

multiple DME trials have been positively correlated with the number of injections, especially in the first year of treatment, overall consistent anti-VEGF dosing until maximal visual and anatomic improvement have been achieved in the setting of DME management is generally recommended.

In the setting of PDR, challenges with patient compliance are especially common. In the prospective DR-CR Network Protocol S, just 66% of living patients completed the 5-year endpoint (101). In most real-world clinical settings, noncompliance can be even more dramatic, with one analysis of more than 2,000 PDR patients followed over a 4-year period reporting that approximately 25% were lost to follow-up for more than 12 months. Age, race, and regional average adjusted gross

income were found to be key risk factors associated with loss to follow-up (110).

Conclusion

The core tenet of DR management is that all patients with diabetes need regular ophthalmic examinations over the long term. The primary reason for this is because patients could have substantial DR and yet remain asymptomatic. Highly effective, ocular-specific treatments are widely available and are often used even when patients have no or limited symptoms. Furthermore, accumulating data from many perspectives indicate that earlier intervention leads to better outcomes, likely with less intensive treatment. If patients receive appropriate screening and follow-up care, much of the visual impairment associated with diabetes and DR could be reduced or prevented.

Emotional Support of People with Diabetes-Related Retinopathy

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Emotional support can be defined as the expression of empathy and understanding toward an individual living with a problem. For people living with diabetes, the provision of emotional support may allow them to communicate their health-related fears and anxieties, provide positive feedback from friends and family, and help to sustain their self-care abilities.

Diabetes requires lifelong self-care and discipline, and many people with diabetes self-manage the disease in the absence of any day-to-day positive feedback. However, emotional support and encouragement from health care providers and others is essential to strengthening patients' motivation to perform routine self-care tasks and thereby improving their self-management of diabetes (111).

Research has consistently documented the beneficial effects of social support and supportive relationships on physical and mental well-being, particularly for people living with diabetes (112,113). This chapter provides primary care providers with practical tips for empowering

their patients with diabetes by addressing their fears and discussing treatments options with them in a respectful and meaningful manner.

A 3D View: Distress, Depression, and Diabetes

Self-care is the cornerstone of diabetes management. Living with diabetes means managing and coping with the condition every hour of every day. This constant effort can be exhausting and stressful for patients and often leaves them feeling isolated and alone. Thus, it is not surprising that people living with diabetes have a higher risk of developing emotional problems than the general population (114). Despite advances in diabetes care, a significant proportion of people with diabetes still experience diabetes-related distress (44.6%) or clinical depression (13.8%) (115). Distress and depression in people with diabetes can lead to worsening of metabolic control and a higher rate of complications, which may in turn lead to end-organ damage and possibly death. Put simply,

diabetes-related distress and depression can limit a person's functional ability and coping mechanisms and thereby have a negative impact on diabetes self-care.

Receiving a diagnosis of diabetes-related retinopathy (DR) can be the source of significant additional emotional stress for people with diabetes, raising concerns about numerous issues, including:

- **Potential loss of eyesight.** A new diagnosis of DR can be especially distressing because it raises fears about potentially losing vision or going completely blind. This anxiety is heightened by the fact that individuals living for many years with diabetes are 25 times more likely to experience visual impairment than those without diabetes (116). People who have had diabetes for some time without retinopathy may view this new diagnosis as a setback in their efforts to manage diabetes. Patients' distress may be further intensified by a lack of relevant information about appropriate care of DR and its prognosis. Social media posts, blogs, and other unreliable information about DR and its complications on the Internet may further exacerbate patients' anxiety and distress.
- **Potential negative effects on quality of life.** For most of us, the world is what we see through our eyes. When confronted with the possibility of vision loss, patients worry about how it could affect their daily life. Patients express fears about losing their ability to work and thereby maintain their standard of living, ensure their financial security, and support their family. They also worry about the costs of care, rising insurance premiums, and higher copayments that could come with needed specialty care.
- **Loss of independence.** For many people, the prospect of vision loss raises concerns about becoming dependent on friends and family for daily tasks they have thus far routinely handled for themselves. Loss of vision may mean having to give up driving, reading, playing sports, or other activities.

It has been well documented that the psychological well-being of patients plays a pivotal role in day-to-day self-management of diabetes (112,113).

As physicians, it is our job to acknowledge patients concerns regarding DR and to help them control risk factors to ensure the best possible visual outcome. Fortunately, as discussed in the previous chapter of this compendium, the medical management of DR has become easier, with improvements in both systemic and intraocular medications. Coupled with advancements in insulin delivery and glucose monitoring, these improvements now allow us to arrest and often reverse the stages of DR that, if left untreated, can lead to visual loss. However, when discussing these treatment modalities with patients, it is important to deliver this care in a supportive and

understanding manner; often, it is not what is said, but rather how it is said that will be remembered.

Throughout this compendium, we have provided information that should ease some common concerns and fears related to the development and management of DR. Here, we wish to stress that, aside from preventing vision loss, we believe the goal from an ophthalmologic point of view should be to help patients improve their self-management skills and reduce the diabetes-related distress that so often hinders the lives of people with diabetes.

Sticks and Stones: The Language of Diabetes

A familiar childhood saying teaches that “sticks and stones will break my bones but words will never hurt me.” Sadly, though, words do hurt, and the language we choose to use with patients can often reflect our unspoken opinions. When talking to patients not only about DR and other complications, but also about diabetes in general, it is important to use language that does not judge, but rather informs (117). Try to avoid language that implies a moral judgment about behaviors and blame. Try to respect and accept that patients have the right to make choices, and use language that reflects your understanding that diabetes may not always take priority in a person's life and that patients have accepted responsibility for their condition. Having diabetes is frustrating, challenging, and distressing for many people. When we focus on what is perceived as patients' “nonadherent” behavior, we can dismiss the efforts patients are making. Remember that wellness and health involve more than just gaining “control” or achieving a number on a laboratory test result. We should enable and educate our patients using appropriate and encouraging language (118).

The Most Powerful Drug Used by Mankind

It can be argued that the role of physicians is evolving toward patients being at the center of care and physicians becoming peripheral health advisors. Physicians empower their patients to use available resources, wanting what is best and practicing under the guiding principle to “first, do no harm.” Physicians recommend tests or treatments when their benefits outweigh their potential harms. What is often unrecognized and unintentional, however, is that the way these recommendations are delivered can cause harm. Patients will draw meaning not only from the words used, but also from the subtle nonverbal cues, tone, and demeanor used for delivery (119).

The English writer Rudyard Kipling once said, “Words are, of course, the most powerful drug used by mankind.” Words can shape how people think and feel about themselves as well as their medical conditions. As physicians, we use words to influence patients to do or feel things that are not normal for them—just as

medications would do. Language can empower people when used in a positive way. Words can link people together, spread knowledge, and improve self-image. However, it is important to realize that language can also be used to disempower people by degrading or harming their self-image. Words can completely wipe out a part of someone's identity and can leave a negative impression, causing their emotions to deflate. Language cannot be separated from thought or experience.

Empowering language should be used to educate and motivate people with diabetes. Careful use of language applies equally to the conduct of health services, health professionals, family, friends, and colleagues of people with diabetes, and the media. When people use language to shame and judge others, it can contribute to diabetes distress and ultimately slow progress and hinder diabetes outcomes. Furthermore, people with diabetes may do themselves a disservice if they also use negative language. There are effective ways of communicating about diabetes. When discussing a medical condition such as diabetes we, as physicians, should use language that encourages positive interactions and positive outcomes (120).

To provide one important example, the word “diabetic” is often used as an adjective or as a noun. When used as an adjective (e.g., “diabetic foot,” “diabetic eye,” and “diabetic person”), the word places focus on the physiology or pathophysiology. It is better, when possible, to put the person first. Avoid using a disease to describe a person, and avoid describing people as a disease. Suggested replacement language would include “foot ulcer,” “infection of the foot,” “diabetes-related retinopathy,” and “person with diabetes.” When “diabetic” is used as a noun, as in, “Are you a diabetic?” this usage labels a person as a disease. There is much more to a person than his or her diabetes. When in doubt, remember that person-first language puts the person first (117), so call people with diabetes by their name. Using mindful language is a simple shift that can have a powerful effect in reducing stigma and negativity.

As health care professionals, we should work toward person-centered care that is based on respectful, inclusive, and empowering interactions (48). We have an opportunity to respect the language used when counseling our patients and should be selecting strength-based, collaborative, and person-centered messages that encourage people to learn about and take action to manage complex diseases.

An Emotionally Supportive Approach to DR Management

Diabetes-related visual loss is a fear that nearly all people with diabetes experience at one time or another. When faced with the thought of blindness, individuals often

focus on what they stand to lose along with their vision. Patients often express concern over the potential loss of their employment, independence, and privacy, along with potential strains on relationships with friends and family. These anxieties are normal and to be expected.

As care providers, it is important for us to acknowledge our patients' fears; it is also our responsibility to help our patients move beyond their fears and reclaim a positive outlook about their vision and diabetes management. Patients find it reassuring to hear from their primary care providers that most people with DR are able to keep most of their vision with proper treatment, although they may need ongoing care. It is also important to help patients recognize that visual impairment does not mean they will be unable to manage their diabetes. Patients with diabetes and visual impairment can learn new skill sets that allow them to live independently and remain productive.

Sadly, it is concern about and fear of going blind that will often lead patients to miss appointments and delay care, which can lead to worsening of their DR and vision. It is currently recommended that adult patients with type 1 diabetes undergo an eye exam 5 years after diagnosis, and adults with type 2 diabetes should have an eye exam at the time of their diagnosis. Subsequent exams should occur every 1–2 years if no signs of DR are detected; more frequent examinations will be required if there is evidence of DR (121). Unfortunately, although 90% of diabetes-related visual loss can be avoided with appropriate treatment (122), less than two-thirds of patients in the United States are receiving appropriate screening (123). By educating our patients about the importance of eye screenings and addressing their fears, we have the ability to prevent visual loss from diabetes.

Eye Exams, Timing, and Experience

As covered elsewhere in this compendium, eye examinations are recommended for patients with diabetes, as these patients can remain asymptomatic even in advanced stages of DR. There are several components to an eye exam that is performed by an ophthalmologist (medical doctor) or optometrist, and patients should be told what to expect. The typical eye examination begins with an initial screening during which a technician may take a complete medical history, including a complete list of the patient's medications and allergies. Both near and distance vision is then checked, with and without eyeglasses. After a careful assessment of pupillary reactions, eye drops are placed in each eye to dilate the iris and check the intraocular pressure. Dilation will typically take about 15–20 minutes. Once the eyes are dilated, the doctor will examine them using a microscope called a slit lamp. Further examination

of the retina may be done with a light source worn on the head, called an indirect ophthalmoscope. Both of these devices allow a view of the ocular structures, including the retina. The light from each instrument may appear very intense but will not injure the eyes. The doctor may also decide to take various photographs of the back portion of the eyes. This may or may not include an injection of a dye to better visualize the retinal vessels and ocular circulation.

Images of the retina are often displayed on a monitor to help the doctor explain the ocular findings. This is meant as a tool to help patients understand their diagnosis and not to criticize or frighten patients. If DR has been detected and requires treatment, it may come in the form of an intravitreal injection, laser treatment, or intraocular surgery. The importance of maintaining glycemic control in the target range, coupled with controlling blood pressure and lipid levels and avoiding tobacco, should also be emphasized.

The Reversal of Retinopathy: Setting Expectations

As discussed in other chapters of this compendium, the past decade has seen a dramatic shift in the management of DR. With appropriate care, we are now able to stabilize retinopathy, and ongoing treatment will often lead to improvement in vision (95). The wonderful aspect about treating conditions that can affect vision is that the eye is an organ that is easily accessed. Although the thought of placing medications into the eye can be frightening at first for patients, the reality is that, by treating the eye locally, we can minimize complications that may occur if the medication were given systemically.

Primary care providers (PCPs) have the ability to help set their patients expectations regarding these therapies, and these discussions should focus on hope, rather than fear and punishment. Too often, we tell our patients, “If you don’t do this, you will have to do that.” “If you don’t control your blood sugar, you will have to go on insulin. You don’t want a shot, do you?” In using this communication style, we create a relationship through which our patients come to believe that they have failed and may view the necessary treatment as a form of punishment. However, we know that diabetes progresses toward the failure of pancreatic β -cells to produce enough insulin (124). This happens early for people with type 1 diabetes and later for those with type 2 diabetes. We should express to our patients that it is this known progression of diabetes—not their personal failure—that leads to the need to take medications to remain healthy. By presenting a positive outlook on how we are able to treat the damage that diabetes causes, and carefully preparing patients for their eye exams and possible treatments, we have the ability to dramatically reduce the number of patients who lose their sight from DR.

Cross My Heart and Hope to Die . . . (Well, You Know the Rest): What to Expect from Intraocular Injection

As previously mentioned, the eye, unlike most organs in the body, is conveniently located where it can be accessed easily. Thus, ophthalmologists can safely inject medications into the eye that will have a targeted and local effect, while avoiding potential complications that could occur if the same medications were delivered systemically. In the past decade, intraocular injections of various medications have become recognized as safe and effective treatments for many ocular diseases, including DR. By reducing patients’ anxiety and increasing their knowledge about a recommended procedure, PCPs can help to reduce patients’ emotional and physical discomfort with intravitreal injections. Eye care specialists can also do their part. For example, Chen et al. (125) reported that diversion methods such as playing classical music before and during intravitreal injections significantly decreased patients’ anxiety.

Explain to patients that, although there are multiple ways to give an injection, the basic principles are as follows:

- The patient is placed in a comfortable supine position with the head supported.
- Numbing drops or a numbing injection will be placed on the eye.
- Topical povidone-iodine (Betadine) drops will be instilled on the eye.
- A small device may be used to help keep the eyelid open and away from the site of injection.
- The patient will then be asked to look in a given direction, often away from the physician.
- Medicine will then be injected into the eye with a small needle. Patients may experience a pressure sensation, but typically not much pain.
- Afterward, the eye may be rinsed with a sterile eyewash.

The procedure is performed in the physician’s office and takes less than 15 minutes. Injections may need to be repeated as often as monthly until DR stabilizes.

General Emotional Support and Information for Patients with Diabetes

Patients living with diabetes should be well educated about the disease, its management, and its consequences. Having a strong knowledge base regarding disease pathophysiology, dietary and lifestyle modifications, treatment regimens, and warning signs of possible complications is prudent for patients and their close family and friends. Patients should also have easy access to information about new treatments and technologies.

The Internet can be a useful resource; however, patients should be educated about reliable websites and information

sources and cautioned about unfiltered and unsubstantiated online perspectives on diabetes, which may provide disinformation and cause additional anxiety and stress.

Following are some trusted information resources.

- American Academy of Ophthalmology's Preferred Practice Pattern for DR. Available from www.aaof.org/preferred-practice-pattern/diabetic-retinopathy-ppp-updated-2017
- American Optometric Association's Evidence-Based Clinical Practice Guideline on Eye Care of the Patient with Diabetes Mellitus. Available from aoa.uberflip.com/i/374890-evidence-based-clinical-practice-guideline-diabetes-mellitus
- American Diabetes Association. Retinopathy: A Position Statement by the American Diabetes Association. Available from care.diabetesjournals.org/content/40/3/412
- American Diabetes Association. *Standards of Medical Care in Diabetes—2019*. Section 11, Microvascular Complications and Foot Care. Available from www.care.diabetesjournals.org/content/42/Supplement_1/S124
- American Association of Diabetes Educators; AADE7 Self-Care Behaviors for Managing Diabetes Effectively. Available from www.diabeteseducator.org/living-with-diabetes/aade7-self-care-behaviors

Patients are also likely to benefit from being involved in a support group. Online support groups through social networking sites provide easy access for patients to share their experiences and learn from the experiences of others. However, patients should be cautioned that information on these platforms is unedited and may not be medically sound. They should be encouraged to confer with their doctors if questions arise. Nonetheless, patients may find solace in the fact that they are not alone and get positive feedback from others in similar situations.

Support for Visual Impairment and Low Vision

“Visual impairment” refers to any reduction in visual acuity that cannot be corrected. In the United States, “legal blindness” is defined as best-corrected vision worse than 20/200 in the best eye or 20 degrees or less of visual field remaining. Fortunately, very few individuals are without sight; even when classified as “blind,” most individuals have various levels of vision. With training and the use of low-vision aids, individuals with visual impairment can improve their function and quality of life.

Visual loss and impairment are rare in the early stage of DR, and thus no visual aids or assistance will be needed for patients at this point. As DR worsens, patients may experience visual loss from cataracts, macular edema, macular ischemia, vitreous hemorrhage, tractional retinal detachment, neovascular glaucoma, and ischemic optic neuropathy. With early identification and treatment, many

of these blinding complications can be prevented, treated, or reversed. Despite our best efforts, however, some patients may still lose vision and go blind, and there is no such thing as being prepared for this turn of events.

It is important to remember that, regardless of the stage of DR, individuals with diabetes and eye complications should continue to control their risk factors to help preserve their remaining vision and minimize other diabetes-related complications. Fortunately, professional support is available and far more accessible than most people realize. There are adaptive techniques and remarkable, ever-advancing technologies and products to help patients with visual loss continue to maintain visual independence.

People with diabetes have specific visual needs related to their diabetes self-care. These include being able to test their blood glucose, administer appropriate oral medication and insulin doses, read food labels and medicine bottles, perform foot examinations, and treat any wounds or sores. The use of visual aids may allow patients with visual impairment to maximize their remaining vision and live independently while managing their diabetes. Although it is always best to seek the consultation of an eye care professional to determine optimal low-vision tools for a given patient's level of vision and task requirements, following are several simple options that can help patients maximize their vision.

- **Good lighting.** Adequate light can improve contrast and definition in some situations. Often, directing light onto a task will improve the image that is being viewed. Remember, though, that too much light can cause glare and often wash out an image and worsen eyesight. When evaluating a patient's environment, pay attention to the availability of directional lighting for near tasks and lights in dark areas where falls are most likely to occur. Contrast enhancement with the use of filters may help many patients with diabetes who experience color vision loss along the yellow-blue axis.
- **Magnification.** Whereas light and filters can improve contrast, it is often important to increase the size of the image that is being viewed. Reading books, newspapers, mail, or food or medicine labels can be made easier with the use of simple reading eyeglasses, a lighted, handheld magnifier, large-print reading materials, e-readers or computer magnification programs, and closed-circuit television systems.
- **Smart devices.** We often think of phones or watches as smart devices, but for people with diabetes and low vision, this can also include smart insulin pens or other insulin delivery devices, as well as smart glucose meters. Many of these devices are Bluetooth compatible and operate via voice commands.

Following are some trusted resources for additional information about visual impairment support.

- American Academy of Ophthalmology's Initiative in Vision rehabilitation. Available from www.aoa.org/low-vision-and-vision-rehab
- American Optometric Association's Care of the Patient with Visual Impairment (Low Vision Rehabilitation). Available from www.aoa.org/documents/optometrists/CPG-14.pdf
- American Association of Diabetes Educators' Diabetes Advanced Network Access, a health care technology resource for diabetes educators. Available from www.danatech.org

Conclusion

DR can be a source of significant anxiety and stress for people with diabetes. This can limit patients' self-care abilities and even prevent some from seeking timely care. PCPs are in a position to identify and address patients' concerns about retinopathy. Providing emotional support begins with the recognition that such support is needed. Patients should be encouraged to voice any concerns and given access to educational information and support. With modern treatment regimens and timely follow-up with a retinal specialist, most patients with DR can expect to keep their vision.

Summary and Conclusion

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The worldwide diabetes epidemic has created an unsustainable financial and personal crisis for health care systems and for patients and their families. At the same time, the ability of patients to maintain useful vision has never been greater. Screening of people who are at risk and timely institution of treatment, combined with coordination of systematic and ophthalmic care, provides the best outlook for people with diabetes.