

# Screening for Retinopathy of Prematurity: The Role of Educating the Parents

S Zeinab Mousavi, MD<sup>1</sup> • Reza Karkhaneh, MD<sup>2</sup> • Ramak Roohipoor, MD<sup>3</sup>  
Mehdi Nili Ahmadabadi, MD<sup>4</sup> • Leila Ghalichi, MD, PhD<sup>5</sup>  
Fariba Ghassemi, MD<sup>3</sup> • Mohammad Riazi Esfahani, MD<sup>4</sup>

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## Abstract

**Purpose:** Childhood blindness due to retinopathy of prematurity (ROP) is an important concern, but this blindness or severe visual impairment may be prevented if at risk infants are screened before occurrence of advanced stages. In this study, we tried to find the role of parental education about ROP in parents' compliance for on-time attendance for ROP screening.

**Methods:** Demographic factors and clinical information of all the consecutive infants screened for ROP in Farabi Eye Hospital during 2003-2007 were recorded and analyzed using independent sample T-test, chi-square and multiple logistic regressions.

**Results:** Among 605 eligible infants, parents of 443 (73.2%) were given a simple written recommendation for their infant's eye examination (group A), while 26.8% were given written information about the consequences of late examination (possibly blindness) and information about the date and place of a free of charge previously made appointment (group B). Mean age at first eye exam in group A was 51.9 days versus 41.8 in group B ( $P < 0.001$ ). The incidence of stage 4 and/or 5 was significantly lower in infants examined before 9 weeks ( $P < 0.001$ ). In group A, 81.2% of the infants were examined before 9 weeks of infantile age versus 95.5% in group B ( $P < 0.001$ ). Gender, being the first child and single or multiple births did not contribute to the time of first eye exam significantly. Logistic regression methods showed that after controlling for gestational age (GA), recommendation type had a significant effect on on-time attendance rate ( $P < 0.001$ ).

**Conclusion:** Giving sufficient information about ROP to parents and educating them about this potentially blinding condition, along with making appointments for them and presence of facilities for free ROP screening exams, can increase the chance of on-time screening.

**Keywords:** Retinopathy of Prematurity, Patient Compliance, Guideline Adherence, Blindness, Visually Impaired Persons

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1. Research Assistant, Eye Research Center, Farabi Eye Hospital, Tehran University of Medical Sciences
2. Professor of Ophthalmology, Eye Research Center, Farabi Eye Hospital, Tehran University of Medical Sciences
3. Assistant Professor of Ophthalmology, Eye Research Center, Farabi Eye Hospital, Tehran University of Medical Sciences
4. Associate Professor of Ophthalmology, Eye Research Center, Farabi Eye Hospital, Tehran University of Medical Sciences
5. PhD Student, Department of Epidemiology, School of Public Health, Tehran University of Medical Sciences

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Correspondence to: Mohammad Riazi Esfahani, MD

Eye Research Center, Farabi Eye Hospital, Tehran, Iran, Tel: +98 21 55414941-6, Email: riazifahimi@yahoo.com, mriazi@yahoo.com

## Introduction

Blindness and vision loss put significant burdens on the person, family and society. It is thought that while childhood blindness is the cause of 1.9-9.5% of total blindness in different parts of the world,<sup>1</sup> its economic cost is about one third of the total global cost of blindness.<sup>2</sup> Each year, about half million of children become blind,  $\frac{3}{4}$  of them are in developing countries and about half of these blindness are avoidable. It is estimated that the number of children with low vision would be 3-4 times more, giving a number of about 5 million children worldwide.<sup>2-4</sup>

Controlling childhood blindness is one of the priorities of the World Health Organization's (WHO's) Vision 2020-The right to sight program. The program has different targets, one of them is to control blindness due to retinopathy of prematurity (ROP).<sup>3,5</sup> Although available treatments for ROP can prevent many infants from progressing to its severe forms and blindness,<sup>6-8</sup> there are evidences that some infants still suffer from severe visual disabilities as a consequence of this disease.<sup>9-13</sup>

In this study, we tried to assess the role of increasing awareness among parents (the impact of getting a proper recommendation from neonatal ICU (NICU) staff and neonatologists and being educated by them about ROP) in on-time attendance rate of premature infants who were screened for ROP in a tertiary eye hospital.

## Methods

### Settings

The study was conducted in Pediatric Retina and Vitreous Division of Farabi Eye Hospital (a teaching tertiary eye hospital affiliated with Tehran University of Medical Sciences) during October 2003 to October 2007.

In Iran, most of the infants are screened for ROP in an eye hospital, those who are discharged before 4 weeks, will be recommended to seek care after their discharge and those with prolonged NICU admission are transferred by the NICU physicians/staff to eye hospitals to perform screening examinations. However, it seems that nowadays the number of infants who are screened in NICU are increasing. In this study, the records of all premature

infants who had been screened for ROP were reviewed and two groups of infants were excluded. First, the infants who did not have any recommendation by NICU staff or neonatologist (they either were brought for examination after occurrence of advanced stages or were brought for examination because of recommendation by other physicians when they already had passed the golden time of screening). The second group was those who had undergone first screening exam during their NICU admission, because NICU staff/neonatologists brought them for examination, and parents had minor role in their on-time examination and their compliance could not be assessed.

### Data gathering and examination

Data on the infants' gestational age (GA), birth weight (BW), gender, singleton or multiple births, being the first child, and their NICU/neonatologist's recommendation for eye examination were recorded based on their medical records. Their age at first eye examination were recorded and indirect ophthalmoscopy was performed using +20 D and +30 D lens after full dilation of pupils by tropicamide 0.5% and phenylephrine 1%. The staging of ROP was done according to the international classification of ROP.<sup>14,15</sup>

Parents who brought their infant(s) too late were interviewed to find their delay reason using open questions.

### Definitions

Upon reviewing NICU and neonatologists' recommendation, we found out that some hospitals had a simple policy for giving recommendation for ROP screening, which was giving a piece of written advice to the parents of premature infants, typically only containing the name of the infant and this sentence: "Please have the eyes of the infant examined". They were defined as group A. However, there were some hospitals with a policy of giving parents a written paper which gave information about the consequences of late ophthalmic examination and the risk of blindness, along with the date and place of a free of charge previously made appointment. Those who had this type of recommendation were defined as group B.

**Statistics**

The role of being in group A or B, GA, BW, gender, singleton or multiple births and being the first child, on the time of first retinal examination were assessed by independent sample T-test and chi-square. All variables were included in a multiple logistic regression method. In addition, the incidence of ROP (all stages) and stage 4/5 ROP were compared in on-time and late attendees. The statistical program of SPSS 15 was used and the level of significance was adopted as  $P < 0.05$ .

**Results**

During the study period, 1,014 infants were examined in Farabi Eye Hospital. Among them, 605 infants were found eligible for the study and the rest were excluded. The reasons for exclusion were: not having any recommendation for eye examination by their neonatologist (60 infants, 5.9%), having previously been screened for ROP during NICU admission (63 infants, 6.2%), unavailable data about neonatologist recommendation (279 infants, 27.5%) and unavailable data about the result of eye exams (7 infants, 0.7%).

In these 605 infants, 52.9% (320 infants) were male and 60.2% (364 infants) were born by singleton pregnancies. Mean GA and BW in these screened infants were 31.4 (SD 2.3) weeks and 1,562 (443) g respectively. The incidence of ROP was 31.4% (190/605); GA of ROP positive infants ranged from 24-36 weeks (mean 30.1 (2.3)) and their BW ranged from 600 to 2800 g (mean 1392 (385)).

Group A included 443 infants (73.2%) while group B had 162 (26.8%). From group A, 81.2% had their first eye exam before 9 weeks of infantile age versus 95.5% in group B ( $P < 0.001$ ). 42.7% of group A had their first eye exam before 6 weeks of infantile age

versus 61.1% of group B ( $P < 0.001$ ). Mean age at first eye exam in group A was 51.9 days versus 41.8 in group B ( $P < 0.001$ , 95% CI: 6.2-14.1).

The incidence of ROP did not have a significant difference in infants examined before and after 9 weeks (31.5% compared to 28.1%, p value: 0.62). However, the incidence of stage 4 and/or 5 of ROP in the infants screened after 9 weeks was significantly higher than the other group (13.5% vs. 1.6%,  $P < 0.001$ ). Seven of these infants (5 of the above 9 week group and 2 of the other one) had bilateral stage 5 of ROP.

Data on the reason of the delay in group A was only available in 32%. Among them, 11 incriminated lack of knowledge about the importance of time in ROP (one had sought care for developmental dysplasia of hip prior to ROP), 1 did not know where to seek for screening, 1 had thought that the baby is too small and weak for such examination, whereas the rest negligently identified the reason as "we were busy". In the group B, data of the reason of the delay was available in 43%; all had delayed the examination negligently.

Univariate analysis showed that infants with first eye exam of above 9 weeks were more likely to be in group A while they had lower GA and lower BW; but gender, being the first child and being born by single or multiple-gestation pregnancies did not contribute to the time of first eye exam (Table 1). In multiple logistic regression analysis, recommendation type had a significant effect on on-time attendance rate after controlling for GA; we found out that being in group A is associated with 6 times increase in the odds of having eye exam after 9 weeks (Table 2).

**Table 1.** Univariate analysis of potential risk factors of late screening

Factors	Odds ratio	95% Confidence interval	P-value
Group A	4.209	1.988 – 8.909	<0.001
Gestational age	0.816	0.739 – 0.901	<0.001
Birth weight (per 100 g)	0.922	0.871 – 0.975	0.005
Gender (female/male)	1.087	0.691 – 1.710	0.717
Being the first child	0.914	0.474 – 1.761	0.788
Single or multiple-gestation pregnancies	1.097	0.686 – 1.754	0.699

**Table 2.** Adjusted odds ratio for late examination

Factors	Odds ratio	95% Confidence interval	P-value
Group A	6.051	2.571 – 14.243	<0.001
Gestational age	0.809	0.733 – 0.892	<0.001

## Discussion

Vision loss is a major problem in the world, specially in countries with higher percentage of blindness. Nearly 3-4% of total blindness in Eastern Mediterranean Region is due to childhood blindness, where about 0.08% of children under the age of 15 are blind.<sup>1</sup> The problem becomes more important when we notice a lifetime of blindness ahead of these children and when we understand that a large percent of these blindness are preventable.<sup>4</sup> ROP is one of the important causes of avoidable childhood blindness<sup>5,16</sup>; however, it requires timely management to prevent infants from blindness.

A cost-effectiveness analysis in 1993 showed that on-time screening and treatment of at risk infants for ROP, can save a net governmental cost of \$38.3 to \$64.9 million per year in US.<sup>17</sup> A recent study also showed that using criteria of early treatment for ROP is cost effective compared with conventional management.<sup>18</sup> These data confirm the role of time in ROP management.

We undertook this study on infants who were screened for ROP in an Eye Hospital, trying to find the impact of educating the parents about ROP on on-time attendance rate. The term of 'on-time attendance' has different definitions in different guidelines (7-9 w,<sup>19</sup> 4-9 w,<sup>20</sup> 6-7 w<sup>3,5</sup> and 4-5 w<sup>16</sup>); however, none of them has recommended the first eye exam to be after 9 weeks. At the time of this study, many physicians recommended the infants to seek care between 4-9 weeks. However, nowadays there is a trend toward changing the golden time of ROP screening to be about 4-6 weeks.

In this study, there was a significant difference in the time of first eye exam among group A and B, which can be a proof for the role of educating the parents about this disease. In addition, the mean age of first ROP screening examination in the group B was about 42 days (6 weeks), which is closer to the present guidelines.

Nowadays there is an emphasis on examining the infants during their NICU admission<sup>21,22</sup> or making appointment for them before their discharge.<sup>16,23</sup> However, none of these 605 infants of our study were screened for ROP in NICU and an outpatient appointment was only made in about one fourth of them. The significant difference in on-time attendance rate in group A and B can show the importance of making appointments for ROP screening before NICU discharge. This can again emphasize the role of increasing general knowledge about ROP.

In a previous study, factors like poor time-scheduled outpatient ophthalmologic examination, poor parental understanding about ROP, problems with the insurance companies, problems occurring in transporting an ill premature infant and forgetting about the appointments were proposed reasons for missing or delaying the examinations.<sup>23</sup> In this study, factors like not knowing enough about the golden time of the screening and a place for seeking care were reasons for delaying the examination. These factors were not found in group B who were educated about ROP. Even though we could not retrieve data about all parents of both groups, this result may confirm the role of educating parents about this disease. Another study from our center in 2003<sup>24</sup> also showed that parents of infants who had severe visual impairment due to ROP, did not have enough information about this blinding condition. This is in line with another study from our center in 2008<sup>25</sup> which emphasises the role of increasing awareness among parents and physicians about ROP.

Nevertheless, some parents sought for screening too late even after many measurements were undertaken to prevent such delay (such as educating them or making free appointments for them). Another study also has reported that there are some parents who did not seek care even after

many phone calls were made to remind them of their infants eye examination.<sup>23</sup>

In a study comparing compliance for follow-up of very low BW children, it was found that although inaccessibility and refusal by parents were the most common cause of missing appointments, the non-compliant had higher rate of multiple birth and lower rate of first child.<sup>26</sup> Further researches are recommended as in our study factors like gender, being the first child and multiple birth did not contribute to the time of first screening examination.

The high percentage of ROP involvement in our population, confirms the third epidemic of the disease in our country, as it was predicted by another study.<sup>12</sup> In addition, the higher rate of stage 4 and/or 5 of ROP in those examined after 9 weeks, puts an emphasis on the role of timely screening in ROP. Seven infants developed bilateral stage 5, who are nearly blind. Five of them were examined after 9 weeks, the two other were examined 6 weeks after birth (40 and 34 weeks postmenstrual age); maybe their disease could have been controlled if we had used a tighter age range for examinations.

There were some shortages in our study. We do not know the number of infants who were not brought for screening. In addition, there were a number of infants who were screened there but we excluded them because of unavailable data. We tried to make phone calls to retrieve the missing data to overcome this shortage, but in many cases it was not successful. However, we believe that

the results of this study can be useful, at least in part, for preventing unnecessary ROP-related blindness. It emphasizes the importance of having systematic screening programs for premature infants and can be a clue for further investigations.

### **Conclusion**

In summery, unnecessary ROP-related blindness is a tragedy which is potentially preventable. Giving sufficient information to parents in terms of consequences of ROP and the exact date of eye exam along with facilities of free of charge ROP screening, can increase the chance of the infants being examined during the golden time regardless of many other factors.

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