Diabetic retinopathy screening program in Southwestern Uganda

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ABSTRACT

Objectives: Between 2019 and 2045, the prevalence of Diabetes Mellitus (DM) will double; associated with this, the burden of Diabetic Retinopathy (DR) is also expected to increase, especially in low-resourced settings. To prevent avoidable visual impairment and blindness, early detection through screening and early treatment are necessary. To enable access to these services, we developed the Lions Diabetic Retinopathy Project for southwestern Uganda to serve the region including 17 Districts with eight million inhabitants.

Methods: A three-pronged strategy for mass screenings levering the existing general health system and opportunistic screening of higher-risk population. Capacity building involved training a vitreoretinal surgeon and allied eye care providers, installing critical infrastructure at the referral eye hospital, and acquiring equipment for primary health centres.

Results: In 1.5 years, 60 DR screening camps were implemented; this led to screening of 9,991 high risk individuals for DM and 5,730 DM patients for DR. We referred 1,218 individuals with DR for further management at the referral eye hospital, but only 220 (18%) attended referral. The main barrier for not attending referral was long travel distance and the associated direct and indirect costs. Human resources trained included 34 ophthalmic nurses, five midlevel providers, and one vitreoretinal surgeon. Major equipment acquired included a vitrectomy system, an outreach vehicle, and non-mydriatic fundus cameras.

Conclusions: DR screening can be implemented in a resource-limited setting by integrating with the general primary healthcare system. However, geographic barriers stymie delivery of therapeutic services and we need to establish models to bring these services closer to areas with poorer access.

Key words: Africa, Diabetes, Diabetic retinopathy, Public health, Screening, Uganda

INTRODUCTION

In 2019, the prevalence of Diabetes Mellitus (DM) globally was 463 million adults, and is projected to increase to 700 million by 2045; 80% of people with DM live in Low- and Middle-Income Countries (LMICs)¹. In Uganda, the prevalence of DM among adults aged 18 to 69 years is 2.7% in urban settings and 1.0% in rural settings². Diabetic Retinopathy (DR), a main complication of DM, is the leading cause of blindness among working age adults globally3. In a robust metaanalysis involving studies that enumerated adults across the lifespan (eg. age 17 to 96 years), 34.6% with DM have any DR, and about one-third of individuals with DR have vision-threatening DR.4 In resourcerich health systems, adults with DM type II undergo a comprehensive eye examination at diagnosis and then annually^{5, 6}, though this is rarely feasible in most health

systems of Uganda. At Mbarara University's adult DM outpatient clinic, only 2% of DM patients were screened for DR, even though DR was the third leading cause of visual impairment (17%) in 2014⁷. In a follow up study in 2017 surveying patients from the aforementioned DM clinic, the referral situation had not improved as significantly as we expected; of the patients eventually diagnosed with any DR, only 13.3% were referred for an eye examination prior to any visual symptoms⁸. The prevalence of DR among DM patients was 13.5%, and the proportion of visual impairment and blindness was 9.6% and 0.5%, respectively. This led to the development of the Lions Diabetic Retinopathy Project for southwestern Uganda.

The main aim of this project was to strengthen the health system for screening and treatment of DR in southwestern Uganda, ultimately preventing visual impairment among those with DM. The aim was

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achieved through: 1) capacity building of the Primary Health Care (PHC) system to screen for DR and to strengthen the capacity of the main referral eye hospital in the region to treat DR; 2) intensify screening efforts in the PHC for early detection of DR; 3) create a demand for screening through sensitisation campaigns.

MATERIALS AND METHODS

This project was implemented by Mbarara University of Science and Technology (MUST) Department of Ophthalmology, Department of Internal Medicine, and Lions Club of Mbarara. Together, we solicited funding from Lions Clubs International Foundation (LCIF) and the Latter-day Saint (LDS) Charities to procure equipment, training of key personnel and conducting screening and sensitisation campaigns.

Project area: This project served 17 Districts in southwestern Uganda covering a total population of about eight million people (Figure 1). Residents from Democratic Republic of the Congo, Rwanda, and Tanzania also reside in this area.



Figure 1: Map of Uganda showing the 17 Districts comprising the area where the project was implemented. The red star represents Mbarara city where Mbarara University and Referral Hospital Eye Centre is located. The red circle represents Kampala, the nation's capital.

Key activities

- 1. Training of human resources:
 - i. Nursing cadre –Ophthalmic Assistants (OA): we aimed to train two nurses from the 17 Districts at MURHEC. The OAs support the midlevel and physician providers in screening patients and undertaking basic diagnostic workup.
 - ii. Midlevel cadre –Ophthalmic Clinical Officers (OCO): Since there were five Districts without an existing OCO; we solicited nominations from the health leadership. These individuals
- underwent a one-year training program at the Jinja School of Ophthalmic Clinical Officers, which is the only training program available in the country. The existing 12 OCOs from other Districts underwent a two-week intensive course on DR.
- iii. Specialist provider vitreoretinal surgeon: An ophthalmologist with previous medical retina training from MURHEC underwent a one-year fellowship in vitreoretinal surgery at the Kilimanjaro Christian Medical College (KCMC) in Moshi, Tanzania and an observership at the

- National Health Service Bristol Eye Hospital (NHS BEH). MURHEC and NHS BEH have a long-standing relationship under the VISION 2020 LINKS programme.
- iv. Project management team: A group of four (chairperson, administrator, coordinator, and technical advisor) underwent a two week course at Lions Aravind Institute of Community Ophthalmology on Project Management Training for Eye Care (http://aurovikas.co.in/webaecshome.aspx).
- 2. Equipment for infrastructural capacity building: This was done at the level of the tertiary referral eye hospital in the region, MURHEC, and the Primary Health Centres (PHCs).
 - i. MURHEC: the existing equipment had been provided by LDS Charities, which donated a Zeiss Cirrus HD-OCT 500 (Carl Zeiss AG, Oberkochen, Germany) for Spectral Domain-Optical Coherence Tomography (SD-OCT) and one argon laser for Panretinal Photocoagulation (PRP), while the NHS BEH donated another argon laser (Appasamy Amogh Plus, Appasamy Associates, Chennai, India) through the VISION 2020 LINKS program.

Using the LCIF funding, we purchased:

- Alcon Constellation Vision System (Alcon Laboratories, Geneva, Switzerland) for vitreoretinal surgery.
- Outreach vehicle: Toyota Land Cruiser 70
 Troop Carrier (Toyota Motor Corporation,
 Toyota City, Japan) to transport a full team during outreach camps.
- Six portable non-mydriatic fundus cameras (Forus 3nethra Classic, Forus Health Pvt Ltd, Bengaluru, India) and six companion laptops.
- Three iCare ic100 (Icare Finland, Helsinki, Finland) for rapid intraocular pressure measurements.
- ii. *Primary Health Centres (PHCs)*: All were provided direct ophthalmoscopes, retinoscopes, and automatic blood pressure cuffs and glucometers.
- 3. Screening outreach camps: We planned and conducted screening outreach camps based on a three-pronged approach
 - i. Screening at PHCs, which had been operating monthly DM clinics: This made it feasible to screen these known individuals with DM for DR. The team performing the screenings travelled from MURHEC to all sites across the region. A more detailed protocol is elaborated in Figures 2 and 3.

- ii. Routine screening at existing DM clinics of District Hospitals, which run weekly DM clinics. One technician setup the non-mydriatic fundus camera to acquire photos during a visit.
- iii. Opportunistic screening of high-risk populations, such as corporate officers where more sedentary individuals can be screened for hypertension, DM, and DR.

Materials:

- Registration materials: patient forms/registration book, pens, portable laptop for registrar (if available)
- Examination: Snellen visual acuity charts (tumbling E should be included), penlight/muscle light, portable non-mydriatic fundus camera
- Diagnostic: Blood pressure cuff, glucometer, portable tonometer (portable tonometry devices based on rebound, non-contact, indentation mechanisms), mydriatic eye drops
- *Treatment:* Reading glasses, ophthalmic suspensions for dry eye and allergy
- Infrastructure support: screening tent/room, backup generator when grid power source fails

Key personnel and stations include:

- Registration, which can be done by a nonmedical personnel
- Health education/waiting area where patients can receive health education. This can be provided by a general nurse or an ophthalmic assistant.
- Vision and other vitals including blood pressure, intraocular pressure, blood sugar, weight, and height can be done by a nurse. In a busy screening, more than one station may be created.
- Fundus photography can be done by a trained non-medical personnel, ideally someone with experience capturing fundus photos or performing ophthalmoscopic examinations. If a dark room is not available, a blanket can be used to cover the patient to reduce ambient lighting for best image quality.
- Counseling and referral should be done by a trained healthcare provider, ideally an ophthalmic clinical officer or a midlevel provider who can interpret fundus photos and provides real time feed back to the patient. Store and forward teleretina or cloud-based artificial intelligence is limited by broadband availability in most rural areas of Sub-Saharan Africa (SSA), but these may become more realistic modalities when the information communication technology infrastructure enables.

Figure 2: Diabetic retinopathy screening outreach camp at a primary health centre

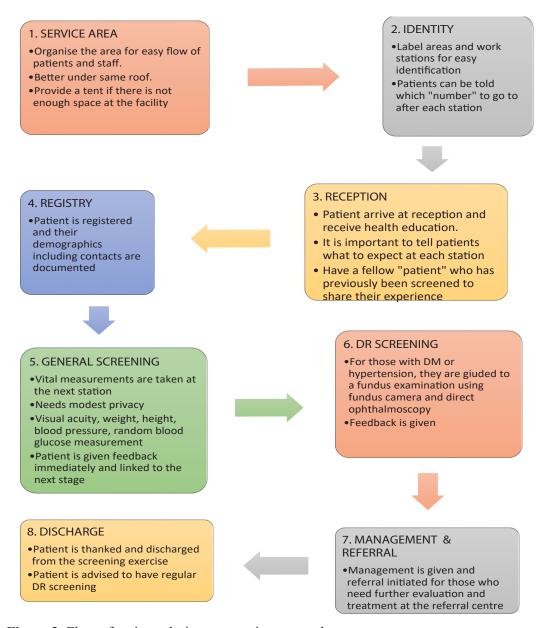


Figure 3: Flow of patients during a screening outreach camp

4. Awareness and advocacy

- i. Stakeholders: DR screening needs multisectoral collaboration including local government (in Uganda's case, the District leadership), national and regional political leaders (for example, the country's national eye health coordinator), management of health facilities, potential funders, opinion leaders, religious leaders, the local Lions Clubs, other NGOs involved in eye health and/or noncommunicable diseases, DM.
- ii. *Media*: We used radio and TV talk shows, social media platform messages inviting people for screening camps and ongoing boots-on-the-ground public awareness activities on DM and DR. This improved demand for screening and receiving therapeutic eye care if indicated.
- iii. Information Education and Communication (IEC) materials: These were developed in

- collaboration with the department of health education at the Ministry of Health, which improved alignment, used established materials, and avoided duplicating work. IEC materials included patient handbills and posters (print and soft copies). They were then officially launched by the Ministry of Health and distributed to several primary health centres in southwestern Uganda.
- iv. Major international awareness events: We used events such as the World Sight Day and World Diabetes Day to raise awareness about the screening activities and eye health in general. They were led by members of the collaborating Lions Clubs and activities included awareness marches and community meetings involving key leaders, such as the Minister of Health.

RESULTS

The metrics used for monitoring and evaluation are provided in Table 1. In brief, 9,991 were screened for DM, and 5,730 were screened for DR, in which 1,218 (21.3%) were then referred for therapeutic

care at MURHEC. However, only 220 of the 1,218 (18.1%) attended referral. Characteristics of this patient population are provided in Table 2. The total budget for a three-year implementation period was USD 548,133 summarized in Table 3.

 Table 1: Scorecard based on the project objectives and targets

Indicator	Target	Completed	(%)	Comment
Training				
Project management team	4	4	100%	Training was done at Aravind, India
Vitreoretinal Surgeon	1	1	100%	Sandwich training done at Bristol Eye Hospital, UK and Kilimanjaro Christian Medical College, Tanzania
Ophthalmic Clinical Officers (OCOs)	5	5	100%	These were formerly nursing staff at the participating facilities from districts without any eye cadre. They received a one-year training at the national school for Ophthalmic Clinical Officers, Uganda
Refresher trainings on DR	34	24	59%	For districts which already had eye health personnel, these were invited and given a refresher training on DR screening and management
Ophthalmic Assistants	34	34	100%	A nurse from each district was identified and trained as Ophthalmic Assistants to support the OCOs in providing routine screening
Infrastructure developme	ent			
Procure an outreach motor vehicle	1	1	100%	A 2 door 13-seater 4x4 Land cruiser for outreach purposes
Non-mydriatic fundus cameras	6	6	100%	3-nethra classic from Forus, India with tabletop chin support
Posterior segment vitrectomy system	1	1	100%	Alcon constellation machine
Portable tonometers	1	3	300%	One air puff tonometer was procured and two were donated by the vision 2020 Links partnership
Backup power generator	1	1	100%	
Service delivery				
Screening outreach camps	60	60	100%	These were conducted mostly at the primary health centres with an active DM clinic in the 17 Districts
Number of people screened for DM	10,000	9,991	100%	Opportunistic screening for DM was conducted to cater for the patients with previously undiagnosed DM type II, which generated more DR screenings
Number screened for DR	10,000	5,730	57%	
Number referred for care	N/A	1,218		21% of patients screened for DR required referral; of these individuals, 20% had visually significant cataract, 15% had uncorrected refractive error, 10% were glaucoma suspects, and 8% had any severity of DR
Number attending referral Number of people treated with anti-VEGF or panretinal photocoagulation	N/A 775	220 175	23%	18% of those referred attended their referral at MURHEC We have not commenced vitreoretinal surgery since the planned launch was March 2020 then the country was locked due to the COVID-19 pandemic

Table 2: Characteristics of diabetic retinopathy screening population (N = 5730)

Age (in years) Median (IQR), range	56 (46 – 66), 10-100			
Sex Female (%)	4189 (73.1)			
Male (%)	1541 (26.9)			
Presenting visual acuity, in better eye (Snellen metric)				
>6/6 to 6/12, frequency (%)	4629 (80.8%)			
<6/12 to <6/18, frequency (%)	288 (5.0%)			
6/18 to 6/60, frequency (%)	561 (9.8%)			
3/60 or worse, frequency (%)	252 (4.4%)			
Any diabetic retinopathy in at least one eye, frequency (prevalence estimate)	290 (5.1%, 95%CI, 4.5 – 5.7)			

Table 3: Budget by category of expenses

Category of expense	Expense in USD (% of total)
Therapeutic services and infrastructural	209,823 (38.3%)
development	
Screening implementation	157,092 (28.7%)
Human resources development	98,492 (18.0%)
Stakeholder involvement, advocacy, operations	60,612 (11.1%)
Community education and sensitization	22,114 (4.0%)

It is important to highlight that this project was intended to be implemented from October 2018 to September 2021. At the midway point, the project was delayed by five months due to the Covid-19 pandemic. From March to July 2020, the government of Uganda enacted a nationwide movement restriction in which any individual walking in public needed to have proof that they were an essential service worker. Motor vehicles without a special permit were stopped, cited, and forced to return to the originating locale. In healthcare, only emergencies were managed at health facilities and this applied to ophthalmic care as well. The screening outreach camps were temporarily suspended, and the intended launch of vitreoretinal surgery was delayed until the third quarter of 2020. In our estimation, there were likely individuals who could have presented for urgent surgery (e.g. macula-on retinal detachment), but the strict movement restriction of civilians severely curtailed healthcare seeking behaviour overall, including general accident and emergency (A&E) visits.

DISCUSSION

Lessons learned - what worked well

Involving stakeholders early was critical for success. Each partner had a strength that created synergy. For example, the Uganda Ministry of Health helped obtain the necessary regulatory approvals, developed IEC materials, authorized procurement of equipment for government health facilities. The local government officials supported establishment of screening outreach camps at local primary health centres, granting permission for training of personnel and recruiting

the most appropriate candidates, and importantly committing to recognising and remunerating the staff for retention. The Lions Clubs each robustly generated awareness and mobilisation for screening. The LCIF's connections to LAICO allowed the project management team to directly learn from proven management techniques and processes from leaders in this field in southern India.

Identifying personnel through the local governments for further training mitigated risk of "brain drain". These individuals were nurses already on their payroll of the local government budget and had strong social attachments to their community. It was very easy for them to return to their stations after the training. The shortage of nurses, midlevel providers, and ophthalmologists is widely documented in SSA9. The vitreoretinal surgeon (Dr. Sam Ruvuma) was already a medical retina specialist on the faculty at MUST. He experienced countless cases in which patients could not attend referral to the capital city for surgical retina and eventually losing vision. This emboldened his resolve to establish a surgical retina service and practice in this region of the country.

Building the DR screening around established DM clinics is a well-recognised, evidence-based intervention that increases uptake of the DR screening⁵. In our project, we were able to support several Districts to start DM clinics that were previously non-existent. This project also facilitated knowledge transfer of establishing and running DM clinics among the Districts.

Leveraging existing collaborations and networks added value to the project goals. For example, the VISION 2020 LINKS programme provided the

opportunity for the vitreoretinal surgeon training at KCMC and enhanced training of MUST's staff on grading DR. Local Lions Clubs were instrumental in serving as hubs for multisectoral collaboration. For instance, a Lions Club members spearheaded screening at a local bottling facility, a local headquarter of a medium-sized bank, and the regional prison.

From a comprehensive eye care standpoint, we were able to identify and refer patients with other common ophthalmic conditions, such as corneal diseases, cataract, and glaucoma suspects. Several common causes of visual impairment can be potentially addressed by any population eye health project with an initial focus on one risk group or disease process.

Challenges and pitfalls

Although over 1,200 patients were referred, only 18% attended referral at MURHEC despite the individual counselling, IEC, media campaigns, and community sensitization efforts. Follow up calls to those not attending referral resulted in over 50% reporting that the costs of transport was the main barrier. This was disproportionately higher among patients who came from far-flung districts compared to those that were nearer to MURHEC. None of those referred from the furthest Districts of Kabale, Kisoro, Rubanga, and Rukiga attended MURHEC, whereas nearly 50% of those referred from Mbarara District attended. While geography and its implicated transportation costs is an independent predictor of healthcare seeking in other studies on DR from East Africa^{10, 11}, the 50% in Mbarara who did not attend suggest that there still existed beliefs about eye health that must be modified given the referral process was clear and patients were educated on how manageable DR can be. Patients tend to perceive that they do not need to be concerned about their vision while still functional. Unfortunately, this perception is one of the reasons why late presentation is so frequent in SSA countries^{7, 12-15}, and the treatment outcomes for DR is suboptimal¹⁶. Even in large randomizedcontrolled trial settings in high-income countries, follow-up noncompliance is as large as one third by the fifth year¹⁷. To deal with this, we must attempt to implement as many "one and done" interventions as possible, such as combined panretinal photocoagulation and anti-VEGF injection, bilateral anti-VEGF injection, or bilateral sequential cataract extraction to name a few.

The second largest barrier for those who do attend referral is out of pocket expenditures. Because of the project's funding, all examinations and diagnostics have been fully subsidized. Treatment costs have been cost shared at 70-80%. A policy level solution to this would be the long-awaited national insurance scheme. The national and local leadership have made significant strides toward realizing this plan since 2005. A medium-term policy solution is through bulk contract purchasing through the essential medicines

programme¹⁸. Bevacizumab costs USD 550 per vial and typically enables 20 injections, thus the patients pay up to USD 27.5 per injection. The price can be as low as USD 2.75 per injection if bevacizumab is included in the essential medicines list and procured as a bulk contract. These financial barriers seem insurmountable, but the cost-effectiveness of proactive screening and treatment of DR is well-established¹⁹, even in low-resourced settings²⁰.

Moving from patient barriers to the service side of the equation, an ongoing challenge is keeping the trained OCOs and ophthalmic assistants engaged in eye healthcare. Our solution is to ensure these individuals have the space and supplies they need to carry on their work. Through intense lobbying by the project management team, the PHCs and District Hospitals allocated space for eye clinics at each of these locations, but there was an existential risk of new leadership reassigning these spaces to more well-funded or higher volume activities, such as expanding immunisation programmes, especially when the Covid-19 vaccines become available, or male circumcision3 and family planning.

At MURHEC, equipment maintenance has been an ongoing challenge. In retrospect, we should have funded the training of a biomedical engineer to service major ophthalmic equipment that can be done independent of the vendor, decreasing the instances where a manufacturer sends a technician from a regional hub. We advocate a more favourable approach to LMIC country health systems by these manufacturers by training local human resources to cover the more basic repair issues. The business benefit to the manufacturers would be expanded volume of purchases by governments. While MURHEC has been able to maintain its ophthalmic equipment, there are many instances of donated equipment falling into disrepair.

CONCLUSIONS

This DR screening and treatment project provided evidence that this can be successfully implemented in resource-limited settings and integrated into the general health system through human resources and infrastructural development. The lessons learned apply to other countries in SSA. However, linking screening to therapy remains challenged by geographic barriers. Based on this, LCIF has supported another project to decentralize a package of basic ophthalmic surgeries, such as cataract extraction, by strengthening the secondary level health facilities.

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