RONC-16. PROTON THERAPY FOR PATIENTS WITH EMBRYONAL TUMOR WITH MULTILAYERED ROSETTES IN EARLY CHILDHOOD – RESULTS OF THE PROSPECTIVE KIPROREG STUDY

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OBJECTIVES: Embryonal tumors with multilayered rosettes (ETMR) are rare malignancies of the central nervous system occurring predominantly in early childhood. Little is known about optimal time point and target volume of radiotherapy for the respective patients. The aim of this analysis was to evaluate treatment outcome in pediatric patients with ETMR treated with Proton Therapy (PT). METHODS: Between May 2016 and August 2021, 15 patients (9 male /6 female) with ETMR received PT in our institution and were enrolled in the prospective registry study KiProReg. Patient characteristics, treatment and outcome according to standardized follow-up data were descriptively summarized by summarized in small sample size. RESULTS: Median age at PT was 3.0 years (range, 1.6-4.0 years). Three patients presented with metastatic disease (M1 n=1; M2 n=1; M2/3 n=1). Eight patients were treated with salvage PT at tumor progression or recurrence. Recurrent disease was present in 7 of 15 patients at start of PT. Tumor site was infratentorial (n=3) or supratentorial (n=12). All patients received Chemotherapy (CTX) prior to PT including high dose CTX (n=9) and intrathecal CTX (n=3). Concomitant CTX with temozolomide was administered in one patient. Patients received local PT (n=8) or concomitant irradiation (CSI) followed by a local boost (n=7). Median dose was 54.0 Gy(RBE) (range, 3.6 -59.4 Gy(RBE)); PT was terminated prematurely in one patient due to cerebral edema and disease progression. Median follow-up after diagnosis was 16.3 months (range, 6.6-65.7 months) and 5.1 months (range, 0.6-24.4 months) after PT. Four patients treated for salvage experienced disease progression within three months after PT, three of them deceased. CONCLUSION: Preliminary results suggest promising outcomes for childhood ETMR after PT, especially in patients treated at initial diagnosis. Longer follow-up and larger cohorts are desirable to assess long-term survival and necessity of CSI.

RONC-17. FEASIBILITY OF PROTON THERAPY WITH AND WITHOUT SIMULTANEOUS CHEMOTHERAPY IN CNS MALIGNANCIES OF CHILDREN AND ADOLESCENTS

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BACKGROUND: Proton therapy (PT) is a valuable alternative to photon therapy in treatment of CNS malignancies. The aim of this study was to investigate the feasibility of recent treatment strategies with a particular focus on the acute toxicity of a simultaneous radiotherapy and chemotherapy (sRCT). PATIENTS AND METHODS: We retrospectively reviewed 199 patients (18.6% ≤ 12 years) who received in total 200 cycles of PT (60.5% at new diagnosis, 39.5% at relapse) from September 2013 to February 2017. Entities included ependymomas (34%), medulloblastomas (16%), low grade gliomas (13%), ATRTs (12%), cerebellar astrocytomas (9%), germ cell tumors (6%), and other entities (10%). SRCT was administered in 32 (26%) treatment cycles. The target tumor was predominantly localized infratentorial (53%), supratentorial (23.5%) and supra-/intrasellar (18%). 38 patients received additional CSI and 8 patients a boost to metastases. Data were collected retrospectively based on patient records. Toxicity was documented according to CTCAE version 4.03. RESULTS: Severe adverse events (SAE ≥ grade 3) occurred in 33.5% of all patients, in particular in form of hematotoxicity (64.1%) and infections (26.8%). In-patient treatment for unexpected SAEs was necessary in 33 patients (16.5%). In the group treated with SRCT 15 out of 32 (48.1%) patients couldn’t receive the recommended dose or time schedule of planned chemotherapy due to SAEs. Comparing the SAE frequency in both groups, the children who have been treated with SRCT had a significantly higher risk of SAEs than the patients who have received proton therapy only (63.5% vs. 23.0%, p<0.001). CONCLUSIONS: PT and concomitant chemotherapy are feasible, but require an interdisciplinary team with continuous in-/patient management of patients, as the risk of toxicity is significantly increased. Risk-adapted adjustment of simultaneous chemotherapy is necessary to reduce relevant interruptions of radiotherapy.

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RONC-18 RADIOSURGERY FOR PRIMARY AND METASTATIC CNS MALIGNANCIES IN THE PEDIATRIC POPULATION

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PURPOSE: The purpose of this study is to describe outcomes after pediatric radiosurgery for malignant CNS lesions. METHODS: Retrospective chart review was performed for 31 pediatric patients treated at a single institution with Gamma Knife stereotactic radiosurgery (SRS) for primary or metastatic CNS malignancies between 2000-2020. RESULTS: 25 patients were treated with SRS for focal recurrences of primary CNS malignancies, 1 patient was treated in the adjuvant setting after initial resection, and 5 patients were treated for brain metastases. Primary CNS histologies included ependymoma (n=14), glioma (n=4), medulloblastoma (n=2), and meningioma (n=2). 65% were WHO grade 3 or 4. 71% of patients had received a prior course of involved-field external beam radiation to the brain to a median dose of 39.4 Gy in 33 fractions. Median age at SRS was 14 years (range 4-21). Radiosurgery was predominantly performed in a single fraction to a median dose of 17 Gy to a total of 42 targets among 29 patients. Two patients underwent fractionated radiosurgery to 30 Gy in 5 fractions for larger lesions. Median follow up after SRS was 44 months. 7 patients (23%) had no evidence of disease after SRS at a median follow up of 39 months. 6 patients (19%) developed local recurrence at the site of their treated lesion at a median of 13 months after SRS. 20 patients (65%) developed recurrent disease in the CNS outside of the radiosurgery field at a median of 11 months after SRS, 4 patients developed toxicity from SRS related radiation treatment alone, all of which occurred outside of SRS. CONCLUSIONS: SRS for malignant CNS lesions in the pediatric population provides effective local control and is well-tolerated. However, there remains a substantial risk of distant CNS failures given the nature of recurrent or metastatic disease in these patients.

SOCIAL WORK/PATIENT SUPPORT/PALLIATIVE CARE

SWK-01. PARTNERSHIP BETWEEN CAREGIVERS, PATIENTS AND HEALTHCARE PROFESSIONALS: PROMOTING COLLABORATION IN A COMPLEX CARE PATHWAY IN PEDIATRIC NEURO-Oncology

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Children with a brain tumor and their families encounter, from the moment of diagnosis, a complex, multidisciplinary and multisite journey. Oscar's Angels (OA) is an association of trained patient advocates volunteers within a hospital structure who provide daily support to pediatric neuro-oncology patients and their families in complex care pathways. The association promotes collaboration in healthcare by facilitating a strong link between the daily reality of patients and their families and that of the hospital. OA volunteers are active and fully accepted members of the hospital structure who provide daily support to pediatric neuro-oncology patients and their families in complex care pathways. The association promotes collaboration in healthcare by facilitating a strong link between the daily reality of patients and their families and that of the hospital. OA volunteers are active and fully accepted members of the hospital.
multi-disciplinary team and collaborate on a very high level in the care of pediatric patients. Such a collaborative setting is possible because the work of OA is structured around three principles: Innovative, practical and theoretical interventions and engagement training and quality assessment of volunteers. Patient and family support from Oscar’s Angels volunteers throughout the care pathway. Government certification, institutional representation and active collaboration in educating healthcare professionals about the importance of the needs of patients and their families. Operating in France since 2010, OA’s services come at no cost to hospitals. This is particularly important for implementing the program in developing countries where healthcare resources are extremely limited. But it is also relevant in developed countries as well where healthcare budgets are under strain. In 2020 an informal internal OA survey highlighted that the patients/family volunteer/hospitalcare professional interface provides added value for all of these stakeholders. A formal survey will be conducted in 2022 to corroborate these results.

**SWK-02. PALLIATIVE SEDATION IN PEDIATRIC PATIENTS SUFFERING FROM BRAIN TUMORS: CHOOSING THE BEST DRUGS TO IMPROVE END OF LIFE**

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**INTRODUCTION:** For terminally-ill children with brain tumors care focuses on quality of life, and patient management fundamentally affects grieving families. We describe our experience of palliative sedation (PS) for children with refractory symptoms caused by solid tumors, focusing on BT (brain tumor). METHODS: Retrospective data on all children treated for BT for which an initial assessment was performed by a specialist. Children were required to demonstrate they could follow simple in the hospital setting. During the COVID pandemic, it has also resulted in a reduction in aerosol generating procedures. As part of the structured programme, each child had an initial assessment with the nurse specialist and was assessed more adequately and interventions more targeted. As part of the structured programme, each child had an initial assessment with the nurse specialist and was assessed more adequately and interventions more targeted.

**RESULTS:** Of the 29 patients eligible for the study, M/F 17/12, the median duration of disease was 12.5 months (range 3-51) and the median age at death was 8.5 years (range 1-22). Fifteen had BT received antiepileptic therapy, apart midazolam. BT patients received oral benzodiazepines before PS less frequently than those with other cancers (p = 0.0033). Throughout the period of PS and on the day of death, patients with BT were given lower doses of midazolam and morphine. Mean dose of midazolam was 0.027 mg/kg/h (range 0.0069-0.036) for patients with BT, 0.055 mg/kg/h (range 0.01-0.38) for the others, while the mean morphine doses were 0.048 mg/kg/h (range 0.0-0.08) and 0.09 mg/kg/h (range 0.013-0.13), respectively. CONCLUSIONS: BT patients require less immediate and antiepileptic therapies before PS in the course of disease. Optimizing pharmacological treatments demands a medical team that knows how drugs (even developed for other indications) work. Emotional-relational aspects are important too, any action to lower a patient’s consciousness should be explained to the family. Guidelines on PS in pediatrics could help, providing they acknowledge that any child’s death is always a unique case.

**SWK-03. NEUROIMAGING IN CNS TUMOURS: TO GA, OR NOT TO GA, THAT IS THE QUESTION.**

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Children with a Central Nervous System (CNS) tumour have frequent magnetic resonance imaging (MRI) scans during their disease trajectory. Younger children have these procedures more frequently (GA) with an associated risk and inconvenience. Our project over a two-year period was to introduce a structured programme to any child over the age of five years old to achieve an MRI scan without the need for a GA. Thirty-six patients took part. The motivation behind this project was to enhance the hospital experience for patients and their families, lessen time spent in hospital and minimise risk. In addition, there was an added incentive of cost saving and increased availability of GA scans for other specialties within the hospital setting. During the COVID pandemic, it has also resulted in a reduction of our patients requiring COVID swabs, and isolation and in turn a reduction in aerosol generating procedures. As part of the structured programme, each child had an initial assessment with the nurse specialist followed by a minimum of one play preparation session with the play specialist. Children were required to demonstrate they could follow simple instructions, engage in social stories and role-play with hospital equipment and specialised resources. During these sessions, the children visited the MRI department where they practiced lying flat on the MRI bed as it moved into the scanner. Over the two-year period, of the total number of MRI scans performed, the amount of MRI scans requiring a GA reduced from 41% to 31%. The quality of the MRI scans was scrutinised and shown not to be significantly affected. In summary, by introducing a structured programme, it is possible to significantly reduce the need for GA in children requiring CNS imaging as part of their tumour journey.

**SWK-04. INVESTIGATION ON ANXIETY AND DEPRESSION OF PARENTS OF CHILDREN WITH CENTRAL NERVOUS SYSTEM TUMORS**

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**OBJECTIVE:** Family members of children with Central Nervous System (CNS) tumors are often accompanied by anxiety, depression and other adverse emotions, which have a great impact on the quality of life of children. This study aims to investigate the incidence of anxiety and depression in parents of children with CNS tumors. METHODS: One of the parents of 165 children with CNS tumors who were hospitalized in Guangdong Sanjue Brain Hospital from January 2021 to December 2021 were evaluated for anxiety and depression using Spielberger’s STAI and Beck’s BDI. RESULTS: The incidence of anxiety was statistically significant with the normal Chinese population (29.78±10.01) (P<0.01). 100 persons (60.61%, 100/165) had depression, and the depression score of the cohort was (53.02±9.98), higher than that of the normal population (33.46, 8.53), with statistical significance (P<0.01). CONCLUSION: The parents of children with CNS tumor are the high risk group of anxiety and depression, which should arouse more clinical attention.

**SWK-05. CLINICAL SOCIAL WORK IN PEDIATRIC NEURO-ONCOLOGY – A RESEARCH PROJECT ON THE SOCIAL DIMENSION USING SOCIAL DIAGNOSTICS**

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**PURPOSE:** A neuro-oncological disease of a child represents a high psychosocial burden for the child and their families focusing on medical, psychological and social care is significant in the course of the disease. Studies show that existential problems or low social support are risk factors. Therefore, this research investigates the impact of a pediatric neuro-oncological disease on the social dimension using a standardized social assessment. **RESEARCH DESIGN:** The project is based on a retrospective cross-sectional study (04/2015-12/2021) including consecutive patients with high-, low-grade gliomas or anaplastic gliomas. **RESULTS:** The social dimension includes social support, economic status, family size, social network, family situation, financial and housing situation, legal status, insurance status, etc. The quality of the MRI scans was scrutinised and shown not to be significantly affected. In summary, by introducing a structured programme, it is possible to significantly reduce the need for GA in children requiring CNS imaging as part of their tumour journey.

**SWK-06. STRUCTURED TRANSITION FROM PEDIATRIC NEURO-ONCOLOGY TO ADULT SURVIVORSHIP FOLLOW-UP CARE - CAN WE CLOSE THE GAP?**

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