

Causes for Treatment Delays in Dystonia and Hemifacial Spasm: A Canadian Survey

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ABSTRACT: Background: Dystonia must be accurately diagnosed so that treatment can be administered promptly. However, dystonia is a complex disorder, with variable presentation, which can delay diagnosis. **Methods:** Data were gathered by questionnaire from 866 patients with dystonia or hemifacial spasm (HFS) treated in 14 movement disorders centres in Canada injecting botulinum toxin, to better understand the path to diagnosis, wait times and obstacles to treatment. **Results:** Most participants were female (64.1%), mean age was 58 years, and patients consulted an average of 3.2 physicians before receiving a dystonia or HFS diagnosis. Many patients (34%) received other diagnoses before referral to a movement disorders clinic, most commonly "stress" (42.7%). A variety of treatments were often received without a diagnosis. The mean lag time between symptom onset and diagnosis was 5.4 years. After the decision to use botulinum toxin, patients waited a mean of 3.1 months before treatment. The most common diagnoses were cervical dystonia (51.6% of patients), HFS (20.0%) and blepharospasm (9.8%). **Conclusions:** Survey results show that diagnosis of dystonias or of HFS, and therefore, access to treatment, is delayed. An educational program for primary care physicians may be helpful to decrease the time to diagnosis and referral to a specialist centre for treatment.

RÉSUMÉ: Enquête canadienne sur les causes de retard dans le traitement de la dystonie et du spasme hémifacial. Contexte : Un diagnostic précis doit être posé pour que la dystonie soit traitée promptement. Cependant, la dystonie est une maladie complexe dont le mode de présentation est variable, ce qui peut retarder le diagnostic. **Méthode :** Nous avons recueilli les données au moyen d'un questionnaire administré à 866 patients atteints de dystonie ou de spasme hémifacial (SHF) qui ont été traités par injection de toxine botulique dans 14 centres de traitement des désordres du mouvement au Canada, afin de mieux comprendre le parcours diagnostique, les délais et les obstacles au traitement. **Résultats :** La majorité des patients étaient des femmes (64%) et l'âge moyen était de 58 ans. Les patients avaient consulté en moyenne 3,2 médecins avant de recevoir un diagnostic de dystonie ou de SHF. Plusieurs patients (34%) avaient reçu d'autres diagnostics avant d'être référés à une clinique des désordres du mouvement, le diagnostic le plus fréquent étant celui de "stress" (42,7%). Différents traitements avaient souvent été administrés, sans qu'un diagnostic n'ait été posé. Le temps moyen écoulé entre le début des symptômes et le diagnostic était de 5,4 ans. Après que la décision d'employer de la toxine botulique ait été prise, les patients avaient attendu en moyenne 3,1 mois avant d'être traités. Les diagnostics les plus fréquents étaient les suivants : dystonie cervicale (51,6% des patients), SHF (20,0%) et blépharospasme (9,8%). **Conclusions :** Les résultats de l'enquête démontrent qu'il existe un retard dans le diagnostic des dystonies ou du SHF et donc que l'accès au traitement en est retardé. Un programme d'éducation destiné aux médecins de première ligne pourrait aider à accélérer le diagnostic et la consultation dans un centre spécialisé dans le traitement de ces pathologies.

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Dystonia has diverse causes, but ultimately results in patterned, directional and often sustained contractions of muscles that result in abnormal postures or repetitive movements.¹ Precise diagnosis is essential for providing optimal therapy; however, the low prevalence of dystonia (e.g., 7.4/100 000 men and 14.5/100 000 women for hemifacial spasm (HFS),² 2.9-8.9/100 000 for cervical dystonia,³⁻⁶ and 1.2-13.3/100 000 for blepharospasm^{4,5,7-9} results in many physicians having little exposure to it in their training or practices.

The low prevalence and the non-specific and intermittent clinical presentation can delay the diagnosis and institution of effective treatment for dystonia.^{1,9-11} Many types of focal dystonia can be treated.¹² Botulinum toxin type A injections, one of the most effective treatments for cervical dystonia,^{12,13} are often administered by movement disorders specialists.

Delays in diagnosis and concentration of movement disorders clinics in urban centres may limit access to treatment in Canada. In order to evaluate this, we conducted an observational study at

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movement disorders centres to understand the path to diagnosis for patients seeking treatment for focal dystonia and HFS, establish a timeline for access to treatment with botulinum toxin type A and identify hurdles to diagnosis and treatment.

MATERIALS AND METHODS

Patients

The inclusion criteria for the study were broad. All patients had received a diagnosis of dystonia or HFS and were attending a clinic at a movement disorders centre, that regularly treats patients with botulinum toxin. Some patients had attended the clinic previously and were returning for further treatment; other patients were attending for the first time. Each centre was asked to enroll up to 80 sequential patients (the study was not randomized). Patients participating in any clinical trial of botulinum toxin were ineligible.

Questionnaire

Study participants completed a one page survey consisting of 19 questions during a clinic visit (see Appendix). The Movement Disorders Survey was developed by Allergan Canada in consultation with a panel of movement disorders specialists (The Canadian Movement Disorder Survey Group Steering Committee), ISIS Digital Media Inc., Toronto, Canada, and AXON Clinical Research, Toronto, Canada.

Study conduct

The research ethics board or institutional ethics committee at each participating centre reviewed and approved the protocol before any patients were enrolled. All patients provided written informed consent before the survey was administered.

Statistical analysis

Results were compared by T-test or Chi-square test and an alpha level of 0.05 was used as a threshold for statistical significance.

A correspondence analysis was conducted with BrandMap (WRC Research Systems, Downers Grove Illinois). Categorical variables included time to diagnosis of dystonia in years (<1; 1-6; ≥ 7 years) wait time for treatment with botulinum toxin in months (no wait; 1- <3 ; 3-6; ≥ 7 months), and distance to a movement disorder clinic in kilometers (km) (<25; 25-50; ≥ 51 km). In a second analysis relationships between time to a final diagnosis (as above), number of doctors consulted (0-1; 2; 3; ≥ 4) and type of doctor or resource consulted (neurologist/movement disorders specialist; family doctor; other doctor; other patient resources) were evaluated for the three most common diagnoses (cervical dystonia; blepharospasm; HFS). Associations between these diagnoses, age in years (30-49; 50-64; ≥ 65), gender (male; female) and distance to the clinic (as above) were evaluated in a third correspondence analysis.

RESULTS

A total of 19 physicians from 14 movement disorders clinics in Canada conducted 886 patient surveys (range 9 to 84 surveys/investigator) between July 16, 2007 and May 27, 2008. The characteristics of study participants are presented in Table 1. The majority of survey participants were female and the mean age was 58 years.

On average, patients consulted approximately three different physicians (3.2) before the current dystonia or HFS diagnosis. Most patients had consulted a family physician (683, 77.1%) and/or a neurologist (650, 73.4%) in an attempt to have their condition diagnosed. A smaller proportion had consulted a movement disorders specialist (289, 32.6%), chiropractor (171, 19.3%), eye care doctor (146, 16.5%) and/or a physiotherapist (150, 16.9%) during their quest to receive effective treatment. The proportion of patients who consulted the internet or other medical references (161, 18.2%), other affected patient (37, 4.2%) other person (50, 5.6%), and or a support group (21, 2.4%) was comparatively small.

The majority of patients (527, 59.5%) reported not receiving

Table 1: Characteristics of patients enrolled in the study

	Characteristic	N (%)
Gender	Male	225 (25.4)
	Female	568 (64.1)
	Not stated	93 (10.5)
Age, years	<25	11 (1.3)
	25-34	33 (3.7)
	35-44	79 (8.9)
	45-54	236 (26.6)
	55-64	268 (30.2)
	65-74	162 (18.3)
	≥ 75	95 (10.7)
	Not stated	2 (0.2%)
	Mean \pm SD	57.6 \pm 13.2
Type of healthcare reimbursement ^a	Employer	423 (47.7)
	Public	459 (51.8)
	Patient	154 (17.4)
Received botulinum toxin	Yes	829 (93.6)
	No	11 (1.2)
	Not stated	46 (5.2)

^a Patients may have had one or more types of healthcare reimbursement coverage.

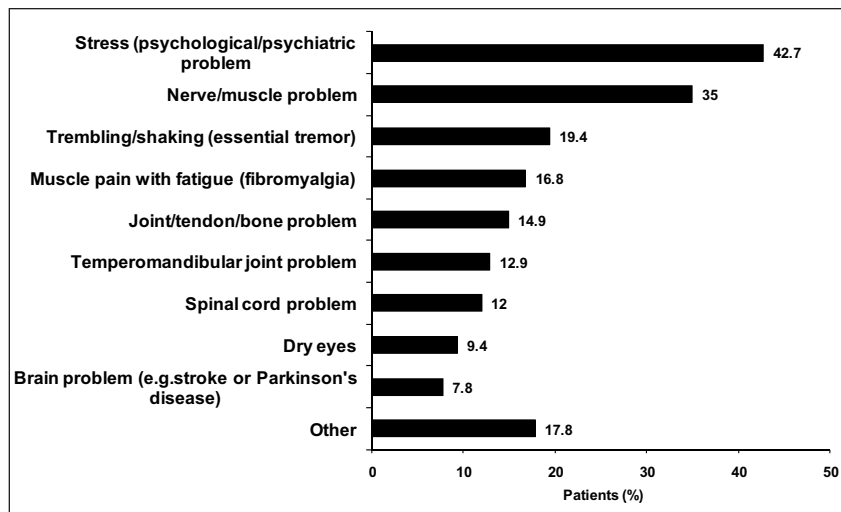


Figure 1: Diagnoses received by patients prior to the diagnosis of dystonia or HFS.

an alternative diagnosis for their movement disorder prior to the dystonia or HFS diagnosis. Among the 309 patients (34.9%) that had received other diagnoses prior to being diagnosed with dystonia, the most common previous diagnoses were “stress” (132, 42.7%) and “nerve or muscle problem” (108, 35.0%) (Figure 1), and nearly 20% (59) were told there was nothing wrong.

The mean age at onset of movement disorders was 43.8 years and the average age at diagnosis of movement disorders was 48.5 years. Among patients that reported both an age of onset and an age at diagnosis, the mean lag time between onset and diagnosis was 5.4 years. The average lag time was longer in females than males (5.6 vs. 4.3 years), was longest in those aged ≥65 years (7.3 years) and shortest in those aged less than 30 years (4.2 years).

The current dystonia or HFS diagnosis was made primarily by a neurologist (564, 63.7%) or movement disorders specialist (291, 32.8%). Family physicians (82, 9.3%), neurosurgeons (47, 5.3%), and eye care doctors (34, 3.8%) made the diagnosis in relatively few patients. The most common diagnoses for which botulinum toxin was prescribed at the participating clinics included cervical dystonia (457 patients, 51.6%) HFS (177 patients, 20.0%) and blepharospasm (87 patients, 9.8%) (Figure 2). Females predominated within each of these three diagnoses (Table 2). Patients with cervical dystonia were younger (mean age 56 years) than those with HFS (61 years) or blepharospasm (62 years). Patients with cervical dystonia had a younger age of onset for their condition (41 years versus 49 years with HFS and blepharospasm) and a longer mean time to diagnosis (six years versus three years for HFS and four years for blepharospasm).

Prior to the diagnosis of dystonia or HFS, 543 patients (61.3%) reported receiving previous treatment with medication (38.6%), physiotherapy (19.0%), chiropractic (15.7%), botulinum toxin (30.1%), and/or other modalities (9.1%). Approximately one-third of patients (35.8%) reported receiving no treatment prior to the current diagnosis. After referral to the movement disorders clinic, patients waited a mean of 3.1 months

before receiving treatment with botulinum toxin. A total of 778 patients (93.8%) received treatment within one year and 4.1% of patients (34) received treatment more than one year after the decision to use botulinum toxin was made. The most frequently reported reasons for waiting to receive a botulinum toxin injection were physician wait list (325, 53%) and time taken to complete paper work with an insurance company (104, 17.0%) (Table 3). Few patients cited lack of coverage by public drug plans (24, 3.9%), cost of treatment (27, 4.4%) or accessibility of the movement disorders clinic (15, 2.4%) as the reason for the wait.

The average distance travelled to the movement disorder clinics was 74.4 km and the majority of patients (726, 82%) travelled by car to their appointment (Table 4).

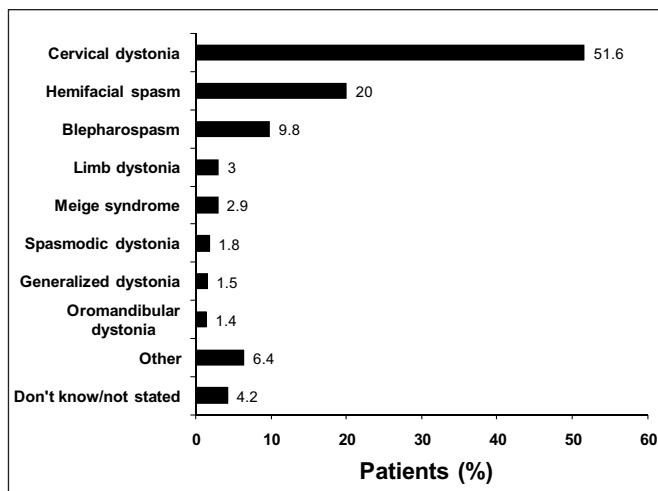


Figure 2: Current dystonia diagnoses.

Table 2: Characteristics of patients with the most frequently reported dystonia diagnoses

Characteristic		Cervical dystonia N=457	Hemifacial spasm N=177	Blepharospasm N=87
Gender, n (%)	Male	92 (20.1)	61 (34.5)	24 (27.6)
	Female	323 (70.7)	96 (54.2)	52 (59.8)
	Not stated	42 (9.2)	20 (11.3)	11 (12.6)
Mean age in years \pm SD		56.4 \pm 12.7	61.0 \pm 12.7	62.3 \pm 13.4
Current age range, n (%)	\leq 24	5 (1.1)	3 (1.7)	0
	25-34	18 (3.9)	2 (1.1)	2 (2.3)
	35-44	47 (10.3)	9 (5.1)	8 (9.2)
	45-54	129 (28.2)	41 (23.2)	13 (14.9)
	55-64	145 (31.7)	53 (29.9)	26 (29.9)
	65-74	77 (16.8)	38 (21.5)	23 (26.4)
	\geq 75	34 (7.4)	31 (17.5)	15 (17.2)
Mean age at onset of symptoms of dystonia, years		41.3 \pm 15.8	48.6 \pm 16.8	49.8 \pm 15.8
Mean age when dystonia was diagnosed, years		47.3 \pm 14.3	51.8 \pm 15.8	53.1 \pm 13.7
Mean time to diagnosis, years		6.4	3.9	4.5
Mean distance from clinic, km		79.5	71.7	71.4
Mean number of healthcare professionals consulted prior to the diagnosis		3.3	2.5	3.2
Health professionals consulted prior to present diagnosis, n (%)	Neurologist/ movement disorders specialist	388 (84.9)	142 (80.2)	66 (75.9)
	Family doctor	361 (79.0)	122 (68.9)	64 (73.6)
	Chiropractor	127 (27.8)	10 (5.6)	7 (8.0)
	Physiotherapist	114 (24.9)	2 (1.1)	3 (3.4)
	Eye Care doctor	23 (5.0)	48 (27.1)	50 (57.7)
Other diagnoses made prior to present diagnosis, n (%)	Yes	183 (40.0)	41 (23.2)	32 (36.8)
	No	249 (54.5)	126 (71.2)	52 (59.8)
	Don't know/not stated	25 (5.5)	10 (5.6)	3 (3.4)
Other diagnoses	Stress	86 (47.0)	15 (36.6)	10 (31.3)
	Nerve/muscle problem	69 (37.7)	16 (39.0)	6 (18.8)
	Tremor	51 (27.9)	3 (7.3)	-
	Fibromyalgia	34 (18.6)	7 (7.3)	3 (9.4)
	Joint/tendon problems	32 (17.5)	2 (4.9)	2 (6.3)
	Temporomandibular joint problem	21 (11.5)	4 (9.8)	3 (9.4)
	Spine	32 (17.5)	1 (2.4)	-
Health professionals who diagnosed present dystonia, n (%)	Neurologist/ movement disorders specialist	408 (89.3)	154 (87.0)	72 (82.8)
	Family doctor	45 (9.8)	13 (7.3)	9 (10.3)
	Neurosurgeon	25 (5.5)	16 (9.0)	1 (1.1)
	Physiotherapist	16 (3.5)	1 (0.6)	-
	Physiatrist	13 (2.8)	-	-
	Eye Care doctor	6 (1.3)	6 (3.4)	17 (19.5)
Received treatment prior to present dystonia diagnosis ^a		323 (70.7)	73 (41.2)	43 (49.4)
Receiving botulinum toxin for the present dystonia diagnosis		424 (92.8)	168 (94.9)	81 (93.1)

^a Previous treatments included medication, physiotherapy, chiropractic interventions, and botulinum toxin injections

The correspondence analyses show that patients living 0-25 km or 26-50 km from a movement disorders clinic were more likely to receive a diagnosis in less than one year and to have shorter wait times for treatment with botulinum toxin A (either no wait, or one to three months). Alternatively, patients living more than 51 km from a movement disorders clinic, were more likely wait one or more years for a diagnosis and to wait three to six months for treatment.

Patients with cervical dystonia were more likely to wait seven or more years for a diagnosis and to have consulted more physicians (>3) and patient resources than patients with HFS or blepharospasm. Patients with HFS were more likely to have a shorter time to diagnosis (less than one year), to have consulted fewer physicians (0-1), but were more likely to have consulted a movement disorders specialist (MD)/neurologist. Patients with blepharospasm were more likely to wait from one to six years to

Table 3: Waiting times for administration of botulinum toxin injection

Characteristic		Mean time from onset of symptoms to diagnosis, years (n)	Mean wait time for botulinum toxin injection, months (n)
Gender	Male	3.5 (225)	2.6 (210)
	Female	4.7 (568)	3.3 (535)
Age range	<30	4.7 (24)	2.4 (23)
	30-49	4.1 (196)	4.0 (184)
	50-64	4.3 (407)	3.1 (383)
	≥65	4.2 (257)	2.6 (238)
Type of healthcare reimbursement ^a	Employer	4.1 (423)	3.2 (399)
	Public	4.1 (459)	3.0 (429)
	Patient	5.0 (154)	3.3 (147)

^a Patients may have had one or more types of healthcare reimbursement coverage

diagnosis, to have consulted at least two physicians and were more likely to have consulted “other types of doctors/specialists”.

Patients with HFS were more likely to be male, to be aged more than 50 years, to live less than 50 km from a movement disorders clinic and more likely to have waited less than one year for a diagnosis. Patients with cervical dystonia were more likely to be female, to be aged 30 to 49 years and to have waited more than seven years for a diagnosis. Patients with cervical dystonia were more likely to live more than 51 km from a movement disorders clinic. Patients with blepharospasm were more likely to be male, to be over the age of 65 years, to have waited from one to six years for a diagnosis and to live 25 km or less from a movement disorders clinic.

DISCUSSION

The results of this survey provide information on the characteristics of patients with movement disorders who present

to a movement disorder clinic across Canada, the majority of whom were treated with botulinum toxin (93.6%), and gives insight into the pathway such patients follow to receive a diagnosis of dystonia or HFS. Most of these patients had consulted a family physician and, on average, more than three physicians in total before the diagnosis was made. Thus delays in diagnosis may not be due to a lack of availability of physicians, but rather, points to the diagnostic uncertainty of initial mild clinical findings, and the nonspecific and highly variable symptoms reported by patients. The low prevalence, the lack of awareness of dystonia and the probable benefits of referring uncertain cases to specialists for assessment may also contribute to the delay.¹⁴ The diagnosis of dystonia is based on clinical diagnostic skills,^{14,15} and often requires the expertise of a neurologist or movement disorders specialist.

A large majority of patients had not received an alternative diagnosis prior to seeing a specialist in movement disorders. Moreover, patients who had received an alternative diagnosis

Table 4: Mode of transportation and distance travelled to movement disorders clinics

Mode of transportation to the clinic, n (%)	Car	726 (81.9)
	Public transit/taxi	106 (12.0)
	Walking	17 (1.9)
	Train	9 (1.0)
	Plane	8 (0.9)
	Wheelchair bus	7 (0.8)
	Other	14 (1.6)
	Not stated	20 (2.3)
Distance travelled to the clinic, km	≤25	346 (39.1)
	26-50	191 (21.6)
	51-100	140 (15.8)
	101-200	108 (12.2)
	201-300	46 (5.2)
	>300	37 (4.2)
	Don't know/not stated	18 (2.0)
Mean distance ^a	74.4	

^a Calculations are based on the midpoint of the reported ranges

were rarely told that they had dystonia. More than three-quarters of such patients had been told that their symptoms were due to stress or nerve or muscle problems. In such cases the physician may have been uncertain of the diagnosis, but believed that the patient had a psychogenic movement disorder or that psychological factors contributed to the symptoms.^{14,15} Even if we assume that some of these problems were recognized as dystonia or HFS, the proportion of patients who had received an accurate diagnosis appears to have been remarkably low until after referral to a neurologist or movement disorder specialist. Historically cervical dystonia and blepharospasm have been inaccurately attributed to psychogenic disorders.¹⁵ As a result of misdiagnosis or delayed diagnosis, many patients may not have received timely and specific treatment.

A substantial proportion of patients reported receiving no treatment for their symptoms prior to the dystonia or HFS diagnosis. Since the study was conducted in movement disorders clinics providing botulinum toxin, it is not surprising that patients had not previously received this mainstay of therapy for the three most common diagnoses – cervical dystonia,¹⁶ HFS,¹⁷ and blepharospasm.¹⁸ Given that effective treatment is available for these individuals, our study raises the concern that the prolonged wait times to diagnosis and treatment might have had a substantial negative impact on quality of life. Dystonia is one of the most under-recognized movement disorders,¹⁴ and some patients may never obtain an accurate diagnosis and appropriate treatment.

Some patients reported receiving prior treatment, including botulinum toxin, prior to receiving their present dystonia diagnosis. The details of these treatments were not captured in the survey.

The results suggest that for patients who are eventually referred to a movement disorders specialist the wait time between the decision to prescribe botulinum toxin and the initiation of treatment is comparatively brief in the Canadian healthcare system. Once the decision to use botulinum toxin was made, treatment was provided within a mean time period of 3.1 months and 94% of patients received botulinum toxin within 1 year. The most common reason given for this relatively short wait time between diagnosis and treatment was time spent on physicians' wait lists and delays while waiting for paper work with insurance providers. Wait times due to paperwork were significantly longer in those with employer insurance plans than among those with public health insurance. Further exploration may be useful regarding ways of improving this obstacle to access. In contrast, those covered under public health care plans were more likely to experience delays due to injectors' wait lists.

Given the mean duration of time taken to arrive at a definitive diagnosis was more than five years, there is an opportunity to educate family physicians, general neurologists, and other clinicians to minimize the time to diagnosis and improve the timing of referral to a specialist treatment centre.¹⁹ Simply training more neurologists to inject botulinum toxin will not alleviate the problems identified in the survey; however, educational programs on diagnosis and treatment of dystonias, as well as informing physicians and other health care workers about the services available at specialist movement disorders clinics may shorten the time from diagnosis to treatment.

Across all patients, the type of health care insurance (public, employer-provided (private), or none) did not appear to affect wait times for treatment as 59% of patients waited less than three months, and 80% waited six months or less. However, when stratified by age, those patients aged up to 29 years and those aged 65 and older had the shortest wait times for treatment, while those aged 30 to 64 years had the longest wait times. This likely reflects the availability of public health insurance for treatment of the three most common conditions in this survey (cervical dystonia, blepharospasm, HFS) in elderly patients. Younger, working-aged patients in several regions of Canada require private insurance coverage or must personally pay for pharmaceutical treatment.

Canada is large, sparsely populated and has a decentralized health care system that is administered by provinces. Thus, the geographic areas covered by participating centres varies greatly, largely because there are no specialists experienced in the administration of botulinum toxin outside of major urban centres. Patients travelled long distances (mean 74.4 km one way), most often by car (82% of the time), to receive botulinum toxin. Given that a disproportionate number of patients with dystonia or HFS are elderly, the need to travel by car places an additional burden on caregivers, patients and the health care system. However, the challenges to maintaining expertise in the diagnosis and treatment of dystonia in the vast rural areas of Canada include the inherent complexity of the disorder and the low volume of patients in regional clinical practices. Consequently, relatively few rural-based clinicians choose to administer botulinum toxin, thus, the current centralization of expertise is likely the most practical arrangement.

The most common movement disorders reported in the survey included cervical dystonia, blepharospasm, and HFS. The proportion of patients in each of these categories was generally similar across the participating clinics. This suggests that participating physicians did not select patients by diagnostic category, but rather that the sample accurately reflects the clinical spectrum of patients with dystonia or HFS on practice rosters. The predominance of female patients is consistent with reports in the literature. As expected patients with blepharospasm were older, but were diagnosed sooner than those with other diagnoses. This may be because blepharospasm is more easily recognized and that patients were more rapidly referred to movement disorders specialists by eye care professionals. In contrast, patients with cervical dystonia present with more complex and variable symptoms, including non-specific complaints of neck pain, and without obvious signs of torsion during the early stages of the condition. As a result the pathway to a diagnosis is less direct.

Correspondence analysis, which is commonly used in the social sciences to investigate associations between variables, revealed an association between distance travelled to the movement disorders clinic, time to diagnosis and wait time before treatment with botulinum toxin. Patients who traveled less than 50 km to specialist movement disorders clinics tended to have shorter times to diagnosis than those travelling further and, once the diagnosis was made, had shorter wait times before receiving botulinum toxin. In contrast those travelling more than 50 km to a clinic waited longer for a diagnosis and for treatment with botulinum toxin.

Reliance on patient-reported data is an inherent limitation of this observational study. Selection bias is also a limitation of a study such as this. The study population may be representative of patients with more severe dystonia as such patients are more likely to be referred to specialist centres. Only patients referred to such centres participated in the survey, thus the study may have bias towards including patients treated with botulinum toxin. In addition, by conducting the survey in specialist centres, the patient cohort does not represent the incidence of dystonia and HFS in the general population, including those who may not have been diagnosed, have been diagnosed appropriately but were not candidates for treatment, or were not referred to a movement disorder specialist centre for further management.

CONCLUSIONS

The results of this study may be used to improve wait times for the diagnosis and treatment of dystonia in Canada. The condition appears to be often misdiagnosed, which may result in delayed access to appropriate treatments, prolonged impairment of quality of life,²⁰ and potentially an increased burden on the health care system as patients seek help from various health care professionals. Resources should be devoted to raising awareness of dystonia and HFS among patients and the general public, by establishing support and advocacy groups, and among primary care physicians and other referring health care professionals. In particular, educational programs should be developed for the purpose of improving the ability of primary care physicians to recognize the various presentations of dystonia, manage the disorder, and to increase awareness that effective and specific treatment, when needed, is available through timely referrals to specialist centres.

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Mandar Jog, MD has served as a speaker, a consultant, and an advisor on behalf of Allergan, Biovail, Merz, Novartis, and Teva and has received research funding from Allergan and Merz. Sylvain Chouinard, MD has served as a speaker and a consultant on behalf of Allergan, Merz, Novartis, and Teva, has served as an advisor on behalf of Merz, Novartis and Teva and has received research funding from Allergan and Novartis. Doug Hobson, MD has served as a speaker and an advisor on behalf of Allergan, and has received research funding from Merz. David Grimes, MD has served as a speaker on behalf of Allergan, Merz and Teva, has served as a consultant for Allergan and Teva and has received research funding from Allergan, IMPAX Pharmaceuticals, the Canadian Institute for Health Research, The National Institutes of Health, the Parkinson Research Consortium and the MJF Foundation. Robert Chen, MD has served as a speaker on behalf of Merz, a consultant for Medtronic and Teva and has received research funding from Medtronic.

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Appendix:
Sample of Questionnaire

3040419539 **MOVEMENT DISORDERS SURVEY** ONTARIO FORM #

1. **Diagnosis** - To be completed by Physician
 Hemifacial spasm Meige syndrome Limb Dystonia (incl. writer's cramp) Generalized dystonia
 Blepharospasm Cervical Dystonia Spasmodic dysphonia Oromandibular dystonia
 Other

2. Please indicate your gender Male Female

3. How old are you now? Please print clearly
 This problem started [] months
 How old were you when this problem started? Please print clearly [] years [] months
 How old were you when this problem was diagnosed? Please print clearly [] years [] months

4. How old were you when this problem started? Please print clearly [] years [] months

5. How old were you when this problem was diagnosed? Please print clearly [] years [] months

6. Please indicate your type of healthcare expense reimbursement: Check all that apply
 Employer Health Insurance Plan Public/Provincial Insurance Plan Patient/Cash

7. How long did it take until **this diagnosis** was made from your initial complaint?
 <6 months 6 - 11 months 1 - 3 years 4 - 6 years 7-9 years

8. How many physicians did you see for this problem before this diagnosis was made?
 0 1 2 3 4 5 6 7 8 9 10 >10

9. Who have you consulted in an attempt to reach the diagnosis for **this problem**? Check all that apply
Physician/specialists
 Internal Medicine doctor
 Movement Disorder doctor
 Neurologist
 Neurosurgeon
 Chiropractor
 Psychiatrist/Rehab doctor
 Physiotherapist
 Family doctor
Other physician
 Eye Care doctor
 Ears, Nose and Throat doctor
 Bone doctor (Orthopedist)
 Dentist
 Psychiatrist/Psychologist
 Foot doctor (Podiatrist)
 Other doctor
Patient resources
 Self-research (Internet, or reference)
 Other affected patient
 Member of support group
 Other person

10. Who made the diagnosis for **which you are currently being treated**? Check all that apply
Physician/specialists
 Internal Medicine doctor
 Movement Disorder doctor
 Neurologist
 Neurosurgeon
 Chiropractor
 Psychiatrist/Rehab doctor
 Physiotherapist
 Family doctor
Other physician
 Eye Care doctor
 Ears, Nose and Throat doctor
 Bone doctor (Orthopedist)
 Dentist
 Psychiatrist/Psychologist
 Foot doctor (Podiatrist)
 Other doctor
Patient resources
 Self-research (Internet, or reference)
 Other affected patient
 Member of support group
 Other person

11. Was there any other diagnosis made prior to this final diagnosis for **this problem**?
 Yes - **if yes, please answer Question 12** No - **if no, please proceed to Question 13**

12. What other diagnoses have you been given for **this problem**? Check all that apply
 Nothing wrong
 Joint/tendon/bone problems - Arthritis; Tendonitis; Trigger finger
 Spine/spinal cord problem (e.g. misalignment of spine, disc compression)
 Jaw problem or Trembling or (Essential) Tremor
 Muscle pain with fatigue (Fibromyalgia)
 Nerve/muscle problem - Carpal tunnel syndrome - Pinched nerve - Nervous system disorder (Neuropathy) - Muscle inflammation
 Brain problem (e.g. stroke, Parkinson's disease)
 Dry eyes
 Stress/psychological/psychiatric problem (e.g. depression)

13. Did you receive any treatments prior to current diagnosis?
 If yes, please indicate the **first** treatment you received:
 Medication Botox injection Physiotherapy Other Chiropractic
 If yes, please indicate the **last** treatment you received:
 Medication Botox injection Physiotherapy Other Chiropractic
 No - I did not receive any treatment prior to current diagnosis

14. How did you travel to the clinic today?
 Walked Public transit/taxi Wheel Trans (wheelchair bus) Car Train Plane Other

15. Please indicate the health region or closest city centre to which you live:
 Champlain (Ottawa/Gatineau/Cornwall)
 Halton-Peel
 Grey, Bruce, Huron & Perth
 Quinte, Kingston & Rideau
 Waterloo-Wellington-Dufferin (Kitchener)
 Muskoka, Parry Sound & Temiskaming
 Durham, Haliburton, Kawartha & Pine Ridge (Peterborough)
 Hamilton-Wentworth
 Algoma, Cochrane, Manitowish & Sault Ste. Marie
 Niagara (Niagara/St Catharines)
 Grand River
 Timmins/Sudbury/Sault Ste. Marie
 Greater Toronto Area
 Thames Valley (London)
 Northwestern (Thunder Bay/Kenora)
 Simcoe-York

16. What is the ONE WAY distance you have traveled to this appointment today?
 0-25 kms (0-16 miles)
 26-50 kms (17-32 miles)
 51-100 kms (33-63 miles)
 101-200 kms (64-126 miles)
 201-300 kms (127-189 miles)
 > 300 kms (> 190 miles)

17. Did you receive Botox injection as part of your treatment for **this diagnosis**?
 Yes - **if yes, Please continue with the remaining survey questions** No - Thank you for your participation in today's survey

PLEASE ANSWER THE FOLLOWING ONLY IF YOU RECEIVED BOTOX INJECTION

18. Please indicate the length of time between when it was determined for you to have a Botox treatment and the initial injection (including wait time for referral to injecting physician):
 Did not wait 1 month 3 months 5 months 7-12 months 15-24 months
 <1 month 2 months 4 months 6 months 13-18 months >24 months

19. Please indicate the reason for this wait time to receive the Botox injection:
 Injecting physician's wait list Cost of injection treatment Delay due to paper work with insurance company Indication by province
 Afraid of needles Accessibility to clinic (distance) Other