

Controlling Visual Loss From Retinopathy of Prematurity in India

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“The future is already here — it’s just not very evenly distributed.”

William Gibson

The recognition that neonatal death contributes considerably to infant mortality – and hence under five mortality rates – has led many countries to expand services for sick and preterm newborn infants. Indeed, the recent expansion of Special Newborn Care Units in India is having a major impact on the survival of sick and preterm neonates, driving down neonatal and infant mortality rates across the country [1]. However, as preterm infants are at greater risk of life-long impairments and disability than their full term counterparts, there is a growing realization that all babies should thrive as well as survive. This is being addressed by the Survive & Thrive Global Development Alliance which brings together governments, professional health associations, the private sector and non-profit partners to support governments and health professionals to improve health outcomes for mothers, newborns and children through clinical training, systems strengthening, and advocacy for policy change [2].

It has been recognized for decades that irreversible visual loss from retinopathy of prematurity (ROP) can be one of several disabling complications of preterm birth, and several epidemics of blindness from ROP have been described [3,4]. Since ROP was first described, much has been learnt about the condition, including risk factors, pathogenesis, and the natural history [5]. There is an international classification for ROP, and several multi-center randomized trials have provided evidence on optimal treatment for the sight-threatening stages of the condition (ST-ROP) in terms of indications, timing, and modality of treatment; all of which are described in an article in this issue by Shah, *et al.* [6].

India is now one of several low- and middle-income countries (LMIC) experiencing the ‘third epidemic’ of

blindness due to ROP. Estimates of the number of babies who survive preterm birth in India each year and are at risk of ST-ROP are described in an article in this issue by Blencowe, *et al.* [7], which also provides estimates of the number of preterm babies who went blind from ROP in India in the year 2010. An article by Chandra [8] highlights that lack of ROP screening was the most important reason why preterm infants attending a tertiary level eye department in India became blind. Similar findings have been reported from other LMIC, demonstrating the vital importance of high coverage with high quality screening and treatment, as described by Dutta, *et al.* [9] in an article in this issue.

Risk factors for ST-ROP are well known, and the control of modifiable risk factors for ROP, such as exposure to inadequately regulated supplemental oxygen, sepsis and failure to gain weight, reduces the incidence of ST-ROP [10]. In this supplement, Sivanadan, *et al.* [11] describe how a neonatal unit providing good quality of care in northern India showed a consistent decline in incidence of ROP needing laser. Good bedside care by nurses is essential for improving quality of care, but this needs investment by governments, policy makers and professionals [12]. Titrating oxygen therapy to keep oxygen saturation within target range, counseling mothers to promote availability of human breast milk for nutrition and following asepsis to prevent healthcare-associated infections are three important domains in which nurses can play major role to prevent ROP [13]. However, translation of these is a challenging task in the neonatal units.

Blindness due to ROP can be prevented by following an evidence-based screening protocol, detecting ROP in pre-threshold stage and providing time-bound treatment. All these need services of skilled ophthalmologists [14]. However, there is a huge gap between the number of babies needing ROP screening and number of available ophthalmologists. With 3.5 million preterm births every

year, and about 15000 ophthalmologists practicing in India each ophthalmologist would need to screen more than 200 preterm neonates every year. Moreover, only a small proportion of ophthalmologists are trained in use of indirect ophthalmoscopy in neonates. This huge demand-supply gap can be met only by technological solutions like use of wide-angle retinal camera, image capturing by trained technicians, and remote image review and reporting by trained ophthalmologists [15]. Despite increasing number of legal cases related to loss of eyesight due to late detection, parents and community in general are unaware about ROP and need of timely screening. Due to patient overload, a large proportion of preterm neonates are discharged home before the screening window starts at 3-4 weeks of postnatal age. An article by Mariam, *et al.* [16] provides information for parents about ROP and how to respond to questions they may ask.

More innovative solutions, like training of ophthalmic technician as in KIDROP model for ROP screening, are needed to reach interiors of India where a large number of preterm neonates are being saved, but cannot be screened due to non-availability of ophthalmologists [17]. Services also need to be in place to detect and manage the longer term ocular complications of preterm birth. In this issue, Vijayalakshmi, *et al.* [18] review the literature on this topic, and provide data from their own institution. However, a recent situation analysis undertaken in the largest eye care training institutions in 11 cities across India [19] shows that there are considerable gaps in the eye health system in relation to the detection and management of ROP, and more needs to be done to increase the coverage of effective programs. Studying epidemiology of ROP in special care neonatal units can help in understanding risk factors of severe ROP and build prediction models to identify neonates requiring early screening. There is need to evaluate the effectiveness and safety of anti-vascular endothelial growth factor (anti-VEGF) agents for ROP, which although quicker and easier to deliver than laser, can be associated with ocular sequelae and systemic complications [20].

Providers of neonatal care play a vital role in reducing the risk of ST-ROP, and should play a central role in coordination of screening and treatment. Professional organizations of pediatricians and neonatologists can accelerate monitoring and evaluation of the effectiveness of these programs so that best practices can be taken to scale, so that preterm infants can survive, and thrive without visual loss from ROP.

Funding : This supplement of the journal is supported by a grant from Queen Elizabeth Diamond Jubilee Trust (QEDJT) through Public Health Foundation of India.

Competing interest: None stated.

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