Adolescent and Young Adult Central Nervous System Tumour Survivors: Documentation of late-effects risks and screening recommendations in British Columbia, Canada

A. Fuchsia Howard, Jordan Tran, Avril Ullett, Michael McKenzie, Karen Goddard. fuchsia.howard@ubc.ca

Survivors of adolescent and young adult (AYA) central nervous system (CNS) neoplasms are at risk for late effects (LE) - treatment-related health problems occurring more than 5 years after therapy. Since, in Canada, AYA survivors are usually followed in the community, information must be conveyed to primary care providers to guide risk-based follow-up care. Objective: To assess documentation of LE risks and screening recommendations (SR) in medical records of AYA CNS tumor survivors treated with radiation therapy. Methods: The medical records of all patients diagnosed with a CNS neoplasm (benign or malignant) at ages 15-39 years, treated between 1985 and 2010 in the province of British Columbia, surviving >5 years and discharged to the community were assessed. Documentation of LE and SR were extracted, and analyzed descriptively. Results: Among 132 survivors (52% female), treated with radiation therapy (95% partial brain, 10% craniospinal, 8% partial spine, and 4% whole brain) and chemotherapy (17%), 19% of charts included no documentation of LE risks, 26% included only non-specific documentation, and 55% had minimal documentation (1 or 2 LE). Documentation of at least one specific LE increased from 24% in 1980-1989, to 54% in 1990-1999, to 86% in 2000 – 2010. Based on treatment information, all survivors were at high-risk for LE, such as radiation induced neoplasm, meningoima and cerebrovascular events. Yet, SR were documented in only 25% of charts. Conclusions: The documentation of LE risks and screening recommendations has been limited, highlighting the need to improve written communication with primary care providers.

Long-term health-related quality of life in adult survivors of pediatric intracranial germ cell tumour

Andrea Lo, Normand Laperriere, David Hodgson, Karen Goddard. Andrea.Lo@bccancer.bc.ca

PURPOSE: To investigate health-related quality of life (HRQOL) in survivors of intracranial germ cell tumors (IGCT). METHODS: Survivors of IGCT were invited to complete the 36-Item Short Form Survey Instrument (SF-36). The SF-36 is scored from 0-100, with a higher number representing a more favorable HRQOL. RESULTS: The study cohort consisted of 12 survivors of IGCT, 6 males and 6 females. Median age was 13 years at diagnosis, and 26 years at time of study. Median follow-up was 11 years. Five patients had germinomas, and 7 had non-germinomatous germ cell tumors. All 12 patients received radiation therapy (RT), 10 to the craniospinal axis, 1 to the whole ventricles and 1 to the tumor bed alone. Nine patients received chemotherapy. Mean SF-36 scores were 67.9 (standard deviation [SD] 33.2) for physical functioning, 58.3 (SD 37.4) for role limitations due to physical health, 77.8 (SD 32.8) for role limitations due to emotional problems, 43.1 (SD 18.4) for vitality, 74.3 (SD 15.3) for mental health; 62.5 (SD 32.0) for social functioning, 74.2 (SD 33.4) for pain, and 57.1 (SD 24.0) for general health; mean scores were >1 SD lower than that of Canadian normative data for vitality, social functioning and general health. Physical component score was 43.6 (SD 13.9) and mental component score was 47.6 (SD 11.2), normalized to a US population with mean of 50 and SD of 10. CONCLUSIONS: Long-term HRQOL for survivors of IGCT is lower than that of the overall population, particularly in vitality, social functioning and general health.