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Retinopathy of prematurity in South Africa: an assessment of needs, resources and requirements for screening programmes

S Varughese,¹ C Gilbert,² C Pieper,³ C Cook⁴

¹ cbm South Asia Regional Office (North), Bangalore, India;

² International Centre for Eye Health, London School of Hygiene and Tropical Medicine, London, UK; ³ Neonatal Service, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa;

⁴ Department of Ophthalmology, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa

Correspondence to:
Dr S Varughese, 4.1 Admin Block, St Stephen's Hospital, Tis Hazari, Delhi, India;
sara.varughese@gmail.com

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ABSTRACT

Aims: Retinopathy of prematurity (ROP) is a major cause of blindness in children in middle-income countries. In 1995, it accounted for 10.6% of blindness in children in schools for the blind in South Africa. This study was undertaken to estimate the number of premature babies at risk and to investigate policies, practices and screening programmes.

Materials and methods: 17 level 1–3 neonatal units were visited in four provinces. Published literature reports were reviewed and staff interviewed.

Results: 13 000–15 000 surviving premature babies are at risk of ROP each year. Shortage of equipment precluded continuous oxygen monitoring in public units. Nursing levels were often below recommendations, and most nurses were unaware of target oxygen saturations. Private units were well staffed and adequately equipped. Ophthalmologists were only visiting four units on a regular basis for screening, using the birth weight criterion of <1500 g for ROP screening. ROP needing treatment rates were low (1.6–2.9%), as were rates of follow-up.

Conclusions: Primary prevention of ROP requires meticulous neonatal care and adequately equipped and staffed units. Secondary prevention requires efficient screening and treatment programmes. Competing demands and limited resources in the public sector in South Africa have precluded prioritising the prevention of ROP. This should be re-evaluated.

Over the last 60 years, three epidemics of retinopathy of prematurity (ROP) have been described. The first, in the 1940s and 1950s, which was due to the unrestricted use of supplemental oxygen,¹ declined with curtailment of oxygen use. The second, in the late 1960s, was due to improved survival of extremely low birth weight (ELBW) infants² (ie, <1000 g at birth). Blindness due to ROP is largely being controlled in industrialised countries on account of high-quality neonatal care and well-organised screening programmes.^{3–5} In the middle-income countries of Latin America and Eastern Europe, ROP is now often the single commonest cause of blindness in children (the third epidemic of ROP).⁶ In these countries, close oxygen monitoring is not always possible, and screening for ROP is not routine. The wide range of birth weights (BW) and gestational ages (GAs) of babies with severe ROP in Latin America and large cities in Asia suggests that this epidemic combines features of the first and second epidemics.^{6–11}

At the country level, the proportion of blindness in children due to ROP seems to be associated with infant mortality rates (IMRs).^{11–13} In countries with

very high IMRs (>60/1000 births, as in most of Sub-Saharan Africa) ROP is not an important cause of blindness, as premature babies do not survive. In countries with IMRs <9/1000 (eg, North America and Western Europe), blindness is uncommon. Countries with IMRs in the range of 9–60/1000 live births are those where ROP is emerging as a major cause of blindness in children. South Africa has an infant mortality of 53/1000,¹² and blindness due to ROP might be expected. In a study undertaken in 1995 of children in blind schools, ROP accounted for 10.6% of blindness.¹³ There were marked ethnic differences: 1.3% of black children were blind from ROP compared with 30.8% of Asian and 28.3% of white children, respectively.

South Africa has a population of 43 million and over a million live births each year. The public health system treats approximately 80% of the population. Over the last few years, South Africa has systematically implemented policies to reduce neonatal and IMRs by improving primary, secondary and tertiary care. Ninety-eight per cent of deliveries are attended by nursing or medical personnel,¹⁴ and small units for premature babies are available in all district-level hospitals. However, improved neonatal survival may increase ROP blindness. Publications on acute ROP from Cape Town¹⁵ and Johannesburg¹⁶ both showed that 1.6% of babies with BWs <1500 g developed stage 3 ROP. Higher rates were reported from Pretoria (6.4% of black babies developed stage 3 ROP)¹⁷ and Tygerberg (7% of ventilated babies had stage 3 or 4 ROP).¹⁸

The current study was undertaken to explore possible reasons for the relatively high overall proportion of blindness in children due to ROP in South Africa as well as ethnic variation in risk, by exploring levels of neonatal care, to estimate the number of premature babies at risk and to ascertain current screening practices for ROP and the findings of screening.

MATERIALS AND METHODS

Nineteen neonatal units in three of the nine Provinces of South Africa were approached by one of the authors (SV) in 2005, and 17 were visited, as permission was not granted in two units. This was a convenience sample in which attempts were made to include units of varying size, levels of care and those in the public and private sectors. Prior to the visit, neonatologists in charge were sent the data-recording form which had been developed and pilot-tested in London.

Data were collected on the policies and practices in neonatal care. In each unit, the following information was collected: the number of incubators, ventilators and equipment for monitoring oxygen levels; the number of nurses and medical staff, and their level of training. Medical and nursing staff were interviewed to determine their knowledge of unit oxygen policies and practices. Where possible, additional data were collected by observation, to ascertain how many babies on oxygen were being monitored at the time of the visit. Data were also collected on ROP screening practices and policies, that is place of examination, screening criteria, methods of examination, indications for and methods of treatment, and the results of screening and treatment. A cross-sectional study of babies on the neonatal intensive care units (NICUs) at the time of the visit was undertaken in which the BW, GA and chronological age of all babies currently admitted were recorded. The proportion of babies eligible for screening using UK guidelines (ie, <1500 g and/or \leq 32 weeks and at least 6 weeks old) who had been examined was recorded.

The size of the population of babies at risk of ROP was estimated from data from the "Saving Babies 2003" document.¹⁹ The Perinatal Problem Identification Program (PIIP) collected information on 462 348 births from 102 centres over the country and covers nearly half of all births in the country. Information was also requested from units visited on the number of deliveries in the local maternity unit, admissions to neonatal units and survival rates by BW, GA and ethnic group. Permission to visit each unit was obtained from the senior neonatologist.

RESULTS

Permission to visit was not granted by two units. Seventeen units were visited, nine in Western Cape, four in Kwazulu Natal and four in Gauteng. Eleven were in provincial capitals and six in smaller towns. Fourteen were in the public sector, and three were private. The units varied in size, with the number of incubators ranging from four to 48. Four were level 3 units (ie, had facilities for ventilating babies and/or neonatal surgery),²⁰⁻²² and all were in the public sector; 12 were level 2 units (ie, had facilities for ventilating babies but not for surgery), nine of which were in the public sector, and there was one level 1 unit (public).

Estimating the size of the population of babies at risk of retinopathy of prematurity

Routine data showed that approximately 16 000 of the 1 006 000 babies born each year in South Africa have BWs in the range 1000–1499 g, with an additional unknown number being ELBW (table 1). Data provided by units visited are shown in table 2. There was considerable variation in survival rates between units. For example, survival of ELBW babies ranged from 33% to 76%, while survival of babies with BWs 1000–1499 g was 82% to 95%. Using survival data provided by the units visited, the number of babies with BWs 1000–1499 g who survive nationally is likely to be 13 000–15 000. It was difficult to collect and compile data on BW and GA of babies in the units visited: some had data on total deliveries in the relevant maternity unit, while others only collected data on live births; other units collected data on NICU admissions. It was not possible to collect data from private units on admissions by BW category. GA information was only available in a few units.

Equipment and infrastructure

The number of high-care incubators ranged from four to 48 (mean 14), and there were 0–14 ventilators per unit (mean 7.3). While no unit lacked incubators, there was a shortage of pulse oximeters, which limited oxygen saturation monitoring. Arterial blood gas analysis was available in most NICUs.

Staffing levels

The national recommendation is one ICU trained staff nurse for every two babies in NICUs. Data on nursing levels were available from 10 units, seven in the public sector. Three public units had sufficient nurses for a 1:2 ratio, and four had one nurse looking after four babies. Nursing shortages also meant that nurse:baby ratios were often lower than recommended at night. Nursing in high-care areas within units was often by enrolled nurses, who have 2 year's training compared with 3 years for staff nurses, though many were very experienced and capable. Public level 1 and 2 units had resident trainee medical officers and experienced registrars, with consultants being available on call. Some level 2 units had no resident medical officers at night, with only general duty doctors on call.

Private units had enough nurses to exceed the recommended nurse:baby ratio. They were responsible for the day-to-day management of all aspects of care, under the supervision of consultant neonatologists on call. None of the private units visited had resident medical staff.

Policies and practices in neonatal care being provided

In the public NICUs, there was a general policy of not ventilating ELBW babies, although this was not implemented uniformly. The BW cut-off for deciding whether to ventilate or not varied from 800 g to 1200 g. ELBW babies who were not ventilated were, however, given other support such as supplemental oxygen by continuous positive airway pressure or nasal prongs and surfactant. In private units, all babies needing ventilation were ventilated regardless of BW.

Recommended target oxygen saturation levels for premature babies in South Africa are 86–92%, similar to western guidelines. However, policies on supplemental oxygen were usually unwritten, and while senior medical staff were aware of the need for restricting oxygen, other staff were either unaware of or were not implementing these policies. Many public-sector nurses thought it more important to prevent hypoxia than hyperoxia, and alarms were often set only for the lower limit of oxygen saturation. Nursing staff usually did not know the recommended target saturation levels.

All babies receiving oxygen in the private sector were continuously monitored, but in the public sector this was only possible in 4/14 units (table 3). Six public units had continuous monitoring of ventilated babies but not those receiving oxygen by other methods. In four public units, continuous monitoring was not possible even for babies being ventilated.

ROP screening policies and practices

ROP screening, whereby the ophthalmologist visited the NICU on a regular basis to examine babies, was being undertaken in all three private units but only in 4/14 public units. Two public units referred babies to an ophthalmologist for examination. Eight units had no provision for detecting ROP, and lack of trained public sector ophthalmologists was cited as the reason. All the units used the same, single screening criterion, that is BW<1500 g, but babies with BWs \geq 1500 g were also examined at the discretion of the neonatologist. Private units were also

Table 1 Number of live births by birth weight and place of birth in South Africa between 1999 and 2003

Birth weight (g)	Metropolitan area	Cities and towns	Rural area	All sites
	n (%)	n (%)	n (%)	n (%)
<1000	No data	No data	No data	No data
1000–1499	4068 (2.0)	2520 (1.7)	765 (0.7)	7353 (1.6)
1500–1999	7928 (3.9)	5204 (3.5)	2449 (2.3)	15 581 (3.4)
2000–2499	18 353 (9.1)	15 073 (10.3)	8743 (8.3)	42 169 (9.3)
≥2500	170 389 (84.9)	124 202 (84.5)	93 233 (88.6)	387 824 (85.6)
Total	200 738 (100)	146 999 (100)	105 190 (100)	452 927 (100)

From "Saving Babies 2003".¹⁹

using GA criteria, usually <32 weeks. During the study, 52 of 250 babies in 10 units fulfilled UK screening criteria, but only 10 (19.2%) had been examined by an ophthalmologist. Ophthalmologists reported very low follow-up rates of babies discharged from inpatient care. The fate of these unscreened babies was not known, but the paediatricians interviewed reported that they were not seeing blind babies coming back during follow-up. However, in one province, approximately 10 ROP blind babies are seen a year in a neurodevelopment clinic, but not all babies admitted to neonatal care were being followed up in these clinics.

Only two ophthalmologists (one public in unit A, and one private in unit B) could provide data on the findings of screening. The incidence of ROP of any stage was 6.7% in unit A, and 25.6% in unit B. Overall 1.7% of examined babies had been treated (five of 301), and all had BWs <1500 g. Data were not available by ethnic group, but most babies in unit A were black, and the majority in unit B were white or Asian. All babies in these two centres had been treated with laser (one ophthalmologist for each unit), but more than one ophthalmologist examined babies in each unit.

DISCUSSION

In this study, 17 NICUs in four cities and surrounding districts were visited. The units serve four of the most populated provinces in the country, covering approximately 70 000 deliveries (ie, 9% of all births). However, units were not randomly selected. The findings may, therefore, be biased towards large public units, staffed by consultants interested in the public health aspects of their work.

Population of babies at risk

The "Saving Babies 2003" document did not report data on ELBW babies. In the units visited, 8.9% to 20% of babies born in the relevant maternity units had BWs in the range 1000–1499 g (mean 15%). A further 1.2% of all births were ELBW. Available data on the number of babies admitted to the NICUs included in this study differ from those in "Saving Babies." These findings almost certainly reflect case mix, as many of the NICUs visited were attached to maternity hospitals caring for high-risk pregnancies. It was not possible to compare survival rates in the different BW groups among babies admitted to the units in this

study with data from "Saving Babies," as the latter only refer to babies with BWs of 1000–2500 g. Overall, the available data seem to suggest that there are approximately 13 000–15 000 babies with BWs <1500 g who survive each year in South Africa, who need to be screened for ROP. There is a need for better standardisation in data collection and reporting, which would allow better estimates of the number of babies at risk to be determined.

Neonatal care

Although there are policies in place which would help to prevent ROP, in reality these are not being uniformly implemented. Monitoring of babies is poor in public-sector units because of nursing shortages and undertrained nurses and shortage of monitoring equipment. While financial constraints may limit the number of nurses and oximeters, greater awareness among nurses of the importance of oxygen as a risk factor for ROP is also required.

Screening for ROP

Screening for ROP is not yet standard of care, being performed in only eight of the 14 public sector units visited. A major constraint is a shortage of trained ophthalmologists, as currently there are approximately 275 ophthalmologists for a total population of 43 million, about 250 of whom work in private practice (serving a population of 9 million) and only about 25 in the government sector (serving a population of 34 million). There are about 30 vitreoretinal surgeons, and only one paediatric ophthalmologist. Screening for ROP would, therefore, represent an enormous potential workload for ophthalmologists, whichever sector they work in. Transporting babies from units without an ophthalmologist for ROP screening and follow-up of babies discharged from neonatal units pose formidable logistical problems in resource-poor environments.

In the UK, approximately 39–55 examinations are undertaken to detect one baby needing treatment,²³ and examining babies in one unit can take half a day. One solution in South Africa might be for one ophthalmologist to examine babies in all NICUs in each city, an approach being successfully used in several cities in Latin America, but this requires highly motivated individuals, salary support and money for transport. Another approach would be to train neonatologists or neonatal nurses to screen.

Table 2 Survival of babies by birth weight categories in public sector units

Birth weight category	Extremely low birth weight (<1000 g), mean (range)	Very low birth weight (1000–1499 g), mean (range)	Low birth weight (1500–2499 g), mean (range)
Percentage of births in maternity unit	6.3% (3.1 to 9.1%) (n = 5)	15.1% (8.9 to 20.0%) (n = 5)	20.2% (15.7 to 28.6%) (n = 8)
Survival rates in neonatal intensive care unit	53.4% (33.0 to 76.2%) (n = 5)	91.4% (81.8 to 95.0%) (n = 7)	91.3% (81.7 to 96.0%) (n = 5)

n, number of units contributing data.

Table 3 Monitoring of oxygen saturations in babies receiving supplemental oxygen, by service provider

Provider	Continuous monitoring of oxygen saturations		Intermittent monitoring of oxygen saturations	
	All babies	Intensive care	Intensive care	High-care babies
Private (n = 3)	3 (100%)			
Public (n = 14)	4 (29%)	6 (43%)	1 (7%)	3 (21%)

The use of digital imaging, with telemedicine for remote grading of images by trained experts, has also been suggested for countries or regions where there are insufficient ophthalmologists.²⁴

Where screening was being undertaken in public units, BW was the only criterion (ie, <1500 g). The finding that larger, more mature babies are also at risk of severe ROP in middle-income countries than in industrialised countries (ie, mean BWs of 903–1527 g compared with 737–763 g, respectively)⁹ means that evidence-based screening criteria need to be developed for South Africa.

Information from screening programmes, where available, showed low rates of sight-threatening ROP (0.6% and 2.9%), and babies needing treatment all had BWs <1200 g. This low rate may be due to high mortality in those most at risk, ethnic variation in susceptibility, examination by inexperienced registrars or low follow-up rates after discharge. Even if only 2% of surviving babies most at risk of ROP require treatment, this translates to approximately 260–300 babies a year across the country, half of whom would become blind without treatment. It was not possible to explore reasons for ethnic variation in rates of ROP blindness in this study, as data on ethnic group are not collected by the NICUs or by examining ophthalmologists.

Conclusions

Preventing blindness due to ROP requires high levels of neonatal care as well as efficient and effective programmes for detecting and treating babies. In South Africa, resources are limited, and there are competing demands for services, particularly in the public sector. Decisions need to be made as to whether additional resources should be allocated to controlling blindness in children due to ROP, bearing in mind that in other countries it is known that the cost of looking after one blind child for life would pay for a significant proportion of screening and treatment programmes. While neonatal care and survival of at risk infants have improved, screening has not been systematically instituted, and in this study the majority of babies at risk of ROP had not been examined. Data on the results of screening were only obtained from two units, which is insufficient to make recommendations concerning which babies should be examined. Screening programmes need to be

instituted and monitored to determine the optimal screening criteria, bearing in mind the additional opportunity costs incurred by including larger, more mature babies.

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