# Effect of an Informative Pamphlet in Improving Parental Knowledge about Retinopathy of Prematurity

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## Abstract

**Introduction:** The childhood blindness due to retinopathy of prematurity (ROP) can be prevented if infants at risk are screened before the progression of the condition. The parental awareness on need of follow-ups for screening and identification of ROP will help in reducing the incidence of childhood blindness due to ROP.

**Method:** In the present study an informative pamphlet was developed and distributed to find its effectiveness in improving the parents' knowledge on retinopathy of prematurity. Quantitative research approach was used with pre-experimental pre-test post-test one group design. Conceptual framework used was General system theory by Ludwig Von Bertalanffy. Using convenience sampling method 30 parents of preterm babies were selected. The baseline proforma and knowledge questionnaire were administered and later an informative pamphlet about ROP were given. Post-test knowledge assessment was done 7 days after the exposure to pamphlet.

**Result and Discussion:** The study finding showed an increase in the knowledge of parents on ROP after the exposure to pamphlet (Z=4.628, p=.001). An association was found between pre-test knowledge and previous parental knowledge on eye diseases in newborn babies (U=59, p=.048). The present study concludes that the pamphlet made by the researcher on ROP was effective in improving the parents' knowledge about ROP.

***Keywords:*** *Retinopathy of prematurity (ROP); Parental knowledge; Informative pamphlet.*

## Introduction

Retinopathy of prematurity (ROP) is a preventable cause of blindness in children. The improvement of neonatal care increased the survival of preterm babies. These babies are at high risk for developing ROP[1]. The study reports in 2010, out of 15 million survived preterm babies, minimum of 1,84,700 reported some stage of ROP, among them 53,800 progressed to potential vision impairment[2]. Preterm births are highest in India, China, Nigeria, Pakistan and Indonesia. East Asia, South East Asia and the Pacific are the regions with the highest number of preterm babies who survive and the highest number who develop visual loss from ROP[3].

A simple screening test by an ophthalmologist within few weeks of birth will prevent ROP related blindness. Eventhough there is highest rate of preterm births, there is an uncertainity about the practices of screening tests in developing countries like India and china All developed countries follow the screening test and protocols very strictly. The practice of remedial measures will decrease the incidence of ROP related blindness[4].

AAP policy on ROP recommends that, "Infants with a birth weight ≤ 1500 gms or gestational age of ≤ 30 weeks and the infants with a birth weight between 1500gms and 2000 gms or gestational age of more than

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30 weeks with an unstable clinical course, should be screened for ROP"[5]. In developing countries like India, a birth weight ≤ 1750 gms and/or gestational age of ≤ 34 weeks is used as a cut-off for ROP screening. According to the guidelines by National Neonatology Forum of India "Screening for ROP should be performed in all preterm neonates who are born < 34 weeks gestation and/or < 1750 gms birth weight; as well as in babies 34-$36^{6/7}$ weeks gestation or 1750-2000 grams birth weight, if they have risk factors for ROP"[6].

ROP is progressive in nature and, the infant has to undergo multiple sequential eye check-ups to identify the likelihood to develop ROP. The goal of an effective ROP screening program is to identify the infants who could benefit from treatment and make appropriate recommendations on the timing of future screening and treatment interventions. If diagnosed to have ROP, the neonate needs to undergo timely treatment by an ophthalmologist who is experienced in the examination of preterm infants for ROP using a binocular indirect ophthalmoscope on a scheduled basis according to their gestational age at birth and their disease severity[5]. A major problem faced by the ROP screening programmes is the missing of follow-up of infants after their discharge from the NICU[7].

Unidentified ROP can lead to permanent blindness, hence it is important that all at risk infants to be screened in a timely fashion, recognizing those who require treatment. Parents should be aware of ROP screenings and should be informed by the staff if the child has ROP, with subsequent updates on ROP progression[5].

As the responsibility of bringing the baby for follow-up ophthalmologic care after discharge is delegated to the parents, they should be made to aware of the importance of timely screening; as there is a critical time period for the successful treatment[8]. The attendance of the multiple visits can be improved only if the parents are informed about the nature of the disease and its magnitude.

The researcher during her exposure in neonatal ICU observed many infants are missing their ophthalmologic assessments after their discharge from the hospital.

The major reason could be the unawareness of the parents. Hence it was planned to develop a pamphlet on ROP emphasising the importance of followups. The information should be given by the healthcare service providers during the hospital stay, either verbally or in writing or both, thus the attendance in the scheduled screening can be improved.

## Material and Method

A quantitative study using One group pretest post-test pre-experimental design was conducted in two multi-speciality hospitals at Tiruvalla, Kerala. The researcher prepared a knowledge questionnaire and an informative pamphlet for the study and was validated by 5 experts. The experts were selected from the field of neonatology, opthalmology and pediatric nursing. Reliability of the tool has been established by administering to 7 samples and found feasible (r = .920). The final tool consisted of two parts. First part is the baseline variables of parent and the baby. Eight items each on parents and the baby were included in the final tool. Second part is the knowledge questionnaire consisted of 16 items. The informative pamphlet prepared by addressing prematurity, general anatomy of the eye, symptoms, prevention, treatment and complications of ROP. The same aspects were included in the knowledge questionnaire. All questions had one correct answer and carried a score of one. Pilot study was conducted among 5 samples. Thirty parents of preterm babies ≤34 weeks of gestation and/or ≤ 1750 gms birth weight admitted in the two hospitals during the month of February – March 2018 were selected using convenience sampling technique.

The tools were distributed to the identified samples and collected back after completion. It took around 20 minutes for the samples to complete the tool. The researcher was present near during data collection to clarify the doubts. After completion of the knowledge questionnaire an informative pamphlet on ROP were given to them. Researcher requested them to read once in front and clarify doubts. Later it was given to them to read as and when time permits. After 7 days a post test was carried out using the same questionnaire. The effectiveness of the pamphlet was analysed by comparing pretest and post-test knowledge scores by using Wilcoxon signed ranks test. The association between pre-test knowledge scores and the baseline variables were analysed using Kruskal Wallis and Mann Whitney U test.

**Findings:**

**Description of the baseline variables of the parents of preterm babies:** Out of 30 parents 23 (76.7%) were mothers and 7 (23.3%) were fathers and

13 (43.3%) were in the age group between 29 to 33 yrs. (Table 1).

Half of the samples were residing in rural area and 43.3%had monthly family income between Rs 16020 – 32049.(Table 1)

Most (53.3%) of them are from joint family and 63.3% did not had knowledge about any eye diseases affecting the new born babies. (Table 1).

**Description of the baseline variables of the babies:** A total of 26 babies were involved in the study including 3 twins. Fourteen babies were male and twelve babies were female. Twelve babies each were first born and second born and 2 babies were third in birth order (Table 1). The mean age of the babies were 6 days. The mean birth weight and mean gestational age were 1720 gms and 31 +6 weeks respectively (Table 2).

**Table 1: Frequency and percentages of baseline variables on parent and baby factors N=30**

| Selected baseline variables | Category | Frequency | Percentage % |
|---|---|---|---|
| **Parent Factors** | | | |
| Age of the parent in years | 18 – 23 | 2 | 6.7 |
| | 24 – 28 | 7 | 23.3 |
| | 29 – 33 | 13 | 43.3 |
| | 34 – 38 | 8 | 26.7 |
| Relationship with the baby | Mother | 23 | 76.7 |
| | Father | 7 | 23.3 |
| Place of residence | Urban | 5 | 16.7 |
| | Semi urban | 10 | 33.3 |
| | Rural | 15 | 50 |
| Family income in rupees | >32,050 | 5 | 16.7 |
| | 16020–32049 | 13 | 43.3 |
| | 12020 – 16019 | 3 | 10 |
| | 8010 – 12019 | 2 | 6.7 |
| | 1601 – 4809 | 1 | 3.3 |
| | <1600 | 6 | 20 |
| Family type | Nuclear family | 14 | 46.7 |
| | Joint family | 16 | 53.3 |
| Previous knowledge of parents about eye disease in newborn | Yes | 11 | 36.7 |
| | No | 19 | 63.3 |
| **Baby Factors** | | | |
| Gender | Female | 12 | 46.15 |
| | Male | 14 | 53.84 |
| Birth Order | First | 12 | 46.15 |
| | Second | 12 | 46.15 |
| | Third | 2 | 7.69 |

**Table 2: Mean age, Birth weight and Gestational age of the baby N=26**

| Parameters | Mean |
|---|---|
| Mean Age | 6 days |
| Mean Birth Weight | 1720 gms |
| Mean Gestational Age | 31 +6 weeks |

**Findings of pre-test and post-test knowledge scores of parents of preterm babies:** The knowledge scores were categorized into poor, average and good. In the pretest, 15 (50%) had average knowledge, 14 (46.7%) had poor knowledge and only 1 (3.3%) had good knowledge. Whereas in the post-test 18 (60%) had good knowledge, 12 (40%) had average knowledge and no one was in poor category.

**Effect of informative pamphlet in improving parental knowledge about retinopathy of prematurity:** Wilcoxon signed ranks test was used to compare the pre-test and posttest scores of the samples. Analysis showed that out of 30 samples, 28 (93.33%) had improved their knowledge and 2 samples (6.66%) had no change in their knowledge after using the pamphlet. There is significant improvement in the knowledge of parents in the post-test as compared to the pre-test (Z= 4.628 p=.001). Hence the null hypothesis $H_{01}$ rejected and $H_1$ accepted. It is proved that the informative pamphlet was effective in improving parental knowledge on ROP.

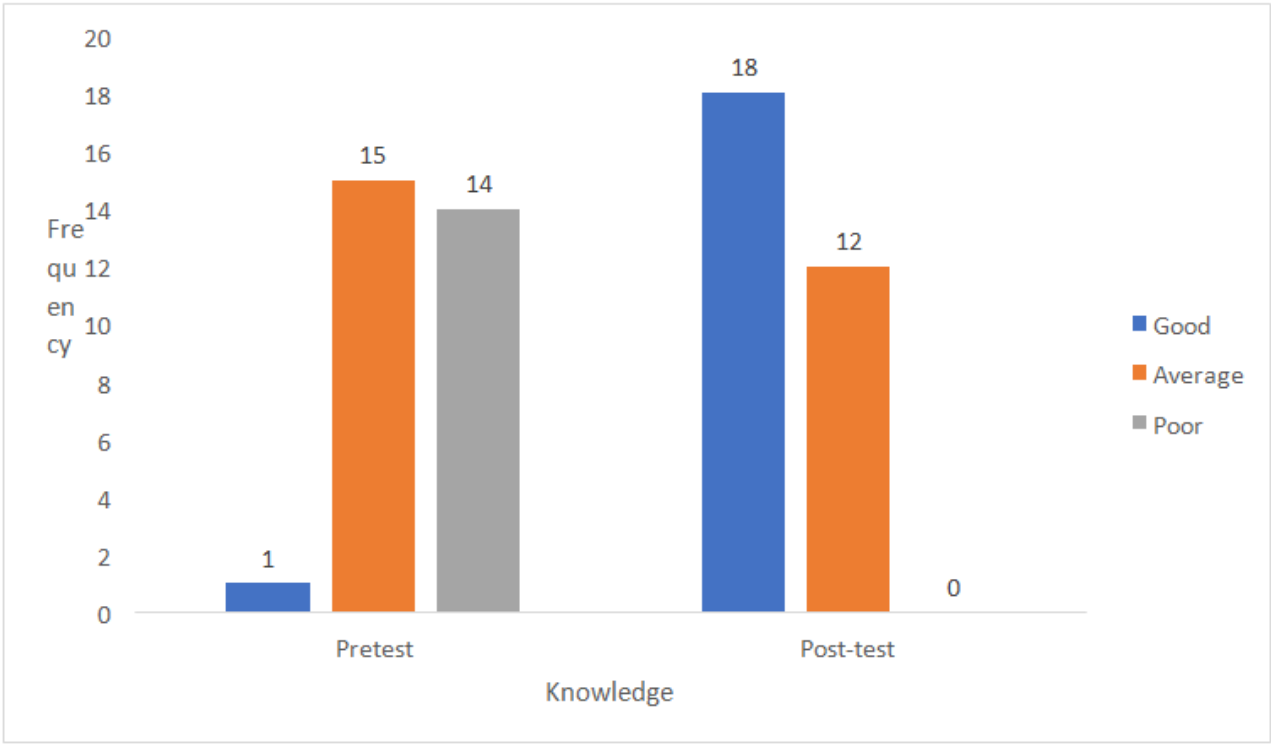


**Fig 1: Parental knowledge on pre-test and post test**

**Table 3: Comparison of pre-test and post-test mean ranks of parents of preterm babies about retinopathy of prematurity. N=30**

| | | f | Mean Rank | Sumof Ranks | Z | p |
|---|---|---|---|---|---|---|
| Pre-test post-test | Negative Ranks | 0 | .00 | .00 | -4.628 | .001* |
| | Positive Ranks | 28 | 14.50 | 406.00 | | |
| | Ties | 2 | | | | |
| | Total | 30 | | | | |

Wilcoxon Signed Ranks Test (*p<.001)

**Association between pre-test knowledge scores with selected baseline variables:** The selected baseline variables were the age of the parents, relationship with the baby, family type,previous knowledge about eye disease in new born, age of the baby and birth order.

**Analysis was done using Mann:** Whitney U test and Kruskal Wallis test. Previous knowledge of the parents about eye diseases in newborn babies had a significant association with pretest knowledge scores (U=59, p=.048). The null hypothesis $H_{02}$ was rejected in favour of research hypothesis in terms of previous knowledge of parents of preterm babies about eye diseases in newborn. Hence it is proved that the parents who had knowledge on any eye diseases in new born had knowledge on ROP.

## Discussion

There were only few published researches on the parental education about ROP. Most of the published researches had mainly focused on the incidence and prevalence.

The study conducted by Mousavi etal. (2010) reports the mean gestational age of preterm babies included in the study are 31.4 weeks[9]. This finding is very similar to the present study were the mean gestational age of babies were 31.6 weeks.

The mean birth weight of the preterm babies included in the present study were 1720gms. The study conducted by

Mousavi et al. (2010) reports the birth weight of the preterm babies included in the study were 1562 gms[9]. These findings were showing a difference of .158gm. This may be because of the difference in geographical location.

In the present study 76.9% of babies were born by singleton pregnancy and the study conducted by Mousavi et al. (2010) reports 60.2% of babies born by singleton pregnancy[9]. When we compare the gender of the babies included in the study both the studies having majority of the babies of male gender.

The study done by Daftarian et al. (2016) reported that parents' knowledge remained the same after and before the pamphlet exposure, however their perception about the importance of timely screening improved which led them to the successful completion of scheduled eye appointment[[10]. On contrary to this, in the present study 28 samples has improved their knowledge in the post test and 2 had the same knowledge before and after pamphlet exposure. All parents acknowledged the importance of timely follow up of ROP examinations, post introducing the pamphlet.

Feng J etal. (2016) reported that 94.1% of parents of ROP infants were informed of ROP and received recommendations for screening, whereas 5.9% of parents were not informed by their attending paediatrician about the need for an eye examination. Among them only 71.1% parents were aware of ROP and 28.1% parents had no idea about the disease[11]. This shows the advantage of written information like a pamphlet on ROP to make the parents aware about the need for timely screening.

## Conclusion

The major conclusion of this study is that most of the parents were unaware about the importance of timely screening and the potential consequences of the missing of followups of ROP screening. A pamphlet with detailed description about the disease could help them to understand their role in preventing childhood blindness.

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## References

1. Retinopathy of Prematurity | National Eye Institute [Internet]. Nei.nih.gov.
2. Blencowe J, Lawn JE, Vazquez T, Fielder A, Gilbert C. Beyond newborn survival: Preterm associated visual impairment and estimates of retinopathy of prematurity at regional and global level for 2010. Pediatr Res. 2013; 54:36–49.
3. March of Dimes, PMNCH, Save the Children, WHO. Born too soon: The global action report on preterm Birth. Geneva: World Health Organization; 2012.
4. Shah PK, Prabhu V, Karandikar SS, Ranjan R, Narendran V, Kalpana N. Retinopathy of prematurity: Past present and future. World J Clin Pediatr. 2016;5(1):35-46.
5. Section of Ophthalmology American Association of Pediatrics, American Academy of Ophthalmology, American Association for Pediatric Ophthalmology and Strabismus. Screening examination of premature infants for retinopathy of prematurity. Pediatrics2006; 117:572-576.
6. Pejaver RK, Vinekar A, Bilagi A. National Neonatology Foundation's Evidence Based Clinical Practice Guidelines. Retinopathy of Prematurity (NNF, India, Guidelines) 2010:253–62.
7. Vinekar A, Jayadev C, Dogra M, Shetty B. Improving follow-up of infants during retinopathy of prematurity screening in rural areas. Indian Pediatrics. 2016;53(2):S151-4
8. Al Amro S, Al Aql F, Al Hajar S, Al Dhibi H, Al Nemri A, Mousa A et al. Practical guidelines

for screening and treatment of retinopathy of prematurity in Saudi Arabia. Saudi Journal of Ophthalmology. 2018;32(3):222-226.

9. Mousavi SZ, Karkhaneh R, Roohipoor R, et al. Screening for retinopathy of prematurity: the role of educating the parents. Iran J Ophthalmol. 2010; 22(2):13–18.
10. Daftarian S, Lin P, Mitchell K. Retinopathy of prematurity: Improving parental awareness and perceived importance of follow-up eye exams using an informative pamphlet. Journal of Neonatal Nursing. 2016;22(5)228-230
11. Feng J, Sun YY, Meng XF, Deng X, Chen Y. Parental awareness of the need for screening of retinopathy of prematurity in Northern China. Int Eye Sci. 2017; 17(6)1011-14.