HEALTH-SYSTEM DETERMINANTS OF RETINOBLASTOMA OUTCOMES: A STRUCTURED AUDIT OF DIAGNOSTIC, THERAPEUTIC, AND SUPPORTIVE RESOURCES RELATIVE TO SIOP STANDARDS

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ABSTRACT

Background: Retinoblastoma is the most common intraocular malignancy of childhood and is highly curable when detected early, with survival exceeding 95% in high-income countries. In many low- and middle-income countries (LMICs), survival remains below 40% due to systemic and cultural barriers. Although the International Society of Paediatric Oncology (SIOP) defines minimum standards for manpower and infrastructure, outcomes in Nigeria remain poor despite progress towards meeting these benchmarks. To our knowledge, this is the first systematic audit in Nigeria to benchmark available resources and outcomes against SIOP standards, thereby providing a unique lens on why survival remains unacceptably low despite apparent infrastructural progress.

Methods: A descriptive cross-sectional audit was conducted among children with retinoblastoma managed at AEFUTHA from July 2016 to June 2022. Data were obtained from patient records, operative notes, chemotherapy registers, and departmental audits. Resources were benchmarked against SIOP standards, and outcomes were stratified by intraocular versus extraocular disease.

Results: At last review, 5/26 (19.2%) were alive and stable, 3/26 (11.5%) were on active treatment, 6/26 (23.1%) had died of metastatic disease, 1/26 (3.8%) received palliative care for brain metastasis, 4/26 (15.4%) had relapsed following non-compliance, and 7/26 (26.9%) had unknown outcome due to loss to follow-up. On-site facilities included examination under anaesthesia, chemotherapy, enucleation with implants, cryotherapy, and customised prostheses; radiotherapy was accessible 75 km away. Human resources broadly met SIOP benchmarks. Interventions included chemotherapy (65.4%), enucleation (30.8%), and cryotherapy.

Conclusion: Survival from retinoblastoma at AEFUTHA remains poor despite the presence of trained manpower and essential infrastructure, largely because children arrive with advanced disease. Community education, financial

protection, and culturally sensitive counselling are urgently needed to reduce late presentation and treatment abandonment. By aligning local outcomes with SIOP benchmarks, this audit contributes a Nigerian perspective that strengthens the evidence for integrated health-system and policy responses aimed at narrowing the survival gap between high-income and resource-limited settings.

Keywords: Retinoblastoma, Nigeria, health-system determinants, outcome

INTRODUCTION

Retinoblastoma, the most common intraocular malignancy of childhood, is a curable cancer resulting from mutation of the RB1 tumour suppressor gene, with an incidence of about 1 in 14,000–18,000 live births worldwide.[1,2] Advances in early detection, multimodal therapy, and multidisciplinary care have improved survival to over 95% in high-income countries. In contrast, outcomes in many low- and middle-income countries (LMICs) remain poor, with survival often below 30%, largely due to late presentation and health system limitations.[3,4]

The International Society of Paediatric Oncology (SIOP) has defined minimum standards for manpower and infrastructure in retinoblastoma care, including subspecialist ophthalmic oncologists, paediatric oncologists, oncology nurses, anaesthetists, radiologists, pathologists, and access to chemotherapy, surgery, focal therapies, and radiotherapy.[5] At the Alex Ekwueme Federal University Teaching Hospital Abakaliki (AEFUTHA), an ophthalmic oncology unit established in 2016 following subspecialty training of fellows in India and Bangladesh, many of these requirements are substantially met. The unit operates with standardised chemotherapy protocols, performs enucleations with orbital implants and prostheses, and provides focal therapies such as cryotherapy, with available resources for radiation therapy nearby, while serving as a referral centre for south-eastern and central Nigeria as well as some West African countries.

Yet despite this capacity, outcomes remain unsatisfactory. Children frequently present with advanced intraocular or extraocular disease, and survival remains unacceptably low. This paradox -that resources broadly comparable to international benchmarks exist, yet poor outcomes persist - highlights the limitations of focusing only on manpower and infrastructural development. Systemic and contextual barriers continue to undermine care: ignorance and poor awareness about available facilities, delayed presentation, cultural and religious beliefs that discourage acceptance of enucleation; poverty and catastrophic out-of-pocket costs drive treatment abandonment; and long distances to both the treatment and radiotherapy facilities impede timely access. In addition, weak referral linkages, fragmented follow-up systems, and inadequate data management compromise continuity of care.[6,7]

These realities underscore the fact that while human and material resources are essential foundations, they are not sufficient to transform outcomes. Improving survival for children with retinoblastoma in Nigeria requires a broader systems-oriented approach that integrates community education, early detection, funding for care, psychosocial support, and policy reforms, with existing

clinical resources. This study, therefore, audits the resources available at AEFUTHA against SIOP standards while situating observed poor outcomes within broader systemic and socioeconomic constraints, providing an evidence base for interventions aimed at bridging the survival gap between high-income and resource-limited settings.

This study aimed to audit the human and material resources available for retinoblastoma care at AEFUTHA in relation to SIOP standards, and to examine patient outcomes in order to highlight barriers that persist despite resource availability.

The specific objectives were to:

1. Compare available manpower and facilities at AEFUTHA with SIOP minimum standards.
2. Review diagnostic and treatment interventions delivered to patients with retinoblastoma.
3. Assess treatment outcomes, including survival, treatment abandonment, and relapse.
4. Identify systemic, socioeconomic, and cultural barriers undermining effective care.
5. To synthesise audit findings into context-specific recommendations for improving survival and continuity of retinoblastoma care.

MATERIALS AND METHODS

Study Design

This was a descriptive cross-sectional audit of resources, diagnostic and therapeutic interventions, and care outcomes of children with retinoblastoma managed at the Alex Ekwueme Federal University Teaching Hospital, Abakaliki (AEFUTHA).

Study Setting

The study was conducted at the Ophthalmic Oncology Unit of the Department of Ophthalmology, AEFUTHA, a tertiary referral centre in South-eastern Nigeria. The unit was established in 2016 following subspecialty training of fellows in international retinoblastoma centres, and has since operated as a referral hub for patients from the southeast, south-south, middle belt of Nigeria, and some West African countries.

Study Population

The study population comprised all children diagnosed with retinoblastoma and managed at AEFUTHA during the audit period. Patients with incomplete records were included in the outcome analysis only where data were available.

Data Sources

Information was obtained from the departmental retinoblastoma register, patient case files, chemotherapy registers, theatre records, and follow-up clinic documentation. All patients were clerked using a unit protocol capturing sociodemographic data, diagnostic timelines, and prior interventions. During the study period, no dedicated data management officer or electronic registry existed, contributing to occasional loss of files and incomplete documentation — an institutional gap highlighted by this audit.

Follow-up system

Routine follow-up was conducted through scheduled clinic visits and telephone contact by ophthalmic oncology residents. However, the absence of an electronic tracking system or dedicated registry or dedicated administrative staff, limited systematic patient

tracing, contributing to loss to follow-up in some cases.

Variables Assessed

a. Human resources- ophthalmic oncologists, fellows, general ophthalmologists, paediatric oncologists, oncology nurses, anaesthetists, radiologists, pathologists, paediatricians, and neonatologists.
b. Material resources- diagnostic facilities (examination under anaesthesia, B-scan, CT, MRI availability), therapeutic facilities (enucleation, chemotherapy, cryotherapy, intravitreal chemotherapy, radiotherapy access), and supportive services (prosthetics, counselling, data management).
c. Interventions- type of diagnostic imaging performed, chemotherapy regimens, surgical procedures, and use of focal therapies and radiation.
d. Outcomes- Outcomes were defined as: alive and stable under observation, on active treatment, relapsed after initial response, abandoned/lost to follow-up, palliative care enrolment, and death from disease. Outcome dependence on disease stage (intraocular vs extraocular) and treatment completion status was examined descriptively.

Routine Diagnostic Protocol: All suspected retinoblastoma cases undergo examination under anaesthesia with indirect ophthalmoscopy and scleral indentation to stage the disease. B-scan ultrasonography is performed routinely to confirm intraocular tumour. Computed tomography is used to assess calcification and extraocular extension when available. MRI is requested when accessible to evaluate the optic nerve and intracranial extension. Staging is assigned based on available imaging and operative findings. Where diagnostic records were incomplete or missing, cases were classified as “unclassified”.

Interventions

Systemic chemotherapy followed SIOP-PODC recommended vincristine–etoposide–carboplatin-based regimens as first-line therapy. Drug availability was consistent during the study period; however, administration depended on the family's ability to fund treatment out-of-pocket. Enucleation using the myoconjunctival technique with polymethyl methacrylate implant of appropriate size, followed by a customised ocular prosthesis after 6 weeks, is available to all patients requiring enucleation. Carbon dioxide cryotherapy is available as focal therapy for appropriate patients.

Benchmarking Framework

All identified resources were benchmarked against the International Society of Paediatric Oncology (SIOP-PODC) minimum standards for retinoblastoma care. According to the SIOP-PODC classification, AEFUTHA corresponds to a Setting II retinoblastoma treatment centre, defined by the availability of systemic chemotherapy, enucleation, focal therapy, anaesthesia services, and referral access to radiotherapy. Facilities were categorised as on-site, regionally accessible, or nationally available to distinguish physical availability from functional access.[5]

Data Analysis

Data were collated in Microsoft Excel and analysed descriptively as frequencies, counts, and percentages. Given the small sample size and audit nature of the study, inferential

statistical testing was not performed. However, outcomes were stratified by disease stage (intraocular versus extraocular) and treatment completion status to demonstrate dependence of survival on diagnostic stage and therapy completion.

Ethics

In accordance with institutional policy, this anonymised retrospective service audit did not require formal ethics committee review. Confidentiality was strictly maintained.

RESULTS

Patient Demographics and Clinical Characteristics

A total of 26 patients were managed for retinoblastoma during the audit period. There were 9 males (34.6%) and 17 females (65.4%), giving a female-to-male ratio of 1:2. The median age at presentation was 2.0 years (range 0.42–6.0 years). Unilateral disease occurred in 18 patients (69.2%), while 8 (30.8%) had bilateral disease. Based on available staging data, 10 patients (38.5%) had intraocular disease and 9 (34.6%) had extraocular disease. In 7 patients (26.9%), staging could not be assigned due to incomplete diagnostic records.

Table 1: Patient Demographics and Clinical Characteristics (N = 26)

Gender distribution

Gender	Number	Percentage (%)
Male	9	34.6
Female	17	65.4

Age distribution

Statistic	Value
Median age	2.0 years
Age range	0.42 – 6.0 years

Laterality

Laterality	Number of patients	Percentage (%)
Unilateral	18	69.2
Bilateral	8	30.8

Disease Classification

Category	Number of eyes	Percentage (%)
Intraocular disease	10	38.5
Extraocular spread	9	34.6
Unclassified	7	26.9

Facilities for Retinoblastoma Care

Table 2 summarises the facilities available at AEFUTHA compared with those regionally or nationally accessible. On-site services include examination under anaesthesia with scleral indentation, systemic chemotherapy, enucleation with orbital implants, customised ocular prosthesis, and cryotherapy. Table 2b outlines other facilities such as radiotherapy, interventional radiology, laser therapy, and intra-arterial chemotherapy, which are available within the region or country.

Table 2: Available Facilities for Retinoblastoma Care – AEFUTHA

Facility	Availability
Examination under anaesthesia with scleral indentation	Available (on-site)
Chemotherapy	Available (on-site)
Enucleation with myoconjunctival technique	Available (on-site)
Customised ocular prosthesis	Available (on-site)
Cryotherapy	Available (on-site)

Table 3: Available Facilities for Retinoblastoma Care Outside AEFUTHA

Radiotherapy	Available within 75 km
Interventional radiologist	Available in the country (not on-site)
Laser therapy (Transpupillary Thermotherapy)	Available in the country (not on-site)
Intra-arterial chemotherapy	Available in the country (not on-site)

Human Resources Compared with SIOP Standards

Table 4 outlines the human resources available at AEFUTHA relative to SIOP minimum requirements. Subspecialist ophthalmic oncologists, oncology fellows, paediatric oncologists, anaesthetists, pathologists, radiologists, and paediatricians are available, meeting or exceeding SIOP expectations in several categories. Nevertheless, outcomes remain poor despite this alignment.

Table 4: Human Resources for Retinoblastoma Care – AEFUTHA vs SIOP Requirements

Category / Role	Our Centre (Number)	SIOP Requirement
Ophthalmology Division		
Ophthalmic oncologists	2	≥1–2 subspecialist ophthalmic oncologists per referral centre
Ophthalmic oncology fellows	2	Fellowship trainees in high-volume centres
Paediatric Ophthalmologist	1	
General ophthalmologists	2	Several for screening/referral; supportive at the tertiary level
Ophthalmic oncology nurses	12	4–6 trained nurses (chemo + perioperative support)
Oncology & Cancer Care		
Paediatric oncologists	2	2–3 per unit; often part of paediatric haematology-oncology teams
Radiation oncologist	1	Dedicated team with in-house radiotherapy services (EBRT/plaque brachytherapy)
Diagnostics & Perioperative Support		
Pathologists	6	≥2 with ocular pathology expertise; access to genetic testing
Radiologists	5	2–3 with paediatric neuroradiology expertise; MRI required
Anaesthetists	6	Essential for EUA, surgery, intravitreal/intra-arterial chemotherapy
Paediatric & Neonatal Care		
Paediatricians	6	General paediatric support team available
Neonatologists	3	Not universally specified; supportive for infant cases

Diagnostic evaluation

Among the 26 patients, 16 (61.5%) underwent B-scan ultrasonography, and 10 (38.5%) had computed tomography imaging documented. MRI was not routinely available during the study period. Seven cases remained unclassified due to missing diagnostic imaging or operative staging documentation.

Treatment interventions

Seventeen patients (65.4%) received systemic chemotherapy in varying combinations with surgery. Of these, 3 (11.5%) had primary enucleation with adjuvant chemotherapy, 5 (19.2%) received sandwich therapy (chemotherapy–enucleation–chemotherapy), and 9 (34.6%) received chemotherapy alone. Nine patients (34.6%) did not commence

chemotherapy because they abandoned care early or their treatment records could not be traced in chemotherapy or theatre registers. See Table 5.

Table 5: Diagnostics and Interventions (N = 26)

Diagnostic / Intervention	Number	Percentage (%)
B-scan ultrasonography	16	61.5
Computed tomography	10	38.5
Received chemotherapy (any)	17	65.4
Primary enucleation + adjuvant chemotherapy	3	11.5
Sandwich enucleation (chemo–surgery–chemo)	5	19.2
Chemotherapy only	9	34.6
No chemotherapy	9	34.6

Nine registered patients did not appear in the chemotherapy or surgical registers. Review of admission and clinic records indicated early treatment abandonment before therapy commencement or loss of case files, reflecting weaknesses in record management and follow-up systems rather than the absence of treatment capability.

Patient outcomes

Of the 26 patients, 6 (23.1%) died from metastatic disease, and 1 (3.8%) was receiving palliative care for brain metastasis. Seven patients (26.9%) were lost to follow-up and had no documented outcome. Four patients (15.4%) relapsed following treatment non-compliance. At the time of analysis, 3 patients (11.5%) remained on active treatment, while 5 (19.2%) were alive and stable under observation (Table 6).

Among patients with classified disease stage (n = 19; 10 intraocular, 9 extraocular), outcome was strongly dependent on stage at presentation. Alive-and-stable status was recorded in 5 of 10 (50.0%) intraocular cases versus 0 of 9 (0%) extraocular cases. Ongoing treatment occurred in 1 of 10 (10.0%) intraocular and 2 of 9 (22.2%) extraocular cases. Deaths occurred exclusively among extraocular cases (6 of 9; 66.7%), with 1 of 9 (11.1%) receiving palliative care. See Table 6. Outcome was strongly dependent on diagnostic stage at presentation. Among classified cases, survival at last review was 50.0% in intraocular disease versus 0% in extraocular disease, despite the availability of chemotherapy and surgical services. This indicates that late-stage diagnosis, rather than absence of treatment capacity, was the dominant determinant of outcome.

Table 6: Outcomes status at last documented review (N = 26)

Status Category	Number of Patients	Percentage (%)
Confirmed dead (metastatic disease)	6	23.1
Palliative care (brain metastasis)	1	3.8
Relapsed (non-compliance)	4	15.4
On active treatment	3	11.5
Stable & under observation	5	19.2
No outcome data available	7	26.9

Table 7: Patient-Specific Barriers to Care

Factor	**Number of patients**
Out-of-pocket payments	26
Poor affordability	24
Multiple dependents distraction	4
Ignorance of disease signs	19
Low health literacy	16
Refusal of care	2
Female caregiver vulnerability	8

All enrolled patients funded care out-of-pocket, as we didn't have a funding programme (Table 7). The 2 familial cases were later supported sporadically by a small NGO. However, their onboarding at the later stages of the disease with irregular funding negated the value of the support. In this series, only 2 families could comfortably afford care and follow the treatment program to the letter. Of these, one did well following sandwich enucleation and is on annual surveillance. The second child had enucleation elsewhere and was sent to us for the prosthesis. However, the child later developed proptosis in the enucleated eye. Tracing surgical data and histopathology from the primary treatment centre revealed a short optic nerve stump (6mm) and tumour cells at the cut end of the nerve. Despite strong efforts and commitment by the family, the child later developed bone metastasis and succumbed to the disease.

Multiple dependent distraction was noted with 4 patients, including a father who missed chemotherapy sessions because his wife had another baby by caesarean section, and he, a welder, could not carry both financial burdens at the same time.

None of the patients in this series was previously aware of the signs of retinoblastoma until it appeared in their child.

Outright refusal of care was noted in 2 patients. One was a police man who refused enrolment/examination under anaesthesia (EUA) despite the willingness of the team doctors to fund the EUA for disease staging. He declared his salary and listed all his other responsibilities, insisting that if the white

reflex could not be treated using eyedrops, he would have none of it. The child returned months later with a fungating mass, never again accompanied by the father. She later succumbed to metastatic disease.

Delayed decision-making occurred with 8 children who were brought in by the mothers or grandmothers. They required a second or third visit to obtain family clearance for the commencement of any form of intervention.

Barriers and Interventions

Table 8: Systemic and Socioeconomic Barriers to Prompt Retinoblastoma Care

Barrier Category	Description of Barrier	Freq (n)
Health-System / Institutional Barriers	• Told at a health centre or chemist that the child would "outgrow the white reflex." - 2 • Advised to "return when older." - 1 • Referral delays or lack of clear communication from health workers - 1	**4**
Knowledge and Awareness Barriers	• Parents did not understand the urgency to present immediately after referral – 4 • Believed the condition was minor or non-urgent.	**4**
Financial / Access Barriers	• Could not afford transport or treatment immediately after referral. • Delay due to lack of funds to reach the tertiary hospital	**9**
Cultural and Religious Beliefs	• Went for prayers believing the disease was "sent spiritually." - 4 • Father denied the child, calling the mother "ogbanje", who brought evil spirits into his family - 1	**5**
Family / Social Decision Dynamics	• Father's approval pending before seeking care – 2 • Decision-making delays within the family.	**2**
Positive Response	• Presented immediately after referral without delay -2	**2**

Figure 1 illustrates the systemic, socioeconomic, and cultural barriers implicated in poor outcomes despite the availability of human and material resources. These include ignorance, cultural beliefs, competing family priorities, poverty, distance from treatment centres, and weak data systems. Proposed interventions include awareness campaigns, community engagement, social support, financial protection, transport subsidies, and dedicated data management.

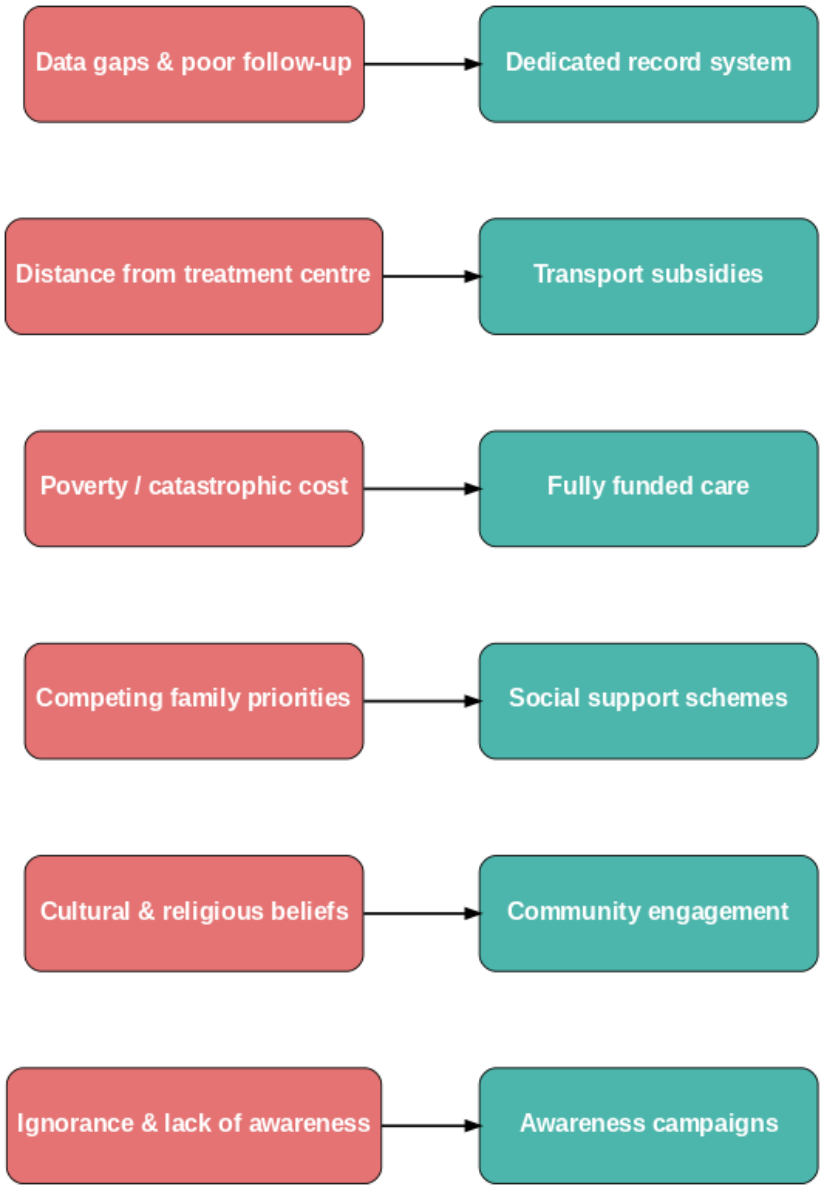

Figure 1: Barriers and Possible Interventions

DISCUSSION

This audit highlights the paradox of retinoblastoma care in a resource-limited setting: despite the presence of trained manpower and treatment facilities at AEFUTHA that meet many international

benchmarks, survival outcomes remain unacceptably low. In high-income countries, survival exceeds 95%, while in sub-Saharan Africa it rarely surpasses 40%. Our findings mirror this disparity, with survival of only 19.2% at last review. Only 5/26 (19.2%) were alive and stable at last review; including those on treatment, 8/26 (30.8%) were alive at last contact. Restricting to classified cases, 5/10 (50.0%) intraocular cases were alive & stable versus 0/9 (0.0%) extraocular; 1/10 (10.0%) intraocular and 2/9 (22.2%) extraocular remained on treatment, while 6/9 (66.7%) extraocular cases died and 1/9 (11.1%) received palliative care. This reinforces that human and material resources alone are insufficient to improve outcomes in retinoblastoma management.

Strengths of Service Provision

AEFUTHA has made important progress in developing a specialised retinoblastoma service. Subspecialist ophthalmic oncologists, paediatric oncologists, anaesthetists, pathologists, and radiologists are available, and focal therapies such as cryotherapy are provided on-site. Chemotherapy and enucleation with orbital implants are routinely performed, and radiotherapy is accessible within 75 km. These demonstrate alignment with many SIOP-recommended benchmarks.

Critical Gaps and Their Limits

Service gaps, however, persist, including off-site radiotherapy, lack of integrated MRI staging, and absence of subspecialist ocular pathology and genetic testing. While these are important for long-term comprehensive care, these deficiencies do not account for the very poor survival observed. Most children presented with advanced intraocular or frank extraocular disease, at which stage the role of sophisticated diagnostics or genetic services is negligible. The decisive factor, therefore, is late presentation, not the absence of advanced technology. Also, our large proportion of patients lost to follow-up and assumed to have deteriorated further worsens the perceived poor prognosis. A national retinoblastoma registry, in collaboration with all treatment centres, would allow tracking of all patients within the network and more comprehensive reporting. A local clinical psychologist on the team would improve the counselling services and retention of patients on the programme.

Comparison with Outcomes Elsewhere

In high-income countries, survival >95% is achieved through early detection, financial protection, and acceptance of interventions such as enucleation.[3,6] Other LMICs with interventions for early presentation present mixed results, with poorer outcomes from delayed presentation.[8-10] In sub-Saharan Africa, survival averages 20–40%, often with predominance of extraocular disease.[4,11,12] Our series aligns with these reports: only 5 of 26 patients (19.2%) were alive and stable at last review. Restricting to classified cases, 5/10 (50.0%) intraocular cases were alive and stable versus 0/9 (0.0%) extraocular. This underscores the overwhelming impact of stage at diagnosis as reported in neighbouring Cameroon by Kruger et al.[13] Additionally, the COVID-19 pandemic during the latter half of the study period likely exacerbated treatment interruption and follow-up losses, compounding pre-existing access barriers.

To our knowledge, this study represents the first Nigerian audit that systematically benchmarks both resources and outcomes against SIOP standards. This makes our findings particularly important, as they

demonstrate that even where manpower and infrastructure align with global benchmarks, survival remains among the lowest reported, largely because of systemic and sociocultural barriers.

Ademola-Popoola et al. demonstrated that with increased awareness campaigns, delays to presentation were significantly reduced, shifting the commonest presenting feature from proptosis to leukocoria over a 7-year period.[14] This highlights the power of community education and suggests a strategy that could be replicated across sub-Saharan Africa. Fabian and colleagues argued that while distance may not always constitute a barrier in high-income settings, in Africa it interacts with poor road networks, difficult terrain, and inadequate transport infrastructure, making simple distance comparisons misleading.[15] This differs significantly from high-income countries, with few treatment centres to which patients travel safely for long distances via good transportation networks to access care. Our results support this context-specific reality, as the 75 km distance to radiotherapy may pose a significant barrier in Nigeria. Moreover, rural, untraveled patients find referral outside the locality a very daunting challenge.

Two familial cases (siblings) were identified (2/26, 7.7%), consistent with reports that familial disease is uncommon in African series (0–10%).[16-18]

Stratification by disease extent confirmed that survival was strongly linked to stage at presentation. Survival at last review among classified cases was 50.0% for intraocular and 0.0% for extraocular disease. This highlights the impact of late presentation on prognosis and mirrors findings across sub-Saharan Africa, where the predominance of extraocular disease continues to drive poor survival rates despite the availability of treatment resources.

Although multimodal treatment (systemic chemotherapy, enucleation, and focal therapy) was available and delivered to most patients in this series, completion of therapy and early-stage diagnosis were the key determinants of survival. Children with intraocular disease who completed planned treatment demonstrated substantially better outcomes, whereas those presenting with extraocular disease or abandoning therapy experienced uniformly poor outcomes. This indicates that therapeutic capability exists within the centre, but its impact is undermined by delayed diagnosis and treatment non-completion rather than by lack of treatment infrastructure.

Sociocultural and Economic Influences

The majority of children in our series presented with extraocular spread or late intraocular disease. Poverty, ignorance of early signs, and competing family priorities contribute to delayed presentation. Out-of-pocket payments create catastrophic expenditure, particularly in families with multiple children requiring support. The state program for health insurance commenced after the study period. Advocacy for complete coverage of these children by the state health insurance scheme is currently ongoing. Sociocultural resistance to enucleation also drives treatment refusal and abandonment, with stigma and fear of disfigurement reinforcing non-compliance. The availability of customised ocular prosthesis with excellent cosmetic outcomes in our centre has

significantly enhanced the uptake of enucleation among patients requiring the service.

Implications for Policy and Practice

Our findings reinforce that manpower and infrastructure alone are insufficient to improve survival in LMICs. Effective retinoblastoma care requires systemic reforms. These include community awareness campaigns, culturally sensitive counselling, government or donor-funded care packages, transport subsidies, incorporation of MRI into standard staging, and the establishment of ocular pathology expertise and genetic testing. Electronic data capture and assignment of a dedicated staff/team for patient tracking and data management would reduce follow-up losses and improve programme evaluation.

By benchmarking both resources and outcomes against SIOP standards, this study contributes a structured Nigerian analysis that complements existing evidence and strengthens the case for policy reform. It highlights that survival gains will depend not only on infrastructural investment but also on addressing systemic barriers — late presentation, out-of-pocket costs, and sociocultural resistance to enucleation.

Study Limitations

This audit is limited by its single-centre design and small sample size, which restricts generalisability. The presence of a similar treatment centre within 2 hours of our location results in the splitting of the patient population, contributing to the low numbers.

The sample size was small, reflecting both the rarity of retinoblastoma and the fact that AEFUTHA serves a defined regional referral population rather than the entire national catchment. Nonetheless, the cohort captures all cases managed at the centre during the audit period and is therefore representative of institutional performance.

Although inferential statistical testing could further explore outcome differences between intraocular and extraocular groups, the limited sample size would render such analyses underpowered. Therefore, outcome dependence was demonstrated through stratified descriptive analysis, which clearly showed survival differences by stage at presentation.

Incomplete outcome data or outright file losses for some patients also reflect systemic weaknesses in record-keeping and follow-up. Nonetheless, the study provides valuable insights into the paradox of apparent adequacy of resources without corresponding improvements in outcomes, a challenge common to many LMIC settings.

The audit period (2016–2022) overlapped with the COVID-19 pandemic, during which travel restrictions, clinic service disruptions, and economic hardship affected hospital attendance and continuity of care. This may have contributed to reduced numbers, treatment interruption, delayed presentation, and loss to follow-up.

As a retrospective audit, the study was subject to missing or incomplete records, reflected in untraceable case files and unclassified staging in some patients. These are recognised limitations of retrospective service evaluations in resource-limited settings.

CONCLUSION

Although AEFUTHA meets many of the manpower and infrastructure benchmarks recommended by SIOP, survival from retinoblastoma remains unacceptably low because most children present with advanced disease. Late diagnosis, catastrophic treatment costs, and sociocultural resistance to enucleation continue to drive poor outcomes, often more decisively than the availability of modern facilities. Sustainable progress will therefore depend on community-level interventions that promote early detection, ensure financial protection, and build trust in recommended therapies, supported by stronger referral and follow-up systems.

What this study adds

1. It provides one of the first Nigerian audits that explicitly benchmarks both resources and outcomes against SIOP standards, offering structured insights into the paradox of adequate manpower and facilities but persistently poor survival.
2. It shows that late-stage presentation, catastrophic out-of-pocket costs, and sociocultural resistance to enucleation remain decisive barriers, outweighing the benefits of available infrastructure.
3. It highlights that meaningful survival gains will depend on integrated strategies — early detection, financial protection, culturally responsive counselling, and robust referral/follow-up systems — alongside existing clinical resources.
4. It positions advanced services such as subspecialised ocular pathology, genetic testing, and integrated radiotherapy as valuable future investments, but only impactful when earlier-stage disease becomes the common mode of presentation.

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