

**QOL-25. NEUROCOGNITIVE ASSESSMENT OF PEDIATRIC MEDULLOBLASTOMA TREATED BY MBMET\_MEYER TRIAL.** CENSULLO M.L.<sup>1</sup>, BERTOLUZZO G.<sup>2</sup>, FONTE C.<sup>1</sup>, PAVONE R.<sup>1</sup>, GUIDI M.<sup>1</sup>, ENRICO G.<sup>1</sup>, GORI C.G.<sup>1</sup>, MARTIN R.<sup>2</sup>, TEODORI C.<sup>2</sup>, SARDI I.<sup>1</sup> <sup>1</sup>NEURO-ONCOLOGY UNIT, DEPARTMENT OF PEDIATRIC ONCOLOGY, MEYER CHILDREN'S UNIVERSITY HOSPITAL, FLORENCE, ITALY <sup>2</sup>PSYCHOLOGY UNIT, MEYER CHILDREN'S UNIVERSITY HOSPITAL, FLORENCE, ITALY

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The MBMET\_MEYER is an interventional monocentric trial of Meyer Children's Hospital. The goal of this protocol is to reduce toxicity by use of protontherapy and reducing chemo-induced neurotoxicity by limited use of high dose chemotherapy. To date, a neurocognitive assessment is the standard in medulloblastomas but it is very difficult an assessment at baseline for clinical problems such as age, intracranial hypertension and immediate intervention. 10 neurocognitive assessments were reviewed in patients with medulloblastoma treated by MBMET\_MEYER protocol: 3 anaplastic medulloblastoma M0 and 7 classic (2 M0, 1 M1, 1 M2, 3 M3). The median age was 10 years (range 5-18). All the patients were treated with surgery (gross total removal), 2 received chemotherapy and conventional radiotherapy, 8 chemotherapy and protontherapy and only 1 received autologous-hematopoietic stem cell transplant for progression disease after induction chemotherapy. As for protocol, the neurocognitive assessment was defined by Wechsler Intelligence Scales, fonemic and semantic fluency, immediate and deferred memory, tests for working memory, attention and visuo-spatial tests at baseline, after treatment and at the end of follow-up. For 3 patients it was not possible a baseline assessment for bad clinic conditions, 8 are still in treatment. From interviews and assessments emerged that 80% of patients had neurocognitive deficits: at baseline 5 had speed elaboration difficulties, 1 of these also presented verbal deficit, 1 showed problems in recalling verbal material and 1 in working memory; after two years from chemotherapy and radiotherapy 2 presented speed processig and working memory deficit. In conclusion, an assessment at baseline is very difficult for post-surgical problems but necessary to perform as soon. In this way, it is possible to evaluate the impact of the treatment on neurocognitive impairment. Further investigations are necessary to well understand the appropriate schedule of neurocognitive assessment of pediatric medulloblastoma.

**QOL-26. EXPLORING THE EXPERIENCE OF YOUNG PEOPLE RECEIVING REMOTELY DELIVERED ACCEPTANCE AND COMMITMENT THERAPY FOLLOWING TREATMENT FOR A BRAIN TUMOUR**

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Despite high survival rates of children and young people diagnosed with a brain tumour, survival is often associated with poor psychological, physical, and social outcomes. Acceptance and Commitment Therapy (ACT) is an evidence-based psychological intervention shown to improve psychological and physical outcomes in adults and children with chronic disease, including cancer. The ACT Now study investigates the feasibility of ACT delivered remotely with young people who have experienced a brain tumour. This study aims to describe participant experience whilst better understanding the impact of therapy and capturing the barriers and facilitators to engagement. Participants of the ACT Now study were invited to take part in a semi-structured interview with questions covering experience of study initiation, receipt of ACT, remote delivery and overall impact of ACT. Ten participants who had previously undergone treatment for a brain tumour have been interviewed to date. Interviews were transcribed verbatim and coded into broad themes. We found that pre-therapy mood and altruism served as motivation for interviewees' involvement in the study. Interviewees reported hoping to learn coping techniques to navigate fluctuating moods and the pressures of young adult life. Despite the technology used for remote delivery occasionally malfunctioning, interviewees reported increased ability to access therapy via this method. However, an overall preference for face-to-face therapy delivery was reported with inter-

viewees describing that they felt communication might have been easier in person. The therapeutic relationship and the therapists' flexible schedules were seen as facilitators to session attendance. Barriers to attendance were scarcely reported but included scheduling conflicts due to work or school. ACT was highly regarded amongst interviewees and provided an opportunity for them to learn about themselves and how they can live in accordance with their personal values. Interviewees benefitted from ACT psychologically, physically, and socially and reported an overall positive experience of study involvement.

**QOL-27. SOCIOCULTURAL VARIABLES HAVE A MAJOR IMPACT ON PARTICIPATION IN PATIENTS TREATED FOR PEDIATRIC POSTERIOR FOSSA TUMORS**

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**OBJECTIVE:** This study investigates the extent of participation barriers in patients with pediatric posterior fossa tumors (PFTs) at long-term follow-up. While most studies focus on pathobiological variables that promote the occurrence of adverse late effects, the present analysis aims to investigate the importance of environmental variables. **METHOD:** Ten years after tumor diagnosis, 42 patients (mean age: 17 years) treated at our pediatric neuro-oncology unit were assessed for school and social difficulties using a questionnaire developed within the framework of this study. Participation barriers were assumed if patients and/or their parents reported difficulties at school or with peers. The children and adolescents were classified into groups with adequate and limited participation. Potential pathobiological (treatment type, hydrocephalus, tumor recurrence, gender, age at diagnosis, seizures, cerebellar mutism) and environmental risk factors (parental and maternal education, siblings, primary language, discrepancies between personal and environmental values, regular physical activity, private housing) were identified and examined to see if the participation groups differed in the amount of risk factors. **RESULTS:** Almost a decade after treatment, two thirds of the patients had school and/or social difficulties. Not only pathobiological risk factors (type of treatment, hydrocephalus, tumor recurrence, cerebellar mutism and seizures), but also environmental factors (low maternal education level, siblings, a main language other than German, discrepancies between social and personal values, and irregular physical activity) were associated with limited participation. These variables discriminated significantly between patients with and without participation barriers. **CONCLUSION:** Participation barriers in patients treated for pediatric PFT are frequent. In addition to pathobiological variables, environmental risk factors also play an important role in limiting school and social participation. This underlines the fact that a sole consideration of pathobiology is not sufficient when examining risk factors for the occurrence of late effects. The adoption of biopsychosocial perspectives in future studies is inevitable.

**QOL-28. CLINICO-MOLECULAR CORRELATES OF QUALITY OF SURVIVAL AND NEUROCOGNITIVE OUTCOMES IN MEDULLOBLASTOMA; A META-ANALYSIS OF THE SIOP-UKCCSG-PNET3 AND HIT-SIOP-PNET4 TRIALS**

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Determinants of survivorship outcomes are emerging from limited studies of medulloblastoma (MB) survivors. We undertook an integrated analysis of biological (tumour group, host genetics) and clinico-demographic features in patients treated on the SIOP-UKCCSG-PNET3 and HIT-SIOP-PNET4 clinical trials with available quality of survival (QoS) data (n=218), to determine key correlates of survivorship, and their clinical potential. Treatment/demographic factors and molecular subgroup (MB<sub>WNT</sub>, MB<sub>SHH</sub>, MB<sub>Grp3</sub>, MB<sub>Grp4</sub>) were assessed against health status, behavioural functioning, and health-related quality of life (HrQoL). In DNA from HIT-SIOP-PNET4 (n=74), 39 candidate SNPs with known modifying effects on neurocognitive outcomes (e.g., involved in oxidative stress/inflammation) were genotyped and assessed against Wechsler Intelligence Scale (WISC) scores. As expected,

MB<sub>SHH</sub> was associated with improved HrQoL, but subgroup did not associate further with QoS outcomes. SIOP-UKCCSG-PNET3 patients receiving chemotherapy before craniospinal irradiation (CSI) had significantly lower health status ( $p=0.021$ ) and behavioural functioning ( $p<0.016$ ) compared to patients treated with CSI alone, and those treated on both arms (maintenance chemotherapy and hyperfractionated (36Gy) or standard (23.4Gy) CSI) of HIT-SIOP-PNET4. SIOP-UKCCSG-PNET3 patients receiving CSI-only had better HrQoL scores than those who received pre-CSI chemotherapy and both HIT-SIOP-PNET4 arms ( $p=0.004$ ). Females reported worse HrQoL/behavioural functioning across both trials ( $p<0.04$ ). In HIT-SIOP-PNET4, longer intervals from diagnosis to CSI predicted worse HrQoL/health status ( $p<0.05$ ). Neither molecular group nor clinico-demographic features tested were associated with neurocognition. In contrast, 6 SNPs significantly associated with  $\geq 1$  WISC domain; 4/6 showed multiple associations and were independently prognostic; further associations were apparent at the gene/pathway level. This large, integrated and multi-disciplinary analysis of two independent trials cohorts has revealed multiple factors predictive of medulloblastoma survivorship including treatment (chemotherapy, time to CSI), tumour (molecular group) and host genetic factors. Assessment in further prospective series are required to determine their potential as a basis for modifications to disease management.

#### QOL-29. NEUROPSYCHOLOGY FOR YOU<sup>®</sup> – TOOLS TO IMPROVE AWARENESS OF AND ACCESS TO NEUROPSYCHOLOGICAL CARE

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**OBJECTIVE:** The occurrence of neuropsychological late effects in childhood brain tumor patients is well known in literature and practice, as well as the use of neuropsychological testing and therapy procedures. Despite guidelines, actual care is quite heterogeneous and often does not meet the needs due to lack of resources. Therefore, a standardized tool to improve awareness of and access to neuropsychological assessment, but even more treatment was developed. **METHODS:** The core of this Quality-Improvement project is a multilevel and interdisciplinary approach characterized by iterative processes (PDSA-cycles): (1) conceptualization by interdisciplinary, multicenter teams of experts, (2) consensus in Delphi surveys by medical, nursing and psychosocial experts (N=45) and final approval by the steering group. (3) Pilot phases (N=44): Manageability and acceptance, emotional well-being and the degree of information were recorded using a process-oriented screening. **RESULTS:** The expert meetings resulted in two booklets ("Look closely - Psychosocial assessment" & "1,2,3 - All about Neuropsychology"): Each booklet offers creative methods with a high prompting character to motivate the child to participate actively in two face-to-face sessions (psychoeducational, work and exercise and reflection section). They enable patients to make themselves experts on these topics with age-appropriate, interactive methods. The Delphi survey revealed a consensus of 69%-93%. Patients using the Psychosocial-assessment booklet showed generally low negative emotions and stable positive emotions, which significantly increased during the second session ( $Z = 2.156, p = .031$ ). Moreover, positive emotions increase significantly during the second session ( $Z = 2.805, p = .005$ ). Self-indicated degree of information increases significantly with both booklets (Psychosocial assessment:  $Z = 3.133, p = .002$ ; Neuropsychology:  $Z = 2.751, p = .006$ ). **CONCLUSION:** The results illustrate a positive emotional approach to neuropsychological assessment and treatment. Likewise, the rapid increase in expert knowledge supports access to this specific topic and can be considered a minimum standard.

#### QOL-30. POSITIVE EFFECTS OF A PSYCHOLOGICAL PREPARATION PROGRAM FOR MRI IN CHILDREN WITH COGNITIVE ISSUES – HOW TO BEST MEET THE PATIENTS' NEEDS

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**BACKGROUND:** A growing body of evidence has supported alternatives to sedation and general anesthesia for increasing treatment compliance of children during MRI examinations. Particularities in children with a brain tumor (frequency of examinations, neuropsychological deficits (attention, memory)) have a significant impact on methods of treatment and are given special consideration in this study. **OBJECTIVE:** The aim of the present study was to (1) evaluate the effectiveness of an MRI training program and to investigate the moderating factors for successful MRI examination for a group of young patients with pediatric brain tumors and/or NF1 and (2) to examine the effect of the training on the patient's well-being. **METHODS:** A total of 87 in the retrospective analyses (Study 1) and a subgroup of 17 patients in the prospective analyses (Study 2, ClinicalTrials.gov: NCT04474678) of the neuro-oncology unit with a mean age of 6.83 years underwent a two-step program to prepare children for MRI, including an in vitro strategy training inside the scanner and were recorded using a process-oriented screening. **RESULTS:** 81 % of the children who had received MRI training managed to successfully undergo the MRI scan. Hence, the rate of successful MRI examinations without anesthesia was almost five times as high in the group that received MRI training compared to the group that did not. Memory, attentional difficulties and hyperactivity were significant neuropsychological moderators for successful or unsuccessful scanning. Furthermore, the training was effective in improving the psychological well-being of the patients. **CONCLUSION:** Based on the results, the MRI training is an effective alternative to sedation of young patients for MRI examinations and a promising tool for improving patient well-being related to the diagnostic procedure. However, the intervention needs to be customized according to the children's individual neuropsychological difficulties, which requires specialized psychological staff and an interdisciplinary approach.

#### QOL-31. A PSYCHOSOCIAL SUPPORT PROGRAM FOR YOUNG ADULT CHILDHOOD CANCER SURVIVORS IN AUSTRIA: A QUALITATIVE EVALUATION STUDY

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**PURPOSE:** Many adolescents and young adult (AYAs) childhood cancer survivors face disease- or therapy-related late-effects, which limit their participation in various areas of daily life. AYAs are often left alone in our health care system and many worry about their ability to cope with long-term sequelae and some are even lost to follow up. Therefore, in the present study a targeted aftercare program was developed and evaluated with the goal of facilitating three important "life skills": (1) self-perception, (2) social interaction and conflict management as well as (3) self-conscious communication of support needs. **METHODS:** A total of n=13 participants (19.2-30.2 years, mean age: 22.8 years) completed a three-day aftercare seminar, at the end of which each participant wrote a reflection letter ("letter to my future self"), elaborating on observed effects of the seminar, applicability of the given information in daily life and the direct impact of the seminar on their individual circumstances. The reflection letters were analyzed using qualitative content analysis. **RESULTS:** All target life skills were mentioned in the reflection letters. The participants reported individual benefits from the program especially with respect to self-perception and self-confidence, giving and taking feedback, and acceptance of personal strengths and weaknesses. Moreover, the feeling of "not being alone" was associated with the survivors' experience of emotional and social support. **CONCLUSIONS:** This evaluation highlights the potential of a one weekend aftercare seminar to address important life skills that are known to positively influence health behavior in AYAs. The detailed description of the seminar can serve as a basis for making this kind of aftercare accessible for other people in similar circumstances.