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SYMPTOM MANAGEMENT/QUALITY OF LIFE

SM-001. HOPEFULNESS IN GLIOMA PATIENTS

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BACKGROUND: Patients diagnosed with a life threatening illness generally feel they have limited options in improving quality of life during this unexpected period in their lives. Learning to cope with such a debilitating disease can be difficult.. Being hopeful is often considered an important factor in personal adjustments but is plagued by illness-related uncertainty. We studied the relationship of Hope to disease status and symptom burden in primary brain tumor (PBT). METHODS: A cross-sectional sample of adult PBT patients completed the Hearth Hope Index (HHI). Data collection: patient completed demographic form, an investigator completed clinician checklist, the HHI, a 12-item assessment of hopefulness with 3 subscales (temporality and future, positive readiness/expectancy and interconnectedness). Descriptive statistics were used to describe the sample and HHI scores. Correlations between clinical characteristics, symptom burden and interference were explored. RESULTS: 71 patients (mean age 44.77(range 22–78) participated in the study. Participants were primarily white (89.4%), male (56.3%) and married (74.6%) with a diagnoses of malignant glioma (glioblastoma, 38%) and no tumor recurrence(53.5%). Average HHI score was 41.09(range 13-48), subscales 13.69(range 4-16), with internal consistency of >0.70. Patients on active treatment had similar average hope scores but a wider range(range 13-48 vs. range 34-48) of scores than those in follow-up. Patients with recurrent tumors had lower total and subscale HHI scores. HHI Total score($r = -0.31$) and HHI Temporality($r = -0.41$) were negatively correlated with MDASI-BT Symptom Severity and HHI total($r = -0.39$), temporality($r = -0.49$) and interconnectedness ($r = -0.29$) subscale scores were negatively correlated with MDASI-BT interference subscales. CONCLUSIONS: As expected, patients not on active treatment and without tumor recurrence reported higher levels of hope than their counterparts. Furthermore, the results indicate high symptom burden and interference is associated with lower hope scores. Future studies are needed to focus on this relationship to implement ways to improve one's coping skills in dealing with diagnoses and treatment changes.

SM-002. CAREGIVERS OF LONG-TERM SURVIVORS OF MALIGNANT BRAIN TUMORS: A DESCRIPTIVE ANALYSIS

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The purpose of this secondary analysis was to analyze the experience of caregivers of long-term survivors (diagnosed 3 years or longer) with malignant brain tumor. Recent studies suggest that caregivers are physically and emotionally challenged by the caregiving process. Survivors ($N = 35$), recruited from five sites across the United States, completed the FACT-Br, MDASI, CES-D, and Brief Fatigue Inventory, and the Cognistat was administered as a brief measure of cognitive function. Caregivers ($N = 35$) completed a demographic survey, CES-D, and BFI. Mean time since survivor diagnosis was 6.6 years (SD 3.2; range 3–15 years); only 3 survivors were receiving active treatment at the time of the study. Caregivers were middle aged (mean 52 years), female (63%), and all but one caregiver was a spouse of the survivor. Job change due to survivor needs was reported by 40% of caregivers, with 86% of caregivers employed (77% full-time) as compared to 34% of survivors being employed (23% full-time). The mean for caregiver CES-D scores was 17.8, indicating mild to moderate depression; 4 (12%) caregivers had scores suggesting severe depression. Caregivers were slightly less depressed and fatigued than survivors. Caregiver depression and fatigue were correlated with survivor Cognistat scores but not MDASI, suggesting that cognitive impairment may contribute to caregiver fatigue and depression. Findings suggest that nurses need to assess and manage symptoms for caregivers as well as survivors, and should screen for depressive symptoms and fatigue. Specific caregiver support in managing cognitive impairment in the survivor may reduce caregiver depression and fatigue. Given the combination of employment and caregiving responsibilities, caregivers may also benefit from support in their workplace, including flexible work hours and access to employee emotional and financial support programs.

SM-003. COMPARATIVE IMPACT OF TUMOR AND TREATMENT ON PATIENT REPORTED OUTCOMES (PROS) IN PATIENTS WITH GLIOBLASTOMA (GBM) ENROLLED IN RTOG 0825

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BACKGROUND: RTOG 0825 tested if adding bevacizumab to standard chemoradiation improves survival(OS) or progression free survival(PFS) in newly diagnosed GBM. While OS was equivalent, PFS was longer with bevacizumab than with placebo. Patients completed quality of life and symptom PROs to evaluate clinical benefit. METHODS: The M.D. Anderson Symptom Inventory-Brain Tumor Module (MDASI-BT) and the EORTC Quality of life Questionnaire/Brain Tumor Module (EORTC QLQ-C30/BN20), were completed by pts at baseline and longitudinally (wk 6,10,22,34, and 46) while on study. Between treatment arm differences were compared longitudinally (0–46 weeks) using general linear modeling covarying for RPA and MGMT status. A p-value of 0.05 was considered significant when comparing the two treatment groups for all analysis. RESULTS: 542 pts consented to participate on this trial component, and 507 randomized pts participated, with completion of forms by 93–95% at baseline, 71–75% at wk10, 56–67% at wk22, 53–54% at wk34, and 46–56% at wk 46. The evaluation of PRO reports over time revealed a statistically significant time by treatment arm interaction effect demonstrating greater deterioration in the bevacizumab arm compared to placebo on the MDASI-BT Overall Symptom Burden ($p = 0.02$), Interference ($p < 0.001$), Activity Interference (($p = .004$), Mood-Related Interference ($p < 0.001$), Cognitive ($p = 0.02$), Treatment ($p = 0.04$) and Generalized/Disease ($p = 0.01$) factors, and EORTQLQ30/BCM20QLQ Cognitive Functioning ($p = 0.01$), Motor Dysfunction ($p = 0.01$), and Communication Deficit ($p = 0.003$) scales. CONCLUSIONS: Based on these PRO results indicating worsening of symptoms and neurocognitive outcomes that also showed worse outcomes in the Bevacizumab arm, the clinical benefit of increased PFS time associated with first-line use of Bevacizumab is in questions. Support: U10 CA21661, U10 CA37422 and Genentech, Inc.

SM-004. HOSPITALIZATION BURDEN AND SURVIVAL AMONG ELDERLY PATIENTS WITH GLIOBLASTOMA

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BACKGROUND: Half of all glioblastoma (GBM) patients are at least 65 years old. The frequency and duration of hospitalization from disease- and treatment-related morbidity in this population are unknown, but are highly relevant to quality of life in the setting of an incurable disease. METHODS: We performed a retrospective cohort study among patients aged 65 years and older with histologically-proven GBM diagnosed before death from 1999–2007 using SEER-Medicare linked data. Patients continuously enrolled in Medicare fee-for-service parts A and B were eligible. Diagnoses and procedures were identified using administrative claims data. Overall survival (OS) was estimated using the Kaplan-Meier method, and multinomial logistic regression was performed to identify predictors of high hospitalization burden. RESULTS: Among the 5,029 patients in the study cohort, 52% were ages 65–74, and 36% were diagnosed from 2005–2007. Twenty-six percent of patients underwent gross total resection, 72% received adjuvant radiotherapy, and 18% received adjuvant temozolomide. Median survival was

4.9 months. Among all patients, 21% were hospitalized for at least 30 cumulative days between diagnosis and death. Twenty-two percent of all patients spent at least 25% of their remaining lives as an inpatient. Higher comorbidity score (adjusted hazard ratio [AHR], 1.71; 95% CI, 1.41-2.06) and black race (AHR, 1.51; 95% CI, 1.08-2.12) were independently associated with a higher proportion of remaining life spent hospitalized (more than 25%), whereas receipt of radiation (AHR, 0.53; 95% CI, 0.45-0.62) and temozolomide (AHR, 0.33; 95% CI, 0.24-0.44) were independently associated with a lower proportion of life spent hospitalized. CONCLUSIONS: These data highlight the burden of hospitalization faced by a large proportion of older GBM patients. In the setting of a short survival times, strategies to reduce the amount of time these patients spend hospitalized are urgently needed, to help maintain quality of life at the end of life.

SM-005. THE EFFECT OF MODAFINIL ON FATIGUE, COGNITIVE FUNCTIONING AND MOOD IN PRIMARY BRAIN TUMOR PATIENTS: A MULTI-CENTER RCT

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INTRODUCTION: Fatigue, cognitive deficits, and depression are frequently reported, but often undertreated symptoms that can profoundly affect daily life in patients with primary brain tumors (PBTs). To evaluate the effects of the psychostimulant modafinil on fatigue, depression, health-related quality of life (HRQOL) and cognitive functioning in PBT patients, we performed a multicenter, double-blind placebo-controlled crossover trial. METHODS: Patients randomly received either 6 weeks of treatment with modafinil (up to 400mg/day) or 6 weeks with placebo. After a one week washout period, the opposite treatment was provided. Assessments took place at baseline, and immediately after the first and second condition. Patients completed self-reported questionnaires on fatigue (CIS), depression (CES-D), HRQOL (SF-36), and self-perceived cognitive functioning (MOS). They also underwent comprehensive neurocognitive testing. RESULTS: In total, 37 patients participated. Relative to baseline, patients reported lower fatigue severity (CIS) and better motivation (CIS) both in the modafinil ($p = 0.010$ and $p = 0.021$, respectively) and placebo condition ($p < 0.001$ and $p = 0.027$, respectively). The same held for physical health (SF-36 PCS score; $p = 0.001$ and $p = 0.008$, respectively), working memory ($p = 0.040$ and $p = 0.043$, respectively) and information processing capacity ($p = 0.036$ and $p = 0.040$, respectively). No improvement in depressive symptoms was found in either condition. CONCLUSIONS: Modafinil did not exceed the effects of placebo with respect to symptom management. Patient accrual was slow and relatively many patients dropped out during the trial, mostly due to experienced side-effects. Other, preferably non-pharmacological intervention studies should be considered to improve symptom management of PBT patients.

SM-006. GREATER LEVELS OF DEPRESSION AND ANXIETY SYMPTOMS ARE ASSOCIATED WITH POOR HEALTH RELATED QUALITY OF LIFE IN ADULT BRAIN TUMOR PATIENTS

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INTRODUCTION: Psychological distress symptoms, including depression and anxiety, are common complications of patients with brain tumors. We evaluated the association of depression and anxiety symptoms with health related quality of life (HRQoL) in neurosurgical brain tumor patients. METHODS: Two-hundred and sixteen (mean age 55.9 ± 14.6 years; 69% women and 31% men) consecutive adult brain tumor patients admitted for surgery were evaluated for HRQoL (SF-36 scale); symptoms of depression and anxiety (Hospital Anxiety and Depression scale); socio-demographic characteristics (education and marital status), clinical characteristics (histological diagnosis of brain tumor and brain tumor treatment history), history of psychiatric disorders, cognitive status (Mini Mental State Examination) and functional status (Barthel Index). RESULTS: The majority of patients were diagnoses with meningiomas (39%), followed by high grade gliomas (18%), pituitary adenomas (12%), and other types of brain tumors (31%). In univariable regression analyses symptoms of depression and anxiety predicted lower levels of all aspects of HRQoL. In multivariable analyses adjusting for socio-demographic characteristics, clinical characteristics, history of psychiatric disorders, cognitive status and functional status, greater depressive and anxiety symptom severity remained independently associated with reduced physical functioning (betas = -0.35 and -0.28, respectively; p-values <0.001), role limitations due to physical problems (betas = -0.17 and -0.28, respectively; p-values ≤ 0.001), role limitations due to emotional problems (betas = -0.22 and -0.31, respectively; p-values ≤ 0.001), energy/fatigue (betas = -0.59 and -0.41, respectively; p-values ≤ 0.001), emotional well-being (betas = -0.63 and -0.46, respectively; p-values ≤ 0.001), social functioning (betas = -0.26 and -0.23, respectively; p-values ≤ 0.001), pain (betas = -0.18 and -0.27, respectively; p-values ≤ 0.001), and general health (betas = -0.52 and -0.52, respectively; p-values ≤ 0.001). CONCLUSIONS: In brain tumor patients, greater symptoms of depression and anxiety are independently associated with poor HRQoL. Symptoms of psychological distress should be systematically addressed and managed in brain tumor patients.

SM-007. PERSONAL HEALTH RECORDS, SYMPTOMS, UNCERTAINTY AND MOOD IN BRAIN TUMOR PATIENTS

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INTRODUCTION: Patient benefits of electronic medical record (EMR) access through fully integrated personal health records (PHR) may be substantial and foremost include enhanced information flow between patient and practitioner. An emergent technology, the actualized benefits to complex patient groups remain largely unknown. MyMDAnderson provides web-based access to M.D. Anderson Cancer Center's EMR, including clinic notes and MRI, pathology and surgical reports. Using patient-sensitive indices, this study sought to characterize PHR use and outcomes in glioma patients. METHODS: Cross-sectional, patient-reported survey and PHR-derived user data from 186 patients were analyzed using descriptive and inferential statistics. Logistic regression assessed disparities between users and non-users. Dependence of PHR access on 3 treatment stages (newly diagnosed, active treatment, or post-treatment) was tested through analysis of variance. Path analysis evaluated relationships between PHR access and disease-related uncertainty, symptom experience, and mood. RESULTS: Patients had a mean age 44.2 years (range 19 - 80), 77% with a high-grade tumor. 60% had logged into MyMDAnderson at least once (range 0 – 126) in the past 6 months. Strongest predictors of PHR access included > college-level education, high KPS, higher income, and Texas residency. Patients undergoing treatment were more active PHR users. High PHR use was associated with lower disease-related uncertainty and lower symptom severity. In the final model, mood (e.g., anxiety) was not directly related to PHR use, but mediated an association between symptom experience and uncertainty. CONCLUSION: While many reports presume better disease and symptom comprehension for patients with access to their EMR, this study is the first to establish the association between low symptom severity, low disease-related uncertainty and PHR use in glioma patients. Early examination with patient-sensitive, universal indices provides an important basis for critical evaluation and continuing discussion to better structure this benefit for neuro-oncology patients and allow cross-comparison to other patient groups.

SM-008. DESIRES REGARDING CHILDBEARING IN WOMEN WITH GLIOMAS

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OBJECTIVE: Over the last decade there is increased awareness of the importance of counseling about reproductive health issues with patients diagnosed with cancer. However, there is no data on understanding the desires in women that are diagnosed with a terminal cancer. This study sought to examine the reproductive desires of women diagnosed with gliomas. MATERIALS AND METHODS: We have recruited 100 women between the ages of 22-45 with grade II-IV primary brain malignancies from the UCSF Neuro-Oncology practice. To date, 70 women have completed a cross-sectional survey which includes questions about demographic information, past ob/gyn history, cancer type and treatment, and reproductive desires (scale most important:1; least important:6). RESULTS: The median age was 35 at the time of diagnosis. 51% had grade II disease, 29% with grade III and 16% with grade IV disease. 93% had been treated with surgery, 73% with chemotherapy and 53% with radiation. The majority of patients were nulliparous (67%); 71% of patients were either interested in or considering having a child prior to the diagnosis of cancer and 76% were interested in future fertility after treatment. Patients' priorities for having a child were less important than their overall health (mean 3.7 vs. 2.7) before treatment; however, the desire to have a child remained similar both before and after treatment (3.7 vs 4.1). Even patients with high-grade disease (90%) and patients who already had children (67%) had a significant interest in future childbearing. Approximately 53% felt their reproductive concerns were addressed. Interestingly, 43% were unaware that treatment might affect their fertility. CONCLUSIONS: A diagnosis of brain cancer does not change a woman's desire to have children. These data support that reproductive health counseling should be included as part of routine care to optimize the treatment process for these patients.

SM-010. SECONDARY PRIMARY HEADACHE SYNDROMES IN PATIENTS WITH GLIOMA

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OBJECTIVE: To describe the author's experience with managing primary headache syndromes in patient with glioma. BACKGROUND: Headache is a common presentation of glioma, characteristically due to raised intracranial pressure (ICP) and is usually not confused with primary headache syndromes. However, we have observed glioma patients, with both low grade and high grade tumours who appear to have migraine-like headaches that can be a difficult management issue, leading to misuse of corticosteroids and misplaced concerns about tumour progression. DESIGN/METHODS: This is a retrospective case series of patients seen over an 18 year period detailing clinical features and management approaches. RESULTS: A number of patterns were seen in this group of patients. Pattern 1: Typical migraine headache leading to diagnosis of 'asymptomatic' low grade glioma (LGG); Pattern 2: Patient with known migraine whose pattern changes prior to diagnosis of tumour; Pattern 3: Migraine like headaches occurring following radiotherapy leading to inappropriate steroid use; Pattern 4: intractable Chronic Daily headache syndrome. Some patients responded well to standard therapies for chronic headaches (pizotifen, Amitriptyline, Beta-blocker) while others were particularly resistant to headache therapies. CONCLUSIONS: This topic is pertinent for both for neurologists and oncologists treating patients with primary brain tumours, as it may be confused with tumour progression, can be readily treated in most patients, but may also dominate the clinical picture in a small percentage of patients.

SM-011. PROGNOSTIC AWARENESS (PA) AND COMMUNICATION OF PROGNOSTIC INFORMATION IN MALIGNANT GLIOMA (MG): A SYSTEMATIC REVIEW

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BACKGROUND: The study of PA (awareness of disease incurability) and patient-physician communication regarding prognosis is a growing area of research and clinical interest in advanced cancer. Full PA and effective communication of prognostic information have been associated with improved quality of life and positive psychosocial outcomes for cancer patients and caregivers. Little is known about PA among patients with malignant glioma (MG). This systematic review synthesized the literature on PA in MG, with an emphasis on patients' understanding of prognosis and preferences regarding communication of prognostic information. METHODS: A PRISMA systematic literature review was conducted of 5 databases (Cochrane, Embase, PsycINFO, Pubmed, and WOS) with search terms related to brain neoplasms, prognosis, awareness, and patient-physician communication. RESULTS: Of the 7219 studies retrieved, 14 studies met inclusion criteria and were included in the systematic review. 2 are from the United States, 2 are from Australia, and the remainder are from Europe. Eleven were prospective or retrospective studies and three were review articles or practice guidelines based on authors' experience. Methods for measuring PA and communication preferences were qualitative and heterogeneous. The findings regarding PA were conflicting, with full PA found in as few as 25% of patients in one study and 100% in another. Studies of communication preferences did not demonstrate consistent findings, although they suggest dissatisfaction with communication regarding prognostic information among MG patients and their caregivers. While many patients prefer detailed prognostic information, some may prefer limited information as a mechanism to preserve hope. CONCLUSION: There is scarce and conflicting evidence regarding PA and communication preferences among patients with MG. Prospective studies using standardized assessments are needed to measure PA and assess preferences for communication of prognostic information in MG.

SM-012. THE DEVELOPMENT OF A PATIENT AND FAMILY QUALITY OF LIFE MONITOR

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A second experience driven initiative, following the initiative to make Dr. Karin Gehring and Prof. Margriet Sitskoorns cognitive rehabilitation available to patients with primary brain tumors via a web-based application, is the development of a patient and family quality of life monitor. Brain tumor patients and their family members endure a large number of effects in quality of life. From fatigue, cognitive problems, personality changes, depression, sleep problems to headaches and function loss for patients to overload problems for caregivers, both partners and children, with severe and potentially long term consequences. Monitoring is currently limited to patient doctor contact moments, MRI's and other imaging techniques giving limited insight in actual day to day problems and solutions. In co-operation with neuro oncologists and caregiver organisations this patient family initiative is oriented towards developing an easy to use quality of life monitoring tool which gives real time and long term insight in patient priorities and quality of life and health effects of disease, hospital treatments, patient initiatives and lifestyle on both patient and family. Goal is to enable better diagnosis and treatment decision making, expected to enhance quality of life at less costs for both patient and family. This increased visibility aims to result in (leads for) further innovation in and availability of quality of life interventions such as the cognitive rehabilition. The amount of data per patient, frequent and over a long period of time also aims to facilitate larger scale research at a lower cost. More attention for health effects and preventive measures for caregivers is expected to profit both family and patient.

SM-013. NITROSOUREA BASED CHEMOTHERAPY AND RADIOTHERAPY FOR GRADE 2 AND 3 GLIOMAS DO NOT AFFECT FERTILITY

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BACKGROUND: Pregnancy and childbirth after chemotherapy and radiotherapy is generally thought to be difficult due to toxicity to reproductive function. There have been some reports about chemotherapy and fertility in patients with breast or ovarian cancers, it is largely unknown whether chemotherapy and radiotherapy for glioma affect fertility. Grade 2 and 3 gliomas tend to arise in younger generation and many patients wish to give birth after the treatment. We retrospectively analyzed whether patients with glioma who underwent surgical resection followed by chemotherapy and/or radiotherapy were capable of pregnancy and childbirth. METHOD: We analyzed 30 women between 16 and 45 years-old with glioma (13 grade 2, 17 grade 3) who had not experienced giving any birth, and underwent chemotherapy and/or radiotherapy after surgical resection between 2000 and 2012. Twenty-one patients were treated with both radiotherapy and chemotherapy (nimustine hydrochloride (ACNU), with/without vincristine and procarbazine). Eight patients underwent radiation only and 1 patient received chemotherapy only. The rate of childbirth of an adjuvant group was compared with a control group of 31 glioma patients who underwent surgical resection without any chemotherapy nor radiotherapy, and also with that of demographic survey in Japan. RESULTS: Mean follow up period of adjuvant group was 5.6 years and 5-year survival rate was 91.5%. Three patients got pregnant without abortion and 3 other patients gave birth to 4 children without any anomaly (7 pregnancy & birth/30), and it is no statistical difference from that of control group (6 birth/31, $P = 0.9495$, ChiSq). The average childbirth in adjuvant group was 0.21/5 years and it was similar to that of Japanese average childbirth rate (0.246/5 years). The mean period from last adjuvant therapy to delivery was 4.3 years (range 1-10). CONCLUSION: Nitrosourea based chemotherapy and radiotherapy for grade 2 and 3 gliomas seems not to affect fertility.

SM-014. DERMATOLOGIC EVENT CHARACTERISTICS AND MANAGEMENT WITH THE NOVOTTF-100A SYSTEM, A NOVEL ANTI-MITOTIC DEVICE FOR THE TREATMENT OF RECURRENT GLIOBLASTOMA (rGBM)

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BACKGROUND: The NovoTTF-100A System is a novel anti-mitotic device that delivers alternating electric fields (tumor treating fields, TTFields) and is FDA approved for use in rGBM. TTFields are delivered through insulated transducer arrays that are applied to the shaved scalp and connected to a battery-operated device. MATERIAL AND METHODS: A systematic review of patient data (including serial photographs of the scalp reviewed by a dermatologist) from the rGBM phase III trial of NovoTTF therapy versus active chemotherapy and the post-marketing program was conducted. Adverse events on the trial were recorded using the CTCAE v3.0. RESULTS: In the rGBM phase III trial (N = 237) the most common device-related adverse event was grade 1 and 2 dermatitis of the scalp beneath the arrays occurring in 16% of NovoTTF-treated patients. The skin events seen in the trial were characterized by three main types of reactions: erythema, punctate micro-ulcerations and/or folliculitis. Events were treated with topical 1% hydrocortisone ointment or mupirocin and relocation of the transducer arrays. In addition, it was essential to minimize electrical resistance with the scalp when placing the arrays. Therefore, any topical ointment was carefully removed with 70% alcohol prior to replacing the transducer arrays. CONCLUSIONS: The NovoTTF-100A System may result in dermatologic events related to contact from the transducer arrays. These events can be readily managed with topical therapies, to ensure consistent quality of life and adherence to therapy. Skin care guidelines and treatment algorithms, which take into consideration the continuous nature of NovoTTF therapy and the requirement for low electric resistance contact, will be presented.

SM-015. CAPITALIZING ON A UNIQUE OPPORTUNITY: ESTABLISHING A SUSTAINABLE BRAIN TUMOUR SUPPORT SERVICE IN MELBOURNE, AUSTRALIA

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Brain tumour patients and families face enormous challenges that are unmet in usual clinical practice. We describe the implementation of a cost effective support program, funded by philanthropy. With limited resources, the model was defined by drawing on the literature, identifying the critical areas of unmet need and meeting with key stakeholders within hospital and consumer communities. Service gaps were identified and strategies developed to address these elements in the most efficient way. Direct patient service commenced in late 2008, with the Brain Tumour Support Officer (BTSO) assisting 40 families in the first 12 months. In 2013, the BTSO provides a range of support services accessed by over 130 families annually. The BTSO also plays active role in community education and awareness activities for consumers and health professionals. The BTSO model is designed to enable patients and families to be supported through their healthcare journey from diagnosis, through their treatment, and beyond. This contrasts with a nurse practitioner model, separated from but integrated with medical care. The key strategies are informing, resourcing, supporting and acknowledging the impacts at different stages. 47% of interventions are individual consultations; group interventions account for 21 % and phone-based consultations make up 23%. Challenges along the way have included management of staff & patient expectations, avoiding the pitfall of being all things to all people. It has also been critical to engage key medical staff, peak bodies & patient advocacy organisations, to ensure all activities are relevant and endorsed. This is a unique opportunity to work across boundaries of private/public health, in partnership with a philanthropic fund passionate about their cause. We have attempted balance between individual support and resourcing, whilst building a range of awareness and educational activities creating a natural impetus within the broader health community and beyond.

SM-016. REGIONAL PROFESSIONAL SUPPORT NETWORK FOR PRIMARY MALIGNANT BRAIN TUMOURS

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BACKGROUND: Supportive care needs of patients and families affected by brain tumours are challenging and unique. Coordinating skilled support in rural areas is difficult, when only small numbers of patients present. This project explored ways of facilitating skill development in health practitioners, and enhancing professional networks between regional and city based brain tumour support personnel. METHODS: Following a comprehensive review of educational needs, including liaising with key stakeholders, two primary strategies where implemented: 1) A clinical education day for regional and metropolitan health professionals focusing on brain tumours, treatment options, complex supportive care needs and available resources. 2) A day placement for regional health professionals with the Austin Brain Tumour Support Service. RESULTS: The clinical education day attracted 116 participants, with 31% travelling from regional areas. 56% of participants were nurses and 23% from allied health backgrounds. 65% of attendees were referred <10 brain tumour patients annually and 44% rated their understanding of brain tumours as fair to poor. The overall evaluation response rate was 81%. Delegates rated content on a 5 point scale, with all presentations rating greater than 4.21. 91% of respondents felt that the forum met their aims for attending and 100% would attend a similar forum annually. Day placement program was conducted with 2 staff from regional Victoria, both rated the experience positively. Post placement surveys indicated improved confidence in needs identification, increased ability to provide practical strategies to assist and seek support. CONCLUSION: Despite the small number of people diagnosed with brain tumours in Victoria, this project demonstrated a strong need for ongoing professional development in this challenging area particularly in regional areas. Through collaboration with Cancer Council Victoria, ongoing planned initiatives include an annual brain tumour clinical professional day, mentor program and a quarterly newsletter for health professionals focused on brain tumours.

SM-017. THE CHANGE OF UNCERTAINTY OVER TIME IN PATIENTS WITH PRIMARY BRAIN TUMORS (PBTs)

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INTRODUCTION: Patients with PBTs face uncertainty related to the disease course and symptoms experienced. Our previous study found that patients' level of uncertainty during treatment was as high as in newly-diagnosed period and was significantly correlated to negative mood states and symptom severity. This study examined the change of uncertainty over time. METHODS: 48 patients completed the questionnaires; twice during the illness trajectory. Instruments included a clinical checklist, a demographic data sheet, and the Mishel Uncertainty in Illness Scale-Brain Tumor Form (MUIS-BT). Paired t-test was used to compare patients' level of uncertainty at different time points in terms of the four subscales of MUIS-BT: ambiguity/inconsistency of illness-related events(Ambiguity); unpredictability of disease prognosis(Unpredictability); unpredictability of symptoms/other triggers(Symptoms); and complexity of the disease process(Complexity). RESULTS: Subjects were primarily white(83%) males(52%) with a mean age of 44.8 ± 11.9 years. Overall, patients' global uncertainty, Complexity, and Ambiguity subscales remained consistent between the two time points. For those whose treatment status changed from 'on treatment' to 'follow-up' (n = 24), Unpredictability and Symptoms reduced significantly at the follow-up assessment(both $p < .01$) when uncertainty level was high at baseline. Patients 'not on treatment' at baseline with lower uncertainty had increased Unpredictability the second time even when they remained not on active treatment ($p < .01$). CONCLUSIONS: The illness trajectory of patients with PBTs is associated with high incidence of uncertainty. Overall uncertainty remained constant when patients were followed longitudinally. Uncertainty related to the unpredictability of the disease and symptoms lessened after completion of treatment, whereas unpredictability related to the prognosis appeared to increase over time, even in the setting of stable disease. Evaluating patients with different levels of uncertainty longitudinally offers better understanding of the patterns of change over time. The findings may help healthcare providers to develop a more individualized symptom management paradigm to lessen uncertainty and improve quality of life.

SM-018. NEURO ONCOLOGY TREATMENT AND SYMPTOM MANAGEMENT LEARNING PREFERENCES FOR HEALTHCARE PROFESSIONALS

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In order to determine the most effective neuro oncology training for healthcare professionals, nurses and social workers were surveyed to target topics of interest and to identify their preferred learning methods. An electronic survey was sent to nurses and social workers who were identified from a support organization database. The survey was also advertized in the organization's newsletter and on professional nursing and social work organization websites. Data were analyzed using Survey Monkey and Excel programs. Descriptive statistics were used to evaluate the results. One hundred thirty nine respondents (60 nurses and 79 social workers) answered most of the questions on the survey. In this sample, 95% were female and worked mainly in urban/metro areas. Sixty one percent of participants saw less than 25% of neuro oncology patients in their practice, and 25% of the participants saw greater than 75% neuro oncology patients. Their preferred topics for prefessional learning included: symptom management (70%), caregiver needs (66%), current treatment (62%), financial aid (60%), and palliative care (60%). The most preferred learning methods included attending conferences (87%), reading articles from peer reveiwed journals (72%), online webinars (70%) and reading online newsletters (68%). Nurses and social workers in urban settings had a high interest in learning about treatment compared to a moderate interest in rural settings. The rural nurses showed higher interest in caregiver needs and financial aid. Both groups had high interest in symptom management. Social workers, in any setting, rated financial aid as a high level of interest. Conclusion: Nurses and socal workers have specific learning needs within neuro oncology and in the methods they choose to obtain new knowledge. Educational programs need to be focused in these areas to obtain the most benefit.

SM-019. RECURRENT STROKE RISK IN CHILDHOOD CANCER SURVIVORS

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BACKGROUND: Survivors of childhood cancer treated with cranial radiation therapy (CRT) are at high risk for first stroke. Little is known about rates and predictors of recurrent stroke in this population. METHODS: The Childhood Cancer Survivor Study (CCSS) is a multi-institutional retrospective cohort of 14,358 five-year survivors of childhood cancer ($<$21 years old at cancer diagnosis; treated from1970-1986), and 4,023 randomly selected sibling controls with ongoing, longitudinal follow up. CCSS participants (or their proxy) periodically completed comprehensive questionnaires on demographics and medical conditions. We surveyed 334 survivors plus 109 proxies of deceased survivors who previously reported stroke, to identify recurrent strokes. We estimated recurrent stroke rates using cumulative incidence and evaluated associations with risk factors using Cox regression. RESULTS: Among 329 respondents (proxy report $n = 76$), 271 confirmed a first stroke. Median age at time of first stroke was 19 years and 119 (44%) carried an original diagnosis of CNS tumor. A second stroke was reported in 70 patients (26%) at median age of 32 years (range 1, 56). Of these, 37 (53%) were reported in CNS tumor survivors. Median time from first to recurrent stroke was 2 years (range 0,31). The 10-year cumulative incidence of recurrent stroke was 21% (95% CI 16, 27) overall, and 33% (21, 44) for those treated with $>$50 Gy of CRT. Independent predictors of stroke recurrence included: CRT dose $>$50 Gy (compared to none, hazard ratio [HR] 4.4; 95% CI, 1.4-13.7), hypertension (HR 1.9; 95% CI, 1.0-3.5), and age $\geq$ 40 years at time of first-stroke (HR 6.4; 95% CI 1.8-23; for the comparison of age $\geq$40 to age 0-17). CONCLUSIONS: Survivors of childhood cancer who suffer a first stroke are at high risk for recurrent stroke, particularly those treated with high-dose CRT. Hypertension independently increases the risk of stroke recurrence in this population.

SM-020. TELEMEDICINE AND PALLIATIVE CARE IN NEURO-ONCOLOGY: WEB ASSISTANCE FOR SYMPTOMS MANAGEMENT AND END OF LIFE SUPPORT

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The role of Information Communication Technology (ICT) has increasingly gained acceptance among practicing healthcare professionals in the last years, defining a concept known as "e-Health". ICT may help to improve communication between hospital and communities services, patients' access to health and social needs and may facilitate the information for patients and families. The project of palliative home care for brain tumor patients developed since 2000 in the National Cancer Institute Regina Elena in Rome is aimed to deliver palliative and supportive care for Brain Tumor (BT) patients in the Rome area. Recently the project was extended to all patients affected by BT in the city area and in the Lazio region. With the aim to allow the management at distance of patients requiring supportive care and symptom management, particularly in advanced stage of disease, we developed an health WEB site portal applied to Neuro-Oncology supportive and palliative care issues. The Web site offer an open web area that allow free access to patients, families and health professionals to disease information, educational tools, and facilitation to health and social services delivery. A "private" area (help desk) of the portal is accessible only with personal registration and allows neuro-oncological/palliative interactive consultations for single patients, physicians and/or caregivers. This section of the Web site offer palliative neuro-oncology "expert advice" for the management of remote patients. The www.portaleneuroncologia.it project started in January 2013. At present 165 patients has been assisted at home in the city Rome area and 83 has been taken in charge outside the metropolitan area. The use of ICT resources are a powerful tool of innovation of health-care systems and may help to optimize the delivery of care and to facilitate the access of BT patients to the best supportive and palliative care.

SM-021. NORMAL TISSUE COMPLICATION PROBABILITY (NTCP) MODEL OF RADIATION-INDUCED MOOD DISRUPTION

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BACKGROUND: Methodology developed in our recently published NTCP model of radiation-induced cognitive toxicity was used to investigate mood scores in a retrospective cohort of cancer survivors $>$6months following radiation treatment to the brain. Participants were enrolled in a Wake Forest Community Clinical Oncology Program NCI - approved clinical trial (CCCWFU97100 or 91105) assessing the efficacy of donepezil (Aricept) for improving cognition, mood and fatigue in cancer survivors. METHODS: Mood was assessed with the Profile of Mood States (POMS) administered three times during the trials (baseline, 12 and 24 weeks). POMS contains subscales for depression, anxiety, anger, confusion, fatigue and vigor along with a calculated total mood disturbance (TMD). Since POMS indexes mood within one week of testing, an average of the 3 time points were used to achieve a more robust value of post-treatment mood state with the caveat that this is confounded by the donepezil intervention in 19 of the 42 individuals sampled. Linear regression analyses ($p < 0.05$) identified brain regions where dose volume data from treatment plans predicted mood scores post-treatment. RESULTS: In all cases, the larger the volume of a region exposed to $>$40Gy resulted in poorer mood scores. Similar to the cognitive toxicity model, total brain dose volume was not predictive of mood. The rostral brain stem, left amygdala and hippocampus predicted confusion ($r^2 = 0.12$, 0.16 and 0.12, respectively). TMD was predicted by the rostral brain stem and left amygdala ($r^2 = 0.10$). The left amygdala also predicted fatigue ($r^2 = 0.10$). CONCLUSIONS: These findings suggest that radiation-induced mood disturbances like cognition are tied to specific neuro-anatomical brain regions (e.g., rostral brainstem contains 3 main neurotransmitter nuclei). These retrospective analyses while intriguing are hypothesis-generating. Prospective validation is required before true thresholds of radiation damage to specific brain regions that lead to mood disturbances are determined.

SM-022. DISTRESS AND QUALITY OF LIFE IN PATIENTS WITH PRIMARY BRAIN TUMORS

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ACOS Commission on Cancer Accreditation Guidelines will require that all patients be regularly screened for distress by 2015. Patients with primary brain tumors may experience significant distress, yet there is limited data regarding the sources and rates of distress. More research is also needed to understand the relationship between distress and quality of life (QOL). This study examines sources of distress and associations with QOL in a large sample of patients with primary brain tumors. One hundred sixteen consecutive brain tumor patients (58 high-grade, 58 low-grade) completed a validated self-report distress screening tool and a standard QOL measure as part of their neuro-oncology visit. 36% needed help completing questionnaires. Results indicate common sources of distress were forgetfulness/memory problems (49%), fatigue/lack of energy (47%), difficulty concentrating (34%), worry (30%) and feeling drowsy (30%). The most distressing concerns were recent loss/grief ($M = 2.5$), housing problems ($M = 2.3$), health care decision-making concerns ($M = 2.1$), problems communicating with the medical team ($M = 2.0$), and diarrhea ($M = 1.9$). There were no differences between high and low-grade tumor groups for distress or QOL. Emotional ($\beta = -.50$, $p = .001$) and Cognitive Concerns ($\beta = -.29$, $p = .001$) significantly predicted decreased QOL. When patients who needed help completing questionnaires were excluded, Physical Concerns also predicted lower QOL ($\beta = -.23$, $p = .04$). Cognitive and physical symptoms are most common in this population, though a variety of psychosocial concerns are more distressing on average. Emotional, physical, and cognitive concerns contribute to decreased QOL for patients able to complete questionnaires independently. More research is needed for those who need assistance completing questionnaires. Since QOL measures are often time-consuming and frequently lack specific cut-offs to recommend clinical intervention, screening for specific sources of distress in brain tumor patients may be more useful for enhancing QOL.

SM-023. ASSOCIATION OF HEALTH-RELATED QUALITY OF LIFE AND NEUROCOGNITIVE FUNCTION WITH PROGRESSION-FREE SURVIVAL AND PROGRESSIVE DISEASE IN PATIENTS WITH GLIOBLASTOMA: A REVIEW OF THE LITERATURE

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BACKGROUND: As disease burden is increasingly of interest in glioblastoma (GBM) trials, investigators now consider sustaining patient function as a critical treatment outcome. However, it remains unclear how the timing and extent of changes in health-related quality of life (HRQoL) and neurocognitive function (NCF) are associated with progressive disease (PD) or progression-free survival (PFS). MATERIAL AND METHODS: Literature searches were conducted for relevant English-language studies in the Embase®, PsycINFO®, and MEDLINE® databases (01/01/2002 – 12/10/2012). Search terms included: GBM, brain cancer, HRQoL, NCF, and disease survival and progression. Reference lists of included studies were also examined. Abstracts for all studies were screened. A sampling of studies were selected based on perceived relevance. RESULTS: Of 88 studies identified as potentially relevant, 25 were selected for full-text review. Four studies reported data regarding the association of PD or PFS with HRQoL (measured by the EORTC QLQ-C30 and QLQ-BN20), and 4 studies with NCF (measured by the MMSE or a battery of NCF tests). With regard to HRQoL: One study reported improved HRQoL scores (in global health status and several functional scales) prior to PD; 1 study reported that HRQoL improvements were more common in patients with a partial/complete response vs. those with PD; 2 studies reported several HRQoL functional and symptom scales declined at PD. With regard to NCF: Two studies (in GBM and brain metastases) reported declines in memory, verbal fluency, fine motor and executive function at PD; 1 study in newly diagnosed GBM reported that NCF improved prior to PD; 1 study in high-grade glioma indicated higher baseline NCF scores predicted better OS but not PFS. CONCLUSIONS: The findings of this review in GBM and brain cancer studies provide evidence of improvement in HRQoL and NCF with disease response or prior to PD, and decline at the time of PD.

SM-024. DEPRESSION AND SURVIVAL IN GLIOMA: THREE-YEAR FOLLOW-UP DATA FROM A TWIN-CENTRE PROSPECTIVE COHORT STUDY

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INTRODUCTION: Major Depressive Disorder (MDD) is associated with reduced survival in patients with systemic cancers. Prospective evidence is lacking on whether depression affects survival in glioma. We studied whether depression occurring in the period shortly after glioma diagnosis was associated with a reduction in median survival after three years of follow-up. METHODS: We conducted a twin-centre prospective cohort study of adults with a new diagnosis of primary glioma. At baseline (8 weeks after primary surgery), patients received a structured clinical interview to diagnose MDD, and completed the Hospital Anxiety and Depression Scale (HADS) and Patient Health Questionnaire (PHQ-9) depression screening scales. Kaplan-Meier curves were used to compare median survival times at 3 years, between patients (1) with and without baseline MDD, (2) with HAD-D scores <8 vs. 8 + , and (3) PHQ-9 scores <10 vs. 10+. RESULTS: N = 155, mean age = 54, 57.4% male, 85.6% had high grade glioma. Twenty-one patients had MDD at baseline (median survival = 324 days, 95%CI 180-1017) and 134 did not (median survival = 474 days, 95%CI 399-681). Despite this magnitude of difference in median survival, the log rank statistic p = 0.381. Neither the HAD-D (log rank statistic p = 0.650) nor PHQ-9 (log rank statistic p = 0.936) appeared in any way prognostic for survival. CONCLUSIONS: Although the difference in median survival of 150 days in patients with MDD might support a link with survival, the modest number of depressed patients (13.5%) led to wide confidence intervals. The aggressive natural course of high-grade glioma could additionally be expected to mask anything other than a large effect on survival. These data do not exclude, at population level, a clinically significant effect of depression on mortality in glioma and a meta-analysis of future studies is suggested.

SM-025. THE EXTENT, ASSOCIATIONS, AND LONGITUDINAL COURSE OF DISTRESS AND FATIGUE IN GLIOMA OUTPATIENTS

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INTRODUCTION: Distress and fatigue are frequent, disabling symptoms of glioma survivorship. We studied their extent, clinical associations and the longitudinal course in glioma outpatients. METHODS: This was a prospective cross-sectional and partial longitudinal cohort study of adults with glioma in neuro-oncology clinic follow-up. The primary dependent variables (distress and fatigue) were each measured using 100mm Visual Analogue Scales. Following previously validated thresholds, distress over 40mm, and fatigue over 60mm was categorized as 'high'. Independent associations were examined using linear regression. RESULTS: N = 171 patients provided cross-sectional data (60.2% male; mean age = 49.1, range 18-77 yrs; 69.6% had high-grade glioma, median Karnofsky Perfomance Status [KPS] = 90 [range 40-100], median 13.5 months since diagnosis). Mean distress = 37mm (SD 32, 'high' = 44.4% [95%CI 36.8-52.2%]). Mean fatigue = 50mm (SD 34, 'high' = 43.9% [36.6-51.3%]). Distress and fatigue correlated with each other (Pearson correlation = 0.418, p < 0.001). In univariate analyses distress was associated with concurrent dexamethasone use (p = 0.036), left-sided tumors (p = 0.026), and KPS (p < 0.001). Fatigue was associated with dexamethasone use (p = 0.015) and KPS (p < 0.001). On multivariable analysis, KPS was the only variable to remain independently associated, with both distress (p = 0.001, R Square = 0.09) and fatigue (p < 0.001, R Square = 0.22). N = 53 patients provided additional longitudinal data. There was no significant change in distress over time (mean 38mm at Timepoint 1 vs 38mm at Timepoint 2), but fatigue increased (mean 41mm at T1 and 51mm at T2, one-way ANOVA p = 0.003). CONCLUSIONS: High levels of distress and fatigue were reported by over 40% of glioma outpatients. Poor performance status was the only variable to be independently associated with either outcome. Fatigue levels increased over time. Future studies could move beyond testing standard tumor- and treatment-related variables to examine psychosocial causes of these disabling symptoms and to study the efficacy of interventions for distress or fatigue in glioma.

SM-026. LONG TERM QUALITY OF LIFE AFTER MENINGIOMA SURGERY OF PATIENTS OF DIFFERENT AGE GROUPS

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Surgery is the standard treatment for intracranial meningiomas in patients of all ages. Nevertheless meningioma resection is not always an absolute indication in comparison to malignant tumors. Apart from general health condition and location of the tumor, the postoperative outcome regarding quality of life should also be part of the decision making process. Only few studies describe the long term health related quality of life (HRQOL) of postoperative patients of different age groups. For this reason we analyzed the quality of life of 133 patients who underwent surgical meningioma resection in different ages in the Department of Neurosurgery of the University of Cologne between 2004 and 2010. Six different age groups of patients ranging from the ages 55 to 84 of which 50 patients were male and 83 female were interviewed with the SF36 questionnaire compared to general population. The average time between surgery and interview was 3.8 years (SD +/- 2.5 years). Our results showed that long term postoperative physical viability was significantly higher in the age groups 55 to 74 compared to higher age groups ($p < 0.05$). Vitality, psychic wellbeing, social viability and pain did not significantly vary in different age groups. Compared to general population patients of all age groups had a significantly higher level of pain ($p < 0.05$), vitality as well as role-physical functionality were significantly lower. In total, however, our findings suggest that meningioma resection affects long term quality of life and should be a substantial part of the surgery decision making process in different age groups.

SM-027. DETECTION OF NONCONVULSIVE SEIZURES IN PRIMARY AND SECONDARY BRAIN TUMORS

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OBJECTIVE: To investigate the rate of nonconvulsive seizures (NCS) and status (NCSE) in patients with metastatic and primary brain tumors. BACKGROUND: Clinical seizures have been reported in 25% of patients with brain metastases and up to 75% of patients with primary brain tumors. Both groups are at risk for sudden changes in mental status which can be due to metabolic, infectious, structural causes, or nonconvulsive seizures. The risk of NCS in patients with neoplastic brain tumors presenting with mental status changes in unknown. DESIGN/METHODS: We performed a retrospective review of patients admitted between 1/2010 and 12/2012 with brain neoplasms and altered mental status who underwent continuous EEG monitoring (cEEG). Patients in the immediate post-operative period were excluded. RESULTS: 188 EEG recordings for 161 patients were identified for this investigation. Seizures were detected in 53 recordings (28%), 30 of which were purely subclinical (57%). Only 47% of seizures were detected on 30 minute EEGs, whereas over 90% were detected after 24 hours of monitoring. Primary CNS tumors and lymphoma were associated with a higher incidence of seizures, with the highest rate found in high grade gliomas (34%) followed by meningiomas (31%) and lymphoma (28%). CONCLUSIONS: NSCE ranging from 6-33% have been reported in patients with impaired mentation and acute brain lesions. Our study shows a similar rate of NCS in brain tumor patients presenting with acute mental status change. Greatest incidence was found in patients with high grade gliomas, though classically reported as lower in comparison to low grade gliomas. The rate of detection of NCS on 30 minute EEG of only 47% and rate of only NCS and NCSE of 57% demonstrate the need for continuous EEG monitoring in the diagnosis of seizures in brain tumor patients presenting with altered mental status.

SM-028. PSYCHOSOCIAL SUPPORT BY MEDICAL SOCIAL WORKER IS BENEFICIAL FOR PATIENTS WITH MALIGN BRAIN TUMORS

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The Karolinska University Hospital (KS) in Solna has northern Stockholm as the catchment area where approximately 100 persons a year are afflicted by malign brain tumors. We present here the psychosocial part of our treatment program from the beginning of 2011. Medical social workers (two employees) included in the medical treatment team shall meet all new patients in this group. The partner, children, parents and siblings of the patients are also offered support. Since 2010 there is a law stating that affected children under 18 years of age have the right to psychosocial support. The aim of the medical psychosocial work is to facilitate the life for these patients and their families in order for them to manage this chronic and lethal disease. The social workers assignments include crisis processing, information and support when meeting the welfare system. The patients and/or their families in the treatment program (2011-2012) have expressed appreciation about their meetings with the social workers. They have experienced it to be particularly beneficial that the social workers also have knowledge about their specific disease and symptoms. The conclusion is that all patients and/or families have a need for psychosocial support.

SM-029. HEALTH-RELATED QUALITY OF LIFE (HRQOL) ANALYSES IN THE AVAGLIO STUDY, A RANDOMIZED, PLACEBO-CONTROLLED PHASE III TRIAL OF BEVACIZUMAB, TEMOZOLOMIDE AND RADIOTHERAPY IN NEWLY DIAGNOSED GLIOBLASTOMA

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BACKGROUND: Glioblastoma impacts negatively on HRQoL. In AVAglio, bevacizumab added to temozolomide and radiotherapy (BEV + RT/T) achieved a statistically significantly longer PFS versus placebo (P + RT/T). HRQoL was a secondary endpoint in this study. METHODS: Patients received BEV + RT/T ($n = 463$) or P + RT/T ($n = 458$) until PD/unacceptable toxicity. HRQoL (EORTC QLQ-C30/BN20) time to definitive deterioration (TDD) was assessed as the primary analysis for five HRQoL scales; a 10-point change from baseline, PD, and death were considered clinically meaningful events. Exploratory post-hoc HRQoL analyses (no adjustment for multiple testing) were TDD excluding PD as an event (all scales) and TDD including PD as an event (21 non-preselected scales). RESULTS: 78–91% of evaluable patients without PD completed each assessment (all scales) in the first year. Baseline scores were comparable between arms. BEV + RT/T achieved a significant delay ($p < 0.0001$) in TDD versus placebo (preselected scales including PD): global health status $HR = 0.64$ (95% CI 0.56–0.74); physical functioning $HR = 0.70$ (95% CI 0.61–0.81); social functioning $HR = 0.63$ (95% CI 0.55–0.73); motor dysfunction $HR = 0.67$ (95% CI 0.58–0.78); communication deficit $HR = 0.67$ (95% CI 0.58–0.77). Post-hoc sensitivity analyses (excluding PD as an event) were supportive for global health status, social functioning and communication deficit ($p < 0.05$). BEV + RT/T benefit ($p < 0.05$) was seen in 8/21 non-preselected scales (TDD including and excluding PD, respectively): cognitive functioning $HR = 0.62$ (95% CI 0.54–0.72), $HR = 0.74$ (95% CI 0.61–0.89); role functioning $HR = 0.67$ (95% CI 0.58–0.78), $HR = 0.82$ (95% CI 0.68–0.99); emotional functioning $HR = 0.65$ (95% CI 0.56–0.75), $HR = 0.78$ (95% CI 0.63–0.97); bladder control difficulty $HR = 0.59$ (95% CI 0.51–0.68), $HR = 0.71$ (95% CI 0.55–0.92); leg weakness $HR = 0.65$ (95% CI 0.56–0.75), $HR = 0.81$ (95% CI 0.66–0.99); visual disorder $HR = 0.65$ (95% CI 0.56–0.75), $HR = 0.80$ (95% CI 0.65–0.99); fatigue $HR = 0.64$ (95% CI 0.55–0.74), $HR = 0.74$ (95% CI 0.62–0.89); and hair loss $HR = 0.67$ (95% CI 0.58–0.77), $HR = 0.81$ (95% CI 0.66–0.98). CONCLUSION: BEV + RT/T-treated patients experienced a longer time to HRQoL deterioration compared with P + RT/T.

SM-030. THE NEURO-ONCOLOGY CARE COORDINATOR: A KEY ROLE IN FACILITATING COMPLEX CARE

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INTRODUCTION: Neuro-oncology cancer care coordinators (NOCCC) remain uncommon across Australia, despite key national and international recommendations supporting this important clinical role. This study aimed to describe the NOCCC (senior nurse) role in South West Sydney and highlight the complex needs of primary brain tumour (PBT) patients and carers. METHODS: Newly diagnosed ($n = 118$) and existing ($n = 29$) PBT patients from May 2012-April 2013 formed NOCCC caseload (total $n = 147$). NOCCC KPIs included: number/complexity of care using Macmillan level interventions [MLI] (1-least to 5-most complex) and psychosocial screening/referrals. Nature of interventions consisted of case management (multiple interventions for the one issue); phone; follow up (face to face) and new consults. RESULTS: Newly diagnosed patients comprised high grade glioma (HGG) = 47 including $n = 38$ GBM; low grade glioma (LGG) = 7;benign brain tumour (BBT) = 64. Twenty-nine received ongoing care; HGG = 18(GBM = 14) and $n = 11$ BBT. A total of 1860 MLIs occurred, ranging from level 1-5, most frequently Level 2 $=$ 1072 (58%) followed by Level 1 $=$ 513 (27%). 79% of MLIs involved carers compared to 55% with patients alone. Notably, 75% patient interventions involved HGGs (62%-GBM). MLIs ranged from 1 -85 per patient spanning diagnosis to end-of-life phases. 1646 MLIs (88%) occurred in outpatient setting. MLIs comprised case management $=$ 899 (48%); follow-up $=$ 538 (29%); phone consults $=$ 305 (16%) and new consults with oncology teams / psychosocial assessments $=$ 118 (6%). Of 119 referrals initiated, 85 (58%) were to Allied Health ($>$90% HGG), and 34 (23%) to community palliative nursing (99% HGG). Twenty HGG patients underwent efficient NOCCC assessment and resolution of select clinical issues averting further medical review, with 34 HGG patients via NOCCC triage received outpatient medical review averting emergency department presentation. CONCLUSIONS: Despite their low incidence, PBT (especially HGG) patients have complex needs and carer burden is high. A NOCCC is well positioned to facilitate symptom and needs assessment, psychosocial support and referrals/intervention throughout the care continuum.

SM-031. STRUCTURE AND RELIABILITY OF THE DEXAMETHASONE SYMPTOM QUESTIONNAIRE-CHRONIC IN PRIMARY OR METASTATIC BRAIN TUMOR PATIENTS

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BACKGROUND: Corticosteroids, often given as initial treatment to alleviate symptoms of peritumoral edema in patients with brain tumors, can have numerous side effects that affect the patient's quality of life and treatment tolerance. The Dexamethasone Symptom Questionnaire-Chronic (DSQ-Chronic) was initially developed to report the incidence and severity of side effects associated with corticosteroid use. This study's objective was to evaluate select measures of reliability and validity of the DSQ-Chronic in brain tumor patients using corticosteroids. METHODS: Patients with primary or metastatic brain tumors participated in this study. Data collection tools included a patient-completed demographic data sheet, an investigator-completed clinician checklist, and the DSQ-Chronic. Descriptive statistics described the patient sample. Factor analysis assessed construct validity. DSQ-Chronic's and its factor groupings' internal consistency was evaluated by Cronbach's alpha. RESULTS: Sixty three patients participated in the study. Participants were primarily white (87%) males (65%) with primary (78%) or metastatic (22%) brain tumors. Ages ranged from 20-75 years (mean 53). All patients were treated with corticosteroids with a median dose of 4 mg/day for a median duration of 1 month (range 0-26 months). The DSQ-Chronic scores ranged from 21 to 60 with mean and median of 33. Increased appetite, trouble sleeping and roundness in face were reported as moderate to severe by over 40% of those on corticosteroids. Factor analysis revealed 4 underlying constructs being measured by the 18-item DSQ-Chronic and explaining 50% of variance: affective (7 items), appetite (5 items), dermatologic (3 items) and indigestion (3 items). The internal consistency (reliability) of the DSQ-Chronic was 0.75. Its derived subscales' reliability ranged from 0.52 to 0.83.Conclusions: This pilot study demonstrates the potential of the DSQ-Chronic to be used as a screening tool for side effects associated with corticosteroid use in brain tumor patients. Future analyses include sensitivity to dosing and duration of therapy.

SM-032. THE EPENDYMOMA OUTCOMES (EO) PROJECT II: SYMPTOMS AND SOCIO-ECONOMIC IMPACT

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INTRODUCTION: Ependymoma is a rare CNS tumor in adults and not much is known about its impact on patient symptoms and socio-economic status. The EO II project is designed to collect patient reported data regarding the clinical presentation and the socio-economic impact through an online survey. METHODS: Adult ependymoma patients completed the online EO II Questionnaire (EOQII). The survey assesses disease status, symptoms, insurance status, employment, direct costs and functional status. ANOVA was used to compare differences in symptoms by income groups. Correlations were calculated between symptoms and cost estimates. RESULTS: 86 patients participated. The economic analysis focused on 78 respondents from the US. The majority is married (64%), White (97%) and male (53%). 53% are employed and 42% earned $\leq$\$80,000. Tumors were located in the brain (44%), spine (51%) or both (5%). Spine patients reported significantly worse pain and numbness compared with brain tumor patients, and had a non-significant tendency to report more severe overall symptoms. The 6 most severe symptoms for brain tumor patients were fatigue, altered vision, drowsiness, problems remembering, difficulty concentrating and difficulty speaking. Spine patients reported numbness, fatigue, pain, weakness, sexual dysfunction, spine pain and change in bowel pattern to be the top 6 worst symptoms. Pain, seizures and concentration were significantly associated with self-reported income. Interestingly, income of \$40k to \$80K was associated with less pain than either those making $<$40K ($p<.029$) or $>$\$80K ($p < .032$). Estimated monthly copays were nearly \$170 and \$804 dollars on prescription medication. Higher hospital costs($r = .33$, $p < 0.025$) and monthly copays ($r = .40$, $p < 0.02$) were related to higher symptom severity. CONCLUSION: Patients with ependymoma are highly affected by their symptoms. Spinal patients report higher symptoms than brain patients. Worse symptoms were related to higher costs. Patients in the low income group of $<$\$40,000 report significantly higher symptoms independent of disease site.

SM-033. UTILIZATION PATTERNS OF PALLIATIVE CARE IN NEURO-ONCOLOGY - RESULTS OF AN INTERNATIONAL PROVIDER SURVEY

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INTRODUCTION: Most patients with brain tumors have limited survival and suffer from high morbidity requiring specific symptom management. Specialized palliative care (PC) services have been developed to address these symptoms and provide end of life management for patients with such malignancies. Utilization patterns of PC in neuro-oncology are unknown. METHODS: A 22 question electronic survey was sent out to all members of the Society of Neuro-Oncology (SNO) and participants of SNO annual meetings ($n = 4487$). An additional paper copy was distributed at the SNO meeting quality of life session. Nonparametric methods including Wilcoxon two sample and Kruskal-Wallis tests were used to assess differences in responses. Demographic information included academic degree, specialty, formal training in neuro-oncology and PC, practice patterns and geographic locations. RESULTS: 239 evaluable responses were received. 79% of respondents were physicians, 17% were nurses and midlevel providers. 59% were male. 40% had no formal training in palliative care, 57% had some formal training and 3% completed a PC fellowship. 79% practiced in an academic setting. 57% of respondents refer patients to PC at the time of symptoms requiring treatment and 18% at end of life. 51% felt comfortable or very comfortable dealing with end of life issues and symptoms, 33% did not. 51% preferred a service called "Supportive Care" rather than "Palliative Care" (MDs $>$ other providers, $p < 0.001$), and 32% felt that patient expectations for ongoing therapy hindered their ability to make PC referrals. Female gender, formal training in neuro-oncology, and medical vs. surgical neuro-oncology training was significantly ($p < 0.05$) associated with hospice referral, comfort dealing with end of life issues, and ease of access to PC services. CONCLUSION: This is the first report of PC utilization patterns in neuro-oncology. There are significant differences in utilization patterns based on gender, sub-specialty and level of training.

SM-034. IMPACTS OF TREATMENTS ON SYMPTOM BURDEN IN PITUITARY TUMOR PATIENTS

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BACKGROUND: Pituitary tumors account for approximately 10% of all intracranial brain tumors. Surgery remains the mainstay of treatment. To better understand the impacts of current treatment on symptom burden in pituitary tumor patients, we performed a pilot study to identify symptom changes in pituitary patients by using the M.D. Anderson Symptom Inventory Brain Tumor Module (MDASI-BT). METHODS: Seventeen adult pituitary tumor patients who received surgical intervention at UNC Cancer

Hospital were enrolled in this study. Data including completed MDASI-BT instrument, demographic and Karnofsky Performance Status scores (KPS), was collected at their pre- and post- surgical resection follow-up visits. Mean symptom severity and interference scores were analyzed. Cluster analysis by six factors, including affective, cognitive, focal neurologic deficit, treatment-related generalized disease and GI indications were used to analyze the symptom severity. RESULTS: A total of 17 patients have completed pre-surgical and post-surgical MDASI-BT. Eight patients had non-functional and nine patients had functional pituitary adenoma. The mean age was 41 years. KPS ranged from 80 - 90. Cognitive, neurologic, treatment-related, generalized diseases and GI symptom scores decreased by at least 33% from pre-surgery to post-surgery. The mean GI factors decreased the most with a 69% reduction in symptom scores. Despite the improvement in most of the affective symptoms, the overall affective factors exhibited a 0% improvement, which was largely caused by the 27% increased severity in disturbed sleep post-operatively. The interference factors were decreased by 41% after the surgery. CONCLUSION: This study demonstrated that surgery effectively alleviates the severity of neurological, cognitive, generalized symptoms, and the interference of symptoms. Disturbed sleep was noted to be the common worsening symptom post-operatively. Exploration of the etiology and interventions to improve sleep following surgical removal of pituitary tumors will improve the quality of life in patients.