The MOSAIC study: A clinical and humanistic burden of illness study among patients with geographic atrophy and their caregivers in the United States and Canada

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Main poster *Supplement*

Introduction

- MOSAIC, a non-interventional cross-sectional burden of illness study in geographic atrophy (GA), was conducted from November 2021 to October 2022 in 251 patients with GA and 238 caregivers in six countries: Australia, Canada, Germany, France, the United Kingdom (UK), and the United States (US).
- Qualitative interviews were conducted from July to September 2021 in 28 patients and 17 caregivers in the US, the UK, and Australia to understand the important aspects of the disease from the patient and caregiver perspective.[1–4]

Purpose

- To characterize the burden of GA in patients and caregivers in the US and Canada.

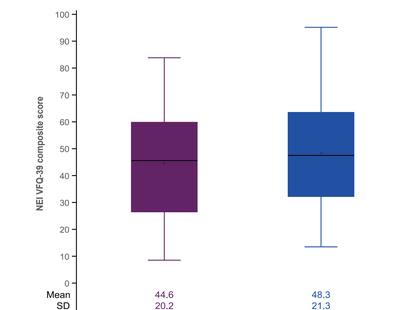
Methods

- Eligible patients were aged ≥60 years, had GA secondary to age-related macular degeneration (AMD) in at least one eye that did not also have wet AMD, and did not have Stargardt disease.
- Eligible caregivers were aged ≥18 years, the primary caregiver of a patient with GA, and 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,[5] the Work Productivity and Activity Impairment questionnaire: Specific Health Problem (WPAI:SHP, 6 items) v2.0,[6] 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),[7] the Caregiver Indirect and Informal care cost assessment Questionnaire (CIIQ, 13 items),[8] and 19 novel items were administered in participating caregivers.

Results

Among US and Canadian study participants, there were 149 patients with GA (102 in the US and 47 in Canada) and 148 unpaid caregivers of patients with GA (102 in the US and 46 in Canada) who participated in the study (**Supplementary Table 1 and 2**).

Figure 1. Distribution of NEI VFQ-39 composite score in patients with GA in the US and Canada



GA=geographic atrophy; N=number of patients;
NEI VFQ=National Eye Institute Visual Functioning Questionnaire; SD=standard deviation

Figure 2. Distribution of NEI VFQ-25 item responses of patients who drive in the US (left panel) and Canada (right panel)

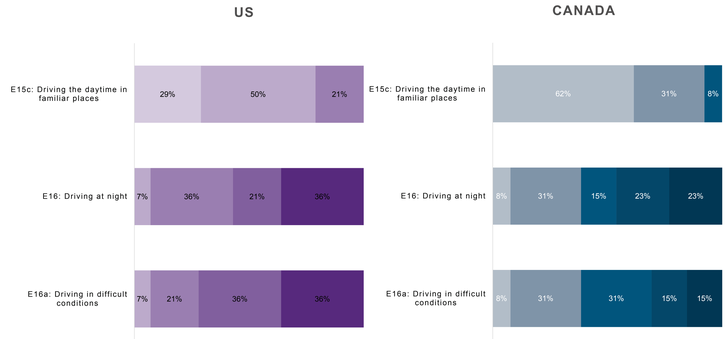


Figure 3. Distribution of ZBI item responses in the US (left panel) and Canada (right panel)

ZBI=Zarit Burden Interview

Patients

- Mean (standard deviation [SD]) NEI VFQ-39 composite scores were comparable in patients from both countries: 44.6 (20.2) in the US and 48.3 (21.3) in Canada, on a scale ranging from 0 (lower functioning) to 100 (better functioning), indicating similar vision-related quality of life (**Figure 1)**.
- Mean (SD) NEI VFQ-39 Vision-specific mental health subscale score was 46.4 (25.1) and!39.6 (24.8) in the US and Canada, respectively.
- A higher proportion of US patients reported needing daily help (68%) or a change in their living situation because of GA (38%) than did Canadian patients (38% and 28%, respectively).
- A total of 51% of US patients and 57% of Canadian patients were able to walk independently in familiar places, but only 22% of US patients and 36% of Canadian patients in unfamiliar places.
- There were few drivers in the US (n=14) and Canada (n=13). Four US patients and 8 Canadian patients had no difficulty at all driving in the daytime or in familiar places, while 5 US patients and 3 Canadian patients had stopped driving at night (**Figure 2**).

Caregivers

- A between-country shift in the distribution of the ZBI item responses was observed with the majority of items most frequently rated "Never" in the US (except items #3, 7, and 8) vs "Sometimes" in Canada (except items #7, 8, and 16; **Figure 3**).
- Mean (SD) ZBI total score was 24.8 (18.7) and 42.4 (11.9) in the US and Canada, respectively, on a scale ranging from 0 to 88 in which higher score indicates more severe burden. A total of 63% of Canadian caregivers were categorized as having moderate to severe burden vs only 15% of US caregivers (ZBI total score between 41 and 60; (**Supplementary Figure 1**).

Conclusion

- These results highlight the substantial multifaceted burden of GA on patients and their caregivers in the US and Canada.
- The cumulative burden of poor vision-related quality of life, as reflected by low NEI VFQ-39 scores is not widely recognized.
- The caregivers of people living with GA share this burden, especially in Canada, potentially due to differing profiles of patients that US and Canada caregivers care for, e.g., partner/spouse (US) vs parent/grandparent (Canada).
- Both patients and their caregivers face various unmet needs including social and mental health support, as well as support in various daily life activities for patients, which require awareness and action.

References

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