

Assessment of Severity of Blepharospasm in Outpatients in a Tertiary Hospital Using Blepharospasm Disability Scale and Jankovic Severity Scale

Pragya Bhandari¹, Bikram Prasad Gajurel¹, Ragesh Karn¹, Rajeev Ojha¹, Reema Rajbhandari¹, Sanjeeta Sitaula², Niraj Gautam¹

Author(s) affiliation

¹Department of Neurology, Maharajgunj Medical Campus, Tribhuvan University Teaching Hospital, Institute of Medicine, Kathmandu, Nepal

²Department of Ophthalmology, Maharajgunj Medical Campus, BP Koirala Lions Centre for Ophthalmic Studies, Institute of Medicine, Kathmandu, Nepal

Corresponding author

Bikram Prasad Gajurel, MBBS, MD
Bikram_gajurel@hotmail.com

ABSTRACT

Introduction

Blepharospasm is a condition characterized by involuntary and excessive blinking of eyelids. It is focal dystonia. The purpose of the study was to assess the severity of blepharospasm by both patient and physician rating scales and to compare the correlation between these two scores.

Methods

It was a single centred retrospective cross-sectional study in outpatient department (OPD) of neurology and Neuro-Ophthalmology of tertiary hospitals of Institute of Medicine (IOM). Data was extracted from the patient files who visited hospital between January 2023 till December 2023. Jankovic Rating Scale (JRS) was used to assess the severity by physician and Blepharospasm Disability Index (BSDI) by patient to self-score their disability. Analysis was done using IBM SPSS version 26. Correlation between physician scored scale and patient reported scores were done by using Spearman's rho. p-value of <0.05 was considered statistically significant.

Results

Seventeen patients were included. The mean age of study population was 56.84 ± 14.37 years, and 58.8% of patients were female. Only 29% were receiving botulinum toxin injection. Mean BSDI score was 5.41 ± 4.77 and mean JRS score was 5.82 ± 0.88 . No significant correlation was observed between the BSDI and JRS scores ($\rho = 0.418$, $p = 0.095$).

Conclusion

JRS and BSDI are both useful and widely used tools to assess severity of blepharospasm. However, our study showed only moderate correlation between physician and patient rating scales. Reason could be due to small sample size. Larger multicentre studies are advisable.

Keywords

Blepharospasm; BSDI; dystonia; Jankovic rating scale

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INTRODUCTION

Blepharospasm is a focal dystonia characterized by excessive eyelid twitching and blinking. It is a disabling condition leading to cosmetic and psychosocial issues, depression and social withdrawal² even though it is not life threatening³. Muscles causing excess spasm are orbicularis oculi (pretarsal, pre-septal and periorbital portions) and nearby muscles including procerus and corrugator³. Blinking is often induced by sunlight, wind, noise, head movements, environmental, or stress factors⁴ and reduced by any tasks demanding attention^{5,6}. It is hypothesized that blepharospasm results from impaired descending control of blink circuits due to dysfunction of the cortico-striato-thalamo-cortical circuits⁷. Though one study showed 27% have first degree relatives with blepharospasm, no gene mutation was detected⁸. The severity of the disease state can be quantified by clinical observer grading systems, physician ratings or eyelid muscle force devices.

There are several types of tools to objectively measure the severity of blepharospasm by both physician and by patient. We used Jankovic Rating Scale (JRS)⁹ for physician assessment and Blepharospasm Disability Index (BSDI)¹⁰ for patient-reported assessment. Since the severity of blepharospasm is not graded as per biochemical report or imaging characteristics and it has to be graded solely on basis of clinical assessment, it is important for physician to perceive the severity of disease in the equivalent way patient is facing.

Objective of our study is to test whether physician rating severity scale matches with

that of patient so that shared decision making can be made about treatment and prognosis and to judge the effectiveness of medications while on treatment.

METHODS

We did a retrospective study and data were collected in cross sectional manner. It was conducted at the Outpatient department of Neurology and the Neuro-Ophthalmology Unit of IOM from January 1 to December 30, 2023 for period of 1 year

Study Population

Eligible patients were those with blepharospasm- either isolated or those with concomitant spasm of face, jaw or neck. Adult patient aged 18 years or above and patient who were vitally and cognitively stable at the time of assessment were included in this study after informed consent was taken. Patients who were acutely ill or have concomitant cognitive impairment due to various causes and having generalized dystonia were excluded. Also, those with incomplete records were excluded from the study.

Data Collection

After screening, eligible patients were listed out. Their demographic profile and clinical information were extracted. It includes age, gender, duration of symptoms, comorbidities, and treatments.

JRS: This is clinician rating scale which measures two parameters, severity of eyelid blinking and duration of eyelid blinking both scored from 0-4 depending upon severity where 0 indicates none and 4 indicates severe

Table 1. Jankovic Rating Scale (JRS)

Severity	Frequency
0: None	0: None
1: 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 in duration
3. moderate, very noticeable spasm of eyelids only, mildly incapacitating	3. Eyelid spasm lasting more than 1 second but eyes open more than 50% of waking time
4. Severe, incapacitating spasm of eyelids and possibly other facial muscles	4. Functionally "blind" due to persistent eye closure (blepharospasm) more than 50 % of waking time

incapacitating spasm or functionally blind. Score would be between 0-8. (Table 1)

BSDI: This is easily measured self-administered questionnaire for patients which comprises of 6 items and scored from 0-4 or NA where 0 indicates no impairment and 4 indicates that the task is no longer possible due to illness. NA denotes not applicable. Score would range between 0-24 depending on the severity where higher score means more severe disease. Items assessed are driving, reading, watching TV, shopping, walking and doing everyday activities. (Table 2)

Table 2. Blepharospasm Disability Index (BSDI)

Driving a Vehicle	Not applicable to me	NA
	No impairment	0
	Slight impairment	1
	Moderate impairment	2
	Severe impairment	3
	No longer possible due to my illness	4
Reading	Not applicable to me	NA
	No impairment	0
	Slight impairment	1
	Moderate impairment	2
	Severe impairment	3
	No longer possible due to my illness	4
Watching TV	Not applicable to me	NA
	No impairment	0
	Slight impairment	1
	Moderate impairment	2
	Severe impairment	3
	No longer possible due to my illness	4
Shopping	Not applicable to me	NA
	No impairment	0
	Slight impairment	1
	Moderate impairment	2
	Severe impairment	3
	No longer possible due to my illness	4
Walking	Not applicable to me	NA
	No impairment	0
	Slight impairment	1
	Moderate impairment	2
	Severe impairment	3
	No longer possible due to my illness	4
Doing everyday activities	Not applicable to me	NA
	No impairment	0
	Slight impairment	1
	Moderate impairment	2
	Severe impairment	3
	No longer possible due to my illness	4

Statistical Analysis

Data were entered and was analysed using **IBM SPSS Statistics version 26**. Continuous variables were expressed as mean $\pm$ standard deviation, and categorical variables as frequencies and percentages. Relationship between BSDI and JRS scores were calculated by **Spearman rank correlation coefficient**. Statistical significance was set at **p < 0.05**.

RESULTS

Manual data of blepharospasm patients were collected from January 2023 till December 2023 for a total duration of 1 year. A total of 17 patients were included in the analysis. The mean age was 56.84 years (± 14.37), ranging from 38 to 79 years. Out of 17 patients, 10 patients (58.8%) were females. Mean duration of symptoms was 5.59 years (± 4.37) including those who visited hospital for the first time for symptoms. Majority of patients reported insidious onset and progressive or static course over time. (Table 3)

Table 3. Demographic and Clinical Characteristics of the Study Population

Variable	Value
Mean age (years)	56.8 $\pm$ 14.4
Female, n (%)	10 (58.8 %)
Mean duration of symptoms (years)	5.6 $\pm$ 4.4
Left eye involvement, n (%), first	11 (64.7 %)
Paranasal muscle contraction, n (%)	13 (76.5 %)
Photophobia, n (%)	7 (41.2 %)
Burning / grittiness, n (%)	6 (35.3 %)
Dry eye, n (%)	5 (29.4 %)
Hypertension, n (%)	5 (29.4 %)
Diabetes mellitus, n (%)	3 (17.6 %)
Dyslipidemia, n (%)	2 (11.8 %)
Treated with trihexyphenidyl + botulinum toxin, n (%)	9 (52.9 %)
Treated with baclofen, n (%)	3 (17.6 %)

Left eye was the first to be involved in 11 (64.7) in majority of cases. Most patients 13 (76.5 %) also reported concomitant twitching of paranasal muscles.

Physical discomfort was evident by difficulty performing activities of daily living due to excessive blinking of eyes. Besides many patients also complained of photophobia, dry eyes, feeling of grittiness. Most were concerned about cosmetic issues especially young patients. Regarding treatment, only around 70% (12 patients) were receiving treatment for blepharospasm. Out of those 9 patients (52.9%) had received trihexyphenidyl. 5 among them had also received botulinum toxin injections, whereas 3 patients (17.6%) were taking tablet baclofen only.

Co-morbidities were collected from patients' records. Hypertension was seen in 29.4% (n=5) of study population followed by Type

2 diabetes in 17.6% (n=3) and dyslipidaemia 11.8% (n=2).

Most of our patients have disease for prolonged duration, with mean duration of 5.6 $\pm$ 4.4 years. Out of those some of the patients had sought medical care for the first time.

In our study, mean BSDI score was 5.41 $\pm$ 4.77, which indicates mild to moderate functional disability, and the mean JRS score was 5.82 $\pm$ 0.88, table 2 which indicates moderate disease severity. Out of BSDI items, watching TV and reading were the most affected activities (mean item scores 1.7 $\pm$ 1.1 and 1.5 $\pm$ 0.9, respectively), whereas **walking** and daily household activities were least affected (mean scores 0.7 $\pm$ 0.5 and 0.8 $\pm$ 0.6). Driving assessment was not-applicable to most of the patients.

Table 4. Severity and Disability Scores

Scale	Mean $\pm$ SD	Range
Jankovic Rating Scale (JRS) Total	5.82 $\pm$ 0.88	4.5 – 7.0
Blepharospasm Disability Index (BSDI) Total	5.41 $\pm$ 4.77	2 – 11

Correlation analysis revealed a Spearman's rho of 0.418 ($p = 0.095$), suggesting a non-significant positive correlation between physician-assessed severity (JRS) and patient-perceived disability (BSDI). (Figure 1)

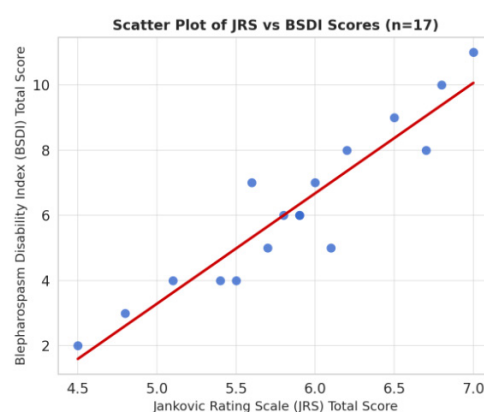


Figure 1. Scatter plot of JRS and BSDI scores

DISCUSSION

In this study a total of 17 patients were assessed. Though females dominated in number (58.8%), it is still low compared to other studies^{3,11} and the mean age of the study population was 56.8 $\pm$ 14.4 years, which is

consistent with previous study³

Main objective of the study was to see the correlation between severity of blepharospasm by patient-rated scale, BSDI and physician rated scale JRI which was moderate ($\rho=0.418$). BSDI mean score was 5.41 ± 4.77 , which indicate mild to moderate functional disability, and the mean JRS score was 5.82 ± 0.88 , which indicates moderate severity. Our Study showed patient rated score to be lesser than physician rated score. Adaption to the condition or access to the effective treatment such as botulinum toxin A injection usually lead to lesser scoring from patients' side but in our study only few cases have received botulinum toxin A. So low scoring could be due to adaptation to the condition or assurance about the disease condition that it is not life threatening or precursor of malignancy or stroke could have caused underestimation and lower scoring by patient. In this regard subgroup analysis would be desirable as females and young patients may overrate their disability.

Study assessing the correlation between patient-rated severity scale and physician severity scale is important because it shows how well the physician has perceived the patients' disability due to this condition. Though both of these scales are widely used rating scale, they only assess the physical problem of patient. This does not assess the psychosocial aspect which is more important. Many patients would frankly tell that the only issue they have with this condition is due to cosmetic reason, nothing more and use hat, glasses or mask to hide their condition. Few patients had history of botulinum toxin A use during festival or wedding season only.

There are many dystonia measuring scales such as Burke-Fahn-Marsden rating scale¹² the Unified Dystonia Rating Scale¹³ and the Global Dystonia Severity Rating Scale¹³ but their drawbacks is that, they measure dystonia of whole body. In this regard BDSI and JRI both seems to be useful scales to measure severity of blepharospasm. Though they themselves are also inadequate to measure patients' overall problem as it measures only physical disability. Blepharospasm is not only disabling, it is disfiguring as well¹⁴. Patient self-rating is important because it will also help to assess effectiveness of medicine¹⁵. Besides few subscales of BDSI may not be

applicable to individual like driving as seen in our studies. As currently we don't have any objective scale to measure the cosmetic and psychosocial distress of blepharospasm, designed for blepharospasm itself, we can probably incorporate other scales such as those designed for anxiety, depression and quality of life scales to understand patients' disability as a whole. Combining these scales together may reflect overall issues and will guide physician to better evaluate and manage patients by individualized therapy and to predict prognosis.

We also documented the types of medication used and its effectiveness. 70% ($n=12$) were using medications. Most of them had used trihexyphenidyl (anticholinergic), Botulinum toxin injection (Botulinum toxin) and Baclofen (Antispasmodic, GABA_B receptor antagonist). Nearly 30 % (29.4%, $n=5$) patients were naïve to medication, the main reason was cost. Few patients were also using antidepressants as blepharospasm causes anxiety and anxiety aggravates blepharospasm although none of them were diagnosed as anxiety disorder per se. Most of our patients belonged to lower or lower middle-class family so botulinum toxin A was unaffordable to them. Besides long duration of disease before presenting to physician also denotes their negligence or constraint for hospital visit as many patients residing in remote area couldn't come or bother to come to hospital for treatment in a timely manner.

Most common co-morbidities were mainly hypertension followed by and type 2 diabetes which closely reflects the overall population-based co-morbidities in our community. Dyslipidaemia was present in 2 patients. None of the other co morbidities were present in any patient.

This study has a few limitations. Sample size was small and it was a single centred, retrospective study. Due to lack of proper or electronic medical record system, documentation of many patients was missing or incomplete especially those collected from neurology outpatient department. This led to underestimation of number of cases and study population for analysis. Assessment scale we used was only for physical discomfort not for emotional and psychological aspect. Subgroup analysis regarding gender based and age-

based analysis was not done. Besides, there were limited similar studies so, comparison with previous studies were limited.

CONCLUSION

Objective measurement is always desirable to measure severity of any disease especially those which is not measured by radiological or by biochemical means. Whether physician perceive disease severity in the same way how patient is perceiving is very important to know as it is the first step in patient management and will help to assess treatment response. Our study shows moderate correlation between patient's self-scored BDSI scaling and physician scored JRS. Even though correlation between patient's and physician scoring was not perfect, it still showed there was some correlation. If large sample size with multicentre study can be performed, probably the correlation seen would be more reliable. In future studies large scale studies with large number of patients and longitudinal follow up are warranted to see the relation and its reliability.

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