Quality of life and long-term prognosis are often severely impaired in craniopharyngioma (CP). Knowledge of risk factors for long-term outcome is important for optimization of treatment. We analyzed long-term survival in 261 pts. with CP diagnosed before 2000.

Methods

In addition to survival rates body mass index (BMI), neuropsychological status (EORTC QLQ-C30, MFI-20), and psychosocial status were analyzed in 108 of 261 patients with childhood-onset CP diagnosed before 2000 and longitudinally observed in HIT-Endo.

Results

20-yr OS was lower (p=0.006) in CP with hypothalamic involvement (HI) (n=132, 0.84±0.04) when compared to CP without HI (n=82, 0.95±0.04). OS was not related to degree of resection, gender, or diagnosis age or year (before/after 1990). PFS was not associated with HI, degree of resection, or gender. HI led to severe weight gain during the first 8-12 yr of follow-up (median BMI increase: +4.59±SD) compared to no HI (median increase: +1.20±SD) (p=0.00). During >12 yr follow-up, patients with HI presented no further BMI increase.

QoL in pts with HI was impaired by obesity, physical fatigue, reduced motivation, dyspnea, diarrhea, and worse psychosocial development.

Conclusions

OS and QoL are impaired by HI in long-term survivors of CP. HI is associated with severe obesity, plateauing after 12 years. OS/PFS are not related to degree of resection, but gross-total resection should be avoided in cases of HI to prevent further hypothalamic damage, exacerbating sequelae.

Patient cohort for QoL assessment

EORTC QLQ-C30, MFI-20, and a newly designed questionnaire created for the current study was used to assess the psychosocial status of the adult (age >20 years) long-term CP survivors of our cohort.

Used instruments / questionnaires

EORTC QLQ-C30, MFI-20, and a newly designed questionnaire created for the current study was used to assess the psychosocial status of the adult (age >20 years) long-term CP survivors of our cohort.

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