The MOSAIC Study: A Clinical, Humanistic, and Economic Burden of Illness Study Among Patients With Geographic Atrophy and Their Caregivers in the United Kingdom

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MOSAIC

Introduction

- Geographic atrophy (GA) is an irreversible, advanced form of age-related macular degeneration (AMD)[1]
- GA accounts for 20% of all legal blindness attributed to AMD[1] and is a leading cause of blindness in the elderly, with approximately 6 to 10 million people affected globally[2]
- Significant visual loss is associated with disability and clinical depression in over one-third of patients[3]
- While the incidence and burden of GA are expected to rise globally, there is limited research on patient and caregiver experience with this condition

Purpose

- To characterize the clinical, humanistic, and economic burden of GA in patients and caregivers in the United Kingdom (UK)

Methods

- MOSAIC was a non-interventional, cross-sectional burden of illness study in GA, conducted from November 2021 to October 2022 in 251 patients and 238 caregivers in 6 countries: United States (US), Canada, Australia, UK, Germany, and France
  - MOSAIC was designed based on preliminary findings from previous qualitative interviews, which were conducted from July to September 2021 in 28 patients and 17 caregivers in the US, UK, and Australia to understand the important aspects of the disease from patient and caregiver perspectives[4-7]
- Eligible patients were ≥60 years of age, had GA secondary to AMD in at least one eye without concomitant wet AMD, and did not have other conditions that could lead to GA, such as Stargardt disease
- Eligible caregivers were ≥18 years of age, the primary caregiver of a patient with GA, and were not receiving any financial compensation for their caregiving services
- The National Eye Institute Visual Function Questionnaire (NEI VFQ-25, 25 items), including 13 optional items,[8] the Work Productivity and Activity Impairment questionnaire: Specific Health Problem (WPAI:SHP, 6 items) v2.0,[9] and 42 novel items specifically developed for the MOSAIC study to address topics related to concepts that were not fully covered by the existing questionnaires were administered in participating patients
- The Zarit Burden Interview (ZBI, 22 items),[10] the Caregiver Indirect and Informal care cost assessment Questionnaire (CIIQ, 13 items),[11] and 19 novel items were administered in participating caregivers
- This poster reports on the results of the MOSAIC study in the UK

Results

Socio-demographic Characteristics

Patients (N=34)

Similar proportion of male and female patients



3% prefer to skip

Ethnicity
88% White

Median (IQR) age
78 (73–84) years
(range 62–94)

40% at least **Bachelor's degree**

82% retired
12% not employed
6% working full-time

59% lived with someone

24% had to change their living situation due to GA

Caregivers (N=35)

More female caregivers



2% prefer to skip

Ethnicity
88% White

Median (IQR) age
61 (47–74) years
(range 23–86)

72% at least some **college education**

51% employed
11% full time
40% part time

Mean (SD) work time per week: **28 (7) hours**

49% not employed

No caregiver stopped working because of the disease of the person they cared for

34% lived with the person they cared for

86% did not change their living situation

IQR, interquartile range; SD, standard deviation.

Health Characteristics

Patients

Median (IQR) **time from diagnosis of GA** (n=33)
8 (5–12) years

Median (IQR) **age at time of diagnosis of GA** (n=33)
69 (63–75) years

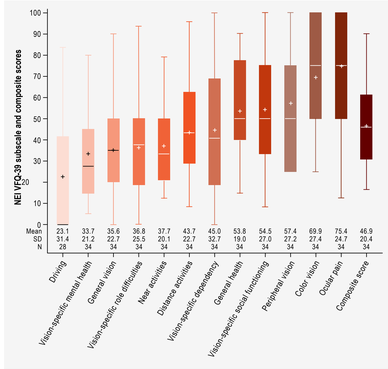
71% of patients experienced visual changes due to GA in **both eyes**

IQR, interquartile range.

Impact of GA on Daily Life

Patient Perspective

NEI VFQ-39 subscale and composite scores



Mean (SD) NEI VFQ-39 composite score: 46.9 (20.4)

The box represents the interquartile range, the band ("-") inside the box is the median, the plus ("+") inside the box is the mean, and the whisker ends denote the minimum and maximum values. The mean (SD) of NEI VFQ-39 subscale and composite scores and the number of patients scored (N) are shown at the bottom of the box plot. SD, standard deviation.

65% of patients **no longer drive**
- **77%** of patients **gave up driving**
  - **100%** of these patients **gave up driving because of their eyesight**

35% of patients were **still driving**
- **92%** of patients reported having **"difficulty driving"** or that they had to **"stop driving"** at night and in difficult conditions

47% of patients **received help from spouse or partner**, **47% from friends, 44% from another family member,** and **27% from children**

50% of patients **needed help every day**

A majority of patients **could not locate an object that is not in its usual place (71%), prepare complex meals (62%), pay bills (59%),** or **write by hand (56%)**

74% of patients **walked more slowly than they preferred**
53% of patients **avoided stairs**
74% of patients **avoided uneven ground**

29% of patients **were unable to read**

Caregiver Perspective

CIIQ items

During the last week:

Median (IQR) hours spent on **household activities and tasks** that caregivers would not have had to perform if the person they cared for was in good health, or if they could have done them independently: **6 (3–14)**

Mean (SD) hours **missed from work** due to the disease of the person they cared for (n=18): **1.9 (3.4)**

Most frequent type of support provided by caregivers in the daily life of GA patients:

Read food labels (80%)
Shop for the patient (77%)

Drive the patient
- **to their eye appointment for GA (69%)**
- **to other medical appointments (66%)**
- **to do errands or shopping (66%)**

Manage their medication (60%)

For 34% of caregivers, the most inconvenient type of support was driving the patient to various places

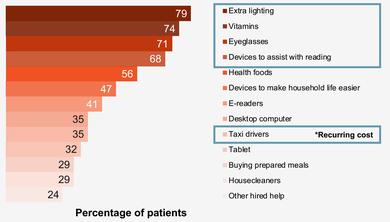
IQR, interquartile range; SD, standard deviation.

Financial Impact of GA

Patients

47% of patients spent **>500£** on **products**
36% of patients paid **>500£** on **services**

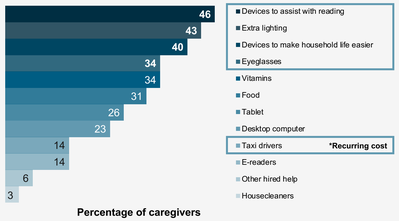
Products and services purchased with patients' money to make living with GA easier



Caregivers

34% of caregivers spent **>500£** on **products**
12% of caregivers paid **>500£** on **services**

Products and services purchased with caregivers' money to make living with GA easier



Top products and services purchased by patients and caregivers to make living with GA easier were similar

Mental Health Burden Due to GA

Patient Perspective

NEI VFQ Mental Health subscale:

56% of patients were **most worried about losing their independence**

76% of patients **worried about their eyesight most or all of the time,** and 18% worried some of the time

Because of their eyesight:
- **82%** of patients reported they **felt frustrated,** and **80% had much less control over what they did** ("definitely true" or "mostly true")
- **44%** of patients reported they **worried about doing things that would embarrass themselves or others** ("definitely true" or "mostly true")

Novel items developed for the MOSAIC study:

62% of patients reported **worry,** and **62%** reported **sadness** as their immediate, main response when told their diagnosis, followed by shock (56%), confusion (41%), and overwhelmed (35%)

Caregiver Perspective

ZBI items:

89% of caregivers were **afraid of what the future holds** for the person they cared for

60% of caregivers **felt that the person they cared for was dependent upon them**

51% of caregivers **felt stressed between caring for the person and meeting other responsibilities**

≥25% of caregivers reported the following as "sometimes":
- Felt they could be doing a better job caring for the person with GA
- Felt to have lost control of their life since the illness of the person with GA
- Felt their social life had suffered because of caring for the person with GA
- Felt they did not have time for themselves due to time spent for the person with GA
- Felt strained when they were around the person with GA

Burden Across Different Caregiver Relationships

	Caring for a Parent	Caring for a Family Member/Friend	Caring for a Partner/Spouse
Employed	80%	54%	27%
Moderate to Severe Burden (ZBI)	30%	8%	0%
Greatest Concerns of Caregiver	Emotional effect of GA on their parent (50%)	Where the person will live if their vision worsens (62%)	Own health concerns interfering with their ability to provide care (27%)

Caregiver burden differed based on caregiver's relationship with the person. Higher burden was perceived by those caring for a parent

Conclusions

- GA has a substantial impact on patients' vision-related quality of life and their daily activities
- There is a significant unmet need for patients with GA, including support in various daily life activities and social and mental health support
- Caregivers of patients with GA have difficulty facing needs for social and mental health support, among other concerns
- The burden experienced by both patients and caregivers translates to societal impact
- People living with GA – not widely perceived as individuals with severe visual impairment – experience substantial daily living burdens as well as financial concerns
- Unmet needs of people living with GA and their caregivers require awareness and action

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Financial Disclosures

These studies were funded by Apellis Pharmaceuticals, Inc.
WA reports grants from Bayer and Boehringer Ingelheim; consulting fees from AbbVie, Allergan, Novartis, and Roche; financial support from AbbVie, Novartis, and Roche. **DJ** and **SS** are employees of Apellis Pharmaceuticals, Inc. **BL, RD,** and **RS** are employees of Apellis International GmbH. **GH, MM,** and **SQ** have nothing to declare. **CD** reports grants from Apellis and Roche; consulting fees from Ora Clinical Scientific; financial support from Almera Sciences, Novartis, Roche, and Topcon.

Acknowledgements

Professional medical writing support was provided by Lisa Feder, PhD, and Gorica Malisanovic, MD, PhD (OPEN Health Communications), and funded by Apellis Pharmaceuticals.

Presented at the RCOphth Annual Congress; May 22–25, 2023; Birmingham, United Kingdom

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