

# Factors affecting short-term prognosis of patients with hemifacial spasm who received botulinum toxin type A injection in the Philippines

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## Abstract

**Background & Objectives:** Hemifacial spasm (HFS) is a chronic disease characterized by unilateral tonic and clonic contractions of the facial muscles innervated by the facial nerve. The persistent attacks can significantly impact patients' daily lives. The most efficacious therapy has been reported to be botulinum toxin (BTX). This study aims to investigate the factors that affect the short-term prognosis of HFS patients treated with BTX type A therapy, as well as to determine the clinic-demographic profile of such patients. **Methods:** This is a retrospective cohort study of patients with HFS who were treated with BTX at the Movement Disorders Clinic of Makati Medical Center (MMC). The HFS Score was used to assess the severity and frequency of the eye and cheek spasms, and the degree of suffering in health-related quality of life (HRQOL) parameters. **Results:** Sixty-four participants were included in the study. The patients' characteristics were the following: mean age of 50.18 years; female predominance; most without comorbidities; mean disease duration of 7.83 years; eye as the most common location of initial spasm (96.88%); disease progression of 22.85 months; majority were previously treated with BTX (79.69%); and mean interval of 10.96 months from last BTX session. Regression analysis revealed that there were factors which influenced the short-term prognosis after treatment: (1) history of prior BTX therapy was associated with better clinical parameters, while (1) history of prior BTX therapy, (2) disease duration, and (3) location of initial spasm were associated with improvement of specific HRQOL parameters.

**Conclusion:** BTX therapy has been established as efficacious in improving the clinical, functional and psychosocial aspects of HFS patients. The factors which influenced the botulinum response were different compared to other papers, highlighting potential differences in predictor variables across populations.

**Keywords:** Hemifacial spasm, botulinum toxin, short-term prognosis

## INTRODUCTION

Hemifacial spasm (HFS) is a chronic disease characterized by unilateral tonic and clonic contractions of the facial muscles innervated by the facial nerve.<sup>1</sup> Most cases are primary/idiopathic (63.2%), while the minority of them (36.8%) are secondary to facial nerve damage.<sup>2</sup> HFS usually starts in the fifth decade of life and its prevalence has been reported to be 14.5/100,000 in women and 7.4/100,000 in men in an American population,<sup>3</sup> while a mean prevalence of HFS is approximately 10 in 100,000 in a Norwegian study.<sup>4</sup> The incidence and prevalence rates were

highest in those from 40 to 79 years of age.<sup>3</sup> The persistent attacks of HFS can significantly impact patients' daily lives, resulting in reduced confidence in social and professional situations.<sup>1</sup> The prevalence of depression among HFS is 16.7%, which is higher than the 5–8% in our general population.<sup>5</sup>

The most efficacious therapy has been reported to be Botulinum toxin (BTX), a biological toxin derived from the bacteria *Clostridium botulinum*<sup>6</sup>, which acts by inhibiting the release of acetylcholine at the neuromuscular junction, thereby blocking neural-muscular

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Date of Submission: 4 December 2024; Date of Acceptance: 21 March 2025

<https://doi.org/10.54029/2025dus>

signal transmission and achieving biochemical denervation-induced muscle relaxation.<sup>7</sup> The therapeutic effect begins at about 3–6 days after treatment and can persist for 2–3 months.<sup>8</sup>

There are just a handful of researches discussing BTX therapy in HFS patients in the Philippines<sup>9–13</sup>, hence this current study may contribute in the existing body of knowledge in the country. One area that has never been studied is the factors affecting the short-term prognosis of HFS patients after BTX therapy among Filipinos. Hence, this study can fill that important gap of knowledge. Therefore, this study aims to retrospectively investigate the factors that affect the short-term prognosis of HFS patients treated with BTX-A therapy among Filipino patients, as well as determine the clinical and demographic profile of such patients.

## METHODS

This retrospective cohort study was conducted in a Makati Medical Center (MMC) involving chart review of patients diagnosed with HFS who received Botulinum toxin type A (BTX-A) treatment during the 2024 Hemifacial Spasm Summit. The patients were later followed-up via telephone and video consultations after 1 month. The independent variables of the study were age, sex, comorbidities, duration of HFS, anatomic location of initial spasm, progression of symptoms, history of BTX therapy, time of last BTX therapy, and concurrent use of oral medications for HFS. The dependent variables were the severity and frequency of spasms and the degree of suffering in health-related quality of life (HRQOL) parameters using the newly validated HFS questionnaire before and 1 month after BTX-A treatment. Regression analysis was then performed to determine which among the clinic-demographic factors contributed with the short-term prognosis of HFS patients after BTX.

### *Participants*

The Hemifacial Spasm Summit is an annual event organized by the Movement Disorders Clinic of MMC. Attendees are patients from various locations in the country who are being managed by their respective physicians. The 2024 summit drew most participants (55%, n=35) from Metro Manila, the capital of the Philippines, while the remainder (45%, n=29) from ten other provinces in the Northern Philippines. In addition, all patients with HFS joined the event regardless of etiology, whether primary or secondary.

The administration of BTX-A was through subcutaneous or intramuscular injection. Muscle selection, medication dosage and injection sites were personalized. Informed consents were obtained from all participants prior to injections.

Because HFS has low prevalence rates in previous studies<sup>3,4</sup>, all of the 64 participants who received BTX-A therapy were included in the study. The inclusion criteria were: Filipino patients; age more than 18 years; symptoms and signs consistent with the diagnosis of HFS; and first-time and previous BTX-A treatment with complete follow-up data. The exclusion criteria were: Age of 18 years old and younger; incomplete medical records; underwent microvascular decompression surgery.

### *Preparation and administration of BTX-A*

BTX-A vials containing 100 units of lyophilized white powder were diluted with 2 ml of 0.9% sterile sodium chloride solution to reduce spreading and then gently mixed before use. The drug was injected via 30-gauge needles. BTX injections were guided by clinical observation and tailored to each patient's unique manifestations. Owing to their superficial location, the muscles affected by HFS were easily injected without special localization techniques, such as ultrasound and electromyography. Ice packs were applied on target muscles to minimize the bleeding and pain.

### *Clinical assessment*

The clinical and demographic data which have been collected include the following: general characteristics (age, sex), comorbidities (hypertension, diabetes, dyslipidemia), medical profile of the disease (disease duration, anatomic location of initial spasm, progression of symptoms), treatment (history of BTX therapy, time of last BTX therapy, BTX-A dosage used, concurrent use of oral medications for HFS) and other relevant information.

The short-term prognosis was based on 2 parameters: (1) severity and frequency of spasms and the (2) degree of suffering in HRQOL. Both parameters were measured using the newly validated HFS questionnaire before and after BTX-A treatment. The first parameter was assessed by two movement disorders specialists and one movement fellow. The second parameter was scored by the patients using a visual analogue scale (VAS). Follow-up consultations were done after one month through telephone and video calls. All the information gathered were transcribed in the patients' records.

### *HFS score questionnaire*

The questionnaire (see Appendix 1) was based on the newly validated scoring by Wabbels and Yaqubi.<sup>14</sup> It is composed of two parts: (1) HFS clinical and (2) HFS subjective. The first part referred to as “HFS clinical” evaluates the clinical severity of the disease by assessing the frequency and severity of the eye and cheek spasms. The muscles contributing to “eye spasms” in this study were the orbicularis oculi, corrugator, and procerus. The muscles contributing to “cheek spasms” were the zygomaticus major and minor, levator labii superioris, and orbicularis oris. Spasm severity was scored from zero (no spasms) to four (severe spasms). A maximum of eight points could be awarded for both eye and cheek spasms, yielding a total maximum score of 16 points. The second part, the “HFS subjective” section, assessed HRQOL using a VAS ranging from 0 (no complaints) to 100 percent (maximum complaints). This section included a question on general complaints (global rating), three questions on functional HRQOL (difficulties in driving, reading and watching television/movie), and four questions on psychosocial HRQOL (depression, eye contact, embarrassment and worry about others’ reaction).<sup>14</sup> Patients could respond “N/A or Not Applicable” to questions irrelevant to their circumstances, such as driving.

### *Statistical analysis*

IBM SPSS Statistics was used for statistical analysis. Normality tests and descriptive statistics were performed on quantitative data. Mean  $\pm$  standard deviation (mean $\pm$ SD) were used to represent normally distributed quantitative data, while median (interquartile range, IQR) was used to represent skewed quantitative data. Regression analysis was carried out with a logistic regression model and linear regression model to identify variables related to short-term prognosis following BTX-A treatment of HFS. The logistic regression results were presented using odds ratios with 95% confidence intervals. A p-value of  $<0.05$  indicated statistical significance.

## **RESULTS**

### *Clinical and demographic profile of patients with hemifacial spasms who received BTX-A*

This study included 64 participants with complete medical records, all of whom were successfully reassessed via video call one month after

treatment. Table 1 presents their clinical and demographic profiles. The mean age was 50 years, with a majority (76.56%,  $n=49$ ) being female. Comorbidities were absent in 48.44% ( $n=31$ ) of participants; hypertension was present in 40.63% ( $n=26$ ); dyslipidemia in 15.63% ( $n=10$ ); and diabetes in only 1.56% ( $n=1$ ). Multiple comorbidities were common. Mean disease duration was approximately 7.83 years. The orbicularis oculi muscle was the most common initial site of spasm (96.88%,  $n=62$ ), with a mean interval of approximately 23 months before the involvement of both upper and lower facial muscles. Most participants (79.69%,  $n=51$ ) had received prior BTX therapy, with a mean interval of 10.96 months since their last treatment. The majority (81.25%,  $n=52$ ) did not use concurrent oral medications for HFS. Of those who did (18.75%,  $n=12$ ), clonazepam was most common, followed by carbamazepine; only one patient used pregabalin.

An average of 22.75 units of BTX-A was administered, ranging from 20 to 28.5 units. The etiology of HFS was undetermined in half the participants (50%,  $n=32$ ) due to financial constraints preventing cranial MRI in their respective provinces. Of those who underwent cranial MRI, 68.75% ( $n=22$ ) showed normal findings, while 31.25% ( $n=10$ ) exhibited vascular loops compressing the facial nerve, predominantly involving the anterior inferior cerebellar artery (AICA).

### *Severity and frequency of eye and cheek muscle spasms before and after BTX-A therapy*

Table 2 presents the frequency and severity of eye and cheek muscle spasms at baseline and one month post-treatment. At baseline, the majority of patients (53.13%,  $n=34$ ) experienced severe, incapacitating eyelid spasms (Grade 4 severity), lasting  $>1$  second and occurring during  $>50\%$  of waking hours (Grade 3 frequency). Similarly, most patients (48.44%,  $n=31$ ) presented with severe cheek spasms (Grade 4 severity), lasting  $>1$  second (Grade 3 frequency).

One month post-treatment (Table 2), most patients (35.94%,  $n=23$ ) exhibited minimal increased blinking elicited only by external stimuli (Grade 1 severity and frequency). Similarly, most (31.81–32.81%,  $n=21$ ) showed mild, barely perceptible cheek spasms, self-reported only (Grade 1 severity and frequency). Significantly fewer patients exhibited severe spasms compared to baseline.

**Table 1: Baseline characteristics of study participants**

Clinical and demographic profile	Overall (n=64)
Age (years), mean $\pm$ SD (range)	50.1875 $\pm$ 10.60829
Sex, n (%)	
Male	15 (23.44%)
Female	49 (76.56%)
Comorbidities, n (%)	
None	31 (48.44%)
Hypertension	26 (40.63%)
Diabetes mellitus	1 (1.56%)
Dyslipidemia	10 (15.63%)
Disease duration (years), mean $\pm$ SD (range)	7.8385 $\pm$ 4.66515
Location of initial spasm, n (%)	
Forehead	0 (0%)
Eye	62 (96.88%)
Cheek	2 (3.13%)
Neck	0 (0%)
Progression of hemifacial spasm (months), mean $\pm$ SD (range)	22.8571 $\pm$ 23.78727
History of BTX therapy for HFS, n (%)	
BTX-naïve	13 (20.31%)
Previously treated	51 (79.69%)
Time of last BTX therapy (months) for those previously treated, mean $\pm$ SD (range)	10.9688 $\pm$ 16.33962
Concurrent use of oral medications for HFS, n (%)	
Yes	12 (18.75%)
No	52 (81.25%)

#### *HRQOL parameters before and after BTX-A treatment*

Table 3 shows HRQOL scores for HFS patients before and one month after BTX-A therapy. Mean HRQOL scores decreased from baseline to the one-month follow-up. All questions in the “HFS Subjective” section were answered by all patients except for “difficulty driving,” which 37 patients left unanswered due to not driving.

#### *Factors affecting the short-term prognosis based on frequency and severity of eye and cheek muscle spasms*

Table 4 presents a regression analysis of clinico-demographic factors associated with clinical outcomes following BTX-A therapy for HFS. Variables included age, sex, hypertension, diabetes mellitus, dyslipidemia, disease duration (years), initial spasm location, HFS progression (months), prior BTX therapy, time since last BTX

therapy (months for previously treated patients), and concurrent oral medication use. Only prior BTX therapy showed a statistically significant association with cheek muscle spasm severity and frequency (test statistic = 5.625,  $p = 0.018$ ), with prior treatment associated with less severe spasms. No other variables showed a significant association with eye or cheek spasm severity or frequency.

#### *Factors affecting the short-term prognosis based on the HRQOL parameters*

Table 5 presents regression analysis results examining the association between clinico-demographic factors and HRQOL improvements one month post-BTX-A treatment for HFS. Disease duration (mean 7.84 years) significantly correlated only with reduced worry about others' reactions (percent improvement from baseline = 2.09,  $p = 0.04$ ). Initial spasm location (96.88%

**Table 2: Clinical parameters in HFS (severity and frequency of the eye and cheek muscle spasms) before and after BTX-A treatment**

Clinical parameters		Baseline, n (%)					After 1 month, n (%)				
		0	1	2	3	4	0	1	2	3	4
Eye	Severity	0 (0%)	0 (0%)	0 (0%)	30 (46.88%)	34 (53.13%)	18 (28.13%)	23 (35.94%)	18 (28.13%)	4 (6.25%)	1 (1.56%)
	Frequency	0 (0%)	0 (0%)	1 (1.56%)	34 (53.13%)	29 (45.31%)	18 (28.13%)	23 (35.94%)	14 (21.88%)	8 (12.5%)	1 (1.56%)
Cheek	Severity	0 (0%)	0 (0%)	6 (9.38%)	27 (42.19%)	31 (48.44%)	17 (26.56%)	21 (32.81%)	17 (26.56%)	9 (14.06%)	0 (0%)
	Frequency	0 (0%)	2 (3.13%)	1 (1.56%)	33 (51.56%)	28 (43.75%)	17 (26.56%)	21 (32.81%)	13 (20.31%)	13 (20.31%)	0 (0%)

\*Severity: Zero (no spasms) to four points (severe spasms)

\*Frequency: Zero (no spasms) to four points (very frequent)

around the eye) significantly correlated with improved general complaints ( $-2.13, p = 0.04$ ) and reduced worry about others' reactions ( $-2.09, p = 0.04$ ). Prior BTX treatment significantly correlated with improved general complaints ( $-2.22, p = 0.03$ ), reduced embarrassment ( $-2.00, p = 0.05$ ), and reduced worry about others' reactions ( $-2.24, p = 0.03$ ). No other clinico-demographic factors showed significant associations with HRQOL improvements.

## DISCUSSION

Etiological determination was incomplete due to cranial MRI inaccessibility for half the participants. However, the consistent response to BTX therapy in both primary and secondary HFS cases, as noted by Colosimo *et al.*<sup>15</sup>, supports our study's inclusion of both etiologies.

Our study employed a newly validated HFS scoring questionnaire comprehensively assessing clinical parameters ("HFS Clinical") and functional/psychological aspects ("HFS Subjective") using a VAS.<sup>14</sup> This allowed for

the detection of subtle HRQOL changes and facilitated remote (telephone/video call) follow-up comparable to in-person assessments, which was particularly useful given the geographical distribution of participants (45% from outside Metro Manila).

At baseline, most patients exhibited severe eye and cheek muscle spasms (Grades 3-4); however, improvement to mostly Grade 1 was observed post-treatment. Similarly, HRQOL improvements were noted across all assessed parameters, consistent with the well-established benefits of BTX-A in HFS.

Regression analysis was done to determine the factors that may affect both the clinical and HRQOL parameters following BTX-A treatment. In terms of the clinical parameters, only one factor was statistically significant – history of prior BTX therapy for HFS was significantly associated with less severity and less frequency of cheek spasms after treatment. The possible explanation is that muscles around the eyes are more steadily active during the day and are more easily triggered by activities, such as reading, driving, bright light,

**Table 3: Effectivity of BTX-A in improving the functional and psychological HRQOL parameters in HFS**

HRQOL parameters	Baseline (in mean $\pm$ SD)	After 1 month (in mean $\pm$ SD)	% improvement from baseline
General complaints	67.42 $\pm$ 22.96	27.66 $\pm$ 21.95	58.9736%
Had difficulty in driving	45.11 $\pm$ 31.68	14.81 $\pm$ 19.64	67.16914%
Had difficulty in reading	47.34 $\pm$ 27.8	16.09 $\pm$ 21.33	66.01183%
Had difficulty in watching TV	45.63 $\pm$ 27.45	15 $\pm$ 21.47	67.12689%
Felt depressed	58.02 $\pm$ 27.05	26.41 $\pm$ 26.55	54.48121
Avoided eye contact	67.89 $\pm$ 26.3	27.11 $\pm$ 27.5	60.06776%
Felt embarrassed about having the condition	71.95 $\pm$ 24.2	28.05 $\pm$ 28.21	61.01459%
Felt worried about others' reaction to you	73.2 $\pm$ 25.14	27.97 $\pm$ 28.21	61.78962%

\*Scores of 0 (no complaints) to 100 percent (maximum complaints)



**Table 4: Regression analysis of the factors that may affect the clinical parameters (severity and frequency of eye and cheek spasms) after BTX-A therapy**

Variable/factors	Eye muscles		Cheek muscles	
	Test statistic	p-value	Test statistic	p-value
Age (years)	0.223	0.637	0.161	0.689
Sex	1.406	0.236	1.044	0.307
Hypertension	0.469	0.493	0.033	0.857
Diabetes mellitus	0.000	1.000	0.000	1.000
Dyslipidemia	0.218	0.641	0.120	0.729
Disease duration (years)	0.214	0.644	2.912	0.088
Location of initial spasm	1.053	0.305	2.493	0.114
Progression of hemifacial spasm (months)	0.054	0.816	1.029	0.310
History of BTX therapy for HFS	1.907	0.167	5.625	<b>0.018</b>
Time of last BTX therapy (months) for those previously treated	0.005	0.942	1.733	0.188
Concurrent use of oral medications for HFS	0.508	0.476	0.674	0.412

**Table 5: Regression analysis of the factors that may affect the HRQOL parameters after BTX-A therapy**

Variables/ factors	General complaints		Had difficulty in driving		Had difficulty in reading		Had difficulty in watching TV		Felt depressed		Avoided eye contact		Felt embarrassed		Felt worried about reactions	
	% improvement from baseline	P-Value	% improvement from baseline	P-Value	% improvement from baseline	P-Value	% improvement from baseline	P-Value	% improvement from baseline	P-Value	% improvement from baseline	P-Value	% improvement from baseline	P-Value	% improvement from baseline	P-Value
Age (years)	-0.06	0.95	0.53	0.61	0.02	0.99	0.94	0.35	-1.43	0.16	-0.55	0.59	-0.97	0.34	-0.73	0.47
Sex	0.26	0.80	-0.61	0.55	-0.81	0.42	-0.65	0.52	-0.33	0.74	0.48	0.64	0.23	0.82	-0.16	0.88
Hypertension	-0.49	0.63	-0.57	0.58	0.18	0.86	0.70	0.49	0.20	0.85	-0.44	0.66	-0.05	0.96	0.18	0.86
Diabetes mellitus	0.42	0.67	1.55	0.14	1.12	0.27	1.00	0.32	-0.13	0.89	0.08	0.94	-0.20	0.85	-0.06	0.95
Dyslipidemia	0.11	0.91	-0.34	0.74	-0.18	0.86	0.08	0.94	-0.13	0.90	0.14	0.89	-0.12	0.91	0.06	0.95
Disease duration (years)	1.81	0.08	1.18	0.25	1.85	0.07	1.50	0.14	1.89	0.06	1.47	0.15	1.92	0.06	2.09	<b>0.04</b>
Location of initial spasm	-2.13	<b>0.04</b>	-1.24	0.23	-1.24	0.22	-1.30	0.20	-1.75	0.09	-1.56	0.12	-1.83	0.07	-2.09	<b>0.04</b>
Progression of hemifacial spasm (months)	-1.14	0.26	-1.42	0.17	-0.84	0.41	-1.02	0.31	-0.97	0.34	-0.45	0.65	-1.10	0.28	-1.30	0.20
History of BTX therapy for HFS	-2.22	<b>0.03</b>	-1.47	0.16	-1.05	0.30	-1.83	0.07	-0.26	0.80	-1.70	0.10	-2.00	<b>0.05</b>	-2.24	<b>0.03</b>
Time of last BTX therapy (months) for those previously treated	0.41	0.68	1.29	0.21	0.68	0.50	0.47	0.64	-0.80	0.43	-0.25	0.80	-0.81	0.43	-0.48	0.63
Concurrent use of oral medications for HFS	0.11	0.92	-0.35	0.73	-0.99	0.33	-1.19	0.24	-0.10	0.92	-0.45	0.66	-0.20	0.84	-0.04	0.97

wind and speaking with other persons, compared with the cheek muscles. Thereby, we theorize that the cheek muscle spasms may appear to be more controlled during repeated BTX injections. In addition, usually there are more muscles around the eye that needs to be targeted during BTX injections, as compared with the cheek muscles.<sup>8</sup> Another possible explanation is that in older patients, a combination of loose skin and attenuated orbital septum can further facilitate the dissection of injected BTX.<sup>16</sup>

On the other hand, three factors showed affectionation with different HRQOL parameters – (1) disease duration of  $\geq 7$  years, (1) initial spasms around the eye and (3) history of prior BTX injection for HFS. First, the disease duration of  $\geq 7$  years was significantly associated with improvement on how the patients felt worried about others' reactions. This can possibly be explained by the patients' adaptation of their disease and associated psychosocial impacts through time. Over the years, patients may have learned several techniques on how to control the spasms, such as sensory tricks. In a study by Loyola *et al.*, some HFS patients massaged the affected hemiface, while other had to slide the fingers on the affected side.<sup>17</sup> Some patients also improved their symptoms by wearing a mask, both as a sensory trick and as concealment of their stigmatizing facial expression.<sup>18</sup> Second, having initial spasms around the eye had better improvements in general complaints about the disease (global rating) and they were less worried about the reactions of others. When the eye has been affected for the longest duration of the disease, patients also tend to become adjusted to the situation. Some of them may have worn eye glasses to help conceal their spasms. Third, being previously injected with BTX was linked to significant improvements in general complaints, feelings of embarrassment, and worry about others' reactions. It can possibly be explained by the fact that previously-treated patients have already experienced the benefits of previous sessions of the botulinum toxin therapy, which gives them hope and assurance.

The above-mentioned clinicodemographic factors that turned out to have influence on the BTX response in our study were different compared to other papers. In one study, factors associated with poor short-term prognosis of BTX-A in the treatment of HFS were male sex, alcohol drinking, diabetes, and hypertension.<sup>19</sup> In another study, the age of 70 years and above showed a decreased risk of poor drug responses

in patients with HFS.<sup>20</sup> Meanwhile, severity of HFS was positively correlated with the severity of depressive symptoms<sup>5,21</sup>, while educational level were inversely correlated.<sup>21</sup> In the study of Batla *et al.*, the severity of spasm was positively correlated with the duration of disease and presence of weakness of facial muscles<sup>22</sup>, although this correlation was not made in relation to BTX therapy.

There are several limitations in the study. One is the lack of etiological determination for all participants. All patients with HFS were included in the study, regardless of whether they had primary or secondary causes. Second limitation was reliance on patient-reported HRQOL data. No separate screening tool was used to assess depression. Patients were only asked if they “felt depressed” during the second part of the HFS questionnaire and provided answers to that using a VAS of 0-100%. The second part is also prone to patients' subjectivity and this limitation arises from the fact that emotional and psychological state of patients may vary from day to day.

In conclusion, BTX therapy has been established as efficacious in improving the clinical, functional and psychosocial aspects of HFS patients. The spasms may be painless and not life-threatening, but the facial contractions cause functional impairments of vision and speech, as well as psychiatric symptoms. The findings of the study regarding the factors that affect short-term prognosis of HFS patients contrast with some previous studies, highlighting potential differences in predictor variables across populations. Hence, future research may focus on prospective studies with larger, more diverse populations.

## DISCLOSURE

Financial support: None.

Conflicts of interest: AbbVie sponsored the BOTOX® vials used at the Hemifacial Spasm Summit. However, AbbVie had no involvement in this study; the sponsorship was provided solely for the benefit of HFS patients who attended the summit.

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## Appendix 1. HFS score questionnaire

### HFS Clinical

#### A. Eye involvement

<b>Hemifacial spasm severity</b>	<b>Frequency</b>
0 = None	0 = None
1 = Minimal, increased blinking present only with external stimuli (e.g., bright light, wind, reading, driving, etc.)	1 = Slightly increased frequency of blinking
2 = Mild, but spontaneous eyelid fluttering (without actual spasm), definitely noticeable, possibly embarrassing, but not functionally disabling)	2 = Eyelid fluttering lasting less than 1 second duration
3 = Moderate, very noticeable spasm of eyelids only, mildly incapacitating	3 = Eyelid spasm lasting more than 1 second, eyes open more than 50% of the waking time
4 = Severe, incapacitating spasm of eyelids and possibly other facial muscles	4 = The involved eye is functionally "blind" due persistent eye closure more than 50% of the waking time

#### B. Cheek involvement

<b>Hemifacial spasm severity</b>	<b>Frequency</b>
0 = None	0 = None
1 = Mild, barely noticeable spasm, only recognised by the patient	1 = Slightly increased frequency of cramps
2 = Mild, but noticeable spasm	2 = Cramps lasting less than 1 second
3 = Moderate noticeable spasm including the corners of the mouth	3 = Cramps more than 1 second
4 = Severe spasm with involvement of the whole cheek	4 = Cramps more than 50% of the waking time

HFS Subjective (Health-related quality of life)

Global rating

Free of complaints

Suffering extremely

0%

I

100%

Had difficulty driving

0%

I

100%

Had difficulty reading

0%

I

100%

Had difficulty watching television/movie

0%

I

100%

Felt depressed

0%

I

100%

Avoided eye contact

0%

I

100%

Felt embarrassed about having the condition

0%

I

100%

Felt worried about others' reactions to you

0%

I

100%