

OBJECTIVES: Huntington's disease (HD) is a rare neurodegenerative disease leading to sustained disability for patients and poor quality of life (QoL) for patients as well as caregivers. This study, conducted in US as a part of an international survey, investigated a disease-specific QoL instrument, the HD QoL Battery for Carers (HDQoL-C). **METHODS:** The shortened version of the HDQoL-C comprised two components: the satisfaction with life (3 items) and the feelings about living with HD (17 items). Caregivers were asked to answer socio-demographic questions and complete the short version of the (HDQoL-C), a previously validated questionnaire. Item response could be chosen among 10 possibilities depending on frequency or intensity. Internal validity was evaluated through the factorial structure and internal consistency. External validation was tested using known-group comparison analyses between three severity subgroups (low, moderate, high), according to dependence, global clinical severity and motor severity. **RESULTS:** The sample was composed of 361 family carers from US with 76% female, 16% single and 51 of average age. The majority of the caregivers represented the main caregivers of the HD patient (73%) and 61% of them lived with the HD patient. There were 2 items out of 20 with potential floor effects and 3 items with ceiling effects. Cronbach's alpha coefficients ranged from 0.68 to 0.90 in the whole sample, indicating high internal consistency. Analyses of the component of HDQoL-C dealing with the feelings about living with HD, demonstrated satisfactory factor analysis. Known group analyses showed that the HDQoL-C scores were higher for carers who cared for patients in the low severity group than the two other groups, meaning that these carers had better QoL. **CONCLUSIONS:** The US shortened version of the HDQoL-C demonstrated good internal consistency and congruent validity when compared to the original English version.

PND44

SEIZURE SEVERITY AMONG SUBJECTS WITH REFRACTORY PARTIAL-ONSET SEIZURES: ANALYSIS OF THE SEIZURE SEVERITY QUESTIONNAIRE IN A PHASE III TRIAL OF ESLICARBAZEPINE ACETATE

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OBJECTIVES: To examine seizure severity across treatment arms among clinical trial subjects with refractory partial-onset seizures (POS) who participated in a phase III clinical trial of eslicarbazepine acetate, a novel once-daily anticonvulsant recently approved for the adjunctive treatment of POS in adults. **METHODS:** The Seizure Severity Questionnaire (SSQ), a validated instrument developed to evaluate the severity and bothersomeness of specific seizure characteristics, was administered. The SSQ total score (TS) and domain scores of frequency and helpfulness of warning signs before seizures (BS), severity and bothersomeness of ictal movement and altered consciousness during seizures (DS), cognitive, emotional, and physical aspects of postictal recovery after seizures (AS), and overall severity and bother (SB) were calculated at baseline and at the end of maintenance therapy (12-week duration) from the per-protocol population. ANCOVA models, adjusted for baseline scores, estimated least square mean (LSM) differences between arms at the end of therapy. **RESULTS:** Among 547 subjects, average age: 38.4, 63.3% Caucasian, 50.8% female, 70.4% (385) had TS results at baseline and at end-of-therapy. Among subjects receiving 1200 mg ESL, the TS LSM was significantly lower compared to placebo (2.80 versus 3.29, $p=0.002$); the LSMs were also significantly lower for DS (3.29 versus 3.70, $p=0.032$), AS (1.95 versus 2.51, $p=0.019$), and SB (3.09 versus 3.65, $p<0.001$), but not for BS. Among subjects treated with 800 mg ESL, the LSM differences vs. placebo for BS, DS, AS and TS did not achieve statistical significance. The SB LSM was significantly lower (3.28 versus 3.65, $p=0.013$). **CONCLUSIONS:** In this post-hoc analysis of a phase III trial, ESL-treated subjects had statistically-significantly lower SSQ total scores (1200 mg), less severity and bother during seizures (1200 mg), less cognitive, emotional and physical impact during postictal recovery (1200 mg), and lower overall levels of seizure severity and bother (1200 mg and 800 mg) than placebo-treated subjects.

PND45

SCREENING FOR PBA SYMPTOMS USING A SINGLE QUESTION VERSUS A 7 QUESTION MEASURE AND ASSESSMENT OF THE ASSOCIATION OF PBA SYMPTOMS WITH HRQOL BURDEN

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BACKGROUND: PBA, characterized by uncontrollable episodes of crying and/or laughing, often exaggerated or inappropriate to the mood state, can occur in persons with neurological disorders or injury of the brain. **OBJECTIVES:** Compare PBA survey instruments and estimate prevalence of PBA symptoms and health-related quality of life (HRQOL) burden in Veterans with TBI. **METHODS:** Cross-sectional survey with patient-level linkage to VA clinical data. OEF/OIF Veterans screening positive for TBI were mailed the seven-item Center for Neurologic Study-Lability Scale (CNS-LS) questionnaire with an initial question asking if the Veteran had "involuntary episodes of crying and/or laughing that were exaggerated or even contrary to how they felt at the time". The EQ-5D, a standardized HRQOL questionnaire, was included. The presence of PBA symptoms was defined in this study as CNS-LS score ≥ 13 . The sensitivity of the "involuntary episodes" question was assessed against the CNS-LS. **RESULTS:** The 4400 Veterans mailed surveys were predominantly male (95%); mean(SD) age 34(8.8) years. 728 Veterans returned surveys. Among respondents, 60% answered "yes" to the "involuntary episodes" question and 70% had CNS-LS ≥ 13 (PBA symptoms). The ROC curve for the "involuntary episodes" question indicates optimal sensitivity/specificity at CNS-LS score of 12. Comorbidities diagnosed in the CNS-LS ≥ 13 population included: PTSD (53.4%), major depression (34.5%), headaches/migraine (20.0%) and anxiety disorders (20.4%); in contrast, prevalence for the same comorbidities among Veterans with CNS-LS < 13

were 32.3%, 22.0%, 13.9%, and 13.0%, respectively. These rates were similar to those in non-responders. Respondents with PBA symptoms (CNS-LS ≥ 13) reported significantly poorer HRQOL in all EQ-5D domains. Mean scores were worse for anxiety/depression, pain/discomfort, and usual activities; 85% reported at least moderate pain or anxiety/depression; 50% reported at least moderate problems with usual activities. **CONCLUSIONS:** PBA symptoms assessed by either CNS-LS or the "involuntary episodes" question are prevalent among Veterans with TBI who responded to the survey. PBA symptoms were correlated with worse HRQOL.

PND46

USE OF DIARY ALARMS ON ELECTRONIC DEVICES FOR COLLECTING DATA FROM MIGRAINE SUBJECTS WITH PHONOPHOBIA

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OBJECTIVES: Electronic Patient Reported Outcomes (ePRO) such as daily diaries are often used in migraine clinical trials to collect information regarding migraine frequency, duration, severity, and symptoms. In general, alarms are an effective tool for prompting subjects to complete diaries on schedule. However, 70-80% of migraineurs suffer from phonophobia during a migraine. Thus, it is possible that an alarm may worsen symptoms. To address this, a decibel meter was used to measure the sound level of alarms on three models of the PHT LogPad handheld electronic device, and readings were compared to published sound aversion thresholds (SAT) for migraineurs. **METHODS:** The LogPad (LW, CV and LV) models were placed at a distance of one or five feet from the decibel meter. Alarm sound was measured on two devices in triplicate at each sound setting. **RESULTS:** The SAT for migraineurs is reported to be approximately 76 decibels (db) (ictal) and 91 db (interictal). Healthy subjects have a SAT of 105 db. When the LogPad LW and decibel meter were placed one foot apart, the decibel meter measured 58, 67, 75, and 83 db at the normal, medium, high and very high sound settings, respectively, and measured 76 db for the CV and 80 db for the LV models. When any LogPad model was placed five feet away from the decibel meter, all readings were below the ictal SAT for migraineurs. **CONCLUSIONS:** Even at a 1 foot distance, the alarm volume on the LogPad LW can be set below the ictal SAT for migraineurs and is also above background sound. At a distance of 5 feet, all models tested are below SAT and above background. Therefore, the LogPad is a suitable handheld electronic device to use with migraineurs that suffer from phonophobia with alarm volumes that can be used below SAT.

PND47

FREQUENCY AND NATURE OF PATIENT-REPORTED OUTCOME CONVERSATIONS BETWEEN PHYSICIANS AND PATIENTS WITH CYSTIC FIBROSIS

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OBJECTIVES: To describe the frequency and nature of patient-reported outcome (PRO) conversations between physicians and patients with Cystic Fibrosis. **METHODS:** A random sample of de-identified patients with Cystic Fibrosis in the United States was selected from a large de-identified database of medical office visit transcriptions. Transcriptions were based on physician-dictated voice recordings detailing every individual patient encounter/visit. De-identified medical visit transcriptions were analyzed to evaluate the burden associated with Cystic Fibrosis, as depicted by PRO topics observed in patient-physician dialog in the real-world practice setting. Descriptive statistics are reported. **RESULTS:** 333 transcriptions of medical encounters between 130 physicians (most commonly pediatricians 11%, internists 10%, pulmonologists 8%, general practitioners 8%, and surgeons 8%) and 183 patients over a 2-year period were evaluated (patient mean age: 31yrs; 27% <18yrs, male: 55%). Non-symptom related PROs, including quality of life and psychosocial impacts, were discussed by 50 patients (27%) (10% of patients <18yrs, 34% of patients ≥ 18 yrs); the most commonly reported concerns were related to anxiety ($n=16(9\%)$), depression ($n=14(8\%)$), ability to perform daily activities ($n=7(4\%)$), and work/school productivity ($n=6(3\%)$). Symptom-related PROs were discussed by 108 patients (59%) (52% of patients <18yrs, 62% of patients ≥ 18 yrs); the most commonly reported symptoms were cough ($n=51(28\%)$), difficulty breathing ($n=25(14\%)$), and difficulty gaining/maintaining weight ($n=15(8\%)$). **CONCLUSIONS:** PROs, as a function of disease burden, were routinely discussed by patients with Cystic Fibrosis. PRO discussions were observed more frequently among adult patients than the pediatric patients, and symptom-related PROs were discussed more frequently than PROs related to quality of life and psychosocial impacts. Modalities to alleviate this patient burden, including appropriate therapeutic interventions, warrant scrutiny.

PND48

DETERMINANTS OF QUALITY OF LIFE OF CHILDREN WITH EPILEPSY IN INDIA

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OBJECTIVES: The objectives of this study were to assess the quality of life and the determinants affecting QoL in children with epilepsy using Pediatric quality of life questionnaire (PedsQL). **METHODS:** A prospective observational study was conducted at a public hospital. In these study children less than 18 years of age, diagnosed with epilepsy were included. HRQoL was assessed using PedsQL, which comprised of 23 questions related to physical, emotional, social and school functioning. After getting consent, scale was administered to both parents and subjects separately. Multivariate logistic regression was done to assess the potential determinants of low HRQoL scores. **RESULTS:** A total of 270 children with epilepsy were included in this study. Mean age and mean duration of antiepileptic drug treatment was found to be 11.2 years and 21.6 \pm 12 months respectively. Mean total score according to PedsQL was found to be 89.6 \pm 6.7 (Psychological subscale score 84.7 \pm 1.2, physical subscale score 94.4 \pm 5.9, emotional subscale score 85.6 \pm 16, social subscale score 94.7 \pm 9.9 and school subscale score 73.9 \pm 12.5). Long duration of antiepileptic