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# Knowledge about glaucoma and barriers to follow-up care in a community glaucoma screening program

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## ABSTRACT • RÉSUMÉ

**Objective:** To assess perceived barriers to glaucoma follow-up care, including the lack of glaucoma knowledge and the lack of health care access, among participants in a community glaucoma screening program.

**Design:** Community survey.

**Participants:** Two hundred forty-three consecutive participants in a series of free glaucoma screenings between November 2002 and August 2003.

**Methods:** The survey consisted of 20 questions designed to elicit knowledge of glaucoma and perception of potential barriers to follow-up care. Our aim was to find correlations between patient demographics and knowledge of glaucoma as well as perceived potential barriers to follow-up care. The data were analyzed using SPSS, v. 10.1.

**Results:** The average age of the respondents was 70 years, and females predominated (66%). About half of the respondents knew of an eye doctor in their neighborhood, and 60% had had an eye examination in the past year. Two hundred twenty-two (91%) indicated they could get to an eye doctor if the screening examination indicated they needed a follow-up examination. Two hundred twenty (90.5%) had medical insurance. One hundred seventy-eight (73%) of the participants had heard of glaucoma; 71 (29%) identified an accurate definition of glaucoma. The level of education and the language spoken at home were correlated with both glaucoma awareness ( $p < 0.001$ ;  $p < 0.001$ ) and knowledge of an accurate definition of glaucoma ( $p < 0.001$ ;  $p < 0.025$ ).

**Conclusions:** In this population, a lack of adequate education about glaucoma may be more significantly associated with poor follow-up rates than a lack of access to care in those identified as glaucoma suspects.

**Objet :** Évaluation de ce que l'on perçoit comme étant des barrières aux soins de suivi du glaucome, y compris le manque de connaissance sur la maladie et d'accès aux soins médicaux, chez les participants à un programme communautaire de dépistage du glaucome.

**Nature :** Étude communautaire

**Participants :** Deux cent quarante-trois participants consécutifs d'une série de dépistage gratuit du glaucome entre les mois de novembre 2002 et d'août 2003.

**Méthodes :** L'étude comprenait 20 questions visant à obtenir le degré de connaissance sur le glaucome et la perception des possibilités de barrière aux soins de suivi, l'intention étant de trouver la corrélation entre le caractère démographique des patients et leur connaissance du glaucome ainsi que les barrières qu'ils perçoivent aux soins de suivi. Les données ont été analysées à l'aide du SPSS, v.10.1.

**Résultats :** La moyenne d'âge des répondants était de 70 ans et le nombre de femmes prédominait (66 %). Environ la moitié des répondants connaissaient un spécialiste des yeux dans le voisinage et 60 % s'étaient fait examiner les yeux dans l'année précédente. Deux cent vingt-deux (91 %) ont indiqué qu'ils trouveraient un médecin oculaire si l'examen de dépistage indiquait qu'ils avaient besoin d'un examen de suivi. Deux cent vingt (90,5 %) avaient de l'assurance médicale. Cent soixante-dix-huit (73 %) avaient entendu parler du glaucome; 71 (29 %) en reconnurent une définition exacte. Le niveau d'éducation et le langage parlé à la maison étaient en corrélation avec la sensibilisation au glaucome ( $p < 0,001$ ;  $p < 0,001$ ) et avec la connaissance de la définition exacte ( $p < 0,001$ ;  $p < 0,025$ ).

**Conclusions :** Chez cette population, le manque d'éducation concernant le glaucome peut être associé au faible taux de suivi de façon plus significative que le manque d'accès aux soins chez les personnes soupçonnées de glaucome.

Glaucoma is the leading cause of irreversible blindness in the world. Yet, because glaucoma is a slowly progressive disease, often with few noticeable symptoms, about half of affected individuals are unaware they have the disease.<sup>1</sup> As such, they do not seek adequate care. Many people assume that the presence of glaucoma would be heralded

by symptoms and therefore they underestimate the serious nature of this insidious disease.<sup>2</sup> Ideally, people should seek medical care early in the course of the disease, thereby preventing further vision loss and preserving quality of life.<sup>3</sup> The motivation to do so, however, would likely stem from knowledge of glaucoma risk factors, symptoms, and an

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understanding of the natural history of the disease. Several studies have found that most people are aware of glaucoma, but few have an accurate understanding of what it is.<sup>3-6</sup> Population studies of glaucoma knowledge have concluded that further community outreach, education, and screening are necessary to promote early diagnosis and treatment.<sup>4,7,8</sup>

Some individuals do seem to understand the disease, especially those who are younger, well educated, and of relatively high socioeconomic class, and those with a family history of glaucoma.<sup>8,9</sup> Glaucoma knowledge does not appear to be correlated with having specific risk factors for glaucoma. One study showed that myopic patients and diabetics, despite their increased risk for eye disease, did not have a greater awareness of glaucoma than those without such risk factors.<sup>9</sup> Based on these findings, glaucoma education targeted at the elderly, less formally educated, and lower socioeconomic classes would likely have the greatest impact on motivating high-risk individuals to participate in a glaucoma screening and, if necessary, seek follow-up medical care.

Lack of glaucoma knowledge is not the only reason people identified at screenings as likely having glaucoma do not seek follow-up care. Unless other potential obstacles, such as a lack of transportation, no medical insurance, or forgotten appointments, are reduced, these individuals also may not seek further help.<sup>6,10</sup> Such barriers are likely to affect the lower socioeconomic classes.

Since 1999, we have been conducting free glaucoma screenings at seniors' centers and churches in the Philadelphia area. More than 1800 examinations have been performed and more than 150 people have been newly diagnosed with glaucoma or suspected glaucoma. Unfortunately, we have found that few people with a potential definitive diagnosis of glaucoma heed the advice of the screening physician to follow up with a doctor.<sup>11</sup>

To design a more effective screening program, we wanted to determine which barriers to subsequent care are most important in our population. We hypothesized that such obstacles might include lack of disease-specific knowledge and lack of access to care due to a lack of either transportation or insurance. The purpose of this study was to assess knowledge of glaucoma and perceived barriers to follow-up care among individuals being screened for glaucoma.

**METHODS**

We designed and administered a survey addressing lack of knowledge about glaucoma as well as other factors perceived as potential barriers to seeking follow-up care among individuals being screened for glaucoma. The survey was administered to consecutive participants as part of a free glaucoma screening in 14 Philadelphia Corporation for Aging-affiliated seniors' centers and 2 predominantly African-American neighborhood churches between November 2002 and August 2003. The study was approved by the Institutional Review Board of Wills Eye Hospital. All patients gave informed consent to participate in the survey and screening.

First, the demographic of the population was recorded. This information included the participant's age, sex, primary language, and highest level of education. Second, the survey was administered. The survey consisted of 20 multiple-choice questions dealing with glaucoma knowledge and potential barriers to care (Fig. 1, available online). The knowledge assessment questions consisted of the following: whether the patients had heard about glaucoma, if they had the disease, the definition of glaucoma, whether glaucoma has symptoms, if treatments are available, the age range that is at increased risk, and whether glaucoma can lead to blindness. Questions about the access to care included the following: if they had medical insurance; if eye doctors were available in their neighborhoods; and whether cost, lack of transportation, lack of insurance, forgetfulness, or not wanting to go would hinder follow-up.

The data were organized and analyzed using SPSS, v. 10.1 (SPSS Inc, Chicago, Ill.). Statistical tests included the independent-samples *t* test and Pearson's  $\chi^2$  statistics.

**RESULTS**

Two hundred forty-three subjects were surveyed. The average age of the respondents was 70 years, and females predominated (66%). Eighty-six percent had a high school education or less. Three quarters spoke English at home, and about one quarter spoke Spanish (Table 1).

One hundred seventy-eight (73%) of the participants had heard of glaucoma; 71 (29%) could correctly identify glaucoma; 20 (8%) confused glaucoma with an eye infection; 17 (7%) confused it with cataract; and 119 (49%) were not sure what it was. One hundred twenty-four (51%) were familiar enough with glaucoma to know that it is more common in older people, can lead to blindness, and can be treated. Ninety-two (38%) were not sure if someone can recognize if they have glaucoma. Seventy-four (30%) thought that people with glaucoma can tell that they have it, 74 (30%) thought that people cannot tell if they do. One hundred twenty (49%) participants knew that glau-

**Table 1—Patient demographics**

Demographic	Patients, n (%)
<b>Sex</b>	
Female	158 (65.0)
Male	80 (32.9)
Missing	5 (2.1)
Age, mean y (SD, range)	70 (14.6, 11–95)
<b>Primary language</b>	
English	167 (68.7)
Spanish	60 (24.7)
Other	3 (1.2)
Missing	13 (5.3)
<b>Education</b>	
Graduate school	5 (2.1)
College	18 (7.4)
High school	94 (38.7)
Vocational school	8 (3.3)
Elementary school	106 (43.6)
None	2 (0.8)
Missing	10 (4.1)

coma can be treated, 110 (45%) did not know about any glaucoma treatment, and 7 (3%) said that there is no treatment for glaucoma. One hundred eighty-one (74%) recognized that glaucoma may result in blindness if not treated; 50 (21%) did not know this. The level of education and the language spoken at home were correlated with both glaucoma awareness ( $p < 0.001$ ;  $p < 0.001$ ) and knowledge of a correct definition of glaucoma ( $p < 0.001$ ;  $p < 0.025$ ). Age and sex did not correlate with either glaucoma awareness or knowledge of the definition of glaucoma.

Two hundred twenty-one (91%) respondents had a medical doctor and had had a medical examination in the past year. Almost all said they could get to their doctor's office: 65 (27%) said they could drive themselves, 71 (29%) said they could have someone else drive them, and 77 (32%) said they could take public transportation. About half knew of an eye doctor in their neighborhood and 60% had had an eye examination in the past year, mostly for routine care or glasses. Of those who had not had an eye examination in the past 2 years, most said they did not have an eye problem.

Two hundred twenty-two (91%) of the respondents indicated they could get to an eye doctor if the screening examination indicated they needed a more thorough examination. Few indicated that there was some problem that would prevent them from doing so, such as lack of insurance or prescription coverage. Two hundred twenty (91%) had medical insurance and 172 (71%) knew that their insurance policy had prescription coverage.

## CONCLUSIONS

This project was an attempt to assess basic knowledge of glaucoma and factors possibly preventing recommended follow-up care among individuals participating in glaucoma screenings at seniors' centers and predominantly African-American churches. The results indicate that lack of education about glaucoma may be more important than lack of transportation or access to care in keeping those identified as possibly having glaucoma from seeking further care. Seventy-three percent had heard of glaucoma, a percentage remarkably similar to that reported in previous studies.<sup>2-4,9</sup> Like previous authors, we documented a poor understanding of what glaucoma is,<sup>2-5</sup> especially among less educated adults.<sup>6,9</sup> Our non-English-speaking population showed a degree of lack of knowledge and awareness of glaucoma that parallels that found among the Chinese-speaking population in Singapore.<sup>6</sup> Encouragingly, despite the lack of understanding of glaucoma, most people seemed to be aware that glaucoma is a potentially blinding disease for which treatment is available. Limitations to our study include a predominantly elderly, inner-city population. The results therefore may not pertain to a younger or a more rural population. There may also be other, more significant barriers to follow-up which we have not explored.

Screening for disease assumes the presence of the following 4 conditions: First, there must be a treatment for the

disease that is superior to its natural progression. Second, there must be access to individuals at risk for the disease. Third, there must be a satisfactory way to differentiate diseased from normal individuals. Fourth, there must be a way to ensure patients can travel from the screening examination to follow-up care.

With regard to glaucoma, recent clinical trials have demonstrated the merits of intraocular pressure reduction. Population prevalence studies have documented who is at risk, and examining those individuals is relatively easy. These facts justify efforts to screen for glaucoma. Because there is no consensus about the most appropriate screening method, we chose to do the most thorough examination possible with readily portable equipment. Despite these conditions, if individuals identified as possibly having glaucoma do not seek recommended follow-up care, the effort spent screening individuals for glaucoma hardly seems justified.

A number of factors have been suggested as reasons for this failure to seek follow-up care. As reported in the Hoffberger program,<sup>10</sup> and in our own experience, follow-up rates are poor despite attempts to reduce potential barriers such as cost and lack of transportation. Issues of insurance and access do not seem to be major problems in this population. Even though 73% of participants had to use public transportation or depend on someone else to drive them, they did not see any problem in getting to the doctor's office. This suggests that these issues are not, in fact, significant barriers to follow-up. Whether failure to access further care reflects indifference to the problem after the screening has passed, mistrust of the screening results, simple forgetfulness, or another barrier to care, we cannot say at this time. Our previous attempt to improve follow-up care with aggressive postscreening reminders did not result in improved follow-up.<sup>11</sup>

However, it is clear that knowledge about glaucoma is inadequate. Although most of those we surveyed claimed to be aware of glaucoma, only a minority understood the symptoms, risk factors, treatment, and possible outcome. Increased awareness and knowledge of a condition may motivate high-risk individuals to seek care and thus permit earlier diagnosis. Innovative information programs aimed at individuals in general, and in particular, at those with limited formal education and non-English-speaking communities, are needed. Such programs to enhance public awareness of glaucoma may improve the effectiveness of health promotion and thus prevent unnecessary blindness.

The authors have no proprietary or commercial interest in any materials discussed in this article.

Fig. 1 can be found on the *CJO* web site at <http://pubs.nrc-cnrc.gc.ca/cjo/cjo.html>. It is linked to this article in the online contents of the February 2009 issue.

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