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Original Research Article

Assessment of health related quality of life in patients with hemifacial spasm

Pavan Kumar Singh[1]*, Alok Verma[2], Vinay Goyal[3]

[1]Department of Medicine, Neuro Unit, B. R. D. Medical College, Gorakhpur, Uttar Pradesh, India
[2]Department of Medicine, Neuro Unit, G. S. V. M. Medical College, Kanpur, Uttar Pradesh, India
[3]Department of neurology, All India Institute of Medical Sciences, New Delhi, India

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***Correspondence:**
Dr. Pavan Kumar Singh,
E-mail: pavan.singh77@gmail.com

ABSTRACT

Background: There is paucity of literature regarding health related quality of life in hemifacial spasm (HFS) especially from India. Little is known about the clinical and demographic factors associated with poor HRQoL and depression in these patients. This study assessed HRQoL in its global and disease specific aspect by previously validated instruments.
Methods: The study was performed in AIIMS, New Delhi. Subjects with hemifacial spasm as well as age and gender matched healthy controls were enrolled from movement disorder and Botulinum toxin clinic, department of neurology, AIIMS, New Delhi. Uneducated patient, those could not read questionnaires, cases that had associated other neurological or debilitating systemic disorders, secondary/pediatrics dystonias, pregnancy or received botulinum toxin within 6 months or underwent surgical treatment were excluded from the study.
Results: Total 102 hemifacial spasm patients were included for study. There was no significant difference in demographic details between patients with dystonia and respective control. All patients with HFS scored significantly worse in all the eight domains of the SF-36 as compared with age and sex matched control population ($P < 0.001$). Among HFS patients 36.27% have no depression, while 63.73% have depression. Among them 23.53% had mild and 23.5% had moderate to severe depression. All patients with hemifacial spasm scored significantly worse in all the 11 subscales of the NEI-VFQ-25 including general vision, ocular pain, near vision, distance vision, social functioning, mental health, role difficulties, dependency, driving and peripheral vision ($p < 0.001$) while no significant difference ($p = 0.199$) in score was observed in colour vision as compared with age and sex matched control population.
Conclusions: This study clearly demonstrated that patients with hemifacial spasm, suffered from significant impairment in HRQoL as compared to controls. Higher proportion of patients with HFS suffered from moderate to severe depression compared to their control. Patients with HFS had severe impairment of vision related quality of life. This study indicates that psychological counseling of patients, their family members and treatment aiming to treat depression may be a part of comprehensive treatment approach for these patients.

Keywords: BDI, BRS, HFS, HRQoL, NEI-VFQ

INTRODUCTION

Dystonia is defined as a "neurologic syndrome characterized by involuntary, sustained, patterned contractions of opposing muscles, causing twisting and repetitive movement or abnormal postures" may be associated with tremor (dystonia tremor) or myoclonus (myoclonic dystonia).[1] Hemifacial spasm is characterized by irregular, involuntary muscle contraction on one side of the face. This disease takes two forms: typical and

atypical. In typical form, the twitching usually starts in the lower eyelid in orbicularis oculi muscle. As time progresses, it spreads to the whole lid, then to the orbicularis oris muscle around the lips, and buccinators muscle. The reverse process of twitching occurs in atypical hemifacial spasm.

Primary dystonia is one of the most prevalent movement disorders. Worldwide prevalence of focal dystonia varies from 3-732 per 1,00,000 population from various studies.[2-4] In only Indian community based study, crude prevalence rate of focal dystonia is 43.9 per 1,00,000 population.[5] In majority of studies cervical dystonia (CD) and blepharospasm (BSP) are found to be common dystonia accounting for about 75% of cases with primary focal dystonia. Indian study by Das et al, shows that writer's cramp and blepharospasm are the most common focal dystonia.[5]

Very little is known about impact of focal dystonia Hemifascial spasms on quality of life. In most cases life expectancy is not reduced, however it may be responsible for considerable morbidity in terms of pain, low self-esteem, depression, embarrassment and poor social interaction. Health-related QOL (HRQoL) is a multi-dimensional concept that encompasses the subjective assessment of the impact of illness or treatment across the physical, psychological, social and somatic domains of functioning and the well-being.[6]

There is paucity of literature regarding health related quality of life in focal Dystonia especially from India. Little is known about the clinical and demographic factors associated with poor HRQoL and depression in patients with focal dystonia.

There are studies in which there is comparison of quality of life before and after injection botulinum toxin but study evaluating quality of life in focal dystonias (with being treated with botulinum toxin) is less. There is no Indian literature about quality of life in any focal dystonias.

Since most of these focal dystonia have a life time visible chronic disability it is important to identify the factors that influence quality of life in these patients to optimize the goal directed therapy. This study was conducted to assess HRQOL in its global and disease specific aspect by previously validated instruments in patients with hemifacial spasm.

Study questionnaire

After enrollment, demographic and clinical details of cases were noted down in a preset form designed for the study. Each patient filled SF-36 (for HRQoL), BDI (beck depression inventory for depression). Patients of HFS filled NEI-VFQ (for disease specific quality of life). BRS severity scale was filled by investigator during same session.

Global HRQoL

SF-36 R (short form 36) is acceptable, internally consistent, valid and reliable measure of the health status of patients.[7,8] SF-36R a 36 item, self-report generic measure that provides a profile assessment of health - related quality measuring 8 multi-item variables, which includes; physical functioning (PF) 10 items; role limitation due to physical problem (RP, 4 items), bodily pain (BP, 2 items),general perception of health (GH, 5 items), vitality (VT, 4 items), social functioning (SF, 2 items), role limitation due to emotional problem (RE, 3 items) and mental health (MH, 5 items). A score ranging from 0 (worst health) to 100 (best health) is generated for each domain/subscale.

Disease specific quality of life scales

In patients of hemifacial spasm, disease specific quality of life was assessed using the 25-item National eye institute visual function questionnaire (NEI-VFQ-25)9. NEI-VFQ Scale comprises 25 items, which constitute 12 following subscales - general health (GH), general vision (GV), ocular pain (OP), near activities (NV), distance activities (DV), social functioning (SF), Mental health (MH), role difficulties (SR), dependency (Dep), driving (DRV), color vision (CV) and peripheral vision (PV). Scoring of subscales was carried out per standard procedures; for each subscale, scores could theoretically range from 0 to 100, with lower scores indicating more disability.[11]

Hemifacial spasm severity was measured by Blepharospsm rating scale (BRS) which assesses involuntary contraction within 45 items. It contribute to 12 sub scales in terms of localization, occurrence, influencing factors, interfering Factors), frequency, and severity. The number of symptoms is added to a sum score for each domain assessed. Results were rated as minor (<25% of max. score), moderate (<50% of max. score), explict (<75% of max score) or severe symptoms (>75% of max. score).

Statistical analysis

Comparison between all of the variables described earlier for patients vs. control was carried out using t- test and X (chi-square) test for continuous and categorical variables, respectively. Association between SF 36 and NEI-VFQ-25 subscales and variables addressing disease duration, age of onset and severity were evaluated by Pearson correlation coefficients. P values of 0.05 or less (2-sided) were considered statistically significant.

METHODS

The study was performed between January 2007 to July 2008 in All India institute of medical sciences, New Delhi. Subjects with hemifacial spasm as well as age and gender matched healthy controls were enrolled from

movement disorder and botulinum toxin clinic, department of neurology, AIIMS, New Delhi. All the patients aged > 15 years with clinical diagnosis of focal dystonias by movement disorder specialist, were screened for the enrollment in the study.

Uneducated patient, those could not read questionnaires, cases that had associated other neurological or debilitating systemic disorders, secondary / pediatrics dystonias, pregnancy or received botulinum toxin within 6 months or underwent surgical treatment were excluded from the study. Ethical clearance was taken from institutional ethical committee (IEC) of All India institute of medical sciences, New Delhi.

Written informed consent was taken after explaining nature and need of the study. Finally study patients were enrolled after fulfilling the inclusion and exclusion criteria.

RESULTS

Total 102 hemifacial spasm cases along with demographically age sex matched healthy controls were enrolled during period 2007-08. Demographic details of these patients are described in Table 1, 2 and 3. There was no significant difference in demographic details between patients with HFS and respective controls.

HR-QoL in hemifacial spasm

Table 1: Demographic characteristics among patients with hemifacial spasm and controls.

Demographic characteristics	HFS (n = 102)	HFS-control (n = 100)
Age mean (SD) years	44.84(10.98)	46.06 (11.80)
Age groups (%)		
≤20 years	1.96	0
21-39 years	26.47	27
40-49 years	38.23	35
50-59 years	21.57	26
≥ 60 years	11.76	12
Sex (%)		
Male	48.04	54
Female	52.94	46
Education (%)		
≤ 12th standard	40.19	26
Graduate	38.23	59
Post graduate or higher	21.57	15
Marital status (%)		
Married	94.11	93
Unmarried	3.92	7
Employment Status (%)		
Employed	58.82	61
Unemployed	41.18	39)
Age of onset mean, SD	40.14 (10.38)	NA
Age of onset groups, No. (%)		NA
≤20 years	1.96	
21-39 years	41.17	
40-49 years	36.27	
50-59 years	17.64	
≥ 60 years	2.94	
Duration mean, SD	4.76 (3.32)	NA
Duration groups No. (%)		
≤ 2 years	24.50	NA
3-5 years	49.02	
> 5 years	26.47	

QOL Characteristics in focal dystonia

All patients with HFS scored significantly worse in all the eight domains of the SF-36 as compared with age and sex matched control population (P <0.001) (Table 2).

Patients with HFS had significantly worse (mean BDI 17.41±7.88 versus 4.59±3.41; P<0.001) score as compared to patients in control group (Table 2). In HFS group 36.27 % have no depression, while 63.73 % have depression. Among them 23.53 % had mild and 23.5 % had moderate to severe depression (Table 2).

All patients with hemifacial spasm scored significantly worse in all the 11 subscales of the NEI-VFQ-25 including general vision, ocular pain, near vision, distance vision, social functioning, mental health, role difficulties, dependency, driving and peripheral vision (p <0.001) while no significant difference (p = 0.199) in score was observed in colour vision as compared with age and sex matched control population (Table 2).

The mean composite score of NEI-VFQ-25 was 70.50±13.93 which was significantly worse than control population mean score 88.64±10.90 (p <.001) (Table 2).

There was no correlation of any sub scale of SF36 with age, gender, education and marital status of patients (p > 0.1). There was no correlation of SF36 subscales with duration of disease and age at onset (p > 0.1).

BRS had significant negative correlation with all domains of SF-36 (p < 0.05) except social functioning.

In NEI-VFQ only subscale near vision, mental health, dependency, peripheral vision, had significant negative correlation with BRD while other subscale including general vision, ocular pain, distance vision, social functioning, mental health, role difficulties, driving and colour vision no significant difference. BRS also reveal negative correlation with BDI and total composite score of NEIVFQ.

Study found no correlation of disease severity with age, gender, marital status, age at onset or duration of disease, educational and occupational status (p >0.05).

Table 2: QOL characteristics among patients with hfs and HFS - control.

	HFS	HFS-Controls	p value
SF 36 subscale, mean (SD)			
Physical functioning(PF)	69.53 (20.80)	88.47 (10.01)	<0.001
Role physical (RP)	44.53 (43.87)	85.16 (21.87)	<0.001
Bodily pain (BP)	63.03 (20.10)	82.03 (20.09)	<0.001
General health (GH)	48.84 (25.95)	77.34 (16.75)	<0.001
Vitality (VT)	50.63 (23.27)	77.19 (17.26)	<0.001
Social functioning (SF)	60.14 (23.22)	83.11 (16.05)	<0.001
Role emotional (RE)	55.28 (42.82)	82.48 (28.29)	<0.001
Mental health (MH)	54.63 (22.04)	79.84 (15.42)	<0.001
BDI mean (SD)	17.41 (7.88)	4.59 (3.41)	<0.001
BDI groups, %			
1 - 10: Normal	36.27	84	
11-16: Mild mood disturbance	23.53	10	
17 - 20: Borderline depression	16.67	2	
21 - 30: Moderate depression	14.7	3	
31 - 40: Severe depression	8.82	1	
Over 40: Extreme depression	0	0	
NEI-VFQ subscale score, mean (SD)			
General health (GH)	42.40 (21.9)	57.25 (29.79)	<0.001
General vision (GV)	52.40 (26.78)	69.90 (23.36)	<0.001
Ocular pain (OP)	62.79 (24.84)	88.50 (16.06)	<0.001
Near activities (NV)	77.32 (17.15)	91.81 (12.76)	<0.001
Distance activities (DV)	76.09 (18.30)	92.42 (13.25)	<0.001
Social functioning (SF)	79.49 (20.11)	94.50 (13.45)	<0.001
Mental health (MH)	54.14 (25.71)	85.12 (20.94)	<0.001
Role difficulties (SR)	58.18 (27.31)	85.54 (18.94)	<0.001
Dependency (Dep)	67.36 (27.97)	88.83 (15.90)	<0.001
Driving (DRV)	76.41 (17.61)	88.80 (13.38)	<0.001
Color vision (CV)	90.69 (12.15)	93.00 (13.33)	0.199
Peripheral vision (PV)	84.07 (19.52)	96.75 (8.45)	<0.001
NEI-VFQ-25 composite score	70.51 (13.94)	88.64 (10.90)	<0.001
BRS severity scales mean (SD)	10.9 (3.25)		
BRS Groups, %			
Minimal ≤ 25%	0.98		
Moderate 26% - 50%	51.96		
Severe 51- 75%	40.19		
Very severe >75%	6.86		

Table 3: Reviews of studies of HFS.

Author, year	No	Scale used	Comments
Blepharospasm			
Reimer J et al	BS: 31 HFS: 21 Total: 52	SF-36 NEI- VFQ, BDRS	In both patient groups global (both SF-36 Component Summaries) and disease-specific (eight of 12 subscales) HRQL were significantly impaired compared with controls.
Hall TA et al	BS: (n = 159) HFS (n = 91)	NEI- VFQ	No healthy controls. Both groups were compared to each other. Pts with BS showed worse scores than HFS in certain domains of NEI VFQ.

DISCUSSION

This study clearly demonstrates that patients with hemifacial spasm suffered from significant impairment in HRQoL. SF- 36 and its both physical mental domains and sub domains reveal significant impairment as compared to healthy control population. A study by Reimer's et al also found that compared with controls both patient groups suffered from statistically significant impaired global HRQL (SF-36) in role physical, general health, vitality and mental health domains ($p<0.05$).[10] This indicates that these dystonias affect a person's physical life as well as social and mental state. This could be because of facial disfigurement and feeling of attracting others attention.

Higher proportion of patients with HFS suffered from moderate to severe depression compared to their control which was statistically significant. In our study patients with hemifacial spasm their vision related quality of life (as measured by NEI-VFQ) is found to be far more affected than the general population. This difference was in all subscale of NEIVFQ except colour vision. While another study conducted by tyler Andrew et al reveal lower scores certain domains of NEI VFQ.

General health and general vision was a particularly most significantly affected subscale, with an average score of 42.4 and 52.4. Psychological and social burden of this disease is noteworthy, with the vision-specific domain scores of peripheral, colour vision and social functioning having among the least affected subscale with t average scores 84.02, 90.59 and 79.49 respectively. This is clearly showing that functional blindness is the key factor which affects everyday performance abilities from the patient's perspective in these patients. This study indicates that psychological counseling of patients, their family members and treatment aiming to treat depression may be a part of comprehensive treatment approach for these patients.[12]

CONCLUSION

The present study's results regarding HRQoL in its global and disease specific aspect provides further evidence for profound impact of above mentioned dystonias on physical, psychological & social aspect of quality of life. Treatment effect should also improve quality of life of patients which is found lacking in several treatment trials of botulinum toxin13 indicating requirement of much more broad and comprehensive approach.

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Ethical approval: The study was approved by the institutional ethics committee

REFERENCES

1. Jankovic J, Tolosa E. Parkinson's disease and movement disorders: 5th edition, edited by Jankovic J; 2007:321-347.
2. Nutt JG, Muenter MD, Aronson A. Epidemiology of focal and generalized dystonias in Rochester, Minnesota. Mov Dis. 1988;3:188-94.
3. Khanh DL, Beate N. The prevalence of primary dystonia in general community. Neurology 2003;61:1294-6.
4. The ESDE Colaborative group. A prevalence study of primary dystonia in eight European countries. J Neurol. 2000;247:77-92.
5. Das SK, Tapas KB. Community survey of primary dystonia in the city of Kolkata, India. Movement Disorders. 2007;14:2031-6.
6. Revicki DA, Osoba D, Fairclough D. Recommendation on health related quality of life research to support labelling and promotional claims in United States. Quality Life Res. 2000;9:887-900.
7. Ware JE, Kosinski M, Gandek. The factor structure of the SF-36 health survey in 10 countries: result from the IQOLA project. International study of life assessment. J Clin Epidemiol. 1998;51:1159-65.
8. Ware JE, Sherbourne CD. The 36 item short form (SF 36): Conceptual framework and item selection. Medcarel. 1992;30:473-83.
9. Mangione CM, Lee PP, Gutierrez PR. Development of the 25-item National Eye Institute Visual Function Questionnaire. Arch Ophthalmol. 2001;119:1050-8.
10. Impact of cervical dystonia on quality of life. Mov Disord. 2002;17(4).
11. Reimer J, Gilg K, Karow A, Esser J, Franke GH. Health related quality of life in blepharospasm or hemifacial spasm. Acta Neurol Scand. 2005;111:64-70.
12. Scheidt CE, Schuller B, Rayki O, Kommerell G, Deuschl G. Relative absence of psychopathology in benign essential blepharospasm and hemifacial spasm. Neurology. I996;47:43-5.
13. Costa J, Espírito-Santo C, Borges A, Botulinum toxin type a therapy for hemifacial spasm. Cochrane Database of Systematic Reviews. 2005;(1):2005.

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