The Importance of Patients’ Perspectives in Providing Ophthalmic Care—Lessons From the COVID-19 Pandemic

Alan R. Morse, JD, PhD

For patients with chronic eye disease, keeping scheduled appointments for monitoring and treatment is essential to minimize avoidable vision loss. Patients with retinal diseases depend on intravitreal injections as the standard of care, whereas for patients with glaucoma, monitoring and access to emergent care is essential. Other eye conditions also are dependent on maintaining time-sensitive treatments. The onset of the coronavirus disease 2019 (COVID-19) virus, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), exacerbated the challenges of addressing eye care, because risk factors for developing COVID-19 are common among patients with chronic eye conditions.1 The challenge for patients is, “How can I preserve my vision without jeopardizing my health?”

During examinations and treatment, ophthalmologists are in unavoidably close physical contact with their patients. To ensure the safety of ophthalmologists and their patients, professional associations issued guidance about care practices during the COVID-19 pandemic.2 On March 18, 2020, the American Academy of Ophthalmology stated that it was essential that “all ophthalmologists cease providing any treatment other than urgent or emergent care immediately.”3 The nature of the risks and their magnitude have to be considered against the potential benefits; ophthalmologists have to weigh the risk of infection to themselves and their patients against potential loss of vision for their patients. These factors should be balanced with patients’ perspectives, and decisions should be made collaboratively with them. However, given the academy’s and others’ clarion calls, appointments undoubtedly were canceled without discussing and considering patients’ concerns or perspectives.

In an analysis of more than 2 million patient encounters in March and April 2020 compared with the same period in 2019, ophthalmology patient volume in the US declined an estimated 81%, including a 97% reduction in cataract surgery and an 88% reduction in glaucoma procedures.4 The American Society of Retina Specialists reported that by mid-July 2020, despite their recommendation for patients to keep their eye care appointments, about 80% of US patients delayed treatment, fearful of contracting SARS-CoV-2. Underestimating the critical nature of intravitreal injections, more than half of these patients had a significant decline in visual acuity and an anatomical change, such as negative optical coherence tomography findings.5 The conundrum faced by ophthalmologists was, “How can I do my job and help my patients without jeopardizing my own health or the health and vision of my patients?”

Physician-patient communication is always important, but its importance increases as patient health literacy decreases. Written patient instructions and information do not work if patients cannot read or understand them; patient-specific questions are not addressed through websites or information sheets, which makes it uncertain whether patients have the individualized information they need to be actively involved in decision-making. Were patients advised about the risks of vision loss resulting from suspension of treatment as well as the steps taken to mitigate that risk? Did a failure to effectively communicate the importance of maintenance of treatment contribute to cancelation of appointments?

In this issue of JAMA Ophthalmology, Lindeke-Myers et al6 highlight the importance of incorporating patient perceptions to improve continuity of ophthalmic care. Using a telephonic questionnaire, they successfully queried 348 of 423 randomly selected patients (82%) with age-related macular degeneration or diabetic retinopathy who received intravitreal injections between January 6 and March 13, 2020, and were scheduled to receive follow-up injections between March 13 and May 6, 2020, the height of the COVID-19 pandemic at the time. All were considered high risk for irreversible vision loss if there was a lapse in care. Almost half of respondents expressed concern about potential loss of vision from missing treatments. Two hundred eight respondents (60%) believed SARS-CoV-2 exposure in the clinic was unlikely or extremely unlikely, but 49 (14%) believed it was likely or extremely likely. Seventy-eight participants (22%) were lost to follow-up, and this was significantly associated with fear of SARS-CoV-2 exposure. Clearly, patients’ perceptions and their competing fears of COVID-19 vs vision loss influenced their care, although they may have had little opportunity to share their perspectives with their ophthalmologist. How patients view their diagnosis and its potential treatment is critical for patient well-being.

The burden of canceled visits is asymmetric. When patients cancel visits because of a lack of knowledge or inadequate opportunity to discuss their concerns, they bear the burden of their decision, including potential for vision loss. But when ophthalmologists cancel an appointment without considering their patient’s perspective, the burden of potential vision loss remains with the patient. Patient views are valid and realistic only if fully informed. Patient perspectives incorporate their knowledge and beliefs, which influence their willingness to engage in a course of care. The strength of their belief that a treatment will minimize vision loss affects how much risk they may be willing to take, balancing personal safety with treatment efficacy. Patients want to be informed and engaged, but treatment decisions often are made without full consideration of the patient’s perspective.

In an era of shared decision-making, maximizing treatment efficacy while protecting patients and physicians requires thorough and effective communication. Letters, emails, checkbox responses, and other non-patient-
physician interaction may transmit information but are probably not effective communication for many patients. Patients need to be able to ask questions about their specific situation, and ophthalmologists need to know their patients’ concerns. Providing time for patients to ask questions is a way to actively involve them in their own care while also supplying necessary information. Over the last several decades, the concept of activation—having the knowledge and confidence to be an active participant in one’s own health care—has emerged as a way to conceptualize patients’ engagement with their own care. Patients who are actively involved often are more satisfied, incorporate more information into their thinking, and have a better understanding of treatment options. Patients who are less engaged often believe they do not have adequate information about their condition and often believe they have insufficient opportunity to ask questions. What opportunities are there for patients to discuss their issues and concerns? Prioritizing patient perspectives engages patients and can improve patient-relevant outcomes. Several years before the COVID-19 pandemic, almost 90% of respondents to a national survey believed that good vision is vital to overall health, and just less than half considered vision loss as the worst possible health outcome. Unsurprisingly, the treatment outcomes that patients with chronic eye disorders value most are those that could help them to minimize vision loss and safely maintain their independence. How, then, should one best address patient perceptions and concerns to facilitate their engagement and minimize vision loss? Why are some patients willing to assume greater risk than others to preserve their vision? Patients’ perspectives mediate their engagement, guiding involvement with their own care. Understanding patients’ perspectives and involving them with their own care is difficult and complicated but necessary and fundamental to good care.

ARTICLE INFORMATION

Author Affiliations: Edward S. Harkness Eye Institute, Department of Ophthalmology, Columbia University Irving Medical Center, New York, New York; Lighthouse Guild, New York, New York.

Corresponding Author: Alan R. Morse, JD, PhD, Edward S. Harkness Eye Institute, Department of Ophthalmology, Columbia University Irving Medical Center, 635 W 165th St, New York, NY 10032 (am2955@columbia.edu).

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