A qualitative study of the health-related quality of life impact of geographic atrophy on patients

PCR203

Main poster

[1]Sarah Hill, [2]Michele Intorcia, [1]Hema Moor, [1]Louise Longworth, [2]Sujata Sarda, [1]Yemi Oluboyede

[1]Putnam PHMR, London, United Kingdom, [2]Apellis Pharmaceuticals, Waltham, Massachusetts, USA.

Aim and objectives

Aim: The overall aim of this study was to develop a set of utility values suitable for use in cost-effectiveness models of newly developed therapies for geographic atrophy (GA) using a vignette approach.

Objective: The objective of this component of the study was to conduct qualitative interviews with a sample of both people with GA and retina specialists to collect data on the HRQoL impact of living with GA

Background

- Age-related macular degeneration (AMD) is a chronic degenerative disease of the retina causing progressive irreversible vision loss [1]. There are two forms of AMD: wet and dry.
- GA manifests as central visual loss and significantly impairs health-related quality of life (HRQoL), causing patients difficulties related to activities of daily living and psychological impacts due to their symptoms [2]
- Utility values for the HRQoL of patients with GA derived from the EQ-5D may not be appropriate because it inadequately covers important aspects of health related to visual impairment (VI).
- No condition-specific utilities currently exist for GA.

Methods

Recruitment
- Patients with GA and retina specialists (see **Table 1** for inclusion criteria)
- Conducted via healthcare market research agency.

Interviews
- Explore the impact of GA on HRQoL of patients with varying levels of VI and condition severity
- Semi-structured interviews conducted by experienced moderators
- Data collected to inform design of a set of health state vignettes describing the experience of living with GA.

Analysis
- Transcripts coded using thematic analysis to identify prevalent meaningful themes related to impact of GA on HRQoL.
- Data synthesised to present a comprehensive view of impact of GA on HRQoL of patients across a range of VI levels – defined by best-corrected visual acuity (BCVA)[a] using Early Treatment Diabetic Retinopathy Study (EDTRS) letters [5]

Sample

- Interviews were conducted with 3 retina specialists and 9 patients with GA. One patient was excluded from analysis because they were unable to provide details of their level of VI.
- The sample of patients with GA covered a range of VI levels based on self-reported bilateral BCVA score. If bilateral BCVA was unknown, better-seeing eye BCVA was used as a proxy. [6]

Table 1. Inclusion criteria for participants

Patient criteria	Retina specialist criteria
• Aged 55 years or older • Living in the United Kingdom or United States and able to read, understand and speak English • Have a diagnosis of GA or advanced dry AMD (unilateral or bilateral) • Have no cognitive impairments that would affect their ability to participate fully in the interview • Not actively taking part in a clinical study for an advanced dry AMD or GA medicine • Not taking medication for advanced dry AMD or GA	• Retinal specialist health care professionals • Based in the UK • Experience treating patients with GA secondary to AMD. • Able to read, understand, and speak English

Findings

- Participant characteristics can be seen in **Table 2.**
- The most common key themes identified in the interviews can be seen in **Figure** 1 and the main aspects of daily life impacted by GA are presented in **Table 3.**

Patient participants

I get books from the library, and I request bigger print books (Patient_9, 'mild' VI)

I cannot read more than 3 or 4 pages without finding it stressful Patient_3, 'moderate' VI)

Symptoms experienced and their impact

- The most common symptoms reported by patients were blurred vision, occasional experience of dizziness, headaches, and brightness/glare irritating eyes.
- Blurred vision was reported as most severe due to its effect on reading ability.
- Reading ability highly impacted patients' HRQoL because it affects many aspects of everyday life.

Anxious that my vision is worsening (Patient_2, 'moderate' VI)

How is it going to impact others around me? (Patient_1, 'mild' VI)

Experience of anxiety, worry and fear

- Patients reported feeling anxiety, worry and fear surrounding their vision getting worse, lack of treatment options, and the impact of their condition on the people around them.
- In general, the patient experience of anxiety, worry and fear grew stronger as VA reduced. However, 1 respondent with 'severe' VI expressed becoming less anxious as they adjusted to their condition..

I won't let anything like that get me down (Patient_4, 'moderate' VI)

Adaptation to daily life

- Many patients reported adapting their daily life to function with GA. For example, listening to podcasts and audio books instead of physical books, using larger computer screens, using magnifiers, and installing LED bulbs in the house.

I have a magnifying screen on my computer. I wear reading glasses in hopes of being able to read fine… (Patient_2, 'moderate' VI)

That [inability to drive] mainly results in this problem of gradual loss of independence (Specialist_2)

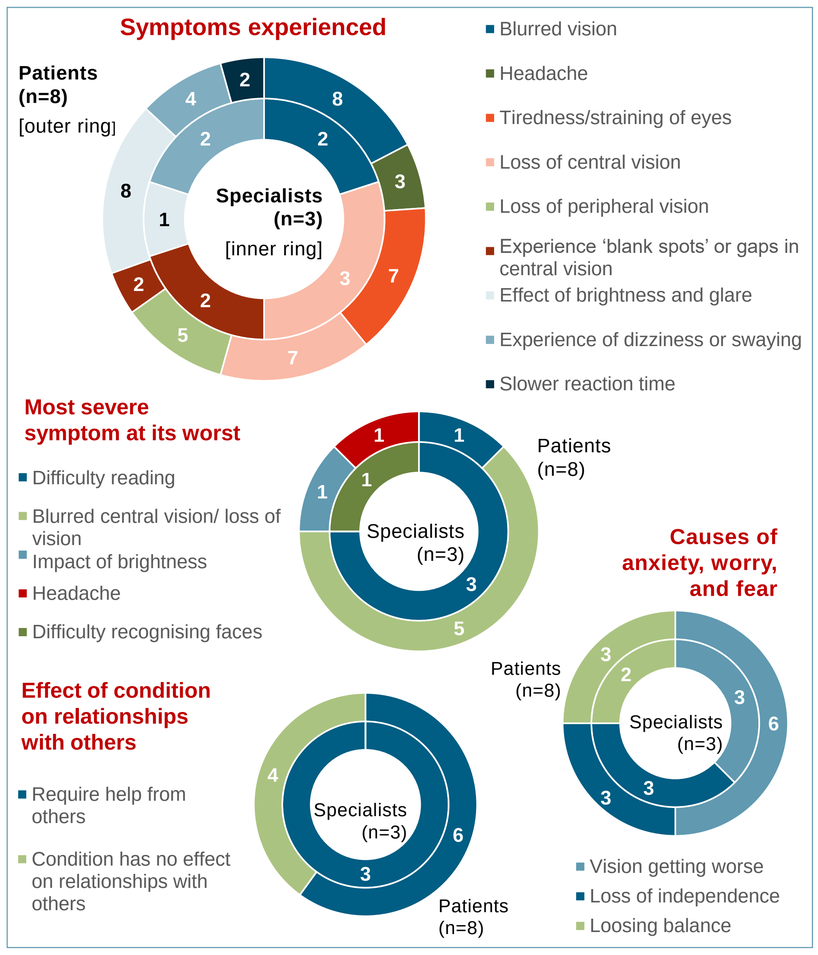
Retina specialist findings

Symptoms experienced and their impact

- Specialists reported that as VI progresses, symptoms such as blurred vision and blank spots worsen to the point where patients with 'severe' impairment can experience difficulties with depth perception, causing difficulty continuing with routing daily activities
- As symptoms develop, specialists' views were that patients can no longer drive and would have problems recognizing faces, which causes a loss of independence.

I think little things might be like [difficulty] making a cup of tea… that is probably when things are really bad (Specialist_1)

Figure 1. The number of patients and retina specialists reporting the most common themes during the interviews



Retina specialist findings, continued

Experience of anxiety, worry and fear

- Retina specialists reported that patients feel anxiety about the progression of their disease, lack of answers from medical professionals, and lack of treatment options.
- One specialist reported that patients with mild VI are more anxious about the progression of their condition compared to patients with severe VI who have adapted to their condition.

Even though you would expect those patients to be really anxious and really struggling, often they are the ones who have accepted the diagnosis (Specialist_3)

The lesser so affected group…they may be reliant on a magnifier…but they can get by pretty okay. I think the middle ['moderate' VI] will require some adaptations, perhaps the reading aids or the illumination devices. The poorest group ['severe' VI] are probably going to be quite reliant on the adjuncts [adaptations]…'(Specialist_3)

Adaptations to daily life

- Patients' reliance on adaptations was reported to increase as their condition worsened.
  - Patients with mild to moderate VI reported use of low-level vision aids but could adapt to tasks.
  - Patients with moderate to severe VI reported as very reliant on adaptations such as magnifiers and electronic aids.

Patient: I have a magnifying screen on my computer' (Patient_2, 'moderate' VI)

Specialist: [a patient with 'moderate' VI] will require a magnifying lens… when reading smaller print (Specialist_2)

Convergence and divergence of views

Convergence
- Generally high level of convergence between patients with similar BCVA scores and amongst retina specialists
- Impacts of GA on areas such as: reading ability, balance, continuing with leisure activities, and performing daily tasks

Divergence

Between patients:
- Symptoms considered most severe.
- Impact of symptoms on a typical day – could be due to different visual requirements and lifestyle differences.

Between retina specialists and patients:
- Perception of disease severity based on levels of VI
- Three patients described their conditions worse, and 1 patient described better, than retina specialists would ascribe based on BCVA score.

Table 2. Participant characteristics

Patient	Patient_1	Patient_2	Patient_3	Patient_4	Patient_5	Patient_6	Patient_7	Patient_8	Specialist	Specialist_1	Specialist_2	Specialist_3
Age	61	57	75	78	77	70	84	63	Current role	Locum consultant / Associate specialist	Retinal specialist consultant	Ophthalmologist
Bilateral / best seeing eye BCVA[a] score (EDTRS letters)	76	61	63	55	Legally blind (<36)	Legally blind (<36)	Legally blind (<36)	80				
Diagnosis time (years ago)	1	1.5	3	13	27	20	20	1	Years of experience treating patients with GA	9	15	7
Self-reported condition severity	Severe	Moderately severe	Slowly deteriorating	Quite severe	Pretty bad	Quite severe	Severely sight impaired	Bad				
WHO severity classification	Mild	Mild	Mild	Severe	Severe	Severe	Severe	Mild	Experience with GA patients	Sees approximately 250 patients per week, of whom approximately 60% have GA.	Sees approximately 100 patients with GA per month.	Sees approximately 60 patients with GA monthly.
Retina specialists' severity classification	Mild/ moderate	Moderate	Moderate	Moderate	Severe	Severe	Severe	Mild				
Unilateral or bilateral	Bilateral	Bilateral	Bilateral	Unilateral[b]	Bilateral	Bilateral	Bilateral	Unilateral[b]				

[a] Where BCVA score was given as a Snellen score, the following formula was applied to convert to estimated EDTRS letters (85 + 50*log(Snellen fraction)). [b] These patients had unilateral GA but had wet AMD in the fellow eye.

Table 3. Main aspects of daily life impacted by GA

Aspect of daily life	Patients (n=8)	Retina specialists (n=3)
Driving	8	3
Reading	8	3
Working	5	2
Using public transport	2	1
Walking outside	3	2
Helping others	3	2
Shopping	3	2

Limitations and Conclusions

- This study was limited by a small sample. Recruitment was challenging; many potential participants were unable to provide necessary details of their condition for inclusion in the study, e.g., BCVA score or their type of advanced AMD (wet or dry).
- Patients were less informed about their condition than expected; future studies may consider recruiting via healthcare professionals so that a larger sample of patients could be interviewed across a greater range of VI and GA characteristics.
- Retina specialist interviews were included in this study to supplement the data collected from patients with GA given the above reported limitations. They were able to provide data on the impacts of GA across a range of VI severities to facilitate the synthesis of the personal experience data collected from patient interviews.
- **GA has a significant negative impact on patients' HRQoL** in many areas including their ability to function in daily life, on their social life, and hobbies. **Patients with GA experience fear, worry and anxiety related to the progression of their disease, lack of treatment options and impact of their disease on family and friends.** This impact generally worsens as the disease progresses, but some patients adapt to their condition in the later stages of the disease.
- Disease severity was perceived worse by some patients than retina specialists would ascribe based on patients' BCVA score. **Patient perception of their disease may not align linearly with BCVA score; which could be due to unique aspects of GA which can impact visual function aside from VA but also that patients may adapt to their condition over time, despite VA worsening.**
- Future studies which can explore the link between time since diagnosis and self-perceived HRQoL across a broader range of patients varying in the structural pathologies of GA would be beneficial to further explore the impact of GA on HRQoL.

References

1. Fleckenstein, M., et al., *The progression of geographic atrophy secondary to age-related macular degeneration.* Ophthalmology, 2018. **125**(3): p. 369-390.; **2.** Rovner, B.W., R.J. Casten, and W.S. Tasman, *Effect of depression on vision function in age-related macular degeneration.* Arch Ophthalmol, 2002. **120**(8): p. 1041–4.; **3.** Day-Storms, J., *FDA Approval of SYFOVRE (Pegcetacoplan) and IZERVAY (Avacincaptad Pegol) Reshapes Management of GA.;* **4.** National Institute for Health and Care Excellence. *5.3 Measuring and valuing health effects*. 2013; Available from: https://www.nice.org.uk/process/pmg9/chapter/the-reference-case#measuring-and-valuing-health-effects.; **5.** Leder, H.A. and M.J. Elman, *Early Treatment Diabetic Retinopathy Study (ETDRS)*, in *Encyclopedia of Ophthalmology*, U. Schmidt-Erfurth and T. Kohnen, Editors. 2018, Springer Berlin Heidelberg: Berlin, Heidelberg. p. 676-679A; **6.** Rubin GS, Muñoz B, Bandeen-Roche K, et al. Monocular versus binocular visual acuity as measures of vision impairment and predictors of visual disability. Invest Ophthalmol Vis Sci. 2000; 41: 3327-34.; **7.** Lee, W., et al., *Estimation of best corrected visual acuity based on deep neural network.* Scientific Reports, 2022. **12**(1): p. 17808.

[a] BCVA is a measurement of the ability to distinguish shapes and details of objects at a given distance with corrective lenses [7]

ISPOR Europe, Copenhagen, 14 Nov 2023

Contact information:

Michele Intorcia michele.intorcia@apellis.com

Financial disclosures

SH, YO, and HM receiving funding from Apellis Pharmaceuticals to conduct this research

MI, SS: employees, Apellis pharmaceuticals and own stock in the company