

Medical Hypothesis, Discovery & Innovation Ophthalmology Journal



Knowledge and Awareness of Glaucoma in Subjects with Glaucoma and their Normal First-Degree Relatives

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ABSTRACT

The objective of this study was to assess knowledge and awareness of glaucoma in subjects with glaucoma and their normal first-degree relatives. Awareness and knowledge of glaucoma were compared between each patient and his/her relative. We designed a questionnaire containing a set of brief and structured questions to gather information regarding the participants' demographics and knowledge and awareness of glaucoma. There were two groups in this study. The first group ("glaucoma" group) comprised patients diagnosed with glaucoma, while the second group ("relatives" group) consisted of the first-degree relatives of the patients. Ninety-one participants aged over 40 years (mean, 48.5 years) filled the questionnaire. Thirty-four participants belonged to the glaucoma group, while the remaining were first-degree relatives of the patients. According to the responses obtained, 26 (76%) participants in the glaucoma group and 47 (82%) participants in the relatives group had heard of the term "glaucoma." There were no statistically significant differences related to age or gender in glaucoma awareness. Glaucoma awareness was positively associated with education level in both groups (p < 0.0001). The definition of "glaucoma" in the glaucoma group and the relatives group was known to 20 (58.8%) and 17 (29.8%) participants, respectively, and the difference was statistically significant (p < 0.0001). The adjusted odds ratios for awareness and knowledge of glaucoma were 75.2 (95% confidence interval [CI], 11.80 to 366.65) and 148.7 (95% CI, 14.07 to 1646.52), respectively, for individuals with a university graduate level of education. In our study, education level was the only demographic indicator that was a predictor of knowledge and awareness of glaucoma. While more scientific evidence is obtained, community education with focus on the promotion of knowledge and awareness of glaucoma would be a practical public health strategy, especially for individuals aged more than 40 years with a family history of glaucoma.

KEY WORDS

KNOWLEDGE; AWARENESS; GLAUCOMA; FAMILY HISTORY; RELATIVES'

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INTRODUCTION

Glaucoma is the second leading cause of irreversible visual impairment worldwide [1]. Former population-based studies have reported varying glaucoma

prevalence, ranging from 0.4% to 8.8%, depending on study design and the ethnicities of the participants [2,3]. Glaucoma prevalence is estimated to affect more than 67



million individuals globally and lead to blindness in 4.5 million individuals [1]. It is estimated that this number will rise to 79.6 million by 2020 [1], and glaucoma will lead to bilateral blindness in 5.9 million individuals [4].

Owing to the asymptomatic nature of glaucomatous progression, it may remain undetectable in the majority of the cases until an advanced stage [5]. This finding highlights the high burden of disease despite the existence of many effective treatments [6]. It is estimated that approximately 90% of glaucoma-related blindness is preventable with proper early treatment [1]. One of the most important and effective actions for early detection of glaucoma and its management may be raising public knowledge and awareness regarding the disease. Different levels of glaucoma awareness have been reported in different populations. Published studies from developing countries indicate low levels of awareness [7-9], while those from developed countries indicate higher levels of awareness [10-12]. Spread of knowledge regarding some well-recognized risk factors for glaucoma may encourage more awareness. These include a positive family history of glaucoma, which is associated with higher glaucoma awareness [8, 10, 13]. This is because the presence of this risk factor encourages a search for more information regarding the disease and its assessment. The most common source of information regarding glaucoma for patients is reported to be their relatives [14]. However, a high awareness level does not indicate that the individual has complete knowledge regarding glaucoma or a sufficient understanding of the disease. For example, a number of studies indicate that most individuals do not have an accurate understanding of this disease despite being aware of this disease, as almost 40% of the study subjects had inadequate knowledge of glaucoma [10, 12, 13].

A positive family history for glaucoma, which is reported in 13% to 25% of patients with glaucoma, has been proven to be a risk factor for the disease [15]. However, even in families with a history of glaucoma, 27% of patients are unaware of their positive family history [16].

The objective of this study was to assess and compare knowledge and awareness regarding glaucoma in patients with glaucoma and in their normal first-degree relatives in a single center in Turkey.

MATERIALS AND METHODS

This cross-sectional study was conducted at Acibadem University Atakent Education and Research Hospital, Istanbul, Turkey using a structured questionnaire. Written informed consent was obtained from all subjects. The Acibadem University School of Medicine Ethics Committee approved the study protocol, and the study procedures were performed in accordance with the tenets of the Declaration of Helsinki. We designed a local questionnaire containing a set of brief and structured questions to gather information regarding the participants' knowledge and awareness of glaucoma. In addition, all participants' socio-demographic data were collected. The questionnaire was pre-tested in a pilot study of 10 participants and medical terms were removed for ease of understanding of the participants. The participants were enrolled consecutively during routine clinic visits and were interviewed personally prior to beginning a routine ocular examination. In order to study the population most at risk and the prevalence of glaucoma in this population, the questionnaire was administered to cognitively aware adults aged more than 40 years. We encouraged all study subjects to answer all questions to the best of their knowledge. There were two groups in this study. The first group ("glaucoma" group) comprised patients diagnosed with glaucoma, while the second group ("relatives" group) consisted of the firstdegree relatives of these patients. The diagnostic criteria for glaucoma were glaucomatous optic neuropathy, including cupped optic discs, retinal nerve fiber layer defects and compatible visual field defects, and open angle in gonioscopy. The first-degree relatives of the subjects with glaucoma were included if an ophthalmic examination revealed that they were normal and did not meet any of the diagnostic criteria for glaucoma. Both study groups completed the same questionnaire, which had two parts. The first part examined the participant's awareness, while the second part examined the knowledge of the participant regarding glaucoma. We used a set of brief and structured questions with mostly "yes" or "no" answers for the questionnaire. The remaining questions were close-ended multiple-choice auestions.

The first question asked the subject whether he/she had heard about glaucoma. An answer of "yes" indicated that the subject was "aware" of glaucoma. The second question in the first part of the questionnaire asked the subject regarding the source of this information. In the second part of the questionnaire, the study subjects were asked to indicate their understanding of the definition of glaucoma. Responses such as "glaucoma is high eye pressure," "glaucoma is optic nerve



destruction," or "glaucoma is associated with optic nerve destruction as a result of high eye pressure" indicated that the subject had "knowledge of glaucoma." The other questions in the second part of the questionnaire were used to obtain details regarding the participant's knowledge of glaucoma. They included questions regarding the symptoms of glaucoma, its treatment options, nature of the disease, type of visual impairments in glaucoma, normal values of eye pressure, and risk factors for glaucoma.

Data were analyzed with SPSS for Windows, version 16.0; SPSS Inc.; Chicago, IL. Age was analyzed as a continuous variable, while questionnaire answers, educational level, and gender were considered non-parametric ordinal categorical variables. The chi-square test was used to evaluate associations between knowledge/awareness of glaucoma and the demographics of the study subjects, including age, gender, and education status. In addition, multivariate logistic regression models were used to assess the effect of the abovementioned demographic data on the knowledge and awareness of the subjects regarding glaucoma. Estimates of multivariate-adjusted odds ratios (ORs) and 95% confidence intervals (CIs) were made. P values <0.05 were considered statistically significant.

Table 1. Demographic properties of the "Glaucoma" and "Relatives" groups

	Glaucoma Group	Relatives Group	
Age [SD]	52 [6.4]	42 [2.5]	
Gender			
Female	18	30	
Male	16	27	
Education Level			
Elementary	6	7	
High School	8	10	
University	20	40	

SD = Standard Deviation

RESULTS

Questionnaires were distributed among 100 study subjects, of which 91 (91%) completed the questionnaire. The mean age of the overall group was 48.5 (±4.6) years. The study population comprised 48 women and 43 men. Thirteen participants (14%) had an elementary school education, 18 (19%) had a high school education, and the remaining 60 (67%) participants had graduated from university. Thirty-four participants belonged to the glaucoma group, while the remaining 57 participants

were first-degree relatives of the patients. Demographic data for each group are shown in Table 1.

Twenty-six (76%) participants in the glaucoma group and 47 (82%) participants in the relatives group had heard about glaucoma. There was no significant difference associated with gender or agein awareness of glaucoma. However, there was a positive association between glaucoma awareness and education level in both groups (p<0.0001). The main sources of information in the glaucoma group were the patients' ophthalmologists (47%), while the main sources of information in the relatives group were other family members (54%).

The two groups had different levels of knowledge. Only 20 participants (58.8%) knew the definition of glaucoma in the glaucoma group, while the number of participants who knew the definition of glaucoma was 17 (29.8%) in the relatives group; this difference was significant (p < 0.0001). Five patients in the glaucoma group did not know the symptoms of glaucoma, while seven participants did not know the symptoms of glaucoma in the relatives group. Fifteen patients with glaucoma knew that a patient with glaucoma could have no symptoms. Twelve patients with glaucoma knew that glaucoma causes peripheral vision loss. Eighteen patients in the glaucoma group and 16 participants in the relatives group believed that there is a treatment option for the disease, and most answered that this treatment option involved the use of eye drops. Sixteen patients in the glaucoma group and 12 in the relatives group believed that the vision loss occurring in glaucoma is reversible. Sixteen patients in the glaucoma group and 2 in the relatives group knew the normal range of intraocular pressure. The responses of each group reflecting knowledge of glaucoma are summarized in Table 2.

ORs were calculated to measure associations between variables. The level of education clearly influenced glaucoma awareness and knowledge. However, no associations were found between gender and awareness or knowledge of glaucoma (p > 0.05) or age (p > 0.05). Multivariate logistic regression models indicated that the adjusted OR for awareness of glaucoma was 75.2 (95% CI, 11.80 to 366.65) in individuals with university graduate levels of education. Knowledge of glaucoma had a much higher OR in individuals with a university education (148.7 [95% CI, 14.07 to 1646.52]).





Table 2. Numbers of participants that replied correctly to questions related to glaucoma awareness and knowledge in the "glaucoma" and "relatives" groups

Have you ever heard of the eye condition glaucoma?				
If yes, what is the source of your information?				
What is the definition of glaucoma? Please circle one of the choices				
below to the best of your knowledge.				
What are the symptoms of glaucoma?				
Do you believe that a patient with glaucoma could have no symptoms?				
If you circled vision loss in the previous question, what kind of vision loss occurs in a patient with glaucoma?				
What are the risk factors for glaucoma?				
10 Family history 15 Do you believe that glaucoma is a treatable disease?				
If your answer is yes, what are the treatment options?				

Do you believe that vision loss in glaucoma is reversible with treatment?			
16	Yes	12	
4	No	5	
Do you know the normal values of eye pressure?			
3	Between 8 and 12	2	
16	Between 11 and 21	5	
1	Do not know	10	

DISCUSSION

The process of behavior change, which culminates in action and maintenance, but requires awareness and knowledge as its starting point, has previously been explained in previous studies [17]. Glaucoma is a highly prevalent ocular disease with a natural course that ultimately leads to blindness. Low levels of awareness of glaucoma highlight the need for public education regarding this disease. The current study is a unique study of the awareness and knowledge of glaucoma in patients with glaucoma and in individuals with a family history of glaucoma. These data may have a significant public health implication, as we found that knowledge regarding this condition is insufficient in subjects aged >40 years with a family history of glaucoma despite its associations with visual disability and blindness. Compliance with treatment may improve with patient knowledge and awareness. It may also lead to awareness among the patients' relatives and encourage them to participate in screening programs. In case of a disease like glaucoma, early diagnosis and institution of treatment can result in reduction of visual impairment and blindness, as the main predictor of eventual blindness is a late presentation of the disease.

We defined "awareness" as having heard about the disease. Our results indicate that 76% of patients with glaucoma and 82% of their relatives had heard of glaucoma. There are some differences in awareness of glaucoma in different nations. This had resulted in significant disparities in different areas of the world. For instance, a study from Melbourne, Australia, reported awareness of glaucoma in 76% of the general population [18], while a population-based study from Nepal reported a very low level of glaucoma awareness [7]. The most striking result from our study is that only 76% of the patients with glaucoma were aware of the disease. In a study in Barbados, 51% of subjects with glaucoma were unaware of their diagnosis [19]. The 80.2% observed level of glaucoma awareness in our study is consistent with the data in published reports from the United States, which indicate that 70-93% of subjects attending



eye clinics have heard about glaucoma [10, 20, 21]. In another survey from Australia, 93% of 3,654 adult study subjects had awareness regarding glaucoma [22]. Costa and associates assessed and compared awareness regarding glaucoma in two groups of study subjects. One group consisted of high level of educated American patients with glaucoma, while the other comprised low level of educated Brazilian patients with glaucoma. The authors found significant differences between these two groups and concluded that differences in educational level lead to this disparity [23]. In the current study, the high number of participants with university educations may have led to the high rate of glaucoma awareness. The findings of a study conducted by Gogate and colleagues from India are consistent with this idea. In that study, which found lower levels of glaucoma awareness, the majority of study subjects were less educated [24]. Our results indicate that level of education is the strongest explanatory variable for glaucoma awareness.

Patients who were unaware of their diagnosis were most probably unaware of the possibility of glaucoma beinga heritable disease. In our study, only 25 of 91 (27.47%) subjects believed that a positive family history is a risk factor for glaucoma. This may indicate the necessity of urgent action regarding patient knowledge of glaucoma and the need to provide patients with useful information regarding inheritance of glaucoma. Lack of awareness regarding heritability of glaucoma has been reported to vary from 21% to 68% [14, 25]. Deokule and associates found that 41% of patients with glaucoma were aware of a risk for glaucoma in their family members, even though 45% of their family members were not screened for glaucoma [26]. Therefore, providing information to patients with glaucoma regarding the heritability of glaucoma and necessity of screening of their family members is crucial. This would encourage patients to inform their family members regarding the prognosis of glaucoma and their high chance of being affected by this blinding disease compared to the general population. To achieve this aim, clinicians should periodically ask their patients about the awareness of their relatives regarding their diagnosis and whether their family members have participated in glaucoma screening examinations.

In our study, while the study subjects had high levels of awareness, only 40.6% of them had knowledge of glaucoma. This low level of knowledge, specifically among the relatives of the patients, highlights the importance of education for enhancing overall knowledge of glaucoma, especially among individuals with a positive family history of glaucoma. This

knowledge may encourage these individuals to seek glaucoma-screening examinations and help reduce the number of severe cases of this blinding condition. However, knowledge regarding glaucoma was high in our study when compared to a study from Australia, which reported that 29% of the subjects had knowledge regarding glaucoma [22]. This difference may be due to the high proportion of patients with glaucoma in our study.

Apositive family history of glaucoma is associated with high levels of knowledge regarding glaucoma in normal subjects [8]. However, the relatives group in the current study had a low rate of glaucoma knowledge when compared to the group of subjects with glaucoma. This may be due to low interest of the relatives group in the disease when compared to the glaucoma group, as they were not affected by disease comorbidities. Consistent with our findings, a clinical study from the U.S. did not find a statistically significant difference in knowledge of glaucoma between patients with glaucoma and their healthy first-degree relatives [10]. To tackle this problem, we should encourage patients with glaucoma to persuade their relatives to seek glaucoma-screening examinations. Certainly, this would lead to early diagnosis of the glaucoma in the relatives.

In a study from Germany, subjects' relatives were the main sources of information regarding glaucoma [27], while mass media was found to be the main source of information in a study from India [28]. In the current study, study subjects declared that close acquaintances were their main source of information. Our observations may be due to selection bias, as a large proportion of our study subjects were relatives of patients with glaucoma. This should be considered when interpreting the results of our study.

There are inconsistent findings regarding the relationship between gender and awareness of glaucoma. In a few studies from various countries, lack of glaucoma awareness was associated with male gender [17, 29], while the opposite has been reported in other studies [7, 30]. Other studies, such as ours, found no gender differences associated with knowledge or awareness of glaucoma [10, 22, 27, 31].

We propose ongoing assessments of knowledge regarding glaucoma, which may help us to discover possible gaps in patient knowledge. Educational tools and efficient communication may be used for the ongoing education of patients. Both patients and their family members should be persuaded to take part in health education programs. In addition, the creation of clubs for patients with glaucoma and the establishment



of periodic focused group discussions with aware and informed patients with glaucoma as coordinators may motivate others to promote knowledge regarding glaucoma. The burden of this irreversible and potentially blinding ocular disease may thus be reduced with increasing efforts for disseminating education regarding glaucoma.

Together with the World Glaucoma Patient Association, the World Glaucoma Association (WGA) launched a global initiative to enhance knowledge and awareness of glaucoma by specifying March 6th to 12th as the annual World Glaucoma Week. This measure was proposed as a solution to combat lack of awareness regarding glaucoma, which may lead to profound loss of vision. The aims of this movement are to initiate awareness activities and to raise support from eye-care professionals, patient support groups, local authorities, and governments in many nations. The aim of the WGA is to lower the rate of undiagnosed glaucoma from 50% to no more than 20% by 2020. This goal is achievable if all involved authorities work together to enhance knowledge and awareness of glaucoma among the public and provide screening examinations for glaucoma by qualified professionals globally [1,32].

There are some limitations to our study. First, the sample size of the study population was small. In addition, as this study is a clinical study, generalizability of the findings is questionable. Furthermore, a selection bias cannot be ruled out, as we included patients with glaucoma and their relatives. This may have resulted in inclusion of a

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percentage of participants who believe that family history is the main risk factor for glaucoma. In addition, selecting a group of patients with glaucoma who already have knowledge of their illness can result in a higher level of knowledge of glaucoma when compared to that in other groups.

CONCLUSION

This study provides data regarding awareness and knowledge of glaucoma in patients with glaucoma and their healthy relatives with a positive family history of glaucoma in a single center in Turkey. No association was found between increased awareness and knowledge of glaucoma. Education level was found to be a predictor of knowledge and awareness of glaucoma. While more standardized studies are performed to further investigate these findings, we propose that community education would be an effective and feasible public health strategy to enhance knowledge and awareness of glaucoma, especially among individuals with a family history of the disease. This approach may ultimately reduce loss of vision due to glaucoma.

DISCLOSURE

No funding or sponsorship was received for this study. All named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship, take responsibility for the integrity of the work as a whole, and have given final approval for the version to be published.

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