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Research Report

A Qualitative Analysis of Reading Rehabilitation of Persons with Age-related Macular Degeneration

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One of the most prevalent visual impairments of people aged 60 and older is age-related macular degeneration (AMD), which ranks third globally as a cause of visual impairment (World Health Organization, 2006). With AMD, central vision is lost and some peripheral vision remains, causing difficulties with fine vision and tasks such as reading and mobility, which results in reduced satisfaction and quality of life (Mackenzie et al., 2002) and anxiety and depression (Brown, Brown, Sharma, Busbee, & Brown, 2001).

Magnification devices can help to improve the reading performance of persons with AMD, but errors occur when a reader misses the ends or beginnings of words and even entire lines of text (Watson, Baldasare, & Whittaker, 1990). Eccentric viewing can be used to regain former visual abilities (Fletcher, Schuchard, & Watson, 1999) by training persons with AMD to use a preferred retinal locus (Schuchard & Fletcher, 1994). An improvement in reading skills may help these persons adjust to their loss of vision (Trudeau, Overbury, & Conrod, 1990).

Qualitative assessment is limited in visual research, particularly research on AMD. Wong, Guymer, Hassell, and Keeffe (2004) reported how persons with AMD made sense of their experiences. The purpose of the study presented here was to extend Wong et al.'s findings and to conduct a tentative subjective assessment of eccentric viewing by persons with AMD. We recruited registered

persons with bilateral AMD who had low vision from the Low Vision Clinic where they had received some instruction in the use of their magnification devices; all lived in London, England. In comparison, the visual acuities of 15 participants in the Wong et al. study ranged from unilateral impairment to a visual acuity greater than 6/60 (20/200) in the better-seeing eye. Eleven of these 15 participants with the lowest visual acuity received instruction in the use of magnifiers, techniques for living independently, and social interaction groups, and half resided in rural areas.

METHOD

Participants

Seven persons with bilateral AMD and no other ocular disability were recruited through the Low Vision Clinic at Moorfields Eye Hospital in London, England. Their visual acuities ranged from 6/18 (20/60) to 6/76 (20/250) in the better eye. All lived in London and were aged 62-83 (see Table 1 for the participants' characteristics).

Reading rehabilitation

All the participants received one hour's instruction in eccentric viewing and page navigation with their magnifier using a method called "steady eye," whereby text was optimally enlarged over their own preferred retinal loci (Collins & Davis, 1999). They completed an additional 0-8 hours of practice at home using Wright and Watson's (1995) Learn to Use Your Vision manual, which was chosen for its variety of exercises in texts ranging from 3M to 0.8M, and recorded a log of the time it took them to complete the exercises, the difficulty of the exercises, and any additional comments.

Procedure

Forty-minute interviews were conducted by the researcher (the first author) before and after instruction, using interpretative

phenomenological analysis (Smith, 1996) aimed at capturing how the participants made sense of their experiences while acknowledging the role of the researcher's interpretative processes. The project was approved by the Moorfields Eye Hospital Research Ethics Committee. All the participants provided informed consent prior to their participation.

Interview schedule and analysis

Initial questions on identity, coping, and social support were adapted from Smith and Osborn's (2003) guide to qualitative research, giving the participants the opportunity to describe their life experiences. Further questions were developed to explore the psychosocial impact of AMD on quality of life (Borglin, Edberg, & Hallberg, 2004; Williams, Brody, Thomas, Kaplan, & Brown, 1998), such as whether vision loss had affected their relationships with family members and friends, and the usefulness of existing magnifiers. This interview was conducted before instruction began. Questions related to eye control and the participants' opinions of eccentric viewing were asked postpractice. This schedule was pilot-tested on two consultant patients (a copy of the full interview schedule is available from the authors).

Using interpretative phenomenological analysis, we coded the transcribed interviews and recorded the initial comments and reactions. Then, we made connections between the themes that emerged and gave clusters of subordinate categories superordinate higher-level theme titles. Each superordinate theme was linked to underlying categories of subordinate themes, which, in turn, were connected to the original quotes from the participants that were used to construct accounts from a thematic table.

RESULTS

The superordinate theme of the initial shock of discovering AMD revealed that the participants took time to understand the chronic progressive effects of their illness and did not make full use of

low vision devices, such as white canes and magnifiers. Society's lack of awareness of AMD proved frustrating for them. Another theme was feeling "only half a person," which indicated that the giving up of tasks that proved too difficult, such as reading and hobbies, led to frustration, irritation, and boredom. Difficulties associated with asking for help from others was another theme, but the participants realized that to expedite daily tasks quickly, it was easier to ask for help. Finally, the participants felt a real fear of the future and the unpredictability of vision loss and their ability to cope, but felt relief that they would not become totally blind, since peripheral vision would remain. These themes reflect those of Wong et al. (2004). Additional superordinate themes related to the participants' assessment of their current magnification devices, social support and independence, and assessment of eccentric viewing.

Examples

Standard rehabilitation: Using magnifiers. Four participants found their magnifiers to be invaluable when needed for "spot" reading, as the following comment illustrates: "The magnifiers have certainly made life possible. Without them, I would find it very difficult."

Social support from family and friends. Two participants found the extra attention they were receiving from family members since the onset of their AMD to be patronizing. They reported that they did not like their arms being held and led, and thought that if they could overcome the difficulties of their vision loss, they should be allowed to cope independently.

Daily tasks and role change. The participants needed to use their other senses, such as sound and touch, to perform daily tasks. They all explained that tasks had to be broken down into smaller stages, but that they had to allow much more time to complete the tasks. Four participants reported losing their confidence to continue with some activities in the home, which led to a change of roles within their families. As one participant noted: "You lose

your confidence with cooking. My son helps me a lot with that. In fact, I don't enjoy cooking now like I used to; now I think it's just a chore."

Maintaining activities. The participants emphasized that they continued to read and recognized that reading was one of the main goals of rehabilitation, as this comment shows:

> I . . . still do read, kind of extensively, poetry, prose, you name it. I also do crosswords; therefore, my brain is working in a sort of way. . . . So when I'm reading a sentence, I know what I'm reading. I know what to expect, in a sense. I mean, I might be running along, and there may be a word there; my brain will now take over and say what that word should be in the context of the text. Do you see what I mean?

Acceptance. Accepting that life was different now was easier for two participants, as one participant stated:

> I'm a more balanced person. I'm a lot more empathic when dealing with other people, and I've developed a better sense of humor than I had before; it's usually targeted at myself. I haven't got sulky or negative in my feelings.

Eccentric viewing: Conscious control. Six respondents did not feel they had any control over their eye movements when they first received reading instruction. However, after they completed the eccentric viewing practice, five could explain the eye movements they were making, said that they had identified an area of the retina that they used throughout their reading, and could describe in which direction they looked when scrolling with their magnifiers. The common complaint, however, was that the practice was tiring, as this participant noted: "It really made my eyes ache, and I had to sit there with my eyes shut for a while afterward."

Outcome of instruction. With regard to reading eccentrically, two participants did not practice eccentric viewing; they both complained of tired eyes, and one did not feel motivated and thought it was boring. Three participants were resigned to the fact that they would not read properly again, and said that reading was no longer enjoyable.

In relation to individual instruction, five participants thought that the fact that someone wanted to help them was a positive reason to go on with the practice, and three of them thought that their reading skills had improved as a result of practice. As one participant said:

> I found it very helpful because it focused my mind on the fact that there were different ways of looking at the text that I hadn't realized before. So I use that, and it's sharpened up my ability a bit.

With regard to the costs and benefits of learning eccentric viewing, the participants thought that it was hard work, but they differed in their opinions of whether there were any real benefits. The three who lived alone thought that the whole experience was invaluable and empowering, whereas the four who lived with their families thought that the costs associated with tiredness in the eyes and the extra effort required outweighed any possible benefits of maintaining independent reading skills. Thus, we found that the split in the assessment of the benefits of eccentric viewing was related to individual living conditions.

DISCUSSION

Many of the themes found in our study mirror the findings of Wong et al. (2004) and demonstrate the similarity of the participants' experiences. There were some differences between the studies, however; for example, all the participants in our study thought that their magnifiers and the rehabilitation they had received prior to the instruction in eccentric viewing had been invaluable, whereas Wong et al.'s participants thought that their magnifiers had become ineffective. This finding may be related to experience and skill in using magnifiers. Wong et al.'s participants also reported feeling isolated, possibly because they lived in rural areas, in contrast to the participants in our study, who lived in London. We also found that, like the participants in the study by Mogk, Riddering, Dahl, Bruce, and Brafford (2000), the participants in our study expressed one or more symptoms of depression, which highlights the importance of rehabilitation

interventions with persons with AMD.

Stelmack, Massof, and Stelmack (2004) reported that overcoming reading difficulties using eccentric viewing requires persons to be highly motivated and the instructor to be skilled in conveying how they should find their best preferred retinal loci. Three participants in our study reported benefiting from the instruction and practice. They were enthusiastic about using their time and effort to improve their reading skills. Their attitude may have been the result of the therapeutic effects of individual counseling from the trainer, which they interpreted as emotional support. In a study of perceptual training and information sharing with persons who are visually impaired, Conrod and Overbury (1998) found that the participants perceived greater benefits if they received one-on-one training than if they received the same training in a group.

In conclusion, we found that the themes pertaining to the subjective assessment of eccentric viewing that emerged from the data were related to instrumental and emotional support and the costs and benefits of acquiring eccentric viewing, which appear to be interactive. Although the participants who lived alone also found reading to be difficult, they felt that they benefited from eccentric viewing as a means of exploring their remaining vision and the possibility of optimizing their reading abilities, possibly because they did not have the option of changing roles to retain their dependence.

Limitations

Despite our efforts to recruit a homogeneous group, the participants varied in age (62-83 years), the length of time since they had registered as having low vision (1-30 months), and instrumental help (living alone or with their families). In addition, the researcher was not a qualified vision rehabilitation specialist.

Future research

Individual counseling would provide a suitable arena for addressing psychosocial issues and adapting to visual impairments, such as AMD. A useful intervention would be to teach new adaptive responses to vision loss by counseling a newly diagnosed person to expect certain reactions from sighted people. This intervention would facilitate social interactions with family members, friends, and the general public (Tuttle, 1996). Further research is needed on eccentric viewing and whether it has distinct benefits for particular individuals with AMD.

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