VIEWPOINT

Diabetic Retinopathy in Youths—A Potentially Unappreciated Public Health Catastrophe

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Ophthalmologists generally consider diabetic retinopathy (DR) to be rare in youths with diabetes. However, recent data from the SEARCH for Diabetes in Youth (SEARCH)[1] and Treatment Options for Type 2 Diabetes in Adolescents and Youth (TODAY)[2] studies demonstrated alarming rates of DR after a mean diabetes duration of only 12 years and at a mean age of 26.4 years.[2] In the SEARCH study, 52% of youths with type 1 diabetes (T1D) had DR, and in the SEARCH and TODAY studies combined, 49% to 55% of those with youth-onset type 2 diabetes (T2D) had DR. For participants with T2D, at a mean 7.5 years after diagnosis, the standardized prevalence of DR was 31.0%, increasing to 55.7% at a mean 12.4 years after diagnosis.

This is surprising given that earlier data from the SEARCH study showed the age-adjusted prevalence of DR at a duration of 7 years to be 4% to 9% in youths with T1D and 4% to 13% in youths with T2D.[1] Another study demonstrated that compared with youths with T1D, youths with T2D had almost twice the risk of developing retinopathy, developed DR sooner after diabetes diagnosis, and were more likely to have vision-threatening retinopathy.[3]

The incidence of both T1D and T2D in youths has risen over the last 2 decades, with the greatest increases among Black and Hispanic youths. Based on incidence trends from 2002 to 2017, projections suggest that the number of youths with diabetes will increase substantially in the coming decades, with an estimated 65% increase in T1D and a more than 600% increase in T2D.[4] In T2D, which disproportionately affects racial and ethnic minority youth populations, existing disparities are expected to widen, with the most affected group being non-Hispanic Black youths.[5] Studies in both youths and adults suggest that racial and ethnic minority populations bear a greater burden of DR compared with their White counterparts, and with the growing prevalence of youth-onset diabetes, there is concern among the diabetes community that DR and associated visual loss will affect young racial and ethnic minority adults in increasingly disproportionate ways.

The results from the TODAY2 observational follow-up study[2] demonstrated that 60% of youths with T2D had at least 1 microvascular complication, and 28% had 2 or more complications, with risk factors of hyperglycemia, low insulin sensitivity, hypertension, dyslipidemia, and minority race or ethnicity. Specifically, at a mean (SD) age of 26.4 (2.8) years (and mean [SD] duration of 13.3 [1.8] years), at least 50% of participants had DR, 46% also had diabetic kidney disease, and 27% had diabetic nerve disease, highlighting the extraordinary risk for complications in this youth-onset cohort.[2] Although optimizing systemic control of blood glucose, cholesterol, and blood pressure can help reduce risk of future complications in patients with diabetes, it is important to note that few patients meet targets for optimal glycemic control as defined by the American Diabetes Association (goal HbA1c <7%), estimated at less than 20% of youths with T1D, and less than 40% of youths with T2D, leading to increased risk for diabetes associated complications.[6]

The guidelines from various advisory groups, including the American Diabetes Association and the American Academy of Ophthalmology, recommend ocular screening for youths with T1D 3 to 5 years after diagnosis in those who are at least 11 years old or are experiencing puberty, and for youths with T2D from the time of diagnosis. With normal screening, follow-up diabetic eye examinations can be performed every 2 years, with some groups advocating for even more infrequent follow-up examinations.[7] These guidelines are rooted in evidence from prior studies showing that it is rare to have advanced retinopathy prior to this age.[8] However, these guidelines have remained largely stagnant in the face of new evidence of increasing diabetes prevalence. Thus, it is difficult to differentiate when and how often children and adolescents with diabetes should be screened for ocular disease.

Even when screening is recommended, children often do not make it to their screening appointments, with pronounced disparities between White youths and racial and ethnic minority youths, as well as between Black youths and Latinx youths.[9] There are a multitude of reasons that youths with diabetes may miss eye screening appointments. Parents of younger children with diabetes frequently have many medical appointments to which they must bring their children, and eye examinations may be delayed for more pressing, systemic concerns. Adolescents and young adults may fall into the "transition period" between being followed by a pediatrician and moving to adult care, during which time they may be leaving their parental home and entering a less structured environment, with fewer reminders and less support to help them attend ophthalmic visits. Their care may subsequently be interrupted by multiple life transitions, such as attending college, starting a new job, acquiring new medical insurance, and challenges in seeking care. All too often, missed visits and lapses in care lead to patients whose eye disease has gone unchecked and who are left with irreversible late-stage vision loss from diabetic retinal disease.

In addition to improving rates of ocular screening for diabetic eye disease, we need more sensitive measures of neuronal pathology and visual dysfunction in diabetes. The Early Treatment Diabetic Retinopathy Study (ETDRS) severity scale is most commonly used to de-

termine the level of retinopathy and stage risk for future worsening. However, this scale only addresses retinal vascular disease, and the microvasculature of the retina is not the only component affected by diabetes. The neurologic component of the retina is also affected, likely prior to any appearance of retinopathy on examination or photographs. In adults, increasing levels of DR on the ETDRS scale are associated with impaired measures of visual function.[10] There is an increasing awareness of the need to develop new assessments of visual function beyond central best-corrected visual acuity in patients with diabetes. These efforts should include youth cohorts to identify the timing for early interventions that may best preserve vision in patients who are likely to live with diabetes across many decades.

Given the rising prevalence of youth-onset diabetes and the significant rates of structural DR seen in the SEARCH and TODAY studies, we must increase our surveillance of patients with youth-onset diabetes. Losing vision at a young age is an unacceptable consequence of diabetes. These young adults have many more years of vision to hold onto and many more years of productive life to live. We must find a way to screen both retinal structure and function to identify youths who need closer scrutiny and earlier intervention. As the landscape of treatment options broadens with new technological advancements, we need to be able to identify those at risk who would benefit from these treatments. Ophthalmologists should work in concert with our colleagues in pediatric and adult endocrinology to achieve better outcomes in youth-onset diabetes.

ARTICLE INFORMATION

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