

Stefanie Frahsek¹, Rene Schmidt⁵, Andreas Faldum⁵, Johannes Wolff⁶, Gudrun Fleischhack⁷, Monika Warmuth-Metz⁸, Jürgen Krauss⁹, Rolf-Dieter Kortmann¹⁰, Niels Galley¹¹, Joachim Kühl¹, and Stefan Rutkowski³; ¹University Children's Hospital, Würzburg, Germany, ²Department of Psychology, University of Bochum, Bochum, Germany, ³Department for Pediatric Hematology and Oncology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany, ⁴Department for Pediatric Oncology, Charité University-Medicine, Berlin, Germany, ⁵Institute of Biometry, University of Münster, Münster, Germany, ⁶Abbview, Oncology Development, Chicago, IL, USA, ⁷Pediatrics III, University Children's Hospital, Essen, Germany, ⁸Department of Neuroradiology, University Medical Center Würzburg, Würzburg, Germany, ⁹Department of Neurosurgery, University Medical Center Würzburg, Würzburg, Germany, ¹⁰Department of Radiotherapy, University of Leipzig, Leipzig, Germany, ¹¹Institute of Psychology University of Cologne, Cologne, Germany

Neurocognitive deficits are frequent in childhood brain tumor survivors and affect mental intelligence, psychomotor and executive abilities. The differential impact of factors such as disease (location, histology) or treatment (local (LI) vs. craniospinal irradiation (CSI)) on these parameters is not fully understood. Between 2007–2011 and 2013–2017 300 testings were performed on-site by one neuropsychologist. Of these, 274 tests from n=208 children with medulloblastoma (MB), ependymoma (EP) and supratentorial embryonal tumors (SET) <4 years at diagnosis are currently included into the analysis. Applied tests included the Bayley II, WUEP-KD, K-ABC, tapping speed (TS), CPT_Hits/CPT_DT, and, as a new score, CPT_Power which integrates the latter. Treatment consisted of surgery and chemotherapy ± LI/CSI. All children receiving CSI and MB children with LI showed substantial deficits in general intelligence scores. In contrast, children with MB or SET without CSI/LI and those with EP receiving LI performed surprisingly well after 2 and 5 years follow-up. Motor function (TS) was reduced in all children except those with SET without irradiation. Of note, mental processing speed (as measured in CPT_Power) was not essentially reduced in MB and EP patients, indicating that mental processing is less affected than motor speed (TS) in children with infratentorial tumors. In conclusion, our data show that besides the established detrimental effects of CSI on general intelligence, infratentorial tumor location is a main risk factor for motor dysfunction irrespective of irradiation. Appropriate sensitive testing tools are warranted to assess cognitive function without the interfering influence of motor dysfunction.

QOL-25. MICROSTRUCTURAL BRAIN CHANGES ASSOCIATED WITH NEUROCOGNITIVE AND FUNCTIONAL OUTCOMES OF INTRACRANIAL GERM CELL TUMOUR SURVIVORS – A DIFFUSIONAL KURTOSIS IMAGING STUDY

Wan-Yee Winnie Tso¹, Sai Kam Hui², Tatia Mei Chun Lee³, Anthony Pak Yin Liu¹, Patrick Ip¹, Kevin Cheng⁴, Daniel Fong⁵, Dorita Chang³, Frederick KW Ho⁶, Ka Man Yip¹, Dennis Ku⁷, Daniel KL Cheuk⁷, Chung Wing Luk⁷, Ming Kong Shing⁷, LK Leung¹, Pek Lan Khong², and Godfrey Chi Fung Chan¹; ¹Department of Paediatrics & Adolescent Medicine, LKS Faculty of Medicine, University of Hong Kong, Hong Kong, Hong Kong, ²Department of Diagnostic Radiology, LKS Faculty of Medicine, University of Hong Kong, Hong Kong, Hong Kong, ³State Key Laboratory of Brain and Cognitive Sciences, The University of Hong Kong, Hong Kong, Hong Kong, ⁴Department of Neurosurgery, Queen Mary Hospital, Hong Kong, Hong Kong, ⁵Department of Nursing, LKS Faculty of Medicine, University of Hong Kong, Hong Kong, Hong Kong, ⁶Institute of Health and Wellbeing, University of Glasgow, Glasgow, United Kingdom, ⁷Hong Kong Children's Hospital, Hong Kong, Hong Kong

BACKGROUND: Childhood intracranial germ cell tumour (iGCT) survivors are prone to radiotherapy-related neurotoxicity which can lead to neurocognitive dysfunction. Diffusion kurtosis imaging (DKI) is a MRI technique that quantifies microstructural changes in the grey and white matter of the brain. This study aims to investigate the associations between MR-DKI metrics, the cognitive and functional outcomes of childhood iGCT survivors. **METHOD:** 20 childhood iGCT survivors who had received cranial radiotherapy were recruited. DKI parameters were determined for iGCT survivors and 18 control subjects. Neurocognitive assessment using the Hong Kong Wechsler Intelligence Scales for Children (HKWISC)/ Wechsler Adult Intelligence Scale – Revised (WAIS-R) and functional assessment using the Lansky/ Karnofsky performance scales were performed for GCT survivors. **RESULTS:** There were significant negative correlation between the IQ scores and the mean diffusivity (MD) in multiple white matter regions of iGCT survivors including: anterior limb of internal capsule, superior fronto-occipital fasciculus, anterior corona radiata, uncinata fasciculus, cingulum and hippocampus. Mean kurtosis (MK) values of the superior fronto-occipital fasciculus were positively correlated with IQ scores. For grey matter, the MD of the olfactory, insula, caudate, heschl gyrus, parahippocampal gyrus, hippocampus, anterior cingulum, frontal inferior operculum, middle and superior temporal gyrus, middle and superior frontal orbital gyri, cuneus and

precentral gyrus were negatively correlated with IQ scores. Most of the microstructural changes with associated functional impairment were white matter regions. **CONCLUSION:** Our study identified vulnerable brain regions with significant white and grey matter microstructural changes that were associated with impaired cognitive function or deficits in physical functioning.

QOL-26. I'VE GOT FRIENDS NOW: PAEDIATRIC PATIENTS' EXPERIENCES OF METHYLPHENIDATE TREATMENT FOR NEUROCOGNITIVE LATE-EFFECTS ASSOCIATED WITH BRAIN TUMOUR

Sarah Verity^{1,2}, Rebecca Hill^{1,2}, Gail Halliday¹, Jade Ryles¹, and Simon Bailey^{1,2}; ¹Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle Upon Tyne, United Kingdom, ²Northern Institute of Cancer Research, Newcastle University, Newcastle Upon Tyne, United Kingdom

BACKGROUND: Whilst rates of survival following paediatric brain tumour have increased, quality of survival continues to present a significant challenge to children and their families. The neurocognitive impact of cranial radiotherapy (CRT) in childhood upon future intellectual development is well established. Both CRT and chemotherapy are associated with medium-term slowed speed of cognitive processing, attention, and memory impairment, and with longer-term failure to achieve pre-morbid intellectual potential and low Health-Related Quality of Life (HRQoL). Methylphenidate is a psychostimulant drug shown to be effective in alleviating some of the neurocognitive symptoms of cancer treatment, however the subjective experience of paediatric participants is not reported. **AIM:** The current study aimed to explore the subjective experience of HRQoL in paediatric neuro-oncology patients currently receiving methylphenidate. **METHODS:** A retrospective audit was conducted on 12 paediatric neuro-oncology patients in receipt of methylphenidate. Both standardised and novel measures were used to assess aspects of HRQoL, specifically; social life, perceived independence, mood, confidence, school life, self-esteem, interpersonal relationships and fatigue levels. Data collected were analysed using Thematic Analysis. **RESULTS:** Five key themes were identified; physical, emotional, social, academic and neuropsychological impact. **CONCLUSION:** The current findings evidence the perception of patients that methylphenidate supported them to regain previously lost functionality. Methylphenidate has the potential to increase HRQoL in this population and to provide children with the opportunity to regain a sense of normality in their lives.

QOL-27. SWALLOWING ASSESSMENT IN PEDIATRIC PATIENTS WITH BRAIN TUMOR

Natalia Oliveira Machado, Ana Paula Duarte, Aline Azevedo dos Santos, Bruna Minniti Mançano, and Carlos Almeida Jr; Barretos' Children and Young Adults Cancer Hospital, Barretos, Sao Paulo, Brazil

BACKGROUND: Neurosurgical intervention is the initial modality of treatment for the vast majority of pediatric brain tumors. However, studies on the swallowing process in pediatric patients with brain tumors are scarce, especially comparing changes that can be identified before and after surgery. In clinical practice, it is possible to observe that these patients may present modifications in the swallowing phases both before and after surgery. Therefore, we conducted a longitudinal study with a cohort of 20 patients ranging in age from 0 to 17 years, in order to characterize the swallowing disorders. **RESULTS:** 30% of the patients presented some change in orofacial motricity in the organs related to initiation, coordination, and maintenance of swallowing at the time of hospital admission, and 65% of the patients exhibited these changes after surgery. Due to worsening in swallowing after surgery, 40% of the patients required modification of the consistency of oral diet or required the use of an alternative route of feeding. **CONCLUSIONS:** There is a high prevalence of swallowing disorders in pediatric patients with brain tumors, mainly regarding the proper functioning of organs related to initiation, coordination, and maintenance of swallowing even before the surgical intervention, and these changes increase after surgery - especially in patients with posterior fossa tumors. The role of the speech/language pathologist is of paramount importance, given their role in the assessment and adequacy of the feeding route, identifying patients at risk of pulmonary aspirations, minimizing swallowing complications, and also facilitating communication with patients and their families.

QOL-28. NEUROCOGNITIVE PROFILE OF PEDIATRIC MEDULLOBLASTOMA PATIENTS PRIOR TO RADIATION THERAPY

Muhammad Baig, Ineke Osthorn, Susan McGovern, David Grosshans, Mary McAleer, Kristina Woodhouse, Arnold Paulino, Grace Yang, Peter Stavinoaha, and Wafik Zaky; MD Anderson Cancer Center, Houston, TX, USA

Neurocognitive late effects are unfortunately common following treatment for pediatric medulloblastoma. While radiation therapy is an essen-

tial component of treatment for most pediatric medulloblastoma patients, it is associated with neurocognitive compromise. Effects include deficits in cognitive speed and performance efficiency, aspects of attention, as well as working memory. Yet long after treatment it is difficult to tease apart relative contributions of other risk factors to neurocognitive functioning beyond radiation. We examined neurocognitive functioning in a sample of pediatric medulloblastoma patients prior to radiation therapy, including investigation of neurocognitive risk factors such as hydrocephalus, presence of posterior fossa syndrome, and duration of neurological symptoms prior to diagnosis. Results indicated that the sample functioned in the average range in terms of overall IQ ($n=34$, $\bar{X}=103$). Patients also functioned in the normal range in terms of language-based ability ($\bar{X}=106$), nonverbal ability ($\bar{X}=104$), and working memory ($\bar{X}=103$). However, the sample performed statistically significantly lower than the general population in terms of cognitive speed and efficiency ($z=-2.026$, $p=.043$). The sample was also rated by parents as exhibiting more attention problems relative to the general population ($z=1.988$, $p=.047$). There was no specific association with hydrocephalus, duration of symptoms, or history of posterior fossa syndrome. Results suggest weaknesses in attention and processing speed may exist in some pediatric medulloblastoma patients prior to radiation therapy secondary to tumor and related complications. Implications for future research are presented, along with difficulties inherent to “baseline” assessment with pediatric brain tumor survivors.

QOL-31. USE OF PATIENT-REPORTED OUTCOMES TO IDENTIFY YOUTH AT RISK FOR IMPAIRED OVERALL HEALTH

Lisa Ingerski^{1,2}, Rebecca Williamson Lewis², Ann Mertens^{1,2}, and Tobey MacDonald^{1,2}; ¹Emory University School of Medicine, Atlanta, GA, USA, ²Aflac Cancer & Blood Disorders Center, Children’s Healthcare of Atlanta, Atlanta, GA, USA

Pediatric brain tumor survivors often experience persistent and clinically significant late-effects following treatment. Critical to understanding morbidity is utilization of patient-reported outcomes (PROs). The current study evaluated PROs of individuals previously diagnosed with a pediatric brain tumor and identified risk factors for less optimal overall health. Participants included 127 youth 10.59±4.81 (M±SD) years old at survey completion and 4.45±3.82 years from diagnosis of a brain tumor (34.6% Pilocytic Astrocytoma, 9.4% Medulloblastoma, 9.4% Ependymoma, 7.9% Craniopharyngioma, 38.6% Other). Outcomes were assessed via Patient-Reported Outcomes Measurement Information System (PROMIS) parent-proxy measures. Overall health was assessed via PROMIS Global Health (i.e., a measure of general, physical, mental, and social health). Univariate and logistic regression analyses examined potential demographic, medical, and psychosocial factors (e.g., age, race, diagnosis, treatment) related to poor global health. Initial descriptive analyses suggested that most youth experienced anxiety symptoms (T-score M±SD=50.71±11.54), depressive symptoms (47.96±10.34), cognitive functioning (46.52±9.10), and fatigue (55.14±10.62) similar to their peers. However, 31.0% of youth experienced impaired global health (T-score<40). After adjusting for other potential covariates, the final model suggested that youth with significant anxiety (OR=6.20, CI=1.56–24.65), youth with significant fatigue (OR=3.96, CI=1.26–12.41), and youth who did not undergo a gross total resection (OR=0.25, CI=0.07–0.96) were at risk for impaired global health. Identifying those at-risk for impaired health is essential to reducing survivor morbidity and optimizing overall quality of life following treatment. Current data suggest potentially modifiable factors that may improve long-term outcomes for survivors of pediatric brain tumors.

QOL-32. THE PROMOTE STUDY: HEALTH-RELATED QUALITY OF LIFE COMMUNICATION NEEDS OF CHILDREN, ADOLESCENTS, AND THEIR FAMILIES ATTENDING OUTPATIENT CONSULTATIONS AFTER TREATMENT FOR A BRAIN TUMOUR

Shelly Stuble¹, Anita Freeman², Christina Liossi³, Anne-Sophie Darlington³, Martha Grootenhuys⁴, Darren Hargrave⁵, Christopher Morris⁶, David Walker¹, Colin Kennedy³, and Kim Bull³; ¹University of Nottingham, Nottingham, United Kingdom, ²St. Mary’s Hospital, London, United Kingdom, ³University of Southampton, Southampton, United Kingdom, ⁴Princess Máxima Centre for Paediatric Oncology, Utrecht, Netherlands, ⁵UCL Great Ormond Street Institute of Child Health, London, United Kingdom, ⁶University of Exeter, Exeter, United Kingdom

BACKGROUND: Childhood brain tumours and their treatment can reduce health-related quality of life (HRQoL) and cause anxiety and depression, withdrawal, and social isolation. Improved communication within outpatient consultations may allow early identification and treatment of these issues. We explored family communication needs in survivors of childhood brain tumours receiving six-monthly follow-up outpatient review within the English NHS. METHODS: Semi-structured interviews were conducted with 18 families whose child aged 8–17 years had finished treat-

ment for a brain tumour within the preceding five years. Thematic analysis used the Framework Method. RESULTS: Adjusting to change and finding a “new normal” was the overarching theme to emerge. HRQoL issues included fatigue, coping with physical changes, challenges at school, isolation, and adjusting to changes in abilities. Survivors described a need for greater knowledge about and more support with changes in cognitive functioning. Parents spoke about the impact on the wider family and their changed role in supporting the child’s HRQoL. Communication barriers included short-term memory loss, shyness, and the need to suppress or regulate emotions evoked by these issues. Communication needs included more information regarding recovery and rehabilitation and/or help managing anxiety or emotional health. CONCLUSION: The above communication needs and barriers should be addressed. Having a digital record to document and monitor this information systematically could improve service planning and provide patients and their families with the resources to reach their full potential and experience a better HRQoL.

QOL-33. THE PROMOTE STUDY: DEVELOPMENT AND TESTING OF KLIK-UK, AN ONLINE PLATFORM, TO ENHANCE OUTPATIENT COMMUNICATION ABOUT HEALTH-RELATED QUALITY OF LIFE (HRQOL) AT THREE UK CHILDREN’S BRAIN TUMOUR TREATMENT CENTRES (CBTCS)

Kim Bull¹, Shelly Stuble², Natalia Kouzoupi³, Anne-Sophie Darlington¹, Martha Grootenhuys⁴, Darren Hargrave⁵, Christina Liossi¹, Christopher Morris⁶, David Walker², and Colin Kennedy¹; ¹University of Southampton, Southampton, United Kingdom, ²University of Nottingham, Nottingham, United Kingdom, ³Great Ormond Street Hospital for Children, London, United Kingdom, ⁴Princess Máxima Centre for Paediatric Oncology, Utrecht, Netherlands, ⁵UCL Great Ormond Street Institute of Child Health, London, United Kingdom, ⁶University of Exeter, Exeter, United Kingdom

BACKGROUND: The HRQoL of survivors of childhood brain tumour is significantly reduced into adulthood but is not systematically assessed. In the UK, referral for appropriate support is often reactive rather than proactive. We developed KLIK, the online Dutch platform, for use to enable the systematic assessment of HRQoL in the UK NHS using patient-reported outcomes measures (PROMs) which could be fed back to clinicians during outpatient review appointments. METHODS: PARTICIPANTS: Children aged 5–17.9 years, receiving outpatient care >6 months for a brain tumour diagnosed within preceding 5 years and their parents and clinicians. SETTING: Three UK CBTCS – UHS, Southampton; GOSH, London; and QMC, Nottingham. PROCEDURE: KLIK-UK was developed throughout the study and barriers and opportunities for its use logged. A. Development phase: relevant PROMs were identified through systematic literature review¹ and families’ views regarding choice of PROMs, communication needs within consultations, and KLIK-UK were obtained by interview. B. Feasibility phase: KLIK-UK was tested in outpatient review appointments followed by interviews with the family and clinician. RESULTS: 57 families and 10 clinicians participated. The PedsQL-Core module was preferred by families. Communication needs and barriers were identified. All clinicians reported that they could see the potential value of using KLIK-UK but views differed as to whether they could use it within their current timetable. Analysis of interviews from the feasibility phase will be reported. CONCLUSION: KLIK-UK is ready for use in the UK but will need to be adapted according to local resources, needs, and preferences. ¹Bull et al. 2019 <https://doi.org/10.1093/nop/npz064>

QOL-34. CAREER FAIR AND RESOURCE EXPO: ADVOCATING FOR THE LONG TERM SUCCESS OF BRAIN TUMOR SURVIVORS

Clay Hoerig^{1,2}, Karlie Allen¹, Kara Noskoff¹, Jamie Frediani¹, Jody Pathare¹, Casey Koerner¹, Veronica DeRosa¹, Nina Madrid¹, Kristin Miller³, Grace Mucci¹, Chenu Abongwa¹, and Ashley Plant^{1,2}; ¹Children’s Hospital Orange County, Orange, CA, USA, ²University of California, Irvine, Irvine, CA, USA, ³Children’s Hospital Orange County, Orange, Ca, USA

Pediatric cancer survivors have increased unemployment and lower educational attainment rates. This is most significant in brain tumor survivors who show five-fold relative odds increase in unemployment over other pediatric cancer survivors. The long-term effects of brain tumor treatment potentiate the difficulty with work and school reintegration seen in the broader Adolescent and Young Adult (AYA) population. To address this, our team designed an annual job fair for AYA Neuro-Oncology survivors. Vendors were invited representing disability advocacy groups, legal services, scholarship organizations, and employers with strong disability services, several who offered on-site interviews. Additionally, brain tumor survivors served as inspirational speakers for the event. Between thirty to forty survivors have attended each event. Pre- and post-surveys, as well as 3- and 6- month follow up was obtained. Universally, the day was engaging and motivating, both for survivors and staff, and stimulated conversation for pursuing career or ac-