

Habilitation services for children blind from retinopathy of prematurity: Health care professionals' perspective in Maharashtra

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Purpose: To explore the knowledge of retinopathy of prematurity (ROP) and habilitation services for children with visual loss from ROP, among health care professionals (HCPs) involved in care of preterm children and to explore their attitudes and practices in relation to referral for habilitation. **Methods:** A modified knowledge, attitude and practice questionnaire were administered to ophthalmologists and paediatricians associated with ROP care. Data were collected about their knowledge, beliefs and practices of ROP and referral to rehabilitation facilities. Data were analysed to establish level of knowledge, type of attitude and practices and its association with speciality. **Results:** Response rate was 78% (25/32). Most (14/25, 56%) were ophthalmologists. All (100%) participants knew that ROP can cause blindness. Knowledge about Indian ROP screening criteria was poor among a third (8/25, 32%), more so in paediatricians (5/11, 45.5%). Most (21/25, 84%) did not have knowledge of what a habilitation service entails and where such facilities are located. More than two-thirds (18/25, 72%) believed that special education should be preferred over inclusive education. Overall, 10/25 (40%) of the HCPs had never referred a child for rehabilitation. More than a half (13/25, 52%) were not confident of counselling parents of blind children. All agreed that rehabilitation services are not part of but should be included in medical curriculum. **Conclusion:** Indian guidelines for ROP screening are not universally known among HCPs. Educating medical undergraduates, providing counselling training to professionals and integration of rehabilitation into the health system will ensure continuity of care for children with visual loss and their families.

Key words: Blindness, early intervention, rehabilitation, retinopathy of prematurity

Retinopathy of prematurity (ROP) has been recognised as an important cause of blindness in children in the middle-income countries of Latin America and Eastern Europe for two decades, and is becoming increasingly important in Asia and some African countries as neonatal care services expand.^[1] In India, in the absence of universal screening, over 3000 preterm infants are estimated to be going blind from ROP every year.^[2] Blindness from ROP is irreversible and for life. Although, the number of children who are blind from ROP is small compared to the number of adults who are blind from other, often age-related causes such as cataract, affected children have many 'blind years' ahead of them.^[3,4] The number of years lived with disability due to ROP and the economic benefit from blind person years saved by timely treatment^[5] makes a strong case for allocating resources to control. Habilitating children who have visual loss from ROP is a tertiary prevention strategy essential for control. Good vision from early in life is critically important for normal child development, as vision is the most important sense for early learning. Vision also coordinates other sensory inputs, allowing a child to gain an integrated understanding of his/her environment and to communicate and interact with people around them. Children who are

born blind or who have profound visual loss in infancy can develop psychomotor and cognitive developmental delay as well as behavioural problems.^[6,7] Developmental delay in blind children can be compounded by other impairments or neurological problems. In addition, over-protective parents, who fear that their child will come to harm if they are allowed to explore their environment, can be a barrier in achieving developmental goals.

Children with profound visual loss of early onset, including from ROP, need early intervention and habilitation to ensure that development delay is minimised. Parents also need extensive counselling so they can contribute towards their child's development, teaching them to explain the world to their child verbally and to encourage learning through touch. Rehabilitation measures have been shown to have a positive impact on a child with disability as well as on family.^[8-11]

How is blinding ROP detected?

If a preterm infant has received care in a neonatal care unit with an established ROP program, parents might be told that their

Access this article online

Website:

www.ijo.in

DOI:

10.4103/ijo.IJO_573_18

Quick Response Code:



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Manuscript received: 13.04.18; Revision accepted: 09.01.19

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Cite this article as: Kulkarni S, Gilbert C, Kakade N, Dole K, Deshpande CM, Azad R. Habilitation services for children blind from retinopathy of prematurity: Health care professionals' perspective in Maharashtra. Indian J Ophthalmol 2019;67:928-31.

child has serious disease by the examining ophthalmologist. However, if the neonatal unit does not provide screening or treatment for ROP it is often the parents who first notice the problem, either by noticing leukocoria or they think that their child does not see normally. These parents are likely to visit a paediatrician or an ophthalmologist, who may or may not make the correct diagnosis and give the right advice.^[12-14] As well as making the correct diagnosis it is also important that these children are referred for habilitation.

The purpose of this study was to explore what ophthalmologists and paediatricians involved in care of preterm children, and working in and around a large city in India know about ROP, to find out whether they have ever seen a blind child, and explore their attitudes and practices in relation to referral for habilitation.

Methods

A modified knowledge, attitudes and practices (KAP) questionnaire was designed by a team of ROP and public health specialists using published guidelines.^[15,16] The questionnaire had three sections: the section to assess knowledge had open-ended questions to avoid participants guessing responses and to better understand their range of knowledge. The sections on attitudes and practices had closed ended questions and participants were requested to tick only one of five options.

The questionnaire was pre-tested and validated before starting the study by administering it to a group of two ophthalmologists and two paediatricians working with neonatal facilities covered under study hospital's ROP program. The institutional ethics committee granted a waiver for the study.

Potential participants were ophthalmologists and paediatricians (health care professionals, HCPs) working in the government or private sector. The study hospital runs a large ROP screening program covering >15 neonatal facilities in and around Pune and is also a training and referral centre for ROP. A database of all ROP practitioners (ophthalmologists) and neonatologists working in various neonatal intensive care units (NICUs) in and around city was obtained from professional bodies (e.g. The National Neonatology Forum of India (NNFI)/Indian ROP Society). Potential participants were identified through this database. All the ophthalmologists were involved in ROP screening and/or treatment, and the paediatricians all worked in NICUs with an established ROP screening program. These professionals were purposively selected as parents would be likely to consult them first if they noticed an eye problem or were likely to be referred to them, and they would be in a position to refer children with visual loss from ROP and their families to habilitation services. The principal investigator explained the purpose of the study to each potential participant by telephone. Once they had agreed to participate, a study co-ordinator either sent the KAP questionnaire electronically or made a personal visit to the participant's office, according to their preference. The questionnaire had a written information sheet on the front page where the purpose of the study was explained, and details were provided on how their responses would be kept confidential. Each participant was allocated a unique code, and only the study coordinator had access to participants' names with corresponding codes.

The following information was collected from each participant: their gender, age and years of professional experience. Participants were requested to complete the form anonymously to promote honest responses. The level of knowledge was categorised as 'good' and 'poor'. Correct response was considered as good knowledge. There were a few questions which elicited a wide range of knowledge (such as components of a rehabilitation service). Each correct response for such questions was coded numerically. Those who answered at least 50% of all correct options were considered as having good knowledge.

Attitudes were grouped as positive, negative or neutral as they were more likely to stem from the knowledge or lack of it. Practices were recorded as they were, without categorising them. This was because practices were possibly likely to be the result of circumstances rather than choice (e.g., a participant who had never seen a child blind from ROP was not likely to refer any for rehabilitation services). The data were entered into Microsoft excel and analysed using the statistical package STATA 14 IC (StataCorp. 2015. College Station, TX).

Results

Over three quarters (25/32, 78%) of the HCPs approached returned a completed questionnaire. All were practising in the private sector. Fourteen (56%) were ophthalmologists, 13 (52%) were female and their mean age was 40 years (range 31–56). The median number of years of professional experience was 12 years (range 3–30). Of the 22% who did not return questionnaire, 4 (57%) were paediatricians and 5 (71%) worked in public sector.

Knowledge

All (25,100%) participants knew that ROP can cause blindness. However, 12% (3/25) thought that visual function can be improved even after vision is lost due to ROP. Knowledge of the Indian criteria for gestational age (GA) and birth weight (BW) cut off for ROP screening was poor in 36% (9/25) and 32% (8/25), respectively. The knowledge of cut off for BW recommended in existing guidelines^[17] and commonly recommended by ophthalmologists^[18,19] was considered good. The knowledge of BW criteria by speciality of participants is shown in Table 1.

Nearly a third (8/25, 32%) had poor knowledge of the fact that children visually impaired from ROP could have multiple disabilities, with no difference by speciality.

When asked about components of a rehabilitation service, 84% (21/25) had poor knowledge of what rehabilitation entails and 20% had poor knowledge of the correct age at which habilitation should start for an infant who has lost vision from ROP. Only 16% reported that they knew of a facility able to provide habilitation and early intervention for such children and all facilities were in the private sector. Nearly a third

Table 1: Knowledge of birth weight criteria for ROP screening

Knowledge	Ophthalmologists (%)	Paediatricians (%)
Good	12 (85.7)	5 (45.5)
Poor	2 (14.3)	6 (54.5)
Total	14 (100)	11 (100)

Fisher's exact test, $P=0.04$. ROP=Retinopathy of prematurity

(8/25, 32%) mentioned schools for the blind as a component of rehabilitation. There was no difference in knowledge of ROP and habilitation component by gender (male vs. female, $P > 0.5$), speciality (ophthalmologist vs. paediatricians, $P > 0.5$) or years of professional experience (<10 years vs. >10 years, $P > 0.5$) except that of BW cut off for screening [Table 1].

Attitudes

Nearly a third (7/25, 28%) thought that once a child has been diagnosed as visually impaired, parents should accept the situation and nothing more can be done; three participants (12%) were neutral about this. More than two-thirds (18/25, 72%) believed that enrolling a visually impaired child in special education was more beneficial than enrolment in a regular school, and most (20/25, 80%) believed that there is a social stigma associated with blindness. All (100%) participants believed that habilitation services are likely to be beneficial to a child and their family and all agreed that rehabilitation was not included in their training curriculum and should be taught to medical undergraduates.

Over half of the participants (14/25, 56%) had seen a child blind from ROP in their practice. Ophthalmologists were more likely to have seen a child blind from ROP (12/14, 86%) than paediatricians (2/11, 18%) ($P < 0.001$, Fisher's exact test).

Practices

Of the 14 HCPs who had seen children blind from ROP in their practice, 4 (29%) were not confident of counselling the parents and 1 (7%) had never referred any to rehabilitation facilities. Overall, 10/25 (40%) of the HCPs had never referred a child for rehabilitation. More than a half (13/25, 52%) had never counselled or were not confident of counselling parents of blind children. Only 5/25 (20%) referred children to an early intervention facility. Those who had never seen a child with vision loss from ROP in their practice were less likely to be confident in counselling parents ($P = 0.01$) or refer a child to a rehabilitation facility ($P < 0.000$) than those who had.

Discussion

Prevention of blindness from ROP must include practices aimed at primary prevention (i.e., improving the quality of neonatal care), secondary prevention (i.e., timely screening and treatment) as well as tertiary prevention (i.e. habilitation of those already blind from ROP). All these components should work hand in hand to ensure maximum possible benefit to the 'at risk' as well as 'affected' populations.

Blindness from ROP can have impact on the whole family and be multidimensional (financial, social, personal and emotional).^[20] Early intervention and habilitation might help in reducing the impact of blindness on the child as well as family. The different components of rehabilitation (medical, educational, economic, social and behavioural) are all important elements which enable the integration of a person with disability into society. Awareness of this among HCPs and strong linkages with rehabilitation services are necessary for such integration. However, there is no evidence of strong linkages between the HCPs and social/rehabilitation workers.

All the professionals taking part in this study were actively involved in the care of preterm infants: paediatricians worked in NICUs with established ROP screening program

and ophthalmologists were actively involved in ROP screening/treatment. All had substantial experience in their professional field and worked in non-government facilities. Knowledge about potentially blinding nature of ROP was good among all. However, most paediatricians had never seen a child blind from ROP in their practice, unlike the ophthalmologists. Possibly parents of children with end-stage ROP go to an ophthalmologist for consultation rather than to a paediatrician.

The NNFI guidelines, which were launched in 2010, recommend ROP screening for infants with a BW <1750 g,^[17] but many published studies from India recommend or report screening infants with a BW of <2000 g.^[18,19]

In our study, either criteria was classified as good knowledge. However, knowledge of GA and BW cut off for ROP screening was poor, particularly among paediatricians. Of the seven HCPs with poor knowledge, five were paediatricians. Most professionals with poor knowledge (5/7) mentioned in the UK criteria of BW (1500 g or less).^[21] This shows lack of awareness about the Indian guidelines and underlines the need to disseminate them among HCPs involved in the care of preterm infants. Perhaps publishing guidelines in a text book of paediatrics rather than on a website and presenting them at scientific meetings would result in more paediatricians gaining this knowledge.

Nearly a third of the participants were not aware that children visually impaired from ROP can have other disabilities, with no difference between paediatricians and ophthalmologists. Possible explanations for this are that end-stage ROP is usually diagnosed when a child is only a few months old, when other impairments may not be apparent. Parents of children with multiple disabilities might access general rehabilitation services and might never report back to the HCP who cared for their child while in the NICU. In India, the government is establishing district level early intervention centres (DEICs) under the Rashtriya Bal Swasthya Karyakram (RBSK) programme for preschool children with a range of disabilities.^[22] There are certain non-governmental facilities (such as study hospital) which too provide early intervention services. However, visual impairment may be overlooked in general rehabilitation services, and providers of care for children born preterm need to know that this is a possibility and adapt their services accordingly.

In addition to lack of referral, there are other reasons why rehabilitation services are not accessed, including cost, fatalistic attitudes of the family, stigmatising attitudes of community members and the severity of the disability.^[23] Most HCPs in this study did not have adequate knowledge of the different components of rehabilitation services and all agreed that this was not taught during their medical education. Sensitising medical students about the value of rehabilitation could go a long way in ensuring better referral practices.

Negative attitudes reported by HCPs, such as a belief that nothing can be done for children with visual loss, and that they should be enrolled in schools for the blind rather than in inclusive education, could reflect their poor awareness of rehabilitation services and their likely impact as well as prevailing attitudes in the community. According to the World Health Organisation's 'World Report on Disability',^[24] there are many obstacles faced by a person with disability, including negative attitudes of the community.

Ophthalmologists, and paediatricians to a lesser extent, are involved in the diagnosis of end-stage ROP, but many HCPs in this study felt ill equipped to counsel parents. These professionals need skills in breaking a bad news, and in listening to parents and providing the initial emotional support and guidance they need. This should include explaining the benefits of early habilitation once they have been able to accept the diagnosis.

All the participants in this study were associated with a ROP program. Hence their level of knowledge and practices are likely to be better than HCPs not involved with a program. The findings may not therefore be generalisable to the entire cadre of HCPs. Knowledge and referral practices among government sector HCPs are likely to be better due to the expansion of EICs. Most participants worked in urban areas and the findings cannot be generalised to those working in rural areas.

Conclusion

In conclusion, Indian ROP guidelines are not universally known to HCPs. Education of medical undergraduates on ROP, training for counseling skills and integration of rehabilitation services into the health system will ensure continuity of care for children afflicted with ROP associated visual loss.

Based on the findings of this study, it is recommended that the Indian guidelines for ROP be widely disseminated especially among paediatricians. The scope and potential impact of rehabilitation needs to be taught to medical graduates. Strategies to improve awareness about early intervention and rehabilitation centres need to be formulated, and counselling training made available to professionals who care for children with disability. In India, integration of rehabilitation services into the health system will ensure continuity of care for this group of children and their families.

Acknowledgements

Authors are grateful to Dr. Ajit Varkar for his active role in data collection and management.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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