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The Technical Ability and Performing Scale (TAPS): A newly developed patient-reported functional rating scale for Musician's focal dystonia

Marina Ramella [1], Rosa Maria Converti [1], Giulia Giacobbi, Anna Castagna, Enrico Saibene, Francesca Borgnis [*], Francesca Baglio

IRCCS Fondazione Don Carlo Gnocchi ONLUS, via Capecelatro, 66, 20148, Milan, Italy

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ABSTRACT

Background: Musician's Focal Dystonia (MFD) is the most common adult-onset dystonia involving the hand and can cause a professional music career to end. MFD affects about 1% of professional musicians and is a challenging clinical condition to treat. This work aimed to validate the Technical Ability and Performing Scale (TAPS), a newly-developed patient-reported functional rating scale for the clinical assessment of the MFD burden.

Methods: Seventy-seven musicians with MFD (40.84 ± 13.14 years) who accessed "Sol Diesis Service" were consecutively enrolled. Each subject filled in the TAPS after playing six technical passages of different complexity for 45 s each. The clinicians also collected the Arm Dystonia Disability Scale (ADDS) and Tubiana-Chamagne Scale (TCS). Cronbach's α coefficient was used to assess reliability; concurrent validity was measured using correlation with validated tools (ADDS and TCS).

Results: Our results showed that the symptoms of dystonia appeared at around 33 years of age and lasted for at least three years. The Cronbach's α displayed good internal consistency (0.817) for Technical Ability (TA). The two TAPS scores, TA and Performing Score (PS), positively correlated with TCS total score and negatively with ADDS total score (concurrent validity).

Conclusions: The TAPS is a reliable and valid tool for the clinical assessment of the MFD burden. This patient-reported outcome measure may facilitate patient engagement in decision-making about their care and can help healthcare professionals to monitor the musician's change during the rehabilitative intervention.

1. Introduction

Musician's Focal Dystonia (MFD) can be considered the most common movement disorder afflicting professional musicians (about 1%) [1]. MFD is a rare, usually progressive, and action-specific disorder [2] due to involuntary and maintained muscular contraction in the upper limbs [3,4], which causes abnormal movements, tremor and often altered postures [5,6]. The dystonic movements interfere with the fine control and high coordination skills required to play an instrument [7]; for this reason, although the MFD is, in most cases, a pain-free condition, 62% of the affected musicians are unable to continue their professional careers [8].

The treatment of this disabling disorder is a primary goal. Currently, few pharmacological (i.e., oral medication, botulinum toxin injections) and non-pharmacological treatments (e.g., retraining, splinting) [8–10] for MFD are available, but a better understanding in treatment is needed [11,12].

A recent review on the state of the art of rating scales showed that validated rating tools for MFD are lacking since no scales have been entirely and rigorously evaluated following the Dystonia Study Group's guidelines [13]. According to these guidelines (2004), a clinically useful rating scale for MFD should be reliable and valid, sensitive to change, specifically designed to measure MFD and practical in a clinical setting. Moreover, most literature studies rely on inherently subjective evaluation (patient-reported or clinician-reported – inter-rater variability), use ordinal ratings, and lack digit-level specificity. In addition, several clinician-reported rating scales, such as Global Dystonia Rating Scale, Unified Dystonia Rating Scale, and Fahn-Marsden [14], were designed for generalised dystonia or focal forms but were not specific for MFD. Specifically, these scales represent global impressions based on clinical observation but are not tailored to task-specific motor impairments. Subsequently, Fahn developed a more specific ordinal scale for arm focal

* Corresponding author. IRCCS Fondazione Don Carlo Gnocchi ONLUS, Via Capecelatro 66, Milan 20148, Italy.
E-mail address: fborgnis@dongnocchi.it (F. Borgnis).
[1] Ramella and Converti equally contributed to this work.

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dystonia: the Arm Dystonia Disability Scale (ADDS - [15]). Finally, among clinician-reported scales, only the Tubiana and Chamagne Scale (TCS - [16,17]), and Frequency of Abnormal Movements scale [18,19] incorporate a symptom-evoking performance element. However, these scales lack task specificity and they have only been used in a few studies. The objective scales involve tools in which human judgment does not affect the score. Only two scales belong to this group: kinematics [20] and Musical Instrument Digital Interface (MIDI)–based Scale Analysis [21]. Although these approaches offer more sensitive and objective measurements, their administrations are complex and require high technology and staff expertise. These elements limit the use in a clinical setting [13]. It is widely known that the quality of musical performance is the most relevant variable for dystonic musician patients. For this reason, several authors underline the importance of using subjective patient-reported scales. These scales include several versions of the Visual Analog Scale (VAS) and the ordinal scale Dystonia Evaluation Scale (DES – [20,22]). These scales evaluate patients' perceptions about their impairments and the quality of their music performances during exercises and symptom-evoking passages but they do not directly stress how much the dystonic symptom affects the ability to play many technical passages [23,24].

Moreover, the DES shows the same problem of ADDS because the change of a single point on an ordinal scale on three points (0–3) amounts to a vast difference.

Considering that, our group has introduced a new functional subjective patient-reported scale specifically designed for MFD: The Technical Ability and Performing Scale (TAPS). This study aims to evaluate TAPS's properties in terms of reliability and concurrent validity and to clinically assess the MFD burden using TAPS in a large clinical sample. We used ADDS and TCS to measure concurrent validity as a recent review recommended [13].

2. Methods

2.1. Sample

Seventy-seven patients diagnosed with MFD were consecutively recruited from the IRCCS Fondazione Don C. Gnocchi of Milan. All participants were professional or amateur musicians who accessed the "Sol Diesis Service" for the first time for diagnosis and rehabilitative treatment (i.e., physiotherapy). The participants played different musical instruments (e.g., piano, guitar, drums and violin) and met the following inclusion criteria: 1) diagnosis of MFD made by clinicians specializing in movement disorders; 2) age $\geq$18 years; 3) absence of other neurological or musculoskeletal condition that could impair hand function; 4) no splints used during the performance.

A specific questionnaire has been used to collect personal (sex, age, the instrument played) and clinical data (the age of MFD onset, duration of the disease, affected side, interested movement and body parts involved) of the recruited subjects.

After being recruited, all subjects had to perform six technical passages of different complexity for 45 s each. During the assessment, the dystonia and performance were evaluated through the new functional subjective patient-rated scale (TAPS) and two subjective clinician-rated scales (TCS and ADDS). ADDS and TCS assessments were provided by clinicians (i.e., neurologists and physiatrists) and physiotherapists (only TCS) specializing in movement disorders. We chose the ADDS because according to a recent review it is the most widely used scale and has been evaluated by multiple independent sources for reliability (Peterson et al., 2013) and the TCS because it allows to assess the impact of dystonia on musical performance, but from the clinician's point of view.

The study was approved by the "Fondazione Don Carlo Gnocchi-Milan" Ethics Committee on February 24, 2016, project identification code. 12_24/02/2016. The clinicians provided all participants with a complete explanation of the purpose and risk of the study before they signed the written informed consent based on the revised Declaration of Helsinki (2013).

2.2. The Technical Ability and Performing Scale (TAPS)

The TAPS is a new self-evaluation scale designed for the assessment of MFD. TAPS arises not only from the consolidated idea that the quality of musical performance is the most relevant variable for dystonic musician patients [25] but also, from our clinical group awareness about the importance of considering the musician's perception of the disorder during MFD rehabilitation.

In this scale, the musicians must evaluate the impact of dystonic symptoms on the execution of six technical passages (TP) and the quality of their music performances in the last week through a mark on seven VAS scales that make up the TAPS. These VAS consist of a 10 cm horizontal line, where at the extremes, two different faces (smiling and angry) are introduced to help the patient self-evaluation. We converted the scales in a numeric range from 0 to 10 (for detail, see Supplementary Material).

TAPS scale provides clinicians with two different scores: one for Technical Ability (TA) and one for global performance perception (PS= Performing Score). The TAPS administration can be done in any clinical setting, and it takes about ten minutes.

TA score. The first six VAS investigate the motor disorder extent while the musician plays different TPs with different complexity. Patients play all the TPs for 45 s each, and at the end of single task, the musician has to mark the VAS scale. Firstly, they must execute the chromatic scale at three increasing speeds: V1 (72 bpm in 1/16), V2 (100 bpm in 1/16) and V3 (120 bpm in 1/16). Then, the musicians have to play a C-major scale ascending/descending (CS) and, subsequently, a Piece (PC) and a Technical Exercise (TE), both chosen by the musician. CS was chosen since it is the most used in MFD [26,27], and several works showed that it is affected since the early stages of dystonia [21]. If the instrument played by musicians does not allow to perform the CS, other scales and other speed values (bpm) could be chosen; for example, the drummers can execute two basic TPs (CS does not exist) and one of them at three increasing speeds. Interestingly, the other technical passages included in the TAPS (e.g., TE or PC) allow for assessing any difficulties in using the black keys or on arpeggios not evaluable with CS. All the execution speeds and TPs are recorded in a specific datasheet. For each TP, the examiner asks the subject to evaluate "how much does the dystonia affect your ability to play this technical passage?" where the smiling face indicates "no disturbance" and the angry face "maximum disturbance/impossibility to play". If the patient is unable to complete one or more TPs, the examiner assigns 0 points to those tasks. The technical ability (TA) is the mean of the six TPs values.

PS score. The seventh VAS scale, instead, evaluates the patients' perception about their last week global performance, therefore the examiner asks the subject "how do you rate the quality of your performance in the last week?". In this case the smiling face indicate "perfect execution" and the angry face "the worse possible execution".

2.3. ADDS and TCS scales

The same TPs performed were also used to evaluate the MFD severity and performance through other two scales: ADDS and TCS. The first is used to provide general information about the severity of dystonia; the second allows to evaluate the impact of dystonia on the global musical performance, like TAPS does, but from the clinician point of view [15]. Specifically, ADDS is designed to quantify disability on a range of 0–3, where "0″ indicates the absence of disability (normal) and "3″ severe dystonia. The TCS is an ordinal scale that evaluates the impact of dystonia on musical performance: the TCS consist of 5 scores that evaluate the ability to play where 0 is "unable to play", 1 is "play several notes but stops because of blockage or lack of facility", 2 is "play short sequences without rapidity and with unsteady fingering", 3 is "plays easy pieces but unable to perform more technically challenging pieces", 4 is "play

almost normally but difficult passages are avoided for fear of motor problems" and, 5 is "returns to concert performances".

2.4. Statistical analyses

All statistical analyses were conducted on the whole sample using the IBM SPSS Statistics software, version 24. Descriptive statistics included frequencies, Median and Interquartile Range (IR) for categorical variables and Mean and Standard Deviation (SD) for continuous measures. The VAS scores of TPs were converted: lower scores corresponded to higher disturbance values. Cronbach's alpha was calculated to verify the validity and the internal consistency among six TPs' VAS to create the variable TA. Possible linear relations were calculated among the scores at TPs and PS, through Pearson correlation and between these scores and sample characteristics, via Spearman correlation. Moreover, a *t*-test for independent samples was calculated to verify possible differences in gender in TPs and PS. Finally, possible relations were also evaluated between the three scales (TAPS, ADDS and TCS), using Spearman correlation. A threshold of $p < .05$ was considered statistically significant.

3. Results

3.1. Participants

Table 1 reports the demographic and clinical characteristics of the whole sample. The subjects (N = 77) are predominantly males (M:F = 66:11) with a mean age of 40.84 years (SD = 13.14, min = 18, max = 71). The average age of onset of dystonia is nearly 33.64 years (SD = 11.97, min = 16, max = 64), while the duration of the disease is around three years (IR = 1–11, min = 0), with about 10% of subjects over 20 years.

76.3% of musicians played a string instrument, in particular, guitar (33%), piano (25%) and violin (6.5%), 14.5% played a wind instrument (e.g., flute, saxophone) and 9.2% the drum. The majority of the participants (62.3%) had symptoms on the right side only, and the dystonic symptoms occurred predominantly on fingers (90.9%). In particular, the majority had one (40.3%) or two fingers (42.9%) affected, while only 1.3% had trouble on four digits. Furthermore, the most affected fingers were the third and fourth for both hands.

3.2. TAPS

Cronbach's α shows good internal consistency among the six TPs (α = 0.817). Analyzing the six variables, the α score increases if the item TE is removed (α = 0.84). However, since item TE evaluates a technical passage and its removal would not significantly change α value (α > 0.8), it was decided to keep this item in the analysis.

Since the six items showed good internal validity, the overall technical ability score (TA) could be calculated and it consists of the mean of the six items. Descriptive analyses (Mean ± SD) of the TAPS scores (see Table 3) show that the subjects attribute on average a low score to PS (3.40 ± 2.38) and a high impact of the dystonic symptoms on TA (3.83 ± 1.96). As regards TA, subjects show lower scores above all on TE (3.01 ± 2.10), V3 (3.30 ± 3.0), CS (3.58 ± 2.92) and PC (3.66 ± 2.50).

Pearson correlation shows a significant and positive linear correlation between the two TAPS scores (r = 0.45, p < .001). T-test for independent samples shows no significant gender difference in TA (F = 0.042, p = .84; t (74) = −0.74, p = .46) and PS (F = 0.098, p = .756; t (74) = -0.762, p = .448).

Table 2 shows Spearman correlations between TAPS scores (TA and PS) and demographic and clinical characteristics.

Among TAPS scores, the Spearman correlation shows a low significant linear relationship between PS and disease duration (r = 0.288, p < .05).

Comparison between three scales:

Table 3 shows all TAPS scores (Mean ± SD) and the scores (Median ± IR) of the other two scales (ADDS and TCS).

Spearman correlation shows a low but significant relationship between both TAPS scores and the subjective clinician-rated scales. In particular, TA correlates positively with TCS (r = .424, p < .001) and negatively with ADDS (r = −0.0.46, p < .001). Similarly, PS correlates positively with TCS (r = 0.373, p < .05) and negatively with ADDS (r = −0.0.419, p < .001).

Table 1
Clinical and demographic characteristics of the sample. N=Number, SD= Standard Deviation, M = Males, F=Female, IR=Interquartile Range.

		Patients [N = 77]
Age	*Mean (SD)*	40.84 (13.14)
Sex (M: F)		66:11
Onset dystonia (years)	*Mean (SD)*	33.64 (11.97)
Disease's duration (years)	*Median (IR)*	3 (1–11)

Table 2
Spearman correlation between TAPS score (TA and PS) and with demographic and clinical characteristics (in bold the significant statistical values, $p < .05$). TA = Technical Ability, PS=Performing Scale.

	Age	Age_Onset	Duration
TA	−0.111	−0.133	0.049
PS	−0.016	−0.136	**0.288**

Table 3
Scores of the evaluation scale. SD= Standard Deviation, IR=Interquartile Range, ADDS = Arm Dystonia Disability Scale, TCS = Tubiana and Chamagne Scale.

TAPS Score	*Mean (SD)*
Technical Ability – TA	3.83 (1.96)
Performing Scale - PS	3.40 (2.38)
TA Subscores	*Mean (SD)*
Chromatic scale - V1	*5.22 (2.70)*
Chromatic scale -V2	4.13 (2.87)
Chromatic scale -V3	*3.30 (3.05)*
C-major scale - CS	*3.58 (2.92)*
Piece Chosen -PC	*3.66 (2.50)*
Technique Exercises - TE	*3.01 (2.10)*
Subjective clinician-rating scale	*Median (IR)*
ADDS	*2.00 (1–2)*
TCS	*3.00 (2–4)*

4. Discussion

In this work, we described a new functional patient-reported scale (TAPS) to assess the MFD burden and tested its properties in terms of reliability and concurrent validity in a large clinical sample.

The need to develop a new scale for MFD evaluation and validate its properties was born from the awareness that the quality of musical performance is the most relevant variable for the dystonic musician [25]. However, musical performance perception is closely influenced by psychological traits [28,29], like perfectionism and concern over mistakes [30]. Moreover, our clinical experience allows us to conclude that the only way to get good results in MFD rehabilitation is to focus on the patient's needs and perceptions about their condition. For all these reasons, the development of this new subjective patient-rating scale appeared necessary.

The collected sample of this study (N = 77) was relatively large considering MFD as a rare condition and covered the heterogeneous spectrum of MFD in terms of demographics (age range 18–71) and clinical characteristics (age of onset and duration). All subjects performed several technical passages of different complexity and completed TAPS.

Statistical results on Cronbach's α shows good internal consistency

among the six TPs of TAPS (reliability); therefore, an overall technical ability score (TA) can be calculated as the average of the six items. Considering the TAPS scores, the participants attributed, on average, a low score to the quality of their global performance (PS) and a high impact of the dystonic symptoms on TA, particularly on C-major scale and Piece.

Moreover, data showed a positive correlation among two main TAPS scores, so participants who perceived their dystonic symptoms as disabling are the same ones that attribute low values to their performance. The TAPS appears to be a useful tool to evaluate a rehabilitative treatment tailored for MFD and to facilitate patients' engagement in decision-making about their care [25]. Interestingly, except for the very low correlation between overall performance and duration of dystonia, both TAPS scores are not influenced by demographic or clinical characteristics. This result appears crucial due to the heterogeneous spectrum of MFD in terms of demographic and clinical characteristics [6]. Furthermore, the correlation between overall performance and duration of dystonia, although low, appears to be an interesting result. Patients with a major disease duration could have learned strategies to manage overall performance, for example playing very slowly or wearing a splint [31]. Similarly, they could have benefited from previous pharmacologic or non-pharmacology treatment (e.g., retraining). However, patients showed low global performance and a high impact of symptoms.

Regarding concurrent validity, statistical analysis showed a significant correlation between TAPS and the two subjective clinician scales (ADDS and TCS). Interestingly, the same TPs were used to evaluate the MFD severity and performance through TAPS and clinical rating scales, ADDS and TCS. Specifically, the negative correlation between ADDS and TAPS scores allows us to see a relationship between the severity of dystonia and personal perceptions of diseases in the dystonic musician. Therefore, patients with a more severe dystonia corresponded to those with lower scores in TA and PS. Moreover, the correlation between TCS and TAPS scores shows a significant correspondence among the impact of dystonia on musical performance from the clinician and patient's point of view. For example, a clinician's rating of 3 corresponds to a low patient rating on PS and a high score on dystonic disorders. Overall, the significant correlation between TAPS and the two standardized scales for dystonia showed a good concurrent validity, allowing us to conclude that TAPS could be considered a valid tool to assess MFD.

All these findings allowed us to consider TAPS as a reliable and valid tool to evaluate the subjective perception of MFD burden regarding dystonic symptoms' influence on musical ability and performance quality. This scale could be able to fill in the lack of validated rating tools specific for MFD [13], in line with the Dystonia Study Group's guidelines. Moreover, TAPS allows to obtain patients' point of view about their performance quality and the MFD influence on technical passages, overcoming the limitation of other patient-rating scales such as DES [13]. It is common knowledge that musical performance is the most relevant variable for dystonic musician patients [25]; therefore, subjective patient-reported scales could facilitate patients' engagement in their care process and may help healthcare professionals evaluate the MFD evolution during a rehabilitative intervention according to patients' needs.

Furthermore, recently, there was a growing interest in incorporating patient-reported outcomes (PRO) into clinical trials [32] because they provide information reported directly by the patient about their experience, which could be target of therapeutic intervention [33]. TAPS, as a PRO measure, is particularly important to include in clinical trials because patient experiences vary and cannot be clearly captured via other measurements [34]. Therefore, TAPS could be considered an important complement to traditional clinical outcomes, such as performance measures.

Notably, the understanding and treatment of dystonic symptoms appears to be a primary goal because MFD is a movement disorder [1], affecting about 1% of professional musicians who become unable to play and continue their performance careers [8].

5. Conclusion

The TAPS scale can be considered a reliable, valid and practical new patient-reported outcome measure (PROM) since it allows to assess the subjective perception of MFD burden on musician performance in a clinical setting. This scale can facilitate patients' engagement in decision-making about their care and may help healthcare professionals to detect even small TA and PS changes during a rehabilitative intervention based on patients concerns. Further study contexts are also needed to verify the effectiveness of this scale in the longitudinal evaluation in MFD patient care (e.g., rehabilitation, botulinum toxin).

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Authors contributions

MR and RMC conceptualized and developed the TAPS scale. MR, RMC, and AC recruited the subjects. MR, GG and ES collected data. FBo and FBa conceived and designed the analysis and conducted the statistical analyses. FBo and FBa wrote the paper. All authors reviewed the final manuscript.

Declaration of competing interest

The authors declare no conflict of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.parkreldis.2022.05.015.

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