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Barriers to diabetic retinopathy screening in public healthcare in northeastern Brazil

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ABSTRACT

Purpose: This study aimed to identify barriers to diabetic retinopathy screening among a socioeconomically vulnerable urban population in northeast Brazil. **Methods:** A cross-sectional study was conducted during a diabetic retinopathy screening campaign at primary healthcare units. Ninety-five patients with diabetes underwent retinal examinations and completed a structured interview. Clinical, demographic, and socioeconomic data were collected. **Results:** The study population consisted predominantly of older adults (mean age: 60.7 ± 10.5 years), with a high prevalence of type 2 diabetes (99.0%) and low educational attainment. Most participants were economically inactive (81.1%) and reported low income (83.2%). Diabetic retinopathy and maculopathy were highly prevalent, affecting 50.0% and 22.9% of participants, respectively. Longer duration of diabetes was significantly associated with greater awareness of diabetic retinopathy (p=0.035), higher HbA1c levels (p<0.001), and increased prevalence of diabetic retinopathy (p=0.013) and maculopathy (p=0.002). Notably, 33.3% of participants reported difficulties attending medical appointments for diabetes management. In addition, 78.1% experienced challenges scheduling ophthalmologic evaluations, and 76.3% reported that no ophthalmologist was available in their city through the public healthcare system. Financial constraints also limited adherence to recommended dietary practices (90.4%) and impaired glycemic control, with more than half of participants reporting difficulty maintaining target glucose levels. **Conclusion:** Major barriers to diabetic retinopathy screening included limited awareness of the importance of screening, financial hardship, and transportation challenges. Targeted educational initiatives and structural interventions such as expanded screening programs incorporating telemedicine and subsidized transportation—may improve screening adherence among vulnerable populations.

KEYWORDS: Diabetic retinopathy; Mass screening; Health services accessibility; Health knowledge, attitudes, practices; Socioeconomic factors

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INTRODUCTION

Diabetic retinopathy (DR) is the most common ocular complication of diabetes mellitus, affecting approximately 30%–40% of individuals with diabetes[1]. The prevalence may reach up to 75% among individuals with more than 20 yr of disease duration[2]. Globally, DR currently affects more than 100 million people, and this number is projected to increase to approximately 190 million by 2030[2,3]. The prevalence of diabetic macular edema—a frequent complication of DR that requires ongoing treatment with costly anti-angiogenic agents to prevent vision loss—is also expected to rise, potentially affecting 24 million individuals by 2030[1].

Diabetic retinopathy often develops during the working years and remains the leading cause of visual impairment among the working-age population[1,2]. The estimated direct medical cost of treating a patient with DR is approximately $40,825 over 5 yr[4], excluding indirect costs such as productivity loss.

Several factors are associated with the progression of DR, including poor glycemic control, systemic hypertension, longer duration of diabetes, dyslipidemia, and microalbuminuria[5]. Screening programs facilitate early detection and timely intervention, including retinal photocoagulation and optimization of systemic disease management, thereby preventing severe visual complications[6].

However, numerous barriers hinder the implementation of effective DR screening programs, many of which are associated with socioeconomic conditions and the increasing prevalence of diabetes[7]. These barriers include limited patient knowledge, negative attitudes toward screening, low motivation, shortages of healthcare professionals, insufficient training programs, limited retinal imaging infrastructure, and high healthcare costs[8-12]. Such challenges are particularly pronounced in developing countries and in resource-limited regions of Brazil[13-17].

Previous studies conducted in Brazil have identified additional obstacles to DR screening, especially in underserved areas. Many individuals with diabetes have limited knowledge of the disease and its impact on ocular health and are often unaware of their right to specialized care within the public healthcare system[13,15]. Furthermore, primary healthcare services exhibit significant structural inequalities across the country's macroregions, including inadequate professional training, lack of equipment, and limited effectiveness of health education initiatives[14,17]. A substantial proportion of individuals with diabetes also remain undiagnosed, untreated, or inadequately controlled, contributing to the underdiagnosis and silent progression of DR[16]. These factors underscore the need for integrated public health policies that address regional disparities and promote more effective strategies for screening and patient education in ocular health.

Given these challenges and the marked regional disparities in healthcare access for patients with diabetes, the present study aimed to evaluate the principal barriers to DR screening in a metropolitan region surrounding Aracaju, Sergipe, in northeastern Brazil.

METHODS

This cross-sectional observational study involved interviews with individuals diagnosed with diabetes mellitus. Participants were recruited consecutively from those who attended a DR screening activity and agreed to participate in the study. The study protocol was approved by the Ethics Committee of the Universidade Federal de Sergipe (CAAE: 64677723.0.0000.5546) and conducted in accordance with the principles of the Declaration of Helsinki. All participants were informed about the study objectives and procedures and provided written informed consent prior to participation.

Eligible participants included individuals of either sex aged 18 yr or older with a diagnosis of type 1 or type 2 diabetes mellitus and residing in the state of Sergipe, Brazil. Participants were excluded if they were unable to provide coherent responses during the interview, had incomplete questionnaire responses, or lacked point-of-care laboratory examination data. Data quality control procedures included verification of questionnaire completeness; participants with missing responses were excluded from subsequent analyses.

This study was conducted concurrently with a DR screening campaign organized by the Sergipe Society of Ophthalmology. Retinal examinations were offered free of charge at multiple primary healthcare units in São Cristóvão, Sergipe.

Participants underwent retinal imaging using the Eyer device (Phelcom Technologies, São Carlos, Brazil). Following imaging, participants completed a structured interview administered by a trained examiner. The interview questionnaire was adapted from Domingues et al.[18], which had previously been applied in a Portuguese-speaking population. The instrument assessed participants' knowledge, beliefs, and perceptions regarding social and economic aspects related to DR screening. The full questionnaire is provided as Questionnaire 1.

For Likert-scale questions, responses were converted into numerical scores ranging from 1 to 5, where 1 corresponded to "completely disagree" and 5 to "completely agree," enabling quantitative analysis of attitudes and perceptions.

Clinical parameters, including glycated hemoglobin (HbA1c), serum creatinine, and microalbuminuria, were obtained on-site during the screening using point-of-care devices: i-STAT 1 (Abbott, Chicago, Illinois) and Afinion 2 (Abbott, Chicago, Illinois). Information regarding insulin use was also recorded. These clinical data were collected immediately after completion of the questionnaire and integrated into the study dataset.

Fundus images were independently evaluated by two retinal specialists, who qualitatively assessed the presence and severity of DR and maculopathy. In cases of disagreement, a consensus decision was reached between the evaluators to ensure consistency in classification.

All data were recorded in electronic spreadsheets in XLSX format and analyzed using JASP statistical software (version 0.18.3.0). Descriptive analyses were performed for all variables. Continuous and ordinal variables were summarized using measures of central tendency (mean and median) and dispersion (standard deviation and range), whereas categorical variables were presented as frequencies and percentages.

For inferential analysis, continuous variables were compared using Student's *t* test, and categorical variables were analyzed using Pearson's chi-square test. Graphical representations were generated using the Matplotlib 3.9.1 library in Python 3.9.0. A p value <0.05 was considered statistically significant.

In addition to descriptive analyses, subgroup comparisons were conducted based on clinical and imaging findings. Participants were categorized according to the presence or absence of DR, maculopathy, and insulin use. These subgroup classifications were used to compare clinical parameters and questionnaire responses to identify potential associations.

RESULTS

Descriptive statistics

The clinical and sociodemographic characteristics of the study population are summarized in table 1. These data include demographic profile, comorbidities, medication use, and ophthalmologic examination findings. The frequency of responses to all questionnaire items is presented in table 2.

Among the main findings, 32 participants (33.6%) reported transportation-related difficulties that interfered with their ability to attend medical appointments. In addition, 77 participants (81.1%) reported difficulties scheduling ophthalmology appointments, and 73 (76.8%) indicated that no ophthalmologist was available in their city through the public healthcare system. These findings highlight significant structural barriers to accessing specialized eye care.

Table 1. Clinical and sociodemographic variables.

Variable	Value
Number of participants	95
Age (mean ± SD, range)	60.71 ± 10.54 (39–82)
Sex	Female: 68 (71.6%)
Living situation	Living with family: 70 (73.7%) Living alone: 25 (26.32%)
Regular family physician follow-up	77 (81.1%)
Self-reported skin color	Mixed-race: 55 (57.9%) White: 23 (24.2%) Black: 17 (17.9%)
Education level	Primary or less: 66 (69.5%) High school: 25 (26.3%) College: 7 (7.4%)
Monthly income	≤1 minimum wage: 79 (83.2%)
Place of residence	Urban: 91 (95.8%)
Employment status	Retired: 46 (48.4%) Unemployed: 31 (32.6%) Employed: 18 (18.9%)
Type 2 diabetes mellitus	94 (99.0%)
Disease duration	10.7 ± 8.4 years
Dyslipidemia	68 (71.6%)
Smoking status	Current: 8 (8.4%) Past: 31 (32.6%)
Use of oral antidiabetic agents	82 (86.3%)
Use of insulin	42 (44.2%)
Maculopathy (valid eval., n=83)	19 (22.9%)
Diabetic retinopathy (valid eval., n=92)	46 (50.0%)
Proliferative DR (within DR group)	25 (27.2%)

Socioeconomic factors also affected treatment adherence and self-care practices. A total of 88 participants (92.6%) reported difficulty maintaining an adequate diet because of financial constraints, and more than half stated that they were unable to maintain blood glucose levels within the recommended target range. Regarding awareness of screening, only 34 participants (35.8%) reported being informed about the purpose and procedure of DR screening.

Insulin use

Insulin-treated participants demonstrated significantly greater awareness of DR screening than non–insulin-treated participants. Specifically, 28 of 42 insulin-treated individuals (66.7%) reported awareness of DR screening, compared with 25 of 53 non–insulin-treated participants (47.2%; p=0.035). Similarly, insulin-treated participants showed greater understanding of the purpose and procedure of screening, with positive responses reported by 21 of 42 individuals (50.0%), compared with 13 of 53 non–insulin-treated participants (24.5%; p=0.015).

Table 2. Aggregated interview form answers.

Question	Yes	No	Does not know		
2.2. Do you know if diabetes can affect the eyes?	68 (71.6%)	27 (28.4%)	-		
2.4. Do you know if there is any type of screening for diabetes-related eye disease?	53 (55.8%)	42 (44.2%)	-		
2.5. Have you ever undergone a screening test for diabetic retinopathy?	50 (52.6%)	45 (47.4%)	-		
2.6. Have you been informed about the purpose of diabetic retinopathy screening and the way it is performed?	34 (35.8%)	61 (64.2%)	-		
2.7. Do you have or have you had a family member with diabetic retinopathy?	22 (23.2%)	54 (56.8%)	19 (20.0%)		
2.8. Have you ever undergone screening for diabetic retinopathy?	42 (52.6%)	50 (44.2%)	3 (3.2%)		
2.9. Was your last diabetic retinopathy screening less than two years ago?	22 (23.2%)	66 (69.5%)	7 (7.4%)		
	Completely disagree	**Partially disagree**	**Neither agree nor disagree**	**Partially agree**	**Completely agree**
3.1. I feel that I will develop diabetic retinopathy in the future.	7 (7.4%)	1 (1.1%)	20 (21.1%)	22 (23.2%)	45 (47.4%)
3.2. I believe I am more likely to develop diabetic retinopathy than the average person.	16 (16.8%)	2 (2.1%)	24 (25.3%)	14 (14.7%)	39 (41.1%)
3.3. I am afraid to think about diabetic retinopathy.	27 (28.4%)	3 (3.2%)	6 (6.3%)	9 (9.5%)	50 (52.6%)
3.4. Any problems I might have with diabetic retinopathy would last a long time.	8 (8.4%)	4 (4.2%)	14 (14.7%)	12 (12.6%)	57 (60.0%)
3.5. If I had diabetic retinopathy, my entire life would change completely.	6 (6.3%)	4 (4.2%)	7 (7.4%)	7 (7.4%)	71 (74.7%)
3.6. Regular screening for diabetic retinopathy can enable an early diagnosis of the disease.	1 (1.1%)	0 (0%)	14 (14.7%)	12 (12.6%)	68 (71.6%)
3.7. If I undergo regular screening for diabetic retinopathy, my chances of going blind will be reduced.	2 (2.1%)	0 (0%)	15 (15.8%)	12 (12.6%)	66 (69.5%)
3.8. I feel uncomfortable talking about diabetic retinopathy.	52 (54.7%)	10 (10.5%)	16 (16.8%)	3 (3.2%)	14 (14.7%)
3.9. Regular screening for diabetic retinopathy will make me more worried about the disease.	51 (53.7%)	13 (13.7%)	12 (12.6%)	5 (5.3%)	14 (14.7%)
3.10. Regular screening for diabetic retinopathy takes up too much time.	60 (63.2%)	3 (3.2%)	18 (18.9%)	8 (8.4%)	6 (6.3%)
3.11. Regular screening for diabetic retinopathy is too expensive.	9 (9.5%)	4 (4.2%)	15 (15.8%)	10 (10.5%)	57 (60.0%)
3.12. I do not undergo diabetic retinopathy screening because I have difficulties with transportation/access to the screening location.	52 (54.7%)	9 (9.5%)	15 (15.8%)	5 (5.3%)	14 (14.7%)
3.13. Because I often feel tired and sad, I am unable to undergo diabetic retinopathy screening.	60 (63.2%)	10 (10.5%)	18 (18.9%)	3 (3.2%)	4 (4.2%)
3.14. I do not understand what is being explained when people talk about diabetic retinopathy screening.	32 (33.7%)	13 (13.7%)	16 (16.8%)	9 (9.5%)	25 (26.3%)
3.15. For religious reasons, I do not consider diabetic retinopathy screening important.	76 (80.0%)	5 (5.3%)	13 (13.7%)	1 (1.1%)	0 (0%)
3.16. I want to identify health problems early.	0 (0%)	1 (0.9%)	1 (0.9%)	6 (6.3%)	87 (91.6%)
3.17. I feel that engaging in health-promoting activities is important.	0 (0%)	0 (0%)	0 (0%)	4 (4.2%)	91 (95.8%)
3.18. I undergo regular medical check-ups even when I am not sick.	24 (25.3%)	5 (5.3%)	0 (0%)	5 (5.3%)	61 (64.2%)
3.19. I know how to access regular screening for DR.	46 (48.4%)	1 (1.1%)	19 (20.0%)	5 (5.3%)	24 (25.3%)
3.20. If I developed diabetic retinopathy, I would continue to undergo regular screening.	2 (2.1%)	0 (0%)	10 (10.5%)	9 (9.5%)	74 (77.9%)
3.21. Undergoing diabetic retinopathy screening is harmful to my health.	72 (75.8%)	2 (2.1%)	16 (16.8%)	1 (1.1%)	4 (4.2%)
	Yes	**No**	**Not Applicable**		
4.1. Do you feel that managing your diabetes is more difficult in the public healthcare system than in the private system?	75 (78.9%)	20 (21.1%)	-		
4.2. Do you feel discriminated against for depending on the public healthcare system?	40 (42.1%)	55 (57.9%)	-		
4.3. Do you have transportation difficulties when attending medical appointments for diabetes care?	31 (32.6%)	64 (67.4%)	-		
4.4. Are you able to obtain all the medications required for diabetes treatment through the public healthcare system?	60 (63.2%)	35 (36.8%)	-		
4.5. If you needed medications not provided by the public healthcare system, would you be able to afford them?	48 (50.5%)	27 (28.4%)	20 (21.1%)		
4.6. Do you believe financial difficulties make it harder to follow a proper diet?	88 (92.6%)	7 (7.4%)	-		
4.7. Are you able to maintain regular medical appointments for diabetes follow-up?	73 (76.8%)	22 (23.2%)	-		
4.8. Are you able to keep your blood glucose within the target range?	48 (50.5%)	47 (49.5%)	-		
4.9. Do you have difficulty scheduling an ophthalmology appointment for diabetic retinopathy screening?	74 (77.9%)	21 (22.1%)	-		
4.10. Is an ophthalmologist available in your city through the public healthcare system?	22 (23.2%)	73 (76.8%)	-		

Interview questions and response values (absolute numbers and frequencies) obtained from 95 participants.

In addition, insulin-treated individuals more frequently reported having received recommendations to undergo DR screening (27/42; 64.3%) compared with non–insulin users (23/53; 43.4%; p=0.043). Insulin users also demonstrated higher mean agreement scores regarding their perceived future risk of developing DR (4.4 ± 1.0; range: 1–5) compared with non–insulin users (3.8 ± 1.3; range: 1–5; p=0.013).

Maculopathy

Participants with maculopathy showed slightly lower mean agreement scores on the belief that early identification of health problems is important (4.7 ± 0.7; range: 2–5) than those without maculopathy (4.9 ± 0.2; range: 4–5; p=0.039). A similar pattern was observed for perceptions regarding the importance of engaging in health-promoting activities (4.8 ± 0.4 vs 4.9 ± 0.1; p=0.011).

Awareness of DR was significantly associated with the presence of maculopathy. Among participants with maculopathy, 18 of 19 individuals (94.7%) reported knowledge of DR, compared with 19 of 64 individuals (29.7%) in the non-maculopathy group (p=0.013). Awareness of DR screening was also higher among individuals with maculopathy (15/19; 78.9%) than among those without maculopathy (32/64; 50.0%; p=0.025). Similarly, 17 of 19 participants with maculopathy (89.5%) reported receiving a recommendation to undergo DR screening, compared with 30 of 64 participants without maculopathy (46.9%; p=0.001). In addition, 13 of 19 individuals with maculopathy (68.4%) reported having received information about how DR screening is performed, compared with 19 of 64 participants without maculopathy (29.7%; p=0.002).

Diabetic retinopathy

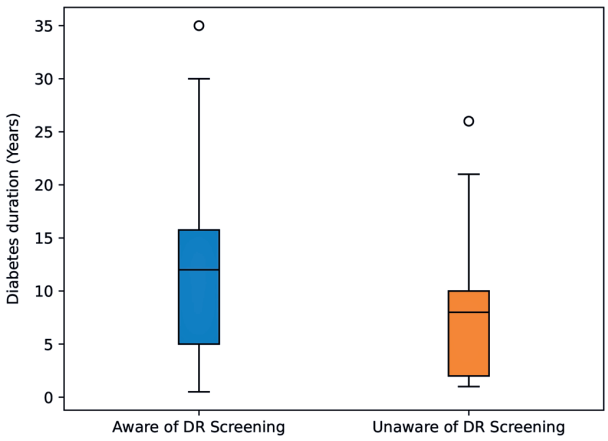
Participants diagnosed with DR demonstrated significantly higher agreement scores regarding their perceived risk of developing retinopathy in the future (4.4 ± 0.8; range: 3–5) compared with those without DR (3.6 ± 1.4; range: 1–5; p=0.003).

Additional findings on screening awareness and socioeconomic factors

Awareness of DR screening was significantly associated with age. Participants who reported awareness had a lower mean age (58.2 ± 9.8 years; range: 39–82) compared with those who were unaware of screening (63.8 ± 10.7 years; range: 39–82; p=0.010).

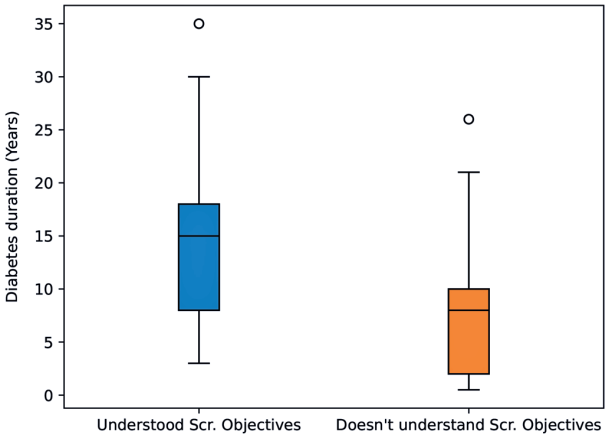
Screening awareness was also associated with longer diabetes duration (12.5 ± 8.4 years; range: 1–35) compared with those unaware of screening (8.1 ± 6.4 years; range: 0.5–26; p=0.021), as illustrated in figure 1. In addition, individuals aware of screening had higher HbA1c levels (8.6 ± 2.3%) than those who were unaware (7.3 ± 1.9%; p=0.006).

Understanding the purpose and procedure of DR screening was similarly associated with longer diabetes duration (14.1 ± 8.3 years vs 7.8 ± 6.2 years; p<0.001), as shown in figure 2, and with higher HbA1c levels (8.8 ± 2.3% vs 7.5 ± 2.1%; p=0.006).



DR: Diabetic retinopathy. Boxplots comparing diabetes duration between participants aware versus unaware of diabetic retinopathy screening existence. The central line represents the median; whiskers denote ±1.5 × interquartile range. Longer disease duration was associated with greater awareness of screening and its purpose.

Figure 1. Diabetes duration and awareness of diabetic retinopathy screening.



Scr: Screening. Boxplot comparing diabetes duration between participants that understand versus don't understand diabetic retinopathy screening objectives. The central line represents the median; whiskers denote ±1.5 × interquartile range. Longer disease duration was associated with greater awareness of screening and its purpose.

Figure 2. Diabetes duration and understanding of diabetic retinopathy screening objectives.

Furthermore, participants who reported being able to maintain blood glucose levels within the recommended target range exhibited significantly lower HbA1c levels (7.3% ± 1.8%) than those who reported difficulties in glycemic control (8.7% ± 2.4%; p=0.003).

DISCUSSION

This study evaluated barriers to DR screening in a population predominantly composed of older adults with type 2 diabetes mellitus, low educational attainment, and limited income. Most participants were economically inactive and resided in urban areas. The high prevalence of DR (50.0%) and maculopathy (22.9%) observed in this study indicates a substantial burden of ocular complications among individuals with diabetes in this setting.

The literature on barriers to DR screening remains heterogeneous, with variations in study design and assessment methods[8–11]. Commonly reported obstacles include excessive workload among healthcare providers[8,10], shortages of trained personnel[8,11,12], limited training opportunities[11,12], inadequate doctor–patient communication[10,19], limited patient availability[9], insufficient healthcare infrastructure[12], low health literacy[9,10,12,19], and the absence of visual symptoms during the early stages of the disease[10,19]. Among these factors, lack of patient knowledge, poor perception of diabetes control, and the asymptomatic progression of DR were particularly consistent with the findings of the present study.

In our sample, individuals with a longer duration of diabetes demonstrated greater awareness of DR screening, consistent with previous reports[20,21]. However, even among these participants, awareness did not necessarily translate into appropriate screening behavior, suggesting persistent misconceptions and limited health literacy. Kumar et al.[10] similarly reported that many patients delay ophthalmologic evaluation until visual impairment becomes evident. In Brazil, where a substantial proportion of individuals with diabetes have not completed secondary education[13,16], accessible communication strategies and culturally adapted educational materials are essential to improve patient engagement. Without such measures, preventive initiatives are unlikely to reach the most vulnerable populations, thereby limiting the potential impact of early detection programs.

Overall, knowledge regarding DR and its screening was limited across participant subgroups and was accompanied by low rates of previous ophthalmologic examinations and poor glycemic control. These findings are consistent with international evidence demonstrating low adherence to DR screening programs, even in high-income countries such as the United States[22,23] and Portugal[24], where organized regional screening programs do not achieve universal coverage. The similarity of these trends suggests that structural and educational barriers—rather than purely economic factors—are key determinants of low screening adherence. In Brazil, where population-based data remain limited, our findings likely reflect broader national challenges in implementing effective DR screening strategies[25].

Transportation difficulties, reported by approximately one-third of participants (Table 2), represented an important barrier to accessing healthcare services. Such challenges often arise from socioeconomic constraints, including advanced age and limited financial resources[9,26]. Potential strategies to mitigate these barriers include providing free or subsidized transportation for high-risk patients, implementing home-based care models, and expanding teleophthalmology services[26,27]. Financial hardship also negatively affected adherence to recommended dietary practices (Table 2), a relationship that has been widely documented in the literature[28].

Beyond individual-level barriers, systemic limitations within the healthcare infrastructure remain critical. Regional disparities in the distribution of ophthalmologists and ophthalmic imaging equipment hinder equitable access to DR screening services[14,17]. Many primary healthcare units in underserved regions lack the infrastructure or referral networks required for timely ophthalmologic evaluation. These challenges reflect the structural limitations acknowledged in the Brazilian Clinical Protocol and Therapeutic Guidelines for Diabetic Retinopathy[29], which assign responsibility to state and municipal health authorities within the Unified Health System for organizing referral networks and ensuring regulated patient flow. Despite these formal policies, implementation remains inconsistent, often resulting in delayed diagnoses and preventable visual impairment. Strengthening coordination between primary and specialized care, investing in mobile retinal imaging units and teleophthalmology, and expanding professional training programs are essential strategies to improve the coverage and efficiency of DR screening nationwide.

Educational interventions also play a crucial role in improving screening uptake and glycemic control[27]. The Brazilian Clinical Protocol and Therapeutic Guidelines for Diabetic Retinopathy highlight that underdiagnosis of diabetes and low population awareness represent major obstacles to early disease management. This underscores the importance of continuous health education integrated into primary care services. In this context, family physicians play a central role in coordinating diabetes management,

facilitating referrals for ophthalmologic evaluation, and providing ongoing patient counseling[30].

Technological innovations, such as artificial intelligence–based screening systems, have demonstrated promising results in other settings. Dow et al.[31] reported a threefold increase in screening adherence and shorter intervals between screening and result reporting when artificial intelligence–assisted image analysis was implemented. However, these technologies remain at an early stage of adoption within the Brazilian Unified Health System and should therefore be considered future perspectives rather than immediate practical recommendations for the present context.

Several limitations of this study should be acknowledged. All data were self-reported and derived from a convenience sample, which may have introduced recall, interviewer, or selection bias. The cross-sectional design precludes causal inference, and the modest sample size limits the generalizability of the findings. Additionally, the lack of formal linguistic validation of the questionnaire may affect measurement reliability. The gender imbalance and predominance of urban participants may also have introduced selection bias. Furthermore, the analyses did not include adjustments for potential confounding variables or corrections for multiple statistical comparisons. Despite these limitations, this study provides valuable real-world evidence regarding barriers to DR screening in vulnerable populations and identifies critical factors that may inform strategies to improve the effectiveness of national screening initiatives.

In conclusion, this study conducted in a socioeconomically vulnerable urban population in northeastern Brazil identified significant barriers to DR screening. The study population—composed primarily of older adults with low educational attainment and limited income—demonstrated a high prevalence of DR and diabetic maculopathy. Key barriers included limited patient awareness and understanding of DR and the importance of screening, compounded by the asymptomatic nature of early disease stages. Socioeconomic factors, particularly financial constraints and transportation difficulties, also substantially limited access to screening services. These findings underscore the need for targeted interventions, including culturally adapted educational programs and structural improvements to healthcare services. Expanding screening availability through telemedicine, strengthening referral networks, and providing subsidized transportation may contribute to improving equitable access to ophthalmologic care among vulnerable populations.

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Questionnaire 1. Barriers Questionnaire Portuguese (Original) version and Barriers Questionnaire English (Translated) version.

QUESTIONÁRIO: Barreiras à adesão de pacientes diabéticos no rastreio de Retinopatia Diabética em usuários do Sistema Único de Saúde no estado de Sergipe.
Questões Sociodemográficas
Nome:
Idade:
Sexo:
Masculino
Feminino
Nível de escolaridade:
Fundamental incompleto
Fundamental completo
Médio completo
Superior incompleto
Superior completo
Situação profissional:
Desempregado
Trabalha um turno
Trabalha dois turnos
Aposentado
Rendimento mensal:
Menos que um salário mínimo
Salário mínimo
Mais que um salário mínimo
Residência:
Capital
Zona metropolitana
Zona rural
Vive sozinho:
Sim
Não
Tem médico da família:
Sim
Não
Questões Clínicas – Avaliação de conhecimentos
Tempo de diabetes (anos):
Sabe se existe diabetes nos olhos?
Sim
Não
Quais órgãos podem ser afetados pelo diabetes
Pés
Rins
Olhos
Estômago
Órgãos sexuais
Coração
Cérebro
Outros?
Sabe se existe algum tipo de rastreio para diabetes nos olhos?
Sim
Não
Alguma vez lhe foi recomendada a realização de um exame de rastreio para avaliar RD:
Sim
Não

continua...

...Continuação

Questionnaire 1. Barriers Questionnaire Portuguese (Original) version and Barriers Questionnaire English (Translated) version.

QUESTIONÁRIO: Barreiras à adesão de pacientes diabéticos no rastreio de Retinopatia Diabética em usuários do Sistema Único de Saúde no estado de Sergipe.
Foi informado acerca do objetivo do rastreio e como ele é feito?
Sim
Não
Teve/tem algum parente com RD?
Sim
Não
Não sabe informar
Se sim, qual familiar?
Já realizou alguma vez o rastreio para RD?
Sim
Não
Não sabe informar
A última vez que realizou o rastreio de RD foi há menos de 2 anos?
Sim
Não
Não sei informar
Crenças de saúde em relação à RD e barreiras de adesão ao rastreio
Instrução: marcar:
1 – Discordo totalmente;
2 – Discordo parcialmente;
3 – Não tenho certeza;
4 – Concordo parcialmente;
5 – Concordo totalmente
Sinto que vou ter RD no futuro
Tenho mais probabilidade de vir a ter RD do que a média das pessoas.
Tenho medo de pensar acerca da RD.
Os problemas que pudesse ter com a RD iriam durar muito tempo.
Se tivesse RD, toda a minha vida se alterava por completo.
Fazer exames de rastreio regulares para detectar a RD pode permitir o diagnóstico precoce da RD.
Se fizer exames de rastreio regulares para detectar a RD, reduzem as hipóteses de vir a ficar cego.
Sinto-me desconfortável quando falo de RD.
Fazer exames de rastreio regulares para detectar a RD, vai me fazer sentir preocupado/a com a RD.
Os exames de rastreio regulares para detectar a RD vão me ocupar muito tempo.
Fazer exames de rastreio regulares para detectar a RD custa muito dinheiro.
Não realizo o rastreio da RD porque tenho dificuldades com o transporte/acesso ao local da realização.
Por andar cansado e triste não consigo fazer o rastreio da RD.
Não percebo o que dizem ou explicam quando falam sobre o rastreio da RD.
Por motivos religiosos, não considero que seja importante fazer o rastreio da RD.
Quero identificar os problemas de saúde precocemente
Sinto que é importante desenvolver atividades que promovam a minha saúde.
Faço exames médicos regulares mesmo não estando doente.
Sei como obter exames de rastreio regulares para detectar a RD.
Se desenvolvesse RD, continuaria a realizar exames de rastreio regulares.
Fazer o rastreio da RD é prejudicial para a minha saúde.
Questões adicionais sobre barreiras
Você sente que é mais difícil conseguir cuidar do seu diabetes pelo SUS do que pelo sistema privado?
Sim
Não
Você se sente discriminado por depender do SUS?
Sim
Não

continua...

...Continuação

Questionnaire 1. Barriers Questionnaire Portuguese (Original) version and Barriers Questionnaire English (Translated) version.

QUESTIONÁRIO: Barreiras à adesão de pacientes diabéticos no rastreio de Retinopatia Diabética em usuários do Sistema Único de Saúde no estado de Sergipe.
Você tem dificuldade de transporte para suas consultas de cuidado do diabetes?
Sim
Não
Você consegue todas as medicações do tratamento do diabetes pelo SUS?
Sim
Não
Caso necessite de medicações não disponíveis pelo SUS, você conseguiria/consegue comprar?
Sim
Não
Não necessito de medicações não disponíveis pelo SUS.
Você acredita que razões financeiras dificultam o seguimento da dieta adequada?
Sim
Não
Você consegue manter consultas regulares para acompanhamento do diabetes?
Sim
Não
Você consegue manter sua glicemia dentro do alvo desejado?
Sim
Não
Você tem dificuldade de marcar consulta com oftalmologista para rastrear a RD?
Sim
Não
Existe oftalmologista pelo SUS em sua cidade?
Sim
Não

Adaptado de: 18. Domingues JC. Barreiras à adesão ao rastreio da retinopatia diabética nos cuidados primários de saúde [dissertação]. Coimbra, Portugal: Universidade de Coimbra; 2018.

QUESTIONNAIRE: Barriers to diabetic retinopathy screening among patients using the Brazilian Unified Health System (SUS) in the State of Sergipe.

Sociodemographic Questions

Name:

Age:

Sex:

- Male
- Female

Educational level:

- Incomplete elementary school
- Completed elementary school
- Completed high school
- Incomplete college
- Completed college

Employment status:

- Unemployed
- Works part time
- Works full time
- Retired

Monthly income:

- Less than minimum wage
- Minimum wage
- More than minimum wage

Residence area:

- Capital city
- Metropolitan area
- Rural area

Lives alone:

- Yes
- No

Has a family physician:

- Yes
- No

Clinical Questions – Knowledge Assessment

Duration of diabetes (years):

Do you know that diabetes can affect the eyes?

- Yes
- No

Which organs can be affected by diabetes?

- Feet
- Kidneys
- Eyes
- Stomach
- Sexual organs
- Heart
- Brain
- Others?

Do you know if there is any type of screening for diabetes-related eye disease?

- Yes
- No

Have you ever been recommended to undergo a screening test for diabetic retinopathy?

- Yes
- No

continue...

...Continuation

QUESTIONNAIRE: Barriers to diabetic retinopathy screening among patients using the Brazilian Unified Health System (SUS) in the State of Sergipe.

Have you been informed about the purpose of diabetic retinopathy screening and how it is performed?

Yes

No

Do you have or have you had a family member with diabetic retinopathy?

Yes

No

Do not know

If yes, which relative?

Have you ever undergone diabetic retinopathy screening?

Yes

No

Do not know

Was your last diabetic retinopathy screening less than two years ago?

Yes

No

Do not know

Health Beliefs Regarding DR and Screening Adherence Barriers

Instructions: Mark the option that best reflects your opinion.

1 – Completely disagree;

2 – Partially disagree;

3 – Not sure;

4 – Partially agree;

5 – Completely agree

I feel that I will develop DR in the future.

I believe I am more likely to develop DR than the average person.

I am afraid to think about DR.

Any problems I might have with DR would last a long time.

If I had DR, my whole life would change completely.

Regular screening for DR can allow early diagnosis of the disease.

If I undergo regular screening for DR, my chances of going blind will be reduced.

I feel uncomfortable talking about DR.

Regular DR screening will make me more worried about the disease.

Regular screening for DR takes up too much time.

Regular screening for DR is too expensive.

I do not undergo DR screening because I have difficulties with transportation/access to the screening location.

Because I often feel tired and sad, I am unable to undergo DR screening.

I do not understand what is explained when people talk about DR screening.

For religious reasons, I do not consider DR screening important.

I want to identify health problems early.

I feel that engaging in health-promoting activities is important.

I undergo regular medical check-ups even when I am not sick.

I know how to access regular screening for DR.

If I developed DR, I would continue to undergo regular screening.

Undergoing DR screening is harmful to my health.

Additional Questions About Barriers

Do you feel that managing your diabetes is more difficult through SUS than through the private system?

Yes

No

Do you feel discriminated against for depending on SUS?

Yes

No

continue...

...Continuation

QUESTIONNAIRE: Barriers to diabetic retinopathy screening among patients using the Brazilian Unified Health System (SUS) in the State of Sergipe.
Do you have transportation difficulties when attending diabetes care appointments?
Yes
No
Are you able to obtain all the medications required for diabetes treatment through SUS?
Yes
No
I don't need any medications that aren't provided by SUS
If you need medications not provided by SUS, would you be able to afford them?
Yes
No
Do you believe financial difficulties make it harder to follow a proper diet?
Yes
No
Are you able to maintain regular medical appointments for diabetes follow-up?
Yes
No
Are you able to keep your blood glucose within the target range?
Yes
No
Do you have difficulty scheduling an ophthalmology appointment for DR screening?
Yes
No
Is there an ophthalmologist available in your city through the public healthcare system?
Yes
No

Translated and adapted from: 18. Domingues JC. Barreiras à adesão ao rastreio da retinopatia diabética nos cuidados primários de saúde [dissertação]. Coimbra, Portugal: Universidade de Coimbra; 2018.