

Counselling and Follow up of Retinopathy of Prematurity Patients

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ABSTRACT

Retinopathy of prematurity (ROP) is a vasoproliferative disorder of the developing retina blood vessels in preterm infants. It is an avoidable cause of childhood blindness. Regular and effective counseling and follow up by the ROP team is critical to ROP blindness prevention efforts which should commence once the child is admitted in the neonatal intensive care unit (NICU). Good communication with parents is critical. Parents who are more aware of their child's condition, and engaged in their care are more likely to bring their child back for follow-up. The active engagement of parents can, therefore, make all the difference between success and failure in preserving their child's vision. One of the major reasons for failure of screening, delay in treatment and development of blindness is poor follow up. Strategies to enhance follow up visits include provision of ROP cards with scheduled dates of visit at the time of discharge. Informational posters and leaflets about ROP in local language can be displayed in waiting areas of neonatal and eye clinics for parents to read. Staff should talk to mothers nicely at the outpatient clinics and provision of feeding areas for mothers will encourage interaction between mothers. Creating awareness and counselling encourages follow up visits and helps prevent vision loss from ROP. The success of any ROP program depends on the team's ability to communicate essential information regarding ROP in accordance with the parents' socioeconomic background and also in a language they are familiar with.

Keywords : Retinopathy of prematurity, Counseling, Preterm , Follow up, Screening.

INTRODUCTION

Retinopathy of prematurity (ROP) is a proliferative disorder of the developing retina blood vessels in preterm infants. ROP as a preventable cause of blindness remains one of the leading causes of vision loss in children.¹ With the rising rate of prematurity and improving survival in low-and middle-income countries, the need for continuous counselling, screening, prompt treatment and long-term follow-up is greater than ever. Recent advances in ROP treatment offer the promise of improved outcomes and prevention of lifelong vision loss necessitating long-term follow-up.¹ The major risk factors for the development of ROP include gestational age, birth weight and number of days of oxygen.¹ Others are multiple births, blood transfusion, respiratory distress syndrome (RDS), Sepsis, Intra ventricular hemorrhage (IHV), anemia and poor weight gain. The sicker the baby, the higher risk of ROP.¹

One of the major reasons for failure of screening, delay in treatment and development of blindness is poor follow up attributed to lack of awareness on the part of the parents.² Parents play a very important role in any ROP screening programme. Their knowledge and awareness of ROP are very important factors in ensuring timely follow up of babies for screening.² Detailed counseling of parents of preterm babies ensures clear understanding of issues related to ROP from diagnosis, treatment, and short- to long-term follow-up leading to a successful outcome.²

METHODS

A search of the literature was made in PubMed, Google Scholar, EyeWiki and Community Eye Health Journal for articles describing, in detail, the counselling of caregivers of preterm babies and follow up of preterm babies with type 1 and 2 ROP and babies at risk of ROP. Search terms used included “retinopathy of prematurity”, “counselling”, “preterm babies” and “follow up”. The number of articles found were 15 in number and 9 were the relevant articles reviewed and the required information extracted from them. Some information was obtained through personal communication with experienced paediatric ophthalmologists and vitreoretinal surgeons with a lot of experience in the provision of ROP services.

DISCUSSION

Counselling

A multidisciplinary ROP team should be formed in any facility providing ROP services. The team should include an ophthalmologist, neonatologist, resident doctor, nurses, obstetricians, parents, records staff at the neonatology and eye clinics. Being a time bound disease, timely, realistic and appropriate counselling of parents and making them a part of the team is critical to getting the best vision for the baby.

Involving parents

The role of parents must not be underestimated, they help to prevent ROP by ensuring that their babies are screened while on admission. They are also responsible for bringing their child back for screening and treatment appointments. Without their active involvement, ROP can have devastating consequences.³ Available evidence shows that parents who are more aware of their child’s condition, and engaged in their care are more likely to bring their child back for follow-up.³ Infants who have had treatment need regular follow-up visits to ensure that the treatment has been successful in the short term, and to detect and manage complications in the longer term. The active engagement of parents can, therefore, make all the difference between success and failure in preserving their child’s vision. Good communication is very important and

as such communication with parents should be kind showing empathy.³ Parents should be allowed to ask questions and should not be interrupted. As part of strategies to develop trust, parents should be informed about ROP screening as soon as possible after admission. This gives them time to synthesize the information and ask questions.³ Communication with parents is critical hence counselling should be done in a language the parents are very familiar with. Parents should be aware of ROP exams and the consequences of ROP should be discussed with them. It is crucial to provide information communication and educational (ICE) materials on ROP to parents of all babies at risk. These materials should explain how ROP develops, examination technique performed on the baby, treatment options for ROP and importance of regular and long-term follow-up. Videos and photos of normal and abnormal retinal vascularization and retinal detachment should be presented to the parents including videos and photos of babies with sequelae of delayed treatment to help create awareness. It is also important to explain the need for regular follow up until retina is completely vascularized as well as the need for long-term follow up and the risk of blindness if follow up and treatment are delayed. Ophthalmologists should personally discuss about the disease and availability of treatment with parents of babies who have developed ROP.

Follow up

Regular follow up of babies at risk of ROP is critical to blindness prevention efforts. Follow up can sometimes be very often, sometimes every three to seven days. The need for very close coordination between all stakeholders during this time is very critical.⁴ At every screening examination for ROP, one of 3 decisions must be made: i) Terminate screening, ii) Treat or iii) Follow up. Screening is stopped only when a baby is no longer at risk of sight-threatening ROP. In babies who have not developed any ROP, the risk of sight-threatening ROP is minimal once the vessels have reached zone 3 and cannot occur once the vessels have reached the ora serata. Babies who develop ROP but do not meet treatment criteria, should be followed-up regularly until there is no further risk of sight-threatening

Table 1: Follow up schedule ⁵

Less than 1 week	1 – 2 weeks	2 weeks	2 – 3 weeks
Stage 1 and 2 in zone 1	No ROP in zone 1	Stage 1 in zone 2	No ROP in zone 2
Stage 3 in zone 2	Stage 2 in zone 2 Regressing ROP in zone 1	Regressing ROP in zone 2	Any stage in zone 3 Regressing ROP in zone 3

ROP. The ophthalmologists should check for signs of regression at each examination. Babies with type 1 ROP require immediate treatment while those with type 2 ROP are to be observed and followed up till regression or progression to type 1 (Table 1).

Follow-up after treatment

This is done to determine if re-treatment is necessary and to monitor disease regression as well as to determine the frequency of medium and long-term follow-up examinations. This should be done 3 – 7 days after treatment and continued weekly thereafter for signs of regression. Re-treatment should be performed usually 10 -14 days after initial treatment when there is failure of the ROP to regress.

Long term follow-up

Pre-term infants successfully discharged from ROP screening and or treatment services should be examined after 6 months for vision development as they are at risk of developing amblyopia, cataract, glaucoma, high refractive errors and strabismus.^{3, 5} Careful and repeated counselling is required to ensure that parents fully understand the need for their child to have long term follow-up.³

Strategies to enhance team work and follow up care

The provision of an ROP follow-up card with scheduled dates of visits at time of discharge and additional counselling on the need for follow up visits would enhance compliance with follow up schedule by parents. Dedicated counselors or records staff can be employed to call patients who miss appointments.

Informational pictures, posters and leaflets about ROP in local language should be displayed at the

waiting areas of Neonatal intensive care units (NICU) and eye clinics for care givers to read. Information brochures and handouts in local languages should be given to parents at the time of admission. Information about the consequences of late screening and the potential risk of blindness if screening does not take place should be included.

If the baby is not going to be discharged early, it is important to ensure that screening is done within 20- 30 days of life. On the other hand, if the baby is getting discharged early then screening should be done before discharge, this helps to sensitize the parents about the need for the next scheduled follow up visit since timely screening is crucial for early treatment and improved outcomes.⁶

At discharge, the appointment date, time and place should be specified to parents, including the person to contact (Name and phone number) if there are problems. The contact details of the parents (address and at least 2 phone numbers) should be obtained and recorded.

At the outpatient department , during follow up visits, staff should be encouraged to talk nicely to mothers as they wait for consultations so they don't get frustrated and refuse to come for subsequent follow up visits. Team members should prioritize some form of social connection with the mothers and other caregivers. Provision of a feeding area for mothers would aid interaction between mothers, such that mothers of babies with stage 5 ROP can encourage mothers of babies with less ROP to come for follow up. Anecdotally, some parents of preterm babies have spoken about the need for peer support from other parents who had also experienced preterm birth, NICU admission and ROP.⁷

It has been shown that parent support groups for parents of preterm babies with ROP have the potential to provide benefits especially in the areas

of awareness, knowledge, and compliance with follow up and alleviating anxiety.⁸

Monetary challenges need to be addressed as cost is a major barrier to follow up and compliance. Parents of babies who miss follow up appointments should be called and another quick appointment scheduled for them. It is important to maintain close communication between the neonatologist and ophthalmologist as well as referring and receiving hospitals in order to ensure that timely ROP screening, treatment and follow up care is provided. In addition, proper referrals with clear instructions should be provided to caregivers of babies that will not be coming back for follow up. Collaboration, co-ordination and communication between neonatal care and eye care providers should be adequately established to ensure that no child at risk of ROP is missed.

CONCLUSION

Creating awareness and counselling encourages follow up visits and helps prevent vision loss from ROP. The role of the neonatal staff (neonatologists and nurses) in increasing awareness, ensuring screening and follow up visits is critical to the success of any ROP program.⁶

The success depends on the team's ability to communicate essential information regarding ROP in accordance with the parents' socioeconomic background and also in a language they are familiar with. Active involvement of the parents can make all the difference between success and failure in preserving the child's vision. Compliance may lie not only in repeated counselling but also in increasing the awareness level in the society as a whole.

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