The Catatonia Foundation

Why is the diagnosis of catatonia so complicated or why is it so often missed?

Dr. Ghaziuddin:
Why is the diagnosis of catatonia so complicated, or why is it so often missed? Because it is, and it continues to be missed. So I think there's the historical reason that we were not taught catatonia. A lot of us, at least 30 years ago, are self-taught. Then there is a problem with the DSM, the Diagnostic and Statistical Manual, that catatonia was misclassified as a subtype of schizophrenia, which is now changed in DSM-5 and is no longer considered a subtype. So that's another reason.

And the third is just by the nature of the illness itself, because it has so many different presentations. Catatonia in those with developmental disorders, I think is another level of challenge. And the reason is that some of the symptoms may be present at baseline.

Just to give you an example, people with autism spectrum disorder, or ASD as we refer to it, may have hand flapping or jumping or twirling, and so if those are then counted towards the diagnosis of catatonia, I think a valid question would be—this patient had these at baseline.

So when we are faced with a patient with a developmental disorder, the key question is, are the symptoms significantly worse than they were at baseline? And I think that's a question that often gets overlooked, even by very experienced psychiatrists, leave alone other disciplines. So the behavior may then be attributed to the baseline disorder itself.

That's one problem: the diagnostic challenge. Another challenge is—and that applies both to neurotypical and neurodiverse patient groups—is looking at catatonia symptoms through a lens of behavior psychology—that somebody who is doing self injurious behavior, and then the mother comes in and says, “Do you want a cookie?” And they may stop for a few seconds. They might even take the cookie and then they start. And if you're looking through a lens of behavior psychology, you may say, “See, this is a behavior that is amenable to environmental manipulation. The child is hitting themselves because they know that the mother will try to distract them and offer them a cookie. And when the cookie was given, the behavior stopped.” I can go into more details and explain what I mean, but just to stay on track, what I'll say is many repetitive behaviors, or most repetitive behaviors that have recently worsened or are new or —so there's an or here—not, are probably a movement disturbance that's consistent with a catatonia diagnosis.

While the behavioral conceptualization is a useful one, it's not useful when you're trying to diagnose catatonia, because catatonia is not a disturbance of behavior. A disturbance of

behavior suggests that there is a volition, that if I start smashing my head, somebody will come in and maybe give me a cookie.

This is an uncontrollable movement, so it's an organic disorder. It's a neuropsychiatric disorder. Often the diagnostic process gets muddied when there is excessive reliance or even sole reliance on the lens of behavior psychology. So that's another one. There are several other reasons.

Another reason that comes to mind is when there is a search for a medical cause. On one hand, we should look for a medical diagnosis. Does this patient have a thyroid illness? Have they contracted a parasitic disease? And all those can trigger catatonia. But that process needs to be quick and, regardless of whether there is an underlying medical or psychiatric disorder, there needs to be a recognition that catatonia needs its independent treatment.

An analogy that I would give from medicine is sick congestive heart failure—that I develop congestive heart failure. I am panting. I can't breathe. I have massive edema on my legs. My legs are swollen. The doctor listens to my chest and they can hear fluid. Now, a person can develop congestive heart failure due to a variety of underlying medical causes. I may have had a heart attack and I've developed heart failure. I may have chronic lung disease and I have developed heart failure, but the immediate treatment has to be for the heart failure. Somebody needs to give me a water medicine, a water pill, or a diuretic as they are called, and get rid of the water from my body so that my breathing can be restored. Somebody needs to give me oxygen so that I remain oxygenated—I don't develop hypoxia. So catatonia has that analogy as well.

The excessive hunt for a medical diagnosis while deferring the treatment of catatonia is also a big problem in overall management of the illness. So recognition itself might be complicated, and when it's recognized, there might be—let's find what's the underlying cause, and I think the lesson here to be remembered is that there may be a cause, the cause may be important, the cause may be treatable in some cases, but it may be untreatable in other cases.

There's no treatment for Down syndrome, per se. There's no treatment per se for autism spectrum disorder—that there may be an underlying cause recognizing that and treating it. If it's treatable *is* important, but you've got to treat the catatonia. So that's another kind of complexity that involves both diagnosis and management of catatonia.

Another is the overlap with other disorders. I'll give you an example of the overlap with OCD. OCD, as we know, includes repetitive thoughts and repetitive behaviors. It's a rare disorder, even in neurotypical patients.

Repetitive behaviors and thoughts are also a feature of catatonia. And these thoughts and behaviors and actions might be simple or they might be really complex. Sometimes they may appear to be somewhat rational and other times they might be completely irrational. So in these cases, unless the clinician is aware that some repetitive behaviors are not generally OCD—the

garden-variety OCD that people can get—but these are repetitive behaviors of catatonia, diagnosis can be inordinately delayed.

I recently encountered a patient who I thought had catatonia within the first few days of when he was seen. And the larger treatment-providing team that was managing the case, it took them about two and a half months to recognize that. So the result was that the illness became more refractory. There was a lot of suffering.

This person, this individual, developed more complications—both medical. There was an immense amount of suffering both on the part of the patient and their family. So overlap with other disorders and recognizing that overlap and trying to make the distinction is another diagnostic dilemma that we face.

So in summary, what are the diagnostic challenges? One is historical, number two is the history of DSM, the third one is the overlap with other psychiatric disorders, the fourth one is overlap or association with medical disorders. And I think a fifth reason that comes into play about diagnosis and management is the stigma, and that is a stigma both towards electroconvulsive therapy and also towards benzodiazepines, which are considered first-line treatment.