MAC-You-Vision: A Progressive Training Application for Patients with Age-Related Macular Degeneration

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***Abstract* – Age-related macular degeneration (AMD) causes damage to the macular, leading to gradual and non-reversible loss of central vision and, in some instances, legal blindness. It is the leading cause of vision loss for adults aged 60 and older. As of 2019, 19.8 million people in the US had some form of AMD. Currently, there are technologies that assist those with visual impairment, but most are aimed at helping those who are already blind. Therefore, we implemented MAC-You-Vision, a progressive training application that tackles two main challenges: (1) how to enhance the livelihood of patients at the current stage of AMD and (2) how to prepare patients for vision loss that may occur in the future as the disease progresses. Our application is not only able to address patients' concerns at any stage of the disease, but it will also keep offering unique features as the disease progresses. User evaluation indicates that our application is a comprehensive platform for AMD patients.**

Keywords— macular degeneration, augmented reality, assistive technology, eye movement training, oculomotor control training, low-vision, low-vision rehabilitation, blind, visual impairment.

I. INTRODUCTION

The leading cause of vision loss for adults aged 60 and older is age-related macular degeneration (AMD). AMD has been estimated to affect one in 30 individuals older than 52 years and one in three individuals older than 75. In a recent study in 2019, up to 19.8 million people (12.6%) aged 40 and older in the United States are affected by AMD [1]-[2]. The disease and accrued vision loss are non-reversible. Currently, there exist technologies that aim to assist patients with visual impairment. However, most of these assistive technologies are geared toward helping those who are already blind. Many technologies designed for AMD patients are expensive and do not remain beneficial to patients once vision loss increases as the disease progresses.

In this paper, we propose and implement a comprehensive application, ***MAC-You-Vision***, specifically tailored to help AMD patients from diagnosis through each stage of the disease. MAC-You-Vision is a mobile/tablet application designed for AMD patients that tackles two major challenges: (1) how to enhance the quality of life of patients at their current stage of AMD; and (2) how to prepare them for vision loss that may occur in the future as they proceed to the next stage of the disease. These are also the primary contributions of our work. Our platform is organized into three stages, corresponding to the three stages of AMD: Early, Intermediate, and Late. Throughout the stages, we incorporated key features such as eye movement and oculomotor control training, text-to-speech, augmented reality adaptation, discussion forums, referral options to related professionals, and educational and informational pages. Five patients with AMD or related central vision disease participated in our study (with a mean age of 70.8 and ranging from 54 to 85 years).

This paper is organized as follows. In Section II, we provide a brief discussion of the disease background and relevant eye movement and oculomotor control training studied in the existing literature. Section III explains the design and implementation of the stages in our application. This is followed by the rationale and user evaluation (Section IV), then the conclusion (Section V).

II. RELATED WORK

A characteristic symptom of AMD progression is the gradual loss of central vision (causing blind spots - scotomas).

As this occurs, patients increasingly rely on their peripheral vision (sight outside the central field of vision). A progression of scotoma size can cause decreases in visual acuity and other difficulties that impact a patient's functioning in daily activities. For example, a study by Taylor et al. (2017) examined how patients performed visual searching in computer-based "real-world" and "everyday" tasks, such as identifying a street name on a photograph and pointing at a landmark on a map. These authors reported that AMD patients experienced limitations in their visual search and scanning abilities [3]. Similarly, Higgins et al. (2020) reported that patients took longer to visually search everyday objects and identify road signs [4]. AMD also decreases patients' ability to read. The reading rates of patients with central scotomas can range between 20 to 50 words per minute or lower. This is at least one-third the rate of those without AMD [5].

To counter these problems, Seiple et al. (2005) developed eye-movement-control exercises that increased reading speed for AMD patients [5]. These exercises include preset and random searches, horizontal saccade training, and identification using a moving-window presentation. They found that reading speed increased even though the exercises did not involve direct practice in reading sentences; that is, reading speed can be increased by focusing on eye position and movement practices. In a later study, Seiple et al. (2011) examined various training module types, including those used in typical clinical interventions. They found that eye movement training was the most effective method of rehabilitation - increasing reading speed among patients with AMD compared to other rehabilitation methods [6]. Eye-movement-control training increases reading speed by up to 35%.

III. Design and Implementation

MAC-You-Vision is organized to address the three clinical stages of AMD: Early, Intermediate, and Late (Figure 1). Additionally, all users can use the connect features while accessing the stage-specific features and implementation.

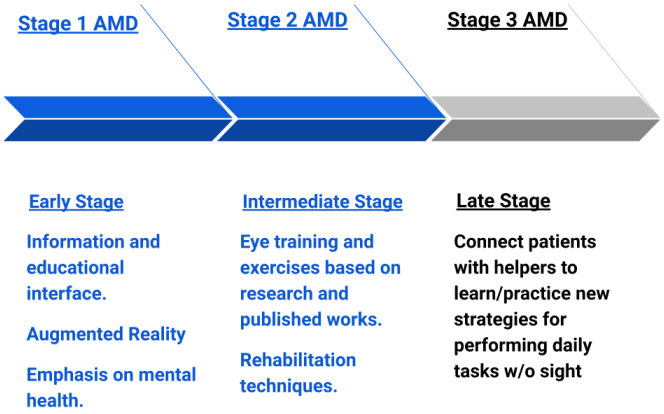

Figure 1: Layout of the key features in MAC-You-Vision. The application is divided into three stages, each corresponding to a stage of AMD.

Stage 1 (Educational interface and augmented reality)

Stage 1 focuses on providing information and support, corresponding to the early needs of patients with early-stage AMD.

Educational interface – Information pages are provided to help patients better understand AMD and to cover essential topics such as: how AMD works and progresses; how previous patients have coped with the disease; and what a person can do to slow progression. The content of these pages is presented in text, external figures, and videos (Figure 2). For example, on the *What to Expect* page, we included images of a patient's visual field through each stage and a reference to a video created by the NIH to complement the text blocks [7]–[11]. A link to ongoing clinical trials is provided through https://clinicaltrials.gov/ at the National Eye Institute [12].

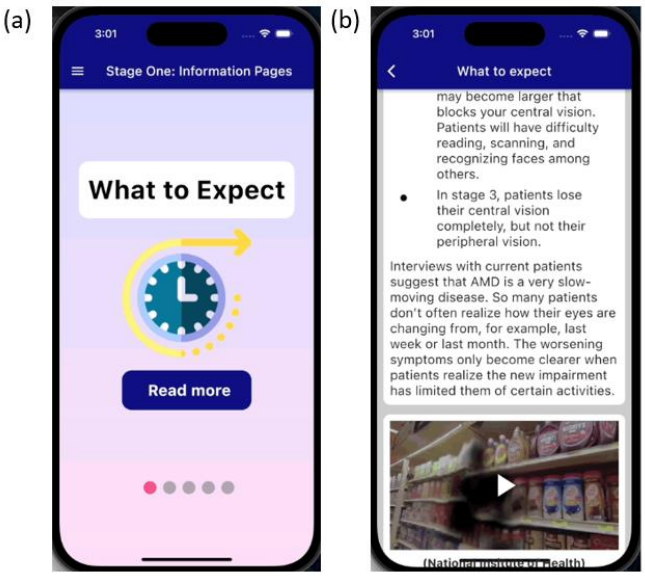

Figure 2: (a) "What to Expect" page is one of the information pages in the educational interface. (b) Part of the "What to Expect" page includes images and external videos.

Adaptation of augmented reality (AR) –We integrated an adaptation of AR technology via Unity into our platform [13]. In real-time, users can move their cameras around, and a "scotoma" is drawn over the center of the image to simulate what it is like to have AMD. The purpose of this demo is to help patients, family members, and the general public to understand what visual field loss is like for late-stage AMD patients (Figure 3).

Page listing support groups and referrals – This single page lists existing support groups at Lighthouse Guild and external organizations to help patients cope with vision loss.

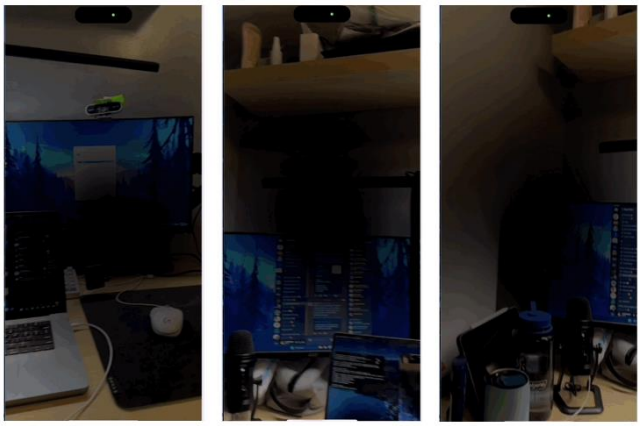

Figure 3: AR implementation used as part of the educational interface in Stage 1 (mobile view). A dark blind is placed at the center of the camera screen to simulate a central scotoma experienced by AMD patients.

Stage 2 (Eye & oculomotor control and rehabilitation training)

Stage 2 focuses on eye movement and oculomotor control training, corresponding to a stage where patients experience moderate vision impairment and larger, non-confluent drusen. Section 4 (Rationale and User Evaluation) further elaborates on their research values and how they were chosen.

Clockwise training – In this training set (Figure 4a), small dots are arranged in a clock pattern with a larger dot at the center of the screen. Patients search and point/click the dot consecutively in a clockwise pattern – a dot disappears when touched. A sound plays as auditory feedback each time the correct dot is touched. The timer starts when the patient touches a dot and stops when all the dots disappear.

Scattered training – This training (Figure 4b) is similar to clockwise training. However, instead of presenting the dots in a specific pattern, the dots are now randomly scattered across the screen.

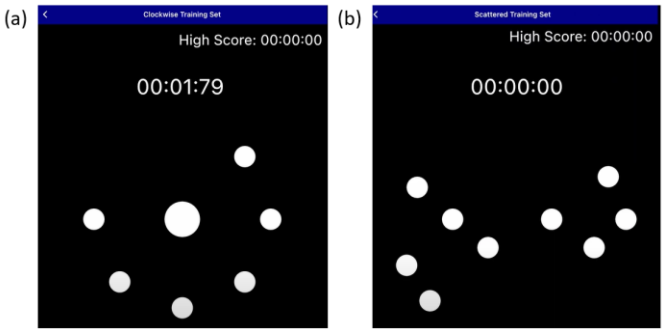

Figure 4: (a) Clockwise training and (b) scattered training set.

Eccentric fixation chart – The chart contains letter sets organized in circular patterns (3 rings, Figure 5). As the screen is filled with letters, patients can use the chart to explore where are their "sweet spots" (*i.e.*, the area in their field of view where they can see best).

Stage 3 (Assisting at the last stage)

Stage 3 corresponds to the Late Stage of AMD. In this stage, dense central scotomas prevent patients from using central vision, and there is significantly altered vision. We designed this stage to continue eye movement training, encourage low-vision rehabilitation, and help patients cope mentally and connect with others with similar experiences living with AMD.

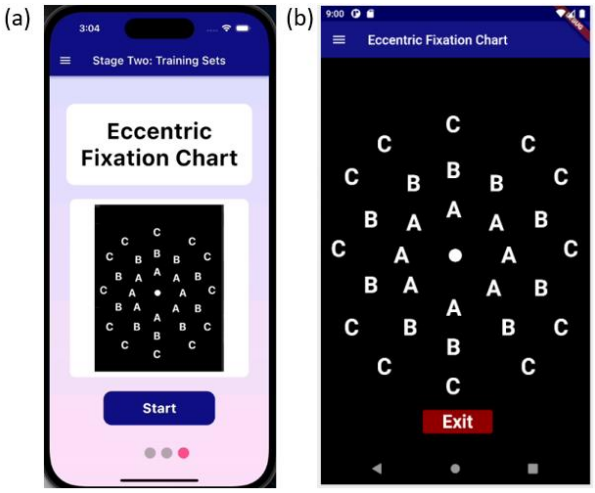

Figure 5: (a) As part of Stage 2, patients can choose the existing training set. Here, the introduction to the eccentric fixation chart is shown. Patients can tap and hold on to the image to listen to a recorded voice describing what the eccentric chart is for. (b) Eccentric fixation chart.

Discussion forum – The discussion forum (Figure 6) connects patients, helpers, volunteers, family members, and other stakeholders. Users can create and like posts and create a thread with comments. This will connect patients with helpers to learn/practice new strategies for performing daily tasks without central vision. Although the discussion forum benefits this stage, users at all disease stages can use it.

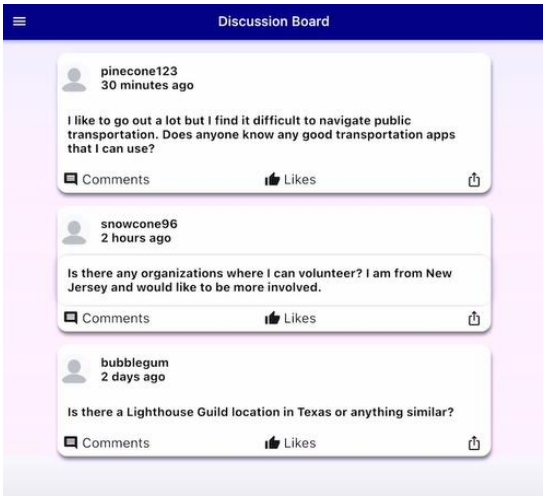

Figure 6: Mockup of the discussion forum.

Other relevant features

We have also designed other relevant features that can be used in all three stages. These include text-to-speech (TTS) and scotoma tracking.

Text-to-speech (TTS) – We implemented a TTS feature that is independent of the built-in option in users' devices. We use a white box framework as the interface to help patients distinguish texts (that many patients cannot see and read) from other parts of the screen. This is done by associating white with text and colors with movement. When patients see a white box, they can tap and hold on to it. The system will then read the text inside that white box.

Scotoma tracking feature – As an ongoing work, we will use the eccentric fixation chart (Figure 5) as the basis to track disease progression over time. Patients can use the scotoma progression tool by pointing to where their blind spots are in their visual field, and this will be recorded for comparison with future testing. This feature will be a self-progression tool for users to track their vision over time (from months to years). This feature is being developed and built based on the eccentric fixation chart.

IV. Rationale and User Evaluation

To assist at the first stage of AMD, where patients have minimal to mild loss of vision and usually near the time of diagnosis, we focused on the patient's mental health and access to information. During the literature review phase of our study, we interviewed two patients with central vision loss (Patients 3 and 4, Table 1). We found that patients were most vulnerable to depression at this stage because they did not fully understand the disease and how it progressed. Therefore, we implemented the educational interface, connect feature, and referrals to low-vision mental health providers to tackle the abovementioned concerns. The purpose of augmented reality (AR) is to further teach patients about the progression of AMD and what vision could be like if the disease progresses. AR simulations, additionally, raise awareness of AMD for the general public and, more importantly, help patients' family members develop an understanding and compassion for the patients.

And while the connect feature is available for use throughout all the stages (Figure 1), patients may find the discussion forum particularly helpful in the first stage, as it can be geared toward helping patients cope mentally and connect with other patients who have the same experience during diagnosis. Additionally, in the future, patients can also utilize our scotoma tracking feature, which is designed to track the progression of the disease in the long-term (scale: months and years). This will not only help family members understand the current symptoms but the patient's ophthalmologist and optometrist may also find such information helpful as well.

We incorporated eye training exercises to assist at the second and third stages of the disease, where patients experience moderate to severe vision. In part, central vision loss is associated with difficulty reading due to decreased eye-scanning efficiency. Therefore, we implemented training exercises targeting the patients' eye movement to enhance search efficiency and reading speed.

Moreover, since our application intends to remain useful to patients throughout the disease progression, we designed a training module requiring only the basic technology they already own (*e.g.*, cell phone or tablet). In our initial interviews, patients reported buying assistive technologies, but after a short time, this equipment was no longer used due to a lack of effectiveness and/or it was longer appropriate due to disease progression.

Interventions at the third stage of AMD are the most difficult to design, primarily because of the consequences of loss of central vision. We included basic features that connect patients with helpers to learn and practice new strategies for performing daily tasks. This stage requires maximum involvement from the community. Therefore, we designed our platform to be usable by the general public and family members, and other stakeholders to help raise awareness and develop understanding.

(a)

Patient	Age (y)	Sex	Cause of vision loss
1	54	F	Macular hole, glaucoma
2	61	F	Stargardt
3	71	F	MD, glaucoma, cataract (removed)
4	83	M	MD
5	85	F	MD, retinal atrophy, glaucoma

(b)

Patient	Current vision	Able to read small texts	Able to read large texts	Able to see light
1	Severely affected	N	N	Y
2	Severely affected	N	Y	Y
3	Severely affected	N	N	Y
4	Severely affected	N	N	Y
5	Severely affected	N	N	Y

Table 1: (a) Characteristics of patients that participated in the user evaluation part of our study (MD = macular degeneration). (b) Patients' current vision.

To guide and assess app development, we performed user evaluations with five patients (four females and one male, with mean age of 70.8) diagnosed with AMD. These participants were proficient users of mobile devices and frequently utilized built-in accessibility features. During the in-person sessions (approximately 1 hour for each patient), we guided the patient through our application on an iPad and allowed each patient to explore all the features. Patient 5's evaluation was conducted via phone.

Overall, we have received positive feedback and support from the patients. Patients reported that the training and eccentric fixation chart helped them find their "sweet spots." For example, Patient 4 described how he could take advantage of the letter cluster in the eccentric fixation chart to find where his vision was the clearest and had the least missing areas for reading texts. During the clockwise and scattered training, many patients had incorrect responses initially, but that training helped them control their eyes to focus on the dots correctly. Patient 3 also suggested gamifying the training set so that the exercises would be more interesting and, more importantly, encourage the daily practice of eye movement.

During the demo, patients could see the text blocks but could not interpret the words. Our text-to-speech feature based on a white-box framework was able to help resolve this problem. Patient 3 reported that the contrast between the white color, which denotes a text block, and other colors (denoting movement) significantly helped with the navigation in the app.

V. Conclusion

MAC-You-Vision is designed to provide assistance and progressive training for AMD patients throughout the disease stages. By organizing the platform into functional stages, we focused on lifestyle adjustments appropriate to the degree of vision loss. This strategy helps patients prepare for potentially more significant vision loss that might occur as the disease progresses and supports patients emotionally. Our work fills the gap left by many current assistive technologies, which use magnification to supplement vision loss for those who are legally blind. Patients have found the clockwise and scattered training and the eccentric fixation chart helpful in practicing spontaneous eye movements and identifying the "sweet spot" in their current visual field. They also have found the connect feature (especially the discussion forum) beneficial when they need emotional support or are seeking/sharing information with other patients. Our approach provides patients with access to these features from their mobile and tablet devices.

In the future, we plan to incorporate additional eye movement and rehabilitation training into our study. We also will extend features by using an external eye tracker. This may add additional costs but will be important by providing feedback loops for eye-movement control. The eye tracker will allow the app to inform the patient of appropriate eye movements during training. Such a feedback-loop system has been studied in optometric research to help patient rehabilitation and will be beneficial to implement in our platform.

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