Awareness, knowledge, and practice: A survey of glaucoma in north Indian rural residents

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Background: Studies done on the prevalence of glaucoma have reported a high proportion of undiagnosed patients. Late diagnosis is related to increased risk of glaucoma associated with visual disability. Lack of awareness and non-availability of appropriate screening procedures are among the major reasons for non-diagnosis or late diagnosis of glaucoma. The present study has been undertaken to evaluate the level of awareness about glaucoma among the North Indian rural population. **Materials and Methods:** A group-administered, questionnaire-based survey, involving 5000 rural residents (aged 20 and above) was conducted through random sampling. The questionnaire was structured to evaluate the level of awareness and knowledge about glaucoma and the effect of gender, education status, and glaucoma diagnosis was also studied. The source of awareness about glaucoma was also questioned. **Results:** Of the 5000 individuals enrolled for the survey, responses from 4927 (98.5%; 95% Confidence Interval (CI): 98.2 - 98.9) participants, including 3104 males (63%; 95% CI: 61.7 - 64.3) and 1823 females (37%; 95% CI: 35.7 - 38.3) were evaluated. A total of 409 (~8.3%; 95% CI: 7.6 - 9.14) respondents were aware about glaucoma and only 93 (1.89%; 95% CI: 1.55 - 2.31) were qualified as having knowledge about glaucoma as per the set questionnaire. Education was the only variable significantly correlated (P value < 0.001) with the awareness and knowledge of glaucoma out of the parameters included in this study. Close acquaintance with a glaucoma patient was the most common source of information. **Conclusions:** There is a lack of awareness about glaucoma among the rural residents of North India. The study findings stress the need to spread awareness about glaucoma for prevention of glaucoma-related blindness.

Key words: Awareness, glaucoma, knowledge, North India

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Introduction

Glaucoma is the leading cause of irreversible blindness worldwide[1] and is estimated to affect over 11 million Indians.[2] India has been projected to be the second largest home of glaucoma cases by 2020.[3] Importance of early diagnosis in glaucoma cannot be underestimated, for its effective management and prevention of blindness. Early detection of glaucoma is often difficult due to its asymptomatic course in the initial stage, as also the lack of a viable screening tool. Studies have shown that 50 - 90% of the glaucoma cases remain undiagnosed[4,5] and a large number of cases are diagnosed at a later stage of the disease.[6,7] Lack of awareness about glaucoma is an important reason for its late presentation,[8,9] which significantly increases the risk of blindness.[10] Awareness about its nature and risk factors is known to affect the behavior for seeking intervention;[11,12] and this is especially important in a disease like glaucoma, which has an asymptomatic clinical course, at least in the initial stage. It is a given fact that patients will seek a screening procedure only if they are aware of the asymptomatic course, risk factors or consequences of glaucoma. Lack of awareness may not only influence the timing of the diagnosis, but also the utilization of eye care services. Assessment of awareness is the first step in the planning of disease management. In India, data published on the awareness of glaucoma mainly comes from southern[13-15] and central India.[16] To the best of our knowledge literature estimating the awareness about glaucoma is not available from northern India. The present study is designed to evaluate the awareness and knowledge about glaucoma among the rural residents of north India.

Materials and Methods

The population-based study, using a group-administered questionnaire, was conducted in the rural block of the north Indian state of Haryana, from February to September 2010. The questionnaire was initially designed in English and then translated into the local language (Hindi). This translated version was applied to 30 patients or their attendant(s), coming to the Outpatient Department of our hospital, for adaptation to locally used terms and consistency. The questions not understood by the respondents were modified and re-tested on another 20 persons. Thus, based upon an 'interactive pilot survey' the questionnaire was validated. Consent for participation was obtained from the enrolled participants. The study was approved by the ethical sub-committee of the hospital and adhered to the tenets of the declaration of Helsinki.

The questionnaire had three sections: The first section pertaining to information about the patient's demographic characteristics (age, gender, education level, residential village). Section two, pertained to the patient's awareness and knowledge about glaucoma, through 10 questions (four questions evaluating their awareness and six assessing their knowledge). The

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questions were divided into awareness and knowledge sub-sections, by applying standard definitions of these terms.[17] Questions asked to assess knowledge required information and understanding of the subject gained through some source or learning, unlike the questions assessing awareness, which merely required information, without the need of understanding. The third section had two questions dealing with the source of information about glaucoma and any screening undertaken in the past one year. This information was used to assess the practice pattern, defined as activity undertaken to protect from the disease. Each question had three options, and the respondent had to tick (√) the response of their choice (Appendix 1). This final version of the questionnaire was applied to the actual participants of the survey. The criterion for awareness and knowledge was set randomly, with at least 50 and 30% correct responses, respectively.

Five thousand individuals, aged above 20 years were enrolled by random sampling. The enrollment was done by arranging health camps in localities, at satellite centers, and at the main hospital center during the study period. Participation in the survey was voluntary. The approximate population of the block was 60,000 in 2001 census, at 95% confidence level, and a confidence interval (CI) of 1.5; the required sample size was 3985. The demographic details and literacy level of the participants were collected. Diagnosed cases of glaucoma were excluded from participating, as we believed they might have acquired information about glaucoma after diagnosis, which would affect the true assessment of the general population. However, the family member(s) or relative(s) were allowed to participate. The survey was done by trained optometrists, refractionists, and healthcare professionals, who had optimum knowledge about glaucoma and the questionnaire. The questionnaire began with the entry level question in the local language (Hindi) — *'kya aapne kala motia ke bare main suna hai? (Have you heard of glaucoma?)'* If the response to this question was yes, the participants were allowed to take up the rest of the questions evaluating awareness and knowledge about glaucoma. Having heard about the term glaucoma (*kala motia* in Hindi) was not considered as awareness, because merely being aware of the term did not ensure awareness about the disease. However, not having heard the term itself meant lack of awareness [Fig. 1]. Reading assistance to the illiterate participants, as well as explanations, if required, to any of the participants was provided; taking maximum care not to influence their response. Interviewer bias was checked by reviewing the trends of responses in terms of age or education level, at times.

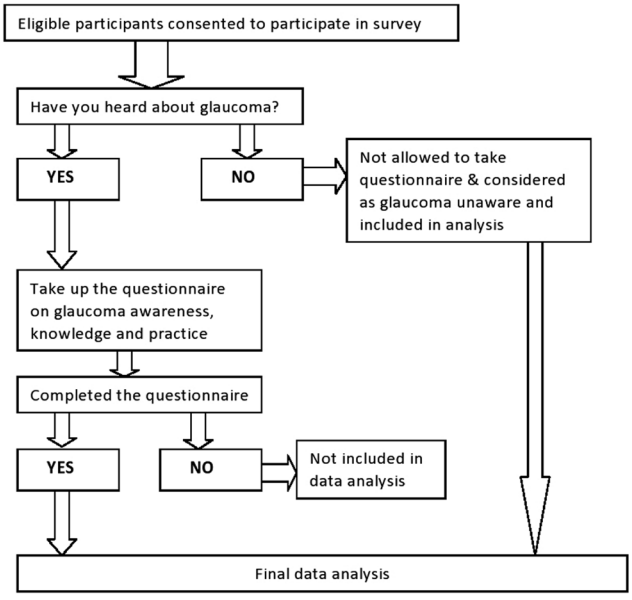

Figure 1: Flow chart depicting the scheme of survey

Statistical package SSPS version 15.0 was used for data analysis. The Chi-square test was used to compare the relationship between these variables (awareness and knowledge) and individual characteristics - age, gender, education level, and odds ratio were calculated by logistic regression. All *P* values are reported were two-tailed and significance level was $P < 0.05$.

Results

A total of five thousand enrolled participants from various villages of an administrative block of Barwala, in western Haryana, undertook the survey. Seventy-three questionnaires were rejected due to incomplete information. Responses from the remaining 4927 (98.5%) participants were analyzed. Table 1 shows the demographic characteristics of the participants. The mean age (SD) was 52 (16) (age range 21-81) years. Males constituted the majority (63%; 95% CI: 61.7 - 64.3) of the participants. Someone with a diagnosis of glaucoma, either in the family, close relationships or friend's circle was declared by 104 (2.1%; 95% CI: 1.7 - 2.5) participants. Among the 1647 (33%; 95% CI: 32.1 - 34.7) illiterate participants, 1094 (66%; 95% 64.1 - 68.7) were males and 553 (34%; 95%:31.3 - 35.9) were females. Reading assistance from the questionnaire administrators was taken by 721 (43%; 95% CI: 41.4 - 46.2) of the illiterate participants; the rest of the illiterate participants took the help of an accompanying assistant. Explanation about questions was requested by 169 (3.5%; 95% CI: 2.9 - 3.9) participants.

A total of 3602 (73%; 95% CI: 71.8 - 74.3) participants had heard about glaucoma, 409 (8.3%; 95% CI: 7.60 - 9.14) were aware, and 93 (1.89%; 95% CI: 1.55 - 2.31) had some knowledge about glaucoma. Awareness of glaucoma was not statistically significant in terms of age ($P = 0.37$) and gender ($P = 0.99$).

Table 1: Demographic characteristics of the participants

Total participants	4927
Gender (%)	
Male	3104 (63)
Female	1823 (37)
Age wise (years) (%)	
<40	1389 (28)
41-60	1554 (32)
>60	1984 (40)
Literacy status (%)	
Illiterate	1647 (33)
Below tenth standard	1802 (37)
Under-graduation/professional courses	833 (17)
Graduation and above	645 (13)

Literate participants were four times more likely to be aware and seven times more likely to be knowledgeable than illiterate participants (*P* value < 0.001). The level of education had a significant association with both awareness and knowledge. In addition, participants who were related or known to glaucoma patients were more likely to be aware and knowledgeable than other participants (Odds ratio: 3.69; 95% CI: 2.45 - 4.55).

A total of 1034 (21%; 95% CI: 19.94 - 22.61) participants understood the risk of familial predisposition to glaucoma. Only 34 (0.7%; 95% CI: 0.4 - 1.0) participants knew about the asymptomatic course of glaucoma. Awareness about the irreversible nature of vision loss in glaucoma was noted in 226 (4.6%; 95% CI: 3.92 - 5.28) of the responses. Six hundred and eighty-nine (14%; 95% CI: 12.71 - 14.96) responded that glaucoma could be treated, but 1921 (39%; 95% CI: 37.04 - 40.22) believed that glaucomatous eyes could not be operated upon. Interestingly, 2265 (46%; 95% CI: 43.9 - 47.19) of the respondents believed that glaucoma resulted from mature cataract [Fig. 2].

One hundred and forty-eight respondents (3%; 95% CI: 2.52 - 3.64) considered that screening could prevent glaucoma, but only 64 (1.3%; 95% CI: 0.9 - 1.7%) had undergone screening/consulted an ophthalmologist in the past one year.

Source of information about glaucoma among the respondents was also queried during the survey. Source of information for 2264 (46%; 95% CI: 44.6 - 47.4) participants was 'word of mouth' from family or friends. Another 1627 (33%; 95% CI: 31.7 - 34.3) participants had received information from visiting hospitals, medical personnel, eye camps or other healthcare recourses. Mass media was source of information for 1036 (21%; 95% CI: 19 - 22) of the participants.

Discussion

This study assesses the awareness and knowledge about glaucoma among rural residents of northern India. The intent of this survey was to evaluate the understanding about the nature of glaucoma, that is, a subtle clinical course, irreversible loss, and the importance of screening, among the general population. Therefore, we did not try to evaluate the anatomical, physiological or technical aspect of the term 'glaucoma'. A large number of participants had heard about the local term used for glaucoma (*kala motia*), but very few were actually aware about it. People could confuse glaucoma for other eye conditions due to the similar terminology.[12,18] We speculate it was one of the two reasons that made many participants respond that they had heard about glaucoma. The terms for cataract and glaucoma used in this part of India are quite similar, they are, '*safed-motia*' for cataract and '*kala-motia*' for glaucoma. Second, it might be due to the awareness about 'phacomorphic/phacogenic glaucoma,' as evident from fact that nearly 46% of the participants believed that glaucoma results from mature cataract. It was not uncommon for the eye-care personnel of this region to be repetitively asked, whether the cataract had changed to glaucoma or not (*motia safed hai ya kala motia ho gaya hai?*), by the patients coming for cataract evaluation.

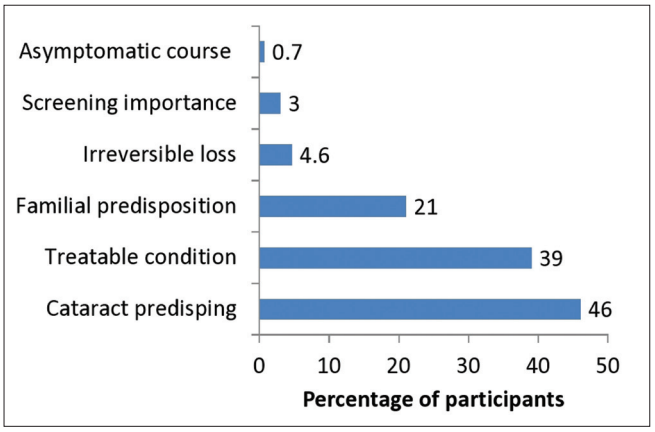

Figure 2: Responses of percentage of participants to some of the questions asked to assess glaucoma awareness and knowledge (please refer to appendix 1 for complete question)

We did not find any relationship between age or gender and glaucoma awareness, like many other studies.[8,18-20] However, a relationship between glaucoma awareness and a particular gender or age[13-16] has been noted previously. Relationship between gender norms and attitude and behavior are not fixed and vary with social, economic, and cultural factors; in fact it evolves with time. Similarly relationship between age and 'health related literacy' is not straightforward and is affected by many factors.[21,22]

In this study, awareness and knowledge was better among individuals with higher elementary education and among close acquaintances of glaucoma patients. Similar trends were reported by other awareness prevalence studies.[8,12,13,19,20,23] This observation signified the importance of education for awareness about the disease, as educated people were more likely to approach the source of information.[24]

Only a small fraction (0.7%) of the respondents knew that glaucoma was an asymptomatic disease, which was a matter of great concern. In a study by Lau *et al*.,[25] 10% of the participants were aware about the symptom aspect of glaucoma. Lack of awareness could often lead to under-diagnosis and late presentation, as noted in several previous studies,[4-9] and therefore, adversely affected the eye care–seeking behavior.[9-12] Another concern was that very few persons knew about the irreversible nature of visual loss in glaucoma. Similar trends were noted in many previous studies.[13,14,18] We believe that, if individuals are aware about these two facts, that is, the asymptomatic course and irreversible loss of vision, it would favorably affect their attitude and concern about glaucoma.

Close acquaintances are the most common source of information on glaucoma. Many other studies have noted friends and family as the most common source of glaucoma information.[13,18,20] This observation has two aspects. First, to use glaucoma patients as a source of awareness to society, as notably suggested by Tenlir *et al*.,[18] who recommended using known glaucoma patients to disseminate information about glaucoma. Second, it necessitates that heathcare personnel, health-related agencies, and mass media participate on a larger scale. This will not only help in increasing awareness, but will also provide authentic, reliable, updated and practical information about glaucoma. Studies from the UK have reported the successful role of media in increasing the awareness about glaucoma.[26]

Overall, the awareness about glaucoma in the Indian

general population is poor, as estimated by population-based studies.[13-16] Although our study results show a similar trend among rural north Indian residents, a direct comparison with other studies is difficult. The major difference among these studies is the definition of awareness. Although 'having heard of glaucoma' has been defined as awareness in most of these studies, we have used a set of questions to define awareness. The content and composition of the questionnaire have also differed, and in this study we have avoided more medical and technical terms. For example, we have framed questions targeting symptoms of the disease (vide appendix) rather than directly addressing intraocular pressure or loss of peripheral vision.[14,15] Framing of questionnaire might have been done depending upon the target population in earlier studies. Unlike these studies we have not studied the impact of the socioeconomic status on the awareness and knowledge of glaucoma.

A limitation of the study is that interviewer bias could not be completely eliminated as an individual's expression, language, and style of explanation may affect the response of the participant.

In conclusion, the findings of our study shed light on the level of awareness and knowledge about glaucoma in rural north Indian residents. As awareness about glaucoma can lead to early detection, a very important step in preventing glaucoma-related blindness;[11] similarly educating masses will offer a promise of improving awareness. Furthermore, there is a need to identify interventions that reinforce people's attitude above the perceived level of awareness about glaucoma and to devise strategies that can influence behavior to the risk of blindness from glaucoma.

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Appendix 1

Participant's information

AGE..... Gender.....

Education status (tick √ any one box)

Illiterate ☐ 10th standard or below ☐

Undergraduate/Professional course☐ Graduate and above☐

Entry question

- Have you heard of glaucoma Yes ☐ No ☐

If your answer is "no"; please return it back; and if it's yes" complete it

Mark (√) in appropriate box

Glaucoma awareness

	Yes	No	Do not know
1. Risk of glaucoma increases with age	☐	☐	☐
2. Anyone can have glaucoma	☐	☐	☐
3. Blindness from glaucoma can be prevented	☐	☐	☐
4. Treatment of glaucoma is possible	☐	☐	☐

Glaucoma knowledge

1. Vision is affected in early course	☐	☐	☐
2. Glaucoma has familial predisposition	☐	☐	☐
3. Glaucoma has asymptomatic course	☐	☐	☐
4. Glaucoma is same as cataract	☐	☐	☐

5. Glaucoma results from

(a) Mature cataract ☐ (c) Progressive increase in glasses numbers ☐ (c) Pressure damage to nerve of vision ☐ (d) Do not know ☐

6. What will happen in untreated glaucoma

(a) Slow, irreversible loss of vision ☐ (b) Eyes cannot be operated ☐ (c) Do not know ☐

Mark most appropriate:

1. Have you undergone ocular examination/screening in past one year Yes ☐ No ☐

2. Source of your information/knowledge about glaucoma

(a)TV/Radio/Newspaper ☐ (b) Hospital/Eye camp/Health personnel ☐ (c) Family/Relative/Friend ☐