BARRIERS IN THE ESTABLISHMENT OF RETINOPATHY OF PREMATURITY SCREENING PROGRAM IN A DEVELOPING COUNTRY

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ABSTRACT

Objective: To study the role of retinopathy of prematurity (ROP) coordinator in improving compliance of patients with ROP screening examination visits.
Study Design: Prospective observational cross sectional study.
Place and Duration of Study: Lahore General Hospital from, 1st Jan 2015 to 31st Dec 2015.
Material and Methods: This prospective observational cross-sectional study was conducted at Lahore General Hospital over duration of one year, from 1st January, 2015 to 31st December, 2015. It included 326 preterm infants discharged from the Neonatal Intensive Care Unit (NICU) of the same hospital. Parents were provided scheduled ROP screening examination appointments at the time of discharge. These preterm infants were divided into 2 groups. Group-I included 163 infants discharged from NICU in the first 6 months (Jan 2015 to June 2015). Group-II included 163 infants discharged from NICU over the following 6 months (July 2015 to Dec 2015). Patients in group-II had the advantages of telephonic reminders provided by ROP coordinator before every follow-up visit, along with targeted education regarding ROP. They were also generously helped during every examination visit. Compliance in the two groups was compared and studied. Non-compliant parents of the infants of both groups-I and II were contacted using telephonic calls to inquire about patients' reasons for missing follow-up visits.
Results: Significant difference was observed with respect to compliance of parents among group-I who were not reminded about follow-up visits through telephone versus parents of infants enrolled in group-II who were contacted by the ROP coordinator through telephonic conversation (*p*-value=0.001).
Conclusion: ROP coordinator can play a vital role in improving compliance and decreasing refusal without reason in ROP screening through telephone reminders.

Keywords: Compliance, Follow-up, Retinopathy of prematurity, Screening.

INTRODUCTION

According to World Health Organization (WHO) world blindness statistics 2014, 1.4 million children from middle and low income countries were blind and ROP was observed to be a major cause of avoidable blindness among those children.

Globally at least 50,000 children are blind from ROP, and most of them live in developing countries[1]. Infants at risk for ROP require properly timed examinations to facilitate early detection of disease, as the time interval between disease onset and irreversible retinal damage and scarring may be a matter of days[2]. The lack of proper screening program has been reported as the main cause of no screening for ROP by many peadriaticians despite of having adequate knowledge about ROP screening guidelines[3]. Multiple studies conducted in Pakistan with the purpose to evaluate ROP screening practices, show that there is lack of referral systems in most of the leading neonatal units in the country[4]. This situation elaborates room for improvement and the need for an organized ROP screening system as infants at risk for ROP require properly timed examinations to facilitate early detection of the disease[2].

To improve screening practice, an effort was made to establish an ROP screening program at Lahore General Hospital (LGH), a 1076 beds tertiary care hospital located in the city of Lahore, Pakistan. ROP screening system started to

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function from 1st Jan, 2015 enrolling all preterm infants discharged from the NICU of LGH and receiving referrals from other parts of the country. However, appropriate delivery of retinal examinations to infants at risk following discharge from NICU can still be difficult even in developed countries, and many infants do not receive the recommended care[2]. This study was conducted to evaluate the compliance of parents with scheduled ROP screening visits, considering parental compliance as one of the documented major barriers in the development of ROP screening program in a developing country[5]. This study also evaluates the efficacy of telephonic reminders by the ROP coordinator in improving compliance in order to maximize the yield of ROP screening.

MATERIAL AND METHODS

This prospective observational cross-sectional study was conducted at Lahore General Hospital over a duration of one year from 1st January, 2015 to 31st December, 2015. ROP screening was performed in all premature neonates discharged from the Neonatal Intensive Care Unit (NICU) of the same hospital. Infants at risk for ROP were those born with a gestational age of 35 weeks or less, and a birth weight of 2000 g or less. All these infants were provided with a schedule for ROP screening examination visits at the time of discharge. Infants referred from other institutes were excluded from the study. Data regarding neonatal morbidity and NICU stay were collected to study their relevance with patients' compliance. These parameters included gestational age, birth weight, oxygen dependency, duration of NICU stay, corrected gestational age at time of discharge. Group-I included 163 infants discharged from NICU from January, 2015 to June, 2015. The ROP coordinator identified the non-compliant patients and contacted them using telephonic calls to inquire about reasons for non-compliance. The reasons given by the children's parents were analyzed to identify the factors resulting in poor follow up. Patients' causes for non-compliance were identified and refusal without reason was estimated. Infants in group-I were noted to have a poor attendance rate at ROP screening clinic. Therefore, the following interventions were implemented: calling families of group-I infants to schedule final appointments regardless of prior attendance; reminder phone calls for remaining visits. Group-II patients were given the advantage of telephonic reminders before every visit along with targeted education regarding ROP at the time of discharge and non-compliant

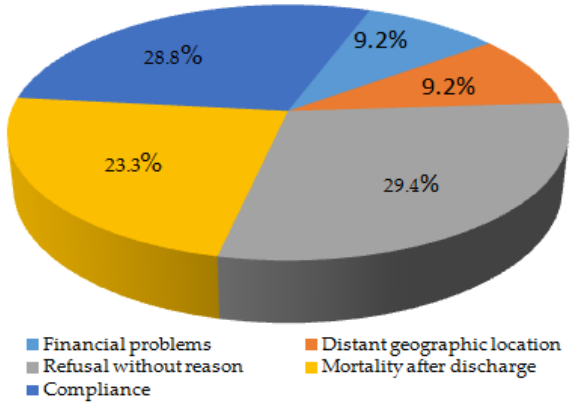

Figure-1: Response of participants in group-I.

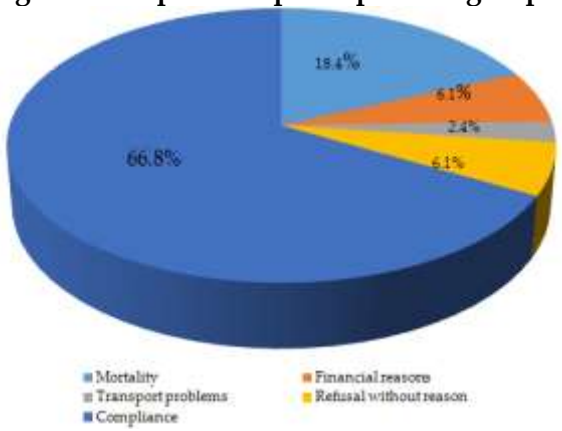

Figure-2: Response of participants in group-II.

patients were also contacted telephonically and reasons for non-compliance were compared in the two groups. Convenience consecutive non-probability sampling technique was used.

All preterm infants meeting the inclusion criteria over the first 6 months of the duration of study were included in group-I and they were numbered from 1-163. Based upon the observed poor compliance, we implemented practice

changes and thereafter, a similar number of preterm infants was included in group-II.

Data were entered into SPSS-20 for analysis. Compliance, non-compliance and reasons for non compliance in both groups are expressed in percentages and frequencies.

Gestational age, birth weight, and corrected gestational age at the time of discharge are expressed in terms of means and standard deviation.

RESULTS

Group-I included 163 infants, only 47 (28.8%) patients underwent retinal examination and no ROP was observed in them. A total of 116 (71.2%) patients failed to appear for follow up.

Telephonic calls were used to inquire the parents of the 116 non-compliant patients about the reasons leading to non-compliance.

Out of 116 patients, 38 (32.7%) patients told that their babies expired after discharge. Telephonic calls were beneficial in revealing a significant mortality, which was otherwise unidentified. A total of 15 (12.9%) patients explained financial problems and inability to afford more work absences, 15 (12.9%) explained distant location of residence and unavailability of affordable transport as they belonged to districts other than Lahore, 48 patients (41.4%) did not respond to telephonic calls, which probably reflects lack of interest in following ROP screening appointments and this was considered as refusal without reason, fig-1.

Group-II included 163 infants, having the advantage of telephonic reminders before every visit, they were provided with targeted education regarding ROP at the time of discharge with enhanced counseling regarding the importance of

Table-I: Birth data and neonatal record.

	Group-I	Group-II
Average gestational age (mean ± sd)	31 ± 2.5 weeks	31 ± 2.6 weeks
Birth weight (mean ± sd)	1542 ± 373.6 grams	1576 ± 397.6 grams
No. of infants with oxygen dependency during admission	142	128
No. of infants not dependent on oxygen during admission in nursery	21	55
Median length of stay (LOS) at NICU	10 days, range: 1-50 days	8 days, range: 1-69 days
Average corrected gestational age at discharge (mean ± sd)	32 ± 4 weeks	32 ± 2.7 weeks

Table-II: Comparison of follow-up rates with and without telephone reminders.

Group of neonate	Compliance				*p*-value
	Yes		No		
	Percentage	Frequency	Percentage	Frequency	
Group-I	28.8	47	71.2	116	0.001
Group-II	66.9	109	33.1	54	

Table-III: Different contributions of reasons for non-compliance among the two groups.

	Group-I (163)		Group-II (163)	
	Percentage	Frequency	Percentage	Frequency
Failed to appear in follow up	(71.2)	116	(33.1)	54
Refusal without reason	(41.4)	48	(18.5)	10
Mortality after discharge	(32.8)	38	(55.5)	30
Financial reasons	(12.9)	15	(18.5)	10
Transport difficulties	(12.9)	15	(7.5)	4

ROP screening examination. One hundred and nine patients (66.9%) appeared for follow-up visits and four infants with clinically significant ROP were identified and treated. The number of patients not appearing for follow-up was reduced to 54 (33.1%).

Among the 109 compliant patients of group-II, 30 (27.5%) appeared for follow-up after single telephone reminder, 37 (33.9%) needed 2nd reminder and 42 (38.5%) responded after 3rd telephone reminder.

When the 54 (33.1%) non-compliant patients in group-II were asked about reasons for non-compliance; 30 patients (55.5%) told that their babies expired after discharge, 10 patients (18.5%) explained financial reasons and 4 patients (7.5%) explained far off location of residence and unavailability of transport. Refusal without reason was decreased to 10 patients (18.5%), (fig-2). Birth data and neonatal history for cohorts on which practice changes were implemented are shown in table-I.

Table-II and III reflect the impact of practice changes, compliance improved from 28.8% in group-I to 66.9% in group-II with reminders (p<0.001) and non-compliance decreased from 71.2% in group-I to 33.1% in group-II with reminders (p<0.001). The main reason for non compliance changed from refusal without reason in the first group (41.4%) to mortality after discharge in the second group (55.5%), which reflects high mortality among preterm infants in Pakistan rather than true non-compliance.

DISCUSSION

There is an increase in the incidence of ROP in the developing countries including Pakistan[6]. The background behind this is that improved neonatal care facilities in the form of well equipped nurseries and trained peadriaticians have recently flourished in those developing countries. As a result, there is improvement in the survival rate of preterm infants who would not be able to survive otherwise in case of poor facilities. Their survival leads to the emergence of prematurity related health problems and ROP is among the most debilitating ones, this is called the third world epidemic of ROP[6]. Here arises the urgent need for alert ophthalmologists and established ROP screening programs in order to compliment improved preterm infant survival with improved peadriatic ophthalmic care facilities and end with surviving preterm infants who can lead healthy productive lives. The sequential nature of ROP creates the requirement of repeated screening examinations at proper times and intervals to detect the changes of ROP before they become permanently destructive[7,8]. This nature of the disease has lead to the need for effective screening programs[9,10]. Parental compliance with follow-up visits is a great challenge in the success of an ROP screening program[2]. Poor parental compliance with screening examination visits leads to missed or delayed detection of treatable ROP. Two studies conducted at high income developed countries observed that only about two-thirds and half of infants who needed retinal examinations after their transfer or discharge from a subspecialty NICU, received eye care within a month of the recommended time subsequently[2,5]. This low rate highlighted room for improvement. Attar et al have studied parental compliance with ROP screening, and found that infants are more likely to complete ROP follow-up when it is started and scheduled for them before discharge from NICU[2]. In our study, compliance was alarmingly low in spite of pre-discharge scheduling in the first group (28.8%), as it was conducted in a public hospital in a community with poor health awareness. Aprahamian et al discussed the need for ample help from hospital staff to maximize ROP screening examination follow-up rates[5]. This directed us to the implication of certain practice changes, mainly including the role of ROP coordinator in provision of ample, easily understandable and targeted education about ROP consequences and the availability of treatment. Telephone reminders before every visit were helpful for the families in organizing for transport and work coverage. Telephone calls were also helpful in revealing significantly high

mortality rate after discharge from NICU among preterm infants in Pakistan. Infant mortality contributed to 32.8% and 55.5% of the presumed non-compliance in each group, this indicates the need for further improvement in neonatal follow-up along with ophthalmic care follow-up[11]. The implemented practice change measures, resulted in decreasing refusal without reason among the patients who failed to follow, from the most common reason accounting to 41.4% of non-compliance in group-I to 18.5% in group-II. Patra et al[12] have also made use of telephone reminders and letters in improving neonatal follow-up attendance from 28% to 75% (comparable to our results 28.8% improved to 66.9%) at the neonatal care clinic of Rush university, Chicago. Wong AD et al[13] observed that telephone based follow-up is more effective in comparison with mail based follow-up in improving compliance in participants of colorectal cancer screening. In a randomized trial of telephone reminders for adolescents, non-attendance decreased from 20% to 8% when patients were reminded of upcoming appointments[14]. Parikh et al found that adults were significantly more likely to attend an outpatient appointment with a reminder phone call and that staff phone calls were more effective than automated computer calls[15]. We have studied the effect of telephone reminders in improving the outcome of ROP screening and it was observed that ROP screening practice can improve with the incorporation of telephone reminders and targeted parental education. Our study provides an example of a successful ROP screening program and it elaborates the role of the ROP coordinator assigned to the NICU.

CONCLUSION

Telephone reminders and targeted parents' education are effective measures in improving compliance and decreasing refusal without reason in an ROP screening program.

CONFLICT OF INTEREST

This study has no conflict of interest to declare by any author.

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