Announcement

ASCO’s Student Award in Clinical Ethics:
2023 Winning Essay

ASCO and its Ethics Educators Special Interest Group are pleased to announce Zebin Dholasaniya, OD, as the winner of the 2023 Student Award in Clinical Ethics. Dr. Dholasaniya is a recent graduate of the University of Houston College of Optometry. Her winning essay, “The Ethical Dilemma: a Pediatric Patient’s Right to Truth vs. Parents’ Nondisclosure Request” appears below.

The Student Award in Clinical Ethics competition, sponsored by Alcon, is open to optometry students during any point in their professional program at an ASCO-affiliated school or college of optometry. The winner receives an engraved plaque and $1,000.

ASCO thanks all students who submitted essays this year.

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The Ethical Dilemma: a Pediatric Patient’s Right to Truth vs. His Parents’ Nondisclosure Request

By Zebin Dholasaniya, OD



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Optometrists are often forced to walk a tightrope in maintaining the delicate balance between their moral obligations and their legal duty. Medical decision-making in the pediatric population is a balancing act

between respecting the autonomy and decision-making privileges of the parent and ensuring the well-being and health of the child. The following case illustrates the complex relationship between an optometrist's duty to care for a pediatric patient and the legal authority of the parents to make decisions on the child's behalf.

Case Description

A 15-year-old African American male presented for a low vision evaluation with the goal of acquiring a Texas driver's license. His ocular history was positive for X-linked retinitis pigmentosa diagnosed at age 5. At the patient's initial visit to the clinic 2 and a half years ago, per the parents' request, the child was not made aware of his ocular diagnosis and only informed that his eyes were "different." At his most recent visit, his best-corrected distance visual acuities were 20/60-2 in the right eye and 20/70-2 in the left eye. Fundoscopic examination revealed bilateral bone spicules 360 degrees in the peripheral retina and arterial vessel attenuation consistent with the diagnosis of retinitis pigmentosa. Esterman visual field testing (binocular) showed restriction to approximately 20 degrees right and 15 degrees left horizontally with some sparing in the far periphery. Additionally, a 30-2 SITA Standard test demonstrated bilateral severe generalized depression on both pattern and total deviation with a mean deviation of -25.74 dB in the right eye and -25.84 dB in the left eye. According to the Texas Medical Advisory Board, the vision requirements for a Texas driver's license are visual acuity of 20/40 or better in each eye and visual field of 140 degrees horizontally.[1] The qualifications for a restricted driver's license in Texas are visual acuities between 20/50 and 20/70 and visual field of 140 degrees horizontally.[1] Patients with visual acuities better than 20/200 can potentially be eligible for a Texas driver's license if their visual acuity improves to 20/40 or better with a bioptic.[1] Based on these guidelines, the patient did not meet the vision requirements for obtaining a Texas driver's license with or without a bioptic due to the visual field restriction.

The challenge that presented itself was determining the extent to which the patient knew about his condition. In the patient's absence, the parents clarified that the patient knew he had retinitis pigmentosa but was not informed about the progressive blindness associated with the condition, and they preferred to keep it that way. It was recommended the parents be honest and fully transparent with the patient about his condition, and resources to retinitis pigmentosa support groups were provided to assist the parents in navigating this difficult conversation. When the patient returned to the exam room, the family was informed that he did not meet the vision guidelines for obtaining a Texas driver's license. The parents implored whether low vision devices could aid in qualification. The family was educated that although a low vision device would not make him eligible, there were devices that could aid in reaching career or education goals. The patient was interested in becoming a veterinarian and committed to extracurricular activities, courses and certification programs involving animals. However, he was currently struggling to perform in his dissection course at school. A clip-on binocular magnifier was presented to the patient. Initially, he refused the device. Previously he had been given a handheld telescope and pocket magnifier but he did not use them due to feeling "different" among his peers in school. However, a month after the most recent visit, the patient requested the clip-on magnifier.

Managing the patient's retinitis pigmentosa mainly consisted of navigating a difficult conversation about the ineligibility to drive and enhancing vision to promote success in education. However, it was complicated by the parents' request to not disclose the progressive permanent vision loss and the realization that the truth would only make the child feel further ostracized by his peers.

Discussion

As healthcare providers, optometrists must abide by the medical code of ethics. The principles central to decision-making in eye care include autonomy, beneficence, non-maleficence and veracity.[2] In this case, the ethical principles challenged by parental involvement in an optometrist's management of a pediatric

patient include the defiance of trust and omission of truth from a child at the authority of the parents.

Patients have the right to make decisions about their medical care, and optometrists have a duty to respect these decisions.[2] This is known as autonomy.[2] However, in children, the capacity to engage in informed decision-making is limited, and until a child reaches age 18, the child's parents have the legal authority to determine what is in the best interest of the child. In this case, there was a conflict between the child's right to know about the progressive blindness associated with his diagnosis, which has the potential to impact his adult life, and his parents' desire to protect their child's emotional well-being. The parents' desire to protect their child paralleled the optometrist's duty to safeguard an especially vulnerable patient from a diagnosis that may compromise his emotional well-being. On the other hand, it was important the patient be made aware of the permanent and progressive nature of his condition so that he may learn to accept his diagnosis and the use of low vision devices to enhance his prospects of becoming a veterinarian. Although there are no guidelines barring a visually impaired individual from the practice of veterinary medicine in Texas, the extent of the visual impairment and its hindrance of the ability to perform surgery may render an individual unable to practice as a veterinarian.[3]

While the patient was not of legal age to be a fully autonomous decision-maker, children exhibit varying degrees of intellectual and emotional aptitude. The patient's cognitive and emotional development was assessed to determine his emotional resilience in handling the prognosis of his condition and his maturity in making decisions regarding his diagnosis. Ultimately, the parents' wishes to withhold the prognosis of the patient's condition was respected. The parents were advised to fully disclose to the child the nature of his condition and were provided retinitis pigmentosa support group resources in hopes they would use them to help navigate that conversation. It was believed that giving the parents some say in how the disclosure is handled would facilitate acceptance of disclosure and show respect for the patient's relationship with his family. Although it is unknown whether the disclosure had taken place following the visit, the patient's desire to have the low vision device after initially refusing it inspires hope. When managing and treating pediatric patients, optometrists must consider their moral and ethical obligations to their patient and the legal authority vested in parents and their nondisclosure requests.

Nondisclosure requests challenge the principle of veracity. Veracity refers to optometrists' obligation to be honest and truthful with their patients about their conditions and treatment options.[2] In this case, initially not disclosing to the patient the specific disease and then its severity per the parents' request was done out of respect for the parents' trust, but at a cost to the patient. Withholding a medical diagnosis or prognosis from a child poses risks to the optometrist-patient relationship. If the patient were to discover the optometrist was hiding information about his ocular diagnosis, he may harbor resentment and distrust the management of his condition. Furthermore, the patient's own curiosity about his diagnosis may have prompted him to conduct his own research. As a consequence, he may know more about his diagnosis than he may be letting on. However, information acquired from non-vetted sources could put him at risk of having inaccurate information or imagining worst-case scenarios. If the patient had the full picture in regard to his diagnosis, he might be more likely to comply with management recommendations such as using low vision devices at home and in school. Transparency may improve acceptance and contribute to better long-term adjustment to the condition. This is despite the discomfort and stress the patient may endure now in realizing he will have to rely on low vision aids and will never be able to acquire a Texas driver's license when his peers can. However, disclosing this to the patient along with providing the resources to his parents were the initial steps toward facilitating acceptance.

Conclusion

Optometrists often serve as bearers of difficult truths when delivering a diagnosis to patients. In pediatric populations, optometrists must weigh the burden of the truth on the child's emotional health against the child's future and right to know. Furthermore, they must juggle the parents' legal privileges to make decisions on the child's behalf and what is in the child's best interest. In this case, the obligations to

protect and care for the pediatric patient and to cooperate with the parents' nondisclosure request were reconciled by encouraging disclosure among the family.

References

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