



## Barriers of Retinopathy Of Prematurity care in Nepal

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Retinopathy of prematurity (ROP) is a potentially blinding disease of the infants born preterm and has been recognised as the fifth leading cause of childhood blindness in post-industrial and developed nations by World Health Organisation's Vision 2020 programme. Three phases of ROP epidemics have been observed worldwide since this disease was first described. Nepal is currently facing the third epidemic with improved neonatal intensive care and survival of the preterm children. The neonatal mortality rate in Nepal has significantly decreased from 27.998 per 1000 live births to 16.998 per 1000 live births over the last decade according to the United Nations Children's Fund (UNICEF) (Gilbert et al. 2001). Each year, globally, about 32,300 babies are substantially affected by ROP out of which around 20,000 result in severe visual impairment or blindness (Hong et al., 2022).

In Nepal, the incidence of ROP has been recorded as 22-30%. Among these, 3.2% had severe stages of ROP requiring intervention. Recently, due to the financial, social, and medical progress there has been expansion of the neonatal services throughout the country leading to increase in the neonatal survival. Thus, an increase can be seen in the prevalence of ROP across various parts of the country. Multiple studies in different centres concluded significant risk factors of developing ROP as oxygen supplementation, low birth weight, low gestational age, and sepsis (Adhikari et al., 2008; Yadav et al., 2020).

Though the survival of the premature and low gestational age babies has increased, ROP screening and treatment are either not universally available or not of sufficient quality.

According to a study by Shrestha et al. (2022)

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regarding Knowledge, Attitude, and Practice among Paediatricians in Nepal, it was found that although they were aware about ROP and the risk factors and need for referral, lack of well-equipped transportation system for sick babies to eye centres was the major barrier reported. In a similar study done by Shrestha et al. (2023), the reasons for non-referral among Paediatricians were absent of indoor screening facilities due to lack of trained ophthalmologists attached to the hospital, poor financial status of the parents, and no trained ophthalmologists in the nearby areas.

According to Padhi and his team (2019), the main reasons for late presentation in a series of patients with advanced ROP were due to barriers to early screening for ROP which were related to availability of trained human resources, ignorance of “parents and health care personnel,” and distance from the point of care. Adams et al. (2020) notes that, since the total prevention of premature birth is not possible and with increased survival seen after premature deliveries, low incidence of ROP is associated with high quality neonatal intensive care units (NICUs) established ROP screening protocols and availability of trained ROP specialists. With education, training, and collaboration between ophthalmologists and neonatologists; and using the skills of other health care professionals, it should be possible to bring ROP standards in middle-income countries up to those in high income countries. This would prevent significant visual morbidity and with it improve the quality and lives of premature children and their parents.

Lack of awareness of the importance of screening can lead to delayed presentation

of severe ROP and damage to vision (Padhi et al., 2019). This has been identified as being more likely in rural areas as opposed to metropolitan areas in India. This is likely to be similar in many other countries with a developing ROP epidemic. Parents need to be educated on the importance of returning for follow-up screening once their baby has been discharged from the neonatal unit. The number of screeners per country varies significantly from 1916 live births per screener in Sweden to 184,400 in China (Adams et al., 2020). The Indian Retinopathy of Prematurity Society has reported that <1% of ophthalmologists in India are directly involved in ROP care (Vinekar et al., 2019). It has 215 members, compared with over 20,000 members of the All India Ophthalmological Society similar to Nepal, with more than 450 Ophthalmologists, only a handful of ophthalmologists are confident in ROP screening and with ROP treatment centres being very limited.

More grim than the shortage of experts are the unmet challenges while facing the situation 1) lack of a uniform pattern of ROP screening, 2) lack of collaboration between the neonatologists, paediatricians, and ophthalmologists, 3) lack of collaboration between the private and public sectors, 4) unsolved medicolegal aspects relating to timely screening, appropriate follow-up and treatment, 5) lack of uniform guidelines for intravitreal anti-vascular endothelial growth factor injections, and 6) lack of a roadmap and resources for long-term follow-up of these ROP graduates.

The main barriers in Nepal would be:

1. Lack of awareness among medical professionals and parents
2. Lack of trained manpower
3. Lack of instruments
4. Geographical location
5. Lack of proper NICU setups for survival of babies/suboptimal neonatal care which places more mature infants at risk.
6. Perinatal mortality high
7. Lack of rigorous counselling
8. Though the government is expanding services for neonates, including those born prematurely, these initiatives do not incorporate control of complications of preterm birth including ROP, as relevant policies and guidelines are not there
9. Inadequate coverage of high quality programmes for detection and treatment of sight threatening ROP
10. Lack of national guidelines
11. Unknown disease burden since there are no community-based surveys and electronic hospital records to know the actual burden of the disease
12. Poor quality of referrals
13. Failure of parents to recognise the importance of early screening due to misbeliefs such as frequent or too early eye examinations could damage the neonates eyes

In conclusion, the main barriers to early screening for ROP are related to availability of trained human resources, ignorance of “parents and health care personnel,” and distance from the point of care. This calls for training of ophthalmologists, advocacy with neonatologists and parents, and creating systems for better coordination and compliance of the care providers.



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