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Glaucoma Literacy in a Portuguese Population

Catarina Pestana Aguiar[1,*], João Alves Ambrósio[1], Isabel Lopes Cardoso[1], Manuela Amorim[1], João Chibante Pedro[1], Jeniffer Jesus[1]

[1]Unidade Local de Saúde Entre o Douro e Vouga, Santa Maria da Feira, Portugal

Abstract

Studies show that individuals with limited health literacy skills experience worse health outcomes in a multitude of chronic diseases including glaucoma. These patients have poorer compliance, worse disease understanding and greater disease progression. The main purpose of our study was to evaluate the knowledge about glaucoma basic concepts in patients with this disease. A 24 question survey was given to patients followed by the glaucoma department, by phone or in person. Epidemiological data and personal therapeutic regimens were collected as well as data concerning the pathophysiology, treatment and prognosis of the disease. Survey responses were obtained from 79 patients with a mean age of 72 years old. Most of the patients had a low education level. The majority of patients could not enumerate glaucoma risk factors (74.5%), their glaucoma type (94.9%) or the best glaucoma definition (57%). However, they were able to relate the disease to a high IOP (75.9%) and the possibility of it leading to blindness (96.2%). We believe that patients, when observed in their glaucoma appointments, tend to retain information related to the prognosis and consequences of the disease and not focus on the understanding of its pathophysiology, causes and mechanisms, which may reflect their concern about their own future. However, this may lead to some misconceptions about the definition of glaucoma and specially about what can cause this disease. Some investment should be done to improve health literacy in the glaucoma population, with appropriate language and handed material.

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Corresponding author:

Catarina Pestana Aguiar, Unidade Local de Saúde Entre o Douro e Vouga, Santa Maria da Feira, Portugal

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Introduction

Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”. Patients with chronic diseases and low health literacy have an inferior knowledge about their disease and its treatment when compared to literate patients. Studies show that this can lead to lower self-management skills, increased rates of hospitalization, less use of preventive services and increased overall mortality. [1, 2] The prevalence of visual impairment has been associated with age, race, general health status, educational level, income, and employment status. Health literacy is related to socioeconomic status.(3) Around 50% of adults with open angle glaucoma have poor health literacy, which can be associated with decreased adherence to intraocular pressure

(IOP)-lowering medication and a more advanced visual field loss.[1, 2] It has been demonstrated that glaucoma patients with low health literacy are medicated with more topical

hypotensive drugs and have higher medication costs, but, on the other hand, have fewer outpatient glaucoma visits.[4] Also, a study demonstrated that health literacy may be associated with the physical ability to instill ophthalmic drops properly in the eye.[5] Since we strive to improve care for patients with glaucoma, further attention to this problem must be taken. The main purpose of our study was to evaluate the knowledge about glaucoma basic concepts in patients from the glaucoma department of our hospital.

Materials and Methods

A 24-question survey was given to patients followed by the glaucoma department of our hospital, by phone or in person. Epidemiological data and personal therapeutic regimens were collected as well as data concerning what patients knew about the pathophysiology, treatment and prognosis of glaucoma. All patients included had primary or secondary open-angle glaucoma. Informed consent was obtained and the research adhered to the tenets of the Declaration of Helsinki. A statistical analysis was conducted with the results of the survey.

Results

The questionnaire was done on 79 patients with a mean age of 72 years old (from 53 to 86 years old). There were 51.9% male (n=41) and most of the patients (83.5%, n=66) were retired. Regarding their education level, the majority only had the 4th grade (70.9%, n = 56). The different education levels are specified in Table 1.

In terms of therapeutic regimen, most patients used 1 or 2 eyedrops containers (41.8%, n = 33 and 44.3%, n= 35, respectively) and used medication twice a day (72.2%, n=57). 89.8% (n=71) were on IOP-lowering medication for at least 2 years. This information is detailed in Table 2.

The questionnaire given about glaucoma concepts is presented in full detail in Appendix 1. Most of the patients reported having heard about the disease (84.8%), but did not know the risk factors for its development (74.7%) or which type they had (94.9%). Most of them could associate glaucoma with a high IOP (75.9%), but only 26.6% could choose the best glaucoma definition. Only half of the patients associated the disease with the absence of symptoms at an initial stage (53.2%), knew about its irreversibility (48.1%) or about the absence of cure (53.2%). 96.2% understood the possibility of blindness. Most of them did not know eyedrops side effects (79.7%) and had an apparently good

Table 1. Education level of the population

Level of Education	**N (%)**
No school attendance	10 (12.7)
4th grade	56 (70.9)
6th grade	3 (3.8)
9th grade	4 (5.1)
High School	4 (5.1)
University	2 (2.5)

Table 2. Therapeutic regimen of the population

IOP-lowering medication usage	**N (%)**
More than 5 years	40 (50.6)
Between 2 and 5 years	31 (39.2)
Less than 1 year	8 (10.1)
Number of eyedrop containers	**N (%)**
Zero	5 (6.3)
One	33 (41.8)
Two	35 (44.3)
Three	6 (7.6)
Daily frequency of medication application	**N (%)**
Once	17 (21.5)
Twice	57 (72.2)
Not applicable	5 (6.3)

compliance with them (75.9%). Most patients showed some or major concern about the disease, the treatment adherence or routine evaluations.

Discussion

As we would have expected, the population from our study was elderly (mean age 72 years old) and studies show that this type of population is disproportionately affected by low literacy.[1,6] The results of our questionnaire reflect the misconceptions and lack of information patients have about glaucoma. Most patients could not choose from a list of options the best glaucoma definition and could not enumerate their glaucoma type. They could not also enumerate any glaucoma risk factor but we believe that this has mainly to do with the fact that patients could not understand the concept of "risk factor" which led to answers like *dry ocular nerve*, *dry ocular vein* and *degenerative disease* in some of those who said they were able to enumerate some. This was also visible with the direct question regarding the most frequent association between IOP and glaucoma, at which 75.9% of the patients answered *high*. Our population had a low education level, with 83.6% of patients only having the 4th grade or inferior which can be the reason for poor definitions' understanding. However, studies have shown that poor education alone may not predict health literacy skills, since many adults read at a level three to five grades below their last completed grade in school.[3] Therefore, health literacy and educational level are not synonymous concepts, being the first more closely related to health outcomes.[1]

A positive aspect of the answers given by the patients, was the fact that almost all of them could recognize that this disease can lead to blindness (96.2%). We believe that this is something medical doctors tend to emphasize during medical appointments to increase patients' compliance with the medication, therefore it is an information well acquired by the glaucoma population. Additionally, an aspect that severely concerned us was the fact that more than half of the patients (51.9%) did not recognize the irreversibility of the disease, even though they understand it had no cure (53.2%). Most could also report the absence of symptoms in initial states (53.2%) and the purpose of IOP-lowering

medication (64.6%). Glaucoma being typically asymptomatic in the earlier stages of the disease leads to patients not feeling the immediate benefit of therapy adherence [7], but acknowledging that is a factor which may improve adherence.

Adherence to eyedrops has been reported to be only 60%, with the most frequent barriers being cost, forgetfulness, side effects, difficulty with eye drop administration, and the need for multiple doses a day.[7] In our study, most of the patients used the drops twice a day (72.2%) but could not recognize their side effects (79.7%). The only reported reason for not using them was forgetfulness (24.1%) even though the majority of them affirmed total compliance, with 75.9% saying they have never missed a drop on the previous 2 weeks. Despite this being a positive value, superior to the one reported in studies [7], we think that this value could be overestimated due to self-reported adherence and possible fear of answering with truth. Most patients stated having some concerns about the disease (48.1%) and finding the treatment and follow up important or very important.

With our results, we concluded patients tend to retain information regarding the prognosis of the disease (potential of blindness, absence of cure) but have difficulty in the understanding of the pathophysiology and the causes of the disease. This could be the reflection of the concerns about their own future or because health care professionals tend to focus on the consequences of the disease and spend less time explaining its mechanisms during regular appointments. Therefore, strategies to increase patients' literacy are essential to diminish glaucoma misconceptions. Various interventions have shown efficacy, namely written instructions targeting specific health literacy, literacy level appropriate education videos, and interactive and personalized educational programs. Also, it has also been shown that doctor-dependent learners had poorer adherence than collaborative and independent learners.[7] During the busy appointment schedules, it may be difficult for medical doctors to spend time educating patients to improve adherence, especially in a single clinic encounter, which is why ancillary support material can improve the impact of educational efforts.[6] However, studies show that health materials are often provided at levels that exceed patients' skills.[2] Medication adherence can be improved in less literate patients through literacy-level appropriate education.[8] Improving the readability of the material is therefore important in this setting, providing literacy-appropriate education, and evidence suggest that easy-to-read materials are preferable to all patients, with no benefits in differentiating the material given to high or low literacy patients.[3] It has been demonstrated that on both academic and community practice settings, about 30% of patients have marginal or inadequate literacy skills. Therefore, lower-level health literacy pamphlets increase retention and understanding on every type of patient.[9] It is also important to improve physician communication, taking into account the needs and competencies of patients with poor health literacy. [2]

We recognize our study had some limitations. First, most of the questionnaires were made by telephone instead of being fulfilled by the patients on their own, which could have led to some inhibition when patients were giving the responses. Second, we conducted the questionnaire in 79 patients that represent a specific Portuguese population, geographically located in the north of Portugal. We know that our results cannot be generalized to the entire Portuguese population, but believe that the implementation of this questionnaire has a significant value in understanding what our patients know about their disease and provides means to implement actions to improve their literacy. Also, this also represents a mean of awareness to other glaucoma departments so they can to take the same actions. Third, it would be interesting to have a control group so that we could understand whether the

glaucoma population has a greater understanding of their disease when comparing to patients that do not have the disease.

Conclusion

In our study we observed a lack of knowledge in some determinant aspects of glaucoma. Ophthalmologists should invest in improving health literacy in the glaucoma population through the usage of an appropriate language during communication and easy-to-read handed material. The main goal of these interventions is to improve patients' understanding of the disease and patients' compliance with the treatment, regular exams and appointments.

Conflict of Interest

The authors have no conflict of interest to declare.

Appendix 1

Questionnaire

1. Have you ever heard about what is glaucoma?

84.8% (n=67) answered Yes.

2. Do you know what are the risk factors for the development of glaucoma?

74.7% (n=59) answered No.

From those who answered Yes, when asked to specified risk factors the answers were: high IOP (n=10), genetics (n=4), systemic hypertension (n=7), age (n=1), diabetes (n=2), dry ocular nerve (n=1), dry ocular vein (n=1) and degenerative disease (n=1).

3. Do you know what is your glaucoma type?

94.9% (n=75) answered No.

From the 4 who answered Yes, when asked to specified they said: high IOP, open angle, terminal and acute.

4. In the majority of cases, glaucoma is associated with a high, low or normal IOP?

75.9% (n=60) answered high; 1.3% (n=1) low; 1.3% (n=1) normal; and 21.5% (n=17) did not know.

5. Which of the following options best defines glaucoma?

It is a disease on which damage to the eye nerve occurs due to high IOP – chosen by 26.6% (n=21);

It is a disease that leads to high IOP – 10.1% (n=8);

It is a disease related to the eye nerve, the nervous system and systemic arterial pressure – 3.8% (n=3);

It is a disease related to cataracts that causes vision loss – 1.3% (n=1);

It is a disease related to age that causes loss of central vision – 1.3% (n=1);

Do not know – 57% (n=45).

6. In the majority of cases, does glaucoma have symptoms on initial states?

53.2% (n=42) answered No, 22.8% (n=18) Yes and 24.1% (n=19) did not know.

7. Do you know what is the purpose of the eyedrops therapy?

To stop the disease from aggravating – chosen by 64.6% (n=51);

To cure the disease – 6.3% (n=5);

To restore lost vision – 5.1% (n=4);

Do not know – 24.1% (n=19).

8. Do you believe it is possible to revert glaucoma damage?

48.1% (n=38) answered No, 11.4% (n=9) answered Yes and 40.5% (n=32) did not know.

9. In your opinion, can glaucoma lead to blindness?

96.2% (n=76) answered Yes, 1.3% (n=1) answered No and 2.5% (n=2) did not know.

10. Do you believe glaucoma has a cure?

53.2% (n=42) answered No, 10.1% (n=8) answered Yes and 36.7% (n=29) did not know.

11. In your opinion, is glaucoma related to cataract?

54.4% (n=43) answered No, 12.7% (n=10) answered Yes and 32.9% (n=26) did not know.

12. If you use eyedrops to lower the IOP, do you know their side effects?

79.7% (n=63) answered No and 15.2% (n=12) Yes.

13. Are you able to put the eyedrops on your own or do you depend on someone to do it?

59.5% (n=47) answered Alone and 34.2% (n=27) Someone else.

14. In the past two weeks, how many time have you not put the eyedrops?

75.9% (n=60) answered Zero, 13.9% (n=11) Twice or more and 3.8% (n=3) One.

15. What is the main reason for not putting the eyedrops?

24.1% (n=19) answered Forgetfulness.

16. How do you face your disease?

48.1% (n=38) answered Some concern, 29.1% (n=23) Major concern and 22.8% (n=18) Indifference.

17. Do you believe it is important to adhere to the treatment to prevent future damage?

59.5% (n=47) answered Very important, 32.9% (n=26) Important, 1.3% (n=1) Not very important and 6.3% (n=5) Indifferent.

18. Do you believe it is important to do period routine evaluations to control the disease?

43% (n=34) answered Very important, 48.1% (n=38) Important, 0% (n=0) Not very important and 8.9% (n=7) Indifferent.

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