

SOCIAL WORK/PATIENT SUPPORT/PALLIATIVE CARE

SWK-02. WEAVING COMFORT AND SUPPORT FOR CHILDREN WITH BRAIN TUMORS AND THEIR FAMILIES IN AN OUTPATIENT CLINIC

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Parents of children diagnosed with brain tumors report high levels of stress at diagnosis and feelings of “being lost” on transition to outpatient follow-up care (Jackson AC, *et al*, 2007). Ssori is a Japanese form of free-style weaving that encourages people facing life-limiting challenges to discover inner strengths. We report our experience with Saori weaving with brain tumor patients and their families in a pediatric oncology outpatient clinic at a major university medical center. During 2019, we offered weaving sessions twice a week. We had a total of 151 encounters with hematology/oncology patients (age 5–18 years), siblings, or parents. Among these patients there were 20 with primary brain tumor diagnoses. Weaving was offered in the art therapy area of the clinic. After creating a fabric, the weavers had the opportunity to have their work sewn into functional objects, such as pillows, bags, purses, or healing pouches filled with beans that can be heated or cooled for comfort. Brain tumor patients readily engaged in weaving, despite various degrees of neurologic disability including hemiparesis or low vision. In the words of an 8 y/o weaver. “This is so cool. Daddy, can we always come when the weavers are here, so I can weave?” And from a mother: “This is great. She’s focused and busy!” Case studies, including a presentation of Legacy work, will be reported. In conclusion, Saori weaving can be an impactful intervention for childhood brain tumor patients and their families in an outpatient clinic setting.

SWK-03. CAREGIVER EXPERIENCES FOR PEDIATRIC BRAIN TUMOR PATIENTS AND THEIR FAMILIES AT A DEDICATED MEDICAL SPECIALTY CAMP

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BACKGROUND: Medical specialty camps have provided children with unique psychosocial experiences; however, dedicated pediatric brain tumor camps are rare in the United States, except in limited locations. This study aimed to glean caregiver perceptions from a dedicated family brain tumor camp, and to learn about the family experience with navigating a neuro-oncology diagnosis. **DESIGN:** Flying Horse Farms is a non-profit organization located in Mt. Gilead, Ohio and a member of the SeriousFun Children’s Network, a global community of camps and programs serving children with serious illnesses and their families, at no cost. The institutional review board at Ohio University approved this project at Flying Horse Farms in September 2017. Consent from caregivers was obtained prior to participation in the study, which provided the opportunity to complete three separate phases: a pre-camp survey, attend a semi-structured interview during the weekend, and complete a post-camp survey. **RESULTS:** 11 families were present for the weekend, and 10 families consented to participate in all three phases. For 6 families, this was their first experience at Flying Horse Farms. For 9 of the 10 families, the camp met their expectations. Additionally, 9 out of 10 families reported they would be interested in attending a diagnosis specific camp again in the future. **CONCLUSIONS:** This work demonstrates the feasibility of conducting research at a medical specialty camp without restricting the camp experience. Better understanding of the attendee’s attitudes toward camp may enhance the experience and the neuro-oncology journey in the future.

SWK-04. A MOBILE AUGMENTED REALITY APP FOR SURGICAL PREPARATION FOR CHILDREN WITH BRAIN TUMORS

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BACKGROUND: Children with brain tumors experience significant anxiety secondary to diagnosis and interventions such as surgical management. Preoperative anxiety is known to adversely affect operative outcomes and overall quality of life. Programs that utilize “child-friendly” approaches have been shown to ease anxiety, decrease analgesic requirements, shorten hospital stay, and contribute toward better outcomes. Implementation of these programs is limited due to time, cost, and staffing constraints as well as sociodemographic factors (i.e., language barriers). Therefore, an effective and cost-efficient method could be advantageous. We sought to develop a

universally available APP that can assist with these goals and address the current barriers. **METHODS:** In conjunction with a philanthropic resource (Brain Tumor Foundation, New York, NY, USA) a developer was tasked with creating an App for children with brain tumors. The developer integrated published clinical research, multi-specialty input, and patient and family testimonials for possible integration into the tool. **RESULTS:** A mobile App was developed that is modifiable for patient-specific features (age, language, and ethnicity). Initial evaluations of the prototype by healthcare providers, appropriately aged children, and their parents have demonstrated positive engagement, appeal, and ease of use. **CONCLUSIONS:** The mobile App provides a rapid, affordable, and modifiable platform for assisting children with brain tumors cope with their diagnosis and intervention options. Validation with measurable outcomes is planned. The App is currently being evaluated for purposes of psycho-social clinical research tool.

SWK-05. EDUCATIONAL APPROACH TO GRIEF MANAGEMENT

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Pediatric neuro-oncology has a high mortality rate compared to other childhood cancers. This project sought to bring Awareness to the Grief and Trauma that families undergo during treatment through end of life. It also sought to create a pool of parent partners to support families receiving palliative care and to mend the healthcare relationship that is severed when a child passes away. The educational series included Grief Workshops for Bereaved Parents using the ATTEND model, a mindfulness-based bereavement model and seminars with traumatic grief experts for providers. This provided a better understanding on how healthcare workers are influential in the “death story” of a child and how this can dictate the family’s life-long grief journey. Grief workshops consisted of 2 English and 1 Spanish speaking cohort each with 10–12 bereaved parents. The curriculum provided psychoeducation with the goal of creating a safe space to validate, clarify, and understand the events that happened in their child’s life; support for the parent as they explore emotional awareness; relief of emotional tension; support as the parent expresses their perspective of their new world to others that are in their life; and support as the parent finds meaning in their child’s life and untimely death. At the end of each group surveys showed that parents found that the group provided a safe community, a place to say their child’s name, a place to share their story, and a need to advocate for future oncology parents who undergo this journey.

SWK-06. ANSWERING 900 VOICES: A NATIONAL NONPROFIT ORGANIZATION RESPONDS TO A NATIONWIDE COMMUNITY HEALTH NEEDS ASSESSMENT THAT ELUCIDATED KEY CHALLENGES FACED BY PEDIATRIC BRAIN TUMOR FAMILIES

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The five-year relative survival rate for childhood primary brain and other central nervous system tumors is nearly 75 percent (Central Brain Tumor Registry of the United States, 2017). Nevertheless, childhood brain tumor survivors often suffer from lifelong side effects caused by their illness or treatments such as surgery, radiation and chemotherapy. To define the nature and extent of problems survivors and their families face, the Pediatric Brain Tumor Foundation (PBTf), the world’s largest nonprofit solely dedicated to children and teens with brain tumors, conducted a 2017 national community health needs assessment in collaboration with the Sol Price Center for Social Innovation at the University of Southern California. The assessment found that pediatric brain tumor patients and their families face key challenges in four general areas: 1) interpersonal and emotional support, 2) logistical and financial support, 3) information and medical education gathering, and 4) educational and vocational anxieties. In 2020, the PBTf’s response to the 900 assessment participants who represent the thousands living with the effects of this disease includes the launch of a national Peer to Peer Mentoring program to meet the ongoing challenges families face; the disbursement of emergency financial assistance to hundreds of families in the throes of treatment; and the distribution of a resource notebook for newly diagnosed families and a comprehensive guidebook for survivors and their families. The results of the needs assessment suggest additional clear, actionable areas for impact not only by the PBTf but by medical professionals, other nonprofit organizations and governmental agencies.

SWK-07. A MULTINATIONAL SURVEY OF PAEDIATRIC NEURO-ONCOLOGY SERVICES: A EUROPEAN RESEARCH NETWORK (ERN) PAEDCAN PROJECT

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BACKGROUND: Brain tumours are clinically and biologically highly diverse and account for 25% of paediatric neoplasms. They carry the highest mortality and morbidity of tumour groups. Their management presents

significant challenges with performing modern diagnostic assessments, applying multimodal treatment and establishing interdisciplinary cooperation. Outcomes across Europe differ significantly with varying 5-year 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 Health Care Insurance Plan (AHICIP) 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 AHICIP 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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