

# Disparities in Diabetic Retinopathy Screening and Disease for Racial and Ethnic Minority Populations—A Literature Review

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Diabetic retinopathy is the leading cause of blindness in the United States. This sight-threatening complication of diabetes mellitus disproportionately affects racial and ethnic minority populations. Tight glycemic control and routine eye screening can diminish the public health impact of this devastating condition in minority communities. However, racial and ethnic minority patients are more likely to have poorer glycemic control and are less likely to be screened for diabetic retinopathy than their white counterparts. Patient, provider, and health care system factors play a role in these disparities. While public health interventions are necessary on a large scale to preserve vision in minority communities, it is also essential that individual health care providers better understand the impact of diabetic retinopathy on minority communities and the available interventions to reduce its impact. Maximizing their efforts to improve diabetes-related vision care for their racial and ethnic minority patients can lead to a decrease in diabetic retinopathy disparities.

**Keywords:** diabetes mellitus ■ ophthalmic ■ race/ethnicity

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## PROFILE OF DIABETES MELLITUS IN THE UNITED STATES

Diabetes and its complications pose significant public health concerns in our nation.<sup>1</sup> In 2000, there were 17.1 million people in the United States estimated to have diabetes.<sup>2</sup> In 2007, the estimate increased to 23.6 million; this figure represents 7.8% of the US population.<sup>1</sup> Of these diabetic individuals, 17.9 million were diagnosed, leaving 5.7 million undetected. The 18.6% of the nation's 23.6 million of the nation's persons with diabetes is made up of 9.8% of non-Hispanic whites and 14.7% of non-Hispanic blacks. After adjusting for population age differences, 16.5% of the American Indian and Alaska Native population who received care from the Indian Health Service had diabetes.<sup>1</sup>

Disparities in incident type 2 diabetes are evident between racial/ethnic groups. The highest prevalence of diabetes in the United States exists among American Indians and Alaska Natives. In some groups, rates exceed 50% of the population.<sup>3</sup> Brancati et al demonstrated that African Americans are at greater risk of diabetes than their white counterparts.<sup>4</sup> On average, non-Hispanic blacks are 1.6 times as likely and Hispanic/Latino Americans are 1.5 times as likely to have diabetes than non-Hispanic whites of similar age.<sup>5</sup>

Several studies have shown that diabetic adults from minority populations are less likely to have good glycemic control than their white counterparts.<sup>6-8</sup> Studies have demonstrated that minority populations are more likely to develop complications of the disease.<sup>9,10</sup> Diabetic retinopathy, the leading cause of preventable blindness in the United States, disproportionately affects racial and ethnic minority populations.<sup>11</sup>

## DIABETIC RETINOPATHY

### Incidence and Prevalence

Diabetic retinopathy is a significant microvascular complication of diabetes. In the advanced stage, it is characterized by abnormal retinal vasculature growth secondary to ischemia.<sup>12</sup> It is estimated that as many as

40 000 new cases of diabetic retinopathy are diagnosed in the United States each year. Diabetics with retinopathy are 25 times more likely to be blind than their nondiabetic counterparts.<sup>13</sup> An estimated 40.3% of diabetic American adults aged 40 and older have diabetic retinopathy, and 8.2% of diabetic American adults have advanced vision-threatening retinopathy. Three percent of the general population has diabetic retinopathy, and 0.75% of the general population has vision-threatening retinopathy.<sup>14,15</sup>

## Public Health Impact of Diabetic Retinopathy

Diabetic retinopathy has significant economic, social, and public health impact. Diabetic retinopathy causes 12 000 to 24 000 new cases of blindness every year.<sup>11</sup> Care (direct medical costs) for diabetic retinopathy has been found to cost \$493 million per year, with \$298 million of this spent for patients aged 40 to 64 and \$195 million spent for those aged 65 and older.<sup>16</sup>

Studies have also been done to determine the impact of diabetic retinopathy on patients' daily lives.<sup>17-19</sup> Focus groups comprised of Caucasian patients with both type 1 and type 2 diabetes identified driving at night, reading, and facial recognition as aspects of daily living most impacted by having diabetic retinopathy.<sup>19</sup> Lamoureux found that patients with diabetic retinopathy reported having the greatest difficulties with reading, mobility, work, and leisure.<sup>18</sup>

## Risk Factors for Diabetic Retinopathy

A number of well-known factors contribute to increased risk of diabetic retinopathy. For every 1% reduction in blood glucose levels, as reflected by hemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>) levels, the risk of developing eye, kidney/end stage renal disease, and lower-extremity amputation is reduced by 40%.<sup>1</sup> Risk factors for diabetic retinopathy include prolonged disease duration, poor glucose control, hypertension, and hyperlipidemia.<sup>12,20,21</sup> Renal disease is an excellent predictor of diabetic retinopathy.<sup>22</sup> Additionally, several studies have shown that minority race or ethnicity is also a significant risk factor for the development and severity of diabetic retinopathy, even after controlling for key risk factors such as risk factors of HbA<sub>1c</sub>, blood pressure, duration of diabetes, or lipid values.<sup>21,23-26</sup>

In the Los Angeles Latino Eye Study (LALES), risk factors for visual impairment included female gender, low education, unemployment, a history of eye disease, and diabetes.<sup>20</sup> Lanting et al reviewed studies of patients with type 1 and type 2 diabetes and found that after adjusting for confounders and other risk factors, Hispanics in the United States were at an elevated risk of developing diabetic retinopathy.<sup>27</sup> In their review of the literature, they also found that blacks in the United States had a higher risk of diabetic retinopathy than their white

counterparts after adjustment for confounders. A veterans administration (VA) hospital study found that factors such as age, time since diabetes diagnosis, and HbA<sub>1c</sub> did not account for the higher prevalence of diabetic retinopathy in Hispanic and black study participants. Increased diabetic retinopathy severity was associated with degree of microalbuminuria, fibrinogen, and amputation. However, the differences were not completely explained by any factor studied.<sup>21</sup> A lack of health insurance, lower socioeconomic status and educational attainment, and elevated levels of HbA<sub>1c</sub> are risk factors for patients obtaining less preventive care.<sup>16,17</sup>

Recent studies have suggested that genetics may also be an important risk factor in the development of diabetic retinopathy. It is "moderately heritable" in Pima Indians with type 2 diabetes. Additional linkage studies are ongoing to determine whether these findings extend to other populations and specific loci or genetic profiles are associated with increased diabetic retinopathy risk.<sup>18</sup> Familial clustering of proliferative retinopathy in patients with type 1 diabetes, not attributable to conventional risk factors, has also been identified.<sup>18</sup> If specific loci or genetic profiles were to be identified, presymptomatic testing of at-risk individuals could become an important part of diabetes management.

## Prevalence of Diabetic Retinopathy in Minority Populations

Diabetic retinopathy has a significant differential impact on nonwhite individuals with diabetes. Multiple studies have explored disparities in the prevalence, incidence, screening, and treatment of diabetic retinopathy in minority populations. In the Salisbury Eye Evaluation (SEE), African Americans were found to have 4-fold risk of visual impairment due to diabetic retinopathy. Munoz et al found that diabetic retinopathy accounts for 17% of vision impairment in African Americans vs 8% in non-Hispanic whites.<sup>18</sup> While data are limited, the documented prevalence of diabetic retinopathy in some Native American groups is as high as 45.3%.<sup>18-20</sup>

The LALES is the largest and most comprehensive epidemiological analysis of visual impairment in Latinos conducted in the United States. More than 6 000 Latinos (primarily Mexican Americans) over the age of 40 had a detailed health interview and clinical examination performed. The study assessed their risk factors for eye disease and measured health-related and vision-related quality of life. One in 5 individuals with diabetes was newly diagnosed during the LALES clinical exam, and 25% of these individuals were found to have diabetic retinopathy. Nearly half (46.9%) of all Latinos with diabetes had diabetic retinopathy.<sup>11</sup>

Prevalence rates of visual impairment in Latinos were higher than those reported in whites and were comparable to those reported in blacks. Nearly half of all study participants with diabetes—almost a quarter of

the LALES population—had some signs of diabetic retinopathy. In addition, more than 10% of participants with diabetes had macular edema, and in 60% of these individuals, cases were severe enough to require laser therapy. Latinos had a higher rate of more severe vision-threatening diabetic retinopathy than whites.<sup>20</sup>

Proyecto VER (Vision Evaluation and Research) was a diabetes and diabetic retinopathy prevalence study of 4 774 Hispanic adults over the age of 40 living in Arizona. The prevalence of diabetes in this population was 22%, and 15% of the cases were individuals with diabetes undiagnosed prior to participation in the study. Of the undiagnosed group, 23% of the subjects had any retinopathy, and 9% had moderate to severe retinopathy. The prevalence of diabetic retinopathy was 48% in this population, which is almost twice that of Caucasians.<sup>28</sup>

## DIABETIC RETINOPATHY SCREENING

### Benefits of Early Detection and Treatment

Early detection and treatment of diabetic retinopathy are cost effective. Blindness in diabetic patients under the age of 65 costs the federal government \$14 296 per person annually, while the cost per patient for retinopathy screening by a primary care physician is \$31.<sup>29</sup> An annual eye exam for diabetes patients results in a cost savings of \$2 162 per year of sight gained.<sup>29-32</sup>

### Current Screening Guidelines

Current US screening guidelines for diabetic retinopathy recommend annual dilated exams for all patients with diabetes be performed by either an ophthalmologist or an optometrist experienced in the diagnosis of diabetic retinopathy. An adequate screening exam should include measures of intraocular pressure, visual acuity, pupils' dilation, and retina examination with slit lamp

and indirect ophthalmoscopes to examine for macular edema and new retinal blood vessels.

For individuals with type 1 diabetes, the recommendations are annual exams after a 3- to 5-year duration of the disease.<sup>33-35</sup> For individuals with type 2 diabetes, exams should be performed at the time of diagnosis of diabetes and then annually thereafter.<sup>36</sup>

### Disparities in Diabetic Retinopathy Screening Completion

Sloan and Orr both reported that African Americans are less likely to be screened for diabetic retinopathy than whites.<sup>37,38</sup> This is significant, as the prevalence and severity of diabetic retinopathy is greater in non-Hispanic blacks and Mexican Americans with type 2 diabetes in the United States.<sup>20,39</sup>

An estimated 33% to 68% of diabetic adults in the United States have dilated retinal exams yearly.<sup>38,40-42</sup> The Healthcare Effectiveness Data and Information Set (HEDIS) is a set of standardized health care performance measures related to many significant public health issues such as cancer, heart disease, smoking, asthma, and diabetes. HEDIS measures relating to diabetes are: HbA<sub>1c</sub> testing, annual eye examinations, cholesterol screening, cholesterol control, and nephropathy monitoring. HEDIS data show that in 2006 only 54.8% of diabetic patients with commercial insurance, 48.6% with Medicaid, and 66.5% with Medicare underwent eye screening. These figures represent an increase in all 3 groups from 2000. In 2000, 48% of commercially insured diabetic patients, 43% of those covered by Medicaid, and 62% of those covered by Medicare received screening.<sup>43</sup>

In the LALES, Latinos with lower educational attainment and lacking health insurance were less likely to have been screened than Latinos with more education and having health insurance.<sup>26</sup>

**Table 1.** Barriers to Recommended Diabetic Retinopathy Screening

Patient-level factors	<ul style="list-style-type: none"> <li>• Lack of education about/understanding of diabetic retinopathy and the availability of treatment<sup>40,42,45</sup></li> <li>• Cost/insurance issues<sup>45,53,54</sup></li> <li>• Noncompliance/patient refusal of services<sup>37,41,42</sup></li> <li>• Lack of access to care<sup>37,41,42</sup></li> <li>• Patient-provider communication (language barriers, health literacy, trust)<sup>52,67,68</sup></li> </ul>
Provider-level factors	<ul style="list-style-type: none"> <li>• Lack of awareness of screening guidelines, skill or equipment to perform eye exams.<sup>41</sup></li> <li>• Patient-provider communication (language barriers, health literacy, trust)<sup>52,67,68</sup></li> <li>• Time limitations<sup>53</sup></li> <li>• Primary care provider referral patterns<sup>40,41</sup></li> </ul>
System-level factors	<ul style="list-style-type: none"> <li>• Insurance issues<sup>45,46</sup></li> <li>• Understaffing of eye care professionals/difficulty obtaining diagnostic imaging<sup>93</sup></li> <li>• Long waiting time for appointments<sup>45,46</sup></li> </ul>

In a qualitative review of 19 studies that included African Americans, American Indians, and Hispanics, data were highly variable for each ethnic group. Five studies found statistically significant differences in screening rates by race and ethnicity, with all 5 showing a lower rate of eye examinations in minority groups.<sup>8</sup>

## BARRIERS TO RECOMMENDED SCREENING

A variety of factors pertaining to patients, providers, and the health care system contribute to racial and ethnic disparities throughout the health care system.<sup>44</sup> These factors also play a role in diabetic retinopathy screening disparities. Table 1 outlines key factors impacting the completion of diabetic retinopathy screening.

### Patient Factors

Patient factors include lack of education about and understanding of diabetic retinopathy and the availability of treatment.<sup>40,42,45</sup> Fear, spirituality, economic issues, noncompliance, reluctance to make follow-up appointments, lack of time, and lack of transportation have also been identified as significant barriers to routine screening.<sup>37,40-42,45-48</sup> In one study, persons of lower socioeconomic status were at greatest risk for not receiving preventive care regardless of race/ethnicity. Those with no health care coverage were twice as likely to not have visited the doctor in the previous year and twice as likely to have not had an eye exam.<sup>20</sup> Health literacy has been shown to impact diabetes knowledge, management, and outcomes.<sup>49,50</sup> It is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions.<sup>51</sup> Language barriers for non-English-speaking Hispanics, lack of health insurance, and access to specialty care have been identified as obstacles to

obtaining recommended screening.<sup>8</sup> Variables that may also contribute to racial and ethnic disparities are mistrust of the medical system, refusal of services, and delay in seeking care.<sup>8,41</sup>

A qualitative research study among American Indians and Alaska Natives showed a disconnect between providers and patients who were considered proactive about their health. Physicians sensed a lack of initiative among these patients, reporting that the patients expected the provider “do everything.”<sup>52</sup>

### Provider Factors

Provider factors include lack of awareness of screening guidelines, skill, or equipment to perform eye exams.<sup>42</sup> Inadequate patient education,<sup>41,42</sup> patient-physician communication,<sup>45</sup> and time limitations<sup>53</sup> contribute to poor screening completion rates. Mukamel et al explored various barriers to compliance with diabetic retinopathy screening guidelines, including those related to physicians and physician-patient relationships. In this study, the most prominent factor was the average number of primary care physician (PCP) visits each patient had. This suggests that an increase in contact may lead to more time for interaction and education of the patient.<sup>52,54</sup> An increase of one monthly visit to the PCP increased the odds of screening by 28%.

### System Factors

The health care system also contributes to disparities in diabetic retinopathy screening. System factors include lack of insurance coverage, a long waiting time for appointments, and difficulty in scheduling appointments.<sup>45,46</sup>

A cross-sectional analysis revealed that physicians treating black patients had more difficulty obtaining subspecialty care and diagnostic imaging for their patients.<sup>8</sup> Additionally, understaffing of optometrists and

**Table 2.** Interventions to Improve Recommended Diabetic Retinopathy Screening

Patient-level interventions	<ul style="list-style-type: none"> <li>• Improved education about diabetic retinopathy, prevention, screening and treatment<sup>55,57,58</sup></li> <li>• Patient reminders/personalized follow-up<sup>61,62</sup></li> <li>• Diabetes self-management programs<sup>59,60</sup></li> </ul>
Provider-level interventions	<ul style="list-style-type: none"> <li>• Provider education regarding diabetic retinopathy, screening guidelines, and performing exams<sup>42,45</sup></li> <li>• Provider aids to increase guideline adherence/provider self-audit tools<sup>65,66</sup></li> <li>• Training to improve provider-patient communication<sup>67,68</sup></li> <li>• Cultural competency training/training in interpreter use<sup>49,54,63,64</sup></li> </ul>
System-level interventions	<ul style="list-style-type: none"> <li>• Patient registries<sup>74,75</sup></li> <li>• Provider reminders, including prompts in electronic medical records<sup>76,77</sup></li> <li>• Improved access (telemedicine, mobile clinics, placing retinal imaging in primary care providers' offices)<sup>70,80-87,95</sup></li> <li>• Population-based screening programs and diabetes management programs<sup>78,48,60,79</sup></li> <li>• Community-based diabetes management and diabetic retinopathy screening programs<sup>48</sup></li> </ul>

ophthalmologists as well as high turnover contribute to poor screening completion.<sup>52</sup>

## INTERVENTIONS TO REDUCE DISPARITIES IN DIABETIC RETINOPATHY SCREENING AND DISEASE

Mitigation of cardiovascular risk factors (tight glyce-mic control, blood pressure control, and lipid control), early detection, and early diabetic retinopathy treatment are necessary to preserve the sight of diabetic patients of all racial and ethnic backgrounds. Interventions that help patients overcome barriers to disease self-manage-ment and compliance with diabetic retinopathy screen-ing recommendations help providers improve screening, and improve the quality of diabetes care may play a sig-nificant role in the reduction of disparities in diabetic retinopathy. Interventions must target patients, provid-ers, and health care systems. Table 2 outlines key inter-ventions at all 3 levels.

### Patient-Level Interventions

A number of interventions focused on patients can lead to improved diabetic retinopathy screening. Educating patients about the benefits of diabetic retinopathy screen-ing,<sup>42,45</sup> patient reminders,<sup>55</sup> and culturally specific screen-ing efforts<sup>48</sup> have been shown to be effective in some set-tings.<sup>40,42,45,55-58</sup> Additionally, diabetes management programs that improve self-management skills can lead to improved diabetes management and increased completion of screen-ing.<sup>59,60</sup> Patient reminders and personalized follow-up can lead to increased screening rates.<sup>61,62</sup> Interventions to improve patient-provider communication should address language barriers and health literacy.<sup>49,63,64,54</sup>

### Provider-Level Interventions

A number of interventions targeting providers can lead to improved diabetic retinopathy screening rates among minority populations. Educating primary care pro-viders about diabetic retinopathy, screening guidelines, and providing exams can have an impact on screening rates.<sup>75</sup> Additionally, training that helps providers increase the quality of screening and aids to help providers track their adherence to guidelines are also effective.<sup>65,66</sup>

Attention to provider-patient communication and cultural competency may help to improve the number of racial and ethnic minority patients who receive recom-mended screening.<sup>67,68</sup> Interventions aimed at patients can be effectively targeted to nonwhite individuals with limited education and low health literacy.<sup>69-73</sup>

### System-Level Interventions

Addressing health care system barriers to diabetic retinopathy screening can lead to improved screening rates. Patient registries and diabetes collaboratives and other efforts to improve the quality of diabetes care can lead to increased diabetic retinopathy screening.<sup>65,66,74,75</sup>

Provider reminders, including prompts in electronic medical records, can help providers track which patients need screening and follow-up of failed screening.<sup>76,77</sup>

Population-based screening programs<sup>78</sup> and diabetes management programs, such as those carried out by health maintenance organizations, can improve screen-ing rates.<sup>48,60,79</sup> Community-based diabetes management and diabetic retinopathy screening programs can impact screening rates as well.<sup>48</sup>

The use of telemedicine,<sup>80,81</sup> mobile screening,<sup>70,81-87</sup> and the placement of diabetic retinopathy screening equipment in primary care offices may also be interven-tions that can serve to decrease the number of cases of diabetic retinopathy that advance to vision impairment and/or blindness. This may be especially true in popula-tions with limited health care access such as rural Native American tribes and other rural populations.

Retinal imaging in primary care settings has been effective in eliminating some of the barriers preventing diabetic patients from undergoing diabetic retinopathy screening.<sup>88</sup> Screening by retinal photography could be an effective method to improve the numbers of diabetic patients receiving diabetic retinopathy screening.<sup>80,89</sup> Patients with detected diabetic retinopathy or ungrade-able photographs are then referred to ophthalmologists for further evaluation and treatment. This could ulti-mately decrease the number of screening referrals to ophthalmology, thereby freeing resources for evaluation of patients with ungradeable photos and treatment of patients with identified disease.<sup>90</sup> While placing digital retinal imaging in primary physician offices could impact diabetic retinopathy screening rates, many other interventions that lead to improvement of diabetic reti-nopathy screening rates for racial/ethnic minority patients remain.<sup>65,87,91</sup>

## CONCLUSIONS

Racial and ethnic minority populations are dispro-portionately affected by diabetes and its complications, including diabetic retinopathy. This complication poses a significant threat to the sight and quality of life of racial and ethnic minority populations. However, these high risk populations are not being adequately screened or treated for this sight-threatening condition.

A number of patient, provider, and system factors impact the disparities in diabetic retinopathy. Interventions to improve diabetes detection and control and to increase diabetic retinopathy screening in minority pop-ulations are needed. Health care providers must work together to decrease the number of minorities with dia-betes who suffer from this sight-threatening condition.

While public health interventions play an important role in reducing disparities in diabetic retinopathy screening and prevalence, individual health care provid-ers can take action to reduce diabetic retinopathy screen-ing disparities in their own practices. They should con-

tinue to take an active role in the recommendation of screening and the follow-up of failed screening.

Implementing patient registries can lead to improvements in the quality of diabetes care.<sup>64,92</sup> Providers should also attempt to identify barriers to screening for individual patients and offer practical recommendations to help patients overcome these barriers. Additionally, diabetic retinopathy–focused education materials that target racial and ethnic minority and low literacy audiences may impact routine diabetic retinopathy screening.<sup>40,42,56,57</sup>

## RECOMMENDED RESOURCES

- American Academy of Ophthalmology: <http://www.aao.org/>
- National Diabetes Education Program: <http://www.ndep.nih.gov/>
- National Eye Institute: <http://www.nei.nih.gov/>
- Indian Health Service Division of Diabetes Treatment and Prevention: [http://www.ihs.gov/MedicalPrograms/Diabetes/resources/r\\_index.asp](http://www.ihs.gov/MedicalPrograms/Diabetes/resources/r_index.asp)
- National Medical Association Diabetes Education Program: <http://www.nmadiabetesnet.org/index.php>

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