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Impact of living with a bilateral central vision loss due to geographic atrophy— qualitative study

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ABSTRACT

Objective Geographic atrophy (GA), a type of dry age-related macular degeneration, affects vision as central vision loss (CVL). The challenges faced due to bilateral CVL in activities of daily living and strategies taken to overcome those challenges are not very well understood in the Indian population. This qualitative study aims to understand the impact on everyday life activities and related adaptive and coping strategies in people with long-standing bilateral CVL due to GA in India.

Design, participants, setting and methods A qualitative study using a semistructured face-to-face interview was conducted on 10 people with bilateral CVL after obtaining written informed consent. The interviews were audio-recorded, and were transcribed verbatim. Thematic analysis was carried out to understand the challenges faced and adaptive methods due to the impact of CVL.

Results Ten participants (50% male) with a median age (IQR) of 72 (70, 74) years were interviewed. All the participants had best-corrected visual acuity of ≤6/60 in the better eye and reported an absolute central scotoma with the home Amsler chart. Qualitative thematic analysis identified four main themes: challenges in everyday living (difficulty in face identification, reading), challenges with lifestyle and socialisation (driving, cooking, reading for a longer duration, watching TV, socially inactive), psychological implications (depression, poor self-esteem, fear due to poor vision) and strategies to overcome the challenges (voice identification, technology support).

Conclusion GA has a severe negative impact on the quality of life in people with CVL. Inability to recognise faces was the main reason for dependency on others and being socially disconnected. The findings will help clinicians in providing improved rehabilitative care.

Strengths and limitations of this study

► Qualitative research helps understand patients' living experience with poor central vision and offers more insights to improve rehabilitation.
► All participants had a longer duration of bilateral central vision loss that helped us understand challenges in daily life and adapted coping strategies.
► Only 10 participants were interviewed; other eligible participants were not ready to participate or did not live where we could access them readily.

INTRODUCTION

Dry age-related macular degeneration (AMD) is the third most common cause of irreversible blindness among the geriatric population. The global prevalence of AMD is 1.8 million by 2020,[1] and it is estimated to increase up to 10 million people globally by 2040.[2][3] Unlike wet or neovascular AMD (nAMD), geographical atrophy (GA) is a version of dry AMD that leads to a gradual, progressive loss of visual function developing as central vision loss (CVL).[4][5] There is no clear treatment available for GA, unlike nAMD.[4] While multiple studies have described the patient-reported experiences with nAMD using qualitative,[6-10] and mixed research methods,[11][12] describing the impact of nAMD on daily living activities (reading speed, household works) and emotional status,[6][9][10] only a limited number of studies have explored the lived experiences of people suffering from GA, and its impact on their quality of life and daily living. Due to the chronic nature of dry AMD leading to gradually deteriorating visual functions and the fact that the patient has to learn to cope with the remaining vision over a longer period, it is possible that there are different barriers and coping strategies that affect people with geographic atrophy (GA) in dry AMD compared with wet AMD.

An ethnography study on patients with GA by Sivaprasad *et al* (2019) reported negative impacts on activities of daily living (ADL), emotional, social, physical and financial support.[13] Another study by Taylor *et al* (2020) identified various other themes, including the psychological impact of diagnosis, visual loss and coping strategies.[14] These studies describe the patients' experiences in developed countries. The infrastructure and lifestyle or social living patterns are different compared with many developed countries. No data exist for developing countries, and it is likely that differences may exist due to

variations in culture, living situations, access to healthcare and socioeconomic status.

Patient-reported outcome measures (PROMs) are often used and recommended to assess the impact of disease in clinical practice and clinical trials.[15] However, validated PROMs are not readily available to study the impact of GA on daily living and adopted coping strategies, particularly in the Indian population.[16 17] In addition, a qualitative approach rather than quantitative enables one to explore factors based on answers to questions that may not be included in questionnaires.[18]

To date, very little research has been conducted on the impacts on daily living and associated adaptive strategies in people with established bilateral CVL due to GA in India. This study will expand our knowledge and understanding of the functional impacts of bilateral CVL and explore the different adaptive and coping strategies using qualitative methods.

METHODOLOGY
Study design
A cross-sectional, qualitative study was conducted using semistructured interviews between May 2019 and July 2019 in India. Face-to-face in-depth interviews were conducted based on a thematic descriptive approach. The semistructured interview guide was developed after reviewing literature and qualitative research work that explored the lived experiences of patients with dry AMD or GA. Experts in ophthalmology (retina specialist), optometry (low vision rehabilitation) and a social scientist peer-reviewed, refined and approved the interview guide. The interview guide had four major themes: (i) challenges encountered with ADL, (ii) adaptations or efforts to overcome the challenges, (iii) sustainability of the adaptations and (iv) unresolved challenges and barriers. A copy of the interview guide used to conduct semistructured interviews is provided as online supplemental file 1.

Sampling and recruitment
Electronic medical records of a low vision care clinic, Sankara Nethralaya, Chennai, India (SN-LVC) were reviewed for patients who attended clinics between January 2009 and June 2019. Inclusion criteria were as follows: patients diagnosed with bilateral GA secondary to dry AMD, those who could communicate in English or Tamil and those who lived in and around Chennai. Exclusion criteria were as follows: patients aged <65 years, those treated for choroidal neovascular membrane or nAMD in either eye, or presence of any other eye diseases. Purposive sampling was carried out to achieve good representation in gender, age, duration of GA and severity of dry AMD. Fifty eligible participants were identified from the SN-LVC database and contacted by investigators (GM and RR) by telephone. All the participants were given clear instructions about the study. Ten participants gave consent to participate in the study. A significant number had migrated or were deceased.

Ethical considerations
The study protocol was approved by the Institutional Research Board (Ethics Committee 760–2019P) of Vision Research Foundation, Chennai. The protocol was registered in the Clinical Trials Registry of India (CTRI/2019/02/017773) before recruiting participants. The study was carried out in accordance with the Declaration of Helsinki. The study procedure was explained, and written informed consent was obtained from all the study participants.

Study setting and data collection
The study was conducted in an urban and semiurban population of south India. Face-to-face interviews were conducted with individual participants at their residence in English or Tamil language. The interviews were conducted by the first author (GM), who has 6 years of clinical and research experience in optometry. The researcher is trained in qualitative research protocols. The interviews focused on understanding the difficulties faced due to poor central vision and how people adapt to compensate for the visual challenges for ADL. A total of 10 interviews were conducted; the data saturation was observed with the eighth interview. However, additional two interviews were conducted to ensure data saturation.[19] All the interviews were audio-recorded. The average duration of the interviews was between 25 and 35 min.

Data analysis
All the individual interviews were transcribed verbatim by the first author (GM), fluent in English and Tamil. Thematic analysis was performed to examine the living experiences and adaptive strategies following bilateral vision loss.[20] The analysis was carried out in the following steps: (1) familiarising with the data, (2) deductive and inductive coding of the data, (3) summarising the codes to develop subthemes and themes and (4) recoding, reviewing and renaming the themes according to the key aspects of the research questions.[21] Agreement between the emerging themes and subthemes was discussed with the authors (SVR, SP and RR) before confirming the final categorisation of themes. This achieved internal validity and investigator triangulation.[22] The data were further analysed using a computer-assisted software programme, Dedoose V.8.3.47 (2021).[23]

Patient and public involvement statement
Patients and the public were not involved in the study's design, recruitment, or conduct.

RESULTS
Sample characteristics
Ten participants took part in the interview, of which 50% were males. The median age (IQR) of the participants was 72 (70, 75) years. The mean (SD) duration of vision

Table 1 Clinical characteristics (n=10)

		Number of patients	%
Gender	Male	5	50
	Female	5	50
Age range (70–75 years)	<75 years	7	70
	≥75 years	3	30
Duration of vision impairment range (8.5–10 years)	8 years	3	30
	9 years	2	20
	10 years	3	30
	12 years	2	20
Distance BCVA (binocular)	=6/60	4	40
	<6/60	6	60
Near BCVA (binocular)	≥N24	5	50
	≤N36	5	50
Comorbidities	DM + HTN	3	30
	HTN	4	40
	Nil	3	30

BCVA, best corrected visual acuity; DM, diabetes mellitus; HTN, hypertension.

impairment due to GA was 9.5 (1.3) years. All participants had best-corrected visual acuity of ≤6/60 for distance (moderate-to-severe vision impairment)[24] and N20 for near binocularly or in the better eye. All the participants reported having an absolute central scotoma on the home Amsler chart. The participants' clinical characteristics and demographic details are shown in tables 1 and 2, respectively.

Impacts of poor central vision
Four overarching themes were identified: challenges in everyday living, challenges with lifestyle and socialisation, psychological implications and strategies to overcome the challenges. A comprehensive overview of the themes related to participants' challenges due to impaired central

Table 2 Demographic details

		Number of males	Number of females
Occupation	Retired	2	2
	Homemaker	–	2
	Unemployed	2	–
	Self-employed	1	–
	Employed	–	1
Source of income	Dependent	2	2
	Independent	3	3
Living situation	Joint family	4	3
	With partner	2	–
	Living alone	–	1

vision is illustrated in figure 1. The main quotations are discussed here, and other supporting quotes are provided in online supplemental file 2.

Theme 1: challenges in everyday living
Most participants reported central blurred vision for distance and near as a major challenge in ADL. All the participants reported having trouble in identifying faces at far and near distances and in poor lighting conditions and crowded places. Identifying street signs and bus numbers was also reported as a challenging task:

> Very difficult to find someone's face especially when they are far and if it's dark…Unfamiliar faces are hard to find… In recent times, I was not able to identify my in-law's face, whom I have seen for the last 30 years…

Reported challenges due to poor near vision were the inability to read easily, writing difficulty, mainly signing documents or a cheque book. All the participants reported that reading newspapers, religious texts, and magazines were challenging:

> I am having trouble reading even the biggest letters in the newspapers and books…

Many participants reported being less able to move freely and having to be more dependent on others to perform daily life tasks:

> Bus numbers I can't see anymore. I have to ask someone who is standing next to me. Same for finding the street signs and names of the stores…

Some reported that handling smartphones with touch sensors was difficult compared with older mobile phones. Others described that reading the medicine names was difficult:

> It's a tough job to read the name of the medicine when my physician changes it…

Being dependent on others to perform ADL was reported as another critical challenge. Independent lifestyle and mobility were reported to be less difficult:

> Mostly I am independent, but sometimes I become dependent when I go out like crowded places, public places…unknown places I need help…

Theme 2: challenges with lifestyle and socialisation
Participants reported reading magazines or religious books, and watching television to be the major leisure disconnects:

> I used to be a voracious reader. I have almost stopped reading the newspaper or religious books…

Almost half of the participants reported that cooking was the second major leisure challenge:

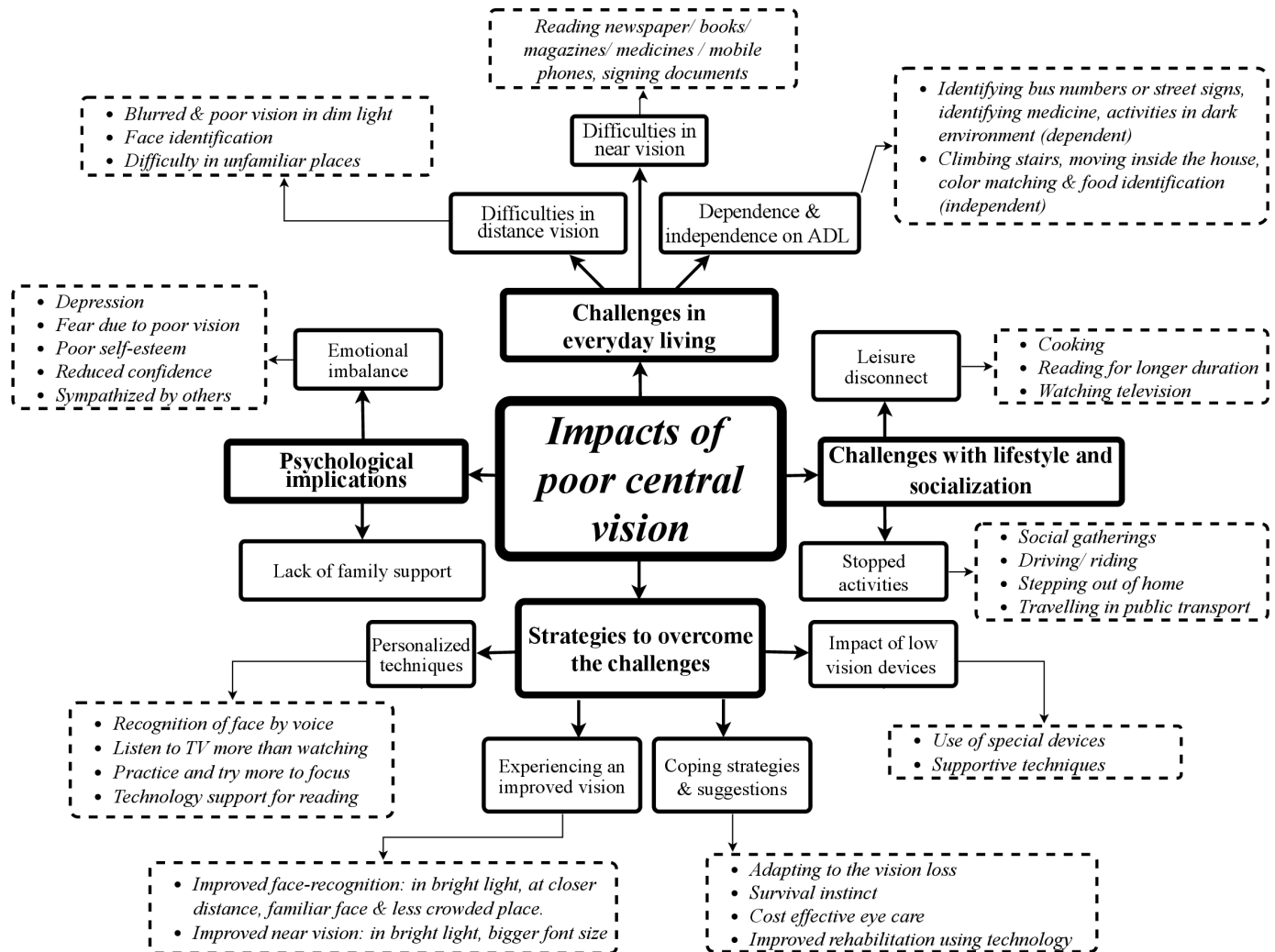> Oh yes, cooking now has become very difficult in the last couple of years…I used to cook for around 180

Figure 1 A comprehensive overview of the themes related to participants' challenges due to impaired central vision. ADL, activities of daily living.

people. But now see, I can't even cook for myself, which is a shame…

Few shared that they lost the social bond with friends and relatives and had difficulty in face recognition, so they avoided social gatherings:

I lost my social life completely…I am not going out to meet my friends because I am not able to find their face…

Poor central vision had stopped various activities for many participants such as driving, cycling, outdoor activities, and using public transport:

I don't drive nowadays. I can't drive anymore. Very rarely I take my bicycle and go to shops, and only in day time…

Theme 3: psychological implications
Challenges in everyday living had affected most people psychologically. Most emotional imbalances were depression, fear of poor vision, poor self-esteem, reduced confidence and sympathised by friends and relatives:

I feel so depressed about my vision. It has put me down in many ways…

Most reported limited support from family members for activities of everyday life, travel, and support:

They help me to an extent …Nowadays, my points are not considered in the family because they feel I'm a burden. I keep myself silent…

Theme 4: strategies to overcome the challenges
Most participants adopted various strategies to overcome the challenges faced due to poor central vision. These included face recognition by voice, listening to television instead of watching it, taking a long time to focus, and using technology for reading:

Nowadays, I try to identify faces by using their voices and some facial features…

Improved face recognition was facilitated by better lighting and moving closer to people. Also, familiar faces were better recognised in less crowded places.

Bright light is better…When they come closer, I can a see little…

Participants reported improved near vision with better lighting condition and bigger font size: all participants used some form of spectacle glasses or low-vision devices, with around half of them reporting that the devices helped them perform challenging tasks (such as reading):

I have my small device prescribed at one of the low vision centres to read out printed documents…

Two participants reported that the devices were not very useful:

Helps me to an extent, but even that is not a user friendly…

A few participants reported adapting to their vision loss by survival instincts:

Survival instinct is also a major factor that drives me. It isn't easy to define it. I have to live, so when I live, I have to do certain things. So, I feel it's the survival instinct. I don't want to sit in a corner and weep. No and never…

Few participants suggested that cost-effective, improved eye care and rehabilitation would help deal with the challenges:

I feel handheld devices for text to speech need to be developed for the elderly for ease of use. No need for high-level technology; it should be as simple as possible. Only devices, not applications, which helps to find the name or identify a product in the grocery shop…

DISCUSSION

This study explored the impact of living with a bilateral CVL from a patient perspective through qualitative research to understand their challenges in daily life and adaptation strategies to meet those challenges. Key findings suggest that participants have trouble in recognising faces, reading books or newspapers in poor lighting conditions, and relying on others to perform daily tasks. Strategies adopted by participants to address various challenges included face identification by voice recognition, listening rather than watching television and use of low vision devices for reading. In addition, participants were more able to identify faces in lower crowding environments. Difficulties in leisure and social domains included cooking, reading for longer, watching television, driving and using public transport. Participants faced emotional impacts including depression, poor self-esteem, lack of confidence and decreased self-independence.

Our study results are consistent with the themes identified in previous studies. Sivaprasad et al's (2019) study on patients from developed countries reported that people with GA had difficulties with reading, driving, watching TV associated with feelings of frustration and fear, reduced social activities and financial difficulties.[13] In addition, we report additional challenges in ADL, such as difficulty in identifying bus numbers and street signs, working in dim light and commuting independently using public transport in people living in India.

Taylor et al (2020) reported the psychological impact of diagnosis, effects of visual loss and managing strategies by patients with GA.[14] While some of these were similar to our findings, we report on additional strategies adopted by participants, such as using auditory cues to recognise faces, find someone and gather information.

Surprisingly, the use of low-vision devices was not widespread, and participants reported that these were not supportive enough to meet their challenges. This is different from the findings of previous studies,[13 14 25] and it may be that our participants may have developed other customised methods including improved hearing ability and taking a longer time to focus to overcome challenges.

Poor face recognition has been previously reported as the leading cause of reduced social interaction,[26] a finding consistent with our results. Unlike financial constraints reported by Sivaprasad et al[13] to acquire low vision devices, our participants did not report this, and it may be that they used low vision devices that were comparatively less expensive.

Although a study by Sivaprasad et al (2018) showed good internal validity and reproducibility for National Eye Institute 25-Item Visual Function Questionnaire for people with GA,[17] the validity was assessed only for reading scores with MN read charts and patient-reported Functional Reading Independence index. The other domains (eg, social function, mental health, dependency, driving) have not been validated among people living in developed or less developed countries, and our results might be helpful in the development specifically for dry AMD PROMs. We suggest future studies to validate the existing PROMs on dry AMD in developing countries such as India as cultural, language and social barriers may be quite different.

All our participants had lived with bilateral CVL for over 8 years which enabled us to understand the long-term adaptations to ADL. We chose to do face-to-face interviews over focus group discussions (FGDs) because all the participants were over 70 years of age and had severe visual impairment. Also, most participants (70%) were not willing to travel to participate in FGDs. Furthermore, face-to-face interviews at their homes helped us understand the living conditions and capture their emotions in their own comfortable environments.[13 27]

There are a number of limitations of our study. We interviewed 10 participants. This is accepted in qualitative studies.[27–29] In future, it may be important to explore the impact of both dry and wet AMD with increased sample size. Although we have suggested a need for a larger study, it is a challenge to recruit participants with bilateral CVL. Many eligible participants were not ready to participate as they did not live in the city, and many were deceased

because of age; so only residents living in the urban and quasi-urban areas were recruited. Participants living in rural areas (40%) and those not willing to participate (20%) due to various reasons were not recruited, leading to the low response rate. However, the small sample size does not detract from the useful findings of this study. Although purposive sampling was attempted, this was not as successful due to the many barriers in patient recruitment. The age range and duration of vision impairment was limited in our study; the range for duration of vision impairment was 8.5–10 years and the age range was 70–75 years. In future, it would be useful to extend these ranges to obtain a more comprehensive profile of the barriers influencing the quality of life in participants with GA.

The progression of vision loss in wet AMD is much faster than dry AMD, it may lead to the need for different adaptation time and methods to meet the challenges of CVL. Hence, we focused on only one type of AMD to avoid potential confounds owing to possible heterogeneity in data, because of which also the sample size was relatively small. Lack of formal patient and public involvement at the start may have limited the inclusion of more domains to the conceptual framework before developing the interview guide; however, this was reviewed by researchers and clinicians working with low vision patients who reviewed and agreed on the interview guide beforehand. Despite these limitations, our study provides insights into understanding patients' problems in ADL and adopted CVL management strategies.

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