

Improving Follow-up of Infants during Retinopathy of Prematurity Screening in Rural Areas

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Objective: To evaluate the challenges of completing and improving follow-up in an retinopathy of prematurity (ROP) screening program in rural centers

Methods: Reasons for dropout from a multi-center ROP screening program in rural Karnataka, over two six-month periods, were collected and categorized. Improvement measures introduced between the two periods and its impact was analyzed.

Results: Reasons pertaining to travel and logistics (15 of 53, 28.3%) and those related to awareness, knowledge and attitude (30 of 53, 56.6%) were the two main categories of reasons for dropout. Following corrective measures, there was a reduction in attrition from 20.8% to 3.8% ($P < 0.001$). Pediatricians' role in ensuring follow-up remained an important persisting reason.

Conclusions: Customizing improvement measures addressing the challenges of rural geographical logistics and enhancing awareness among rural families can enhance participation and improve follow-up.

Keywords: Follow up Studies, Neonatal screening, Premature infant, Telemedicine.

The number of 'at risk' infants for retinopathy of prematurity has increased manifold in the recent decades due to increased survival of low-birth and premature infants even in the rural areas [1,2]. Until recently, ROP was only reported from urban centers [3-6], particularly from level III neonatal intensive care units (NICUs). More recently, reports from rural India have shown that ROP is a significant problem even in district and remote hospitals [2,7]. This has given rise to new challenges of tackling the unmet screening burden, even as ROP specialists remain far below the required number in the rural outreach areas.

One of the main challenges faced by any ROP screening team is sustaining high levels of compliance and follow-up of infants after their discharge from the NICU. ROP demands multiple visits before the baby is diagnosed to require treatment or detected to have a mature retina on subsequent follow-up exams. In rural areas, after discharge, families often travel with the infant to very remote interior areas of the district or even the adjoining districts, making frequent follow-up visits to the NICU for ROP examination difficult.

This study was designed to identify the reasons for loss of follow-up in rural mothers of premature infants who are enrolled in, but fail to complete ROP screening

and suggest operational measures that could improve the follow-up rates.

METHODS

The KIDROP program has been providing ROP screening in rural Karnataka since 2008. The area of coverage is divided into several zones, each serviced by a dedicated ROP team. The model has been reported elsewhere [2,8-11]. All babies born ≥ 2000 grams or ≥ 34 weeks are eligible for screening [12].

Before visiting each center, the list of follow-up babies scheduled at that center is prepared a day prior and the project manager calls each of these families on the mobile number of the parent to remind about the venue and time of the scheduled screening on the following day. At the end of each screening day, a list of new babies enrolled on that day is added and those who re-visited the center are also updated in the database. Those who were scheduled and did not visit the center (the 'no show') are flagged red and called at the end of the day to determine the reason(s) for missing the appointment. They are requested to visit the center in the subsequent week in most cases. If in the previous session the diagnosis in the database indicated a 'high risk' baby who could have progressed to Type 1 ROP, measures to screen the baby

'outside the routine schedule' is arranged.

Study Periods: The study period was divided into three phases. Phase 1 was between January 1st and June 30th, 2010, during which the assessments were performed. Phase 2 was between July 1st and December 31st 2010, during which new measures were introduced. Finally, Phase 3 was between January 1st and June 30th, 2011 when a re-assessment was performed to study the impact of the modifications introduced.

Assessments (Phase 1 and 3): Phone interviews of mothers who missed follow-up for four or more consecutive appointments or were completely lost to follow-up were recorded. In cases where the defaulting mother returned to the screening program after 4 visits, the interview was obtained in person. The mother was asked to state all reasons she believed were responsible for her not being able to comply with the prescribed schedule. At least one important reason was solicited and noted and more than one reason, if present. Owing to the personal rapport of the project manager with the family, the reasons were elicited in a friendly manner, during routine conversation, which centered on the health and condition of the baby. This allowed the parent to be honest and frank with their responses. Screening and treatment were performed free of cost in all government rural centers during both study periods.

The measures undertaken to improve the follow-up were (Phase 2): (1) Increasing the number of screening sites in the given district, (2) counseling parents prior to discharge from the NICU and handing them the ROP card with the scheduled date of first screening, (3) emphasizing to the neonatologist to mention the ROP screening visit date in their discharge summary and also to counsel parents about the same at each visit, (4) showing them videos of the procedure, which can alleviate the fear of the procedure, (5) showing the family retinal images captured on the Retcam at the end of each session. This could possibly help them understand the pathology and consequently increasing their involvement in the screening by realizing its importance, (6) suggesting to the government that the vehicle at the disposal of districts under other health schemes such as the Janani Suraksha Yojana (JSY) could be used to transport the infants from the remote 'taluk' to the district headquarter for the screening, (7) reimbursing travel in cases where financial resources was a challenge. This was preferentially done for infants requiring treatment, (8) recording alternate mobile numbers of other relatives and neighbors, (9) a mobile helpline number was printed on the ROP card and provided to the NICU staff. Parents were encouraged to call 24/7 to clarify their doubts, seek

appointments and discuss other logistic difficulties 10) a project manager acted as a liaison between neonatologists and parents. He would convey periodically the status of the baby to build up a rapport with the parents. 11) Increasing enrollment from centers where the team does not visit, but is in close proximity to another center in the same district or zone, using the REDROP method [11].

RESULTS

In Phase 1, 510 infants imaged through 6052 imaging sessions performed in 23 enrolled NICUs from six districts were screened. In Phase 3, the program had expanded to 47 NICUs and 1479 babies imaged through 10,236 imaging sessions were screened from 13 districts. Of the 510 infants in Phase 1, 106 (20.79%) did not complete follow-up compared to 56 of 1479, (3.79%) babies in Phase 3 ($P < 0.001$).

The results of the 106 phone interviews in the first and 56 in the second period respectively, have been summarized in **Web Table I**. These were categorized into those related to logistics and travel (1-15), those related to poor awareness or lacunae in knowledge, attitude or practice of ROP (16-45) and others (46-53). It must be noted that since multiple responses were permitted, the total exceeded 100%. The most common reasons in the first category related to travel and logistics remained identical during both phases with 'distance from the screening center being too much' (80.9% and 23.2% respectively). Relocation to 'another taluk', which was recorded in 67.1% of responses in Phase 1, was not recorded in Phase 3 because the program had expanded to neighboring districts. A significant reduction in all the reasons in the second category relating to awareness was noted between Phase 1 and 3 with the 'pediatrician not emphasizing the need for follow-up' being the most common reason (29% and 17.9% respectively). In the third category, loss of wages (64.5% and 32.1% respectively) of the parents and a sick child incapable of traveling for ROP screening (58.6% and 41.1% respectively), were the two most common reasons in both the study periods.

DISCUSSION

This study summarizes some of the most important reasons why families who have to attend the ROP screening program in rural areas are likely to default. In our imaging based telemedicine program wherein a single team visits several centers on a scheduled weekly timetable, babies who are screened do not always belong to the resident center or district. The frequent visits that parents have to undertake to complete ROP screening in

WHAT IS ALREADY KNOWN?

- Retinopathy of prematurity in rural India has now become a large, unmet problem.
- Loss to follow-up before completion of ROP screening is a universal challenge

WHAT THIS STUDY ADDS?

- Reasons for attrition of ROP follow-up in rural families are several and unique
- Addressing geographical and logistic issues can enhance participation
- Improving awareness and promoting a positive influence can improve follow-up
- The role of the neonatologist or pediatrician in ensuring screening compliance is critical and has scope for further improvement

such a rural setting appears to be influenced by these reasons. Addressing some of these modifiable challenges resulted in a reduction of attrition from 20.8% to 3.8%. Fifteen of the 53 reasons (28.3%) are related to travel logistics or reaching the center on time. By expanding the number of teams, promoting remote site scheduling to the closest on-site team using the REDROP method [11], customizing the timing of screening schedule to match the neonatologists clinics are some of the measures that can enhance follow-up.

ROP screening currently in India is by the ROP specialist or a ROP trained ophthalmologist who either screens infants referred to him or her in their outpatient clinic or hospital or travels to the NICU on an 'ad-hoc' or regular basis to conduct the screening within the premises of the neonatal care center itself [13,14]. Predominantly, this experience so far has been urban [3-6,15]. Although no study thus far reports the average distance travelled by the family to visit an ophthalmologist's clinic to undergo ROP screening, our experience in providing ROP screening for urban [11] and rural centers [2,7,9,11,16] suggests that operational logistics differ between the two.

This study analyzed the reasons for attrition to complete ROP screening, retrospectively. There was no formal questionnaire or reporting techniques used. The responses were recorded in the patient's native language and grouped in hindsight. There is also no follow-up of the babies who were lost to follow-up for their visual outcome and the magnitude of vision impairment or blindness that may have resulted was not assessed in this cohort. Furthermore, the cost related to the team, and reimbursements have not been formally evaluated. Another limitation is the fact that the proportional impact of each of the measures introduced to improve follow-up have not been sub-analyzed. Finally, the objectivity of the reasons recorded from the defaulting families was not validated. There could be an unmeasured bias in favor of

the team or hospital, as the parent is less likely to criticize the treating team or hospital.

In the current scenario, rural ROP screening programs are not a norm. With the expansion of the Rashtriya Bal Swasthya Karyakram (RBSK) [17], over 600 special new born care units are mandated to provide neonatal care to district headquarters. ROP screening in most of these centers is currently not established. Understanding the unique challenges faced by families in the rural context will help strategize better ROP follow-up practices. Our study shows that by improving awareness, promoting positive attitudes and encouraging participation of the parents, a significant proportion of these reasons can be corrected. Of the 30 such reasons (*Table I*, 16-45), only seven remained in the phase 3 after corrective measures were introduced. The role of the pediatrician and the support from the neonatal staff remain critical areas that need further improvement.

In conclusion, understanding the reasons for loss to follow-up in a rural ROP screening program has helped us understand the gap in the knowledge-attitude-practice axis of the operational logistics of implementing such a program. Some of the measures that we introduced have resulted in fewer dropouts subsequently. More detailed operational research including cost based analysis are required to understand the most important measures that will improve follow-up of these infants and hence reduce the incidence of preventable ROP blindness in our rural centers.

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WEB TABLE I REASON FOR FAMILIES TO DROPOUT OF FOLLOW-UP FOR ROP SCREENING OF THEIR INFANTS IN RURAL INDIA IN THE TWO STUDY PERIODS

<i>Reason given by mother or father (Translated from the native language)</i>	<i>Phase 1 Proportion of responses (%)*(N= 106)</i>	<i>Phase 3 Proportion of responses (%)*(N= 56)</i>
<i>Related to Travel and Logistics</i>		
Distance from the center was too much	80.9	23.2
Relocated to another district/taluk	67.1	0
Transportation not convenient	59.2	21.4
Cannot afford travel	48.7	10.7
Came late	35.5	0
Breakdown of transport mid-way	25.0	0
Readmitted elsewhere	20.4	7.1
Inconvenient timing of scheduled appointment	15.8	0
Difficulty in bringing twin / triplets	13.8	0
Centers for screening changed	11.2	0
Harvest time, adults needed at home	9.2	0
Uncomfortable waiting area in NICU (feeding problem)	7.2	0
Could not trace the center	2.6	0
“Bandh”	2.6	0
Transport strikes	1.9	0
<i>Related to knowledge, attitude and practice of parents</i>		
Lost interest after initial one or two visits	42.8	0
Gender bias (‘female’, so did not bring)	31.6	<1
Pediatrician did not tell us the importance	29.0	17.9
Lack of awareness of the serious nature of the disease	29.0	0
Family function, felt that was more important	22.4	0
Overconfidence (nothing will happen to my baby)	20.4	0
Forgot to come	20.4	5.4
Unsupportive neonatal center staff	18.4	5.4
Unsupportive family (no permission from home)	15.8	0
Forgot the ROP card, was scared of being reprimanded	15.1	0
Other mothers misinformed us	13.8	0
Fear of the procedure	13.8	0
Frustration with prolonged NICU admission	13.2	0
Festival	12.5	0
Sickness in the family (caretaker required)	11.8	0
ROP team did not remind	9.9	<1
Sibling of the ROP baby at home, needs care	9.9	0
Do not trust the parent hospital	7.9	0
Did not meet the doctor last time	6.6	0
Other babies did not have a problem, mine too will not	6.6	0
Miscalculated the date of the screening visit	4.6	<1
Did not understand the counseling of the ROP team	3.9	0
Indifference	2.6	0
Did not believe that premature babies need screening	2.6	0

Contd...

<i>Reason given by mother or father (Translated from the native language)</i>	<i>Phase 1 Proportion of responses (%)*(N= 106)</i>	<i>Phase 3 Proportion of responses (%)*(N= 56)</i>
Had work at home	1.9	0
ROP card was not given by the nurse	1.3	<1
Did not want to travel alone	1.3	0
Superstition	1.3	0
Did not want to miss a television program	<1	0
Unsatisfied with the level of care	<1	0
<i>Others</i>		
Loss of wages	64.5	32.1
Baby was too sick to travel for the ROP screening	58.6	41.1
Parental discord	10.5	0
No reason	4.6	0
Death in the family	3.2	0
Climate	3.2	<1
Mother died or was invalid	<1	0
Took another opinion	<1	0

**Since multiple responses were possible, the total does not add to 100%; NICU – Neonatal intensive care unit; ROP – retinopathy of prematurity.*