

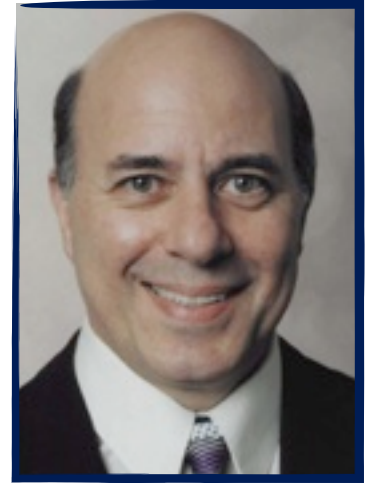
A Nagging Question...

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Since I began practicing low vision rehabilitation in the middle 1970s, there has been an ever-increasing realization that there is a need for these services, and that the need is expected to continue to grow, primarily due to the ocular disease processes associated with the aging population. That said, since I began practicing low vision rehabilitation, and to this very day, there is one nagging question that seems to always escape a rational answer: Where *are all* the visually impaired people?! Where are those people who we know would like the opportunity to function better visually, and why are they not being given the opportunity to do so? Unfortunately, I am not alone in the quest for an answer. Recently, and serendipitously as I was putting the final touches on this editorial, there was an email post to a low vision interest listserve, in which a physician who does low vision rehabilitation commented, "If you asked me what presents the most difficulty in treating a low vision patient, I would have to answer that it is the fact that they don't get referred!"² As I travel around the world lecturing on low vision rehabilitation, and in talking to my colleagues, I find, and they do too, that this is the most difficult part of providing low vision rehabilitation: the patients are not referred for the help we can provide.

Years ago, according to the National Eye Institute, one of the reasons for lack of low vision rehabilitative care was the lack of knowledge on the part of professionals and lay people about the services available. The reality today is that optometry and ophthalmology both have written guidelines that are not considered out of the mainstream of eye care that admonish eye care providers to seek vision rehabilitative services for their patients when conventional optics or medical intervention can no longer satisfy the functional needs of the patient.^{3,4} The lay public is also well aware of pathological eye conditions that can cause a visual impairment (most notably macular degeneration). Such conditions regularly appear in the news media. In fact, recently it was reported that the actress Dame Judith Dench has age-related macular degeneration.⁵ Refreshingly, it was also reported, she said that she is not going "blind" and has lenses and glasses and "good old bright light to help her see," although she has difficulty seeing faces and has people read her scripts to her. The curiosity here is what type of low vision devices she has, and why, based on the fact that both she and her mother have experienced this condition, would she not be asked to become a spokesperson for vision rehabilitative services.

I am not suggesting all eye care practitioners do not refer visually impaired patients, but I am curious about how the selection process works. So, what presumably might be some reasons for the lack of referrals of visually impaired individuals by eye care professionals?



1. *Many visually impaired patients seem not to have pressing visual needs. This erroneous thinking is based on how the questions are asked of the visually impaired patient: "How are you doing? Are you having any problems?" The answer to those "superficial" questions is typically... "no problem" (implied: "for my age"). Unfortunately, the next level of questioning is not typically asked, undoubtedly for many reasons, i.e., the doctor is too busy to deviate from the task at hand (the medical reason for the visit), or the patient was not forthcoming with a complaint, so "everything must be all right." Often I ask the same initial question to a visually impaired patient who is referred to me, "How are you doing?" And the response is typically "OK." However the next question I ask is "How is your reading?" This evokes a completely different response: "I want to be able to see better to read, to do my own checks, etc.," or the equivalent of the conversational flood gate that most other practitioners are not ready to engage in, and to have that chat tie up a "busy day."*
2. *Professionals are too busy, and often, after they have completed their (medical or surgical) service, do not "remember" to recommend further care, or do not want to get into a lengthy conversation about visual rehabilitative alternatives. Although there is no magic bullet for a resolution to this concern, i.e., "tying up" a busy practitioner with a seemingly endless list of questions, a place to start might be using handout materials (prepared by a low vision service provider or the AOA's pamphlet written by the Low Vision Rehabilitation Section) explaining low vision rehabilitation services, or using ancillary staff who are given specific guidelines for suggesting additional care. This will, at least, give the patient or family member information to ponder. Identifying those practitioners who provide low vision care, and explaining that the patient can get most of the answers to their questions from them, and then indicating how to reach them, might be all that is necessary to offer the patient a valuable service that might otherwise have gone unrecognized.*

3. *Professionals feel if they can't do everything to help their patients, they might be perceived as failing in their health care responsibilities. A number of people have presented this as a subconscious rationale for not referring patients (which I find hard to believe). It seems to me this is somewhat analogous to deciding that when a patient has to be referred for cataract surgery, it suggests that the referring practitioner has failed in being able to help that person see clearly with conventional lenses. This is an obviously preposterous statement!!*
4. *Patients will not wear or use the devices recommended as they are not conventional in appearance or in their use, and most are paid for with out-of-pocket dollars, making patients potentially resistant to pursue this type of care. In discussing this with professionals or lay people I use 2 very simple rules. First, do no harm. Second, once the patient has been educated, let the patient decide! In fact, not all patients who have a visual impairment have a visual disability, or need intervention. In a 1994 article, John Tanton, M.D. vividly explained it this way: "Providing rehabilitation services for their visually impaired patients is the medical and moral...responsibility of all ophthalmologists. It is no more acceptable for an ophthalmologist to abandon a patient once the medical treatment is completed but before needed rehabilitation services have been provided, than it would be for an orthopedic surgeon to abandon an amputee to hopping around on one leg."⁶ Optometry should heed this reproach as well. Patients will make their own decision, once they are given the options, but without those options, they do not have a full complement of choices. And, until any one of us has had the experience that our patients have, imposing our bias is unfair.*
4. American Academy of Ophthalmology. Vision rehabilitation for adults. American Academy of Ophthalmology: San Francisco, CA, 2007
5. Dame Judi Dench: Vision problems, yes; going blind, not so much, Feb 20, 2012, <http://latimesblogs.latimes.com/gossip/2012/02/dame-judi-dench-eyesight-macular-degeneration-not-going-blind.html>, last accessed 2/27/2012
6. Tanton J H, Nothing more can be done...a fable for our times, *Ophthalmology Clinics of North America* 1994;7:203-205
7. Canavan N, Less Depression With Early Intervention in Patients With AMD, Medscape Medical News, Feb 21, 2012, <http://www.medscape.com/viewarticle/758938>, last accessed 2/27/2012

When one looks at the perceived dearth of referrals of visually impaired patients for rehabilitative care, the only apparent option low vision providers have left (other than to continue to educate eye care professionals) is to go to others in the medical community whose health care culture is more in tune with offering "ancillary" or rehabilitative services to their patients, i.e., gerontologists, diabetologists, primary care doctors, physiatrists, etc., or to go directly to the public to educate them in a more aggressive way, trying to increase awareness of rehabilitative services and their obvious benefits. The numbers tell us there is a need; the demographic is aging.

And the sooner, the better, for lots of reasons. In a recent small pilot study it was reported, "early intervention using low-vision aids can greatly reduce the severity of depressive symptoms related to the vision loss experienced by people with age-related macular degeneration."⁷ I suppose this applies to any other pathology that can cause a visual impairment. As my colleague from Michigan said, "Even though it may be true that nothing more can be done for the eye, it is *almost never true* that nothing more can be done for the *patient*."⁶

References

1. Freeman PB, The elusive low vision patient, *Optometry* 2009; 80: 275-276
2. Sunness J, Vision Rehabilitation Forum, February, 20, 2012
3. American Optometric Association. Care of the patient with visual impairment (low vision rehabilitation). American Optometric Association: St. Louis, MO, 2007