Improving Diabetic Retinopathy Screening Through a Statewide Telemedicine Program at a Large Federally Qualified Health Center

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Abstract: **Background**. Diabetic retinopathy (DR) is the leading cause of acquired blindness in U.S. adults. Early detection prevents progression. Screening rates are only 10% in medically underserved populations. **Methods**. A statewide telemedicine-based program within primary care centers was implemented to improve DR screening, detection and referrals for underserved patients. **Study design**. Retrospective, descriptive study. **Results**. A total of 568 adults were screened during a comprehensive nurse visit from July 2009–June 2010 and had complete data available. Nearly 60% were minorities and 24% were uninsured. A total of 145 cases of DR were identified. The majority were recommended to return in one year for follow-up, while 75 were referred to a specialist. **Conclusions**. Telemedicine using digital imaging technology in the primary care office is a strategy that can be used to screen underserved and at-risk patients for DR, increase compliance with screening, and streamline specialist referrals.

Key words: Telemedicine, diabetic retinopathy, community health center, minority health.

Diabetes is a growing epidemic among all groups in the United States (U.S.), with more than 20 million Americans of every age, gender, and race/ethnicity now diagnosed with the disease.[1] This number is expected to grow exponentially in the next few years, with an estimated 48.3 million persons (one out of every three adults) projected to have diabetes in the U.S. by 2050.[2] Vulnerable populations, including

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racial/ethnic minorities and the elderly, are disproportionately affected by diabetes.[3] For example, diabetes prevalence is estimated at 7.8% of the U.S. population in total, 23.1% of adults ages 60 and over, 6.6% of non-Hispanic Whites, 7.5% of Asian-Americans, 10.4% of Hispanic/Latinos, 11.8% of non-Hispanic Blacks, and 14.2% of American Indian/Alaskan Natives.[3] In response to these disparities, the American Public Health Association has recommended that federal, state, and privately funded health care organizations focus on screening for diabetic complications for high-risk minority populations.[1] The increased prevalence of diabetes has led to an increase in diabetes-related microvascular and macrovascular complications, including blindness from diabetic retinopathy, lower extremity amputation, destructive periodontitis, and tooth loss.[1] Of these, diabetic retinopathy is the most common microvascular complication of diabetes and the leading cause of blindness among working-age U.S. adults,[4] causing approximately 12,000–24,000 new cases of blindness in the U.S. every year.[3,5] This number is expected to increase due to the aging of the U.S. population, increasing prevalence of diabetes, and the projected demographic changes of the U.S. population.[3,6] Disparities also exist—compared with White Americans, after adjusting for confounding and risk factors, research has shown that Blacks and Hispanics have an increased risk of retinopathy, and that these two groups represent a disproportionate share of morbidity as measured by visual impairment and blindness.[7,8] However, opportunities for decreasing vision-related morbidity caused by diabetic retinopathy do exist.[8] The loss of vision from diabetic retinopathy can be avoided by early detection through annual ocular screenings.[2] Earlier recognition of diabetes, better glucose control, and early detection and treatment of diabetic retinopathy can slow or prevent the development of blindness.[3] Detecting and treating diabetic eye disease early with laser therapy can decrease the occurrence of severe vision loss by 50–60%.[3,5] To decrease this morbidity, screening strategies for high-risk groups should be identified, improved, or expanded.

The evolution of the diabetes epidemic will be accompanied by a heavy economic burden on the U.S. health care system if interventions are not developed to reduce diabetes-related complications.[2] Compared with no screening, systematic screening has proven to be a cost-effective method for diabetic retinopathy prevention.[9] For example, telemedicine-based diabetic retinopathy screening in primary care settings can both effectively detect retinopathy and significantly increase compliance with systematic retinal screenings.[10] Ocular telemedicine programs such as the Joslin Vision Network Diabetes Eye Care Program can accurately assess diabetic retinopathy severity, detect the presence of nondiabetic eye disease, and provide appropriate treatment recommendations.[4] Similarly, EyePACS® (Picture Archive Communication System) is a license-free Web-based DRS system designed to improve access to care and simplify the process of image capture, transmission and review so that primary care providers can adopt retinopathy screenings with minimal effort and resources. To date, EyePACS® has recorded over 34,000 diabetic retinopathy screens, with an overall rate of referral of 8.21% for sight-threatening retinopathy and 7.83% for other conditions (e.g., cataracts and glaucoma).[10] These types of telemedicine programs or platforms extend access to evidence-based diabetes eye care and can be applied in other settings in which patients can be assessed within their own communities.[4,11,12] The telemedicine approach to diabetic retinopathy screenings overcomes barriers in access to eye care for underserved

and vulnerable populations, decreases the time of treatment, and prevents unnecessary referrals.[11,12]

The purpose of this retrospective study was to determine if a telemedicine screening program for diabetic retinopathy would increase screening rates in a high-risk population in a large statewide health center. Creative ways to incorporate screening into primary care practices have been explored, including training primary care providers (PCPs) in diabetic retinopathy assessment, which has shown mixed results,[13–18] as well as contractual arrangements with in-house optometrists and ophthalmologists. Telemedicine, employing retinal imaging with remote interpretation by eye care specialists has shown more promise, and has been very successful in many parts of the country and the world at addressing limitations in primary care provider skills in retinal image interpretations and the resource intensiveness of embedding eye care specialist in a primary care office.[11,19–20] Diabetic retinopathy has certain features that make it ideal for telemedicine disease management and is well-suited to become central to eye health care.[19–21] In fact, digital retinal imaging is the standard for diabetic retinopathy screening in the United Kingdom[22,23] and has been shown to significantly improve screening rates in primary care sites as compared to conventional methodology in a single site practice in the United States.[12] The American Academy of Ophthalmology (AAO) and the American Diabetes Association (ADA) recommend screening and early detection of retinopathy with annual dilated exams and recognize that validated digital image technology can be sensitive and effective.[24,25,26] The AAO also acknowledges various forms of retinal screening, with and without dilation, as having value where access to ophthalmic care is limited,[19] such as in many medically underserved areas. Fortunately, effective screening and treatment programs can greatly reduce the burden of blindness in vulnerable and underserved populations.[19] Approximately half of the U.S. diabetic population obtains the recommended screening through a traditional referral to the eye specialist by the PCP.[12,27,28] Therefore, screening for diabetic retinopathy in vulnerable and underserved populations, which often have inconsistent access to specialists, is difficult to achieve. Among minorities and other populations with limited access to specialty medical care, diabetic retinopathy screening rates are generally in the range of 10% to 20%,[5,27–29] and diabetes-related vision loss is disproportionately higher in these groups.[12] There are many reasons for such low rates in such settings, including limited access to specialty care.

The need for more coordinated and integrated screening for diabetic retinopathy is particularly important in Federally Qualified Health Centers (FQHCs), which serve predominately low-income, uninsured and racial/ethnic minority populations.[24,30] Community Health Center, Inc. (CHCI), the study site, had nearly 3,500 patients with diabetes at the time of the study, many being members of racial/ethnic minority groups (13% African American/Black, 48% Hispanic/Latino).[31] Because these groups are more likely to be uninsured or underinsured, they have less access to medical and specialist care[25] and are therefore, as mentioned earlier, disproportionately affected by the complications of diabetes, including diabetic retinopathy.[5,27–29] In fact, rates of blindness associated with diabetic retinopathy are only half as high for Whites as they are for non-Whites.[29] Minority group members are also less likely to receive timely eye care, due to a combination of factors, including impeded access to specialists, transportation
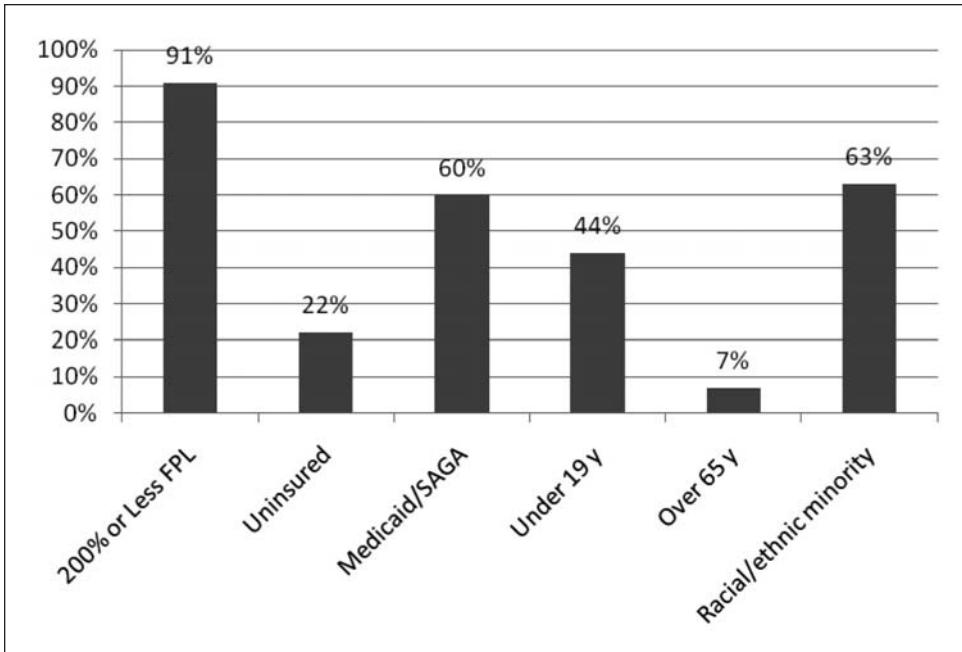
Figure 1. Community Health Center Inc. patient demographics.

FPL = Federal Poverty Level
SAGA = State-Administered General Assistance
Y = Years

challenges, other logistical issues, and non-compliance.[25] Therefore, it is critical that FQHCs such as CHCI develop strategies to provide screening for such complications, as well as treatment and referral options as indicated. Doing this requires a comprehensive, coordinated, patient-centered approach to diabetes and chronic disease care. The Chronic Care Model (CCM) poses one such model, as it identifies the essential elements of a health care system that promote high-quality care for chronic diseases. These elements include the integration of the community, the health system, self-management support, delivery system design, decision support, and clinical information systems.[32–33] This has been the platform for primary care delivery, prevention and screening at CHCI and provided a framework for developing a telemedicine program for diabetic retinopathy screening.

Methods

This is a retrospective, descriptive study of the model employed and patient population screened during the first year of a statewide telemedicine initiative for diabetic retinopathy screening. Approval for this study was obtained from the Community Health Center, Inc. Institutional Review Board. We hypothesized that such a program would be useful in improving screening rates for an at-risk population of patients, compared with conventional referrals for specialist care.

Setting. Community Health Center, Inc. (CHCI) provides comprehensive primary care services to over 100,000 of Connecticut's most underserved patients in 12 towns. Over 60% of CHCI patients are racial/ethnic minorities, over 90% are below 200% federal poverty level, 60% are on Medicaid or state insurance, and 22% are uninsured (Figure 1).[32] Baseline data on patients with poorly controlled diabetes shows that CHCI's Hispanic patients are the most likely to have *poor control* of their diabetes, defined as HbA1C >9% per the Health Resources Services Administration's Uniform Data System (UDS) reporting criteria for all health center grantees.[34] Fifty-three percent of patients with poor control of their diabetes by the Health Resources Services Administration's Uniform Data System (UDS) standards are Hispanics *vs*. 27% Whites. In early 2009, an internal review within CHCI found that of patients with diabetes reviewed over a three-year period, only 600 (18%) had active referrals for annual retinal examinations with Optometry or Ophthalmology.[35] Many of these referrals (30–40%) were not executed or fulfilled[35] because of lack of insurance, travel distance and transportation challenges, communication issues, and patients not making it to scheduled appointments. Therefore, only 10–12% of CHCI patients with diabetes were up-to-date with recommended diabetic retinopathy screenings prior to implementation of this program.[35] In addition, some referrals may have been generated by providers, but not recorded in such a way that this information was easily retrievable. Through a partnership with the Yale Eye Center/Department of Ophthalmology, CHCI launched a telemedicine-based diabetic retinopathy program within its primary care centers in July 2009 to improve screening, detection and referral rates as primary goals.

Secondary goals of the telemedicine program were:

a. To achieve enhanced diabetes planned care for patients through a comprehensive nursing assessment (e.g., labs, testing, foot checks, vaccinations);
b. To increase patient activation, diabetes education and self-management goal setting;
c. To improve communication and referral processes between primary care providers (PCPs) and specialists; and
d. To reduce unnecessary referrals to eye specialists and ensure necessary referrals are completed.

The CHCI selected EyePACS® as the Web-based application for the telemedicine platform. EyePACS®, as mentioned earlier, is a non-proprietary, freely accessible, secure, open source Web-based application for communicating and exchanging eye-related patient information, images and diagnostic data.[10,21] Founded by optometrists at University of California at Berkeley, it has been used successfully for consults, telemedicine, screening, and education at primary care locations around the United States and in developing countries. Retinal images and patient data were uploaded into the EyePACS® Picture Archiving System for specialist retrieval, review and consultation.[10,21] In EyePACS®, relevant clinical data and eight high-resolution images per patient (two external and six retinal images) were encrypted and transmitted to a secure Internet server, using a standard computer and Web browser. Retinal images were then interpreted by Yale Ophthalmologists, who were also certified as EyePACS® reviewers through the EyePACS®

Retinopathy Grading System. Reports indicating retinopathy level and referral recommendations were transmitted back to PCPs through the EyePACS® website. EyePACS® data was transported into Excel, and any missing data was retrieved from the electronic health record (EHR).

Program development. We convened a multi-professional workgroup to construct and outline the program prior to its launch. This workgroup consisted of representatives from Senior Leadership, Information Technology (IT), Health Applications, Practice Management, Nursing, Medicine, Purchasing, Facilities, Risk Management, Performance Improvement, Finance and Public Relations. The workgroup developed and delegated roles and responsibilities and met bi-weekly from January 2009 through the launch date in July 2009. We identified key partnerships, created new workflows, designed EHR templates, developed policies, mapped a consent process, developed or modified promotional materials and talking points, and engineered a training plan.

Through a formal memorandum of understanding, CHCI and Yale came together to provide retinal screening to patients regardless of their ability to pay. We worked with the Yale Eye Center/Department of Ophthalmology for the reading, interpretation and assessment of the digital retinal images in EyePACS®. Yale received a flat fee for each patient case, including all consultative interactions with CHCI providers, and agreed to provide follow-up care for patients that required ophthalmology at the Yale Eye Center in New Haven if they were uninsured or otherwise could not obtain ophthalmology care. Local ophthalmologists and optometrists were also provided information about the program and many elected to serve as referral sources for CHCI patients who screened positive for diabetic retinopathy.

We chose and purchased the Canon CR-1 digital retinal camera, a state of the art non-mydriatic retinal camera, for use in the program. This camera has been used in other settings where motion between geographically distant sites was required,[21] and with appropriate handling, can be moved between various locations. Numerous staff (including medical assistants, nurses, facilities personnel, medical care providers, receptionists, and finance team members) were trained in the handling of the camera, operation of the camera, conduction of the nurse visits and billing. (Details of the training protocols are beyond the scope of this paper.) We created a rotating schedule for the camera, so all sites had access for one week at a time. We developed four new policies that governed the tele-ophthalmology program referrals, nurse visits, image uploading, and image transmission/specialist communication.

Referrals. All adult patients with an ICD-9 code for diabetes (250.xx) on their problem list in the EHR were eligible for referral to the tele-ophthalmology program. Registry reports identifying patients with diabetes were prepared by CHC's Health Applications Director and electronically provided to the on-site medical directors, nurse managers and front line care teams ("Pods") at each medical site. We did mass mailings to all CHCI patients with diabetes explaining the program, and flyers were posted in our sites in CHCI's most commonly spoken patient languages (English, Spanish, Polish, and Portuguese). Pod teams reviewed the lists and identified patients in need of diabetic retinal screening (i.e., patients not actively engaged in care with ophthalmology or optometry or those for whom the last retinal exam was over one year

ago). Patients were referred for screening by their PCP/Pod team or by self-referral. Since the camera was at each site for one full week, providers could refer patients for retinal screening adjacent to the provider visit, for point-of-care testing. Patients were educated about the program and provided information on eye health for patients with diabetes, as well as education about diabetic retinopathy by their first and subsequent retinal screening contact (i.e., the team nurse, trained receptionist, or trained medical assistant). Patient educational material and talking points used by EyePACS® and the National Eye Institute were used and/or adapted for this program.[10,21,36]

Visit protocol. Patients who elected to have the screening done were scheduled for a nursing visit as described above, which consisted of the following: review of the telemedicine program and patient education by the camera operator/medical assistant, patient consent, visual acuity and blood pressure testing, retinal screening (non-dilated) by the trained camera operator and uploading of retinal images into EyePACS®; a comprehensive nursing assessment including administering/offering of any due immunizations under CHCI standing order; identification and ordering of overdue labs or screening tests specified under CHCI standing orders for diabetes planned care; comprehensive diabetic foot exam if due; review and resolution of CDSS (Clinical Decision Support System) measures, which have been shown to enhance clinical performance for preventive and other aspects of medical care;[37,38] and review, coaching on and update of self management goals, which have been shown to be a crucial part of comprehensive diabetes care[39] and central to the Chronic Care Model.[32,33] Templates were used to ensure that all elements of the visit were completed.

Post-visit. Following this, the case was transmitted securely to the EyePACS® system, and the Yale Retinal Specialist and Retinal fellows reviewed the case and provided comment and consultation through EyePACS® within 48 hours of notification.

Data collection. Patients participating in the telemedicine program completed telemedicine consent forms and a basic information sheet similar to a protocol previously successful with EyePACS®.[10,21] Demographic information was extracted from patient's electronic health records (EHR) and clinical data (hemoglobin A1C, blood pressure, etc.) was obtained by CHCI medical assistants and/or registered nurses either at the time of the visit or by abstraction from the electronic record. Planned care components of the nursing visit, including self-management goal setting, diabetes education, comprehensive foot exams, vaccination and lab ordering, were all documented in the patient's record on the date of the visit.

Results

A total of 611 patients were screened for diabetic retinopathy through the tele-ophthalmology program from July 2009–June 2010, of which 568 had complete demographic and clinical data available (Table 1). The mean age of the patients was 53.1 years and nearly 60% of patients were racial/ethnic minorities. Twenty-four percent (24%) of patients were uninsured and approximately 63% were publicly insured (Medicaid or managed Medicaid, state-administered General Assistance, Medicare). The mean HbA1c was 8.0%. Many patients had diabetes for more than 10 years (30.8%) and most did not currently use insulin therapy (65.5%). The majority of patients had a diagnosis of HTN

and the mean SBP and DBP were 130.2 and 79.4 mmHg, respectively. Approximately 40% of patients were at blood pressure target of less than 130 mmHg SBP and less than 80 mmHg DBP, per ADA targets for blood pressure control in diabetes.[26]

Of the 568 patients for whom complete data is available, 145 cases of diabetic retinopathy were identified (Table 2), or 25% of patients. Seventy five patients (13%) required a referral to an eye care specialist at the time of their screening, while the majority of patients (n=403, 71%) were cleared for follow up in one year.

All patients (100%) had a retinal screening examination performed in concert with a comprehensive nursing assessment where planned care tasks could be performed. After discussion with the nurse, 150 patients (26.4%) set a self management goal (SMG) while 62 patients (10.9%) expressed themselves as not being ready to set SMGs. The majority of patients (n=356, 62.7%) did not set an SMG during the visit. A comprehensive foot exam was completed during the screening in the majority of patients (n=409, 67%).

Table 1.

DEMOGRAPHICS AND CLINICAL CHARACTERISTICS OF PATIENTS SCREENED

Patient demographic/characteristic	N (%)
Age (mean ± Standard Deviation or SD)	53.1 ± 11.5
Males	265 (46.7)
Racial/ethnic group	
Black/African American	72 (12.7)
Asian	18 (3.2)
White/Caucasian	183 (32.2)
Hispanic/Latino	238 (41.9)
Native American/ American Indian	3 (0.5)
Other	20 (3.5)
Not specified	34 (6.0)
Uninsured	136 (23.9)
Publically insured	354 (62.3)
Duration of DM >10 years	175 (30.8)
HbA1C (mean ± SD)	8.0 ± 2.0
Insulin therapy	196 (34.5)
Hypertension	401 (70.6)
Systolic Blood Pressure (mean ± SD)	130.2 ± 16.9
Diastolic Blood Pressure (mean ± SD)	79.4 ± 9.7
Blood Pressure at goal	261 (46.0)
Hyperlipidemia	387 (68.1)
Coronary artery disease	50 (8.8)
Chronic kidney disease	46 (8.1)

Table 2.

ASSESSMENTS AND RECOMMENDATIONS MADE BY OPHTHALMOLOGISTS FOR PATIENTS SCREENED

Assessment	N (%)
Total	568
No disease	423 (74.5)
Mild NPDR	70 (12.3)
Moderate NPDR	39 (6.9)
Severe NPDR	21 (3.7)
PDR	15 (2.6)
Recommendation	
Return in 1 year	401 (70.6)
Refer to specialist	75 (13.2)
Return sooner than 1 year	92 (16.2)

NPDR = Non-Proliferative Diabetic Retinopathy
PDR = Proliferative Diabetic Retinopathy

Conclusion

The CHCI was able to screen nearly 20% of its patients with diabetes across the state for diabetic retinopathy in one year, using two non-mydriatic retinal cameras that were rotated between multiple medical sites, and combining the retinal screening with a provider-ordered comprehensive nursing assessment. Twenty-five percent (25%) of these patients were uninsured and would otherwise not have been able to receive this testing without a potentially prohibitive cost. Nearly 60% of the patients screened were racial/ethnic minorities.

The primary goal of this initiative was to increase screening, detection, and referral rates for diabetic retinopathy through the elimination of access barriers. Secondary goals were to enhance diabetes planned care through comprehensive nursing care, improve patient activation through diabetes education and self-management goal setting, reduce unnecessary or premature referrals to eye care specialists, and ensure timely referral for patients with evidence of diabetic retinopathy. The first and primary goal was accomplished by providing access to this telemedicine service in the PCP's office, which reduced the barriers of transportation, language and inconvenience, and allowed for point-of-care testing when the camera was on site. Prior to this endeavor, only 10–12% of diabetic patients at CHCI were up-to-date on diabetic retinopathy screening.[35] In the first year of this program, we were effectively able to screen 20% of our patients with diabetes and coordinate referrals as needed, representing a nearly 10% increase. The inclusion of additional cameras at more sites would have increased the number of patients screened. In addition, by combining the retinal screening with

a comprehensive nursing assessment, patients were able to benefit from the expertise of the primary care nurses, who, in most cases, were able to provide diabetes education and discuss self-management goal setting, perform foot exams for patients who were overdue, administer needed vaccinations, and order overdue laboratory tests. Though patient satisfaction was not formally assessed, patients anecdotally reported great benefit in having this digital screening in the primary care office. This is an area to be studied formally in the future. In addition, over 70% of patients did not have evidence of disease and therefore did not require referral to the eye care specialist for diabetic retinopathy. The system also provided a simple method for "closing the loop," eliminating delays in communication, as the primary care provider quickly and consistently received a consultation note from the eye specialist through EyePACS®. Preliminary cost data shows cost savings of $25.00 per patient utilizing telemedicine *vs*. conventional fundus examination (paper in progress), and detailed cost analysis will be performed in the future. Additional areas for future study include more detailed, multivariate analyses to determine predictors of diabetic retinopathy in health center patients, so targeted screening efforts can be performed.

The primary limitations of this study concern generalizability, as the platform for this initiative was a large multi-site FQHC network with resources to fund the purchase of the equipment and reimburse the specialists in the absence of a reimbursement model for telemedicine. In addition, this was a retrospective review of a group of patients without a control group, so conclusions regarding significance of telemedicine-based screening *versus* conventional screening methods from an outcomes perspective cannot be drawn. Patients were not diverted from eye care providers if they were already actively engaged, so comparisons with patients receiving ophthalmologic/optometric care cannot be made. Additionally, pupil dilation was not performed, though emerging data suggests that non-mydriatic exams are sensitive in many cases.[40] Finally, the long-term clinical impact of the telemedicine intervention, including prevention of vision loss and blindness, remains an area for future study.

Diabetes prevalence is expected to double or triple in the next few decades, with one-third of U.S. adults expected to have diabetes by 2050.[2,41] With such rapid growth in prevalence of diabetes and ultimately its sequelae, as well as disproportionate population growth in minority populations,[3,41] demand for eye-care specialists to provide diabetic retinopathy screening will increase. However, as the incidence of diabetes increases, the number of practicing ophthalmologists in the U.S. is decreasing[42] and access to ophthalmology will be even more limited for medically underserved patients and those receiving care from community health centers.[25] Therefore, incorporating diabetic retinopathy screening into primary care settings will be necessary to ensuring that at-risk patients and those that lack access to specialty eye care are screened in a timely fashion, while better utilizing the eye care specialist for the treatment of patients with clinically significant diabetic retinopathy. Reimbursement schemes for telemedicine will be important in the future. We propose a model here that was successful in increasing access to retinal screening and comprehensive nursing/planned care for patients with limited access, and streamlining referrals to ophthalmologists for those with the greatest need.

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