involvement meant as none of them had heard of it before. Patient involvement needs education of both patients and healthcare professionals to be taken further than informed consent.

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Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2020-eular.1835

AB1338-HPR

GLOBAL PATIENT PERSPECTIVE ON TOP CHALLENGES IN LUPUS CARE AND RESEARCH PARTICIPATION

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Background: The Addressing Lupus Pillars for Health Advancement (ALPHA) Project is a global consensus initiative to identify, prioritize and address top barriers in lupus drug development, clinical care and access to care. The Lupus Foundation of America convenes ALPHA with Tufts Center for the Study of Drug Development and a Global Advisory Committee of lupus experts representing clinician-scientists, industry and patients.

Objectives: Collect global patient input to determine alignment with the lupus clinician-scientist community on prior published consensus of top lupus barriers.

Methods: A 23-question online Qualtrics survey was developed to identify challenges across lupus diagnosis, clinical care and research participation. The survey, available in English, Spanish, Korean and simplified Chinese, was fielded in November 2019 to people with lupus and caregivers of children <18 with lupus. SPSS 26 and SAS 9.4 were used for descriptive statistics and sub-analysis.

Results: Analysis included only consented responses with ≥ 68% survey completion (n=3,447) received across 83 countries. 95% were female with a mean age of 45. Respondents reported being White (57%), Black or of African descent (14%), Hispanic or Latino (18%) and Asian (10%). 65% resided in the US while 35% resided in countries outside of the US. 97% were people with lupus while 3% were caregivers to children <18 with lupus.

Highest ranked challenges were similar globally and across children and adults: medication side effects, lack of treatment options and high out-of-pocket costs. Managing side effects ranked significantly higher (p<.05) outside of the US (48%) compared to US (40%). 50% of caregivers reported managing side effects as the top challenge for children compared to 43% of adults (p<.05). Research participation was low (24%) and lower among children (16%). The top reason for not participating in a clinical trial was not being asked by their doctor.

Conclusion: This global survey revealed that medication side effects and lack of effective treatments are top challenges for people with lupus, including children. Most respondents were never asked by their doctors to participate in a clinical trial, which may explain difficulties in trial recruitment. These barriers are consistent with prior published barriers identified by the clinician-scientist community.

Acknowledgments: ALPHA sponsors: EMD Serono, GSK, Aurinia, Mallinckrodt
Disclosure of Interests: Karin Tse: None declared, Yaritza Peña: None declared, Kathleen Arntsen: None declared, Sang-Cheol Bae: None declared, Lauren Bloch Consultant of: Faegre Drinker Consulting is a division of Faegre Drinker Biddle & Reath, a law and consulting firm that represents patient advocacy organizations and sponsors developing drugs, Ian N. Bruce Grant/research support from: Genzyme Sanofi, GSK, and UCB, Consultant of: Eli Lilly, AstraZeneca, UCB, Iltoo, and Merck Serono, Speakers bureau: UCB, Karen Costenbader Grant/research support from: Merck, Consultant of: Astra-Zeneca, Bradley Dickerson Employee of: Aurinia, Thomas Dörner Grant/research support from: Janssen, Novartis, Roche, UCB, Consultant of: Abbvie, Celgene, Eli Lilly, Roche, Janssen, EMD, Speakers bureau: Eli Lilly, Roche, Samsung, Janssen, Kenneth Getz: None declared, Amy Kao Employee of: EMD Serono, Susan Manzi: None declared, Eric F. Morand Grant/research support from: AstraZeneca, Consultant of: AstraZeneca, Speakers bureau: AstraZeneca, Sandra Raymond: None declared, Brad H Rovin Grant/research support from: GSK, Consultant of: GSK, Laura Schanberg Grant/research support from: Sobi, BMS, Consultant of: Aurinia, UCB, Sanofi, Victoria Werth Grant/research support from: Biogen, Celgene, Gilead, Janssen, Viela, Consultant of: Biogen, Gilead, Janssen, Abbvie, GSK, Resolve, AstraZeneca, Amgen, Eli Lilly, EMD Serono, BMS, Viela, Kyowa Kirin, Joan Von Feldt Shareholder of: GSK, Employee of: GSK, David Zook Consultant of: Faegre Drinker Consulting is a division of Faegre Drinker Biddle & Reath, a law and consulting firm that represents patient advocacy organizations and sponsors developing drugs, Leslie Hanrahan: None declared

DOI: 10.1136/annrheumdis-2020-eular.2871

AB1339-HPR

SAFETY AND ADHERENCE OF THE JAK INHIBITORS IN CLINICAL PRACTICE IN RHEUMATOID ARTHRITIS

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Background: The Janus Kinase (JAKi) inhibitors Baricitinib (BAR) and Tofacitinib (TOF) are indicated for moderate to severe active rheumatoid arthritis (RA). Data about safety, effectiveness in refractory patients and adherence in real clinical practice in our population are scarce.

Objectives: An evaluation of safety, adherence and reasons to consider suspension of JAKi in routine clinical practice.

Methods: Retrospective observational study of patients with RA treated with BAR and TOF according to usual clinical practice between September 2017 - December 2019. Data were collected from the electronic medical record and from the Dominion® Outpatient Drug Dispensing program.

Demographic, clinical, laboratory and treatment-related variables were collected, including reasons for discontinuing JAKi (inefficiency and toxicity). Adherence was calculated using the Compliance Questionnaire on Rheumatology (CQR-5), and the average possession ratio (RMP), which is defined as the number of days with treatment dispensed between the total days of the period analyzed, considering the adherent patient when RMP had a ≥ 0.8.

Laboratory abnormalities were defined according to normal limit values (NLV) and specifications of data sheet. A descriptive analysis was performed using proportions, medians and interquartile ranges (IQR) using the SPSS v.15 program.

Results: Thirty patients were included in treatment with BAR and nine with TOF. The median age was 62.9 (RIQ 49.9-74.4), 34 (87.2%) were women, 28 (71.2%) anti-CCP and 32 (82.1%) were rheumatoid factor positive, with erosive disease in 34 (87.2%) patients. In the previous treatment, 9 (23.1%) were naive to biological, 6 (15.4%) had received 1 biological, 18 (46.1%) 2 biologicals, and 6 (15.4%) ≥ 3 biologicals. The median treatment time was 8.4 months (RIQ 6.5-20.3) in BAR and 13.2 (RIQ 3.9-20.7) in TOF.

The reasons for consider suspension shown in Table 1.

Table 1. Treatment Discontinuation

BARICITINIB		
	Initial DAS28 [median (IQR)]	Final DAS28 [median (IQR)]
Continue treatment n (%): 17/30 (55.6)	4.20 (2.95-5.72)	2.60 (1.70-2.77)
Reasons for suspension		
-Refractory n (%): 7/13 (55.8%)	4.38 (4.16-5.43)	4.16 (3.56-5.23)
-Side effects n (%): 4/13 (30.7)	4.16 (3.45-4.84)	3.15 (2.69-4.41)
◦Thrombocytosis (1)		
◦Herpes Zoster (1)		
◦Anemia (1)		
◦Tuberculosis (1)		
-Patient decision n (%): 2/13 (15.4)		
TOFACITINIB		
Continue treatment n (%): 6/9 (66.6)	4.82 (3.28-6.20)	2.61 (2.45-3.70)
Reasons for suspension		
-Refractory n (%): 2/3 (66.6)	5.27 (5.23-5.31)	5.48 (5.04-5.92)
-Side effects n (%): 1/3 (33.3)		

Based on the CQR5 questionnaire, all patients treated with BAR and TOF were adherent "HIGH" class, and a median of RMP = 1.01 (IQR = 0.93-1.06) was obtained for BAR and RMP = 1, 00 (IQR = 0.91-1.01) for TOF, all adherents (≥ 0.8).

Table 2. Safety results of the treatment shows the safety results.

Side Effect	Baricitinib (n, %)	Tofacitinib (n, %)
Hb <11 g/dl	7 (23,3)	0
Hb < 8 g/dl	0 (0)	/
Hb Recovery >11 g/dl	2/7 (28,6)	/
Neutrophils < 1500/mm ³	0 (0)	/
Lymphocytes < 1000/mm ³	3 (10,0)	2 (22,2)
Platelets > 600 × 10 ³ /mm ³	1 (3,3)	0
AST o ALT > 1 NLV	4 (13,3)	0 (0)
Hypercholesterolemia (> 1 NLV)	13 (43,3)	5 (55,5)
Infections	13 (43,3)	0 (0)
Herpes zoster	6 (20,0)	0 (0)

Conclusion: In our population, mostly refractory to biological, more than half of the patients maintain treatment with JAKi, with optimal adherence. The main reason for the suspension of both drugs was inefficiency. The most frequent adverse effects were hypercholesterolemia in both groups and infections in BAR, with a high frequency of herpes zoster. No cardiovascular or thromboembolic events were observed.

Disclosure of Interests: Cristina Valero: None declared, Alberto Calvo Garcia: None declared, Noelia García Castañeda: None declared, Ana Ortiz: None declared, Irene Llorente Speakers bureau: Gebro, Janssen, Sanofi, Lilly, Blanca Varas: None declared, Santos Castañeda: None declared, Rosario Garcia de Vicuna Grant/research support from: BMS, Lilly, MSD, Novartis, Roche, Consultant of: Abbvie, Biogen, BMS, Celtrion, Gebro, Lilly, Mylan, Pfizer, Sandoz, Sanofi, Paid instructor for: Lilly, Speakers bureau: BMS, Lilly, Pfizer, Sandoz, Sanofi, Esther Ramirez: None declared

DOI: 10.1136/annrheumdis-2020-eular.6097

HPR Service developments, innovation and economics in healthcare

AB1340-HPR

PATIENTS' OUT-OF-POCKET EXPENSES ANALYSIS IN PATIENTS WITH RHEUMATOID ARTHRITIS ENROLLED IN A EDUCATIONAL PROGRAM

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Background: The increasing health and economic burdens of deaths and disabilities from non-communicable diseases (NCDs) are emerging as major concerns worldwide, particularly for low- and middle-income countries (LMICs) (1). Rheumatoid arthritis (RA) NCD is considered as one of the most common causes of disability. RA affects from 0.5% to 1% of the worldwide population. Little is known about the out-of-pocket (OOP) expenditures for prescription of pharmacological treatment for patients with RA, including drugs, diagnostic tests, mobility aids among others.

Objectives: To describe the out of pocket costs in patients with rheumatoid arthritis

Methods: We performed a cross-sectional study among patients who are participating in an educational program in a specialized center for RA. We collected sociodemographic variables; in addition, we collected data related to the expenditures in drugs, diagnostic tests and mobility aids that were not covered by the health system. Descriptive epidemiology was done, we calculated means, and standard deviations for continuous variables and categorical variables were presented as rates. The costs are presented in the US dollars with the average exchange rate for 2019

Results: We included 181 patients, 92% were female. Mean age was 59 years ±9.5. Regarding occupation, 24% were employees, 40% were economically inactive, and 36% were pensioners. Most of patients 45% had a low income, 43 % middle income and only 12% high income according to the Colombian socioeconomic classification. Most of out of pocket expenses (47%) were associated to the acquisition of medical devices such as reading glasses or orthopedic braces. Secondly, the OOP expenses were related to medications (38%) such as antibiotics prednisone or pain control medications. Finally, 25% of patients reported that they had pay for their diagnostic tests such as x rays or laboratory tests. When assessed the costs patients expended between 30-100 USD purchasing aid devices, medications or laboratory tests.

Conclusion: In the Colombian context OPP are relevant and represent an important expenditure for patients with RA especially for those who have low or middle income. Due to the above, it is important to find alternatives in order to help vulnerable segments of the population. Additionally, OPP needed to be taken into account due to its association with treatment adherence(2).

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Acknowledgments: This project has been funded by a collaboration between the Ministry of Science, Technology and Innovation COLCIENCIAS (contract 746-2018), the Fundación Universitaria de Ciencias de la Salud and Biomab - Center for Rheumatoid Arthritis

Disclosure of Interests: Diana Buitrago-García: None declared, Fernando Rodríguez: None declared, GUILLERMO SÁNCHEZ: None declared, Pedro Santos-Moreno Grant/research support from: I have received research grants from Abbvie, Biopas-UCB, Janssen, Novartis, Pfizer., Speakers bureau: I have been a speaker for Abbvie, Biopas-UCB, Janssen, Lilly, Novartis, Pfizer, Roche, Sanofi.

DOI: 10.1136/annrheumdis-2020-eular.5526

AB1341-HPR

FEASIBILITY OF THE BACK AND FORTH SCHOOL BOOKLET, A SHARED SELF MANAGEMENT INSTRUMENT FOR YOUNG CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS (JIA) AT SCHOOL

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Background: Young children with JIA have to cope with pain and fatigue during schooldays, facing problems with writing, climbing stairs, physical education and playing outside.¹ They need to develop age-appropriate self management skills, encouraged by their parents and teachers in a therapeutic alliance with the health professional team.² For this purpose a shared management tool, called the "Back and Forth Schoolbooklet"(B&FS), is developed, containing 1) Educational pages about JIA, pain and fatigue management 2) Diary pages with a colour-in puppet for expressing location and amount of pain, spaces for writing alternatives for limited activities, feedback spaces for parents and teachers and a self-evaluation scale of general well-being for the child. Children, parents and teachers are instructed how to use the booklet by therapists during outpatient rehabilitation. Structured evaluation of the use of the instrument is necessary to improve its applicability and effectiveness.

Objectives: To study the feasibility, defined as practical and experienced applicability and effectiveness, of the B&FS.

Methods: Pilot feasibility study with a mixed-method design. Parents, teachers, therapists and children with JIA were invited to fill in questionnaires after using the booklets in school. Adults had to sign informed consent. Practical applicability was assessed by multiple choice questions on duration and frequency of use. Used diary items and pages were counted in returned booklets. Experienced applicability and effectiveness were assessed by open-ended questions and 5 points Likert scales. Topics were experienced barriers, facilitators and benefits using the mentioned items of the booklets. Practical applicability was analysed descriptively. Atlas-ti8 was used for analysing and coding the answers on the open-ended questions using a thematic approach.

Results: Eight children(4-8 years) used the booklets. Six parents of six children, four therapists and four teachers signed informed consent and answered questionnaires. Six booklets were returned.

Practical applicability: Five children used booklets for a period of 2 to > 12 week, almost every day. One child stopped in the first week. Counting diary pages