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ABSTRACT

Diabetic retinopathy (DR) is the leading cause of new-onset blindness in American adults aged 20–74 years old. The number of diabetics living with diagnosed DR increased by 89%, from 4.06 million to 7.69 million, between 2000 and 2010. Projected numbers from the Vision Health Initiative by the CDC predict that the rate of DR will triple by 2050, from 5.5 million people living with DR to 16 million. Screening guidelines aim to detect cases early because the treatments for DR can reduce severe vision loss by up to 94%. However, adherence to these guidelines is quite low. It is estimated that more than half of patients with diabetes may fail to receive necessary screening. Risk factors for non-screening discussed in this study include low health literacy, lack of access to care, pregnancy, physician adherence to guidelines, unique factors present in different minority populations, gender and age disparities, and living in rural regions. This paper also aims to address potential interventions that may improve adherence rates.

Keywords: Diabetes, diabetic retinopathy, health disparities, ophthalmology, screening

INTRODUCTION

Diabetic retinopathy (DR) is the leading cause of new-onset blindness in American adults aged 20 to 74 years old.1 Around 4.2 million Americans, or 28.5% of diagnosed diabetics aged 40 and older, have DR.2 About 23,000 people are estimated to become legally blind from their diabetes every year.3 Moreover, diabetes-related blindness costs the United States an average of $500 million annually in lost income.1

Screening guidelines aim to detect cases early as the treatments for DR can reduce severe vision loss by up to 94%.4 Joint guidelines set by the American Academy of Ophthalmology (AAO), the American Diabetes Association (ADA), and the American College of Physicians (ACP) recommend annual screenings for patients with type 2 diabetes and all postpubertal type 1 diabetics who have had the disease greater than five years. Patients with type 2 diabetes should be screened at the time of diagnosis as up to 21% may already have some degree of DR.5 The ADA also recommends funduscopy exams at all routine diabetes-related visits.6 Both groups of patients with diabetes should be screened at least yearly afterwards with a dilated exam by an ophthalmologist or optometrist.6 However, adherence to these guidelines is quite low. It is estimated that more than half of patients with diabetes may fail to receive necessary screening.3 Several proposed factors impact adherence levels, including patient demographics and the duration and type of diabetes.4 The authors aim to review the ophthalmic literature to identify disparities in rates of screening for DR and to pinpoint risk factors for non-screening in the United States.
PUBLIC HEALTH IMPACT

The prevalence of diagnosed diabetes in 1994 was less than 6% in almost all states. In 2013, no states had a prevalence of less than 6% and 25 states exceeded 9%. In 2012, 9.3% of the American population, or 29.1 million people, had diagnosed diabetes. Rates of DR have concurrently risen. The number of diabetics living with diagnosed DR increased by 89% from 4.06 million to 7.69 million from 2000 to 2010. Projected numbers from the Vision Health Initiative by the CDC predict that the rate of DR will triple by 2050 from 5.5 million people living with DR to 16 million. The number of people with vision-threatening DR will also triple from 1.2 million to 3.4 million.

Nearly all patients with type 1 diabetes manifest some degree of DR after an average disease duration of 15 years. 72% of those patients will develop proliferative diabetic retinopathy (PDR) requiring treatment. Patients with type 2 who are over 30 years old and have had known diabetes for less than five years exhibit retinopathy at rates ranging from 40% of those who are on insulin to 24% of those who are non-insulin-dependent. A quarter of type 2 diabetics with a disease duration of 25 years or more develop proliferative retinopathy.

DR significantly affects vision-related quality of life. Persons with DR report higher rates of emotional distress and depression. They also report difficulty with tasks that require fine visual acuity (e.g., reading fine print, newspapers, or medication labels). This impairment limits their mobility and ability to partake in work and leisure.

Screening for diabetic eye disease has proven to be one of the most cost-effective medical interventions in ophthalmology. Blindness from diabetes results in more than $500 million of lost wages per year in the United States. Appropriately detecting and treating DR is estimated to save between 62.1 and 108.6 million federal dollars annually. For every 10% incremental increase in compliance to screening guidelines, an estimated $16.5 million per year could be saved. Treatment of diabetic eye disease has also proven to be cost-effective with regards to vision saved. Models based on clinical trials predict a cost of $966 per person-year of vision saved for patients with PDR and $1120 per person-year of central visual acuity saved for patients with macular edema. The cost of treating appropriately is less than the cost of a year of Social Security disability. Moreover, this does not take into account the even greater costs saved by preserving patients’ productivity and quality of life. Despite DR’s substantial economic and personal burden, persons with diabetes mellitus still reportedly underuse health-care services, especially preventative care.

RISK FACTORS FOR NON-SCREENING

Socioeconomic

Walker and colleagues evaluated the impact of socioeconomic status on the likelihood of receiving guideline-concordant screening for diabetic retinopathy. Persons with a poverty-income ratio (PIR) of less than 1.50 were less likely to see an eye-care provider or undergo a dilated eye exam compared to people with a PIR of 5.0. Visits to an eye-care provider also correlated with a person’s education level. Walker theorized that higher education levels facilitate better understanding of diabetes self-care and may also improve access to information. Lastly, immigrants, who may be of a lower socioeconomic status, are more likely to exhibit an “optimistic bias,” believing that they are at less risk for diabetic complications than their counterparts and, as a result, are less likely to adopt preventative measures.

Health Literacy

Health literacy is defined as the extent to which patients understand their diagnosis and can act upon that knowledge. Those at risk for lower levels of health literacy include the elderly, racial and ethnic minorities, those from a lower socioeconomic status or lower education backgrounds, and non-native English speakers. Difficulty with self-management skills such as understanding glucose values, dosing schedules, and understanding educational brochures can propagate health disparities. A study supported by the Vanderbilt Diabetes Research and Training Center examining the role of literacy and numeracy in diabetes found that patients often have difficulty understanding nutrition labels. This was especially true for those with low levels of health literacy. The study demonstrates that patients face barriers even when trying to manage their primary disease, which may inhibit their ability to prevent and/or understand the complications of their diabetes. As expected, limited health literacy is associated with poor diabetes self-care and lower utilization rates of preventative services. It is important to recognize the prevalence of limited health literacy within a community as that may affect how to effectively deliver health information. When developing an eye health education program for Native Americans, researchers found that participants with limited health literacy preferred one-on-one counseling or storytelling over written materials.

Moreover, an inadequate understanding of the disease and its progression may contribute to disparities in adherence to screening examinations. Patients with
TABLE 1. Summary of factors that impact adherence to screening guidelines.

<table>
<thead>
<tr>
<th>Group/Determinant</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socioeconomic</td>
<td>• Persons with a Poverty Index Ratio (PIR) of &lt;1.50 are less likely to see eye-care provider compared to people with a PIR of 5.0.</td>
</tr>
<tr>
<td></td>
<td>• Education levels play a key role in understanding diabetes self-care and in access to information on medical management.</td>
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<tr>
<td>Health Literacy</td>
<td>• Limited health literacy is associated with lower utilization rates of preventative services.</td>
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<td></td>
<td>• Public health programs should evaluate prevalence of limited health literacy in a community in order to effectively deliver health information.</td>
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<td></td>
<td>• There are currently many missed opportunities for patient counseling from eye-care providers or diabetes nurse educators.</td>
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<tr>
<td>Access to Care</td>
<td>• Traditional screening methods require on-site skilled technicians, photograph readers, and advanced photography equipment. Process can be both time-consuming and uncomfortable.</td>
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<td></td>
<td>• Scarcity of medical resources in rural areas contributes to these disparities.</td>
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<tr>
<td>Pregnant Women</td>
<td>• AAO/ADA guidelines recommend women with preexisting diabetes undergo a dilated eye exam in their first trimester.</td>
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<tr>
<td></td>
<td>• Adequate screening is more likely to occur in Caucasians, older women, those who attend prenatal classes, and those with a longer duration of diabetes.</td>
</tr>
<tr>
<td></td>
<td>• Primary care physicians and OB/GYNs may underutilize referrals and guidelines for caring for dilated eye exams in this population.</td>
</tr>
<tr>
<td>Physician Adherence to Guidelines</td>
<td>• Rates of referrals to eye-care providers differ across specialties.</td>
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<td></td>
<td>• Barriers can include incomplete knowledge of updated guidelines and ageism, not feeling comfortable performing direct ophthalmoscopy.</td>
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<tr>
<td>African Americans</td>
<td>• Perceived barriers impact adherence, including cost, insufficient insurance, transportation.</td>
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<td></td>
<td>• Chief motivating factor for scheduling an eye exam was “experiencing visual symptoms.”</td>
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<tr>
<td></td>
<td>• Potential knowledge gap regarding screening intervals, disease progression, and manifestation.</td>
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<tr>
<td>Latin Americans</td>
<td>• Potential barriers include language barriers, insufficient insurance.</td>
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<tr>
<td></td>
<td>• Risk factors for noncompliance: lower education level, male gender, lacking a physical examination in the past year.</td>
</tr>
<tr>
<td>American Indians/Alaska Natives</td>
<td>• Potential patient barriers: insufficient understanding of disease, financial limitations for care or transportation, language barriers, social stigma of disease.</td>
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<tr>
<td></td>
<td>• Potential system barriers: insufficient number of trained medical personnel, suboptimal access to basic preventive services.</td>
</tr>
<tr>
<td>Asian Americans/Pacific Islanders</td>
<td>• Patients may be less likely to have a primary care provider.</td>
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<td></td>
<td>• Widely diverse labels may make it difficult to identify risk factors for subgroups in this population.</td>
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<tr>
<td>Gender</td>
<td>• There is little research on why women are more at risk for progression of DR.</td>
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<td></td>
<td>• Women are more likely to receive DFE than males.</td>
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<tr>
<td>Youth vs. adult-onset diabetes</td>
<td>• High prevalence of insurance coverage amongst youth may improve adherence to eye exam guidelines.</td>
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<td></td>
<td>• Symptomatic presentations of hyperglycemia in youth may make them more likely to seek treatment earlier.</td>
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<tr>
<td>Urban Areas</td>
<td>• Risk factors for noncompliance: larger family size, inadequate vision care coverage, absence of established care provider, low education levels.</td>
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<td>• Insufficient screening by providers in inner city county hospitals.</td>
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<td>Rural Areas</td>
<td>• Risk factors: insufficient insurance, lower education levels, transportation, insufficient number of providers.</td>
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<tr>
<td>Veterans Administration</td>
<td>• The VA has implemented a nationwide standard for diabetic care for all VA hospitals to ensure adherence to screening guidelines.</td>
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<td></td>
<td>• VA hospitals have very high rates of annual DFE compared to commercially managed patients as a result of a comprehensive diabetes registry, automated patient reminders, automated feedback on quality care, and standardized guidelines and diabetes management programs.</td>
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<tr>
<td>Older Americans</td>
<td>• Women and Caucasian Americans were more likely to see an eye-care provider in this population.</td>
</tr>
<tr>
<td></td>
<td>• Age, access to transportation impact likelihood of following screening guidelines.</td>
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</table>

Buying screening equipment is likely to enable nurses to counsel patients on the severity of their illness and the importance of preventative care. However, a cross-sectional analysis of data from the National Health and Nutrition Examination Survey of diabetic adults conducted in 2010 found that only 44.7% of persons with diabetic macular edema reported learning from a physician that diabetes affected their eyes or that they had retinopathy. Moreover, only 46.7% reported meeting with a diabetes nurse educator or nutritionist and having an ophthalmologist or optometrist conduct a dilated eye exam in the last year. The combination of missed opportunities for counseling from care providers and a patient’s limited capability to access, understand, and act upon diabetes care may contribute to...
disparities in screening rates amongst varying levels of health literacy.

**Lack of Access to Care**

The gold standard for the detection and classification of DR, as set by the Early Treatment Diabetic Retinopathy Study, is stereoscopic color fundus photographs in seven standard fields. The technique requires skilled photograph readers and advanced photography equipment. This process can be both time-consuming and uncomfortable for patients. As such, ophthalmologists have traditionally screened for DR by dilated eye exams and indirect ophthalmoscopy. However, this method is limited in its success by the availability of eye care. Certain minority populations, especially Native Americans and those living in rural areas, have limited access to medical care. Analysis of data from the Behavioral Risk Factor Surveillance System (BRFSS) demonstrated that persons living in rural areas had lower rates of dilated eye examinations than those in urban regions. A scarcity of medical resources, including eye-care providers, may contribute to this disparity. The BRFSS also identified discrepancies in screening adherence between states. Massachusetts is the only state where the prevalence of annual examinations does not correlate with income and education level. Chou theorized that the increased prevalence across socioeconomic groups may be a result of the state’s Medicaid program, MassHealth, which requires all residents to acquire health insurance. Massachusetts is also the only state that offers free vision care for families with incomes <300% below the poverty line. Hispanics, who traditionally have higher rates of diabetes and are at a higher risk for visual complications, were more likely to have visited an eye doctor in the previous year if they lived in Massachusetts, which differed from Hispanics in other states. This also raises the question as to whether we may see similar increases in screening adherence as more states have adopted the Medicaid expansion.

**Pregnancy**

American Academy of Ophthalmology and American Diabetes Association guidelines recommend women with preexisting diabetes undergo a dilated eye exam in their first trimester as DR can worsen throughout pregnancy. However, many pregnant women may not be receiving these exams in accordance with guidelines. Adequate screening is more likely to occur with older women, Caucasians, those who attend prenatal classes, and those with a longer duration of diabetes. A study by Marrero et al. attempted to identify disparities in care that might exist between patients who utilize a family physician during their prenatal visits versus seeing an obstetrical specialist. The researchers looked at over 95% of all hospitals in Indiana that offer obstetrical services and asked family and obstetrics/gynecology (OBGYN) specialists about their screening practices for DR in pregnant patients with types 1 and 2 DM or gestational diabetes. Only 9.6% of family physicians routinely referred patients to an ophthalmologist, as compared to 35% of OBGYNs surveyed. 74.6% of the family physicians examined fundi on their own versus 40% of OBGYNs. However, only 3% of family doctors and none of the OBGYNs followed the screening guidelines that recommend dilated fundus examinations. The researchers concluded that while both groups underutilized resources and guidelines, significant discrepancies existed in the care provided by family providers and OBGYNs. Fewer family physicians utilized universal screening of pregnant patients for DM and the use of HbA1c to monitor the disease. Moreover, as stated previously, family doctors were less likely to refer patients to a specialist for diabetes care, especially to ophthalmologists. However, even amongst OBGYNs in the study, only a third sent patients to an ophthalmologist. This puts the pregnant population at a high risk of progression of DR that goes undetected. The authors of this study suggested improving access to care guidelines for family physicians and instituting postgraduate education programs for diabetes care. According to the researchers, the American College of Obstetrics and Gynecology has specific recommendations available to its members on the management of diabetes in pregnancy. However, the American Academy of Family Physicians did not have an equivalent document at the time of the study. Furthermore, they encouraged postgraduate education to emphasize when collaboration and/or referral to a specialist is necessary. Interestingly, an updated study by Marrero et al. found similarly low rates of referrals amongst OBGYNs and family physicians (28% and 24%). Moreover, few physicians were following the recommendation of dilated retinal exams (11% of FPs and none of the OBGYNs).

**Physician Adherence to Guidelines**

Physicians can positively impact screening rates by increasing patient referrals. However, researchers found that overall referral and funduscopic examination practices could be improved. This is especially true for the care of type 2 diabetics, who generally receive less aggressive screening compared to type 1 diabetics.
Kraft et al., as well as Bowman et al., examined whether the type of physician may impact adherence to screening guidelines.\textsuperscript{6,27} Kraft et al. found that general interns were the most likely to report high adherence to screening guidelines.\textsuperscript{6} They theorized that this might be secondary to the type of training and patient populations to which they are exposed.\textsuperscript{6} However, Bowman et al. found that family and general interns may spend less time with patients, order fewer laboratory tests, and make fewer referrals to subspecialty clinics.\textsuperscript{27} Similarly, a study conducted by Leinung et al. found that adherence to ADA guidelines was significantly better when patients were followed by endocrinologists versus primary care providers.\textsuperscript{28} 90% of patients who were followed by endocrinologists in the study received yearly eye examinations versus 50% of those seen in a primary care clinic.\textsuperscript{29} Furthermore, the ADA found that rural health-care providers were less likely to follow ADA guidelines for managing diabetes.\textsuperscript{29} Barriers reported in the study included incomplete knowledge of updated guidelines, ageism, “provider inertia,” and patient factors including prohibitive costs of care and inadequate access to patient education resources.\textsuperscript{29} The number of years a physician has been out from training may also affect referral rates. Those closer to graduation were more likely to report higher rates of referral.\textsuperscript{27} Furthermore, a physician’s perspective on guidelines may affect screening rates. Bowman et al. theorized that since few primary care physicians are members of the ADA, they may not be familiar with or find the ADA guidelines as relevant to them in primary care.\textsuperscript{27} Finally, those who perceive the funduscopic exam as time-consuming and difficult are less likely to perform one in the office.\textsuperscript{27}

Minority Populations

African Americans

African Americans are disproportionately more likely to suffer from preventable blindness and visual impairment than their White counterparts.\textsuperscript{30} African Americans also have a four-fold increased risk of developing DR over non-Hispanic Whites (NHWs).\textsuperscript{30} The disease accounts for 17\% of the most common causes of visual impairment in African Americans.\textsuperscript{30} In a U.S. population study, Harris et al. found that the increased risk of DR in African Americans was secondary to a higher prevalence of risk factors for the disease.\textsuperscript{31} In fact, by adjusting for these factors, researchers found no significant difference in risk for developing DR in African Americans with undiagnosed diabetes over their White counterparts.\textsuperscript{31}

African Americans are less likely to receive eye examinations compared to NHWs.\textsuperscript{32} In a series of focus groups on the perceived benefits and barriers to receiving an eye examination, participants cited the chief motivating factor for receiving an eye examination as experiencing visual symptoms. \textsuperscript{32} Only 42\% of African Americans believed that yearly examinations were needed.\textsuperscript{32} 38\% believed that screening guidelines recommended an eye examination every two years.\textsuperscript{32} Finally, 60\% of participants believed that all vision changes were inherently normal aspects of aging.\textsuperscript{32} Some participants reported not being told to receive a DFE. Interestingly, when patients were asked to freely comment on the benefits of a DFE, few reasons were generated besides preventing eye disease.\textsuperscript{32} However, prevention was rarely cited as a motivating factor for scheduling an appointment.\textsuperscript{32}

Exacerbating the knowledge gap, perceived barriers also contribute to nonadherence.\textsuperscript{33} The most commonly cited barriers amongst the focus group participants included cost and insufficient insurance.\textsuperscript{33} Older African Americans cited transportation as a common barrier.\textsuperscript{33} The absence of symptoms, lack of free time, and the inconvenience of an eye exam also discouraged patients from undergoing screening.\textsuperscript{13,33} Some participants pointed to cultural factors as barriers to seeking out medical care.\textsuperscript{13,33} These included spirituality (faith and hope that one’s medical situation will improve), denial of a problem, and pride.\textsuperscript{13,33} Older African Americans in the study felt that inadequate communication from providers led to patients’ misunderstanding of their disease.\textsuperscript{33} Owsley et al. found that only 36\% of participants reported hearing of retinopathy and only 8\% of participants could correctly describe it. Owsley concluded that this incongruity in perspectives may contribute to the gap between physician recommendations and a patient’s actual understanding of what is necessary for their care.\textsuperscript{33}

Latin Americans

Latin-Americans make up 17\% of the U.S. population and are projected to make up the majority of Americans by 2043.\textsuperscript{34} In 2014, 12.8\% of Hispanics were living with diagnosed diabetes.\textsuperscript{8} The Los Angeles Latino Eye Study (LALES) has provided the most extensive documentation of the burden of diabetic visual problems in this community.\textsuperscript{35} LALES examined over 6,000 Latinos over the age of 40 for risk factors for the disease and for the presence of eye disease and/or visual impairment. Of 1263 patients who had definite diabetes mellitus, gradable fundus photographs were available for 1217 of them. Of those 1217, 46.9\% had DR.\textsuperscript{35} Furthermore, the 4-incidence of DR in 4,658 study participants who received a baseline examination was 34.0\%.

Hispanics are less likely than NHWs to have had screening tests for diabetes, including an HbA1c test or a foot exam.\textsuperscript{36} This is related to several factors, including language barriers and being uninsured.\textsuperscript{36} Studies
Risk factors for non-compliance include a lower education level (odds ratio [OR] of 1.5), being uninsured (OR 2.5), lacking a routine physical examination within 12 months prior to the LALES examination (OR 1.8), and having a glycosylated hemoglobin level ≥9.0% (OR 1.7). Other significant risk factors included insulin use (OR 1.85), a history of hypertension (OR 1.64), and being of the male gender (OR 4.11). In a study by Varma, Latino males had a 50% higher risk of having any DR (OR 1.50). 

American Indians/Alaska Natives
Native Americans have some of the highest rates of diabetes in the nation; however, limited data exist on potential etiologies for this significant disparity. The prevalence of DR in some Native American tribes can reach as high as 45.3%. In an effort to enhance preventative care for American Indians and Alaskan Natives, the National Eye Institute conducted a qualitative study that asked tribal members and local health-care providers to share their understanding of diabetes care. The communities all agreed that diabetes was a top health concern, but many participants only had a basic understanding of the disease. Furthermore, financial limitations to providing comprehensive care and transportation barriers impede access to appropriate diabetes care, regardless of tribe resources, location, or the size of the tribe. Women are the primary caretakers of the family and are the primary seekers of care and diabetes information, but often lack adequate diabetes care themselves. Silver et al. also note a disconnect between patients’ readiness to change and physicians’ perceptions of the community. Physicians surveyed in the study believe that American Indians and Alaskan Natives respond to illness with “denial, anger, and fear.” Other barriers encountered by health professionals include language difficulties and the social stigma associated with the disease. However, patient participants in the study did not mention these concerns. Rather, they requested programs that ensure continuity of care in order to establish a personal connection with their provider. In addition, understaffing of key personnel (e.g., optometrists, ophthalmologists) and high staff turnover rates prevent adequate continuity care. One study participant also expressed the desire for diabetic eye disease campaigns to integrate themselves with traditional medicine approaches for treatment. Physicians reported suboptimal access to basic preventative services for American Indians more often than physicians serving Black or White patients.

Disparities in Diabetic Retinopathy Screening

In a study of a national eye health education program for Native Americans, researchers found that most Native Americans could not afford comprehensive health insurance and often struggled with transportation. 29% of physicians from the Indian Health Services (IHS) believed that their patients had adequate access to subspecialized care, in comparison with 76% of physicians serving Black patients. Inadequate funding for the IHS resulted in the number of denied out-of-network patient services rising by 68% between 2003 and 2006. According to Sequist, the IHS only receives about half of the funding necessary to serve its patients. The study also found significant disparities between Medicare/Medicaid and the IHS. While the IHS ranked ahead of national health plans when it came to basic diabetes care (such as annual HbA1c levels), it ranked in the lower twenty-fifth percentile for completion rates of DR screenings. Per the study, this low clinical performance reflects the lack of adequate specialized equipment or trained personnel available to the IHS. Ultimately, the study concluded that creating education programs that emphasize prevention of diabetes and its complications, the consequences of non-adherence, and also concurrently emphasize the logic behind annual eye exams may improve screening rates amongst American Indians and Alaska Natives. Moreover, system-wide changes to the IHS that allow for improved continuity of care and access to specialized services may improve the disconnect between patients and physicians.

Asian Americans/Pacific Islanders
A total of 9.0% of Asian Americans/Pacific Islanders (AAPIs) were living with diagnosed diabetes in 2010. Similar to Native Americans, there exists a significant gap in the literature regarding the health status of AAPIs in the United States. Based on the 2000 census survey, 266 U.S. counties had medically underserved AAPIs. However, 52% of these counties were missing a medically underserved designation by the Bureau of Primary Health Care. In the Behavioral Risk Factor Surveillance System (BRFSS) survey, it was found that AAPIs with diabetes actually came from a higher SES on average and had fewer risk factors and coexisting chronic disease as compared to Whites with diabetes. Similar to Native Americans, compared to NHWs, AAPIs were less likely to have their own personal health-care provider. A study on the disparities in access to health care and preventative services amongst AAPIs found that this population was significantly less likely to utilize preventative services compared to NHWs.

Despite their favorable risk profile, AAPIs in the BRFSS were almost 1.5 times more likely (27.6%) to have DR compared to Whites (18.2%). In a study by McNeely et al. that utilized results from the BRFSS to analyze the prevalence of diabetes-related comorbidities
across ethnicities, it was found that the prevalence of retinopathy in Asians was similar to that of NHWs. However, only 186 Asian Americans were asked about retinopathy in the study compared to 7,513 NHWs.

The diversity of people labeled under AAPI may also make it difficult to identify risk factors applicable to the group as a whole. For example, due to the preponderance of English-proficient AAPIs and the high rates of higher education in this population (almost 60% had a college degree or higher, in comparison to 36% of NHWs in the BRFSS), language may initially seem less of a barrier for AAPIs than it may be for other ethnic minorities. However, the label fails to differentiate between newer AAPI immigrants who may differ from the U.S.-born Pacific Islanders in levels of English proficiency.

**Gender Disparities in Adherence to DR Screening**

Rates of diagnosed DR were similar amongst men and women in 2010, with 51% of cases being female and 49% being male. Women are more likely to receive dilated eye examinations compared to their male counterparts. However, despite the higher rates of screening in women, significant disparities still exist in the risk of progression of DR. In the Wisconsin Epidemiologic Study of Diabetic Retinopathy, older women were more likely than older men to have some degree of visual impairment (13.3% vs. 9.9%) and slightly more likely to be legally blind (1.7% vs. 1.4%). Certain risk factors that are more prevalent amongst women may contribute to this disparity, including the prevalence of poverty in Black and Hispanic women, which impacts access to medical and preventative services. Unfortunately, there is limited research available on potential etiologies for this disparity in rates of blindness between genders.

**Youth- vs. Adult-Onset Diabetes**

Disparities related to the utilization of services and continuity of care also exist between patients with youth-onset, both types 1 and 2, and adult-onset diabetes. Symptomatic presentations of hyperglycemia in youth-onset diabetes may make younger diabetics more likely to seek treatment earlier on. A study of children with youth-onset diabetes found a marked transition between pre-diagnostic and diagnostic glucose concentration levels. Conversely, adults may have more subtle elevations, causing them to remain undiagnosed for several years. However, those with youth-onset diabetes also had a lower risk of retinopathy in the short term. In the study, none of the patients had evidence of retinopathy before 20 years of age. Retinopathy occurred more frequently in patients who developed diabetes at an older age with the same disease duration. Youth were more likely to have lower blood pressures and have slightly lower glucose levels than adults with similar disease durations, which may have also contributed to lower rates of retinopathy. Insurance coverage can also significantly affect adherence to eye exam recommendations. Despite the low prevalence of uninsured children, due to the high rate of Medicaid available for children without private insurance, eye exams are still the most often missed examinations. The rates are highest in low-income populations. Ultimately, children with a high continuity of care on Medicaid and those whose families earn ≥200% above the federal poverty level are more likely to see an ophthalmologist.

Moreover, the transition from pediatric to adult health care can contribute to progression of disease as patients leave long-time pediatricians and as they begin to experience changes in health-care benefits. As youth-onset diabetics age, they are more likely to fall into health insurance coverage gaps that further propagate barriers to care. Furthermore, a premature transfer of responsibility from parents to children as they transition into adult care may contribute to non-adherence as teenagers may be less likely to follow through with appointments. That transition also comes during a time when there is a tendency towards risk taking, patients are still learning about their disease and self-management and may not be developmentally ready to understand the severity of future health risks, Furthermore, there is the risk that “diabetes burnout” can occur, when children who were diagnosed early tire from dealing with a chronic illness.

**Urban Medicine**

A study by Baker et al. examined the utilization of eye-care services amongst communities living in urban public housing in Los Angeles. Baker argues that inner-city public housing can reflect the greater well-being and health determinants of metropolitan cities. Over three million Americans live in publicly subsidized housing. A large proportion of these people are African Americans and Hispanics, who are at a higher risk for diabetes and diabetic complications, as shown earlier. However, only 62% of study participants had received an eye examination in the last two years. 12% of the sample reported that their last eye exam was over five years ago. Those who had received an eye examination in the last two years were significantly more likely to have a smaller family size, have vision care coverage, already have established continuity of care, and have a health-care provider who recommended an eye examination.
Similarly, a study that identified clinical and sociodemographic characteristics of patients newly presenting for diabetes eye care at an urban public hospital found that 46% of patients had a grade-school education or less, 91% were unemployed, and 64% lacked health insurance. Patients were more likely to have type 2 diabetes (91%) and 31% of patients had it for longer than 10 years. The researchers concluded that, in inner-city county hospital settings, insufficient screening has resulted in inadequately treated and advanced disease at the time of presentation for these patients. However, these public hospitals also serve as a primary source of care for many socioeconomically disadvantaged patients. As a result, they receive patients who often have not had access to appropriate preventative screening or continuity of care before presenting to their hospital.

**Rural Medicine**

Rural communities also experience disparities in adherence to screening. In a study of disparities in diabetes care across rural communities, Hale et al. found that the prevalence of self-reported diabetes was 17% higher in adults across all race/ethnicities, except for Hispanics, compared to metropolitan areas (9.0 vs. 7.7%). Many of the barriers reported were similar to those in urban communities, including affordability/insurance coverage issues and lower education levels. However, traveling further to access care was cited as a barrier that did not apply to metropolitan areas.

Rural adults in the study had a higher rate of diabetic retinopathy compared to metropolitan counterparts with an odds ratio of 1.21. The authors theorized that this is probably a result of the scarcity of physicians needed to provide comprehensive preventive screening services and education/monitoring. However, clinics with a mid-level provider had higher rates of vision screenings. Moreover, Rural Health Clinics, clinics certified by the Census Bureau as serving the medically underserved, have higher rates of rural adults receiving eye examinations. These clinics receive enhanced, cost-based Medicare and Medicaid reimbursement, even if those services are provided by non-physicians. A supervising physician must only be onsite once every two weeks. The expectation is that this will allow for more efficient use of scarce resources and enhance access to primary care services by either increasing access to providers generally, or access to primary care physicians who are incentivized through increased reimbursement. A study examining the impact of RHCs found that the presence of at least one RHC may have a “corrective effect” on the quality of care provided to rural patients. Non-RHC Medicaid patients were less likely to receive the recommended number of diabetic primary care services (at least three visits) than their urban counterparts. However, the presence of an RHC improved eye examination rates to the level of those in urban areas. Lastly, these clinics are also incentivized to partake in telehealth services by receiving a facility fee for organizing telehealth consults with consulting physicians. There are currently 4084 RHCs registered in the U.S. The number of clinics per state vary immensely. Missouri has the highest, with 382 clinics, while several states, especially in the Northeast, have zero. Ultimately, the use of mid-level providers, enhanced incentives for working in rural areas, and utilizing telehealth services, which is covered later in this review, may significantly improve care for patients in rural areas.

**Veterans Administration**

The prevalence of diagnosed diabetes amongst veterans is around 20%, much higher than the national average of 9%. The Veterans Health Administration (VA) provides health care for five million eligible patients. The VA has implemented specific programs to ensure that diabetic patients receive screenings for DR and other diabetic complications at appropriate intervals. Moreover, an external peer review program created a nationwide standard of diabetic care for all VA hospitals. A study by Kerr et al. compared diabetes management by the Department of Veterans Affairs with that provided by commercially managed organizations. The commercially managed clinics selected performed at or near the top of the National Committee for Quality Assurance quality measures. The cross-sectional patient survey of eight VA hospitals and five commercially managed clinics found that the outcomes and quality of care was higher in the VA system. Specifically, they examined the rates of annual dilated eye examinations across the different clinics. 91% of VA patients (n=1285 diabetics) reported that they received an annual eye examination, compared to 75% of commercially managed patients (n=6920). Importantly, the rates of annual eye examinations documented in the medical records were much lower for both populations (57% of the VA population versus 28% of commercially managed patients). The authors attributed the higher rates of adherence at the VA to the presence of a comprehensive diabetes registry, automated patient reminders, automated feedback on quality care, as well as standardized guidelines and diabetes management programs. Moreover, the presence of an integrated health-care system like the VA allows for streamlined interventions, including an integrated electronic medical record system, consolidated nationwide guidelines, efficient performance monitoring, and efficacious incentives. Finally, a teleretinal program started in 2000 has proven to increase access to
Interventions

Despite its prevalence, there remains a significant knowledge gap amongst patients in understanding diabetic retinopathy, its manifestations, and appropriate prevention. The most critical interventions to preventing the progression of DR are minimizing cardiovascular risk factors through controlling glucose levels, blood pressure, and lipid levels. Moreover, diabetic patients must have access to regular and adequate screening and early treatment for moderate/severe DR. Formulating interventions that make provisions for the current barriers to care may significantly reduce disparities in DR rates.

Currently, efforts by major organizations such as the National Eye Health Education Program may not be reaching the specific population groups they aim to target. Successful programs have focused on appropriate cultural sensitivity. Metghalchi et al. created a comprehensive diabetes education program in Spanish in an effort to create targeted and relevant programs for the Hispanic community. Participants experienced significant changes in diabetic endpoints, including HbA1c, fasting plasma glucose, cholesterol/HDL ratio, and LDL, after only three months of starting the program. They also documented significant changes in participants’ weight and BMI profiles. Participants experienced on average a 0.82% reduction in HbA1c from baseline, a value above the 0.5% reduction recommended in the Diabetes Control and Complications Trial to achieve a significant risk reduction in diabetic complications. Similar interventions done in urban Hispanic populations also produced significant reductions in HbA1c and lipid profiles. These studies demonstrate that culturally sensitive programs on diabetes self-management result in increased knowledge of the disease and its management. The authors concluded that the success of the program was attributable to teaching realistic and applicable strategies for disease management and providing refresher courses at regular intervals (e.g., six and nine months). In a meta-analysis of randomized control trials of culturally appropriate diabetes education programs, the Cochrane review found significant reductions in HbA1c that persisted post-intervention. Patients also experienced an increased knowledge base compared to those study participants who were randomized to “usual care.” Moreover, educational interventions that target low-literacy populations can increase screening rates. Basch et al. found that the use of color informational booklets, motivational videotapes, and telephone education and counseling doubled the rate of ophthalmic examinations compared to routine care. However, this should be contrasted with the results from an RCT run by the Diabetic Retinopathy Clinical Research Network, which found that ophthalmologist office-based personalized education and risk assessment did not result in

diabetic eye screening for VA patients in the primary care setting, allowing for effective characterization of the extent of DR.

Older Americans

The Salisbury Eye Evaluation, a population-based survey of 2,520 adults aged 65–84 years old, examined patterns of eye-care utilization amongst older Americans. The study found that greater than half of the study participants had visual impairment/blindness that was surgically treatable or potentially preventable. African Americans in the study had a disproportionate burden of blindness diseases that were preventable. Older African Americans were less likely to see an eye-care provider than their White counterparts (50 vs. 69%), despite a higher rate of ocular complications. Women (OR 1.13–1.68) and White adults (OR 1.28–2.05) in the study were more likely to see eye-care providers in the previous year. Age also impacted screening rates, as the older study participants were more likely to have had a vision screening in the last year: 70–74 years old (OR 1.12–1.75), 75–79 (1.33–2.27), and 80–84 (1.49–3.12). Education level was a strong predictor of seeing an eye-care provider: ninth to twelfth grade (1.02–1.71) and greater than twelfth grade (1.44–2.64). The most common motivating factor amongst this population was experiencing an eye problem (OR 4.38–6.55). However, requiring glasses was not a significant predictor of seeing an eye-care provider. Self-reported diabetes also increased the likelihood of seeing an eye-care provider (OR 1.15–1.93). The city of Salisbury lacks a public transportation system, which made patients who had the ability to drive more likely to visit an eye-care provider than those who did not.

![FIGURE 1. Screening fundus camera (Aris, Canon, Kowa, Nidek, Topcon, Zeiss, Inoveon, Optos). Adapted with permission from P. Sternberg, Screening for diabetic retinopathy: Is it cost effective? © 2015, P. Sternberg. Permission for reuse must be obtained from the rightsholder.](image-url)
a reduction in HbA1c compared to usual care over one year. This prompts further research into what may constitute effective counseling by physicians.

Current health-care reform efforts may increase access to preventative services. The Patient Protection and Affordable Care Acts mandate zero-cost diabetic screenings for all patients. Moreover, the shift to a quality-based payment system may encourage doctors to place a higher premium on visual outcomes. Similarly, recent changes to the IHS budget aim to increase access to specialty services for Native Americans. However, it is important to note that research on the Massachusetts health reform indicates that increased access to care may still not be the panacea to health disparities. Minors in Massachusetts, who had higher rates of vision screenings and adherence to screening guidelines, still did not show any significant improvement in health status compared to peers of a higher socioeconomic status.

Chou argues that the disparities persisted because of “comparable or larger improvements” among people of a higher socioeconomic status or White background.

Telemedicine is purported to overcome the current barriers to screening patients that have resulted in less than 50% of patients with diabetes receiving appropriate screening each year. In a commentary appearing in *JAMA Ophthalmology* in 2015, Silva and Aiello point to the success of the U.K. National Health Service’s telemedicine screening program in contributing to reduced rates of diabetic retinopathy. For the first time in five decades, diabetic retinopathy was not the leading cause of blindness in the working-age population in the U.K. Studies in other countries have also demonstrated that rates of visual impairment and blindness are lowest in populations that provide retinal evaluations for all patients with diabetes. This feat was largely accomplished through nationwide DR teleretinal programs. In a study by Mansberger et al., researchers found that, even in settings where eye care is readily available, the option for telemedicine may increase the proportion of patients who undergo screening. This suggests that telemedicine may play a role in improving compliance, even in insured populations, by allowing this population to undergo screening while visiting their internist or endocrinologist instead of requiring another medical visit to an eye-care provider. Furthermore, as it is estimated that more than half a billion persons will be living with diabetes by 2030, telemedicine may also serve as a more effective screening method for DR.

The Tribal Vision Project studied the comparative effectiveness of telemedicine versus traditional screening methods via a multicenter randomized clinical trial. Study participants were randomized to either screening with a non-mydriatic camera in a primary care clinic or traditional care (screening with an eye-care professional). Researchers found that the telemedicine group was more likely to receive a DR examination compared to their traditional counterparts (94.6% vs. 43.9% during the six months or less period and 53.0% vs. 33.2% at the 6–18-month follow-up period).

Stereoscopic non-mydriatic cameras have been validated as an accurate tool for assessing DR. In a prospective study of 108 eyes using the ocular telemedicine program developed at the Joslin Diabetes Center, researchers compared interpretations from two different retinal specialists grading images from a non-mydriatic camera and images after pupil dilation. They found substantial agreement between the images (K=0.65). Furthermore, there was a strong agreement between clinical level of DR as determined by the ocular technology and as determined by the retina specialist. The study validated the ability of their ocular telemedicine program in determining clinical levels of DR and DME, timing of next retinal evaluation, and the need for referral to ophthalmology specialists.

Critical barriers to receiving an in-person screening exam include lack of adequate transportation or time to dedicate to medical care, as patients may have to leave work or school and lose pay to see a physician. Telemedicine may serve as a potential solution to connect patients who have traditionally been hard to reach. The technology may also reduce the number of medical personnel needed and the cost of screening. In a modeled economic analysis of a VA telemedicine program, the use of teleretinal imaging was both less costly and...
either equally or more effective than traditional ophthalamoscopy. The study examined a non-mydriatic digital teleophthalmology screening system (the Joslin Vision Network ocular technology) and conventional ophthalamoscopy in a clinic with pupil dilation for the detection of PDR. The modeled population comprised the entire number of type 1 and type 2 diabetics in the Department of Veteran Affairs system. Of 505,300 patients, teleretinal technology could detect an extra 96 cases of proliferative DR and save $2,966,111 compared to conventional therapy; 91 additional patients could receive PRP treatment while saving $2,410,281; finally, five patients would be caught before developing severe vision loss, saving $2,263,744.

The Informatics for Diabetes Education and Telemedicine (IDEATel) demonstrated that telermedicine might have the potential to reduce disparities in diabetes management across racial/ethnic groups and socioeconomic status. Researchers randomized Medicare patients to either telermedicine or usual care. Patients in the telermedicine group watched home videos and received visits from a diabetes educator. They were also encouraged to regularly upload their glucose levels every 4–6 weeks onto a clinical database. The intervention was associated with an improvement in glycemic control, especially for the Hispanic cohort in the study, who had the highest A1C levels at baseline. In an updated study in 2013, researchers also found that lower-SES patients had at least as much benefit as higher-SES patients from telermedicine management of their diabetes.

A study of 100 safety-net clinics piloting the use of telermedicine found that patients with traditionally limited access to care, who were universally uninsured, were able to receive screening through the program. Clinics serving these patients also reported higher screening rates than before the intervention. However, just the act of identifying pathology on a screening examination does not ensure access to treatment. Fewer than 30% of patients who were identified as having severe DR were successful in accessing care over a year after their initial screen. For those who were able to receive treatment, average wait time was still seven months. Follow-up care for uninsured patients also posed a significant challenge. Mansperber et al.’s RCT comparing long-term effectiveness of teleretinal screenings to traditional screening found similarly low rates of compliance (annual rates of 40–55%), suggesting that there are additional barriers to care that won’t be addressed by telermedicine alone.

Telermedicine may also require a level of infrastructure that most small primary care clinics cannot justify. The initial costs of training and equipping clinics with the necessary software are prohibitive. The commercially available fundus camera currently costs more than $20,000. While there is active research and development in the field of low-cost imaging technology, low-cost fundus cameras are not yet available. The investment is also compounded by the uncertainty facing reimbursements. New reimbursement codes have led to much lower reimbursement rates. Specifically, CPT code 92227 indicates that the images are read by non-physicians under the supervision of a physician, which leads to much lower reimbursement rates that do not cover the cost incurred for most DR telermedicine programs. The second new CPT code (92228) is for images that physicians read, allowing for a “more reasonable” reimbursement; however, it is only applicable to patients with “active” disease. Therefore, a physician who is on a fee-for-service model, versus being part of a single-payer model like the Veterans Administration, could risk providing care that is continually uncompensated and may also result in fewer office visits, which further impact revenue. Moreover, malpractice and antitrust concerns have limited implementation. Some physicians have expressed concerns over the legality of practicing medicine beyond state borders. If these physicians face a malpractice suit, they may face legal actions both in the state in which they practice and in the state where the alleged patient injury occurred. The state of Georgia has already addressed this issue through the Georgia Partnership for TeleHealth to protect telermedicine as a legal and covered service by malpractice insurance carriers.

**CONCLUSION**

Improving adherence to screening rates is inevitably a critical public health initiative as the rate of diabetes and the proportion of Americans suffering from preventable diabetes-related blindness continue to rise. The studies discussed in this article identify risk factors for non-adherence by age, ethnicity, gender, location, socioeconomic status, type 1 vs. type 2 diabetes, as well as by the type of provider. These are all disparities that the Healthy People 2020 call to action focuses on eliminating. Researchers have also implemented and successfully piloted interventions that target each of these risk factors with the common goal of improving diabetes education and self-management as well as access to care to improve adherence rates.

**Recommendations for Future Research**

The studies discussed in this article have started to pinpoint risk factors for disparities in adherence to DR screenings that are unique to specific population groups within the United States. It is vital to continue systematic and regular research into the risk factors for non-adherence amongst these specific population groups. Within this study, some groups lacked more
research than others, such as Native Americans, Asian American and Pacific Islanders, pregnant women with diabetes, women in general, as well as research on the outcome and access disparities between type 1 and type 2 diabetics as well as youth- vs. adult-onset diabetes. Furthermore, it is important to elucidate why women with diabetes are more likely to progress to blindness from their disease than men. Finally, it will be important to study the impact of new government programs such as the Patient Protection and Affordable Care Acts to see if they improve adherence and actually narrow disparities over time.

Recommendations for Future Policy

Improving adherence to screening guidelines in diabetic retinopathy through the field of public policy should focus on (1) systematically improving access for populations that have traditionally been at risk for barriers to accessing care; (2) nationwide research on risk factors for non-adherence; (3) easing the implementation of technology that can improve adherence and access to care; and (4) improving access for ophthalmic care when DR is diagnosed by the screening programs. In the studies noted earlier, rural populations seem to have benefited greatly from the implementation of rural health clinics that emphasize mid-level providers and physician incentives for practicing in traditionally disadvantaged areas. Future policy should advocate for wider implementation of these programs for different disadvantaged populations, including Native Americans and residents of poorer urban areas. Moreover, it should facilitate continued research on the efficacy of the Rural Health Clinic program. Lastly, current research programs such as the Behavioral Risk Factor Surveillance System should expand to include data on specific at-risk populations that are not traditionally identified and studied separately.

DECLARATION OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

REFERENCES


Disparities in Diabetic Retinopathy Screening


