Characterizing Real-World Functional Outcomes in Patients With Geographic Atrophy: An IRIS Registry Analysis

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July 15, 2022
40th Annual Meeting of the American Society of Retina Specialists, NY
Financial disclosures

• Durga Borkar has the following financial interests or relationships to disclose:
  – Consulting Fees: Allergan, Glaukos, Regeneron

• This study was funded by Apellis Pharmaceuticals
Introduction

• GA accounts for one-third of the cases of late AMD
  – Including 20% of cases of severe vision loss\(^1\)
• GA significantly impairs visual function and QoL\(^2\)
  – Real-world data on correlations between GA progression and functional
decline are lacking
• We performed a retrospective cohort analysis of patient notes to
  assess the feasibility of quantifying VR-QoL and PROs in GA
  – Emphasis was placed on social, functional, and mobility-related outcomes

Part 1. Keyword objective and methodology

**Part 1 – Keyword objective:** From clinical notes\(^a\) of patients with GA, determine clinically and potentially contextually relevant **keywords** associated with social, mobility, and other activity/QoL endpoints

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**Cohort 1**
- Newly diagnosed GA
  - First GA diagnosis occurred in 2019
  - Captured notes associated with initial GA diagnosis date
  - Random sample of 100 notes evaluated

**Cohort 2**
- Prevalent GA, 3-yr follow-up
  - First GA diagnosis in 2016
  - Must have ≥3 yrs of follow-up
  - Captured notes associated with a GA diagnosis at 3-yr's follow-up
  - Random sample of 100 notes evaluated

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**Endpoints**
1. Keyword prevalence
2. Context matches

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\(^a\)Obtained from the American Academy of Ophthalmology IRIS® Registry (Intelligent Research in Sight), a real-world electronic health record dataset. GA=geographic atrophy; QoL=quality of life; yr=year.
We searched across all clinical notes (i.e., any text field which is completed), looking at the note on the day of GA diagnosis for Cohort 1, and note with a GA diagnosis after year 3 of follow-up for Cohort 2.

ADL=activity of daily living; GA=geographic atrophy.
Patient demographics and disease characteristics

<table>
<thead>
<tr>
<th></th>
<th>Cohort 1 (n=101)</th>
<th>Cohort 2 (n=94)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (SD), years</td>
<td>80.6 (7.5)</td>
<td>81.9 (6.3)</td>
</tr>
<tr>
<td>Subfoveal GA, %</td>
<td>53.5%</td>
<td>62.4%</td>
</tr>
<tr>
<td>Concomitant glaucoma, %</td>
<td>27.7%</td>
<td>37.6%</td>
</tr>
<tr>
<td>Concomitant cataract, %</td>
<td>39.6%</td>
<td>34.6%</td>
</tr>
</tbody>
</table>

- The majority of patients were managed by retina specialists

GA=geographic atrophy; SD=standard deviation; yr=year.
Part 1. Results

<table>
<thead>
<tr>
<th>Keyword</th>
<th>Matches\textsuperscript{a}, n (%)</th>
<th>Context Matches\textsuperscript{b}, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Driving</td>
<td>6 (6%)</td>
<td>4 (67%)</td>
</tr>
<tr>
<td>Reading</td>
<td>12 (12%)</td>
<td>10 (83%)</td>
</tr>
<tr>
<td>Low vision</td>
<td>3 (3%)</td>
<td>3 (100%)</td>
</tr>
<tr>
<td>Depression</td>
<td>7 (7%)</td>
<td>1 (14%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>2 (2%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Limited</td>
<td>11 (11%)</td>
<td>2 (18%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Keyword</th>
<th>Matches\textsuperscript{a}, n (%)</th>
<th>Context Matches\textsuperscript{b}, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Driving</td>
<td>1 (1%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Reading</td>
<td>10 (11%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>Low vision</td>
<td>2 (2%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Depression</td>
<td>5 (5%)</td>
<td>1 (20%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0 (0%)</td>
<td>–</td>
</tr>
<tr>
<td>Limited</td>
<td>14 (15%)</td>
<td>3 (21%)</td>
</tr>
</tbody>
</table>

\textsuperscript{a}Keywords with 0% matches: ADL, Face, Fine Print, Sad, Autonomy, Independence, Caregiver, Disability, Mobility, Rehab.

\textsuperscript{b}Context match refers to whether the keyword was mentioned in our context of interest.

ADL = activity of daily living; GA = geographic atrophy.
Key learnings from part 1

Documentation patterns of retina specialists
- Retina specialists’ documentation of PROs and functional vision impact are limited
- Low-vision specialists may play a larger role in management of vision deterioration due to GA

PROs in the electronic health record notes
- Documentation is generally sparse, with an emphasis on disease progression over patient outcomes
- Functional terms more likely to be mentioned: “driving ability”, “reading ability”, and referral to a low-vision specialist
- Overall documentation of these keywords was highly infrequent
  - Particularly those related to patient function

GA=geographic atrophy; PRO=patient-reported outcome.
Part 2. Context objective and methodology

**Part 2 – Context objective:** From the keywords found to be associated with social, mobility, and other activity or QoL outcomes, what context or concepts are being represented in the patient clinical notes.

**Cohort 1 – New GA Diagnosis (N=77,444)**

<table>
<thead>
<tr>
<th>Keyword</th>
<th>Matches, N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Driving</td>
<td>1,848 (2.4%)</td>
</tr>
<tr>
<td>Reading</td>
<td>3,355 (4.3%)</td>
</tr>
<tr>
<td>Low vision</td>
<td>2,411 (3.1%)</td>
</tr>
</tbody>
</table>

- Captured notes associated with initial GA diagnosis date
- Pull all clinical notes that contain keyword of interest
- Random sample of 50 notes evaluated per keyword

GA=geographic atrophy; QoL=quality of life.
Part 2. Context results

### Driving Concepts
- **Night Driving**: 30%
- **Trouble Driving**: 34%
- **Other**: 36%

### Reading Concepts
- **Difficulty reading**: 44%
- **Reading Glasses**: 20%
- **Reading Aids**: 12%
- **Other**: 24%

### Low-Vision Concepts
- **Low Vision Consult**: 74%
- **Low Vision Aids**: 16%
- **Other**: 10%

**Notes**
- “Patient noticing drive at night becoming a problem”
- “Complains of glare and halos when driving at night”
- “Patient states she has been having a lot of trouble driving”
- “Advised patient that she may no longer be able to drive”
- “Patient does not drive and at this time no significant ADLs are being affected”
- “She has trouble reading and seeing distance”
- “Her poor vision affects her ability to read”
- “He has no other complaints today but desires a new glasses prescription to read large print and read small print”
- “Advised patient to try magnifiers and additional lighting when trying to read small print”
- “Increase frequency of artificial tears use, 1 drop/eye before all reading and TV watching”
- “A standard pair of eyeglasses will not improve his vision, but he could consider a low-vision evaluation”
- “Discussed an appointment with the low-vision center to help patient maximize what vision is present”
- “Consider low-vision aids. Discussed tablet use, low-vision aids, as well as TVs and things that will be more useful for him in the future. Low-vision books on tape considered”
- “Family history of blindness/low vision. Low-vision refraction: No significant improvement”

ADL=activity of daily living; TV=television.
Key learnings from part 2

- It is difficult to determine if the impacts on functional vision are due to other comorbid ocular conditions
  - Including cataracts, presbyopia, other retinal disease
- Despite these limitations, understanding the holistic health burden among patients with GA is valuable
- Future studies should focus on:
  - Patients with GA and a substantial visual acuity decline
  - Those managed by low-vision specialists
  - Eyes with asymmetric GA
  - Those without cataracts

GA=geographic atrophy.
Conclusions

• VR-QoL and PROs are infrequently documented
  – This limits the utility of the EHRs for assessing functional outcomes
• Retina specialists often refer patients with GA to low-vision specialists
  – They may be more likely to monitor and document changes in VR-QoL
• Additional data sources may be needed to characterize the impact of GA on patient QoL
  – Patient-centric monitoring devices (digital apps/wearables) and PROs
• Real-world assessment of PROs is lacking, necessitating improved tools to collect real-world data on patient QoL