

# Patient education in glaucoma: what do patients know about glaucoma?

*Educação de pacientes sobre glaucoma: o que os pacientes sabem sobre glaucoma?*

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## ABSTRACT

**Purpose:** To evaluate the knowledge glaucoma patients have about their disease and its treatment. **Methods:** One hundred and eighty-three patients were interviewed at the Glaucoma Service of Wills Eye Hospital (Philadelphia, USA, Group 1) and 100 at the Glaucoma Service of University of Campinas (Campinas, Brazil, Group 2). An informal, relaxed atmosphere was created by the interviewer before asking a list of 18 open-ended questions. **Results:** In Group 1, 44% of the 183 patients did not have an acceptable idea about what glaucoma is, 30% did not know the purpose of the medications they were taking, 47% were not aware of what was an average intraocular pressure, and 45% did not understand why visual fields were examined. In Group 2, 54% gave unsatisfactory answers to the question "What is glaucoma?", 54% did not know the purpose of the medications they were taking, 80% were not aware of what was an average intraocular pressure, and 94% did not understand why visual fields were examined ( $p < 0.001$ ). Linear regression analysis demonstrated that level of education was positively correlated to knowledge about glaucoma in both groups ( $r = 0.65$ ,  $p = 0.001$ ). **Conclusions:** This study showed that patients' knowledge about glaucoma varies greatly, and that in an urban, American setting, around one third of the patients have minimal understanding, whereas in an urban setting in Brazil around two thirds of patients were lacking basic information about glaucoma. Innovative and effective methods are needed to correct this situation.

**Keywords:** Patient education; Glaucoma; Physician-patient relations

## INTRODUCTION

Noncompliance with prescribed drug regimens is a major obstacle to the treatment of chronic diseases, including glaucoma. The long-term treatment of this asymptomatic condition provides no subjective improvement, is expensive, and may be associated with unpleasant side effects. All these factors contribute to discourage patients from using the medications that have been prescribed<sup>(1)</sup>.

Several studies have suggested a positive relationship between incorrect usage of medication and ignorance about the disease<sup>(2-4)</sup>. Others have demonstrated that increasing patients' knowledge about their disease and "tailoring" the therapeutic regimen into the patients' daily life effectively increased correct usage of medication<sup>(5-10)</sup>.

It has been reported that glaucoma patients have little understanding of their disease and its treatment<sup>(2-4,11-12)</sup>, but there are few studies assessing this information directly. In a previous study, some of us reported that the

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knowledge glaucoma patients had in Campinas was unsatisfactory<sup>(13)</sup>. The immediate objective of the present study was to compare the knowledge glaucoma patients in two different countries have about their disease and its treatment. The broader goal was to learn about factors that affect how glaucoma patients care for themselves, and even more broadly, to understand how to promote the health of patients.

## METHODS

Between January and April 1994, patients with primary open angle glaucoma (POAG) were interviewed at two institutions. One hundred and eighty-three patients were interviewed at the Glaucoma Service of Wills Eye Hospital (Philadelphia, USA, Group 1) and 100 at the Glaucoma Service of the University of Campinas (Campinas, Brazil, Group 2). In Philadelphia, the subjects were from both a glaucoma clinic and a private practice, whereas patients in Campinas were exclusively from a glaucoma clinic. Each patient was interviewed by one of two investigators (C.N.U. and J.P.C.V.) during a routine office visit. An informal, relaxed atmosphere was created by the interviewer before asking the following list of open-ended questions:

- 1) Which eye disease do you have?
- 2) When did you first learn you had glaucoma?
- 3) When you first learned you had glaucoma, did you have any difficulty with your vision?
- 4) (If the answer to question 3 is yes). What kind of difficulty did you have with your vision?
- 5) Do you take medications - pills or eyedrops - for your eyes?
- 6) What is (are) the name (s) of the medications you take? How many times a day do you take it (them)?
- 7) Do you always take all your medicines?
- 8) Have you ever stopped the medication on your own?
- 9) (If the answer to question 8 is yes). Why did you stop the medication?
- 10) Do the medicines have side effects?
- 11) Have the side effects of the medications been explained to you?
- 12) What is glaucoma?

- 13) Do you know your intraocular pressure at your last visit?
- 14) What is an average intraocular pressure? That is, if you measure the intraocular pressure in 100 people, what would be the most common pressure?
- 15) What is the purpose of the medications you use?
- 16) Does glaucoma cause blindness?
- 17) Why is the visual field measured?
- 18) Is it important to have your relatives examined?

The answers given by the patients to questions #12, 14, 15, and 17 were classified as unsatisfactory or satisfactory. For question # 12, satisfactory answers included:

- It is a disease caused by high intraocular pressures.
- It is a disease that affects the optic nerve.
- It is a disease that affects the visual field.

For question # 14, satisfactory answers included:

- Any number between 10 and 20.

For question # 15, satisfactory answers included:

- To lower intraocular pressure.
- To prevent progression of glaucoma.

For question # 17, satisfactory answers included:

- Because optic nerve damage leads to visual field damage.
- Because the visual field can be affected in patients with glaucoma.
- To analyze glaucoma progression.

All other substantially different answers given to these questions were considered unsatisfactory.

Statistical analyses were performed with Student's "t" test or the Kruskal Wallis test for continuous variables and the chi square (Yates corrected) or Fisher's exact test for categorical variables. Linear regression analysis was performed to evaluate variables associated with lack of knowledge. P values of less than 0.05 were considered significant.

## RESULTS

Table 1 describes the demographics of both populations. Sex and race distributions were found to be similar between the groups, but patients in Group 1 were significantly older

Table 1. General characteristics of the population

	Wills Eye Hospital (n=183)			UNICAMP (n=100)			p
Sex	F= 110 M= 73			F= 52 M= 48			0.233
Race	W= 109	B= 70	A= 4	W= 61	B= 39	A= 0	0.329
Age (years)	69.1 ± 16.2			63.1 ± 10.1			0.001*
Instruction level							
Illiterate	3			36			<0.0001*
High school	89			56			
College	91			8			
Time of diagnosis (years)	10.6 ± 9.7			3.8 ± 1.2			<0.0001*
Distance from office (km)	81.0 ± 60.8			122.6 ± 35.8			<0.0001*
F= Female; M= Male; W= White; B= Black; A= Asian							
* = p<0.05							

than in Group 2 ( $p=0.001$ ), those in Group 2 tended to live further away from the office ( $122.6 \pm 35.8$  km) than those in Group 1 ( $81.0 \pm 60.8$  km) ( $p<0.0001$ ). Patients in Group 1 had glaucoma longer than in Group 2 ( $10.6 \pm 9.7$  years, and  $3.8 \pm 1.2$  years, respectively) ( $p<0.0001$ ), and had reached a higher educational level than patients in Group 2 ( $p<0.0001$ ).

Table 2 displays the answers to questions related to the way patients felt about their eye disease. One hundred seventy-three patients in Group 1 (95%) and 70 of the 100 patients in Group 2 (70%) knew they had glaucoma ( $p<0.0001$ ). A significantly higher percentage of patients in Group 1 (51%, compared to 33% in Group 2) indicated that they had experienced vision difficulty when they first learned they had glaucoma ( $p=0.012$ ). In both groups, the main difficulties included blurry vision, difficulty reading, and misty vision.

Table 3 shows the patients' knowledge about the medications they were using. One hundred and seventy patients in Group 1 and 95 patients in Group 2 were under antiglaucoma therapy. Twelve patients in Group 1 (7%) and 20 patients in Group 2 (21%) neglected to always take their medicines ( $p=0.001$ ). In Group 1, among the 170 patients who took medications, 97% were using betablockers, 64% pilocarpine, 34% dipivalil-epinephrine, 10% apraclonidine, and 19% carbonic

anhydrase inhibitors. In Group 2, among the 95 patients receiving medications, 95% took betablockers, 52% pilocarpine, 20% dipivalyl-epinephrine, and 12% carbonic anhydrase inhibitors. Fifty-two patients in Group 1 (31%) and 51 patients in Group 2 (54%) did not know the purpose of the medications they were taking ( $p=0.0002$ ). In Group 1, 22 (12%) patients indicated stopping their medications on their own, the main reasons being: side effects ( $n=7$ ), no apparent effect noted by the patient ( $n=6$ ), or no improvement noted by the patient ( $n=3$ ). In Group 2, 21 (21%) had stopped their medications, due to economic reasons ( $n=10$ ), side effects ( $n=7$ ), and absence of change ( $n=2$ ). One hundred twelve (61%) patients in Group 1 and 68 (68%) patients in Group 2 ( $p=0.313$ ) could not remember any discussion of possible side effects.

Eighty-one patients from Group 1 (44.3%) and 54 patients in Group 2 (54%) gave unsatisfactory answers to the question "What is glaucoma?" ( $p=0.1489$ ). A larger percentage of patients in Group 2 (35%) than in Group 1 (8%) did not know that glaucoma may cause blindness ( $p<0.0001$ ). When questioned about intraocular pressure, 60 patients in Group 1 (33%) and 75 patients in Group 2 (75%) did not know their last intraocular pressure measurement ( $p<0.0001$ ). Eighty-seven patients in Group 1 (48%) and 80 patients (80%) in Group 2 were not aware of what

Table 2. Questions related to the way patients felt about their eye disease

Questions	Wills Eye Hospital (n=183)		UNICAMP (n=100)		p
What eye disease do you have?					<0.0001*
Glaucoma	173		70		
Other / None	10		30		
Did you have difficulty with your vision?	Y= 93	N= 90	Y= 67	N= 33	0.012*
What kind of difficulty?					0.426
Blurry vision	47		45		
Difficulty reading	13		11		
Misty vision	9		6		
Others	29		15		
Y= Yes; N= No					
*= $p<0.05$					

Table 3. Questions related to the use of medications

Questions	Wills Eye Hospital (n=183)		UNICAMP (n=100)		p
Do you take medications for your eyes?	Y= 170	N= 13	Y= 95	N= 5	0.661
Do you always take all your medicines?	Y= 158	N= 12	Y= 75	N= 20	0.001*
Which medications?					0.019*
Betablockers	165		90		
Pilocarpine	108		49		
Dipivalyl-epinephrine	57		19		
Apraclonidine	17		0		
C.A.I.	32		11		
Have you ever stopped the medication?	Y= 22	N= 161	Y= 21	N= 79	0.066
What is the purpose of the medications?	S= 131	U= 52	S= 49	U= 51	0.0002*
Do the medicines have side effects?	Y= 81	N= 102	Y= 48	N= 52	0.632
Have the side effects been explained?	Y= 71	N= 112	Y= 32	N= 68	0.313
Y= Yes; N= No; S= Satisfactory answer; U= Unsatisfactory answer; C.A.I.= Carbonic anhydrase Inhibitors					

constitutes an average intraocular pressure ( $p < 0.0001$ ). Eighty-four patients in Group 1 (45%) and 94 patients in Group 2 (94%) gave unsatisfactory reasons as to why the visual field is examined ( $p < 0.0001$ ). A smaller proportion of patients from Group 2 (27%) indicated that they knew the importance of screening their relatives for glaucoma (Group 1 - 61.7%) ( $p < 0.0001$ ).

Linear regression analysis demonstrated that level of education was positively correlated to knowledge about glaucoma in both groups ( $r = 0.65$ ,  $p = 0.001$ ). Other variables, including age, sex, race, time of diagnosis, and distance from the office were not associated with lack of knowledge.

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## DISCUSSION

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Compliance, a term routinely used to define "correct use of medications as ordered by the physician", is a complex problem that may be influenced by a variety of factors such as instillation technique, complexity of drug regimens, costs and side effects of medications, and doctor-patient relationship<sup>(1,4)</sup>. Several studies have demonstrated a relationship between knowledge and correct use of medications<sup>(2,4,6)</sup>. We wished to revisit this issue, specifically comparing populations from two different cultures, to search for commonalities and differences that might help doctors work with patients in a way more likely to result in good self care, of which proper use of medications is but one aspect.

The present study demonstrates that while there are significant differences in certain characteristics of patients in glaucoma in Philadelphia and Campinas, in both populations many individuals are ignorant about their condition. In Philadelphia, 44% of the patients did not have an acceptable idea of what glaucoma is, 31% did not know the purpose of the medications they were taking, and 45% did not understand why visual fields were examined. The situation was worse in Campinas: 54% gave unsatisfactory answers to the question "What is glaucoma?", 54% did not know the purpose of the medications they were taking, and 94% did not understand why visual fields were measured. The differences observed between Philadelphia and Campinas were, at least in part, secondary to a disparity among educational levels, a finding that has also been reported by Kim et al.<sup>(14)</sup>.

In a previous study<sup>(2)</sup>, conducted in the same American institution in 1969, it was shown that 75% of the patients knew they had glaucoma, and 38% had an idea of the nature of glaucoma. In the present investigation, there was an improvement in the proportions of patients who knew they had glaucoma (94%), and who had an acceptable idea about what glaucoma is (56%). Although comparisons between these two groups interviewed at the same institution 25 years apart are limited, the creation of a glaucoma clinic and an improved access to information (including the Internet) may have played a role.

One or more of the following factors may justify the lack of knowledge shown by two populations of glaucoma patients:

1) The doctor-patient relationship may be poor, preventing the patient from receiving all the information that is being

given. Ophthalmologists should make an effort to avoid the "activity-passivity" type of relationship, in which the patient is passive and is acted on by the doctor. As suggested by Riffenburgh<sup>(1)</sup>, the relationship should begin with the "guidance-cooperation" model, where the patient listens to the doctor and follows his directions. As knowledge about the disease increases, the doctor-patient relationship can gradually change to the "mutual-participation" type, where the physician helps the patient to help himself.

2) Patients may have a low concern about their health and may be too diffident to ask questions. In our series, there is evidence pointing to a lack of interest of the patients towards their treatment: a) 5% in Group 1 and 30% in Group 2 were unaware of having glaucoma, and b) 33 in Group 1 and 75% in Group 2 did not know their last intraocular pressure measurement. Encouraging patients to obtain the information they require from their physicians has been shown to enhance the doctor-patient relationship and the likelihood that medications are properly used<sup>(9,15)</sup>.

3) Not enough information is being given. This may be associated with little time dedicated to the discussion of the disease during the consultation. Our series showed that 61% of the patients in Group 1 and 68% of the patients in Group 2 under antiglaucoma medication did not receive explanations about side effects.

4) The way the information is being given does not enable the patient to understand it. Ophthalmologists have to be flexible in the way they choose to explain the disease so that it is in accordance with the education level of the patient. In other areas, it has been shown that approximately one third of all patients are dissatisfied with the communication aspect of their consultations<sup>(16-17)</sup>. Inui et al. suggested that, with brief educational input, physicians could increase their skills as communicators, thus leading to better knowledge levels<sup>(18)</sup>.

In general, ophthalmologists do not have enough time to give a detailed explanation to each and every patient coming to their offices. Educational plans need to be developed to increase patients' knowledge about glaucoma. Videotapes presenting basic information about glaucoma and its treatment, accompanied by a booklet in which patients record medications and instillation times have been suggested as strategies to enhance patients' education<sup>(6-7,11,19)</sup>. Similarly, ophthalmic assistants can be instructed to explain the basics of glaucoma and its treatment to small groups of patients<sup>(20)</sup>.

This study was limited to patient knowledge about glaucoma, its diagnosis and treatment. One aspect of human nature is a disconnection between knowing and doing. Merely having knowledge does not guarantee healthy behaviour. For example, millions of people smoke cigarettes, even though they know that smoking is unhealthy. Nevertheless, knowledge is an important part of self care.

In spite of the remarkable developments in glaucoma treatment and diagnosis, this progress is worthless if patients do not care for themselves properly. Our study showed that few glaucoma patients have a good understanding of the extent, the treatment, and the prognosis of their disease, even in a

practice devoted to glaucoma in a major American city. The major factor determining whether patients with glaucoma retain their sight or become blind is how they care for themselves. A part of their care is use of medications, with appropriate frequency. Other factors are also important, such as returning for appointments with the physician, and providing accurate and pertinent history to the physician. The successful treatment of glaucoma requires competent self-care. As healers, we have a responsibility to help patients learn about their health, including glaucoma, and to stimulate their participation in their treatment. It seems appropriate to develop and study innovative and effective methods to promote this concept.

### RESUMO

**Objetivo:** Avaliar o conhecimento de pacientes glaucomatosos sobre sua doença e tratamento. **Métodos:** 183 pacientes foram entrevistados no Serviço de Glaucoma do Wills Eye Hospital (Philadelphia, EUA, Grupo 1) e 100 pacientes foram entrevistados no Setor de Glaucoma da UNICAMP (Grupo 2). Dezoito perguntas abertas foram feitas aos pacientes num ambiente informal. **Resultados:** No Grupo 1, 44% dos 183 pacientes não tinham conceito adequado sobre o que é glaucoma, 30% desconheciam porque usavam medicações, 47% não sabiam valores de pressão intra-ocular considerados normais e 45% não sabiam porque campos visuais eram testados. No Grupo 2, 54% responderam inadequadamente à pergunta “O que é glaucoma?”, 54% desconheciam porque usavam medicações, 80% não sabiam valores de pressão intra-ocular considerados normais e 94% não sabiam porque campos visuais eram testados ( $p < 0,001$ ). Análise de regressão linear demonstrou que o nível de educação estava positivamente correlacionado ao conhecimento de glaucoma em ambos os grupos ( $r = 0,65$ ,  $p = 0,001$ ). **Conclusões:** Este estudo mostrou que o conhecimento sobre glaucoma varia muito e que, num hospital norte-americano, cerca de um terço dos pacientes tem compreensão mínima sobre a doença, enquanto no Serviço brasileiro, dois terços dos pacientes desconheciam conceitos básicos sobre o glaucoma. Métodos efetivos e inovadores devem ser desenvolvidos para melhorar essa situação.

**Descritores:** Educação do paciente; Glaucoma; Relações médico-paciente

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