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## **An evaluation of referral system for retinopathy of prematurity in leading health centers across Karachi, Pakistan**

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### **Abstract**

**Objective:** Retinopathy of prematurity (ROP) is emerging as a significant avoidable cause of childhood blindness in developing countries. This study was conducted to assess the referral system for ROP in the leading health care centers involved in the provision of services to newborns in Karachi, and to assess the awareness of this condition among health care workers in these centers.

**Methods:** A purposeful sampling technique was employed to select ten health care centers in Karachi, Pakistan, which had the highest number of deliveries per year. Key informants interviews were held with the health care providers involved in the decision-making at these centers. A content analysis was performed on their responses.

**Results:** A total of 20 physicians (5 neonatologists and 15 pediatricians) were interviewed. Most of the surveyed centers did not have any referral system for ROP. The two centers that did have a referral system were not following standard protocol for such referrals. Most interviewees had inadequate knowledge of ROP. Only 2 out of 20 physicians were aware that ROP can lead to blindness.

**Conclusion:** There was no referral system for ROP screening at most of the surveyed centers. The few centers that did have a referral system were not following international screening guidelines for such referrals. There is lack of recognition of ROP as a sight-threatening condition as shown by the inadequate knowledge of ROP among the concerned staff (JPMA 60:840; 2010).

### **Introduction**

Retinopathy of prematurity (ROP) is an important cause of childhood blindness which can lead to a lifetime of social, emotional and economical challenges. Currently, at least 50, 000 children worldwide are blind from ROP.<sup>1</sup> Its major risk factors include prematurity, low birth weight and exposure to high oxygen concentration.<sup>2</sup>

The proportion of children who are affected by ROP varies depending on the level of development of the country and the effectiveness of ROP screening programmes in place.<sup>3</sup> With improved survival rates of premature and low birth weight infants, especially in the developing countries, ROP is emerging as an important cause of blindness in children worldwide. This has been referred to as the "third epidemic" of ROP.<sup>1,3</sup> However, if appropriate screening strategies are implemented, it is a potentially avoidable cause of blindness.<sup>4</sup>

A key strategy used by ROP screening programmes is the timely referrals of high risk children. The idea of this study stems from our experience of seeing several cases of advanced ROP as a result of delayed referral. All these children were high-risk for ROP but their parents were not made aware by health care providers of the condition, its management and blinding consequences. They were all born in the leading hospitals of Karachi, reportedly adequately equipped to deal with premature births. Based on this

experience, we conducted a study in the ten leading health care centers across Karachi to assess if they had a referral system for ROP. We also assessed the level of awareness of this condition among health care workers directly involved in decision-making and provision of services to the newborns in these centers.

### **Methods**

A purposeful sampling technique was employed to select 10 hospitals / maternity centers in Karachi with the highest number of deliveries per year (Table 1). The selected centers included private and public sector hospitals and maternity homes in different localities of the city, catering to large populations. Informed written consent to conduct the study was obtained from the administrators of the respective centers. In each center, information about referrals for ROP and related practices, and whether a standard protocol was being followed, were obtained from two paediatricians or neonatologists, involved in the primary decision making regarding the care of all newborns. We assessed if the selected centers were following a standard protocol for ROP screening. By standard protocol we mean, the joint statement on screening guidelines for preterm infants, which was issued by The American Academy of Ophthalmology, Section on Ophthalmology American Academy of Pediatrics, and American

**Table-1: Characteristics of the surveyed hospitals and maternity homes in Karachi.**

Center (Hospital/ Maternity Home)	Public/Private sector	No of deliveries per year*	No of preterm births per year*
A	Private	1500	120-140
B	Private	2000	300-360
C	Charity	2000	180-240
D	Private	2000	120-180
E	Private	3000	180-240
F	Private	3500	120-240
G	Public	7000	1200-1400
H	Public	9000	1200-1800
I	Charity	10,000	1800-2000
J	Public	16,000	3000-3600

\* Average number of deliveries and preterm births as reported by the respective centers.

Association for Pediatric Ophthalmology and Strabismus in 2006.<sup>5</sup> These guidelines recommend that "infants with a birth weight of less than 1500 g or with a gestational age of 32 weeks or less (as defined by the attending neonatologist) and selected infants with a birth weight between 1500 and 2000 g or gestational age of more than 32 weeks with an unstable clinical course, including those requiring cardiorespiratory support and who are believed by their attending paediatrician or neonatologist to be at high risk, should have retinal screening examinations performed after pupillary dilation using binocular indirect ophthalmoscopy to detect retinopathy of prematurity (ROP)."

Each interview lasted for around half an hour. The interview with the primary decision makers also asked open-ended question about their awareness and practices (Appendix-1).

#### Appendix 1:

1. What advice would you give to the parents of a baby with gestational age  $\leq$  32 weeks or birth weight  $\leq$  1500 grams?
2. What are the criteria for giving oxygen to babies in your center?
3. If oxygen is given, what is the usual saturation and duration in your center?
4. What do you think could be the benefits and adverse effects of giving oxygen?
5. Have you ever heard of retinopathy of prematurity? If yes, what have you heard?
6. Do you routinely advise an eye examination for premature babies? If yes, at what age?

Relevant records and documents were examined and field notes were taken through interviews and document reviews. Content analysis technique was used to identify key features from the responses given by the interviewees regarding their practices of dealing with preterm infants. The typical responses that were obtained have been discussed here.

## Results

A total of 10 centers providing maternity services in Karachi were invited to participate in the study. All decided to participate. The annual number of babies born ranged from approximately 1500 to 16,000 (Table-2). A range of

**Table-2: Key findings of the study.**

- ◆ Most of the surveyed hospitals did not have any referral system for ROP screening
- ◆ Prematurity and LBW are not considered as reasons for giving an ophthalmologic referral
- ◆ If a preterm and LBW baby is stable no advice is given to the parents besides follow up with the paediatrician
- ◆ Though health care providers were aware of ROP, the extent of awareness was minimal
- ◆ The most common misperception is that only those premature babies who are given oxygen are at risk of developing ROP
- ◆ In the 2 hospitals where preterm, low birth weight (LBW) infants were given ophthalmologic referral, the timing for the first ophthalmologic visit was not in accordance with international guidelines
- ◆ Although most doctors were aware that excessive exposure to oxygen could lead to eye problems, the oxygen saturation and duration of oxygen therapy were not monitored in any hospital.

**Table-3: Responses by the Physicians.**

Responses	n=20
No advice is given other than follow up with the paediatrician if a premature baby is stable	16
We routinely refer preterm, low birth weight infants for eye examination	4
Counseling for parents of preterm infants is done keeping security concerns in mind	2
Oxygen was given if the baby was in distress, appeared cyanosed and oxygen saturation was less than 85-90%	20
Regarding the appropriate use of oxygen in the preterm infants, generally the practice in the surveyed centers was to maintain oxygen saturation above 95%	18
Oxygen has harmful effects on brain and eyes	14
Oxygen saturation levels are not monitored because of lack of human and capital resources to do so	2
Premature babies are not given oxygen if they did not show signs of respiratory distress	1
ROP can lead to blindness	2
I have heard of ROP but I do not know anything about it	1

responses were obtained for the questions we asked at these centers (Table-3).

### Ophthalmic referral system for premature babies:

Most (8 out of 10) of the surveyed centers did not have any referral system for ROP. The two centers that did have a referral system were not following standard protocol for such referrals. Prematurity and low birth weights were not considered reasons for referral to an ophthalmologist. Generally if the baby was stable, regardless of gestational

age, no advice was given other than for follow up with a paediatrician. At a hospital where approximately 7200 deliveries take place a year, the neonatologist said:

"We do not advise parents to have their child's eyes examined, unless the baby was given oxygen which would lead to retrolental fibroplasia. In that case we advise them to visit an ophthalmologist. Or we advise an eye examination if there is any 'obvious abnormality'. But we do perform eye examination on every baby ourselves as well."

When asked when the first eye examination on a new born baby should take place, the interviewee replied that the timing depends on the parents. At one of the hospitals where premature babies were regularly seen by an ophthalmologist, the senior registrar said that he was not sure of the age at which the child was seen by an ophthalmologist.

A major misconception among the interviewees was that only those premature babies who received oxygen were at risk of developing ROP. Only few were aware that ROP can lead to blindness. Another paediatrician cited "discharge from their baby's eyes" as the reason for referral to an ophthalmologist.

In another hospital where nearly 2000 babies were born annually, the paediatrician said that parents were advised to have their baby's first eye examination at 6-8 weeks of life.

The two centers that did have a referral system were not following standard protocol for such referrals. In one of these hospitals, all babies in the Neonatal Intensive Care Unit with birth weight less than 1500 grams were examined by a visiting ophthalmologist once a week.

In one maternity home, which caters to a large population of a very low socioeconomic stratum, where nearly 9600 deliveries take place per year, the paediatrician said:

"Giving advice for eye examination is useless as no ophthalmologist visits our hospital from the institutes where [expertise in ROP management] exist. How can we refer our children? Our patients cannot afford to and will not seek any medical care outside of this charity hospital."

Another interviewee from the same hospital was of the opinion that the patients were too poor to afford an ophthalmic consultation and follow up. "They," he said, "do not even have money for the treatment of more serious problems." "They [the patients] do not have money even for injections to treat sepsis; how can they afford to see an ophthalmologist?"

A neonatologist at a maternity home with 3000 births a year, including 180-240 premature ones, cited security concerns when handling families of premature children.

"This hospital caters to a population which is quite poor and uneducated. If we [start] educating parents about the possibility of complications associated with preterm births, they will think that we did not handle their child

correctly and will get hostile, so our safety is threatened. That is why we have to deal with our patients keeping security concerns in mind."

### **Availability and use of oxygen therapy:**

All surveyed hospitals had incubators. 20 out of 20 physicians we interviewed mentioned that oxygen was given if the baby was in distress, appeared cyanosed and oxygen saturation was less than 85-90%. However, in one out of ten hospitals premature babies were not given oxygen if they did not have any signs of respiratory distress.

According to most interviewees, duration of oxygen therapy depended on the condition of the baby.

Regarding the appropriate use of oxygen in the preterm infants, in 9 out of the 10 selected centers the practice was to maintain oxygen saturation above 95%. However, some of the centers reported not monitoring oxygen saturation levels because of lack of human and capital resources to do so. Instead, the practice was to give 1 to 2.5 liters of oxygen per minute till baby's condition improved.

Regarding the harmful effects of supplemental oxygen, the common responses were damage to lungs due to hyperoxia, retinopathy, metabolic alkalosis and free radical injuries.

Fourteen physicians said that they were aware that excessive exposure to oxygen can have harmful effects on the brain and eyes.

### **Awareness of ROP and its risk factors:**

When asked if they had ever heard of ROP and what its main risk factors were, majority of the respondents were aware of the fact that it was a condition of premature infants with excessive exposure to supplemental oxygen being the main risk factor. However, only few mentioned that it can result in irreversible blindness. Several interviewees confessed to having no or very little knowledge of the condition. As one senior doctor at the NICU of a leading maternity home, where nearly 9000 deliveries occur per year, said: "Yes, I have heard of ROP, but I do not know anything about it."

A paediatrician in a maternity home where 3000-3600 babies are born per year, with 120-240 preterm, LBW infants said:

"I have as much knowledge [of ROP] as a final year MBBS student. I am aware of the pathophysiology and outcome. Every child who is given oxygen should have an eye examination."

## **Discussion**

Our study revealed that majority of the leading health centers and maternity homes in Pakistan's largest city, Karachi, do not refer preterm and low birth weight infants at

risk of developing ROP to an ophthalmologist. Majority interviewees, irrespective of where they worked, showed inadequate knowledge of ROP, its risk factors and screening.

Timely referral of the high risk babies is critical as it prevents the occurrence of threshold disease as recommended by guidelines titled, Screening examination of premature infants for retinopathy of prematurity.<sup>5</sup> Ocular examination of premature infants should be performed by an ophthalmologist trained to deal with preterm infants, with sufficient expertise and knowledge to be able to identify the location and sequence of the disease. "The International Classification of Retinopathy of Prematurity Revisited" should be used as a guideline for recording these retinal findings.<sup>6</sup> The first examination should normally be performed between 4 and 6 weeks of post natal age and the follow up examinations should be scheduled by the examining ophthalmologist.<sup>5</sup> However, it was disturbing to note that in our study prematurity and low birth weights were not considered as reasons for advising neonatal ophthalmologic examination. In addition, the majority of interviewees were not aware of its pathology, risk factors and consequences. We identified a number of misperceptions, the most common being that only those premature babies who were given oxygen therapy were at risk of developing ROP. To date, there is insufficient evidence to suggest what the optimal oxygen saturation is or PaO<sub>2</sub> values to aim for in preterm infants who receive oxygen. Research has shown that despite the common belief that oxygen therapy increases the risk of ROP, it can occur even with carefully controlled oxygen therapy and therefore, prematurity is the most important risk factor.<sup>2</sup>

In the 2 hospitals where ophthalmologic referral was given for premature, low birth weight infants, the timing for the first ophthalmologic visit was not in accordance with international guidelines; parents were advised to visit an ophthalmologist either at 6-8 weeks after birth, immediately after first visit to a pediatrician or no time frame was given.

Lack of attention to ROP as an important cause of childhood blindness in medical curriculum and the limited number of trained people in neonatal care may explain these misconceptions.

A prior local study, which reported the incidence of ROP as 32.4% in a tertiary care center, revealed that a large number of infants who satisfied the screening criteria remained unscreened in our country and could have developed ROP with consequent blindness.<sup>7</sup> Thus, implementation of proper screening guidelines in hospitals and maternity homes with special focus on the education of staff involved is essential.

According to World Health Organization — Vision 2020 program, after corneal scarring and cataract, ROP is one of the leading causes of avoidable childhood blindness

worldwide.<sup>4</sup> Due to improvements in neonatal care in the developing world, more premature infants are surviving. Thus ROP is emerging as a cause of blindness in middle and low-income countries.

Prematurity and low birth weights are important issues in our country contributing to infant morbidity and mortality. In Pakistan 35% of neonatal mortality is due to prematurity and related complications.<sup>8</sup> With improvements in neonatal care, more premature infants are now surviving in developing countries such as ours. Therefore, there is a much greater percentage of population that is "at risk" of developing Retinopathy of Prematurity in our part of the world. Due to limited resources the economic burden of the disease is also higher in such countries.

An important question which arises is that who should be making the decision for referral in these centers and where these babies should be referred to. Unless there are appropriate ROP services available with effective linkages to maternity homes and other health care facilities, referrals cannot be meaningful. In industrialized countries, effective screening programmes and high standard of neonatal care has resulted in reduced rates of blindness due to ROP.<sup>1</sup> Screening programmes are also being implemented in India, however they show a need to develop region specific guidelines.<sup>9,10</sup>

A strength of our study was that it involved all major hospitals and maternity homes with the highest rates of births, in all the major parts of the city. It would be important to see if the same pattern of inadequate knowledge of ROP and variable referral system exist in smaller units.

A qualitative methodology was chosen because this topic is not very well explored in our part of the world. Such a method was useful in providing an in-depth understanding of the issues explored.

One limitation of our study was that we could not confirm the reliability of the responses we obtained since we did not directly observe the practices regarding ROP referrals in the selected centers and our conclusions are based on the responses we received from the health care providers in these places.

In conclusion, there is no referral system for premature infants at the surveyed hospitals and maternity homes which have the highest number of deliveries in the city. There is lack of recognition of ROP as a sight-threatening condition as shown by the inadequate knowledge of ROP among the concerned staff.

We recommend that all at-risk babies born in hospitals and maternity homes should be registered and automatically referred to ophthalmologists. Staff involved in the care of premature infants should be trained in ROP through workshops and seminars. Parents of all prematurely born babies should be informed about the risk of development of

ROP, and the importance of timely ophthalmologic review and follow-up should be stressed. The importance of a critical time window for successful treatment and blindness as a possible consequence of untreated disease should be emphasized.

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