

# Awareness of Retinopathy of Prematurity Among Parents in Turkey

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## ABSTRACT

**Purpose:** The aim of this study is to measure the level of knowledge of parents about retinopathy of prematurity (ROP), and provide insight into programs that can be designed to raise awareness in parents about ROP.

**Materials and Methods:** The study enrolled parents of infants who were born before the 32th week of gestation, and brought to retinopathy of prematurity examination between the 4th and 6th postnatal weeks. Prior to the ROP examination, an 11-item survey was administered to measure the level of knowledge of the parents about ROP.

**Results:** The study included 200 parents with premature infants. Of the parents, 43% (86) were mothers and 57% (114) were fathers. Of the patients, 78% were referred by a pediatrician/neonatologist, 14% by another ophthalmologist, 8% by a family physician, and 7.5% presented to the hospital without any doctor's reference. 72% of the parents knew for which examination they had presented to the hospital. 63.5% did not know what ROP was, and 75% were not aware of the fact that ROP is a disease that causes blindness. Only 31.5% of the parents had obtained information about ROP and they mostly obtained information from doctors. It was found that as the education level of the parents increased, their awareness about ROP increased.

**Conclusion:** In order to protect premature babies from irreversible blindness, there is a need for informative programs for parents on retinopathy of prematurity.

**Key Words:** Awareness, Childhood blindness, Education level, Parent, Retinopathy of prematurity.

## INTRODUCTION

According to World Health Organization data, in 2010, 11.1% (approximately 14.9 million) of births in the world were preterm. The obtained data show that preterm birth rates increase every year in the world and that preterm births occur most frequently in underdeveloped or developing countries.<sup>1</sup> Preterm births are known to be one of the most common causes of death of children under 5 years of age.<sup>2</sup> In addition, preterm delivery has been shown to be a high-risk factor for neurological, developmental, visual, and auditory sequelae in children in the long term.<sup>3,4</sup>

In 2010, an estimated 185.000 infants worldwide developed any stage of retinopathy of prematurity (ROP), and approximately 20.000 infants experienced blindness or severe visual loss due to ROP.<sup>5</sup> When ROP-induced

blindness is examined, it is seen that most of these babies were born in underdeveloped countries where neonatal care conditions were inadequate.<sup>5</sup> Furthermore, it was reported that in these countries, unlike developed countries, more mature and high-birth-weight infants also developed blindness due to ROP.<sup>5,6</sup> It was shown that of the infants treated at the appropriate time due to the diagnosis of Type 1 ROP, approximately 25% might develop blindness or severe vision loss despite all interventions, and 40% might develop mild visual impairment.<sup>7</sup> Nowadays, when the third epidemic of ROP is being witnessed in some countries, of the premature babies hospitalized in intensive care in Turkey, 27% developed any stage of ROP, and 6.7% developed severe ROP.<sup>8</sup> ROP frequency and severe ROP rate vary in different neonatal intensive care units in our country. Also, it was argued that ROP screening criteria should also include higher-birth-weights and more

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mature infants than those in developed countries to prevent blindness in premature infants.<sup>8</sup>

Turkish Neonatology and Turkish Ophthalmology Societies published the "Guideline on the Retinopathy of Prematurity." This guideline aimed to increase the knowledge of neonatologists and ophthalmologists about ROP and to guide physicians in ROP follow-up and treatment.<sup>9</sup> However, no matter how sufficient knowledge and skills neonatologists and ophthalmologists have related to ROP, follow-up is primarily the responsibility of the parents after the premature baby is discharged from the intensive care unit. It is obvious that parents' having sufficient knowledge about ROP is one of the most important conditions of compliance and cooperation in follow-up and treatment. So far, no study has been conducted in Turkey to measure the level of ROP-related knowledge of parents of infants receiving cardiopulmonary support in neonatal intensive care units.

The present study aims to measure the level of ROP-related knowledge of parents of infants who require ROP follow-up, to reveal the factors affecting their knowledge levels, and through the results to be obtained, to provide insight into programs that can be designed to raise awareness in parents about ROP at national/international level.

## MATERIALS AND METHODS

The study was approved by the Ethics Committee of Diyarbakir Gazi Yasargil Training and Research Hospital (20.12.2018 / 195) and carried out in accordance with the Helsinki Declaration. Informed consent was obtained from all parents.

The study was carried out in the ROP Diagnosis and Treatment Center of Diyarbakir Gazi Yasargil Training and Research Hospital. The study enrolled parents of infants who were born before the 32th week of gestation, received cardiopulmonary support in the neonatal intensive care unit after birth and brought to ROP examination after discharge. The survey was administered to the parents when they brought their babies to the ophthalmology outpatient clinic for ROP examination for the first time. The parents who refused to participate in the survey and the parents of the infants who were born preterm but not hospitalized in the intensive care unit were not included in the study.

Prior to the ROP examination, an 11-item survey was administered to measure the level of knowledge of the parents about ROP.

Survey for Measuring the ROP-related Knowledge Levels of Parents of Infants Presenting for ROP Examination

Question 1: What is your relationship with the baby?

1. Mother
2. Father

Question 2: How old are you?

Question 3: What is your education level?

1. I never attended any school
2. I am a primary school graduate
3. I am a secondary school graduate
4. I am a high school graduate
5. I am a university graduate

Question 4: Who referred you to the ROP (Retinopathy of Prematurity) examination?

1. Pediatrician
2. Family Physician
3. Ophthalmologist
4. I presented to the hospital without any doctor's reference

Question 5: Do you know for which disease you have been referred/ are presenting to the hospital?

1. Yes
2. No

Question 6: Do you know what ROP (Retinopathy of Prematurity) is?

1. Yes
2. No

Question 7: Do you think ROP (Retinopathy of Prematurity) causes blindness?

1. Yes
2. I do not have any idea
3. No

Question 8: Do you think follow-up is important for the treatment of ROP (Retinopathy of Prematurity)?

1. Yes
2. I do not have any idea
3. No

Question 9: Will you be able to visit the hospital for the follow-up on the date specified by your doctor?

1. Yes
2. Maybe
3. No

Question 10: Did you obtain any information about ROP (Retinopathy of Prematurity)?

1. Yes
2. No

Question 11: What sources did you use for obtaining information? (10. Answer if your answer to Question 10 is yes)

1. Internet
2. Doctor (pediatrician, ophthalmologist, family physician, etc.)
3. Books/magazines

## STATISTICAL ANALYSIS

Mean, standard deviation, median, and lowest and highest frequency and ratio values were used in descriptive statistics of the data. SPSS 22.0 program was used for the analyses.

## RESULTS

Of the 200 parents who participated in the study, 43% (86) were mothers and 57% (114) were fathers, and the mean age was  $30.5 \pm 6.8$  (18-55). 70.5% (141) of the parents were referred by pediatricians, 14% (28) by another ophthalmologist, 8% (16) by the family physician, and 7.5% (15) presented to the hospital without any doctor's reference. 72% of the parents knew for which examination they had presented to the hospital. 63.5% did not know what ROP was, and 75% were not aware of the fact that ROP is a disease that causes blindness. 65.5% did not have any idea that the follow-up was important and 92.5% stated that they would bring their baby to the follow-up on the specified date. Only 31.5% of the parents obtained information about ROP and 29% stated that they obtained information from doctors. The participants' responses to the items in the survey are presented in Table 1. The responses of the parents according to their education level are presented in Table 2.

## CONCLUSION

ROP is the leading cause of preventable blindness in premature babies all over the world.<sup>5</sup> Prevention of visual loss in the baby with a high risk of blindness through

immediate treatment depends on the quick decision to be made by the neonatologist, ophthalmologist and parents. During the hospitalization period, ROP follow-ups and treatments are performed jointly with neonatologists and ophthalmologists. After the discharge, parents are responsible for the ROP follow-ups. In this period, the neonatologist gives the parents all the information related to the baby's health and makes follow-up appointments for conditions requiring follow-up (neurological and ophthalmologic examination, hearing test, etc.).

In a study, 92 countries responded to the online survey of ROP screening programs in 141 countries worldwide, and 78 of these countries were found to have ROP screening in at least one center. Also, it was found that 68 countries had guidelines for ROP screening and in 31 of these countries, the guidelines were prepared by a neonatologist and an ophthalmologist together. The least participation in the survey was in Africa, which was attributed to the lack of interest of neonatologists and ophthalmologists or to the lack of awareness about ROP in neonatal care.<sup>10</sup> As a result of a ROP survey administered to the pediatricians in South India, China, and Thailand, it was found that most pediatricians do not have ROP awareness.<sup>11-13</sup> According to other surveys conducted in Nigeria and Palestine, they were observed that pediatricians knew what ROP was but did not know about ROP follow-up and screening programs.<sup>14,15</sup> In India, it was found that only a small number of pediatricians considered international recommendations in ROP follow-up and that there were not enough ophthalmologists to perform ROP examinations.<sup>16</sup> In our study, it was found that approximately 70% of the parents were referred to the ROP examination at the right time by a pediatrician or neonatologist, which indicates that pediatricians in Turkey pay attention to the ROP screening program. It is thought that the guideline prepared jointly by Turkish Neonatology and Turkish Ophthalmology Societies as well as the attention of physicians has a great effect in this high rate.

The results of the survey indicate that although the majority of the parents knew for which disease they were referred to the hospital, they did not know what ROP was, whether it caused blindness, and whether the follow-up was important. It is clear that this result is consistent with their responses to the question inquiring whether they had obtained information about ROP. As a result of the survey, it is seen that parents' ROP awareness increased as their education level increased. However, the level of knowledge of people with a high level of education is still not sufficient to protect the baby. Although the parents' levels of knowledge were not sufficient, most of them stated that they would bring their baby to the follow-up on the date specified. This result is promising in that through the detailed information to be provided by doctors to the

**Table 1.** The participants' responses and rates.

		Min-Max			Median	Mean±s.d./n-%		
		18	-	55	30.0	30.5	±	6.8
Age								
What is your education level?	I never attended any school					16		8.0%
	I am a primary school graduate					36		18.0%
	I am a secondary school graduate					38		19.0%
	I am a high school graduate					51		25.5%
	I am a university graduate					59		29.5%
What is your relationship with the baby?	Mother					86		43.0%
	Father					114		57.0%
Question 4: Who referred you to the ROP (Retinopathy of Prematurity) Examination?	Pediatrician/neonatologist					141		70.5%
	Family Physician					16		8.0%
	Ophthalmologist					28		14.0%
	I presented to the hospital without any doctor's reference					15		7.5%
Do you know for which disease you have been directed/applied to the hospital?	Yes					144		72.0%
	No					56		28.0%
Do you know what ROP is?	Yes					73		36.5%
	No					127		63.5%
Do you think ROP causes blindness?	Yes					50		25.0%
	I do not have any idea					150		75%
	No					0		0%
Do you think follow-up is important in ROP?	Yes					68		34.0%
	I do not have any idea					131		65.5%
	No					1		0.5%
Will you be able to visit the hospital for the follow-up on the date specified by your doctor?	Yes					185		92.5%
	I do not have any idea					14		7.0%
	No					1		0.5%
Did you obtain any information about ROP?	Yes					63		31.5%
	No					137		68.5%
What sources did you use for obtaining information?	Internet					4		2%
	Doctor					58		29.0%
	Books/Magazines					1		0.5%

ROP: Retinopathy of prematurity

parents, blindness can be prevented in infants with a high risk for developing ROP with the treatment to be applied immediately.

It was seen that about 70% of the parents had not obtained any information about ROP, and the majority of those who had information obtained it from their doctors. It was also determined that parents' rate of obtaining information increased as their education levels increased. This shows that parents are not worried enough about the health problems of a premature baby, and many are satisfied with the information provided by the doctor. This result shows

that equipping parents, who are responsible for bringing their baby for follow-ups after discharge, with necessary information about ROP is important to prevent irreversible blindness due to the disease.

High-risk disease due to ROP does not cause any pathological findings in the anterior segment of the eye that is visible to the eyes of parents in the early period. This may lead parents to think that their babies' eyes are healthy. However, in cases that were not followed up for ROP and where blindness developed, after the period when the loss of vision could have been prevented with

		Educational Status									
		Unschool ed		Primary School		Secondary school		High school		University	
		n	%	n	%	n	%	n	%	n	%
Who directed you to the ROP examination?	Pediatrician/neonatologist	8	50.0%	27	75.0%	28	73.7%	39	76.5%	39	66.1%
	Family Physician	3	18.8%	6	16.7%	2	5.3%	1	2.0%	4	6.8%
	Ophthalmologist	2	12.5%	3	8.3%	5	13.2%	6	11.8%	12	20.3%
	I presented to the hospital without any doctor's reference	3	18.8%	0	0.0%	3	7.9%	5	9.8%	4	6.8%
Do you know for which disease you have been directed/applied to the hospital?	Yes	11	68.8%	26	72.2%	27	71.1%	34	66.7%	46	78.0%
	No	5	31.3%	10	27.8%	11	28.9%	17	33.3%	13	22.0%
Do you know what ROP is?	Yes	5	31.3%	9	25.0%	9	23.7%	19	37.3%	31	52.5%
	No	11	68.8%	27	75.0%	29	76.3%	32	62.7%	28	47.5%
Do you think ROP causes blindness?	Yes	3	18.8%	4	11.1%	5	13.2%	14	27.5%	24	40.7%
	I do not have any idea	13	81.3%	32	88.9%	33	86.8%	37	72.5%	35	59.3%
	No	0	0%	0	0%	0	0%				
Do you think follow-up is important in ROP?	Yes	3	18.8%	10	27.8%	7	18.4%	18	35.3%	30	50.8%
	I do not have any idea	13	81.3%	25	69.4%	31	81.6%	33	64.7%	29	49.2%
	No	0	0.0%	1	2.8%	0	0.0%	0	0.0%	0	0.0%
Will you be able to visit the hospital for the follow-up on the date specified by your doctor?	Yes	14	87.5%	33	91.7%	35	92.1%	48	94.1%	55	93.2%
	I do not have any idea	2	12.5%	3	8.3%	3	7.9%	2	3.9%	4	6.8%
	No	0	0.0%	0	0.0%	0	0.0%	1	2.0%	0	0.0%
Did you obtain any information about ROP?	Yes	4	25.0%	6	16.7%	8	21.1%	17	33.3%	28	47.5%
	No	12	75.0%	30	83.3%	30	78.9%	34	66.7%	31	52.5%
What sources did you use for obtaining information?	Internet	1	6.3%	1	2.8%	0	0.0%	1	2.0%	10	16.9%
	Doctor	3	18.8%	6	16.7%	8	21.1%	17	33.3%	24	40.7%
	Books/Magazines	0	0.0%	0	0.0%	0	0.0%	1	2.0%	0	0.0%

**ROP:** Retinopathy of prematurity

treatment, parents can only recognize the loss of eye contact and object tracking with leukocoria. Doctors must provide information about this to parents and warn them that their babies might develop irreversible blindness if they do not bring them for follow-ups. Also, doctors must make a follow-up appointment for the parents to bring their baby for the ROP examination.

One study found that discharge education given to the parents of premature babies enables parents to be more careful about the care and health of the baby (16). Seminars on ROP and other premature birth-related diseases during hospitalization for the parents with premature infants who

are in intensive care, informative videos explaining the importance of ROP on screens in intensive care waiting rooms, and public service ads to be broadcast on national television channels will surely create awareness in parents about ROP. In addition, it will be useful to distribute hand brochures that explain ROP and related problems in a way that parents can understand in newborn intensive care units, pediatrics clinics, and ophthalmology clinics.

In conclusion, the present study found that although parents' levels of awareness about ROP increased as their education level increased, still, they did not have sufficient knowledge about ROP. Considering that

parents mostly obtain information from their doctors, it is thought that detailed information about the disease during hospitalization, after discharge, and during follow-ups in ROP outpatient clinics may be more effective in increasing ROP awareness. Furthermore, considering that medical malpractice lawsuits impose serious sanctions on the physician and that the physician and the parents have a great responsibility for the health of the baby, policies should be developed to increase the knowledge levels of physicians and parents about ROP.

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