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BRIEF REPORT

Living with Geographic Atrophy: An Ethnographic Study

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ABSTRACT

Introduction: The specific impact from the patient's perspective of geographic atrophy (GA), an advanced form of age-related macular degeneration (AMD), is not well understood.
Methods: An ethnographic study was conducted to understand the impact of bilateral GA secondary to AMD on daily functioning by observing regular activities performed at home and through semi-structured interviews. Eligible subjects had a definitive GA diagnosis, including presence of drusen, GA lesion size of at least one disc area in the better-seeing eye, and no other confounding ophthalmologic diagnosis. Data were collected via video recordings and field notes, and analyzed by coding video transcripts.
Results: Functional impact domains affecting more than two of the 16 subjects from the United Kingdom, United States, or Germany were activities of daily living (difficulty reading, $n = 16$; driving, $n = 12$; and watching movies, television, or theater, $n = 11$), emotional (frustration, and fear of blindness, $n = 7$ each), social/leisure (interference with hobbies, $n = 8$, and diminished social activities, $n = 4$), physical ($n = 4$), and financial ($n = 10$). Subjects with a best-corrected visual acuity (BCVA) of 20/100 or better in the better-seeing eye ($n = 10$) reported similar functional impacts to those with a BCVA

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of worse than 20/100 in their better-seeing eye (n = 5).
Conclusion: This study helps address gaps in patient-focused research into GA, which negatively impacts the day-to-day functioning of patients. Larger qualitative and quantitative studies are needed to quantify patient experiences and assess the correlation between BCVA score and impact of GA.
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Keywords: Activities of daily living; Age-related macular degeneration; Ethnography; Geographic atrophy; Quality of life; Visual acuity

INTRODUCTION

Geographic atrophy (GA) is an advanced form of age-related macular degeneration (AMD) that affects more than 5 million people worldwide and is expected to affect at least 10 million people by 2040 [1]. No approved treatment for GA is currently available. The disease is characterized by distinct areas in which there is complete loss of photoreceptors, retinal pigment epithelium, and choriocapillaris in the macula, leading to progressive and irreversible loss of visual function [2, 3]. The foveal center (and therefore central vision) is often spared until late in the disease [4]. Consequently, patients with GA initially have a good best-corrected visual acuity (BCVA) as long as the fovea is not affected by the atrophic process. This common finding suggests that BCVA may not fully capture the impact of visual impairment in GA [3, 5].

The specific impact of GA on daily life from a patient's perspective is not well known. Most studies reporting on the patient perspective describe the impact of advanced AMD and do not differentiate GA from neovascular AMD [6, 7]. Several studies have described the negative impact of advanced AMD on the ability to perform activities of daily living (ADL, such as reading, managing finances, shopping, and basic housework) and its association with higher levels of emotional distress [8–12]. As visual function declines over time with disease progression, vision-related quality of life worsens. In one study, patients experienced a 17% decrease in their quality of life even with mild AMD (defined in the study as BCVA 20/20–20/40 in the better-seeing eye), while the effect of very severe AMD (defined as BCVA $\leq$ 20/800 in the better-seeing eye) on quality of life was reported to be a 60% decline, similar to that of end-stage cancer or a severe stroke [13]. However, GA and neovascular AMD are distinct conditions and the unique impact of GA is not well documented and may not be well understood, particularly when BCVA is preserved.

Qualitative research, including ethnographic studies, increases our understanding of patient experiences in ways in which quantitative research cannot. In such studies, trained ethnographers visit participants in their home environment to contextualize their lived experience through discussion and observation [14]. Ethnographic methods have been used in healthcare to gather qualitative data on factors affecting patient behavior and response to medication (e.g., patient factors that determine adherence to medication against human immunodeficiency virus [15] and identification of patient barriers to participation in oncology clinical trials [16]). These data enable healthcare professionals to develop primary care strategies that focus on patient welfare beyond symptomatic management of the disease, thus increasing patient confidence and cooperation.

There are no ethnographic studies on GA in the current literature. Consequently, the lived experience of GA secondary to AMD is not well documented or understood. To our knowledge, this is the first ethnographic study to be conducted on GA, based on subjects from the United States, the United Kingdom, and Germany. The aims of this study are to improve our understanding of the lived experience of the disease, improve our knowledge of its functional impacts, and address a gap in patient-focused research in GA.

METHODS

Study Design

This was a cross-sectional ethnographic study that characterized the lived experience of GA

through observation and semi-structured interviews of subjects in their home environment.

Face-to-face interviews were conducted by trained, experienced ethnographers who spent up to 6 h in each subject's home. All interviews were conducted in the local language, and data were collected via video recordings and field notes.

The study was approved by independent review/ethics boards for conduct in the United States, Germany, and the United Kingdom, prior to the recruitment of subjects. The study was conducted according to the Declaration of Helsinki. Written informed consent was obtained from all subjects (with assistance from caregivers if needed due to reading difficulties) prior to the start of the interviews.

Subjects

The BCVA letter score for each eye was measured by the referring ophthalmologist prior to enrollment in the study. Study subjects were enrolled if they had a definitive diagnosis of bilateral GA secondary to AMD, including the presence of drusen; a GA lesion size of at least one disc area (equivalent to approximately 2.54 mm^2) in the better-seeing eye (in the clinical opinion of the referring ophthalmologist); typical visual symptoms, such as difficulty with reading, recognizing faces, driving, or seeing at night or in reduced light; and consistent interaction with the healthcare team (in the opinion of the healthcare team). There were no specific criteria for the inclusion of subjects based on BCVA in either eye, but the target within each country was to obtain a mix of subjects with a BCVA of 20/100 or better and a BCVA worse than 20/100 in the better-seeing eye.

Subjects were excluded if there was evidence of current or prior choroidal neovascularization in either eye, or any other ophthalmological diagnosis that could confound the diagnosis or assessment of reduced visual function related to GA secondary to AMD; if they were living in an assisted-living environment; or if they had been diagnosed with dementia, Alzheimer's disease, or any other debilitating condition.

Outcome Measures

Each interview session with the ethnographer followed a semi-structured guide, with questions focusing on the subjects' daily routines and challenges associated with their routines as a consequence of deterioration of visual function. The discussion guide included questions relating to the subjects' ophthalmologic history (when they noticed visual function decline as a result of GA), activities of interest, changes to daily routine as a result of GA, treatment experiences, and interactions with their doctors. The subjects were also interviewed about the impact of visual function decline on productivity, social life, and its emotional impact.

At the end of the interview, subjects were administered the 25-Item National Eye Institute Visual Function Questionnaire (NEI VFQ-25), a patient-reported outcome measure designed to assess vision-related quality of life and vision-related functioning in patients with low vision [17]. The NEI VFQ-25 includes 25 vision-related core items, one general health item, and 13 optional vision-related appendix items, and is scored on a scale ranging from 0 (worst) to 100 (best). A decrease in NEI VFQ-25 score is associated with a decrease in visual acuity [18].

Interviews were video recorded for subsequent transcription and analysis.

Statistical Methods

To analyze each video recording, researchers transcribed and coded the interview while watching the video to detect body language and visual nuances. Coding was guided by established qualitative research methods, including grounded theory (collecting and analyzing data in parallel) and the constant comparative method (constantly comparing and contrasting concepts to inform relationships between data). Individual cases (e.g., unique concepts) were identified and ultimately formed broader categories (e.g., domains), which helped to identify and explain patterns and relationships within the data set (e.g., a conceptual framework) [19].

Analysis was completed using ATLAS.ti v7.5.15 (ATLAS.ti GmbH, Berlin), a software program designed for qualitative data analysis.

Subgroup Analysis

Subjects were categorized into two subgroups based on BCVA in the better-seeing eye: one subgroup had subjects with a BCVA of 20/100 or better and the other subgroup had subjects with a BCVA worse than 20/100. The impact of GA on daily routines and on emotional, financial, social, and physical aspects was explored between the two subgroups.

RESULTS

Ethnographic interviews were conducted for 16 subjects, with an overall mean age [± standard deviation (SD)] of 80 (± 7.28) years. The distribution of subjects across countries was $n = 5$ (31.3%) in the United States, $n = 5$ (31.3%) in Germany, and $n = 6$ (37.5%) in the United Kingdom (Table 1). The majority of the subjects were female ($n = 10$; 62.5%). Ten subjects (62.5%) had a BCVA of 20/100 or better in their better-seeing eye, and five subjects (31.3%) had a BCVA worse than 20/100 in their better-seeing eye. BCVA was unknown in one subject (6.3%) due to an illogical/out-of-range reported score; therefore, the subject was not included in BCVA subgroup analyses. The mean (SD) NEI VFQ-25 composite score was 67 (± 17) on a scale of 0 (worst) to 100 (best), while a mean score of < 60 was obtained for general vision and both near and distance activities. Mean (SD) driving score was the lowest, at 22 (± 32).

Ethnographic Results

A total of 35 individual impacts of GA, or "concepts," were reported by the 16 subjects. Concepts reported by more than two subjects were categorized into the following broad domains: ADL, emotional, financial, social/leisure, and physical (Fig. 1, Tables 2, 3).

Table 1 Demographic data

Characteristic	Total sample ($n = 16$)
Age, years	
Mean (SD)	80 (7.3)
Range	67–96
Sex, *n* (%)	
Female	10 (62.5)
Male	6 (37.5)
BCVA in the best-seeing eye, *n* (%)	
20/100 or better	10 (62.5)
Worse than 20/100	5 (31.3)
Unknown[a]	1 (6.3)
NEI VFQ-25 score, mean (SD)[b]	
General health	66 (15)
General vision	57 (18)
Ocular pain	83 (21)
Near activities	53 (26)
Distance activities	58 (24)
Social functioning	82 (23)
Mental health	74 (18)
Role difficulties	65 (26)
Dependency	81 (23)
Driving[c]	22 (32)
Color vision	89 (18)
Peripheral vision	64 (27)
Composite	67 (17)
Country, *n* (%)	
United States	5 (31.3)
United Kingdom	6 (37.5)
Germany	5 (31.3)

BCVA best-corrected visual acuity, *NEI VFQ-25* 25-Item National Eye Institute Visual Function Questionnaire, *SD* standard deviation

[a] Illogical/out-of-range BCVA value reported by subject

[b] NEI VFQ-25 is scored on a scale ranging from 0 (worst) to 100 (best)

[c] Driving subscale $n = 11$; not applicable for five subjects

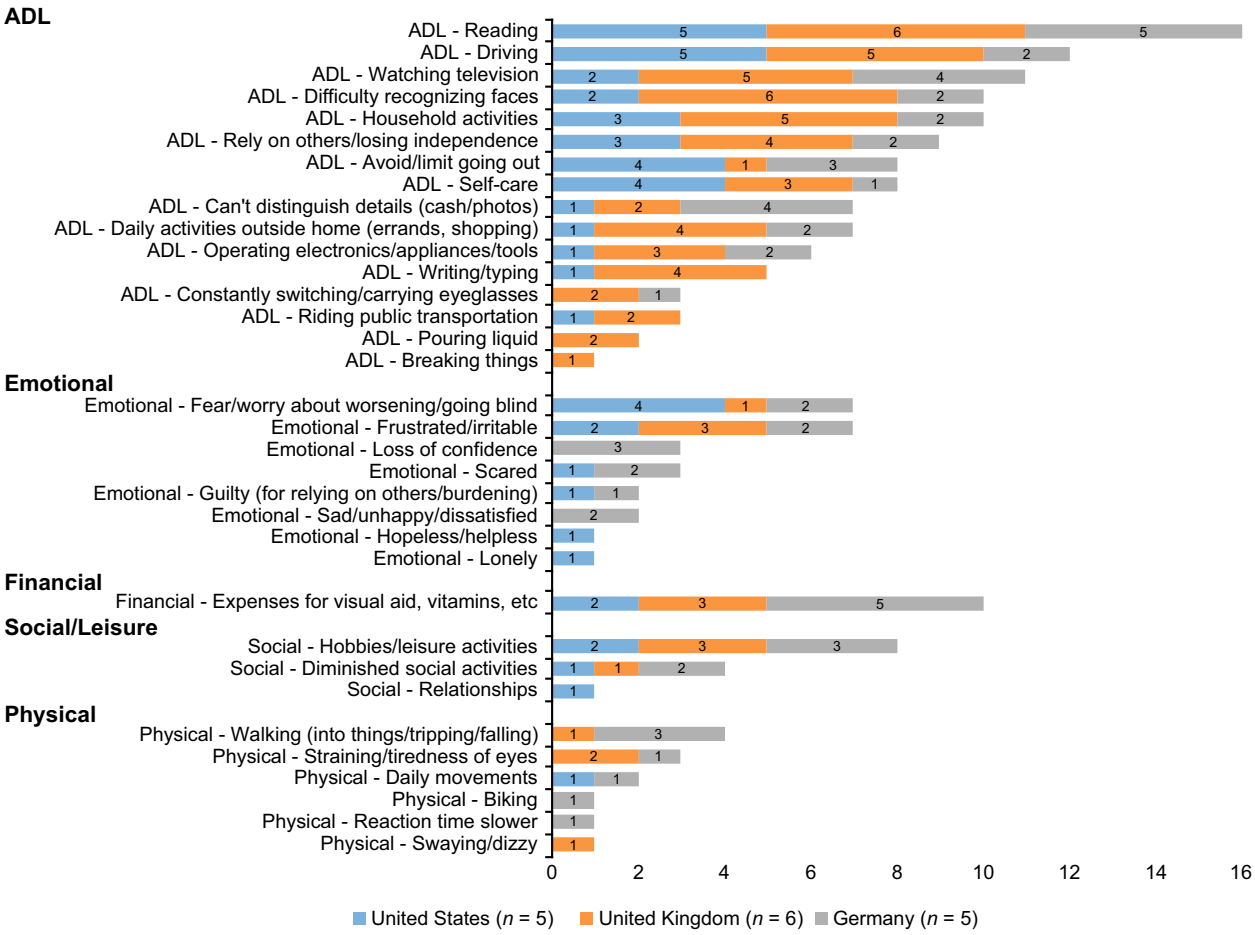

Fig. 1 Number of subjects reporting a significant negative impact of geographic atrophy. Individual functional impacts of geographic atrophy, or "concepts," were categorized into domains as shown. Figure shows domains affecting more than two subjects. *ADL* activities of daily living

Impact of GA on ADL

The ADL domain contained the greatest number of individual concepts (16) and included any routine activities that subjects typically performed, such as reading, driving, activities inside the house, errands outside the house, paying bills, and hygiene-related self-care. The most frequently reported ADL concepts were difficulty in reading ($n = 16$; 100.0%), driving ($n = 12$; 75.0%), and watching movies, television, or theater ($n = 11$; 68.8%). Subjects also reported loss of independence ($n = 9$; 56.3%), difficulty recognizing faces ($n = 10$; 62.5%), and difficulty performing household activities (e.g., chores, cooking; $n = 10$; 62.5%).

Emotional Impact of GA

The most prevalent concepts in the emotional domain were the fear of worsening vision and of going blind ($n = 7$; 43.8%), and being frustrated or irritable due to difficulties experienced with simple tasks ($n = 7$; 43.8%).

Financial Impact of GA

The costs of visual aids, vitamins, insurance, and visits to the doctor were frequently reported in the financial domain ($n = 10$; 62.5%).

Impact of GA on Social/Leisure Activities

Half of subjects reported a negative impact of GA on hobbies and leisure activities, including indoor activities such as playing cards and

Table 2 Categorization of the functional impact of geographic atrophy and the impact of BCVA

Impact domain, *n* (%)[a]	Overall (*n* = 16)[b]	BCVA worse than 20/100 (*n* = 5)	BCVA 20/100 or better (*n* = 10)
ADL (16 concepts)	16 (100.0)	5 (100.0)	10 (100.0)
Emotional (8 concepts)	11 (68.8)	4 (80.0)	6 (60.0)
Financial (1 concept)	10 (62.5)	2 (40.0)	7 (70.0)
Social/leisure (3 concepts)	9 (56.3)	3 (60.0)	6 (60.0)
Physical (6 concepts)	8 (50.0)	2 (40.0)	5 (50.0)

ADL activities of daily living; *BCVA* best-corrected visual acuity

[a] Domains affecting more than two subjects

[b] One subject reported illogical/out-of-range BCVA value in the better-seeing eye and was therefore excluded from subgroup analyses

Table 3 Selected subject quotes relating to geographic atrophy impact domains

Impact domain[a]	Patient quote
ADL	
Reading	"Can't read a menu if it's too small and it's too dark"
	"Real blurry to me… So it takes me forever to read this"
Driving	"Well, horrible that you can't see, you can't drive… You have to depend on other people for taking care of you. You lose your independence"
Emotional	
Fear of going blind	"Because there's a fear creeps into all this… Will I go blind eventually?"
Frustrated or irritable	"Once in a while I get real frustrated when we go out to eat or something. It would be nice to look at it and say, oh, I think I want this"
	"When I'm reading a book that I want to continue to read and then all of a sudden, my vision blurs, then I get… very irritable"
Financial	"The machine actually, it costs about £3000, but I haven't got £3000"
Social/leisure	"I don't do the puzzles anymore. I can't see the pieces good enough"
	"I used to play golf up until a few years ago. But I was having trouble following—once I'd hit the ball I couldn't see where it went, so I needed people with me to help"
Physical	"I tripped over a curb… On the side of the road that I couldn't see"
	"I don't see if the cupboard's open or not… And I will walk into it"

ADL activities of daily living

[a] Domains affecting more than two subjects

sewing as well as outdoor activities such as playing golf, birdwatching, taking photographs, and woodworking (*n* = 8; 50.0%).

Physical Impact of GA

In the physical impact domain, the most frequently reported concept was an impact on

walking due to poor vision (i.e., walking into things, tripping, and/or falling; $n = 4$; 25.0%).

Impact of GA in BCVA Subgroups

When analyzed by subgroups based on a BCVA of 20/100 or better in the better-seeing eye and a BCVA worse than 20/100, there were similarities between the groups; both reported functional impacts of GA in each of the broad functional domains identified (Table 2). Difficulties with ADL were reported by all subjects in both groups, and impacts on the social/leisure and emotional domains were reported by more than half of the subjects in both groups. There were slight differences in the financial and physical domains, with a greater frequency of reporting among subjects with a BCVA of 20/100 or better.

DISCUSSION

This study explored the impact of GA from a patient's perspective through ethnographic methods, in an attempt to understand the functional impact of GA on the daily lives of study subjects. All subjects reported that GA affected ADL—particularly reading; driving; watching television, movies, or theater; recognizing faces; and performing household activities. Most subjects also reported financial and social impacts. These findings were in line with the poor (low) NEI VFQ-25 scores reported, particularly for driving, as well as to a lesser extent general vision and both near and distance activities. However, formal correlations between the ethnography and NEI VFQ-25 are not possible due to the low sample sizes.

It is noteworthy that across all functional impact domains, the frequency of reported visual impact was not related to BCVA score. Reported functional impact across the domains was similar for subjects with a BCVA of 20/100 or better and those with a BCVA worse than 20/100 in the better-seeing eye. Financial and physical impacts were reported slightly more frequently by subjects with a BCVA of 20/100 or better. Such findings suggest that BCVA score may not fully reflect the functional impact of the disease, but because of the small sample size in this analysis, these considerations should be interpreted with caution.

Our findings are consistent with a previous study from Sunness et al. [4], who reported that patients with GA who had a preserved BCVA score without foveal involvement experienced difficulties with reading, low-light adaptation, and other visual tasks.

Qualitative research, such as ethnographic studies, increases our understanding of patient experiences beyond what is gathered through quantitative research. Ethnographic studies provide a rich and more layered qualitative insight into patients' lives. Observations and interviews with patients in their home environment allow for spontaneously elicited answers, helping ethnographers discover impacts that are not covered in closed-ended questions in standardized questionnaires, such as the NEI VFQ-25. Additionally, ethnographic research provides insights into patient behavior in response to the progression of the disease. However, these data are scarce, and the impact of GA from the patient's perspective, particularly with regard to their day-to-day experiences, is not well documented in the literature. Studies by McCloud et al., based on interviews of patients with AMD [20] or neovascular AMD [21], provided insights into patient experiences and anxieties about coping with feelings of profound loss as a consequence of declining visual function, adaptation to physical and psychological limitations as a result of the disease, and patient attitudes toward upcoming intravitreal treatments. However, there was little focus on how patients' daily lives and routine activities were affected, and the research did not capture the unique impact of GA. Ethnographic studies, such as the preliminary study reported herein, provide healthcare providers with deeper insights into the impact of GA on the daily lives of patients beyond that of visual acuity impairment. Such data also may prove to be useful in evaluating the potential benefits of emerging treatments for GA from a patient's perspective. The impact of GA and potential future treatments on patient daily lives is not currently well understood, particularly when BCVA is preserved.

Limitations

This study was limited by a small sample size, particularly when subjects were classified into subgroups based on BCVA score. As a result, no statistical inferences could be made. Comorbid conditions (e.g., depression, arthritis) could confound these results. Subjects may have had different living conditions (e.g., availability of an informal caregiver, access to visual aids) that could influence the type of impact reported. Another limitation was that this study did not capture the subjects' clinical phenotyping data to assess the sizes and locations of GA lesions, so it was not possible to explore the relationship between the reported functional impact of GA and the extent of foveal involvement. Additionally, the cutoff for defining the BCVA subgroups (i.e., 20/100 or better and worse than 20/100 in the better-seeing eye) was arbitrary, and may not have fully captured the correlation between the functional impact of GA and BCVA score due to the small number of subjects in the study. Finally, the correlation between NEI VFQ-25 scores and ethnography findings was not explored, given the lack of an adequate sample size for quantitative analyses, as well as the use of closed versus open-ended questions in these assessments.

Despite these limitations, this hypothesis-generating study provides a first step in understanding the lived experience of GA from the patient perspective. An area for future research is the assessment of longitudinal data to determine how GA impacts daily functioning as the disease progresses or is successfully treated by a future therapy.

CONCLUSIONS

In summary, understanding the patient's perspective is an integral part of defining the functional impact associated with GA and the potential benefits of future treatments. To our knowledge, this is the first study to explore the impact of GA from a patient's perspective via ethnographic methods. Our findings illustrate the value of qualitative research in gaining a deeper understanding of how GA negatively impacts many aspects of patients' daily lives, including ADL as well as emotional, financial, social, and physical aspects. The emergence of common themes across subjects in this study will help inform patient-centered care for GA and identify endpoints for measurement in larger quantitative studies to further improve our understanding of the impact of GA on patients.

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Compliance with Ethics Guidelines. The study was approved by independent review/ethics boards for conduct in the United States, Germany, and the United Kingdom, prior to the recruitment of subjects. The study was conducted according to the Declaration of Helsinki. Written informed consent was obtained from all subjects (with assistance from caregivers if needed due to difficulty with reading) prior to the start of the interviews.

Data Availability. Data sharing is not applicable to this article as the data described in this study are derived from the analysis of videos with patient interviews in their native language and their transcripts by coding.

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