Clinical Ophthalmology Dovepress

Open Access Full Text Article ORIGINAL RESEARCH

Baseline Characteristics and Clinical Outcomes of Patients Seen Through the Free Diabetes Screening (FDS) Program

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Purpose: To characterize the baseline characteristics and clinical outcomes of patients seen through the Free Diabetic Screening (FDS) program, a free diabetic retinopathy screening program for uninsured patients, in the ophthalmology resident clinic at the Wilmer Eye Institute.

Patients and Methods: This retrospective longitudinal cohort study included uninsured patients ≥18 years with diabetes mellitus seen through the FDS clinic from 2013 to 2023. Data extraction was performed using manual chart review of the first FDS visit, and automated extraction of the data warehouse related to all other office visits. Patient demographic and clinical characteristics at presentation, treatments, and follow-ups were collected.

Results: A total of 422 patients were included in this study (mean age 52 years; 59% female; 47% Hispanic; 49% Spanish as primary language). One-third of patients had some form of diabetic retinopathy or diabetic macular edema, and 12% had vision-threatening diabetic retinopathy at presentation. In all, nearly 10% of patients were referred for further specialty care, and 71% of these patients completed at least one follow-up visit. The majority of patients (55%) returned for care as recommended and were followed for a mean length of 200 weeks and 10 office visits.

Conclusion: The FDS clinic provided much needed diabetic retinopathy screening and treatment for uninsured patients in Baltimore City and surrounding areas. This study highlights the need for strong integration between initial screening and downstream services, as nearly 10% of patients require further sub-specialty intervention or care.

Keywords: uninsured, free clinic, diabetic retinopathy, health disparities

Introduction

Vision loss from diabetes is a leading cause of blindness in the United States.[1] Blindness and vision impairment have profound negative impacts including loss of quality of life, decreased work productivity, and even increased risk of mortality.[2–4] Fortunately, vision loss from diabetes can largely be prevented but requires screening and follow-up eye exams.[5] Not having insurance is a major barrier to accessing these critical eye exams.[6,7] Uninsured adults, compared to those with health insurance, have less access to recommended care, receive inferior quality of care, and experience worse health outcomes with more vision impairment and vision loss.[7,8]

There are few avenues to free or low-cost health care options for the uninsured. Community health centers, which include Federally Qualified Health Centers (FQHCs), deliver affordable primary care to underserved populations but do not offer many other health services.[9,10] Access to vision care services within community health centers is limited–estimates suggest less than 3% of community health center patients received vision care services in 2019.[11,12] Mobile

Received: 17 September 2024
Accepted: 5 November 2024
Published: 11 November 2024

screening clinics exist, but these systems have difficulty getting patients follow-up care for the definitive eye exams.[11–13] Local volunteer or free clinics have to fill in the gaps in health services provision.[10]

In this study, we report our experience with collaborations between community health centers in Baltimore City and the Free Diabetes Screening (FDS) program in the ophthalmology resident clinic at the Wilmer Eye Institute as a means of providing free diabetic retinopathy screening to the uninsured population. The purpose of this study is to report the baseline characteristics and clinical outcomes of patients seen through the FDS program.

Material and Methods

Free Diabetes Screening (FDS) Program

The Free Diabetes Screening (FDS) program was started in 1989 by Dr. Arnall Patz and Dr. Daniel Finkelstein. Local community health centers, including Shepherd's Clinic, the Esperanza Center, St. Clare Outreach Center, Healthcare for the Homeless, Walnut Street Community Health Center, and Baltimore Medical Center among others, refer uninsured patients with diabetes to the FDS program for their diabetic retinopathy examinations. Only patients who do not already have other forms of financial assistance, for example through the Johns Hopkins The Access Partnership (TAP), are seen through the FDS program.[14] A single fellowship trained vitreoretinal specialist oversees the diabetic retinopathy screening (previously Dr. Finkelstein and since 2021, Dr. Cai) performed in conjunction with ophthalmology residents. Due to the nature of the clinic, only limited vitreoretinal services, such as optical coherence tomography imaging and panretinal photocoagulation, are provided through the FDS clinic. Further subspecialty care requiring intravitreal injections or cataract surgery are referred to other Wilmer clinics. A dedicated financial counselor through the resident clinic works with patients to obtain charity funds or financial assistance for further subspecialty eye care.

Study Design

This was a retrospective longitudinal cohort study of all patients ≥18 years with diabetes mellitus seen through the FDS program from 1/1/2013 to 9/13/2023 at Johns Hopkins Hospital (JHH). These dates were chosen because the electronic health record (Epic Systems Corporation, Epic) at JHH was instituted in 2013. This study was approved by the Johns Hopkins University School of Medicine Institutional Review Board, adhered to the tenets of the Declaration of Helsinki, and the Health Insurance Portability and Accountability Act (HIPAA). As this was a retrospective study of routinely collected clinical data, the Institutional Review Board waived the need for informed consent.

Data Extraction

The first FDS office visit available in Epic for each patient was reviewed and data obtained using manual chart review of unstructured data and extraction of structured data from the JHH data warehouse (Precision Medicine Analytics Platform). Data extraction was performed from 7/17/2023 to 12/19/2023. Additional structured data from all other visits at JHH before and after the first FDS visit were extracted from the data warehouse. Details of the variables and methods of data extraction are included in Supplemental Table 1.

Demographic data were extracted including age, sex, race/ethnicity, and primary language spoken. The patient home address was extracted and geocoded to a 12-digit Federal Information Processing Standards Publication block group code based on the 2018 US Census Bureau TIGER/Line Shapefiles.[15] The block group was then matched to the national 2018 Area Deprivation Index (ADI).[16] ADI is a factor-based index that uses US census indicators with higher percentile ranks indicating more neighborhood socioeconomic disadvantage. The distance between the East Baltimore JHH campus and the patient home address was also calculated in miles using the Python Geopy package.

Baseline medical characteristics were recorded including the self-reported type of diabetes, duration of diabetes (years), hemoglobin A1c (%), fasting blood glucose levels (mg/dL), and complications from diabetes (neuropathy, nephropathy, heart attacks, and strokes). Whether the patient had a primary care physician was extracted. The severity of the patient's diabetic eye disease was identified from manual chart review of the physician's Assessment and Plan and divided into diabetic retinopathy and diabetic macular edema (DME). Other ophthalmic conditions cataracts, glaucoma (or glaucoma suspect or neovascular glaucoma), and refractive error were also recorded. The patient's self-reported

history of ophthalmic procedures including intravitreal anti-vascular endothelial growth factor (anti-VEGF) injections, pars plana vitrectomy (PPV), cataract surgery, panretinal photocoagulation (PRP), and focal laser was recorded, since this information is not available in the structured data of the EHR. Ophthalmic examination elements including the best recorded visual acuity (converted into logMAR) and intraocular pressure for each eye were extracted from the data warehouse.[17] International Classification of Diseases 10th Revision (ICD-10) diagnostic codes associated with all office visits across JHH prior to and including the first FDS visit were extracted. ICD-10 codes were used to calculate the Charlson Comorbidity Index (CCI) and Diabetes Complications Severity Index (DCSI).[18,19]

The clinical outcomes of the patient were recorded including whether the patient was referred for further retina care, a cataract surgeon, or further glaucoma care. Other outcomes included whether the patient was prescribed glasses, obtained insurance, received additional funding, and when he/she was recommended to return for follow-up. Outcomes including intravitreal anti-VEGF injections, PPV, cataract surgery, and glaucoma surgery during their follow-up were extracted using Current Procedural Terminology (CPT) codes[20] (Supplemental Table 2). The duration of each patient's follow-up in ophthalmology, and the number of office visits were also extracted. A lapse in care after the patient's first FDS visit was calculated as previously described.[21]

Statistical Analysis

Descriptive statistics were calculated. All analyses were conducted in Python (Python Software Foundation, Python Language Reference, version 3.8.5), and SAS statistical software version 9.1, and Microsoft SQL Server Management Studio 19.

Results

A total of 422 patients were included in the study. The average age was 52 years (standard deviation 10 years). Most patients were female (59%), Hispanic (47%), and spoke Spanish as the primary language (49%). (Table 1) On average, patients lived within 10 miles from the clinic, and came from neighborhoods with an average ADI of 53. Most patients

Table 1 Baseline Characteristics of Patients Seen Through the Free Diabetes Screening (FDS) Program from 2013 to 2023

Characteristic	
Age* (years)	52 (SD 10)
Sex, n (%)	
Male	172 (41%)
Female	250 (59%)
Race / Ethnicity, n (%)	
Non-Hispanic White	33 (8%)
Non-Hispanic Black	123 (29%)
Hispanic	197 (47%)
Other	69 (16%)
Primary Language, n (%)	
Spanish	206 (49%)
English	199 (47%)
Other	17 (4%)

(*Continued*)

Table 1 (Continued).

Characteristic	
Distance of residence from clinic* [miles]	9.83 (SD 29.158)
National Area Deprivation Index (ADI)*	52.75 (SD 22.13)
Primary Care Provider, n (%)	
No	59 (14%)
Yes	363 (86%)
Type of Diabetes, n (%)	
Type 2	322 (76%)
Type 1	5 (1%)
Other	1 (0.2%)
Unknown	94 (22%)
Duration of Diabetes [years]	6.5 (SD 7.4)
Hemoglobin A1c [%]	
≤7.0%	90 (21%)
>7.0%	103 (24%)
Unknown	229 (55%)
Fasting Blood Glucose [mg/dL]	152.6 (SD 54.4)
Complications from Diabetes, n (%)	
Neuropathy	18 (4%)
Nephropathy	1 (0.2%)
Heart Attacks	38 (9%)
Strokes	32 (8%)
Unknown	333 (79%)
DCSI	0.39 (0.03)*
0	302 (72%)
=1	77 (18%)
≥2	43 (10%)
CCI	1.25 (0.02)*
No chronic condition	6 (2%)
One chronic condition	305 (72%)
Two or more chronic conditions	111 (26%)
Diabetic Retinopathy, n (%)	
No DR	305 (72%)
Unspecified NPDR	4 (1%)

(*Continued*)

Table 1 (Continued).

Characteristic	
Mild NPDR	34 (8%)
Moderate NPDR	32 (8%)
Severe NPDR	11 (3%)
PDR	31 (7%)
Unknown	5 (1%)
DME, n (%)	
Not Present/Not Mentioned	404 (96%)
Present	18 (4%)
Cataracts, n (%)	
Not Present/Not Mentioned	324 (77%)
Present	98 (23%)
Glaucoma or Glaucoma Suspect (includes Neovascular Glaucoma), n (%)	
Not Present/Not Mentioned	399 (95%)
Present	23 (5%)
Refractive Error, n (%)	
Not Present/Not Mentioned	183 (43%)
Present	239 (57%)
Visual Acuity at Presentation*	
Right eye	0.16 (SD 0.46) (20/28)
Left eye	0.14 (SD 0.43) (20/27)
Intraocular Pressure at Presentation*	
Right Eye	16.6 (SD 3.7)
Left Eye	16.4 (SD 3.7)
Prior anti-VEGF treatments, n (%)	
No	417 (99%)
Yes	5 (1%)
Prior PRP or focal laser, n (%)	
No	390 (92%)
Yes	32 (8%)
History of PPV, n (%)	
No	419 (99%)
Yes	3 (1%)

(*Continued*)

Table 1 (Continued).

Characteristic	
History of Cataract Surgery, n (%)	
No	413 (98%)
Yes	9 (2%)

Notes: * Mean (Standard Deviation).
Abbreviations: DCSI, Diabetes Complications Severity Index; CCI, Charlson Comorbidity Index; DR, diabetic retinopathy; NPDR, nonproliferative diabetic retinopathy; PDR, proliferative diabetic retinopathy; DME, diabetic macular edema; anti-VEGF, anti-vascular endothelial growth factor; PRP, panretinal photocoagulation; PPV, pars plana vitrectomy.

had a primary care physician (86%), and reported having type 2 diabetes mellitus (79%) for an average of 6.5 years. Few had self-reported non-ophthalmic complications from diabetes mellitus (<10%), and similarly few had a DCSI score of ≥2 (10%). Few patients had a CCI of at least 2 (26%). Most patients did not have any diabetic retinopathy (72%), but some had vision threatening diabetic retinopathy with proliferative diabetic retinopathy (PDR) (7%) or DME (4%). Patients also had other ocular conditions including cataracts (23%), glaucoma (5%), and refractive error (57%). At presentation, patients had good vision (better than 20/30) with normal intraocular pressure (<21mmHg). Very few patients had a self-reported history of prior intravitreal anti-VEGF treatments (1%), PRP or focal laser (8%), PPV (1%), and cataract surgery (2%).

After the first FDS visit, 9% of patients were referred for further retina specialty care. Eight percent of all patients received intravitreal anti-VEGF, 6% PRP or focal laser, and 4% PPV. (Table 2) Three percent of patients were referred to a cataract surgeon after the first visit, and 8% underwent cataract surgery during follow-up. Some were recommended to undergo

Table 2 Clinical Outcomes of Patients Seen Through the Free Diabetes Screening (FDS) Program from 2013 to 2023

Characteristic	N (%)
Referred to Retina	
No	384 (91%)
Yes	38 (9%)
Underwent anti-VEGF injection(s)	
No	389 (92%)
Yes	33 (8%)
Underwent PRP or focal laser	
No	395 (94%)
Yes	27 (6%)
Underwent PPV	
No	407 (96%)
Yes	15 (4%)
Referred to Cataract Surgeon	
No	409 (97%)
Yes	13 (3%)

(*Continued*)

Table 2 (Continued).

Characteristic	N (%)
Underwent Cataract Surgery	
No	390 (92%)
Yes	32 (8%)
Referred to Glaucoma or Recommended Additional Glaucoma Testing	
No	398 (94%)
Yes	24 (6%)
Underwent Glaucoma Surgery	
No	418 (99%)
Yes	4 (1%)
Glasses Prescribed	
No	403 (95%)
Yes	19 (5%)
Obtained Own Insurance	
No	418 (99%)
Yes	4 (1%)
Received Financial Assistance or Charity Funds	
No	363 (86%)
Yes	59 (14%)
Recommended follow-up	
≤ 8 weeks	57 (14%)
>8 to ≤ 20 weeks	27 (6%)
>20 to ≤ 32 weeks	48 (11%)
>32 to ≤ 52 weeks	269 (64%)
>52 weeks	3 (<1%)
Unknown	18 (4%)
Average Duration of Follow-Up (weeks)*	200 (SD 174)
Average Number of Office Visits*	10 (SD 17)
Lapse in Care	
No	213 (50%)
Yes	172 (41%)
Unknown	37 (9%)

Notes: * Mean (Standard Deviation).
Abbreviations: anti-VEGF, anti-vascular endothelial growth factor; PRP, panretinal photocoagulation; PPV, pars plana vitrectomy.

additional glaucoma testing or to see a glaucoma specialist (6%), and 1% ultimately underwent glaucoma surgery. Glasses were prescribed for 5% of patients. A few patients were able to obtain their own insurance (1%), while 14% received financial assistance or charity funds for more advanced ophthalmic care (14%). Most patients were recommended to follow up in 32 to 52 weeks (64%). Many (41%) had a lapse in care and did not follow-up as recommended after the first FDS office visit. Of patients who were recommended for further subspecialty care (N=49), 71% completed the follow-up visit. On average, patients continued follow-up at JHH ophthalmology for 200 weeks, or 10 office visits.

Discussion

Since its inception, the Free Diabetic Screening (FDS) clinic has provided much needed diabetic retinopathy screening and treatment for uninsured patients in Baltimore City and surrounding areas. The clinic helped a primarily non-Hispanic Black and Hispanic population with more than half non-English speaking patients. Twelve percent of patients presented with vision threatening diabetic retinopathy (including severe non-proliferative diabetic retinopathy, proliferative diabetic retinopathy, or DME). Nearly 10% of patients required further subspecialty retina care and underwent either intravitreal anti-VEGF injections, PRP or focal laser, or even surgical intervention with pars plana vitrectomy. Some patients also needed further ophthalmic care with cataract surgery and glaucoma surgery. This study highlights the need for strong integration between initial screening and downstream services as nearly 10% of patients require further subspecialty interventions and care.

There are significant disparities in diabetic retinopathy care and vision health. Race, ethnicity, and insurance coverage are particularly important predictors of vision care and outcomes.[7] Historically marginalized populations including non-Hispanic Black and Hispanic populations bear a greater burden of disease with higher prevalence of vision threatening diabetic retinopathy, worse vision outcomes, and lower preventive eye care utilization.[21–24] Similar trends are seen among patients who are uninsured compared to those who have insurance.[7] Social determinants of health are significant drivers of health disparities and inequities.[7,25] The population served by the FDS clinic has a high burden of adverse social determinants of health and face many barriers to care including access to health care and language barriers. Programs such as the FDS clinic are important ways to decrease some of those barriers and provide necessary eye care to vulnerable populations.

Despite the barriers, the rates of lapses in care in this population are lower than another study performed at the same institution among all patients with diabetes.[21] Among all comers with diabetes who sought diabetic retinopathy screening or treatment at JHH, 77.6% of patients had a lapse in care. Applying the same definition to this sample, only 41% of patients in the FDS clinic had a subsequent lapse in care after the initial visit. Furthermore, most patients who were recommended for further ophthalmic subspecialty care were able to receive the additional services. The lower rates of lapses in care likely was a result of lowering the barriers to care. We decreased the financial barrier of following up for care by having an on-site financial counselor to help patients apply for financial assistance, charity funds, or their own insurance. Financial assistance programs have been shown to increase receipt of high-value care.[26] It could be that we have robust interpretation services to lower language barriers and improve understanding of health conditions. It could be that we have access to on-site social workers to connect patients to community resources to address other adverse social determinants of health. It could also be that since there is a robust referral system in place from the community health centers, patients' primary care physicians help remind patients to follow-up with eye care.

The baseline characteristics of the patients seen through the FDS clinic are comparable to other studies of patients with diabetes. There was a higher prevalence of vision-threatening diabetic retinopathy (12%) compared to the general population (3.2% to 10.0%), but a similar prevalence of any diabetic retinopathy or diabetic macular edema (31% compared to 26.4% to 50.3%).[27,28] This population appeared have fewer diabetes complications and other comorbid conditions. We found a lower DCSI score compared to Medicaid beneficiaries with diabetes in Washington DC and a lower CCI score compared to a national cohort of patients with diabetes using the National Health Interview Survey.[25,29] These differences could arise because the majority of our patients are under the active care of a primary care physician and potentially have better managed diabetes and fewer comorbid conditions. Another possibility is that there is a significant degree of missing data since our data collection relies on self-reported complications and physician coded comorbidities.

Although there was a high rate of follow-up from the FDS program to further subspecialty care in Wilmer, one limitation is that we do not know how many patients were initially referred to the FDS program but never received care. If we extrapolate from the experience of community-based vision screening programs, as many as 50% do not follow-up for the definitive eye

examinations.[12,13,30–33] These abysmal statistics emphasize the potential value of integrating vision care into the primary care setting.[11] Integration of vision care in other contexts have been shown to improve health equity by reducing barriers to care, for example school-based vision programs partner with schools and eye care providers to offer vision care services within the school setting.[34,35] This model of integrating diabetic retinopathy screening in the primary care setting is now very possible with the advent of FDA approved artificial intelligence (AI) tools that can detect more referable diabetic retinopathy without the need for an eye care professional at the initial step. Even with integration, the pathways and collaborations between local community health centers and ophthalmology clinics still need to exist as patients who fail the initial screening still need definitive eye exams with eye care professionals.

There are several limitations to this study. Because we are only using data available in the EHR, we are unable to report outcomes of patients seen through the FDS program prior to 2013 or distinguish between patients who were new or established. We are also missing outcomes of patients who sought eye care elsewhere, not at our institution. Since most of these patients were referred to us by their primary care providers, we do not capture uninsured patients with diabetes who were not referred. There are limitations to using self-reported metrics, for example, there was a high degree of missing data for hemoglobin A1c measures. As mentioned previously, we could be underestimating the prevalence of diabetes complications and other comorbidities in this population due to limitations of secondary use of EHR data for research purposes.

Conclusion

The FDS clinic has provided essential diabetic retinopathy screening for the uninsured population in Baltimore City and has served as the entryway for many patients who need further ophthalmic care, including procedures and surgeries. Programs such as this one serve an important purpose. Even as the landscape of diabetic retinopathy screening changes and more of it can be done at the point of care with the primary care physician, strong referral systems with ophthalmology departments are still needed as patients who fail screening and need further care.

Funding

This project was supported by a K23 award from the NIH/NEI (award number K23EY033440) (CXC), the Wilmer Summer Scholars Program (PLN), and an unrestricted grant from Research to Prevent Blindness (Wilmer Eye Institute). Dr. Cai is the Jonathan and Marcia Javitt Rising Professor of Ophthalmology.

Disclosure

CXC: grant support from Regeneron. The authors report no other conflicts of interest in this work.

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