Original Article

Assessment of psychosocial impact of primary glaucoma and its effect on quality of life of patients in Western India

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Purpose: To assess the impact of primary glaucoma of varying severity and duration on psychosocial functioning and quality of life of patients. **Methods:** A cross-sectional observational study was carried on 200 patients attending the glaucoma clinic of a tertiary care hospital in western India. After obtaining approval from the institutional ethics committee, written informed consent was taken. All patients underwent a thorough ophthalmic examination. Those with primary glaucoma were classified as per Hodapp–Parrish–Anderson criteria and asked to respond to the National Eye Institute Visual Function Questionnaire (NEIVFQ)-25 questionnaire. Responses were analyzed statistically. **Results**: Overall mean NEIVFQ 25 composite score was 74.4 ± 18.6. Mean scores were 87.0 (SD 7.2) for mild, 75.9 (SD 8.1) for moderate, and 47.0 (SD 13.7) for severe glaucoma groups. Lower scores were associated with males. Driving (62.2, SD 34.6) and ocular pain (63.5, SD 18.7) were maximally affected while color vision (90.1, SD 18.7) and social health (86.7, SD 20.1) were least affected. The duration of treatment had no effect on mean composite scores with impaired scores seen even in newly diagnosed cases. Age of the patient negatively correlated with NEIVFQ 25 composite score. **Conclusion**: With disease progression, the psychosocial functioning of the patients is negatively affected. This effect is irrespective of treatment duration and newly diagnosed cases can have impaired Quality of life scores. Quantification of psychosocial status along with education and counseling for all patients may play a definitive role in customizing treatment and providing patients with a better quality of Life.

Key words: Glaucoma, National Eye Institute Visual Function Questionnaire-25 (NEIVFQ-25), quality of life

Glaucoma is one of the leading causes of irreversible blindness worldwide, affecting more than 60 million people globally and 12 million people in India alone.[1-4] The number of patients with glaucoma is expected to rise to 79.6 million by the end of this decade.[4] Unfortunately due to the silent progression of disease, at the time of the first presentation, many patients have significant irreversible visual field deterioration.

World health organization (WHO) has defined quality of life (QoL) as an individual's perspective of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.[5] Impairment of QoL in glaucoma may be attributed to visual disability and psychosocial factors such as lack of awareness about the disease as well as knowledge of having a potentially blinding condition. Studies have reported negative emotions in 80 percent of subjects diagnosed with early glaucoma that reduced with proper awareness about the disease.[6] Additional factors such as long term medications, adverse effects of medications, long-term follow up, and increased financial burden may further aggravate the problem.

Various tools or questionnaires are available for quantification of the quality of life. National institute visual function questionnaires are considered to be comparative benchmarks against which all the new glaucoma specific tools are compared.[7] The NEIVFQ-25 is a vision- specific, 25-item self-administered questionnaire measuring 12 QoL related subscales covering various aspects such as general health, visual function, psychosocial health, and dependency. The mean of eleven of the twelve subscales gives a composite quality of life score.

In the coming years, the number of persons with glaucoma is expected to rise, and therefore, the quantification of quality of life and psychosocial impairment is mandatory to customize treatment options and providing patients with a decent quality of life. Data from studies done in other parts of the world may not be applicable to Indian population.[8,9] Also, studies done in one part of a country, as diverse as India may yield different results when performed in other parts due to cultural differences as well as disparity in the health services and awareness. Hence, this study was planned and conducted in view of assessing the psychosocial impact of glaucoma on the quality of life of patients in western India.

Methods

A cross-sectional observational study was conducted at a tertiary care eye hospital in Pune, India, after obtaining clearance from the institute ethics committee. All newly diagnosed and review patients with primary glaucoma, attending the glaucoma outpatient department between December 2017 and November 2018 were explained in detail about the study and the procedure. Informed written consent was obtained from those patients who were willing

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to participate. A detailed history including personal history, family history, and history of treatment for glaucoma was obtained. All patients underwent a thorough examination by a trained glaucoma specialist, including slit-lamp examination, Goldman applanation tonometry, gonioscopy, pachymetry, dilated fundus examination with + 90 D biomicroscopy, and standard automated perimetry.

Exclusion criteria included patients with secondary glaucoma, age less than 25 or more than 80 years and those with other ocular comorbidities significantly affecting visual function. Those with a refractive error of more than 5 D or astigmatism of more than 2.5 D were also excluded. Patients with primary glaucoma were classified into mild, moderate, and severe using Hodapp–Parrish–Anderson criteria.[10,11] The mean deviation (MD) of the better eye was taken into consideration for classifying patients, as better eye determines the degree of visual impairment when viewing binocularly. Patients were also categorized on the basis of treatment duration in to 3 groups. Group 1 had patients with treatment duration of less than 12 months. Group 2 consisted of patients with treatment duration of more than 12 months but less than 3 years. Patients with treatment duration of more than 3 years were categorized in Group 3.

All the patients included in the study were explained about the NEIVFQ-25 questionnaire. The subjects were requested to answer the questionnaire by themselves. Trained health care staff provided assistance when required. For participants who were unable to read due to poor eyesight, a research staff member read the questionnaire to them in a neutral and uniform manner and recorded their choices. Scoring was done for each question according to the guidelines mentioned in the manual available with the NEIVFQ-25 questionnaire. The data obtained from the NEIVFQ-25 questionnaire was recorded and analyzed statistically using SPSS Statistics for Windows, Version 21.0. (Armonk, NY: IBM Corp). Tukey's honestly significant difference test was used for multiple comparisons.[12]

Results

A total of 200 patients participated in the study, out of which 113 were males and 87 were females. The mean age of the study group was 59.2 (SD 12.6) years. A total of 148 patients were diagnosed as primary open-angle glaucoma while the remaining 52 were diagnosed as primary angle-closure glaucoma. The mean NEIVFQ-25 composite score for the study group was 74.4 (SD 18.60). Females (77.6) were found to have significantly better NEIVFQ composite scores than males (71.9). Based on Hodapp–Parrish–Anderson criteria, 97 patients were classified as mild glaucoma, 55 as moderate, and remaining 48 as severe glaucoma. The mean scores for all the twelve subscales measured in NEIVFQ-25 are shown in Table 1.

Color vision and social functioning were found to have better scores while the lowest scores were associated with driving and ocular pain and discomfort. The mean difference among the NEIVFQ-25 composite scores of the three groups was found to be statistically significant [Table 2]. The comparison of the composite scores for the three treatment duration groups is shown in Table 3. There was no significant difference between the mean composite scores and the duration of treatment among the three groups on statistical analysis.

Mean mental health subscale scores were 81.8 for mild disease, 71.9 for moderate disease, and 40.9 for severe glaucoma. However, no statistically significant difference was observed in the mental health scores with respect to treatment duration. The age of the patient was negatively correlated with NEIVFQ composite scores [r= -0.14 at $P < 0.05$, Fig. 1].

Discussion

Although the progression of disease can be decelerated therapeutically, factors such as lifelong treatment and psychological fear of blindness add to patients' woes. All of the above factors contribute to treatment noncompliance in patients.[13] Due to these reasons, studies have been undertaken in the recent decades to quantitatively measure the impact of glaucoma and its treatment on the quality of life of patients. These have helped in providing an estimate of the magnitude of functional and psychological impairment of patients. However, the study data pertaining to the Indian population is limited.

In this study, there was male preponderance in the sample with males constituting 56.5% of the sample size. Although the gender difference was not found to be significant, our data was demographically similar to a few similar studies done previously. In a study done by Kumar *et al.*, males constituted 63% of the total sample size with mean age of 62.15 years.[14] Study by Kong *et al.* on Chinese population had males comprising 53% of the study sample with a mean age of 56.46 years.[8]

The effect of glaucoma on Quality of life can be demonstrated by the lowering of NEIVFQ-25 composite scores. In our study, the mean composite score was 74.40 (SD 18.60), which was better in comparison to study done by Kong *et al.* in China (70.6, SD 15.4) but worse than that observed by Sawada *et al.* in Japan (78.3) and Onakoya *et al.* in Nigeria (85.2, SD 16.07), as documented in the literature.[8,9,15] As the disease progresses, visual functions deteriorate, patients find it more and more difficult to carry out basic activities like driving, reading, and socializing. This in turn impairs psychological thinking and self-confidence leading to poorer quality of life scores. These findings were observed in our study, as well as similar studies done previously in various

Table 1: Comparison of NEIVFQ 25 subscale scores amongst varying degrees of disease severity

NEIVFQ subscale	Population mean	Mild (*n*=97)	Moderate (*n*=55)	Severe (*n*=48)	*P*
General Health	63.8±26	73.2	62	47.0	<0.001
General vision	68.1±21.0	78.2	68.9	46.6	<0.001
Ocular pain	63.5±18.7	71.5	62.3	48.8	<0.001
Near Vision	74.9±21.5	86.7	76.4	49.3	<0.001
Distance vision	75.1±22.3	88.3	74.5	49.1	<0.001
Social functioning	86.7±20.1	96.4	92.6	59.9	<0.001
Mental health	69.2±21.9	81.8	71.9	40.7	<0.001
Role difficulty	68.1±26.3	84.4	66.7	36.8	<0.001
Dependency	81.5±26.4	95.4	89.1	44.8	<0.001
Driving	62.2±34.6	84.6	66	12.8	<0.001
Peripheral vision	73.3±25.2	90.8	67	45.4	<0.001
Colour vision	90.1±18.6	98.4	95.4	90.0	<0.001

Table 2: Comparison of mean NEIVFQ 25 scores with respect to disease severity

	n	Mean	Standard deviation	95% confidence Interval for Mean	
				Lower Bound	Upper Bound
Composite score					
Mild	97	87.0*	7.2	85.5	88.4
Moderate	55	75.9*	8.1	73.7	78.2
Severe	48	47.0*	13.7	43.1	51.0

*The difference was statistically significant at $P<0.001$

Table 3: Comparison of NEIVFQ 25 composite scores with duration of treatment

	n	Mean	Standard deviation	95% Confidence Interval for Mean	
				Lower Bound	Upper Bound
Composite score					
Group 1	67	78.22	17.5	74.02	82.42
Group 2	49	69.36	20.4	63.52	75.22
Group 3	84	74.31	17.81	70.43	78.19

Differences were not significant on multiple analyses. ($P>0.05$). *Group 1: Treatment duration for <12 months duration. *Group 2: Treatment duration for more than 12 months but <36 months. *Group 3: Treatment duration for more than or equal to 36 months

Figure 1: Scatter plot showing correlation between age and NEIVFQ composite scores

countries.[8,9,14] Using NEVFQ-25, we were able to identify and differentiate between mild, moderate, and severe cases ($P<0.01$), as confirmed by multiple comparison analysis.

Females were observed to have a significantly better quality of life scores than males, despite early to moderate field defects, which was similar to observations by Onakoya *et al*. in the Nigerian population.[15] In our opinion, females having better scores can be possibly attributed to the sociocultural and work practices prevalent in developing and underdeveloped societies. In our study, the majority of the female participants were involved in household chores, which would probably be less affected by attributes such as reduced contrast sensitivity, dark adaptation, and peripheral field defects.

Age is another factor that can affect the daily activities and psychological thinking of an individual. Elderly patients are more prone to impairment of quality of life scores due to various causes that include increased dependency, social insecurity, and fear due to the risk of falling.[16,17] In this study we tried to find any association between the age of the patient and the mean NEIVFQ scores, and found a small but statistically significant negative correlation (r= -0.14). It implies that younger patients had a slightly better quality of life scores than elderly patients. This finding is in accordance with the fact that elderly patients tend to score lower in all daily activity functions and are more prone to develop depression.[18,19]

We also analyzed the effect of treatment duration on quality of life — if longer treatment duration had any significant impact on patients QoL, irrespective of disease severity. On multiple comparisons, using the Tukey honestly significant difference test, we found the overall difference between the groups to be statistically insignificant. Literature has documented that many patients develop negative emotions such as anxiety and depression on mere knowing the diagnosis of glaucoma.[20]
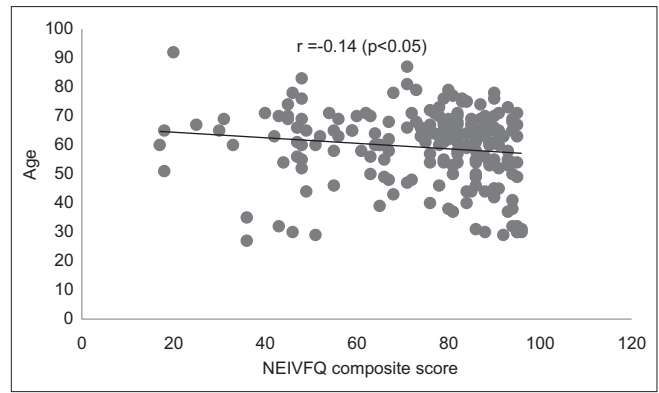
Odberg *et al*., in their study, reported that 80% of subjects reported negative emotions on just learning the diagnosis with almost one third having the fear of going blind.[6] This psychological fear is caused by the lack of awareness about glaucoma and its management options. Collaborative glaucoma study done by Janz *et al*. also found that newly diagnosed patients reported impairment in quality of Life and visual function that improved after patient education and counseling.[21] We found that even patients with a recent diagnosis of glaucoma had impaired quality of life scores. Hence the role of patient counseling for newly diagnosed and early glaucoma cases cannot be underestimated.

Using NEIVFQ 25 subscales, we were able to analyze the disease impact on various daily routine activities and psychological functions. Among all the subscales, driving, and ocular pain had the lowest scores and were most commonly affected. Driving is an activity requiring binocular visual function, good scotopic vision as well as higher functions such as contrast sensitivity, especially for night time driving. Peripheral visual fields also play a major role. Reports in literature have mentioned the role of decreased contrast sensitivity, impaired dark adaptation, and increased glare sensitivity reportedly experienced by glaucoma patients that results in difficulty in night time driving.[22,23] Studies done Sawada *et al*. in Japan and Kong *et al*. in China have also documented driving as the most severely affected function in glaucoma patients.[8,9] Low ocular pain scores signified ocular discomfort. In our opinion, increased ocular discomfort could possibly be a result of ocular surface disorders caused due to chronic use of topical medications, especially the ones with preservatives. High prevalence of ocular surface problems due to preservatives and polypharmacy, in patients with glaucoma, has been previously demonstrated in some of the studies.[13,24,25] Highest scores were seen with color vision (90.1, SD 18.6) and social functions (86.8, SD 20.1). The score for these two entities were minimally affected in mild to moderate diseases, implying that patients do not perceive or report any difficulty with color perception and social interactions in early to moderate disease. These findings were similarly found in the studies done in Japan and China.[8,9] Near vision (Pearson's coefficient, r = 0.847), distance vision (r = 0.840), mental health (r = 0.845), dependency (r = 0.877), and driving (r = 0.893) demonstrated strong correlation with NEIVFQ composite score.

On NEIVFQ mental health subscale, the mean score was 69.26 (SD 21.94). It was better in comparison to the study done by Kong *et al*. (64.46, SD 19.97) but poorer to that done by Sawada *et al*. in Japan (74.8).[8,9] However, the mental health score was not found to be affected by the duration of treatment and no significant difference was observed between the three groups. The majority of patients, including the recently diagnosed

cases, had impaired mental health scores. This has been attributed partly to a lack of knowledge and awareness about glaucoma amongst the masses. Previous studies done in newly diagnosed glaucoma patients have also demonstrated anxiety and fear of blindness in almost one-third of patients.[6] They also stated the fact that glaucoma comprehension is usually poor at the early stages of diagnosis.[21]

This data underlines the importance of psychological assessment and counseling, along with the medical or surgical treatment. Comprehension of glaucoma plays a vital role in patient's psychological thought process, which may in turn affect the compliance and quality of life. Sometimes, even just knowing the diagnosis of potentially blinding disease leads to depression or anxiety. Also, the noncurable nature of the disease with visual impairment may lead to a negative outlook in some. The role of disease comprehension and its effect on glaucoma has already been mentioned in some of the studies done previously.[8,19,26]

This study demonstrates the magnitude of impact that the diagnosis of glaucoma has on quality of life in even newly diagnosed patients. Hence, QoL scores for all glaucoma patients should be assessed periodically regardless of the stage of disease and treatment duration. Patients should be made more aware about the disease, treatment options available to them, and the fact that the disease progression can be slowed down with modern treatment options. This should be done at the time of diagnosis itself by the treating ophthalmologist. Periodic motivational counseling can be included as a part of the glaucoma management protocol. Vocational training and low vision devices for advanced cases might be able to improve patients' psychosocial wellbeing.

Strengths and limitations

Strengths of our study include a large sample size with an adequate number of cases of various degrees of disease severity. We were also able to eliminate interobserver bias as the examination and administration of the questionnaire was done by a single trained ophthalmologist. However, there were a few limitations in our study, such as the fact that the study was conducted at a single center in an urban area and may not accurately represent the population with glaucoma in the country. Moreover, this study did not analyze the impact of factors such as education level, socioeconomic status, and effect of antiglaucoma medications on quality of life scores. These factors may have a confounding effect and should be evaluated in future studies.

Conclusion

Glaucoma negatively affects psychology even in patients with early diagnosis. It is essential to quantify and understand the psychosocial state of the patient so that a more holistic treatment approach can be adopted and noncompliance avoided. Large multicentric longitudinal studies would also be required in the future so as to investigate the causative role of various socioeconomic and medication-related factors on quality of life, with use of relevant questionnaires.

Patient education at diagnosis, periodic counseling, and psychological assessment should be made a part of the treatment protocol of glaucoma, for all newly diagnosed as well as old patients. Also, disease awareness should be promoted amongst patients' family members as well as the general population. Through these efforts, we may be able to provide a better quality of life to the patients.

Conflicts of interest
There are no conflicts of interests

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