

Perception about aspects of the disease and its treatment in patients with glaucoma

Percepção sobre aspectos da doença e de seu tratamento em pacientes portadores de glaucoma

Amanda Venturini Arantes^{1,2} <https://orcid.org/0000-0003-1142-774X>
Alexandre Tomio Umino¹ <https://orcid.org/0000-0001-8466-4215>
Daniel Martin¹ <https://orcid.org/0000-0001-7493-2044>
Farid José Thomaz Neto¹ <https://orcid.org/0000-0002-4816-5838>
Henrique La Rock Moreira Pinto¹ <https://orcid.org/0000-0003-4577-9663>
Renata Magrino Pereira¹ <https://orcid.org/0000-0002-2304-241X>
Leandro Pocay Alves da Silva¹ <https://orcid.org/0000-0002-9512-7359>
Leopoldo Ernesto Oiticica Barbosa^{1,2} <https://orcid.org/0000-0002-6112-8409>

ABSTRACT

Objective: Compare, through structured questionnaires, the knowledge about disease, management of eye drops and adherence to treatment of glaucoma patients disposed in two groups according to educational levels and socioeconomic levels. **Methods:** A cross-sectional analytical study was carried out applying structured questionnaires based on an exploratory study to assess the level of Glaucoma patients' knowledge related with the disease in two different audiences: the single health system (SUS) and private health plans. The questionnaires were used by doctors residents in Ophthalmology. A sample was composed of 202 patients among which 100 were attended by SUS and the others 102 patients were holders of private health plans. All questionnaires have a free and informed consent form signed by the participant and the responsible researcher. **Results:** Patients were divided into two groups, consisting of: 100 SUS patients and 102 private health plans. The results revealed that: 58.6% of SUS patients had incomplete elementary schooling and 25.5% of private health insurance patients had some level of higher education; 49% of the SUS group had an income with less than 2 minimum wages while the health insurance group presented 39.4% with more than 4 minimum wages ($p < 0.001$); 51.5% of the SUS group has no spending on eye drops and 67.4% of the health insurance group spends more than R \$ 30.00 ($p < 0.001$) so, 77% of the SUS group receives financial aid and 52.5% of the health insurance group does not receive any financial support ($p < 0.001$); 63.6% of the health insurance group believes that the bigger amount of instillations than eyedrops does not improve glaucoma, while approximately 50% of the SUS group reports that there is an improvement when increasing instillations or has no idea ($p = 0.030$); Both groups obtained a similar level of general knowledge of the disease, with no statistical difference. **Conclusion:** We conclude that regardless of educational and socioeconomic level if prevails a good doctor-patient relationship, in addition to close monitoring, it is possible to transmit adequate knowledge about the disease, increasing levels of treatment adherence.

Keywords: Glaucoma; Patient education; Physician-patient relations; Blindness/prevention & control; Health public.

¹Instituto Suel Abujamra, São Paulo, SP, Brazil.

²Hospital das Clínicas, Faculdade de Medicina, Universidade de São Paulo, São Paulo, SP, Brazil

The author declare no conflict of interest

Received for publication 6/9/2020 - Accepted for publication 21/11/2020.

RESUMO

Objetivo: Comparar por meio de questionários estruturados, o conhecimento sobre a doença, o manejo de colírios e a adesão ao tratamento de portadores de glaucoma pertencentes a dois públicos com nível de escolaridade e nível sócio econômico distintos. **Métodos:** Foi realizado um estudo transversal analítico aplicando-se questionários estruturados, com base em estudo exploratório para avaliação do nível de conhecimento dos portadores de Glaucoma em relação a doença em dois públicos diferentes: sistema único de saúde (SUS) e planos privados de saúde. Os questionários foram aplicados por médicos residentes em Oftalmologia. A amostra é composta de 202 pacientes dentre eles 100 atendidos pelo SUS e os outros 102 pacientes dos planos privados de saúde. Todos os questionários possuem termo de consentimento livre e esclarecido assinado pelo participante e pelo pesquisador responsável. **Resultados:** Os pacientes foram divididos em dois grupos, compostos por: 100 pacientes SUS e 102 planos de saúde privado. Os resultados revelaram que: 58,6% dos pacientes do SUS tinham escolaridade nenhuma a fundamental incompleto e 25,5% dos pacientes de convênio tinham algum nível superior); 49% do grupo SUS tinham renda com menos de 2 salários mínimos enquanto que grupo convênio apresentou 39,4% com mais de 4 salários mínimos ($p < 0,001$); 51,5% do grupo SUS não tem gastos com compra de colírios e 67,4% do grupo convênio gasta mais de R\$30,00 ($p < 0,001$) portanto 77% do grupo SUS recebe ajuda e 52,5% do grupo convênio não recebe ajuda ($p < 0,001$); 63,6% do grupo convênio acredita que a quantidade de instilações a mais do colírios não obtêm uma melhora do glaucoma, enquanto aproximadamente 50% do grupo SUS relata que há uma melhora com aumento das instilações ou não tem ideia ($p = 0,030$); Ambos os grupos obtiveram um nível de conhecimento geral da doença semelhante, sem diferença estatística. **Conclusão:** Concluímos que, independente do nível de escolaridade e nível socioeconômico, havendo boa relação médico-paciente, além de acompanhamento orientado e próximo, é possível transmitir conhecimento adequado sobre a doença elevando o nível de adesão ao tratamento pelo paciente.

Descritores: Glaucoma; Educação do paciente; Relação médico-paciente; Cegueira/prevenção & controle; Saúde pública.

INTRODUCTION

Glaucoma is the leading cause of irreversible blindness in the world and responsible for 10% of global blindness, this prevalence is increasing due to population aging and longer life expectancy.^(1,2) Estimates suggest that at the end of 2040 approximately 111.8 million people will be affected by the disease.⁽²⁾

The concept of glaucoma has been dynamic and now defined as a chronic optic neuropathy characterized by progressive damage to the optic nerve, with consequent loss of visual field.⁽³⁾ It is a condition that, due to its clinical characteristics and visual prognosis, requires commitment of the patient to the treatment, and should receive prolonged follow-up, conditions that prevent blindness.⁽⁴⁾

The main risk factors for the progression of glaucoma are increased intraocular pressure (IOP), age, ethnicity, family history, non-adherence to treatment and ignorance of the population regarding the disease and its visual consequences.⁽⁴⁾

Glaucoma reduces quality of life proportionally to the severity or evolutionary stage of the disease, leading patients to face daily challenges such as reduced mobility, difficulty in reading, factors that indirectly lead to an increase in the number of falls from the own height, a negative psychological behavior that in some cases cause depression.⁽⁵⁻⁷⁾ In addition, blindness and visual impairment also affect family members, the health system and society in general, creating a substantial socioeconomic problem.⁽⁸⁾

The treatment of the disease is lifelong and has several alternatives, the most used of which is the topical use of antihypertensive eye drops, the preferred choice among patients and ophthalmologists themselves.⁽⁹⁾ However, for its effectiveness, the cooperation of patients and their caregivers is necessary. Instillation of eye drops and the spacing between them to obtain an effective reduction of intraocular pressure are required to stop or slow the progression of visual impairment due to Glaucoma.⁽¹⁰⁻¹²⁾ Adherence to treatment is lower than desired as it is influenced by the severity of the disease, the number of eye drops in use, the level of literacy and the cost of medication.^(13,14)

In view of factors already described as the cause of failure to treat glaucoma, studies suggest a positive relationship between the incorrect use of medications and unknown about the disease,

therefore demonstrating that increasing the knowledge of patients about their disease and “adapting” the therapeutic regimen to the patients' daily lives effectively increased the correct use of medication.⁽¹⁵⁾ The assessment of the knowledge of the general population is a topic that is sparse in the literature. The objective of this study was to compare between two distinct groups: Brazilian National Health System (SUS) and private system (health insurance): the level of knowledge about the disease, the management of eye drops and adherence to treatment according to socioeconomic levels on the perception of patients with Glaucoma treated at the Suel Abujamra Institute, São Paulo-SP.

METHODS

A cross-sectional research was made among 202 patients with glaucoma of the Brazilian National Health System (SUS) and Health insurance of the Suel Abujamra Institute, in the city of São Paulo. The sample was obtained from the following criteria: age over 18 years, diagnosed with glaucoma. This article has a certificate of presentation of appreciation (CAAE) 17518219.6.0000.5477.

A questionnaire (Appendix 2) was prepared based on a preliminary study of reality - called an exploratory study. This methodological resource has the purpose of obtaining information about terminology, verbal and variable expressions, present in a similar population. The knowledge thus obtained allows introducing elements that integrate that reality into the research questionnaire, which facilitates communication with the sample subjects and the understanding of the instrument's questions. The exploratory study often leads the researcher to discover new approaches, perceptions and terminologies for him, contributing so that, gradually, his own way of thinking is modified.⁽¹⁶⁾

The present study presents the following variables: sex, age, race, profession, education, socioeconomic level, assiduity in the use of eye drops, among others. All the patients received explanations about glaucoma and self-assessment of knowledge regarding glaucoma. The variable “self-assessment of knowledge” was measured using an ordinal scale, including the categories: knows well or knows nothing about the disease and its treatment, and in this way, an attempt was made to increase the accuracy of the measurement. The adequacy of this scale was confirmed in the

exploratory and previous test phases of the instrument.

Data collection was carried out from December 2015 to May 2017, using the questionnaire application (Appendix 2), considering the possible limitations of the population with below grade level of school. Interviews was conducted by residents in ophthalmology for both different groups of individuals attended by SUS and by the health insurance. Respondents were guaranteed anonymity and data confidentiality.

A statistical analysis was performed using the chi-square test, established significance level of 0.05.

Statistical analysis

The frequency distribution was used to describe categorical variables and measures of central tendency and variability for numerical variables.

To compare strategic variables from a specific group (SUS and health insurance), chi-square frequency tests was used in a 2x2 tables, when at least one expected frequency was less than 5 the Fisher's exact test was adopted. The Shapiro-Wilk test was used to verify the normality of numerical variables

The association between categorical variables and the group (SUS and Health Insurance) was verified using the Mann-Whitney U non-parametric test.

The significance level of 5% was adopted for all statistical tests.

The STATA version 10.0 program was used for statistical analysis.⁽¹⁷⁾

RESULTS

The sample consisted of 202 patients, 100 SUS patients and 102 from the health insurance group.

Table 1 shows the demographic data for each group, such as age and race. Grouped by schoolarity, 58.6% patients from SUS had incomplete elementary schoolarity and 25.5% of health insurance patients had higher education (<0.001).

Table 2 shows the association regarding socioeconomic level, obtaining eye drops and money spending. It shows that 49% of the SUS group has an income less than 2 minimum wages while the health insurance group presented 39.4% with more than 4 minimum wages (p <0.001). It also shows that 51.5% of the SUS group has no expenses with the purchase of eye drops and 67.4% of the health insurance group spends more than R\$ 30,00 (p <0.001). However, 77% of the SUS group receives help and 52.5% of the health insurance group does not receive help (p <0.001). 76.6% of the SUS group receives help from SUS and 52.1% of the health insurance group receives some help from SUS (= 0.004).

Table 3 shows the distribution of variables on the level of knowledge of the disease: Importance of carrying out the appropriate treatment, level of knowledge of the disease and treatment according to the service group (SUS / Health Insurance), emphasizing that both groups were followed up by the same team of gaucomatologist, so there was no statistically significant difference between the groups, suggesting the same level of information about the disease and the doctor-patient relationship between them.

Table 1
Demographic distribution according to service group (SUS / Health insurance) 202 patients.

Variable	Category / Measures	Group		p-value
		Health insurance	SUS	
		Freq. (%) / Measures		
Genre	Female	68 (66,7)	60 (60,0)	0,325
	Male	34 (33,7)	40 (40,0)	
Age (Years)	Number	98	96	0,796 *
	Variation	24 – 88	42 – 90	
	Average	64,3	64,9	
Ethnic group	Black	13 (14,4)	23 (25,0)	0,006
	White	50 (55,6)	50 (54,3)	
	Pardo/ Brown	15 (16,7)	18 (19,6)	
	Yellow	12 (13,3)	1(1,1)	
Profession	Retired	32 (35,6)	35 (40,2)	0,589
	Home occupation	17 (18,9)	19 (21,8)	
	Others	41 (45,6)	33 (37,9)	
Education Level	None – incomplete fundamental	41 (40,2)	58 (58,6)	<0,001
	Fundamental complete - High school	35 (34,3)	36 (36,4)	
	Superior incomplete or complete	26 (25,5)	5 (5,0)	

p-value obtained by chi-square frequency test

* p-value obtained by the Mann-Whitney U Test

Table 2
Distribution of socioeconomic variables according to service group (SUS / Health Insurance) - 202 patients

Variable	Category	Group		p-value
		Health Insurance	SUS	
Income (Minimum Wages)	< 2	22 (23,4)	47 (49,0)	NA
	2 – 4	35 (37,2)	41 (42,7)	
	4 – 10	28 (29,8)	8 (8,3)	
	10 – 20	3 (3,2)	0 (0,0)	
	> 20	6 (6,4)	0 (0,0)	
Income (Minimum Wages)	< 2	22 (23,4)	47 (49,0)	<0,001
	2 – 4	35 (37,2)	41 (42,7)	
	> 4	37(39,4)	8 (8,3)	
Money spend on eye drops (R\$)	0	26 (26,5)	51 (51,5)	<0,001
	≤ 30	6 (6,1)	11 (11,1)	
	> 30	66 (67,4)	37 (37,4)	
Stop using eye drops if money is running out	No	88 (86,3)	79 (81,4)	0,354
	Yes	14 (13,7)	18 (18,6)	
Receives help to obtain eye drops	No	53 (52,5)	23 (23,0)	<0,001
	Yes	48 (47,5)	77 (77,0)	
From where receive help and / or donation	SUS	22 (45,8)	54 (70,1)	NA
	Family and / or Friends	4 (8,3)	7 (9,1)	
	Free Samples	7 (14,6)	8 (10,4)	
	Others	12 (25,0)	3 (3,9)	
	SUS + (Family and Friends)	1 (2,1)	1 (1,3)	
	SUS + Free Samples	2 (4,2)	4 (5,2)	
From where receive help and / or donation	SUS or SUS+others	25 (52,1)	59 (76,6)	0,004
	Others non SUS	23 (47,9)	18 (23,4)	

p-value obtained by chi-square frequency test
 NE= Not statistically evaluable

Table 4 shows the answers to the questions related to the management of the used eye drops and their knowledge about them, according to the service group. It shows that 63.6% of the health insurance group reports that they do not think that if more drops are instilled the disease changes the prognosis and approximately 50% of the SUS group reports that they think the quantity of the drops changes the prognosis or have no idea about this ($p = 0.030$).

On the other hand, 69.4% of the health insurance group reports that there is some difficulty in the process of instill eye drops and 53.3% of the SUS group reports that does not ($p = 0.002$).

We can say that there is a small significant difference association for adverse reaction knowledge with the use of eye drops, with 67% of the health insurance group reported that it does not exist and 46.4% of the SUS group say that there is some reaction ($p = 0.055$), there is a tendency to be different. There are

no statistically significant associations with the other variables.

Table 5 does not present statistical differences considered for important data, such as: the frequency of glaucoma patients in consultations with their ophthalmologists, 45.9% in the health insurance group and 50% in the SUS group. It also demonstrates the patient response to the doctor-patient relationship that is being used as 100% good in the health insurance group and 99% in the SUS group.

DISCUSSION

Glaucoma is classified as a chronic disease and has a high prevalence generating high costs for the public or private health system. According to a North American study, the direct annual medical costs for patients with initial glaucoma, advanced glaucoma and end-stage glaucoma averaged \$ 623, \$ 1915 and \$ 2511,

Table 3
Distribution of variables on the level of knowledge of the disease: Importance of carrying out the appropriate treatment, level of knowledge of the disease and treatment according to the care group (SUS / Health Insurance)

Variable	Category	Group		p-value
		Health Insurance	SUS Freq. (%)	
Importance of performing the proper treatment	2 – Prevent disease progression	14 (14,3)	13 (13,1)	0,031
	4 – Avoid going blind	16 (16,3)	26 (26,3)	
	2; 4	23 (23,5)	9 (9,1)	
	1;2;4	19 (19,4)	26 (26,5)	
	Outthers (1;3) (1:Better vision/ 3:Cure)	15 (15,1)	36 (36,4)	
Meaning of glaucoma	No	29 (29,6)	38 (38,0)	0,211
	Yes	69 (70,4)	62 (62,0)	
Knowledge about glaucoma being a chronic disease - it can lead to blindness	No	7 (7,1)	5 (5,0)	0,540
	Yes	92 (92,9)	95 (95,0)	
Lifelong treatment and constant use of eye drops	Não	12 (12,0)	7 (7,0)	0,228
	Sim	88 (88,0)	93 (93,0)	
TTreatment starting right after diagnosis	Não	11 (11,1)	9 (9,1)	0,637
	Sim	88 (88,9)	90 (90,9)	

p-value obtained by chi-square frequency test

respectively. The use of resources and direct medical costs increase as the disease progresses, ranging from 42% to 56% direct costs at each stage of the disease.⁽¹⁸⁾ These numerical data emphasize the need for studying ways to obtain an adequate treatment of the disease, avoiding its progression to more advanced stages.

In the present study, we observed that there is a significant difference in the level of education and socioeconomic level between the groups, being higher in the group health insurance. Studies have observed that patients with higher educational levels showed better commitment to treatment.⁽¹⁹⁾ However, we collected the patients responses about “the importance of carrying out the appropriate treatment”, “the knowledge about what Glaucoma is and the chronicity of the disease” and also about the “need for lifelong treatment and use of eye drops”, we observed that both groups were aligned with similar responses even though they had different levels of education and socioeconomic status.

Another criterion evaluated in this study was the classification of patients on the relationship with their ophthalmologist, and we obtained a predominance response in both groups that have an “excellent doctor-patient relationship”, there were no answers to a bad or terrible doctor-patient relationship. Therefore, we believe that this similarity of knowledge about Glaucoma between the groups is a consequence of a good doctor-patient relationship and also for the guidance on the disease since the groups are treated and monitored by the same team of ophthalmologists. It is important to develop a good doctor-patient relationship, as the main cause of therapeutic failure occurs due to low fidelity to clinical treatment and not due to the ineffectiveness of the drugs used.⁽²⁰⁾

Some studies suggest that ophthalmologists should avoid the type of passive relationship, in which the patient is only treated by the doctor. As suggested by Riffenburgh, the relationship must begin with the “mentoring cooperation” model, in which the patient listens to the doctor and follows his or her guidelines. As the knowledge about the disease increases, the doctor-patient relationship may change to the type of “mutual participation”, where the doctor helps the patient to help himself.⁽²¹⁾ The disease must be explained to the patient according to their level of education, so doctors must increase their skills as communicators leading to better levels of knowledge.⁽²²⁾

In other areas, it has been shown that approximately one third of all patients are dissatisfied with the communication aspect of their appointments.⁽¹⁵⁾ Kim et al. demonstrated that a 12-minute video produced by the American Academy of Ophthalmology improved knowledge about glaucoma after one week, but not after three months.⁽²³⁾ These facts reinforce the need to maintain guidance and continued dissemination of information on prevention and treatment of Glaucoma in offices and in the community. In our study, follow-up was quarterly for most patients in both groups, therefore, information on disease and treatment management was renewed every 3 months.

Regarding the treatment of the disease by the use of eye drops, our study demonstrates that most patients have difficulty in the process of using eye drops and almost all of them drip the eye drops by themselves. Analyzing the adverse effects: 67% of the health insurance group related that does not had anything and 46.4% of the SUS group had some adverse reaction, with a tendency to be different.

Table 4
Distribution of treatment variables according to service group.
(SUS /Health Insurance).

Variable	Category	Group		p-value
		Health Insurance	SUS	
Adverse effects	No	67 (67,0)	52 (53,6)	0,055
	Yes	33 (33,0)	45 (46,4)	
Stopped using medication for any reason	No	74 (74,0)	69 (69,7)	0,500
	Yes	26 (26,0)	30 (30,3)	
More drops have a better prognosis?	No	63 (63,6)	43 (44,8)	0,030
	Yes	14 (14,1)	21 (21,9)	
	No idea	22 (22,2)	32 (33,3)	
Drips the eye drops by yourself?	No	13 (13,3)	13 (13,1)	0,978
	Yes	85 (86,7)	86 (86,9)	
Is there any difficulty on this process?	No	30 (30,6)	49 (53,3)	0,002
	Yes	68 (69,4)	43 (46,7)	
If yes, Which one?	1- Drips out of the ocular mucosa	12 (17,9)	5 (7,5)	NA
	2 - Drip 2 drops at once	5 (11,6)	3 (7,0)	
	3 - Drips in the corner of the eye	39 (58,2)	29 (67,4)	
	4 - Other	11 (16,4)	2 (4,7)	
	1 ; 2	0 (0,0)	2 (4,7)	
	2 ; 3	0 (0,0)	2 (4,7)	

p-value obtained by chi-square frequency test
 NE= Not statistically evaluable

Table 5
Distribution of variables on Medical Consultation (SUS / Health Insurance)

Variable	Category	Group		p-value
		Health Insurance	SUS	
How often do you go on an ophthalmologist consult?	Every month	10 (10,2)	9 (9,0)	0,901
	Every 6 month	35 (35,7)	35 (35,0)	
	Every 3 months	45 (45,9)	50 (50,0)	
	Once a year	8 (8,2)	6 (6,0)	
Como classifica relação com médico oftalmologista	Great	73 (76,0)	63 (63,6)	NA
	Good	23 (24,0)	35 (35,4)	
	Average	0 (0,0)	1 (1,0)	
	Bad	0 (0,0)	0 (0,0)	
	Terrible	0 (0,0)	0 (0,0)	
How do you rate your relationship with an ophthalmologist?	Great	73 (76,0)	63 (63,6)	0,059
	Good or average	23 (24,0)	35 (36,4)	

Some studies have linked the irregularity of treatment with: economic difficulty, forgetting medication schedules, the lack of visual improvement, side effects and the difficulty of self-ins-tillation of eye drops.⁽²⁴⁾ Although studies have demonstrated the impact of economic difficulties in the purchase of eye drops and, therefore, poor adherence to treatment, in our study 81.4% of SUS patients and 86.3% health insurance group reported that they do not stop using eye drops if the money to buy is running out. Furthermore, within the SUS group, we showed a bias in 77% of patients receiving help to obtain eye drops, 70% of which are helped by the public health system.

However, it is not enough to have the eye drops at home, but to perform an adequate management following the proposed guidelines. Often patients present in outpatient clinics with IOPs higher than expected despite prescribing hypotensive eye drops, the doctor faces a dilemma, as the IOP reflects the patient's physiological response to the drops and the patient's level of adherence to the drops. Generally, this high level of IOP leads doctors to assume a poor response to medication instead of low adherence to eye drops, adding alternative or additional drugs to achieve the desired IOP reduction. This practice can adversely affect the outcome if adherence is a problem, as adherence rates tend to fall with more complex medication regimens.^(25,26)

Glaucoma is a chronic disease that causes significant visual impairment and ends up damaging the daily lives of individuals in terms of: mobility, reading, social, psychological and also economic for the individual himself and for the governmental system of his country. There is a great diversity of people with the disease, whether economic or educational, so we emphasize the importance of transmitting knowledge about Glaucoma according to the level of education and always maintaining a good doctor-patient relationship, which have been shown to increase the rates of attendance to treatment. This “doctor-patient relationship”, in our study, broke the barrier of socioeconomic difference and educational level since it was reported by patients in both groups as “Excellent” and consequently both had similar levels of knowledge about the disease and adherence to the treatment.

CONCLUSION

When analyzing the two groups of people with glaucoma, in relation to socioeconomic and educational differences, and understanding what is different between them and if it impacts on the treatment of Glaucoma we have concluded that regardless of educational level and socioeconomic status, if there is a good doctor-patient relationship, clear communication between them according to each patient's level of understanding, in addition to close monitoring, it is possible to transmit adequate knowledge about the disease, raising levels of treatment adherence.

REFERENCES

1. Flaxman SR, Bourne RR, Resnikoff S, Ackland P, Braithwaite T, Cicinelli MV, et al.; Vision Loss Expert Group of the Global Burden of Disease Study. Global causes of blindness and distance vision impairment 1990-2020: a systematic review and meta-analysis. *Lancet Glob Health*. 2017;5(12):e1221-34.
2. Tham YC, Li X, Wong TY, Quigley HA, Aung T, Cheng CY. Global prevalence of glaucoma and projections of glaucoma burden through 2040: a systematic review and meta-analysis. *Ophthalmology*. 2014;121(11):2081-90.
3. Silva MJ, Temporini ER, Neustein I, Araujo ME. Conhecimentos sobre prevenção e tratamento de glaucoma entre pacientes de unidade hospitalar. *Arq Bras Oftalmol*. 2004;67(5):785-90.
4. Paula JS, Ramos Filho JA, Cecchetti DF, Nagatsuyu DT, Rodrigues ML, Rocha EM. Medical decision, persistence of initial treatment, and glaucoma progression in a Brazilian reference hospital. *Arq Bras Oftalmol*. 2010;73(2):141-5.
5. Freeman EE, Muñoz B, West SK, Jampel HD, Friedman DS. Glaucoma and quality of life: the Salisbury Eye Evaluation. *Ophthalmology*. 2008;115(2):233-8.
6. McKean-Cowdin R, Wang Y, Wu J, Azen SP, Varma R; Los Angeles Latino Eye Study Group. Impact of visual field loss on health-related quality of life in glaucoma: the Los Angeles Latino Eye Study. *Ophthalmology*. 2008;115(6):941-948.e1.
7. Varma R, Lee PP, Goldberg I, Kotak S. An assessment of the health and economic burdens of glaucoma. *Am J Ophthalmol*. 2011;152(4):515-22.
8. Feldman RM, Cioffi GA, Liebmann JM, Weinreb RN. Current knowledge and attitudes concerning cost-effectiveness in Glaucoma pharmacotherapy: a glaucoma specialists focus group study. *Clin Ophthalmol*. 2020;14:729-39.
9. Shadid A, Alrashed W, Bin Shihah A, Alhomoud A, Alghamdi M, Alturki A, et al. Adherence to medical treatment and its determinants among adult Saudi glaucoma patients in Riyadh city. *Cureus*. 2020;12(2):e6847.
10. Harasymowycz P, Birt C, Gooi P, Heckler L, Hutnik C, Jinapriya D, et al. Medical management of glaucoma in the 21st century from a Canadian perspective. *J Ophthalmol*. 2016;2016:6509809.
11. Hark LA, Leiby BE, Waisbourd M, Myers JS, Fudemberg SJ, Mantravadi AV, et al. Adherence to follow-up recommendations among individuals in the Philadelphia Glaucoma Detection and Treatment Project. *J Glaucoma*. 2017;26(8):697-701.
12. Kim CY, Park KH, Ahn J, Ahn MD, Cha SC, Kim HS, et al. Treatment patterns and medication adherence of patients with glaucoma in South Korea. *Br J Ophthalmol*. 2017;101(6):801-7.
13. Fudemberg SJ, Lee B, Waisbourd M, Murphy RA, Dai Y, Leiby BE, et al. Factors contributing to nonadherence to follow-up appointments in a resident glaucoma clinic versus primary eye care clinic. *Patient Prefer Adherence*. 2016;10:19-25.
14. Sheer R, Bunniran S, Uribe C, Fiscella RG, Patel VD, Chandwani HS. Predictors of nonadherence to topical intraocular pressure reduction medications among Medicare members: a claims-based retrospective cohort study. *J Manag Care Spec Pharm*. 2016;22(7):808-817a.
15. Costa VP, Spaeth GL, Smith M, Uddoh C, Vasconcellos JP, Kara-José N. Patient education in glaucoma: what do patients know about glaucoma? *Arq Bras Oftalmol*. 2006;69(6):923-7.
16. Piovesan A, Temporini ER. Pesquisa exploratoria: procedimento metodológico para o estudo de fatores humanos no campo da saúde pública. *Rev Saude Publica*. 1995;29(4):318-25.
17. STATA Corp. Stata Statistical Software: Release 10.0. College Station (Texas): Stata Corporation; 2007.
18. Feldman RM, Cioffi GA, Liebmann JM, Weinreb RN. Current Knowledge and Attitudes Concerning Cost-Effectiveness in Glaucoma Pharmacotherapy: A Glaucoma Specialists Focus Group Study. *Clin Ophthalmol*. 2020;14:729-39.
19. Zimmerman TJ, Zalta AH. Facilitating patient compliance in glaucoma therapy. *Surv Ophthalmol*. 1983;28 Suppl:252-8.
20. Sociedade Brasileira de Glaucoma. II Consenso Brasileiro de Glaucoma Primário de Ângulo Aberto. São Paulo: Sociedade Brasileira de Glaucoma; 2012.
21. Riffenburgh RS. Doctor-patient relationship in glaucoma therapy. *Arch Ophthalmol*. 1966;75(2):204-6.

- 22. Inui TS, Yourtee EL, Williamson JW. Improved outcomes in hypertension after physician tutorials. A controlled trial. *Ann Intern Med.* 1976 Jun;84(6):646–51.
- 23. Kim S, et al. Glaucoma patient education. *Invest Ophthalmol Vis Sci.* 1996;37 Suppl: S642.
- 24. Cintra FA, Costa VP, Tonussi JA, Jose NK. Avaliação de programa educativo para portadores de glaucoma. *Rev Saude Publica.* 1998;32(2):172–7.
- 25. International Council of Ophthalmology (ICO). *ICO Guidelines for Glaucoma Eye Care*, 1st edition. Melbourne: ICO; 2016. [cited 2020 Jan 7]. Available from: <http://www.icoph.org/downloads/ICOGlaucomaGuidelines.pdf> [
- 26. Waterman H, Read S, Morgan JE, Gillespie D, Nollett C, Allen D, et al. Acceptability, adherence and economic analyses of a new clinical pathway for the identification of non-responders to glaucoma eye drops: a prospective observational study. *Br J Ophthalmol.* 2020 Mar 4;bjophthalmol-2019-315436

Autor correspondente:
Amanda Venturini Arantes
amandava89@hotmail.com

Appendix 1

FIRST ATTACHMENT

FREE AND CLARIFIED CONSENT

We invite you to participate in the “Perception about aspects of the disease and its treatment in patients with glaucoma with different educational and socioeconomic levels” under the responsibility of Alexandre Tomio Umino research MD, who intends to carry out a questionnaire about Glaucoma (definition, treatment, consequences and rate of adherence).

Your Participation is voluntary and will take place by answering the 15- minute questionnaire questions, while waiting for your routine appointment at the Ophthalmologist at the Ophthalmological Institute Suel Abujamra, there will be no risk for the participant. If you agree to participate, you are contributing to improving continuing education about Glaucoma.

If after consenting to your participation, you give up continuing to participate, you have the right and freedom to withdraw your consent at any stage of the research, whether before or after data collection, regardless of the reason and without any prejudice to your person. You will have no expenses and you will not receive any remuneration. The results of the research will be analyzed and published, but your identity will not be disclosed and will be kept confidential. For any other information, you may contact the Research Ethics Committee of Ophthalmological Institute Suel Abujamra (11) 33992044, address Rua Tamandaré 693, Aclimação – ZIP code: 01525001 – city of São Paulo/SP – Brazil.

Post-Informed Consent

I, _____, was informed about what the researcher wants to do and why he needs my collaboration and understood the explanation. Therefore, I agree to participate in the Project, knowing that I will not receive any amount of Money and that I can leave whenever I want. This document is issued in two copies that will be signed by both me and the researcher, leaving one copy with each one of us.

Participant’s signature

Researcher’s signature

Appendix 2

QUESTIONNAIRE

A. PERSONAL DATA

Full name: _____

Age: _____ Gender: F () M ()

Profession: _____

Race: Black () White () Pardo () Asian () Another ()

Educational level:

Elementary School () Incomplete Middle School () Middle School () Incomplete High School () High School () Incomplete Higher Degree () Higher Degree ()

B. Socioeconomic conditions

1. Income (including everyone that works and lives at the same house): Until 2 minimum wages () between 2 and 4 minimum wages () 4 to 10 minimum wages () 10 to 20 minimum wages () more than 20 minimum wages ()

2. How much do you spend monthly in order to buy eye drops?

() Nothing () until R\$ 30,00 () more than R\$ 30,00

3. Do you stop using eye drops if your money is low?

() Yes () No

4. Do you receive any governmental aid or donations to buy one of this medicines?

() Yes () No

If your answer was yes, from whom do you receive this aid or donation?

() By the Brazilian National Health System (SUS) () Relatives/Friends

() Free samples () Others

C. Diagnosis/ Level of disease knowledge

1. How long has glaucoma been diagnosed? _____ years

2. The Glaucoma was diagnosed in a routine medical appointment with an ophthalmologist?

() Yes () No

3. Have you been into a Glaucoma surgery?

() Yes () No

If you answered yes, when? _____

4. Do you know what Glaucoma is? () Yes () No

5. Why is so important to carry out the appropriate treatment?

() Improve vision () To avoid the disease advancing () Heal () Avoid blindness () To avoid other diseases () There is no importance

6. Do you know that Glaucoma is a chronic disease that can lead you to blindness?

() Yes () No

7. Do you know that glaucoma treatment is lifelong and the eye drops should to be constantly used for unevolved glaucoma?

() Yes () No

D. Treatment

1. The drug treatment was started just after the diagnosis? () Yes () No
2. Which eye drop(s) are you currently using against glaucoma and how many daily applications?
 - () Maleato de timol () 1 () 2 () 3
 - () Tartarato de Brimonidina () 1 () 2 () 3
 - () Acetazolamida (Diamox) () 1 () 2 () 3
 - () Cloridrato de Pilocarpina () 1 () 2 () 3
 - () Latanoprost () 1 () 2 () 3
 - () Bimatoprost () 1 () 2 () 3
 - () Travoprost () 1 () 2 () 3
 - () Dorzolamida () 1 () 2 () 3
 - () Betaxolol () 1 () 2 () 3
 - () Dorzolamida + maleate de Timolol () 1 () 2 () 3
 - () Latanoprost + maleato de Timolol () 1 () 2 () 3
 - () Tartarato de brimonidina + maleato de timolol () 1 () 2 () 3
 - () Others
3. About your current eye drop(s), how many bottles do you use monthly?
 - a. _____, _____ bottles
 - b. _____, _____ bottles
 - c. _____, _____ bottles
 - d. _____, _____ bottles
4. Have you experienced any adverse reaction? () Yes () No
If yes, which ones?
() eye irritation () burning () headache () visual turbidity () weight loss () bitter taste in the mouth () dryness of conjunctiva () tearing () hypotension () other _____
5. Have you ever stopped using the medication because of any reason?
() Yes () No
If you have already interrupted your treatment, why?
() side effects () too costly () difficulty in instilling eye drops () number of eye drops to be instilled () forgetfulness
6. Do you think that dripping more drops will help glaucoma to heal faster?
() Yes () No () No idea
7. Do you drip the eye drop by yourself? () Yes () No
If no, who drips? son () spouse () parents () others ()
8. Have you any difficult dripping the eye drop? () Yes () No
If yes, which ones: () drips outside the ocular mucosa () drip 2 drops at once () drips in the eye corner () others _____
9. How often do you have medical appointments with your ophthalmologist?
() monthly () every six months () every 3 months () once a year
10. How do you classify your relation with your ophthalmologist?
() Great () Good () Fair () Bad () Horrible
11. Associated diseases
Do you have another disease? () Yes () No
If yes, which ones? Diabetes () Hypertension () Others _____
Do you take any medicine to control diabetes? Yes () No ()
Do you take any medicine to control hypertension? () Yes () No