

Awareness, Attitude and Treatment Seeking Behavior among Established Glaucoma Cases: A Questionnaire Based Study

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Abstract

Purpose: Glaucoma is one of the leading causes of preventable blindness. An understanding of patient awareness, attitude and barriers to treatment may help enhance treatment seeking behavior.

Design: This is an observational, hospital based study in which a structured questionnaire was administered.

Participants: 200 established cases of primary glaucoma under medical treatment for 3 months or more, in age group of 20-80 years.

Method: The questionnaire had four parts and was administered by single examiner to maintain uniformity of collection. Data was analyzed by descriptive analysis, Chi-square test and Mann Whitney U test using SPSS Software.

Result: Majority of the participants (96%) were aware that they were suffering from glaucoma and had fair knowledge of disease (78.5%). Treating physician was the source of information mostly. Patients had sympathetic attitude towards threat of blindness to themselves (65.5%) as well as others (77.5%). Treatment seeking behavior was positive as majority had faith in physician (94%) and medication (87.5%). The non-adherent patients (59.5%) identified forgetfulness and financial issues as the commonest barriers. Adherence was significantly related to male gender (OR=2.85), higher socioeconomic status (OR=4.61) awareness score ($p < 0.01$) and treatment seeking behavior ($p < 0.01$).

Conclusion: Our study highlighted various facts on glaucoma which have important implications for future management trends towards the disease. Physicians are an important source in disseminating information about glaucoma as people trust them. Our study is unique as we identified the factors which will significantly improve adherence as: increasing awareness, building positive treatment seeking behavior, social upliftment and education.

Keywords: Glaucoma; Awareness; Attitude, Adherence; Barriers to adherence

Introduction

Glaucoma is second amongst the leading causes of preventable blindness globally [1,2]. At present, more than 60 million [1] of the world population is suffering from glaucoma, with almost half of these people unaware of having the disease. In 2010, an estimated 8.4 million individuals worldwide went blind from primary open-angle glaucoma. By the year 2020, it is estimated that there will be 11 million individuals will go blind due to this disease [1]. Glaucoma is estimated to affect 12 million Indians; it causes 12.8% of the total blindness in the country and is considered to be the third most common cause of blindness in India [2]. Population based studies carried out in different parts of world so far have found low level of awareness among general population about glaucoma [3]. It has been reported that approximately 50% of the patients with glaucoma were unaware of their condition at the time of diagnosis [4] and presented at an advanced stage of the disease [5,6]. This has been attributed to the lack

of awareness among people so that they present at advance stage of disease.

Our study proposed to determine awareness of and attitude towards glaucoma and treatment seeking behavior and barriers to treatment in patients with glaucoma.

Materials and Methods

This was a hospital based, observational, questionnaire study. The sample size was calculated assuming the awareness in glaucoma patients to be 50% and keeping the precision of 7.5%. The following formula was used to calculate sample size.

$$N = \frac{Z^2_{(1-\alpha/2)} P(1-P)}{d^2}$$

[N (sample size), P (prevalence of the disease), d (Absolute precision of our study taken)]

Based on this, we arrived at a sample size of 200. Patients, between 20-80 years of age, diagnosed as having primary glaucoma (open angle, chronic angle closure or normal/low tension), and receiving medical treatment since 3 months or more were included. The diagnosis had to be supported by records to that effect. Patients who did not give consent, or who had cognitive abnormalities, hearing problems or a mental disease, such that they could not cooperate, were excluded.

After institutional review board clearance and informed consent, a structured questionnaire was administered to 200 established cases of glaucoma that were under treatment for glaucoma in the Out Patient Department of UCMS and GTB Hospital, Delhi. These interviews were conducted in a separate room away from relatives and other patients to ensure reliability and prevention of bias in data collection.

Socio demographic data was collected and each person was classified as per Modified Kuppasamy's scale (with update of economic range of 2010) [7]. The study questionnaire was divided into four major parts as follows:

Questions on awareness

A set of questions to assess the awareness about glaucoma etiology, risk factors and treatment (Table 1). One point was awarded for each correct answer. If a patient rightly answered the sixth question, two points were awarded, since the mainstay of therapy is medical treatment. Patients were ranked upon a total score of 14, as having low (0-5), average (6-10), and good (11-14) awareness level. They were also asked about the source of information but it was not scored.

Awareness variables	Number of participants who answered correctly No (%)
1. What eye disease are you suffering from?	192 (96)
2. What according to you is glaucoma?	
a) High eye pressure	32 (16)
b) High eye pressure causing blindness	168(84)
3. Is blindness due to glaucoma reversible?	55 (27.5)
4. Can someone have glaucoma without symptoms	69 (34.5)
5. Factors identified as risk factors for glaucoma	
a) Family history	57 (28.5)
b) Old age	60 (30)
c) Gender	18 (9)
d) Socio economic status	9 (4.5)
e) Systemic Disease	72 (36)
f) Religious Beliefs	5 (2.5)
g) Drugs	14 (7)
6. How is glaucoma treated?	
a) Surgery	163 (81.5)
b) Drugs	200 (100)
c) Laser treatment	97 (48.5)
d) Visiting Ophthalmologist	5 (2.5)
e) Herbal Medicine	21 (10.5)
7. Source of information	
a) Doctor	180 (90)
b) Close acquaintance	26 (13)
c) Television, Radio, Newspaper	40 (20)
d) Family member/relative not suffering from glaucoma	14 (7)
e) Family member/relative suffering from glaucoma	32 (16)

Table 1: Awareness questionnaire and response of the participants.

Questions on attitude

This part of questionnaire tried to identify the proportion of individuals who rank 'blindness due to glaucoma' as their main priority from which they would like to prevent themselves as well as

provide support to others among other equally morbid diseases (Table 2). Preferential rank to other diseases was also calculated. This part of questionnaire was taken from the study of Livingston et al. [8].

Questionnaire Item	Response No. (%)
1) If it was possible to prevent only one of the following diseases, which of these diseases would you prevent first?	
Cancer	38 (19)
Schizophrenia (a mental disorder)	12 (6)
Heart disease	5 (2.5)
Total blindness	131 (65.5)
Stroke/paralysis	14 (7)
Can't say	0 (0)
2) If it were possible to provide treatment and support to somebody for one of the following disabilities, which of the following disabilities would you provide treatment and support for first?	
a) Paralysis of one side of body	24 (12)
b) Loss of speech as a result of stroke	5 (2.5)
c) Total deafness	3 (1.5)
d) Total blindness	155 (77.5)
e) Amputation of one arm	10 (5)
f) Can't say	3 (1.5)

Table 2: Attitude towards disease in 200 patients with glaucoma.

Questions on treatment seeking behavior

Included provider factors, medication factors, information seeking behavior for medicine, and attitude towards drug use, with one point

given to each correct answer (Table 3). This part of questionnaire was taken from the study of Stryker et al. [9].

Variables	Total N=200; Yes (%)
1. Provider factors	
Whom did you go first on having ocular problem?	
() Ophthalmologist	170 (85)
() General physician	12 (6)
() Pharmacist	13 (6.5)
() Quack.	5 (0.5)
a) Whom would you trust the most with your eye treatment?	
() Ophthalmologist	188 (94)
() General physician	8 (4)
() Pharmacist	1 (0.5)
() Quack.	3 (1.5)
2. Medication Factors	

a) Taking non allopathic medication (ayurvedic, local preparation, etc.)	26 (13)
3. Information Seeking Behavior	
a) Looked for information about glaucoma?	22 (11)
b) Looked at information that comes with eye medicine?	28 (14)
3. Attitude towards treatment	
a) Taking regular medication reduces progress of disease?	175 (87.5)
b) Taking medication regularly prevent blindness in future/control glaucoma?	175 (87.5)
c) Taking medication regularly provide immediate symptomatic relief?	149 (74.5)
d) There is no benefit of taking medication regularly?	38 (19)
e) Believed medication taking will prevent/reduce loss of sight?	175 (8.5)

Table 3: Treatment seeking behaviour displayed by 200 patients with glaucoma.

Barriers to treatment adherence

A patient was identified as being non adherent to treatment if his case record form showed a note about missed appointment or non-compliance to medicines or the patient confessed to missing a dose of

drug once or more often in a week. Twelve barriers relating to patients attitude to treatment, service delivery, cost and affordability were investigated and a score was calculated (Table 4). We used the similar barriers as were used in the study of Dhaliwal et al. [10].

Barrier type	Number of patients who reported the barrier (% of non-adherent group)
1) Barriers related to patient attitude to treatment	
If you have ever missed doses of medication, is it because	
a. You do not remember to take treatment?	111 (93.3)
b. You stay alone?	2 (1.7)
c. You are very old?	33 (27.7)
d. Your work makes it hard to remember medicine?	45 (37.8)
e. Side effect of medicine makes it hard to take medicine?	9 (7.5)
f. Inconvenience is caused by number of drugs (≥ 2)?	18 (15.1)
g. There is no one to keep appointments and remind them?	7 (5.9)
2) Barriers related to service delivery, cost and affordability:	
If you have ever missed an appointment with the doctor, or missed doses of your medicine, is it because	
a. You are living very far from the hospital?	2 (1)
b. There is no transport from residence to hospital?	0 (0)
c. No one could accompany you to hospital?	10 (8.4)
d. Your family income is not sufficient?	49 (41.2)
e. Your doctor does not spend enough time?	42 (35.3)

Table 4: Barriers reported by 119 patients who were not adherent to treatment.

Analysis of data

Descriptive statistics were used to evaluate the questionnaire on awareness, attitude, and treatment seeking behavior, and barriers to

treatment adherence. Chi square test was used to evaluate qualitative data as relation of gender to socio-economic status and type of glaucoma; as well as that of type of disease with adherence and attitude towards disease. One Way ANOVA was used for finding variation of

treatment and awareness score amongst various socio-economic groups. Spearman rank correlation to find association between the various scores and duration of disease. Mann Whitney U test used to find association of various factors with non-adherence to treatment. SPSS 17 Software was used to analyze data.

Results

A total of 200 participants were recruited; age ranged from 25-78 years (average 55.13 ± 11.28); 121 (60.5%) were females; number (48.5%) belonged to socioeconomic class IV, number (%) to class III, number (%) to class II, and number (11%) belonged to the class I. Most patients had chronic OAG 126 (63%); 70(35%) had chronic ACG; four (%) had mixed mechanism glaucoma. The average duration of ongoing treatment was 30 months (median: 3-384 months).

Responses to the Awareness questionnaire are shown in Table 1. With respect to disease etiology, risk factors and treatment options, most participants (157; 78.5%) had a fair awareness score (6-10); however, 28 (14%) had poor, and 15 (7.5%) had good awareness score. Males (average SD) were significantly more aware of their disease than females (average SD; $p=0.036$). A Turkey post hoc test revealed that participants belonging to socio-economic Class I had a higher awareness score (9.82 ± 2.32) as compared to other groups (class II: 7.9 ± 1.72 ; class III: 8.08 ± 1.47 ; class IV: 6.85 ± 2.01 ; class V: 5.75 ± 1.54). There was a positive co-relation between awareness score and duration of disease ($r=0.192$, $N=200$; $p<0.007$) as well as between awareness score and treatment seeking behavior ($r=0.385$, $N=200$; $p<0.01$). Patients who had a higher awareness score were more adherent to treatment ($U=3079.5$; $p<0.01$).

Attitudes toward disease are displayed in Table 2; treatment seeking behavior in Table 3. Patients with a greater treatment score were more adherent, this relation was statistically, highly significant ($U=3263.0$; $p<0.01$).

Adherence to treatment

Was seen in number (40.5%) of participants. Demographic factors associated with adherence were gender ($p=0.036$), and socio-economic status ($p=0.01$); age had no relation ($p=0.73$). There was a highly significant association between male gender and adherence X^2 (1, $N=200$)= 12.5 ; $p<0.01$). Adherence to therapy was significantly associated with awareness score ($U=3079.5$; $p<0.01$), treatment seeking behavior score ($U=3263.0$; $p<0.01$), and socio-economic status ($OR=4.61$ for upper class).

Barriers to treatment adherence

Attitudinal and financial barriers were reported more frequently by the non-adherent group, as compared to those of accessibility and medicine side effects. Inability to remember was an important barrier identified in 93.3% of the cases, financial barrier amongst 41.2% cases. 35.3% believed that doctor did not give them enough time. This may be due to the fact that the Hospital is a government setup with a large patient load. Old age (27.7%), numbers of drugs (9%) were other reported barriers (Table 4). On the other hand, lack of transport and distance from the hospital were reported by no one as a barrier.

Discussion

Most of the patients were females, were in the age group of 50-80 years, and belonged to the upper-lower socioeconomic class. These

findings add to our existing knowledge that the risk of glaucoma increases with age [11] and females are more predisposed to ACG [12].

More than two-thirds of our patients were aware of disease etiology, risk factors and treatment options. This level of awareness is much better than reported from population-based studies (0.27-13.3%) [13-15]. since ours was hospital-based population, it was not surprising that the patients were more aware; however, being on treatment for greater than three months, they should have been better informed about their illness. Our study found that awareness correlated positively with duration of treatment; perhaps, three months is too little to really learn about their disease. Because they were already diagnosed and on treatment, our questions exploring awareness were more detailed than others in the literature, where awareness meant 'having heard about glaucoma'.

Awareness was statistically higher in males ($p=0.032$). Similar results were reported in Southern Indian population [13,14]. On the other hand, some previous studies have also identified contrary results that males were less aware of glaucoma [15,16]. Some authors found no relation between gender and level of awareness [17]. In our study, higher awareness in males may be due to their 2.4 times odds higher socioeconomic class as compared to females.

Mass media had a very limited role to play in informing our patients about glaucoma; in most instances the treating physician was the primary source of information. Studies from South India, on the other hand have [18] reported that mass media was the source of information in nearly half their participants. Health promotion and communication as key public health strategy has been mentioned by others too [19]. This finding, along with the results of community-based studies which highlight poor awareness, underscores the need to improve publicity so that people in the community report earlier for diagnosis and treatment of glaucoma.

Two-thirds of the participants affirmed that prevention of total blindness concerned them more than other disabling diseases like cancer or stroke both in themselves and in others. Other authors reported that only 25% of their participants were concerned with blindness [8]. This difference in attitude may be explained by the fact that our patients were already suffering from a potentially blinding disorder, while the participants from the study reported above were general community dwellers. However, as far as treatment was concerned, both our participants and those from the community based study would treat blindness first before other disabling diseases. Since blindness, though non-fatal when compared to stroke, heart disease and cancer, is more likely to cause significant long term morbidity, the fact that our participants were likely to treat it first is encouraging; perhaps these persons could be exploited and encouraged to educate other people in the community to present earlier.

Most of our patients visited an ophthalmologist at the time of developing ocular complaints and only a few took non allopathic medication. While this is encouraging from the point of view of appropriate treatment, more than half of our patients were non adherent to treatment. Both these findings highlight the important role of the treating ophthalmologist in communicating to their patients the need of strict adherence to treatment. Very few of our patients looked for information about glaucoma or read the drug insert. One reason could be that most of the patients belonged to the lower socio-economic status and had lower level of education. However it is also possible that they had a high degree of trust in their treating physician and so did not feel the need for more information. Other studies have

shown the role of an ophthalmologist and trust plays a big role in adherence to treatment [20].

While most of our patients believed that regular medication improved symptoms, delayed disease progression and reduced chances of blindness, we are concerned about the 19% who were unconvinced about the benefit of regular medication (Table 3). This group of patients reaffirms our belief that the treating physician must at all times communicate to and keep the patient informed. Since the treatment and follow up of glaucoma is likely to be life long, motivating the patients is important [20].

More than half of our patients were non adherent to treatment. Thus, even though they were visiting the hospital for treatment, they might not benefit. These were hospital based patients; the situation may be even worse for community patients with glaucoma who are unable to visit a hospital regularly for one reason or the other. Men, those with better awareness score, better treatment seeking behaviour score and upper socioeconomic status were more likely to be adherent. In our study, men were more aware which might have influenced the finding that gender impacted adherence. Similarly those that were more aware also had a better treatment seeking behaviour score. That awareness of a condition or disease can positively influence self-care practice has been reported in various other studies [20,21].

We observed that people with a longer duration of disease were more adherent ($p=0.041$). This result is contrary to the findings of Osterberg et al. [22], who found that adherence rates were typically higher among patients with acute conditions, in comparison with those with chronic conditions. Perhaps our patients, fearing blindness, and aware that regular medication reduces the risk, were adherent.

In our study attitudinal and financial barriers to treatment adherence were reported more frequently as compared to barriers of accessibility and drug side effects. Forgetfulness was reported as the commonest barrier (93.3%). Other studies from India and the West have shown that forgetfulness is a major barrier [23,24]. Ophthalmic care providers could encourage patients to link medication with a daily activity or set alarms to remind them. Since a handful of patients reported that they had no one to remind them, relatives accompanying the patients could be advised to ensure adherence.

Family income was another major barrier perhaps government could make available some of the more commonly used antiglaucoma medications so that patients are not constrained financially. The other barrier reported by our patients was that the doctor did not spend enough time communicating with them. Ophthalmologists have an important role in motivating patients to be compliant [20]. Identification and elimination of barriers is a very important strategy in blindness prevention.

One of the limitations of our study is that we used indirect methods of evaluating adherence to treatment. Although such methods are useful in clinical settings, being simple and inexpensive, they are susceptible to error because of recall bias. The other limitation is that participants were interviewed only once; they may become non-adherent later, which factor could not be evaluated since this was a cross sectional study. The findings of this study, being a hospital based study, and including mostly patients of lower socio-economic group, may not be applicable to the community at large and to patients from other parts of the country.

Conclusion

Our patients were aware, males more so, that they had glaucoma and that it can be treated by drugs; most had learned from the treating doctor, very few from the media. Patients were sensitive to the threat of blindness, fearing it above disability caused by other morbid systemic diseases. Treatment seeking behavior was positive; majority of patients trusted their treating physician to the extent that they did not enquire about the medication; however, adherence to treatment was not entirely satisfactory. Attitudinal and financial barriers were reported more frequently as compared to those of accessibility and side effects.

Thus there is need to improve publicity so that people in the community report earlier for diagnosis and treatment of glaucoma. The treating ophthalmologist should understand their role in communicating to their patients the need of strict adherence. The government should make the availability of commonly used antiglaucoma drugs at a cheaper rate so as to ensure that financial constraint is not a barrier to adherence.

References

1. Quigley HA, Broman AT (2006) The number of people with glaucoma worldwide in 2010 and 2020. *Br J of Ophthalmol* 90: 262-267.
2. Glaucoma Society of India. GSI. Glaucoma in India: Facts and figure.
3. Gogate P, Deshpande R, Chelkerkar V, Deshpande S, Deshpande M (2011) Is glaucoma blindness a disease of deprivation and ignorance? A case-control study for late presentation of glaucoma in India. *Indian J Ophthalmol* 59: 29-35.
4. Tielsch JM, Sommer A, Katz J, Royall RM, Quigley HA, et al. (1991) Racial variations in the prevalence of primary open angle glaucoma - The Baltimore Eye Survey. *JAMA* 266: 369-374.
5. Dandona L, Dandona R, Srinivas M, Mandal P, John RK, et al. (2000) Open-angle glaucoma in an urban population in southern India: the Andhra Pradesh eye disease study. *Ophthalmology*, 107: 1702-1709
6. Dandona L, Dandona R, Mandal P (2000) Angle-closure glaucoma in an urban population in southern India. The Andhra Pradesh eye disease study. *Ophthalmology* 107: 1710-1715.
7. Patro BK, Jeyashree K, Gupta (2012) PK.Kuppuswamy's Socioeconomic Status Scale 2010—The Need for Periodic Revision. *Indian J Pediatrics* 79: 395-396.
8. Livingston PM, Mc Carty CA, Taylor RH (1998) Knowledge, attitude, and self-care practice associated with age related eye disease in Australia. *Br J of Ophthalmol* 82: 780-785.
9. Stryker JE, Beck AD, Primo SA, Echt KV, Bundy L, et al. (2010) An exploratory study of factors influencing glaucoma treatment adherence. *J Glaucoma* 19: 66-72.
10. Dhaliwal U, Gupta SK (2007) Barriers to the uptake of cataract surgery in patients presenting to a hospital. *Indian J Ophthalmol* 55: 133-136.
11. Leske MC, Connell AM, Schachat AP, Hyman L (1994) The Barbados Eye Study. Prevalence of open angle glaucoma. *Arch Ophthalmol* 112: 821-829.
12. Amerasinghe N, Aung T (2008) Angle-closure: risk factors, diagnosis and treatment. *Prog Brain Res* 173: 31-45.
13. Dandona R, Dandona L, John RK, McCarty CA, Rao GN (2001) Awareness of eye diseases in an urban population in southern India. *Bull World Health Organ* 79: 96-102.
14. Krishnaiah S, Kovai V, Srinivas M, Shamanna BR, Rao GN, et al. (2005) Awareness of glaucoma in the rural population of Southern India. *Indian J Ophthalmol* 53: 205-208.
15. Sathyamangalam RV, Paul PG, George R, Baskaran M, Hemamalini A, et al. (2009) Determinants of glaucoma awareness and knowledge in urban Chennai. *Indian J Ophthalmol* 57: 355-360.

16. Landers JA, Franzco IG, Graham SL (2002) Factors affecting awareness and knowledge of glaucoma among patients presenting to an urban emergency department. *Clin Experiment Ophthalmol* 30: 104-109.
17. Gasch AT, Wang P, Pasquale LR (2000) Determinants of glaucoma awareness in a general eye clinic. *Ophthalmology* 107: 303-308.
18. Krishnaiah S, Kovai V, Srinivas M, Shamanna BR, Rao GN, et al. (2005) Awareness of glaucoma in the rural population of Southern India. *Indian J Ophthalmol* 53: 205-208.
19. Garber N (1990) Health promotion and disease prevention in ophthalmology. *J Ophthalmic NursTechnol* 9: 186-192.
20. Friedman DS, Quigley HA, Gelb L, Tan J, Margolis J, et al. (2007) Using Pharmacy Claims Data to Study Adherence to Glaucoma Medications: Methodology and Findings of the Glaucoma Adherence and Persistency Study (GAPS). *Invest Ophthalmol Vis Sci* 48: 5052-5057.
21. Olthoff CM, Schouten JS, Van BW, Webers CA (2005) Noncompliance with Ocular Hypotensive Treatment in Patients with Glaucoma or Ocular Hypertension: An Evidence-Based Review. *Ophthalmology* 112: 953-961.
22. Osterberg L, Blaschke T (2005) Adherence to Medication. *N Engl J Med* 353: 487-497.
23. Taylor SA, Galbraith SM, Mills RP (2002) Causes of non-compliance with drug regimens in glaucoma patients: a qualitative study. *J Ocul Pharmacol Ther* 18: 401-409.
24. Sleath BL, Krishnadas R, Cho M, Robin AL, Mehta R, et al. (2009) Patient-reported barriers to glaucoma medication access, use, and adherence in Southern India. *Indian J Ophthalmol* 57: 63-68.