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Retinoblastoma at a Tertiary Eye Centre in Kathmandu, Nepal: A 10-Year Cohort Study of Presentation, Stage, Treatment and Follow-Up

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Abstract

Background

Retinoblastoma is the most common primary intraocular malignancy of childhood with the worldwide incidence of 10000 to 15000 cases per live births. This study describes the presentation, stage at diagnosis, treatment patterns and follow-up outcomes of children diagnosed with retinoblastoma at Tilganga Institute of Ophthalmology, Kathmandu, over a 10-year period.

Methods

We performed a retrospective cohort study of consecutive children diagnosed with retinoblastoma at Tilganga Hospital between 2016 and 2025. Patient-level variables included age at diagnosis, sex, country/province of origin, laterality, presenting sign and follow-up status. An eye-level subset was analysed for ICRB group, stage and treatment received. The primary endpoint was advanced intraocular disease at presentation, defined as ICRB Group D/E. Secondary endpoints included enucleation and loss to follow-up.

Results

A total of 236 patients were included. Mean age at diagnosis was 30.7 months (median 24, range

0.5-160); 132/236 (55.9%) were male. Disease was unilateral in 176/236 (74.6%) and bilateral in 60/236 (25.4%). Bilateral cases presented younger than unilateral cases (mean 20.1 vs 34.3 months, $p=0.000054$). Among 226 classifiable presenting signs, leukocoria/white reflex was most common (191/226, 84.5%), followed by proptosis/orbital disease (31/226, 13.7%). In the eye-level subset, 117/142 eyes (82.4%) presented with ICRB Group D/E disease, including 99/142 (69.7%) Group E eyes. Any enucleation was recorded in 65/142 eyes (45.8%), including 55/142 (38.7%) primary enucleations. Group E eyes were significantly more likely to undergo enucleation than non-Group E eyes (59.6% vs 14.0%, $p<0.001$). Among patients with available outcome data, 77/173 (44.5%) were lost to follow-up.

Conclusion

This 10-year Nepal cohort demonstrates persistently late presentation of retinoblastoma, with a very high burden of advanced intraocular disease, frequent enucleation and substantial loss to follow-up. These findings support the need for earlier detection, streamlined referral pathways and stronger retention in care in low-resource settings.

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