Glaucoma knowledge in a black community in Toronto

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Background: Black people are at high risk of glaucoma. Routine eye exams are the only way of identifying early glaucoma for treatment and blindness prevention. Public education on glaucoma risk factors and detection may be an important public health strategy to encourage those at high risk to have their eyes checked.

Purpose: To evaluate glaucoma knowledge (including presentation, risk factors and detection) and associated socio-demographic factors in a black community in Toronto to aid the development of future public education programs.

Materials and Methods: Questionnaire surveys from 5 black people centered churches or organizations.

Results: The mean age of participants (n=201) was 48.7 years. Most participants reported glaucoma can cause blindness (88.6%) and run in families (76.0%). However, only few participants (4%) correctly reported glaucoma affects peripheral vision. Over 1 in 4 participants (26.7%) reported incorrectly glaucoma always causes eye symptoms. Less than half of the participants knew black people are at higher risk of glaucoma (48.7%) and glaucoma most likely affects people 40 years or older (46.2%).

A history of parents or siblings with glaucoma was not associated with better knowledge of three established glaucoma risk factors (40 years or over, African origin and positive family history). Participants 40 years or older did not have greater knowledge than those under 40 that older people are at higher risk of developing glaucoma (prevalence ratio (PR)=0.90, 95% confidence interval (CI) 0.63-1.26). Participants with and without postsecondary education equally reported that eye examinations are the only way to identify glaucoma (PR=1.02, 95% CI 0.72-1.46). Poverty was associated with lower levels of knowledge of the aforementioned three glaucoma risk factors and that glaucoma is identified through eye examinations.

Conclusion: Glaucoma knowledge in Toronto’s black community is inadequate. Education about glaucoma presentation, risk factors and detection should be prioritized in this high-risk group.

Key words: African Origin; Family History; Glaucoma Knowledge; Socio-Demographics; Toronto

Glaucoma usually has no noticeable symptoms until the later stages of the disease.[6-7] Early detection and treatment are the only known methods of preventing blindness from glaucoma. In North America, more than half of the glaucoma patients are diagnosed at routine eye examinations.[8-9] In Canada, amongst those with newly diagnosed glaucoma, half have moderate or advanced disease upon first diagnosis.[10] Routine screening for glaucoma at the population level however is not recommended due to low cost effectiveness.[11-12] Identifying, or incentivizing, high risk groups to have an eye examination produces higher
The purpose of this study was to evaluate glaucoma awareness and the level of knowledge of glaucoma presentation, risk factors, detection methods, and associated socio-demographic factors in a black community in Toronto, Canada.

Materials and Methods

Self-identified black people, aged 30 years or older, residing in Toronto, participating in social activities organized by five community groups (see Acknowledgements) were orally invited by one of us (GM) to complete a self-administered questionnaire. The questionnaire was completed on site, or taken home and returned completed to the confidentially sealed “drop box”.

There are no validated questionnaires on glaucoma awareness and knowledge. We therefore developed a new questionnaire based on questions used in prior published studies.[14-21] The questionnaire included 4 questions on common eye disease awareness (defined as having heard of glaucoma, cataracts, retinopathy and macular degeneration) and 12 specific questions on glaucoma knowledge (see Appendix 1). In addition, the survey questionnaire included 21 questions on socio-demographics, and 5 questions on eye care utilization. The questionnaire was tested in a pilot study before use in the main study. The study protocol was approved by the Research Ethics Board at the University of Toronto.

Statistical analysis

A correct or incorrect answer to each of the 12 questions on glaucoma knowledge was reported as a separate proportion. In addition, a summarized glaucoma score, with one point assigned for each correct answer, and zero point for each incorrect or “Don’t know” answer, was used to measure general understanding of glaucoma knowledge. This score ranged from 0 to 12, with higher scores indicating better understanding of glaucoma. The mean scores in two categorized socio-demographic groups were statistically tested using a Student t test.

We paid particular attention to questions concerning 3 established glaucoma risk factors (aged 40 or over, African ancestry and positive family history) and glaucoma detection (i.e. glaucoma identified via eye examinations). Answers to these 4 questions were linked to detailed socio-demographic factors through univariate and multivariate analyses. Differences in proportions for each of these 4 questions across different socio-demographic groups were statistically tested by Chi square test, or Fisher’s exact test if data were too sparse. The prevalence ratios (PR) which were derived from log-Poisson regression models were used to assess the association between each of the 4 selected glaucoma knowledge questions and associated socio-demographic factors, due to the common occurrence of the study outcome.[22-23]

Results

In all, 249 questionnaires were filled out. Thirty-one questionnaires contained missing information on age and 17 questionnaires were from persons aged 16-29 years. These were excluded, leaving 201 questionnaires for analysis.

The mean age of the participants was 48.7 years (SD 12.7 years). The majority were females (76.1%), immigrants (86.6%) and university or college educated individuals (78.1%).

About one in five participants (19.0%) were using eye drops. A similar proportion of participants (22.2%) reported parents with glaucoma. Siblings with glaucoma were reported in 11.3% of the participants. About 1/3 of people (30.2%) responded “Yes” to the question "Have any of your blood relatives become blind in one or both eyes (include even if no longer living)?"

Over 90% of the participants reported having heard about glaucoma and cataracts, which was significantly higher than the awareness for diabetic retinopathy and macular degeneration (Figure 1). Among those who had heard of glaucoma, the main source of information was through relatives/friends and eye doctors (Figure 2). The usual media source for information was TV and the least common was radio (Figure 2).

Table 1 shows the 12 tested questions on glaucoma knowledge and the percentage answered correctly for each question. The majority of participants reported knowing that glaucoma causes blindness (88.6%) and runs in families (76.0%, Table 1). However, 11% of the participants did not believe or did not know that glaucoma causes blindness. Nearly 1/4 (24.0%) of the respondents reported not knowing glaucoma runs in family. Only 4% of the participants correctly recognized that glaucoma affects peripheral vision (Table 1). One in four participants (26.7%) reported glaucoma always causes eye symptoms such as eye pain.

Less than half of the participants reported that black people were at higher risk of glaucoma (48.7%) and glaucoma affects people 40 years or older (46.2%) (Table 1). Slightly over half (56%) of the participants reported that blood relatives of a person with glaucoma are at higher risk of developing glaucoma. Around 2/3 of the participants (65%) stated correctly that an eye doctor’s check-up is the only way of identifying early glaucoma.

The mean glaucoma knowledge score was 7.07 (SD 2.62) out of a full score of 12. There were no significant differences on the average glaucoma score between socio-demographic groups, including age (under vs over 40 years of age, p=0.35), gender (men vs women, p=0.60), education (with vs without postsecondary education, p=0.39), parents having glaucoma (p=0.13), or those currently using eye drops (p=0.43).

Participants with a university or college education have increased knowledge regarding advanced age as a risk factor for glaucoma (PR=1.82, Table 2, p<0.05) in univariate analysis. However, this educated group did not have improved knowledge that blood Lack of money after all expenses are paid (i.e. poverty) is a risk factor for reduced glaucoma knowledge (Table 2). For example, compared to those with available funds, the poor, i.e. those with-
Figure 1. The proportion of having heard of 4 common eye diseases among black people aged 30 years or older in Toronto.

Figure 2. The main source of information for having heard of glaucoma.
Table 1. 12 testing questions on glaucoma knowledge

<table>
<thead>
<tr>
<th>Questions and correct answers in parenthesis</th>
<th>Answer correctly (%) and 95% confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Can glaucoma cause blindness? (Yes)</td>
<td>88.6 (83.3-92.4)</td>
</tr>
<tr>
<td>2 Can early treatment stop glaucoma from getting worse? (Yes)</td>
<td>77.7 (71.3-83.0)</td>
</tr>
<tr>
<td>3 Does glaucoma affect: (The side vision)</td>
<td>4.26 (2.2-8.2)</td>
</tr>
<tr>
<td>4 Does glaucoma develop slowly over time or strike people suddenly? (Slowly)</td>
<td>77.0 (70.5-82.4)</td>
</tr>
<tr>
<td>5 Can glaucoma be developed by contacting a person with glaucoma? (No)</td>
<td>85.4 (79.7-89.7)</td>
</tr>
<tr>
<td>6 Does glaucoma always cause eye symptoms such as eye pain? (No)</td>
<td>31.4 (25.3-38.3)</td>
</tr>
<tr>
<td>7 Is glaucoma caused by reading books, newspapers or using a computer for a long period of time? (No)</td>
<td>62.5 (55.5-69.0)</td>
</tr>
<tr>
<td>8 Can glaucoma run in families? (Yes)</td>
<td>76.0 (69.5-81.5)</td>
</tr>
<tr>
<td>9 Who is most likely to have glaucoma? (People aged 40 years old or over)</td>
<td>46.2 (39.3-53.2)</td>
</tr>
<tr>
<td>10 Compared with the majority of (or general) population, blood relatives of a person with glaucoma are at: (Higher risk of getting glaucoma)</td>
<td>56.2 (49.2-63.0)</td>
</tr>
<tr>
<td>11 Compared to white people, black people are at: (Higher risk of getting glaucoma)</td>
<td>48.7 (41.8-55.7)</td>
</tr>
<tr>
<td>12 Is an eye doctor's check-up the only way of early identifying glaucoma? (Yes)</td>
<td>65.0 (58.0-71.3)</td>
</tr>
</tbody>
</table>

Table 2. Prevalence ratio/probability of having correct glaucoma knowledge and its 95% confidence interval in parenthesis

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>People aged 40+ is at higher risk</th>
<th>Blood relatives are at higher risk</th>
<th>Black people are at higher risk</th>
<th>eye exam is the only way of early identifying glaucoma</th>
</tr>
</thead>
<tbody>
<tr>
<td>University/College edu Yes vs No</td>
<td>1.82 (1.10-3.03)</td>
<td>0.94 (0.70-1.27)</td>
<td>1.12 (0.77-1.63)</td>
<td>0.98 (0.76-1.26)</td>
</tr>
<tr>
<td>Using eye drops Yes vs No</td>
<td>0.99 (0.67-1.45)</td>
<td>0.96 (0.69-1.34)</td>
<td>0.80 (0.52-1.22)</td>
<td>1.06 (0.81-1.37)</td>
</tr>
<tr>
<td>Parents/siblings had glaucoma Yes vs No</td>
<td>0.82 (0.56-1.18)</td>
<td>1.10 (0.84-1.44)</td>
<td>0.95 (0.68-1.33)</td>
<td>1.05 (0.83-1.32)</td>
</tr>
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</table>

Multivariate analysis (potential risk factors were selected from results of univariate analysis)

<table>
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</tr>
</thead>
<tbody>
<tr>
<td>Born in Canada No vs Yes</td>
<td>0.9</td>
<td>0.76</td>
<td>0.8</td>
<td>1.38</td>
</tr>
<tr>
<td>University/College edu Yes vs No</td>
<td>1.43</td>
<td>0.88</td>
<td>0.83</td>
<td>1.02</td>
</tr>
<tr>
<td>Read flyers Yes vs No</td>
<td>0.53</td>
<td>1.04</td>
<td>0.83</td>
<td>0.8</td>
</tr>
<tr>
<td>Respondent’s age 40+ vs &lt;40</td>
<td>0.9</td>
<td>1.41</td>
<td>0.86</td>
<td>0.93</td>
</tr>
<tr>
<td>Having money left to do as wishes No vs Yes</td>
<td>0.63</td>
<td>0.78</td>
<td>0.78</td>
<td>0.68</td>
</tr>
</tbody>
</table>

relatives are at an increased risk of glaucoma (PR=0.94, Table 2, p>0.05) and that eye examinations are the only way of early identifying glaucoma (PR=0.98, Table 2, p>0.05). In multivariate analysis, having a postsecondary education was not associated with correctly answering any of the four selected glaucoma questions (Table 2).

Current use of eye drops or having parents or siblings with glaucoma was not associated with improved knowledge regarding glaucoma risk factors and detection (Table 2). Participants aged 40 or over had improved knowledge about blood relatives and their increased risk of developing glaucoma (PR=1.41, Table 2, p<0.05). However, they did not know that older people are at higher risk of developing glaucoma (PR=0.90, Table 2, p>0.05).
out money “to do as they wish”, had a nearly 40% lower probability of knowing that age 40 years or above is a risk factor for developing glaucoma (PR=0.63, Table 2).

More than half of the participants (57%) reported not seeing an eye doctor (optometrist or ophthalmologist) in the past year. Major reasons were "I see well, therefore not necessary" (24.4%) and "Eye examination is expensive and can't afford to pay" (16.5%). Transportation (8.9%) and language (0%) problems were not reported as barriers to seeing an eye doctor.

Of those who visited an eye doctor in the past year, major reasons for having had such a visit included an eye check-up paid by OHIP (Ontario Health Insurance Plan) (29%) or by other health insurance plan (12%), need for new glasses (22%) and vision problems (14%).

A large proportion of the participants (37%) did not know that OHIP covers eye examinations once a year for residents younger than 20 years and older than 64 years. Nearly all participants (99.4%) preferred to receive health care information in English. Many participants (73.7%) read flyers delivered to a mailbox.

Discussion

Our results suggest that black people in Toronto are well aware of glaucoma (98%), know that it causes blindness (88.6%) and runs in families (76.0%). However, average knowledge regarding glaucoma presentation, risk factors and detection methods seem inadequate. Only a few participants (4%) correctly reported glaucoma affects peripheral vision. Over 1/4 of the participants (26.7%) incorrectly reported glaucoma produces eye symptoms. With regards to the three established glaucoma risk factors, over half of the participants did not know that being of African descent places them at a higher risk of contracting the disease. Similarly, over half of the participants did not know that increased age (40 years or older) is a major risk factor for the disease. Surprisingly, a family history of glaucoma in parents or siblings did not increase participants’ awareness that they are at increased risk of developing glaucoma. This lack of glaucoma knowledge from a high-risk community is disturbing and suggests that educational efforts need to be focused on this high-risk group.

Studies on awareness and knowledge of glaucoma have been reported in other ethnic groups. In Hong Kong, glaucoma awareness was reported at 78.4%, but only 10.3% of the participants could describe the symptoms correctly.[18] In India, three glaucoma studies reported awareness rates of 0.27%, 2.4% and 13.3% - the lowest awareness rates documented in the literature to date. [19-21] In the USA, a telephone survey (n=368) reported that over 80% of respondents knew that glaucoma causes blindness, but approximately two-thirds of the sample could not identify even one risk factor.[15] In Australia, glaucoma awareness ranges from 79% to 93%.[14,16] The Australian studies also reported that high levels of education are associated with increased levels of glaucoma awareness and knowledge. In Germany, a face-to-face interview revealed that 75% of the respondents (n=2742) had heard of glaucoma and that 25% of the respondents thought all people of different ages had an equal risk of developing glaucoma.[17] In Canada, a study of 33 family practitioners' patients in British Columbia reported that 41% of the participants (n=882) were familiar with glaucoma and that women and people with higher educational attainment were significantly more likely to report familiarity with the disease.[13] In an online survey (n=800) by the CNIB (Canadian National Institute for the Blind) in 2009, 70% of the respondents incorrectly reported that glaucoma has associated symptoms, with a third associating the disease with pain or a change in how their eyes feel.[24] In this study, we surprisingly report the highest level of glaucoma awareness documented to date (98%). These varied results may be explained in part by different study populations, different study periods and different study methods.

One contributing factor to the high level of glaucoma awareness in this study may be the high level of education of the participants: 78% of the participants in our study vs 49.9% of black Torontonians possess university or college education (p<0.0001).

[25] High levels of education are associated with high levels of glaucoma awareness.[14,16,17] This constitutes one of the study limitations. However, it is well-known that highly-educated people are more likely to participate in health surveys and researches.[26-27] In addition, participants currently using eye drops and those with a positive family history of glaucoma and blindness were possibly more motivated to participate in the survey. This may also contribute to the high level of awareness and constitute another study limitation. As a result, our study sample may not be representative of the general black community in Toronto. Obtaining a random sample to generate population estimates is desirable but is a challenge issue faced by all studies, particularly when attempting to assess ethnic minorities.[28-30] To overcome potential issues related to the study sample, we surveyed 5 different black organizations to increase sample variations. Despite this effort, the sample is biased towards well-educated. This underscores the difficulties in obtaining a random sample in population-based research. On the other hand, our results from a well-educated sample revealed the level of glaucoma knowledge, such as peripheral visual field loss, was low, suggesting that our findings are conservative. Furthermore, since participants who were currently using eye drops and those who had a family history of glaucoma did not report improved glaucoma knowledge, we recommend these highly motivated participants should also be included in future educational endeavours, although financially disadvantaged individuals are clearly the most important group to target.

Strengths of this study include the fact that this is the first glaucoma awareness and knowledge study in a black community - a high-risk group for glaucoma. Secondly, our questionnaire focused specifically on glaucoma and its presentation, risk factors and methods of detection.

To prevent avoidable blindness, Noertjojo and associates called for a population-based approach to eye health education rather than a clinic-based approach.[13] They also recommended that innovative educational programmes for non-European-Canadian communities be created. We echo their views and recommend TV, newspapers, magazines, internet and flyers as the primary means of mass communication. Radio seems to be the least useful dissemination tool in Toronto, although in the UK, radio has been reported to be the most effective way to improve glaucoma awareness in an Indian community.[31]

Conclusions

The level of glaucoma awareness seems to be high amongst Toronto's black community but knowledge regarding risk factors and the detection methods is low. Considering the high prevalence in the black community, education about glaucoma's presentation, risk factors and detection methods should be prioritized
as part of an educational campaign, especially amongst those less financially well-off.

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