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Factors Influencing the Receipt of Diabetic Retinopathy Screening  
in a High-Risk Population

A Thesis Submitted to  
the Yale University School of Medicine  
in Partial Fulfillment of the Requirements for the  
Degree of Doctor of Medicine

By

Elizabeth A. Fairless

2020

## FACTORS INFLUENCING THE RECEIPT OF DIABETIC RETINOPATHY SCREENING IN A HIGH-RISK POPULATION.

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Diabetic retinopathy (DR) is among the leading causes of vision loss in the US, yet an estimated 50% of patients with diabetes do not receive recommended annual screening eye exams for reasons that are incompletely understood. Patients with diabetes and low socioeconomic status or who are racial/ethnic minorities are at increased risk for vision loss. Qualitative interviews were conducted with 30 patients with diabetes at a federally qualified community health center and a primary care clinic in New Haven, CT regarding factors influencing their use of screening exams. The interviews were recorded, transcribed, and analyzed line by line to identify themes. The themes were organized in a theoretical framework of factors influencing receipt of screening. Participants identified as black (16), white (5), Hispanic (5), Asian (1), and other/no answer (3). Twenty-eight had health insurance. Twenty-four had received an eye exam within in the past year, but one-third of participants reported they did not receive eye exam yearly. 415 comments were coded at 22 nodes under 7 broader themes and two overarching categories of individual factors and institutional/structural factors. Themes included vision status, competing concerns, emotional context, resource availability, in-clinic experience, cues to action, and knowledge about diabetes. Among the patients who had not received an eye exam within the past year, the cost of an exam, lack of insurance coverage, and lack of prompting by a health provider were among the reported reasons for not pursuing eye screenings. Many patients lack knowledge about diabetic retinopathy and the utility of preventative eye care. New strategies for engaging high-risk populations are necessary.

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## **Published work**

A portion of this work has been published in the Journal of Racial and Ethnic Health Disparities. Please see: Fairless, E. & Nwanyanwu, K. J. Racial and Ethnic Health Disparities (2019) 6: 1244. <https://doi.org/10.1007/s40615-019-00627-3>

## **Introduction**

### **I. The Diabetes Epidemic**

The number of people with diabetes mellitus in the United States and worldwide is rapidly expanding, leading some scholars to call diabetes the largest epidemic in human history [1]. Past predictions have underestimated the number of people worldwide who would develop diabetes. In 2000, the World Health Organization (WHO) predicted there would be 366 million people worldwide with diabetes by 2030, but by 2015 there were already 415 million people with the disease [1]. In the United States in 2015, there were an estimated 30 million people with diabetes, equaling 9.4% of the population [2]. The WHO estimates that 1.6 million deaths in 2016 worldwide were directly attributable to diabetes [3].

Diabetes mellitus is a chronic metabolic disease characterized by elevated blood glucose that over time causes macrovascular and microvascular damage throughout the body. Diabetes can lead to serious morbidity including cardiovascular disease, stroke, kidney disease, and limb amputations. Type 2 diabetes, characterized by insulin resistance, is the most common type. Type 1 diabetes, also known as juvenile diabetes, is characterized by impaired insulin production. The risk factors for type 2 diabetes are heterogenous. Obesity, inactivity, and poor diet have demonstrable links to an increased risk of diabetes, and correspondingly, lifestyle interventions aimed at addressing these factors have been shown to reduce the incidence of diabetes [3,4]. However, other non-

modifiable factors such as genetic susceptibility and epigenetic changes are increasingly being recognized [1,4,5].

There are disparities in who is affected by diabetes. According to the Centers for Disease Control, in the United States in 2015 the prevalence of diabetes was 12.7% for non-Hispanic blacks, 12.1% for Hispanics, 8% for Asians, and 7.4% for whites [2]. American Indians/Alaska Natives had over double the prevalence (15.1%) compared to whites. Indigenous people are disproportionately affected by diabetes, with some Aboriginal Australian communities and Native American communities having the highest rates of diabetes in the world [1]. Black, Hispanic, and Native American people are also more likely than their white counterparts to suffer complications from diabetes, such as diabetic retinopathy [6].

## **II. Diabetic Retinopathy**

Diabetic retinopathy (DR) is a microvascular and neurodegenerative complication of diabetes. Chronic hyperglycemia triggers a cascade of biochemical changes within the retina that include increased inflammation, oxidative stress, and advanced glycation end-products that result in vascular damage and neuroretinal compromise [7]. The initial disease stages are a spectrum of non-proliferative retinopathy characterized by vascular endothelial injury within the blood vessels of the retina. This vascular damage leads to microhemorrhages, microaneurysms, retinal infarcts, or leakage of lipids and plasma proteins into the retina [5]. If this leakage occurs in the macula, it can cause macular edema and vision loss. Over time, retinal non-perfusion can trigger growth of abnormal

retinal blood vessels, a state termed proliferative diabetic retinopathy. This neovascularization can extend into the vitreous, putting traction on the retina and leading to detachment. In addition, the fragile, abnormal vessels easily hemorrhage. Both of these complications can lead to severe vision loss [5,8]. The presence of DR heralds systemic vascular complications: it is associated with double to triple the risk of stroke, coronary artery disease, and heart failure [9–11].

One meta-analysis estimates that there are 93 million people worldwide with DR, including 28 million with vision-threatening DR [12]. In the United States, diabetic retinopathy is among the leading causes of vision impairment and blindness [5]. The prevalence of DR in patients with diabetes is approximately 30% [13]. DR can occur in both type 1 and type 2 diabetes. Nearly all patients with type 1 diabetes eventually develop retinopathy and 50-60% of patients with type 2 diabetes develop some degree of retinopathy during their lifetime [8,13]. Up to 21% of patients with type 2 diabetes already have retinopathy at the time of their first diagnosis with diabetes [8]. One in ten people with diabetes will develop a vision-threatening form of DR [14].

There are a number of risk factors for DR that are well-documented, including poor glycemic control, poor blood pressure control, and a longer duration of diabetes [12]. However, these factors only account for some of the risk of developing DR, and much of the remaining risk is not well understood [15]. Socioeconomic factors may have a profound effect the health of patients with diabetes and their ability to influence the aforementioned risk factors [16]. Socioeconomic status can potentially affect many facets

of a patient's experience, from access to medical care, community resources, and social support, to knowledge about diabetes, communication with providers, and ability to adhere to treatment plans [16]. The environment in which a patient lives may influence their risk for diabetes and its complications. For example, whether a patient lives in a neighborhood that is safe, walkable, and with access to healthy foods [17].

Paralleling the racial disparities in the prevalence of diabetes, racial and ethnic minorities are also at increased risk of developing DR and vision-threatening forms of DR [2,18–20]. In one study that examined the third National Health and Nutrition Examination Survey (NHANES III) data, non-Hispanic Blacks were found to have a prevalence of DR 46% higher than non-Hispanic Whites, and Mexican-Americans were found to have a prevalence of DR 84% higher [20]. For Native Americans, there are few studies of DR rates. Prevalence of DR in this population has been documented as between 38-59% in reports from the 1980s and 1990s, whereas a newer study places the prevalence of DR at 20% [21].

### **III. Prevention and Treatment of Diabetic Retinopathy and the Role of Screening**

Blindness from diabetic retinopathy is largely preventable, yet one in ten people with diabetes will develop vision-threatening DR [14,22]. Diabetic retinopathy, like many eye diseases, has no early symptoms or warning signs [5]. Many patients with DR are unaware they have the condition: one study of NHANES data from 2005-2008 found that of patients with DR evident on fundus photographs, only 26.1% answered yes to “Have you been told by a doctor that diabetes has affected your eyes or that you

had retinopathy?" [23]. Of patients with diabetic macular edema, only 44.7% answered yes [23].

Intensive glycemic and blood pressure control can significantly reduce the risk of developing DR and slow its progression [24,25]. A 1% reduction in glycated hemoglobin (HbA1c) can reduce the risk of retinopathy by approximately 40% [5,7,24]. Tight blood pressure control (< 150/85 mm Hg) can reduce the risk of DR progression by approximately one-third [25]. Treatments to reduce vision loss in proliferative DR include panretinal laser photocoagulation or intravitreal anti-vascular endothelial growth factor (VEGF) therapy, each aimed at reducing the pro-angiogenic signaling that leads to neovascularization in the retina [5]. Anti-VEGF therapies can also be used to treat diabetic macular edema, as can intraocular steroids in some cases [5]. In patients with a tractional retinal detachment or persistent vitreous hemorrhage, surgical removal of the vitreous (vitrectomy) may be necessary [7]. These treatments for DR are highly effective and can reduce severe vision loss by 50- 94% [26,27].

Early detection of DR through routine eye examinations and early treatment is key to prevent major vision loss [5,28]. The rationale for screening for DR is clear: DR is highly prevalent within a distinct group of people (patients with diabetes), early disease is asymptomatic and can be easily detected with screening methods, and there are effective treatments that can reduce disease burden [5]. Screening is also a cost-effective intervention, saving approximately \$100 million federal dollars annually [26,29].

Screening guidelines recommend that patients with type 2 diabetes be screened for DR with a comprehensive dilated eye examination at the time of their diagnosis and annually thereafter. Adult patients with type 1 diabetes should be screened annually after they've had the disease for greater than five years [8,30]. Although screening with a clinical examination by an ophthalmologist would be ideal, there are logistical and resource limitations to screening every patient with diabetes in this manner. The invention of non-mydratic digital retinal photography offers a new solution large-scale DR screening. Retinal photographs can be taken in a primary care setting and transmitted to reading centers where they can be evaluated for DR, and appropriate referrals to an ophthalmologist can then be made [5].

#### **IV. Utilization of Screening for Diabetic Retinopathy**

Despite the importance of annual screening for DR in order to receive early treatment and prevent vision loss, it is estimated that non-adherence to screening is high. Various studies estimate that between 35-50% of patients with diabetes do not receive necessary screening [22,26,31,32]. There are a number of factors that have been shown to be associated with receipt of appropriate screening, or eye care utilization more generally. These include, but are not limited to, socioeconomic status, insurance status, access to care, and race/ethnicity.

*Socioeconomic status.* Zhang et al. found that patients with any age-related eye disease (age-related macular degeneration, cataract, diabetic retinopathy, or glaucoma)

were less likely to have had an eye examination in the last year if they had a lower income or less than a high school education [33]. Chou et al. found similar disparities along income and educational lines using data from the 2006-2009 Behavioral Risk Factor Surveillance System [34].

*Insurance status.* A study by Lee et al. used data from the National Health Interview Survey to examine eye care utilization. For people without insurance, eye care utilization rates of 14%, 24%, and 36% were found for people with no, some, or severe visual impairment respectively. For those with insurance, utilization rates were found to be significantly higher at 34%, 54%, and 60% for the same degrees of visual impairment, respectively [35]. A study by Shi et al. using data from the Medical Expenditure Panel Survey Household Component (2002–2009) including the Diabetes Care Survey found that insurance was the most significant factor for receiving an eye examination, but noted racial/ethnic disparities even among insured patients [36]

*Access to care.* People living in rural areas have been shown to have lower rates of eye care utilization [37]. Native Americans have well documented barriers to access and utilization of healthcare, even if they reside in urban areas [38].

*Race/ethnicity.* Racial/ethnic minority status has consistently been shown to be associated with decreased utilization of eye examinations and decreased access to eye care [26,36,39–41]. Lee et al found lower rates of eye care utilization among certain Hispanic subgroups: Mexican Americans and Cuban Americans [35]. In the SEE

Project, a population-based survey of persons aged 65-84 in Maryland, only half of black participants reported seeing an eye doctor in the past year, compared to 69% for white participants [42]. In one study at a large Indian Health Service clinic, adherence to DR screening was 50%, although this was able to be increased to 75% with implementation of a digital retinal imaging system in the primary care setting [43].

## **V. Purpose of Current Study**

A review of the literature has demonstrated that the patient populations with greater disease burden from diabetic retinopathy, in particular racial/ethnic minorities and those with low socioeconomic status, are also the same patient populations less likely to get necessary screening examinations. In other words, the patients that need screening the most are less likely to receive it. As detailed above, there are a complex network of biologic, socioeconomic, and environmental factors that influence the risk of developing diabetes and diabetes-related complications, and influence screening utilization. Understanding and intervening upon these factors is key to improving outcomes for patients with diabetes.

Despite a wealth of data indicating disparities in DR screening utilization, there remains relatively few studies that examine patient perspectives on screening, especially from patient populations at high risk for vision loss, namely racial/ethnic minorities and those with low socioeconomic status. Previous studies have used focus groups to investigate the receipt of eye care more generally and have shown that patients' perceived barriers to eye care include cost, insurance status, transportation, lack of communication

with the physician, lack of trust, burden of systemic disease, absence of symptoms, and no perceived need for examination [20,28,44,45]. Elam and Lee conducted focus groups with high risk patients in North Carolina and found that a lack of trust in their provider or in the healthcare system was the most common barrier cited among under-utilizers of eye care [44]. Alexander et al. conducted focus groups with randomly selected participants from each racial group and reported participants generally lacked knowledge about eye health and that few were counseled by their primary care providers about eye care [28]. Fisher et al. conducted focus groups about adherence to dilated eye exams with both patients with diabetes and with physicians in internal medicine and ophthalmology. The authors report that a lack of awareness of insurance benefits was the most common barrier identified by patients, whereas a lack of education about the importance of eye exams was the most common barrier reported by physicians [45].

Research that solicits the experiences of patients with diabetes at higher risk for vision loss, namely racial and ethnic minorities and patients with low socioeconomic status, is necessary to understand how this unique population engages with diabetic eye care. Understanding the factors that influence receipt of eye care by high-risk patients with diabetes is essential for the design of effective interventions that increase screening utilization and decrease the burden of DR. In this study, we present the findings from individual qualitative interviews with high-risk diabetic patients from a federally qualified community health center about their use of DR screening, and propose a theoretical framework to characterize the factors that influence receipt of diabetic eye care in this population.

## Methods

### I. Qualitative Methods and Their Utility

Qualitative research is research that attempts to answer why or how a phenomena occurs using non-numerical data. It typically uses inductive rather than deductive reasoning and seeks to generate rather than test hypotheses [46]. Qualitative methods may be useful in describing a range of phenomena, as Curry et al describes:

“Although quantitative methods have historically been the primary approach in health sciences research, many contemporary phenomena in health and health care are difficult, if not impossible, to measure using quantitative approaches alone. Examples include complex and dynamic social processes; beliefs, values, and motivations that underlie individual health behaviors; and social, political, economic, and organizational contexts relevant to health...The goal is to produce depth of understanding, and perhaps generate hypotheses regarding a phenomenon, its precursors, and its consequences [46].”

Qualitative methods offer a way to explore the diverse experiences of patients, particularly from at-risk communities [14–16][46]. In qualitative research, data is typically collected through observational or descriptive methods, such as one-on-one interviews or focus groups, using purposeful sampling of individuals with direct experience or knowledge of the topic under study. Data is analyzed in an iterative manner in which data is collected, coded, and interpreted. The products of analysis in qualitative data often include recurrent themes, hypotheses, or conceptual models [46].

In this study we sought to understand the factors influencing DR screening utilization by patients from racial/ethnic minority groups and low socioeconomic status. The complexity of this phenomena makes qualitative methods an ideal method to gain

understanding about the personal choices and factors that influence individual patient's decision-making.

In this study, the data was gathered and analyzed in accordance with the principles of grounded theory, a systematic methodology in which theories are developed through inductive reasoning [47]. As qualitative data is reviewed, repeated concepts are tagged with “codes,” and refined as more data is collected and codes are re-reviewed. Then, codes can be grouped within concepts and larger categories that may become the basis for a new theory. This allows the researcher to “develop a theoretical account of the general features of a topic while simultaneously grounding the account in empirical observations or data [48].”

## **II. Setting**

The institutional review board of Yale University approved the study protocol and exempted it from continued oversight. Discussion with leaders of local community health organizations through the Yale Center for Research and Engagement informed the study design. The mission of the center is to “facilitate the collaboration of community organizations with trainees to design and implement research projects on topics identified as priorities by the New Haven community [49].”

Semi-structured, qualitative interviews were conducted with patients with diabetes at the Cornell Scott Hill Health Clinic, a federally-qualified community health center (FQHC) in New Haven, CT, and its satellite clinics in New Haven and nearby

Ansonia, CT. Additional interviews were conducted at the Yale Primary Care Clinic in New Haven, CT. The FQHC serves a patient population that is 69% Black or Latino and 64% of patients have income below the poverty line [50]. The Yale Primary Care Clinic serves a similar patient population. The interview settings included primary care clinics, a diabetes/wellness education center, and an on-site eye clinic.

### **III. Participants**

A convenience sample of English-speaking patients with diabetes was recruited by approaching patients before or after their appointments. Author E. Fairless recruited 26 of the 30 participants, and A. King, also a medical student, recruited the remaining 6. All participants gave written informed consent and consent to be audio-recorded. No compensation was given to the first 24 participants, the 6 final participants received \$20 gift cards for their time. Only patients with a diagnosis of diabetes for at least one year were included. Self-reported participant demographic information was collected, including age, gender, race/ethnicity, insurance status, time since diagnosis with diabetes, time since last eye exam, and frequency of eye exams.

### **IV. Participant Interviews**

Semi-structured qualitative interviews were conducted in English with participants by in a one-on-one setting. Author E. Fairless conducted 24 out of 30 interviews, and A. King conducted an additional 6 interviews. Based on the principles of grounded theory, the purpose of these interviews was to generate hypotheses rather than to test a predetermined hypothesis [46,47,51]. Participants were asked open-ended

questions about their experiences with eye exams, what factors influenced their decision to pursue or not to pursue an eye exam, and any barriers they might have faced to accessing eye care. Author E. Fairless developed the interview guide that was used to direct questioning (Table 1).

<b>Interview Guide</b>
When was the last time you had an eye exam? How often do you get eye exams?
Can you tell me about your experience the last time you had an eye exam?
What made you decide to get an eye exam? What motivated you to go?
At the time that you were diagnosed with diabetes, what, if anything, were you told about eye care?
Have you ever been told by a healthcare provider that diabetes can affect your eyes?
Has anything ever prevented you from having an eye exam? Have you ever cancelled or not shown up to an eye exam appointment? If so, why?

Table 1. Interview guide.

Follow-up questions were used to encourage participants to elaborate as necessary. The interview guide was periodically re-evaluated and rephrased by the author using a reflection checklist as necessary to ensure clarity and internal validity [51].

**V. Data Analysis**

The interviews were recorded using a H4next Handy Recorder (ZOOM corporation.), transcribed verbatim with Trint online transcription service (Trint Ltd.), and analyzed with NVivo software, version 11 (QSR International.) The author E. Fairless transcribed the 24 interviews she conducted, and A. King transcribed the 6

interviews she conducted. The transcripts were analyzed according to the concepts of grounded theory [47]: the transcripts were reviewed line by line and codes were created to define concepts inductively from the data. Coded text was reviewed to identify overarching themes and codes were refined as appropriate until a final comprehensive coding framework was reached. All interviews were reviewed and coded by author E. Fairless. Dr. K. Nwanyanwu reviewed the transcripts and coding.

This coding framework became the basis of a theoretical model of factors affecting screening utilization. Author E. Fairless and Dr. K. Nwanyanwu developed the theoretical model. The broader themes of the coding framework were organized in a socio-ecological model, which situates health behaviors in the context of individual (e.g. attitudes, behaviors), social (e.g. social networks, social support), and structural (e.g. access to care) factors [52,53].

## Results

### I. Participant Demographics

A total of 30 people participated in the study. The median age of participants was 57.3 (range 35 –73). Fifteen participants identified as female and 15 as male. Participants identified as black (16), white (5), Hispanic (5), Asian (1), and other/declined to answer (3). Twenty-eight participants had health insurance. Twenty-four had received an eye exam within in the past year, but one-third (10) of participants reported they did not receive eye exam yearly. Half of the participants had had diabetes for over 10 years. The demographic information is summarized in Table 2.

<b>Demographic Information</b>	<b>N = 30</b>
<b>Age, median (range)</b>	57.3 (35-73)
<b>Gender, No. (%)</b>	
Female	15 (50)
Male	15 (50)
<b>Race/ethnicity, No. (%)</b>	
Black	16 (53)
White	5 (16.6)
Hispanic/Latino	5 (16.6)
Asian	1 (3.3)
Other/declined to answer	3 (10)
<b>Insurance Status, No. (%)</b>	
Insured	28 (93)
Uninsured	2 (7)
<b>Most Recent Eye Exam, No. (%)</b>	
Within previous 12 Months	24 (80)
Not within previous 12 months	6 (20)
<b>Eye Exam frequency, No. (%)</b>	
Annually or more frequently	20 (66)
Less frequently than annually	10 (33)
<b>Duration of diabetes, No. (%)</b>	
1 to 5 years	12 (40)
6 to 9 years	3 (10)
10 years or longer	15 (50)

Table 2. Participant demographic information.

## **II. Interview Comments**

415 interview comments were coded at 22 nodes under 7 broader themes. These themes were further classified into either individual factors or institutional and structural factors based on a socio-ecological model. Individual factors included the themes of vision status, competing concerns, and emotional context. Institutional and structural factors included the themes of resource availability, in-clinic experience, cues to action [54,55], and knowledge-creating experiences. This coding framework became our theoretical model of the factors affecting utilization of eye examinations in our patient population (Figure 1).

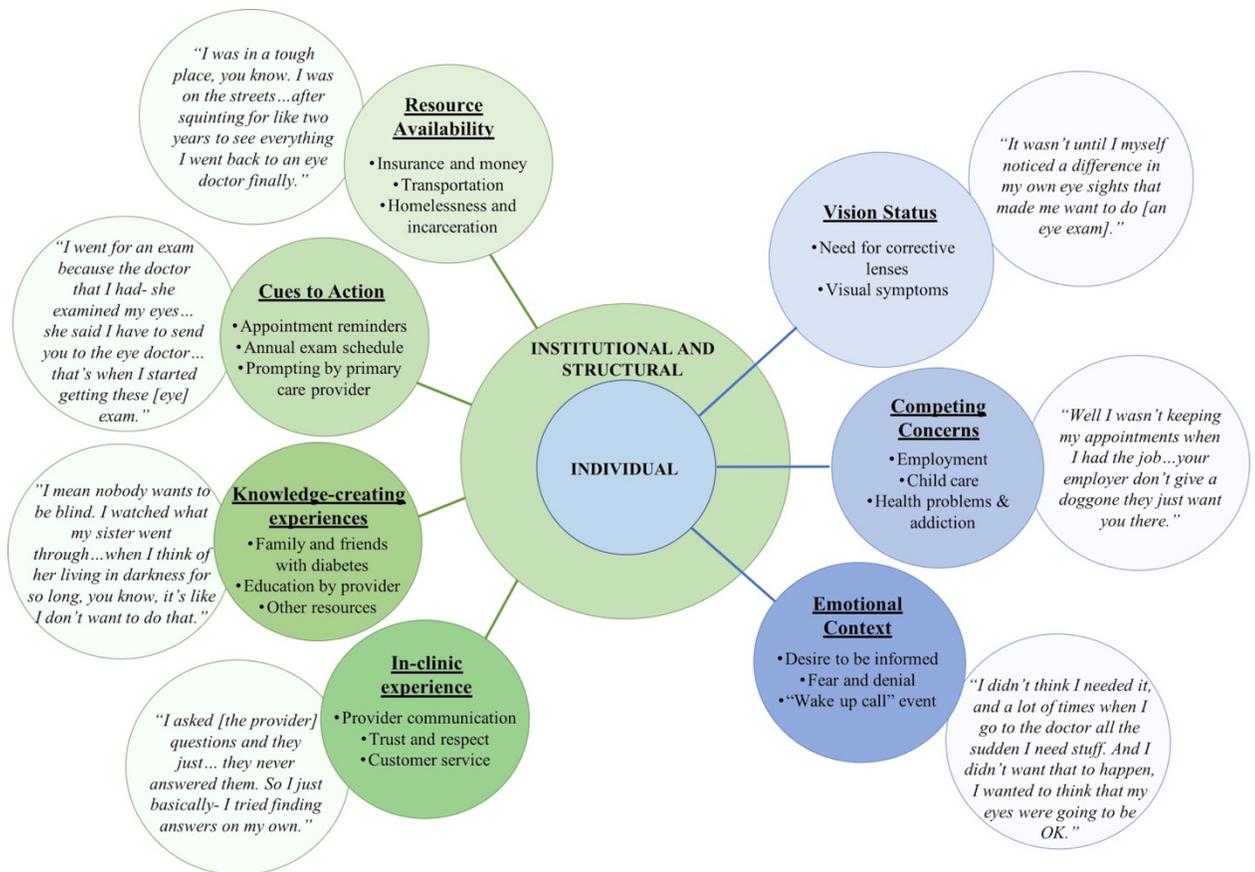


Figure 1: Theoretical framework of factors affecting utilization of eye exams in patients with diabetes, and representative quotes from participants.

**Individual factors.** Individual factors included vision status, competing concerns, and emotional context. Individual factors encompassed factors that were either specific to a patient, such as attitude and behaviors, health issues, or were factors closely relating to their daily lives.

**Vision status:** Many participants indicated that changes in their vision or a need for updated corrective lenses was the primary factor that prompted them to seek an eye examination. In the absence of any visual symptoms, some participants saw no reason

to obtain an eye exam. One participant with diabetic retinopathy recalled not seeking an eye exam until his vision was affected by a retinal hemorrhage: “[The doctors] started saying ‘You gotta see an eye doctor.’ ...[I] blew off the first appointment, and then I was half-blind, so I saw the doctor properly.” Another participant stated ‘It wasn’t until I myself noticed a difference in my own eyesight that made want to [get an exam.]’” Many participants stated that updating their glasses each year was an independent motivating factor to get exams regardless of their need for DR screening. One participant with gout recalled: “I was struggling to get here [to the eye clinic]. I wasn't gonna come. I was going to call because of my foot, because I can't put pressure on my foot... I made it here, I struggled. Again, because I want some new glasses.”

**Competing concerns:** Participants expressed that competing concerns such as other health problems, childcare responsibilities, struggles with addiction, and employment scheduling influenced their ability to get regular eye exams. One participant recalled that her previous job schedule kept her from making health appointments: “I canceled a few appointments over the last three months because I had a new job. So now I'm going to work on getting all those appointments rescheduled and done because I'm not working now.”

**Emotional context:** Some participants expressed fear or hesitation about receiving eye exams because they were concerned that they would receive bad news about their health or because they wanted to avoid painful procedures. One participant stated: “I didn't think I needed [an eye exam]. And a lot of times when I go to the doctor

*all of the sudden I need stuff. And I didn't want that to happen, I wanted to think that my eyes were going to be OK.*” In contrast, others indicated that a desire to be informed about their health motivated them to seek exams. Some participants mentioned having a major health event, such as a hospitalization, that was a “wake up call” that motivated them to be proactive about accessing healthcare.

**Institutional and structural factors.** Institutional and structural factors that influenced receipt of eye care included resource availability, in-clinic experience, cues to action, and knowledge-creating experiences. Institutional and structural factors were defined as factors relating to the patient-provider relationship, the healthcare system, or larger social structures.

**Resource availability:** Insurance status and the cost of an eye exam were important factors for participants, particularly among those that had not received an eye exam in the last year. One participant describes not returning to the eye clinic because of lack of funds: *“I didn't have the money to pay for the amount of money [the eye clinic] said that I had to pay... I know that [an exam] was important. But I – as a single parent with three kids – I mean, seeing was not a priority at that time.”* Another patient reported that despite ongoing eye symptoms, he did not get an exam because *“it was a financial thing... I didn't have the money for it.”* Some participants reported being uninsured as a barrier to receiving eye care. One participant reported that *“I was doing like a yearly exam...but I haven't got one since I haven't had any insurance maybe 5 years.”* She further elaborated that despite prompting by her doctor to get an eye exam,

she could not find an eye clinic that would see her without insurance coverage. She reported her income put her a coverage gap where she made too much to qualify for state Medicaid, but not enough to afford her employer's health insurance. Several participants commented that they received eye exams only every two years, as they believed that annual exams were not covered by their insurance (however, medically necessary eye exams for patients with diabetes are typically covered annually by most insurance plans.)

Access to transportation to the eye clinic was another important factor, though most participants reported that they had no issues with finding adequate transportation. Additionally, some participants reported that experiencing homelessness or being incarcerated prevented them from seeking eye exams. One participant described not having access to eye care while incarcerated: *"I was in prison, so they didn't- they don't do all that [eye care]. So when I came home I got everything done."*

**In-clinic experience:** Participants reported that communication with their healthcare providers influenced their use of eye care either positively or negatively. One patient with a positive experience said, *"The diabetes has not affected me so far from what [the doctor] tells me when she sees me in here [at the eye clinic.]...I think the process works. They are on top of it every year when they go in they are doing the full work up on me and letting me know that nothing's happening so far."* Another participant spoke about conflicting information from her providers:

*"I'm still having these blurred visions as of today, and- but they're saying that my eye vision is OK... I don't really know what to think of it because this [doctor]*

*saying that and this one is saying that, but I still have the blurry vision from time to time...what can I do about it? And this one's saying it's OK, this one's saying I have a trace of cataract but don't worry about it."*

Other participants described instances of clear miscommunication: one participant who needed surgery on his retina mistakenly believed that the doctors would remove his eye to perform the surgery. Participants reported that feeling respected by their eye doctor and having good interactions with clinic staff were also factors that influenced their experience with eye care.

**Cues to action:** Participants reported that being prompted by a primary care provider to receive an eye examination played a large role in their decision to seek an eye exam. One participant said: *"If the doctor would suggest me have an eye exam, regardless of whether I had diabetes or not I would have followed out the instructions. If I was on my own I don't think I would have."* This is exemplified by the experience of another participant who reported being told about the importance of an eye exam and appropriately referred:

*"[My doctors] told me you have to get [an eye exam] done because we want to see if there's any damage done by you having diabetes and high blood pressures, so they can both damage your eyesight. And that's why they referred me from here. They did the appointment and everything, and then all I had was a phone call and come in."*

In contrast, another participant felt that eye care was not emphasized by his primary care provider, which delayed his seeking an eye exam:

*"I should have been scared into going [to the eye doctor] a little bit, or at least, you know, given some kind of explanation as to what [diabetic retinopathy] was. It seemed to be at the bottom of the list. I have a lot of side effects from diabetes like neuropathy and, you know. But my eyes for some reason seemed to be at the bottom of the list of the importance layer when I talked to doctors."*

Participants also reported that following an annual exam schedule and getting appointment reminders were useful prompts to seek eye exams.

**Knowledge-creating experiences:** Several participants reported experiences that informed them about diabetes' effects on the eye and motivated them to obtain eye examinations. Some participants learned about diabetic eye disease from their provider, while others learned from family and friends with diabetes. Some participants reported knowing people who had become blind from diabetic eye disease. For one man, this was a powerful motivator to get exams: *“One of my sisters lost her eyes [because of diabetes]...I watched what my sister went through... when I think of her living in darkness for so long...I don't want to do that if I don't have to.”*

In contrast, some participants appeared to be unaware or misinformed about diabetic retinopathy: one participant believed that cataract surgery protected him from diabetic eye disease: *“The diabetes... won't affect me because I've got it - I got lenses in my eyes. So...it don't really affect my vision like it do some people...They said I could go get an eye exam, but what am I getting the eye exam for? I already see long distance....”* Some participants stated that they had never been told by their doctor that diabetes could affect their eyes or that they needed a diabetic eye examination. One participant states: *“I don't think as far as being diagnosed with diabetes...I don't recall no one telling me [about eye exams], and I'm being completely honest.”*

## **Discussion**

Diabetes is a burdensome disease that places patients, especially racial/ethnic minorities and people with low socio-economic status, at risk of developing diabetic retinopathy and vision loss [26,36,39–41]. Many patients at high risk of developing DR are not receiving the annual screening examinations necessary to identify DR and intervene before preventable vision loss occurs [18,22,26]. We have proposed a theoretical framework of factors that influence receipt of DR screening based on qualitative interviews with high-risk patients with diabetes. These factors are complex and the results of this qualitative study add depth and detail to our understanding. The participants in this study spoke about the emotional context behind their disease, their satisfaction or frustration with their providers' communication, and their experiences balancing the demands of their lives with their health issues and available resources.

The results of our interviews indicate a gap in many patients' understanding of DR and the utility of preventative eye care. Although DR is asymptomatic in its early stages, many participants did not seek eye care unless they noticed changes in their vision or they did not perceive a need for annual eye exams if they felt their vision was good. Many participants stated that their need for glasses or contacts was a main motivating factor to pursue a yearly eye exam. It is unclear whether these participants would still be receiving eye exams to screen for DR if they did not already visit the eye doctor for corrective lenses. Participants exhibited a range of knowledge about DR, with some participants understanding that blindness can result from DR and others only expressing that they knew vision could be affected in some way.

Our results reinforce the important role primary care providers play in educating patients about DR and prompting them to stick to annual examination schedules. Many participants identified their provider's prompting as a leading reason they sought an eye exam, even if they did not fully understand the role of an eye exam in their diabetes care – though education by a provider about DR was demonstrably positive too.

Unfortunately, several participants reported never being told by their primary care provider about diabetes' effects on the eye and the need for eye exams, or reported that they felt eye exams were not emphasized by their provider. Patients with diabetes often have complex medical needs, other comorbidities, and often other specialists they must see on an ongoing basis, such as podiatry and dentistry. It is therefore not surprising that primary care providers often have little time during an appointment to discuss eye care. The chronic care model is a framework that has been shown to improve the quality of diabetes care [56]. It includes, among many things, an expanded role for health care teams and electronic health record tools that can help coordinate delivery of care, both of which may be useful to primary care providers taking care of the complex needs of patients with diabetes.

Our results also show that insurance continues to be an important factor influencing patients' receipt of eye care, with lack of insurance being a frequently cited barrier among patients who had not received an eye exam in the past year. In addition, the overlapping benefits of vision insurance and medical insurance are a source of confusion for some patients that may negatively impact screening adherence [55].

Physicians and other healthcare professionals must continue to advocate for policies that expand insurance coverage.

Many of the factors influencing the receipt of DR screening identified by this study, such as insurance status, communication with physicians, burden of systemic disease, absence of visual symptoms, and no perceived need for examination, align with barriers identified by previous literature about receipt of eye care more generally [18,28,44]. There are several limitations to our study. Though this study drew participants from a population that is at higher risk for screening non-adherence, patients who had indeed received an eye exam within the past year were over-represented in this study. Nonetheless, these participants provided valuable insights on factors that facilitated DR screening, and many commented on periods in the past when they were unable to receive eye care. Patients who have not been screened may be less likely to seek primary care as well, and were therefore difficult to capture in this study design. Finally, by nature of being a qualitative study, our data does not allow us to quantitative comparisons about any of the factors affecting screening that were identified.

New, innovative approaches are necessary to increase awareness about DR, expand access to screening, and increase screening utilization. Telemedicine provides one such approach, in which digital retinal photographs are taken and sent to reading centers for interpretation. Telemedicine can provide high diagnostic accuracy, increase rates of DR screening, and can be an important tool in settings that serve minority patient populations [58–61]. In addition, electronic health records are a tool that can generate

screening reminders and improve communication and coordination between primary care providers, eye care providers, and patients to facilitate screening [62]. Finally, federally qualified community health centers (FQHCs) are well-positioned to address the eye care disparities in high risk patient populations, but further integration of eye care services is necessary [63,64]. The FQHC in this study had an on-site comprehensive eye clinic, making it among the only 29% of FQHCs that provide on-site dilated eye examinations for patients with diabetes [63,65].

Further research is essential to furthering our understanding of underutilization of care, barriers to care, and factors that facilitate access. The findings reported here may provide the basis for interventions to increase screening utilization in high-risk populations. Improving the utilization of DR screening by high risk populations is a critical imperative given the disproportionate burden of DR and preventable diabetes-related blindness faced by these populations.

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