

in platelet count. During recovery phase WBC count increased first followed by platelets count production after 3-4 days. Among 1000 confirmed dengue fever patients 812 were considered dengue hemorrhagic fever cases on the basis of clinical finding. In most of these cases (n=783; 96.47%), directly proportional relation was observed between WBC and platelets count. **CONCLUSIONS:** It is wrongly perceived in community that dengue virus infection is still progressing when platelets count is below normal even the white blood cells counts is getting better during recovery phase. White blood cells production during recovery phase is a good indicator about recovery of disease rather than focused on platelets counts production.

#### PSY87

##### PHYSICIANS' AND PATIENTS' PREFERENCES OVER THE ATTRIBUTES OF BIOLOGICAL AGENTS USED IN THE TREATMENT OF RHEUMATIC DISEASES IN SPAIN: A CONJOINT ANALYSIS

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**OBJECTIVES:** To define the importance values assigned to the attributes of biological agents (BA) by Spanish rheumatologists and patients with rheumatic diseases: rheumatoid arthritis (RA), ankylosing spondylitis (AS) and psoriatic arthritis (PA). **METHODS:** Observational, cross-sectional design based on conjoint analysis. RA, AS and PA patients diagnosed at least 2 years prior and currently or previously ( $\leq 1$  year ago) receiving BA for a minimum of 1 year were consecutively recruited. Rheumatologists with at least 3 year experience on BAs participated. A literature review and 4 focus groups were undertaken to identify attributes and levels. Scenarios were selected using orthogonal design. Participants ranked 8 scenarios from 1 (most preferred) to 8 (least preferred). Relative importance (RI) of attributes was calculated. Multivariate regression analysis was performed for each attribute. **RESULTS:** 488 patients [male=50.9%; mean (SD) age=50.6 (12.06) years; RA=33.8%, AS=32.4%, PA=33.8%; mean time from diagnosis=12.6 (8.2) years] and 136 rheumatologists [male=50.4%; mean age=46.4 (9.1) years; mean time of practice=16.7 (8.8) years] took part. Most important attributes selected by patients and physicians, respectively, were: 'Pain relief and improvement of the functional capacity' (RI=49.1% and 48.9%); 'Risk of adverse events' (RI=31.8% and 31.5%), 'Administration method' (RI=10.2% and 11.4%) and 'Time to perceive the need for a new dose' (RI=9.0% and 8.2%). The ideal BA, for patients and physicians, should allow pain relief and an improvement of the functional capacity, with a low risk of adverse events, a long time prior to perceiving the need for a new dose and self-administration at home, when possible. **CONCLUSIONS:** Although efficacy and safety are key for patients with rheumatic diseases and rheumatologists to make a choice over a BA, the need for a low frequency of administration and the administration method also play an important role as preference attributes for BAs in Spain.

#### PSY88

##### PREFERENCES OF SPANISH PATIENTS OVER THE ATTRIBUTES OF BIOLOGICAL AGENTS FOR THE TREATMENT OF RHEUMATIC DISEASES DEPENDING ON THE ADMINISTRATION ROUTE

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**OBJECTIVES:** Biological agents (BA) to treat rheumatic diseases are commonly administered by either the subcutaneous or the intravenous route. The objective of this study was to assess rheumatoid arthritis (RA), ankylosing spondylitis (AS) and psoriatic arthritis (PA) Spanish patients' preferences over BA considering the administration route. **METHODS:** Observational, cross-sectional design. Participants were RA, AS and PA patients (diagnosed  $\geq 2$  years prior to study entry; currently or previously ( $\leq 1$  year ago) receiving BA for a minimum of 1 year. Conjoint analysis was performed to define preferences over 8 scenarios combining 4 attributes ['Administration method' (ADMINISTRATION), 'Pain relief and improvement of the functional capacity' (RELIEF), 'Risk of adverse events' (AE) and 'Time until perceiving the need for a new dose' related to the frequency of administration (TIME)]. Relative importance (RI) was calculated for patients on subcutaneous or intravenous administration, respectively. **RESULTS:** A total of 488 patients [male=50.9%; mean (SD) age=50.6 (12.06) years; RA=33.8%, AS=32.4%, PA=33.8%; mean time from diagnosis=12.6 (8.2) years; receiving currently BA=98.2%] were included. The patients currently receiving subcutaneous (n=305) or intravenous (n=174) administration with BA gave highest importance to 'RELIEF' (45.4% and 46.7%) and 'AE' (28.2% and 31.8%), followed by 'ADMINISTRATION' (19.7% and 10.2%) and 'TIME' (6.7% and 11.3%, respectively). Both groups of patients preferred to stay on the same route of administration, either subcutaneous or intravenous, they had been on. Moreover all patients considered most crucial a longer time until perceiving the need for a new dose (8 over 4 over 2 over 1 week). **CONCLUSIONS:** Spanish patients with rheumatic diseases placed high importance on pain relief and risk of AEs as preference attributes for BAs. The frequency of administration (time until perceiving the need for a new dose) also plays a crucial role as all patients indicated their preference for lower vs. higher frequencies of BA administration.

#### PSY89

##### PREFERENCE FOR RITUXIMAB SUBCUTANEOUS (SC) AND INTRAVENOUS (IV) AMONG PATIENTS WITH CD20+ NON-HODGKIN'S LYMPHOMA (NHL) COMPLETING THE RASQ MEASURE IN RANDOMIZED PHASE III STUDIES PREFMAB AND MABCUTE

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**OBJECTIVES:** Rituximab SC reduces administration times (~5 minutes) compared with the IV route (~4 hours). We examined the extent of patient preference for rituximab SC versus IV in the PrefMab and MabCute studies using the Rituximab Administration Satisfaction Questionnaire (RASQ). **METHODS:** In PrefMab (NCT01724021) patients with untreated CD20+ DLBCL/FL received 1 cycle of IV rituximab (375mg/m<sup>2</sup>) followed by either SC rituximab (1400mg, x3) then IV rituximab (x4), or IV rituximab (x3) then SC rituximab (x4), with chemotherapy. In MabCute (NCT01461928) patients with relapsed/refractory CD20+ indolent NHL received induction rituximab IV (375mg/m<sup>2</sup>; 1 cycle) then rituximab SC (1400mg; cycles 2-8) plus 6-8 chemotherapy cycles. RASQ evaluated preference by assessing patients' perceptions of the impact of administration route and treatment satisfaction. Conceptual validation of RASQ has been conducted and psychometric data will be reported. **RESULTS:** Median RASQ scores for PrefMab were: convenience IV (n=211) 58.3 (interquartile range: 41.7-75.0) and SC (n=207) 83.3 (75.0-91.7); satisfaction: IV (n=211) 75.0 (62.5-87.5), SC (n=208) 87.5 (75.0-100.0); impact on daily life: IV (n=145) 50.0 (41.7-83.3), SC (n=163) 83.3 (83.3-100.0); physical impact IV (n=211) 83.3 (66.7-100.0), SC (n=208) 83.3 (75.0-100.0); psychological impact IV (n=211) 80.0 (65.0-90.0), SC (n=208) 88.8 (75.0-95.0). SC administration was preferred by 80.3% and 85.9% of patients with IV or SC as most recent dose, respectively. Results were similar irrespective of treatment sequence. Median RASQ scores for MabCute (n=92) were: convenience: IV 58.3 (33.3-66.7), SC 83.3 (66.7-83.3); satisfaction: IV 62.5 (50.0-87.5), SC 87.5 (75.0-100.0); impact on daily life: IV 58.3 (41.7-66.7), SC 83.3 (66.7-83.3); physical impact IV 75.0 (66.7-91.7), SC 83.3 (66.7-91.7); psychological impact IV 70.0 (60.0-85.0), SC 85.0 (75.0-95.0). **CONCLUSIONS:** Consistent patient satisfaction and preference for SC versus IV rituximab was demonstrated in the PrefMab and MabCute studies. RASQ is a reliable and valid measure of patient treatment preference.

#### PSY90

##### A SYSTEMATIC LITERATURE REVIEW OF THE HUMANISTIC BURDEN OF MULTIPLE MYELOMA

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**OBJECTIVES:** We conducted a systematic literature review to identify published evidence from observational studies on the humanistic burden of multiple myeloma (MM). **METHODS:** We searched MEDLINE, Embase, EconLit, and the Cochrane Library for English-language articles and analysed these qualitatively. **RESULTS:** The review identified 20 publications based on 18 observational studies; these were mainly cross-sectional in design (n=14). Most studies (n=15) examined populations with MM in general, typically without stating the proportion with relapsed (R) or relapsed and refractory (RR) MM. Fewer studies examined patients with newly-diagnosed MM (n=2) or RMM/RRMM (n=1). Health-related quality of life (HRQoL) was typically assessed using validated cancer-specific instruments (e.g., the EORTC-QLQ-C30; n=9; and the MM-specific EORTC-QLQ-MY20; n=4). On average, patients with MM had poorer HRQoL compared to the general population (n=6), and compared to patients with certain other hematologic cancers (n=2). MM patients whose disease duration ranged from diagnosis to 11 years had greater physical function impairment (p<0.001) than other hematologic cancer patients. Other complaints included fatigue, bone pain, tingling, and non-specific pain. Patients on active treatment had worse side effects than those in a first treatment-free interval (p<0.001); the latter had better scores on HRQoL dimensions including role and social function, future perspectives, and body image (all p<0.05). Between baseline and one year, patients experienced worsening on the EORTC-QLQ-C30 global health scale (p<0.001) and in fatigue, nausea/vomiting, and pain scores (all p<0.05). Symptomatic patients had lower physical functioning scores (p<0.05) than asymptomatic patients; those with severe symptoms had lower EORTC-QLQ-C30 global health scores (p<0.05; mild/moderate symptoms: p=NS). Fatigue, bone pain, and anaemia were associated with lower. **CONCLUSIONS:** HRQoL in patients with MM deteriorates with disease duration, symptom severity, disease progression, or development of complications. This evidence suggests substantial unmet needs in MM patients.

#### PSY91

##### PATIENT-REPORTED OUTCOMES IN MODERATE TO SEVERE HEMOPHILIA PATIENTS: FINDING FROM A CROSS-SECTIONAL STUDY IN KOREA

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**OBJECTIVES:** There are approximately 2,000 hemophilia patients in Korea, but patient-reported outcome (PRO) studies involving a large number of hemophilia patients have been rarely studied. The aim of this study was to assess PROs in moderate to severe hemophilia patients in Korea. **METHODS:** It was a cross-sectional, multi-centered and observational study. Moderate to severe, male hemophilia patients aged 8 to 65 were recruited at 2 of Korea Hemophilia Foundations and 3 other pediatrics from November 2012 to September 2013. All patients completed self-reported questionnaires to measure patients' characteristics and PROs including health-related quality of life (HRQoL) and productivity loss. HRQoL was examined using EQ-5D, ranged 0-1, which higher values indicate better HRQoL and Heamo-QoL, ranged 0-100, where higher values imply lower HRQoL. Productivity loss was estimated with absenteeism and presentism in terms of lost productivity time (LPT). **RESULTS:** For a total of 605 patients, the mean scores of heamo-QoL and EQ-5D were 32.28 and 0.68 respectively. The mean scores of EQ-5D in this study are comparable to 0.68 in rheumatoid arthritis patients from Korea Observational Study Network for Arthritis. Significantly lower EQ-5D was found in patients with the following clinical factors compared to those with reverse conditions: joint bleedings (0.68 vs. 0.73, p=.001),

hemophilic joint health (0.67 vs. 0.73,  $p < .001$ ) or disability (0.65 vs. 0.70,  $p < .001$ ) as similar as in the results of Haemo-QoL. With patients who were either on a job or students ( $n=467$ , 77.2%), LPT was estimated at 127.81 hours per month on average. Of 467, patients with inhibitor or disability showed higher LPT compared to those without inhibitor (130.61 vs. 126.61 hours per month,  $p=0.486$ ) or disability. (132.27 vs. 124.95 hours per month  $p=.087$ ). **CONCLUSIONS:** The study findings suggest that patients' clinical characteristics should take into account for the management of hemophilia given patient-reported outcomes differed by clinical manifestations.

#### PSY92

##### BURDEN OF LUPUS NEPHRITIS (LN) AMONG PATIENTS MANAGED IN ROUTINE CLINICAL PRACTICES IN EUROPE (EU)

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**OBJECTIVES:** To assess the burden of LN in comparison to SLE patients without Nephritis (Non-LN) in routine clinical practices in EU. **METHODS:** A multi-center medical chart-review of adult (16-89yrs) SLE patients was conducted among rheumatologists and internal medicine physicians in UK/France/Germany/Italy/Spain (5EU). Physicians were recruited from a geographically representative sample in each country. Approx. 5 consecutive eligible persistent active or relapse remitting SLE patients currently managed as part of usual care were identified. Physicians abstracted de-identified patient data on disease characteristics, lab values and treatment patterns. LN and Non-LN cohorts were compared using descriptive statistics. **RESULTS:** 168 LN patients and 569 non-LN patients with SLE were analyzed. Patient characteristics included (LN/Non-LN): age (yrs): 40.2/42.7; % Female: 82.7/79.4; % Caucasian: 82.7%/88.8%; % full-time employment: 32.1/36.0; % part-time employment: 19.0%/22.0%. Among LN/Non-LN cohorts, frequency of clinic visits was: 9.5wks/10.6wks, % currently receiving care in in-patient setting was: 14.9/8.8, % hospitalized  $\geq 1$  in the past-year was: 49.4/29.7; mean # of organ manifestations was: 3.9/3.0. Top-5 organ manifestations were (% LN/Non-LN): musculoskeletal: 85.1/90.8, mucocutaneous: 85.1/84.8, haematologic: 51.8/52.2, renal: 100.0/5.9, pulmonary: 16.7/16.2; % experiencing a flare was (LN/Non-LN): 23.2/16.6. Renal biopsy was performed in 87.5% (LN) and 4.0% (Non-LN) of patients. Steroids were used by 82.1% (LN) and 69.4% (Non-LN). % patients with low C3 and C4 was LN: 66.3/48.1/Non-LN: 60.2/50.0; mean ESR scores were 40.2 (LN) and 36.8 (Non-LN). Among patients with available data, SELENA-SLEDAI scores were 11.5 (LN) and 8.5 (Non-LN). Humanistic burden (reported via physician ratings, on a scale of 0 (most impact) to 7 (least impact)) was (LN/Non-LN, mean scores): ability to perform every-day tasks: 5.0/5.3, ability to interact fully with family and friends: 5.4/5.6, and ability to work/keep employment: 4.5/5.0. **CONCLUSIONS:** LN cohorts had higher clinical and humanistic burden in 5EU in comparison to their non-LN SLE counterparts. Factors influencing the observed burden, including the therapeutic strategies used in these geographies warrant further investigation to manage SLE, and LN in particular, optimally.

#### PSY93

##### QUALITY OF LIFE (QOL) WITH PSORIASIS: ETHNOGRAPHY STUDY EVALUATING THE IMPACT OF PSORIASIS ON MODERATE TO SEVERE PATIENTS IN EUROPE (EU), FROM A PATIENT'S PERSPECTIVE

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**OBJECTIVES:** To qualitatively assess the impact of Psoriasis on patient QoL. **METHODS:** An ethnographic study with moderate/severe Psoriasis patients was conducted in 4EU (UK/France/Spain/Italy) and the US to explore patients' views on treatment options and Psoriasis impact on QoL. Anthropologists and ethnographers spent several-hours with consented patients and filmed their behaviours inside and outside their homes in everyday situations. 175 hours of recordings/notes were analysed to identify QoL-related themes: self-image, psychological effects of psoriasis (e.g., anxiety/depression), life-style changes due to Psoriasis, relationship with family, friends and colleagues. **RESULTS:** Study included 35 adult patients (4EU: 20, US: 15; mean age: 39 yrs; female: 65%). Patients described their appearance with a sense of disgust and self-loathing. Feelings of frustration were often expressed due to a perceived lack of control of their lives. Prior to biologic initiation, daily rituals absorbed good part of their day, including waking up earlier to apply creams, going to work earlier to check their appearance and cover patches of dead skin. Due to lack of cultural discourse and patient's difficulty in articulating Psoriasis' impact, partners and family did not know how to react nor did they realize the full extent of the problem. Difficulty in getting appropriate psychological support needed left them with a feeling of resignation. As a result, majority dealt with their issues in isolation. Most patients experienced social discriminations due to Psoriasis which led some to lie about their disease, keeping it a secret. Biologic experienced patients noticed a significant improvement physically, but psychological scarring remained. Despite their regained confidence owing to the effectiveness of biologics, they still did not discuss their condition with family and friends. **CONCLUSIONS:** Patients with Psoriasis experienced significantly lower quality of life and high psychological scarring. Ethnographic study design vividly depicted the unarticulated and emotional impact of Psoriasis on patients' everyday lives.

#### PSY94

##### HEALTH RELATED QUALITY OF LIFE OF PATIENTS AND THEIR CAREGIVERS IN RARE DISEASES RESULTS OF THE BURQOL-RD PROJECT IN HUNGARY

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**OBJECTIVES:** The Social Economic Burden and Health-Related Quality of Life in Patients with Rare Diseases in Europe (BURQOL-RD, <http://www.burqol-rd.com/>) project aimed to investigate disease burden and self-perceived health outcomes of patients and their caregivers in rare diseases in eight EU countries (Bulgaria, France, Germany, Hungary, Italy, Sweden, Spain, UK). **METHODS:** An online questionnaire

survey was developed for patients (adults/children) and caregivers. Patients were recruited by patient organisations in cystic fibrosis (CF), Prader-Willi syndrome (PWS), haemophilia (HEMO), Duchenne muscular dystrophy (DMD), epidermolysis bullosa (EB), fragile X syndrome (FXS), scleroderma (SCL), mucopolysaccharidosis (MPS), juvenile idiopathic arthritis (JIA) and histiocytosis (HIS). Demography and main characteristics were recorded. Patients' and caregivers' health state was assessed by the EQ-5D-5L, disability and caregivers' burden by the Barthel Index and Zarit Burden Interview questionnaires. **RESULTS:** In Hungary, 296 Hungarian patients (children: 161, 54%) participated in the study (CF 110, PWS 5, HEMO 58, DMD 57, EB 6, FXS 12, SCL 38 and MPS 10 patients), no data were obtained in JIA and HIS. Mean age among adults/children was 37.0 (SD 16.1) / 9.6 (SD=4.5) years, and disease duration was 18.5 (SD=14.4) / 7.1 (SD=4.5) years, respectively. The lowest average EQ-5D-5L score was found in MPS (0.134 / 0.070) and DMD (0.310 / 0.198) just alike with the Barthel Index (MPS: 35.6; DMD 58.0). Caregivers' (N=95) mean age was 39.2 (SD=8.0) years and their EQ-5D-5L score (0.797, SD=0.251) was not significantly different from the general populations' average. Satisfaction with health care (1-10 Likert scale) was the lowest in MPS, DMD and EB (mean 4.1, 5.2 and 4.3). **CONCLUSIONS:** Rare diseases induce substantial deterioration of patients' quality of life and impose burden on caregivers. Taking an integrated approach our results can serve for international comparisons and facilitate further investigations in other orphan diseases.

#### PSY95

##### IS THE DISEASE-SPECIFIC LUPUSQOL SENSITIVE TO CHANGES OF DISEASE ACTIVITY IN SYSTEMIC LUPUS ERYTHEMATOSUS PATIENTS AFTER TREATMENT OF A FLARE?

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**OBJECTIVES:** The aim of the UK multi-centre LupusQoL Sensitivity Study is to assess whether the LupusQoL, a systemic lupus erythematosus (SLE) specific, health-related quality of life measure is sensitive to change when disease activity improves or deteriorates. **METHODS:** Patients with SLE experiencing a flare (baseline) & requiring an increase in treatment were recruited. Assessments were undertaken at baseline & monthly for 9 months & included BILAG-2004 disease activity index & the LupusQoL with 8 domains and scores ranging from 0 (worst) to 100 (best HRQoL). LupusQoL domain scores when disease activity improved or deteriorated between consecutive time-points are reported as mean changes, with 95% CI constructed using robust standard errors to account for repeated patient assessments. **RESULTS:** Mean (SD) age was 40.9 (12.8) & duration since diagnosis was 9.3 (8.1) years for the 101 patients recruited; 94% females, 62.6% white Caucasians. At baseline all mean LupusQoL domain scores were <52. Scores for LupusQoL physical health (+4.0, 95%CI 1.9 to 6.1), pain (+7.7, 95%CI 4.8 to 10.5) & fatigue (+4.1, 95%CI 1.7 to 6.5) increased when BILAG improved. Scores for physical health (-4.9, 95%CI -0.4 to -9.4) and pain (-6.9, 95%CI -12.9 to -0.8) decreased with a major BILAG deterioration but changes with a minor deterioration were small and non-significant. The effects of improvements & deterioration in BILAG on the other LupusQoL domain scores were smaller. **CONCLUSIONS:** Improvement and deterioration of LupusQoL domain scores for physical health, pain & fatigue domain scores was seen in patients with significant changes in disease activity over 1 month. Sensitivity to change of other LupusQoL domains in relation to changes in disease activity may need to be evaluated over a longer interval as the more emotive type of response to the disease & its consequences may be latent and therefore not evident at monthly intervals.

#### PSY96

##### THE QUALITY OF LIFE OF PATIENTS TREATED WITH ROBOTIC VERSUS TRADITIONAL SURGERY RESULTS FROM AN ITALIAN OBSERVATIONAL MULTICENTER STUDY

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**OBJECTIVES:** To assess the Quality of Life (QoL), focusing on level of pain, of patients submitted to surgical interventions with robotic technique in comparison with traditional approach in the Italian setting. **METHODS:** The prospective multicentre study analysed the QoL of 699 patients submitted to surgical interventions, enrolled in 8 Italian Hospitals for the period February 2011-May 2014. The specialties were general, thoracic, gynecological surgery performed with open, manual laparoscopic or robotic technique. Patients completed two questionnaires: one related to pain intensity during the hospitalization and one fulfilled at home related to pain intensity and its impact on daily activities, mood, relationship, sleep. Pain was measured using the scale of facial expressions corresponding to the Visual Analog Scale. For each intervention and specialty, linear regression for repeated measure, corrected by length of stay and use of analgesics, were performed to explain level of pain during hospitalization and at home, respectively. **RESULTS:** Level of pain during hospitalization is significantly ( $p=0.05$ ) lower in general and gynecological robotic surgery versus the open technique, but not versus laparoscopic, while robotic thoracic surgery presents significant differences with laparoscopic but not with open surgery ( $p=0.059$ ). Level of pain at home is significantly different for robotic interventions versus open both in general and gynecological surgery; moreover, with respect to laparoscopic interventions, the differences are significant both in gynecological and in thoracic but not in general surgery. **CONCLUSIONS:** The study gives us insightful knowledge about QoL, focusing on pain, of patients submitted to surgical interventions with robotic technique vs traditional surgery. Further analysis are in progress to combine results on QoL, not only referred to level of pain, with clinical severity and other indicators of clinical efficacy as length of stay, operating