161. LONG-TERM NEUROLOGIC AND NEUROCOGNITIVE STATUS OF CHILDHOOD BRAIN TUMORS: A CHILDHOOD CANCER SURVIVOR STUDY (CCSS) REPORT

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The long-term neurologic and neurocognitive status of children surviving brain tumors has been poorly characterized. The CCSS, a NIH-sponsored questionnaire study of 20,345 children surviving cancer diagnosis between 1970 and 1986 at 25 institutions, identified 1,845 with brain tumors who survived at least five years. 1,172 (63.4%) had gliomas, 375 (20.3%) had medulloblastomas/PNETs (MB/PNETs), and 68 (7.2%) ependymomas (Es). At time of follow-up, 75% of patients were 18 years of age or greater. Seizures, convulsion or blackout were quite common, reported in 28% of survivors (32% with gliomas, 21% of MB/PNETs and 11.8% of Es) and 24% of MB/PNETs were considered to have epilepsy. Headaches were a concern in 661 of 1,809 (37%) patients, and migraines were reported in 16.9% of gliomas, 16.5% with MB/PNETs and 15.5% with ependymomas. Motoric disabilities included balance problems in 873 (46% of gliomas, 60% of MB/PNETs and 51% of Es); tremors in 26.3%; weakness of arms in 28%; and weakness of legs in 33%, with 281 of 1,813 complaining of paralysis. 17% of children with gliomas and 6.6% of those with MB/PNETs complained of blindness in one or both eyes. Double vision occurred in 21%. Hearing loss was noted in 16.7% of MB/PNETs and 7% of gliomas, with tinnitus being experienced by 26%. 175 survivors were retarded, but over 60% completed high school, including 16% who graduated college. Of those less than 3 years at diagnosis, 87% completed high school, 915 (53%) required special education or a learning disabled classroom, including 52% of gliomas, 68% of MB/PNETs and 55% of Es; 70% of those less than 3 years at diagnosis and 62.8% of those between 3 and 9 years required special school help. In summary, survivors of childhood brain tumors commonly have significant neurologic sequelae which are varied and occur in patients with all tumor types. Although learning impairment is frequent, the majority will complete high school, independent of tumor type or age at diagnosis.