

*abstract*

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## Real-world experience in dealing with children with suspected central nervous system (CNS) tumors at the largest public-sector center in Pakistan

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**Introduction:** There is scarce data on CNS tumors in children from LMICs. The objectives of this study were to document the trajectory of children with CNS tumors at the largest, public-sector center in Pakistan.

**Methodology:** This prospective, analytic, observational, cohort study recorded all new cases of suspected CNS tumors (birth to 16 years) presented from 2023/01/01 to 2023/12/31 at Children's Hospital Lahore, Pakistan.

**Results:** Total 145 cases were included. Median age at presentation was 7.0 years (1.5 months–15 years). Male-to- female ratio was 1.4:1. Median time to presentation was 2 months (0.1 – 96 months); delay of >6 months was observed in 30.5% of cases due to delayed presentation to medical facility (74%) and healthcare delay (26%). Headaches and/or vomiting (56%), focal neurological deficits (23%), and seizures (15%) were the most common presenting complaints. Consanguinity (46%), and family history of cancers/brain tumors (19%) were frequent; café au lait macules were observed in 9.7%. 50% tumors were Infratentorial, 46% supratentorial and 4% spinal. Tumor excision was done in 45%, VP-shunts in 42%, and upfront chemotherapy in 2%. Median time to surgery was 1 month (0.1 – 48 months). Only 60% had a final diagnosis: 39% with histopathological and 21% with radiological diagnosis.

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Medulloblastoma (32%), Pilocytic Astrocytoma (27%), and High-grade glioma (16%) were the commonest histopathological diagnosis, while DIPG/DMG (12%), Craniopharyngioma (7.6%), and Optic Pathway Glioma (1.4%) were the radiological diagnosis. Seventy patients (48%) expired, including 38 (26%) before surgery, 39 patients (27%) were alive (on treatment/follow-up), and 36 (25%) LAMA/LTFU/defaulted treatment. One-year survival was 36% with median survival of 4 months (0.07-96 months).

**Conclusion:** CNS tumors in children have a poor survival rate at our center. Less than half of the patients with CNS tumors undergo active treatment, and a large proportion leave treatment/follow-up. Considerable cases with cancer predisposition syndromes are suspected.