THU0641 THE DISEASE BURDEN OF SYSTEMIC JUVENILE IDIOPATHIC ARTHRITIS FOR PATIENTS AND CAREGIVERS: AN INTERNATIONAL HEALTH RELATED QUALITY OF LIFE SURVEY AND RETROSPECTIVE CHART REVIEW

S. Shenoi[1], G. Horneff[2], M. Cidon[3], A. Ramanan[4], Y. Kimura[5], P. Quartier[6], I. Foeldvari[7], A. Zeft[8], K.G. Lomax[9], J. Gregson[10], A. Tineke[11], S. Campbell[12], J. Weiss[13], N. Marinsek[12], D. Patel[12], N. Wulffraat[14]. *[1]Seattle Children's Hospital, Seattle, United States; [2]Asklepios Kliniken GmbH, Hamburg, Germany; [3]Stanford University, Palo Alto, United States; [4]University Hospitals Bristol, Bristol, United Kingdom; [5]Hackensack University Medical Center, New Jersey, United States; [6]Paris-Descartes University Necker-Enfants Malades Hospital, Paris, France; [7]Hamburger Zentrum für Kinder-und Jugend Rheumatologie, Hamburg, Germany; [8]Pediatrics Rheumatology, Cleveland Clinic, Cleveland; [9]Novartis Pharmaceutical Corporation, New Jersey, United States; [10]Novartis Pharma AG, Basel, Switzerland; [11]VU University Medical Centre, Amsterdam, Netherlands; [12]Navigant Consulting Inc., London, United Kingdom; [13]Navigant Consulting Inc., San Francisco, United States; [14]Wilhelmina Kinderziekenhuis, Utrect, Netherlands*

Background: Systemic juvenile idiopathic arthritis (SJIA) is a severe autoinflammatory disease characterised by systemic features including high fevers, rash and arthritis. SJIA can impose a high physical, psychosocial, behavioral and financial burden on patients (pts) and their families.
Objectives: To analyse the impact of the burden of SJIA by evaluating caregiver perspectives of disease burden utilising a SJIA-specific questionnaire combined with physician data about disease severity and treatment in an international, real-world study.
Methods: SJIA treatment centers in France, Germany, Netherlands, UK and the US participated. Pts (aged 4–18 years) with confirmed SJIA received one of the following biologic treatments for ≥2 months: anakinra (ANA), canakinumab (CAN), or tocilizumab (TOC). SJIA burden in patients on biologics was assessed using a caregiver questionnaire and retrospective chart review. Validated measures included: Child Health Questionnaire Parent-Form 50 (CHQ-PF50), 36-Item Short-Form Health Survey (SF-36v2) and Work Productivity and Activity Impairment questionnaire: Specific Health Problem (WPAI:SHP). Caregivers completed function, treatment satisfaction and resource utilization questions.
Results: Sixty-one pts enrolled from June 2015- June 2016: 12 on ANA, 25 on CAN, 24 on TOC; 46% from the US; 48% female; mean age at survey was 11.3 years. Mean age at SJIA diagnosis was 6.4 years, mean age at start of ANA, CAN, and TOC treatment was 9.9, 9.1, and 7.5 years, respectively. Caregivers were 79% female, mean age 41.2 years, and 36% reduced or stopped working due to their child's SJIA. Of the pts enrolled on CAN and TOC, 72% and 46% respectively had previously been on ANA. Baseline CHAQ, CHQ-PF50, and WPAI scores were worse in CAN and TOC than ANA pts. Mean (±SD) CHQ-PF50 physical (PhS) and psychosocial (PsS) summary scores were significantly lower in SJIA patients than a normative population (PhS: 40.0±18.2 vs. 53.0±8.8; PsS: 46.6±11.3 vs. 51.2±9.1) as was caregivers' mean SF-36v2 mental component score (46.2±10.7 vs. 50.0+10). Highest caregiver stressors were worry over long-term SJIA impact on their child (45%) and uncertainty about the future (28%).
Conclusions: Treatment sequencing and patient-reported outcome measures indicate ANA is used as 1st line for less severe SJIA while CAN and TOC are used as 2nd/3rd line for severe SJIA. Caregivers expressed stress over the long-term impact of SJIA and fear for the future and had variable treatment satisfaction and resource utilisation levels.
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THU0642 THERE IS A COMMUNICATION PROBLEM BETWEEN PATIENT AND PHYSICIAN DURING PRE-CONCEPTIONAL PERIOD: HUR-BIO REAL LIFE RESULTS

O.A. Uyaroglu[1], E. Seyhoglu[1], A. Erden[2], L. Kılıç[2], B. Armagan[2], A. Sarı[2], Ö. Karadağ[2], A. Akdoğan[2], S. Apraş Bilgen[2], S. Kiraz[2], I. Ertenli[2], U. Kalyoncu[2]. *[1]İnternal Medicine; [2]Division of Rheumatology, Hacettepe University School of Medicine, Ankara, Turkey*

Background: A significant part of patients with inflammatory arthritis are at their reproductive ages. Biological drugs are one of the important treatment options for inflammatory artritis which can cause fetal morbidity and mortality. Management of arthritis during pre-conceptional period is one of the challenges in rheumatology.
Objectives: This study aims to assess whether patients under biological treatment share their conception intents with their physicians.
Methods: 1580 patients admitted to our outpatient clinic between July 2015 and July 2016 who were received biological treatment. A questionnaire was performed to 373 patients who are at their reproductive ages. Patients were asked whether they or their wifes had got pregnant after the start of biological agent. If they had got, they were asked;
1. Was the pregnancy intented?
2. Did your physician know if you were going to get pregnant while taking a biological agent?
Results: There were total of 79 patients who or whose wifes had got pregnant after the start of biological agent. 34 (%43) out of 79 were female and 45 (%57) out of were male. Mean age of patients were 35.1 (5.3). Median disease duration was 10 (IQR=9) years. 24 (30.4%) pregnancies out of 79 were not planned [15 female (44.1%), 9 male (20%), p=0.021]. In addition, 43 (54.4%) out of 79 patients did not share their pregnancy plans with their physicians [15 (44,1%) female and 28 (62,2%) male (p=0.110)]. 28 (35.4%) of all patients stated that their disease was active during pre-conceptional period [20 (58,8%) female patients, 8 (17,8%) male patients, (p<0,001)].
Conclusions: In our study group, almost one third of the patients had unplanned pregnancies particularly with in female patients. One third of the patients were in active state before conception according to patients' report. Almost half of the patients did not share their plan of pregnancy with their physicians. We suggest that in routine practise, physicians should ask plan of pregnancy in every clinical visit.
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THU0643 WHAT FACTORS RELATE TO PATIENTS CONTRIBUTING LONGITUDINAL DATA USING SMARTPHONE TECHNOLOGY? FINDINGS FROM RA PATIENTS PARTICIPATING IN ARTHRITISPOWER REGISTRY

W.B. Nowell[1], H. Yun[2], J. Willig[3], J. Beaumont[4], B. Johnson[3], S. Ginsberg[5], C. Wiedmeyer[5], R. Crow-Hercher[5], B.J. Johnson[5], S. Yang[3], J.R. Curtis[3]. *[1]Global Healthy Living Foundation, Upper Nyack; [2]University of Alabama at Birmingham School of Public Health; [3]University of Alabama at Birmingham, Birmingham; [4]Northwestern University Feinberg School of Medicine, Evanston; [5]CreakyJoints, Global Healthy Living Foundation, Upper Nyack, United States*

Background: Data capture of patient reported outcomes (PROs) is gradually shifting from data collection on paper in medical office settings to use of computer or mobile based technologies between doctor visits. Concerns have been raised that patients may have limited interest in contributing data over time or that they may only record new data when there has been a change in their clinical status.
Objectives: The objective of this study was to evaluate the patterns and factors associated with longitudinal PRO data capture among participants in the PCORI-funded Patient Powered Research Network for adult rheumatologic conditions, ArthritisPower.
Methods: Patients in the registry were asked to voluntarily complete PROs including the RAPID3 and 4 PROMIS instruments plus disease-specific information via a mobile application (App) on their smartphone or computer. We evaluated the average time it took the patient to record each of the instruments and the total number of unique days that patients recorded PROs on the smartphone. Given the newness of the registry (launched late 2015), longitudinal data was defined as contributing at least 2 sets of PROs on unique calendar days. We tested the hypothesis that patients would contribute longitudinal data only when at least one of their scores exceeded a minimally important difference (MID) of any of the 5 PROs examined (generally 2–3 units for PROMIS instruments; 3.6 units for RAPID3). Demographic factors associated with multiple PRO reports were identified using logistic regression among patients who had been enrolled in the registry for at least 3 months.
Results: At the time of analysis, ArthritisPower had recruited 2,103 patients, most (approximately 68%) had RA, and 20% provided their Twitter handle. Average (SD) age was 50 (12); 87% were women. The mean assessment time for each of the PROMIS instruments ranged from a low of 16 seconds (Sleep Disturbance) to a high of 105 seconds (RAPID3). The average score for Pain Interference was 64.3 (SD: 6.3), Physical Function 37.5 (6.5), Sleep Disturbance 59.3 (8.4), Fatigue 64.2 (8.4), and RAPID3 15.7 (5.3). Of 1,946 patients who registered the Smartphone App more than 3 months prior to analysis, 20.6% never contributed any PRO information, 53.3% answered once, and 26.1% answered at least twice. Among patients with longitudinal data (≥2 assessments), the mean change score of PROs between pairwise PRO assessments was <1 point for all instruments

Table: Mean change between 1st and 2nd visit among ArthritisPower patients with longitudinal data

	Mean change from 1st to 2nd visit	Absolute mean change from 1st to 2nd visit	% of patients exceeding change > MID
PROMIS Physical Function	-0.4 (3.8)	2.7 (2.7)	34.2%
PROMIS Pain Interference	-0.4 (5.4)	3.9 (3.6)	52.3%
PROMIS Sleep Disturbance	0.2 (6.1)	4.6 (4.0)	56%
PROMIS Fatigue	-0.03 (6.6)	4.8 (4.4)	55.6%
RAPID3	0.2 (3.8)	2.8 (2.6)	29.8%
MID: Minimally important difference (using 3 points for PROMIS instruments and 3.6 for RAPID3)			