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Examining Care Collaborations for Patients with SMA

Announcer:
You're listening to *NeuroFrontiers* on ReachMD. Here's your host, Dr. Andrew Wilner.

Dr. Wilner:
This is *NeuroFrontiers* on ReachMD. I'm Dr. Andrew Wilner. And joining me to share their perspectives on care collaboration for patients with spinal muscular atrophy, or SMA for short, are doctors Vanessa Battista and Nassim Rad. Dr. Battista is the Senior Nursing Director of Palliative Care at Dana Farber Cancer Institute, Dr. Battista, thanks for being here today.

Dr. Battista:
Thank you for having me. I'm looking forward to it.

Dr. Wilner:
And Dr. Rad is the Director of the SMA Program and Co-Director of the Muscular Dystrophy Association Clinic at the University of Washington Medical Center. Dr. Rad, it's great to have you with us.

Dr. Rad:
Thank you. It's great to be here today.

Dr. Wilner:
Sure. Well, starting with you, Dr. Rad, what are some initial considerations you factor into your assessment of patients with SMA?

Dr. Rad:
Well, I like to start by getting a better understanding of when they were diagnosed. I typically see adult SMA patients. So, this would include, 'At what age did they develop symptoms? At what age did they start losing motor milestones? What was the highest motor milestone they achieved,' is a good starting ground for where I like to begin with my patients.

Dr. Wilner:
And turning to you now, Dr. Battista, what kind of role do nurses have in the management of SMA?

Dr. Battista:
Well, that's a great question. Nurses have a variety of different roles in the management of SMA, depending on how that particular clinic functions. So, in many instances, the nurses are very heavily involved in the actual visits when a family comes into clinic or into the, you know, appointment space to see their team. The nurses are very heavily involved as far as actually taking them back to the room, doing their vital signs. Sometimes it's a medical assistant, but often that's a nurse. Especially in a specialized neuromuscular clinic, it might be the nurse who's very familiar with the family who meets them first, goes in, does an intake, may get, you know, a history of what's been going on, check all their medications, do all the things to prepare for the visit so they actively participate in the actual visit.
Nurses also tend to do a lot of the coordination, not only in the clinic space in the management of the visit that day, but also behind the scenes in coordinating things for the child or the individual living with SMA and their family. We know that often the care for families living with SMA is interdisciplinary. And so, the nurse is often the one who takes on that role to make sure that all of the providers are present in clinic and that things are flowing well for everybody to get in to see the patient or the individual in their family. And then they are often that piece in between to bring all of the pieces together.

They will also often work with the school if there's different accommodations or things that are needed in the school system for that child. And that can be at any age. We have often done this even for individuals we've had that were in law school who were living with

SMA.

So the nurse really takes on lots of different roles, but I'd say the main role is often being the one who coordinates all of the different pieces of the interdisciplinary care. And so, they often serve in that capacity as the primary contact for the family and so they're constantly in communication with them.

Dr. Wilner:
Thanks for that. That was very helpful.

Coming back to you, Dr. Rad, which team structures and care coordination practices are needed to improve care for these patients?

Dr. Rad:
And I think as, Dr. Battista has mentioned, I think the structure that's really needed for these patients, regardless of if they're pediatrics or adults is multidisciplinary care with that nurse coordinator. These patients are complex and have a lot of different needs, whether it be swallowing issues, respiratory issues, bone health issues, managing their nutrition, monitoring for weight gain or weight loss, equipment needs, working with various disciplines, including physical therapy and occupational therapy as well as speech therapists. And I think the best type of care for these patients would be in a place where they're able to see all the disciplines that they need.

Traveling for these patients can be rather difficult. Spreading out appointments can be hard for patients, and that's often a way that they missed appointments or are lost to follow-up.

And so, making sure that they have all their needs in one place and having a really strong nurse coordinator, making sure that all recommendations from various disciplines are in place and that patients are following through, I think should be standard of care for these patients.

Dr. Wilner:
For those just tuning in, you're listening to *NeuroFrontiers* on ReachMD. I'm Dr. Andrew Wilner, and I'm speaking with doctors Vanessa Battista and Nassim Rad about care collaborations for patients with spinal muscular atrophy.

Now, Dr. Battista, if we take a look at this through the lens of a patient case, can you tell us about a time you coordinated care among specialists for a patient with SMA? And how did this impact the patient's outcome?

Dr. Battista:
Sure, absolutely. As I mentioned in my previous response, and also Dr. Rad and in her response, one could say that care for individuals living with SMA, and their families is really a team sport. This is, by necessity, interdisciplinary.

So my role working as both a nurse and a nurse practitioner within this setting with individuals living with SMA has often been to coordinate that care. And I can think of an instance where we had a young child with SMA who needed to come into the hospital because he was having some trouble breathing. The parents were transporting him home from a medical appointment and noticed that he was having some trouble breathing in the car and decided that they wanted to come into the emergency department. And so, I was the first point of contact because I had that relationship with their family, and they knew to reach out to me. And so, they let me know that they were on their way. And right away began that process of coordinating all the different pieces. So, there was correspondence between the emergency department to let them know that somebody was coming in on their own, not in an ambulance, but in respiratory distress. And the family didn't want an ambulance because they were already en route in the car and close by. But it took a lot of coordination of getting them seen right away. And then, once they got through the emergency department, they ended up being admitted. And so, it was letting the pulmonologist from our team know that the patient had been admitted, and letting the cardiologist know, because there were some questions there, as well, if there was something going on from a cardiac perspective. And so there was really a lot of coordination between the different teams.

And you know, it would be easy for there to be a lot of confusion without somebody coordinating that. It's, you know, confusing enough when a family gets into the hospital, and there's lots of different providers, but to reach out to all the specialists and let them know so that you can really have continuity of care so that the providers who are really specialized in SMA could be the ones to go and see this particular child in the hospital and the one who already knew that perhaps the elevated troponin meant something different in SMA than it would in a child with a different disease. And so, having that cardiologist who had already seen them go and be the one to check them out who's familiar with them, and coordinating all of that, was really essential.

And for this particular child, he ended up being intubated and was for a while and then eventually was extubated but had a lot of things that happened in that time. And it really, I think, impacted the outcome for this family because he eventually did really well, was successfully extubated, had a lot of follow-up care and follow-up in our clinic.

But just keeping sort of that thread going of communication between all of the teams I think made it not only helpful for that family to get the specific care they needed for that child for their child, but also for them to feel safe and to feel supported by people that they knew and to feel like they had somebody that they could reach out to to coordinate all of this. And, this family, I don't take credit for all of that alone, but sort of orchestrating the team, the family let us know after that they felt really supported and that it was really helpful to have the people they know be the ones to come and see them when they were in the hospital.

So, I think that's just one example of how coordinating care can be really essential to how things go.

Dr. Wilner:
Before we close, I'd like to hear some thoughts from you both on how we can use collaborative tactics to improve patient communication and care planning. Dr. Rad, let's start with you.

Dr. Rad:
Well, I think Dr. Battista said it beautifully with her last example about what we can do to increase collaboration among the specialists taking care of SMA patients. I think it's really important for all the specialists to be aware of what is happening. I think in an outpatient clinic, oftentimes patients may forget to share one aspect of their symptoms with one provider. And I often find myself reaching out to our pulmonologist who specializes in our patients with SMA and pulling them into decision-making and management. That happens across multiple disciplines. And I think that continuing that coordination of care is very important for these patients.

Dr. Wilner:
And Dr. Battista, I'll turn to you for the final word.

Dr. Battista:
Oh, thank you. So, I would echo a lot of what Dr. Rad said just now. I think, really, communication is the key to what we do. And in families with SMA and the people we're seeing in clinic and all the specialists that are involved in the interdisciplinary team, I think communication is really the corner piece or the cornerstone of what we do. Because, as we've both talked about, there's lots of specialists involved. There's often family members who may or may not be really stressed out depending on what's going on at that time. And making sure that everybody's on the same page, or at least communicating the same message. Even just arriving to clinic and needing to move throughout the building or multiple buildings to know where somebody is. You know, are they getting their pulmonary function tests? Are they, you know, somewhere else? Did they go down for lunch? Where are they? Someone's waiting for them. There's so much communication that goes on just for one visit, not to mention throughout the trajectory of care throughout one's lifespan in living with this. And so, I think just really keeping open communication on the team, having a plan, not only for every visit, but again, for what's going to happen along, the whole course of this is really important.

We are very fortunate that we now know a lot more about SMA than we did a few years ago. And I think with that comes the ability to have some foresight and planning for what's coming next. And so, we’re able to do that and to help families prepare and to really communicate with them and to have a plan in place for changes that may occur or things to look out for. And so, I really can't stress it enough that just working collaboratively as a team and communicating well is the most important thing.

Dr. Wilner:
Well, with those considerations in mind, I want to thank my guests, Dr. Vanessa Battista and Nassim Rad, for joining me to discuss care collaborations for patients with spinal muscular atrophy. Dr. Battista, Dr. Rad, it was great having you both on the program.

Dr. Battista:
Thank you.

Dr. Rad:
Thank you.

Announcer:
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