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

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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

AMD=age-related macular degeneration; GA=geographic atrophy; PRO=patient-reported outcome; QoL=quality of life; VR-QoL=vision-related quality of life.

1. Biarnés M et al. Optom Vis Sci. 2011;88:881–9; 2. Sarda SP et al. Clin Ophthalmol. 2021;15:4629–44.

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

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

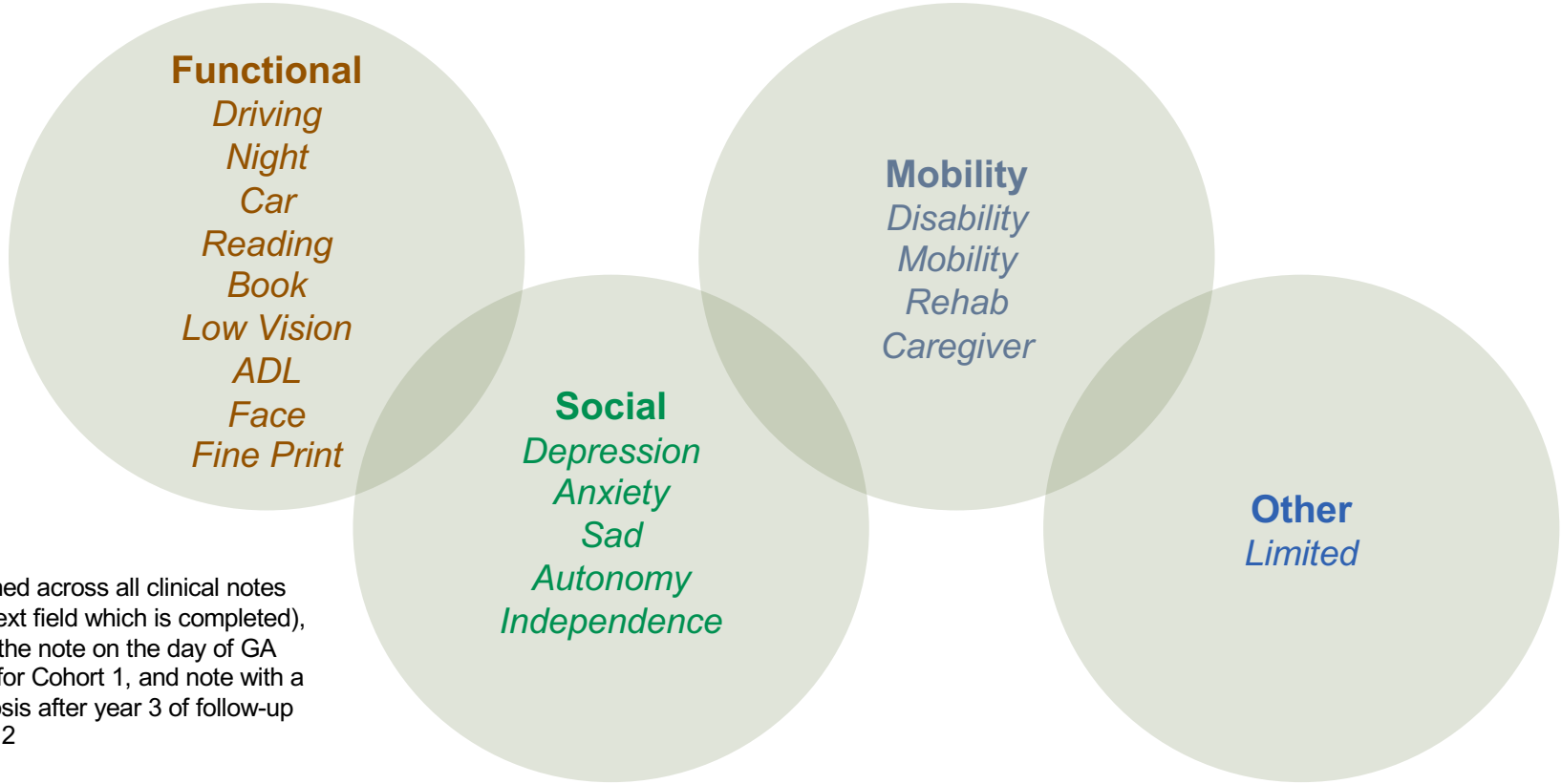
- First GA diagnosis in 2016
- Must have ≥3 yrs of follow-up
- Captured notes associated with a GA diagnosis at 3-yrs of follow-up

Random sample of 100 notes evaluated

Endpoints
1. Keyword prevalence
2. Context matches

[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.

Keywords



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

	Cohort 1 Newly diagnosed GA (n=101)	Cohort 2 Prevalent GA, 3-yr follow-up (n=94)
Age (SD), years	80.6 (7.5)	81.9 (6.3)
Subfoveal GA, %	53.5%	62.4%
Concomitant glaucoma, %	27.7%	37.6%
Concomitant cataract, %	39.6%	34.6%

- The majority of patients were managed by retina specialists

GA=geographic atrophy; SD=standard deviation; yr=year.

Part 1. Results

	Cohort 1 – New GA Diagnosis (n=101)			Cohort 2 – Prevalent GA Diagnosis (n=94)		
	Keyword	Matches[a], n (%)	Context Matches[b], n (%)	Keyword	Matches[a], n (%)	Context Matches[b], n (%)
Functional:	Driving	6 (6%)	4 (67%)	Driving	1 (1%)	0 (0%)
	Reading	12 (12%)	10 (83%)	Reading	10 (11%)	7 (70%)
	Low vision	3 (3%)	3 (100%)	Low vision	2 (2%)	2 (100%)
Social:	Depression	7 (7%)	1 (14%)	Depression	5 (5%)	1 (20%)
	Anxiety	2 (2%)	2 (100%)	Anxiety	0 (0%)	–
Other:	Limited	11 (11%)	2 (18%)	Limited	14 (15%)	3 (21%)

[a]Keywords with 0% matches: ADL, Face, Fine Print, Sad, Autonomy, Independence, Caregiver, Disability, Mobility, Rehab.
[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
Newly diagnosed GA

- Captured notes associated with initial GA diagnosis date
- Pull all clinical notes that contain keyword of interest

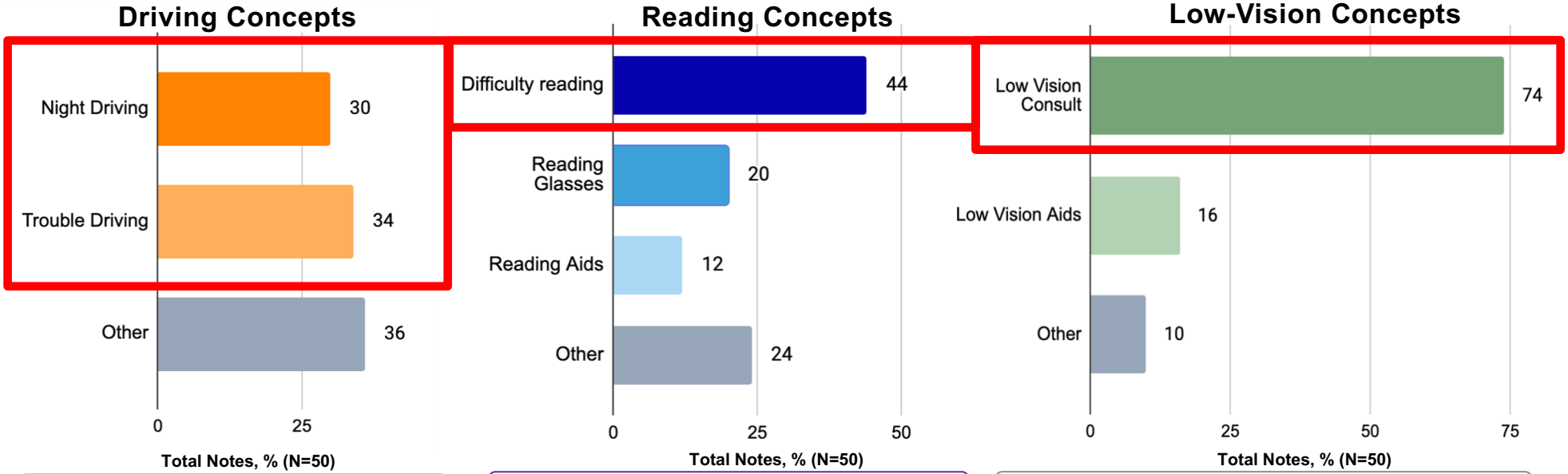
Random sample of 50 notes evaluated per keyword

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

Keyword	Matches, N (%)
Driving	1,848 (2.4%)
Reading	3,355 (4.3%)
Low vision	2,411 (3.1%)

GA=geographic atrophy; QoL=quality of life.

Part 2. Context results



"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

EHR=electronic health record; GA=geographic atrophy; PRO=patient-reported outcome; QoL=quality of life; VR-QoL=vision-related quality of life.