response in part II and III (p = 0.0078 and p = 0.0072, respectively), a trend to better results for the LCE group was observed in part I and IV. CONCLUSIONS: Levodopa/carbidopa/entacapone shows a significant better patient and physician global perception in the LCE treatment group vs. LC group in PD patients with early WO and ADLs deterioration.

DIFFICULTIES IN IDENTIFYING THE ORIGINAL SOURCE QUESTIONNAIRE FOR USE IN TRANSLATIONS: THE ADAS-COG CASE STUDY

PND18

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OBJECTIVES: Since its development in the 80’s, variations of the Alzheimer’s Disease Assessment Scale-Cognitive subscale (ADAS-Cog), a Clinician-Reported Outcome (ClinRO) measure, have been used to monitor disease progression and treatment efficacy in Alzheimer’s disease. The objective of this study was to identify all versions used as a basis for translation in Mapi Institute projects and to take stock of existing translations. METHODS: The review was based on all ADAS-Cog translation projects performed by Mapi Institute. RESULTS: Sixteen projects were identified representing a total of 70 languages and 219 translations. Translations were based on 11 source versions which differed in terms of content (number of items, order of items and instructions), and format. The number of items ranged from 11 to 15. Four studies used 13 items, but only in two cases the same items were used although in a different order. Four studies used 12 items: only two studies used the same items (with a different list of words for the Word Recognition Task), but again in a different order. Format and instructions differed in all cases. In most projects the source version provided by the sponsor was a single document, mixing instructions with the rater and response forms. Only in 3 cases the original consisted in a separate instrument manual and response form. With regard to available translations, more than one translation was identified in 56 of the 70 available languages and in one language (Swedish) as many as 7 translations. CONCLUSIONS: The abundance of different versions of the same questionnaire both in its original US English form as in translations makes comparisons between studies or pooling of data difficult for both researchers and users. In the light of FVA’s recent PRO guidance it would be beneficial to demand the same scientific rigor when using ClinROs in international studies.

RESPONSIVENESS OF THE MULTIPLE SCLEROSIS INTERNATIONAL QUALITY OF LIFE QUESTIONNAIRE TO EXPANDED DISABILITY STATUS SCALE SCORE CHANGES IN PATIENTS WITH MULTIPLE SCLEROSIS: MONTH 12 RESULTS FROM AN INTERNATIONAL OBSERVATIONAL STUDY

PND19

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OBJECTIVES: Quality of life (QoL) is an important measure that is often overlooked in the assessment of multiple sclerosis (MS). The MS International Questionnaire (MusilQoL) questionnaire is a validated, MS-specific instrument. This study aimed to assess the responsiveness of the MusilQoL questionnaire to changes in Expanded Disability Status Scale (EDSS) scores in patients with MS. METHODS: In this ongoing, 24 months observational study MusilQoL and EDSS scores were recorded at baseline (BL) and at 6-month intervals. The primary endpoint is change in MusilQoL index score from BL to month 24 (including effect size). Secondary endpoints include change in MusilQoL index score from BL to month 12 and change in MusilQoL scale scores. RESULTS: Of 900 patients enrolled, 474 had evaluable BL and month-12 EDSS and MusilQoL index data. At BL, mean (SD) EDSS score was 2.9 (1.9); mean (SD) MusilQoL index score was 68.5 (14.4); and mean (SD) MusilQoL scale scores ranged from 59.9 (24.8) to 85.4 (18.5). At month 12, 68 patients (14.3%) had a worse EDSS score than that recorded at BL. Mean (SD) change in MusilQoL index score was 0.48 (10.99) overall, and −1.00 (9.88) in “worstened” patients; effect sizes were 0.03 and −0.08, respectively. Changes from BL to month 12 in MusilQoL scale scores were mostly small. However, there were large (mean [SD]) decreases in some subscales at month 12 for “worstened” patients: ‘Activities-of-daily-living’ (−4.20 [18.07]); ‘Relationships-with-family’ (−5.14 [23.43]); ‘Sentimental-and-sexual-life’ (−4.11 [17.56]); and ‘Relationship-with-health-care-system’ (−3.56 [14.11]). Effect sizes were −0.17, −0.25, −0.14 and −0.21 respectively. Conversely, the mean (SD) change in ‘Symptoms’ score was 1.36 (17.27) at month 12 for ‘worstened’ patients (effect size: 0.24). CONCLUSIONS: As expected, most MusilQoL scores decreased over 12 months in patients with worsening EDSS scores, indicating poorer QoL and confirming the utility of the MS-specific MusilQoL in rating QoL.

QUALITY OF LIFE OF CAREGIVERS IN HUNTINGTON’S DISEASE—FIRST RESULTS FROM EURO-HDB STUDY

PND40

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OBJECTIVES: Huntington’s disease (HD) is a rare neurodegenerative disease leading to significant disability for patients and poor quality of life (QoL) for patients as well as caregivers. This study investigated the impact of HD on caregivers’ QoL and its drivers. METHODS: The European HD burden study (Euro-HDB) is an ongoing cross-sectional survey among HR patients and their caregivers in six countries (France, Italy, Germany, UK, Sweden and Australia). The burden of Huntington’s disease Quality of Life Battery for Carers (HDQ-C-L) short version, a previously validated questionnaire by Aubeluck A. and Buchanan H., was administered. Pearson correlations with generic HR-QOL (SF36, EQ5D) and the specific HR-QOL in HD for patients (HQQOL) were evaluated. The determinants of caregiver QOL among drivers among patients’ clinical characteristics (voluntary movement disorders, chorea, depression/anxiety, psychotic disorder, cognition, temper) were studied by regression analysis adjusting on age, sex and occupational categories. The relationship between QOL of patients and caregivers were also explored. RESULTS: To date, 201 caregivers in France and 124 in Italy have been enrolled. For France (respectively Italy) 6% (12%) were significantly satisfied by their overall QOL and 7% (5%) were totally satisfied. HDQ-C-L scores were poorly correlated with generic caregiver HR-QOL: correlation equalled 0.31 for EQ3D utility and varied between 0.04 and 0.45 for the eight domains of SF36. Correlation was quite high (0.59, p < 0.01) between HDQ-C-L and HQQOL. Drivers of caregiver’s QoL were voluntary movement disorders (p = 0.049), depression/anxiety (p = 0.02), psychotic disorder (p = 0.01) and cognition (p = 0.01). Temper and chorea were not drivers of caregivers’ QoL independently of other clinical characteristics. CONCLUSIONS: Caregivers HDQ-C-L worsened the patient clinical characteristics especially voluntary movement disorders, depression/anxiety, psychotic disorders and cognition disorders. Patients and caregiver QoL was indirectly correlated via patient clinical scores. The potential impact on caregiver QOL should be considered in evaluations of innovative HD treatments.

THE IMPACT OF PAIN SEVERITY AND FREQUENCY ON HRQOL IN THE BIG 5 EUROPEAN UNION COUNTRIES

PND41

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OBJECTIVES: This study assesses, for an estimated EU pain population of 50 million patients, the impact of pain severity and frequency on three dimensions of health related quality of life (HRQOL): the SF-12 MCS and PCS scores and (ii) the SF-6D absolute utility scores. METHODS: The study is based on data from the internet based 2008 National Health and Wellness Survey undertaken in the UK, France, Spain, Germany and Italy. This study identified 11,000 respondents (1 in 3 of the estimated big 5 EU countries) who had experienced pain in the last month. The assessment of the quantitative impact of pain status on HRQOL is estimated via three single equation general linear (ordinary least squares) models which estimate the impact of pain on PCS, MCS and utility scores. The model includes a range of variables which have previously been shown to influence report HRQOL status. RESULTS: Pain has a substantial impact on all three of the dimensions of health status (PCS = −3.85; MCS = −4.72; SF-6D utilities = −0.147). There is a marked gradient on scores by severity and frequency of pain experience. The impact of pain on HRQOL is more significant than the impact of socio-demographic characteristics, health risk behaviors, comorbidity status, medication utilization, duration of medication utilization and satisfaction with care. The experience of pain is captured by a combination of severity and frequency categorical variables. CONCLUSIONS: Pain has a substantial impact on all three of the dimensions of HRQOL with a significant burden on persons reporting pain in the big 5 EU countries; the burden increases the greater the frequency and severity.

THE RELATIONSHIP BETWEEN SOME INDICATORS INFLUENCING THE QUALITY OF LIFE OF PEOPLE WITH DOWN’S SYNDROME LOOKED AFTER IN THE FAMILY AND PARENTAL QUALIFICATION IN CONJUNCTION WITH A STUDY CARRIED OUT IN HUNGARY

PND42

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OBJECTIVES: The aim of the study was to survey some subjective and objective indicators determining the quality of life of people with Down’s syndrome (DS), born between 1975 and 2005, looked after in their families in the Southern-Transdanubian region of Hungary. The relationship between the parental level of education and the above factors was explored. METHODS: On the basis of the VRONY database (National Registry of Congenital Anomalies) health visitors contacted families looking after DS people (N = 107), and conducted anonymous, questionnaire surveys in 2006-2009. Reading was examined from school-age (N = 79), drawing and writing was examined depending on age. RESULTS: The abilities under examination moved...