Retinal Vascular Diseases of the newborns: emerging opportunities for AI, imaging and other 'big' technologies to prevent a growing epidemic of very early childhood blindness

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ABSTRACT

Retinal vascular diseases and many other diseases in the newborn retina are often progressive and can lead to complete irreversible blindness very soon after birth or in early childhood. With current understanding following deep scientific research, technological advancements in the field, and acquired skills by retinal surgeons, many of these conditions are now amenable to good treatment options, leading to prevention of blindness and preservation of visual function. The caveat and the challenge are an early diagnosis of these disorders that are often silent and asymptomatic. They can be often diagnosed soon after birth by universal fundoscopy/ fundus imaging by a retinal camera. The gap in care is absence of robust global public health approach to preventing visual disability of newborns and innovative development for a handy camera, like an 'EyeStetho'' at bedside of every newborn.

Keywords: Newborn fundus camera, Neonatal eye screening, Blindness prevention in newborns, Artificial intelligence, Sustainable development goals.

Retinal vascular diseases of the newborn eye include a group of diseases that are very much amenable to currently available treatments. The caveat and the challenge are an early diagnosis of these disorders that are often silent, asymptomatic and 'hidden' from the view of the children's specialists and other caregivers, during the 'routine care of a newborn'.

As the most critical tissue of the eye that provides' vision,' the retina cannot be replaced at the current level of medical science. The good news is that a newborn retina is pristine and almost the same across the diverse people on our planet, except for some differences in color and is very much suited for photography and Machine learning systems. Managing retinal diseases by appropriate newborn fundus screening, and timely preventive and curative treatments is the only way to approach these disorders before irreversible tissue damage and consequent visual dysfunction occurs.¹⁻⁴

Retinal vascular disorders in babies can be congenital or acquired very often soon after birth.¹ Congenital conditions include most commonly Coats disease, familial exudative vitreoretinopathies, syndromic conditions associated with retinal vasculopathies and persistent fetal vasculature syndrome. Universal newborn fundoscopy/ Fundus photography can detect these treatable conditions very much in the neonatal period of life and can detect many other conditions such as eye cancer (Retinoblastoma), viral and other retinal infections (TORCH infections) etc.^{1.4}

Amongst the acquired newborn retinal vascular disease, Retinopathy of prematurity (ROP) has emerged as an epidemic of huge proportions.⁵.⁶ It may seem that all these retinal vascular disorders are rare conditions, but the impact on the whole life of the newborn and their family is tremendous and treating early is cost-beneficial³, and highly successful in most cases. ROP has brought medical experts from many regions of the world together who have

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collaborated and updated the international classification to represent the current scenario.^{7,8}

ROP is currently considered to be in a third epidemic status,^{5,6} though one could argue that emerging trends of ROP in the last few years could be categorized as an alarming 'Fourth epidemic'. Numbers are huge and rapidly increasing.^{5,6,9}

The difference from the third epidemic is that it has now extended into the hinterland and rural populations, and into the urban and rural areas of almost all countries, especially the low-income countries in Africa and Asia,^{6,10} and not confined to the few urbanized pockets of the low and middleincome countries, as seen in the third epidemic. The varied and unusual manifestations of ROP in these communities are slowly coming to the notice of ROP specialists in high income urban centers. Atypical fulminant ROP, exudative ROP, severe oxygen induced retinopathies, bleb-shaped ROP, Hybrid ROP, posterior Zone I ROP, are few of the newer entities that were not seen in the first three ROP epidemics.¹¹ These unusual presentations, compounded by the extremely poor weight gain, severe anemia, sometimes chronic and generational, with no accessibility, awareness and the rampant use of intraocular anti-VEGF injections^{12,13} with least monitoring, guidelines, skills and follow-up are all throwing up very huge challenges and in large numbers -these constitute a new ROP epidemic quite different and extremely challenging to manage, as compared to the third epidemic.

As with any big challenge, the opportunities also are galore. One can learn from past public health approach successes. With very poor resources, no big technology and very basic communication links, the world under guidance of WHO conquered smallpox many decades ago.¹⁴ The success has been attributed to the coordinated global teamwork, a very robust plan and individual efforts of the grassroots community health workers in every country and an inexpensive, innovative two-pronged needle, which improved the efficacy of the small-pox vaccine. The WHO-Polio eradication program, owned and executed by child health care teams, again through grassroots community health workers is recent decades that helped in prevention of limb deformities from a communicable disease of early childhood.

'Sarvendriyanam Nainam Pradhanam' in ancient Sanskrit texts refers to the fact that 'of all sense organs, eyes are of supreme importance'. Prevention of newborn 'visual disability' as a public health problem needs to be given the same importance and attention as the limb disability of polio. NCD's (Non communicable diseases) are the new buzzword at the WHO. Governments and many health policy makers and NGOs are embarking on ambitious programs to reduce mortality and morbidity from NCD's. However, the newborn eye and its retinal vascular diseases, that are often like Diabetic Retinopathy (an NCD morbidity), but more destructive and impacting lives and livelihoods of growing up citizens, do not receive the same thrust in healthcare. The silent newborns and their families do not have a voice since the conditions manifest only much later when the eye is irreversibly blind or visually impaired and the underlying cause may not be obvious in a 'phthisical eye'. Since vision is paramount to developmental milestones in a baby, visual disability has profound impact on overall development and whole life of the baby and family.

So far, the ROP screening and newborn retinal disorders case finding programs, especially in the communities that are seeing the 'fourth epidemic,' has been largely owned and executed by Eye specialists.^{3-7, 9,10} Many children present quite late with irreversible blindness or advanced disease that has suboptimal outcomes even with advanced intervention.^{1,5,6,15} To scale up the reach to a universal retinal screening, that would detect all these early treatable retinal vascular and other diseases, a paradigm shift is needed, both in the approach and in the technological innovation.

As a pediatric retinal surgeon, having experienced over the last three decades the pain and despair of children and families who lost vision due to lack of a universal complete eye screening program in newborns, an urgent need is felt to address this issue on a large scale. Eye and retinal screening should be owned and driven by child health care providers, who are the best to get trained in eye screening of every newborn baby, like screening at birth for major organs like the heart, lungs, digestive system -mostly, though not exclusively, by the humble stethoscope as the primary tool at the grassroots level besides looking for early symptoms. It is heartening that in 2024, the WHO-South East Asia Regional office (WHO-SEARO) released the guidelines for Universal newborn eye screening.¹⁶ This is a welcome step in the right direction but does not address the emerging epidemic of ROP and other congenital retinal vascular diseases. The current cameras to image a newborn baby are too big, expensive, have maintenance costs, cannot be used by grassroot health workers, and are not universally available.^{2,4,10}

We have reached the moon and are going to Mars and even

exploring the sun. AI (Artificial Intelligence), imaging technologies, cameras, social media outreach, and big Tech companies are all revolutionary in the times of today. Yet a simple 'Eyestetho'' like camera to image rapidly the 15-18mm inside a newborn baby eye is not in the hands of our health workers. The eyes that will use the AI, see the stars and the moon should be a priority of our technology teams and health policy makers. All of them have a greater opportunity now than ever before, to get together and address the emerging problem of Non-communicable Diseases (NCD) of newborn retinal vascular blinding diseases. The aspirational development of an individual newborn and the Sustainable Development Goals (SDG's) at the global level both cannot be achieved if the vision disability is not prevented in our newborns.¹⁷ The baby born today cannot wait any longer to get their 'Right to Sight'.

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