The Catatonia Foundation

What's your experience with autism or developmental disabilities and catatonia?

Dr. Dhossche:
As you know, I was trained in Stony Brook at the time when they were developing the catatonia scale, and Max Fink was there, and he wanted to bring catatonia back to the foreground because it was neglected at the time. And some people say it disappeared completely, which is not true.

So I was there at the time, and I did have an interest in catatonia before my training because I had seen cases — well, I was in Belgium at the time, but I mean, these cases are so dramatic, you never forget. So, I said, this is a great place — I mean a fascinating syndrome, and Dr. Fink was focusing on that, and a lot of people were focusing on that. But I also wanted to do child psychiatry. So I went into child psychiatry and I thought, well, maybe I'll never see any catatonic patients anymore. But I mean, it was interesting at the time.

So that's what I wanted to do, until I saw an adolescent with catatonia. I had been trained to recognize catatonia, and I was just surprised that it also seemed to happen in adolescents because I think I saw my first case in a 16 year old. And the boy also had a developmental disorder. He had Prader-Willi syndrome. And that's when I did this literature review. I said, maybe there are other cases. There were just a handful of cases of catatonia in adolescents, and some of them had autism. And some of them had another developmental disorder or a cognitive disability. Some cases already had been described with toxic substance-induced LSD catatonia and, of course, organic cases — encephalitis, herpes encephalitis. So it was quite exciting to recognize catatonia in the younger population.

One of my colleagues said, “Yeah, but I've treated an autistic child with catatonia,” and he treated the child with clozapine and ativan and benzos. So we wrote this case up. And I was reading about a British psychiatrist — her name was Lorna Wing. She was an adult psychiatrist, but she had a daughter who had autism, and she wrote a few cases or talked about how she was an autism expert. Given that her daughter had autism, she recognized a catatonic syndrome in her daughter. So she was one of the parents who saw that, I mean, she was a psychiatrist, and she knew it existed.

Later on, she has done some systematic studies on this, but since I was getting more experience in this field, I saw more patients, where parents were coming to get our opinion and treatment from different places in the United States. I was in Mississippi at the time, so because of the difficulties of getting treatment for catatonia, especially ECT in New York, California, Texas — they forbid ECT in kids under 12 — I was having a few cases.

I met Lorna Wing at a meeting in London, and we co-edited a book, “Catatonia in Autism Spectrum Disorders” — I think it was 2006. We asked all the people who were interested to write their contributions and collect the cases. There weren't very many at the time, but we knew it was important. We tried to figure out what would be the next step — how you would structure the treatment. I am very grateful to Lorna Wing, who has died since then, but we dedicated the book to her daughter, who actually died while we were making this book.

Lorna Wing was not a big fan of ECT, but she allowed me to put that piece in there because I had positive experiences, and she was not very familiar with ECT. It was a very interesting project. We had very little material, but we had good experiences. She knew catatonia exists, and I had the ECT experience that ECT seemed to work in younger ones.

That was a long time ago that we tried to make a new permutation. I mean, autism is recognizable, but not very treatable. In Catatonia, it's very treatable, but nobody seems to recognize it. So, we combined it a bit as a treatable part of autism when they develop catatonia. And it does happen, more than you expect or more than people realize, because people think it's all autism, but it's not. There's a part of it that is treatable.

So, yeah, that's kind of what we forged from our experiences a long time ago.

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