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Original article

A comprehensive strategy of diabetic retinopathy screening in a public health system: Identifying and overcoming obstacles for implementation

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A B S T R A C T

Aims: This study reports the implementation of a diabetic retinopathy (DR) screening program in Aracaju, Brazil, emphasizing the challenges and premature termination.
Methods: The program, a collaboration between local health authorities, national DR screening experts, private clinics, trained retinal imaging technicians, a portable retinal camera with artificial intelligence (AI), telemedicine, and AI-assisted image analysis, was established. Screening occurred at primary care centers, with free specialized treatment for high-risk DR cases.
Results: After a public tender, two clinics were selected for screening, and four for secondary management. Initially, diabetic patient attendance at primary care clinics varied considerably, posing a challenge. Nonetheless, the screening continued, with 3,561 patients screened within six months. However, due to complaints and disputes between providers and authorities, the program was prematurely terminated, achieving less than a quarter of the initial screening target.
Conclusions: The DR screening program faced significant challenges, including low adherence and organizational issues at primary care centers. This experience highlights the need to standardize clinical workflows, enhance organization and integration among primary care units, and address cultural factors to improve adherence rates. These insights are valuable for implementing screening programs, particularly in low- and middle-income countries.

Introduction

Diabetic retinopathy (DR) is one of the leading causes of preventable blindness in the adult population; vision loss from DR could be prevented by established measures such as increasing patient's awareness with health education programs, screening programs, and timely referral and treatment for severe stages of DR [1].

Screening identifies diseases in asymptomatic individuals, and diabetic retinopathy (DR) meets the criteria for screening due to its significance as a health problem, available tests, accepted treatment, and improved prognosis with early intervention [2]. However, successful screening programs require accessible facilities for diagnosis and treatment, which can be hindered by financial, cultural, and organizational constraints, such as infrastructure limitations, lack of specialized personnel, and poorly designed workflows or misfinancing [2].

It has been advocated that in order to attain an equitable distribution of care at different levels in each country, DR screening should be performed at the primary care level, with a continuum of care from community to tertiary care. A proposed pathway includes nonmydriatic fundus imaging at the primary level, comprehensive eye examination and laser treatment at the secondary level, and intravitreal injections and vitrectomy at tertiary level [3].

In Brazil, the public health system, SUS, provides free healthcare coverage to the population, with the majority relying on it as their primary provider [1]. However, Brazil lacks a national organized DR screening program, relying on referrals or volunteer campaigns for screening [4,5]. Challenges in implementation include health education, economic considerations, referral pathways, access to timely treatment, and adherence to care [3,6].

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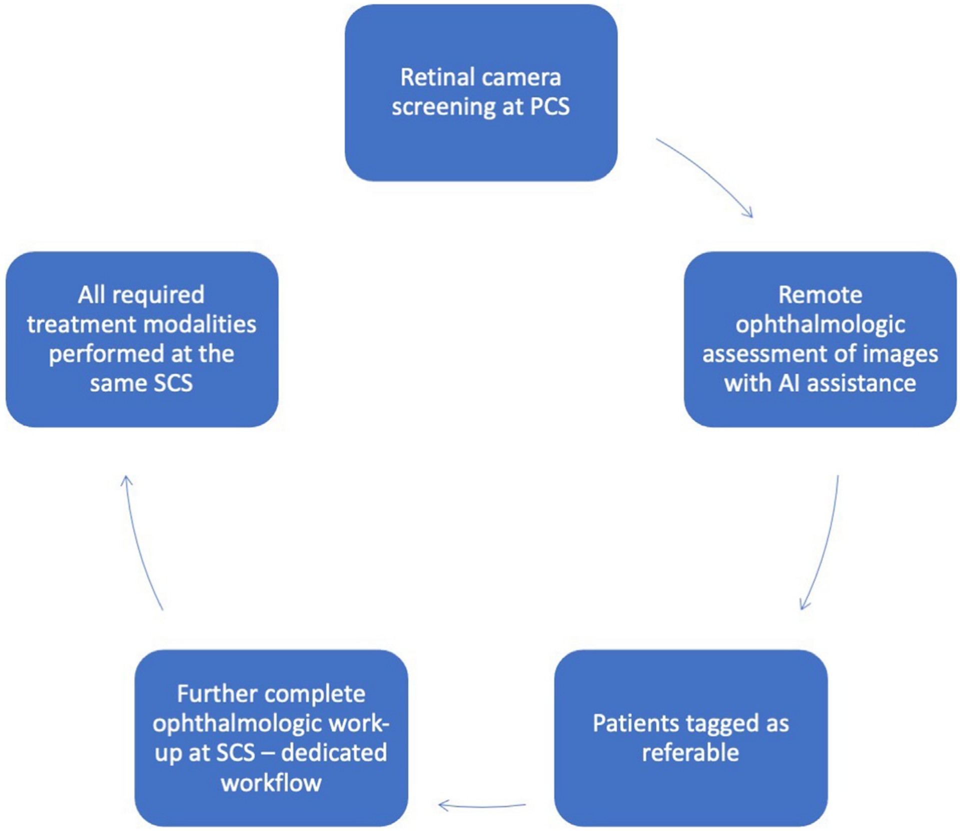

Fig. 1. . Dedicated workflow for the individual with diabetes: from screening at the primary care site (PCS) to a thorough treatment offer at the secondary care site (SCS). AI- artificial intelligence.

Our main objective is to report the brief experience of a DR screening program that was designed and initiated in a Brazilian Northeastern Capital City, as well as to describe the challenges and the problems that ultimately caused the premature termination of the program.

Methods

With the support from the Leadership Training Program of the Brazilian Council of Ophthalmology and the Brazilian Diabetes Society, a screening program for DR was designed for implementation in Aracaju, the capital of Sergipe State in the Northeastern Region of Brazil. The Northeastern region of Brazil is traditionally associated with low social and economic indexes and has been considered the region with the lowest coverage rate for DR treatment in Brazil [1]. As the state's capital, Aracaju [7,8] is the reference for higher complexity treatments, with the best infrastructure and personnel in the state. As is the case within Brazil and several others low to middle income countries (LMIC), DR screening rates are insufficient according to official sources, with pre-pandemic rates ranging 6.4 %–9.9 % in the period from 2014 to 2019 [1]. Treatment rates for DR are even lower, coverage rates ranging from 0.0 % to 2.4 % in the same period [1].

In order to plan and design the screening program, two of the authors (F.K.M. and G. B. M.) in the beginning of 2019 performed an extensive search for alternatives to overcome the gap in diabetes eye care in Aracaju, which involved countless conversations with healthcare experts specialized in ophthalmology and/or in public management at national and local levels. The result was the proposition of a different-than-ever-before strategy for DR screening which involved the partnership of a local health authority (the City of Aracaju) and private clinics, trained technicians for retinal imaging, a portable handheld retinal camera with a previously validated imaging protocol, telemedicine and artificial intelligence (AI) [9]. The screening would be performed at the primary care level, and treatment for all patients with high-risk DR with laser photocoagulation would be offered in specialized clinics. The designed workflow was presented to the city's healthcare administration (Fig. 1). In the following paragraphs, the proposal is described in detail.

Screening

The traditional referral of patients from the primary care physician (usually, general practitioners) to a secondary care ophthalmic clinic (relying mainly on retina specialists) was to be replaced for the deployment of an AI-embedded, low-cost, handheld portable retinal camera that should be made accessible to every patient with diabetes in each of the 45 primary care clinics spread throughout the city. Such AI system had been previously validated with a high sensitivity for the detection of more than mild DR in a similar population [9]. Due to the lack of a legal framework for AI-assisted screening in Brazil as of the program implementation, all images would be also interpreted by retinal specialists on a later occasion, and occasional false-negative cases would be recalled.

At each site, all patients previously known for having the diagnosis of diabetes would be invited by phone call or text message for screening over a stipulated period of time. Moreover, every diabetes patient attending the primary care site (PCS) for any reason should be invited. And, finally, a more proactive search for patients could be employed by having the community healthcare agents visiting the patients' home in order to make sure they were definitely aware of the screening availability and schedule.

Previously trained technicians would visit all city's PCS over one year. Ideally, each site should have the presence of the technician and the camera for at least one day a week and for at least a month, so that those missing the initial dates could still be able to be rescued at further dates.

Images should be categorized as either “normal” or “abnormal” by AI in order to streamline the retina specialist further remote assessment. Patients tagged as “normal” would be dismissed and counseled to keep an annual reassessment of their retina. Those tagged as “abnormal” by AI or whose image could not be properly analyzed due to media opacity would be scrutinized by a retina-trained ophthalmologist in the short term, asynchronously. Any signs of moderate nonproliferative DR or worse, cataract, enlarged cup-to-disk ratio or other potentially dangerous retinal diseases would lead the patient to be referred to an in-person medical visit at the secondary ophthalmic care site.

Referral for additional assessment and treatment

Instead of having diabetic patients waiting for a long time (up to a year) for a retina specialist visit at the secondary care site (SCS), along with patients with other retinal pathologies (vitreous floaters, retinal detachment, epiretinal membrane, and so on), we idealized what we called a dedicated workflow exclusive for those diabetics who had been considered referable at screening. Of note, SCS were mostly private practices hired by the public government.

All referred patients at the screening level should have a follow-up, detailed and complete ophthalmological assessment at the secondary care ophthalmic clinic. The main goal should be to offer a comprehensive ophthalmic care, regardless of the level of retinal pathology. For instance, if cataract was detected in one eye, which precluded retinal assessment, while the contralateral eye had an enlarged cup-to-disk ratio and proliferative DR, this patient should be able to have all diagnostic tests and different treatment modalities performed at the same site. In general, the status quo was to have the three aforementioned pathologies managed independently by different ophthalmic clinics, at different and, sometimes, exceedingly far apart time points. The designed workflow included specialized treatment for each condition. In the case of DR, the following therapeutic modalities would be made available: laser photocoagulation, intravitreal injections and vitrectomy.

Economic aspects

In order to attain sustainability of the program, cost-effectiveness was a core concern from the beginning. This involved the lowest cost possible for the payor (the public system), while, on the other hand, offering attractive values to the private partners. Values for screening and treatment were previously debated; for some cases, values above the regular fees usually paid by the public health system were proposed. Estimates of the referral rates were taken from the available literature [10] and the experience of local specialists, and financial sustainability would ultimately rely on such forecasts being met (i.e., an attendance lower than expected would jeopardize the program from a financial standpoint). The sustainability of the proposal also relied on strict indications for treatment with costly procedures, such as intravitreal injections and vitrectomy; such criteria were based on international guidelines and took into account the budget of the program.

After this workflow was drafted, it was introduced to Aracaju’s healthcare administration as well as to the Mayor in the end of 2019 and early 2020. After some meetings to define practical issues for implementation, the program was approved as originally planned.

Since this is a descriptive study that does not involve direct patient management, an IRB oversight was not required.

Results

A public tender was published in early 2021 (delayed by the pandemics) and spread to all private ophthalmic clinics of the city, so that they could adhere to the program, which was divided into two independent stages (Table 1): 1) screening and 2) secondary management. Two clinics were ultimately contracted for the development of the first stage, and four for the second stage. Of note, even though the estimated number of adults with diabetes that relied on the public health system in Aracaju was around 31 000, corresponding to three quarters of the estimated number of adults with diabetes in Aracaju (46 800) [1,11,12], the tender arbitrarily stipulated a total of 15 000 individuals with diabetes to be screened based on the expectation by the local authorities that not all of the estimated individuals in town would be willing or available to be screened and also on the available budget for the first year of the program.

After some additional delay due to the pandemics, the screening effectively began in November 2021. Two trained technicians from each clinic had their shifts scheduled by the public healthcare administration monthly. On average, each local PCS was visited on the same day of the week for up to four weeks (subject to some variation due to different population size encompassed by each site). The technician would, in general, visit five different clinics every week, resulting in 10 primary care clinics being visited per week.

After the screening began, a previously unanticipated challenge stood out: the attendance of diabetic patients at the primary care clinic was extremely uneven, ranging from none to 40 per day. The clinics

Table 1
. Public tender to contract private providers to run the diabetic retinopathy screening program and its secondary dedicated flow. Stage level, procedure, cost per unit in Brazilian reais, number of units (procedures) per month, total monthly cost, number of units per year, and yearly cost are presented.

Stage	Procedure	Unit cost (BRL)	Units per month	Monthly cost (BRL)	Units per year	Yearly cost (BRL)
Screening/Primary care	Retinal camera fundus photograph	24.68	1250	30,850	15,000	370,200
Secondary care	Pan-retinal photocoagulation	300.6	64	19,238.4	768	230,860.8
Secondary care	Focal photoaculation	75.15	64	4809.6	768	57,715.2
Secondary care	Ultrasonography	24.2	38	919.6	456	11,035.2
Secondary care	A-scan biometry	24.24	64	1551.36	768	18,616.32
Secondary care	Retinal indirect ophthalmoscopy	24.24	128	3102.72	1536	37,232.64
Secondary care	Corneal specular microscopy	24.24	64	1551.36	768	18,616.32
Secondary care	Fluorescein angiography	64	64	4096	768	49,152
Secondary care	Optical coherence tomography	48	150	7200	1800	86,400
Secondary care	Phacoemulsification + IOL implantation	771.6	32	24,691.2	384	296,294.4
Secondary care	Phacoemulsification without IOL implantation	483.6	5	2418	60	29,016
Secondary care	Secondary IOL implantation	1112.83	5	5564.15	60	66,769.8
Secondary care	Pars-plana vitrectomy level 1	1863.63	5	9313.15	60	111,757.8
Secondary care	Pars-plana vitrectomy level 2	2921.17	5	14,605.85	60	175,270.20
Secondary care	Pars-plana vitrectomy level 3	3283.41	10	32,834.1	120	394,009.2
Secondary care	YAG-capsulotomy	78.75	5	393.75	60	4725
Secondary care	Ophthalmologic appointment	16.74	255	4268.7	3060	51,224.4
Secondary care	Intravitreal innjection of bevacizumab	1500	20	30,000	240	360,000

hired for this stage observed that some PCS offered well-organized logistics/infrastructure/personnel for the purpose, while others simply demonstrated a complete lack of knowledge, or even interest, in adhering to the program, even though all PCS managers were strictly and clearly notified by the city's healthcare administration in advance.

Despite this challenging beginning, the program was continued. A list of all screened patients tagged as referable by the remote assessment of a retina-trained or supervised ophthalmologist was regularly fed at an on-line integrated platform. Subsequently, those individuals were remotely scheduled for a follow-up ophthalmic work-up at the SCS.

The four clinics hired for managing patients from screening did not seem to face any challenging difficulty in carrying out the diagnostic tests and required treatment procedures. The so-called dedicated workflow worked out seamlessly. The only point that should be remarked is that some patients were found to miss the appointments for this secondary assessment. However, this summarized piece of data was not made available to the authors for the purpose of this publication.

Although the city's authorities received multiple complaints by the contracted clinics, the screening stage was carried out, with its important flaws previously stated, until July 2022, when 3561 patients had already been screened. In that occasion, the public administration announced a halt in the program. Consequently, several meetings occurred over the following two months for technical negotiations between the contracted providers and the contracting authorities. Finally, a decision to cancel the program was made less than one year after the beginning if its implementation, with the achievement of less than one fourth of the initial goal of screening 15 000 individuals. Not only the screening but also the supposedly successful secondary stage was halted. With the end of the program, a patient with diabetes currently needs that a general practitioner asks for ophthalmological evaluation to schedule a visit, this time with a specialist (screening based on a first evaluation of images obtained by a technician is no longer available). There is scarce availability for such specialized evaluations. In addition, there is no longer the possibility for a diabetic patient with detected retinal changes to pursue the designed fast track for timely treatment since the workflow is no longer active. Hence, patients must wait usually long periods for treatment again, risking a worse prognosis.

Discussion

We herein describe the conceptualization, implementation, and outcome of a dedicated workflow to prevent blindness from DR in the public primary care of Aracaju, Brazil. For such an initiative, a dedicated and exclusive workflow for referral path and treatment was designed, so that all individuals with treatment indication could be referred to secondary level units, where they could undergo complete diagnostic and treatment procedures, including laser, cataract extraction, vitrectomy and intravitreal injections. To our knowledge, this could be the first full population-wide approach in a large Brazilian area. Additionally, it would comprise the deployment of cutting-edge technology in a cost-effective manner, attaining a larger screening and coverage. We believe the lessons learned from such experience, along with comparisons to other screening programs elsewhere, could add value to the implementation of screening programs in settings currently devoid of such initiatives, which is the case of Brazil and other LMIC.

We believe the main problem that led to the interruption of the program was low adherence, mainly caused by lack of organization of the PCS. It led to a lack of an adequate volume of diagnostic and treatment procedures, which ultimately jeopardized the economic sustainability of the program. Several issues contributed to such low adherence rates, such as the lack of standardization of a clinical workflow, the lack of organization or integration between the several primary care units, as well as cultural issues: since screening is a preventive measure, attitudes towards health promotion and the perception of future risk probably play a role on adherence rates.

There are several examples of successful DR screening programs around the world, most of them carried by the government, such as the cases of the United Kingdom [13], Denmark [14], whereas other countries rely on the private health sector for such task, with variable rates of success. In the United States, for example, it is estimated that more than half of patients with diabetes may fail to receive necessary screening [15]. In the case of the initiative presented herein, the public system was not able to guarantee the implementation of the program on its totality, thereby relying on private partners. However, due to the issues discussed below, such partnership also failed in providing sufficient inclusion.

Iceland and Denmark are examples of countries with successful DR screening programs. If, on one hand, they are culturally very different, much richer countries in comparison to Brazil, on the other hand their experience may bring relevant lessons in terms of organization, health education and motivation of all stakeholders fur such enterprise. Iceland was among the frontrunners of national DR-screening [16], and among the first to introduce individualized screening with screening intervals based on risk factors. The successful reduction of DR-induced blindness in Iceland [16] has effectively demonstrated the importance of regular DR-screening and timely treatment of sight-threatening DR and has paved the way for national DR-screening programs, in particular throughout Europe.

In Denmark, a key of success for the national DR-screening program was the establishment of a national database of DR-screening [17], as this has been a vital step towards standardization and dedication among all partners involved in DR-screening. Establishment of an effective common ground for all partners involved, has also paved the way for additional initiatives, such as use of pre-specified image standards, individualized screening, use of optical coherence tomography for early detection of diabetic macular edema, and predefined guidelines for high-risk and vulnerable patients [18]. Currently, telemedicine-based screening has been added as a third-generation initiative. Hence, for selected patients in Denmark, DR-screening is now performed at diabetes-departments in combination with diabetes control for other micro- and macrovascular complications. Combining screening for all diabetes-related complication on the same day is expected to improve adherence and save time and resources for patients [2].

In the implementation of the screening program, primary units followed different workflows, with some actively reaching out to diabetes patients at their homes or scheduling appointments, while others had no strategies to promote screening. This resulted in situations where technicians were available, but no patients appeared for retinal exams. The autonomy of each primary care manager contributed to the lack of prioritization of the program across the 45 sites. To address this drawback, future initiatives could establish screening coverage goals for local health teams, provide incentives, and implement penalties. It is proposed that a dedicated staff from the central healthcare administration should organize a standard workflow and ensure its implementation on-site. Additional measures, such as using mobile devices during home visits, could help meet the target number of visits. Conducting a pilot project in a few units before scaling up the program would allow for better planning by gathering data on adherence and referral rates.

There was no general communication campaign from the health authorities. In addition, several local unities failed to convince the targeted population on the importance of adhering to screening. We now understand that any broad screening program, even at its smallest level (the PCS) requires advertisement that encompasses the widest number of individuals as possible. Prior population-based campaigns at specific time points, such as on the World Diabetes Day, have shown us how effective providing information on the media (TV, radio and internet campaigns), along with local communication by PCS community agents during home visits. Compliance to lifestyle changes, treatment and follow-up care is reportedly a challenge for such programs [3], while health education initiatives have also been proved to raise attendance levels [6].

To ensure the comprehensive diabetic retinopathy (DR) program's financial sustainability, a public-private partnership was established due to limitations in budget and human resources of the public health system. However, low attendance rates prevented continuous participation of private healthcare providers in the program, highlighting the need for engaging private partners effectively. The state sector should actively participate in communication initiatives to increase attendance rates and involve private providers in bundled health initiatives that include both screening and lucrative treatment procedures.

Implementing people-centered eye care that encompasses various levels of care, from community to tertiary, presents challenges in terms of capacity building. Patient compliance is identified as a significant challenge, and global advocacy by organizations such as the International Diabetes Federation, World Health Organization, and International Agency for the Prevention of Blindness, as well as local advocacy, is crucial to address this issue and ensure successful DR screening programs.

In conclusion, the description and analysis of the failed implementation of the Aracaju initiative in tackling preventable blindness and managing chronic diseases in LIMC provide valuable insights. Lessons learned include the importance of identifying barriers and developing strategies for program design, integration of public and private health systems, health education, communication campaigns, and resource allocation. These insights can guide future initiatives in LMIC to ensure the success of DR screening programs.

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Declaration of competing interest

The authors declare that they have no financial or personal relationships with other people or organizations that could inappropriately influence (bias) the work

CRediT authorship contribution statement

Fernando Korn Malerbi: Conceptualization, Data curation, Methodology, Writing – original draft, Writing – review & editing. **Jakob Grauslund:** Funding acquisition, Writing – review & editing.

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