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THE QUEEN ELIZABETH DIAMOND JUBILEE TRUST

Policy Brief on Control of Retinopathy of Prematurity in India

- ROP is a major cause of blindness in children in many middle income countries including India.
- India has the highest number of preterm births – 3.5 million annually in 2010.
- Up to 18,000 infants will go blind every year in India unless control is scaled up.
- Prevention of blindness from ROP requires collaborative efforts from all government and other agencies.
- A strong policy framework is the need of the hour to prevent infants going blind from ROP.

The problem

Retinopathy of prematurity (ROP) is a potentially blinding eye condition which affects infants born preterm. Babies born at or before 34 weeks gestational age (i.e., 6 or more weeks preterm) or weighing less than 2000gms at birth are at greatest risk.[1] ROP is a major cause of blindness in children in many middle income countries[2,3] and is becoming an increasingly important cause in India, as neonatal services expand and more preterm babies survive.[4,5]

ROP was first described almost 80 years ago[1] and the risk factors are also well known i.e., low gestational age, inadequately monitored supplemental oxygen from immediately after birth, infection and failure to gain weight after birth. Clinical trials have also clearly demonstrated that urgent laser treatment for the sight-threatening stages of ROP is very effective at preserving vision.[6]

Studies show that countries with infant mortality rates (IMRs) in the range 9-60/1000 live births are the most affected (Figure 1).[7] In countries with high IMRs, most preterm infants do not survive. At the other end of the spectrum countries with very low IMRs have low rates of ROP blindness as neonatal care services are of high quality and ROP screening and treatment services are available.

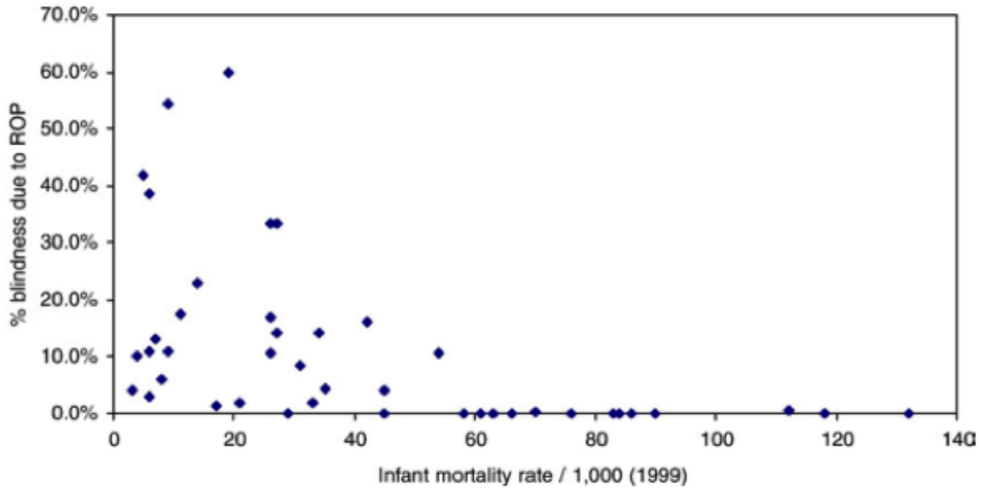
(c)IPH, Hyderabad

A preterm infant being screened for ROP at Niloufer Hospital, Hyderabad, Telangana.

As a result of concerted efforts to reduce infant and child mortality in India[8], the IMR is falling (28/1000 live births in 2015),[9] but blindness from ROP is increasing.[4,5] India has the highest number of preterm births[10] – 3.5 million annually in 2010. Recent estimates of visual impairment and blindness due to ROP suggest that 10% of the 32,300 infants affected globally (in 2010) were born in India.[4] The expanding provision of neonatal care services in India means that the number of preterm infants at risk of blindness from ROP will continue to increase. A conservative estimate suggests that up to 18,000 infants will go blind every year in India unless control is scaled up.[5]

Unfortunately, regular ROP screening programmes are not mandatory for neonatal intensive care units in India, including in Sick Newborn Care Units which are being scaled up across India. However, screening for ROP is included in the Government's RBSK programme.[11]

Figure 1. Proportion of blindness due to ROP, by infant mortality rate for the year 1999.



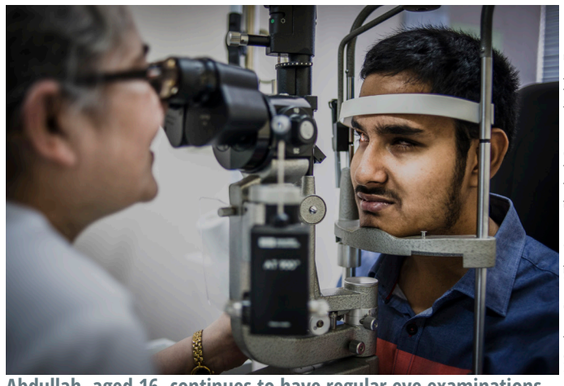
The impact

Blindness from ROP has economic, legal and social implications for affected children and their families, governments and civil society. For example, in 2015 the Supreme Court of India ordered Tamil Nadu State Government to compensate INR 1.8 crores to a 18-year-old girl who lost her vision from ROP in a medical negligence case against a government-run hospital.[12] Another hospital was ordered to pay INR 68 Lakhs for another child.[13] Providing services for the prevention, detection and treatment of ROP is, therefore, financially and legally prudent.

A recent study from India, in which parents of ROP blind children were interviewed, powerfully illustrated the impact on families. Many parents experienced social isolation and most were concerned about the future of their child. Most had borrowed money or sold assets to pay for treatment, and several marriages had come under intolerable pressure.[14]

The strategies required for control

- Prevention of preterm birth, which is challenging, but could include regulation of assisted fertilization practices, by limiting the number of fertilized embryos implanted;[15]
- Antenatal steroids for all threatened preterm deliveries, which reduces many of the complications of preterm birth, including ROP;[16] High quality neonatal care for preterm infants from immediately after birth, to control the known risk factors;
- High coverage of weekly ROP screening by ophthalmologists in neonatal units, or in eye units or District Early Intervention Centres for babies who have been discharged from neonatal care, to detect infants with the sight-threatening stages. Screening can also be undertaken by trained technicians using wide-field digital cameras, supported by an ROP expert ophthalmologist;
- Urgent laser treatment of sight-threatening ROP by skilled ophthalmologists; [17]
- Long term follow up to detect and manage the eye complications of preterm birth and ROP [18]
- Empowering ASHA workers and ANMs to ensure mothers threatening preterm delivery give birth in facilities with a neonatal unit, and counselling mothers of preterm infants of the need for screening for ROP and for long term follow up.
- Strengthen at least one tertiary eye care department in each State as an ROP centre of excellence.[19]



(c)Poulomi Basu/ The Queen Elizabeth Diamond Jubilee Trust

Abdullah, aged 16, continues to have regular eye examinations by Dr. Subhadra Jalali who has seen Abdullah grow up since he was only a few weeks old.

Scaling up services for ROP in India

Scalable and effective initiatives to improve neonatal care and for ROP screening and treatment and are urgently required to prevent blindness from ROP. The Queen Elizabeth Diamond Jubilee Trust is supporting senior neonatologists in AIIMS, New Delhi and PGIMER, Chandigarh to build capacities of neonatal teams to reduce the risk of ROP in medical colleges and 22 district SCNUs in four States across India. Public-private partnerships are also being supported to build the capacities of local ophthalmologists in ROP screening and treatment in the same facilities.[20]

The cost of setting up a ROP screening and treatment program in a cluster based on the Trust-supported program (i.e., in one medical college neonatal unit and 4 SNCUs in neighbouring districts) is approximately Rs 40,00,000 per cluster, with annual running costs of Rs 60,000 per cluster. A recent study in Brazil estimated that the incremental cost of integrating screening and treatment for ROP was less than 1% of the cost of providing neonatal care.[21]

A study in Mexico and the USA estimated the costs to families of raising a blind child, and the lost productivity of carers and ROP blind individuals. These costs were considerable in both countries: in Mexico and the USA the incremental net annual monetary benefit of providing a service to prevent blindness from ROP was $206,574,333 and $205,906,959 respectively.[22]

The WHO/UNICEF initiative Every Newborn: An Action Plan to End Preventable Deaths, states that "a healthy society is one in which women and adolescent girls, newborns and children survive and thrive."[23] The same applies to children who are born preterm.

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