

Quality of Life and Burden of Care in Glaucoma Patients and Their Families in a South Asian Population

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Abstract

Purpose: To study the quality of life and burden of care in glaucoma patients and their families and to compare it with cataract patients.

Methods: This was an observational, prospective, cross-sectional study in which 100 glaucoma patients and 50 patients with age-related cataract as controls, 40 years of age or older were enrolled. Patients were interviewed to obtain information on visual disability and vision-specific quality of life using NEI VFQ-25 and on general quality of life using WHOQoL-BREF. Burden of care of glaucoma was assessed using Family Burden Interview Schedule. Scores of these three questionnaires were taken as main outcome measures.

Results: Scores for patients with glaucoma were significantly lower than those with cataract in visual function, social function, mental health, role difficulties and dependency sub-scales in NEI VFQ-25 questionnaire ($P < 0.05$). General quality of life scores were significantly poor in glaucoma as compared to cataract patients in all domains of WHOQoL-BREF questionnaire including general well-being, physical health, psychological, social relationship and environment ($P < 0.05$). There was more burden of care in glaucoma patients and their families as compared to cataract patients in Family Burden Interview Schedule questionnaire for all sub-scales including financial burden, disruption of routine family activities, family leisure, family interaction, physical health and mental health ($P < 0.05$).

Conclusions: The general quality of life was poor, and influence of limitation in visual functioning on health related quality of life, and burden of care was significantly higher in glaucoma patients as compared to cataract patients.

Keywords: Cataract; Disease burden; Family burden; Glaucoma; Quality of life

Introduction

Glaucoma is a chronic progressive optic neuropathy that usually affects people over 40 years of age. It has characteristic visual field loss and is often associated with high intraocular pressures [1]. Glaucoma is typically bilateral and causes progressive loss of peripheral vision leading to significant disability. If unchecked patient may continue losing vision and become blind. Because of this threat of potential blindness, glaucoma patients are under continuous psychological stress, which along with the cost and side effects of the treatment adversely affects quality of life [2].

Multiple chronic illnesses like diabetes mellitus [3], hypertension, cancers [4,5] etc., are known to affect quality of life (QoL). Chronic stress not only affects QoL but also affects treatment outcomes. The available data consistently documents that glaucoma is associated with significant psychological distress and reduced function, comparable to that of other serious chronic illnesses [6].

Glaucoma patient may lose QoL and feel disabled for several reasons e.g. due to psychological impact of diagnosis, inconvenience of treatment for whole life, side effects, cost of treatment and damage to visual fields [6,7]. This disability and loss of QoL not only affects

glaucoma patients, but has the potential to cause medical, social and financial difficulties to the whole family.

This study is important especially in the Indian context as family members are the main care givers to patients of chronic illnesses. Though there are studies assessing quality of life in patients of eye diseases but very few studies address to glaucoma in particular [7-10]. There is no study from India which assesses quality of life of glaucoma patients using questionnaire methods.

Also data on disease burden caused by glaucoma on families or primary caregivers is scanty which is even more relevant to societies where family members are the main caregivers to people with disabilities including visual disability.

Hence, this study was designed to study the QoL in patients with glaucoma and to assess burden of disease on patients and their families using three standardized questionnaires.

Patients and Methods

The Institutional Review Committee of Post Graduate Institute of Medical Education and Research, Chandigarh, India approved the protocol for the study. Informed consent was obtained from each patient after a complete description of the study. This study was in accordance with the Tenets of the Declaration of Helsinki.

Design

This was an observational, prospective, cross-sectional study with single time assessment of each subject. The study included consecutively selected 100 patients with bilateral glaucoma and 50 patients with bilateral visually significant age related cataract as controls, which were group matched for age and gender. Patients were recruited from Glaucoma and Lens clinics of Advanced Eye Centre, Post Graduate Institute of Medical Education and Research, Chandigarh, India, spanning a period of one year from July 2008 to June 2009.

Inclusion criteria

Patients diagnosed as primary open angle glaucoma, primary angle closure glaucoma, normal tension glaucoma or ocular hypertension aged 40 years or more and on regular follow up for at least 3 years were included in the study group. Control group included age and gender matched subjects with visually significant age related cataract on regular follow up for at least 3 years. (To remove the factor of chronic illness causing decrease in quality of life, we chose cataract patients as our control who have chronic illness but with a different treatment outcome as compared to glaucoma patients).

Exclusion criteria

Presence of any organic disorder or cognitive impairment or current use of any medication due to a psychiatric disorder, all glaucoma patients with co-existing ocular pathology such as retinal and macular diseases, cataract patients with co-existing ocular pathology such as glaucoma, media opacities except cataract, who had undergone ocular surgery except glaucoma surgery within the last 6 months. Subjects with systemic chronic diseases such as diabetes mellitus, hypertension, bronchial asthma, arthritis, and kidney disease and drug or alcohol dependence were also excluded. All patients with unilateral glaucoma or cataract were also excluded.

All patients were subjected to a detailed ophthalmological examination including best corrected visual acuity, contrast sensitivity; slit lamp examination of anterior segment, intraocular pressure (IOP) measurement by Goldman's applanation tonometer, gonioscopy, detailed stereoscopic examination of fundus with +90D lens. All glaucoma patients underwent 24-2 visual field testing with Swedish interactive threshold algorithm strategy (SITA) on Humphrey HFA 730 II Visual Field Analyzer (Carl Zeiss Meditec, Dublin, CA).

Visual acuity was measured in all patients using ETDRS charts under standard light conditions for each eye while patients were wearing their current or "walking about" correction. Patients with visual acuity so poor that they could not read any of the largest letters at 4 meters were asked to count fingers or recognize hand movement or light perception. ETDRS visual acuity was recorded on numerical scale and then converted to logMAR scale (logarithm of the minimum angle of resolution) for analysis.

Progression of disease in glaucoma patients was defined as appearance of new scotoma or deepening of previous scotoma on visual fields in the preceding 3 years. In the control group patient's perception about the progression of cataract and a 2 step decrease in visual acuity were taken as criteria for progression.

A cross-sectional examination was completed over 1-2 sessions (not more than 72 h apart).

Visual disability and influence of limitation in visual functioning on Health Related Quality of Life (HRQoL) was measured using the National Eye Institute Visual Functioning Questionnaire-25 (NEI VFQ-25) [8]. NEI VFQ-25 is composed of 25 questions that fall into 12 vision specific subscales (General health, General vision, Near vision, Distance vision, Ocular pain, Vision related social function, Vision related role function, Vision related mental health, Vision related dependency, driving difficulties, colour vision and peripheral vision).

General QoL was assessed by WHO Quality of Life Brief (WHOQoL-BREF) which is used for the assessment of QoL in patients of chronic illnesses [11]. It lays emphasis on subjective evaluation of respondent's health and living conditions rather than their objective functional status. Four domains of QoL were measured: Physical health, psychological health, social relationships, and environment, based on the past two weeks.

Burden of care of glaucoma on family members of glaucoma patients was assessed by Family Burden Interview Schedule [12]. The Family Burden Interview Schedule has 26 items, 25 of which objectively assess family burden in six domains: financial burden, effect on the family members daily routines, effect on family members' leisure activities, effect on interpersonal relationships within the family, self-reported effects on physical health of other family members, and self-reported effects on the mental health of other family members. The final item asks respondents about their perceived subjective burden related to having an ill family member. Each item is rated on a 3-point Likert scale: 0 (No burden), 1 (moderate burden) and 2 (severe burden).

All patients continued in the care of their primary treating unit (Glaucoma and Lens clinic). No change in treatment was done to facilitate intake into the study.

Statistical analysis

Statistical analysis was carried out using the Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA, ver. 15.0 for Windows). All quantitative variables were estimated using measures of central location (mean, median) and measures of dispersion (standard deviation and standard error). Normality of data was checked by measures of skewness and Kolmogorov Smirnov tests of normality. For normally distributed data, means were compared using Student's t-test. For skewed data Mann Whitney test was applied. All statistical tests were two-sided and performed at a significance level of $P < 0.05$. To see correlation between different variables, spearman coefficient was used as our study variables involved questionnaires).

Results

The mean age of the subjects was 58.84 ± 10.72 years in glaucoma group and 61.76 ± 10.59 years in cataract group. Both the study and the control groups were age matched ($P = 0.117$).

The groups were sex matched ($P = 0.638$) with a male preponderance in both glaucoma (58%) and cataract (62%) groups.

The patients in both the groups were evenly distributed among the income groups with housewives forming the bulk of 'up to 5000 Indian rupees' income group. Difference in distribution of income between glaucoma and cataract group was insignificant ($P = 0.084$), therefore both groups were income matched. Income of patients is important in regard to the ability to purchase medications and afford expenditure of surgery. Financial burden of disease on both the groups is likely to be

related to their income. The patients were evenly distributed among the education groups with illiterate or up to ninth class forming 36% in glaucoma group and 28% in cataract group. 26% glaucoma and 36% of cataract patients were educated till class tenth or were Diploma holders. 38% and 36% patients were graduate or postgraduate in glaucoma and cataract group respectively. Both glaucoma and cataract groups were education matched (P=0.084).

Most of the subjects in this study belonged to Hindu and Sikh religions in both glaucoma and cataract group [Hindu (57%) and Sikh (39%) in glaucoma and Hindu (80%) and Sikh (20%) in cataract

group] and hailed from extended/joint families (51% of glaucoma group and 46% of cataract group; P=0.564) of Punjab, Haryana, Himachal Pradesh and Chandigarh. This is expected as the institute is located in Chandigarh, and acts as a referral centre for neighbouring states of North India which have predominance of Hindus and Sikhs.

The mean duration of illness, visual acuity, IOP, mean deviation of visual field, contrast sensitivity were significantly different in the two groups as shown in Table 1. Majority of patients in glaucoma group were of open angle glaucoma (Table 2).

Variable	Mean (n)		P value
	Glaucoma (Mean ± SD)	Cataract (Mean ± SD)	
Duration of illness (in years)			
Right eye	6.16 ± 5.11	3.25 ± 2.08	0.001
Left eye	6.13 ± 5.10	3.46 ± 1.74	0.009
Visual acuity (logMAR)			
Right	0.31 ± 0.35	0.42 ± 0.30	0.006
Left	0.32 ± 0.41	0.49 ± 0.42	0.004
Intraocular pressure (mmHg)			
Right	15.37 ± 4.182	13.28 ± 2.516	0.001
Left	15.33 ± 4.793	13.56 ± 1.939	0.04
Cup Disc Ratio			
Right	0.62 ± 0.20105	0.34 ± 0.09588	0.001
Left	0.63 ± 0.21066	0.34 ± 0.10510	0.001
Visual field (mean deviation)			
Right	-11.27 ± 9.72560	-6.43 ± 5.52106	0.012
Left	-10.10 ± 9.23211	-7.15 ± 6.62798	0.112
Contrast sensitivity			
Right	29.67 ± 8.996	26.10 ± 8.742	0.001
Left	28.87 ± 11.061	22.90 ± 11.666	0.001

Table 1: Status of vision and optic disc cupping in the studied glaucoma and cataract groups.

Diagnosis	Frequency	
	R/E (n) (%)	L/E (n) (%)
Primary open angle glaucoma	36 (36)	36 (36)
Primary angle closure glaucoma	38 (38)	39 (39)
Primary angle closure	14 (14)	13 (13)
Primary angle closure suspect	5 (5)	5 (5)
Ocular hypertension	4 (4)	4 (4)
Normal tension glaucoma	3 (3)	3 (3)

Total	100	100

Table 2: Subtypes of glaucoma in the studied glaucoma group.

In our study 20% of glaucoma patients had progressive illness compared to 92% of cataract patients. The difference between glaucoma and cataract group was statistically significant (P value=0.001). Previous 3 years records of patients were reviewed to know about the course of disease. In glaucoma patients, progression of visual fields (appearance of new scotoma or deepening of previous scotomas) was taken as criteria for progression in cataract, patient's perception about the progression of cataract and decrease in visual acuity were taken as criteria for progression. Standard treatment protocols were followed in both the groups. No beneficial treatment

was withheld and treatment was not altered in any way to facilitate intake into the study.

Scores for glaucoma group for general health, ocular pain, near activities, distance vision, social function, mental health, role difficulties, dependency, colour vision, peripheral vision subscales were significantly lower than cataract ($P < 0.05$) on NEI VFQ-25 [8] (Table 3). Scores for general vision and driving were higher in glaucoma group as compared to cataract group but were not statistically significant ($P > 0.05$).

NEI VFQ-25 Subscales	Groups		P value
	Glaucoma Mean (SD)	Cataract Mean (SD)	
General Health	46.00 (20.32)	61.50 (16.13)	0.001
General Vision	64.60 (15.00)	60.40 (11.05)	0.050
Ocular Pain	78.00 (19.55)	99.00 (3.42)	0.001
Near Activities	77.79 (22.38)	86.16 (7.64)	0.289
Distance Activities	77.54 (20.76)	91.67 (8.14)	0.001
Mental Health	64.10 (24.26)	86.75 (12.15)	0.001
Dependency	69.00 (26.30)	87.20 (16.07)	0.001
Driving	63.54 (31.80)	57.26 (35.21)	0.601
Colour Vision	94.75 (14.34)	99.00 (4.94)	0.057
Peripheral Vision	75.00 (25.62)	98.50 (5.99)	0.001
Total score	73.13	88.03	0.001

Table 3: Scores of National Eye Institute Visual Functioning Questionnaire-25 (NEI VFQ-25) in glaucoma and cataract group.

Scores for glaucoma group were significantly poor as compared to cataract group in all domains of WHOQoL-BREF 11 including general well-being, physical health, psychological, social relationship and environment ($P < 0.05$) (Table 4).

Scores for glaucoma group were higher as compared to cataract group in Family Burden Interview Schedule 12 for all subscales including financial burden, disruption of routine family activities, family leisure, family interaction, physical health, mental health ($P < 0.05$) (Table 5).

Mean deviation of visual fields in glaucoma patients and logMAR visual acuity in cataract patients had statistically significant negative correlation with most of the parameters of NEI VFQ-25 questionnaire and WHOQoL-BREF questionnaire and a statistically significant positive correlation with financial burden and disruption of family leisure in the Family Burden Interview Schedule.

WHOQOL-BREF Sub domains	Groups		P value
	Glaucoma Mean (SD)	Cataract Mean (SD)	
General well being	3.63 (0.65)	3.85 (0.44)	0.035
Physical Health	3.71 (0.42)	4.34 (0.30)	0.001

Psychological	3.47 (0.39)	3.92 (0.35)	0.001
Social Relationships	3.71 (0.50)	4.23 (0.47)	0.001
Environmental	3.38 (0.49)	3.58 (0.47)	0.019
Total Score	3.53 (0.38)	3.92 (0.35)	0.001

Table 4: Scores of WHO Quality of Life (WHOQOL-BREF) Brief Hindi version in glaucoma and cataract group.

Family Burden Interview Schedule Subscales	Groups		P value
	Glaucoma Mean (SD)	Cataract Mean (SD)	
Financial Burden	0.18 (0.22)	0.04 (0.09)	0.001
Disruption of Family Activities	0.11 (0.22)	0.01 (0.05)	0.001
Disruption of Family Leisure	0.18 (0.26)	0.01 (0.07)	0.001
Disruption of Family Interaction	0.09 (0.19)	0.004 (0.03)	0.001
Physical Health	0.05 (0.19)	0.00 (0.0)	0.041
Mental Health	0.08 (0.27)	0.00 (0.0)	0.015
Total Score	0.13	0.01	0.001

Table 5: Scores of Family Burden Interview Schedule in glaucoma and cataract group.

Inter-correlation study among the three questionnaires proved that poor general quality of life was associated with more visual disability and poor vision specific quality of life which in turn was associated with more burden of care of disease in families.

Discussion

We studied QoL and burden of care in families of glaucoma patients. QoL was significantly decreased in glaucoma patients and burden of care in their families was increased as compared to controls. (To remove the factor of chronic illness causing decrease in quality of life, we chose cataract patients as our control who have chronic illness but with a different treatment outcome as compared to glaucoma patients).

Reduction in QoL of glaucoma patients is well documented in western population [2,7,9,10]. There is hardly any data on these issues from the South Asian region where a large population of the world lives.

The QoL in patients with glaucoma can be measured using either utility scores or various standardized questionnaires. Utility values using time trade-off method are calculated by dividing the number of years traded by the number of expected remaining years of life and subtracting this proportion from 1.0 [13].

A study from India to ascertain utility values and associated QoL with different severity and duration of glaucoma, using time trade off

method, revealed that visual acuity loss occurring secondary to glaucoma was associated with substantial decrease in patient utility value and QoL [13]. However, in our study we used questionnaires which lay emphasis on objective evaluation of respondent's health and living conditions rather than their subjective functional status. The time trade-off consists of a hypothetical trade-off between living shorter and living healthier. Also, time trade-off method is a generic measure of health related quality of life whereas questionnaires like the NEIVF-25 is a specific measure. Generic measures enable us to measure and compare the health status and quality of life of patients with different diseases, whereas specific measures are needed to measure and compare the health status and quality of life of patients with a specific diseases as these measures are focused on the aspects of the disease that are most important to the patients who have the disease or condition we are studying [14].

Chronic illnesses are known to affect quality of life and have psycho-social impact [3,5]. To remove the factor of chronic illness causing decrease in quality of life, it is best to have a control group for comparison. We chose cataract patients as our control who have a chronic illness but with a different treatment outcome as compared to glaucoma patients. Only a few studies have used a control population. Lee et al. [10] and Gutierrez et al. [15] had control population of 44 people without any eye disease and Wilson et al. studied 135 people without any ocular disease except cataract as controls.

Lee et al. [10] developed a brief symptom survey specific for persons with glaucoma, the Glaucoma Symptom Scale (GSS). GSS consisted of 6 nonvisual and 4 visual symptoms for use in clinical practice and to quantify symptoms in glaucoma patients and to investigate the effect of glaucoma and treatment in glaucoma patients. The GSS was applied to 147 glaucoma patients and 44 patients without eye disease. The GSS was able to discriminate between persons with and without glaucoma. However, it did not address treatment related factors relevant to quality of life in glaucoma patients.

Wilson et al. [7] used Medical Outcomes Study 36 item questionnaire for 121 open angle glaucoma patients, 42 glaucoma suspects and 135 with no chronic ocular conditions except cataract. They found that patients with glaucoma had lower scores, control subjects had higher scores and glaucoma suspects had scores intermediate between two groups indicating glaucoma patients have less functional status than patients without glaucoma.

It is desirable to have patients and controls with longer duration of disease because the diagnosis of a chronic disease itself can induce psychological stress and decrease quality of life [15]. Patients typically pass through the stage of denial, followed by acceptance of their illness as part of their life and become less anxious. We enrolled patients who had glaucoma for at least 3 years to remove the factor of immediate depression and anxiety due to diagnosis of a disease.

Most patients in our study were currently married in glaucoma (89%) and cataract (98%) groups. This may be ascribed to universality of marriage in India and comparatively lower mean age in the study sample. This factor has not been taken into account by any of the previous studies [7-10,15]. Marital status is important, as life partner is likely to be the primary care giver. Patients with living spouses are likely to have better emotional, social and financial support. This fact probably accounted for the lesser number of patients without living spouse in our study (11% in glaucoma group and 2% in cataract group).

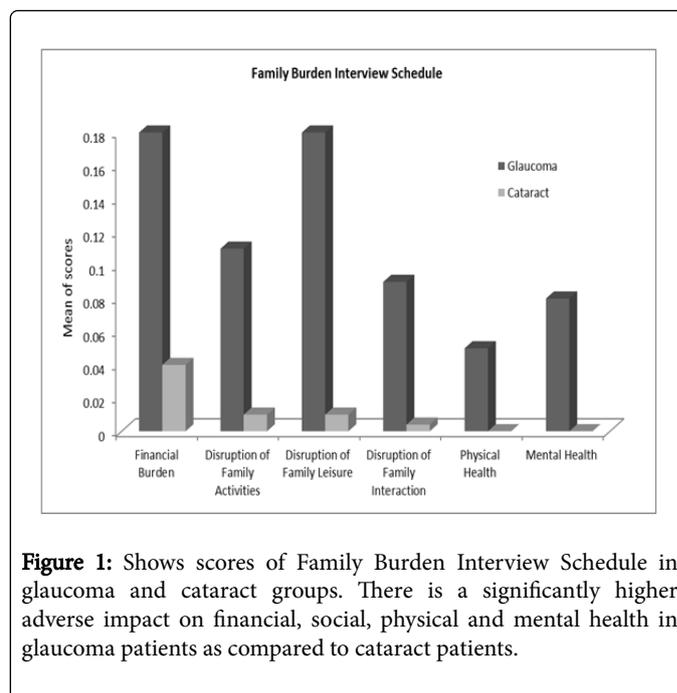


Figure 1: Shows scores of Family Burden Interview Schedule in glaucoma and cataract groups. There is a significantly higher adverse impact on financial, social, physical and mental health in glaucoma patients as compared to cataract patients.

Vision specific QoL in glaucoma patients had significantly lower scores on all domains except general vision and driving. The difference was greater in domains of general health, ocular pain, distance activities, mental health, dependency and peripheral vision ($P \leq 0.001$). There was no significant difference in domain of near activities. A higher incidence of real-world and simulator accidents has been found in patients with glaucoma as compared to normal age and sex-matched controls without any eye disease [16]. However, in our study, the scores for driving and general vision were insignificantly better in patients with glaucoma as compared to controls. The reason for this may be that glaucoma patients maintain central vision for near and distance for a long period of time, and peripheral constriction of vision goes unnoticed. Cataract on the other hand causes blurring of central vision early and also produces glare which may be reason that scores for general vision and driving were lower in cataract patients. This may also be due to the fact that in glaucoma patients, scotoma in the visual field are not seen by the patient as brain 'fills up' the missing parts of the scene ahead from memory. This is a potentially dangerous situation while driving because brain cannot recreate sudden or unexpected changes in the scenery ahead. Previous studies have uniformly demonstrated decreased vision specific quality of life and more visual disability in glaucoma patients [2,9,10,15].

When compared on domains of burden of care of disease on family members as rated on Family Burden Interview Schedule 12 the glaucoma group had higher scores on all domains including financial burden, physical health, mental health, disruption of routine family activities, family leisure and family interaction. The difference between two groups was significantly ($P \leq 0.001$) higher indicating increased burden of care in glaucoma patients and their families as compared to cataract group (Figure 1). There is no published data on burden of care in glaucoma families. However significant burden of care has been reported in Indian families with chronic mental illnesses: both psychotic [12] and neurotic [17]. This is especially important in the South Asian region where per capita incomes are low, health insurance is inadequate or non-existent, governmental support is inadequate and

there are no support groups for glaucoma patients. The entire burden of care falls on patients and their immediate caregivers. As a result the whole family experiences reduction in QoL. There is need to create support systems for patients with glaucoma as this disease has significant medical, social, psychological and financial adverse effects.

Limitations of the Study

The study patients had variable knowledge and insight regarding the diagnostic and prognostic implications. All glaucoma patients were aware that they had a visual problem; some knew about the diagnosis and the fact that glaucoma is a progressive disease which can be controlled but cannot be cured completely. All cataract patients were aware that they had a visual problem related to age which is completely curable after surgery. Some patients thought that the anti-glaucoma medication they were receiving is curative. Very few patients understood the prognosis of the disorder. Quality of life and disability have to be understood in the background of the patient's understanding about his illness. Thus, the relationships with this variable (or lack of it) in our study have to be interpreted with care. We did not take this factor of variable knowledge and insight into account.

To summarise, QoL was significantly decreased in glaucoma patients and burden of care in their families was increased as compared to controls in our study.

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