

Title	“I’m like something out of Star Wars”: A qualitative investigation of the views of people with age-related macular degeneration regarding wearable electronic vision enhancement systems.
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“I’m like something out of Star Wars”: A qualitative investigation of the views of people with age-related macular degeneration regarding wearable electronic vision enhancement systems.

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“I’m like something out of Star Wars”: A qualitative investigation of the views of people with age-related macular degeneration regarding wearable electronic vision enhancement systems (wEVES).

Abstract

Purpose:

This study explores the initial views of people with age-related macular degeneration towards wearable electronic vision enhancement systems.

Methods

Ten adults with age-related macular degeneration participated in semi-structured interviews, which were analysed using reflexive thematic analysis.

Results

Four themes were identified. Firstly, participants spoke of the wide-ranging impact of sight loss and how current helpful coping strategies still had significant limitations, affecting their desire to seek new solutions. The second theme showed that “other people” offered welcomed support with existing electronic coping solutions and are needed to provide suitable advice and training. However, “other people” limited the acceptability of using new solutions in public places. The third theme captured participants’ desire for a wearable aid providing image magnification and enhancement over a range of distances. The final theme covered the reality of some current wearable technology, perceived as heavy, enclosing, or strange in appearance. Appearance caused some to lose interest in use, although others reframed the devices’ desired usefulness to solo and sedentary activities.

Conclusion

This population are interested in the potential benefits of wearable electronic vision enhancement systems. More work is needed to understand the suitability of current solutions due to participant concerns about training, appearance and performance.

Keywords: AMD, Head-mounted display, image enhancement, low vision aid, visually impaired persons, wearable devices, wEVES

Implications for Rehabilitation.

- A device that offers image enhancement and variable magnification in a hands-free, wearable form is very desirable to people with age-related macular degeneration.
- Some potential users are not seeking new solutions to well-described problems, which may be a useful coping strategy but alternatively may be motivated by fear of the unknown, financial worries, or concerns about appropriate training.
- The weight and appearance of some of the current wearable electronic vision enhancement systems are not immediately appealing and would stop some from proceeding with a performance trial.
- After viewing the current devices, the desirable times to use a wearable electronic vision enhancement system may be reframed by users to focus predominately on sedentary tasks taking place in isolation at home.

Introduction

Age-related Macular Degeneration (AMD) is a progressive, chronic disease occurring later in life, producing vision loss due to damage to the central retina (1). While intravitreal anti-vascular endothelial growth factor therapy has successfully reduced sight loss due to the wet form of AMD, for many people treatment options are either absent or do not prevent significant vision impairment (VI) (2). AMD accounts for the majority of people certified as sight impaired or severely sight impaired in the United Kingdom (3, 4). The resultant VI is associated with increased dependency as well as negatively affecting a person's quality of life, psychological well-being, and capacity to carry out daily tasks (5-8).

There is good evidence that assistive devices providing magnification are beneficial in improving the functional ability of people with AMD (9-12). Wearable electronic vision enhancement systems (wEVES) are head-mounted assistive devices consisting of a camera, a display screen set close to the eye and software to manipulate the resulting images. These wearable devices allow hands-free image enhancement and variable magnification over a range of different distances. Data show that wEVES can improve distance and near acuity for people with VI, as well as some indication they can improve vision related quality of life (VRQoL) (13). There are several distinctive styles of commercially available wEVES, which can be broadly classified into two categories (14):

- Virtual Reality (VR), or immersive reality, presents a bright image that can be readily manipulated but also disconnects the user from the real world.
- Augmented Reality (AR) see-through displays present added information and enhancement in images overlaying the view of the real world. Wearers retain

some awareness of the real world; however, images tend to be duller with a narrower effective visual field than the VR equivalent.

Some wEVES use proprietary equipment specifically designed for the intended population, such as the eSight4 (esighteyewear.com/gb). In contrast, others have developed new user interfaces to repurpose headsets designed for mainstream consumer use, for example, IrisVision Live's use of the Samsung Gear VR headset (irisvision.com/).

An earlier scoping review identified that sustained use of wEVES is not exclusively predicted by the generated improvement in vision. Other factors, including the design, weight, and form also influence whether a device was used successfully (13). When trying to understand the distinctive benefits of wEVES for people with AMD, the results of earlier studies may be confounded by including mixed populations with different causes of VI or by sampling biases towards younger early adopters and individuals who have already purchased the device. An older cohort of people are likely to have distinct views towards the use of technology as well as additional sensory, mobility and cognitive impairments. Therefore, mixing the reflections of people with AMD with those with different demographic backgrounds questions the generalisability of findings to the specific needs of people with AMD wishing to consider whether a device was suitable for them.

“Inclusive Design” is the principle of ensuring that products and services address the needs of the broadest possible audience, irrespective of age or abilities (15). The inclusive design philosophy describes the need to recognise that having a disability is a prevalent and normal characteristic within a community, thus shifting the designer's focus from a view of working with “THEM” to “US” (16). The case for inclusive design is not just a moral one: more inclusive products have been proven to reach wider

markets, improve customer satisfaction and, by extension, enhance profitability (17). The different levels of sensory, mobility and cognitive impairment found within the VI community means these principles of inclusive design are just as applicable to a specialist device as to a mainstream product. To ensure that wEVES are designed and developed inclusively, it is crucial to understand the constructed realities of individuals with AMD, including their initial perceptions of the benefits of this evolving coping solution.

This paper seeks to understand the non-performance related factors influencing the initial perception of the usefulness of wEVES amongst non-users with AMD. Our results can be used to allow practitioners and device manufacturers to accommodate different views regarding the potential for wEVES to support the vision rehabilitation of people with AMD.

A series of interviews with participants diagnosed with AMD was undertaken to answer the following research question:

“What are the initial viewpoints of people with AMD towards wEVES?”

Materials and methods

Participants:

Participants had VI due to AMD but were excluded if they had previously trialled or used wEVES, had VI primarily caused by a disease other than AMD, were non-English speakers or failed the Six-Item Cognitive Impairment screener (18). Purposive sampling was conducted from a low vision clinic in Birmingham, United Kingdom, with interviewees recruited to reflect the profile of people with age-related macular disease seen in this clinic, in terms of age, sex, time since diagnosis and severity of vision impairment.

Procedure

Age, gender, ethnicity, sight loss registration status, number of years VI had affected life, and the type of low-vision aids (LVAs) currently used were recorded. Monocular and binocular Distance Visual Acuity were measured with the participants' habitual spectacles using a Lighthouse Series ETDRS logMAR letter chart (Precision Vision Woodstock, IL, USA). Binocular contrast sensitivity was measured using a MARS chart (Mars Perceptrix, Chappaqua, NY, USA). Patient identification of binocular comfortable print size (CfPS) was used as a proxy measure for critical print size using habitual spectacles and a Bailey-Lovie Word Reading Chart (National Vision Research of Australia) (19).

Data were collected in a series of individual semi-structured interviews, which took place either at the participant's home or within the low-vision clinic. Interviews were conducted from July to October 2022 by researcher AM using a topic guide developed following a scoping review of literature assessing the benefits of wEVES for people with AMD (13).

Open-ended questions were used to explore the impact of VI on daily life, opinions about the current devices used to support their VI and their initial viewpoints on the concept of wEVES. Interviewees were then shown two different wEVES; the GiveVision SightPlus (givevision.net/en/sightplus) as an example of a VR-style device and the OxSight Crystal (oxsightglobal.com/crystal/) as an example of an AR-style wEVES. The order of presentation of the wEVES was alternated between participants to ensure the findings were not influenced by the first device seen. Devices were disabled, and a demonstration of the wEVES was not undertaken to ensure participants reflected on the device's characteristics and not its practical performance. Further questions were used to gather opinions about the relative merits and limitations of the two styles of device, covering design characteristics, methods of interaction, and potential usage.

Topic guides were reviewed and iteratively developed throughout the interview process to ensure the data addressed the identified research question.

Audio-recorded interviews were pseudo-anonymised and transcribed before being analysed line by line with the support of NVIVO (Release 1.7) software (qsrinternational.com).

Qualitative data analysis

A broadly experiential orientation was taken to provide a platform for the participants to express their views and allow experiences to be heard by both the designers and prescribers of devices.

Reflexive Thematic Analysis (RTA) (20-22) was chosen to analyse the data as its flexibility allowed the development of themes which captured both the semantic and potentially latent meanings of the results, whilst requiring the authors to appreciate and recognise the influence of their role on the nature of the data captured. RTA does not have a predetermined theoretical framework; instead, it requires the researcher to articulate the methodological decisions made (23). It was believed that the data collected would reflect the participants' mediated reality shaped by their cultural and situational context. Therefore, a critical realist approach to analysis was taken, which could be seen to reflect a combination of a realist ontology (a defined and knowable truth exists waiting to be found) with a relativist epistemological approach (human practices create "truths" that are dependent on perspective and context) (24). This approach allows the interpretation of the data to give "*situated interpreted realities*" of the participants (25), presenting the key messages of importance to the participants whilst also reflecting on social, physical, and other influences that underpinned the data collected. The roles of the authors within the 6 phases of RTA (25) are outlined in Table 1.

Table 1: Authors' contribution to the six phases of Reflexive Thematic Analysis (25).

Abbreviations indicate author initials.

Phase	Author Involvement
Phase 1: Data familiarisation	AM conducted and transcribed interviews verbatim. Interviews and transcripts were listened to and read multiple times to enable deep familiarisation with the content. Initial notes were discussed with JM.
Phase 2: Coding	AM coded interviews using NVIVO software. Codes were developed iteratively using a largely semantic framework towards meaning.
Phase 3: Generating initial themes	AM collapsed codes with the same content and clustered codes with shared ideas to develop candidate themes
Phase 4: Developing and reviewing themes	AM and JM reviewed candidate themes to check the fit with the data and ensure they reflected the patterns seen in the data set.
Phase 5: Refining and naming themes	AM further reviewed the dataset to refine themes to ensure a strong core concept and clear differentiation from other themes. All other authors reviewed this process.
Phase 6: Writing Up	AM selected extracts of the dataset as illustrative examples of the themes. AM wrote the final paper with input from all other authors.

Generated codes represent the researcher's interpretive analysis which happens at the intersection of the data, the theory used in the analysis, and the skills brought by the researcher (26). The data analysis was informed and dictated by the principal researcher, a fully sighted male optometrist with 30 years experience providing low-vision assessments and leading support teams in hospital and community settings in the UK and developing countries (AM).

When using RTA to analyse datasets, the concept of data saturation to establish a sample size can be problematic with endpoints of data collection necessarily subjective due to themes being an "*interpretation of, not excavated from, data*" (27). Data analysis was interwoven with collection at a predominately semantic level with a homogenous population in a relatively non-provocative topic area. Therefore, the concept of data sufficiency with consistently identified and well-developed themes was used to cease data collection at 10 participants.

Ethical considerations

This study was approved by the Faculty of Science and Engineering Research Ethics Panel at Anglia Ruskin University, UK (eth2122-0703) and followed the principles of the Declaration of Helsinki. All participants gave informed written consent to take part in the study.

Results

Ten interviews were completed with the characteristics of interviewees summarised in Table 2. Three interviews were conducted within the clinic and seven in the participants' homes. Interviewees were allowed time to develop their answers fully, and interview length ranged from 26 minutes to 1hr3 minutes (median 44 minutes). Interviewees have been provided pseudonyms rather than numbered identifiers to ensure that the quotes are attributable to human participants rather than experimental subjects.

Table 2: The demographic characteristics and visual function of the study participants. VI = Vision Impaired; VA = distance binocular visual acuity; CS = contrast sensitivity.

Participant	Location	Sex	Age	Ethnicity	Years VI	VA (logMAR)	Patient identified comfortable print size	CS (logCS)
Elsie	Clinic	Female	81	White British	6	1.02	<N80	1.08
Emily	Home	Female	74	White British	17	0.62	N40	1.04
Jacqueline	Home	Female	86	White Other	1	0.48	N16	1.16
Steven	Home	Male	95	White British	10	1.12	N80	0.56
David	Home	Male	88	White British	9	1.30	N80	0.28
Pat	Clinic	Female	78	White British	6	0.16	N8	1.40
Leonard	Home	Male	90	White British	1	0.12	N14	1.44
Mira	Clinic	Female	83	Asian British	6	0.58	N16	1.24
Margaret	Home	Female	78	White British	6	1.12	N32	0.88
Gwen	Home	Female	85	White British	8	1.00	N40	1.44

Overview of themes

Exploration and interpretation of the data resulted in the development of four main themes describing participants' initial views towards wEVES.

- (1) Before We Start, There's No Point Getting Your Hopes Up
- (2) My VI Journey is Steered by Other People
- (3) Flying High with wEVES
- (4) Back Down To Earth

The four themes were set against an overarching concept of a 'Mutual Voyage of Discovery' (see Figure 1). The themes captured the temporal shifting of views and understanding of the participants and researchers as the interview progressed from introduction, through imagined usage, and onwards to recognising the design practicalities of wEVES and how they might be accepted into the lives of the interviewees.

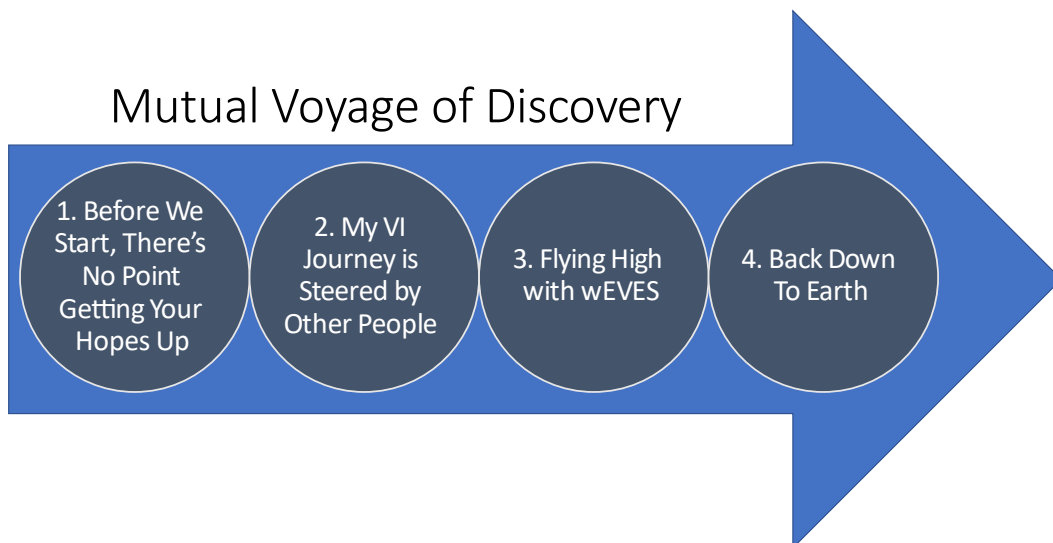


Figure 1: The Four Identified Themes and the Overarching Concept of the Mutual Voyage of Discovery. Where VI= Vision Impairment; wEVES=wearable Electronic Vision Enhancement Systems.

1. Before We Start, There's No Point Getting Your Hopes Up

This theme acknowledges the articulate and vivid descriptions of the widespread impact of vision impairment on the lives of people with AMD. The VI creates

frustrations and challenges in many areas, including practical household tasks, mobility, facial recognition, hobbies and pastimes. However, difficulties are most acutely noted in all aspects of reading. For some, the effects of sight loss are so wide-ranging that it has a defining role in their current identity:

“...it has affected me terribly. Stopped me doing practically everything I loved doing...It does affect my life completely, and I really don't feel like I'm me anymore.” Jacqueline

Furthermore, this theme reflects a resigned acceptance that existing coping strategies, whilst helpful and enabling, are imperfect and do not fully correct the sensory impairment. This feeling can also influence their thoughts and desire to investigate new coping strategies:

“...I use the light and I use the magnifiers. But they're not brilliant. It's not like having my eyes.” Emily

This feeling is not just restricted to aids and devices, it is also used to reflect on the negative influence of broader society due to attitudes, systems and procedures which are not designed to be accessible and therefore create further barriers and difficulties:

“[I] don't always see people, they're almost on top of me, and they're usually doing their phones. Which makes me very angry. Because I think don't they know what dark glasses and white sticks are?” Elsie

Within this framework, some interviewees questioned whether they had a right or the desire to ask wider society to flex to their needs:

“Every day there is a letter ... I cannot read and I have asked, ‘Could I have it in larger letters’ and they tell me some piece ‘It's not possible’....I can't fight it. So, I've got a pile of things to read, and I've got to find somebody who could read it to me.” Jacqueline

This theme also captures that participants understood that innovative solutions also come with a financial cost that may be unaffordable, preventing them from exploring the potential offered by the new technology. This expression of the costly nature of new devices was often set against estimated values which were significantly below the actual UK retail cost of the device (£1,499 Oxsight Crystal

<https://www.visionaid.co.uk/oxsight-crystal> £2,995 GiveVision SightPlus

<https://www.visionaid.co.uk/sightplus> 21st December 2022)

“I’m not very rich, but I’m not very poor. I think £100 should be not bad. I mean, it could be higher, for what it is. But I would be willing to pay £100.” Mira

The expressions amplify the feeling that the limitations and fresh challenges generated by new technology-based solutions can lead to further frustration and disappointment. Participants find themselves in a state where there may be greater serenity found by not actively seeking answers to the well understood visual difficulties:

“Can I suggest age comes into... I’m getting old. It’s probably past my time of life now. I’ve had this [hand magnifier]. I muddle through... I go more on memory than what I do on sight. If that makes sense. So, I probably wouldn’t buy anything. It’s a lot of money at my age.” David

There were almost universal descriptions that the limitations and inadequacies of current coping strategies to address the visual disability led to discontinuity of tasks. At times stopping tasks was seen as preferable to the continuation of the search for a new solution which may again ultimately prove to be inadequate:

“The craftwork ...has gone into a bit of a decline really. It’s been upsetting for me when I have tried, and as I say, it slows me down terrifically. Even threading a needle, I have to get somebody to thread the needle for me, and it’s just [pause] in the end I’ve gone to a point, I think it’s not worth bothering with really. Which is [pause] it’s not nice...” Emily

There was latently expressed resignation that, whilst not perfect, at least the frustrations created by existing coping strategies are known and easier to tolerate:

“I always say ‘I’m not interested. I just find it clumsy to have to do something, to have something like that. I suppose it’s just vanity probably to a point.

And he [partner] says, ‘there’s this going on, you want to try that’ I said, ‘no, I’m happy with what I’ve got’, and I think I’m sort of a stick in the mud to a point really.” Pat

Within these conversations, it was found that participants talked eloquently and at length about the nature of their sight loss and the way it created limitations on their current life. However, when offered a new device not limited by demonstrations of practical performance, some participants chose not to imagine using the device to solve these challenges. We label this disconnect between recognised visual problems and a new coping strategy as “settled acceptance”. This approach reflects participants using the acceptance of being unable to do tasks as a substitute for actively searching for a coping strategy that may disappoint in terms of its performance or their ability to employ it successfully. This self-acceptance is a valuable proxy for a coping strategy but was not seen as a state of happy contentment, merely a conduit to manage the difficulty. Neither was it necessarily felt that the situation was due to the failings of rehabilitation services or society to meet their needs. Instead, it was often self-interpreted as due to their own inadequacy or apathy:

“I must admit I have got lazy as regards reading things. I leave them, or I’ll just get someone else to do it for me. When I could, if I tried, do it for myself.” Margaret

2. My VI Journey is Steered by Other People

Participants discussed the influence of others on their experiences as a person with VI and the solutions they would need or use. These interactions could be expressed

positively, such as discussing the benefits of supportive family members who provided significant assistance without which they would struggle to manage. This support was widespread, including help with practical tasks such as shopping and paperwork, but also with guiding and supporting them to purchase and use electronic-based coping solutions:

“I’ve got two sons, one’s in Blackpool... he’ll try and find things out for me...he’ll say, ‘Well Mum, you can do this, or you can do this.’ Sometimes, then he’ll get on to my iPad. I don’t know how you do it... but he can get on there and see what I’m doing and helps me in that way.” Gwen

However, there was also an acknowledged stoicism, noting that they had to be independent to reduce the burden of reliance on family and friends.

The role of other people was also expressed negatively, with descriptions of how the views of others may influence their choice or ability to use a coping solution, especially one like wEVES, that may draw attention to themselves. These feelings ranged from a sense of self-consciousness that would discontinue the use of a device to ones reflecting that the use of an obvious disability aid would increase their feelings of vulnerability to verbal abuse or attack:

“I think it’s embarrassment more than anything really... people said, ‘Why don’t you use a white stick?’ ... I feel vulnerable with the white stick. So, I’ve never used it to tell you the truth... ‘There’s something wrong with me.’ He’s ‘easy meat’ type thing. If that makes sense.” David

However, in this area, there was a dichotomy of thought, with others feeling that if a device was able to improve their functionality, they would be happy to use it despite the views of others:

“...at the age of 90 I’ve been through all that.... I’m not a fashion person. I want results. I am more practical, you know. I don’t care what a car looks like. I’m more interested in how it functions.” Leonard

Participants recognised that modern technology could do more to support their needs arising from their sight loss. However, there was also an understanding that many participants would need extensive support and training from others to use a new device. It was unclear to the participants who would deliver this training, with this burden regularly falling on the family, who many felt were already under pressure to provide support in other areas due to their sight loss:

“I mean people have said to me you should do it on your iPad, to read, but I haven’t got around to. I do need a bit of guidance to get that set up.” Emily

This theme also captures the value that participants placed on the input of professionals and family members. Despite their lived experience of sight loss, there was an expression that this was not just about the mechanical use of the device. There was a desire for others who understood their sight loss to help them judge the suitability of wEVES compared with other solutions:

“I’ll let you do that work. I’m not putting my head into all the details..... because we’re not an expert in it...expert in the sense because we’re using things... But still there are other people who know a bit more... it’s teachers and students.” Mira

3. *Flying High With wEVES*

This theme is used to capture the numerous very positive and effusive reactions of participants at the time when the concept of a wearable magnifying device was first introduced to them:

“Have you got one with you? Can I buy it now!” Leonard

Participants were frequently enthused by many of the prospective features offered by wEVES. The key benefits expressed by participants included the ability to apply magnification in a compact device whilst at the same time having hands free for manipulation:

“It’d be absolutely superb. I always want three hands to tell you the truth...there’s DIY. That would be ideal for repairing electrical things. That would be ideal.”

David

Participants repeatedly talked about their desire and need for solutions that can manipulate contrast as well as magnification—something which is not delivered by traditional optical magnifiers, which only offer simple illumination:

“That would be of great value. Because you can alter the contrast with the colour. Because that is one of the main issues getting the colour {right}.” Steven

In addition to this, an ability to theoretically provide magnification over a range of distances was warmly received. Many participants reflected on the inadequacy of current solutions here, especially when trying to find items when shopping:

“Because we’ve retired now, it’s one of the highlights of the week is going shopping, but I can’t see what’s there.” David

“I can’t just scan the shelves. I have to really stop; look closely and still I can’t always see what’s on the packet or the tin or the prices.” Emily

Participants also applied the prospective benefit of variable focusing distances to practical household problems such as cleaning, television and checking the cooker. However, this imagined use was similarly extended to other less functional tasks, including the desire to see paintings, photographs, and theatre productions with more clarity:

“Well, this is the only drawback now with macular, I can’t go to the theatre. I love the theatre, and we’ve always gone to the theatre. We used to do trips in London and everything.” Pat

There was very little expression of concern about trialling a device or the potential for any side effects whilst using wEVES. Any reported worries centred around the possibility of eyestrain or the practicalities of the device to work against the background of a declining eye condition.

4. *Back Down To Earth.*

Following the imagined and idealised reality of wEVES, the final theme captures the change and shift in views that occurred after seeing and handling the devices for the first time. For many, this was initially reflected in expressions of significant disappointment due to the practical realities of the two presented devices. The theme captures the widespread feelings expressed about the challenges of the weight and enclosed nature of the VR headset. Discussions about the weight of the device included, but also transcended, the practical issues of the mass, creating a situation where participants described that they felt the device was no longer an assistive aid but was dictating to them how it was to be used:

“You know, it’s controlling me, rather than I’m controlling it. It’s got a heavy presence for a start, and it is telling me where to put my head.” Steven

Due to the weight, some questioned the suitability of VR devices for older people or women. Ultimately a few described that the weight and claustrophobic nature of the VR headset would mean that they would not consider it as a solution, whatever the practicalities of its delivery when turned on:

“No. I personally couldn’t put that on. Definitely couldn’t wear that. That is too enclosed. The weight of it as well, I couldn’t have it on.” David

Whilst the lighter weight of the AR device was appreciated, there were still expressions of concern about the lack of adjustability of the device and the way the small screen sizes would dictate the head positioning when the device was worn.

Interaction with the devices was discussed, with a preference for tethered or device-mounted, high contrast, tactile controls with fewer buttons. These decisions are made primarily due to ease of use, comorbidities, and the fear of misplacing a separate control system which would render the wEVES unusable:

“I’d make the button a bit more protruding I’ve lost the fine sense of touch in the ends of my fingers. So, I can’t feel when I press my thumb over there. I can’t feel that: the button. So, it would need to be a little bit more protruding.” Leonard

Both AR and VR styles of devices were viewed as unconventional, with many describing that the devices did not have any of the cachet of looking hi-tech, innovative, or modern. Instead, participants reflected on their “otherworldly look” that would make some users feel disinclined to wear them around others regardless of their performance:

“I’m like something out of Star Wars or out of them weird programmes they’re watching.” Pat

“I don’t think I’ll sit in a room and talk to you with those on though. I’d feel stupid. And I’d look stupid as well [laughing]. Let’s face it you don’t look your best with them on, do you.” Gwen

This tempered reality of holding and manipulating the devices often modified users’ views of the practicalities of wEVES usage either due to the now realised weight, size, or thoughts about the practicality of the devices:

“Can I wear it for three hours in a film? Or even 1 1/2 to 2 hours. No. It seems a bit too much. I mean, with the break, Indian films are three hours.” Mira

Or the appearance and potential reactions of others:

“...if I could read what’s on a tin or a box or whatever, the sell-by dates, that sort of thing. But I don’t know if I would want to wear that!” Margaret

Despite the challenges presented by the reality of the devices, what was also captured is the potential offered by wEVES was still seen by many as tangible and valuable.

Participants showed a desire to explore the practical potential of the devices. In doing this, participants reframed the times and context of when they envisaged a device being used, now seeing the devices’ uses as predominately sedentary tasks taking place in isolation at home:

“This would only be appropriate in certain situations, I think, wouldn’t it. You know, sitting down to read or watch television. Or if I was able to do knitting.”

Emily

“Outside it’s a little bit over the top. Question of weight and bit claustrophobic. Other than that, I think in the home, you know, by yourself, I could cope with it.”

Jacqueline

Discussion

The four identified themes were connected by the shifting journey of the participants, flowing from the imagined musing of a new device to the practical discovery of the current engineered concept and then onwards to reimagining its potential to offer support. But this was a shared journey with the researchers hearing the views about wEVES and learning how new solutions can place stressors on the serenity of settled acceptance. This acceptance may be at odds with reablement professionals’ natural drive to seek to introduce solutions to the practical issues facing the people they support.

It was apparent that the initial reactions of participants indicate that many of the unique features of wEVES, such as variable magnification, flexible working distance

and hands-free use, resonate as being beneficial to people with AMD. This response suggests that if wEVES' performance and cost could match expectations, there would be a desire to use these devices among people with AMD. However, findings from this study mirror others exploring users' opinions about wEVES which suggest that the aesthetics of the device are of considerable interest to users, with the device's weight being the principal design concern (28-32). Weight and poor comfort are significant causes of device abandonment or non-use in mixed populations of people with VI (31, 33) and this would also be an area of concern for potential users with AMD.

Interaction with wEVES was discussed by the participants, who expressed concerns about the complexity of interaction, echoing the findings of other work showing that ease of use and simple controls were of considerable importance to users (30, 34). In a home trial of a mixed age and pathology group, a number of participants found focusing (27%) and controls (20%) "hard to use" on a VR style wEVES (35). However, our results suggest that the desire for simplicity was only partly driven by the desire for a device that is easy to use. Other determinants for our participants included challenges from comorbidity limiting sensation and dexterity as well as concerns about misplacement of separate controllers rendering wEVES unusable.

There were clear and consistent expressions showing a dislike of the overall form of VR headset as a wEVES for people with AMD. However, evidence in the literature shows a willingness to purchase and ongoing use of VR wEVES in mixed populations, including those with AMD (31, 35-38). The diversity in opinion within the group about the relative importance of the device's performance over functionality reflects the disparity seen in other papers. Some papers report that the most significant user concern was the device's appearance compared with its functionality (39) others stated that users were significantly more motivated by performance despite aesthetic

issues (40, 41). Some of this disparity could be explained due to the difference in papers seeking opinions from established users (40) compared with prospective ones (39).

Further quantitative work is needed to understand the factors affecting this dichotomy of thought and how it evolves or changes with a trial of the functionality of devices for people with AMD.

The imagined use of the devices shifted through the passage of the interview, with potential uses not fully aligning with areas of previously described visual disability. Following initial disappointment seeing the devices, participants reframed their potential usefulness to solo, sedentary activities. This imagined utility was not limited to routine daily tasks but included arts, hobbies, and crafts. Research indicates that individuals with VI tend to abandon their participation in hobbies and craft activities, which have been shown to be important for maintaining quality of life (42). Discontinuing these tasks may be caused by the inadequacy of current low-vision solutions that may deliver unreasonably close working distances or occupy the hands controlling a magnifying aid. It will be of considerable interest to investigate whether wEVES can motivate and enable individuals to reclaim lost recreational skills if participants are given the freedom to choose their preferred activity and coping solution.

Apathy, Ableist agenda or Digital Divide?

Visual disability can be framed using a medical model to explain the underlying functional failings or a social model suggesting that disability arises from the barriers that society places in front of people with VI (43). A sizeable proportion of the more recent academic research about wEVES uses a medical model for their outcomes, mainly concentrating on visual function changes from the baseline. However, the danger in viewing sight loss in these terms is that the loss is merely seen as a deviance from “normality” in search of a correction, a standpoint disability studies resolutely

oppose (44). Our results showed that when viewing visual disability from a social model perspective, some individuals are not actively seeking technological solutions to change their situation. Professionals may need to respect the individual's right to "settled acceptance" and recognise this as a considered coping strategy. The platitude "It's OK not to be OK" has widespread use when discussing mental health issues, but the question is, should this right be extended to people with sight loss and their visual disability? There is an indication from the data that the nature of the settled acceptance is not simply a coping mechanism bringing peace of mind. At times, the lack of desire to explore technology solutions appears to result from the societal digital divide, further marginalising an already disadvantaged community (45). If settled acceptance is motivated by fear of the new, lack of opportunity or knowledge, then it is reasonable to want to understand if an individual's position would change if they were better supported with more accessible products, improved information, or training.

The older population is known to be the most digitally diverse and divided demographic (46, 47) with over half of all adult internet non-users in the UK over 75 (48). This lack of comfort with technology was reflected in the data which showed that for many participants, technology offers assistance for their VI. However, at the same time it could also add to the frustrations of their sight loss, with feelings that there is a better solution just out of reach, which they are failing to grasp due to a lack of skills, finance, training, or motivation. This need is seen in the general population of older people, with motivated older adults expressing a desire for training support to access technology set up in a way that understands their distinct needs (49).

Results showed that using aids that highlight a disability in public was a divisive topic within the group. With several large brands developing and releasing new head-mounted devices (HMD) for mainstream use (Apple, Meta, Google, Microsoft), there is

hope that the societal acceptability of HMD, and therefore by extension, wEVES, may improve. Many of these emerging mainstream consumer devices may be repurposed as new variants of wEVES. Inappropriate design of systems leads to further digital exclusion of older adults (50, 51) and in the move to mass market use of HMD the needs of older users must not be forgotten in the rush to appeal to younger, more technologically capable individuals. There is a need to close the digital divide by understanding the best way to articulate the benefits of a device to consumers who may initially be dissuaded by appearance, cost, or “settled acceptance”. To better meet the needs of older adults with AMD, there needs to be consideration of their requirements at all stages from product conception through to retail. This should involve inclusion at the design stage of a device and within usability testing but also consideration of their needs with initial exposure to the device, demonstrations, training, and after-sales support.

Implications for clinical practice

Our results showed that the participants had clear, articulate, and considered thoughts about the design of wEVES. Whilst there was congruity of view in some areas, others displayed a diversity of thought. Likewise, the opinions expressed showed some alignment with other studies with mixed populations but also some inconsistency. Within the tenants of inclusive design, there is hope that the qualitative views of people with sight loss are considered when designing and assessing future products, not just the quantitative outputs of changes in visual function. Within the paradigm of inclusive design, more must be done to hear all the different voices of people with sight loss. This work should not just be centred on younger, technically capable individuals but must also include the older population, who might initially seem disinterested but may be disconnected and excluded.

Practitioners wishing to work holistically with older adults with VI need to see beyond the medical model where VI is seen as a disability waiting to be fixed to understand the broader needs of the person with VI. This inclusion necessitates an understanding that assistive technology such as wEVES produce multi-faceted opinions dependant on the individual's needs and experiences. Therefore, when considering the suitability of wEVES for people with AMD, it is necessary to look further than the simple changes in clinical function that can be achieved using the device. Broader influences need to be considered, including the initial introduction of the concept, weight, controls of wEVES and the quantity and quality of follow-up training. It is the designers' and prescribers' responsibility to ensure that "*A desirable future for disability is one where assistive technologies are solely that, assistive, anticipated, welcomed and in which all disabled people thrive*" (52)

Further research

Participants were deliberately denied the ability to observe the device's performance to limit their thoughts to its design and aesthetics. It is known that the judgement of wearable low-vision aids can shift once participants understand the functionality and usability. A study showed that when participants were asked to assess a wearable optical telescope before its use, they initially rated field of view and acuity as having the greatest importance to their selection. However, following a home trial, users shifted their selection criteria, favouring a telescope that delivered a narrower field of view and duller image than the alternatives (53). Future research to gather the opinions of people with AMD following a trial of wEVES against other coping strategies is needed to understand if these initial views evolve. A better understanding of this area would allow practitioners a richer knowledge of how to introduce, demonstrate and market devices to prospective users with AMD.

Reflections and Limitations

Within quantitative research, there is a desire to consider how reproducible and generalisable data are. This qualitative study has allowed a better understanding of the views of the ten people interviewed without a naïve belief that this encompasses all the disparate views of people with AMD. There is confidence that the participants reflect the diversity of patients with AMD seen within a low vision clinic in a city in the UK with the consistency of the responses allowing belief in the validity of the themes discovered. But there must be caution in extrapolating how well this data would reflect the collected views of people in other countries and cultures. The richness of the data found gives a better understanding of the initial views of people in the UK with AMD regarding the potential for wEVES to support them in their visual rehabilitation and can be used to guide and inform future studies in the UK and elsewhere.

The devices chosen in this study were used to illustrate the two broad manufacturing approaches of VR and AR wEVES. Within each category of wEVES currently on the market there is a notable degree of similarity between devices. As participants were reflecting on the overall concept of wEVES rather than device performance it was felt that the use of a single example of each type of device was sufficient to allow results that were broadly generalisable to the two styles of devices currently available. However future work to test the consistency of findings with other devices would improve the robustness of these findings.

RTA was chosen for the data analysis because of its requirement for the authors to reflect on their active role in data analysis, coding, and thematic development (20). The themes were set against an overarching concept of a mutual voyage of discovery to reflect that this process has informed and modified the views of the researchers as well as the participants. Fully sighted practitioners working to support people with sight loss

must be cautious of the ableist issues that can come from only recognising and assessing sight loss against a framework of sightedness. Concentrating on a loss that must be fixed is to miss the point of ensuring that the holistic needs of the person with sight loss are central to the interventions needed. Whilst every effort was made to ensure that participants gave a full and frank account of their feelings, there were concerns that the presence of a rehabilitation professional may have modified participants' willingness to express negativity about the benefit of devices. To balance this concern, participants were informed that the researchers wished to capture detailed and frank views and had no commercial or vested interest in the sale or supply of the devices.

Conclusion

The concept of wEVES providing variable magnification and image enhancement in a wearable form is attractive to people with AMD. However, the realities of the appearance, enclosed structure, and, most importantly, the weight of some devices temper the initial thoughts of usefulness. This change in view could be due to the practicality of long-term wear or the potential reaction of others to the use of a device. For some, this initial response would cause them to discontinue interest. For others, this leads them to rethink wEVES' usefulness, reframing their potential to imagine support with sedentary tasks at home, which may also include activities which may not be achievable with current solutions.

Assistive technology, including wEVES, can be regarded from several differing viewpoints by the same individual, at times providing help and tangible benefits, and at others, frustration. As a mechanism to cope with the reality that current solutions all have significant compromises, some people choose not to pursue further support from technology. This coping mechanism could be seen as a positive choice but equally could be driven by challenges due to cost, cognition or lack of knowledge and training.

More work is needed to understand the factors influencing where wEVES sit in this model for people with AMD.

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MDC has served on the Technical Advisory Board for OxSight but has no commercial interest in any materials mentioned in this article. AM, JM and KL report no conflicts of interest and have no proprietary interest in any of the materials mentioned in this article.

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