

# Patient-, Caregiver-, and Eye Care Professional-reported Burden of Geographic Atrophy Secondary to Age-related Macular Degeneration

Rishi P. Singh<sup>1</sup>, Sunil S. Patel<sup>2</sup>, Jared S. Nielsen<sup>3</sup>, Jordana K. Schmier<sup>4</sup>, Yamina Rajput<sup>5</sup>

<sup>1</sup>Center for Ophthalmic Bioinformatics, Cole Eye Institute, Cleveland Clinic, Cleveland, Ohio, United States, <sup>2</sup>West Texas Retina Consultants, Abilene, Texas, United States, <sup>3</sup>Vitreoretinal Diseases and Surgery, Wolfe Eye Clinic, West Des Moines, Iowa, United States, <sup>4</sup>Health Sciences Practice, Exponent, Alexandria, Virginia, United States, <sup>5</sup>US Medical Affairs, Genentech, Inc., a Member of the Roche Group, South San Francisco, California, United States



## Corresponding Author:

Rishi P. Singh, Center for Ophthalmic Bioinformatics, Cole Eye Institute, Cleveland Clinic, 9500 Euclid Avenue, I-32, Cleveland, Ohio, 44195, United States.  
Phone: 216-445-9497.  
Fax: 216-444-2226.  
E-mail: drrishisingh@gmail.com

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## ABSTRACT

**Objective:** Geographic atrophy (GA) is a progressive, irreversible advanced form of age-related macular degeneration. There is limited information on the burden of illness of GA from patient, caregiver, and eye care professional perspectives. This study identifies key factors that should be included for assessment in future studies of patients with GA. **Methods:** In this cross-sectional qualitative study, patients with symptomatic GA ( $n = 8$ ), their caregivers ( $n = 6$ ), and eye care professionals who treat patients with GA ( $n = 5$ ) were interviewed at US sites. Interview guides were designed to evaluate the understanding of the disease, costs and burden of illness, use of vision aids or services, and impact on emotional or psychological well-being and on daily activities. **Results:** Half of the patients mentioned social, psychological, or helplessness issues. Patients reported the impact of GA on sports and outdoor hobbies, meals or food preparation, religious activities, and long-distance travel. Patients reported having stopped driving or changing driving patterns as a major concern. 38% of all patients reported previously modifying their work schedules due to vision impairment. All patients reported the use of at least one vision aid, with 88% of patients purchasing the aids out of pocket. Caregivers reported modifying their schedules to provide assistance as needed and expressed frustration over their inability to improve patients' health. Eye care professionals noted the emotional impact of vision loss, accidents, and injuries, and identified mental health as a key topic for patients with GA. **Conclusions:** Although limited by size, this study indicates that GA has a major negative impact on patients' and caregivers' social functioning and health-related quality of life. This study has identified indirect resource use, including caregiving needs, and direct patient out-of-pocket costs as factors relevant to patients with GA. Future larger studies are needed to further characterize the burden of illness of GA for patients and caregivers.

**Keywords:** Age-related macular degeneration, Burden of illness, Geographic atrophy, Health-related quality of life, Patient-reported outcomes

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## INTRODUCTION

Geographic atrophy (GA) is a progressive and irreversible advanced form of age-related macular degeneration (AMD),<sup>[1]</sup> with no current US Food and Drug Administration-approved treatment. GA affects >5 million individuals worldwide,<sup>[2]</sup> including >1 million

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in the United States,<sup>[3]</sup> indicating that GA is as common as neovascular AMD.<sup>[3]</sup> The prevalence of GA increases exponentially with age, from 4% at 80 years to ~15% at 90 years.<sup>[4]</sup> GA has a devastating effect on health-related quality of life (HRQOL) and on patients' ability to read, drive, and perform other day-to-day activities,<sup>[5-7]</sup> leading to frustration, annoyance, and even clinical depression.<sup>[8]</sup>

Previous studies have shown that ophthalmic conditions, particularly those causing loss of visual function, can deprive patients of independence and increase caregiver burden.<sup>[5,9]</sup> Patients new to low-vision rehabilitation express difficulty with reading, driving, using vision aids, mobility, in-home activities, lighting and glare, facial recognition, and social interactions.<sup>[5]</sup> In a multicountry observational study of neovascular AMD,<sup>[10]</sup> >20% of patients were prescribed vision aids, and 19–41% required assistance with daily activities.

Previously, we performed a comprehensive literature review (Singh *et al.* presented at the American Society of Retina Specialists Annual Meeting, August 9–14, 2016) to identify knowledge gaps and instruments regarding the patient-reported and socioeconomic burden of GA. The review identified the dimensions of HRQOL relevant to patients with GA or instruments used to assess them, in addition to information related to caregivers of patients with GA. The results of this literature review are currently in preparation for publication.

In the present study, we sought to know more about issues concerning patients with GA, their caregivers, and eye care professionals, directly from these individuals. We carried out a qualitative study to better understand the burden of illness of GA from patient, caregiver, and eye care professional perspectives.

## METHODS

### Study design

This was a cross-sectional qualitative study conducted at two clinical sites in the United States (Wolfe Eye Clinic, West Des Moines, IA; West Texas Retina Consultants, Abilene, TX). Researchers at the sites recruited patients with symptomatic GA and their caregivers to participate in face-to-face interviews. Five eye care professionals were recruited to participate in phone interviews.

The study was declared exempt from the need for ethical review by an institutional review board; patients/caregivers and eye care professionals provided written and verbal consent, respectively, to be in the study and were compensated for their time.

### Participants

Patients aged at  $\geq 70$  with symptomatic bilateral GA secondary to AMD, without choroidal neovascularization

or previous treatment with anti-vascular endothelial growth factor agents, were eligible for participation. Existing patients at the study site for  $\geq 12$  months were identified and invited to participate in the study.

Patients with a caregiver were informed of the caregiver component of the study. Caregivers providing unpaid assistance with daily activities were invited to participate in the study and accompany the patient with GA to their study visit. Patients with GA without a caregiver, or with a caregiver unwilling to participate, remained eligible to participate in the study.

### Interviews

Three sets of interview guides were designed for patients with GA, their caregivers, and eye care professionals (Supplementary Tables 1, 2, and 3, respectively). These semi-structured interviews included the same topics from each perspective: Understanding of disease, costs and burden of illness, use of vision aids/services, impact on emotional/psychological well-being, and impact on daily activities. All interviews were conducted by the same interviewer (J.K.S.) and were recorded.

**Table 1:** Participant characteristics

Participant type	Characteristic
<b>Wolfe Eye Clinic</b>	
Patient 1	Male, not driving, retired
Caregiver 1	Female, wife, retired
Patient 2	Female, driving in daytime, retired
Caregiver 2	Female, neighbor, retired
Patient 3	Male, driving in daytime, retired
Caregiver 3	Female, wife, retired
Patient 4	Female, not driving, retired
<b>West Texas Retina Consultants</b>	
Patient 1	Male, driving on own property only, working
Caregiver 1	Female, wife, working
Patient 2	Male, driving, retired
Patient 3	Male, driving, semi-retired
Caregiver 3	Female, wife, retired
Patient 4	Male, not driving, retired, living in independent living facility
Caregiver 4	Female, paid caregiver (~9 h/week)
<b>Eye care professionals</b>	
Eye care professional 1	MD, low-vision/retina specialist
Eye care professional 2	MD, retina specialist
Eye care professional 3	Optometrist, specialist in geriatric care
Eye care professional 4	MD, retina specialist
Eye care professional 5	Optometrist, strong interest in retina

**Data analysis**

All participants (patients with GA, caregivers, and eye care professionals) meeting the eligibility criteria and enrolled in the study were included in the study population. Data elicited from the interviews were summarized by topic and frequency of mention.

**RESULTS**

Table 1 provides baseline participant characteristics for the eight patients with GA, six caregivers, and five eye care professionals interviewed. Figure 1 includes quotes from patients and caregivers. Supplementary Table 4 provides aggregated data from interviews with all participants. No participants withdrew from the study after providing consent.

**Patient perspective**

**Impact on daily activities and HRQOL**

Figure 2 summarizes findings from patients, distinguishing spontaneous topics (i.e., sports and hobbies, household chores and activities, and personal hygiene) from those covered by the interview guide (reading, transportation and driving, and everyday activities). Spontaneous topics were not identified in previously published studies of patients with AMD or GA. The topics mentioned most frequently were driving, reading, and psychological issues. One-fourth of respondents specifically mentioned curtailing long-distance trips, 63% of respondents reported difficulty reading for everyday tasks or leisure, and 38% of respondents felt helpless or embarrassed that they required assistance. In addition, all respondents

reported that they still performed household chores, even though they sometimes took longer to complete.

**Costs and burden of illness**

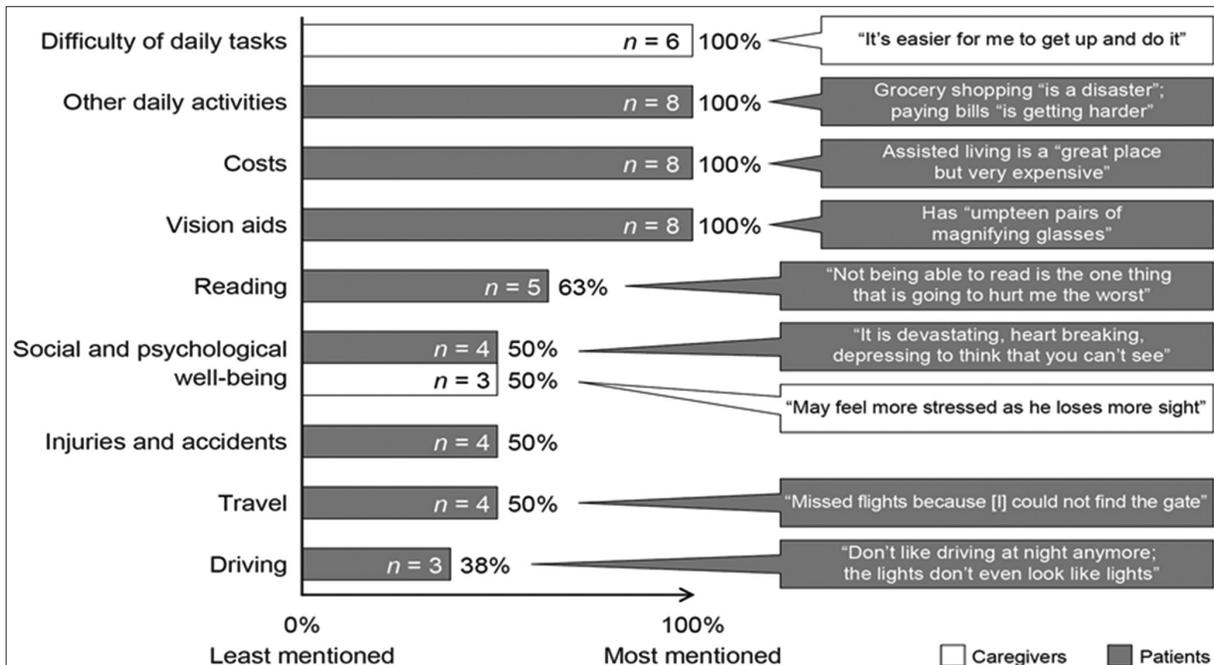
The frequency of direct medical resource use associated with GA, including visits, procedures, and tests, had not changed for patients since diagnosis. All reported purchasing Age-Related Eye Disease Study-recommended vitamins out of pocket. Vision aids ranged from a flashlight (reported by all respondents) to a talking watch and magnifying system. No vision aids were covered by insurance, except for a patient with Veterans' Administration coverage. All patients were retired, except for one working on his family farm; 38% of patients reported having previously modified their work schedules as a result of their vision challenges. Half of respondents were unaware of visual rehabilitation training. Patients did not identify injuries or accidents associated with GA.

**Caregiver perspective**

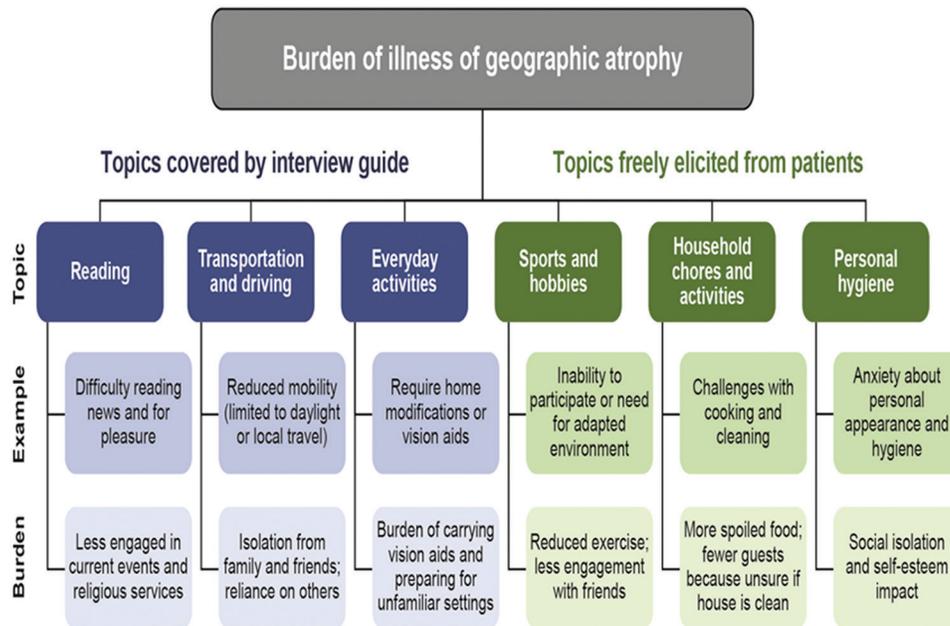
Caregivers' comments echoed patient's reports of the challenges associated with GA, and caregivers reported frustration at watching patients struggle. Caregivers provided transportation, assisted with household tasks, and subtly offered help or checked on patients. Caregivers linked injuries (a broken ankle, a cut requiring stitches) to GA even when patients did not. No participating caregiver reported working full time outside of the home other than working on a farm.

**Eye care professional perspective**

Eye care professionals reported that they routinely and informally screen for psychological well-being. Caregivers



**Figure 1:** Mentioned topics with quotes from patients (gray boxes) and caregivers (white boxes). n = 8 patients; n = 6 caregivers.



**Figure 2:** Burden of illness of geographic atrophy: Patient perspective.

typically accompany patients to visits, but their involvement varies. Eye care professionals from different regions suggested that patients in urban areas have less difficulty getting around due to public transportation, while patients in rural areas are more isolated. Although professionals suspect that some injuries may be associated with GA, age and comorbidities may affect gait and balance, complicating attribution. Although they identified visual aid training as essential for optimal benefits, professionals acknowledged the lack of resources to instruct or follow up with patients.

## DISCUSSION

GA is a leading cause of irreversible vision loss in the developed world,<sup>[11]</sup> yet limited information is available about the burden of GA on patients and their caregivers. A comprehensive literature review that we conducted to identify knowledge gaps on the socioeconomic burden of GA<sup>[11]</sup> is currently in preparation for publication. This literature search provided guidance for developing the semi-structured interview guides.

Patient interviews confirmed that many areas noted as relevant to AMD in the literature<sup>[12]</sup> are similarly relevant to GA. Interviews also identified new areas, such as sports and outdoor activities, religious participation, and personal hygiene. Caregivers confirmed concerns raised by patients, describing the influence of GA on their own schedules and activities, and providing additional input about injuries. Eye care professionals recognized the burden of GA on patients' mental health and acknowledged the distinction between availability of vision aids and sufficient training and reinforcement for optimal benefit.

As there are many knowledge gaps regarding the burden of GA, these interviews provide a valuable glimpse into the important concerns facing patients and caregivers, despite the limitation of a small sample size. Using a semi-structured interview approach encouraged respondents to raise issues rather than limiting responses to a pre-specified set, thereby allowing identification of topics previously unmentioned in the literature.

This study did not include capture of visual acuity data either by prospective assessment or chart review, which would have provided clinical context to the survey findings. Nevertheless, this pilot study provides the basis to design a more substantive and systematic survey in patients with GA to explore further the issues mentioned in these interviews. Additional topics for future research include direct medical resource use, impact on caregiver well-being, indirect costs, and differences between patients with GA and patients with normal vision.

## CONCLUSIONS

In conclusion, this qualitative study provided valuable insights into the extensive burden of GA secondary to AMD on patients, caregivers, and eye care professionals. It also highlighted the need for more studies to further characterize the burden of this progressive and irreversible disease.

## AUTHORS' CONTRIBUTIONS

Conception and design: Singh, Patel, Nielsen, Schmier, Rajput. Data collection: Schmier. Analysis and interpretation of data: Singh, Patel, Nielsen, Schmier, Rajput. Drafting

the article or revising it critically for important intellectual content: Singh, Patel, Nielsen, Schmier, Rajput. Final approval of the version to be published: Singh, Patel, Nielsen, Schmier, Rajput.

### Declaration of patient consent

The study was declared exempt from the need for ethical review by an institutional review board; patients/caregivers and eye care professionals provided written and verbal consent, respectively, to be in the study and were compensated for their time.

### Financial support and sponsorship

Funding was provided by Genentech, Inc., a member of the Roche Group, for third-party writing assistance, which was provided by Charlotte A. Osborne, PhD, of Envision Pharma Group.

### Conflicts of interest

Dr. Rishi P Singh is on the Editorial Board of the Journal. Singh: Alcon, Genentech, Inc., Regeneron, Shire (consulting fees); Alcon, Apellis, Genentech, Inc., Regeneron (financial support); American Journal of Ophthalmic Clinical Trials (Editor in Chief). Patel: Allergan, Genentech, Inc. (consulting fees); Alcon, Allergan, Clearside Biomedical, Daiichi, Genentech, Inc., Ophthotech, Regeneron, Samsung, Mylan, Chengdu Kanghong Biotechnology, Graybug, and Kodiak Sciences (financial support). Nielsen: Genentech, Inc., Regeneron (consulting fees); Alcon, Genentech, Inc., Ophthotech, Regeneron (financial support). Schmier: Exponent from Genentech, Inc. (financial support). Rajput: Genentech, Inc. (employee).

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## SUPPLEMENTARY FILES

### Supplementary Table 1: Patient Interview

File format: .pdf

Title: Patient interview data collection form

Description: Semi-structured guide for interviews with patients.

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### Supplementary Table 3: Eye Care Professional Interview

File format: .pdf

Title: Eye care professional interview data collection form

Description: Semi-structured guide for interviews with eye care professionals.

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### Supplementary Table 2: Caregiver Interview

format: .pdf

Title: Caregiver interview data collection form

Description: Semi-structured guide for interviews with caregivers.

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### Supplementary Table 4: Aggregated Interview Data

File format: .pdf

Title: Aggregated interview report tables

Description: Aggregated data from interviews with all participants (patients with geographic atrophy, their caregivers, and eye care professionals).

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