

Vision related quality-of-life among patients with traumatic or non-traumatic ocular disease and its association with the Rights of Persons with Disabilities Act: Unveiling-the-hidden

Nitin Vichare, Kumar Pushkar¹, Mohini Agrawal, Imroz Jindal²

Purpose: To assess vision-related quality of life (VrQoL) in cases with visual loss after ocular trauma (OT) or non-traumatic ocular disease (NTOD) using the National Eye Institute's 25-Item Visual Function Questionnaire 25 (VFQ-25) and its association with visual disability % (VD%) based on the Rights of Persons with Disabilities (RPwD) Act, 2016. **Methods:** This was a prospective observational study conducted among cases with ocular morbidity in either or both eyes with a visual acuity of $\leq 6/24$. VFQ-25 questionnaire was administered to measure QoL scores. Statistical analysis was done using the Statistical Package for the Social Sciences (SPSS) version 23. $P < 0.05$ was taken as significant. **Results:** Eighty-eight respondents completed the questionnaire. Mean age of participants was 40.272 ± 9.35 years (range: 23–55 years). Forty-three (48.9%) and 45 (51.1%) participants had OT and NTOD, respectively. The most common cause was traumatic optic neuropathy (21.6%) followed by corneal causes (19.4%). Low visual QoL scores were reported in all the cases (57.52 ± 16.08). Between OT and NTOD, a significant difference in terms of age ($P = 0.001$) and general vision ($P = 0.03$) was seen. Lowest scores were for driving. Based on VD%, 77 cases had ≤ 40 and the rest had $>40\%$ VD with a significant difference in overall mean scores ($P = 0.03$), specifically in domains of general vision ($P = 0.00$), near activities ($P = 0.00$), and driving ($P = 0.007$). QoL was decreased in each subscale of $\leq 40\%$ VD group, who faced the same predicament everywhere as by the cases with more disability. **Conclusion:** Ocular morbidity is associated with low QoL, predominantly in domains like general vision, near activities and driving. The RPwD Act leaves out a huge population with VD without any government benefits. One might need to consider other vision-related factors also to provide them with social, psychological, and employment benefits.

Key words: Ocular disease, ocular trauma, quality of life, RPwD act, VFQ25 questionnaire, visual disability

Ocular diseases are an imperative cause of visual loss and morbidity among the young population. Be it traumatic or non-traumatic ocular disease, it affects day-to-day visual functioning. Ocular trauma (OT) accounts for 1.37% of overall blindness.^[1,2] Its causes include workplace-related injuries, domestic injuries, road-traffic accidents, and sports injuries.^[2] Various chronic non-traumatic ocular diseases (NTOD) like glaucoma, keratoconus, macular hole, and diabetic retinopathy are also not uncommon in young population and affect their quality of life to a greater extent.^[3,4]

Vision-related quality of life (VrQoL) is a measure of influence of visual disability (VD) and visual symptoms on various generic health domains like emotional well-being, mental health, and social functioning, in addition to task-oriented domains related to daily visual functioning.^[4,5] For this, the National Eye Institute's 25-item Visual Function Questionnaire-25 (NEI VFQ-25) was designed to measure factors of VrQoL which are significant to patients with ocular morbidity.^[5,6] Indian literature lacks in reporting how this VD affects VrQoL.

Moreover, in India, the VD% of 40% or more is considered significant and eligible for monetary or government benefits to those who have a best-corrected visual acuity (BCVA) of 6/24 or worse in both the eyes based on the Rights of Persons with Disabilities (RPwD) Act, 2016.^[7] While assessing this percentage, BCVA is the only single factor in consideration, whereas decreased vision-related factors such as ocular pain, inability to participate in sports, social well-being, dependency on others, being unable to drive, difficulty in performing near activities, mental stress, and loss of jobs are not considered.

Thus, this is a novel study which evaluates VrQoL using a standard VFQ-25 in young Indians who suffer vision loss due to OT or NTOD. It also aims to measure outcomes of VrQoL after stratification based on VD% provided by the RPwD Act.

Department of Ophthalmology, Command Hospital, ¹Department of Community Medicine, Command Hospital, ²Department of Orthopaedics, Armed Forces Medical College, Pune, India

Correspondence to: Dr. Mohini Agrawal, Department of Ophthalmology, Command Hospital, Pune - 411 040, Maharashtra, India. E-mail: mohiniiafmc.15@gmail.com

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		Left Eye Vision [Best Corrected Visual Acuity (BCVA)]							
		6/6 to 6/18	6/24	6/36	6/60	3/60	2/60	1/60	HMCF to PL-
Right Eye Vision [Best Corrected Visual Acuity (BCVA)]	6/6 to 6/18	0%	10%	10%	10%	20%	30%	30%	30%
	6/24	10%	40%	40%	40%	50%	60%	60%	60%
	6/36	10%	40%	40%	40%	50%	60%	60%	60%
	6/60	10%	40%	40%	40%	50%	60%	60%	60%
	3/60	20%	50%	50%	50%	70%	80%	80%	80%
	2/60	30%	60%	60%	60%	80%	90%	90%	90%
	1/60	30%	60%	60%	60%	80%	90%	90%	90%
	HMCF to PL-	30%	60%	60%	60%	80%	90%	90%	100%

• Yellow- Right eye is Better eye Brown- Left eye is better eye
 • Percent disability is marked inside the box corresponding to the visual acuity for both eyes

Figure 1: Matrix table recognized under the RPwD Act, 2016, to provide visual disability percentage to individuals with ocular morbidity

Methods

This cross-sectional study was conducted at a tertiary eye care center from January 2021 to January 2022. It was approved by the Institutional Ethics Committee vide Ethical committee number 05/04/AUG/CHWC/2020 dated 04 August 2020.

This study included participants between 20 and 55 years of age, who had OT or NTOD in either or both eyes with vision loss decreased to 6/24 or below and had been stable for the last 6 months.

Cases with any associated significant head or limb trauma that may have caused restriction on independent mobility leading to an adverse impact on QoL and who were unwilling or unable to undergo vision testing due to mental or physical conditions were excluded from the study.

Questionnaire

All the cases underwent baseline ocular examination and were then administered the standardized NEI VFQ-25 for data collection.^{15,61} It is a well-established interviewer-administered survey tool that was developed to assess the effect of eye disorders on a patient's VrQoL.

It contains a base set of 25 vision-targeted questions representing 11 vision-related subscales, along with an additional single-item general health-related question. The 12 dimensions of VrQoL are general health, general vision, ocular

pain, near activities, distance activities, vision-specific social functioning, vision-specific mental health, vision-specific role difficulties, vision-specific dependency, driving, color vision, and peripheral vision.

The questionnaire is scored on a scale of 0 to 100 in accordance with the VFQ-25 scoring algorithm with a score of 100 indicating the best VrQoL. After this, items within each subscale are averaged together to create 12 subscale scores. Scores represent the average for all items in the subscale that the participant answered. Lastly, it needs to calculate an overall mean score (or composite score) for the VFQ-25 after taking the average of the vision-targeted subscale scores, excluding the general health domain. By averaging the subscale scores rather than the individual items, it gives equal weight to each subscale.

The RPwD Act, 2016⁶⁷

Based on the RPwD Act, 2016, a "person with disability" means a person with long-term physical, mental, intellectual, or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others. The government of India uses the term "benchmark disability" quite often in the official communications regarding persons with disabilities. Often, we come across a question like "are you a person with benchmark disability?" In India, under the RPwD Act, low vision is considered to be a disability. A person having benchmark disability can avail disability benefits from the government.

Benchmark disability refers to having at least 40% disability of any type recognized under the RPwD Act, 2016 [Fig. 1]. Thus to be in this category, a person has to have at least 40% disability mentioned on their disability certificate or Unique Disability ID Card (UDID Card) to gain government benefits.

Data collection

The data collection was done by a single interviewer who administered the questionnaire. After written informed consent was obtained, all the participants were asked to provide the best-suited response for each question as per the survey format. The response obtained was converted into a raw score as per the scoring key provided. An overall composite score was calculated for all the cases and also separately for both the groups (OT and NTOD) as an average of all subscales, excluding the general health subscale. Scores of each subscale were also analyzed after stratification based on VD% grouped as $\leq 40\%$ and $>40\%$.

Table 1: Mean scores of each subscale and overall mean scores of VFQ-25 among all participants

Subscale	n=88	
	Mean	SD
General health	51.99	27.65
General vision	51.65	19.34
Ocular pain	71.16	19.99
Near activities	59.50	23.22
Distance activities	50.84	22.07
Social functioning	70.43	22.47
Mental health	53.06	24.45
Role difficulties	49.15	25.41
Dependency	71.58	25.95
Driving	22.71	23.21
Color vision	88.29	13.62
Peripheral vision	44.32	25.63
Overall mean score	57.52	16.08

Statistical analysis

Data was entered in a Microsoft Excel sheet. Double entry and accuracy of the entered data was rechecked, and appropriate corrections were made. The Statistical Package for the Social Sciences (SPSS) version 23 was used for data analysis. Categorical variables were presented as number (*n*) and percentage (%). Continuous variables were calculated as mean \pm standard deviation (mean \pm SD). The QoL scores were expressed as mean \pm SD. Independent sample *t*-test was used to see the difference between the groups. $P < 0.05$ was considered statistically significant.

Results

A total of 88 participants were enrolled in the study. Mean age of presentation was 40.72 ± 9.35 years (range: 23–55 years). Maximum cases (43 cases; 48.7%) belonged to the age group of 31–40 years. The most common cause of ocular morbidity was traumatic optic neuropathy (19 cases, 21.6%) followed by corneal causes like keratoconus, failed graft, and healed keratitis (17 cases, 19.4%).

Of the 88 cases, 43 (48.9%) had vision loss due to OT and the rest (45 cases; 51.1%) had NTOD. Various causes included choroidal rupture (4 cases), operated case for retinal detachment (4 cases), choroidal neovascular membrane scar (6 cases), glaucoma (12 cases), compressive optic neuropathy (7 cases), macular hole (1 case), perforating injury with enucleation and prosthesis *in situ* (6 cases), retinitis pigmentosa (1 case), and others (11 cases).

Of the 88 cases, 30 (34.1%) had BCVA of 6/24 to 3/60 in the worst eye; more than 50% of cases had 3/60 to perception-of-light (PL) negative (59.1%); and 6 had enucleated eyes (6.8%). In the better eye, 77 cases had BCVA of 6/6 and the remaining 11 cases had vision of 6/24 to 3/60. All the OT cases had monocular involvement, whereas in NTOD group 12 cases had bilateral disease.

The overall mean QoL score of all the cases was 57.52 ± 16.08 , depicting low QoL. The mean scores of each subscale are stated in Table 1, depicting minimum scores of 22.71 for driving to maximum of 88.29 for color vision. Low scores were related to

Table 2: Analysis of each subscale and overall mean scores between cases with ocular trauma and non-traumatic ocular disease

Subscale	Ocular Trauma (n=43) Mean (SD)	Ocular Disease (n=45) Mean (SD)	t	P
General health	56.39 (21.89)	47.78 (31.90)	-1.47	0.15
General vision	56.16 (15.73)	47.33 (21.55)	-2.19	0.03*
Ocular pain	67.15 (21.48)	74.99 (17.87)	1.86	0.07
Near activities	61.48 (21.14)	57.61 (25.15)	-0.78	0.44
Distance activities	54.44 (20.27)	47.39 (23.36)	-1.51	0.14
Social functioning	68.89 (22.05)	71.89 (23.01)	0.62	0.54
Mental health	51.49 (24.09)	54.56 (24.97)	0.59	0.56
Role difficulties	45.64 (24.83)	52.50 (25.78)	1.27	0.21
Dependency	73.44 (25.02)	69.80 (26.97)	-0.66	0.51
Driving	21.50 (22.57)	23.87 (24.01)	0.48	0.64
Color vision	87.09 (14.77)	89.44 (12.49)	0.81	0.42
Peripheral vision	41.28 (23.71)	47.22 (27.29)	1.09	0.28
Overall mean score	57.14 \pm 15.67	57.87 \pm 16.64	0.21	0.83

Test used was independent sample *t*-test; **P* was significant

Table 3: Distribution of cases and their overall mean scores based on visual disability percentage

Ocular Morbidity	Visual Disability (%)			
	10-20 (n=20)	20-30 (n=57)	30-40 (n=0)	>40 (n=11)
Ocular disease (NTOD)	4	30	0	11
Ocular trauma (OT)	16	27	0	0
Overall mean score	61.42	58.05	0	47.65

Table 4: Cross tabulation of each subscale and overall mean scores with cases stratified based on visual disability percentage under the RPwD Act, 2016

Subscale	Visual disability% Mean (SD)			
	≤40% (n=77)	>40% (n=11)	t	P*
General health	57.14 (23.59)	15.91 (28.00)	5.29	0.000*
General vision	54.87 (18.15)	29.09 (10.44)	4.56	0.000*
Ocular pain	70.61 (20.75)	75.00 (13.69)	-0.68	0.499
Near activities	63.68 (21.55)	30.28 (9.33)	5.05	0.000*
Distance activities	52.36 (22.86)	40.16 (11.07)	1.74	0.086
Social functioning	70.62 (22.92)	69.09 (19.95)	0.21	0.835
Mental health	52.54 (25.59)	56.74 (14.33)	-5.31	0.597
Role difficulties	50.49 (25.52)	39.77 (23.59)	1.31	0.193
Dependency	72.82 (25.52)	62.85 (28.48)	1.19	0.235
Driving	25.20 (23.72)	5.28 (5.59)	2.76	0.007*
Color vision	89.22 (13.69)	81.82 (11.68)	1.07	0.092
Peripheral vision	45.78 (26.72)	34.09 (12.61)	1.42	0.158
Overall mean score	58.93 (16.48)	47.65 (8.00)	2.22	0.029*

Test used was independent sample t-test; *P was significant

general vision, distant activities, mental health, role difficulties, driving, and peripheral vision subscales (scores <55).

The analysis of each subscale among the cases in the OT and NTOD groups revealed that the subscale scores were more decreased in traumatic cases as compared to cases with NTOD in domains like ocular pain, social functioning, mental health, role difficulties, driving, color vision, and peripheral vision as listed in Table 2. The difference was not statistically significant between the subscale score in both the groups except for the domain of general vision ($P = 0.03$). However, the overall mean score was low in both the groups.

On analyzing the distribution based on VD% from the RPwD Act, it was found that in this study maximum cases belonged to the group of ≤40% VD (77 cases, 87.5%) and 11 cases (12.5%) had >40 VD% [Table 3]. Of those 77 cases, 34 cases from NTOD group and 43 cases from OT group had VD% of ≤40%. None of the cases in the OT group had >40% VD in view of monocular involvement.

It was found that the overall mean score was low in both the VD groups (≤40% and >40 VD%) and the difference was statistically significant ($P = 0.029$). The VFQ-25 mean scores were lower in each subscale in the group with more VD% (>40%), except those for ocular pain and mental health. The lowest scores were found for driving domain in both the groups with a statistically significant difference between the

two ($P = 0.007$). All the mean scores of these two groups are depicted in Table 4.

Discussion

Vision-related QoL is an unrecognized public health problem primarily in the young working population of a developing country like India. Usually, BCVA alone is considered as an ocular disability parameter; however, it works poorly in explaining various other domains of visual function. To date, VrQoL has been evaluated in various ocular morbidity conditions, but our study differs in many aspects from previous studies which have reported low QoL.^[8-12] The difference might lie in the case selection, inclusion criteria, different study population, or type of questionnaire.

QoL was negatively affected in cases with open globe injuries as reported by Schrader *et al.*^[11] Yet, in that study they did not report the use of any questionnaire. In another study, most cases had difficulties in domains like ocular pain and daily activities. But they involved patients shortly after the injury. On the other hand, our study had an inclusion period of 6 months after the trauma, as mitigation of pain, adjustment to injury outcome, and treatment may recover QoL over time.^[13]

Indian studies done on OT are mainly based on epidemiology or pattern rather than QoL.^[14-21] In support of our study, we could find only one Indian study by Sharma *et al.*^[22] that reported low QoL following orbito-facial trauma along with disturbing physical, mental, and social health, reflecting the grim impact the trauma has on the QoL.

Even for cases with NTOD, the overall mean score for reported QoL was low, like in glaucoma (88 ± 12), age-related macular degeneration (88 ± 10), dry-eye disease in Sjögren's syndrome (84 ± 20), after surgery for retinal detachment (80 ± 15), cataract (76 ± 21), and keratoconus (75 ± 17).^[23-28] This difference in QoL might be in view of a different study population, varied sample size and severity, and duration of disease. As with time, cases may be accustomed to their visual acuity and vision-dependent functioning providing improved QoL.

This study provides an insight into these individuals where their day-to-day activities are being affected, besides general vision. Though the majority of them were able to manage themselves and not dependent on others in view of monocular involvement and good vision (6/6) in the fellow eye—this included patients with enucleated globe as well—their overall QoL deteriorated at various domains. This underlines the uneven social burden of ocular morbidity. Furthermore, this points to the understanding that BCVA should not be the only factor to correlate an individual's perceptions with their ocular disease.

The disability scheme in India like the RPwD Act, 2016, is a tower of strength for patients with ocular morbidity, where it promotes and protects the rights and dignity of people with disabilities in various aspects of life like educational, social, legal, economic, cultural, and psychological. To be in this category, a person has to have at least 40% disability mentioned on their disability certificate or Unique Disability ID Card (UDID Card). There is the other side of the coin too: This leaves out a lot of people with ocular morbidity when the percentage is not 40% or above.

Like in our study, the overall QoL decreased but because all the OT cases had monocular involvement and good vision in fellow eye (6/6), they were not considered for any of the government benefits. The story is no different for cases with monocular NTOD. Only cases with BCVA <6/24 or less in both the eyes receive the benefits [Fig. 1]. The scores were low in domains such as ocular pain, social functioning, mental health, role difficulties, color vision, driving, and peripheral vision.

When stratified based on VD%, analysis showed that overall mean score was low in both the VD% groups ($\leq 40\%$ and $>40\%$). The VFQ-25 mean scores were lower in each subscale in the group with more VD% ($>40\%$), except those for ocular pain and mental health. This big impact on mental health might be due to the relaxation with government benefits to patients with $>40\%$ VD in the form of employment help and monetary help, which is not provided in any form to patients with $\leq 40\%$ VD and who face the same predicament everywhere. This provides an anecdotal picture of the current situation in a developing country like India where a majority of people with disabilities in their working age are unemployed.

While the lowest scores were found for the driving subscale in both the VD% groups, many patients still did not give up driving even though problems with distance judgement, depth perception, and peripheral vision persisted. Patients with monocular involvement continued to drive depending on their better seeing eye; a few had given up driving despite having good vision in the fellow eye as a result of inability to fully adapt to monocular visual loss and patients with binocular disease tried to avoid driving in view of decreased vision.

The cases in $\leq 40\%$ VD group are being neglected in our society and need a wider vision to improve their QoL. These cases face a similar plight as cases in VD $>40\%$ group because of decreased social well-being, difficulty in near and distant activities, difficulty in driving affecting their movement, difficulty in getting jobs, and no consideration in monetary/emotional or mental support. This needs to be revolutionized and a multidisciplinary approach needs to be adopted along with a rehabilitation team involving social workers and psychologists which will be of utmost value. They can support patients in various daily living activities by arranging jobs and providing psychological and social care.

To the best of our knowledge, this is the first study to report VrQoL in patients with ocular trauma and non-traumatic ocular disease using a validated VFQ-25 in the young Indian population. Our study supports the fact that vision alone is a poor indicator of visual function. This study will help sensitize ophthalmologists and other physicians toward people with VD (moreover, toward those with low vision and no monetary benefits), which to a large extent are being neglected in our society. This will allow them to formulate a more realistic prediction of their situation and raise their VrQoL.

This study will definitely change the way of thinking and the way of treating an individual with low vision and provide them with better support wherever possible. This study also measured outcomes of VrQoL after stratification done based on VD%. It studied association of QoL with VD% provided to an individual based on the RPwD Act, 2016. Further studies with a larger sample size and analysis with other health disorders

in a patient with VD will further facilitate our understanding regarding VrQoL.

Conclusion

Ocular morbidity in the young Indian population is associated with low visual quality of life. They have physical, emotional, and social impairment. The VD%, based on the RPwD Act of 2016, partially commensurate with the vision-related QoL in the young population with ocular morbidity. This Act leaves out a lot of people who have an ocular disability but the percentage is not above 40. One might need to consider other vision-related health factors (apart from visual acuity alone), which affects an individual's QoL on a daily basis to provide them with social, psychological, and employment benefits accordingly.

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Conflicts of interest

There are no conflicts of interest.

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