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ORIGINAL ARTICLE

Patient Knowledge, Attitude and Perceptions towards Botulinum Toxin Treatment for Movement Disorders in India

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ABSTRACT

Objective There is limited literature on the knowledge, attitude, and perceptions (KAP) of botulinum toxin (BoNT) treatment among patients and caregivers. The objective of this study was to assess the KAP in patients undergoing BoNT treatment for movement disorders.

Methods One hundred patients with movement disorders from National Institute of Mental Health and Neurosciences Hospital in Bengaluru, South India, were recruited. The patients underwent demographic, clinical, and Patient Knowledge Questionnaire on Botulinum Toxin Use in Movement Disorders (PKQ-BMD)-based evaluations.

Results The mean age of patients at the time of presentation was 47.97 ± 14.19 years (range, 12–79). Of all the patients, 26 (28%) patients were anxious, and 86% of these patients were reassured after appropriate counseling. There were 83 (89%) patients who found BoNT to be a costlier option. Education and previous Internet searches influenced positive performance in the "knowledge" domain and overall PKQ-BMD scores. The "number of injections" was also positively correlated with KAP performance.

Conclusion This study showed that knowledge and perceptions about BoNT treatment need to be further improved. Wider availability of the Internet has provided a positive impact on patients' and carers' KAP. Internet-based information, higher educational qualifications of the patients, and a higher number of BoNT injection sessions are the most important predictors of satisfactory KAP related to BoNT injection treatment in patients with movement disorders.

Key Words Knowledge; Attitude; Perception; Botulinum toxin; Movement disorders.

Botulinum neurotoxin (BoNT) is the most toxic substance known to humans, with an LD50 (median lethal dose) ranging from 0.1 to 1 ng/kg.[1] It blocks the release of the neurotransmitter acetylcholine at cholinergic nerve terminals of autonomic and peripheral nerves. Currently, seven serotypes of BoNT are available, and each has unique and specific activity at the molecular level.[2] The safety and efficacy of serotypes A and B are well established and are clinically useful in many neurological disorders.[3,4] In the 1970s, BoNT type A was studied as a pharmaceutical drug for the management of strabismus and focal/segmental dystonias.[5-7] Currently, the spectrum of its usage has widened, and it is used in focal dystonia, inappropriate detrusor/sphincter contraction, hyperkinetic movement disorders, spasticity, eyeball movement disorders, cosmetic purposes, autonomic dysfunctions such as hyperhidrosis, and some chronic pain syndromes.[8,9]

Gradually, the usage of BoNT has spread worldwide, but there is limited literature available on the knowledge, attitude, and perceptions (KAP) of BoNT treatment among patients and caregivers globally.[10]

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Hence, studies are required to know the existing knowledge among patients receiving BoNT to focus on education related to its use, the fears and apprehensions of adverse effects, its duration and mechanism of action, and the frequency of injections before starting the treatment.[10,11] Thus, we planned to study the knowledge, attitude, and perception of patients with movement disorders coming to a tertiary care center in South India for BoNT treatment.

MATERIALS & METHODS

Study design

This was a hospital-based prospective cross-sectional study. One hundred patients (age > 18 years) with movement disorders who had been advised or were already on BoNT treatment at the "Movement disorders sub-specialty" Neurology services of the National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru, India were recruited. Consecutive patients with movement disorders and other disorders requiring BoNT treatment were included after obtaining informed consent. Patients not willing to participate in the study were excluded. Subjects were recruited from the "Botulinum Toxin Clinic." Seven patients were excluded due to insufficient data, and 93 were included in the final analysis. The study period was from November 2018 to March 2020. All the participants and caregivers gave written informed consent. All subjects underwent detailed demographic, clinical, and questionnaire-based evaluations of knowledge, attitudes, and perceptions according to a structured protocol. During the interview, the Patient Knowledge Questionnaire on Botulinum Toxin Use in Movement Disorders (PKQ-BMD) questionnaire was applied in a language that participants found familiar and comfortable for comprehending and giving an appropriate response.[10] The questionnaire had four domains, namely, general knowledge, expectations, pathophysiology, and adverse effects. The initially designed questionnaire by Schoffer et al.[10] had two responses: "Right" and "Wrong." We modified it for the Indian population and added another response, "No idea (do not know)," which indicated a lack of knowledge about the question that was asked. We used the third response to avoid bias.

Statistical analysis

Data were analyzed using SPSS software version 25 (IBM Corp., Armonk, NY, USA). We used descriptive statistics for continuous variables and frequency distributions for categorical variables. After assessing normality, we used an appropriate test for the comparison of groups. The different educational levels, the mode of acquiring information on BoNT and the number of BoNT injections were correlated with the various domains of the PKQ-BMD. Kruskal-Wallis tests of significance and Spearman's rank correlation tests were used. P values < 0.05 were considered statistically significant.

RESULTS

We recruited 93 patients in the study. The mean age of the patients at the time of presentation was 47.97 ± 14.19 years (range, 12–79 years). There were 58 (62.4%) males and 35 (37.6%) females. The education level of patients varied from illiterate to postgraduate education. Most of the patients (33.5%, n = 33) were employed either in the private or government sector. The detailed demographic characteristics are shown in Table 1.

The median duration of illness was 36 [interquartile range (IQR) 72, range 0–336] months, and the median duration of treatment was 24 [IQR 48, range 0–204] months. The chief indication for BoNT therapy was hemifacial spasm (n = 29, 31.1%), followed by cervical dystonia (n = 20, 21.5%) and blepharospasm (n = 11, 11.8%), and other conditions, such as lingual and oromandibular dystonias, spasmodic dysphonia, writer's cramp, poststroke spasticity, familial ALS, and hemidystonia, constituted the indication for 35.6% (n = 33). Most of them (n = 86, 92.4%) were self-paying with no medical insurance, and some benefitted from federal funding.

Nearly half (n = 46, 49%) of the patients had heard about BoNT before the consultation, and 25.8% (n = 24) of the patients had acquired the knowledge by browsing the Internet. Although 28% (n = 26) had a fear of BoNT treatment, 86% (n =

Table 1. Demographic characteristics of the patients with movement disorders recruited in the study

Variable	Value
Age at presentation (years)*	47.97 ± 14.19 (12–79)
Duration of illness (months)†	36 [72] (0–336)
Duration of treatment (months)†	24 [48] (0–204)
Type of movement disorders, *n* (%)	
Hemifacial spasm	29 (31.2)
Blepharospasm	11 (11.8)
Writer's cramp	6 (6.5)
Cervicofacial and other dystonia	41 (44.1)
Others	6 (6.5)
Education, *n* (%)	
Illiterate	6 (6.4)
Primary school	11 (11.8)
Secondary school	38 (40.8)
Graduate	23 (24.7)
Post graduate	12 (12.9)
Not available	3 (3.2)

*Data are shown as mean ± standard deviation (range). †Data are shown as median [interquartile range] (range).

80) were reassured after receiving the treatment. The median number of injections received by patients was 2 [IQR 4, range 0–46]. The dose of BoNT varied from 10 units to 500 units based on the indication.

Only four patients had adverse effects, such as headaches, ptosis, nausea, and transient dysphagia, for a few days. The majority (n = 83, 89%) found BoNT treatment to be costlier and had difficulty with its affordability. Approximately 68% (n = 63) of the patients were satisfied with the treatment response, and 11% (n = 10) were disappointed based on their level of expectation. A complete cure was the expectation of 57 (61.3%) patients for their medical condition, although they were periodically doing well on regular BoNT injections.

PKQ-BMD questionnaire: A large subset of the patients (n = 64, 68.8%) knew that BoNT injections are usually given once over a few months period of time, and 65.6% (n = 61) of patients were aware that only physicians with expertise could give the injections. In the next domain, most patients were aware that BoNT treatment was "not a cure" (n = 64, 68.8%) and "the average duration of action of BoNT is for three months" (n = 67, 72% patients). Nearly 40.9% (n = 38) of patients incorrectly responded that with every subsequent injection, the clinical response would be better. In the "adverse effects" domain, the question regarding permanent side effects not seen with BoNT treatment was answered correctly by 34.4% (n = 32) of patients. In general, the patients poorly understood the other aspects (Figure 1). The summary of answers obtained from the PKQ-BMD questionnaire is shown in Table 2.

The understanding of BoNT varied across domains and depended on the educational status of the patients. Graduate and postgraduates answered better in general knowledge and expectation domains. Although patients came from different educational backgrounds, they performed well in the "General knowledge" domain compared to the others, and this difference was statistically significant (p = 0.005).

Each domain was analyzed by grouping the patients into different phenotypes, such as hemifacial spasm, blepharospasm, writer's cramp, cervicofacial and other dystonias (cervical, oromandibular and lingual), and others (dysphonia, poststroke spasticity, ALS). There were no statistically significant differences noted between the different phenotypes among the various domains.

The patients who had performed Internet searches about BoNT before the consultation clearly showed better performance than those who did not (Figure 2). We looked for a correlation between the number of injections and performance on the PKQ-BMD questionnaire. There were 85 patients who had previous experience with BoNT (i.e., who had received BoNT at least once), and 8 were BoNT-naïve patients. The patients who had previous experience with BoNT performed better in the "General knowledge" and "Expectation" domains. In addition, there was a positive correlation between the number of injection sessions and performance scores (Supplementary Table 1, 2 and 3 in the online-only Data Supplement; Figure 2).

DISCUSSION

Our study is one of the few studies assessing the existing knowledge, attitude, and perception regarding BoNT treatment among a large cohort of patients with various movement disorders.

The mean age in the current study shows that our cohort included people who were at least a decade younger than the study by Del Brutto and Del Brutto.[12] They analyzed 579 adults with movement disorders from Ecuador, and the overall mean age was 62.9 ± 17.5 years, whereas the mean age in patients with involuntary movements (tics, dystonia, chorea, athetosis, and

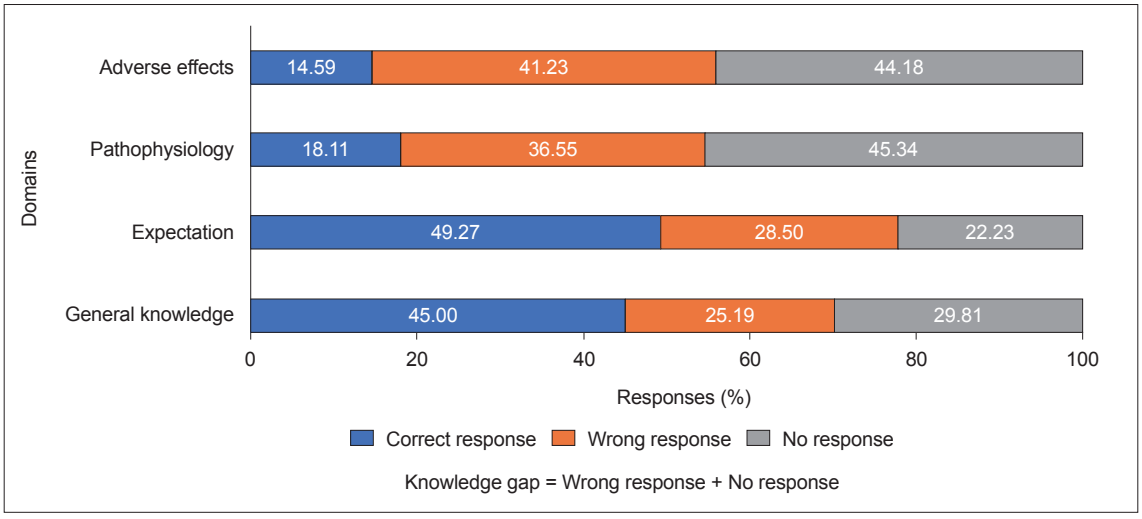

Figure 1. Distribution of responses to the botulinum toxin knowledge questionnaire.

Table 2. PKQ-BMD

	Interpretation of responses [*n* (%)]			
	Correct response	Wrong response	No response	Knowledge gap (wrong response + no response)
General knowledge				
Fish toxin	14 (15.1)	28 (30.1)	51 (54.8)	79 (84.9)
Treat wrinkles	44 (47.3)	20 (21.5)	29 (31.2)	49 (52.7)
Used as it is less expensive	44 (47.3)	28 (30.1)	21 (22.6)	49 (52.7)
The only botox brand	20 (21.5)	44 (47.3)	29 (31.2)	73 (78.5)
Any doctor can give injection	61 (65.6)	15 (16.1)	17 (18.3)	32 (34.4)
Only limited injection	46 (49.5)	15 (16.1)	32 (34.4)	47 (50.5)
Given once in 3 months	64 (68.8)	14 (15.1)	15 (16.1)	29 (31.2)
Expectation				
Not a cure	64 (68.8)	15 (16.1)	14 (15.1)	29 (31.2)
98% improve	37 (39.8)	37 (39.8)	19 (20.4)	56 (60.2)
Every subsequent injection	36 (38.7)	38 (40.9)	19 (20.4)	57 (61.1)
Average 3 months	67 (72.0)	14 (15.1)	12 (12.9)	26 (28.0)
Higher dose lasts longer	28 (30.1)	31 (33.3)	34 (36.6)	65 (69.9)
Toxin works within 2–3 hours	43 (46.2)	24 (25.8)	26 (28.0)	50 (53.8)
Pathophysiology				
Acts on brain	18 (19.4)	38 (40.9)	37 (39.8)	75 (80.7)
Bacteria injected-release toxin	17 (18.3)	36 (38.7)	40 (43.0)	76 (81.7)
Toxin into muscle's blood supply	10 (10.8)	39 (41.9)	44 (47.3)	83 (89.2)
Blocks muscle's signal to nerve	11 (11.8)	35 (37.6)	47 (50.5)	82 (88.1)
Blocks nerve's signal to muscle	29 (31.2)	23 (24.7)	41 (44.1)	64 (68.8)
Toxin spreads outside muscle	16 (17.2)	33 (35.5)	44 (47.3)	77 (82.8)
Adverse effects				
Large doses-tetanus	6 (6.5)	42 (45.2)	45 (48.4)	87 (93.6)
Permanent side effects	32 (34.4)	32 (34.4)	29 (31.2)	61 (65.6)
Cannot be reversed	18 (19.4)	39 (41.9)	36 (38.7)	75 (80.6)
Toxin can be removed in emergency	10 (10.8)	44 (47.3)	39 (41.9)	83 (89.2)
Flu-like reaction	22 (23.7)	44 (47.3)	27 (29.0)	71 (76.3)
Addictive	20 (21.5)	43 (46.2)	30 (32.3)	73 (78.5)
Egg-cross allergy	9 (9.7)	43 (46.2)	41 (44.1)	84 (90.3)
Safe in pregnancy	17 (18.3)	31 (33.3)	45 (48.4)	76 (81.7)
No drug interaction	12 (12.9)	39 (41.9)	42 (45.2)	81 (87.1)
Antibodies, if developed, will not respond to antibiotics	2 (2.2)	32 (34.4)	59 (63.4)	91 (97.8)
Antibodies make it less effective	1 (1.1)	33 (35.5)	59 (63.4)	92 (98.9)

PKQ-BMD: Patient Knowledge Questionnaire on Botulinum Toxin Use in Movement Disorders.

ballismus) was younger at 49.8 ± 19.4 years, which is comparable with the mean age of 47.97 ± 14.19 years in our study comprising a majority of patients with movement disorders. Craniocervical dystonias are more common in women, and most focal task-specific dystonias and tics are common in men.[13] In our study, which was a combination of all movement disorders, we observed a slight male predominance that was similar to the cohort from Bäumer et al.[14] that included children suffering from movement disorders in Germany.

Educational status was variable. The number of uneducated patients was fewer than the patients with different educational backgrounds, which reflects the poor reach/awareness of BoNT treatment among the less educated and illiterate patients with movement disorders.

Our study showed that hemifacial spasm was the most common movement disorder treated by BoNT; this was similar to a study by Tan[15] but in contrast to Hsiung et al.,[16] which was a study from Canada where cervical dystonia was the most fre-

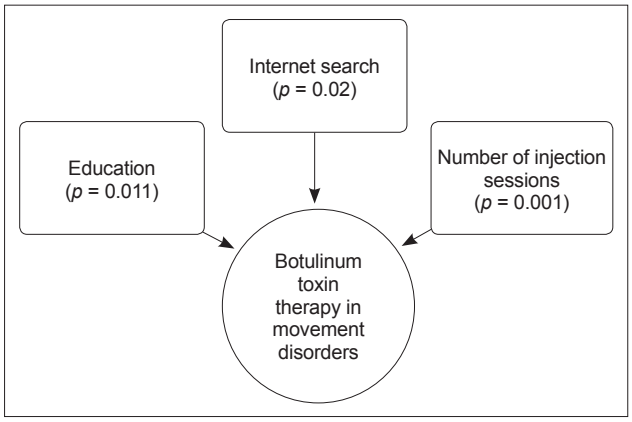

Figure 2. Significant factors in the study that increased awareness of knowledge, expectations, mechanism of action and adverse effects of botulinum toxin treatment in patients with movement disorders.

quent, followed by hemifacial spasm, blepharospasm and other focal/segmental dystonias. The other indications for BoNT in our study were similar to those in other studies.[16] The adverse effects of BoNT were minimal, which was similar to Kwan et al.,[17] who reported only minor, transient complications such as ptosis, mild facial asymmetry, and epiphora that are generally dose- and site-related. A few other studies have also observed a similar profile of side effects.[18-21]

Almost all patients were self-financed, and < 1% benefited from federal health schemes/sponsorship. Health insurance coverage should be widened to include treatments such as BoNT. In India, it is common to seek indigenous/alternative medicines before consulting physicians/specialists. Our study found that one-third of the patients had tried Ayurveda and homeopathic medications but without benefit.

Many patients were not aware of the use of BoNT in the management of various neurological illnesses, and only half of the cohort was aware either by browsing the Internet or by hearsay. Robust measures that publicize the availability of BoNT as a treatment for a broader range of conditions are needed. A proportionate number of people who are qualified injectors of BoNT should be trained.[22] BoNT is not easily affordable by people belonging to low socioeconomic status. Approximately 89% of patients in the study found BoNT as a costlier treatment option. However, few studies have investigated the cost comparison for various movement disorders requiring BoNT. In developing countries, it is necessary to consider the cost of any therapy before initiation, or it might result in poor compliance and clinical response. Our study also showed that 82.7% (n = 77) of the patients reported either nonavailability or unawareness about the existence of expertise in their residential locations. There is a need to propose guidelines for training an adequate number of physicians/neurologists/movement disorder specialists who intend to treat patients with BoNT.[23,24] BoNT cannot be given according to a standard treatment protocol. It must be planned according to the needs and therapeutic response of the individual patient. Injections should be given only by physicians who are skilled in the diagnosis and management of movement disorders.

When patients were asked about their satisfaction after receiving the BoNT treatment, 68% (n = 63) of patients were happy and satisfied with the therapy but had expected a "complete cure" and "reduction in frequency" of taking BoNT injections. Those who were not satisfied with the therapy had an inadequate clinical response. The possible reasons for this may be inappropriate doses, reconstitutions, or incorrect injection sites. Bensmail et al.[25] performed cross-sectional surveys on patients' and physicians' satisfaction with BoNT for poststroke spasticity and found it to be very good overall. In their study on 79 patients, 40.5% of patients were very satisfied, and 48.1% were somewhat satisfied; among 109 physicians, 57.7% were moderately or very (36.5%) satisfied. Our observations were also consistent with the above study in terms of satisfaction in the study group.

Schoffer et al.[10] formulated the PKQ-BMD questionnaire, which can be used to assess knowledge about BoNT for patients with various movement disorders. This questionnaire was adapted for our study, and we found the "General knowledge" and "Expectations" domains to be well answered. It is evident from our study that more than half of the patients on BoNT understood that it was not a cure, and the average duration of action was approximately 3 months. They also experienced that the toxin starts working a few days after receiving the injection. More than 50% (n = 65) of the patients had false assumptions about or were unaware that a higher dose of BoNT may have a longer duration of action, and therefore, the BoNT injections could be administered at longer intervals.

Despite having a maximum duration of treatment up to 204 months, many of them had less knowledge about the "Pathophysiology" and "Adverse effects" of BoNT injections. Hence, patient education should focus on these domains, which includes common aspects such as "how does BoNT act" and "what are the adverse effects." Queries on the pathophysiology and adverse effects of BoNT, which elicited incorrect answers, were the most encountered questions in our outpatient clinics. Measures to educate patients through reliable Internet sources, regular awareness through radio/TV talks, pharmaceutical pamphlets, and non-neurological health professionals such as speech therapists are significant sources of knowledge in the current world.

A study by Beniwal et al.[26] from India on the assessment of awareness, attitude, and behavior of patients with common chronic diseases, such as coronary artery disease, chronic pulmonary disease, hypertension, and diabetes, noticed that a majority of patients were ignorant about their disease, the importance of compliance with medicines and precautions regarding

the disease. Likewise, a study performed by Shetty et al.[27] showed that awareness about the diagnosis and treatment of various movement disorders in different subpopulations was limited even among patients who were on regular follow-up. We also observed that satisfactory performance in the "knowledge domain" compared to other domains was not related to demographic, educational, occupational, or geographical backgrounds. Unlike the observations by Shetty et al.,[27] the number of follow-up visits had a positive impact on patient responses. The number of correct answers positively correlated with the number of injections received. This indicates that knowledge about the treatment comes with repeated education about the illness, as there is ample opportunity to interact with treating staff to clarify doubts and address queries.[28]

A dedicated "movement disorders" clinic may also help to improve the knowledge and perception of these patients, as they will have more exposure to other patients suffering from movement disorders with whom they can have discussions and interact with people that have similar problems.

The strength of the study was an adequate sample size, and the study was carried out at a dedicated movement disorder center. We acknowledge the lack of a control group for comparison as a limitation of the study. The results may not be generalizable, as the characteristics of the patient population will determine the outcomes in a similar scenario.

Patient education plays a pivotal role in increasing public and societal awareness of this treatment and successful treatment strategies.[29] It is essential to educate the community, general practitioners, and policymakers regarding the availability of advanced BoNT treatment, cost factors, efficacy, safety, etc. to accentuate the utility of BoNT for a larger number of patients. Our study shows that there is a gap in the various KAP parameters in patients undergoing botulinum toxin therapy, and the Internet can be a very powerful tool in addition to health care providers to improve knowledge about this advanced and complex therapy. The health care providers of BoNT therapy should develop reliable sources of information on the Internet where patients can find answers in a "frequently asked questions format" in their native language.

Supplementary Materials

The online-only Data Supplement is available with this article at https://doi.org/10.14802/jmd.20094.

Conflicts of Interest

The authors have no financial conflicts of interest.

Acknowledgments

None.

Ethical Standards

All procedures involving human participants were performed in accordance with the ethical standards of the institutional and/or national research committee and with the 1975 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by NIMHANS hospital ethics committee with letter number NIMH/DO/IEC (BS & NS DIV)/2018-19 dated 29/11/2018.

Author Contributions

Conceptualization: Ravi Yadav. Data curation: Thavasimuthu Nisha Mol, Nitish Kamble, Vikram Holla. Formal analysis: Thavasimuthu Nisha Mol, Ravi Yadav. Methodology: Thavasimuthu Nisha Mol, Ravi Yadav, Nitish Kamble, Vikram Holla, Pramod Kumar Pal. Project administration: Thavasimuthu Nisha Mol. Supervision: Ravi Yadav, Pramod Kumar Pal. Visualization: Ravi Yadav, Pramod Kumar Pal. Writing—original draft: Thavasimuthu Nisha Mol, Ravi Yadav. Writing—review & editing: all authors.

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REFERENCES

1. Schiavo G, Rossetto O, Montecucco C. Clostridial neurotoxins as tools to investigate the molecular events of neurotransmitter release. Semin Cell Biol 1994;5:221-229.
2. Peck MW, Smith TJ, Anniballi F, Austin JW, Bano L, Bradshaw M, et al. Historical perspectives and guidelines for botulinum neurotoxin subtype nomenclature. Toxins (Basel) 2017;9:38.
3. Brin MF. Dosing, administration, and a treatment algorithm for use of botulinum toxin A for adult-onset spasticity. Spasticity Study Group. Muscle Nerve 1997;20:S208-S220.
4. Odergren T, Hjaltason H, Kaakkola S, Solders G, Hanko J, Fehling C, et al. A double blind, randomised, parallel group study to investigate the dose equivalence of Dysport and Botox in the treatment of cervical dystonia. J Neurol Neurosurg Psychiatry 1998;64:6-12.
5. Pellizzari R, Rossetto O, Schiavo G, Montecucco C. Tetanus and botulinum neurotoxins: mechanism of action and therapeutic uses. Philos Trans R Soc Lond B Biol Sci 1999;354:259-268.
6. Lang A. History and uses of BOTOX (botulinum toxin type A). Lippincotts Case Manag 2004;9:109-112.
7. Albanese A, Barnes MP, Bhatia KP, Fernandez-Alvarez E, Filippini G, Gasser T, et al. A systematic review on the diagnosis and treatment of primary (idiopathic) dystonia and dystonia plus syndromes: report of an EFNS/MDS-ES Task Force. Eur J Neurol 2006;13:433-444.
8. Panicker JN, Muthane UB. Botulinum toxins: pharmacology and its current therapeutic evidence for use. Neurol India 2003;51:455-460.
9. Schantz EJ, Johnson EA. Properties and use of botulinum toxin and other microbial neurotoxins in medicine. Microbiol Rev 1992;56:80-99.
10. Schoffer KL, O'Maley K, O'Sullivan JD. Development and utilization of the patient knowledge questionnaire on botulinum toxin use in movement disorders. J Clin Neurosci 2007;14:737-741.
11. Orsini M, Leite MA, Chung TM, Bocca W, de Souza JA, de Souza OG, et al. Botulinum neurotoxin type A in neurology: update. Neurol Int 2015;7:5886.
12. Del Brutto OH, Del Brutto VJ. Movement disorders among adult neurological outpatients evaluated over 20 years in Guayaquil, Ecuador. Neurol Int 2013;5:e18.
13. Meoni S, Macerollo A, Moro E. Sex differences in movement disorders. Nat Rev Neurol 2020;16:84-96.

14. Bäumer T, Sajin V, Münchau A. Childhood-onset movement disorders: a clinical series of 606 cases. Mov Disord Clin Pract 2016;4:437-440.
15. Tan AK. Botulinum toxin for neurological disorders in a movement disorders clinic in Singapore. Singapore Med J 1998;39:403-405.
16. Hsiung GY, Das SK, Ranawaya R, Lafontaine AL, Suchowersky O. Long-term efficacy of botulinum toxin A in treatment of various movement disorders over a 10-year period. Mov Disord 2002;17:1288-1293.
17. Kwan MC, Ko KF, Chan TP, Chan YW. Treatment of dystonia with botulinum A toxin: a retrospective study of 170 patients. Hong Kong Med J 1998;4:279-282.
18. Park YC, Lim JK, Lee DK, Yi SD. Botulinum a toxin treatment of hemifacial spasm and blepharospasm. J Korean Med Sci 1993;8:334-340.
19. Hassell TJW, Charles D. Treatment of blepharospasm and oromandibular dystonia with botulinum toxins. Toxins (Basel) 2020;12:269.
20. Truong D, Duane DD, Jankovic J, Singer C, Seeberger LC, Comella CL, et al. Efficacy and safety of botulinum type A toxin (Dysport) in cervical dystonia: results of the first US randomized, double-blind, placebo-controlled study. Mov Disord 2005;20:783-791.
21. Bakheit AMO. The possible adverse effects of intramuscular botulinum toxin injections and their management. Curr Drug Saf 2006;1:271-279.
22. Madhugiri VS. Publication performance and research output of neurology and neurosurgery training institutes in India: a 5-year analysis. Neurol India 2015;63:338-346.
23. Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology. Training guidelines for the use of botulinum toxin for the treatment of neurologic disorders. Neurology 1994;44:2401-2403.
24. Deo MG. Doctor population ratio for India-the reality. Indian J Med Res 2013;137:632-635.
25. Bensmail D, Hanschmann A, Wissel J. Satisfaction with botulinum toxin treatment in post-stroke spasticity: results from two cross-sectional surveys (patients and physicians). J Med Econ 2014;17:618-625.
26. Beniwal S, Sharma BB, Singh V. What we can say: disease illiteracy. J Assoc Physicians India 2011;59:360-364.
27. Shetty B, Mittal S, Kukkle P. Knowledge, attitude and practices about movement disorders in India [abstract]. Mov Disord. 2019;34(suppl 2):1835.
28. Yadav R, Shukla G, Goyal V, Singh S, Behari M. Knowledge of Parkinson's disease among patients and caregivers attending movement disorder clinic at a tertiary care centre in North India. Ann Indian Acad Neurol 2012;15:294-296.
29. Strobach D, Vetter-Kerkhoff C, Bogner J, Breugst W, Schlöndorff D. Patient medication counseling-patient counseling about discharge medication. Med Klin (Munich) 2000;95:548-551.

Supplementary Table 1. Comparison of each domain across different educational levels in the study group

Domain	Illiterate (*n* = 6)	Primary (*n* = 11)	Secondary (*n* = 38)	Graduate (*n* = 23)	Post graduate (*n* = 12)	*p*-value
General knowledge	3 (1.50, 3.25)	3 (1, 4)	3 (1, 4)	4 (3, 5)	5 (3.25, 6.75)	0.01
Expectation	2 (0.75, 2.75)	3 (2, 4)	2 (0.75, 5)	4 (2, 4)	4 (3, 4.75)	0.32
Pathophysiology	0.5 (0, 1.25)	0 (0, 1)	1 (0, 1.25)	2 (0, 2)	2 (0.25, 4.75)	0.05
Adverse effects	1 (0, 2.50)	1 (0, 3)	1 (0, 2)	1 (0, 2)	1.5 (1, 5.25)	0.37
Total score	7 (4.5, 8.75)	9 (3, 11)	7.5 (2.75, 11.25)	11 (8, 13)	13 (8, 19.25)	0.01

Data are shown as median (Q1, Q3).

Supplementary Table 2. Comparison between Referred versus Direct cases and prior internet search affecting the performance of PKQ-BMD questionnaire

Domain	Referred (*n* = 47)	Direct (*n* = 46)	Prior internet search (*n* = 24)	No prior search (*n* = 69)
General knowledge	0.47 ± 0.26	0.42 ± 0.28	0.6 ± 0.26	0.39 ± 0.25
Expectations	0.52 ± 0.31	0.47 ± 0.31	0.63 ± 0.25	0.45 ± 0.31
Pathophysiology	0.17 ± 0.20	0.19 ± 0.22	0.31 ± 0.30	0.13 ± 0.15
Adverse effects	0.15 ± 0.14	0.13 ± 0.19	0.23 ± 0.25	0.11 ± 0.11

Data are shown as mean ± standard deviation. PKQ-BMD: Patient Knowledge Questionnaire on Botulinum Toxin Use in Movement Disorders.

Supplementary Table 3. Correlation between the number of injections and the performance scores

Domain	Number of injections	
	Correlation coefficient	*p*-value
General knowledge	0.341*	0.001
Expectations	0.439*	< 0.001
Pathophysiology	0.149	0.155
Adverse effects	0.156	0.134
Total score	0.343*	0.001

*correlation is significant at the 0.01 level (2-tailed).