What studies have you done involving catatonia? What studies would you like to do in the future?

Dr. Ghaziuddin:
Some of my work has involved in—we published a case series a few months ago which described catatonia in patients younger than age 12. So prepubertal catatonia. That was interesting because it's I think often overlooked. I think that was recognizing that catatonia occurs over the age span.

We also identified that in each of the cases, rather than developing motor symptoms first, the initial presentation was regression—that they just lose their skills all of a sudden. They don't know how to use a fork and knife, they were maybe potty trained and now they're unable, they've become incontinent, or their speech is not as robust as it used to be. What we call regression was the first symptom. That was an interesting study we published.

Another interesting study that we found was—this was done during COVID—patients who were receiving maintenance ECT. So we have a core group, and that core group changes over time. Some people move, or they make true recovery and we stop the ECT. So that group changes. It's a relatively small group of patients who have received ECT over many years now. During COVID, at a very short notice—either their schedule was significantly changed that they were getting two, three treatments a week and we had to suddenly call them and say, “Hey, we can only do one treatment every other week because we just don't have the resources and the risk of infection is so great.”

So in that series that we published, what we found was that when ECT was either stopped altogether, or it was significantly reduced, signs of a recurrence appeared within three weeks. They are usually subtle. That was another lesson we learned. They tend to be in motor functions. But we found that there was a very predictable pattern in relapse. So that emphasized the importance of maintenance treatment.

Another interesting presentation—which is yet to be written up, but it's published in the proceedings of the American Academy of Child and Adolescent Psychiatry presented last year—was a descriptive study: who are these patients with autism who are getting ECT? As you know, it's an emotive topic, even within the field of autism among experts. We looked at cases up to 2020. There were about, I don't remember the exact number—I think it was 54 patients. The majority were being treated for catatonia. That was the single biggest indication, but they

were not exclusively catatonia. There were other patients who had either depression or a bipolar kind of a picture or psychosis. So a smaller group.

The lessons we learned by examining this data—one was that the index course of ECT tended to be much, much longer than what is used in patients with, say, unipolar depression or bipolar depression. So long courses. So please don't call me and tell me my patient is not responding to ECT because they've had 14 treatments. In this group, we found 57 treatments was the mean of the index course. Index course is defined as either receiving two or three treatments per week at the start of the treatment. The second thing we learned was many of them required maintenance treatment. The third thing we learned from this dataset was that epilepsy and intellectual disability and catatonia clustered together. So patients with autism who are getting ECT and have developed epilepsy or have epilepsy were all in this catatonia subgroup. Out of 54, 35 had a catatonia diagnosis, and we found that epilepsy and intellectual disability were exclusively associated with the catatonia subgroup. So that was another important lesson we learned.

What kind of a study would we like to do in the future? I think there are very many studies that are waiting to be done. I think underdiagnosis of catatonia is very important, very clinically relevant, and has a lot of implications for families. If I go to the ER and I have a child and the clinician can't recognize catatonia, I'm done. That note will say that we've ruled out catatonia, and that will have treatment implications for the next, I don't know, a few months, maybe a couple of years, because somebody will read that note and say, “Oh, the patient went to the ER and they ruled out catatonia.”So I think the underdiagnosing of catatonia in medical settings is a study that I would love to do. The death rate is, as you probably know—there aren't very many studies.

Outcome is another thing that I would love to study—longitudinal outcome. The death rate, including suicide, is probably the highest of any psychiatric disorder.