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How Does Glaucoma Look?

Patient Perception of Visual Field Loss

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Objective: To explore patient perception of vision loss in glaucoma and, specifically, to test the hypothesis that patients do not recognize their impairment as a black tunnel effect or as black patches in their field of view.

Design: Clinic-based cross-sectional study.

Participants: Fifty patients (age range, 52–82 years) with visual acuity better than 20/30 and with a range of glaucomatous visual field (VF) defects in both eyes, excluding those with very advanced disease (perimetrically blind).

Methods: Participants underwent monocular VF testing in both eyes using a Humphrey Field Analyzer (HFA; Carl Zeiss Meditec, Dublin, CA; 24–2 Swedish interactive threshold algorithm standard tests) and other tests of visual function. Participants took part in a recorded interview during which they were asked if they were aware of their VF loss; if so, there were encouraged to describe it in their own words. Participants were shown 6 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.

Main Outcome Measures: Forced choice of an image best representing glaucomatous vision impairment.

Results: Participants had a range of VF defect severity: average HFA mean deviation was −8.7 dB (standard deviation [SD], 5.8 dB) and −10.5 dB (SD, 7.1 dB) in the right and left eyes, respectively. Thirteen patients (26%; 95% confidence interval [CI], 15%–40%) reported being completely unaware of their vision loss. None of the patients chose the images with a distinct black tunnel effect or black patches. Only 2 patients (4%; 95% CI, 0%–14%) chose the image with a tunnel effect with blurred edges. An image depicting blurred patches and another with missing patches was chosen by 54% (95% CI, 39%–68%) and 16% (95% CI, 7%–29%) of the patients, respectively. Content analysis of the transcripts from the recorded interviews indicated a frequent use of descriptors of visual symptoms associated with reported blur and missing features.

Conclusions: Patients with glaucoma do not perceive their vision loss as a 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 for glaucoma detection.

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Entering the term *glaucoma* into an Internet search engine will return a plethora of images illustrating what a patient with the disease is believed to see. Most of these images, typically developed for patient information and glaucoma awareness programs, imply that a 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 a misrepresentation. Perception of visual field (VF) loss is far more complex, yet there is a paucity of research evidence directly assessing how patients with glaucoma actually describe their awareness of VF loss. Assembling an evidence base of what patients see, and what they do not see, would be helpful for at least 2 reasons. First, it would aid raising awareness of the true symptoms of the condition—particularly important because estimates of those with the disease who remain undiagnosed are so high.[1,2] Second, it may help patient adherence to their treatment regimen if they are falsely reassured about not having the severe symptoms depicted by the typical images of how glaucoma patients see.

Good evidence, reviewed extensively elsewhere,[3–5] 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 patients' perception of their vision.[6,7] For example, some patients are surprised to find there is something wrong with their vision or attribute noted changes to the normal ageing process, and this is supported by qualitative studies investigating patient perception of glaucoma.[8] 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 besides light sensitivity, such as motion perception, discrimination of high spatial frequencies, and color vision, also are involved. Furthermore, key ideas from psychophysics and neuroscience about the mechanisms of compensation for VF loss[9,10]

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largely are 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.[11] To our knowledge, there has been no direct assessment of patient descriptions of the perception of glaucomatous VF loss. Having a narrative directly 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 with the condition.

The main aim of this report was 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 areas 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.

Patients and Methods

The target population for this study was patients with glaucoma between 50 and 80 years of age with a range of VF loss in both eyes. Patients were recruited from a convenience sample from Moorfields Eye Hospital NHS Foundation Trust, London, United Kingdom, 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 results outside normal limits according to the Humphrey Field Analyzer (HFA; Carl Zeiss Meditec, Dublin, CA) at their most recent clinic visit. The HFA mean deviation (MD) from the eye with the better MD (better eye MD [BEMD]) was used as an estimate of VF defect severity. Mean deviation is a standard age-corrected clinical measure of the overall severity of VF loss, with more negative values indicating greater VF loss.

Participants were included only if they had a corrected binocular visual acuity of 0.18 logarithm of the minimum angle of resolution units or better (Snellen equivalent, 20/30), as measured by an Early Treatment Diabetic Retinopathy Study chart. Astigmatic error was less than ± 2.5 diopters in all those recruited. Participants underwent slit-lamp biomicroscopy performed by an ophthalmologist and were not recruited if they had any other ocular disease (except for uncomplicated cataract surgery). To attempt to eliminate further significant media opacity (cataract) and other ocular media-type confounding conditions, all participants were required to have results within normal limits for light scattering in the ocular media using the Oculus C-Quant straylight meter (Oculus Optikgerate GmbH, Wetzlar, Germany). The study was approved by the Ethics Committee for the School of Health Sciences, City University London, and the National Health Service–approved Moorfields and Whittington Hospital Research Ethics Committee. Written informed consent, according to the tenets of the Declaration of Helsinki, was obtained from each participant before examination. All the data from the study, with patient identifiers removed, were transferred to a secure computer at the university.

Fifty participants were recruited. For the study itself, all patients underwent the following measurements: binocular visual acuity with an Early Treatment Diabetic Retinopathy Study chart, binocular contrast sensitivity (CS) with a Pelli-Robson chart, and monocular VF testing in both eyes using an HFA (24-2 Swedish interactive threshold algorithm standard tests). For the latter, HFA reliability criteria using fixation losses less than 25% and false-positive responses less than 15% were applied. All testing was performed in 1 session, but with adequate rest times between tests.

A forced-choice experiment was used to select an image that best represented the patient's perception of their VF loss. Six candidate images (Fig 1) were shown to the patients on a 13.3-inch liquid crystal display computer monitor at a distance of 40 cm (with appropriate refractive correction), covering the full area of the screen. For all 6 images, the same outdoor scene was used, but each image was manipulated with Adobe Photoshop (Creative Suite 5; Adobe Systems Inc., San Jose, CA) to provide views of the image obscured and degraded in a range of distinct ways: a tunnel with black edges, a tunnel with blurred edges, black patches, blurred patches, and missing patches. For the latter, the Photoshop content-aware fill tool was used to create a filling-in effect. After the unmodified (original) image was shown, the others were displayed to the study participant in random order. Images were viewed binocularly. The patients were allowed to toggle between the images, but they were asked simply to make a forced-choice decision about which of the 6 most closely related to their perception of their visual loss with glaucoma. Features about the images deliberately were not explained to the patients.

Patients then were asked 2 open-ended questions, and their responses were recorded: (1) In your own words, could you describe how your glaucoma affects your vision? and (2) When you are aware of your visual field loss, can you describe how it looks, or how it impacts your vision and everyday life? Patients deliberately were encouraged to say as much as they could in response to the questions. The interviewers (N.D.S., F.C.G., and R.B.) took special care to avoid saying anything that could be interpreted as leading or coercive, and their interaction was limited to indirect probes. All the recorded interviews were transcribed and are freely available from the authors.

Statistical Analysis

The responses to the forced-choice experiment were counted and compared using statistics for proportions. Summary statistics for BEMD were calculated and compared for the groups of patients choosing a particular image. An integrated VF (IVF) also was constructed for each patient to give a representation of their binocular VF.[12,13] This method involves the combination of the measured monocular VFs simply by taking the best sensitivity value at each corresponding test point to represent the person's binocular VF. Grayscales of the IVFs were generated using Progressor software (Medisoft, Ltd., Leeds, UK). Integrated VF MD values (computed as the mean of all the point-by-point total deviation values from the IVF) were calculated to take account of any intereye asymmetry of VF defects and were used to compare groups of patients choosing a particular image.

The transcribed interviews were subjected to a form of content analysis.[14] Each transcript was assessed by highlighting words considered to be a descriptor of the symptoms of perception of glaucoma or how a VF loss looks. This was performed by 3 of the authors (D.P.C., N.D.S., and F.C.G.) arriving at a consensus about a definition of a descriptor and whether a word or term was meaningful. For example, *blurry*, *blurred*, *blurs*, and *blurriness* were all considered to be derived from the verb *blur*. If, however, a 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, for example, a patient used the word *blur* 4 times during their interview, then this would count only as 1 occurrence. Also, only positive descriptors were identified and counted. So for

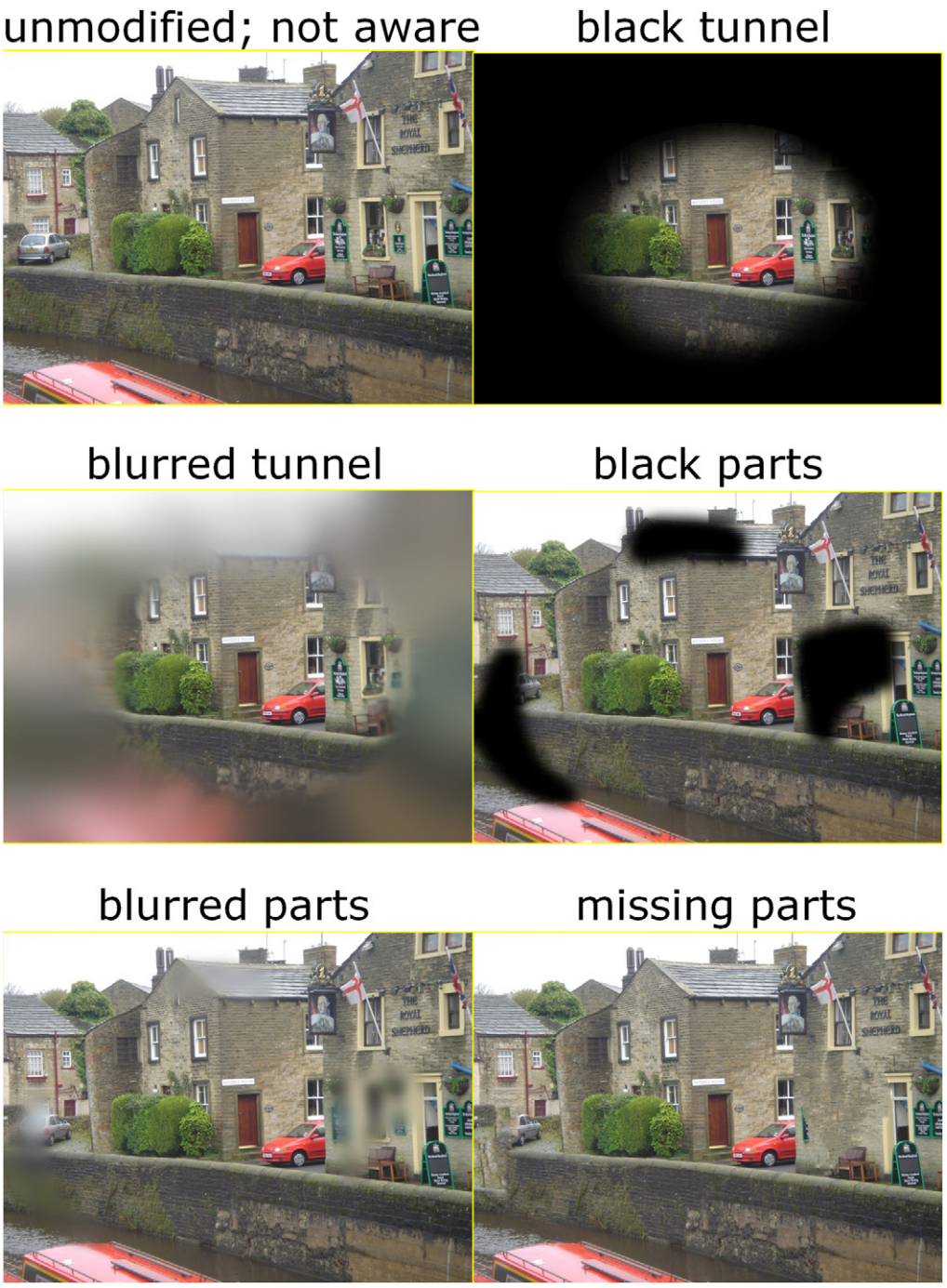

Figure 1. Images used in the forced-choice experiment.

example, if a patient said, "My vision is not blurred," then 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 mean age of the 50 patients was 70 years (standard deviation [SD], 7 years). Twenty-six of the patients (52%) were female. The patients had a range of VF defect severity: average HFA 24-2 MD was −8.7 dB (SD, 5.8 dB), −10.5 dB (SD, 7.1 dB), and −7.3 dB (SD, 5.7 dB) in the right eye, left eye, and best eye (BEMD), respectively. The mean binocular CS and visual acuity of the patients was 1.8 Pelli-Robson log CS (SD, 0.18 PR log CS) and 0.07 logarithm of the minimum angle of resolution units (SD, 0.10 logarithm of the minimum angle of resolution units), respectively.

The results for the forced-choice image experiment are shown in Figure 2A. None of the 50 participants in this study chose the image altered to have a tunnel with black edges effect or the image

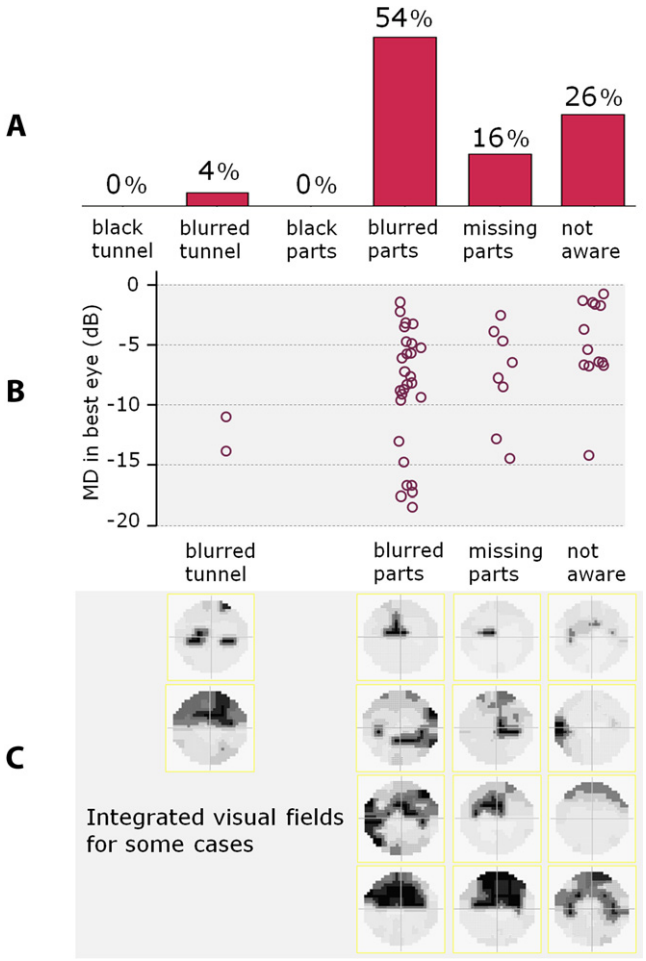

Figure 2. A, Bar graph showing the percentage of participants who chose an image with attributes as described. **B,** Graph showing the distribution of participants' best eye Humphrey mean deviation (MD) stratified by their selected image, with each point representing an individual participant. (Horizontal jitter has been used to displace the points to make the distributions easier to see.) **C,** Grayscale representations of integrated visual fields for some of the participants, again stratified by their choice of image. dB = decibels.

with black patches. Thirteen participants (26%; 95% confidence interval [CI], 15%–40%) were completely unaware of their VF defect affecting their visual function, choosing the original unedited image. Twenty-seven participants (54%; 95% CI, 39%–68%) and 8 participants (16%; 95% CI, 7%–29%) chose the images with blurred patches and missing patches, respectively. Only 2 participants chose the image with a tunnel with blurred edges (4%; 95% CI, 0%–14%). Figure 2B shows individual BEMD for patients stratified by their choice of image. There was some statistical evidence that patients unaware of their VF loss had better average BEMD compared with those who chose altered images (one-way analysis of variance on BEMD stratified by choice of image [group]: $F = 3.0$, $P = 0.04$). Similar results were observed with the IVF MD (1-way analysis of variance on IVF MD stratified by choice of image [group]: $F = 3.7$, $P = 0.02$). However, the distribution of values for BEMD (and IVF MD) in each group was wide; some participants with similar severity and type of VF defect reported different perceptions. Figure 2C shows IVF grayscales for some of the patients in each group. There was no statistical evidence of any average differences in CS between the groups choosing different images (1-way analysis of variance: $F<1$, $P = 0.42$).

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*, *unfocused*) also were evident. Only 1 person in the study used *black* as a descriptor, and not 1 of the 50 participants used the word *tunnel*. The results are shown in Figure 3A as a word cloud (www.wordle.net; accessed July 1, 2012). The size of a 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 a VF loss was noted by an individual also is shown as a word cloud in Figure 3B.

Discussion

This study provided some evidence, from patients themselves, about the visual symptoms of glaucoma. The study sample represented a population of patients with a range of VF loss in both eyes (Fig 2B), with more than one fifth having quite advanced VF loss (MD worse than −12 dB in both eyes). Twenty-six percent of the patients (typically with better MD values) 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; a combination of perceiving blur and missing areas seems to be the main visual indications of the condition. The narratives from patients themselves provide an interesting personal insight into symptoms. (Some excerpts are given in Fig 4.)

Insights into the subjective perception of VF loss have been considered previously[11]; however, to our knowledge, this study is the first to attempt to have patients with glaucoma actually describe what they see. Eloquent descriptions of visual symptoms from patients with other retinopathies have been reported,[15–18] and this has, for example, led to appropriate simulations and pictures of vision with macular disease.[19]

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.[20] The quality of Internet information about glaucoma accessed by patients has been shown to be in need of improvement (Zaidi F, Ansari E. Glaucoma and the Internet. Paper presented at: 2010 European Association for Vision and Eye Research Conference, October 9, 2010; Crete. Acta Ophthalmologica 2010;88(Suppl):S246). 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, are as realistic as possible before

Figure 3. A, A word cloud (www.wordle.net; accessed July 1, 2012) showing the occurrence of descriptors of glaucomatous vision loss calculated as the number of participants who used the term. The size of a word in the visualization is proportional to the frequency of its use. **B,** A similar word cloud of named everyday activities where visual field loss was noted by an individual.

they are published. Providing realistic insights about patients' symptoms may 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 noting part of the VF as missing or described their functional loss as a type of blur. These responses seem orthogonal to the conventional view of the visual symptoms associated with glaucoma, which include the simplified view of narrowing of the peripheral VF. These findings therefore are relevant to the practitioner in primary eye care responsible for screening and identifying cases of glaucoma, especially when making the differential diagnosis between the need for a refractive prescription or correctable vision loss and investigating a complaint of, for instance, blur as a potential symptom of glaucoma. The results from this study also are 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 may be strengthened if the doctor can demonstrate that he or she appreciates the impact of the disease on the patient. After all, research evidence has indicated the importance of the role of a clinician as an educator to bridge the gap in knowledge transfer and to encourage adherence to treatment.[21,22] 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 like the IVF.[23]

When participants were asked to name everyday situations when they noted the impact of their VF loss, many of the themes reported in studies of quality of life and visual disability in the patient with glaucoma re-emerged. For example, mobility, driving, fear and experience of falling, and reading all were mentioned consistently (Fig 3). It was noteworthy that many of the participants in this study became more aware of the vision loss at night, and this has been highlighted previously as a perceived impairment in

"....It's very difficult because nobody can tell you what your sight is like, and it's very difficult to describe...."

"....There's no sort of black, not like the picture, not with me anyway, not like that, no, not at all. It's blurred....But as I say there are areas of blur and then ordinary, it's difficult to describe it sometimes really...."

"....I don't often do it because it frightens me to see what I've got missing, but the other day when I was sitting in the garden I looked down and I thought, oh gosh, there is a great chunk missing...."

"....I get very much blurred, like a mist, and I keep cleaning my glasses but it's not there. It's like a mist you know...."

Figure 4. Excerpts from the transcripts of the response to the question "How does glaucoma look?" from 4 participants in the study.

glaucoma.[24] An everyday activity that has received little attention in glaucoma, but has emerged here as being associated commonly with recognizing 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.[25] This list of activities where visual symptoms are noted can be considered to be only 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.[4,5]

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 a black tunnel effect or as seeing black patches. Yet the size and distribution of the sample was not 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 (IVF) being associated with a certain description, although preservation of the VF in points adjacent to fixation was a notable feature in those patients declaring no visual symptoms resulting from their condition. Of course, these results may not apply to a population of patients with, for example, only a very small island of preserved central binocular VF or with very advanced VF loss worse than a MD of −20 dB in both eyes. Yet none of the participants who came close to the latter category reported seeing black in their field of view. Another shortcoming of the study was the forced-choice experiment itself and the investigator-driven creation of the images, limiting the possibilities of describing individual visual symptoms. Furthermore, patients obviously looked at the images with their visual symptoms, meaning it may 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 a 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 a sample of patients volunteering for a 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 may be embarrassed or reticent about their condition. Finally, the open-ended questions generated only a simple list of vocabulary of the symptoms of the condition, but more sophisticated qualitative research approaches, perhaps using a focus group design, could yield a more complete narrative about patient perception of the condition. A between-eye study in individual patients evaluating monocular perception of VF defects also would be informative.

In summary, this study showed 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.

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