

# Case Series of Retinopathy of Prematurity Blindness in Nigeria: A Wakeup Call to Policy Makers, Hospitals, Ophthalmologists and Paediatricians

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## Abstract

**Background Statement:** Inadequate retinopathy of prematurity (ROP) screening coverage portends a high risk for increasing the cases of ROP blindness. This study aims to report the clinical profile of pre-term babies who developed ROP blindness, highlight the usefulness in determining screening criteria and the role of private hospitals in ROP blindness prevention. **Case Series Report:** Online Google form and telephone survey was conducted from May to December 2020 among paediatric ophthalmologists who provided the clinical details of ROP blind children seen between 2016 and 2020. The main outcome measured included type of the hospital of birth, gestational age, birth weight, ROP Screening and treatment, and blinding ROP Stage among children born premature. The SPSS-IBM version 26 was used for the analysis. Eighteen children blind from ROP with an equal male-to-female ratio were reported. Mean gestational age was  $28.4 \pm 2.2$  weeks (range 26 - 34 weeks, median was 28.0 weeks). Mean birth weight was  $1173.7 \pm 317.9$  grams (range 776 - 2100 grams, median 1125 grams). Six (33.3%) babies were born in private hospitals between 28 and 32 weeks. Sixteen (88.9%) children never had ROP screening. Fifteen (83.3%) were blind in both eyes. Six (33.3%) had Stage IVb and 12 (66.7%) Stage V. **Conclusion:** About 90% of the babies who became blind did not undergo ROP screening. It is crucial that all babies born at 34 weeks or earlier and have birth weight of < 1500 grams in public/private hospitals be screened for ROP to prevent this avoidable blindness in Nigeria.

**Keywords:** National policy, public and private hospitals, retinopathy of prematurity blindness, retinopathy of prematurity service extension

## INTRODUCTION

Retinopathy of prematurity (ROP) used to be a disease of high-income countries, its incidence in middle- and low-income countries is becoming a public health concern.<sup>[1,2]</sup> Over 60% of the world's preterm birth takes place in South Asia and Sub-Saharan Africa, with Nigeria having the third-highest prematurity birth rate in the world.<sup>[3]</sup> Globally, ROP is a preventable cause of needless blindness in children associated with abnormal vascular development in pre-term children.

Despite the WHO "Every Newborn Action plan" initiative, non-affordability of neonatal care and non-existent government

subsidies including lack of insurance coverage for neonatal care remains and may have affected uptake of ROP screening services in Africa.<sup>[4]</sup>

In South Africa, the third epidemic of ROP is already occurring but tackled with established and comprehensive neonatal services and high survival rate.<sup>[5]</sup> In other African countries such as Nigeria, Kenya and Ghana, there has been

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a collaborative movement involving ophthalmologists and paediatricians to initiate, improve and sustain ROP screening services in every neonatal intensive care unit.<sup>[4]</sup>

In Nigeria, ROP screening services are expanding even though the coverage is still inadequate. Most of the screening services are carried out in tertiary hospitals, thus neglecting private hospitals with neonatal intensive care units (NICUs). This invariably implies that several babies will not be screened and may likely develop ROP blindness. Optimal neonatal care, timely ROP screening for prompt detection (Type 1 disease), adequate treatment of Type I ROP and follow-up are needed to prevent ROP blindness.<sup>[6]</sup>

This study presents the clinical profile of pre-term babies who developed ROP blindness in Nigeria. The gestational ages and birth weight of the babies who became blind from ROP presented would be useful in determining what screening criteria should be used for ROP in the country.

This study also brings to fore the role of private hospitals in the management of babies born premature who are at the risk of developing ROP, thus emphasizing the need to extend ROP screening services beyond teaching hospitals in preventing needless blindness from ROP in Nigeria. The outcome of this study will hopefully help in improving national and international policies peculiar to the sub-Saharan African environment in ROP management.

## METHODS

This was a non-comparative case cross-sectional study, was conducted within ethics approvals by the National Health Research Ethics Committee (NHREC/01/01/2007-04/12/2020)

and the Ethics Research Committee of the University of Ilorin Teaching Hospital-ERC PAN/2020.06/0027.

The data were generated through survey Google form and sent to paediatric ophthalmologists in the six geopolitical zones of Nigeria regarding their encounter with children with ROP blindness between the year 2016 and 2020. Analysis was done using the SPSS version 26 (SPSS Inc., Chicago, Illinois, USA). Fisher Exact test was used to determine the association between variables with *P* value set at 0.05.

## CLINICAL FINDINGS

This is as presented in Tables 1-3 and Figure 1.

## DISCUSSION

Improvement in neonatal care and technological advancement in developing countries have impacted positively on the survival of high-risk premature infants. However, the absence of a national policy for ROP screening has placed Africa at the frontier for ROP and ROP-related blindness.<sup>[4]</sup> There were a large number of extreme pre-term babies and those with ELBW in our study who developed blinding ROP. It has been suggested that these are pointers to the import of quantitative improvement in neonatal care without the necessary accompanying qualitative improvement, which must then become the focus.<sup>[7]</sup>

The babies presented at tertiary hospitals in four of the six geopolitical zones. None was reported from the North East and North West. This may point to the inadequate human capacity for neonatal care rather than a better outcome. These zones have the highest rate of fertility in Nigeria (NDHS 2018).<sup>[8]</sup>

**Table 1: Summary of 18 children who were blind from retinopathy of prematurity in Nigeria 2016-2020**

Sex	Gestation age (weeks)	Weight (grams)	ROP screening done yes/no	Hospital of birth and care	Eye affected	Had treatment	Blinding ROP stage
Male	32	1200	No	Private	Both	No	V
Male	26	1200	No	Public	Both	No	V
Male	34	2100	No	Public	Right	No	IVb
Female	27	1050	No	Public	Both	No	V
Female	29	1330	No	Public	Both	No	IVb
Male	26	1300	No	Public	Left	No	V
Male	29	1600	No	Public	Both	No	V
Female	27	900	No	Public	Both	No	IVb
Male	28	1200	Yes	Public	Both	Yes	IVb
Female	27	910	No	Public	Both	No	V
Female	27	1000	No	Public	Both	No	V
Male	32	1500	No	Private	Both	No	V
Female	28	1000	No	Public	Both	No	V
Female	28	1000	Yes	Private	Both	No	IVb
Female	28	960	No	Private	Both	No	IVb
Female	29	776	No	Private	Left	No	V
Male	29	1200	No	Private	Both	No	V
Male	26	900	No	Public	Both	No	V

The mean gestational age was  $28.4 \pm 2.2$  weeks (range 26 - 34 weeks, median age was 28.0 weeks), mean birth weight was  $1173.7 \pm 317.9$  grams (range 76 - 2100 grams, median birth weight was 1125 grams). ROP: Retinopathy of prematurity

The 18 children with ROP-related blindness were children seen or referred to the teaching hospitals for care. Teaching hospitals are located in urban areas; hence, there may have been inequity in access for the diagnosis and treatment of ROP to infants born in rural areas. Thus, ROP blindness may be under-diagnosed and under-reported. Perhaps, a significant number in those rural communities who relatively have inadequate resources could also have died before ROP blindness could be established.

The 18 cases of ROP blindness in this study are proportionately similar to 10 reported between 2016 and 2019 in Ethiopia with a population of about 112.1 million (2019) compared to 201 million in Nigeria.<sup>[9,10]</sup> Consequently, it is important to create awareness of ROP to all relevant stakeholders, across sub-Saharan Africa, including the policymakers, the public, caregivers, obstetricians, midwives, neonatologists and ophthalmologists. It is also important to develop robust strategies backed by policy at each level of the health system to prevent blindness from ROP. The fact that almost all the children in this report did not have any ROP screening highlights the gaps in the management of pre-term and low birth weight infants.

Unlike childhood cataract or retinoblastoma, ROP is unseen by parents and caregivers until the very late stages, which are refractory to treatment. Uptake of screening and treatment becomes a major challenge for a disease not easily seen or felt by parents, especially within a myriad of other health challenges affecting the mothers and the child.

**Table 2: Distribution of gestational ages and birth weight of children who became blind from retinopathy of prematurity**

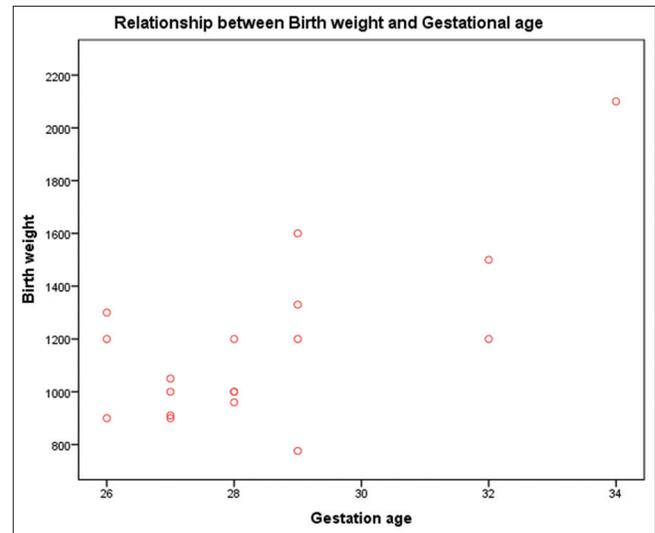
	Frequency (%)
<b>Gestational ages</b>	
Moderate pre-term >32 weeks	1 (5.6)
Very pre-term (28-32 weeks)	10 (55.5)
Extreme pre-term <28 weeks	7 (38.9)
<b>Birth weight</b>	
LBW <2500 g	2 (11.1)
VLBW 1000-1500 g	11 (61.1)
ELBW <1000 g	5 (27.8)

LBW: Low birth weight, VLBW: Very low birth weight, ELBW: Extremely low birth weight

Regarding the birth weight and gestational ages of the children that became blind from ROP, it is noteworthy that about 94.4% were <32 weeks and 88.9% had a birth weight of <1500 g; these are probable pointers to the cut-off level to be established as screening criteria and indicators for the treatment of babies in this environment.

While most did not have ROP screening, of the two that were screened and became blind, one was unable to afford treatment and this underscores the need for universal health coverage policy in our environment.<sup>[11]</sup> This study further emphasizes the fact that screening alone without timely, appropriate and adequate treatment with follow-up is not an approach to consider. The management of ROP is expensive and not affordable by the majority of the parents, some may rely on the health insurance scheme (which covers <5% of the population) which regards the treatment as exclusion, and thus, patients are forced to pay out of pocket.<sup>[12]</sup>

Furthermore, surgical retinal services are not readily accessible to patients in sub-Saharan Africa because of few available retinal specialists, expensive services because equipment, consumables and maintenance services are not readily available. Available ones are mostly focused on adults thus



**Figure 1:** Describes the relationship between birth weight and gestational ages of children who became blind from retinopathy of prematurity

**Table 3: Gestational ages and the stage of blinding retinopathy of prematurity in children born at different types of hospital**

Gestational age (weeks)	Type of hospital where child was born		Blinding ROP stage		Total, n (%)
	Public, n (%)	Private, n (%)	IVb, n (%)	V, n (%)	
26	3 (25.0)	0	0	3 (25)	3 (16.7)
27	4 (33.3)	0	1 (16.7)	3 (25)	4 (22.2)
28	2 (16.7)	2 (33.3)	3 (50.0)	1 (8.3)	4 (22.2)
29	2 (16.7)	2 (33.3)	1 (16.7)	3 (25)	4 (22.2)
32	0	2 (33.3)	0	2 (17.7)	2 (11.1)
34	1 (8.3)	0	1 (16.7)	0	1 (5.6)
Total	12 (100.0)	6 (100.0)	6 (100.0)	12 (100.0)	18 (100.0)

ROP: Retinopathy of prematurity

children who require retinal surgeries may not have the best outcome.<sup>[13]</sup> This will definitely affect prompt intervention with subsequent irreversible visual loss.

The reported incidence of Type I ROP from the previous studies in the same environment was about 8.9%,<sup>[7]</sup> this study confirms the need for continuous screening and treatment for ROP.

Several other studies have reported ROP-related blindness in Africa. The study by Melesse in a tertiary hospital in Ethiopia documented a 13.9% (13 out of 93 children with ROP) prevalence of blindness or visual impairment among ROP children. These children presented with stage 5 disease.<sup>[9]</sup> Furthermore, in South Africa, Jacoby reported 7 (0.8%) ROP-related blindness (stage 5 disease) out of the 919 new cases seen.<sup>[14]</sup> In Nigeria, Olowoyeye *et al.* reported a case of blindness from ROP following the screening of 116 children in school for the visually impaired.<sup>[15]</sup>

This study showed that one-third (33.3%) of the children were born at a private hospital. This shows the importance of the often-overlooked private hospitals' involvement in Nigeria to the successful prevention of ROP blindness. The retrospective nature of the study probably confers some limitations on issues with recall and in-complete recording.

The time has come to review the call by a previous study that screening for ROP and affordable treatment facilities should be provided in public hospitals.<sup>[16]</sup> This call is therefore directed at Nigeria and other similar African countries to create national awareness, interest, policy and to seek collaborations with countries that have better established ROP programmes so as to have a headway in tackling blindness from ROP. Specifically, there must be the deliberate engagement of all hospitals, private and public, that undertake the care of babies born prematurely at <32 weeks and birth weight <1500 g in Nigeria. ROP screening and management services need to be extended beyond teaching hospitals to include all such hospitals.

Parents and other stakeholders must be carried along to ensure that no child is needlessly blind from ROP, being such an avoidable cause of blindness in early life with the attendant long blind years and the socio-economic impact to persons, family, community and nations.<sup>[17]</sup>

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### Conflicts of interest

There are no conflicts of interest.

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