transition visit and building that in and then slowly developing the resources that we need—and always considering that people have their individual needs for their quality of life and trying to suss those out with people and really figuring out how we can all come to better outcomes in the future, and then even thinking about what are the next steps to look into this transition needs and success and finding out the quantitative elements that we can use to create better programs for everybody throughout the country and the world.

Dr. Caudle:
And unfortunately, that's all the time that we have for today, but I'd like to thank my guest, Dr. Vikram Bhise, for sharing his research on pediatric MS. Dr. Bhise, it was a pleasure speaking with you today.

Dr. Bhise:
Oh, happy to be here. Thank you for speaking with me.

Dr. Caudle:
And for ReachMD, I'm your host, Dr. Jennifer Caudle. To access this and other episodes in our series, please visit ReachMD.com/NeuroFrontiers, where you can Be Part of the Knowledge. Thanks for listening.