The Patient Perspective on Tardive Dyskinesia

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The article by Bron and colleagues[1] in this issue of JCP represents an opportunity to revisit the challenges and opportunities that tardive dyskinesia (TD) represents. *DSM-5-TR* in 2022 defines it as "involuntary athetoid or choreiform movements lasting at least a few weeks, developing in association with the use of a neuroleptic medication for at least a few months, and persisting beyond 4 to 8 weeks."[2] But, as the authors review, we have known about TD for a long time. The term was first used in 1964 by Faurbye.[3] By 1982, John Kane and I suggested that common diagnostic criteria for TD that included information describing the movements using rating scale criteria and information about the causative medications, including duration and in particular dose reduction or discontinuation, would be useful.[4] We recommended use of rater-assessed scales and identified two: the Abnormal Involuntary Movement Scale (AIMS)[5] and the Rockland Simpson Tardive Dyskinesia Rating Scale.[6] Although the AIMS does include an item that assesses patient-reported awareness of involuntary movements, we did not include that as part of diagnosis. Indeed, as Bron and colleagues[1] note, it was widely believed that patients were not aware of or bothered by the movements even though TD movements could interfere with many activities of daily living, including eating, when severe.

Thus, the availability of the Tardive Dyskinesia Impact Scale (TDIS), a detailed Patient Reported Outcome (PRO) rating scale to assess the impact of involuntary movements from the patient's perspective, is a welcome addition.[7] The TDIS includes 11 questions, 8 that ask about physical effects such as mouth noises and speaking and 3 that ask about socioemotional impacts. These are self-consciousness, embarrassment, and unwanted attention. This scale was developed in conjunction with development of valbenazine, one of two vesicular monoamine transporter 2 (VMAT2) inhibitors that have recently become available with an FDA label for the treatment of TD.[8] Deutetrabenazine is the other.[9] These are the first medications indicated for TD, although the literature is littered with trials of treatments that haven't worked. Tetrabenazine, an older VMAT2 inhibitor, has been studied in the treatment of TD with positive results, but its use remains "off-label".[10]

What do we know about the TDIS? First, drug development is a powerful stimulus to providing novel assessment strategies. As noted above, the TDIS was developed because the developers were interested in supplementing the information provided by the AIMS, the primary outcome measure for the valbenazine trials. Second, it is an exemplar of the increased emphasis that is being placed on patient perceptions, in particular what treatment outcomes patients value. Third, the TDIS has been developed following modern scale development methods.[7] The AIMS, like many older scales, would not meet modern criteria for scale development.

These are all general points that reflect the current times and apply quite broadly. More specifically, what has the TDIS taught us about TD? The valbenazine trials included patients with diagnoses of schizophrenia and mood disorder who had moderate or severe TD. That should serve as a reminder that TD is not limited to patients with schizophrenia but can occur in patients who receive dopamine receptor antagonist medications, regardless of diagnosis. The TDIS was included as an exploratory measure. The trial participants were able to complete a PRO. That tells us that we can ask patients about their experience of TD. Detailed data about the psychometric properties of individual items in the TDIS were evaluated using Item Response Theory analyses. The degree to which items provide information across levels of severity does vary, but it appears that all contribute to the physical and socioemotional domains. The total score of the TDIS had only moderate correlations with both the total movement score and the global severity rating of the AIMS. That tells us that although it is related to how clinical assessors define the signs of TD, it adds independent information that goes beyond the signs we traditionally capture with the AIMS. Patients who completed either 48 or 52 weeks of open-label treatment with valbenazine (N = 181) reported overall improvement that exceeded the threshold for Minimal Clinically Important Difference (MCID) at all time points. In addition, these patients exceeded the threshold for all 3 items in the socioemotional scale but only 3 of the 8 items in the physical scale. That tells us that patients who receive this treatment for an extended time report benefit; the items with highest level are self-consciousness, embarrassment, unwanted attention, and mouth noises. Only one of these, mouth noises, is in the physical cluster, and it also identifies something that others are likely to notice. All of these experiences could impact the ability and willingness to interact

with others and therefore contribute to social isolation.

What is missing that should be the focus of future research with the TDIS? Critically, none of the comparisons reported in the article compare valbenazine to placebo. We do know from the primary reports of the valbenazine trials that valbenazine is significantly better than placebo as viewed by blinded raters. But we don't know whether that improvement is reflected in patient report. Thus, there is no control for either the improvement that can be seen because of the variation in TD signs that does occur over time or for effects of receiving attention, assessment, and some financial support for participation. Also important is that the MCID analyses were restricted to the 181 patients who completed the full treatment period with valbenazine for 48 or 52 weeks. Often referred to as "per protocol" analyses, that limitation means that these were the patients for whom both the treating clinician and the patient decided to stay the course. Those analyses are important, but the experience of those who discontinue treatment is equally if not more important. Did patients leave treatment because they or their treating clinicians did not see improvement? Did they drop out because they experienced side effects that troubled them? Did they simply fail to show up and were defined as having withdrawn consent? Examination of change in individual items with valbenazine (shown in Supplementary Figure 1 of the article) is restricted to the same 181 patients who completed the open-label trial and is therefore subject to the same questions about dropouts. The patient population included patients with schizophrenia spectrum and mood disorders, so we don't know whether the concerns expressed are the same across diagnoses. The scale has only been used in trials with valbenazine, so we don't know whether it is useful with other treatments or in untreated patients with TD. Thus, we should look forward to future research with the TDIS, both from the group that developed it and from other research groups interested in TD and the role that PROs can play in our understanding its course and treatment.

Finally, can a clinician take advantage of what we have already learned about the TDIS? The clearest message is one that we are increasingly hearing. Patient preferences and experiences matter, and tools are available to facilitate learning what they are. The TDIS targets physical and emotional experiences that the patient perceives as being due to TD. For those who practice measurement-based care, the TDIS is an added tool to incorporate in clinical service delivery for patients who have TD diagnoses and are aware of their symptoms. But in many clinical settings, treatment is not formally measurement based and patients do not routinely complete rating scales. The information we have so far suggests that the items the TDIS measures that have the least overlap with the assessment that defines TD diagnosis are the socioemotional ones: self-consciousness, embarrassment, and unwanted attention. Asking about those experiences could occur in two contexts. The first is when a patient reports or acknowledges TD symptoms. The second is by asking a patient who has limited social contacts why that is.

In summary, the article by Bron and colleagues[1] is of interest because it is an exemplar of the value of the patient perspective on their experiences and what matters to them and because it provides information about TD that goes beyond the information provided by clinician assessments. That perspective can only improve treatment outcomes.

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