

Glaucoma awareness and screening uptake in relatives of people with glaucoma

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Abstract

Purpose To assess glaucoma awareness and screening uptake in relatives of people with glaucoma.

Methods A questionnaire was administered to 52 patients with primary open-angle glaucoma. They were asked about their awareness of glaucoma clustering within families, and the need for glaucoma screening in relatives of glaucoma patients. Patients were asked to identify one or more first-degree relatives, aged over 40 years and thus eligible for free glaucoma screening in the United Kingdom. These relatives were mailed a similar questionnaire. In performing the statistical analysis we corrected for possible clustering within families. The study was approved in advance by our local ethics committee, and all participants were informed of the United Kingdom's free screening service afterwards.

Results Ninety relatives were identified, of whom 70 (78%) returned questionnaires. Only 53% of responding relatives thought they were at increased lifetime risk of developing glaucoma. Though 81% of relatives had been screened, many were screened infrequently. We compared the responses of patients' siblings and patients' offspring. Perceived lifetime glaucoma risk was similar in the two groups, but the (older) siblings had a significantly lower awareness of the free screening service ($p = 0.03$) and attended for screening less frequently ($p = 0.07$). Uptake of regular, free glaucoma screening at least every 2 years was 57% among offspring and 30% among siblings ($p = 0.005$). Because of selection bias (good communicators were more likely to be invited to participate) the true rates of glaucoma awareness and screening uptake are almost certainly lower than this.

Conclusions Relatives of people with glaucoma should be made more aware of the need for glaucoma screening, and encouraged to use the free screening service. Older relatives should be particularly targeted.

Key words Family relationship, Glaucoma – open angle, Glaucoma screening, Vision screening

It has long been recognised that cases of primary open angle glaucoma (POAG) may cluster in families.¹ POAG is a chronic, irreversible, blinding condition, though treatment may preserve the visual field.² To improve detection in the presymptomatic stage, the government funds a glaucoma screening service in the United Kingdom. Free screening, provided by optometrists (opticians), is available on request to first-degree relatives of people with POAG from the age of 40 years. Since 1989, most other adults have been charged a fee of around £15 for an optometrist's eye test, which should include glaucoma screening (Health and Medicines Act, 1988). Our study was carried out prior to the announcement of resumed free eye tests for the elderly. We investigated the degree of awareness of the free screening service among POAG patients and their relatives, and the actual uptake of screening.

Methods

The protocol was approved by the local Research Ethics Committee. Patients with POAG were recruited from general ophthalmology outpatient clinics. Recruitment criteria were: POAG diagnosed at least 1 year previously, no other significant ocular pathology, age 40 years or more, European ethnic origin, and at least one first-degree relative eligible for the free UK glaucoma screening service (i.e. living in the UK, aged 40 or more years and not thought to have glaucoma already).

A multiple-choice questionnaire was developed, and piloted with patients prior to the survey itself. Questionnaires were administered to patients by an ophthalmologist. After confirmation of patients' awareness of their diagnosis, questions were asked to assess the following: their awareness of the familial

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Proprietary interest: None
Received: 19 January 1999
Accepted in revised form:
6 July 1999

predisposition in glaucoma, their awareness of the UK screening service, and whether they had informed their relatives of the need for screening.

Patients were invited to supply the names and addresses of first-degree relatives, eligible for the screening service, who were likely to respond to a postal questionnaire. These relatives were sent a different questionnaire, regarding: awareness of a family member with glaucoma, attendance at an optometrist, glaucoma screening uptake, and perceived risk of personally developing glaucoma. Patients were assumed to have been screened for glaucoma if they recalled having had at least one of three tests: tonometry, perimetry or ophthalmoscopy ('Some opticians measure the pressure in the eye, often with a device which blows a small puff of air at the eye. They may do a field test, when you are asked whether you can see small dots on a screen. The optician may look into the eye using a light held very close to the eye.') All participants were subsequently sent a leaflet explaining the free glaucoma screening service,³ regardless of whether or not they had returned a questionnaire.

In the statistical analysis, comparisons were adjusted for possible clustering within families, using a mixed logistic regression model in which 'family' was treated as a random effect.⁴

Results

Patients and relatives

Fifty-two patients with POAG were recruited. No patient refused to participate in the study, though 4 other patients were excluded because they could not name any eligible relatives. All 52 patients were aware that they had glaucoma. Ages ranged between 56 and 91 years (mean age 73.8 years). There were 23 men and 29 women. They identified a total of 90 first-degree relatives – 1 parent, 26 siblings and 63 offspring – all aged over 40 years. Completed questionnaires were returned by 70 relatives: 1 parent, 20 siblings (77%) and 49 offspring (78%). Replies were received from relatives of 49 of the 52 patients; in 32 families one relative replied, in 13 families two relatives, and in 4 families three relatives replied. As indicated above, a correction was made for possible family clustering when performing the statistical analysis.

Patients' awareness of family history of glaucoma

Twenty-five per cent of patients stated that they had a close relative with glaucoma (13/52); of these, 92% (12/13) were aware that this is a common phenomenon. Of the patients without a positive family history, 77% (30/39) were aware of the familial predisposition. Eighty-six per cent of patients were aware of the free glaucoma screening service (45/52).

Communication within families

Of the POAG patients, 96% (50/52) thought that their first-degree relatives knew of their diagnosis. Of the relatives who replied, 97% (68/70) knew of a family member with glaucoma. Although 2 of the patients thought that their relatives did not know that they had glaucoma, their relatives confirmed that they were, in fact, aware. Only 52% of patients (27/52) had specifically told their relatives that they needed to be screened.

Perceived risk of glaucoma among relatives

Only 53% of relatives (37/70) thought they were at increased risk of developing glaucoma during their lifetime. Perceived risk was lower in patients' siblings than in offspring: only 35% of siblings felt that they were at higher than average risk, compared with 62% of offspring (not significant when adjusted for family clustering).

Screening behaviour in relatives

The overall proportion of relatives who were screened was 81% (57/70). Screening uptake did not appear to be related to whether or not the patient had told their relatives to be screened (83% (34/41) in relatives who had been told, 79% (23/29) in those who had not). Overall uptake of screening was similar in siblings and offspring: siblings had an overall screening uptake of 85% (17/20) and in offspring of patients it was 80% (39/49) ($p = 0.60$). However, a higher proportion of siblings were screened infrequently: 41% of siblings (7/17) and 15% of offspring (6/39) left more than 2 years between visits to their optometrist ($p = 0.07$). Although all the relatives were eligible for free screening, 35% (7/20) of siblings and 10% (5/49) of offspring paid around £15 each for their eye tests (a significantly lower proportion of siblings getting screened free of charge, $p = 0.03$).

Thus, the proportion of relatives responding to our questionnaire who took full advantage of the free glaucoma screening service at least every 2 years was 57% (40/70). In offspring of patients the figure was 67% (33/49). In siblings of patients the figure was significantly lower, at 30% (6/20) ($p = 0.005$).

Discussion

This survey shows significant deficiencies in the pattern of attendance for glaucoma screening among relatives of people with POAG. The study design introduces some selection bias, in that patients who are good communicators are more likely to be recruited from a busy outpatient clinic, and families who are good communicators were more likely to participate in the study. It is therefore likely that the overall rates of glaucoma awareness and screening uptake are rather lower than this study implies.

Of the relatives who responded to our survey, nearly all were aware of their family history of POAG, and 81% had attended for screening. However, nearly a quarter of those screened attended at intervals significantly longer than 2 years, and about one-sixth appeared to be unaware that the screening service is free of charge. The proportion of relatives in whom free screening was performed at least every 2 years was 57%.

About half the relatives did not know that they were at increased risk of developing glaucoma. This proportion was higher in the sibling group than among patients' offspring. Epidemiological studies⁵ have identified increasing age as the major risk factor for glaucoma, even exceeding positive family history. As a group, patients' siblings are older than patients' offspring, and hence they are at higher short-term risk of developing glaucoma. However, the sibling group were more likely to wait longer than 2 years between screenings. This longer delay between attendances correlates with a lower perceived personal glaucoma risk in siblings. The sibling group also seemed to be less aware of the free glaucoma screening service, in that one-third of siblings paid for their eye tests when they did not need to. In our survey, only 30% of siblings were screened, free of charge, at intervals of 2 years or less.

Older relatives may be disinclined to attend for eye screening for a variety of reasons: lower perception of risk, relatively stable requirement for spectacles, poorer mobility, and the cost of the eye test itself in those who are unaware that they can be screened free of charge. Introduction of the sight test fee in 1989 was associated with a significant decrease in the number of tests performed,^{6,7} and studies have shown cost to be a deterrent, particularly in the elderly.^{6,8}

Conclusion

There are several strategies which could improve uptake of glaucoma screening. The general population should be made more aware of the condition, and of the consequences of delayed diagnosis. It should be emphasised that screening is quick and painless, and free of charge to certain higher-risk groups. In our own unit,

discussions with medical staff are augmented by patient information literature published by the International Glaucoma Association,⁹ Royal National Institute for the Blind¹⁰ and the Department of Health.³

Our survey has shown that people with a family history of glaucoma should be made more aware of the free glaucoma screening service, and encouraged to attend for regular screening. Older relatives are at particular risk, and should be specifically targeted. General practitioners, ophthalmologists, optometrists and patients should be encouraged to improve glaucoma awareness and screening uptake, both in high-risk groups and in the general population.

The authors wish to thank Dr H.E. Jones and Mr P.G. Corridan for assistance with the study design, Mr M.J. Houlford for general advice, and Dr J.R. Thompson for statistical analysis.

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