

# THE EYE DISEASE DIAGNOSIS: ADDRESSING COMMUNICATION CHALLENGES

## CONTRIBUTORS

**Brian Chou, O.D., F.A.A.O.**  
San Diego, California

**Kirk Smick, O.D., F.A.A.O.**  
Atlanta, Georgia

**Madeline L. Romeu, O.D., F.A.A.O.**  
West New York, New Jersey

**Vincent Young, M.D.**  
Philadelphia, Pennsylvania

While going to the family doctor is one of Americans' top 10 fears,<sup>1</sup> the eyecare appointment is typically perceived as a less stressful experience. Nearly four out of five Americans have experienced some type of eye-related problem,<sup>2</sup> from refractive errors to dry eye, and while Americans don't seek as much regular care as they should, they are more likely to visit their eye doctor for an annual exam than to get a routine physical with their general physician.

However, whether patients come in for a regular check-up or because they are noticing problems with their eyes or vision, an actual eye disease diagnosis – reported by one in 10 Americans<sup>3</sup> – usually comes as a shock to the patient, and is a revelation no one can be truly “prepared” for. The emotional response to a diagnosis – both initially and over time – can heavily influence the patient's prognosis. Understanding and properly addressing any communication barriers associated with delivering a diagnosis – including the emotional response itself – is of primary importance for eyecare professionals to minimize anxiety and maximize understanding of the disease and its treatments.

### An Emotional Response to Vision Loss

Sight is our most valued sense,<sup>4</sup> and people fear losing it more than they fear even serious medical conditions such as Alzheimer's and heart disease.<sup>5</sup> Given this, it is not surprising that a person would have an emotional response to the diagnosis of a vision-threatening condition. Consider that, in a recent survey conducted on behalf of Transitions Optical, Inc., nearly six out of 10 patients who received a diagnosis of a severe eye condition said they felt some kind of emotional distress when they were diagnosed, with the top three emotional repercussions including feeling old (21%), feeling insecure (22%) and feeling depressed (22%).

Related to this initial reaction, numerous studies have suggested that vision impairment is associated with a higher risk for clinical depression. In fact, one study found that people with vision impairment had a 2.3 times greater risk for depression than those without vision impairment.<sup>6</sup>



It makes sense that if people don't see well, they don't feel well – mentally as much as physically. Therefore, eyecare professionals should be conscious of the emotional side of dealing with vision problems, which can impact a patient's reaction to an eye disease diagnosis, and therefore his or her level of understanding of the disease at the end of the eyecare appointment, as well as treatment compliance down the road.

### Understanding the “Grief Model”

To better understand the emotional impact of vision loss (or pending vision loss), one might consider several stages of the well-known grief cycle model defined by Dr. Elisabeth Kübler-Ross: Denial, Anger, Depression and Acceptance.<sup>7</sup>

#### Denial

Unlike many sudden medical crises, such as accidents, operations or serious illnesses, several eye diseases, such as age-related macular degeneration, develop slowly and quietly, leading to a diagnosis that the patient may find too frightening to accept.<sup>8</sup> Especially if the patient hasn't noticed symptoms yet, he or she may go through a period of shock or denial, not wanting to believe that this condition or disease is happening to him or her, and refusing to discuss or begin treatment. In such a case, eyecare professionals should consider sending patients home with educational materials they can absorb post-appointment, and also be vigilant about scheduling follow-up care to discuss and/or treat their condition.

## Anger:

Understandably, the patient will then begin to feel angry about the situation and look to assign blame – either to themselves, and/or to others, including to their doctor and those close to them. Patients ask themselves questions like, “Whose fault is this?” and “What did I do to deserve this?” It is important for eyecare professionals not to withdraw from the patient if this anger is misplaced on them, but to continue to provide critical information and support.

## Depression:

Once the patient begins to accept the diagnosis, he or she may start thinking about how the disease will affect daily life, including relationships, professional work and other duties, travel and family arrangements. Behind this depressed state, patients may associate vision loss with any of the following, according to the American Federation for the Blind:<sup>9</sup>

- **Loss of Independence:** “I won’t be able to do even the most basic things without assistance, like prepare meals, clean my home, or manage neighborhood errands. I’ll be an impossible burden to my family and friends.”
- **Loss of Confidence and Self-Worth:** “All my life I’ve been athletic and physically active. I’ve always been handy, doing most of my own home repairs. That’s all over.”
- **Loss of Privacy:** “I’ll no longer be able to handle my finances and other private matters alone. I’ll have to surrender control of my life to someone else.”
- **Loss of Employment:** “I’ll have to quit my job.”
- **Loss of Friends and Family:** “Who wants to be around me when I can’t do anything anymore?”

Losing one’s vision often means confronting the prejudices, assumptions and expectations of those without vision loss, including the stigma connecting vision loss to old age or helplessness, which, in turn, may contribute to feelings of loneliness and isolation.<sup>10</sup> The combination of the potential impact of vision loss on one’s physical capabilities, relationships and psyche can contribute to the development of depression. Especially if significant vision loss has already occurred, the patient may even think “What’s the point of treatment?” Of course, not every patient will experience depression, and the level of severity may vary greatly depending on factors unique to the individual patient, such as existing risk for depression, the eye disease prognosis and the patient’s support network.

However, this type of emotional response can lead to a vicious cycle because depression negatively impacts overall health – consider that depressed patients are three times more likely to be non-adherent with treatment<sup>11</sup> – which can further exacerbate visual symptoms and disease progression. This is just another reason why regular care and consistent engagement on the part of the eyecare professional are so important following an eye disease diagnosis.

## Acceptance:

Once a patient accepts that he or she has a sight-threatening eye disease and hopefully decides to take steps to slow the progression of the disease, eyecare professionals can better serve the patient by carefully answering questions – such as “Will I go blind?” and “Can we slow the disease?” – and helping the patient commit to treatment and investigate options to improve quality of vision or minimize further damage.

Awareness of these possible stages can help eyecare professionals better prepare for varied patient reactions to an eye disease diagnosis, such as by reiterating key messages over several appointments, since the patient may be more receptive to information and treatment over time.

## Strategies to Support Patient Understanding and Engagement

The emotional response to vision loss is one of the most significant communication barriers when delivering an eye disease diagnosis, and is further compounded by the presence of other communications challenges.

For example, the **complexity of information** eyecare professionals must deliver with a diagnosis can overwhelm patients, making achieving a full understanding – and therefore treatment compliance – challenging. Eyecare professionals must also **overcome misperceptions** about the disease or its treatment that arise from “homework” or hearsay from family, peers and online sources. Additionally, **language or cultural barriers** can interfere with communication.

Eyecare professionals can help to address these challenges and alleviate potential negative impact on patients by using the following strategies to deliver a clear and comprehensive, yet empathetic, diagnosis.

1. **Focus on positive and reassuring messages.** First and foremost, eyecare professionals should take time to assure patients that they are not alone in tackling the eye disease, and that every effort will be made to treat the condition and to prevent or slow vision loss. While being supportive and empathetic, they should also be honest and realistic about treatment options, including how quickly and to what degree treatment may be successful.

If a patient already has vision loss, reassure him or her that lifestyle adjustments can improve quality of vision and help the patient lead a rewarding and even independent lifestyle. For example, better lighting, magnifiers for reading and writing and other professional low-vision products and services can make a notable difference. Similarly, numerous organizations, such as the American Federation for the Blind, offer resources and strategies for navigating daily tasks with vision loss, from personal care to cooking.

Finally, eyecare professionals should do their part to make sure patients have access to community support services, as well as caretakers, family and/or friends who can assist them overcome physical and emotional obstacles associated with their condition.

- 2. Follow a logical path in explaining the disease – from origin, to current symptoms and treatment options, to potential outcomes.** Patients will logically have a barrage of questions running through their heads – such as “How did this happen?” and “What is going to happen to my sight?” and “How am I going to treat this?”

They may be quick to assume that it is their fault that they developed the disease, and have limited knowledge of genetic or environmental factors that placed them at higher risk for developing the condition. Taking the time to explain the origin and various stages or types of the particular eye disease will help the patient understand how far the disease has progressed and what they can expect in terms of a “successful” treatment at their particular stage of progression.

As for treatment options, patients may find comfort in understanding the types of treatment that are available – especially if they had a family member with the same eye disease who perhaps didn’t have access to the latest treatment technologies. To help patients make the most informed decision it is important for eyecare professionals to be up-front not only about the likelihood of success, but also about any side effects of treatment, and consequences of non-treatment.

- 3. Don’t forget vision wear.** Vision wear can make a real difference in helping patients protect and maximize their vision – arguably even more important for patients who are already experiencing deteriorated vision. This discussion should take place both during delivery of the diagnosis and during a patient’s visit to the dispensary, and in subsequent appointments.

Consider, for example, that UV protection in the form of photochromics or sunwear is critical to protect already vulnerable eyes from further damage, such as in the case of cataract, age-related macular degeneration, diabetic retinopathy and pterygia. Additionally, lens treatments such as Transitions® lenses and anti-reflective coatings may be necessary and helpful to address light sensitivity and contrast recognition issues associated with many of these eye diseases – and in the cases of diabetic retinopathy and hypertensive retinopathy, the medications used to treat the underlying systemic disease.

For patients who suffer from depression in connection with their eye disease diagnosis, consider recent research revealing that depressed people have a lower retinal response to contrast than those without depression,<sup>12</sup> therefore suggesting that depressed people may benefit from vision wear that enhances contrast.

- 4. Address language and cultural barriers during and after the diagnosis.** With the growth of minority groups in the United States in the last several decades, it makes sense that the proportion of Americans who rely on languages other than English has increased as well. Nearly 50 million Americans (19 percent of U.S. residents) speak a language other than English at home and more than 8 percent have limited English proficiency, according to self ratings.<sup>13</sup> Research has shown that language barriers can have a negative impact on a patient’s healthcare regimen. These people are less likely to receive regular medical care, and they have a higher risk for non-adherence to medication and treatment.<sup>14</sup>

Even if an eyecare professional is fortunate enough to have a translator available in the exam room, in-language materials are invaluable to promote understanding as well as questions from patients during the diagnosis, and then to help patients review the information in their language of choice later, at their own pace and with family or caretakers.

In the absence of a language barrier, cultural differences can also impact communication. Especially if the eyecare professional is a different demographic than his or her patient, it is important to be aware of these potential communication barriers. For example, because of their cultural value of respecting authority figures, Hispanics may be agreeable and give the impression that they understand what is being discussed by the eyecare professional, when, it is possible that they do not. Similarly, many Asian Americans tend to nod “yes” to be polite, even if they mean to say “no.” Therefore, it is extremely important for eyecare professionals to ask questions to check for patient understanding.

For more examples of cultural barriers, read the Cultural and Linguistic Considerations for Vision Care white paper available through Transitions® Partners in Education, under the Education/Clinical Papers section at [Transitions.com/pro](http://Transitions.com/pro).

## Focusing on the Whole Patient

Failure to understand their diagnosed condition or the importance of follow-up care is one of the most common reasons why patients don’t adhere with recommended treatment,<sup>15</sup> often resulting in significant vision loss. In the United States, where quality eye care is much more available than in developing parts of the world, it is alarming that preventable vision loss still occurs.

Today’s eyecare professionals are a source of patient support, not just the bearers of bad news. Adapting one’s diagnosis approach to account for language barriers and patients’ emotional response can help bridge this gap. Comprehensive treatment should focus on the whole patient – addressing both physical treatment to reverse or delay progression, and also emotional treatment to minimize patient anxiety and provide the best opportunity for treatment adherence and long-term prognosis.

- <sup>1</sup> Gallup Poll, February 18-21, 2001 (1,016 respondents; + or - 3%).
- <sup>2</sup> Online survey conducted by Wakefield Research on behalf of Transitions Optical, Inc. between June 29 and July 6, 2010 among 1,000 Americans 18+.
- <sup>3</sup> Online survey conducted by Harris Interactive on behalf of Transitions Optical between December 17 and 19, 2008 among 2,207 U.S. adults.
- <sup>4</sup> Schepens Eye Institute.
- <sup>5</sup> Online survey conducted by Wakefield Research on behalf of Transitions Optical, Inc. between June 29 and July 6, 2010 among 1,000 U.S. adults.
- <sup>6</sup> Caraballese, C., et al. Sensory impairment and quality of life in a community elderly population. *Journal of the American Geriatrics Society*, 41(4), 401-407.
- <sup>7</sup> *On Death & Dying*. Elisabeth Kübler-Ross, 1969.
- <sup>8</sup> Mogk, Lylas G. and Marja. Saving lives: the impact of vision loss in later life. Presented at Pfizer Ophthalmology Therapeutic Area Conference. March 25, 2004.
- <sup>9</sup> AFB Senior Site. Coping with vision loss. URL: [www.afb.org/seniorsite](http://www.afb.org/seniorsite). Accessed July 16, 2010.
- <sup>10</sup> Mogk, Lylas G. and Marja. Saving lives: the impact of vision loss in later life. Presented at Pfizer Ophthalmology Therapeutic Area Conference. March 25, 2004.
- <sup>11</sup> DiMatteo, M. Robin, et. al. Depression is a risk factor for noncompliance with medical treatment. *Arch Intern Med*. Vol. 160, July 24, 2000.
- <sup>12</sup> Bubl, Emanuel, et al. Seeing gray when feeling blue? Depression can be measured in the eye of the diseased. *Biological Psychiatry*, 68(2). July 15, 2010.
- <sup>13</sup> Flores, Glenn, M.D. Language barriers to health care in the United States. *The New England Journal of Medicine*, 355(3). July 20, 2006.
- <sup>14</sup> Flores, Glenn, M.D. Language barriers to health care in the United States. *The New England Journal of Medicine*, 355(3). July 20, 2006.
- <sup>15</sup> The Merck Manuals Online Medical Library. Adherence to drug treatment. URL: <http://www.merck.com/mmhe/sec02/ch016/ch016a.html>. Accessed July 19, 2010.



This publication was produced as a professional education resource by Transitions Optical, Inc.