Abstracts

Kremer, Kevin & Hansen, Oettingen

Vuurden, Oeffinger, Karim-Kos et al.

Wesseling et al.

Department of Neurosurgery, Aarhus University Hospital, Aarhus, Denmark, and Yasmin Hoving, Department of Neurosurgery, Aarhus University Hospital, Aarhus, Denmark, Bene

Schroeder et al.

Mineharu, Keiko, Hoving, Claire, Howell, Kevin, Oeffinger, Daniel, and Schroeder et al.

BACKGROUND: Pediatric neuro-oncology (PNO) survivors suffer long-term physical and neurocognitive morbidity. Comprehensive care addressing late effects of brain tumors and treatment in these patients is important. Clinical guidelines offer a framework for evaluating late effects, yet lack of extended follow-up is a significant barrier. The electronic health record (EHR) allows novel and impactful opportunities to construct, maintain, and leverage survivorship cohorts for health care delivery and as a platform for research. METHODS: This survivorship cohort includes all PNO patients ≥18 years-old reported to the state-mandated cancer registry by our institution. Data mining of the EHR for exposures, demographic, and clinical data of identified patients with lack of extended follow-up (>1000 days since last visit). Explanatory variables included age, race/ethnicity, and language. Primary outcome included date of last clinic visit. RESULTS: Between January 1, 2013 and December 31, 2018, there were 324 PNO patients reported to our institutional registry with ongoing analysis to identify the specific survivorship cohort. Thirty patients died with an overall mortality of 9.3%. Two-hundred-and-sixteen patients were seen in PNO clinic, of which 18.5% (n=40) did not receive extended follow-up. Patients without extended follow-up averaged an age of 3.3 years older up (p=0.01); however, there was no statistical difference in preferred language (p=0.97) or race/ethnicity (p=0.57). CONCLUSION: Integration of EHR and cancer registry data represents a feasible, timely, and novel approach to construct a PNO survivorship cohort to identify and re-engage patients without extended follow-up. Future applications include analysis of exposures and complications during therapy on late effects outcomes.

EPID-16. INTEGRATION OF EHR AND CANCER REGISTRY DATA TO CONSTRUCT A PEDIATRIC NEURO-ONCOLOGY SURVIVORSHIP COHORT AND IMPROVE LONG-TERM FOLLOW-UP CARE

David Novell, Claire Howell, Kevin Oeffinger, Daniel Landi, and Kristin Schroeder, Duke University Medical Center, Durham, NC, USA

BACKGROUND: Pediatric neuro-oncology (PNO) survivors suffer long-term physical and neurocognitive morbidity. Comprehensive care addressing late effects of brain tumors and treatment in these patients is important. Clinical guidelines offer a framework for evaluating late effects, yet lack of extended follow-up is a significant barrier. The electronic health record (EHR) allows novel and impactful opportunities to construct, maintain, and leverage survivorship cohorts for health care delivery and as a platform for research. METHODS: This survivorship cohort includes all PNO cases ≥18 years-old reported to the state-mandated cancer registry by our institution. Data mining of the EHR for exposures, demographic, and clinical data of identified patients with lack of extended follow-up (>1000 days since last visit). Explanatory variables included age, race/ethnicity, and language. Primary outcome included date of last clinic visit. RESULTS: Between January 1, 2013 and December 31, 2018, there were 324 PNO patients reported to our institutional registry with ongoing analysis to identify the specific survivorship cohort. Thirty patients died with an overall mortality of 9.3%. Two-hundred-and-sixteen patients were seen in PNO clinic, of which 18.5% (n=40) did not receive extended follow-up. Patients without extended follow-up averaged an age of 3.3 years older up (p=0.01); however, there was no statistical difference in preferred language (p=0.97) or race/ethnicity (p=0.57). CONCLUSION: Integration of EHR and cancer registry data represents a feasible, timely, and novel approach to construct a PNO survivorship cohort to identify and re-engage patients without extended follow-up. Future applications include analysis of exposures and complications during therapy on late effects outcomes.

EPID-17. A SINGLE INSTITUTE EXPERIENCE IN THE REGISTRATION STUDY OF PEDIATRIC SOLID TUMOR IN JAPAN CHILDREN’S CANCER GROUP

Keiko Furukawa1, Yohsei Mineharu2, and Yoshiki Arakawa1; 1Kyoto University Hospital Cancer Center, Kyoto City, Kyoto Pref., Japan, 2Department of Neurosurgery, Kyoto University Graduate School of Medicine, Kyoto City, Kyoto Pref., Japan, 3Department of Neurosurgery, Kyoto University Graduate School of Medicine, Kyoto City, Kyoto Pref., Japan, 4Department of Neurosurgery, Kyoto University Graduate School of Medicine, Kyoto City, Kyoto Pref., Japan

A larger scale prospective registration study has been conducted nationwide in Japan since 2011, called as “registration study in pediatric solid tumor”, in Japan Children’s Cancer Group (JCCG). In this study, clinical data and surgical specimen are collected into the National Center for Child Health. Kyoto University Hospital has participated in this study since IRB approval in 2011. We reviewed our registered patients to the registration study and assessed the current status. 40 patients with pediatric brain tumors participated in this study from 2011 to 2020. There were 13 intracranial germ cell tumors, 9 medulloblastomas, 6 gliomas in 4 diffuse midline gliomas, 4 pilocytic astrocytoma, and 4 other types of tumor. The informed consent was obtained from 36 patients by pediatricians and 3 patients by neurosurgeons. Twenty-five surgical specimens were collected for central review. The reasons of no surgical specimens were nonsurgical management in 6 patients and no enough FFPE sample in 5 patients. There were no discrepancy between central review and institutional diagnosis. The status of clinical data entry was complete in 13 patients and incomplete in 9 patients.

These registration data including pathological diagnosis, molecular diagnosis, treatment, clinical information in patients with pediatric brain tumor are very important to realize current status. To conduct this study certainly, the collaboration among pediatrician, neurosurgeon, and supporting staff should be needed in collecting specimens and clinical data.

EPID-18. TRENDS IN INCIDENCE AND SURVIVAL OF MALIGNANT PEDIATRIC CENTRAL NERVOUS SYSTEM TUMORS IN THE NETHERLANDS

Rasoul Hoogendijk, Jasper van der Lugt, Dannis van Vuarden, Efko Hoering, Leoniet Kremer, Pieter Wesseling, and Henrike Kemmsen; 1Prinses Máxima Centrum for Pediatric Oncology, Utrecht, Netherlands, 2Amsterdam University Medical Centers/Emma Children’s Hospital/AMC, Amsterdam, Netherlands, 3Amsterdam University Medical Centers/Umc, Amsterdam, Netherlands, 4Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, Netherlands

BACKGROUND: Variation in survival of pediatric central nervous system (CNS) tumors is large between countries. Within Europe, the Netherlands had one of the worst reported survival rates of malignant CNS (mCNS) tumors during 2000–2007. METHODS: Using the Netherlands Cancer Registry, we evaluated trends in incidence and survival of pediatric mCNS tumors (behavior 1/3, 5th digit in the morphology code) diagnosed between 1990–2017. RESULTS: 8,399 newly-diagnosed patients <18 years were registered between 1990–2017. Incidence of mCNS tumors remained stable (average incidence rate, 21.6 per million person-years). However, an increased incidence of malignant gliomas, NOS was found for a prolonged Annual Percentage Change (EAPC) 11.6% (p<0.001). This appears to relate to a registration shift between 1990–1999 and 2000–2009 as brainstem tumors increased (+25%, n=79) for astrocytomas and other gliomas but decreased (-31%, n=32) for unspecified intra- and extraparenchymal brain tumors. Survival increased from 51% in 1990–1999 to 61% in 2010–2017 (P for trend<0.01). This increase was not constant over time, as 5Y-OS for the period 2000–2009 was 47%. The only significant decrease in survival was found for malignant astrocytomas and other gliomas with a 5Y-OS of 36% in 1990–1999 decreasing to 48% in 2010–2017 (P for trend<0.001). CONCLUSION: Between 1990–2017 incidence of mCNS tumors in the Netherlands remained stable and survival increased. However, a decrease in survival of malignant astrocytomas and other gliomas which was partially explained by the registration shift of brainstem tumors. The impact of this shift on survival for all mCNS tumors is subject to further research.

ETMR-01. TREATMENT OUTCOME OF TWO CASES WITH HIGH-GRADE NEUROEPITHELIAL TUMOR WITH BCOR ALTERATION

Ines Kirsten, Louise Lindholt Hansen, Torben Stamm Mikkelsen, Louise Tram Henriksen, Benedate Farm Udland, Gorm von Oettingen, Soren Cormorn, and Yasmin Raoull; 1Pediatric Department, Aarhus University Hospital, Aarhus, Denmark, 2Aarhus University Hospital, Aarhus, Denmark, 3Department of Neurosurgery, Aarhus University Hospital, Aarhus, Denmark, 4Department of Centre for Particle Therapy, Aarhus, Denmark

INTRODUCTION: High grade neuroepithelial tumor with BCOR exon 13 internal tandem duplication (HGNET-BCOR) is a recently described tumor entity of the central nervous system (CNS) with a distinct methylation profile and characteristic genetic alteration. We report the outcome of two cases after 1st line multimodality therapy. MATERIAL AND METHOD: A 7 year old girl with a ventricular tumour and a 6 year old boy with a tumour in the occipital region with infiltration of the transverse and sigmoid sinuses were both diagnosed based on histology and methylation with HGNET-BCOR. No spinal or liquor dissemination were found at diagnosis in both cases. Treatment consisted of radical resection of the the child the case of the boy with a residual tumour in the vessel could not be removed. Both children were postoperatively treated with radiotherapy (craniospinal 36 Gy and boost to 54 Gy), concomitant Vincristin and adjuvant Cisplatin, Lumostine and Vincristine. RESULTS: The girl developed a local recure at the primary tumour site 18 months after diagnosis. Reoperation showed the same histology. Start of 2nd line chemotherapy with Temozolomid and Irinotecan is being discussed. The boy with sinus infiltration developed seven months after diagnosis multifocal Tumors in the occipital region, lung and bone metastasis. Biopsy of a liver lesion showed HGNET-BCOR. He was treated with Temozolomid, Irinotecan and died nine months after diagnosis. CONCLUSION: We report two cases with failure after 1st line treatment for HGNET-BCOR. To our knowledge HGNET-BCOR with development of hematological disease dissemination is a rare finding.