Transcript Details

This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: https://reachmd.com/programs/neurofrontiers/reducing-the-als-diagnostic-delay-the-impacts-of-a-rapid-access-clinic/26389/

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Reducing the ALS Diagnostic Delay: The Impacts of a Rapid Access Clinic

Announcer:

Welcome to *NeuroFrontiers* on ReachMD. On this episode, we'll hear from Dr. Kelly Gwathmey from Virginia Commonwealth University about how diagnostic delay in ALS patients can be minimized. Dr. Gwathmey is VCU Health's ALS Clinic Director and Chief of the Department of Neurology's Division of Neuromuscular Medicine. She also gave a presentation on this very topic at the 2024 American Association of Neuromuscular and Electrodiagnostic Medicine Annual Meeting. Here's Dr. Gwathmey now.

Dr. Gwathmey:

Diagnostic delay in ALS continues to be a considerable concern, with studies reporting anywhere from a 10 to 16-month delay from symptom onset to official diagnosis with about an average of 12 months in patients. So at Virginia Commonwealth University, we had previously published our analysis of racial disparities in ALS diagnostic delay, with our Black patients being diagnosed 15.8 months after symptom onset and our White patients being diagnosed 9.8 months after symptom onset. So this realization really inspired us to start to come up with possible solutions, including the rapid access ALS clinic, which we have been piloting over the last two years. So when we started out developing and creating this clinic, we advertised it to the community and academic healthcare providers with webinars, emails, and print communication. The webinar that I held included education on the signs and symptoms of ALS. We also have used the thinkALS Tool, which was developed by the ALS Association in partnership with the Time to Diagnosis Working Group, as a tool to educate these providers in the community about the signs and symptoms of ALS.

And so this rapid access ALS clinic is open to any patient in the region suspected to have ALS, and they will be seen, within four weeks of referral, by me and a smaller multidisciplinary group of providers, including occupational therapy, respiratory therapy, our registered dietitian, social worker, as well as our nurse navigator. And then patients who come in that need EMGs completed will have those performed on the same day as their initial evaluation. So from September 2022 to May 2024, the rapid access ALS clinic assessed 70 patients that were referred for possible ALS, and of those, 33 were ultimately diagnosed with ALS, 8 were diagnosed with non-ALS motor neuron disease, such as primary lateral sclerosis, and 39 were diagnosed with non-motor neuron disease diagnoses, most of which ended up being neuromuscular conditions, such as myasthenia gravis or myositis.

And so we compared the performance of this rapid access clinic model to patients who are diagnosed and referred to our multidisciplinary clinic through the normal avenues, and so these are patients diagnosed by community neurologists and referred directly into our ALS clinic, the so-called traditional model. So we found that those patients that were diagnosed in the rapid access ALS clinic had less severe disease at time of diagnosis, so their ALS Functional Rating Scale Score was 31 points versus 38 points who were diagnosed out in the community and referred into the multidisciplinary clinic directly. Also, for patients who were diagnosed in the community as opposed to in our rapid access clinic model, the upright forced vital capacity scores were lower at 60 percent compared to 77.8 percent in those who were diagnosed in the rapid access clinic.

And so we also found that there was a difference in diagnostic delay between these two models of just over two months. So the patients who came to us directly from the community, bypassing oftentimes the community neurologist directly into the rapid access clinic, were diagnosed on average two months sooner than those who were diagnosed out in the community and referred to the multidisciplinary clinic, and the average time from referral to the rapid access clinic visit appointment was 29 days, so this model really holds promise that it could address some of the diagnostic delay that we are seeing in the ALS field.

Announcer:

That was Dr. Kelly Gwathmey talking about her session at the 2024 American Association of Neuromuscular and Electrodiagnostic Medicine Annual Meeting, which focused on solutions to reducing diagnostic delay for ALS patients. To access this and other episodes in our series, visit *NeuroFrontiers* on ReachMD.com, where you can Be Part of the Knowledge. Thanks for listening!