

## Tackling diabetic retinopathy from the grassroots

India is home to approximately 70 million people with diabetes, and this epidemic is estimated to increase to 130 million by 2045. India also has the most number of people with blindness worldwide. Diabetic retinopathy is the most common complication of diabetes, and approximately 2.6% of global blindness is caused by diabetes. In absolute terms, approximately 3–4.5 million people in India is estimated to suffer from vision threatening diabetic retinopathy (VTDR).<sup>[1]</sup> The treatment options for VTDR require costly devices and medications and the disease requires regular follow-up from diagnosis to the end-of-life. Given that 70% of the Indian population rely on out-of-pocket expenses for their healthcare, one person with VTDR in a household is sufficient to drive a family to below poverty line. Therefore, all measures should be initiated urgently to prevent people with diabetes to enter into the vicious cycle of diabetes, blindness, and poverty.

The authors of this special edition of the journal, the funder, the Queen Elizabeth Diamond Jubilee Trust, and the grant holders from Public Health Foundation of India (PHFI) and London School of Hygiene and Tropical Medicine (LSHTM) are to be commended for addressing this important public health problem by diverse and multiple initiatives at grassroot level. In the 5 years, the group has improved both the operational and clinical issues by involving and encouraging public-private partnerships. The initiatives range from capacity building, peer support, helplines, diverse screening models for VTDR both at community level and targeted screening for Type 1 diabetes and developing both operational and clinical guidelines focusing on the preventive strategies of this blinding condition.

As diabetic retinopathy programs require a systematic approach for regular screening of all individuals with diabetes, the group has emphasized the need for sustainable services and not one-off screening episode. The group has, therefore, crucially focused on building capacity for systematic screening. As an approximate calculation, India would require 70 million screening appointments every year as a start and exponential rise of capacity building is required every year to cater to the rising numbers diagnosed with diabetes.

Screening for VTDR is only one component of the blindness prevention program for people with diabetes. A parallel and equally important area is the prevention of risk factors that cause VTDR. Gilbert *et al.*, in the clinical guidelines stress the importance of controlling these risk factors, especially the control of diabetes and hypertension.<sup>[1]</sup> Therefore, in any capacity building exercise, it is crucial to empower every one involved in diabetes care with targets required to control these risk factors. This is well illustrated in the report by Balla *et al.* where a Certificate Course in Evidence Based Management of Diabetic Retinopathy (CCDR) has been developed and evaluated for physicians.<sup>[2]</sup> Over 575 physicians have successfully completed this competency-based certificate course. Rolling this to every physician involved in diabetes and retinopathy will significantly increase the impact already created by this initiative. Murthy *et al.* have further developed

operation guidelines to ensure a pyramid structure for capacity building beginning with empowering patients and caregivers and extending to community level staff, that is, to physicians and ophthalmologists. As these patients regularly attend primary care clinics for their medications, it provides ample opportunity for the primary care staff to share their knowledge on optimal control of these risk factors to patients at every visit.<sup>[3]</sup>

While community-based diabetic retinopathy screening is ideal for mass screening of people with diabetes, public awareness of blindness related to diabetes is key to success of these programs. As people with diabetes with VTDR are usually asymptomatic and the screening is technically challenging, patients need to be encouraged to be screened. Most programs, even in developed countries such as the United Kingdom, had to beat the inertia of patients accepting a screening episode. Gudlavalleti *et al.* describe how peer support groups were developed to solve these challenges in community health centers.<sup>[4]</sup> As we increase public awareness and patients are empowered with new knowledge either from the service providers or peers or any sources including the internet, the patients need their questions answered. Mukpalkar *et al.* set an example by developing a helpline for patients and show the numbers of people who accessed it highlighting the impact it can cause on both screening and treatment uptake.<sup>[5]</sup> Peer support is especially useful for special groups who are at most risk of nonattendance despite higher risk of visual loss. Rajalakshmi *et al.* report how peer support increased the uptake of screening for Type 1 diabetes.<sup>[6]</sup>

Type 1 diabetes is at particular risk of VTDR in the working age. As youngsters, these patients require significant mentoring both from their own family as well from healthcare professionals. With increasing incidence of Type 1 diabetes in India, special clinics should be encouraged for these patients and Praveen *et al.* emphasize how screening for Type 1 diabetes in tertiary care may be a successful model for the whole nation.<sup>[7]</sup>

Several screening models have been evaluated in this edition of the journal. A scalable and sustainable model in India is the telemedicine approach catering to a wider region than those attending the clinics. Currently, patients registered within the noncommunicable disease (NCD) clinics are the ideal low-hanging fruit to target. Murthy *et al.* showed how 85% of people enumerated in the NCD registers can be screened and treated simultaneously, if required.<sup>[7]</sup> Separating screening from treatment is a challenge as patients may be less willing to go elsewhere for treatment. However, laser devices are costly and ophthalmologists must be trained; hence, this ideal model may not be translatable nationally in India. However, telemedicine screening can be initiated widely. To scale up and sustain a DR screening program for systematic follow-up of individuals over years, a fundamental area that needs significant resources is electronic medical record (EMR) to maintain and recall the patient annually. The model developed by Murthy *et al.* with wide catchment area, telemedicine, and simultaneous treatment facilities and electronic patient record is vital for sustainability.<sup>[8]</sup>

There are a few unanswered questions that require further research. First, should everyone with diabetes in India be screened for VTDR annually or can we achieve targeted screening in India to ensure a more cost-effective model?

Epidemiological studies from India have shown that only 18% of people with diabetes have any retinopathy and only 2–3% have VTDR.<sup>[9,10]</sup> Although every individual with diabetes are at risk of VTDR, we need ways of identifying the high-risk groups who require urgent attention so that we can impact on rates of blindness more rapidly and cost-effectively. Second, cataract remains the most common cause of blindness<sup>[11]</sup> and more prevalent in people with diabetes; hence, screening programs should also encourage cataract referral and surgery to improve the quality of life of people with diabetes. The ORNATE India project funded by the Global Challenge Research Fund from the United Kingdom Research and Innovation will attempt to answer some of these questions to complement the activities completed and the work reported by the researchers in this edition of the journal.

In conclusion, there is a huge national drive for screening for diabetic retinopathy but unless associated with treatment opportunities and facilities for annual or biennial recall of patients, reducing blindness due to VTDR will remain a challenge. Therefore, the capacity building and initiatives in sustainable screening services as shown in several examples in this edition of the journal are key to reducing blindness due to this condition.

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