

Ophthalmology

ROUNDS

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Vision Rehabilitation and the Epidemic of Vision Impairment

BY MARY LOU JACKSON, MD

This issue of *Ophthalmology Rounds* addresses the emerging epidemic of vision impairment that ophthalmologists will face over the coming decades and the role that vision rehabilitation should play in the continuum of ophthalmic care.

America is getting older. By 2020, there will be 53 million Americans aged >65 years and 6.5 million of this cohort will be aged >85 years. This demographic shift will create new demands on healthcare services. Because the risk of vision impairment increases 3-fold with each decade after age 40 years, the healthcare demands will disproportionately affect the ophthalmology specialty. By 2020, almost 3 million Americans will have advanced age-related macular degeneration (AMD)¹ and, in the upcoming decades, nearly 1 in 4 Americans will eventually lose vision due to AMD.² The following case and subsequent discussion illustrates the important role that vision rehabilitation can play in the management of patients whose visual loss cannot be reversed.

A case presentation – Patient A

Patient A, an 82-year-old woman, was diagnosed with AMD in both eyes 2 years before presenting to the Massachusetts Eye and Ear Infirmary (MEEI). When first seen, she is recuperating from hip replacement surgery. Her central visual acuities measure 20/100 in her right eye and 1/300 in her left eye. Her family members are puzzled because she is able to pick up small objects on the carpet, but has great difficulty recognizing people and seeing the food on her plate in a restaurant. They are concerned that she is becoming demented because she insists that she can see “little men in green leprechaun outfits dancing” in her garden. They are also concerned that she still wants to drive. The patient readily admits to being depressed about her vision loss. After retinal assessment is completed and potential for treatment is ruled out, this patient is referred for vision rehabilitation.

What are the best methods to assess her level of visual function? Should a neurological evaluation be recommended because of her visual hallucinations? How should the question of driving be handled?

Overview of patient management and vision rehabilitation

The field of ophthalmology provides many very successful medical and surgical interventions. New therapies, especially those for AMD – the most common cause of vision impairment in the industrialized world – are rapidly emerging (see *Ophthalmology Rounds*, 2006, Volume 1, Issue 1 for a review). However, even with the broadening range of therapeutic options for eye disease, many patients will, nonetheless, continue to be incapacitated, or at least, significantly impaired, by vision impairment.

A recent issue of the *Journal of the American Medical Association* reported a clinical case of a patient – a surgeon – who developed visual loss from AMD.³ His description is an explicit example of how vision loss can impact function. This patient reported, “It was during the summer about 3 years ago that I became aware, while I was driving, of a subtle change in the shape of billboards. And then I noticed that if I looked at a page, the upper right hand corner of the page would sag. And I thought this was most unusual. My ophthalmologist could not find anything on her examination, so she referred me to a



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retina specialist. I've received 4 treatments, but I've had a substantial loss of vision. The issue that bothers me most is that I can no longer work as a surgeon, I can no longer operate. It's been absolutely devastating. My eye-hand coordination was my life. In the operating room, I can't demonstrate a procedure. It's astoundingly defeating. I want to protect the vision in my good eye. I would like to know what else I can do to protect the vision in that eye and I'd like to do everything I can so that I can read with greater ease. Not being able to read, write, or drive, and not being able to function with fluidity is a terrible handicap."

Vision rehabilitation addresses functional impairment due to vision loss. Historically, services focused on severely impaired young adults and children, but they have now expanded to include older patients with partial vision, such as those with AMD who retain peripheral vision. Services have also expanded to include many newer technologies such as computer adaptations and occupational therapy that add very significantly to the more traditional options of optical and non-optical aids. Vision rehabilitation has firmly established itself as part of the continuum of ophthalmic care and referral to vision rehabilitation service is included in the American Academy of Ophthalmology Preferred Practice Pattern for AMD, Open Angle Glaucoma, Diabetic Retinopathy and Idiopathic Macular Hole.⁴

The American Academy of Ophthalmology-sponsored initiative in vision rehabilitation, *SmartSight*TM outlines a graduated model of vision rehabilitation (Figure 1) and recommends that all patients with a visual acuity <20/40, a decrease in contrast sensitivity, scotoma, or other visual field loss be advised of the potential benefits of vision rehabilitation.⁵ Incorporation of a vision rehabilitation specialist in the care of patients with vision impairment addresses the patient's quality of life and enables the ophthalmologist to take a very positive role in the case management of situations where there are few good therapeutic options. It was Dr. Osler who challenged physicians to consider that, "The good physician treats the disease, the great physician treats the patient who has the disease."⁶

Vision and patient function

Ophthalmologists consider both visual function (eg, visual acuity) and a patients' functional capabilities (eg, their confidence and ability to drive) when, for example, they evaluate patients for cataract extraction.

By comparison, when vision rehabilitation clinicians evaluate patients, they use a wider battery of tests, such as reading fluency, reading accuracy, performance on activities of daily living, contrast sensitivity, macular field testing and visual acuity testing. Vision rehabilitation clinicians use the results of these tests to focus on the relationship between a patient's vision and their functional capability, which directs the approach to rehabilitation interventions.

Figure 1: The SmartSight™ Model of Vision Rehabilitation
(Abbreviated from the American Academy of Ophthalmology Initiative in Vision Rehabilitation available at http://www.aao.org/patient_ed/smartsight.cfm)

For patients <20/40, contrast sensitivity loss, scotoma or field loss

Level 1: Recognize and Respond – For All Ophthalmologists
Recognize that even a little loss of vision has an enormous impact on function. With 20/50 acuity or mild loss of contrast sensitivity, reading newsprint and managing medications are difficult. At 20/60 drivers' licenses are in jeopardy. Vision loss is feared and associated with high rates of depression, rates that are lower among those who have the skills and resources to maximize their independence. Ophthalmologists can **respond** by giving patients the AAO SmartSight Patient Information.

Level 2: Record, Refract, Rx, and Report – For All general Ophthalmologists
Record precise acuity at 1 meter, **refract, prescribe** higher adds such as +4.0 or +6.0, stress the importance of lighting and **report** to both the PCP and the patient, the risk of depression, falls, medication mix-ups, social isolation, and the Charles Bonnet Syndrome (visual hallucinations associated with visual impairment).

Level 3: Basic and Comprehensive Low Vision Evaluation
Ophthalmologists interested in offering comprehensive low vision evaluation will address Level 2 above and obtain a functional history emphasizing patient needs and goals, adjustment to vision loss and driving status. Contrast sensitivity, assessment of central and peripheral field, reading ability and assessment of individual factors such as a tremor will direct the choice of magnification aids. Patients may be assisted by being offered referral to support groups or other agencies.

Level 4: Vision Rehabilitation Training
Multi-disciplinary rehabilitation involves other professionals such as occupational therapists, certified low vision therapists, rehabilitation teachers, orientation and mobility specialists and vocational counselors who will address scotoma/preferred retinal locus training, environmental adaptations, fall prevention, transportation alternatives, adjustment to vision loss and training in activities of daily living such as reading, shopping, managing finances, self-care, and taking medications safely.

Visual acuity

Visual acuity is the gold standard of ocular function in ophthalmology. Vision rehabilitation testing includes measurement of central acuity, which is often made at a close testing distance (eg, 1 meter) with a chart such as the Early Treatment Diabetic Retinopathy Study (ETDRS) chart, since this provides more lines of optotypes and, hence, more precise measurement of acuity in patients with poorer vision compared with traditional chart used for Snellen acuity testing. The vision rehabilitation clinician is interested in how the patient reads the chart, including such details as the relative ease or difficulty in performing the test, which letters are missed or misread, the tendency for the patient to miss letters only to the left vs right, and the presence of head movements and searching eye movements that the patient might have used to identify the optotypes.

Assessing the integrity of the central visual field

Methods of testing the central visual field include simple and more complex testing methods. The size, shape, and position of central scotomas will affect a patient's function and should also influence the recommendation for visual aids. Patients with AMD commonly have an eccentric (ie, extra-foveal) "preferred retinal locus" (PRL), which will impact their ability to perform. Amsler Grid testing has been used extensively in ophthalmology, however, the brain's ability to fill in missing areas causes this technique to significantly underreport central scotomas and limits its usefulness in vision rehabilitation. The scanning laser ophthalmoscope (SLO) is perhaps the most sensitive method to assess the integrity of the central visual field, but its cost and availability has limited its widespread use in the clinical arena. The SLO, however, has been an invaluable tool for the study of central visual function in the field of vision rehabilitation, since the real-time imaging of the retina during the test allows the examiner to place the test target precisely where desired, even when patients have poor fixation. SLO testing also allows the examiner to directly observe which areas of the retina are preferentially used by the patient.

An eccentric PRL can develop spontaneously, as shown by Crossland et al., who reported 25 patients, all of whom developed a PRL within 6 months of losing vision in the second eye due to AMD.⁷ Based on SLO research, we now know that patients most commonly fixate above scotomas,⁸ and that they may use multiple loci for reading,⁹ or different loci under different lighting conditions.¹⁰ The presence of multiple sites that serve as a PRL is more common when there are scotomas $>20^\circ$ in diameter.¹¹

Longitudinal observational series suggest that 3 factors are associated with the ability to read large print competently using an eccentric PRL: 1) the ability to have stable fixation with the PRL; 2) having a consistent number of PRLs; and 3) being able to utilize the PRL without awareness. Training strategies to enhance the effective use of a PRL include the creation of patient awareness of the PRL, enhancement of the facility to move one's eye to access the PRL, and development of the ability to read using the PRL. Although some investigators have reported success with training patients to develop appropriate ocular movements to utilize a PRL,¹² others have failed to document improvement in reading speed using trained PRLs.^{13,14}

The advantage of SLO perimetry can be demonstrated with respect to Patient A described above. The SLO provided exquisite mapping of dense central scotomas (Figure 2) that would not necessarily have been predicted by viewing her macula (Figure 3) or as accurately outlined with traditional automated perimetry requiring steady fixation.

The SLO is also useful in trying to understand a patient's reading difficulties. Figure 4 shows an SLO image from a different patient (ie, Patient B) who had AMD, acuity of 20/50, and subjective reports of

Figure 2: Perimetry obtained with a scanning laser ophthalmoscope (SLO) in Patient A. The fixation point is indicated by the red oval. Areas of dense scotomas (DS) and variable scotomas (VS) are shown as they were mapped on the retina. The SLO test is advantageous in that the clinician is provided with a map of visual field performance that is directly superimposed over the patient's retina.



"words jumping" when attempting to read. The SLO demonstrates that Patient B is using a foveal area of fixation, but it also shows that there is a ring scotoma surrounding the foveal area of fixation. As such, only a very small retinal area is available for reading. The words appear to "jump," presumably because they are moving in and out of the seeing retinal areas as saccadic eye movements are generated in an attempt to read.

A patient's ability to develop an eccentric PRL is evidence of "plasticity" within the visual system that develops in response to vision loss. Cortical plasticity in patients with AMD has also been investigated by functional magnetic resonance imaging (fMRI). Baker et al. reported that areas of visual cortex that normally respond only to central visual stimuli are strongly activated by peripheral stimuli in adult patients with AMD.¹⁵ Other researchers, using different testing methods, have also found a reorganization of visual cortex in patients with retinitis pigmentosa.¹⁶ Further

Figure 3: Fundus photograph of Patient A. The funduscopic appearance does not allow one to predict the scotomas documented in Figure 2 above.

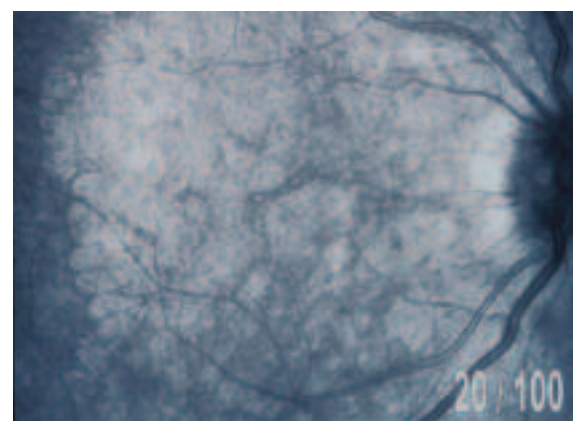


Figure 4: Using a scanning laser ophthalmoscope (SLO) to examine the reading ability of Patient B. In the SLO test, any letter, word, or other visual objects can be projected onto any location within the central retina. In this case, the word "Mississippi" was projected onto the retina. The patient was unable to see several of the central letters of this word (ie, SSIS) because these letters fell into a scotomatous zone.



research is required to definitively answer questions about cortical plasticity and the role of training for visually-impaired patients.

Contrast sensitivity

Contrast sensitivity significantly impacts visual function. Documentation of the ability of patients to perceive contrast provides insight into patients' functional problems and also potential solutions to these problems. Clinicians may suspect reduced contrast sensitivity when visual difficulties do not seem to be compatible with the presence of reasonably good central acuity. The ability to see facial detail, the edges of steps, or items of food when eating all require reasonably good contrast perception. There are many tests of contrast sensitivity that, in one way or another, explore the relationship between the spatial frequency of an image (ie, how coarse or fine the image appears), and the amount of contrast in the image compared to the background (ie, "contrast"). The relationship between the ability to perceive objects that are defined by some range of spatial frequencies and some range of contrasts yields a "contrast sensitivity curve," which can be affected by both age and disease. Tests that use larger images, like the Pelli-Robson charts, are not as susceptible to decline in function with age¹⁷ and these tests have correlated well with a patient's ability to perform activities of daily living, such as driving or navigating.^{18,19} Vision rehabilitation clinicians select illuminated aids and specifically counsel patients on appropriate environmental adaptations when poor contrast sensitivity is detected.

Morbidities and other challenges associated with reduced vision

It is important to note that patient functioning is significantly impacted by minimal vision loss.

Even at levels of vision as good as 20/40, patients have twice the risk of falling, 3 times the risk of developing depression, and 4 times the risk of having a hip fracture.²⁰

Falls in the elderly are a significant problem, with 1 of every 3 persons aged >65 years in the United States falling each year. Ten percent of falls in elderly persons result in a serious injury, most commonly hip fractures. Only 50% of patients who experience a hip fracture ever walk normally again.²¹ Vision loss is a risk factor for falling because vision is required to identify obstacles and because visual input plays an important role in maintaining an upright position once balance is compromised.²² Cataract surgery improves vision and reduces the risk of falling by a factor of 2.²³ Conversely, wearing multi-focal lenses increases the risk of falling because these lenses decrease contrast sensitivity and depth perception in the lower field.²⁴ Vision rehabilitation aims to reduce fall risk through education, optimal optical correction and devices, environmental adjustments and multi-disciplinary referrals.

Depression

All patients are challenged to adjust to the limitations in lifestyle that are imposed by visual impairment. Additionally, many patients are concerned about the risk of further decline in vision. Although most patients make the adjustment to living with reduced vision successfully, approximately one-third develop clinical depression that may worsen as vision declines further.²² The emotional distress experienced by patients with AMD is significant and comparable to the distress experienced by patients who develop chronic illness or cancer.²⁵ Because depression is a treatable disease, the ophthalmologist needs to be aware of the risk for developing depression in patients who acquire vision loss and should recommend a referral to a specialist when appropriate. More research to assess the impact of vision rehabilitation on depression is required.

Visual hallucinations

Recurrent, vivid, visual hallucinations are commonly experienced by patients with vision impairment, but they are not commonly reported. The hallucinations are typically well-formed and can range from simple shapes to complex images, such as colorful flowers, miniature people, or detailed scenery. The symptom is referred to as the Charles Bonnet syndrome, named after the philosopher who first described the hallucinations experienced by his visually-impaired grandfather in 1769.²⁶ The development of these "release" hallucinations is considered to be due to reduced afferent input to the primary visual cortex.²⁷ Remarkably, at least one-third of patients who have reduced central acuity or contrast sensitivity experience this type of hallucination.²⁸

Most, however, do not spontaneously report their hallucinations, perhaps out of concern that this would suggest that they are “crazy” or that their cognitive capabilities are declining. Although patients are aware that the images are not truly present in their environment and usually do not report being bothered by the hallucinations, they are always reassured when their ophthalmologist or vision rehabilitation clinician explains why these visual hallucinations occur and that these hallucinations are not related to the development of dementia which is often a concern for older patients and their family members.

Advising patients on driving

Our patient A wanted to drive despite the fact that her acuity in her better-seeing eye was 20/100. Perhaps her ability to “see” using her extra-foveal or extra-macular regions of her retina led her to believe that she had adequate vision for driving. A clear outline of each state’s licensing requirements and reporting laws, as well as information about the assessment of vision, and the counseling of patients is presented in the American Medical Association document, *Physician’s Guide to Assessing and Counseling Older Drivers*.²⁹ Vision rehabilitation can support a “driving retirement” by educating patients about transportation alternatives and offering appropriate counseling.

Two challenges faced by the field of vision rehabilitation

The modern field of vision rehabilitation therapy faces two significant challenges. The first challenge is to evaluate outcomes and develop an evidence-base to direct interventions. Although many of the currently used strategies to assist visually impaired individuals might intuitively seem to be appropriate and useful, there is a relatively sparse foundation of evidence-based data to support the use of many interventions. The field of vision rehabilitation has in the recent past begun to obtain evidence related to the use of various interventions, which is procured with appropriate randomization, use of control subjects, attention to “masking” or other confounding effects, and other design elements that are certainly going to better inform the approach to patient care.

The second substantial challenge for the field is to develop a pathway by which rehabilitation services can become both more routinely available and more effectively integrated into comprehensive geriatric care. Diabetes is an example of a disease in which ophthalmic care is integrated into systemic disease management. Similarly, vision rehabilitation could become integrated into the comprehensive medical care of geriatric patients. Our challenge in approaching the geriatric patient is to look beyond ourselves as eye doctors and

participate in the larger discussion of how “whole person” care can be optimized, particularly for our elderly patients and for the 53 million Americans over the age of 65 years who will be our patients in 2020, just 14 years from now.

Case presentation – Patient A

The ophthalmologist conducting the vision rehabilitation consultation found this patient to have very reduced contrast sensitivity. In order to achieve the patient’s goals of reading her mail and doing her banking independently, the patient was advised to obtain a video magnifier unit (closed circuit TV) and a 20 diopter illuminated magnifier. Her reduced visual function was discussed with her and with her family, with particular reference to her driving ability, her visual hallucinations, and her risk of falling. The patient developed the ability to view eccentrically, which allowed her to see her food on her plate more easily and read with her video magnifier. She became adept at using a white support cane, and more accustomed and confident in utilizing transportation services independently. She participated in a support group and was referred to a geriatrician for assessment of her reported depression. This wide variety of visual rehabilitation interventions resulted in the patient being grateful to her ophthalmologist for her ophthalmic care and for the referral to the rehabilitation specialists.

Key Points

1. Patient functioning is significantly impacted by minimal vision loss.
2. The ophthalmologist is the key person to recognize patients with <20/40 visual acuity, contrast sensitivity loss, a scotoma, or field loss and can respond by advising these patients about vision rehabilitation.
3. Patient information and vision rehabilitation referral information is available on the American Academy of Ophthalmology website at http://www.aaopt.org/patient_ed/smartsight.cfm

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Patient Information SmartSight™: Making the Most of Remaining Vision

http://www.aao.org/patient_ed/smartsight.cfm

Is it difficult for you to read the newspaper, write your checks, or manage your medications? You may need strategies of vision rehabilitation to help you make the most of your vision. Comprehensive vision rehabilitation services include a low vision evaluation and rehabilitation training. For more information, see the Academy handout at www.aao.org/patient_ed/smartsight.cfm

To locate services you may contact:

Veterans: U.S. Dept of Vet Affairs: 877-222-8387, www.va.gov/blindrehab

Everyone: SmartSight's partner VisionConnection: 800-829-0500, www.visionconnection.org, and select "Help Near You". Note if services include: low vision evaluation, device prescriptions, loans before purchase, rehabilitation training, home visits, lighting or computer adaptations and if services are free, billed to Medicare or charged for?

RESOURCES

National Organizations for support, information, research updates:

MDSupport: www.mdsupport.org.
 Macular Degeneration Partnership: 888-430-9898, www.amd.org
 National Eye Institute: www.nei.nih.gov.

Audio Books and magazines: on tape and by phone

U.S. National Library Service, tape player included: www.loc.gov/nls
 American Printing House for the Blind: 800-223-1839, www.aph.org
 Choice Magazines: 888-724-6423 and NFB Newsline: 866-504-7300

Large print books, materials

NAVH: large print books on loan, 212-889-3141, www.navh.org
 Large-print checks and registers, from your bank (Deluxe catalog)

Vision Rehabilitation Self-Help Books:

Macular Degeneration: The Complete Guide to Saving and Maximizing Your Sight, L. Mogk, MD, & M. Mogk, PhD, NY: Ballantine, 2003;
Making Life More Livable, M. Duffy, NY: AFB, 2001, 800-232-3044.
The First Year - Age Related Macular Degeneration: An Essential Guide for the Newly Diagnosed, D. Roberts, NY: Marlowe, 2006.
The First Year - Age Related Macular Degeneration: Overcoming Macular Degeneration: A Guide to Seeing Beyond the Clouds, Y. Solomon, MD, & J. Solomon, NY: Avon, 2000

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