

MONTHLY Feature

The Evolving Mental Healthcare Landscape



These are times of change, and the coronavirus pandemic is only underscoring how the healthcare field is adapting and evolving. That's certainly true for how providers approach mental health for people living with neuromuscular diseases. Adopting telehealth, including mental health in multidisciplinary care, and helping patients transition from pediatric to adult care are just a few of the considerations.

Providing psychosocial care is necessary to help patients, family members, and caregivers cope with the anxiety and stress of a neuromuscular disease. After all, some patients have neurobehavioral symptoms as a manifestation of the disease itself, which can be a great burden. The toll can be devastating, even for diseases without neuropsychological manifestations.

Group effort

Care for mental health is not traditionally an aspect of multidisciplinary care for patients with neuromuscular diseases. That's partly due to a lack of resources — not

all facilities have psychologists or neuropsychologists, says Aravindhan Veerapandiyan, MD. He holds several roles at Arkansas Children's Hospital: director of the Comprehensive Neuromuscular Program, director of the MDA Care Center, director of the PPMD Certified Duchenne Care Center, medical director of the Headache Clinic, and assistant professor of Pediatric Neurology.

Dr. Veerapandiyan and his team are now advocating for mental health to be included in a multidisciplinary approach. "The hope is that every clinic has a social worker, psychologist or neuropsychologist who can address these needs."

Dr. Veerapandiyan's clinic addresses mental health needs primarily through a neuropsychologist and social worker; however, other members of the comprehensive team discuss these needs as well. These providers have in-depth conversations with families and patients. For very young patients, they can help families learn to handle outbursts or tantrums and how to discipline.

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“Our social worker and neuropsychologist meet with the family from the beginning to give them support, resources, and advice on how to cope with the new diagnosis,” Dr. Veerapandiyan says.

Virtual aid

COVID-19 has created a lot of added stressors: Routines are interrupted, schools are closed, and kids can't see their friends. People with neuromuscular disease also might worry about getting COVID-19 because they may have an increased risk for severe manifestations.

Such natural worries highlight the need for mental health care. “Telemedicine is playing a huge role, and I think that should open up a lot of space for these patients to get psychological and psychosocial care,” Dr. Veerapandiyan says. “I think that could actually be a standard of care moving forward, even without a pandemic.”

For younger kids, for instance, clinicians can get a good sense of their functional assessment through video observation: Are they moving around, walking, lifting their hands? Providers also get to see patients in their natural environment, observing behavior that isn't always on display in a clinic.

Given how quickly some care transitioned to being virtual, Dr. Veerapandiyan says that providers are still learning telehealth best practices. Some barriers

remain: Providers can't complete all assessments remotely; telehealth eliminates a familiar, in-person connection; and some families don't have stable internet, which can be a major challenge.

Ultimately, in these times, the goal is to be proactive and let patients and families know that they have someone to turn to. At Dr. Veerapandiyan's clinic, a social worker and care coordinator called a list of Duchenne muscular dystrophy (DMD) patients to see if they needed any assistance. “I learned a lot of interesting information about what they were needing, and it's mainly related to therapy and mental health support,” he says.

Transitioning care

As people with neuromuscular diseases live longer, a new approach to mental health management is needed to help them transition from pediatric to adult care. Doing so requires looking at patients holistically, an area where clinicians need to improve. “I don't think a lot of us get into these details when we see kids in the clinic,” Dr. Veerapandiyan says. “A lot of them aren't getting comprehensive care as they transition to adult places.”

Many families don't want to transition after they've developed trust and familiarity with the staff and facilities. To help ease this transition, providers need to address aspects of adult life, such as employment, after patients turn 13 or 14.

Once again, a multidisciplinary approach is helpful. It's also important for an adult clinic provider to see a patient at least twice while they're still at the pediatric clinic. “That builds confidence and trust, and it's easier for them to move on.”

As Dr. Veerapandiyan and his team spend more time with patients, they are learning more about the patients' feelings and hopes. “Most of them want to be in a relationship, be independent, get out of their parents' house, live on their own,” he says. “It's important for us to encourage them and give them the support to overcome the fear and anxiety they have about these conditions.”

