Research Report

How does glaucoma look? Patient perception of visual field loss.

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Summary:

The purpose of the research was to explore patients' perception of vision loss in glaucoma and, specifically, to test the idea that patients do not recognize their impairment as a black 'tunnel effect' or 'black patches' in their field of view.

Fifty patients (age range: 52 to 82 years) with visual acuity better than 20/30 and with range of glaucomatous visual field (VF) defects in both eyes were recruited to the study.

Participants performed monocular VF testing in both eyes using Humphrey Field Analyzer (HFA; 242 SITA Standard tests) and other tests of visual function. They then took part in recorded interviews where they were asked if they were aware of their VF loss, and if so, were encouraged to describe it in their own words. Participants were shown six images modified in a variety of ways on a computer monitor and were asked to select the image that most closely represented their perception of their VF loss.

Thirteen patients claimed to be completely unaware of their vision loss. None of the patients chose the images with distinct black tunnel effect or black patches. Two patients chose the image with tunnel effect with blurred edges. An image depicting blurred patches and another with missing patches was chosen by 54% of the patients respectively. Analysis of the transcripts from the recorded interviews indicated frequent use of descriptors of visual symptoms associated with 'blur' and 'missing'. Patients with glaucoma do not perceive their vision loss as black 'tunnel effect' or as 'black patches' masking their field of view. These findings are important in the context of depicting the effects of glaucomatous vision loss and raising awareness of the need for regular routine eye examinations for all those over the age of forty and those at increased risk of glaucoma.

Background to the research:

If one enters the term 'glaucoma' into an internet search engine it will return many images illustrating what the patient with the disease is believed to

see. Most of these images, typically developed for patient information and glaucoma awareness programmes, imply that patient's perception of the world is through a 'black tunnel', or with parts of their field of view obscured by 'black patches'.

Most clinicians and most patients with the disease know this is misrepresentation. Perception of VF loss is far more complex, yet there is very little research evidence that assesses how patients with glaucoma actually describe their awareness of VF loss. Assembling an evidence base of what patients 'see', and what they don't 'see', would be helpful for at least two reasons. First, it would aid in raising awareness of the true symptoms of the condition – particularly important since estimates of those with the disease that remain undiagnosed are so high. Second, it might help patient adherence to their treatment regime if they are falsely reassured about their condition because they do not have the 'severe' symptoms depicted by the typical images of how glaucoma 'looks'.

Good evidence, reviewed extensively elsewhere, is beginning to emerge highlighting the impact of glaucomatous VF loss on everyday function. Nevertheless, results from clinical tests of vision do not necessarily correlate well with patient perception of their vision. For example, some patients are 'surprised' to find there is something wrong with their vision, or attribute noticed changes to the normal ageing process.

Perimetric measurements of retinal sensitivity to light (depicted in VF test charts by grey areas, becoming black patches in more damaged regions) represents a simplistic view of vision loss in glaucoma. Other aspects of visual function such as motion perception, discrimination of high spatial frequencies and colour vision are also involved. Furthermore, key ideas from psychophysics and neuroscience about the mechanisms of compensation for VF loss are largely underappreciated, yet provide an explanation for the asymptomatic nature of glaucoma until late stages in the disease process. One report speculated that cortical reorganization, in concert with resulting filling in, almost certainly affects the recognition of VF loss in glaucoma and used this premise to design some helpful images illustrating how these phenomena would look to patients. To our knowledge there has been no direct assessment of patient's description of the perception of glaucomatous VF loss. Having narrative directly

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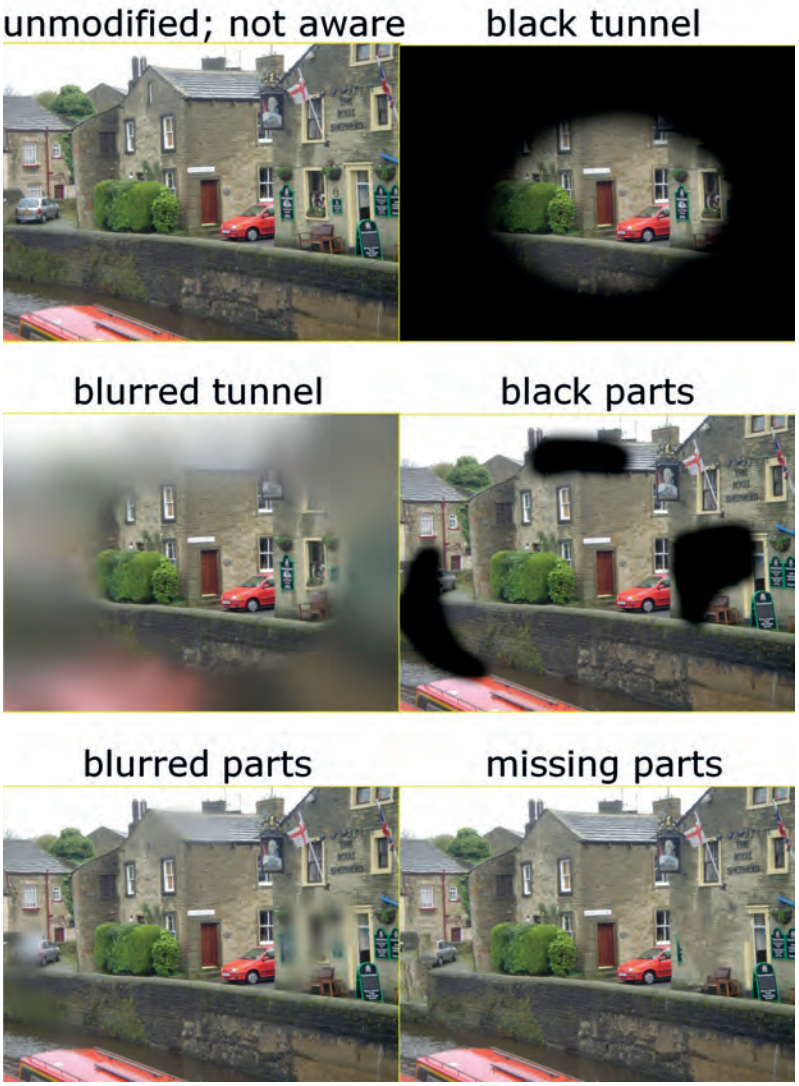
from patients themselves, would be helpful in constructing images and films of what is seen and, perhaps more importantly, dispelling myths about how glaucoma is meant to 'look' to the person suffering from the condition.

The main aim of this report is to test the hypothesis that patients with bilateral glaucoma would not choose to describe their perception of VF loss as a 'black tunnel effect', or as 'black parts' masking their field of view. By using open ended interview questions, the study also aimed to investigate how patients describe the perception of their functional impairment, and how this manifests in their day-to-day life.

Method

The target population for this study was patients with glaucoma aged between 50 and 80 years, with a range of VF loss in both eyes. Patients were recruited from Moorfields Eye Hospital, and all had an established clinical diagnosis of primary open angle glaucoma in both eyes. Glaucomatous VF loss was defined as repeatable Glaucoma Hemifield Test (GHT) 'outside normal limits' classification from the Humphrey Field Analyser at their most recent clinic visit. Participants were included only if they had corrected binocular visual acuity of equal to or better than Snellen 20/30. Participants had slit lamp biomicroscopy performed by an ophthalmologist and were not recruited if they had any other ocular disease.

Figure 1



A 'forced-choice experiment' was used to select an image that best represented the patient's perception of their VF loss. Six candidate images (figure 1) were shown to the patients on a LCD computer monitor

at a distance of 40cm. For all six, the same outdoor scene image was used, but each was manipulated to provide views of the image obscured and degraded in a range of distinct ways: 'tunnel with black edges', 'tunnel with blurred edges', 'black patches', 'blurred patches' and 'missing patches'. After the unmodified (original) image was shown, the others were displayed to the study participant in random order. The patients were allowed to toggle between the images, but they were simply asked to make forced-choice decisions about which of the six most closely related to their perception of their visual loss with glaucoma.

Patients were then asked two open-ended questions and their responses were recorded:

In your own words could you describe how your glaucoma affects your vision?

When you are aware of your visual field loss, can you describe how it looks, or how it impacts on your vision and in everyday life?

Patients were deliberately encouraged to say as much as they could in response to the questions. The interviewers took special care to avoid saying anything that could be interpreted as 'leading' or 'coercive'. All the recorded interviews were transcribed.

Analysis

The responses to the forced-choice experiment were counted and compared using statistics for proportions. Summary statistics were calculated and compared for the groups of patients choosing a particular image. An integrated visual field (IVF) was also constructed for each patient to give representation of their binocular VF. This method involves the combination of the measured monocular VFs by simply taking the best sensitivity value at each corresponding test point to represent the person's binocular VF. The transcribed interviews were subjected to a form of content analysis. Each transcript was assessed by highlighting words considered to be descriptor of the symptoms of perception of glaucoma or how VF loss looks. This was done by three of the authors arriving at consensus about definition of descriptor and whether word or term was meaningful. For example, 'blurry', 'blurred', 'blurs', 'blurriness' were all considered to be derived from the verb, 'blur'. If, on the other hand, patient used, for example, 'foggy', 'smear' or 'blot' then these would be considered separate descriptors.

Frequency of the occurrence of identified terms was calculated as the number of participants who used the word; if patient, for example, used the word 'blur' four times during their interview then this would only count as one. Also, only 'positive' descriptors were identified and counted. So, for example, if patient said, "…my vision is not blurred…" this was not counted.

The same analysis was conducted for words used to describe everyday activities used by participants as examples of when they were aware of their vision impairment.

Results

The results for the forced-choice image experiment are shown in figure 2(a). None of the 50 participants in this study chose the image altered to have 'tunnel with black edges' effect or the image with 'black patches'. Thirteen participants (26%) were completely unaware of the VF defect affecting their visual function, choosing the original unedited image. Twenty-seven (54%) and eight (16%) participants chose the images with 'blurred patches' and 'missing patches' respectively. Only two participants chose the image with 'tunnel with blurred edges' (4%). IVF grayscales are shown for some of the patients in each group in Figure 2(c).

Fig 2 (a)

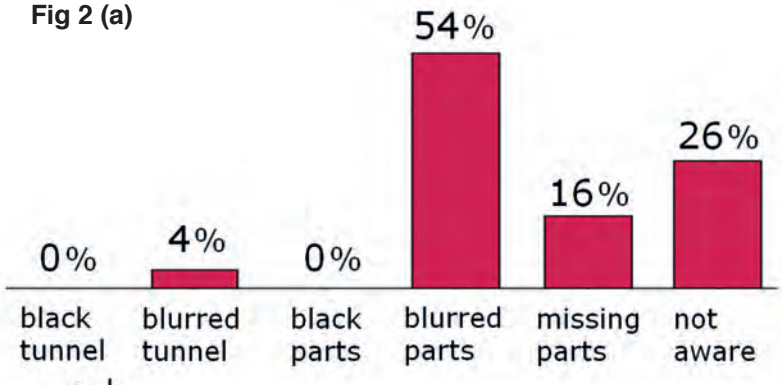


Fig 2 (b)

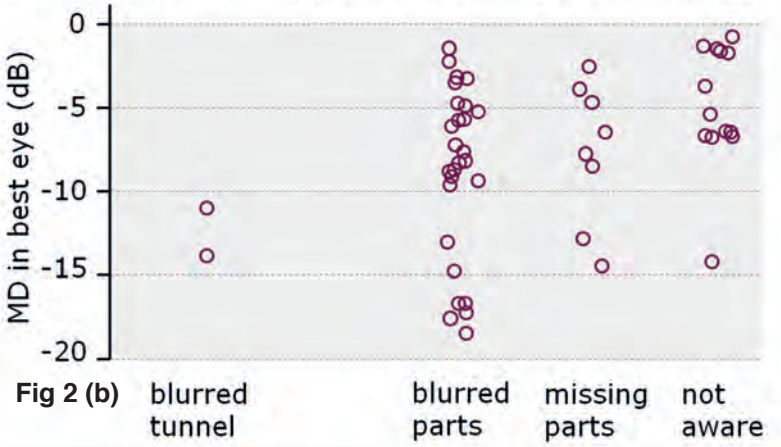
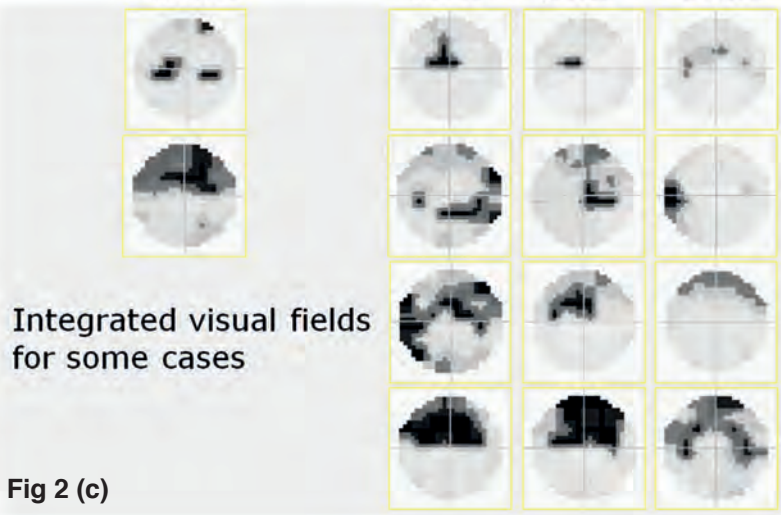


Fig 2 (c)



The most frequently used descriptor of a VF defect was 'missing' (n=10) and 'blur' (n=6). Other synonyms of 'missing' (e.g. 'blank', 'blind-spot', 'hole') and 'blur' ('foggy', 'fuzzy', 'unfocussed') were also evident. Only one person in the study used 'black' as descriptor and not one of the 50

participants used the word 'tunnel'. The results are shown in figure 3(a) as 'word cloud'. The size of word in the visualization is proportional to the frequency of its use by the participants in the study. Similarly, results for the named everyday activities where VF loss was noticed by an individual is also shown as 'word cloud' in figure 3(b).

Fig 3(a)

Fig 3(b)

Discussion

This study provides some evidence, from patients themselves, about the visual symptoms of glaucoma. The study sample represented a population of patients with range of VF loss in both eyes, with more than one-fifth having quite advanced VF loss. Twenty-six percent of the patients reported no visual symptoms, confirming the frequently reported asymptomatic nature of the disease even in the presence of diagnosed bilateral VF loss. The main finding is that patients with visual symptoms do not report seeing black areas in

their field of view, as is commonly (but incorrectly) shown in images and simulations of what patients with the condition are believed to perceive. Moreover, tunnel vision does not adequately describe the visual experience of patients in this study; combination of perceiving 'blur' and 'missing areas' appears to be the main visual indications of the condition.

Insights into the subjective perception of VF loss have been considered previously but, to our knowledge, this study is the first to attempt to get patients with glaucoma to actually describe what they see.

The results from this study are important in terms of stimulating the design of appropriate information about the visual symptoms of glaucoma. There has been a shift in the role of the patient from passive recipient to active consumer of health information, especially via the internet. All stakeholders with an interest in glaucoma, including patients, patient groups, clinicians, researchers and glaucoma societies, could start by ensuring that depiction of the symptoms of the disease, especially on the internet, is as realistic as possible. Providing realistic insights about patients' symptoms might be helpful for educational and public awareness material associated with glaucoma; the results from this report should be considered carefully in this context.

The results from this study also have important clinical implications. Many patients eloquently articulated the recurrent phenomena of noticing part of the VF as 'missing', or described their functional loss as type of 'blur'. These responses are, to an extent, at odds with the conventional view of the visual symptoms associated with glaucoma, which include the simplified view of narrowing of the peripheral VF. These findings are, therefore, relevant to the practitioner in primary eye care responsible for screening and case finding glaucoma, especially when making the differential diagnosis between the need for a refractive prescription, and investigating a complaint of say 'blur' as potential symptom of glaucoma. The results from this study are also relevant to the dialogue between the clinician and diagnosed patient about adherence to treatment and worsening of visual symptoms, especially in the context of the patient who may think their disease is not severe enough to see, for example, 'black patches' in their field of view. Linked to this suggestion is the idea that the doctor/patient relationship might

be strengthened if the doctor can demonstrate that (s)he appreciates the impact of the disease on the patient. After all, research evidence has indicated the importance of the role of clinician as an educator to bridge the gap in knowledge transfer and encourage adherence to treatment. Interestingly, in response to the open-ended questions, some patients clearly did not relate their perception of lack of vision to the greyscale output on the VF chart. The results from this study should prompt those involved in research and development of perimetry to think of imaginative graphical ways of restoring the important connection between the VF measurement and what the patient perceives of their condition.

A starting point could be the use of binocular representations when participants are asked to name everyday situations when they noticed the impact of their VF loss, many of the themes reported in work on quality of life and visual disability in the patient with glaucoma re-emerged. For example, mobility, driving, fear and experience of falling and reading were all consistently mentioned (Figure 3). It was noteworthy that many of the participants in this study became more aware of the vision loss at night-time and this has previously been highlighted as perceived impairment in glaucoma. An everyday activity that has received little attention in glaucoma, but emerged here as being commonly associated with recognising symptoms, was computer use, especially locating the cursor and using the computer mouse. Perhaps this is reflective of the increasing use of computers and the internet in an elderly population. This list of activities where visual symptoms are noticed can only be considered to be illustrative; fortunately, well designed research in this area, using patient reported outcomes and performance based measures, is gathering momentum and should provide better evidence of the impact of the disease on quality of life.

This study has some limitations. The sample size was sufficient to test the main hypothesis, that patients with bilateral glaucoma do not describe their visual symptoms as 'black tunnel effect' or seeing 'black patches'. Yet, the size and distribution of the sample wasn't broad enough to untangle any specific relationship between the type of VF defect and reported symptoms. The example cases in figure 3 show no obvious pattern in a binocular VF being associated with certain description, although preservation of the VF in points adjacent to fixation was a noticeable feature in those

patients declaring no visual symptoms from their condition. Of course, these results might not apply to population of patients with very advanced VF loss, although none of the participants that fell close to this category reported seeing black in their field of view. Another shortcoming of the study is the forced-choice experiment itself; limiting the possibilities of describing individual visual symptoms. Furthermore, patients obviously looked at the images with their visual symptoms, meaning it might be difficult to disambiguate what they perceive from what has been modified. Also, representing vision loss as static defects in an image may not illicit the same response from patients as a defect that maintains constant position with respect to the point of regard. Nevertheless, patients understood the task at hand sufficiently well to be able to describe the impact of their glaucoma on their visual experience and any bias is unlikely to interfere with the main findings about the 'black tunnel effect' or seeing 'black patches'. Note that sample of patients volunteering for study where they know they are expected to describe symptoms and, to some extent, discuss feelings about their disease are not representative of all patients, many of whom might be embarrassed or reticent about their condition. Finally, the open-ended questions only generated a simple list of vocabulary of the symptoms of the condition but more sophisticated qualitative research approaches, perhaps using focus group design, could yield more complete narrative about patient perception of the condition.

In summary this report has shown that patients with glaucoma do not see 'black' areas in their field of view. These results are mainly important in the context of raising awareness for glaucoma detection and in developing appropriate information about the disease. In conclusion, the study provides evidence from patients themselves to contradict the common depiction of the visual symptoms of glaucoma: the end of the black tunnel.

Editors note: This report is has been edited for publication from a more comprehensive and detailed research report provided to the International Glaucoma Association by Professor Crabb. This research was funded by an International Glaucoma Association research grant.