

Retinopathy of Prematurity: Screening Delayed is Screening Denied

Somnath Chakraborty*

Retina Institute of Bengal, India

***Corresponding Author:** Somnath Chakraborty, Retina Institute of Bengal, India.

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Abstract

Introduction: Retinopathy of Prematurity (ROP) is emerging as the leading cause of childhood blindness in India. Babies are not born with ROP hence, with proper screening, detection and treatment of eligible cases; ROP related blindness can be prevented. In remote parts of India babies often do not get the first screening within the stipulated time.

Aim: This study was done to analyze what proportion of babies did not receive their first ROP screening within the 30 days of life and what were the reasons for the same.

Methods: A retrospective analysis of data from all babies screened for ROP at a dedicated retina clinic, in remote part of Eastern India, from April 2018 to April 2019. For babies who had delayed screening, discussions were held with the neonatologists and the parents to try and ascertain the reasons for the same.

Results: Of the 142 babies who got their first ROP screening in the study period, 42.3% received the same beyond 30 days of life. 28.3% received their first screening beyond 60 days of life. Of these, 53.3% had Gestational age at birth (GA) < 30 weeks and 33.3% had birth weight < 1200 grams. Based on discussion with parents and neonatologists, four important reasons were found for the delay in referrals.

Conclusion: As NICU facilities evolve in remote parts of India, it is important to create greater awareness regarding ROP screening criteria and appropriate timing. Otherwise we may fail to save many precious eyes.

Keywords: *Retinopathy of Prematurity; Retina; Childhood Blindness; Community Ophthalmology*

Key Messages

With developed Neonatal care, the incidence of ROP is on the rise in India. Timely screening and intervention can prevent ROP related blindness. However, ROP screening is often delayed in remote parts of the country due to various reasons. This challenge has to be overcome

Introduction

Nearly 2% of total live births in India are infants with birth weight less than 1500 grams and gestational age below 34 weeks [1]. Although the exact prevalence of ROP in India is not known, the incidence reported is between 22 - 52% [2,3]. 20% of these babies have severe ROP and can go completely blind, if not diagnosed and treated at the right time [4]. With improved survival rate of premature babies across the country the number of infants who need ROP screening is bound to increase [5]. A neonate is not born with ROP, which allows us a unique opportunity to screen out babies at risk of blindness from ROP.

The Indian guidelines of ROP screening mandates that the first screening should be done in all eligible babies at 31 weeks PCA (post conceptional age) or 3 - 4 weeks after birth (whichever is earlier) [6]. For infants weighing less than 1200 grams at birth and those born at 24 - 30 weeks gestational age (GA) screening has to be done early, usually not later than 2 - 3 weeks after birth [6].

As GA in weeks is often difficult to calculate in developing countries like ours hence, to avoid confusion, Jalali, *et al.* have recommended a strategy based on age: 'Complete one ROP screening session definitely before 'Day 30' of life and in smaller babies (possibly less than 30 weeks and/or birth weight less than 1200 gms), by day 20 of life' [7].

Our institute has been running a regular ROP screening programme since inception. There is a lack of centers doing regular ROP programme in our area and we realized babies referred to us, were often getting their first ROP screening beyond 30 days of life. Therefore, we did a retrospective analysis of our in-house ROP data to find out how many babies received their first ROP screening beyond 30 days of life and what were the reasons, for this delay.

Subjects and Methods

In this retrospective, observational case series data of all babies who received their first ROP screening at our center from April 2016 till April 2019, was collected. A note was made of the GA at birth, Birth Weight and age at the time of first screening. For babies who received their first screening beyond 30 days of life, we talked to the referring neonatologist and parents, to try and understand the reason for the delay.

Results

In the time period of the study, 142 babies received their first ROP screening in our center. Of these for 60 babies, the age at the time of the first screening was more than 30 days. Of these for 17 babies the age at the time of the first screening, was more than 60 days. 3 out of these 17 babies were screened at 5 months of age, 1 at 6 months, 1 at 7 months and another at 11 months.

For 32 babies, GA at birth was < 30 weeks and for 28 GA at birth was \geq 30 weeks. Amongst the 32 babies with GA < 30 weeks, 26 were seen between > 30 to 60 days of life, 4 between > 60 to 90 days of life and 2 beyond 90 days of life (1 at 5 months of age and 1 at 11 months of age). 11 of these babies developed ROP, 2 of whom regressed spontaneously, 6 regressed after Laser, 1 presented with Stage 5 ROP and had to be referred to a higher center and 2 were lost on follow-up.

Amongst the 28 babies with GA \geq 30 weeks, 17 babies were seen between > 30 to 60 days of life, 7 between > 60 days to 90 days, 4 beyond 90 days of life (2 at 5 months of life, 1 at 6 months and 1 at 7 months of life). 3 babies developed ROP, 2 of who regressed spontaneously, 1 regressed after Laser.

20 of these 60 babies had birth weight < 1200 grams, 13 of whom were also very premature, with GA < 28 weeks while, 7 had GA at birth \geq 30 weeks. 16 were seen for the first time between > 30 to 60 days of life, 3 at 3 months and 1 at 5 months of age. 7 developed ROP, of whom 1 regressed spontaneously, 5 resolved after LASER and 1 was lost on Follow-up.

Amongst the 13 babies who had GA at birth < 30 weeks and Birth weight < 1200 grams, 11 received their first screening between > 30 to 60 days of life and 2 babies at 3 months of age. 7 of them developed ROP, 1 regressed spontaneously and 5 regressed after Laser and 1 was lost on Follow-up.

On enquiring with the neonatologists and parents regarding the reason for delay we found that, in 25 babies the NICU was located in a remote area with no trained specialists to do ROP screening. In 20 babies parents had been told about the need for ROP screening but, they were not sure how urgent it was or where to go for the same. In 10 babies the parents themselves hesitated in taking the baby for an eye check-up. They wanted to delay the evaluation as they felt the baby was too small for the same. Of these, 4 babies had GA < 30 weeks at birth, 1 of whom was brought at 5 months of age. Parents of 5 babies claimed that they were never told about ROP screening. All of these 5

babies were seen beyond 60 days of life. 2 had GA < 30 weeks at birth and 1 had Birth weight < 1200 gram. 1 of these babies (GA 28 weeks, Birth weight 1.3 Kgs) presented at 11 months of age with Bi-lateral Stage 5 ROP.

Discussion

In our series, 42.3% (60/142) babies received their first ROP screening at an age beyond 30 days and 28.3% (17/60) beyond 60 days of life.

For infants weighing < 1200 grams at birth and/or GA < 30 weeks at birth ROP screening needs to be performed earlier, usually not later than 2 - 3 weeks after birth [6,7]. In our series more than half (53.3% (32/60)) of the babies had GA < 30 weeks and 1/3rd (20/60) had birth weight < 1200 grams. There were 13 babies who fulfilled both criteria and yet did not receive their first ROP screening within 30 days of life, with 2 of them getting their first screening at 3 months.

As a direct result of late referral, 1 baby presented with Bi-lateral Stage 5 ROP. The baby had a GA < 30 weeks at birth and was brought to us by the parents at 11 months of age. The parents claimed they were never told about ROP screening by the neonatologist. In a report from a tertiary retina center in North India, 86.4% of infants presenting with Stage 5 ROP were never screened and nearly 2/3rd of infants were brought to the clinic by the parents. In that series too, none of the babies were referred by pediatricians [8]. In our series parents of 8.33% (5/60) babies claimed they were never told about ROP screening by their neonatologists. In a telephonic survey by Patwardhan., *et al.* [9] amongst pediatricians registered with Indian Academy of Pediatrics from six states of India, in spite of 100% awareness regarding ROP, 34% were found to never refer babies for screening. This practice was more so amongst doctors in rural areas or government sectors. This non-referral was because of a perceived lack of ophthalmologists trained in ROP, in their vicinity. If a Registry of ophthalmologists certified to screen for ROP can be created for the country and circulated with the help of various associations of Paediatricians and Neonatologists, this may help us overcome this challenge.

Amongst babies screened late, 23.3% (14/60) developed ROP. This was more than 4 times (4.9% (4/82) vs. 23.3% (14/60)) the incidence of ROP in our series amongst babies screened before 30 days of life. Though delayed screening itself cannot be considered a risk factor for ROP yet, this observation probably suggests that babies who are most premature or sick and therefore, likely to stay in NICU longer, are the ones who are also getting screened late. This hypothesis is supported by the fact that in our series more than half (53.3% (32/60)) of these babies had GA < 30 weeks and 1/3rd (20/60) had birth weight < 1200 grams. This is also the reason why ideally all eligible babies should be screened at the NICU itself. Jalali., *et al.* [7] has shown a 1.92 times higher risk of a baby presenting in Stage 4 and 5, in a direct referral based ROP screening programme compared to a NICU based ROP screening programme. Unfortunately, there is a lack of availability of ophthalmologists trained in ROP, more so in remote parts of India. In the geographical area where we practice, there are no trained ROP specialists in the four districts beyond our city limits. Therefore, it is difficult to provide a NICU-based ROP screening programme for our whole community. In our series lack of a trained retina specialist in vicinity of the NICU was the reason for delayed screening in 41.7% (25/60) cases. Patwardhan., *et al.* [9] reported that in India, non availability of a trained ophthalmologist is a major hindrance in ROP screening, resulting in much lower screening in rural areas than urban areas (39% vs 75%) even with similar awareness. The KID-ROP model [10] has successfully surmounted this challenge in South India and a nationwide programme on similar lines can be very helpful.

In 1/3rd (20/60) of the babies in this series the reason for delay was inadequate counseling of the parents regarding the importance of timely ROP screening at the time of discharge. Some of the parents also got delayed as they were not told clearly where the facility for ROP screening was available near-by. The National Neonatology Forum of India (NNF) in its guidelines for ROP screening states that, communication with the parents regarding timely screening for ROP, seriousness of the issue, possible findings and consequences is extremely important [10]. Though awareness about ROP may have improved amongst Neonatologists, still a lot more is probably needed to be done to ensure proper counseling of parents regarding the same at the time of discharge. Development of counseling materials jointly by the Indian Academy of Paediatricians (IAP) and All India Ophthalmological Society (AIOS), can help overcome this challenge. The availability

of an online list of certified ophthalmologists trained in ROP screening, with their location can help reduce delay in locating a proper screening facility.

Another reason for delay identified in our series in 16.7% (10/60) babies was non-compliance by parents. In these cases, parents were skeptical about exposing their “small babies” to any procedures, more so as to them, the eyes appeared normal. In 25% (4/10) of these cases the babies were extremely premature (< 30 weeks GA at birth) and at least 1 of these babies was brought for the first screening at 5 months of age. The lack of external signs of ROP means that, parents in our area are often skeptical about the need for the screening. Lack of imaging devices like Ret Cam sometimes further aggravate the situation and lead to non-compliance with follow-ups. In our series there were 3 babies who were lost on follow-up, all of who had various stages of ROP and 1 of who had been advised laser. Nationwide public awareness campaigns like those for Diabetic Retinopathy, seems a possible way to make people understand the dangers of ignoring timely ROP screening.

Our experience may have been unique to our geographical location. However, as NICU facilities evolve in remote parts of India it is possible that lack of awareness of the importance of timing of ROP screening may prevent us from saving many precious eyes. Availability of nationwide programmes similar to the KID-ROP model [10] can definitely have a positive impact. Till then simple steps like ensuring greater awareness about the importance of timing in ROP screening amongst neonatologists, public education programmes regarding this preventable cause of life-long blindness and creation of an online list of ophthalmologists trained in ROP screening with their locations, can go a long way.

Conclusion

As NICU facilities evolve in remote parts of India, it is important to create greater awareness regarding ROP screening criteria and appropriate timing. Otherwise we may fail to save many precious eyes.

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