

# Impact of Visual Impairment on the Wellbeing and Functional Disability of Patients with Glaucoma in India

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## Abstract

**Purpose:** To investigate the impact of glaucoma-associated vision loss on quality of life and social functioning in Indians.

**Methods:** A cross-sectional study with prospective enrollment was conducted. Participants were divided as: mild, moderate, and severe. Severity of glaucoma was stratified by the degree of binocular visual field loss in accordance with the Nelson Glaucoma Severity Scale (NGSS). The Glaucoma Quality of Life-15 (GQL-15) and a self-developed social function scale (SFS) were utilized to assess patients' wellbeing.

**Results:** A total of 260 patients (mean  $\pm$  SD age = 58.1  $\pm$  12.01 years; 106 females) participated in the study. Univariate analyses revealed a significant relationship between final quality of life score and number of anti-glaucoma medications ( $P = 0.01$ ), previous surgeries ( $P = 0.00$ ), patients age ( $P = 0.00$ ), patients education level ( $P = 0.02$ ), and severity of glaucoma ( $P = 0.00$ ). Previous surgeries ( $P = 0.04$ ) and severity of glaucoma ( $P = 0.00$ ) were significant predictors of GQL-15 summary score. With increasing glaucoma severity, patients noted greater difficulty with peripheral vision, glare and dark adaptation, and outdoor tasks ( $P < 0.0001$ ). Severe glaucoma also impacted patients' functional performance—a significant decline was observed in sense of personal ( $P < 0.0001$ ) and social wellbeing ( $P < 0.0001$ ).

**Conclusions:** Patients with advanced glaucoma report significant decline in functioning, their ability to interact in community, take care of self, and do leisure activities. Glaucoma imposes greater social burden on the elderly by impacting their sense of personal safety. Targeted visual and social rehabilitative programs are necessary to improve their wellbeing and independent functioning.

**Keywords:** Functional disability, Glaucoma, Indian patients, Quality of life

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## INTRODUCTION

Glaucoma is the second leading cause of irreversible blindness worldwide.<sup>1</sup> Globally, an estimated 60.5 million people above 40 years of age (roughly 3% of the world population) were affected by glaucoma in 2010, with a projected prevalence of 79.6 million in 2020.<sup>1</sup> Epidemiologic studies anticipate the largest increases to be in China and India, which will represent nearly 40% of cases worldwide.<sup>1,2</sup> The rising prevalence of glaucoma imposes significant direct and indirect economic costs.<sup>3</sup> Direct costs are secondary to the financial burden from medical treatment, provision of government rehabilitation

programs, guide dogs, and nursing home care.<sup>2</sup> On the other hand, indirect costs reflect lost productivity, which can include loss of employment of the affected individual as well as the costs borne by the caregivers.<sup>2</sup> Additionally, the financial burden of glaucoma increases with advancing disease severity.<sup>1</sup> Specifically, patients with severe cases of glaucoma have increased dependency on others and need more specialized rehabilitation, which drives up the overall costs of managing advanced disease.<sup>1,4-6</sup>

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The actual disability from a chronic disease is manifested in the impact on a person's social life and functional ability. A relatively indolent course of early stage damage results in delayed diagnosis, due to which the majority of cases remain undetected until the disease has reached advanced stages of severity.<sup>7-9</sup> Although the characteristic early-stage loss of peripheral visual field in glaucoma goes unnoticed, progression to moderate stage marks the threshold towards quality of life limitation.<sup>3,6,10</sup> Previous studies have associated the severity of visual field loss in glaucoma with disability in managing instrumental activities of daily living (such as cooking, grocery shopping, out-of-home travelling),<sup>11</sup> inability to drive,<sup>3,6</sup> greater fear of falling,<sup>12</sup> and reduction in levels of physical activity.<sup>13</sup>

Culture strongly influences an individual's understanding of disease etiology as well as his/her illness experience.<sup>14</sup> Furthermore, gender, socio-economic status, and nature of employment may affect how the individual responds to the consequent disability. While the Indian subcontinent faces a significant global burden of glaucoma,<sup>1</sup> few studies have actually explored the impact of this chronic progressive disease on the wellbeing and functional disability of Indian patients. Understanding these dynamics is key to making micro and macro level health care decisions<sup>15,16</sup> and developing targeted rehabilitation programs.

This study investigates: (1) the impact of irreversible visual impairment resulting from glaucoma on the wellbeing and quality of life in Indian patients; (2) the effect of glaucoma-associated vision loss on activities fundamental to independent living and social functioning; and (3) the role of demographic factors such as economic status, employment, and gender on patients' perception of wellbeing.

## METHODS

Participants were recruited during their routine follow-up visit between June 2012 and July 2014. Ethics approval was obtained from the Hospital Committee for human research, and the research followed the tenets of the Declaration of Helsinki. All participants completed the Glaucoma Quality of Life-15 (GQL-15) and a self-developed social function scale (SFS).

All individuals with an established diagnosis of primary glaucoma, visual acuity of at least 6/60 or better in one eye, and an age over 18 years were eligible. Patients with less than two reliable visual fields in the past 9 months (less than 20% fixation losses, less than 20% false-positive, and false-negative response rates), visually significant cataract, and presence of co-existing ocular morbidity such as diabetic retinopathy and/or maculopathy of any etiology were excluded. Moreover, patients who had undergone intraocular surgery within the past 2 months or had cognitive impairments that prevented them from consenting to the study or hindered their ability to complete the study questionnaires were also excluded from the study. Patients on anti-psychotic drugs or any other chronic systemic illnesses were also excluded as they may affect the

patients' wellbeing and quality of life. All eligible candidates were invited to participate by either the research coordinator or the clinic fellow. Informed consent was obtained from the participants after explanation of the nature and possible consequences of the study.

Medical records of all participants were screened prior to their appointment to obtain necessary clinical data including diagnosis, visual acuity and visual field, number of years since first diagnosis of glaucoma, number and type of glaucoma medications, history of previous glaucoma treatment (surgery or laser), and ocular comorbidity. Demographic data including age, gender, employment, education, and income were recorded for all participants. Ophthalmic assessment was performed including visual acuity with Snellen chart, contrast sensitivity with Pelli-Robson chart, and Estermann binocular visual fields.

Severity of glaucoma was stratified based on degree of binocular visual field loss in accordance with Nelson Glaucoma Severity Scale (NGSS). The NGSS has been shown to correlate strongly with perimetric mean deviation and classifies patients into 3 groups: "mild" (unilateral loss of < half of visual field), "moderate" (unilateral loss of > half of visual field, or bilateral loss of < half of visual field in each eye), or "severe" (bilateral loss of more than half of visual field in either eye).<sup>17</sup> For the purpose of statistical analysis, participants were stratified into 3 groups: mild, moderate, and severe glaucoma.

### **Glaucoma quality of life-15 questionnaire**

The GQL-15 questionnaire is a validated glaucoma-specific scale that explores the degree of difficulty with various visual tasks such as reading the newspaper, walking or seeing at night, walking on uneven ground or climbing stairs, tripping over objects, seeing objects coming from side, crossing the road, judging distance, adjusting to different light intensities, and recognizing faces.<sup>17</sup> The 15 items were rated on a scale of 0 to 5. 0 indicated abstinence from activity for non-visual reasons. 1 signified no difficulty while 5 represented severe difficulty secondary to vision limitation. The individual items were grouped into 4 factors to capture different aspects of visual disability: factor 1- central and near vision; factor 2- peripheral vision; factor 3- dark adaptation and glare; and factor 4- outdoor mobility.<sup>17</sup> The final GQL-15 summary score for each patient was computed by adding the item-level responses on all 15 questions for each patient to produce a mark out of 75, with higher scores indicating a poorer quality of life.

### **Social functional scale**

Six-item SFS was developed based on literature review, clinical expertise, and data from an initial pilot study with 26 glaucoma patients. This questionnaire assessed disability in the following areas: personal care, personal safety, and ability to fulfill responsibility, navigate oneself outdoors, interact with society, and perform leisure activities. Two global questions were asked to capture an impression of patient general wellbeing by inquiring about overall trouble

with vision and satisfaction with present visual health. Individual items on the social function questionnaire were grouped under two broad categories to reflect on the primary aspects of functional performance: 1. Personal wellbeing (personal safety, personal care, leisure activities) and 2. Social wellbeing (fulfill responsibilities; interact with the world, social interaction). Patients ranked these eight items on a scale of 1 to 5: 1 indicated no/little difficulty in performing tasks and 5 suggested severe difficulty owing to visual disability.

Data were collected by face to face interview using English questionnaires. Both questionnaires were administered by an independent study optometrist in a separate room.

**Statistical analysis**

Demographic variables, mean GQL-15 sub-factor scores, GQL-15 summary score, and functional wellbeing responses were compared across different severity of glaucoma diagnoses with Kruskal-Wallis analysis of ranks and Wilcoxon rank sum Mann-Whitney test for non-parametric variables, and analysis of variance for parametric variables. Post-hoc Mann-Whitney U test was utilized for pair-wise comparisons within groups. Multiple regression analysis was used to explore predictors for the GQL-15 questionnaires. All tests were two-sided, and P value less than 0.05 was considered significant. Rasch analysis was conducted to determine whether the overall subscale scores are valid and reliable.

**RESULTS**

Two hundred sixty participants (mean ± SD age = 58.1 ± 12.01 years; 106 females) were recruited for the study. Participants were subdivided into three groups in accordance with NGSS: mild (n = 99), moderate (n = 87), and severe (n = 73). Univariate analyses revealed a significant relationship between final quality of life score and number of anti-glaucoma medications (P = 0.01), previous surgeries (P = 0.00), patients age (P = 0.00), patients education level (P = 0.02), and severity of glaucoma (P = 0.00) [Table 1]. Gender did not show any correlations with GQL-15 summary and subscale scores.

Patients with severe glaucoma reported significantly greater difficulty in performing tasks assessed by SFS [P < 0.0001; Figure 1]. Patients with advanced disease also experienced greater overall dissatisfaction with their vision (P < 0.0001). Patient’s social wellbeing was correlated to their income (P = 0.03) and employment (P = 0.05). The retired and homemakers reported more difficulty with personal chores. Gender was not significantly correlated with either social or personal well being subscale.

Stepwise multiple regressions were performed with GQL-15 summary score as the dependent variable and age, education, number of anti-glaucoma medications, number of surgeries, and severity of disease. This model explained 49.21% of variability, and only previous surgeries (P = 0.04) and severity

**Table 1: Univariate analysis of characteristics of study participants and their associate with final quality of life score**

Variable	Category	n	Mean±SD	P
Gender	Male	153	26.9±14.2	0.42
	Female	106	25.6±12.2	
Anti-glaucoma medications	Yes	229	26.8±13.9	0.01
	No	30	22.7±8.0	
Previous surgeries	≥1	105	30.4±16.2	0.00
	<1	154	23.6±10.4	
Comorbidity	Yes	65	28.0±15.3	0.25
	No	194	25.8±12.8	
Age (years)	≥50	206	27.5±14.3	0.00
	<50	53	21.9±8.0	
Age at diagnosis	≥50	191	26.6±12.6	0.60
	<50	68	25.6±15.7	
Anti-glaucoma medications	Nil	30	22.7±8.0	0.00
	One	114	24.5±13.0	
	Two	86	26.6±11.8	
	Three	19	30.6±16.6	
Education	Uneducated	48	21.5±8.3	0.02
	Up to senior secondary	102	28.3±13.7	
	Graduate and above	109	26.6±14.6	
Employment	Dependent	102	25.3±12.1	0.58
	Service	106	27.0±14.2	
	Business	51	27.2±14.3	
Income (Indian rupee)	Up to 10,000	74	29.4±15.4	0.34
	10,001-20,000	41	25.1±12.1	
	20,001-30,000	19	26.1±13.0	
	30,001-40,000	9	26.3±19.1	
	40,001-50,000	16	23.4±11.0	
	Dependent	100	25.2±12.2	
Diagnosis	Mixed	8	20.0±6.5	0.10
	Others	20	32.1±18.9	
	PACG	64	27.2±13.5	
	POAG	167	25.6±12.8	
Severity	Mild	99	18.9±6.7	0.00
	Moderate	87	23.9±8.5	
	Severe	73	39.5±15.6	

SD: Standard deviation, PACG: Primary angle closure glaucoma, POAG: Primary open angle glaucoma

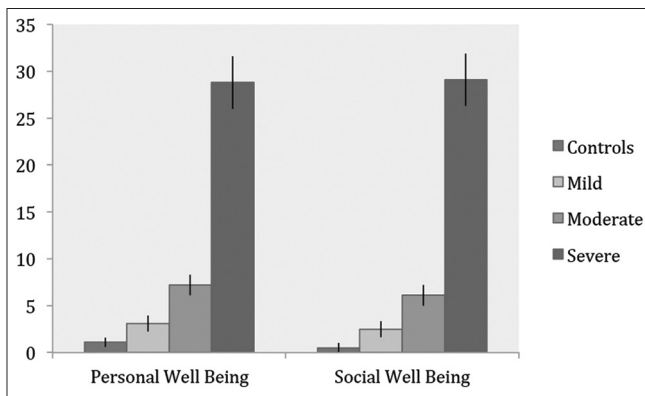
of glaucoma (P = 0.00) were significant predictors of GQL-15 summary score [Table 2].

The Rasch analysis revealed unidimensionality of scale with no misfit item and good performance of the response options for all 23 questions. The category probability curves for the rating scale are shown in Figure 1. Participants did not use the response categories as intended. Categories that perform adequately should have ordered structure calibration thresholds. This indicates that each category has a distinct probability of being chosen more than any other category for a particular item of endorsability. Figure 2 shows this pattern. The person separation reliability was 0.94, and Cronbach’s alpha was 0.93.

**Table 2: Results of multivariate analysis**

Model	Coefficients <sup>a</sup>				Significant
	Unstandardized coefficients		Standardized coefficients ( $\beta$ )	<i>t</i>	
	B	SE			
Constant	2.165	3.760		0.576	0.565
Age	0.057	0.056	0.051	1.020	0.309
Previous surgery	2.219	1.103	0.105	2.012	0.045
Anti-glaucoma medications	1.141	0.778	0.079	1.467	0.144
Education	0.387	0.734	0.026	0.527	0.599
Severity level	9.138	0.874	0.551	10.460	0.000

<sup>a</sup>Dependent variable: Final quality of life score. SE: Standard error

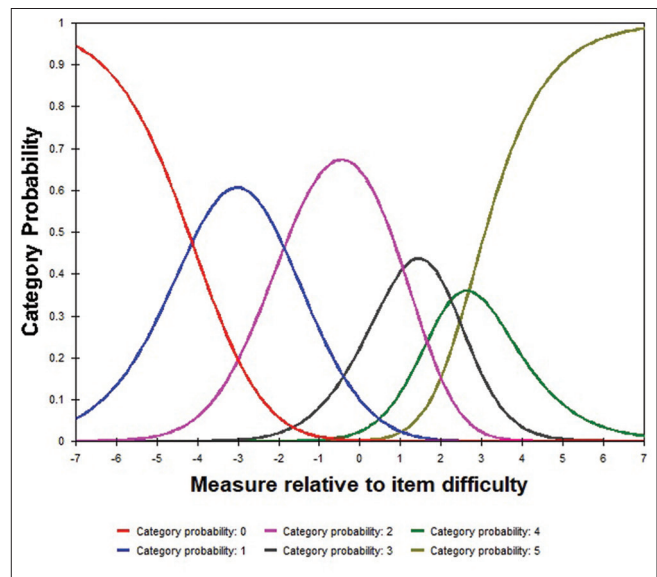


**Figure 1:** Relationship between severity of glaucoma and social wellbeing of patients using self-developed questionnaire

## DISCUSSION

We investigated the impact of glaucoma on quality of life and functional wellbeing of Indians. Similar to Richman *et al.*,<sup>18</sup> our study delved into illness impact by evaluating both perceived quality of life and performance-related disability to independently capture two essential aspects that define patients’ wellbeing. In consensus with previously reported studies,<sup>10,19,20</sup> we found that advancing severity of glaucoma predicted poorer patient-reported quality of life. This relationship was true for each sub-component assessed by the GQL-15 scale. Patients with severe disease noted greater difficulty with central and near vision tasks, peripheral vision tasks, glare and dark adaptation, and outdoors mobility. Freeman *et al.*<sup>21</sup> found that advancing severity of glaucoma affects patients’ ability to carry out their activities of daily living. Moreover, difficulties with day-to-day functioning often alter the individual’s involvement in physical activity and walking.<sup>12,13</sup> Our study delved deeper into exploring the functional disability from glaucoma.

The SFS closely examined the burden of disease on patients’ personal wellbeing such as ability to carry out self-care related tasks, ensure personal safety within one’s environments, and pursue hobbies. It investigated social wellbeing, which was measured by individual’s ability to participate in the society, navigate oneself in his or her environment, as well as carry out social responsibilities. Severity of glaucoma again predicted a greater functional disability. Health outcomes from



**Figure 2:** Rasch model category probability curves for all items together showing the likelihood that a participant with a particular coping ability will select a category. The scale (x-axis) from +7 to -7 symbolizes the latent trait of health-related quality of life, and the y-axis represents the probability of category being selected. Response categories: 0 “abstinence from activity for nonvisual reasons,” 1 “no difficulty with performing activity,” and 5 “severe difficulty with performing activity.” For any given point along this scale, the category most likely to be chosen by a participant is shown by the category curve with the highest probability

a disease are inextricably linked to patients’ social position, which is measured by age, levels of education, occupation, and income.<sup>22</sup> These social determinants of health impact an individual’s vulnerability to illness and ability to cope with impairment.

We observed that patient’s age and employment had a significant correlation with the severity of disease. Similar studies found an overall trend of worsening utility values with increasing age,<sup>16,18</sup> increasing number of intraocular pressure lowering drops,<sup>16</sup> lack of education,<sup>18</sup> and decreasing vision.<sup>16,18</sup> We observed that patients’ level of education predicted their GQL-15 scores, i. e., patients with college-level training reported better quality of life in comparison to patients with no formal education. Previous studies have noted that patients who are knowledgeable about their condition tend to be adherent to



treatment, translating into better disease outcomes.<sup>23</sup> However, our analysis did not find patients' level of education to predict the severity of visual field loss. That leads us to hypothesize that higher levels of education correlated with differences in socio-psychological status and vulnerability to ill health.<sup>19</sup> Our study investigated the influence of income as well as employment status on patient's perception of personal and social disability. We found that individuals who were retired or homemakers felt a greater burden of disease-related disability.

The strengths of our study are the relatively large sample size and inclusion of a control group (i.e., disc suspects facing no visual field loss) along with mild to severe visual field loss. Additionally, our study population represented an equivalent gender distribution, employment status and education level. We explored not only the impact of glaucoma on perceived quality of life but also used a self-developed and validated questionnaire to examine the impact of this chronic disease on patients' functional ability. However, our study has some limitations. This study was conducted in an urban tertiary care center; consequently, our study sample may not be entirely representative of the general population but rather may have a preponderance of patients with more advanced disease.

Overall, our study found that advancing severity of glaucoma predicted poorer quality of life and higher dissatisfaction from vision. This translated into greater disease burden-related disability in the community. Furthermore, our study illustrates the significance of awareness on quality of life in patients with glaucoma.

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Nil.

### **Conflicts of interest**

There are no conflicts of interest.

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