

Retinopathy of Prematurity Profile and Trend Over the Years: Experience From a Two-tier City in Eastern India

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The Retinopathy of Prematurity (ROP) epidemic is no more confined to metro cities and has spread to interior states including Eastern India. There is hardly any published data available on the subject, including the incidence and profile of babies with ROP, screening experience with binocular indirect ophthalmoscope and wide-field digital retinal imaging, as well as the difficulties faced with each model. In our cohort, 33.2 % had ROP and 25.3 % of babies with ROP required treatment. Mean (SD) gestational age and birth weight were 30.7 (2.53) weeks (range: 23 to 37 weeks) and 1315.09 (322.30) grams (range: 650-2500 grams), respectively. The hurdles in establishing a screening program are discussed. Binocular indirect ophthalmoscopy and wide-field digital retinal imaging were complementary rather than a substitute for each other in a non-telescreening model.

Keywords: Binocular indirect ophthalmoscope, Retinopathy of Prematurity, Telescreening, Wide-field digital retinal imaging.

Retinopathy of Prematurity (ROP) remains one of the leading causes of childhood blindness worldwide [1]. India, like other middle-income countries, is experiencing the 'third epidemic' of blindness due to ROP[2] and is the country with highest number of preterm births *i.e.* 3.5 million annually [3]. Of the 27 million live-births, approximately 9% are born below 2000 grams [4], some of which would be the potential 'at-risk' population for ROP. Realising the importance, Government of India has recently included ROP in the new born screening program under Rashtriya Bal Swasthaya Karyakram (RBSK). The disease profile varies remarkably from developing to the developed nations [1], and Eastern India is no exception. We herein report the profile of ROP, changing trends over years, our personal experience and hurdles faced with both methods of screening *viz.*, binocular indirect ophthalmoscope (BIO) and wide-field digital retinal imaging (WFDRI).

METHODS

This perspective is based on the retrospective analysis of ROP data-base and personal experience of the pediatric retina specialists involved with ROP screening with BIO and WFDRI at a centre in Eastern India from January 2010 to December 2015. Screening was performed in all preterm neonates who were born <34 weeks of gestational age and/or <1750 grams birthweight; as well as in babies 34-37 weeks of gestational age or 1750-2000 grams birthweight, if they had risk factors for ROP [5].

Bhubaneswar, the capital of Odisha in Eastern India, has a population of 8,37,737 as per 2011 census. Seven years ago, there was hardly any organized ROP screening program at Bhubaneswar despite budding neonatal intensive care units (NICU) across the city. In 2008, we initiated the screening in two pediatric units within the city. In the initial two years, screening was irregular and erratic with poor data collection and documentation; the strategy kept on changing and evolved over time. The pool of babies for screening was less initially in 2010 and reached its maximum in 2015. Parental counselling, putting up ROP awareness wall posters at all the NICUs in the city, continued medical education (for pediatricians, parents and other child health care providers), workshops among government policy makers, ROP-related talks in regional television channels, and public awareness programs on special occasions (like national new born week, world ROP day and children's day) strengthened the screening further.

1. *Year 2010:* At the start of our program in 2010, we had to depend entirely on BIO. With one retina specialist to screen the babies, it was difficult attend all the babies on time. The awareness for screening among pediatricians and parents was very poor and depended upon their prior experience and exposure on the subject. Some centres were highly sophisticated but had high resistance for screening partly due to apprehension that ROP in their units might reflect a suboptimum care. In contrast, there were NICUs with low infrastructure but high level of

awareness for screening. The pool of babies was mainly from our weekly visit to the nearby NICUs and our request to allow us to screen the babies at risk with poor compliance to follow-up. Sometimes we had to screen too early before discharge just to keep them under our screening net. The reluctance for laser from the pediatricians was high due to their apprehension that it could harm the health and life of the baby. We did not have any means to show the ocular pathology except free hand drawings. The babies referred from the ophthalmologists for ROP screening were mostly 6 months and older with cicatricial ROP and blindness.

2. *Years 2010-14:* There was an increase in the number of babies referred by the pediatricians after we procured RetCam in 2010. However, screening with BIO was still the preferred choice. RetCam was used for disease documentation whenever feasible or as a backup/additional strategy in special situations, time constraints or unavailability of the pediatric retina specialist. Attending the babies at NICU on the same day of request helped gain their confidence. Use of ROP evaluation leaflets, ROP help line number and a brief message on the subject helped too. A reminder call from us prior to each visit also ensured a high compliance to follow-up.

3. *Years 2014 onwards:* From 2014 onwards, we have been using both BIO and RetCam for screening unless the baby is too sick for examination. With the addition of another pediatric retina specialist we had an opportunity to go out for screening twice a week in addition to two specialized ROP clinics at the campus every week. The parents were counselled together by showing the RetCam images of their babies on a large screen, ensuring a better compliance to follow up.

4. *Tele-consultation of the screeners (2010 onwards):* Whenever and wherever required, the images used to be electronically transmitted to another pediatric retina specialist at a centre of excellence in Southern India for a second opinion in challenging circumstances.

OUTCOME OF SCREENING

Out of the 2240 babies screened, 744 (33.2%) had ROP. This was found to be higher than the incidence reported by some [6] but lower than that found by others [7-10]. The mean gestational age of the babies with ROP was 30.7 (SD, 2.53) weeks (range: 23 to 37 weeks) and the mean birth weight was 1315.09 (SD, 322.30) g (range: 650-2500 g). Among the babies with ROP, 31.9% had a birth weight more than 1500 g, the limit set by American Academy of Pediatrics [11]. The increasing load each year could have been due to increase in the number of NICUs, new NICU in the peripheral districts, better

neonatal care and increased survival. **Fig. 1** depicts the trend of babies screened and detected to have ROP from 2010 to 2015. Six babies had ROP despite being near term and birthweight well beyond screening standards. All these babies had a stormy neonatal course and two among them had aggressive posterior retinopathy of prematurity (APROP), and required laser. While only two babies were diagnosed with APROP in 2010, this number rose to 28 in 2015.

The disease regressed spontaneously in 511 babies, while 188 (25.3%) needed treatment. The number of babies treated with laser increased each year. The proportion of babies with APROP among those who required treatment increased every year (**Fig. 2**). Majority of babies (76.6%) regressed only with laser photocoagulation; rest required additional modalities of treatment including intravitreal vascular endothelial growth factor inhibitors (24 babies) and vitreo-retinal surgeries.

There were 45 babies who presented for the first time (treatment naïve) with cicatricial stage 4B and stage 5 ROP, with profound visual impairment. The chronological age at presentation ranged from 6 months to 12.5 years. The increase in number of these babies with advanced cicatricial ROP over the years (**Fig. 3**) was a major concern for us. Majority (41 babies, 91.1 %) of them belonged to districts in the peripheries, while the rest belonged to the city of our screening location. The probable cause for an increased number of treatment naïve advanced ROP hailing from peripheral districts

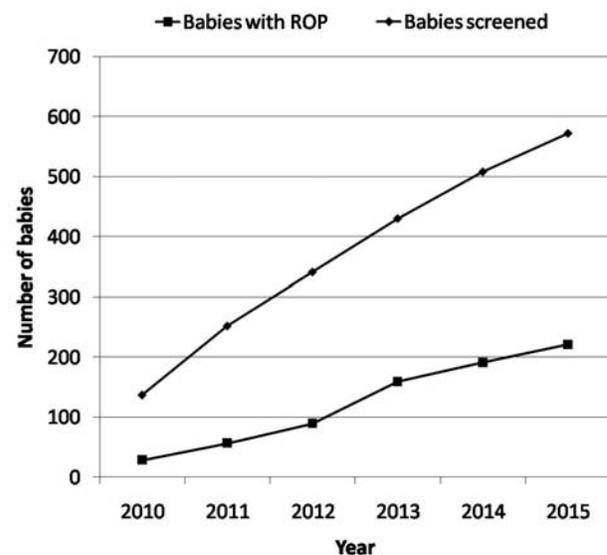


FIG. 1 Year-wise distribution of babies screened and those with retinopathy of prematurity.

could be attributed to the budding special newborn care units in these areas without adequate ROP care facilities. In the last two years, we have hardly noticed any case of advanced ROP among those screened and treated in time. However, babies with advanced ROP continue to present from remote towns.

Screening with BIO and WFDRI

Our experience has been different than that reported so far. We realize that detection of mild ROP in the peripheral zones appears to be better with WFDRI than BIO, unlike the findings reported by others [12]. A demarcation line and an early pale ridge in a small sector in peripheral zones are more likely to be missed during BIO with scleral indentation by an examiner in a rush to screen a large number of babies at a time. On the other hand, BIO was more reliable in detecting early plus disease since a gentle pressure with RetCam probe would obliterate it. But serial and frequent imaging with RetCam provides an additional safety net to catch any missed or inadequately imaged retinopathy in subsequent visits. Hence we realized that both BIO and RetCam were mutually exclusive and could not substitute the other. Whenever feasible we used both of them together as our method of screening. When there were time and manpower constraints, we used WFDRI alone for screening with a follow-up at a closer interval than we would have done otherwise with BIO. There was some concern and resistance from pediatricians and possibly parents for screening by WFDRI by a paramedic alone rather than an ophthalmologist. However, a telephonic call, and sometimes sharing the captured images with the

pediatrician from the ROP screener, helped. When BIO and RetCam both were done at the same time, the onsite sharing of the images with the parents, ensured better compliance for follow-up.

CONCLUSION

The never screened cicatricial stage 4B and stage 5 ROP and their rise over years in Odisha is still a matter of grave concern. There were hurdles at multiple levels at screening initiation and establishment. The population to be screened and the incidence of ROP and APROP have increased every year. Bigger and older babies do get ROP in our set-up. In a non-telescreening model, when available and feasible, examination with both BIO and WFDRI were complementary to each other.

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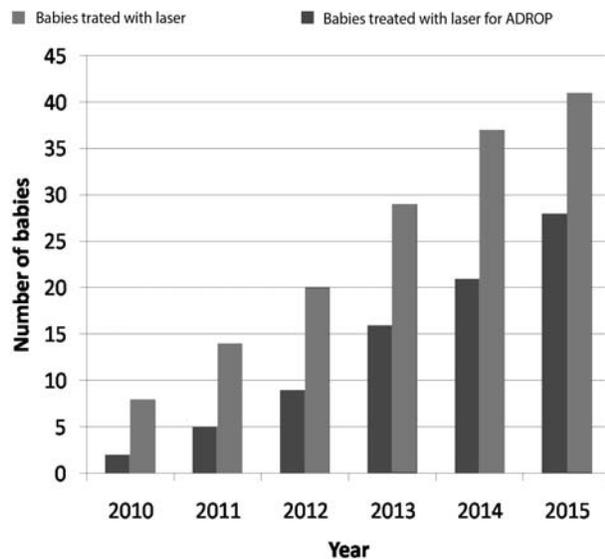


FIG. 2 Yearly distribution of babies receiving laser therapy.

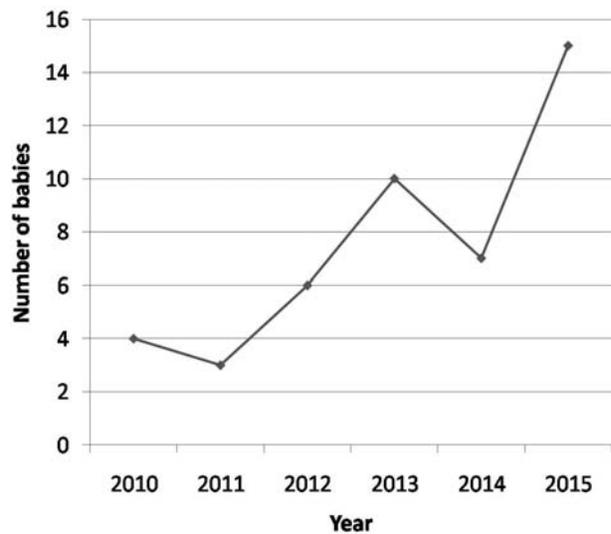


FIG. 3 Year-wise distribution of advanced cicatricial retinopathy of prematurity (stage 4B and stage 5).

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