Abstract

Non-arteritic ischaemic optic neuropathy (NAION) is a common cause of visual loss and yet is poorly understood and has no reliable treatment. This reports on a survey questionnaire sent to an internet group of NAION sufferers. It suggests an association between cholesterol levels, central obesity and the extent of visual loss. The results also demonstrate the profound emotional impact of NAION on individuals and the reality that diagnosing teams provide little information or support and scant advice on coping with the visual loss or preventing or minimising future episodes. Key words: NAION, ischaemic optic neuropathy, patient survey

Introduction

Non-arteritic Ischaemic Optic Neuropathy (NAION) is one of the commonest causes of visual loss. Despite this, little is known of its causes and no treatment has been found to prevent or reverse its effects. Although the nerve damage in the optic nerve is caused by a reduced blood supply. The exact mechanism and risk factors are unclear. Small optic discs and a low cup to disc ratio may be one risk factor. The optic nerve regulates its blood flow depending on circumstances, and anything that damages blood vessels may reduce the capacity of the optic nerve to regulate its blood supply. When an additional factor is added, such as a drop in blood pressure at night, this triggers the loos of blood supply the front of the optic nerve that results in NAION. Even this process is poorly understood although. It does not seem related to large artery disease and NAION does not increase the risk of stroke. Rather than being a problem in the small arteries, the problem may lie in the small veins resulting in back pressure. The resulting swelling, especially in an already crowded small disc, will further reduce or stop blood flow resulting in the death of optic nerve axons.
The fact that NAION appears suddenly without warning, often on waking, results in a profound emotional impact on individuals. When its affects both eyes the disability can be life-changing. There is little work looking at this emotional impact on individuals.

The Yahoo NAION group of affected individuals has been providing support for over a decade and is an important source of personal experience. In 2007 a questionnaire was sent out to members.

Method

The NAION group was asked to contact the author (CR) if they wished to take part. Those who responded were emailed a questionnaire. Questions included treatment prior to the NAION, comorbidities, the eye affected, their estimate of visual loss, accompanying symptoms, treatment (including communication), progress, personal measurements at the time of the episode (height, weight, waist, cholesterol), emotional impact, what treatments were tried and what factors help of hinder their coping.

Results

In total, 38 individuals responded to the emailed questionnaire, 26 men and 12 women. The median age was 54 for both men and women, with a range of 35-77 years.

Drugs and co-morbidities at the time of the NAION

Drugs to treat hypertension were the commonest prior to the NAION (34%), with aspirin the second commonest (26%). Only one patient was taking sildenafil, a drug that had been thought to cause NAION although surveys consider this view to be incorrect. Raised cholesterol was present in 34%, hypertension a problem in 26% and sleep apnoea in 16%. There was a wide range of events that individuals thought might have contributed to the NAION, but no consistent factor.

Affected eye(s)

The left eye was the most commonly involved eye, being the only eye involved in 49% while the right was the only eye involved in 17%. In 34%, both eyes were affected. One individual had an episode in both
eyes at the same time, but for others there was a delay. The delay to a second episode of NAION in the other eye varied from 10 days to 20 years. However, in 75% of these individuals the second episode occurred within 2 years.

**Symptoms of NAION**

Most (67%) noticed a problem on first waking, with 19% finding it developed during the day and 11% over several days. The commonest description of the visual loss was ‘grey area’ (37%) or a ‘smudge’ (29%). Individuals noticed a range of symptoms after the event. These included a pattern after switching off lights (47%); discomfort in bright light (37%); brief flashes at night (32%); a brief flash after a sudden noise (24%); after images in the area of visual loss on rubbing the eyes (21%); and changes in colour perception (18%). The after images disappeared after 2-3 months, but other symptoms took up to a year to resolve.

After the initial event the visual loss worsened in 49%, stayed the same in 37% and improved slightly in 11%.

**Diagnosis and communication**

Eight individuals were initially misdiagnosed as having problems such as vitreous humour detachment, macular oedema, multiple sclerosis or Druzen bodies. A delay in diagnosis was a common experience such that 84% did not realise the visual loss was permanent. It took these individuals between a few days to a year to realise they would not regain their vision. Once diagnosed, communication was usually clear, although sometimes abrupt. No written information was provided in 35%. All individuals found the internet and support groups helpful, except one individual who found the web information depressing.

**Visual loss**

The lower part of the visual field was more affected than the upper field (fig 1). There was little difference between the two eyes: the right sided eyes suffered an average 53% loss and the left sided eyes 49%.
Fig 1: areas of the visual field affected (based on individual estimates)

Emotional impact
The emotional impact on individuals was profound. Common themes were fear of the other eye being involved, fear of going to sleep, helplessness and concern that it was their fault.

Anxiety: The majority (90%) were anxious with 64% of these having severe anxiety defined as being anxious for more than half the time and for more than two weeks. It took individuals between 2 weeks and 2 years to resolve their anxiety, but it remained unresolved in three individuals at the time of the questionnaire.

Depression: the majority (85%) described feeling depressed, with 61% of these having severe depression defined as being depressed for more than half the time and for more than two weeks. It took individuals between 2-6 months to resolve their depression, but it remained unresolved in two individuals at the time of the questionnaire.

Anger: 43% described feeling angry, with two finding it difficult to control. It took between 2-12 months to resolve their anger.

The majority (66%) found physical exercise helped with 63% finding relaxation therapies helpful such as meditation, massage and yoga. Talking therapies such as counselling or psychotherapy helped 32%, while drug therapy such as antidepressants or night sedatives helped 24%. A few found their faith helpful.
NAION treatments
Aspirin was the commonest drug used (63%), followed by a trial of steroids (45%) and levadopa (11%). Acupuncture was tried by 13% of individuals. No individual reported any benefit from these treatments.

Individuals started and continued a number of treatments to prevent a worsening or recurrence of NAION including omega-3 fish oil (42%), vitamins (C, B and folic acid)(34%) and cholesterol reducing drugs (26%).

Coping with NAION
Individuals found a number of factors could make the visual loss more difficult to manage: nighttime (42%), sunlight (40%), boredom (29%), low mood (24%), cloudy conditions (24%) and fluorescent lighting (21%). However, they found many factors which helped: sunglasses (50%), large print or font (47%), being busy (37%), reading glasses (32%), reading light (32%) and night time glare reducing glasses (11%).

Does visual loss relate to any factors?
There is no relationship to age with individuals as young as 35 being as badly affected as individuals of 77 (Fig 2).

![Age vs visual loss](image)
There was a modest relationship between visual loss and Body Mass Index (BMI) and the ratio between height and waist (Fig 3). The median BMI was 26.5 (range 22-44) and the median waist/height ration was 52%. Both of these are high, but there were individuals with low BMI who had 100% loss of vision. However, no-one with a normal waist/height ratio had a large visual loss.

**Fig 3: relationship between visual loss, BMI and waist/height ratio**

Having a second episode of NAION does not mean that episode will be worse. On the contrary in most it was the same or less severe (fig 4). However, the impact of having both eyes affected is much greater than having a single eye involved.

**Fig 4: visual loss between first and second episodes.**

There was little difference between the visual loss for men (average 55%) and women (average 52%). People who snored had a lower average visual loss (38%) than those who did not snore (61%).
In contrast there appeared to be a relationship between cholesterol levels and the visual loss (Fig 5).

![Cholesterol and visual loss](image)

**Discussion**

Many individuals (34%) were on antihypertensive drugs prior to their NAION episode suggesting either a direct effect of raised pressure on optic nerve circulation or, paradoxically, the effect of lowering blood pressure especially if medication was taken at night. Over a third (37%) were on treatment for a high cholesterol and a link between NAION and elevated cholesterol is known. What has not been shown previously is that the level of cholesterol appears to relates to the extent of later visual loss. There also appears to be a relationship between BMI and later visual loss, but the stronger link between visual loss and the height/weight ratio suggests that central obesity is a more important risk factor than weight alone. It is likely that other factors such as the disc/cup ratio also contribute but central obesity and cholesterol levels are potentially reversible risk factors, along with hypertension and night-time antihypertensives. Very few in this group had sleep apnoea or diabetes and yet they still developed NAION. Recent work suggests that there is a low absolute risk of NAION in sleep apnoea. This may explain why snoring did not relate to visual loss. Age was not a factor, with some young individuals having profound visual loss and some twice their age having very little loss.
In this group no treatment was effective, despite some studies suggesting benefit from steroids (by minimising optic nerve swelling) or levadopa (as a neuroprotective agent).\textsuperscript{9 10} The pattern of visual field loss, particularly affecting the lower visual field, is well recognised.\textsuperscript{11} The predominance of left eyes being affected, or the difference between first and second episodes, has not been noted previously. Although some individuals had their other eye affected a decade or more after the initial episode, most second episodes happened within 2 years. The symptoms described by individuals and the factors they found helpful have not been reported in any detail elsewhere and do not feature in specialist advice or literature.

The emotional impact on individuals is profound, an issue poorly recognised by the diagnosing and treatment teams who could be slow to diagnose the condition and often provided little support. Despite no treatment being shown to be effective, reducing the risks to prevent or minimise a second episode should be a priority. Patients often found their advice came from support groups or the internet rather than clinicians. Such groups often share their experiences, including what they have found helps or hampers their vision.

This study was limited by the relatively small numbers and the nature of self-reported information. For example, the estimates of visual loss were subjective but are perhaps more useful for being so since they reflect what individuals experience. In addition the self reporting of the emotional impact and the factors that help individuals cope are not available in objective studies. A repeat questionnaire with more numbers is warranted. In the meantime the findings of this survey could form the basis of a patient advice leaflet.

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