

Original Article

What do people with glaucoma know about their condition? A comparative cross-sectional incidence and prevalence survey

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ABSTRACT

Purpose: To assess and compare glaucoma knowledge between patients with established glaucoma, newly diagnosed glaucoma and the general population.

Methods: 208 glaucoma patients, 100 newly diagnosed glaucoma patients from three clinical centres and 100 controls from non-ophthalmology outpatient clinics, were recruited and completed a validated self-administered true/false questionnaire assessing glaucoma knowledge. Demographic data were also recorded. Glaucoma knowledge score, out of a maximum of 22, and odds ratios (OR) with 95% confidence intervals (CI) of survey characteristics associated with falling in the lowest quartile of the overall knowledge score was evaluated for each study group.

Results: Established glaucoma patients had (median 17, interquartile range 15–19) marginally but significantly ($P < 0.05$) greater glaucoma knowledge scores than new patients (median 16, interquartile range 13–18). Both of these groups scored significantly better than the control population (median 13, interquartile range 10–14, $P < 0.05$). Significant misconceptions regarding glaucoma include: 80% of all participants thought that topical medications could not have systemic side-effects, 48% of established glaucoma patients believed symptoms would warn them of disease progression. One-third of new patients considered blindness to be a common outcome of having glaucoma. For established patients, factors associated ($P < 0.05$) with a lesser likelihood of scoring in the lowest quartile of the total score included having family (OR 0.33, 95% CI 0.11–0.98) or

friends (OR 0.28, 95% CI 0.06–0.97) with glaucoma, being referred by an optometrist compared with general practitioner (OR 0.21, 95% CI 0.08–0.57), speaking English at home (OR 0.13, 95% CI 0.04–0.49) and being seen in the private health-care sector (OR 0.13, 95% CI 0.04–0.42).

Conclusion: Patients with established glaucoma have only slightly greater knowledge than newly diagnosed patients, with both patient groups harbouring significant misconceptions regarding glaucoma. Educational programmes and material should be tailored to address these misconceptions.

Key words: glaucoma, knowledge, misconception, patient education.

INTRODUCTION

Inadequate treatment, one component of which is poor patient compliance, is considered to be an important factor in glaucoma blindness. Patients with a good knowledge and understanding of glaucoma are considered to have better compliance.^{1,2} Furthermore, patient misconceptions regarding glaucoma may result in either unnecessarily heightened anxiety levels or conversely, lack of insight into potentially blinding outcomes. Consequently, there is an increasing demand on ophthalmologists to educate patients on important aspects of their disease and its treatment. Several studies have evaluated the perception of glaucoma in the general population^{3–9} and others, the level of the glaucoma patients' awareness of glaucoma.^{10–14} However, no study to date has objectively assessed the level of knowledge regarding

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glaucoma among established as well as those who are newly diagnosed with glaucoma.

The aim of this study was to assess the level of glaucoma knowledge in patients with established glaucoma, those referred to an ophthalmologist for their first glaucoma assessment and the general population, to identify any commonly held misconceptions regarding glaucoma and to determine patient factors that may predispose to poor understanding of their condition.

METHOD

Participating centres in this clinic-based case-control study were the glaucoma clinics at the public hospital in Auckland, a specialist private practice with university affiliations in Auckland and a general private ophthalmology practice in Christchurch. Patients were recruited into three groups: established glaucoma patients, patients presenting to the ophthalmologists for their first assessment of possible glaucoma (new patient group), and controls. The research followed the tenets of the Declaration of Helsinki and was approved by the Auckland and Christchurch Ethics Committees.

Patients were eligible for inclusion in the established glaucoma patients group if they had a diagnosis of open angle glaucoma made by an ophthalmologist for a duration of 6 months or more, and were on topical medications. Patients with angle closure glaucoma or who had undergone laser peripheral iridectomy were excluded. The new patient group included patients referred for the first time to an ophthalmologist, and were excluded if they had a previous diagnosis of glaucoma, ocular hypertension or had previously been seen by an ophthalmologist. The control population was randomly sampled from patients and support members attending other non-ophthalmology outpatient clinics in a public hospital, who stated they were not aware they have glaucoma.

Demographic and referral information collected included: age, sex, ethnic origin (Caucasian, Maori/Polynesian, Asian and other), source of referral (general practitioner, optometrist, within the Ophthalmology department or other) and educational level obtained (university or similar, high school, partial high school qualification or no formal qualification). Questions identifying whether participants had friends or family members with glaucoma as well as other sources of knowledge acquisition (books, Internet, family, friends, ophthalmologist and health professional) were also included. The second part contained 22 true/false statements regarding knowledge of symptoms/signs, associations and management of glaucoma.

The knowledge questions were validated both internally and externally. The questions were initially selected following a focus group discussion that included ophthalmologists and glaucoma specialists. The questionnaire was then considered by 25 ophthalmologists/ophthalmology registrars/fellows, not involved in the design of the questionnaire for depth and breadth. A group of glaucoma specialists provided confirmation of content and construct validation and face

validation. Criterion-related validation was performed by testing the questionnaire on a group of patients that were given an information sheet about glaucoma, the content of which contained information sufficient to answer the questionnaire with 100% accuracy. The questionnaire was then piloted on 200 participants (both glaucoma patients and the general public) prior to recruitment for the present study.

Differences between groups for normally distributed continuous data (i.e. knowledge score) were sought using one way analysis of variance (ANOVA). The Kruskal-Wallis test was used for non-normally distributed variables. Significant group effects were further explored using Tukey's method to preserve an overall pairwise error rate of 5%. Differences between groups for categorical data were sought using chi-squared analysis. To identify patient characteristics associated with a risk of poor glaucoma knowledge, stepwise logistic regression was used to determine the independent predictors of being in the lowest quartile of the knowledge score. The following variables, age > median, male gender, Caucasian ethnicity, English spoken at home, family with glaucoma and friends with glaucoma, were included. Data are presented as odds ratio (95% confidence interval). All analyses were performed using SAS (SAS Institute Inc, v9.1, College Station, TX, USA), and all tests were two-tailed and $P < 0.05$ was considered significant.

RESULTS

The study was undertaken over a 4-month period with 408 consecutive patients from the three centres recruited: 208 established glaucoma patients (108 public, 100 private), 100 new glaucoma suspects (50 public, 50 private) and 100 controls.

Demographics

The demographics of the individual study groups are outlined in Table 1. Established patients were older (median 72 years, interquartile range [IQR] 60–80) than new (60 [51–73] years) and control (61 [50–73] years) patients ($P < 0.0001$). The average duration of a diagnosis of glaucoma in the established group patient was 7.1 ± 6.5 (\pm SD) years. Duration of diagnosis and glaucoma knowledge score were not correlated ($r = -0.03$, $P = 0.78$).

Overall score

The overall glaucoma score out of 22 for the different groups is shown in Fig. 1. Established glaucoma patients scored (median 17, IQR 15–19), marginally but significantly ($P < 0.05$) better than the new patient group (median 16, IQR 13–18, $P < 0.05$). Both of these groups scored significantly better than the control population (median 13, IQR 10–14).

Univariate logistic regression analysis of patient characteristics evaluating the likelihood of scoring on the lowest quartile of the overall knowledge score was performed independently in each of the three groups (Table 2) for each

Table 1. Demographic profile of survey participants

Patient variable	Established (<i>n</i> = 208)	New (<i>n</i> = 100)	Control (<i>n</i> = 100)
Age (years): median (interquartile range)	72 (60–80)	60 (51–73)	61 (50–73)
Gender: (% male)	50	49	50
Ethnicity (%)			
Caucasian	85	82	75
Asian	8	4	7
Maori/Pacific Island	0.5	5	7
Other	7	9	11
Private sector (%)	50	49	NA
Referral source (%)			
Optometrist	59	73	NA
General practitioner	19	17	NA
Within Ophthalmology department	8	5	NA
Other	13	5	NA
English spoken at home (% yes)	97	99	92
Highest education level (%)			
Partial high school qualification	26	20	22
High school qualification	26	28	24
University degree/diploma or similar	30	38	32
No formal qualification	15	14	22
Knowledge of family members with glaucoma (% yes)	63	26	16
Knowledge of friends with glaucoma (% yes)	55	11	16

NA, not applicable.

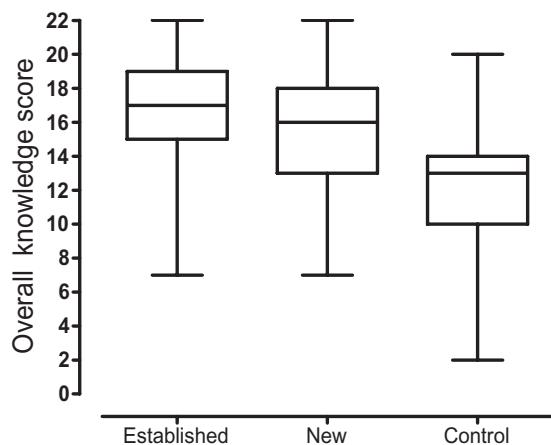


Fig. 1. Overall knowledge score for the different study groups. Box and whisker plots showing median score, upper and lower quartiles and range for the three participant groups.

variable. Within the established patient group, speaking English at home ($P = 0.006$), knowledge of family members ($P = 0.02$) or friends ($P = 0.04$) with glaucoma, being referred in by an optometrist ($P = 0.003$) and being seen in the private health sector ($P = 0.0008$) lowered the likelihood of scoring within the lowest quartile. On multivariate analysis, adjusting for all survey characteristics outlined in Table 3, speaking English at home (OR 0.13, 95% CI 0.03–0.49, $P = 0.0003$), being referred by an optometrist (OR 0.23, 95% CI 0.64–0.71, $P = 0.01$) and being from the private sector (OR 0.3, 95% CI 0.09–0.95, $P = 0.04$) remained as significant variables.

For the new patient group, univariate analysis showed that being of Caucasian ethnicity ($P = 0.03$) and from the private sector ($P = 0.006$), significantly reduced the likelihood of scoring in the lowest quartile of total score. The latter remained significant on multivariate analysis (OR 0.16, 95% CI 0.036–0.68, $P = 0.01$) which permitted adjustment for the remaining independent variables.

Within the control group, having no formal education increased the risk of falling within the lowest quartile ($P = 0.03$), and knowing family with glaucoma ($P = 0.02$) significantly reduced the risk of falling within the lowest quartile of the knowledge score. After adjustment for the variables listed in Table 3 the multivariate model showed knowledge family members with glaucoma (OR 0.13, 95% CI 0.02–0.17, $P = 0.01$) to remain as a variable associated with a reduced the risk of falling within the lowest quartile of the knowledge score.

Knowledge of glaucoma

The questions in the knowledge component of the survey and percentage of correct responses are outlined in Table 3. Post-hoc pairwise comparisons were done for the three groups for responses to statements 1–22. With Bonferroni adjustment, the critical P -value for this analysis is 0.017. Several general facts about glaucoma (questions 1, 11, 12 and 13) were well understood by all three groups, however, 81% and 80% of new and established glaucoma patients, respectively, were not aware that their glaucoma medications may have systemic side-effects. Other poorly understood facts by all groups include that 'watery eyes' are not associated with a

Table 2. Logistic regression analysis of the likelihood of scoring within the lower quartile of overall glaucoma knowledge score

Patient variable	Odds Ratio (95% CI)		
	New	Control	Established
Age: (>61 years <i>vs.</i> <61 years)	0.96 (0.43–2.18)	1.76 (0.68–4.54)	0.58 (0.26–1.29)
Gender: male	1.81 (0.81–4.05)	1.64 (0.65–4.15)	1.40 (0.63–3.09)
Caucasian ethnicity <i>vs.</i> rest	0.17 (0.07–0.41)*	0.30 (0.10–0.89)*	0.42 (0.16–1.07)
English spoken at home	0.13 (0.04–0.49)*	NA (all spoke English)	0.69 (0.15–3.25)
Highest education level			
Partial high school qualification	1	1	1
High school qualification	2.8 (0.83–9.7)	1.67 (0.47–5.96)	1.22 (0.38–3.94)
University degree/diploma or similar	1.3 (0.35–4.9)	0.26 (0.05–1.22)	0.76 (0.25–2.32)
No formal qualification	3.6 (0.97–13.7)	2.25 (0.52–9.70)	4.9 (1.3–18.2)*
Knowledge of family members with glaucoma	0.33 (0.11–0.98)*	0.49 (0.15–1.60)	0.12 (0.03–0.55)*
Knowledge of friends with glaucoma	0.28 (0.06–0.97)*	0.68 (0.14–3.37)	0.30 (0.09–1.02)
Private patient	0.13 (0.04–0.42)*	0.20 (0.08–0.51)*	NA
Referral source			
General practitioner	1	1	
Optometrist	0.21 (0.08–0.57)*	0.31 (0.10–0.98)	NA
Within Ophthalmology department	0.88 (0.23–3.3)	0.36 (0.03–3.92)	
Other	0.48 (0.13–1.71)	0.95 (0.13–7.30)	

* $P < 0.05$. NA, not applicable.

Table 3. Responses to the knowledge component of the survey

No.	True/false statements	Percentage (%) correctly answered		
		Control	Established	New
1	Glaucoma is a disease that affects the eyes and no other part of the body	95	97	97
2	Most glaucoma is painful	81*	94	88
3	Raised eye pressure can cause glaucoma	69*†	90	85
4	Glaucoma affects central vision before side vision	33*†	64	56
5	Vision loss in glaucoma usually occurs very quickly	64*	81	79
6	Glaucoma can be cured	22*†	75‡	54
7	The most common treatment for glaucoma is surgery	56*†	88	77
8	Lost eyesight from glaucoma can be restored	57*†	88	78
9	Most people with glaucoma go blind	56*	75	65
10	Treatment for glaucoma is life long	57*†	93‡	84
11	Regular check-ups are not necessary for glaucoma patients	80	87	82
12	Glaucoma can run in families	72	86	85
13	Glaucoma is more common as you get older	86	92	92
14	Most people will have symptoms that warn them their glaucoma is getting worse	24*	52‡	34
15	Stress can make glaucoma worse	40	54	45
16	A healthy diet slows the progression of glaucoma	41*	62	59
17	Using a computer will make glaucoma worse	62*	82	69
18	Fluorescent lights will make glaucoma worse	60*	78	72
19	Eye drops can have side-effects that affect other parts of the body	19	20	19
20	Watering eyes indicate that there is a build-up of fluid inside the eyes	54	64	56
21	A lot of reading may make glaucoma worse	65*	83	80
22	Lowering the eye pressure is a treatment that slows the worsening of glaucoma	72*	93	88

*Significant ($P < 0.017$) difference between established and control groups. †Significant ($P < 0.017$) difference between new and control groups. ‡Significant ($P < 0.017$) difference between established and new groups.

build up of pressure inside the eye, and that that stress is not known to be related to glaucoma.

Established glaucoma patients had significantly better understanding than their newly referred counterparts that glaucoma is not curable (75% *vs.* 54%, $P = 0.0004$), and that

treatment for glaucoma is life long (93% *vs.* 84%, $P = 0.014$). More established patients were aware that they will not have symptoms warning them of disease progression but this was poorly answered by sizable portion of established patients as well (52% *vs.* 34%, $P = 0.0047$).

Resources providing information about glaucoma

Ophthalmologists are the main source of glaucoma knowledge for 80% of established and 50% of new patients. Established patients were also likely to obtain information from books (32%) and other health professionals (22%). Newly diagnosed patients tended to use family members (25%) as a resource, followed by other health professionals (20%). Internet was identified as a resource by 24% of established, 11% of new patients and 7% of controls and was more often indicated by respondents under the age of 65 years (16.0% *vs.* 5.3%, $P = 0.0009$) and those educated to a university level or equivalent (21.0% *vs.* 5.1%, $P < 0.001$). Respondents over the age of 65 years were more likely to indicate ophthalmologists as a source of information (67.6% *vs.* 48.4%, $P < 0.0001$). Within all three groups ophthalmologists were identified as being the most useful resource (established 69%, new 50% and controls 30%) and no association between overall knowledge and the type of resource that the respondents found most useful ($P = 0.22$).

A large proportion of all three groups indicated that they would prefer to have information in the form of pamphlets (59% of the established group, 70% of the new patient group and 47% of the control group). Forty per cent of established glaucoma patients indicated that they would like to receive more information regarding glaucoma through their ophthalmologists and a significant association was identified between having a university education or equivalent and indicating a preference for receiving information via the Internet (32% *vs.* 14%, $P < 0.0001$).

DISCUSSION

Patients referred to an ophthalmologist for their initial glaucoma assessment may have preformed ideas on the implications of having glaucoma and consequently have anxiety levels that may pose a barrier to their adjustment to the disease. An understanding by the ophthalmologist of the level of knowledge in their glaucoma patients both established, and on first presentation, will facilitate optimal care by allowing the limited consultation time to be focused on emphasizing the important aspects of glaucoma knowledge and dispelling misconceptions. This is the first study to evaluate the level of knowledge regarding glaucoma in established glaucoma patients and newly diagnosed patients and to compare both groups with the general population.

One of the major findings of this study is that nearly 50% of established glaucoma patients and 66% of newly diagnosed patients believed that symptoms would warn them that their glaucoma is deteriorating. This may explain the poor adherence to both return consultations¹⁵ and prescribed medication¹⁶ that have been described. Also, 80% of patients who are on topical therapy for glaucoma were unaware that their treatment may produce systemic side-effects, despite the fact that in New Zealand, over 70% of glaucoma patients were treated, at the time of this survey, with a beta-blocker.¹⁵

These findings are of concern given the large spectrum of potential systemic side-effects from topical glaucoma medications, in particular the beta-blockers and alpha-agonists^{11,16-19}. The present study indicates the need to inform glaucoma patients of the potential systemic side-effects of their treatment, as they may fail to attribute certain symptoms to their topical medication and consequently omit to mention it to their ophthalmologist.

In all questions, established patients performed better, but only minimally so, than those presenting for their first glaucoma assessment. One explanation for this may be that patients presenting at their first visit have been educated by prior medical personnel or have investigated on their own, the potential implications of glaucoma. Alternatively, this may indicate that the educational attempts of ophthalmologists, whatever they may be, have not increased the fund of knowledge since the patients' initial presentation. The former hypothesis is supported by our observation that the median score of new patients compared with that of the controls was significantly higher indicating an effort on the patient's part to gain information on their possible diagnosis prior to their appointment. The level of knowledge among our control group was similar to studies in other countries looking at the knowledge among general patient populations in developed countries.³⁻⁵

Patient variables associated with poor glaucoma knowledge were identified by assessing the likelihood of falling within the lowest quartile of the knowledge score. Those recruited from the public sector had a greater risk of being in the lowest quartile of the knowledge score. It is likely that being referred to the private sector is a surrogate measure of socioeconomic status. Previous studies have also identified higher socioeconomic status and education level to be associated with earlier presentation to a medical practitioner, greater knowledge of disease and better compliance.^{4,20-23} Our study identified those patients who do not speak English at home, performed worse than an English speaking population. While this finding may not be surprising given that the questionnaire was in English,^{5,8} it suggests the need to provide information in the patients native language to improve levels of glaucoma knowledge. Our study, similar to findings by previous investigators, identified an association between better glaucoma knowledge and having a family member or friend with glaucoma.^{3-5,7}

Finally, the present study is the first to identify the source of referral to the ophthalmologist as a determinant of glaucoma knowledge. Patients referred from an optometrist were at five times lower risk compared with patients referred by general practitioners, of falling in the lowest quartile of the knowledge score. Better support and information made available to the general practitioner may enable them to provide a greater level of education for their patients.

This study has identified a number of misconceptions that ophthalmologists need to dispel in both established glaucoma patients and those presenting at first diagnosis. Ophthalmologists remain the key source of education for patients and with the use of tailored education material can

optimize patient understanding and therefore adjustment to glaucoma.

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