

Disparities in Diabetes-Related Retinal Disease and Approaches to Improve Screening Rates

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According to the Centers for Disease Control and Prevention, an estimated 37.3 million people (11.3% of the U.S. population) have diabetes, and an additional 96 million people >18 years of age (38% of the U.S. adult population) have prediabetes (28). Sociodemographic factors such as race, ethnicity, income, education level, and insurance status have all been shown to affect diabetes prevalence rates (80–83). Ecological studies of diabetes prevalence have recently identified a “diabetes belt”: a region of the United States that encompasses 644 counties in mostly southern states in which diabetes prevalence is $\geq 11\%$ (24). Research on these geographical disparities has shown that community factors such as racial/ethnic mix, income, and food environment all contribute to rates of diabetes. Diabetes-related retinal disease (DRD), the most common ocular complication of diabetes and a leading cause of blindness in the United States (84), also disproportionately affects certain populations.

Disparities in Prevalence

Correlations between race/ethnicity and rates of DRD in the United States have been well established in multiple studies. Harris et al. published several studies in the 1990s that found that Blacks had significantly higher rates of DRD than non-Hispanic Whites. One study (85) reported that Black men were $\sim 23\%$ more likely to develop DRD than other race-sex groups, and another study (86) found that Blacks were more likely to develop DRD than Whites, with a calculated odds ratio (OR) of 2.96 after adjusting for glycemic control, blood pressure, and diabetes treatment. A third report by Harris et al. (87) showed that non-Hispanic Blacks and Mexican Americans not only have a higher prevalence of DRD compared to their White counterparts (46% and 84%, respectively), but also have higher rates of moderate and severe stages of DRD. This report concluded that, for Blacks, much of the difference in DRD rates could be attributed to higher levels of risk factors in that population.

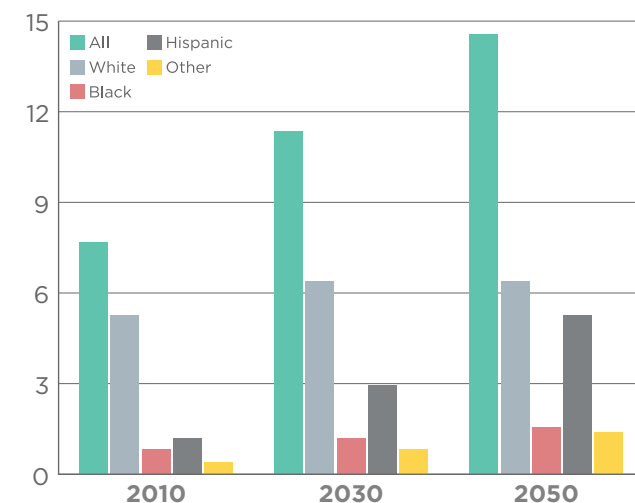
Prevalence rates of diabetes in the Hispanic population are generally reported to be about twice that of non-Hispanic Whites (88). DRD is also noted to develop at higher rates in this population. The National Eye Institute reports that, in

2010, Hispanic Americans ≥ 50 years of age had the highest prevalence of DRD (8%) of any racial/ethnic group (84). Almost half of Latino people with diabetes have DRD, with reported rates of 46.9 and 48% in two large epidemiological studies (88,89). In addition, while the number of Americans with DRD is expected to nearly double between 2010 and 2050, Hispanic Americans are expected to experience the greatest rise in cases, with a nearly three-fold increase in that time frame (84). Figure 1 illustrates projected increases in DRD cases in the United States by race/ethnicity.

Native Americans/Alaska Natives also have a prevalence of diagnosed diabetes that is about twice that of non-Hispanic Whites (1). Studies conducted in the 1980s and 1990s reported rates of DRD in these populations as high as 35–49%, but in a more recent study published in 2018, Bursell et al. (90) reported prevalence rates of DRD that were approximately half of those reported in earlier studies. They hypothesize that improvements in rates of DRD are associated with improvements in diabetes management.

Diabetes-related macular edema (DME), a vision-threatening stage of DRD, also disproportionately affects communities along racial/ethnic lines. Wong et al. (91) showed that the prevalence of DRD and DME was significantly higher in Blacks and Hispanics than in White and Chinese cohorts; however, despite the differences

FIGURE 1 Projections of DRD in the United States for 2030 and 2050 (in millions).



Adapted from ref. 84.

in rates of disease, their analysis found that race was not an independent predictor of the development of DRD. Another study (92) reported that the prevalence of DME was approximately threefold higher in non-Hispanic Blacks than in the non-Hispanic White population.

Proliferative diabetes-related retinal disease (PDR) is an advanced, vision-threatening stage of DRD. In a large database study, Malhotra et al. (93) reported that Black and Hispanic individuals had higher rates of PDR compared to their White and non-Hispanic counterparts. They also noted that Black and Hispanic people had worse visual acuity at initiation of treatment for vision-threatening disease compared to White and non-Hispanic people. Blacks and Hispanics had ORs of 1.23 and 1.71, respectively, for presenting with one level of DRD severity worse than White or non-Hispanic people. Black individuals presented with not only more severe DRD, but also significantly worse visual acuity.

Given the significant disparities in the rates of DRD, DME, and PDR, as well as differences in severity of disease at presentation, it is not surprising that visual impairment from DRD also disproportionately affects certain populations. Data from the Salisbury Eye Evaluation, reported two decades ago, showed that African Americans were four times more likely than Whites to suffer visual impairment from DRD (94).

In addition to race and ethnicity, there are significant correlations between other socioeconomic factors and prevalence of diabetes and DRD. A 2010 study (95) looked at prevalence of diabetes in Appalachian counties within the diabetes belt based on 3-year unemployment rate, per-capita income, and poverty rate. Counties were deemed “distressed” if they were in the bottom 10% of all counties in the country on these measures. The researchers found that residents of distressed Appalachian counties had 33% higher odds of having diabetes than those in non-Appalachian counties. The reasons for this disparity are likely complex and multifactorial, including higher rates of obesity, less physical activity, food insecurity, poor health literacy, and lack of access to care. A study of people with diabetes in North Carolina (96) reported that, in addition to increased prevalence in Blacks and individuals with a longer duration of diabetes, self-reported DRD was more common in adults who were not married or living with a partner, those with less than a high school education, those without health insurance, and adults with an annual household income <\$25,000; these findings underscore the impact of socioeconomic status on rates of DRD.

Disparities in Rates of DRD Screening

Most people are asymptomatic in the early stages of diabetes-related eye disease. Nwanyanwu et al. (97) found that nearly 11% of people with type 2 diabetes were unaware of their DRD diagnosis, which represents an estimated 9.8 million individuals. Screening for DRD is a cost-effective way of identifying it early and providing opportunities for both systemic and vision-preserving interventions (98). Early detection and treatment of DRD can reduce severe vision loss by 94% (99), and up to 21% of people with type 2 diabetes may already have some degree of DRD at the time of their diabetes diagnosis (100). Despite these statistics, adherence to DRD screening guidelines is low, with one study demonstrating that 35% of its cohort with diabetes did not receive appropriate screening (99). Other estimates suggest that nearly half of all people with diabetes do not receive eye health screenings as recommended in guidelines. 2020 data from the National Committee of Quality Assurance (NCQA) show that less than 50% of individuals with commercial insurance, 50.6% of those with Medicaid, and less than 69% of those with Medicare underwent DRD screening as recommended (101).

Racial minority groups have lower rates of eye screening than non-Hispanic Whites. One study demonstrated that, from 2002 to 2009, while the screening rate for Whites increased from 56 to 59%, the screening rate in minorities decreased from 56 to 49% (102). Although not specific to people with diabetes, another study reported that African Americans were less likely than non-Hispanic Whites to receive any eye care examinations (103). In the Los Angeles Latino Eye Study (104), 65% of participants had not had guideline-recommended eye care for people with type 2 diabetes.

In addition to race and ethnicity, household income, education level, health literacy, and geographical location have all been shown to be significant barriers to meeting eye health screening guidelines. Lower income and education levels, rural residence, and lack of health insurance have all been linked to fewer visits to eye care professionals and fewer dilated eye exams, and all of these factors also contribute to the lower screening rates noted in minority populations (103–105).

Screening in youth is important because 20.1 and 7.2% of youth with newly diagnosed type 1 and type 2 diabetes, respectively, in a large U.S. managed-care network developed DRD during 3 years of follow-up (8). Disparities in DRD screening rates have also been documented in youth with diabetes. Thomas et al. (106) reported that 34.2% of the youth with type 1 or type 2 diabetes in their cohort had not had a prior diabetes-related eye exam. Being of non-White race and having Medicaid or other public insurance, lower household

income, and parents with a high school education or less were all associated with being less likely to have had a prior eye exam. Another study involving youth with type 1 diabetes reported that White children were significantly more likely than Black children to be screened for DRD (OR 1.64) and that Black children in the study cohort were seven times more likely than White children to have public health insurance (107). The authors noted that youth who were not screened were more likely to have poorer diabetes control, suggesting that those who were not receiving eye exams were also the most at risk for DRD.

Interventions to Improve DRD Screening Rates

Numerous barriers to obtaining guideline-recommended screening exams have been documented, including patient-, physician-, and system-level factors (Table 1) (103,105,108,109). It is important to note that, in addition to patient-level factors, several provider- and system-level factors can be addressed to improve DRD screening rates.

Various strategies have been implemented successfully to improve retinal screening rates. These have included patient and provider education programs, strategies to improve access to health care, computer-based registration or reminder systems, collaboration among organizations that provide retinal screenings, and the development of a community-based health care system (110). Interventions aimed specifically at non-White, low-income, and low-health literacy communities may also be effective (105).

Health education and reminder interventions focusing on both people with diabetes and their health care providers have been shown to improve screening rates (110–112). Educating patients about diabetes-related eye disease can help them understand the importance of regular screening and motivate them to participate more in their own care. Educating primary

care providers about eye screening guidelines and improving provider-patient relationships by increasing providers' cultural competency may help to reduce the disparities in screening rates noted in minority populations. Walker et al. (113) increased DRD screening by 74% using a telephone intervention in a minority, low-income population. The telephone intervention, which was conducted by a bilingual interventionist, served to educate and motivate individuals about the importance of having an annual dilated eye examination and afforded the opportunity to discuss risk and the frequent lack of symptoms early in DRD and elicit and troubleshoot barriers. Another study (114) tested a health education intervention using a face-to-face session delivered in the local language, with pictorial educational materials in the local language, and telephone reminders. It found that personalized health education was the most important predictor of follow-through with screening referrals. Basch et al. (111) doubled the rate of ophthalmic examination among African Americans with diabetes from 27.3 to 54.7% using educational materials that included a low-literacy booklet, a motivational videotape, and telephone education and counseling.

At the system level, patient registries, collaboratives, and prompts within electronic medical record (EMR) systems have all been shown to help providers identify patients who are not getting recommended DRD screening (115,116). Kollipara et al. (116) increased screening rates in a large endocrinology clinic from 49 to 69% using a multifaceted approach that included a diabetes patient registry and decision-support tools within the EMR system. Use of the registry facilitated the identification of care gaps, and use of the EMR system facilitated patient outreach using bulk messaging through the patient portal as well as placement of referrals to ophthalmology and provided an efficient system for tracking the successful delivery of care.

TABLE 1 Barriers to Recommended DRD Screening

Component	Considerations
Patient-level factors	<ul style="list-style-type: none"> ▶ Lack of education about/understanding of DRD and the availability of treatment ▶ Cost/insurance issues ▶ Lack of follow-through on referral/recommendation ▶ Lack of access to care ▶ Patient-provider communication issues (e.g., language barriers, limited health literacy, and lack of trust)
Provider-level factors	<ul style="list-style-type: none"> ▶ Lack of awareness of screening guidelines, skill, or equipment to perform eye exams ▶ Patient-provider communication issues (e.g., language barriers, limited health literacy, and lack of trust) ▶ Time limitations ▶ Inconsistent primary care provider referral patterns
System-level factors	<ul style="list-style-type: none"> ▶ Insurance issues ▶ Understaffing of eye care professionals/difficulty obtaining diagnostic imaging ▶ Long wait times for appointments

Adapted from ref. 105.

Telemedicine to Improve DRD Screening Rates

The use of telemedicine using retinal imaging with remote interpretation by eye care specialists can increase DRD screening rates (117–119). Studies have shown a high degree of accuracy in detecting DRD by image-based telemedicine, with sensitivity of >80% and specificity of >90% in most studies (120). This approach has been implemented widely in many countries, including Singapore, China, and India (121), and is the standard for DRD screening in the United Kingdom (45). In 2014, Liew et al. (10) noted a decline in the absolute number and relative proportion of blindness certifications resulting from DRD/maculopathy among working-age adults after the 2003 introduction of the National Health Service Diabetic Eye Screening Programme in England. These authors also reported that, by 2009–2010, DRD/maculopathy was no longer the leading cause of certifiable blindness among working-age adults in England and Wales for the first time in at least five decades. In the United States, digital retinal imaging with remote interpretation has been implemented successfully by the Veterans Health Administration (VHA) and found to be cost-effective and to increase population reach (122).

The placement of digital imaging equipment in primary care offices for point-of-care testing can further reduce patient-level obstacles such as lack of transportation, inconvenience, and language barriers (123). This strategy decreases the travel distance and time required for DRD screening because it does not require a separate visit to a different location. In the Tribal Vision Project (124), people randomized to telemedicine were more likely to receive a DRD screening exam than those receiving traditional surveillance throughout a 6-month period.

Although studies of the VHA's teleretinal screening program have demonstrated cost-effectiveness (122), these results are not directly applicable to teleretinal programs implemented in community primary care clinics in the United States (125). The initial investment for retinal imaging devices and training may be prohibitively high for many primary care clinics without additional sources of funding. Although there is active research and development in the field of retinal imaging, a low-cost, validated, nonmydriatic retinal camera is not yet commercially available (103,125).

In addition, reimbursement for telemedicine Current Procedural Terminology (CPT) codes for retinal screening does not adequately reflect the work performed and is

insufficient to cover the cost of most DRD telemedicine programs (103). In 2011, CPT codes 92227 and 92228 were introduced for remote imaging for detection of retinal disease. For individuals with no known retinal disease, CPT code 92227 (remote imaging for detection of retinal disease with analysis and report under physician supervision) has no compensation for physician work and is associated with very low reimbursement (average allowable amount <\$16). CPT code 92228 (remote imaging for monitoring and management of active retinal disease with physician review, interpretation, and report) is used for people with active retinal disease and has slightly higher reimbursement (average allowable amount <\$40). Despite the benefits of telemedicine for DRD screening, financial sustainability continues to be a major barrier to its widespread implementation (103,125).

Conclusion

Significant disparities exist in rates of both DRD and DRD screening. Black, Hispanic, and Native American populations are disproportionately affected, with higher rates of DRD and lower rates of DRD screening. Additionally, screening rates are affected by socioeconomic factors such as income, education level, insurance payor, and geographical location. Numerous patient-, physician-, and system-level factors contribute to these disparities, and various interventions have been shown to be effective in addressing barriers at each of these levels.

It is important for practitioners to recognize that socio-demographic factors play key roles in diabetes management and risk for complications such as DRD. Strong clinician-patient relationships and a better understanding of barriers faced by different racial/ethnic and socioeconomic groups will allow for targeted interventions such as providing people with literature in their native language and at an appropriate health literacy level, offering financial counseling, or engaging social work services to assist with transportation. System-level changes such as instituting EMR reminders and prompts and teleretinal imaging are also important strategies to improve rates of DRD screening. In particular, teleretinal imaging is an emerging and important strategy to address disparities in DRD disease burden, although financial sustainability remains a barrier to its widespread implementation. Recognition of the value of telemedicine services by payers and government agencies could lead to significant improvements in access to care and reductions in DRD disparities.