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PSY48

INDIRECT COSTS OF SYSTEMIC LUPUS ERYTHEMATOSUS-RELATED ABSENTEEISM IN POLAND: AN ANALYSIS BASED ON SOCIAL INSURANCE

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PSY49

CHARACTERIZING DISEASE BURDEN IN AN ULTRA-RARE DISEASE IN THE UNITED STATES: TRANSTHYRETIN (TTR) AMYLOIDOSIS PATIENTS &

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OBJECTIVES: TTR amyloidosis, a progressive, degenerative ultra-rare genetic disease, can cause familial amyloid polyneuropathy (TTR-FAP) and cardiomyopathy (TTR-CM), requiring substantial caregiver support. This study evaluated the burden of illness on patients' and caregivers' work productivity, health care resource use (HCRU), and health-related quality of life (HRQoL). METHODS: An online survey including the Work Productivity & Activity Impairment (WPAI) questionnaire, EQ-5D, & HCRU questions recruited TTR-FAP and TTR-CM patients and caregivers through two U.S.-based patient advocacy groups. RESULTS: Thirty-three TTR patients (26 males) and 18 caregivers (7 males) completed the survey. Most were aged over 60; mean disease duration was approximately 6 years (patients) or 5 years (caregivers with disease). Most patients and caregivers had a college degree. Generally caregivers (77.8%) were the primary caregiver for their patient; 61.1% also had amyloidosis. Unemployment was high in patients with TTR-FAP (42.9%), TTR-CM (60.0%), both TTR-FAP/CM (71.4%); only 33.3% of caregivers reported working part/full-time. Employment was highest for TTR-FAP patients (n=10), yet 11.8% missed work, 32.2% were impaired at work and 38.5% reported overall work impairment due to TTR. Liver transplant, the primary treatment option, occurred in 42.4% patients and 18.2% caregivers with disease. A majority of patients reported outpatient visits to health care providers in the past 3 months for disease: 85.7% TTR-FAP, 100% TTR-CM, and 85.7% for TTR-FAP/CM. Hospitalization rates ranged from 14.3-30.0% across all patient groups, with 14.3-23.8% for emergency visits. EQ-5D Index scores for patients were 0.80 (SD=0.14) with transplant, and 0.68 (SD=0.16) without transplant. Caregivers with disease and transplant had lower EQ-5D Index scores (M=0.14, SD=0.35) than those without transplant (M=0.41, SD=0.32). The pattern was similar for EQ-5D VAS results for patient and caregiver groups. **CONCLUSIONS:** TTR amyloidosis is associated with substantial disruption in employment rates, work productivity, high levels of resource use, and poor HRQoL for patients and caregivers.

RESOURCE CONSUMPTION EVALUATION ASSOCIATED WITH RITUXIMAB ADMINISTRATION IN PORTUGAL

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OBJECTIVES: Determine the costs associated with rituximab intravenous (iv) preparation and administration in follicular non-Hodgkin lymphoma (NHL) and estimate the difference versus rituximab subcutaneous (sc) formulation, considering material resources (MR) consumption and health care professionals (HCP) time spent in each procedure. Patient's and chair time savings in hospital Day Care Unit (DCU) were also estimated. METHODS: Rituximab iv data was collected, between November 2012 and January 2013, through face to face interviews with pharmacists and DCU nurses responsible for the preparation and administration in each hospital. The HCP time cost was calculated by multiplying their income per hour by the average time spent on each procedure; MR costs were determined based in official databases or in "table values" provided by the manufacturers. Rituximab sc administration time was based in the respective pivotal clinical trial - SABRINA (BO22334). RESULTS: Ten hospitals from mainland Portugal were included, with a weekly average of 7 NHL patients treated with rituximab iv. The HCP average overall active time spent

with rituximab iv preparation and administration, per treatment cycle, was about 89 minutes versus 16 minutes estimated for sc. An average overall cost reduction of 93% was estimated with sc versus iv (3€ versus 45€, respectively). DCU chair time capacity could be increased by 3 and 7 fold if one considers combination or maintenance therapy, respectively, with rituximab sc versus iv, due to SC much faster administration. Rituximab sc reduces the overall time patients spend in an infusion chair by 95% (7 min with sc vs.143 min with iv). CONCLUSIONS: Rituximab sc formulation potentially offers significant resource (material and HCP time) savings, improves hospital organization and provides clear benefits for patients regarding time saved and administration convenience. Ultimately, rituximab sc increases hospital efficiency that's critical in the current economic climate.

SYSTEMIC DISORDERS/CONDITIONS - Patient-Reported Outcomes & Patient Preference Studies

THE ASSOCIATION BETWEEN SEVERITY OF 'AVERAGE' PAIN (NPRS) AND THE EQ-5D INDEX IN PATIENTS WITH NEUROPATHIC PAIN Chambers C¹, Odeyemi I², Currie C³, Poole CD³

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OBJECTIVES: Pain is an important driver of health-related utility. Our purpose was to characterise the association between pain severity and the EQ-5D index. METHODS: Paired values for the Numerical Pain Rating Scale (NPRS) average pain score (previous 24 hours) and the EQ-5D index were available from a prospective, non-interventional study of people with neuropathic pain treated with an 8% capsaicin patch (QutenzaTM). The NPRS records pain on an integer scale between 0 and 10 units, representing no pain and worst imaginable pain, respectively. The EQ-5D index is derived from impairment level (none/moderate/severe) across five domains (Mobility, Self-care, Usual activities, Pain & discomfort, Anxiety & depression), and values health-related utility on a scale of 1 to 0, meaning perfect health and death, respectively. Generalized linear mixed models with a normal probability distribution, identity link function, and a first-order autoregressive covariance structure were tested to determine the relationship between EQ-5D index score (scale) and NPRS average 24 hour pain score (ordinal). **RESULTS:** For the purposes of this preliminary analysis, 170 patients with NP contributed 353 combined observations from baseline observation and follow-up assessments at week-8 and week-12. The GLMM model that best fitted the data (smallest Information criterion) had one random effect (subject + intercept) and one fixed effect (NPRS + intercept). The fixed-effects coefficients were: (Intercept) 0.728 + (NPRS1: β 0.000; 95%CI -0.0186, 0.186) + (NPRS2: -0.045;-0.205,0.116) + (NPRS3: -0.075;-0.227,0.078) + (NPRS4: -0.207;-0.364,-0.049) + (NPRS5: -0.181;-0.338,-0.024) + (NPRS6: -0.315;-0.471,-0.159) + (NPRS7: -0.323;-0.478,-0.167) + (NPRS8: -0.458;-0.618,-0.299) + (NPRS9: -0.638;-0.825,-0.451) + (NPRS10: -0.740; -0.927,-0.553). Predicted utility was highly correlated (R^2 =0.753) with observed utility. Mean squared error for predicted utility was 0.033 (sd 0.052). CONCLUSIONS: Neuropathic pain was highly correlated with utility with a difference of around 0.8 utility units across the NPRS range. All domains of the EQ-5D differed across the NPRS.

PSY52

MEASURING PROS THAT MATTER TO BARIATRIC AND BODY CONTOURING SURGERY: THE BODY-Q

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OBJECTIVES: Health care payers are interested in funding bariatric surgery because it resolves a range of obesity-related health problems. However, following weight loss, many patients are left with unsightly excesses of skin and require body-contouring surgery. Our team has developed a new PRO instrument (i.e., the BODY-Q) to measure satisfaction and quality of life of bariatric and body-contouring surgery patients. Unlike existing PRO instruments, the BODY-Q is composed of scales that measure appearance-related concerns, which is an important reason why patients seek treatment. The BODY-Q also stands apart as it the only PRO instrument designed to measure change in patients concerns throughout the entire weight loss journey. METHODS: We followed international guidelines for the development of a PRO instrument. This abstract presents Phase I results, i.e., qualitative phase. Patient stories were used to develop a conceptual framework covering the key concerns of patients, and to develop a set of preliminary items. Items were grouped into clinically meaningful scales and instructions and four-point response options were developed. The scales were refined by obtaining feedback from a sample of surgical experts and patients. RESULTS: From 59 patient interviews, we developed a conceptual framework. Over 3,500 preliminary items were developed and used to inform the following 17 independently functioning scales: 1) appearance scales measuring the body, abdomen, upper arms, buttocks, inner thighs, hip and outer thighs, skin and scars; 2) quality of life scales measuring body image, sexual, psychological and social wellbeing, physical function and symptoms; and 3) process of care scales measuring satisfaction with information, doctor and office staff. **CONCLUSIONS:** Phase II involves a multicentered field-test in Canada and the USA. Rasch Measurement Theory analysis will be used to determine which items to retain in each scale based on their performance against a standard set of psychometric criteria.

THE USE OF PREFERENCE BASED MEASURES IN HAEMOPHILIA: IS THE CURRENT EVIDENCE BASE USEFUL FOR EVIDENCE BASED DECISION MAKING?

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