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AMD Journee: A Patient Co-designed VR Experience to Raise Awareness Towards the Impact of AMD on Social Interactions

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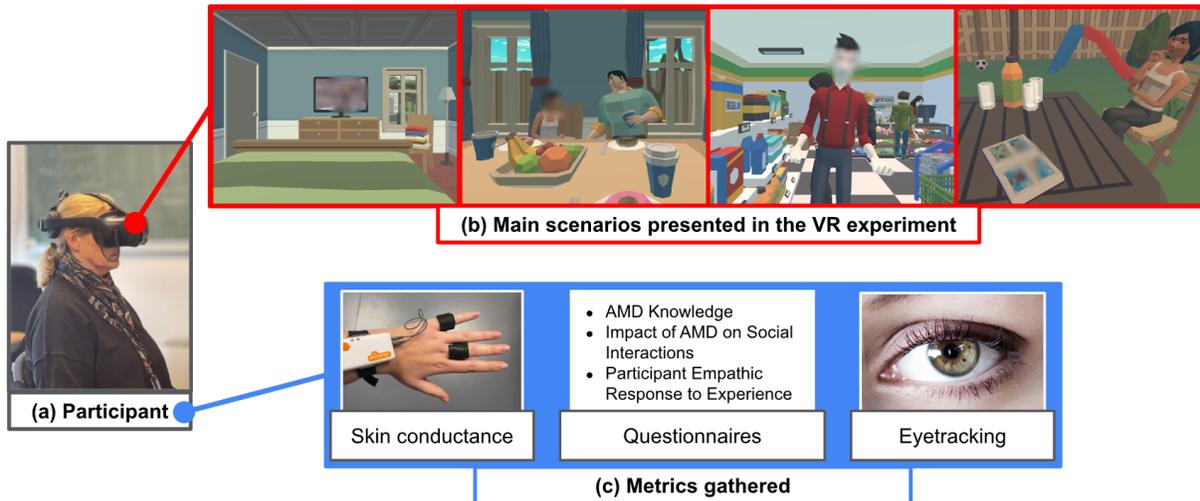


Figure 1: General workflow of the VR experiment: (a) the participant wearing a headset is going through (b) four main scenarios designed to show “what it is like” to live with AMD and interact with others. (c) Multiple types of data on the user experience are collected including skin conductance response, eye tracking, and questionnaires.

ABSTRACT

We present a virtual reality (VR) experience designed to raise awareness towards the impact of low-vision conditions on social interactions for patients. Specifically, we look at age-related macular degeneration (AMD) that results in the loss of central visual field acuity (a.k.a. a scotoma), which hinders AMD patients from perceiving facial expressions and gestures, and can bring about awkward interactions, misunderstandings, and feelings of isolation. Using VR, we co-designed an experience composed of four scenes from the life of AMD patients through structured interviews with the patients and orthoptists. The experience takes the perspective of

a patient, and throughout the scenarios, provides voiceovers on their feelings, the challenges they face, how they adapt to their situation, and also bits of advice on how their quality of life was improved through considerate actions from people in their social circles. A virtual scotoma is designed to follow the gaze of the user using the HTC Vive Focus 3 headset with an eye-tracking module. Setting out from a formal definition of awareness, we evaluate our experience on three components of awareness – knowledge, engagement, and empathy – through established questionnaires, continuous measures of gaze and skin conductance, and qualitative feedback. Carrying out an experiment with 29 participants, we found not only that our experience had a positive and strong impact on the awareness of participants towards AMD, but also that the scotoma and events had observable influences on gaze activity and emotions. We believe this work outlines the advantages of immersive technologies for public awareness towards conditions such as AMD, and opens avenues to conducting studies with fine-grained, multimodal analysis of user behaviour for designing more engaging experiences.

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CCS CONCEPTS

• **Human-centered computing** → **User studies**; • **Social and professional topics** → **People with disabilities**; • **Applied computing** → **Psychology**; • **Computing methodologies** → **Virtual reality**; **Perception**.

KEYWORDS

Virtual reality, awareness, age-related macular degeneration, emotion analysis, gaze analysis

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1 INTRODUCTION

Have you ever heard of the phrase “93% of all communication is nonverbal” [25]? Visual signs play a non-negligible part in our everyday lives, from carrying out social interactions to receiving life-saving information. These signs can involve facial expressions, gestures, or general image and text information all around us. For people suffering from low-vision conditions such as Age-Related Macular Degeneration (AMD), resulting in a scotoma – the loss of visual acuity in the central field vision – the loss of access to these signs can lead to depression, feelings of powerlessness, despair, and even suicidal thoughts in some cases, significantly impacting their quality of life [3, 13]. These visual impairments are not completely correctable through glasses nor surgical procedures, and can only be temporarily halted or slowed down. While AMD is projected to impact over 288 million people by 2040 [34], it is still a largely invisible condition, not only in the appearance of people who suffer from it, but also in the ignorance of the general public on the challenges patients face [19].

With the introduction and popularization of virtual reality (VR) technologies, we can now put audiences “in the skin” of others. VR has been rightly coined as the “empathy machine” for its capacity to trigger deep emotions through strong immersive technologies, as highlighted in the seminal work of Nonny De La Peña when she re-created scenes of hunger in immersive journalism that brought audiences to tears [10]. VR would also be an exciting medium for raising awareness towards low-vision conditions like AMD with gaze tracking technologies to simulate the pathology. While some work has been done to use VR to simulate a virtual scotoma for road crossing studies [28, 35], currently no experience proposes a more realistic characterization of AMD, nor addresses the problem of social interactions from a patient’s point of view.

In this work, we propose *AMD Journee*, a VR application that aims to raise awareness in the general public of the impact of AMD on social interactions with realistic simulations of the pathology. “Journee” plays a pun on the discovery of AMD through a “journey” following a patient’s daily life (“journée” in French). The challenges of this work are threefold: (1) in the design and conception: accurately simulating the scotoma as well as a depiction of real-life

social scenarios that patients encounter, (2) in VR and 3D content: creating dynamic, interactive scenes with a high degree of freedom to move and interact, and (3) in the affective understanding of user experience: evaluating the outcomes and impact of the VR experience with the general public, through both questionnaires and biological responses such as gaze and emotion. Specifically, our contributions are:

- co-designing 4 realistic social scenarios in individual and group interviews with AMD patients, validated by orthoptists
- implementing a blurred scotoma with gaze tracking
- investigating the impact of the experience through a experiment involving 29 participants using a VR headset, with measures of eye tracking, physiology and questionnaires

The remainder of the article is structured as follows. We first provide a positioning of our work in Section 2. We then present our methodology in Section 3 as well as the study design and metrics gathered in Section 4. Finally, we discuss the results in Section 5 and conclude in Section 6.

2 RELATED WORK

In this section we review the relevant work. We first look at studies on the impact of AMD on social interactions of patients. We then review the works related to the understanding and simulation of AMD affects on vision loss. Finally, we elaborate how VR has been previously used for raising general public awareness through scenarios in situ.

2.1 AMD awareness and impact on social interactions

Previous studies highlight a general lack of public awareness of AMD, exacerbating misunderstandings and social challenges faced by AMD patients. Livingston et al. [19] conducted a structural interview where participants were inquired about their awareness and understanding of prevalent age-related diseases, glaucoma, cataract, and AMD. Of the 3166 participants, only 5% knew of the existence of AMD, and only 2% had correct knowledge of AMD. In a different interview by Lane et al. [18], more than 76% of AMD patients with mild to severe vision loss stated that other people don’t understand how AMD impacts their vision. Even more alarming, more than a third of them reported being worried that other people think they are faking their disease. Lane et al. argue that improving the understanding of patient’s experience requires not just awareness of AMD’s existence but a deeper understanding of its symptoms. This recognition and understanding were identified as important factors for social engagement [3].

To our knowledge, a few references exist on vision loss awareness experiments. The interactive French exposition on AMD, “Dans tes yeux”¹, presents a series of 30 photos that depicts the impact of AMD and highlights the crucial support role of relatives for AMD patients. This online experience combines a strong narrative with artistic representations of vision loss. Similarly, “Notes on Blindness: Into Darkness”² by Arte is a VR project on experiencing

¹<https://expo.dmlainfo.fr/> (last access on February 4th 2024)

²<https://www.arte.tv/digitalproductions/en/notes-on-blindness/> (last access on February 4th 2024)

blindness, offering a cognitive and emotional insight. Despite these examples, there is a lack of public awareness experiments that illustrate AMD's impact on social interactions, backed by narrative, realistic and ecologic depiction of vision loss, which we want to address with our experiment.

Marc and Picard [23] defined social interaction as an “interpersonal relationship between at least two individuals through which the behaviors of these individuals are subject to mutual influence, each individual modifying their behavior based on the reactions of the other”. In our work, we focus on face-to-face interactions, where individuals share the same space and exchange verbal and non-verbal signals such as posture, gestures, facial expressions, and gaze direction. This transfer of signals is possible only when individuals can see each other. Cañigüeral and Hamilton [8] emphasize the role of gaze in social interactions. They establish that the direction, duration and behaviour of gaze can carry important social information, such as the emotional state of the individual, the need for attention, the seeking of understanding, and so on. This information goes in both directions, speaker-to-listener and vice versa.

However, when it comes to face-to-face interactions between a normal-sighted individual and an AMD patient, this flow of information is disrupted due to the patient's impaired ability to perceive these non-verbal cues. Activities such as recognizing the identity of a person speaking to them or understanding facial expressions and underlying messages thus become particularly challenging for AMD patients. Lane et al. [18] and Logan et al. [20] discuss how AMD impacts the recognition of faces and expressions, linking these difficulties to the specific challenge in processing internal facial features, such as the nose, eyes, mouth and eyebrows.

2.2 AMD simulation

Macnamara et al. [21] reviewed various AMD simulation methods: contact lenses, computer manipulation, gaze contingent, glasses and others, each of them having their advantages and drawbacks. The gaze contingent method is the most promising method, due to its capacity to align the vision loss with the gaze in real time. With recent technological advancements, gaze-contingent methods can now be integrated into VR headsets equipped with eye-tracking modules. This integration allows for a more ecologic simulation of the pathology while maintaining complete control over the simulation.

However, to our knowledge, most AMD simulators in VR depict vision loss as a black circle with smoothed edges, which does not correspond to the symptom descriptions provided by patients [28, 33, 35]. The work of Jones et al. [15, 16] stands out by offering more accurate representations of vision loss symptoms, not only AMD but also glaucoma, such as blur, distortions and light sensitivity among others. Furthermore, they demonstrate that such vision-loss simulators can impair the performance in various everyday tasks for normally-sighted individuals, mirroring the challenges faced by AMD individuals. However, these studies, primarily focused on understanding the pathology and testing rehabilitation methods for sighted individuals, are not designed to increase public awareness of AMD. Indeed, simulating the visual perception of the pathology is just one aspect of the AMD experience. To fully understand the

experience of AMD, the visual depiction of the condition must be integrated in the context of real-life situations experienced by patients.

2.3 VR for public awareness and affective impact

Bizarri et al. [4] provides a working definition of awareness that is broken down into three main components: cognitive awareness: a profound comprehension of one's own perceptions, thoughts, and behaviors; awareness at different levels of consciousness and unconsciousness, which is an end-stage experience resulting from processing multiple simultaneous experiences; and empathy and awareness of one's influence on others. Following this definition, we can extract three main concepts to consider when creating awareness-raising experiences:

- **Knowledge:** Increase participants' understanding of the issue by giving them factual, comprehensible information
- **Engagement:** Presenting information in an understandable and engaging manner to highlight the subject's importance in people's lives and its impact on others
- **Empathy:** Addressing individuals not only on a rational but also on an emotional or intuitive level

By immersing users in a 3D space and enabling them to interact with objects and virtual agents as if in real life, we can create powerful immersive experiments in VR that can alter the way people behave and perceive the world. The degree of immersion, or the level of sensory fidelity, directly influences the participant's feeling of presence. Slater et al. [31] define “presence” in VR as comprising “Place illusion” (the sense of being in a real environment) and “Plausibility illusion” (the belief that virtual events are actually happening). Advancements in VR technology now enable the creation of realistic scenarios in safe, controlled settings, facilitating these illusions. This technology simulates difficult or unsafe real-world situations, allowing users, when embodied in avatars, to react more authentically through the avatar's experiences. This subjective experience enhances understanding of the challenges faced by the avatar and fosters empathy in the user [30]. Such immersion is the key to designing emotionally affective experiments.

Linking these elements together, VR stands out as a powerful tool to address these aspects among other available methods, such as 2D computer experiences, expositions or printed supports, thanks to its ability to provide a high level of immersion in ecological conditions that the alternatives don't provide or not at the same level, as supported by Gillespie et al. [11]. The feeling of presence in VR can increase empathy in users, leading to greater engagement and more effective learning outcomes. Experiencing someone else's perspective in first person not only increases empathy but also allows the issue to be seen at a closer psychological distance, which is the key to changing social behaviour attitudes [27]. In addition, first-person embodiment has been shown to have a strong influence on changing social attitudes and behaviours, with effects that can persist beyond the virtual experience and translate into the real world [1]. VR has been previously used as a platform for awareness-raising experiences in domains such as environment conservation [2], medical topics [24, 38], and social issues [36]. However, Kasowski et al. [17] highlighted a lack in the literature

regarding the involvement of individuals affected by these issues in the design process and their contribution of expert insights to the created studies.

To measure the affective impact of an experience, physiological responses, in particular Electrodermal Activity (EDA), have been adopted as an indicator of arousal, reflecting the autonomic changes in the skin's electrical properties [5]. For example, if participants experience a stressful situation, their arousal levels are likely to increase, resulting in a spike following the stimulus. EDA is gaining popularity for the experiment of the relation between user emotions and attention in relation to visual content, such as 360° videos [12, 37] or 3D virtual scenes [28]. These works demonstrate the current importance of EDA measures in the VR research, in particular its advantages to continuously measure emotion and detect fine-grained responses to events, as compared to questionnaires that usually measure a global emotion at well-defined points in time. It has yet to be used to measure the emotional response to content that is meant to change one's perspective, such as for education or awareness.

3 METHODS

Our goal is to design an application that would raise awareness to the difficulties in social interactions for AMD patients. The design process we adopted is comprised of three steps:

- (1) Co-design of VR experiment with AMD patients and medical staff
- (2) Realisation of selected scenes in VR with further iterations
- (3) Implementation of a gaze-contingent virtual scotoma

Below we present each step of the above process in detail.

3.1 Co-design of the VR-experiment with experts and AMD patients

Best quoted by Kat Holmes in *Mismatch* [14], our goal is to “Designing with, not for, excluded communities”. Thus, we wanted to create scenarios based on true patients' experiences. In order to have an accurate representation of their challenges regarding social interactions, we wanted to consider existing studies from the field as well as having a direct interaction with AMD patients and medical experts. Our experience was thus co-designed with AMD patients through structured interviews, and under the supervision of the orthoptist team. During the interviews, we asked them to recount stories, instances, and situations on:

- How AMD generally impacted their everyday life
- Any unpleasant situations related to the impact of AMD on vision
- Feelings and emotions during social interactions with close ones and with strangers
- Situations requiring extra investment because of AMD
- The role of family and friends, and their understanding of AMD

Six patients participated to those interviews, four women and two men, aged from 67 to 93 years old, with mild to severe vision loss. We then organized a collective interview with the four women who had already attend the first interview. The goal was to give them more freedom when talking between them, and observe if

they depicted similar challenging situations that we could recreate in VR. We framed the general discussion to focus on getting stories they experienced in their life showing the impact of their disease on their social interactions. We noted the people involved in the stories and their role, the place where the stories happened, the feelings participants felt during these situations and how the vision loss impacted these situations. We chose the stories that received the most agreement and that were recurrent among patients during the collective interview, and validated by orthoptists. We then presented a prototype of the scenarios to the patients and orthoptists, and made further changes according to their feedback. We present the stories included in the VR scenarios in Table 1. Interviews were carried out in French, with the questions and transcripts translated in English for this paper.

3.2 Engaging VR scenarios to raise awareness on AMD

As established in the related work section, understanding and knowledge growth are two main components of a successful awareness raising experience. VR is particularly suited to creating immersive experiences where the user can live the first-person experience of someone, which elicits empathy and better understanding of the challenges faced by the embodied person. In our experience,³ the participants engage in the experience by embodying, in the first person, an old man or woman affected by AMD. Throughout this article, we will refer to this embodied character as the avatar. The avatar's thoughts are voiced so that participants can hear them as if they were their own. These thoughts help guide the participants and express the avatar's feelings in various situations.

The experience was designed for the HTC Vive Focus 3 using the Unity game engine. We chose this headset because it features eye tracking we need for this experiment and it is standalone, which makes it light and easy to transport for discussions with the design team and carry out studies. However, the standalone feature makes the headset less powerful compared to one linked to a PC. The application thus needed to be as optimized as possible in order to run smoothly. We thus chose to use low poly assets for the entire experience, which in addition also allows us to avoid the uncanny valley effect [26].

Environments and secondary characters assets were purchased from Synty Studio⁴ and virtual agents are Akishaqs' models⁵, which can have facial animations. The animations were created with Mixamo⁶, and the virtual agent voices were chosen from ElevenLabs' voice library⁷.

Following the interviews, four scenarios that depict a typical day of social interactions for an AMD patient were conceived that involved the key difficulties patients recounted. They were set around the patient welcoming their son and granddaughter home for holidays (Figure 1). Participants take a first-person point-of-view throughout the experience and embody the avatar from the beginning.

³To find more information and test the experience, please visit <http://team.inria.fr/biovision/amd-journee>

⁴<https://assetstore.unity.com/publishers/5217>

⁵<https://assetstore.unity.com/publishers/12741>

⁶<https://www.mixamo.com/>

⁷<https://elevenlabs.io/>

Table 1: Quotes from interviewed AMD patients when investigating faced challenges during social interactions that inspired the scenarios.

Quotes from patients	Main themes	Final scenario
<ul style="list-style-type: none"> •“The TV, I no longer watch it. I listen to it but I don’t watch it.” •“To see the faces on TV, we have to move closer” 	<ul style="list-style-type: none"> Troubles watching TV Faces are hard to see on TV 	Scene 1: Watching TV
<ul style="list-style-type: none"> •“I have the habit of saying hello to everyone. Often people, instead of replying hello, they just smile, nod, etc. Sometimes, I am annoyed and say: ‘I’m saying hello to you, why aren’t you responding?’ ” •“It’s the same when I go for a walk. I say hello to everyone and sometimes, I complain: ‘why don’t you respond?’ But they just gestured. That’s when it feels awkward.” •“If I have trouble reading my mail, someone reads it to me.” •“I am surrounded by friends and family who are my age. I’m the one with the best memory amongst friends and family because they can write things down in their agendas, [...] but I can’t, so I end up remembering everything that is said. Everything.” 	<ul style="list-style-type: none"> Hard to see faces, Problem recognizing facial expression, feeling of missing-out Problem recognizing facial expression, feeling of missing-out, embarrassment Reading issue, family support Memory development, strategies to cope with AMD 	Scene 2: Talking with family in the living room
<ul style="list-style-type: none"> •“It’s like in stores. [...] I have to ask for help because I can’t see what I’m buying. One day, I asked a gentleman. Maybe I wanted aluminum or baking paper, I’m not sure. And I asked the gentleman, can you tell me which one is the right one? He looked at me and said, why don’t you put on your glasses?” •“Yes, that has happened to me too. That people don’t understand your illness because they still see us as able-bodied.” •“Otherwise, they help. When you say that you are visually impaired, they help. When they know.” •“I say that ‘I can’t see, that I am visually impaired, so can you help me?’ I’ve never encountered someone who said no. Not even someone who said they were in a hurry. Never.” •“I recognize voices and also clothing. I take note in the morning of how people are dressed. Whether there’s a red sweater or other visual details.” 	<ul style="list-style-type: none"> Dependence to others, people misunderstanding the disease People misunderstanding the disease, invisible disease Others are willing to help Others are willing to help Strategies to cope with AMD 	Scene 3: Find an item in supermarket
<ul style="list-style-type: none"> •“The photos. They show you all the photos. [...] Because they don’t really understand what we can’t see.” •“They want me to recognize. That’s it. Often, they will move into the light. People try. Now, in my family, they don’t mention it anymore. I can’t look at photos anymore [...] distinguishing eyes, nose, mouth, it’s more difficult.” •“I don’t take photos anymore because I can’t see them.” •“I no longer see the photos. Except on the tablet, there I can enlarge them and, up close, to see the photos a bit.” 	<ul style="list-style-type: none"> Hard to see faces, people misunderstanding the disease Hard to see faces Hard to see faces Using technology to cope with AMD. 	Scene 4: Looking at photographs with family

Scene 1: Start of the day. participants start the experience embodying the avatar, without the scotoma. They are alone in a bedroom with standard furnitures and a TV in front of them. The avatar introduces themselves and briefly explains what AMD is. The scotoma appears during this explanation. The participants thus watch the TV with and without the scotoma, allowing them to easily understand its effect on the vision. The participants listen to the avatar, then pick up the remote to go to the next scene. The primary difficulty addressed in this scene is watching the television. While watching TV is not a face-to-face interaction with another human being, it is a unanimous challenge faced by the AMD patients. The TV allows people to stay connected to the world, and the inaccessibility of visual information from TV programs has strong indirect implications on daily social interactions. The scene also introduces the participant to the scotoma, which accompanies them for the remainder of the experience as different social situations emerge and evolve.

Scene 2: Breakfast in the living room. participants are at the dining table with the avatar’s son and granddaughter. The breakfast starts with greetings between the virtual agents and the avatar, the granddaughter recounting a vivid dream, and ending with the avatar receiving a shopping list to go to the supermarket. This scene addresses the difficulty of recognizing faces and expressions during conversations: this includes gestures such as the son nodding to

indicate greeting at the scene start, and also the struggles to interpret emotions during the granddaughter’s story. The difficulty of reading text is also depicted when sharing the shopping list on the phone.

Scene 3: At the supermarket. participants are in a supermarket while the avatar is doing their regular shopping activities. The avatar is unable to find a particular item on the list, and encounters an employee ignorant to their condition who tells them to simply put on their glasses. A sympathetic bystander helps the avatar out. This scene, is based on a story told by a patient during our interview, which illustrates the general public’s lack of knowledge about low vision and the resulting inappropriate reactions. On the other hand, it also emphasizes that patients do also encounter kind individuals who gladly assist them, and demonstrating examples of positive behaviour the participants can emulate.

Scene 4: Garden scene. participants are with the granddaughter who is showing them photographs that they cannot see. The son proposes a solution by showing the pictures enlarged on a tablet. He also emphasizes that nowadays, there are a lot of visual aids that can help AMD patients to cope with their disease. The granddaughter then offers to narrate the events associated with the photos to trigger the avatar’s memories without relying on sight. This scene addresses the challenge of recognizing people in photographs and also serves to conclude the experience on a positive note, conveying

the message that having a social circle that is supportive and understanding allows AMD patients to better cope with their disease, and that despite the challenges, one can always find a solution to better manage their disability. It also emphasizes how members in a social circle can adapt and find solutions to ease the life of AMD patients.

After the fourth scene, a real voice testimony of an AMD patient we interviewed was added with subtitles:

“First, there is something very important to say. This is what a doctor once told me: You will never be in darkness. That’s crucial. [...] You must not despair and get depressed, but on the contrary, try to find techniques. And it’s possible. I constantly reflect on this, telling myself: well, there are plenty of things you can no longer do, but there are still plenty of things you can do.”

This message was included to highlight the importance of not succumbing to despair or depression when faced with the challenges and setbacks of AMD. Instead, the patient emphasizes the importance of developing new procedures or methods to address these issues. This viewpoint promotes an optimistic attitude and adaptability to conclude the experiment.

Once we developed the complete prototype of the experiment with all four scenes, we scheduled a new appointment with the patients to collect their feedback to finalize our application.

We did not include the vision loss simulator when we presented them the prototype. Three AMD patients tested the prototype, two women who participated to individual and collective interview, and one man who only attended the individual interview. The patients expressed high satisfaction with the scenarios, appreciating their accurate representation of daily challenges. However, initial unfamiliarity with the controllers distracted them from the content. To address this, we introduced a preliminary scene dedicated to controller and object interaction tutorials, ensuring a uniform experience for both novice and experienced VR users. AMD patients also highlighted that certain dialogues felt overly pessimistic. They emphasized the importance of maintaining optimism and the existence of strategies to better manage the disease.

We integrated these comments in the experiment and showed the new version to the orthoptists for validation and final corrections. The medical staff applauded the balance of content between both the negative and positive sides to stay true to patients’ experiences, as well as the insertion of suggested actions and attitudes to adopt that can better assist AMD patients, for whom the support and assistance of close ones is invaluable in managing their condition.

3.3 The scotoma simulator

As reviewed in Section 2.2, many studies illustrate scotomas using a black circle positioned at the center of the gaze to obstruct clear sight. While this representation effectively obstructs the view, it does not correspond to descriptions provided by AMD patients, which typically involve experiencing a blurred vision at the center of the visual field.

In this experiment we wanted to create a virtual scotoma more closer to reality. We investigated different techniques for blurring

a specific region of the screen to achieve the desired effect. In addition, we want to precisely control the placement, size, and intensity of the blur effect within the screen, representing the position, size, and intensity of the scotoma. Our solution involved two concentric circles (as shown in Figure 2). The inner circle defines the region where the pixels are fully blurred, and the outer circle defines a ring where the intensity of blur gradually diminishes in a linear fashion. The outer region enables a more faithful representation, as the boundaries of the scotoma are usually diffused. Different interpolation approaches, like using two linear interpolations or a Hermite interpolation, were compared but we did observe significant differences between the end results of the two.

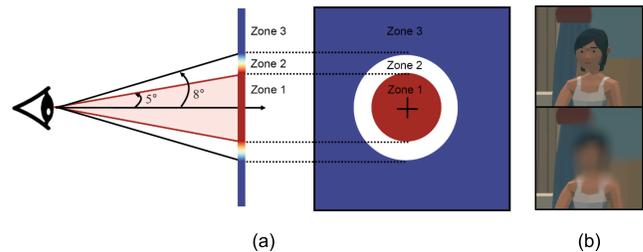


Figure 2: (a) This depiction of the virtual scotoma schema shows a 10° visual zone that is fully blurred (Zone 1) with an additional 16° of gradually diminishing blur (Zone 2). The resulting visual effect is shown in (b) when looking straight at the face of a virtual agent.

In terms of parameters, the eccentricity of the inner circle was set to 10 degrees based on common scotoma sizes reported in [7]. The eccentricity of the outer circle was set to 16 degrees. As a reference, the vertical field of view of the VR headset that we used (a Focus 3) is 96.68 degrees.

The inner-circle blur was achieved by applying a box filter to the output image. A box filter replaces the color of a given pixel by the average color of a squared region center at that pixel. To achieve a smooth scotoma (i.e., to support different intensities), every pixel within the circular region applies a box filter with a different kernel size (the size of the squared region). This technique lets us control the intensity of the blur for each pixel individually. Pixels that use a larger kernel size end up averaging more of the surrounding pixels, making the pixel more homogeneous to surrounding colors, compared to a smaller kernel size. In addition to box filters, we also tried sampling different levels of the mipmaps of the output image. This technique, while fast thanks to hardware acceleration, did not achieve good visuals, discretizing the scotoma into fewer levels and producing a banding effect. For the maximum blur, the kernel-size was set to 15. This configuration lets us achieve a smooth scotoma with no visual artifacts (like banding effects) while also being fast-enough (over 30 frames per second).

The position of the scotoma, i.e., the center of the concentric circles, was controlled by the gaze direction, obtained using the WaveSDK plugin for Unity, which lets us access gaze origin and directional vector of combined left and right eye gaze data provided by the headset HTC VIVE Focus 3.

Table 2: Questions used in the pre- and post-study AMD Knowledge Questionnaire with answers of either “True”, “False”, or “I don’t know”.

ID	Question (translated from French)
Q1	AMD prevents correct central vision.
Q2	Wearing glasses can correct AMD.
Q3	It is possible to cure AMD.
Q4	AMD often leads to blindness (i.e., here, refers to total blackness)
Q5	AMD develops rapidly over a few weeks.
Q6	AMD affects the elderly population (> 50 years old).

4 STUDY AND METRICS

To evaluate the impact of our experience, the effectiveness of various components of awareness, and validate the product of our co-design, we carried out a user experiment with participants. Our goal was to measure the affective responses of the participants towards the experience, for which we presented a number of questionnaires and also sought qualitative feedback. In addition, we also took continuous measures of gaze and emotional activity to understand the attention and emotional response of participants in different scenes and events. This section describes the questionnaires used, continuous measures, and the experiment rollout. We present equally our hypotheses on these elements.

4.1 Questionnaires

We selected and adapted three questionnaires from existing studies that would address the three concepts for awareness-raising experiences. As well as our hypotheses on the outcome of this experience.

AMD Knowledge Questionnaire. Corresponds to the knowledge component of awareness. A set of 6 questions (see Table 2) about AMD inspired from a quiz for the French national day of AMD⁸, and based on information given in the experience to evaluate participants’ knowledge growth on AMD after doing the experiment⁹. The questionnaire was reviewed and approved by the orthoptists during the co-design sessions. Participants answer with “True”, “False” or “I don’t know” to each question.

Impact of AMD on Social Interactions Questionnaire. Corresponds to the engagement component of awareness. Based on the work of Lane et al. [18] surveying difficulties encountered by AMD patients through a qualitative interview. We included difficulties that were related to challenges that AMD patients face in social interactions. Every question was evaluated using a five-point Likert scale, from “strongly disagree = 1” to “strongly agree = 5”. We used a 5-point scale for to allow participants to nuance their answers without having to consider too many options. Questions are shown in Table 3.

Participant Empathic Response to Experience Questionnaire. Corresponds to the empathy component of awareness. A series of 11

⁸<https://www.journees-macula.fr/quizz-etes-vous-bien-informes-sur-les-maladies>

⁹There exists two forms of AMD: wet and dry. Participants were aware that this questionnaire is built around dry AMD and the information in the experience were given accordingly.

questions to assess participants’ empathy score after the experiment, adapted from the English version used by Cho et al., as detailed in Table 4) [9], which was itself adapted from the Consumer Empathic Response to Advertising Scale [32]. Every question was evaluated using a seven-point Likert scale, from “strongly disagree = 1” to “strongly agree = 7”. We retained the 7-point scale in line with the original questionnaire. We chose this questionnaire among other available such as the Basic Empathy Scale [6] because, to our knowledge, it was the only one that included the identification component of empathy, a factor we considered important for analysis in our study.

These questionnaires do not assess the long term effects of the experience in participants’ knowledge and behaviour. The evaluation focuses only on the participants’ immediate knowledge and empathy towards AMD patients after undergoing the experience.

H1-Questionnaire: On measuring the impact of our experience on awareness through questionnaires, we hypothesize that the score on the AMD Knowledge Questionnaire will increase between pre- and post-study.

4.2 Continuous measures

In addition to questionnaires we collected continuous measures of emotion and attention for the purpose of understanding to a fine-grained level what the impact of (1) the virtual scotoma and (2) the events in the scenario were on the participants’ attention and emotion.

4.2.1 Eye tracking. To cope with the loss of visual acuity in central field vision, AMD patients often use their remaining peripheral vision: they place their gaze beside the target they want to look at, such that it is visible in the peripheral vision. We were curious to see if participants would also use the same strategy for looking at the faces of other virtual agents, either through learning or automatically.

During the experience, we collected eye tracking data of participants using the integrated eye tracker of the HTC Vive Focus 3 with a data rate of 90Hz. Each log comprised of the timestamp, gaze origin (using the combined left and right eye – a.k.a. “cyclopean” – vector), gaze direction, and normalized direction vector. In addition, the system logs contain the center position of a bounding sphere around each virtual agent’s head, which measures 15 cm. In order to extract fixations, which are the moments of visual information intake, the gaze data is processed with an I-VT algorithm (identification by velocity threshold) with the threshold set at 90 angular degrees [29].

For each virtual agent in each scene, we defined a set of three circular co-centered Areas of Interest (AOI) that are perpendicular to the gaze vector. The areas are shown in Figure 5. The parameters for defining the AOIs are as follows:

- *AOI_A_radius_meters* radius of the innermost circle in meters, set to fit the virtual agent’s face. This value is currently fixed at 15 cm
- *distance_meters* the distance between the camera in VR (e.g. participant’s head) and the center of the AOI
- *scotoma_radius_degrees* the radius of the generated scotoma. This value is currently fixed at 5°

Table 3: Selection of daily challenges faced by AMD patient addressed in the experiment and corresponding entry of the Impact of AMD on Social Interactions Questionnaire.

ID	Selection of daily challenges faced by AMD patients [18]	AMD patients who reported this difficulty(%)	Questions adapted for the experiment
			Due to the AMD simulation in the experiment..
SI1	AMD has made it harder to see faces	100	I had difficulty seeing the faces of the virtual agent.
SI2	Social interactions are slowed or take more mental effort	62	My social interactions seemed slowed or required more mental effort.
SI3	Problems with eye gaze	52	I had difficulty seeing the gaze of other virtual agent.
SI4	Problems with facial speech	48	I had difficulty seeing the mouths of other virtual agent.
SI5	Missing out (e.g. can't join with jokes; didn't realise my old friend was at the funeral)	76	I felt like I was missing out on certain events.
SI6	Faces are hard to see on TV	71	I had difficulty seeing certain objects around me (images on TV, text messages, photo albums, etc.).
SI7	I sometimes feel bad (embarrassed, frustrated,sad, upset)	100	I sometimes experienced negative emotions (embarrassment, frustration, sadness, anger).

Table 4: Items used for the Participant Empathic Response to Experience Questionnaire. The original item text [9] is in bold, and the adapted item in italics in the form of [original text → adapted text]

ID	Items [original text → <i>adapted text</i>]	Empathy component
ER1	I understood [the characters' → <i>my avatars'</i>] needs.	
ER2	I understood how [the characters' → <i>my avatars'</i>] were feeling.	
ER3	I understood the situation [of the video → <i>in the four main scenes</i>].	Cognitive empathy
ER4	I understood the motives behind the [characters' → <i>virtual agents'</i>] behavior.	
ER5	I felt as if the events [in the video → <i>happening to my avatar</i>] were happening to me.	
ER6	I felt as if I was in the middle of the situation.	
ER7	I felt as if I was one of [the characters → <i>my avatar</i>]	Affective empathy
ER8	I experienced many of the same feelings that [the characters portrayed → <i>my avatar expressed</i>].	
ER9	I felt [the characters' → <i>my avatars'</i>] needs were similar to mine.	
ER10	[The events in the video → <i>The situations presented in the experiment</i>] were similar to my experience.	Identification empathy
ER11	I felt as if [the events in the video → <i>a similar situation to those in the experiment</i>] could happen to me.	

We can then define each area as:

$$AOI_A_radius_{degrees} = \tan(AOI_A_radius_{meters}/distance_{meters}) \quad (1)$$

$$AOI_B_radius_{degrees} = AOI_A_radius_{degrees} + scotoma_radius_{degrees} \quad (2)$$

$$AOI_C_radius_{degrees} = AOI_B_radius_{degrees} + scotoma_radius_{degrees} \quad (3)$$

Semantically, if the gaze falls in AOI_A , the virtual agent's face will be completely or partially covered by the scotoma. The ringed area of $AOI_B \setminus AOI_A$ represents the optimal focus point location to keep the face in near peripheral vision, and finally $AOI_C \setminus AOI_B$ is the maximum bounding sphere where we consider the face to be the object of interest.

H2-Attention: On measuring the impact of the virtual scotoma on gaze behaviour, we hypothesize that the fixation time on faces will be significantly higher in $AOI_C \setminus AOI_A$ when the scotoma is present.

4.2.2 Physiologic response. To measure the emotional impact of individual events, we adopted electrodermal response (EDA), also

known as skin conductance or galvanic skin response, using Shimmer GSR+ units. EDA corresponds to the activity of the sweat glands, where changes in electrical conductance are caused by variations in sweating. Measurements are generally taken unobtrusively by placing two electrodes on either the hands or feet. In our study, we placed them on the non-dominant hand of the participant to limit excessive noise in the data. An undetectable electrical current is applied to the participant between two points in contact with the skin (e.g. two adjacent fingers), and the electrical flow between them is measured. The resulting measurement is then separated into two components: the tonic component (skin conductance level, SCL), which varies slowly and represents long-term changes, and the phasic component (skin conductance response, SCR), which varies quickly in response to a stimulus. EDA is representative of a person's level of arousal, which indicates the intensity of the emotion.

For data processing, we used the Python toolkit Neurokit2 [22] to clean and normalize the raw EDA signal, then extract all the detected peaks and associated onsets from the phasic component. We then filter the peaks based on the SCR amplitude (minimum set to $0.01\mu S$) and latency between the stimulus and the onset (latency

should be between 1 and 3 seconds to claim that the peak is event-related and not randomly happening). An example result of this processing is shown in Figure 6, where we can observe multiple events (black dots) followed by significant peaks (red vertical lines).

H3-Emotion: On measuring the emotional impact of our experience, we hypothesize that social events will trigger a strong emotional response in our participants, characterized by significant event-related peaks in the SCR recordings.

4.3 Study overview

We recruited 29 participants in total. 11 participated (six women and five men, from 22 to 38 years old with an average age of 26 years) in a pilot experiment to provide feedback. We incorporated the feedback over a three month period and then ran the formal experiment with 18 new participants, seven women and eleven men, from 23 to 55 years old with an average age of 34 years. Participants were recruited through institute and university diffusion lists. Our experiment was ethically approved by the Université Côte d'Azur ethics committee N°2022-057.

The experiment took place in our lab. Participants had to sit in a chair without wheels and armrests to ensure safety and mobility during the experiment. They had a free space of $2m^2$ around them without any objects they could potentially collide with. After filling the consent form, participants were asked to provide basic information such as age group and gender. Then, we presented the pre-study AMD Knowledge Questionnaire. Following the questionnaire, the headset and Shimmer GSR+ units were introduced and equipped. The participants then did the experience, which was approximately 10 minutes long. We did not talk to nor interact with the participants during the experiment to avoid any influence, and to let them fully take part in the story. Once the experiment was over, the equipment was removed. We then presented them with the Participant Empathic Response to Experience Questionnaire, followed by the Impact of AMD on Social Interactions Questionnaire. Finally, we repeated the AMD Knowledge Questionnaire which was identical to the pre-study one. Participants were invited to provide open-ended feedback before concluding the study.

5 RESULTS

Here we present the results of our study and analysis from our experience, and respond to the hypotheses posed in the previous section.

5.1 Questionnaires

For the AMD knowledge questionnaire, we show the distribution of the scores pre- and post-study in Figure 3. We found that scores improved significantly after the study ($p < 0.001$), with a 2.5 increase in the median score and a global improvement in the number of correct responses on all individual questions. With this result, we can say that our study improved participants' knowledge about AMD, and thus validate **H1-questionnaire**.

On the engagement and empathy components of awareness, we look at the responses to the two respective questionnaires in Figure 4. In the Impact of AMD on Social Interactions Questionnaire, we observe that more than 50% of the participants strongly agree with every listed challenge. Most notably, we observed a

very strong agreement (94% strongly agree and the remainder 16% agree) on item SI1 "I had difficulty seeing the faces of the virtual agents", which corresponds to what was observed in the literature by patients (Table 3). On the other hand, only 50% of the participants strongly agreed with SI7 "I sometimes experienced negative emotions (embarrassment, frustration, sadness, anger)" which is in line with the outcome of the co-design process where patients emphasized the importance of maintaining optimism and focusing on strategies to live with the disease.

Since there are a different number of questions per component of the empathy questionnaire, in order to compare them, we summed the scores for each component per participant, and then normalized the score onto a 10 point scale. In the Empathic Response to Experience Questionnaire, we found there was a significantly lower identification empathy compared to cognitive and affective empathy components. This we consider normal because of the age and social context: the mean age of participants is 34, while AMD patients' avatar is 65. AMD patients' avatar has a disability, while participants had functional vision outside of VR. In the light of our objectives to raise awareness, this result also shows that the target audience is suitable given the difference in their personal experiences from the patients, but at the end of the experiment, they obtain a high cognitive and affective empathy.

Before concluding the study, we invited participants to provide open-ended feedback on the experience. All participants reported that the experience enhanced their understanding of AMD and its impact on social interactions. The scenarios were particularly well-received, with comments such as, "I really felt how a person with this disease interacts with the world, and I gained a better understanding of how AMD affects activities. It's tough." One participant compared the blurred scotoma simulation with the traditional representation (i.e. the black circle), explaining, "It's more realistic but more frustrating to have blurriness instead of a black dot because you can catch glimpses of elements through the blur, compelling you to focus on them." Additionally, several participants attempted to compensate for visual loss using peripheral vision, suggesting that the simulation elicits the same type of ocular behavior observed in AMD patients. This is corroborated by the gaze data analysis described in Figure 5. These observations underscore the significant impact of this immersive VR experiment on participants' understanding of AMD.

5.2 Eyetracking data

From the workflow detailed in Section 4.2.1, using the gaze tracking data, we calculated the time spent during fixations in various areas of interest (AOI) to see if the simulated scotoma impacted the viewing behaviors of the participants. Figure 5 describes how the AOIs are characterized in (a) from the front view of a virtual agent, and (b) from the side view of the participant. *AOI_A* represents the face of the virtual agent in the central visual field, *AOI_B* with the face of the virtual agent in the close peripheral region, and *AOI_C* as the maximum region where the face is the object of attention. Plot (c) shows the average percentage of time spent by all the participants in each AOI for each scene. Scene 1 is excluded from this analysis, given that the avatar is alone in the scene.

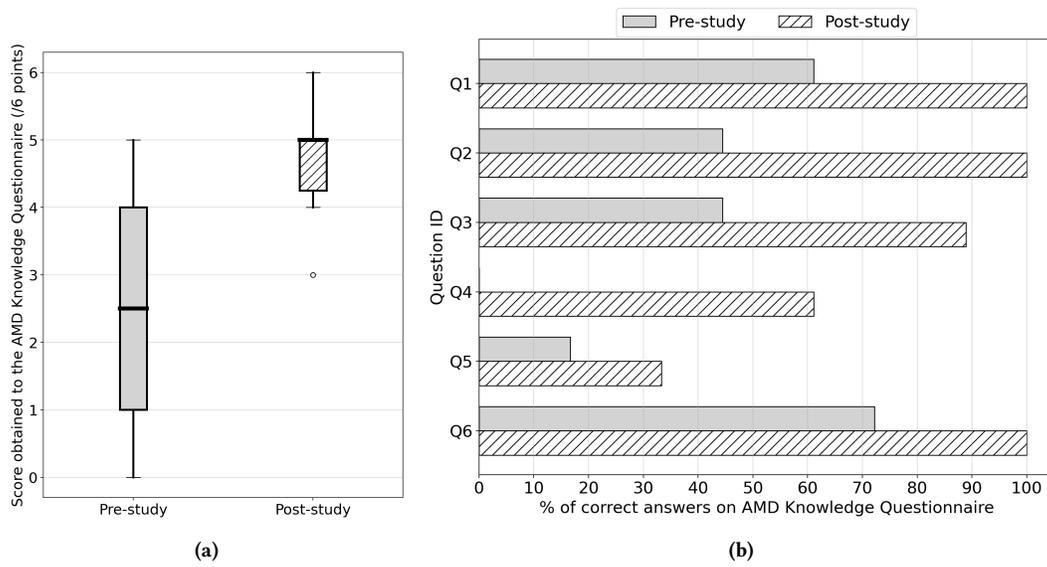


Figure 3: Comparison of the scores obtained by participants on the AMD Knowledge Questionnaire pre- and post-study (see detailed questions in Table 2). The results in (a) show a significant increase of participants’ knowledge on AMD after the experiment ($p < 0.001$) and (b) global improvement on number of correct responses for every question.

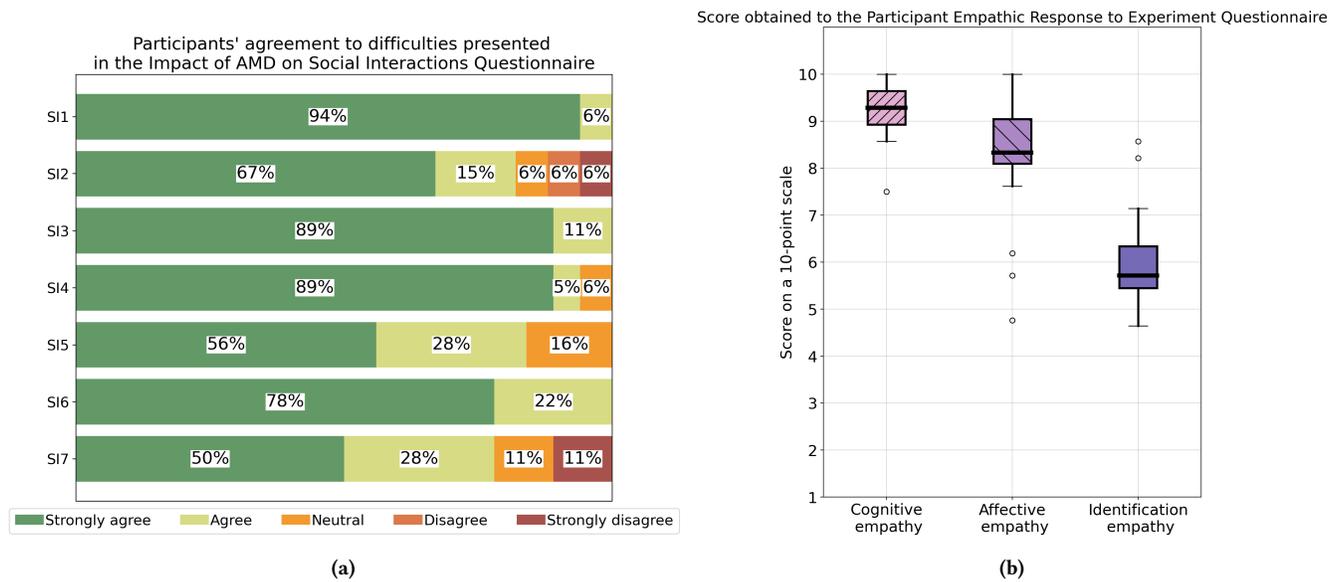


Figure 4: Results on Engagement and Empathy components of awareness with (a) Percentages of participants’ level of agreement with the argued challenges faced in the experiment (detailed questions in Table 3). All challenges show strong participant agreement for more than 50%, and (b) Participants scored higher on the Cognitive and Affective empathy component than in the Identification empathy component (detailed questionnaire in Table 4), showing that the experiment successfully induced empathy in the participants.

The results are striking when we compare Scene 0 where there is no scotoma with the remainder scenes 2, 3, and 4 where there is the virtual scotoma in Figure 5-(a). Participants have quickly adapted their viewing behaviour to the virtual scotoma, placing their gaze in *AOI_B* and *AOI_C* instead of *AOI_A*. In Scene 0, participants spent

on average 18.77% of their fixation time looking straight at the face of the virtual agent. We must consider that in this scene, participants are asked to look around them and pick up some objects, which could lead to a decrease in the amount of time they would have spent on *AOI_A* in another configuration. In the following scenes,

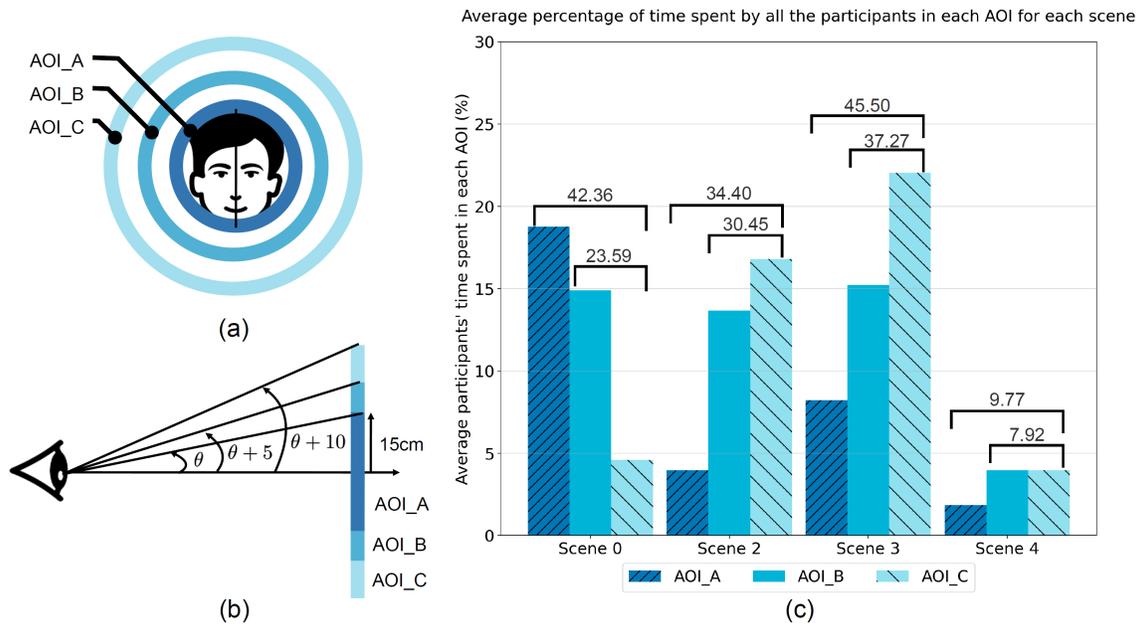


Figure 5: We show the processing and results of the gaze data in relation to virtual agents. Scene 1 has no virtual agents, and is thus excluded. The regions of AOI_A, AOI_B, and AOI_C are characterized in (a) from the front view of a virtual agent, and (b) from the side view of the participant. In (c) we show the average percentage of fixation time of participants spent in each of the three region. The difference between Scene 0 without the scotoma and the remaining scenes with the scotoma is striking in how participants switch from dominantly central vision (AOI_A) to peripheral vision (AOI_B \cup AOI_C) when the scotoma is present.

they spent respectively an average of 3.95%, 8.25% and 1.85% of their fixation time on AOI_A, in favor to AOI_B and AOI_C, which combined, represent respectively 30.45%, 37.27% and 9.77% of the fixation time. The less amount of time spent in the AOI in Scene 4 can be explained by the task given to participants, i.e., trying to fixate on pictures instead of looking at the virtual agents. We can thus accept **H2-Attention** with confidence that the scotoma has a clear impact of viewing behaviours, resulting in a shift of the gaze from primarily AOI_A in Scene 0 to AOI_B and AOI_C in the remaining scenes.

On the other hand, we also recognize the limitations of this analysis. Notably, the parameters of the different AOIs were selected based on the size of the scotoma. However, we see that users spend more time in AOI_C than AOI_B, which means that the active region in the peripheral vision may be larger than what we reviewed. This value can be better adapted to empirical studies of actual viewing behaviours. Another limitation is since we focus on social interactions, we only take into account faces of virtual agents. However other objects of interest – including the photo album, television, and interactable items throughout the experience – also play a role in social interactions and could be included in a broader analysis.

5.3 Physiological data

Due to the malfunctioning of the Shimmer GSR+ units, the EDA data for two participants was not properly recorded. The following results are thus based on only 16 participants. Following the process

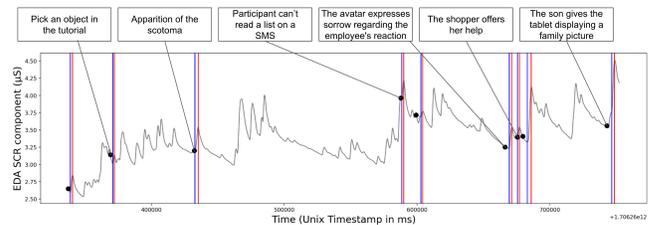


Figure 6: We used the Python Neurokit2 tool to extract the event-related peaks showing an increase in participant's arousal, indicated by dots for the time of event(black) and horizontal lines for the onset before the peak (blue) and the time of the peak (red). In this example we show a SCR recording for one participant for the entire experiment. We observed that multiple instances of selected events were followed by a raise the arousal, characterized by a significant peak.

described in Section 4.2.2, we detected all the event-related peaks for each participant and grouped them by scene and event. The results are summarized in Figure 7 where each pie chart shows the proportion of event-related peaks detected in a given scene, for each event. Each count (shown in parenthesis) indicates that a significant peak was detected as a result of a specific event.

Most of the events we selected corresponded to dialogues, though significant event-related peaks were observed only in one event in

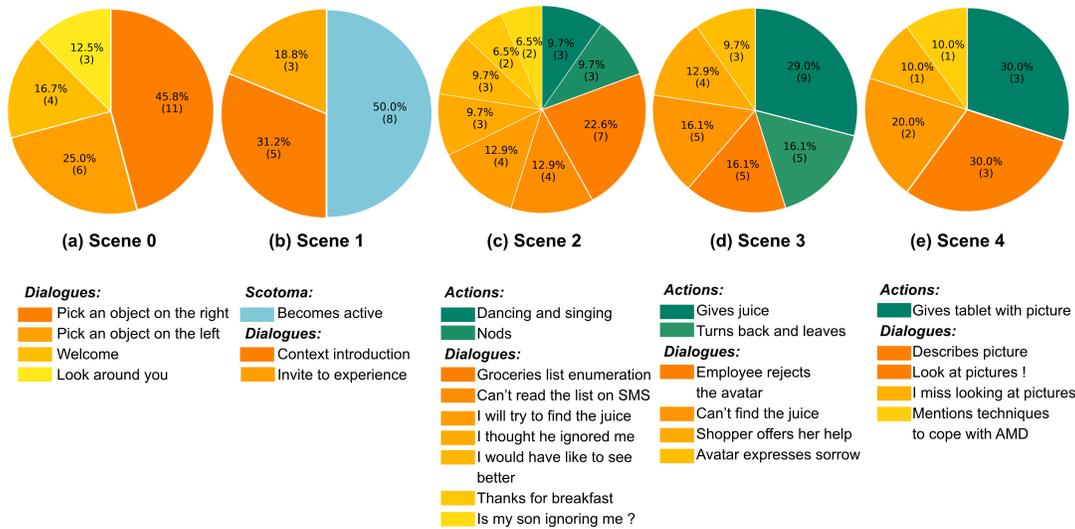


Figure 7: Out of all significant SCR peaks observed in each scene, the percentage relevant to each selected event (and in parenthesis, the number of participants out of 16).

Scene 1, when the context of the experience – a family visiting the avatar – is introduced. Some of the scenes had clearly emotionally strong events. We point out notably in Scene 1 (bedroom) that the appearance of the scotoma induced a peak in arousal for 50% of the participants. In Scene 3 (supermarket), which was more action charged, we also had more observations for the actions of receiving the orange juice from a kind virtual agent (9), the unsympathetic employee turning their back (5), and the player being rejected (5). Figure 6 provides a more qualitative view of the evolution of SCR for a single participant through the experiment, with screenshots of the event at the times a event-related peak occurs.

It is important to note the limitations of analyzing physiological response. First of all, noise can be easily introduced into the data due to movements. Though we accommodated this by placing the sensors on the non-dominant hand, full bodily movements such as leaning, turning, or slight motions during interactions can cause fluctuations in the recorded data. It is also important to take into account the variability in biology for each person, their sensitivity to certain events, as well as responses that could correspond to memories and feelings indirectly related or even completely unrelated to the current scenarios. Finally, the number of observations is also constrained by the events we choose to observe. As such, we can only partially accept **H3-Emotion** in saying that while many of the events triggered strong emotions in our participants, data of better quality and establishing of baseline measurements would strengthen the conclusions we wish to draw on the emotional impact of our experience.

6 CONCLUSION

In this work we have presented a VR experience aiming at raising awareness towards low-vision conditions, specifically AMD, co-designed with patients and medical staff. An experiment conducted with 29 participants allowed us to refine our scenarios and also validate the impact of the experience on the components of awareness,

including knowledge, engagement, and empathy through adapted questionnaires. We also illustrate the analysis on continuous metrics of eye tracking and physiological data, showing the strong impact of the virtual scotoma and designed events on the user’s gaze behaviour and emotion.

We believe this work highlights the benefits of using immersive technologies to raise public awareness about diseases such as AMD, allowing the general public to have a better understanding of the challenges faced by patients. By extension, it could also have a positive impact on patients themselves by proposing a way of understand their disease and potentially contributing in the development of more effective support methods. In future work, we aim to propose a more realistic simulation of the scotoma, such as from actual microperimetry data. In addition, we believe the experience could benefit from feedback and perspectives with patients at a larger scale, and from more diverse backgrounds. Finally, this work opens avenues to conducting studies in immersive VR with fine-grained, multimodal analysis of user behaviour for designing more engaging experiences.

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