
Evaluating the Impacts of TD: The Role of Patient-Reported Outcomes

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Dr. Turck:

Welcome to *NeuroFrontiers* on ReachMD. I'm Dr. Charles Turck, and here with me today to discuss the role of patient-reported outcomes in tardive dyskinesia care are Dr. Stacy Finkbeiner and Mr. Bill Cote. Dr. Finkbeiner is US Medical Director at Teva Pharmaceuticals. Dr. Finkbeiner, thank you for joining us.

Dr. Finkbeiner:

Thank you so much for having me.

Dr. Turck:

And Mr. Cote is the Senior Director of the National Organization for Tardive Dyskinesia, which is a nonprofit charity dedicated to raising awareness and giving hope to those with tardive dyskinesia. Mr. Cote, it's a pleasure to have you with us today.

Mr. Cote

Thank you so much for asking me to participate. It's a real honor.

Dr. Turck:

So why don't we start with you, Mr. Cote. Would you tell us how tardive dyskinesia can impact the physical, psychological, social, and professional lives of patients?

Mr. Cote:

Well, that's a great question. I mean, tardive dyskinesia is obviously a movement disorder, but it affects beyond just physical movements. It could affect your speech, your eating, and then activities of daily living, such as holding a coffee cup, writing with a pen, or typing away on your computer. All of these things could be affected by how you are exhibiting tardive dyskinesia and creating these involuntary movements. It affects every other aspect of your life. I mean, because you're having the physical movements, you may have psychological issues. We've seen through surveys that many people with tardive dyskinesia exhibit depression, so it effects your overall mood because you're having a situation where, perhaps, you can't control your movements. And say, a social situation, you may be in a typical social situation amongst friends, family, or on a date. So if you're unable to control your movements, you could be very embarrassed; it could crank up your anxiety, and then of course, your professional life could be affected as well. It all depends on if you have a lot of like face-to-face contact with, say, clients if you're a salesperson, or if you're a teacher and you're lecturing and you're making these movements, they could be either misinterpreted or cause you embarrassment because you know that they're happening. So it's a broad impact, but just like you said, physical, psychological, social, and professional.

Dr. Turck:

And if we turn to you now, Dr. Finkbeiner, how does the impact Mr. Cote just described compare to what's been reported in the literature, especially across different underlying conditions?

Dr. Finkbeiner:

So there's been a couple of interesting studies that were done that monitored social media posts, which I think as we all know people tend to have a little less inhibition of what they post online. And so what we saw there is that some of the posts that people made around tardive dyskinesia really highlighted a lot of the social and psychological impacts that they were experiencing because of the condition. And so that was kind of a really interesting one where they talked about being angry or depressed as Mr. Cote was talking about and feeling self-conscious as well as judged by others.

And then, you know, as a precursor to some of the work that we're going to be talking about today, I also participated in a relatively large online survey of individuals living with tardive dyskinesia, and we highlighted many of the specific examples of TD Mr. Cote was talking about. So in the physical domain, there were issues of not being able to hold things, do chores, difficulty eating, or speaking. From a psychological perspective, it's those feelings of sadness, anxiety, embarrassment, and low self-esteem. From a social aspect, the survey respondents reported limiting their social activities because of their TD the TD interfering with their ability to take public transportation or run errands in public. And then it also showed individuals reported TD interfering with them applying or getting a job or a promotion that they may have wanted and that it impairs them at work.

Dr. Turck:
For those just tuning in, you're listening to *NeuroFrontiers* on ReachMD. I'm Dr. Charles Turck, and I'm speaking with Dr. Stacy Finkbeiner and Mr. Bill Cote about the impacts of tardive dyskinesia.

So now that we know how tardive dyskinesia can impact patients, let's zero in on the IMPACT-TD Registry for just a few moments. Dr. Finkbeiner, would you tell us what this registry is and how it incorporated input from patients and their caregivers?

Dr. Finkbeiner:
So we designed the IMPACT-TD Registry as a large observational study with the design to better understand many of the things that we don't currently understand that well about tardive dyskinesia. Particularly, what it's like to live with the condition and the ways in which it can affect someone's overall quality of life.

So to do this we brought in clinicians to kind of get us started by sharing some common examples of how they've seen TD affect their patients' lives. And from that, we developed a draft questionnaire that we would then present to patients. So what we did is a process called cognitive debriefing. So we shared that draft questionnaire with 19 individuals living with the condition and 5 caregivers, and what they do is they actually read each question out loud in front of our researcher; they talk through how they interpret the question, their response to it, and how they're thinking about it. And what that does is it allows us to really understand was the question clear? Did the individual get confused when trying to answer it? Were they answering the question that we intended to ask? And then, we also asked for feedback. Was the overall questionnaire relevant to you? Was it repetitive? Were there things that were missing? And the process really highlighted the value of having this input from patients and caregivers because there were some questions that they suggested adding.

Dr. Turck:
As a follow-up to that, Dr. Finkbeiner, what are the patient-reported outcomes from the interim IMPACT-TD Registry?

Dr. Finkbeiner:
Two-thirds of the patients in the study report that the severity of their movements are mild or moderate, and that's also pretty consistent with how the clinicians would rate the severity of the movements. So what that means is that this is a relatively milder study population compared to some of the other TD trials that people may have seen results from. And when it came to describing the impact that they're experiencing because of their movements, what we saw is that psychosocial impacts seemed to be reported by the largest proportion of the study participants. A little over half indicated experiencing embarrassment in social situations because of their TD, that TD affected their ability to enjoy the things that they do for fun, and that they limited their social activities because of their TD. And when it came to some of the physical limitations on daily activities of life, we saw a substantial portion, about 40 percent of participants in the study, reported difficulty holding things like a glass or fork. Also, a similar proportion reported that TD affects their ability to do household chores. Things like making a bed, washing dishes, or even exercising.

And then, our questionnaire also included some specific questions on choking and swallowing as well as speech difficulties, and we saw that about a third of the respondents indicated that they had difficulty swallowing. They had to eat more slowly to avoid choking, and that they had trouble speaking clearly and felt frustrated and self-conscious about their speech difficulties.

Dr. Turck:
And with those outcomes in mind, let's come back to you, Mr. Cote, and look at the bigger picture here. Why are patient-reported measures like these so important to the overall management of tardive dyskinesia?

Mr. Cote:
Well, great question. I really must thank Stacy and her team for the incredible work that they've done in really getting to the heart of the

matter here, which is the varying ways that tardive dyskinesia can actually affect the quality of life of the patient. So it used to be that someone was on their AIM scale, which is a tool that's sort of the gold standard. It focuses primarily on the movements that the patient is making. So if a patient was making say a minor movement, it may not be seen by the clinician or the patient as something—without diving into some of these questions, as she mentioned—that needed treatment or needed to be really looked at. And it all depends on what you what you do, your career or your state in life, if you're retired or you're in the workforce. A minor movement for one person can have a major impact for someone else.

Dr. Turck:
And sticking with you, Mr. Cote, for the final word. It’s become clear from our discussion today that tardive dyskinesia can have a considerable impact on patient quality of life. So do you have any advice or final thoughts on how clinicians and patients might navigate a discussion about that and manage that impact?

Mr. Cote:
I would suggest—and I'm sure a lot of clinicians do this, although there's limited time in their medication management in the 20 minutes that they have with their patients—delving into some of these probing questions about how tardive dyskinesia is affecting the quality of their life because TD is sort of different every day. They could be stressed one day, and not the next, and it could affect the amount of movements that they're making. So if a clinician sees someone one day and they're not really making that many movements, unless you get into these probing questions, is it affecting your social life? Is it affecting your emotional life? Is it affecting your professional life? Then you really will have difficulty understanding what would be the best treatment. So having these in depth discussions with your patients to really flesh out the real quality of life impacts that TD is having, that would be the advice that I would have for a clinician.

Dr. Turck:
Well, with those final thoughts in mind, I want to thank our guests, Dr. Stacy Finkbeiner and Mr. Bill Cote, for joining me to discuss the important role of patient-reported outcomes in tardive dyskinesia management. Dr. Finkbeiner, Mr. Cote, it was great speaking with you both today.

Dr. Finkbeiner:
Great. Thank you so much. I really appreciate the opportunity to talk about our work with everyone.

Mr. Cote:
Thank you very much.

Announcer:
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