SCIENTIFIC REPORT

The prevalence of sight-threatening uveitis in Scotland

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Aim: To identify and quantify the prevalence of patients with uveitis receiving systemic immunosuppression in Scotland.

Methods: Anonymised data were prospectively collected on all patients with uveitis requiring systemic immunosuppression. Seven health boards participated over a 4-month period between 1 August 2005 and 30 November 2005.

Results: 373 patients were identified, of whom 205 (55%) were female. The mean age was 46.4 (range 7–97 years). Using the data from the seven participating health boards, an estimated Scottish prevalence of 9 per 100 000 was calculated. Prevalence varied between 2 and 59 per 100 000. In National Health Service Grampian, all patients with uveitis, whether sight-threatening or not, are followed up at a specialist clinic. Extrapolating this figure to Scotland gives a prevalence of 25 per 100 000.

Discussion: The data from National Health Service Grampian suggest that there is a significant shortfall in the number of patients identified by survey. If the “missing population” exists, then where are they? Some might be receiving appropriate treatment at non-specialist clinics, although simple under-reporting may play a part. Greater concern is for those patients receiving inappropriate treatment for their uveitis, or for those within the community who are either oblivious to or in self denial of their condition.

Uveitis is a significant, but largely unrecognised cause of visual impairment in the UK. In the Western world, current incidences of uveitis vary between 38 and 200 per 100 000.^{1–3} These reports do not differentiate sight-threatening uveitis from non-sight-threatening uveitis.^{1–3} The proportion of people with marked visual loss may be as high as 35%.⁴ Uveitis ranks fifth in the causes of legal blindness in the developed world,^{3, 5, 6} and is believed to be responsible for 10% of cases of visual loss in the age group of 20–60 years.^{7, 8}

Systemic steroids reduce intraocular inflammation, but either side effects or an incomplete response on reducing the dose to minimise side effects has led to the increasing use of second-line immunosuppressive treatment for sight-threatening uveitis. This is now an accepted practice by specialists internationally.^{9, 10}

It has been suspected that appropriate treatment might be denied to patients with sight-threatening uveitis.¹¹ This might be because the type of uveitis the general ophthalmologists encounter frequently—namely anterior uveitis—is deceptively simple to manage. Unfortunately, if this treatment protocol is applied inappropriately to all forms of uveitis, unnecessary visual morbidity may result.

The aim of this survey was to identify and quantify the prevalence of patients with uveitis receiving systemic immunosuppression in Scotland.

PATIENTS AND METHODS

Ophthalmologists in Scotland with an interest in uveitis met in January 2005 to consider how the care of patients with

sight-threatening uveitis could be delivered in a more uniform manner. A decision was made to develop a Scottish Uveitis Network involving clinicians and the Uveitis Information Group—a UK-based patient organisation. The Network’s first priority was to quantify patients with sight-threatening uveitis in Scotland. Representatives from seven health boards (National Health Service (NHS) Argyll and Clyde, NHS Fife, NHS Grampian, NHS Greater Glasgow, NHS Lanarkshire, NHS Lothian, NHS Shetland) agreed to prospectively collect data on all patients requiring systemic immunosuppression for uveitis (systemic steroids, second-line immunosuppression or a combination of these treatments). For this first survey, it was decided to record the minimum of information.

To prevent duplication of data (eg, patients who attended more than one ophthalmic centre), four pieces of information were requested. These were (1) the first part of the patient’s address, (2) the patient’s sex, (3) age and (4) the last four digits of the community health index number. The community health index number is a unique patient identifier used throughout NHS Scotland. Use of only the last four digits maintains anonymity. Data collection was anonymised, in accordance with the Confidentiality and Security Advisory Group Scotland guidelines.¹² Details of individual patient treatment were not recorded.

This prospective survey took place over a 4-month period between 1 August 2005 and 30 November 2005. Participants were requested to record data for all appropriate patients seen during the study period. Regular reminders were sent to encourage accurate data collection. The data were collated in one centre (Aberdeen) where data analysis was performed.

RESULTS

Scotland has a population of approximately 5.1 million inhabitants distributed among 15 health boards. These boards vary in both geographical area and population (fig 1).

A total of 373 patients were identified, 363 of whom were residents of Scotland. The 10 patients of non-Scottish residence were from England, Ireland or Northern Ireland. Gender information was provided on 347 of the patient cohort, of whom 191 (55%) were women. The mean age of the entire cohort was 46.4 years, and the mode was 39 years (range 7–97 years).

Owing to the variation in health board size, data were calculated to show health board prevalence. By using the data from the seven participating health boards, an estimated Scottish prevalence of 9 per 100 000 was calculated (fig 2). The highest prevalence was in NHS Shetland at 59 per 100 000. The lowest prevalence was in NHS Greater Glasgow at 2 per 100 000.

Three consultants received tertiary referrals from regions out of their own health board region. Extra-regional referrals accounted for between 24% and 74% of the workload in these centres.

Abbreviations: NHS, National Health Service

Figure 1 Map of Scotland showing NHS Board populations (000s) at the time of uveitis survey. Reproduced by the kind permission of Scottish Diabetes Survey 2003. <http://www.scotland.gov.uk/Resource/Doc/26350/0012822.pdf>

DISCUSSION

We have identified 363 patients in Scotland on systemic immunosuppression, an indicator of sight-threatening uveitis, from 13 of Scotland's 15 health boards. We have no data

regarding patients from two health boards, and minimal indirect data based on tertiary referrals for patients from six other health boards.

NHS Grampian had a prevalence of 25 per 100 000. We feel that the data from this region are likely to be the most complete, as in this health board all patients with uveitis, whether sight-threatening or not, are followed up at a specialist inflammatory eye clinic. In comparison, a recent population study in Northern California suggested an overall prevalence for uveitis of 134.4 per 100 000. Unlike previous studies, uveitis was subclassified as anterior, intermediate, posterior, diffuse or indeterminate uveitis. To allow comparison with our study, we have assumed that all cases of posterior and diffuse uveitis were sight-threatening, giving a prevalence of 14.8 per 100 000. The actual prevalence in this study is likely to be higher as it would be expected that a proportion of their patients with anterior, intermediate or indeterminate uveitis would also have had sight-threatening disease.¹³ The accuracy of this study has been questioned as, unlike other studies, the highest prevalence of uveitis was found in people ≥ 65 years of age.¹⁴

Figure 2 Prevalence of sight-threatening uveitis in participating health boards. Prevalence is shown as number per 100 000.

Scotland's population at the latest estimate (30 June 2005) was 5 094 800. Over the past 50 years, Scotland's population has remained relatively stable. It peaked in 1974 (5.24 million), and since then there has been an overall gradual decline, although rising slightly over the past three years. In the period 2004–5 Scotland's population increased by 0.25%, and Grampian's population by 0.4%.¹⁵

Extrapolating the NHS Grampian prevalence figures to the Scottish population, the potential number of patients in Scotland either on, or requiring, systemic immunosuppression could be as many as 1275 patients. This would suggest a potential shortfall of 912 patients not identified by the survey. Even within participating health boards, there are considerable discrepancies between values calculated using this data projection and the numbers actual recorded (fig 3). These unidentified patients may be a quirk of our crude statistical extrapolation. This is one possibility considering that the prevalence for other health boards vary between 59 per 100 000 for NHS Shetland and as low as 2 per 100 000 for NHS Greater Glasgow. The low prevalence suggests a level of either under-diagnosis or under-reporting; the high prevalence suggests the quirk of using data with too small a denominator.

If we accept that the prevalence in NHS Grampian is accurate, then the question arises as to the nature of Scotland's missing population. Some might be receiving appropriate treatment by a general ophthalmologist at non-specialist clinics, whereas under-reporting may explain some of the missing others. In Lothian, for example, we have data only for one of three clinicians managing patients with uveitis. In addition, a proportion of patients will be from regions that did not participate in the survey, where presumably patients are being managed by non-specialist ophthalmologists. Finally, a proportion of patients might be receiving orbital or intravitreal steroid treatment, and therefore are not being considered for systemic immunosuppression. Greater concern is for those patients receiving inappropriate treatment for their uveitis—for example, topical treatment when systemic treatment would be more appropriate—or those patients within the community oblivious to or in self-denial of their condition. In NHS Greater

Glasgow, referral rates from neighbouring health boards to NHS Greater Glasgow were greater than referral rates in NHS Greater Glasgow itself.

It could be argued that the NHS Grampian prevalence is an overestimate and that in this health board region patients are being overtreated with potentially toxic drugs. The risk of over or excessive treatment is a constant concern when using immunosuppressive treatment.

Currently, in most of the centres in the UK, patients with perceived non-sight-threatening uveitis are managed in general ophthalmology clinics. Any triage system, despite increasing the specificity of referrals and thus reducing unnecessary specialist workload, must by its very nature also delay the institution of appropriate treatment leading to potentially avoidable visual impairment.¹⁶

How we encourage non-specialists to refer patients to the right place at the right time is a matter for debate. Referral protocols may be of benefit, but only if sufficient specialists exist to treat people who are referred. This may require restructuring of the delivery of ophthalmology in some regions.

How we identify the missing population is another challenge. Positive encouragement to all those involved in the study to improve data collection and wider involvement, including specialists previously not involved in the survey, may allow more accurate data collection. Those within the population unaware of their potentially treatable condition (community oblivious) and those who are in self-denial are a much more difficult challenge, and we feel much less capable of detecting these patients. We would suggest that unless considerable population variation had occurred in Scotland this group would not have been identified in the Grampian region, and therefore this group contributes little to the missing population.

A more accurate measure of patient numbers may provide useful information for future workforce planning. The Scottish Uveitis Network intends to repeat the survey in 2006 to improve the robustness of these findings. In addition, clinical guidelines will be developed for referral to aid non-specialists in deciding which patients should be considered for immunosuppression.

Figure 3 Within participating health board regions, predicted patient numbers have been extrapolated. Those identified are patients from the survey. Those not identified are the predicted short fall when a prevalence of 0.025% is used to predict the expected number of patients for health board populations. The figures shown on the graph are actual patient numbers. With Shetland having the highest prevalence, the not identified patients are shown as a negative percentage.

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