

## How We Can Improve the Lives of Our Patients Who Have Already Lost Vision or Will Lose Vision in the Future

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### Abstract

An overview of "How We Can Improve the Lives of Our Patients Who Have Already Lost Vision or Will Lose Vision in the Future," presented at the American Glaucoma Society Meeting, 2015.

### Keywords

Vision loss, quality of life, glaucoma

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Thirty-nine million people in 2012 could not see the external world at all. Two hundred and forty-six million people saw the world poorly. Many of these people lose the ability to function and consequently have a decreased quality of life. Much of that decreased ability to function, along with the attendant worsening of quality of life, is unnecessary. It is truly tragic that many patients and many physicians do not know what can be done to help the lives of those who have already lost vision or who will lose vision in the future. Among my patients, for example, only 12 % know how to use a computer to magnify, and only 4 % are aware of how to use a computer to turn print into voice, or vice versa. Many agencies, such as Associated Services for the Blind and Visually Impaired (ASB) in Philadelphia, and many support groups exist to help those who have reduced vision, but a large number of patients are unaware of these agencies, and physicians are slow to refer to them.

Ophthalmologists, of course, have a primary responsibility to preserve vision, but they can do much more than that. While their first task is to be knowledgeable, skilled, and appropriate, they need to remember that to enhance the ability to function, they need to care for their patients *with that goal in mind*. Different aspects of vision have different effects on a person's ability to function. For most acts, for example, VA is more important than visual field. *Figure 1* illustrates the relationship between VA and the ability to perform nine different activities of daily living (finding boxes in a store, reading signs from a distance, and recognizing faces). On the vertical axis is the score of the test known as the Assessment of Disability Related to Vision (ADREV). The higher the score, the better the function. The closeness of the relationship between acuity and the ability to perform the activities of daily living is clear. By contrast, in *Figure 2*, using the same test and comparing to the score for field, the scatter is obviously much greater.

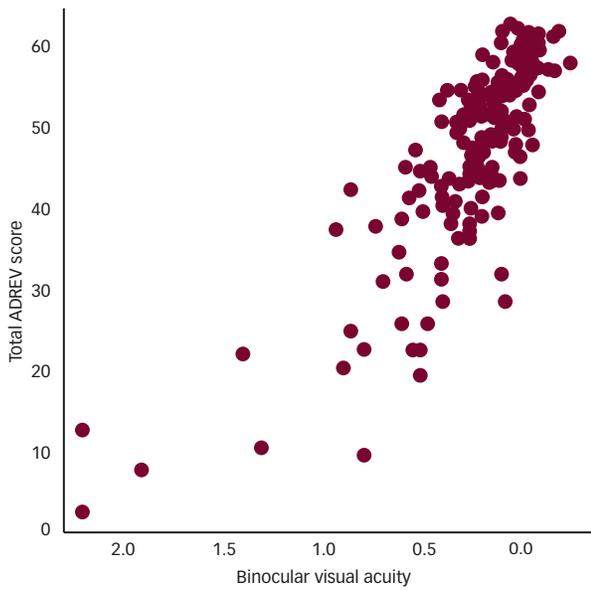
The results are important for those taking care of patients who have glaucoma, but there are many other causes of visual loss. A common one is ocular surface disease resulting from various conditions, including medications used to treat the glaucoma itself. Making sure that excessive medications are not used is an important step in keeping people maximally functional. The goal is not regulation of intraocular pressure, or even preservation of visual field, but rather preservation of function and feeling.

Physicians should know about how patients can be helped, including through use of optical magnifiers, both those that are self-illuminated and electronic devices, including computers. Much adaptive hardware and software can now assist character recognition, voice recognition, and voice reading. Many agencies, such as ASB, are expert in helping people remain mobile and independent and functioning well. Those dealing with people who lose vision need also to be aware of experimental devices, such as OrCam, a device attached to eye glasses that can recognize objects and "speak" the identity to the wearer.

Perhaps the most important way ophthalmologists and other physicians can help preserve quality of life is simply to be aware of the problems associated with visual loss and to listen to their patients empathetically and knowledgeably. Ophthalmologists should want to know, should ask about, and should learn about their patients' reactions to loss of vision that has already taken place, as well as fear that vision may be lost in the future, not to mention certainty of future visual loss.

Several years ago I interviewed a large number of patients who had significant visual loss, not just from cataract, but from other causes as well. There were three commonalities: (1) they feared becoming

**Figure 1: Relationship Between Visual Acuity and the Ability to Perform Nine Different Activities of Daily Living**



The y axis is a measure of the ability to perform the activities of daily living, as measured by the Assessment of Disability Related to Vision (ADREV): 63 is a perfect score; 0 is inability to perform any of the tests. The x axis measures binocular visual acuity, with 2.0 being poor acuity and 0.0 being normal.

dependent, (2) they found that they did not become as dependent as they thought they would be, and (3) they were surprised to learn that they did not know who their friends were until they lost their sight; then they found that some individuals considered long-term friends abandoned them, whereas others with whom they had lost touch suddenly reappeared and became major supporters.

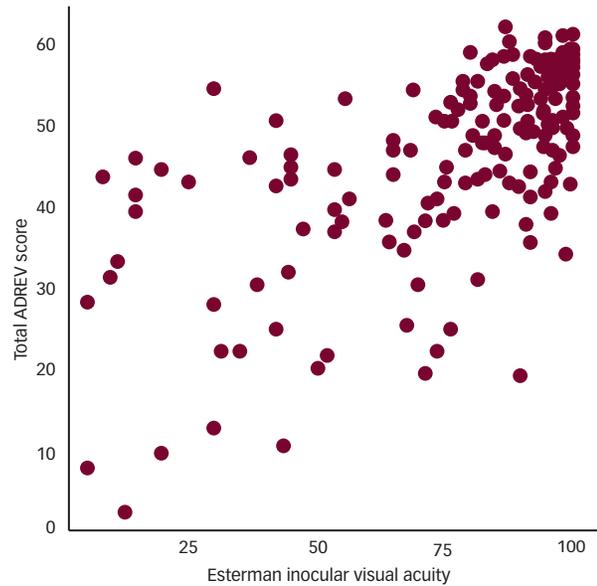
Some patients become angry about losing vision: “Why me?” they ask, as if being discriminated against. Some feel guilty, as if punished for some bad act in their past. Many feel isolated. Understandably, they become concerned about losing their jobs. All these concerns need to be addressed effectively. A useful comment to make to patients who are losing their vision is, “You are entering a more meaningful stage of your life.”<sup>2</sup>

Ophthalmologists can be of help to patients who are losing vision by referring them to other visually handicapped people who are coping well with their problem, or by putting them in contact with support groups. Perhaps above all, ophthalmologists must make absolutely clear that their patients’ attitudes will be far more important in their continuing life than their level of VA or the fullness of their visual field.

Figure 3 shows that patients can lose a great deal of function as a result of poor vision, yet still have a good quality of life. It can also work the other way around. Even small amounts of visual loss can cause some people to become severely depressed.

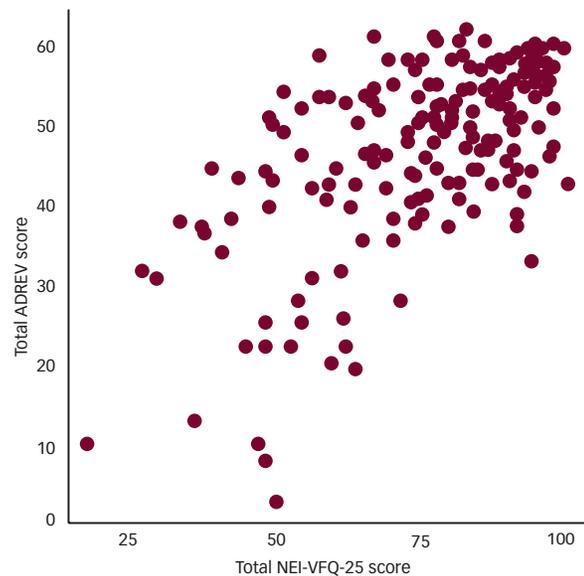
It is not only the attitudes of patients that are important, but also those of caregivers. The caregivers must want to help by learning how they can help their patients function and feel better. Those who are losing vision need knowledgeable friends and advocates, and few are in a better position to be effective in that regard than their ophthalmologists.

**Figure 2: Correlation Between the Ability to Perform the Activities of Daily Living and Visual Field**



Correlation between the ability to perform the activities of daily living and visual field. Note that there is much greater scatter with visual field than there is with acuity. ADREV = Assessment of Disability Related to Vision.

**Figure 3: Relationship Between Poor Vision and Quality of Life**



Some individuals who have poor vision can have an excellent quality of life, and vice versa. ADREV = Assessment of Disability Related to Vision; NEI-VFQ-25 = National Eye Institute Visual Function Questionnaire 25.

Following are some comments made about and by individuals who have lost vision.

A 30-year-old woman who had congenital glaucoma had multiple surgeries resulting in almost totally opaque corneas. She came to Wills to see about a keratoprosthesis. I saw her to check on her glaucoma. She was beautifully dressed and ebullient and had just graduated first in her class from law school at the University of Toronto.

A 30-year-old man was referred to me for the onset of a glaucoma after a trauma leading to a ruptured globe. The rupture was well repaired. He now had 20/20 in his healthy eye and 20/30 with a full field in his damaged eye. In response to my question, “What kind of work do you do?” He said, “I am disabled.” And he was disabled: He said, “I can’t see.”

Sabriye Tenberken, cofounder of Braille without Borders, says, “I was sighted until I was 9, and then I lost my vision, slowly but steadily. That was a tough time. The worst thing is the isolation—how other children and society react.

“Around the age of 13, I started to concentrate on the beauty of blindness. I am a very visual person, and before I became blind I was easily distracted. I was superficial, and I tended to judge people by how they looked. I became less judgmental, and I found I could learn faster, memorize things, communicate better.

“I became a problem-solver, because I was constantly having to think of solutions.”

Ganzorig Ganbaatar says, “I am 35 years old and became blind in 2010. The cause was glaucoma. I had perfect sight before that. Glaucoma is very common in my country. The doctors told me there was no treatment. It’s

very tough being blind in Mongolia. Some people believe that blindness happens because you have done something bad in a previous life. People have said this to me.

“My eyes look okay, so people are surprised to learn I can’t see. They think blind people have no eyes or look strange, and they think blind people can’t talk, that when they lose their sight they also lose their ability to speak. So people assume I can’t do things like walk or travel independently. Their ignorance is terrible.”

Jennifer Wong Ming-Ywai, a psychotherapist in Hong Kong writes, “I was born with perfect sight. Everything was good. Then, when I was 8 years old, I got Stevens Johnson syndrome. I almost died. I lost all my sight. Blindness is a blessing. There are lots of challenges, but the benefits are greater. I experience blessings around me every day and everywhere even though I can’t see. My blindness opened my eyes in a different way.”<sup>1</sup>

The lives of people who have already lost vision and of those who will become blind can be improved. Lives are improved by both doctors and patients knowing that the lives of visually handicapped persons can be improved, by knowing how those lives can be improved, and then by acting on that knowledge! ■

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1. *South China Morning Post*, February 2, 2015;20–2.

2. Spiegel D, Personal communication, July 23, 2015, Frauenchiemsee, Germany.