Seeing it differently: self-reported description of vision loss in dry age-related macular degeneration

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Abstract

Purpose: A realistic description of visual symptoms associated with dry age-related macular degeneration (AMD) is important for raising awareness of the condition and educating patients. This study aimed to develop a set of descriptors for dry AMD and examine the realism of images currently and frequently used to show visual symptoms of the condition.

Methods: Volunteers with dry AMD with a range of disease severity were given an eye examination and were asked to describe visual symptoms of their condition in a conversational interview. Participants were also asked to comment on a photograph typically used to portray the visual symptoms of AMD. Interviews were audio recorded, transcribed and subjected to content analysis.

Results: Twenty-nine participants were interviewed. Median (interquartile range [IQR]) age was 75 (70, 79) years. Median (IQR) binocular visual acuity (VA) and Pelli-Robson contrast sensitivity (CS) was 0.2 (0.18, 0.36) logMAR and 1.65 (1.50, 1.95) log CS respectively. Three, 17 and nine patients had early, intermediate and late (geographic atrophy, GA) AMD, respectively. The most frequently reported descriptor group was *blur* (n = 13) followed by *missing* (n = 10) and *distortion* (n = 7). We chose the most popular image used to portray the visual symptoms of dry AMD based on an internet search and showed this to 21 participants. Sixteen participants (76% [95% confidence interval 53–92%]), including three out of the seven people with geographic atrophy, unequivocally rejected the realism of the image.

Conclusions: People with dry AMD use a wide range of descriptors for their visual experience. Visual symptoms of dry AMD as portrayed by commonly shown images were not the experience of most people in this study.

Introduction

Age-related macular degeneration (AMD) is the most common cause of visual impairment in developed countries; its prevalence is set to increase as the population ages. For example, 196 million people are estimated to have the condition by 2020.[1] AMD impacts negatively on patients' visual ability and quality of life.[2] Yet, disease awareness of AMD in the public is limited.[3–6] At the same time, many people with early and intermediate AMD do not recognise that they have the disease,[7, 8] whilst others with more advanced AMD are reported to be unaware of their scotomas.[9]

Age-related macular degeneration can be divided into a number of stages.[10] Early and intermediate AMD are characterised by yellow/white deposits (drusen) beneath the retinal pigment epithelium, and areas of hyperpigmentation or hypopigmentation. Later stages may take one of two forms: neovascular (wet or exudative) AMD, characterised by growth of new blood vessels beneath the retina with a tendency to leak, causing sudden vision loss, or geographic atrophy (GA), characterised by sharply demarcated areas of hypopigmentation caused by atrophy, causing more insidious vision loss.[10, 11] Non- neovascular AMD (i.e. early and intermediate AMD and GA) may also be known as dry AMD, and comprises about 90% of

diagnosed cases of AMD.[12] A realistic description of visual symptoms associated with dry AMD is important for raising awareness of the condition and educating patients; this is the subject of our study.

A simple search on the internet will yield common depictions of the visual symptoms of people with AMD. Typically, this will be a photograph with a grey or black patch superimposed over its centre. A widely used example of this is the National Eye Institute (NEI) photograph, 'A scene as it might be viewed by a person with age-related macular degeneration' (*Figure 1*).[13] In this study, we aim to explore the accuracy of these representations with respect to the patient experience of people with early and intermediate AMD and pre-end stage GA. In addition we ask patients to develop a set of descriptors for visual symptoms of dry AMD.

Methods

Images

To establish which images are used most frequently to depict the vision of people with AMD, a Google Image search was conducted independently by two of the authors (LAE and DJT). The search term used was, 'vision age related macular degeneration'. The first 50 images produced by the search were evaluated and a description of each image's content was entered into a spreadsheet.

Participants

People with dry AMD were recruited from Moorfields Eye Hospital NHS Foundation Trust (London), optometrists local to City, University of London, and the membership of the Macular Society (www.macularsociety.org). Eligibility criteria required participants to be aged ≥60 years, have sufficiently clear ocular media, adequate pupillary dilation and fixation to allow quality fundus imaging (Lens Opacities Classification System [LOCS] III grade <3), and to have dry AMD (early/intermediate/late) in their better-seeing eye (assessed by best-corrected visual acuity [VA]). Fellow eyes of patients were permitted to be of any AMD status because the impact of the better eye has been found to have a stronger relationship with vision related quality of life than the worse eye.[14–16] Binocular VA was required to be 0.7 logMAR or better (Snellen equivalent of 6/30, 20/100) as measured using an Early Treatment Diabetic Retinopathy Study (ETDRS) chart. Patients were excluded if they had neovascular AMD in their better-seeing eye, had any ocular or systemic diseases that could affect visual function or history of medication known to affect macular function (e.g. tamoxifen or chloroquine), or high risk of angle closure during pupillary dilation (Van Herick <Grade 2, history of angle closure or experience of prodromal symptoms of angle closure). In addition patients were required to pass an abridged version of the Mini Mental State Evaluation[17,18] and to have sufficient knowledge of the English language to carry out the interview.

The study was approved by a National Health Service (NHS) approved Research Ethics Committee and was conducted according to the tenets of the Declaration of Helsinki. Written, informed consent was obtained from each participant prior to examination. Participant information was anonymised before being entered into a secure computer database.

Clinical examination and screening

All tests and interviews were conducted by an optometrist (DJT). Structured history and symptoms were taken including questions from the EQ-5D questionnaire[19] to

Figure 1. Image frequently used for education about age-related macular degeneration (AMD). The image on the left shows 'normal vision' whilst the image on the right shows 'vision with AMD'. Source: https://nei.nih.gov/health/examples.

assess general health. Best-corrected VA was determined with subjective refraction to correct the full spherical and astigmatic refractive error using a trial frame and a backlit ETDRS chart (mean luminance of 204 cd m^{-2}) at 4 m (mono- and binocularly). This was scored per letter (and in logMAR format) and participants were encouraged to read down the chart until they were unable to read three out of a possible five letters on a line. Contrast sensitivity (CS) was tested with the Pelli-Robson chart at 1 m (binocularly) with best-corrected distance prescription (as described above). This was scored per letter (if participants read 'C' instead of 'O' or vice versa this was counted as correct). Following their interview, participants underwent dilated fundus examination. Lens clarity was graded using the slit lamp biomicroscope, according to the LOCS III grading scale.[20] Fundus imaging was conducted, including colour fundus photography, Spectral Domain-OCT and fundus autofluorescence. These were used to classify and grade AMD status by better-seeing eye as early, intermediate or late according to the Beckman classification scale.[10] This widely used scale grades macular disease according to drusen size, pigmentary abnormalities and presence/absence of GA or neovascular AMD.

Interviews and data analysis

The following questions were asked as part of a longer interview about participants' wider experiences with AMD. Interviews were recorded using an audio recorder, transcribed verbatim by an independent transcription company and transcripts were checked by the interviewer (DJT).

Participants were asked, 'When you are aware of your AMD, can you describe how it looks?' and, 'How would you describe what it is wrong or different about your vision to someone without AMD?'

The analysis of the responses was similar to that described elsewhere.[21] In brief, transcribed responses to the questions were read individually by two of the authors (LAE and DJT) and words or phrases considered to be descriptors of visual symptoms were highlighted. The authors then compiled a list of individual descriptors. Where one participant used the same descriptor multiple times, this was counted as one occurrence of that descriptor. Numbers of participants to use each descriptor were then counted. A matrix was generated showing combinations of descriptors used by each participant.

Participants were then given an A4 size page showing the NEI photograph, in both its unaltered (i.e. 'normal vision') and manipulated (i.e. 'vision with AMD') forms (*Figure 1*). They were encouraged to hold the sheet at an angle and distance to allow for optimal viewing conditions for them to see the images as clearly as possible. Participants were asked to comment on how these images tie in with their experiences. Care was taken to avoid asking the question in a leading manner.

Two of the authors (DJT and LAE) independently read through the transcribed responses and assessed whether the response indicated that the image tied in with the patient's experience ('YES'), whether it didn't ('NO') or if the answer was unclear ('UNCLEAR'). Any disagreements were arbitrated by another author (DPC). At the time of assessment, both researchers were masked to the identities and AMD severity of participants.

Results

A Google Images search for 'vision age-related macular degeneration' was conducted independently by two of the authors (DJT and LAE) on 27 March 2017. From the top 50 images produced by the search, 10 images (20%) were the NEI photo of boys with a ball (*Figure 1*). Twenty-seven (54%) were similar depictions of AMD with different photographs (i.e. a black or grey patch in the centre of an image). The remaining 13 (26%) images were mainly diagrams of the eye or textual information about AMD. Others included a photograph of a celebrity known to have AMD and a poster for macular degeneration awareness. There were no disagreements between the two independent investigators for this exercise.

We repeated our Google Images search with a variety of similar phrases: 'how will age-related macular degeneration affect my vision'; age-related macular degeneration sight'; 'age-related macular degeneration eyesight'; 'age-related macular degeneration vision loss'; 'age-related macular degeneration symptoms'; 'how does age-related macular degeneration look'; 'what do people with macular degeneration see'. A similar array of results was observed; at least 10% (and up to 26%) of the top 50 results consistently showed the NEI image.

Twenty-nine patients were interviewed about how their vision looks. The median (interquartile range [IQR]) age of patients was 75 (70, 79) years. Median (IQR) binocular VAand Pelli-Robson CS were 0.2 (0.18, 0.36) logMAR and 1.65 (1.5, 1.95) log CS, respectively. Better and worse eye median (IQR) were 0.24 (0.20, 0.39) logMAR and 0.40 (0.30, 0.83) logMAR respectively. Three patients had early AMD, 17 had intermediate AMD and nine patients had late AMD (GA). Some descriptions given regarding vision loss are shown in *Table 1*.

Thirty-one individual descriptors were identified. Synonyms were grouped together, creating 10 descriptor groups. Synonyms used to create descriptor groups are given in *Table 2*. A large percentage of participants (45%) reported their visual symptoms in a way that implied an experience of blur. Visual distortions and missing parts of the image were also commonly reported. The most common visual

Table 1. Examples of descriptions of vision loss with descriptor words/phrases in bold

AMD Classification	Description of vision
GA	*'Lampposts, sort of . . . **bending**. . .. . .As I'd gone on looking at the wall now it's got bricks in, I know I can see – they're sort of a bit **wobbly**. . ...I know they're straight really.'*
	*'It's **foggy** all the time. . . that's what I noticed first. I used to be saying gosh, is it **foggy** today and he'd say no, no.'*
	*'It's like if I'm looking at a scene, something on television or even out in the road, it's – there's **part of it missing**. There's **part of it missing** there. I can't see the whole picture anymore.'*
Intermediate AMD	*'I'm looking out from two discs that are **shimmering**, like two little suns but not as bright.. they're really **shimmering**. . ...like. . .gold.'*
	*'Well it's things like when I was standing on the station today, when you're looking at a long platform, it **can look a wavy line**.'*
Early AMD	*'I've lived in [the same town] for 44 years so I should know quite a lot of people but I never see them, well not never but I don't see acquaintances very well because it's a bit **blurry**.'*
	*'I don't draw my curtains so I look outside and I can see on the house opposite **I see two chimneys instead of one**.'*

Table 2. Words and phrases used by dry AMD patients to describe vision. Descriptions considered to be synonyms of each other were grouped together into descriptor categories

Descriptor category	Synonyms of descriptor
Blur	*Not clear, Out of focus, Fuzzy, Foggy, Hazy, Misty, Cloud*
Distorted	*Bendy, Crooked, Wavy, Wobbly, Wiggled*
Missing part/s	*Black parts, Space, Patchy, Grey area, Words dropping from page*
Shiny area/s	*Flash, Sparkles, Spiral of light*
Double vision	
Dark	*Dull*
Colours difficult	
Speckled	
Smeary	
Bullseye	

symptom reported by GA patients was 'missing parts' ($n = 6$) whilst the most common symptom reported by patients with intermediate AMD was 'blur' ($n = 8$). Participants often reported more than one visual symptom. A matrix showing descriptors used by each participant is shown in *Figure 2*. Descriptors were considered a 'primary descriptor' if they were the initial symptom mentioned by a participant. All subsequent descriptors were considered 'secondary descriptors'. For example, one participant responded 'I've noticed letters missing from exhibitions particularly when I go. . . Slightly more hazy than it was . . . Sometimes it's difficult to distinguish colours that are very similar'. In this instance 'missing parts' would be the primary descriptor, 'blur' and 'colours difficult' would be secondary descriptors. Use of multiple descriptors was most common amongst people with GA. The most common primary descriptor amongst participants with intermediate AMD was 'blur', whilst the most common primary descriptor for those with GA was 'distortion'.

The interviewer felt it was inappropriate to show six participants the NEI photograph because they had expressed emotional distress at the prospect of their vision worsening; this complied with the ethical aspects of the interview protocol. Two participants were unable to see either photograph adequately to make a judgement due to their poor vision. Therefore, our assessment of response to the NEI image (the photo of the boys) was restricted to 21 participants (three, 11 and seven respondents who had early, intermediate and late [GA] AMD in their better-seeing eye, respectively). Median (IQR) binocular VA and CS scores for these 21 participants were 0.24 (0.20, 0.36) logMAR and 1.65 (1.35, 1.90) log CS respectively. Median (IQR) better and worse eye VA scores were 0.22 (0.2, 0.36) and 0.46 (0.32, 0.92) logMAR respectively. Example responses are shown in *Table 3*.

Only two participants reported the image to be a good indication of their visual symptoms. One of these individuals had GA and a binocular VA of 0.32 (better eye 0.32 and worse eye 0.40) logMAR and CS of 0.75 log units. The other individual to report the NEI image to be a good indicator of their visual symptoms had intermediate AMD and binocular VA of 0.44 (better eye 0.4 and worse eye 0.8) logMAR and CS of 1.35 log units. Sixteen participants, representing 76% (95% confidence interval of 53–92%) of our sample, clearly stated that the image did not represent their visual symptoms. Three gave answers that were deemed to be unclear. *Table 4* shows the summary results for different severities of AMD.

Discussion

Images showing a patch of distortion or blackness in central vision surrounded by a clear periphery (*Figure 1*) are frequently used illustrators of vision with AMD. Our survey of a sample of images yielded from an internet search supports this observation – three quarters of images showed virtually the same basic representation. However, only a small number of our sample of people with dry AMD reported this to be an accurate depiction of their visual experience and this was a key finding from our study. Most

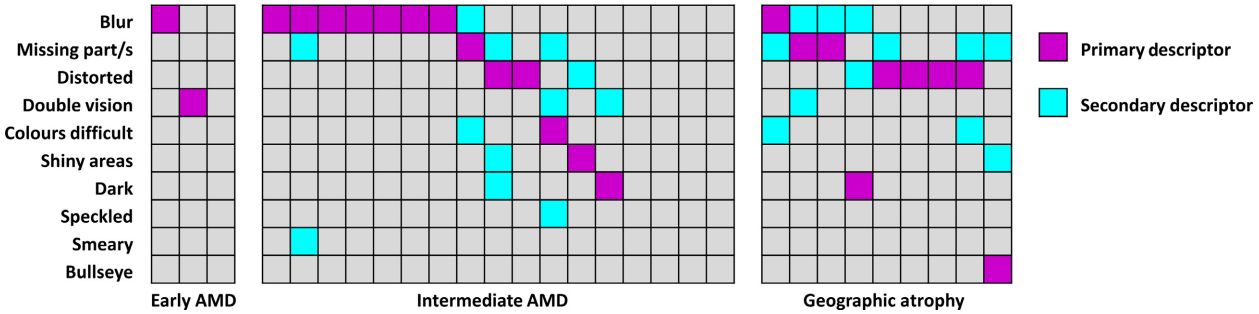

Figure 2. Matrix type chart showing descriptor categories reported by each participant. Each column shows descriptors from one participant. Rows are organised by frequency of occurrences for each descriptor category across all participants; 'blur' was reported most frequently, followed by 'missing part/s' and 'distorted', whilst 'speckled, 'smeary' and 'bullseye' were reported least frequently. Five columns are empty – these represent participants (one with early age-related macular degeneration (AMD) and four with intermediate AMD) who did not report any descriptors of visual symptoms when asked.

Table 3. Example responses to the NEI image for participants who positively reported the NEI image to be a good indication of their visual symptoms (top) and for those who stated that the NEI image did not represent their visual symptoms (bottom). (AMD classification shown in parentheses)

Is NEI image an accurate representation of vision with AMD?	
Yes	*'Yes. . ..that's quite a good indication. . .'* (GA)
	'Yes, that is it, the blurred one. . .' (Intermediate AMD)
No	*'. . .nothing like that one. . .'* (Intermediate AMD)
	'Well I haven't got anything at all like that. . .' (GA)
	'That wouldn't happen to me. . . the colours wouldn't be there. . .' (Intermediate AMD)
	'No. I don't recognise that . . .' (Intermediate AMD)
	'Well . . . absolutely not. . .., no relation to me at this moment. . . So I'm quite pleased about that..' (Early AMD)

Table 4. Number of participants reporting the NEI photograph was an accurate representation of their vision ('Yes'), did not depict their vision ('No') and those whose responses were not clear ('Unclear'). Totals from the whole sample are represented as percentages (95% confidence intervals [CI])

Is NEI image an accurate representation of vision with AMD?			
AMD type	*Yes*	*No*	*Unclear*
All (n = 21)	2	16	3
% (95% CI)	10 (1–30)	76 (53–92)	14 (3–36)
Early/intermediate AMD (n = 14)	1	13	0
Geographic atrophy (n = 7)	1	3	3

people in our study did not think these images represented their visual symptoms. There was no strong evidence for this depiction representing visual symptoms for those with advanced dry AMD in the better-seeing eye either: only one person out of seven with geographic atrophy stated that it was clearly representative of their visual symptoms. From this study we have also learnt that noticeable and describable vision loss is not limited to those with neovascular AMD or even just those with late AMD. This is an important finding. For instance, people in our sample with intermediate AMD provided a variety of descriptors of their visual symptoms rather than saying they were asymptomatic. Moreover, these descriptions were far more complete and varied than those implied by images that are used to depict the condition.

Our main findings are important for several reasons. First, the images we have scrutinised in this study are designed to educate the public about AMD and we have shown they are not fit for this purpose. Second, the images could be misinterpreted to be a sign of early visual changes in AMD but this clearly does not fit with the experience of people with early or intermediate AMD in our sample. Third, the visual symptoms experienced by most people with AMD are likely more subtle and less simplistic than those depicted in the images; this could have ramifications for individuals about misunderstanding the severity of their own condition and may in turn affect adherence to management strategies such as self-monitoring of vision and lifestyle changes to minimise risk of disease progression.

Our results show how heterogeneous descriptions of vision loss in dry AMD can be. Thirty-one individual descriptors, and 10 separate descriptor groups were identified. The most frequently used descriptor, 'blurred vision', was only reported by half of our participants. Distortion, which is often commonly associated with neovascular AMD,[22] was reported by participants with intermediate AMD and GA in their better eye. Only two of these had unilateral neovascular AMD in their worse eye. Moreover, when participants reported multiple visual symptoms, there was no obvious pattern of symptoms commonly occurring together.

Previous research has highlighted the inaccuracy of depicting peripheral vision as being a clear surround to a patch of dysfunction in central vision. Visual acuity reduces

with distance from the fovea and one paper has produced illustrations theorising what a more realistic simulation of macular disease may look like with a blurred, rather than clear, periphery.[23] However, the realism of these images is thrown into question when one considers the fact that we do not perceive our peripheral vision as blurred.[24] Other research has attempted to simulate central vision loss in AMD using contact lenses with central opacities.[25] Yet this type of simulation cannot easily capture the real experience of patients, where size and depth of scotoma may vary from person to person.[26] Whilst other studies have attempted to build realistic representations of glaucomatous visual field loss using reports from patients,[19, 27] to our knowledge this has not been attempted in AMD. Reports in the literature on perceptions of vision loss in AMD tend to come from descriptions made by individual patients.[28, 29] No studies have brought together reports from multiple patients. Fletcher and colleagues[9] did ask a large number of people with AMD attending their initial low vision rehabilitation evaluation whether they had experiences that led them to believe that they had defects in their field of vision. Interestingly, the majority of these patients were asymptomatic but many reported experiences of items in their vision 'disappearing'; this observation is somewhat dissimilar to the idea of a noticeable and constant disturbance in central vision as depicted in the images we have scrutinised in this study. Moreover our results indicated 'missing parts' was a common description of the visual loss. Given the heterogeneity of the descriptors of visual symptoms reported in our study, it is perhaps unlikely that vision in dry AMD can be encompassed by a single image. It may be more appropriate to develop a series of images or a dynamic representation, perhaps a series of movies or digital media, to more accurately depict vision in dry AMD. Future studies might build on this idea.

Our experimental design was a study strength because we have directly captured views from people with dry AMD. Our image search experiment illustrated the ubiquity of the NEI image. The remaining simulations of vision in AMD found using our image search were, on the whole, similar to the NEI image in that they depicted a black or grey patch in the centre of a photograph. However, there were some differences between these simulations; for example some scotomas had a straight edge but the majority had a gradual fade, some retained some detail within the area of the scotoma, whilst others did not. It is possible that some of these might be better representations of visual symptoms in dry AMD than the NEI image.

One limitation of our study relates to lens opacities. Although participants were excluded if they were graded '3' or higher on any of the domains of the LOCS III scale, there is a possibility that blur caused by minimal cataract could have affected the results of the study. However, without limiting our interview to those who had undergone cataract extraction (and excluding anyone with posterior capsular opacification), it would be extremely difficult to overcome this limitation in this age group. Moreover, only four participants had LOCS III scores of '2' or higher (three participants bilaterally for nuclear colour and one participant unilaterally for posterior subcapsular cataract); none of these participants used any descriptors that had not been used by other participants with more negligible lens opacities.

Other limitations of our study are worth noting. Participants were asked to view the NEI image with their own spectacles if worn for near. There is the chance that discrepancies between best-corrected subjective VA and habitual near VA could have affected the way in which the NEI image was perceived. However, our recruitment method meant that all participants were motivated individuals and likely to be proactive in their own eye care (for example, wearing up-to-date spectacle prescriptions). There is no evidence that wearing progressive (rather than single vision) spectacle lenses to view the image was a factor in the perception of peripheral parts of the image; no participant reported peripheral distortion on the NEI image. Furthermore, participants were allowed and indeed encouraged to hold the NEI image at an optimal viewing distance and angle to allow ideal viewing conditions and mitigate any perceptual distortion. The NEI image was viewed binocularly in order to replicate habitual vision for participants. However, we permitted fellow eyes to be of any AMD status, and graded severity of AMD according to the better-seeing eye because the better eye is believed to have a greater impact on vision-related quality of life than the worse eye.[14–16] Of course, this study does not assess vision-related quality of life, rather it assesses visual descriptors for dry AMD, for which the contribution of better eye and worse eye may not be equivalent. Future work might assess the impact of each eye's visual symptoms on binocular descriptions of vision in dry AMD.

Another key limitation is our small sample size. Our estimates of people's response to the picture are also restricted because it was deemed inappropriate to show some participants the photograph if they had already expressed emotional distress about their vision. Moreover, two participants were unable to see the photograph due to poor vision. It is certainly possible that these two participants could have similar visual symptoms to that depicted in the NEI image. Also, we limited our sample of participants to those with VA better than 0.7 logMAR (Snellen 6/30, 20/100); perhaps for AMD patients with worse VA, possibly as a result of end stage GA, the NEI image is representative of how they see. This is untested and would have to be the subject of a different study design. Despite these limitations surrounding the sample of people interviewed, the

experimental effect supporting the hypothesis that typical images do not accurately depict visual symptoms for AMD was very large. For instance, and loosely speaking, the lower bound for our 95% confidence interval (53%) at least infers one half of all people with dry AMD, as represented by our sample, would likely reject the image in a wider population.

To conclude, images currently used to represent vision in AMD are unrealistic for many people with dry AMD of varying severities. A wide range of descriptors are used to describe vision loss in dry AMD, indicating that vision loss in this condition may manifest itself in a variety of ways. These descriptions could be used to educate people about the range of possible symptoms of dry AMD and are a step towards building simulations of the view of AMD through the patient's eyes. In turn this might lead to better recognition of symptoms for people with and without the condition. The results from our study certainly suggest a need to develop more realistic images of the visual symptoms of AMD for patient and public education.

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