Stigma and quality of life for patients with facial dystonia: a cross-sectional study

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Abstract

Background

Facial appearance and expressions influence social interaction. However, few studies have reported on the stigma associated with spasms from facial dystonia. This study investigated the stigma and quality of life for these patients.

Methods

This cross-sectional study included 90 patients with facial dystonia (hemifacial spasm [HFS], blepharospasm [BSP], and blepharospasm-oromandibular dystonia [BOD]; 30 patients per group) and 30 individuals without dystonia (control group) from October 2019 to November 2020. All participants underwent stigma, quality of life, and mental health evaluations using seven questions related to stigma, the 36-item Short Form Health Survey, the 14-item version of the Hamilton Anxiety Scale (HAMA), and the 24-item version of the Hamilton Depression Scale.

Results

Nineteen patients (21.11%) felt stigmatized. Patients with BPS and HFS had more difficulty finding a job and were more susceptible to discrimination than healthy individuals. The role-physical and social function scores were significantly lower in the dystonia groups than in the control group. The vitality score of the BPS group and the mental health scores in the BPS and BOD groups were significantly less than those of the control group. The HAMA scores in the BPS and BOD groups were significantly higher than in the control group. Regression analysis demonstrated that the disease course influenced depression.

Conclusion

Enacted stigma from a negative public attitude may be the main factor triggering stigma in patients with facial dystonia, with detrimental effects on psychosocial outcomes, including social rights, quality of life, and mood.

Background

Facial dystonia usually presents as primary hemifacial spasm (HFS) and Meige syndrome, which includes blepharospasm (BPS) and blepharospasm-oromandibular dystonia (BOD).\(^1\) The disease is characterized by involuntary clonic or tonic contraction of the facial expression muscles. Spontaneous remissions are rare, occurring in less than one-tenth of patients.\(^2\) Facial expression strongly influences
social interactions. Patients have reported more depression and anxiety than individuals without dystonia, potentially leading to stigmatization and a decreased quality of life. Moreover, psychological problems can aggravate clinical symptoms.

Stigma is defined as a mark of disgrace that contributes to unequal social outcomes. There are two primary classifications of stigma: internalized or ‘felt’ stigma (associated with low self-esteem or self-doubt) and enacted stigma (experiencing negative public attitudes). The level of stigma is evaluated according to six dimensions: concealability, course, disruptiveness, aesthetics, origin, and peri. Some diseases, such as schizophrenia and epilepsy, are highly stigmatized. Facial dystonia conforms to the six dimensions of stigma, with chronic dystonia affecting interpersonal relationships and causing physical deformations. Further, it is not well known to the public and can be misinterpreted as dangerous. Stigma is usually ignored in clinical diagnosis and treatment, leading to poor treatment outcomes.

Health-related stigma research is lacking worldwide, especially in developing countries. There are no studies on the effects of stigma in Chinese patients with facial dystonia. Therefore, this study investigated the psychosocial consequences and influencing factors of stigma and the quality of life among patients with HFS, BPS, and BOD.

**Methods**

**Selection and Description of Participants**

We consecutively enrolled 90 patients with facial dystonia, including 30 with HFS, 30 with BPS, 30 with BOD, and 30 without dystonia (healthy controls). All patients were identified from the outpatient dystonia clinic of our hospital from October 2019 to November 2020. The inclusion criteria were: 1) aged 30 to 85 years, and 2) diagnosis of HFS or Meige syndrome according to the Guidelines for the Diagnosis and Treatment of Dystonia. Patients with Meige syndrome were classified as BPS or BOD. The exclusion criteria were: 1) brain computed tomography or magnetic resonance images suggesting brain damage, 2) central nervous system diseases (e.g., epilepsy and myasthenia gravis), 3) secondary dystonia, 4) serious medical diseases (e.g., tumors), and 5) mental disorders or trauma.

All participants underwent stigma, quality of life, and mental health evaluations. Informed consent was obtained from all subjects. This study was approved by Research Ethics Committee of the First Affiliated Hospital of Sun Yat-sen University (2021-248).

**Technical Information**

Seven questions related to stigmatization were administered to evaluate stigma; the internal consistency was moderate to high (Cronbach's $\alpha = 0.75$). Questions one to three assessed internal stigma regarding the patient’s fear of enacted stigma and sense of shame. Questions four to seven explored enacted stigma regarding the patient’s experience with discrimination and prejudices from the public.
because of facial dystonia.\textsuperscript{[14]} Disease-related quality of life was assessed using the 36-item Short Form Health Survey (SF-36). Anxiety severity was assessed using the 14-item version of the Hamilton Rating Scale for Anxiety (HAMA); a score of seven or more indicates mild anxiety. Depressive symptoms were assessed using the 24-item version of the Hamilton Rating Scale for Depression (HAMD); a score of eight or more indicates mild depression. HAMD and HAMA have good reliability and validity.\textsuperscript{[15]}

**Statistical Analyses**

Statistical analysis was performed using the SPSS software version 25 (IBM Corp., Armonk, NY, USA). Descriptive data are presented as means ± standard deviations (SD), and categorical variables are presented as frequencies and percentages. All variables were compared using t-tests or Z-tests for continuous variables and the chi-square test or Fisher’s exact test for categorical variables. Linear regression models were used to analyze associations among variables. \(P\)-values of 0.05 or less (two-sided) were considered statistically significant.

**Results**

**Patient Demographics**

In total, 120 participants completed the questionnaires. Table 1 presents the patients’ demographic characteristics. Of the 90 patients with dystonia, 78.89% were female, 21.11% were male, and the disease duration ranged from 0.5 to 20 years.
| Variables              | BPS (n = 30) | HFS (n = 30) | BOD (n = 30) | Control (n = 30) | P-value |
|-----------------------|--------------|--------------|--------------|------------------|---------|
|                       | n (%)        | n (%)        | n (%)        | n (%)            |         |
| Sex (male)            | 8 (36.36)    | 8 (36.36)    | 3 (10.00)    | 12 (40.00)       | 0.071   |
| Age, years            |              |              |              |                  | 0.0578  |
| 31-40                 | 4 (13.33)    | 1 (3.33)     | 1 (3.33)     | 2 (6.67)         |         |
| 41-50                 | 5 (16.67)    | 6 (20.00)    | 5 (16.67)    | 5 (16.67)        |         |
| 51-60                 | 10 (33.33)   | 14 (46.67)   | 10 (33.33)   | 10 (33.33)       |         |
| >60                   | 11 (36.67)   | 9 (30.00)    | 14 (46.67)   | 13 (43.33)       |         |
| Disease duration, years |          |              |              |                  | 0.012   |
| <5                    | 11 (36.67)   | 5 (16.67)    | 12 (40.00)   |                  |         |
| 5-10                  | 12 (40.00)   | 9 (30.00)    | 12 (40.00)   |                  |         |
| 10-15                 | 5 (16.67)    | 8 (26.67)    | 4 (13.33)    |                  |         |
| 15-20                 | 2 (6.67)     | 8 (26.67)    | 2 (6.67)     |                  |         |
| Education             |              |              |              |                  | 0.001   |
| Less than high school | 9 (30.00)    | 15 (50.00)   | 20 (66.67)   | 8 (23.33)        |         |
| High school           | 10 (33.33)   | 9 (30.00)    | 7 (23.33)    | 10 (36.67)       |         |
| College or higher     | 11 (36.67)   | 6 (20.00)    | 3 (10.00)    | 12 (50.00)       |         |

**Abbreviations:** BPS, blepharospasm; HFS, hemifacial spasm; BOD, blepharospasm-oromandibular dystonia

**Stigma Assessment**

Overall, 19 of 90 dystonia patients (21.11%) reported feeling stigmatized (Table 2). Twenty-two patients (24.44%) felt that they did not receive more attention from their family members, and seven (7.78%) kept their diseases a secret. Regarding external stigma, one patient reported separating from their partner due to facial dystonia. The unemployment rate was 25.56%, and nine patients (10%) were fired from their jobs because of the disease.
| Question                                                                 | Percentage (%)                                      |
|-------------------------------------------------------------------------|----------------------------------------------------|
| 1  Did you ever feel different from people without facial dystonia?     | 21.11% / 78.89%                                    |
| 2  Do you think that your family members are more protective of you?    | 75.56% / 24.44%                                    |
| 3  Do your friends know about your facial dystonia?                     | 92.22% / 7.78%                                     |
| 4  Did your partner ever break up with you because you have facial dystonia? | 1.11% / 98.89%                                    |
| 5  Have you ever been fired from a job because you have facial dystonia? | 10.00% / 90.00%                                    |
| 6  Have you ever had difficulty finding a job because you have facial dystonia? | 25.56% / 74.44%                                   |
| 7  Do you think that people's attitudes changed when they learned that you have facial dystonia? | 28.89% / 71.11%                                   |

Job-seeking activity significantly differed between those with and without dystonia ($X^2 = 13.750, P = 0.003$; Table 3). Patients with BPS and HFS reported more difficulty finding a job (Bonferroni correction, $X^2 = 7.124 P=0.008$) and were more likely to perceive attitude changes ($X^2 = 14.06, P = 0.002$). Twenty-six patients (28.89%) thought that people’s attitudes worsened when they learned about the patient’s disease. We did not find correlations between stigma and gender, age, or disease duration.
**Table 3**

Stigma comparisons [n (%)]

| Question* | 1   | 2   | 3   | 4   | 5   | 6   | 7   |
|-----------|-----|-----|-----|-----|-----|-----|-----|
|           | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| n (%)     | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) |
| BPS       | 5   | 25  | 28  | 0   | 4   | 10  | 12  |
|           | (16.67) | (83.33) | (93.33) | (0.00) | (13.33) | (33.33) | (40.00) |
| HFS       | 7   | 21  | 29  | 1   | 4   | 10  | 8   |
|           | (23.33) | (70.00) | (96.67) | (3.33) | (13.33) | (33.33) | (26.67) |
| BOD       | 7   | 22  | 26  | 0   | 1   | 3   | 6   |
|           | (23.33) | (73.33) | (86.67) | (0.00) | (3.33) | (10.00) | (20.00) |
| Control   | 4   | 24  | 21  | 0   | 0   | 1   | 0   |
|           | (13.33) | (80.00) | (70.00) | (0.00) | (0.00) | (3.33) | (0.00) |
| $\chi^2$ | 1.452 | 0.982 | 10.962 | 3.025 | 5.954 | 13.750 | 14.730 |
| $P$       | 0.693 | 0.806 | 0.012 | 0.388 | 0.100 | 0.003 | 0.002 |

Abbreviations: BPS, blepharospasm; HFS, hemifacial spasm; BOD, blepharospasm-oromandibular dystonia. *See Table 2.

Abbreviations: BPS, blepharospasm; HFS, hemifacial spasm; BOD, blepharospasm-oromandibular dystonia. The mean scores in BPS, HFS, and BOD for SF (A) and RP (B) were significantly lower than in the control group. The VT score (C) was poorer in the BPS group and BOD groups than in the control group. The MH score (D) in the BPS and BOD groups significantly differed from the control group. *$P < 0.05$, **$P < 0.01$, ***$P < 0.001$

Abbreviations: HAMA, Hamilton Anxiety Scale; BPS, blepharospasm; HFS, hemifacial spasm; BOD, blepharospasm-oromandibular dystonia; *$P = 0.021$, BPS vs. controls. *$P = 0.020$, BOD vs. controls.

**Quality of Life Assessment**

Patients with facial dystonia had lower mean SF-36 scores on multiple dimensions than those without dystonia. Regarding the SF-36 variables, the role-physical (RP), energy (i.e., vitality, VT), social function (SF), emotional function (role-emotional, RE), and mental health (MH) scores were significantly lower in the patient groups than in the control group (all $P < 0.05$). The mean scores for SF ($F = 8.755, P = 0.0004$) and RP ($F = 14.460, P = 0.0004$) significantly differed between those with and without dystonia. The VT scores were poorer in the BPS and BOD groups than in the control group ($F = 13.833, P = 0.024$ and $F = 11.83, P = 0.036$, respectively). The MH scores in the BPS and BOD groups significantly differed from those of the control group ($F = 12.133, P = 0.017$ and $F = 14.267, P = 0.003$, respectively) (Figure 1).

**Depression and Anxiety Assessment**
Thirty patients (33.33%) had anxiety; twenty-five were women (83.33%), and five were men (16.67%). Among them, twenty-three people were slightly anxious (25.56%), six were moderately anxious (6.67%), and one was severely anxious (1.11%). Thirty-seven patients (41.11%) were depressed; thirty women (81.08%) and seven men (18.91%) were mildly depressed. The most common manifestation of depression was sleep disorders; thirty-three people (36.67%) reported insomnia, twenty-three (25.56%) were easily awakened and had more dreams, and seventeen (18.89%) awoke early. The prevalence of depression did not differ between the groups; however, the prevalence of anxiety significantly differed across the four groups (H = 6.123, \( P = 0.009 \)). The BPS (\( P = 0.021 \)) and BOD (\( P = 0.020 \)) HAMA scores significantly differed from those of the control group (Figure 2). Further, the HAMD scores correlated with disease duration in the multiple linear regression model (\( \beta = -0.269, \ P = 0.004 \); as the disease duration increased, the depression scores decreased.

**Discussion**

This study examined stigma and the quality of life among Chinese patients with facial dystonia, finding significant stigmatization. Previously, stigma has been considered when evaluating chronic disease therapy.\[16\] For example, stroke survivors in a Ghanaian cohort reported experiencing some form of stigma,\[17\] as have patients with diabetes.\[18\] Rinnerthaler et al.\[19\] also reported that patients with cranial and cervical dystonia were less likely to be accountable for their actions, less self-confident, and subject to serious prejudice and enacted stigmatization. In this study, we found that stigma associated with facial dystonia mainly manifested as enacted stigma (i.e., by the public), unlike those of Parkinson's disease\[20\] and epilepsy,\[21\] which tend to manifest as an internal stigma. Collectively, these issues underscore that stigma occurs at multiple levels, ranging from intrapersonal to interpersonal, and to various structural levels.\[22\]

Patients with facial dystonia experience stigmatization by the public because of involuntary facial clonic contractions. Previous studies have suggested that the effect of social stigma has been underestimated among the unemployed.\[23\] Our research indicated that it was difficult for patients with facial dystonia to obtain basic social rights compared to the general population. Some patients have experienced bias and have been rejected for jobs. Employers often hold negative attitudes towards people with poor appearances, and self-stigma and the ‘why try’ effect\[24\] after rejection can lead to insufficient motivation for employment. Patients with BPS and HFS were more susceptible to the negative attitudes of the people around them concerning their condition. However, most patients with facial dystonia do not feel different from unaffected people and will not deliberately conceal the disease from their friends. Developing self-adaptation and self-acceptance could account for this. As a patient’s understanding of the disease gradually improves, the negative experience of self-discrimination and internal (or felt) stigma decreases.

All of the facial dystonia groups had lower RP and SF scores. Previous studies showed that stigma limits social opportunities, resources, and well-being;\[16–18\] groups experiencing stigma have lower employment rates, marriage rates, and education levels. Affected by involuntary facial movement and
enacted stigma, most patients have limitations regarding job selection, and extra effort is required to complete the same work. Studies have shown that patients with mental illness due to stigma and mild mental health problems also have a negative attitude towards job hunting.\textsuperscript{[25]} The majority of patients reduced their time for social activities, restricting the things they wanted to do. The BOD group had lower SF-36 scores than the BPS group, including general health (GH), PF, bodily pain (BP), RE, and MH, potentially bearing a greater burden on the physiology and psychology of these patients. In addition, the disease duration correlated with the GH, VI, PF, RP, and MH scores. Patients with a first onset or a short course of illness experienced helplessness when encountering the disease. Together, these findings suggest that dystonia-associated stigma may differentially affect the quality of life indicators.

Regarding mental health assessment, our findings correspond to those of Fabbrini et al.,\textsuperscript{[26]} who reported that patients with BPS and BOD are more susceptible to emotional disorders. Women had higher scores for anxiety and depression, which could be explained by appearance anxiety. However, there was no relationship between anxiety and sex, age, or the disease course. There was also no difference in the prevalence of depression among the three dystonia groups. The most common problem regarding depression was poor sleep quality. A previous study indicated that patients with BSP may experience insomnia-related complaints.\textsuperscript{[27]} Dystonic movement and associated pain may increase sleep onset latency and the number of awakenings, reducing total sleep time and sleep efficiency. The multiple linear regression analysis indicated that patients had higher depression scores in the early stages of the disease. Therefore, more attention should be paid to the mental health of patients who visit the clinic for the first time.

Our study has some limitations. First, this was a cross-sectional study that failed to compare the changes in stigma after treatment with botulinum toxin. Second, the questions regarding stigma were derived from Turkish research. Therefore, the questions may not have adequately assessed the self-stigma of Chinese people due to differing cultural backgrounds. Patients may not be honest with strangers about their experiences with stigma during face-to-face questionnaires.

**Conclusions**

In conclusion, patients with facial dystonia experience varying degrees of stigma while suffering from the disease itself. Enacted stigma may be the primary triggering factor, potentially leading to a multidimensional decline in a person's quality of life, affecting employment, livelihood, and mood. Therefore, stigma assessment and intervention should be considered in the management of patients with facial dystonia.

**Abbreviations**

HFS  
hemifacial spasm  
BSP
Declarations

Ethics approval and consent to participate

This study was approved by Research Ethics Committee of the First Affiliated Hospital of Sun Yat-sen University (2021-248). Informed consent was obtained from all subjects.

All methods of this study were performed in accordance with the relevant guidelines and regulations.

Availability of data and materials

All data generated or analysed during this study are included in this published article. The raw data are included as an additional file to the manuscript.

Competing interests

The authors declare that they have no competing interest.

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Authors' contributions

Y.M., D.C. and Z.W.X. conceived of the presented idea. L.G and L.J. verified the analytical methods. O.Z.L, L.Y.M and L.J. contributed to sample preparation. Y.M. and L.J. wrote the original draft. D.C. and L.G reviewed and edited the manuscript. Z.W.X and W.Y. helped supervise the project. All authors provided critical feedback and helped shape the research, analysis and manuscript.

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Figure 1

The comparison of mean SF-36 scores.
Abbreviations: BPS, blepharospasm; HFS, hemifacial spasm; BOD, blepharospasm-oromandibular dystonia. The mean scores in BPS, HFS, and BOD for SF (A) and RP (B) were significantly lower than in the control group. The VT score (C) was poorer in the BPS group and BOD groups than in the control group. The MH score (D) in the BPS and BOD groups significantly differed from the control group. \( *P < 0.05, **P < 0.01, ***P < 0.001 \)

Figure 2

HAMA scores.

Abbreviations: HAMA, Hamilton Anxiety Scale; BPS, blepharospasm; HFS, hemifacial spasm; BOD, blepharospasm-oromandibular dystonia; \( *P = 0.021 \), BPS vs. controls. \( *P = 0.020 \), BOD vs. controls.
Supplementary Files

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- rawdata.xlsx