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Diabetic Eye Screening: Knowledge and Perspectives from Providers and Patients

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Abstract

Purpose of review: Diabetic retinopathy remains the leading cause of blindness among working-age U.S. adults even though timely screening and treatment prevent 90% of blindness. We summarize current knowledge and perspectives to better understand why diabetic eye screening rates remain low and future directions towards preventing blindness from diabetes.

Recent findings: Significant advancements in the past 10 years include primary care and patient-oriented interventions as well as the use of teleophthalmology. In England, diabetic eye disease is no longer the leading cause of certifiable blindness following the implementation of a national teleophthalmology program for diabetic retinopathy.

Summary: Multiple workflow and systems-level barriers affect providers. Patient barriers include a limited understanding of screening and lack of access to care. Interventions have been developed, but new barriers exist towards sustaining their impact. More research is needed to identify and implement the best practices to increase diabetic eye screening rates long-term.

Keywords

Diabetic eye screening; Diabetic retinopathy; Teleophthalmology; Primary care; Patient barriers; Perspectives

Introduction

Diabetic retinopathy affects an estimated 126.6 million people worldwide and is expected to increase rapidly with the continued rise in the diabetes population [1]. The World Health Organization (WHO) estimated that in 2002, diabetic retinopathy accounted for blindness in nearly 5 million people internationally and that over 75% of people living with diabetes for more than 20 years will develop retinopathy [2]. Diabetic eye screening is critical for saving

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Conflict of Interest

Yao Liu and Rebecca Swearingen declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent

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sight through timely intervention with effective treatments, but only about 50% of adults with diabetes in the USA follow screening recommendations [3]. There have been significant advancements over the past 10 years, particularly in England where for the first time in 50 years, diabetic eye disease is no longer the leading cause of certifiable blindness following the establishment of a national teleophthalmology diabetic eye screening program [4••]. We seek to review knowledge and perspectives from providers and patients to better understand barriers to diabetic eye screening, as well as discuss current and future interventions aimed at increasing screening rates and preventing blindness from diabetes (Table 1).

Rationale and Guidelines for Diabetic Eye Screening

Diabetes is the leading cause of blindness in working-age adults in the United States, resulting in over 10,000 new cases of blindness each year [22]. Landmark multi-center, randomized controlled trials showed that early identification and treatment can prevent the risk of vision loss by 90%, but fewer than 50% of people with diabetes in the USA follow diabetic eye screening guidelines [3, 23–26], and even lower screening rates (10–20%) have been described among underserved and minority populations [18, 27–30]. The American Diabetes Association (ADA) guidelines recommend adults with type 1 diabetes to begin diabetic eye screening within 5 years of diagnosis. Adults with type 2 diabetes should have eye screening at the time of diabetes diagnosis. Yearly eye screening is recommended, but if there is no evidence of diabetic retinopathy, screening every 2 years thereafter may be considered [31].

While diabetic eye screening recommendations have been well established for several decades and serve as a major quality measure tied to reimbursement by many accountable care organizations [32], many health systems have found it very challenging to improve screening rates. As the 2015 National Committee of Quality Assurance (NCQA) benchmarks demonstrate, the difference between the 25th and 90th percentile nationally in diabetic eye screening rates is quite narrow (46.25% and 68.04%, respectively) [33]. The annual costs of visual disorders in the USA are estimated at $139 billion—making it one of the most costly among all disease conditions—with diabetic retinopathy accounting for $6.2 billion [34]. Thus, increasing diabetic eye screening rates remains a top priority to reduce avoidable healthcare costs and to prevent blindness among our rapidly growing diabetes population.

Primary Care and Eye Care Provider Perspectives

Primary care and eye care providers both play vital roles in diabetic eye screening. Primary care providers can have a significant impact on preserving vision in patients with diabetes, yet their importance has been under appreciated [35]. While eye care providers traditionally perform diabetic eye screening through dilated eye exams, primary care providers are critical for educating, recommending, and sometimes referring patients for screening. It is essential to understand both primary care and eye care provider perspectives to better address provider barriers to increasing diabetic eye screening rates. Primary care providers have adequate knowledge and awareness of diabetic eye screening guidelines [36], but encounter

barriers to ensuring patients obtain screening due to the high burden and complexity of tasks they are required to complete during an average 15–20 min patient clinic visit as well as lack of access to patients' eye exam records [5]. Additionally, eye care providers face rapidly growing demands for diabetic eye screening, with an increasing shortage of eye care providers in many areas of the USA and worldwide [13, 14••].

Most primary care providers are knowledgeable regarding diabetic eye screening guidelines. In a knowledge-based survey, 81% of primary care providers achieved adequate scores, demonstrating that low screening rates are more likely to be explained by factors other than lack of provider knowledge [36, 37]. Most primary care providers do not feel that their eye exam skills are adequate to perform diabetic eye screening. Although they are usually trained to perform eye exams with a direct ophthalmoscope during medical school, this training is often quite limited and most primary care providers are not comfortable with the accuracy of their exams for diabetic eye screening [8, 37]. Thus, eye care providers traditionally provide diabetic eye screening through dilated eye exams performed in separate clinics.

While primary care providers do not directly perform diabetic eye screening, an opportunity exists in that primary care providers have much greater access to patients with diabetes than do eye care providers. Indeed, at least 90% of U.S. patients diagnosed with diabetes are treated by primary care physicians [38]. As a result, primary care providers develop more relationships and can influence more patients with diabetes to have eye screening by providing their recommendation. Unfortunately, primary care providers have a heavy workload burden with many competing priorities during the limited time allocated for each patient's clinic visit. A study by Ostbye et al. estimated that 10.6 h are required each day for a primary care provider to manage the top 10 chronic disease conditions in the clinic, assuming these conditions were uncontrolled [6]. Furthermore, a study by Yarnall et al. estimated that an additional 7.4 h each day would be needed to manage all recommended preventative care services [7]. These studies demonstrate the enormous challenge that primary care providers experience in regards to time constraints on the many tasks needed to provide high-quality, comprehensive patient care. Diabetic eye exams are just one of a multitude of acute and preventative care issues providers are expected to discuss with patients, many of whom often have more than one chronic disease condition. As a result, providers must prioritize problems they view to be urgent and those issues that the patient prioritizes. Similarly to many other preventative care issues, diabetic eye screening frequently becomes a low priority agenda item that is not discussed because more urgent issues took precedence [5].

Further compounding the difficulties faced by primary care providers is a lack of access to patients' diabetic eye screening records. Holley and Lee's qualitative research study found that of all the barriers to diabetic eye screening, the one most cited by primary care providers was poor communication from eye care providers [8]. Many eye care providers practice outside of larger health systems and, consequently, do not use the same electronic health record as a patient's primary care provider. Thus, eye care providers must be proactive in sending records to primary care providers—a practice which is not uniformly followed. As a result, there is often a failure to systematically communicate results from diabetic eye

screening to primary care providers. Primary care providers then frequently rely on patient self-report to determine whether and when diabetic eye screening was completed, as well as the date when screening is next due. The time and resources needed for primary care clinic staff to request records from eye care providers often not easily available. Furthermore, even when primary care clinic staff are assigned to facilitate and schedule eye care appointments on patients' behalf, there can be many obstacles including long eye appointment wait times [9].

Diabetic eye screening and treatment guidelines are part of the core curriculum for training eye care providers, but the current eye care provider workforce is insufficient to meet the growing demand for diabetic eye screening. The pathophysiology of diabetic eye disease and screening guidelines are considered basic knowledge needed to obtain board certification for ophthalmology [39] and optometry [40]. Eye care providers play a key role in providing diabetic eye screening, but access to eye care remains a major barrier. Many areas of the USA require patients to drive long distances to obtain eye care, making it inaccessible to many patients with limited resources [15, 41]. Patients with diabetes also account for a large proportion of eye care visits. A study in Alabama showed that 22–27% of patients seen by eye care providers have diabetes [13]. Patients with diabetes comprise a large share of eye care provider clinic time, but only 1 in 20 patients have vision-threatening diabetic eye disease [22]. Thus, traditional diabetic eye screening, consisting of dilated eye exams performed by an eye care provider, is highly inefficient. Without a substantial, concordant expansion of the eye care provider workforce, traditional screening methods are unsustainable as the number of patients with diabetes is projected to reach approximately half a billion people worldwide by 2030 [14••].

Primary care and eye care providers face many barriers to increasing diabetic eye screening rates despite knowledge of its importance. Primary care providers are limited by their immense workload, necessitating the prioritization of more urgent medical issues, and a lack of access to diabetic eye screening records from eye care providers. Care coordination between providers is limited by a lack of shared access to electronic health records across different health systems. Finally, eye care provider access is already insufficient in many areas of the USA as well as worldwide, and is only expected to become increasingly more limited [34]. Interventions to address these provider barriers are needed to increase eye care access and diabetic eye screening rates.

Patient Perspectives

In 2010, there were 25.8 million people diagnosed with diabetes in the USA [23], 7.7 million of whom had diabetic retinopathy [3]. Approximately 50% of Americans with diabetes adhere to eye screening guidelines, with even lower screening rates observed in underserved communities [30]. In addition to the barriers faced by providers, a variety of barriers also prevent patients from obtaining diabetic eye screening. These include a lack of understanding of the purpose for screening, the burden of managing other aspects of their diabetes, a dislike of dilating eye drops, a lack of financial resources, as well as a lack of access to eye care.

While many patients are aware that diabetes can lead to eye disease, there is a gap between this knowledge and an understanding of the purpose for screening [9]. Many patients who are not experiencing vision problems assume that diabetic eye disease is not present or deprioritize this aspect of their diabetes care [10•, 18, 19•]. The challenge of helping patients to understand that screening can detect diabetic eye disease in earlier, often asymptomatic stages and allow the opportunity for treatment to preserve vision before more advanced and sometimes intractable complications of retinopathy develop, is a persistent obstacle analogous to other types of preventative care screenings. Communicating the purpose and importance of diabetic eye screening, even in the absence of visual symptoms, can be an additional challenge for providers.

Once this first barrier to diabetic eye screening has been overcome, patients may be overwhelmed by other aspects of managing their diabetes, as well as by financial and eye care access limitations. An “overshadowing of eye disease by diabetes burden,” has been described, meaning that other aspects of diabetes self-care and management often compete for patients’ attention and outweigh concerns about possible eye disease [9]. In addition, many patients describe the use of dilating eye drops as a deterrent to screening [10•]. The discomfort from the drops themselves and the resulting blurred vision can be unpleasant. Furthermore, time and financial constraints are also a major factor. Some patients may not be able to read, drive or return to work for hours after their eyes are dilated. The costs of seeing an eye care provider remain out of reach for some patients, especially for those who are under- or uninsured [18]. Studies have shown that only a third of Medicare beneficiaries with diabetes saw an eye care provider [43] and only 46% of Medicaid patients had an annual eye exam, with lower rates of exams among underserved minority populations [28–30]. Disparities exist among rural, underserved urban, and minority patients who may experience additional barriers to screening. Rural communities often have limited access to eye care [15, 43]. Some patients have been reported to wait a year to obtain an eye care appointment and many must travel long distances to receive care [8, 13, 44].

Following diabetic eye screening guidelines remains challenging for patients due to a variety of barriers. Patients may lack an understanding about the purpose of screening, may be more focused on managing other aspects of their diabetes, dislike the effects of dilating eye drops, experience time and financial barriers, as well as limited access to eye care, with even greater barriers experienced by those in underserved communities. Taken together with those barriers experienced by providers, Odom concluded, “more research is needed to refine strategies for creating, maintaining and evaluating community based eye care programs and integrating with existing programs [45].”

Interventions to Increase Diabetic Eye Screening

Given the critical importance of preventing blindness from diabetes, many strategies have been tested to increase diabetic eye screening. Researchers have examined the effectiveness of clinic-based interventions such as telephone calls to schedule follow-up eye exams. A major advance has been in teleophthalmology, which has significantly increased diabetic eye screening rates in specialized health systems.

Standard reminder systems have had modest impacts on increasing adherence with diabetic eye screening [46, 47]. A multipronged clinic-based intervention reported by Zangalli et al. showed improved patient adherence with diabetic eye exams [20•]. In this prospective randomized study at an urban eye clinic, the intervention group received telephone assistance with scheduling an eye appointment along with an educational mailing and automated reminder phone call prior to their appointment. This was compared to usual care, which was comprised of a standard form letter and the automated reminder phone call. The intervention group was significantly more likely to schedule (RR 1.56; CI 1.31–1.86) and to obtain an eye exam (RR 1.58; CI 1.27–1.97) versus the usual care group. However, only 48% of patients in the intervention group completed their eye exam appointment, with even lower rates of completion (30%) in the usual care group. While such multipronged interventions are effective, their adoption may be limited both because of their complexity and because they are resource-intensive to implement.

The difficulty of encouraging patients to adhere with diabetic eye exams has helped spur the development of new technologies leveraging advances in telemedicine. Teleophthalmology offers an evidence-based form of diabetic eye screening that increases patient access and adherence [16, 48]. This form of screening offers high-quality, cost-effective eye care and often can be performed without pupil dilation [17]. Successful protocols have been developed at the Joslin Vision Network and implemented across the Veteran's Affairs healthcare system and Indian Health Service [17, 49]. In England, the National Health Service's teleophthalmology program has increased screening rates to over 80% and for the first time in 50 years, diabetic retinopathy is no longer the leading cause of certifiable blindness in working age English adults [4••]. Despite the success of these programs, there has been limited adoption of teleophthalmology in the USA. Some barriers include an unclear billing reimbursement strategy as well as significant equipment and personnel expenses [50]. A randomized controlled trial of teleophthalmology versus traditional diabetic eye screening failed to show sustained improvements in screening rates [51]. Additionally, the challenges of establishing teleophthalmology programs may be greater in rural than urban areas [52].

Furthermore, it is possible to integrate patient education into teleophthalmology systems, for example, by providing patient educational materials or education at the time of retinal imaging. Trained, nonphysician imagers have demonstrated excellent sensitivity and specificity in providing real-time evaluation of diabetic retinopathy in a teleophthalmology program [53]. This suggests that it would be possible to provide patients with instant feedback on their retinopathy status and education regarding individualized diabetes risks. However, a recent cluster-randomized trial by Aiello et al. showed that providing patients with comprehensive personalized data and diabetes risk assessments during ophthalmology clinic visits was not effective at reducing HbA1c or retinopathy severity, nor did it have a significant impact on responses to diabetes self-management practices and attitudes surveys at 1 year [54]. Postulated reasons for this lack of efficacy included that effective behavioral change for diabetes management requires much more intensive, personalized interactions [55]. Furthermore, patients may have higher thresholds for behavioral change due to their perceived tradeoffs between the burden of treatment and risk of disease progression [56]. Thus, these brief point-of-care educational interventions may instead best serve to reinforce

more comprehensive, long-term patient education provided by diabetes educators, health coaches, and peer counselors to achieve effective behavioral changes [11, 12, 21].

In summary, some clinic-based educational interventions and teleophthalmology have increased diabetic eye screening rates and adherence with follow-up eye examinations. The ability to provide substantive behavioral changes through point-of-care, personalized diabetes education at eye care visits to improve overall diabetes management may be limited. Continued testing and refinement, as well as integration, of these interventions within larger diabetes care initiatives may allow for optimizing diabetic eye screening rates.

Future Challenges and Opportunities in Diabetic Retinopathy Screening

While many innovative strategies and new technologies have shown promise for increasing diabetic eye screening rates, many new challenges exist. For example, questions have been raised regarding the optimal interval for diabetic eye screening given improvements in glycemic control and changing retinopathy treatment protocols. In addition, opportunities exist in leveraging team-based care approaches, patient self-management programs, and emerging telemedicine imaging technologies.

Some recent reports, including that from the Diabetes Complications and Control Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC), provide the rationale for less frequent screening of patients with no or minimal diabetic retinopathy [57–60]. However, some authors express concerns that such tailored screening algorithms are too complex to be effectively implemented and that the expanding role of anti-vascular endothelial growth factor (anti-VEGF) agents for treating earlier stages of retinopathy may be a countervailing force supporting more frequent screening [58, 61]. Changes to guidelines regarding the recommended frequency of retinopathy screening could cause confusion among patients and providers, potentially worsening screening rates if effective decision-support systems are not well-established. Thus, there is a growing need for proactive care coordination and communication between primary care and eye care providers, which has been shown to facilitate diabetic eye screening [10•]. Integrated, team-based care approaches, such as the use of diabetic educators, health coaches, and peer counselors [11, 12, 21], as well as patient self-management programs [62], can provide additional education and support for diabetic eye screening as patients are empowered to take a more active role in their health.

Patient access to diabetic eye screening has been greatly expanded using teleophthalmology. While guidance on best-practices is available from the American Telemedicine Association’s Telehealth Practice Recommendations for Diabetic Retinopathy [63], more research is needed to understand how to implement teleophthalmology programs across diverse health settings and apply new imaging modalities. Offering teleophthalmology in primary care clinics has shown success primarily in single-payer and safety net health systems in the USA [17, 64, 65]. However, it can be difficult for teleophthalmology programs to sustain increased screening rates long-term and patients may not obtain recommended follow-up eye care even when cost and accessibility barriers are minimized [51, 66]. Implementation science approaches may be able to help address barriers limiting

the effectiveness of “real-world outcomes” from teleophthalmology programs [14••]. Newer camera technologies such as ultrawide field imaging provide enhanced visualization of the peripheral retina and reduces ungradable images [67]. Cameras that include optical coherence tomography (OCT) imaging are more sensitive for detecting diabetic macular edema [68]. Automated image grading provides reasonable accuracy and decreases the need for trained human graders [50, 69]. Future opportunities include the use of handheld cameras [70] as well as smartphone-based camera screening [71].

Integrating novel systems-based, educational, and technological approaches may be key to improving outcomes. Given its tremendous impact on the burden of blindness in the USA, the evolving landscape of diabetic eye disease epidemiology, treatment paradigms, and screening modalities continue to drive the field of diabetic eye screening forward as a prominent area of research focus and innovation.

Conclusions

Providers and patients are aware of the importance of diabetic eye screening, but screening rates remain unacceptably low in the USA, especially among underserved minority and rural communities. Barriers include inadequate care coordination and communication between primary care and eye providers, as well as provider workload constraints and limited access to eye care. Patients face a wide range of barriers including not understanding the purpose for screening, disease burden, limited eye care access, time constraints, and financial considerations. Methods to overcome these barriers and increase access to diabetic eye exams have been developed, but need further integration into health systems to facilitate widespread adoption and implementation. Opportunities exist to leverage team-based care approaches and emerging imaging technologies to increase diabetic eye screening. Continued research is needed to optimize diabetic eye screening given the rising demand that cannot be met by the current eye care provider workforce. Diabetic eye screening remains vital to prevent blindness and ensure the health of our communities worldwide.

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Table 1.

Summary of Perceived Barriers and Interventions for Primary Care, Eye Care Providers, and Patients in Diabetic Eye Screening

	Perceived Barriers	**Interventions**
Primary Care Providers	Workload constraints [5-7] Lack of access to records from eye care providers [8] Difficulty facilitating eye care appointments [9]	Integrated, team-based care [10•, 11, 12] Electronic health records-based best practice alerts [8]
Eye Care Providers	Shortage of eye care providers unable to meet increasing demand for screening [13, 14••, 15] Many eye care providers practice outside large health systems, limiting communication with primary care providers [8]	Teleophthalmology [4••, 16, 17]
Patients	Lack of understanding of the purpose for screening [9, 10•, 18, 19•] Burden of managing other aspects of diabetes [9] Dislike of dilating eye drops [10•] Lack of access to eye care providers [8, 15] Time and financial constraints [10•, 18]	Patient education and self-management support programs [11, 21, 62] Telephone calls, reminder letters, and educational brochures [20•]