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Burden of geographic atrophy and treatment expectations of therapies: perspectives from patient-driven research funding and support organizations

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PURPOSE:

- Geographic atrophy (GA), an advanced form of dry Age-related Macular Degeneration, impacts over 5 million people globally and leads to progressive, irreversible vision loss.[1]
- The economic burden of GA is estimated at $39.4 billion in the United States alone.[2-3]
- Current approaches to GA treatment aim to prevent and delay the progression of existing atrophy, allowing individuals to extend their remaining vision considerably longer. However, there is a lack of understanding regarding the impact of GA and meaningful treatment outcomes among relevant stakeholders.
- The aim of this study was to provide the perspectives of patient leaders from patient-driven retinal research funding and patient support organizations on the challenges faced by people living with GA and treatment expectations of current and potential therapies.

METHODS:



Figure 1. Steps involved in the Nominal Group Technique

- The study employed a modified nominal group technique (NGT), (Figure 1) a widely used validated consensus building method with five experienced leaders from 5 patient-driven organizations based in 5 countries (Switzerland, Australia, South Africa, Spain and Brazil).
- Two questions:
  - the perceived impact of GA on patients and caregivers
  - perceived treatment expectations of current and future therapies for GA
- The NGT process was partly conducted in-person and partly online.

RESULTS:

BURDEN of GA

Daily Living Activities
Watching TV
Recognizing faces
Orientation & Mobility
Groceries
Shopping
Using technology
Reading

Mental Health
Anxiety
Depression

Visual function
Blurred vision
Photophobia
Difficulty in low light
Poor light/dark adaptation
Poor contrast
Poor depth
Progressive vision loss and deterioration of the condition

Burden to family/caregivers
Feeling guilt
Job reduction
Anxiety and Depression
Loss of leisure time

Employment
Job loss
Job reduction
Unproductive at work

Emotional and Social
Fear
Loneliness
Frustration
Social isolation
Sadness
Anger
Altered feelings
Limited interaction with family members

Losing independence – Relying on others for activities of daily living including shopping, groceries, travel, medical visits, handling confidential documents etc

Figure 2. Items generated by the group/literature review with regards to the challenges faced by people living with GA

- Items regarding impact of GA among people living with the condition were generated via literature review and the NGT process.
- Generated items fell into 7 categories (Figure 2) - Activities of Daily Living, Mental Health, Independence, Family Burden, Employment, Visual Function & Emotional and Social.

Table 1. Top 10 items as raked by the group on burden/challenges

Items	Ranking					Total Score
Loss of independence	5	9		10	8	**32**
Recognizing faces	7	8	10	3		**28**
Orientation and mobility		10	5	4	4	**23**
Depression		1	6	5	9	**21**
Deterioration of the condition	6			8	6	**20**
Anxiety	9		3	6	1	**19**
Reading	8	2	8			**18**
Cooking		3	9			**12**
Social isolation	2		4	2	3	**11**
Watching TV		6			5	**11**

- The group ranked the most significant challenges faced by people living with GA as loss of independence, difficulty recognizing faces and impairment in daily living activities (Table 1).
- Mental health issues such as depression and anxiety were also ranked high.

TREATMENT EXPECTATIONS

Mode of delivery
Oral
Eye Drops
Intra-vitreal injection
Sub-retinal injections

Frequency of treatment
One time
3 monthly
6monthly
1 yearly

Visual outcome
Vision improvement
Stability of vision
Delay further loss

Regain of function
Recognize faces
Improve balance
Reading
Driving
Independent walking
Watch TV/movies
Shopping

Side effects: Less discomfort, Less risk of wet AMD or other vascular disorders, reduction in injection anxiety

Figure 3. Items generated by the group/literature review with regards to treatment expectations

- Generated items on perceived treatment expectations from the leaders and literature review fell into 5 categories (Figure 3) – Mode of delivery, frequency of treatment, visual outcome, regain of function & side effects.
- Stability of vision, one time therapy and ability to recognise faces were top perceived expectations from GA treatments.(Table 2)

Table 2. Top 10 items as raked by the group on treatment expectations

Items	Ranking					Total score
Stability of vision	10	10	10	10	7	**47**
Able to recognise faces	8		7	4	8	**27**
One time therapy		7	3	9		**19**
Oral	6	6	2		5	**19**
Improvement in vision		9			9	**18**
Able to walk independently			5	3	10	**18**
Intra-vitreal injections	5	4		7		**16**
Delay further loss of vision	7		9			**16**
Able to read	9		6	1		**16**
Able to drive		8	8			**16**

- Ability to perform daily living activities such as reading, driving, walking were also ranked in the top ten treatment expectations. (Table 2)

CONCLUSIONS:

- This study provides important insights into the multifaceted impact of Geographic Atrophy and patients' expectations from treatments as perceived by leaders from patient driven retinal research funding and support organizations.
- The findings emphasize the need for a holistic approach to the management and care of GA that addresses not only clinical vision measures but also functional abilities, independence, and mental health.
- Moreover, the study demonstrated that the patients value stabilisation of vision as a meaningful treatment outcome and are keen to reduce the burden of frequent treatments by accepting one-time therapies.

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