more accessible and informative, and require less filtering through irrelevant posts. As an example, posts from breast cancer patients typically discuss side effects of investigations and treatments and how to manage them, as well as offering emotional support. The limitations of using this type of information include the lack of a mechanism to confirm that contributors really do have the relevant disease, although the number of participants on social media is likely to be outweighed by “true” patients and caregivers. CONCLUSIONS: This study showed that more valuable information can be found in patient-to-patient correspondence in forum threads than in general social media. Breast cancer patients appear to be more vocal in patient forums than schizophrenia patients, possibly due to the stigma attached to mental health problems. Little was found on what matters to breast cancer caregivers, since patients tend to present their own personal experience.

PCN196

PATIENT AND DISEASE CHARACTERISTICS ARE IMPORTANT DETERMINANTS OF QUALITY OF LIFE IN PATIENTS WITH MULTIFACETED RENAL CELL CARCINOMA RESULTS FROM A POPULATION-BASED REGISTRY

OBJECTIVES: Limited data are available on the health-related quality of life (HRQOL) of patients with metastatic renal cell carcinoma (mRCC) in daily practice. The aim of this study was to estimate the HRQOL of patients with mRCC in daily practice, and to assess the influence of patient- and disease characteristics, such as comorbidities and adverse events on HRQOL.

METHODS: Patients with mRCC were selected from a Dutch population-based registry (PERCEPTIVE). In this RCC registry, data were collected on patient- and disease characteristics, treatments and adverse events. To measure HRQOL, a generic questionnaire (EQ-5D) was used. Multiple linear regression was used to determine which patient- and disease characteristics were associated with the EQ-5D. RESULTS: In this study, 1004/456 (22.1%) patients were presented with or progressed to mRCC. Average age at diagnosis was 62.9 years (range: 40-82) and 77% was male. Patients with mRCC reported an average EQ-5D utility score of 0.73 (95%CI: 0.64-0.82) at diagnosis. Two to six months after diagnosis, the average EQ-5D utility score was 0.75 (95%CI: 0.66-0.84) (P<0.001). Multiple linear regression showed that presence of comorbidities (>1), number of metastatic sites (>1), radiotherapy and presence of grade 3 or grade 4 toxicity were significantly associated with a lower EQ-5D utility score. Although presence of bone metastases significantly lowered the EQ-5D utility score, this factor was not significant after adjustment for other factors. CONCLUSIONS: This is one of the first studies that provides insights into the HRQOL of patients with mRCC in daily practice. In contrast to previous studies this study also identified patient- and disease characteristics that influence HRQOL. Presence of comorbidities, number of metastatic sites, radiotherapy and presence of severe toxicity related to targeted therapies were significantly associated with HRQOL. This information can be used to correct EQ-5D scores for these characteristics and will be useful in future cost-effectiveness analyses.

PCN197

DEVELOPMENT OF A CONCEPTUAL MODEL FOR PEDIATRIC ONCOLOGY PATIENTS: RESULTS FROM A REVIEW OF QUALITATIVE RESEARCH LITERATURE AND CLINICIAN INTERVIEWS

OBJECTIVES: Childhood cancer’s profound effects should be assessed appropriately within clinical trials; however, a conceptual model is required to help design appropriate measurement strategies. The aim of this study was to develop an initial pediatric oncology conceptual model to facilitate the measurement of patient outcomes.

METHODS: Two research groups (n=12) assessed for articles focused on qualitative research with children (ages 0–18) with cancer and/or their parents. Participants were recruited from patient/parent internet forums were reviewed. Telephone interviews with five pediatric oncology clinicians were performed. Data were analyzed using grounded theory methods.

RESULTS: 112 qualitative studies were reviewed. Few studies presented data by specific cancer type/age or child age; blogs(clinician interviews provided insights into these areas. Across cancer types, but especially for hematology, patients, pain, fatigue, and “feeling unwell/fever” were emphasized, as well as impacts on daily functioning. For brain tumors, headaches, sudden lack of coordination/balance, blurred vision, seizures, vomiting, dizziness and cognition-related impacts on mood and language were highlighted. For solid tumors, tumor location often related to related mobility and/or functioning problems, clinicians emphasized lymphopenia and weight loss. Adolescents appeared to be most impacted by cancer, due to their grasp of the cancer’s gravity, self-image issues, loss of autonomy, school absences and social life limitations. Though patients/patient/caregivers found it difficult to distinguish between treatment- and cancer-related symptoms, treatments caused several problems, such as neuropenia, changes in appearance, irritability, nausea/vomiting, fatigue and pain. Not emphasized by clinicians but reported frequently in literature/blogs, mucositis and changes in taste remains pertinent/caregiver. Clinicians strongly emphasized short-term/long-term working memory loss and that anxiety contributed to the occurrence/severity of other side-effects/impacts. CONCLUSIONS: Cancer’s impact on children is multifaceted and an impaired ability to understand these potential contributing factors. When designing outcomes strategies are: the child’s age, cancer type and stage, delineating disease and treatment symptoms/impacts, and short/long term side effects impacts on nutrition and development.

PCN198

MISUSE, ABUSE, AND DIVERSION OF INSTANTYL® (FENTANYL NASAL SPRAY) IN FRANCE

OBJECTIVE: Instanyl® (fentanyl nasal spray) received European market authorisation in 2014 for the management of breakthrough pain in adults already receiving maintenance opioid therapy for chronic cancer pain, with precise indications on indications for use and dosage. The study objectives were to evaluate patient-reported misuse, abuse, and diversion of Instanyl® in real-life in France. METHODS: Convenience sampling of 277 eligible patients at the time of drug dispensation between 27 July 2011 and 12 November 2012. The questionnaire could be completed by patients who declared having cancer, 76% declared cancer, 76% at least one indication/contraindication and 86% at least one posology misuse. Widening the definition of use for breakthrough pain to use for both breakthrough and chronic pain in cancer patients, reduced the indication/contraindication misuse (63%), but when posology misuse was also considered this did not markedly change overall misuse (93%). Abuse of Instanyl® (using the drug for emotional reasons, relaxation, or sleep disorders) concerned 21 patients (15 with cancer and 6 without); diversion (passing the drug to another person) concerned 2 patients (1 with cancer and 1 without). CONCLUSIONS: Misuse of Instanyl® was widespread. Nearly half reported not to have cancer, and among those who did, only a few used this drug correctly. There seems to be a communication deficit as to the proper prescribing of this drug, and its proper use when prescribed.