

ORIGINAL PAPER

The COVID-19 Pandemic: a Study on Its Impact on Patients with Dystonia and Related Conditions Treated with Botulinum Toxin in a Tertiary Centre in Romania

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Abstract

Background and Objectives: The COVID-19 pandemic triggered significant delays in the treatment of people with movement disorders who depend on face-to-face clinic encounters for receipt of their regular botulinum toxin injections. Against this background, it was the aim of this study to look into pandemic-related characteristics of patients with dystonia and hemifacial spasm treated with botulinum toxin at a tertiary centre in Romania and identify potential correlations between delays in treatment and health perceptions.

Materials and Methods: A cross-sectional, questionnaire-based, study was conducted between May-September 2021 on the 175 patients in the centre's botulinum toxin database.

Results: Of the 90 patients who qualified for inclusion most were late middle-aged females with long-standing dystonia, of which torticollis and blepharospasm were the most common phenotypes. Treatment was delayed by an average of 8.5 months, whereas the overall quality-of-life health score was 61.1, with 60% of respondents rating themselves above 50. No statistically significant correlation was identified between delays in treatment and overall healthscores. Instead, statistically significant differences were uncovered based on type of disorder (dystonia vs. hemifacial spasm).

Conclusion: The results of this study may go on to show that, in the event of similar pandemic surges, patient management by type of disorder may be part of a well-balanced restriction-cum-access health policy.

Keywords: dystonia, hemifacial spasm, botulinum toxin, SARS-CoV-2, COVID-19, vaccine, Romania.

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INTRODUCTION

The COVID-19 pandemic has most likely affected many patients across the whole spectrum of medical specialties. Of these, patients whose treatment implied regular clinic visits for interventions not amenable to on-line services have been most affected. Patients with dystonia and related conditions (i.e. hemifacial spasm) receiving periodic treatment with botulinum toxin – whose hospital access was suddenly curtailed in the absence of safeguards as to when treatment might be resumed – are a typical case in point.

In line with the latest consensus in the field¹, dystonia is a movement disorder consisting of sustained or intermittent muscle contractions leading to abnormal movements and/or postures that are often repetitive, stereotyped, contorted and made worse during voluntary action. With the dopaminergic system lying at the crossroads between motor and non-motor symptoms², patients with dystonia are afflicted not only with motor manifestations but also with depression and anxiety³, correlating strongly with reduced health-related quality of life⁴. Furthermore, patients with dystonia have particular psychological profiles that seem to require well-modulated patient-doctor interactions for therapeutic compliance and success⁵.

To date, no cure has been identified for dystonia patients. Symptomatic treatments are nevertheless available⁶, with botulinum toxin injections (BTI) ranking high among the most effective therapies for people with dystonia and related conditions such as hemifacial spasm. BTIs are delivered periodically – about once every three months – in keeping with botulinum toxin pharmacodynamics/pharmacokinetics⁷. Treatment is not only periodic, but also highly individualised, requiring several *right muscle-right dose* optimisation sessions per each patient⁸.

As of this writing, there is no official registry of patients with dystonia in Romania. By way of consequence, no population-wide data is available as to the magnitude of the dystonic phenomenon that public authorities might use in their policy-planning efforts, whether they be during pandemic or business-as-usual scenarios. Nor is well-curated data available as to the health centres that might be abilitated to offer botulinum toxin to patients with dystonia and related conditions such as hemifacial spasm. It is nevertheless an established fact that the Colentina Clinical Hospital in Bucharest is one such specialist tertiary cen-

tre and, probably, one of the largest centres providing BTI services for patients with movement disorders. In the context of the COVID-19 pandemic, this hospital was re-configured to serve exclusively as a COVID-19 support unit. As such, botulinum toxin services were suspended in March 2020 and then resumed – below capacity and via dedicated patient circuits – in September 2020. For some patients, though, fear of contamination in a hospital dealing with COVID-19 cases (despite assurance as to the separation of circuits) meant a protracted cessation of their treatment and aggravation of movement symptoms. It should be noted, at this point, that while telemedicine could address part of the non-motor problems of patients with dystonia – although no telemedicine/face-to-face consultation equivalence studies are available⁹ – the provision of injectable treatment for motor symptoms can be carried out solely in a face-to-face/on-site format.

Several studies have been published to date on the effects of the COVID-19 pandemic on patients with dystonia being treated with BTIs in Germany - 45 patients¹⁰, India - 100 patients¹¹, the Philippines - 3 patients¹², Spain - 71 participants¹³, Italy - 94 cases vs 43 controls and 62 participants, respectively^{14,15} or the United States - 64 patients¹⁶. On the other hand, one single study has been published on the topic in Romania, on a lot of 50 patients (members of the Children's Joy Association of Patients with Dystonia), focusing on quality of life issues and physiotherapy alternatives to BTIs¹⁷.

Against the background outlined above, it is the aim of this study to capture a snapshot of health-perceptions among patients with movement disorders (dystonia and hemifacial spasm) being treated with botulinum toxin in a tertiary centre in the capital city of Romania (Colentina Clinical Hospital – Bucharest). Beyond assessing quality-of-life issues, it is equally the aim of this study to present data on motor and non-motor particulars in the life of patients with dystonia and related conditions, at three distinct moments during the course of the pandemic, as follows:

- **prevention** – assessing the impact of hand-hygiene or mask-wearing requirements on the welfare of patients with dystonia and hemifacial spasm
- **restriction** – assessing the impact of lockdown measures in the setting of hospital visits or outdoor purchases of comorbidity-related medications
- **resolution** – assessing the impact of vaccination recommendations on patients with dystonia and re-

lated disorders, including concerns about potential interferences between botulinum toxin and anti-viral vaccine injections.

It is expected that the results of the study will help shape future health-related public policies in the event of similar pandemic events. Raising awareness among national health centres and patient associations as to potential co-operation towards the creation of a national registry of patients with dystonia and related conditions as a foundation for future joint activities in the benefit of these patients is also expected.

MATERIALS AND METHODS

The study was conducted between May-September 2021, as per approval by the local Ethics Committee (no.14/23.04.2021). Patient selection relied on entries in the relevant database already in place at the study location. Inclusion criteria consisted of the following items:

- age 18 or above
- Romanian speakers
- a diagnosis of dystonia or hemifacial spasm irrespective of the type of dystonia or treatment duration before the start date of the study
- informed consent given in writing by the patient or a legal representative
- absence of any disability that might impinge on the self-administration of study questionnaires during hospital visits (e.g. bilateral blepharospasm affecting eye-sight or invalidating hand postures that render hand-writing impracticable).

Two separate questionnaire sets were administered during the study period: a more quantitative, validated, one concerning quality of life in general (EQ-5D) and a more qualitative questionnaire designed by the research team concerning pandemic-related specifics. The first consisted of a five-item multiple-choice questionnaire, including a 0 to 100 health-state self-score, whereas the latter included 44 open-ended, yes/no or multiple choice questions divided into four parts – demographics (8 questions), treatment access (13 questions), prevention-restriction issues (13 questions) and vaccination (10 questions).

Written approval was sought from, and granted by, the EuroQoL Research Foundation for use of the EQ-5D paper-based version of the quality-of-life questionnaire. Following provision of the relevant informed consent, all patients filled in the paper version of the

questionnaires as part of their short hospital visit for botulinum injection purposes. As such, patients were not additionally exposed to potential infectious threats. In keeping with personal data protection requirements (EU Regulation 2016/679 and the national Data Protection Act 3 of December 5, 2018), the research team then aggregated all data entries in an Excel-based anonymised format.

Data analysis was carried out in line with statistical best practices reporting on means, medians, standard deviations, frequencies and proportions, correlations etc, as applicable to quantitative and/or categorical variables. Bar charts and boxplots/histograms have been used to illustrate categorical and quantitative data, respectively. For comparison of means (continuous outcome variables) between two independent groups, a Wilcoxon rank-sum test was run (assumptions of normality, homogeneity and sample size violated). Correlation tests were run on continuous variables for the purposes of identifying relevant relations. Data processing was performed using R software version 3.6.3 (significance set at $p < 0.05$).

RESULTS

Of the 175 patients in the database as many as 90 participants qualified for inclusion as per the relevant criteria. The remainder consisted of 20 new entries (diagnosis after the study had begun) and 65 older entries (of whom 6 refused to participate in the study, 1 was not a Romanian speaker, 15 came to the clinic after the study ended and 43 did not visit the clinic during the study period for fear of the pandemic or because of having temporarily accessed toxin injection services at a different facility).

General data

Of the 90 patients in the study, 68 were females, whereas only 22 were males. As many as 72 patients had dystonia, while 18 patients in the study lot had hemifacial spasm. As could be expected, most patients were from the capital city of Romania (Bucharest) but the clinic is approached by patients throughout the country (except for the West/North-West regions) as per Figure 1.

Overall, the mean age was 58 years ($SD \pm 12.5$; range

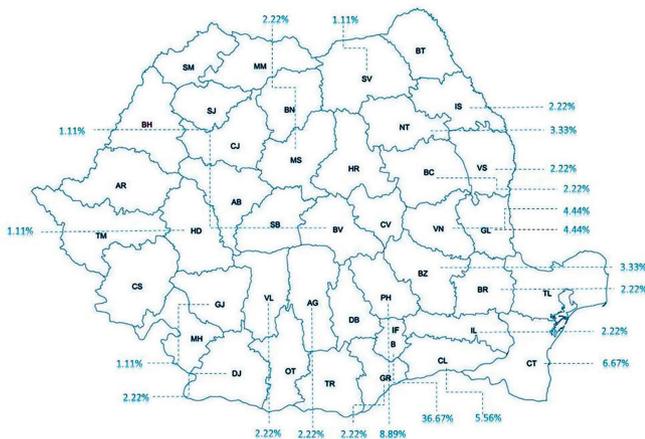


Figure 1. Distribution of patients by place of residence

21-82) and the mean age at disease onset was 48 years (SD±12.15; range 17-72). The mean disease duration was 9.85 years (SD±7.74; range 2-36), whereas the mean duration of treatment with botulinum toxin was 5.12 years (SD±3.98; range 0.3-20), reflecting delays in diagnosis (mean 1.48 years; SD±3.04; range 0-15) and/or toxin availability at the time of diagnosis. Most patients (86%) were treated every 3 to 6 months, most often (56 patients) with abobotulinumtoxin (ABO, Dysport®) versus 34 with incobotulinumtoxinA (INCO, Xeomin®). More precise treatment periodicity details are available in Figure 2.

A breakdown of general characteristics per type of

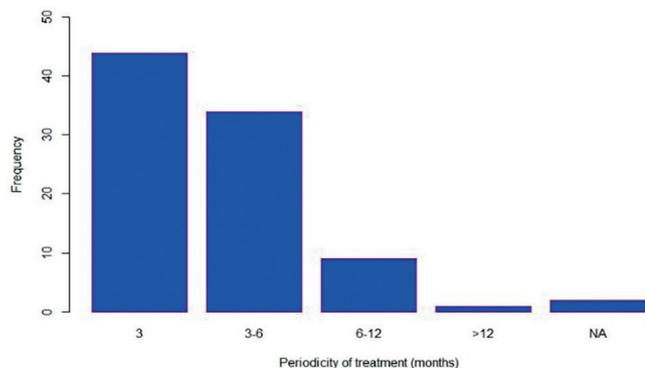


Figure 2. Distribution of patients per category of treatment periodicity

disorder (dystonia or hemifacial spasm) is available in Table 1.

Focal dystonia was the most frequent type of dystonia.

Table 1. Summary of general data by disorder (D=dystonia; H=hemifacial spasm)

Characteristic	D, N = 72 ¹	H, N = 18 ¹	p-value ²
Sex	54/72 (75%)	14/18 (78%)	>0.9
Age	57.12 (12.65)	65.11 (10.15)	0.013
Onset	47.25 (12.37)	54.78 (9.29)	0.020
Disease Duration	9.78 (7.67)	10.17 (8.23)	0.8
Toxin Type	50/72 (69%)	6/18 (33%)	0.005
Treatment Duration	5.05 (4.00)	5.44 (4.03)	0.6
Periodicity			0.004
3 months	41/72 (57%)	3/18 (17%)	
3-6 months	22/72 (31%)	12/18 (67%)	
1-12 onths	7/72 (9.7%)	2/18 (11%)	
>12 months	0/72 (0%)	1/18 (5.6%)	
NA	2/72 (2.8%)	0/18 (0%)	

¹n/N (%); Mean (SD)
²Fisher's exact test; Wilcoxon rank sum test; Pearson's Chi-squared test

Of the focal dystonias, torticollis and blepharospasm ranked first and second in frequency with 23 and 13 cases, respectively. Also present were segmental (10), multifocal (1) and generalized (1) dystonias as per Figure 3. All dystonias had a progressive and persistent pattern. Most were primary, isolated, sporadic dystonia cases (only three familial instances and two combined cases associating parkinsonism were identified). As many as 67 patients (74%) had concurrent diseases.

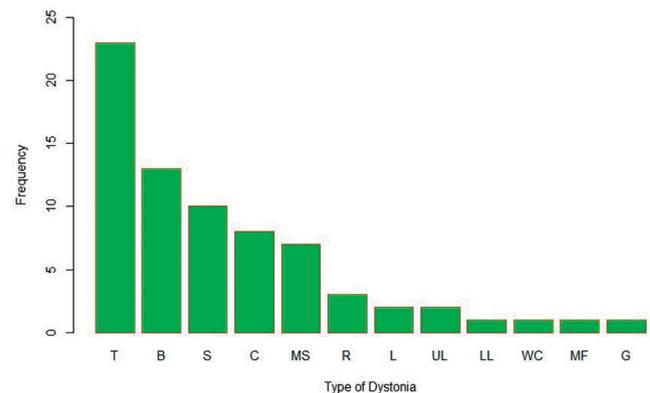


Figure 3. Distribution of patients per type of dystonia (T - Torticollis, B - Blepharospasm, S - Segmental, C - Complex Cervical, MS - Meige Syndrome, R - Retrocollis, L - Laterocollis, UL - Upper Limb, LL - Lower Limb, WC - Writer's Cramp, MF - Multifocal, G - Generalized)

Heart conditions were the most frequent (47 cases), followed by rheumatic (20), psychiatric (13), gastric (13) and diabetic (10) conditions as per Figure 4.

Except for 12 patients, all other participants were on medications other than botulinum toxin, with clonazepam, trihexyphenidyl and blood pressure tablets among the most widely used.

Prevention

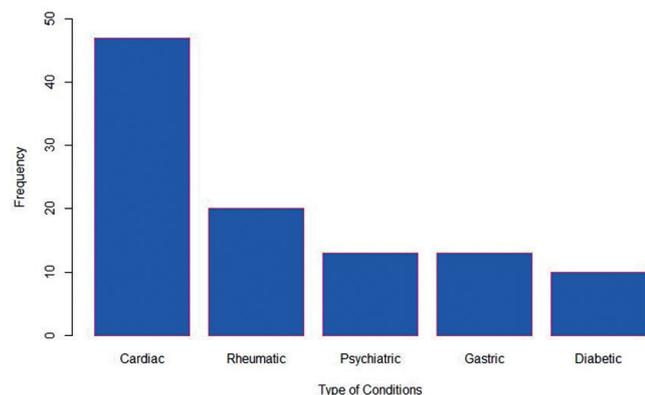


Figure 4. Distribution of concurrent diseases in the study lot

As regards pandemic-related prevention measures, most participants reported no problems complying with hand-hygiene or mask-wearing regulations. Some 34% of all respondents indicated difficulties with performing their usual sensory tricks as per summary data in Table 2 (N.B. - all hemifacial spasm patients included as NA with respect to sensory tricks given that hemifacial spasm is not considered a dystonia per se). Only 6 patients got infected with the SARS-CoV-2 virus during the pandemic (3 participants chose not to reply).

Restriction

Table 2. Distribution of participants per prevention-related difficulties

(0 = reported difficulties; 1 = reported no difficulties; NA = not available)

Characteristic	N = 90 ¹
Hand Hygiene	
0	11/90 (12%)
1	74/90 (82%)
NA	5/90 (5.6%)
Mask Wearing	
0	28/90 (31%)
1	60/90 (67%)
NA	2/90 (2.2%)
Sensory Trick	
0	31/90 (34%)
1	37/90 (41%)
NA	22/90 (24%)
¹ n/N (%)	

As a result of restrictive measures, including a general lockdown of the capital city of Romania and the reorganisation of our clinic as a COVID-only unit, treatment for patients with dystonia and hemifacial spasm was delayed for an average of 8.5 months (SD±4.5; range 0-24). During the restrictive period of the pandemic, most participants would have appreciated continuing their regular treatment (94%); also, as many as 80% had no access to, or could not afford, a different clinic for injection-administration purposes; under the circumstances, a few patients (19%) opted for alternative treatments such as acupuncture; however, not all patients considered their right to treatment violated during the pandemic (61% - violation vs. 31% no violation). More details are available in Table 3.

Not only were patients affected in terms of their

Table 3. Distribution of participants per restriction-related general difficulties/perceptions

(0=yes; 1 = no; 2 = don't know; NA = not available)

Characteristic	N = 90 ¹
Different Location	
0	9/90 (10%)
1	72/90 (80%)
NA	9/90 (10%)
Alternative Treatment	
0	17/90 (19%)
1	70/90 (78%)
NA	3/90 (3.3%)
Right Violated	
0	55/90 (61%)
1	28/90 (31%)
NA	7/90 (7.8%)
¹ n/N (%)	

health, but their welfare was also economically challenged. As per Table 4 summary data, as many as 74% of patients could not afford to buy their medications, 50% had their work affected one way or another, while 20% had to discontinue their jobs either because they had to apply for sick leave or as a result of pandemic-related lay-offs/enterprise downsizing or part-time policies.

Last but not least, about half of the respondents

Table 4. Distribution of participants per restriction-related economic difficulties
(0 = yes; 1 = no; NA = not available)

Characteristic	N = 90 ¹
Could Afford Medication	
0	13/90 (14%)
1	67/90 (74%)
NA	10/90 (11%)
Work Affected	
0	45/90 (50%)
1	34/90 (38%)
NA	11/90 (12%)
Job Discontinuation	
0	18/90 (20%)
1	44/90 (49%)
NA	28/90 (31%)
¹ n/N (%)	

appreciated they had been more anxious during the pandemic compared to before the pandemic and considered their dystonia/ facial spasm symptoms worsened against that background (Table 5).

Resolution

Table 5. Distribution of respondents considering their anxiety and dystonia worse during the pandemic than before the pandemic
(0 = yes; 1 = no; NA = not available)

Characteristic	N = 90 ¹
Anxiety Worsened	
0	42/90 (47%)
1	44/90 (49%)
NA	4/90 (4.4%)
Symptoms Worsened	
0	36/90 (40%)
1	44/90 (49%)
NA	10/90 (11%)
¹ n/N (%)	

In terms of resolute measures (Table 6), it must be noted that about half of all participants (51%) did get a vaccine, whereas a further 22% indicated they would get a vaccine. Of those who did get a vaccine, 19% did have some sort of adverse reaction (with headache, fever and muscle pain among the most frequent possibilities) and only 28% indicated preference for one particular vaccine over another (trust or ease of administration being the main reason for having a preference). About 58% of respondents were not concerned about potential interactions between BTIs and the anti-SARS-CoV-2 vaccine. Of those who did not get a vaccine, many chose

not to give a reason for their option, whereas the few who did so (14 patients) singled out fear and mistrust as the main impediments.

Overall health-state perception

Table 6. Distribution of respondents per resolute measures
(0 = yes; 1 = no; NA = not available)

Characteristic	N = 90 ¹
Did Get A Vaccine	
0	46/90 (51%)
1	42/90 (47%)
NA	2/90 (2.2%)
Would Get A Vaccine	
0	20/90 (22%)
1	22/90 (24%)
NA	48/90 (53%)
Concern For Interaction with BTI	
0	31/90 (34%)
1	52/90 (58%)
NA	7/90 (7.8%)
¹ n/N (%)	

Against the specifically-pandemic background detailed above, participants also filled in the EQ-5D quality of life validated questionnaire. Their responses are aggregated in Table 7 in line with EQ-5D guidelines. As could be noted from the summary data, most of the potentially problematic variables were rated in the no problem-moderate problems range, with mobility and self-care being mostly non-problematic, usual activities and anxiety/depression being non- to slightly-problematic and pain mostly moderately problematic.

Table 7. Distribution of EQ-5D ratings per level of severity
(0 = yes; 1 = no; NA = not available)

	Mobility n(%)	Self-Care n(%)	Usual Activities n(%)	Pain/ Discomfort n(%)	Anxiety/ Depression n(%)
Level 1 (no problems)	37 (41)	59 (65)	30 (33)	16 (18)	32 (35)
Level 2 (slight)	22 (25)	11 (12)	27 (30)	21 (23)	26 (29)
Level 3 (moderate)	13 (14)	10 (11)	20 (22)	32 (35)	22 (24)
Level 4 (severe)	13 (14)	5 (6)	8 (9)	14 (16)	5 (6)
Level 5 (extreme)	5 (6)	5 (6)	5 (6)	7 (8)	5 (6)
TOTAL	90 (100)	90 (100)	90 (100)	90 (100)	90 (100)

Overall, the average self-perceived health score among all respondents was 61.11 (SD±21.2; range 0-100) as per histogram details Figure 5. In spite of all pandemic-related shortcomings, more than half of respondents (54 – 60%) rated their overall health on the day of presentation above 50.

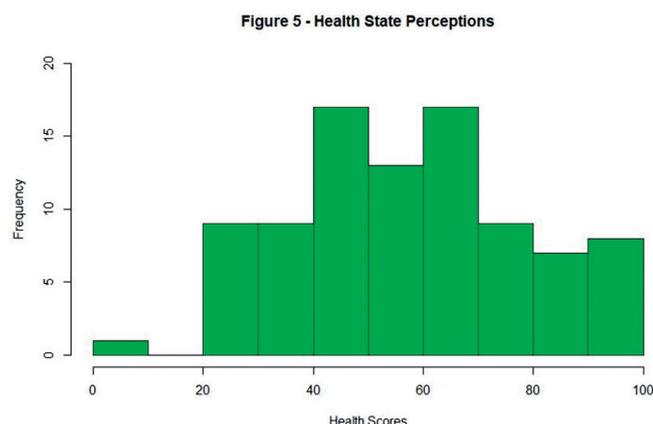


Figure 5. Health State Perceptions

A breakdown of scores per disorder type (Figure 6) indicates a significant difference in the healthscore means of the dystonia and hemifacial spasm group, respectively. On average, the hemifacial spasm group had a higher healthscore mean compared to the dystonia group (70 versus 58.8).

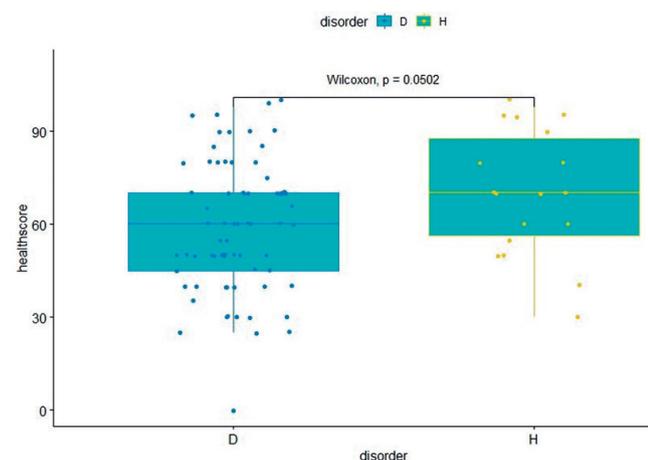


Figure 6. Comparison in the healthscore means of patients with dystonia (D) and hemifacial spasm (H)

As one of the aims of this study is to raise awareness about the impact of the pandemic on people with dystonia and hemifacial spasm and – based on that –

help identify potential ways of optimising treatment delivery, we have deemed it useful to explore the relation between pandemic-triggered delays in treatment and overall health scores. The reason for this step was based on the assumption that the latter are, in effect, a fairly good numeric/averaging reflection of the five separate relevant EQ-5D variables (pain, regular activities, mobility, anxiety/depression and self-care) and an indicator – albeit transient – for the authorities as to the general health welfare of the specific population under investigation. In so doing, we have identified no correlation whatsoever between delays in treatment and individual patient healthscores (Figure 7).

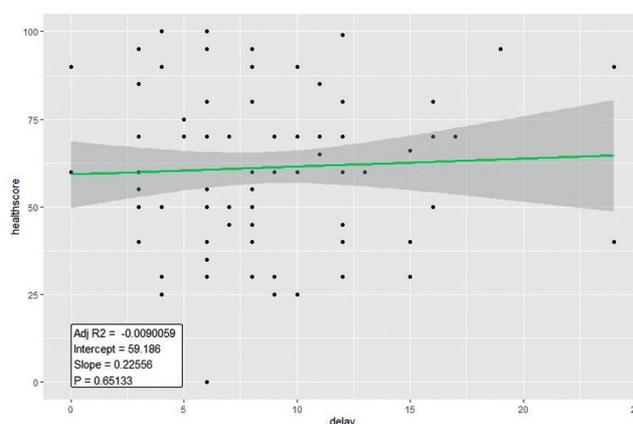


Figure 7. Correlation between delays in treatment and healthscores

DISCUSSION

The results of this study are, by and large, consistent with past findings with respect to female:male prevalence ratios favouring women^{18,19}, although not as steeply as in our study, which might be explained by selection bias. However, another Romanian study¹⁷ reported differences closer to our results.

Also similar to past results is the finding that focal dystonias are more frequent than segmental, multifocal or generalized ones, with torticollis ranking first among focal dystonias²⁰.

Mean age at onset was lower in the dystonia group – 47 years compared to about 55 in a similar report²¹– and higher in the hemifacial spasm group – 54 years compared to 48.5 in a relevant article²²; however, decade-wise, differences are not very large and, at least in the latter case, could be explained by highly unequal sample sizes.

Time till diagnosis in our lot averaged 1.48 years compared to much larger time spans in previous reports such as 4-6.4 years for dystonia^{23,24} and 3.9 years for hemifacial spasm²⁴, again, possibly a reflection of selection bias (most of the patients in our lot had been diagnosed at our tertiary center). As expected, concurrent disease was a common occurrence among patients with dystonia and hemifacial spasm, with psychiatric and rheumatic conditions prominent across the spectrum of medical conditions^{25,26}, fairly similar to our findings (75% patients had concurrent disease, with heart, psychiatric and rheumatic conditions among the top three disease associations).

In pandemic-preventive terms, and quite contrary to expectations given reports of – for instance – skin conditions in the context of frequent hand washing²⁷, most participants in our lot reported no problems with hand-hygiene or mask-wearing requirements and a little more than half of the people with dystonia reported inconvenience in the performance of their usual sensory trick. Interestingly, other articles on the topic²⁸ found that mask wearing had positive effects in some hemifacial spasm and dystonia patients by dint of facial symptom concealment in the first group and muscle hyperactivity alleviation (the mask operating as a sensory trick prop) in the latter group. However, our results could not corroborate those findings given that our questionnaire did not reach the requisite level of refinement, the relevant questions being framed in less informative binary (yes/no) terms.

With respect to restriction-related measures, our findings indicated an average delay in treatment of 8.5 months – significantly higher compared to 73.61 ± 26.54 days reported in a case-control study from Italy¹⁴ and 6.6 ± 2.3 weeks in a similar study from Germany¹⁰, but closer to delays reported in a study from India (4-8 months in 42% of cases)¹¹. Beyond sample sizes, differences in these findings may be attributable mainly to differences in clinic status, ours having been converted to a COVID-19-only medical facility for six months with a rather slow transition to a mixed set-up (COVID-19 and two limited programs open for the public – toxin injections for movement disorders and multiple sclerosis) for yet another six months.

As many as 61% participants considered their right to treatment had been violated during the pandemic, with associated economic difficulties coming on top of health-related preoccupations. This is significantly lower compared to 98% of the German respondents

having felt their patient rights had not been respected¹⁰. The difference may spring from sample sizes, population-specific right-claiming mentalities or even terminologic blurriness as to what violations of rights might encompass during a pandemic.

Finally, in resolute terms, only half of the respondents in our study did get a vaccine, corresponding to a higher proportion compared to the national average of 29% of the entire population having had two full doses as of this writing (official data available on vaccinare-covid.gov.ro, accessed on October 16, 2021). The caveat against which this finding should be interpreted is that patients in our lot reported vaccination on a yes/no basis, data being unavailable as to whether they had run the full double-dose vaccination course.

Fear and mistrust were indicated as the two main obstacles to vaccination by those who did choose to answer the 'why not vaccinate' question. Reports of fears fuelled by social media videos implicating that various conditions – movement disorders included – might follow as a direct toxic effect of the anti-COVID-19 vaccine are not limited to Romania²⁹. In effect, scientific reports on actual cases of post-vaccine movement disorders have indeed been published, but the manifestations described therein were rare, monophasic and reversible^{14,30,31}.

Interestingly, most of our respondents were not concerned with a potential interaction between BTIs and vaccination shots, a finding we could not corroborate with other studies as none on this topic has been identified (other than in dermatology-related contexts).

With respect to general health self-perceptions, the overall (EQ-5D) health score was on average 61.1, with 60% of respondents having rated their health above 50. However, despite pain having been mostly moderately problematic, we found no statistically significant correlation between delays in treatment (which are known to exacerbate pain following toxin wash-out as per the relevant pharmacokinetics) and overall healthscores. This resonates with the findings of a case-control study in Italy¹⁴ that spotted no reflection of actual clinical worsening into health-related quality of life scores. A three-fold reason may underpin the non-correlation finding:

- healthscores as designed in the EQ-5D questionnaire are only a 'blitz' snapshot reflecting fleeting perceptions on the day of questionnaire self-administration
- appreciation of healthscores may have been

skewed by questionnaire self-administration on the same day with botulinum toxin injections, with the prospect of imminent improvement in dystonia or hemifacial spasm having perhaps obscured appreciation of recent discontent; this may well be one of the main limitations of our study

- healthscores as self-perceptions may be fuzzier notions than expected from the mere sum-total of presumed components, with pain-freedom not the main driver of welfare.

Instead, we identified statistically significant differences in healthscore means based on type of disorder (dystonia vs. hemifacial spasm), a finding more in line with the differences outlined in a similar study from India¹¹ than with the results of the relevant German study¹⁰ that reported on similar substantial reduction in the well being of both groups (based on self-estimation of overall welfare reduction percentages).

CONCLUSIONS

As cures for dystonia and hemifacial spasm do not exist or are not readily available – financially or otherwise – it is expected that patients with these disorders will continue to call upon the services of botulinum toxin clinics. Not only will such chronic patients stay with their clinics, but the numbers of people with dystonia may go up as per a recent report from the United States³² having identified a rise in functional movement disorders during the pandemic, corresponding to a 60.1% increase in incidence compared to a similar period in 2019 (dystonia ranking as the second most common phenomenology - 31.1% – after tremor).

Against this background, solutions are badly needed that accommodate both patient rights to treatment and possibly inevitable treatment delays during pandemic conditions. One such solution would be botulinum toxins with longer half lives; relevant studies on a novel toxin formula - the effect of which might span six months – are currently under way³³. Yet another solution would be for the relevant clinics to operate in line with the recommendations for the management of botulinum toxin services during pandemic-like conditions issued by the ToxNet group³⁴, which are predicated on telemedicine assessment of emergencies and video support.

However, until such time as clinical trials on novel toxin products are seen through and associated prices become affordable, and until telemedicine services

are both equipped and regulated, bridge-over solutions need be identified and implemented. Our study has shown that delays in treatment may not be a major determinant of health-related welfare. Instead, clinic-specific patient micro-management based, for instance, on disorder-driven prioritisation (i.e. prioritising patients with dystonia over patients with hemifacial spasm if further studies confirm that group differences in pain and health welfare scores are indeed significant) might be dove-tailed with governmental macro-management of wider restrictions.

Compliance with ethics requirements: The authors declare no conflict of interest regarding this article. The authors declare that all the procedures and experiments of this study respect the ethical standards in the Helsinki Declaration of 1975, as revised in 2008(5), as well as the national law. Informed consent was obtained from all the patients included in the study.

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