The Blind Spot in Vision Care

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The world continues to move toward a new paradigm of precision medicine — care that is tailored to the individual and more personal. However, when Judith Goldstein, O.D. (https://www.hopkinsmedicine.org/profiles/details/judith-goldstein), looks at this new world, she sees instead a blind spot. And for her, patient care has always been personal.

Goldstein is clinical director of the Lions Vision Center (https://www.hopkinsmedicine.org/wilmer/services/low_vision/) at the Johns Hopkins Wilmer Eye Institute, and she recently became the director of the Lions Vision Research and Rehabilitation Center. A leading low-vision rehabilitation physician for over two decades, she has observed a rapidly graying population translate to a population in need of low-vision care.

What is low-vision care and why is it so important to Goldstein? Low-vision care is for people with mild to severe vision loss whose sight cannot be restored surgically or medically. A behavioral intervention that includes the use of specialized lenses, lighting, technology, counseling and education, low-vision care is provided by a unique team of rehabilitation professionals focused on maintaining or improving independence and quality of life. But there are not enough low-vision specialists to address the need, and for a number of reasons, it can be difficult to encourage student physicians to pursue a career in the field.

When people find themselves in need of low-vision care, it often means a loss of independence and a change of lifestyle. Family members frequently become caregivers, and most often, the job falls to women. “The challenge for these caretakers is that they have to be part physician, therapist, counselor and educator,” Goldstein says. “It’s an incredible burden for caregivers that often leaves the patient in need.” It can be a double whammy when the patient also is the family’s caregiver.

While this specialized field presents unique challenges for professional care providers, it is also very rewarding. Without exception, it begins with making the patient feel comfortable, “which seems basic at first,” says Goldstein. “But understanding the sense of hesitancy, uncertainty and even futility a person with vision loss feels, and responding to that, often lays the groundwork for rehabilitation success.”

Loss of vision means a loss of self-confidence. Everyday tasks such as greeting someone, reading, cooking or even finding a jar of mayonnaise in the refrigerator become monumental challenges.

Beth Glassman knows firsthand about such challenges. More than a decade ago, she was suffering from glaucoma when she lost the vision in her “good” eye due to an accident. Today, she is considered legally blind.

“Imagine brushing your teeth,” Glassman says. “You take the top off the toothpaste. The top is white, your counter is probably white. You brush your teeth and the top is gone, because you can’t see it, so you stumble around looking for the top, and it falls on the floor, which is also white.

The list is long: Imagine turning on your oven to 350 degrees when you can't see it. Or trying to find an outlet. "Imagine taking a sip of coffee and you burn your mouth every single time because you can't see the coffee. If you share a refrigerator with people, everything's moved around on you. When you're talking about everyday tasks, everything is difficult."

While lenses, prisms, assistive technology and specialized lighting can be prescribed to address activities such as reading, many pivotal solutions involve small changes in daily lifestyle. "Often, it's the simplest modifications that have an impact," Goldstein says. "For example, using a black placemat under a white cup to enhance contrast — sometimes that can be the spark of progress a patient needs."

Glassman, who has benefited greatly from low-vision services, agrees. "There are systems you can learn to make life wonderful," she says. "And for things like turning on your oven, dishwasher or washing machine, they have clear, stick-on tactile bumps. I have two in my kitchen around an outlet, so I feel for the bumps instead of sticking my finger in the socket."

As people with vision loss begin to recover a sense of independence in their daily lives, their self-confidence grows. "It is incredibly inspiring to see what people are capable of — and as a physician, it's very gratifying to be a part of their success story," says Goldstein.

Because low-vision care is so connected to quality of life, it has become one of Goldstein's missions. "It's incumbent upon us to put experts into the field so that they can direct programs, teach their students, and develop more skilled individuals to go out and care for people with vision loss," says Goldstein. Paying forward to the profession is a shared theme on Goldstein's team. Dedicating a career to rehabilitation medicine requires a unique commitment to caring for the entire person, and recognition that the success of treatment often depends on engaging and motivating the patient to understand and participate in the process.

Why is attracting physicians to the field so difficult? One reason is straight-up economics. There simply are more lucrative career paths for a medical professional to follow, and many young ophthalmologists and optometrists — often burdened by school debt — opt for higher paying careers in other specialties. The nature of low-vision care requires devoting much time and attention to working with patients and caregivers to coordinate the best combination of treatment strategies. Time spent on extensive patient education and counseling, and in-depth evaluation and treatment with rehabilitative professionals, means fewer patients can be seen in a day. "Low vision is not a high-volume field," Goldstein says, "and there are too few who do this kind of work."

Goldstein has been working to expand the number of trained physicians in the field — and with the muscle of longtime partner the Lions Club, some progress is budding. Over the past decade, the organization's Multiple District 22 has underwritten $100,000 annually for the Lions Low Vision Rehabilitation Fellowship, a program that provides a full year of clinical and research training for low-vision specialists at the Wilmer Eye Institute. The program has had eight fellows since its inception, with Goldstein's team slated to welcome the ninth in mid-July.

The fellowship, which is completely funded by private donations, entails a full year of intensive training at the Wilmer Eye Institute, and it is open to ophthalmologists and optometrists who have completed their residencies. Each fellow's time is split 80% in the clinic and 20% doing research. "Being a clinician alone in vision rehabilitation requires a high degree of excellence, and being a clinician-scientist doing research is really at the top level, where we want our fellows to be," says Goldstein. In the program's research component, fellows learn key data gathering, analysis and writing skills that are needed to establish solid research careers. Most complete their year at the Wilmer Eye Institute with a published paper to show for it.

Goldstein says the fellowship has an additional intent that is not always apparent. "The Lions fellowship is just a year of training in one's life, but fellows truly connect to the mission and grow in their love for the work," she says. "Then it becomes a career that they have their heart in." Instilling a passion among the fellows for vision rehabilitation is satisfying, Goldstein says, but the objective is to place more trained specialists in the field. "We're really excited about the program," she says. "And most importantly, we're excited about what our prior fellows have done to expand the field."

"I see that the ultimate aim of our work is to improve quality of life for people with vision loss," says Goldstein. "No one should have to suffer when there are solutions available."

It is difficult for patients to access reliable information about low-vision rehabilitation, and for people with vision loss whose surgical options are exhausted or eliminated, there is the misconception that nothing else can be done. "This is what I mean by the 'blind spot' in vision care," explains Goldstein. "It's not really a blind spot — it's the lack of available trained specialists doing this important work."

"Anyone can recognize the problem once you become aware of it," Goldstein says. "And then, you're compelled to do something about it."

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