# High rate of incidental glaucoma detection in New Zealand

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#### ABSTRACT

**AIM:** To investigate how glaucoma is initially detected in New Zealanders and what factors aroused disease suspicion.

**METHODS:** A postal survey of 500 randomly selected members of the Glaucoma New Zealand database was undertaken in 2012 to analyse factors relating to their initial presentation and diagnosis of glaucoma. Online surveys and telephone interviews were used to increase the response rate.

**RESULTS:** The overall response rate was 80% (376/468) of eligible participants. The sample had an average age of 76 years. Prior to diagnosis, 80% (290/361) of participants who responded to this question reported no suspicion of glaucoma. A positive family history for glaucoma was the most common reason (71%) for presenting to a health care professional with a suspicion of glaucoma (13% of total sample). After diagnosis, 95% (357/376) of respondents reported that they had informed family members of their diagnosis.

**CONCLUSIONS:** This study confirmed that the majority of glaucoma was discovered through incidental findings. A positive family history was the most common risk factor prompting examination, knowledge about which appeared to increase dramatically post-diagnosis. These findings indicated that there was potential to educate the public about glaucoma in order to raise awareness and diagnose the disease earlier.

Glaucoma is the leading cause of preventable blindness in developed countries, including New Zealand.<sup>1</sup> Population-based studies find high rates of undiagnosed glaucoma<sup>2,3</sup> with over 50% of people with glaucoma living in developed countries remaining undiagnosed and unaware of their disease.<sup>4</sup> Early detection is vital to reduce the burden of unnecessary blindness due to glaucoma. The Royal Australian and New Zealand College of Ophthalmologists recommends that the public should have their eyes checked every two years<sup>5</sup> and the New Zealand Association of Optometrists recommends a regular eye examination every two to five years for healthy adults.<sup>6</sup> However, like other developed countries, New Zealand does not have a formal screening program for glaucoma.

A preliminary, unpublished study by the same investigative team reviewed the medical records of 400 patients seen in a nurse-led glaucoma clinic in the Dunedin Hospital Ophthalmology Department, Dunedin, New Zealand in 2011, and found that 72% of new cases of glaucoma were detected incidentally during referral for another reason unrelated to glaucoma. This high rate of incidental detection of glaucoma in a subset of glaucoma patients prompted this survey of a more representative national sample.

The aim of this study was to determine how people came to be assessed and diagnosed with glaucoma, given that it is largely a "silent disease" without symptoms, and what prompted those whom were not found incidentally to seek examination.

# Methods

Five hundred members of Glaucoma New Zealand were randomly selected from the 3,595 members who had indicated they had a diagnosis of glaucoma. They were sent a postal questionnaire in January 2012 along with a unique code allowing them to answer an identical online questionnaire



| <b>Gender</b><br>Male<br>Female   | 137 (36%)<br>239 (64%)                               | <b>Place of residence</b><br>Urban<br>Rural                                      | 351 (93%)<br>25 (7%)                          |
|---|--|--|---|
| <b>Ethnicity</b><br>NZ European<br>NZ European + Other<br>British<br>Māori<br>Other | 314 (84%)<br>16 (4%)<br>30 (8%)<br>2 (1%)<br>14 (4%) | Mean age in years (SD)<br>Employment status<br>Retired<br>Employed<br>Unemployed | 76.4 (7.7)<br>307 (83%)<br>62 (17%)<br>3 (1%) |

**Table 1:** Demographic characteristics of study participants.

using Surveymonkey.<sup>7</sup> A reminder letter, containing an additional copy of the questionnaire was sent to all non-responders two weeks later. This letter highlighted the availability of a toll-free phone number for participants to call with any queries, comments or to request assistance over the phone to complete the questionnaire. Participants who did not respond to either the letter or online survey within two months were contacted by phone and requested to complete the questionnaire by direct questioning. All phone interviews were conducted by the same investigator (JE).

Data from posted questionnaires, online surveys and phone interviews were collated in Microsoft Excel. The only inclusion criterion was having a diagnosis of glaucoma. Individuals were excluded if they indicated that they did not have glaucoma but had been misclassified by Glaucoma New Zealand, had an incorrect address or were deceased. The presence of actively treated glaucoma was confirmed through the questionnaire to ensure that all participants were either receiving glaucoma treatment or had undergone surgical and/or laser glaucoma treatment. Blank answer fields in the location section of the written questionnaire were completed using details from the Glaucoma New Zealand database. When other answer fields were left blank, answers

were interpreted as answers of "zero", "not applicable" or "none" as appropriate to the question. If one or more of the answer fields immediately before or after the blank field was also left blank, the question was classified as having been missed.

*Classification Coding System (CCS)* software by *Statistics New Zealand* was used to convert street addresses into 2006 meshblock codes which were used to link each individual participant to a New Zealand Deprivation (NZDep) Score.<sup>8</sup>

Ethnicity data was retrieved from Dunedin Hospital records. In New Zealand, ethnicity is a measure of self-perceived cultural affiliation.<sup>9</sup>

### Results

Of the 3,595 members of the Glaucoma New Zealand database, 500 were randomly selected to participate in this study. Members who had not been treated for glaucoma, had incorrect addresses or were deceased were excluded, leaving 468 eligible participants. The initial postal survey provided 27 responses and the second postal survey provided an additional 301 responses. A further 48 participants were contacted by phone or completed the survey online to give an overall response rate of 80% (376/468). The demographic characteristics of participants are described in Table 1.

Table 2: Initial suspicion of glaucoma and reason for suspicion.

| Respondent suspicion of glaucoma |           | Reason for suspicion of glauco | Reason for suspicion of glaucoma |  |
|----------------------------------|-----------|--------------------------------|----------------------------------|--|
| Not suspicious                   | 290 (80%) | Family history only            | 46 (65%)                         |  |
| Suspicious                       | 71 (20%)  | Family history and symptoms    | 4 (6%)                           |  |
|                                  |           | Symptoms only                  | 19 (27%)                         |  |
|                                  |           | Unspecified                    | 6 (9%)                           |  |



|              | Initial consultation regarding glaucoma |                 |                      |        |  |
|--------------|---|-----------------|----------------------|--------|--|
|              | Optometrist                             | Ophthalmologist | General practitioner | Other  |  |
| Suspicion    | 35 (51%)                                | 28 (41%)        | 3 (4%)               | 2 (3%) |  |
| No suspicion | 230 (82%)                               | 30 (11%)        | 14 (5%)              | 7 (3%) |  |
| Total        | 265 (76%)                               | 58 (17%)        | 17 (5%)              | 9 (3%) |  |

Table 3: Initial consultation and suspicion of glaucoma.

Prior to being diagnosed with glaucoma, 80% (290/361) of participants who answered this question had no suspicion of glaucoma. Of those who were suspicious about glaucoma, 65% (46/71) sought examination due to having a positive family history for glaucoma (Table 2).

When glaucoma was suspected, respondents were more likely to have chosen to have their initial consultation with an ophthalmologist. Most (82%, 230/265) respondents who had no initial suspicion of glaucoma were most likely to be seen and had an initial suspicion of glaucoma raised by their optometrist (Table 3).

Only 4% (17/374) of respondents who answered this question did not use spectacles of any type. The majority of spectacle wearers (322/357) had their glasses prescribed by their optometrist. Nearly half, 47% (178/376) of all respondents were aware of having at least one "blood-relative" with glaucoma and 95% (357/376) reported informing relatives that they had glaucoma. Of those who had discussed their diagnosis with family members, 93% (332/357) had also reported advising their relatives to have regular examinations.

## Discussion

The most striking finding of this New Zealand wide survey of a randomly selected group of people with glaucoma was that 80% did not have any suspicion of glaucoma prior to being diagnosed. Of the 20% who did present with a suspicion of glaucoma, the most common cause for concern was a positive family history. Participants were well aware of the importance of a positive family history after their diagnosis, with 95% reporting that they informed their own family members and 93% of these advising family members to have their eyes examined.

This study supported the often quoted statistic from large population-based studies that in the developed world, more than 50% of glaucoma cases remain undiagnosed.<sup>10</sup> The presence of a first-degree relative with glaucoma is a risk factor for glaucoma.<sup>11</sup> The percentage of respondents with a positive family history (47%) was higher in this study than that found in population-based studies such as the Baltimore Eye Survey (16%)<sup>3</sup> or the Barbados Eye Study (17%)<sup>2</sup> as would be expected with a targeted glaucoma population. Gender and age trends were in keeping with larger studies of glaucoma detection.<sup>10</sup> Wong et al<sup>12</sup> found that all previously undiagnosed people in their study with glaucoma who had been seen by an eye health professional in the previous year were aged 50 years or older. The mean age of our study population was in keeping with increased age being a risk factor for glaucoma.<sup>13</sup>

This study highlighted the silent nature of glaucoma and showed the importance of opportunistic screening by healthcare providers in order to detect the disease early. Most participants had worn or currently wear spectacles, representing an excellent potential point of contact where patient education and examination can be optimised to catch as many cases of undiagnosed glaucoma as possible.

An encouraging finding was that when glaucoma was diagnosed, people were informing family about the disease and recommending examination. While this appears reassuring that the general public are aware of the increased risk of glaucoma associated with having a positive family history, the group who suspected glaucoma due to family history only comprised 13% of the study population. More importantly still, 47% of participants stated that they



were aware of having at least one relative with glaucoma. This disparity between those who knew they had a relative with the disease and those who are also suspicious that it may affect them suggests that many do not comprehend the significance of the increased risk they face. Education of healthcare workers who come in contact with an at-risk population could potentially prompt patients with a family history of glaucoma to be assessed earlier and to discuss it with their family.

Respondents were selected from the Glaucoma New Zealand database for our study. Membership is voluntary and members do not have to have a diagnosis of glaucoma. While efforts were made to exclude members who did not have a diagnosis of glaucoma, it is often difficult for people to know whether they have glaucoma or are merely a "glaucoma suspect" given the nature of glaucoma and its variable diagnostic criteria over time and between studies.<sup>14</sup> One strength of this study was achieving a high response rate through the use of multi-mode survey methods.

This survey provided further evidence that many people with glaucoma have no suspicion of their disease prior to being diagnosed, and raises the question of whether a glaucoma screening programme should be implemented rather than relying on the recommendations of professional bodies.<sup>5,6</sup>

#### Competing interests: Nil. Acknowledgements:

The authors would like to thank Glaucoma New Zealand and the Dunedin School of Medicine for providing scholarships to Joshua Erceg to help fund this study. Tui Bevin was supported by a grant from the Healthcare Otago Charitable Trust.

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http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2016/vol-129-no-1446-2-december-2016/7081

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