• Investigation •

Knowledge and awareness of glaucoma in Mexican patients with and without glaucoma diagnosis in an Ophthalmology Referral Center

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Abstract

● **AIM:** To assess and compare knowledge and awareness of glaucoma in subjects with and without glaucoma diagnosis attending an Ophthalmology Referral Center.

● **METHODS:** This cross-sectional study was conducted at Asociación Para Evitar la Ceguera in Mexico City, using a questionnaire formulated by a group of experts following the Delphi panel rules, and pre-tested in a pilot study. The questionnaire was applied and compared between: glaucoma patients, relatives of glaucoma patients and patients without glaucoma. Socio-demographic data was collected to assess correlation with the level of knowledge using Logistic regression models, estimating the odds ratios (OR), 95% confidence intervals, and $P<0.05$.

● **RESULTS:** Three hundred and ninety-four subjects were enrolled; with a median age of 61y. One hundred and thirty-four (34%) were patients with glaucoma, 152 (38.6%) patients without glaucoma, and 108 (27.4%) relatives of patients with glaucoma. Two hundred and ninety-one (73.9%) participants were aware of the term "glaucoma". Regarding knowledge 46.7% had moderate knowledge, 37.8% had poor knowledge, and 15.5% good knowledge. Overall, relatives of glaucoma patients had the highest scores, and patients without glaucoma got the lowest scores. A positive correlation was found between better knowledge and frequent ophthalmological examinations OR 2.24 ($P=0.02$), higher education level OR 4.17 ($P=0.00$) and having a family member with glaucoma OR 3.28 ($P=0.00$).

● **CONCLUSION:** Awareness and knowledge of glaucoma in subjects attending an Ophthalmology Referral Center is predominantly moderate or poor. This has important implications regarding attitudes that can result in lack of follow up in ophthalmological care.

● **KEYWORDS:** glaucoma; awareness; knowledge; vision loss; treatment

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INTRODUCTION

Glaucoma is the leading cause of irreversible blindness in the world. More than 70 million people worldwide have glaucoma, and approximately 10% will develop blindness. Glaucoma is a silent disease that can remain asymptomatic in early stages until it progresses to a severe and irreversible condition, where it significantly reduces the patient's visual field, vision and quality of life[1].

Due to the asymptomatic nature of the early stages of glaucoma, the number of people affected is likely to be much greater than the number of people who know they have it, in fact, population surveys suggest that only 10% to 50% of people with glaucoma know their diagnosis[1].

Vast evidence indicates that a late diagnosis of glaucoma is an important risk factor for blindness, and that blindness from glaucoma is also associated with poor awareness and knowledge of the disease[2]. This makes patient education and awareness projects an essential part of the global fight against blindness. Educating the population encourages ophthalmological check-ups, directed screening, and active participation in follow-ups and treatments, thus, improving adherence and reducing disease progression[3].

In previously published studies on glaucoma knowledge, it is estimated that 29%[4] to 59%[5] of the population have good knowledge of the disease. Among the causes that can contribute to the lack of knowledge in patients with glaucoma

are a poor doctor-patient relationship, patient's lack of interest or shyness to ask, brief medical consultations that do not leave time to explain the disease in detail, and use of complex language during the explanation[6]. A poor level of knowledge has been found to be associated with low level of education[6-8], a short-term diagnosis, and advanced age. On the other hand, the factors that were associated with a higher score in glaucoma knowledge were having a family member or friend with the disease and being treated in the private healthcare sector[9].

Regarding glaucoma awareness, previous studies have shown that from 35% to 79% of ophthalmology patients are aware of the existence of glaucoma. It has also been reported that developed countries have better glaucoma awareness compared to developing countries[10-12]. Having a family member diagnosed with glaucoma is also associated with greater awareness[2,13], as this has been shown to encourage education about the disease. However, a high level of awareness about glaucoma does not imply that patients have adequate knowledge, in fact it has been shown that most people have a poor understanding of glaucoma despite being aware of the disease[11,14].

The purpose of this study is to assess and compare knowledge and awareness of glaucoma in a population attending an Ophthalmology Referral Center in Mexico City.

SUBJECTS AND METHODS

Ethical Approval The Institutional Ethics and Research Committee of Asociación Para Evitar la Ceguera, Mexico City, approved the protocol, and the methodology adhered to the tenets of the Declaration of Helsinki. Written informed consent was obtained from all participants before enrollment.

This cross-sectional study was conducted at the Asociación Para Evitar la Ceguera in Mexico City, Mexico. Following a review of the literature, we designed a questionnaire containing a set of brief, structured questions in Spanish with easily understandable options to gather information on participants' knowledge and awareness of glaucoma adapted to our population. The questionnaire was divided into 4 parts: sociodemographic data, glaucoma awareness, glaucoma knowledge, and the patient's personal preferences to receive education. Questions on sociodemographic data included participant's age, sex, religion, marital status, educational degree, occupation and monthly income. Glaucoma awareness questions and general ophthalmological knowledge explore whether the participant has glaucoma, has previously heard about glaucoma, has family members or friends with a diagnosis of glaucoma, frequently attends ophthalmic evaluations, and their medical or surgical treatment for glaucoma, if applicable to the case. Glaucoma knowledge questions aim to determine basic knowledge about the affected anatomical site, types of glaucoma, signs and symptoms, risk factors, visual field alteration and patterns, progression and treatment. We also included questions about participants' preferences for obtaining educational information about glaucoma. The questionnaire was developed by a group of experts following the rules of the Delphi panel, then it was validated in a pilot group and Cronbach's alpha was determined to assess internal consistency, obtaining a Cronbach's alpha of 0.885. Glaucoma knowledge was classified into three groups according to the score obtained in the questionnaire (total score: 19) as: good (≥15 points), moderate (9 to 14 points), or poor (≤8 points).

The sample size was calculated by sample distribution of proportions, it was determined separately for awareness and knowledge. For the final calculation, glaucoma awareness of the participants was taken as the main outcome measure. The *n* required 440 patients, considering a 15% loss of participant due to incomplete questionnaires the minimum of patients required for statistical significance is 374 participants.

The questionnaire was applied to patients over 18 years of age attending an Ophthalmology Referral Center and to their companions. Incomplete questionnaires were excluded. The data was collected in a spreadsheet (Excel, 2018, Microsoft, Redmond, WA, USA) and analyzed with SPSS, version 25, Chicago, IL, USA.

A descriptive statistical analysis was carried out to determine knowledge and to compare it between groups (patients with glaucoma, without glaucoma and companions). Socio-demographic data were collected to assess the correlation between the level of knowledge and awareness using the Chi-square test and Logistic regression models, estimating the odd ratios (OR), 95% confidence intervals (CI), and $P<0.05$ were considered statistically significant.

RESULTS

Three hundred and ninety-four adults participated, the male to female ratio was 1:1.7 with a median age of 61y (interquartile range of 48 to 70). The most frequent educational levels were university (100, 25.4%), high school (87, 22.1%) and middle school (102, 25.9%). Regarding occupation, the group that represented the largest number of participants was housewives (121, 30.7%), followed by professionals (62, 15.7%) and retirees (61, 15.5%). Of the 394 participants, 63.7% (251) belonged to a low socioeconomic stratum according to monthly income. The complete socio demographic data is shown in Table 1.

Classifying the 394 respondents by group, 134 (34%) were patients with a diagnosis of glaucoma, 152 (38.6%) were ophthalmic patients without glaucoma and the remaining 108 (27.4%) participants were companions of patients.

Table 1 Participants' general socio demographic data *n* (%)

Items	*n*=394
Age	61 (48-70)y
Sex	
Female	247 (62.7)
Male	147 (37.3)
Religion	
Catholicism	312 (79.2)
Judaism	26 (6.6)
Christianity	1 (0.3)
Evangelist	4 (1)
Jehovahs Witness	11 (2.8)
None	40 (10.2)
Marital status	
Single	107 (27.2)
Married	204 (51.8)
Separated	13 (3.3)
Divorced	18 (4.6)
Widower	52 (13.2)
Level of education	
Elementary school	76 (19.3)
Middle school	102 (25.9)
High school	87 (22.1)
University	100 (25.4)
Postgraduate	18 (4.6)
None	11 (2.8)
Occupation	
Professionist	62 (15.7)
Merchant	33 (8.4)
Technician	54 (13.7)
Housewife	121 (30.7)
Farmer	4 (1)
Unemployed	38 (9.6)
Student	21 (5.3)
Retiree	61 (15.5)
Monthly income	
<$ 5000	251 (63.7)
$5000 to $10000	81 (20.6)
$10000 to $15000	25 (6.3)
$15000 to $20000	16 (4.1)
>$20000	21 (5.3)

Table 2 Glaucoma awareness responses

Items	*n* (%)
Media by which participants heard about glaucoma (*n*=291)	
Family member	90 (31)
Ophthalmologist	84 (29)
Acquaintance	29 (10)
Health personnel	27 (9)
Television	25 (9)
Brochure/poster/newspaper	14 (5)
Website	13 (4)
Radio	9 (3)
Participants with diagnosis of glaucoma	100 (34)
Participants with a family member with glaucoma diagnosis	137 (47)
Family member (*n*=137)	
Mother	40 (29)
Father	21 (15.5)
Sibling	21 (15.5)
Spouse	18 (13)
Uncle	12 (9)
Child	7 (5)
Grandparent	6 (4.5)
Nephew	4 (3)
Inlaws	3 (2)
Brother-in-law or sister-in-law	3 (2)
Cousin	2 (1.5)
Participants with a frequent ophthalmological examination (*n*=291)	178 (61)
Glaucoma patients' topical treatment (*n*=100)	
1 drop medicine	31 (31)
2 drop medicine	14 (14)
3 drop medicine	18 (18)
4 drop medicine	9 (9)
None	13 (13)
Unknown	15 (15)
Glaucoma patients with surgical treatment (*n*=100)	34 (34)

Glaucoma Awareness Regarding glaucoma awareness, 291 (73.9%) participants had heard of the term "glaucoma," the prevalence of awareness by study group did not show differences, with 100 (34%) in the group of patients with diagnosis of glaucoma, 92 (32%) in the group of ophthalmic patients without glaucoma and 99 (34%) in patients' companions group. Ninety (31%) of those surveyed had heard the term "glaucoma" from a family member, 84 (29%) from an ophthalmologist, 29 (10%) from an acquaintance, and the remaining 88 (30%) from some other medium such as other health care personnel and the media (Table 2). Additionally, 47% of the participants (137) who were aware, had a family member with glaucoma disease, and most of them were first-degree relatives. Of the patients who were aware and had a diagnosis of glaucoma (100, 34%), the majority (around 85%), knew their treatment and the drops that they used, 15% did not know their treatment. No association was found between awareness and age, level of education, occupation, or monthly income.

Glaucoma Knowledge Knowledge was classified into three groups according to the score obtained in the questionnaire (total score 19) as: good (≥15 points), moderate (9 to 14 points) and poor (≤8 points). Most of the respondents (184, 46.7%) had moderate knowledge, 149 (37.8%) had poor knowledge and only 61 (15.5%) good knowledge. The comparison of knowledge between study groups is shown in Figure 1. We found that most ophthalmic patients without glaucoma had poor knowledge (99), most patients with glaucoma had moderate knowledge (79), and most patient companions had

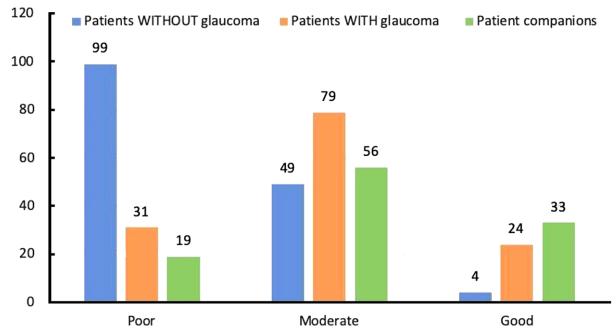

Figure 1 Glaucoma knowledge degree among the study groups.

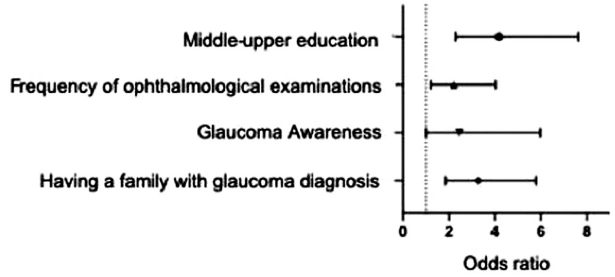

Figure 2 Association between better scores and good knowledge.

good knowledge (33). Patient companions were the group with overall highest scores.

Regarding the specific knowledge of glaucoma (Table 3), most of the respondents (251, 63.7%) did not know the anatomical site of the glaucoma damage, 188 (47.7%) did not know if glaucoma was associated with high intraocular pressure, 33.8% (133) could recognize the different treatments available, and 149 (37.9%) knew that the goal of treatment is to delay the progression of glaucoma. The majority of the participants had the notion that people could have glaucoma and not know it (78%, 306), that glaucoma affects the visual field (79%, 312), even when they did not know the pattern of visual loss and glaucoma progresses over time (72%, 282) and causes blindness (80%, 316).

Better scores regarding knowledge were associated with frequent ophthalmological examinations (OR 2.24, 95%CI 1.33-3.77; *P*=0.02), higher level of education (OR 4.17, 95%CI 2.28-7.64; *P*=0.00), and having a family member with glaucoma (OR 3.28, 95%CI: 1.85-5.78; *P*=0.00; Figure 2).

Preferred Source of Information The preference of the majority of the participants for receiving information about glaucoma was an oral explanation (31%) followed by brochures (23%) and educational videos (22%), the rest is shown in Table 4.

Regarding who should provide information, 74% of the participants preferred that they be an ophthalmologist. With respect to the topics of interest, most of the participants wanted more general information about the diagnosis and clinical evolution (313, 79%), types of glaucoma and risk factors (295, 75%), surgical treatment options (273, 69%) and showed less interest in information on the treatment's adverse effects (202, 51%).

Table 3 Frequency of responses regarding basic glaucoma knowledge

Questions	*n* (%)
Altered anatomical site in glaucoma	
Retina	27 (6.9)
Optic nerve[a]	143 (36.3)
Cornea	9 (2.3)
I don't know	215 (54.6)
Existence of different types of glaucoma	
Yes[a]	88 (22)
No/don't know	306 (78)
People can have glaucoma and not know it	
Yes[a]	291 (74)
No/don't know	103 (26)
Glaucoma can occur without symptoms	
Yes[a]	173 (44)
No/don't know	221 (56)
Glaucoma is more common in people above 60 years	
Yes[a]	128 (32)
No/don't know	266 (68)
High eye pressure, family history and advanced age are glaucoma risk factors	
Yes[a]	258 (65)
No/don't know	136 (35)
Associated with high intraocular pressure	
Yes	160 (40.6)
No	10 (2.5)
Not always[a]	46 (11.7)
I don't know	178 (45.2)
Visual field is affected	
Yes[a]	312 (79)
No/don't know	82 (21)
Glaucoma starts affecting peripheral vision	
Yes[a]	92 (23)
No/don't know	302 (77)
Glaucoma progresses over time	
Yes[a]	282 (72)
No/don't know	112 (28)
Glaucoma causes blindness	
Yes[a]	316 (80)
No/don't know	78 (20)
Glaucoma can be cured	
Yes/don't know	211 (54)
No[a]	183 (46)
Glaucoma has treatment	
Yes[a]	299 (76)
No/don't know	95 (24)
Available treatment options	
I don't know	99 (25.1)
Drops, laser and surgery[a]	133 (33.8)
Drops and surgery	90 (22.8)
Only drops	63 (16)
Only surgery	9 (2.3)
Purpose of the treatment	
I don't know	89 (22.6)
Regain vision	50 (12.7)
Delay progression[a]	149 (37.9)
Stop progression	106 (26.9)
Glaucoma treatment reduces intraocular pressure	
Yes[a]	228 (58)
No/don't know	166 (42)
Glaucoma progresses rapidly without treatment	
Yes[a]	242 (61)
No/don't know	152 (39)
Glaucoma damage is reversible	
Yes/don't know	211 (54)
No[a]	183 (46)
Glaucoma is inherited	
Yes[a]	143 (36)
No/don't know	251 (64)

[a]Correct answer.

Table 4 Participants' source preferences to obtain information about glaucoma

Information source	*n*=394
Oral explanation	122 (31%)
Brochure	91 (23%)
Video	86 (22%)
Website/Internet	83 (21%)
Poster	12 (3%)

DISCUSSION

This cross-sectional study was conducted to report on awareness and knowledge of glaucoma in a population attending an Ophthalmology Referral Center in Mexico City, Mexico, using a multiple-choice questionnaire validated for our population. Our results show the general proportion of awareness was 73.9%, but despite this high percentage of awareness, scores reflecting good knowledge among respondents was only 15.5% (similar to the Uche *et al*[15] study). This could bring important public implications when we consider the visual impairment that glaucoma could cause.

We defined "awareness" as having heard about the term glaucoma, considering this, the proportion of awareness about glaucoma in a Mexican population in our study is higher (73.9%) than previously reported by Paczka *et al*[13] in a survey conducted in an ocular disease detection campaign, where they found that 54% of their studied population had heard the term glaucoma. The difference between glaucoma awareness in these studies may be due to several factors, but we consider it is mainly because our study population was attending an Ophthalmology Referral Center, where people could have access to more information on ocular diseases. Also, our study was conducted 15y after the Paczka *et al*'s[13] study, and nowadays patients have easier access to information and patient education.

Published studies have shown that in general, between 25% and 79% of patients are aware of the existence of glaucoma[16]. Developing countries have low levels of awareness, as observed in studies carried out in Southwestern Ethiopia where the current level of glaucoma awareness was reported to be only 2.4%[10] and in Northwest Ethiopia where the proportion of awareness was 35.1%[17], while studies conducted in developed countries indicate higher levels of awareness as reported in an American study in Massachusetts[11], with a proportion of awareness around 72% or in Melbourne, Australia[18] where it was 79%.

One of the most striking results of our study is that only 34% of the patients with glaucoma were aware of the disease, this makes it more important to think about educational interventions that increase awareness of the disease due to the visual disability that it implies. According to the source of awareness, the most common source was from close acquaintance with relatives, family members, and friends of glaucoma patients, similar to what was found by Maharana *et al*[19].

Many of the results of these studies depend on the demographic characteristics of the population such as the level of education, urban or rural area, and age, however, in our study we did not find a positive correlation between awareness and age, level of education, occupation, or monthly income[19-22]. Likewise, we consider that one of the most important factors that determines the results relies on the definition of "glaucoma awareness". In some previous studies and even in ours, participants were considered aware of glaucoma if they answered positively ("yes") to the simple question "Have you heard the term glaucoma?" in which the percentage of awareness was higher, while in studies where the definition was stricter or more complex, requiring participants to give a description about the disease (glaucoma) in the answer, showed lower percentages of awareness.

As opposed to what we found with respect to awareness of glaucoma, the level of good knowledge in our participants was lower (15.5%) than in the Paczka *et al*[13] study, which also included Mexican population (31%). In other international studies the range varies from 6.3% in the study by Ogbonnaya *et al*[23] to 59% in the Pfeiffer *et al*[5] study. On the other hand, the finding of the present study is consistent with reports from Yenegeta *et al*[24] supporting that there is less knowledge of glaucoma in developing countries, that could relate to the level of education and acess to information of the general population.

It is important to mention that the tools used to determine knowledge also differ between studies, since we used a questionnaire with 19 knowledge question and some studies only required a global definition that covers some aspects of glaucoma such as that it occurs with high intraocular pressure, that it affects the elderly and the visual field or that it causes visual loss. It can be observed that when the knowledge measure becomes more specific through a series of questionnaires and not only by asking for a definition that includes some aspects of glaucoma, the percentage of "good knowledge" decreases. In addition to the number and the type of questions asked, in our study the scoring criteria to consider "good knowledge" were stricter than in other publications (we required 80% of correct answers).

Most of our participants had a moderate knowledge (46.7%), and the overall highest scores were observed among the companions of patients, followed by patients with a diagnosis of glaucoma (30% and 18%, respectively). This contrasts with a previous study by Celebi[14], where the patients with a glaucoma diagnosis had the highest knowledge scores, although in this study knowledge was not assessed as good,

moderate, or poor, as in ours. This could be due to different factors, but in our study group the level of education was higher in the companions of patients than in the patients with a glaucoma diagnosis. Also, a high percentage of companions were the primary caregivers, which could impact their interest in obtaining information on ocular diseases, since they observe the consequences that it has in their family members.

We analyzed factors related to a higher score and better knowledge and found a positive correlation between the level of knowledge and having frequent eye exams, similar to the results in the studies by Alemu *et al*[17] and Yenegeta *et al*[24]. We believe that by having more eye evaluations, the patient is more exposed to ophthalmological patient education simply by being in a hospital setting. Additionally, there was a positive correlation between level of knowledge and a higher level of education, as well as having a family member with glaucoma. In previous studies, the level of education and having a relative with glaucoma have been found to be associated with better glaucoma knowledge[6-7,17,20,25]. Moreover, Sood *et al*[21] observed that the most educated people were less likely to share their condition with their spouse or family. The authors believe that sharing this information with their immediate family can help remind and monitor usage of medication and ensure timely visits to the doctor for glaucoma monitoring, as well as educating family members on having their eyes checked.

Our results showed that the participants preferred to obtain patient education about glaucoma through an oral explanation, followed by brochures and videos. Also, most prefer that the information be provided by an ophthalmologist. This finding is similar to that obtained by Odberg *et al*[26] and by Hoevenaars *et al*[7].

Our findings reflect that we must focus on carrying out educational strategies to get information to the population. Knowing that the participants prefer an oral explanation, brochures and videos, exhibits could be held and/or illustrative educational videos could be shown in the waiting rooms to inform patients about glaucoma while they wait for their appointment, and also brochures should be available on various shelves of the hospital so that patients can be informed. These educational materials save time at the moment of consultation, where only remainings doubts or concerns can be answered more broadly.

Also, according to the results obtained in the study by Daly and Agarwal[27], providing patients with a logbook that includes basic information on glaucoma, as well as intraocular pressure records and changes in treatment between medical visits, increases the knowledge and understanding of the patient about their disease and could help in adherence to treatment[28]. On the other hand, we must consider that mobile media such as social networks, blogs or chats, among other resources, can currently be used to transmit educational information about glaucoma and increase awareness and knowledge in the population[29].

There are limitations to this study that must be considered when interpreting the results, one of these limitations is the population studied, because it is not a representative sample of the general Mexican population as it was carried out in an Ophthalmological Referral Center, where patients may be more aware of the existence of eye diseases such as glaucoma. Another limitation we recognize is the lax definition for measuring awareness as it was assessed with only “yes or no” questions.

It would be worth carrying out a study to evaluate the association between knowledge, quality of life and adherence to treatment in this population, since in previous studies carried out by Chen *et al*[30] it was found that patients with good knowledge of glaucoma have a better quality of life, Waterman *et al*[31] in their research observed that educational interventions and the patient’s knowledge improved adherence to treatment, and also Skalicky *et al*[32] found that a patient-centered glaucoma-related education and support services may improve knowledge and can reduce anxiety for newly diagnosed glaucoma patients.

In conclusion, this study provides data on the awareness and knowledge of glaucoma in patients with and without a diagnosis of glaucoma and in their companions in an Ophthalmology Referral Center. Our results showed that although the level of awareness is high, the level of glaucoma knowledge is low.

This questionnaire allowed us to detect areas of educational deficit and reinforce our strategy for patients and general population regarding glaucoma in order to increase check-ups, and to help promote adherence to treatment and clinical follow-up in those who already have a diagnosis of glaucoma.

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