

Parental awareness of the need for screening of retinopathy of prematurity in Northern China

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早产儿视网膜病变患儿家长对眼部筛查的认知调查

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摘要

目的:分析中国北部地区患有重度早产儿视网膜病变患儿的家长对该病的认知情况。

方法:采用问卷调查形式。问卷于 2013-01/2013-04 发放并回收,问卷对象为 230 名患有重度早产儿视网膜病变患儿的家长。问卷收集了患儿的基本情况和家长对该病认知度的信息。

结果:回收有效问卷共计 221 (96.1%) 份,其中 128 (57.9%) 名患儿曾在住院期间接受过眼底检查,208 (94.1%) 名患儿家长曾被儿科医生告知并建议进行早产儿视网膜病变筛查,而 13 (5.9%) 名患儿家长并未曾被告知进行眼底筛查。仅有 159 (71.9%) 名患儿家长对早产

儿视网膜病变有所了解,而 62 (28.1%) 名患儿家长对该病一无所知。由于晚期早产儿视网膜病变(如 IV 期或 V 期病变)预后极差,患儿家长是否被医生告知需要进行眼底检查与病变的严重程度密切相关($P < 0.001$),一定程度上影响患儿的预后。然而,医院的级别与家长是否知情之间并无显著相关关系($P = 0.625$)。

结论:中国北部地区的儿科医生和早产儿家长对于早产儿视网膜病变的认知有待进一步提升。而儿科医生与眼科医生对于患儿家长进行更多的沟通和宣教将有助于改善现状。

关键词:早产儿视网膜病变;家长认知;问卷调查

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Abstract

• **AIM:** To analyze the awareness of retinopathy of prematurity (ROP) among parents of ROP patients in Northern China.

• **METHODS:** A questionnaire was given to 230 parents of ROP infants and collected in person between Jan. and Apr. 2013. Basic information on the ROP infants and the parents' awareness of ROP were collected from the parents.

• **RESULTS:** In all, 221/230 (96.1%) questionnaires were returned. Based on these completed responses, 128 (57.9%) premature infants received screening during hospital stays, 208 (94.1%) parents were informed about screening and received a recommendation for screening by pediatricians, and 13 (5.9%) parents did not receive any recommendation for screening. Only 159 (71.9%) parents were aware of ROP, while 62 (28.1%) were not aware of the disease. Because stages 4 and 5 of ROP had a poor prognosis, we determined whether parents were informed by pediatricians closely associated with the severity of ROP ($P < 0.001$). However, we found no association between the grade of hospital and whether the parents were informed ($P = 0.625$).

• **CONCLUSION:** Awareness of ROP among parents and pediatricians in Northern China still needs to be improved. Better and more timely communication and education of parents regarding ROP from pediatricians and ophthalmologists will help.

• **KEYWORDS:** retinopathy of prematurity; awareness in parents; questionnaire

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INTRODUCTION

Retinopathy of prematurity (ROP), characterized by the development of abnormal vessels of the retina in premature infants, is a preventable cause of blindness in children. Appropriately timed treatment for ROP can lead to significant improvements in visual outcomes^[1-2]. This raises an important question concerning the strategy for reducing the incidence of blindness as a result of ROP, which should include ensuring that all at-risk infants are examined in screening programs^[3-7].

With the rapidly improving survival of very-low-birth-weight infants, ROP has emerged as a significant problem in China^[2]. Infants who suffer severe ROP are more mature and larger in China than those in similarly affected developed countries, and this is reflected in the wider screening criteria in China^[4-5,8]. However, ROP infants were not routinely screened in most cities until guidelines on oxygenation policies and practices were issued by the Chinese Ministry of Health in 2004 [≤ 2000 g birth weight (BW) and/or ≤ 34 wk gestational age (GA); initial examinations are at postnatal weeks 4-6, or at 32-34 wk of gestation], which formed the first guidelines for ROP screening of premature infants in China^[9].

The initial signs of ROP can be detected a few weeks after birth, and the condition progresses rapidly, which means that screening must be timely, as there is only a very narrow window of opportunity for treating these infants^[10-12]. Awareness among parents and pediatricians is crucial to address this problem^[10]. Before 2004, most ROP infants were brought to hospitals because their parents or pediatricians noticed the white reflex in their eyes or realized that the infants' vision was impaired. However, it was generally too late to do anything to retain normal vision. It has been 9y since ROP guidelines were issued in China^[4]. However, few studies have addressed how these guidelines have been applied in these years.

This prospective study analyzed the level of awareness of ROP among parents in Northern China, to provide preliminary data on the current screening situation, and to determine what drawbacks may be affecting screening.

SUBJECTS AND METHODS

The study was conducted in accordance with the Declaration of Helsinki, and we received approval from the Investigational Review Board of the People's Hospital affiliated with Peking University.

A questionnaire survey was distributed between January 2013 and April 2013 in the People's Eye Center, People's Hospital of Peking University, which is one of the most prestigious ROP-referral eye centers in North China. Severe ROP patients from all over the country come to this center for treatment. We use the term "severe ROP" to refer to patients

ROP questionnaire

Date: _____

Infant Name: _____
Gender: _____
Date of birth: _____
Gestational age (wk): _____
Birth Weight (g): _____
Hospital at birth: _____
NICU admitted: _____

NI
CU stay: () wk

Oxygen usage: Yes () No ()

ROP screening in NICU: Yes () No ()

Did Pediatrician tell you to get your baby ROP screened? Yes () No ()

Do you know the disease of retinopathy of prematurity? Yes () No ()

Do you know premature infants should get ROP screening? Yes () No ()

Do you know why your baby should get eye examination? Yes () No ()

Figure 1 The questionnaire of parental awareness for screening of ROP

treated for type 1 pre-threshold and threshold stage 3 ROP requiring laser surgery and anti-VEGF treatment, as well as to refer to those presenting with stages 4 and 5 ROP who may need surgical treatment. The questionnaire consisted of eight questions and took less than 10min to answer. No personal questions were asked. The questionnaire was distributed and collected in person. It did not implicitly define the guidelines. If a questionnaire was returned blank or more than two questions were not answered, the parent was classified as a non-responder. The questionnaire is shown in Figure 1.

The patients were divided into two groups: stage 3 ROP, referring to threshold and pre-threshold ROP; and stage 4 and 5 ROP. A commercially available statistical software package (SPSS for Windows, version 17.0, SPSS Inc., Chicago, Illinois, USA) was used to analyze the data. A one-sample Kolmogorov-Smirnov test was performed to examine whether samples were distributed normally. The Chi-square test was used to test the association between different variables. Two-tailed probabilities less than 0.05 were considered to indicate statistical significance.

RESULTS

In all, 230 questionnaires were distributed, of which 221 (96.1%) were returned; 73 ROP patients were female (33.0%), 69 were twins (31.2%), and 3 were triplets (1.4%). Mean GA was 30.3 ± 2.2 wk. Mean BW was 1524.5 ± 1.0 g. Based on the completed responses, 128 (57.9%) premature infants received screening during their hospital stay. In total, 100 (45.2%) premature infants had more than a 6-week stay in a pediatric hospital, and 33 (33.0%) did not receive any screening during their stay (Table 1).

Pediatricians informed and gave recommendations to 208 (94.1%) parents, and 13 (5.9%) parents did not receive any recommendation for screening. Only 159 (71.9%)

Table 1 Characteristics of 221 infants treated for severe ROP

Parameters	Data
Gender (F, %)	73 (33.0%)
Mean gestational age (wk)	30.3±2.2
Mean birth weight (g)	1524.5±1.0
Grade of hospital admitted	
Tertiary hospital	184 (83.3%)
Non-tertiary hospital	37 (16.7%)
Whether screened	
No	93 (42.1%)
Yes	128 (57.9%)
Hospital stays of more than 6wk whether screened	
No	33 (33.0%)
Yes	67 (67.0%)
Who informed screening	
By pediatrician	208 (94.1%)
No idea	13 (5.9%)
Parents aware of ROP	
Yes	159 (71.9%)
No	62 (28.1%)

ROP: Retinopathy of prematurity.

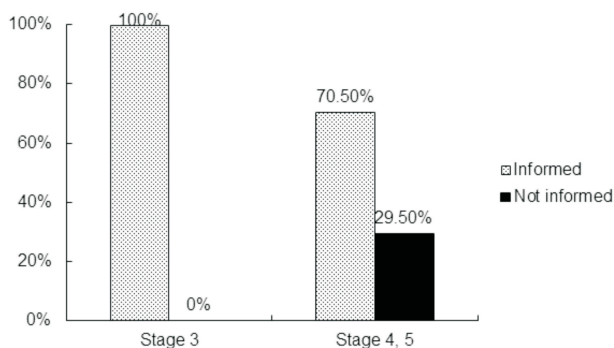


Figure 2 Whether parents with ROP infants at different stages were informed about ROP.

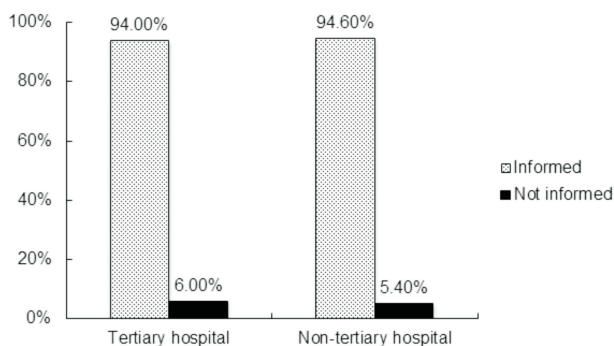


Figure 3 Whether parents with ROP infants at different-grade hospitals were informed about ROP.

parents were aware of ROP, while 62 (28.1%) were not aware of it (Table 1).

In addition, whether parents were informed by pediatricians was associated with ROP stage, where fewer parents of stage 4 and 5 patients were informed (31/44) than parents of stage 3 (177/177) ($P < 0.001$; Figure 2). However, there was no association between the grade of hospital and whether the

parents were informed (tertiary hospital *vs* non-tertiary hospital: 173/184 *vs* 35/37) ($P = 0.625$; Figure 3).

DISCUSSION

In this paper, we report the results of a questionnaire survey of parents with severe ROP infants to ascertain whether the parents were informed and aware of ROP.

We found that 94.1% of parents with ROP infants were informed of ROP and received recommendations for screening by pediatricians. Awareness and screening of ROP has been promoted since the government issued guidelines for it in 2004. Pediatricians are required to inform parents of the need for an ocular examination by an ophthalmologist^[13]. Most pediatricians recognize the need for ophthalmological examinations with the help of ophthalmologists. However, in this study, 5.9% of parents had not been informed by their attending pediatrician about the need for an eye examination for their children. These infants never had an eye exam and came to us only after the parents noticed that their children did not see well. Thus, awareness of ROP is lacking among some pediatricians. The same thing happens in other developing countries. A survey in India showed that only 54 (65.1%) of 83 pediatricians were aware of ROP, while 29 (34.9%) were not aware of the disease. Educational programs on ROP should be promoted among pediatricians^[14]. In our study, only 57.9% of premature infants received screening during pediatric hospital stays, of which 33.0% did not receive any screening during stays of more than 6wk, which exceeds the recommend screening timing. There are many reasons for this. One reason is the shortage of ophthalmologists who can screen ROP infants. In China, there are many maternal hospitals that lack an ophthalmology department. Very few ophthalmologists can do the required screening and those who can do it are usually in tertiary hospitals. To correctly diagnose ROP, an ophthalmologist should have experience with the indirect ophthalmoscope technique. This is very time consuming and high risk, particularly in China. Ophthalmologists generally do not wish to be involved in this area. Even in the United States, a lack of properly trained ophthalmologists is common. A survey of the American Academy of Ophthalmology in 2006 showed that only half of retina and pediatric ophthalmology subspecialists treated ROP, and about one-fifth of those were planning to discontinue the practice in the near future. A study of ROP case management and ophthalmologist practice in this area is needed for China.

There are many reasons for the barriers to screening, particularly whether parents had been informed of the requirement for screening. Recently in China, screening did not take place regularly in neonatal units; there was still a lack of clarity about the responsibility for ensuring the continuation of screening, transfer to another hospital, or discharge, which means there was a lack of a convenient and efficient referral system. Thus, parents could not take their infants to an ophthalmologist in a timely fashion; some parents did not even know where to find an ophthalmologist. It is

necessary to strengthen the level of cooperation and communication between ophthalmologists and pediatricians. Although the level of ROP awareness may be high among pediatricians, our study shows that it is very poor in parents. Only 71.9% of parents were aware of ROP, while 28.1% had no idea about the disease. To improve awareness among parents and pediatricians about ROP, we recommend instituting frequent developmental medical education in hospitals and communities. There is a need for improved communication^[15-16]. Pediatricians should not only inform parents of the screening, but also explain in detail to parents when and why they should screen^[17-19].

We found that some infants were diagnosed with stage 4 or 5 ROP on first arriving at our hospital. Whether parents were informed by pediatricians was closely associated with the severity of ROP ($P < 0.001$). However, there was no association between the grade of the hospital and whether the parents were informed ($P = 0.625$). Tertiary hospitals generally implemented screening and informed most parents during their hospital stay. This result may be due to regional differences in China. Poor prognoses were related with a lack of information. Reports from other developing countries, such as India, Thailand and Vietnam showing a similar trend^[10, 20-21].

Awareness of ROP among parents in North China needs to be further improved. Better communication, education, and support from pediatricians and ophthalmologists, as well as informing parents in a timely fashion, would help. Educating pediatricians about ROP and training more ophthalmologists to do ROP screening are needed in China.

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