significant challenges with performing modern diagnostic assessments, applying multimodal treatment and establishing interdisciplinary cooperation. Outcomes across Europe differ significantly with varying 5year survival reports of 42–79%. This SIOP-Europe PaedCan survey assessed the structures and facilities for individual states and highlight areas for cooperation and support. DESIGN: An online questionnaire was sent to SIOP-Europe Brain Tumour Group members. This had 55 questions assessing pathology, staging, surgery, radiotherapy and paediatric oncology infrastructure. For analysis of the data we divided countries into lower and higher economic status according to GDP (World Bank 2019) with a cut off of $30,100. RESULTS: There were 388 respondents from 44 countries in 181 different institutions. In the lower GDP group we noted decreased access to biological characterisation of tumours and interdisciplinary tumour boards. In this group of nations, patients were less likely to have treatment by a paediatric specialist neurosurgeon, paediatric neuro-oncologist, neuroradiologist, and paediatric radiation oncologist. There was also less availability to perform early MRI (ventilated) and less access to proton beam therapy. This study supports the aim of the ERN to produce a roadmap document with specific standards and publish guidelines for all relevant diagnostic and therapeutic components of care. The ERN also aims to identify a network of institutions to provide patient advice and training to equalise treatment and outcomes for all children across Europe.

SWK-08. DELAYED DIAGNOSIS OF CENTRAL NERVOUS SYSTEM (CNS) TUMORS IN CHILDREN: PERSPECTIVE FROM THE FRONTLINE

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Delayed diagnosis of CNS tumors in children is well documented, partially due to challenges in recognizing rare diagnoses. Our objective was to describe Canadian family physicians' attitudes and confidence in diagnosing and managing pediatric CNS tumors. A standardized questionnaire was administered at a Canadian national family physicians' conference. Items were based on observations from our institutional study of prediagnostic symptomatic interval in pediatric CNS tumors. 449 surveys were completed. 302/443 (68%) physicians practice in cities. 153/447 (34%) report encountering parents that inquire about their children having brain tumors. 261/449 (58%) have not managed a pediatric brain tumor. 153/447 (34%) report they are not confident, 255/447 (57%) somewhat confident and 39/447 (9%) confident in managing a suspected brain tumor in a stable child. 259/447 (58%) would refer directly to a hospital/specialist. The reported median time for suspicion of a brain tumor was 8–14 days for children with vomiting and/or headache and 1 day for children with seizure and/or ataxia. 410/447 (97%) report not knowing any guidelines to help with management. 235/447 (53%) suggested barriers they experience to include 52/235 (22%) wait times for imaging/specialists, 37/235 (16%) geographical location of the child, 27/235 (12%) knowledge, 25/235 (11%) access to imaging/specialist, and 15/235 (6%) patient-related factors or system barriers, and 8/235 (3%) specialist attitudes. 68/235 (29%) identified no barriers in their practice. This study provides insight into family physicians' perceived challenges and barriers in diagnosing and managing new suspected pediatric CNS tumors. Educational effort and overcoming systemic perceived barriers may increase physicians' confidence.

SWK-09. SELF-CARE OUTCOMES AND INTERVENTIONS FOR CHILDREN WHO HAVE HAD A BRAIN TUMOUR: EVIDENCE AND HYPOTHESES. WHAT SHOULD SELF-CARE INTERVENTIONS FOR CHILDREN WITH PAST OR PRESENT BRAIN TUMOUR BE?

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OBJECTIVE: To determine the evidence with regards to self-care outcomes and interventions for children who have been treated for a brain tumour and identify when best to intervene. METHODS: A scoping review of the literature with regards to self-care interventions, outcomes and mechanisms was undertaken. The information from these themes were populated onto a logic model alongside the clinical expertise of the team. The logic model was used to develop hypotheses to inform subsequent research; and identified areas for further patient and public involvement. RESULTS: Of 27 papers found, 13 were deemed relevant. The literature suggested the diagnosis of a brain tumour can have a long-term negative impact on self-care outcomes whilst evidence with regards to interventions to promote self-care is scarce. The child's physical and cognitive functions were identified as hypothesised factors influencing self-care, while health related quality of life and participation in other life domains were secondary consequences of self-care. The team expertise was further used to hypothesise that parent factors (emotions, identity, actions), the child's emotional functions and personal factors as well as peer relationships and norms may influence children's self-care. These factors were not covered in the existing literature. CONCLUSIONS: Subsequent research will investigate the hypotheses developed to further specify factors that self-care interventions for children and young people with a brain tumour should target. This will involve specifying when, how and to whom interventions should be targeted.

SWK-10. TELEHEALTH IN OUTPATIENT PEDIATRIC NEURO-ONCOLOGY CARE

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BACKGROUND: Telehealth is an emerging modality that can include patient evaluation, review of test results, and clinical decision-making. Access to care and quality of life are challenges for patients with pediatric brain tumors and their families. Herein we describe the introduction of video visits within our outpatient services led by nurse practitioners and nurse coordinators. METHODS: The pediatric neuro-oncology program at University of California, San Francisco - Benioff Children's Hospital (UCSF) established a robust telehealth practice to improve access to care for children and young adults with brain and spine tumors. Our nursing team identifies appropriate time points to offer video visits in lieu of in-person visits. Families are guided to connect through secure video conferencing. Data was collected retrospectively through electronic medical record schedules, billing records, and UCSF patient satisfaction surveys. RESULTS: Since 2015 we have utilized telehealth for over 400 encounters. The service was limited to patients located in California. Introduction of telehealth resulted in savings of 2300 hours of travel by car, over $22,000 in gas, and over 127,000 miles traveled. Surveys indicate patient satisfaction is equal to or better than in-person experiences. Anecdotally, this service allows for face-to-face contact with patients who have significant barriers to travel. Challenges have included technology platforms, native language, provider and patient acceptance, and billing. CONCLUSION: Overall, telehealth is feasible as a tool to deliver outpatient care in pediatric neuro-oncology. Implementation of video visits in clinical practice increases access to neuro-oncologic care and improves quality of life for patients and families.

SWK-11. ASSESSMENT OF THE INDIRECT COSTS ASSOCIATED WITH PROTON THERAPY TREATMENT FOR ALBERTA PATIENTS REFERRED OUT OF COUNTRY

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BACKGROUND: Proton therapy for benign and malignant tumors has dosimetric and clinical advantages over photon therapy. Patients in Alberta, Canada are referred to the United States for proton treatment. The Alberta Heath Care Insurance Plan (AHCIP) pays for the proton treatment and the cost of flights to and from the United States (direct costs). This study aimed to determine the out-of-pocket expenses incurred by patients or their families (indirect costs). METHODS: Invitation letters linked to an electronic survey were mailed to patients treated with protons between 2008 and 2018. Expenses for flights for other family members, accommodations, transportation, food, passports, insurance, and opportunity costs including lost wages and productivity were measured. RESULTS: Fifty-nine invitation letters were mailed. Seventeen surveys were completed (28.8% response rate). One paper survey was mailed at participant request. Nine respondents were from parent/guardian, 8 from patients. All patients were accompanied to the US by a family member/friend. Considerable variability in costs and reimbursements were reported. Many of the accompanying family/friends had to miss work; only 3 patients themselves reported missed work. Time away from work varied, and varied as to whether it was paid or unpaid time off. CONCLUSIONS: Respondents incurred indirect monetary and opportunity costs which were not covered by AHCIP when traveling out of country for proton therapy. Prospective studies could help provide current data minimizing recall bias. These data may be helpful for administrators in assessing the societal cost of out-of-country referral of patients for proton therapy.

SWK-12. PEDIATRIC NEURO-ONCOLOGY PARENT PERSPECTIVE ON ASPECTS OF SOCIAL AND EMOTIONAL SUPPORT FOR ONLINE APPLICATION

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