

patients' concerns regarding family planning and pregnancy (FPP) were inadequately or inconsistently addressed.¹

Objectives: To investigate the general level of information on FPP and the potential concerns among Danish patients with CIDs.

Methods: An online survey to identify FPP issues was designed, and CID patients aged 18–50 years (yrs) were included. Respondents were recruited through patient organisations providing their members with a link to the questionnaire. In addition to demographics, information relating to time of diagnosis, treatments received, pregnancies, and course of disease were collected along with access to and concerns regarding FPP. Descriptive statistics were applied.

Results: Eligible patients included 368 with rheumatological diagnoses (RA, PsA, JIA, nr-axSpA, or AS; 304 [83%] female, mean age: 40 yrs; 64 [17%] male, mean age: 42 yrs) and 95 with dermatological diagnoses (PSO or PsA; 64 [67%] female, mean age: 37 yrs; 31 [33%] male, mean age: 42 yrs). Among the rheumatic patients, 43% of females and 53% of males were currently receiving systemic treatment and 37% of females and 22% of males had received >3 different systemic treatments (other than painkillers and non-steroidal anti-inflammatory drugs [NSAIDs]). Lack of access to FPP information was consistent across age groups, but higher in those with dermatological diagnoses (Table).

In total, 68% of patients with rheumatological and 73% with dermatological diagnoses had biological children and among these 18% and 23% of patients, respectively, indicated their disease had affected how many children they had or planned to have. The most frequent concerns among patients with rheumatological diagnoses were the potential physical impact of a pregnancy, disease worsening, heredity and being able to take care of the child (19, 16, 16 and 13%, respectively), whilst disease worsening and heredity (12 and 16%, respectively) were the most frequent concerns in those with dermatological diagnoses. Many patients experienced disease worsening during or after pregnancy (rheumatological diagnoses: 16% and 34%; dermatologic: 20% and 59%, respectively).

Conclusion: Danish CID patients of reproductive age have concerns related both to their disease and to FPP, which affect their decisions around family planning. The majority of patients responding to this survey reported limited access to information about FPP, pointing to a need for healthcare professionals to provide standardised family planning information.

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Table. Proportion of patients with rheumatological or dermatological diagnoses who reported having little or no access to FPP information, stratified by age

Age	Rheumatological diagnosis N (%)	Dermatological diagnosis N (%)
18–29 yrs	19 (49)	14 (74)
30–39 yrs	61 (58)	16 (73)
40–50 yrs	134 (60)	34 (63)

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RMD research

PARE0025 “RA - DON'T GIVE UP” - LIFE WITH RHEUMATOID ARTHRITIS FROM PATIENTS' PERSPECTIVE

T. Sobierajski¹, J. Grygielska², E. Godlewska³. ¹The Institute of Applied Social Science Warsaw University, Warszawa, Poland; ²Polish Rheuma Federation “REF”, Warszawa, Poland; ³KnowPR, Warszawa, Poland

Background: Rheumatoid arthritis (RA) as chronic and progressing to disability disease decreases a quality of life of every person suffering from it. Knowledge about this influence from patient perspective is important to limit burden of RA and organize appropriate care for patients.

Objectives: RA has input on every area of individual and social lives. Recognition of patients' situation in daily life, professional life, participation in treatment, taking life decision gives possibilities to better understanding of diseases and starting activities to change lives with RA. Aim of research was to learn attitudes, knowledge and experiences of people living with RA.

Methods: The study was initiated by KnowPR in partnership with Polish Rheuma Federation ‘REF’. Main researcher was Tomasz Sobierajski PhD., sociologist from Warsaw University. The first stage of the study was a workshop with patients with RA organized by REF. It was brainstorming to identify main problems, appropriate understand life with RA and discussion on questionnaire. After small pilot study on questionnaire, research was made by CAWI technique. Questionnaire had been linked on professional websites, facebook, Twitter, health forums. The data had been completed during one month - January 2019.

Results of survey were presented in booklet with comments. Opinions introducing results were done from persons represented patronages of project: minister of patient rights, president of Polish Society for Rheumatology, national consultant in rheumatology, directors of National Institute of Geriatrics, Rheumatology and Rehabilitation. Publication was enriched by stories of people with RA living full lives. Publication was launched during press conference and disseminated in hard copies and on-line with free access.

Results: In survey took part 619 respondents with RA - mostly women (90%). The biggest group of respondents (34%) was in age 46-60 years old. Duration of disease was different – from few months to more than 40 years. More than half of respondents are suffering from RA more than 10 years. Disease influences of every life area. Only 38% of respondents participate in decision about their treatment and took it together with rheumatologist. There are different opinions about way of taking medication. There are not differences among age groups and duration of disease in this. Majority of patients suffer from pain (73%), from limited abilities (68%) and from permanent fatigue (69%) in everyday lives. Rheumatologist has the biggest confidence among patients like a source of information about disease (73%). Other health professionals have lower confidence (35-40%). Majority of respondents (68%) note his knowledge about diseases like rather good and better. Respondents didn't connected their decision of having a child with disease how it has been before (59%). Part of respondents had to change or resign of professional work (30%). Part of them resigned from social life and hobbies before disease. In opinion of 57% of respondents RA changed totally their lives (57%).

Conclusion: Results of survey was used like a tool in lobbying for accessibility in newest treatment in RA. Further recognize of quality of life in RA is needed. Interviews of focus groups and individuals are planned.

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[1] T. Sobierajski. *Codziennosc z reumatoidalnym zapaleniem stawow*. Warszawa 2019

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PARE0026 WHICH PATIENT-REPORTED OUTCOMES DO RHEUMATOLOGY PATIENTS FIND IMPORTANT TO TRACK DIGITALLY? A REAL-WORLD LONGITUDINAL STUDY IN ARTHRITISPOWER

W. B. Nowell¹, C. L. Kanno², K. Gavigan¹, Z. Cai², A. Cardoso², T. Hunter², S. Venkatachalam¹, J. Birt², J. Workman², J. Curtis³. ¹Global Healthy Living Foundation, Nyack, United States of America; ²Eli Lilly & Company, Indianapolis, United States of America; ³University of Alabama at Birmingham, Birmingham, United States of America

Background: Development of a standardized approach to assess key elements of disease activity in rheumatology clinical trials has been the goal of Outcome Measures in Rheumatology Clinical Trials (OMERACT), American College of

Rheumatology (ACR), and European League Against Rheumatism (EULAR).^{1,2,3} The core sets of measures developed include assessments and composite indices incorporating use of patient-reported outcomes (PROs) and clinical measures and clinicians' assessments to quantify disease activity over time.² PROs are important indicators of disease activity and variability, and they are increasingly used to evaluate treatment effectiveness. Little is known about PROs that patients with rheumatic conditions find most important to convey their experience with their condition and its treatment.

Objectives: To examine PROs selected by patients with rheumatic conditions in the ArthritisPower registry to identify symptoms they found most important to track digitally.

Methods: Adult US patients within the ArthritisPower registry with rheumatoid arthritis (RA), psoriatic arthritis (PsA), ankylosing spondylitis (AS), systemic lupus erythematosus (SLE), osteoporosis (OP), osteoarthritis (OA), and fibromyalgia syndrome (FMS) were invited via email to participate in this study. Enrolled participants (pts) were prompted to select ≤ 10 PRO symptom measures they felt were important to track for their condition at baseline via the ArthritisPower app. At 3 subsequent time points (Month [m] 1, m2, m3), pts were given the option to continue tracking their previously selected PRO measures or to add, remove and/or select different measures. At m3, pts completed an exit survey to prioritize ≤ 5 measures from all measures selected during study participation and to specify other symptoms not available that they would have wanted to track. Measures were rank-ordered based on number of pts rating the item as their 1st, 2nd, 3rd, 4th or 5th choice and weighted by multiplying the rank number by its inverse for a single, weighted summary score for each measure. Values were summed across all pts to produce a summary score for each measure.

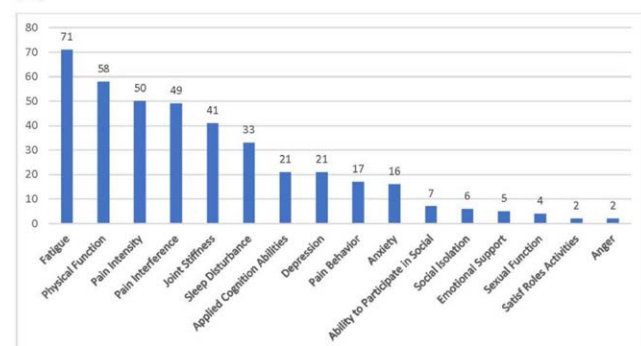
Results: Among pts who completed initial selection of PRO assessments at baseline (N=253), 184 pts confirmed or changed PRO selections across m1-3. Mean (SD) age of pts was 55.7 (9.2) yrs, 89.3% female, 91.3% White, mean disease duration of 11.6 (10.6) yrs. The majority (64.8%) self-reported OA, followed by RA (48.6%), FMS (40.3%), PsA (26.1%), OP (21.0%), AS (15.8%) and SLE (5.9%), not mutually exclusive, and were similar to the overall ArthritisPower population. The average number of instruments (SD) selected for baseline completion was 7.0 (2.5), 7.1 (2.4) at m1, 7.2 (2.4) at m2, and 7.0 (2.5) at m3. The top 5 PROs ranked by pts overall as most important (weighted summary score) for tracking were Fatigue (71), Physical Function (58), Pain Intensity (50), Pain Interference (49), Duration of Morning Joint Stiffness (41) (Figure 1). Fatigue, Physical Function, and Pain were consistently in the top 5 across diseases while Depression was more frequent among pts with OA, AS and FMS. Pts' PRO selections showed stability over time except for the RA Flare measure which decreased from 70.5% of RA pts at baseline to 13.6% at m3.

Conclusion: The symptoms prioritized by pts included fatigue, physical function, pain, and joint stiffness. Pts' choices were consistent over time. These findings provide insights into symptoms rheumatology patients find most important and will be useful to inform design of future patient-centric clinical trials and real-world evidence generation.

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Figure 1. Overall Participant Ranking of PRO Selections (weighted summary score) at Study Conclusion (m3)*



*Considering all PROs selected during the 3-month study, participants selected their first through fifth choice by importance; only those participants who completed the 3 months of the study (N=184). Weighted summary scores were generated based on rankings overall. Measures were rank ordered based on number of pts rating the item as their 1st, 2nd, 3rd, 4th or 5th choice and weighted by multiplying the rank number by its inverse to achieve a single weighted summary score for each measure. For instance, a measure scored 1/1 if ranked as the most important, 1/2 if rated second most important, and so on.

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Company, Employee of: Eli Lilly and Company, Anabela Cardoso Shareholder of: Eli Lilly and Company, Employee of: Eli Lilly and Company, Theresa Hunter Shareholder of: Eli Lilly and Company, Employee of: Eli Lilly and Company, Shilpa Venkatchalam: None declared, Julie Birt Shareholder of: Eli Lilly and Company, Employee of: Eli Lilly and Company, Jennifer Workman Shareholder of: Eli Lilly and Company, Employee of: Eli Lilly and Company, Jeffrey Curtis Grant/research support from: AbbVie, Amgen, Bristol-Myers Squibb, Corrona, Janssen, Lilly, Myriad, Pfizer, Regeneron, Roche, UCB, Consultant of: AbbVie, Amgen, Bristol-Myers Squibb, Corrona, Janssen, Lilly, Myriad, Pfizer, Regeneron, Roche, UCB

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PARE0027 PATIENT PERSPECTIVE ON INTRA-ARTICULAR THERAPIES IN RMDs: RESULTS FROM A EUROPEAN SURVEY

L. Pitsillidou¹, J. De la Torre-Aboki², J. Uson Jaeger³, E. Naredo⁴, L. Terslev⁵, M. Boesen⁶, H. Pandit⁷, I. Möller⁸, M. A. D'agostino⁹, W. U. Kampen¹⁰, T. O'neill¹¹, M. Doherty¹², F. Berenbaum¹³, V. Vardanyan¹⁴, E. Nikiphorou¹⁵, S. C. Rodriguez-Garcia¹⁶, R. Castellanos-Moreira¹⁷, L. Carmona¹⁸. ¹Cyprus League Against Rheumatism, Nicosia, Cyprus; ²Hospital general universitari d'Alacant, Alacant, Spain; ³Hospital Universitario de Móstoles, Móstoles, Spain; ⁴Hospital Universitario Fundación Jiménez Díaz, Madrid, Spain; ⁵Rigshospitalet, København, Denmark; ⁶Bispebjerg and Frederiksberg Hospital, Copenhagen, Denmark; ⁷University of Leeds, Leeds, United Kingdom; ⁸Institut Poal de Reumatologia, Barcelona, Spain; ⁹APHU-Université Paris-Saclay Versailles, Inserm, Boulogne-Billancourt, France; ¹⁰Rad. Allianz, Nuklearmedizin Spitalerhof, Hamburg, Germany; ¹¹Manchester University, Manchester, United Kingdom; ¹²University of Nottingham, Nottingham, United Kingdom; ¹³AP-HP Sorbonne Université, Inserm, Paris, France; ¹⁴Mikayelyan University Hospital, Yerevan, Armenia; ¹⁵King's College, London, United Kingdom; ¹⁶Hospital Universitario de la Princesa, Madrid, Spain; ¹⁷Hospital Clínic de Barcelona, Barcelona, Spain; ¹⁸InMusc, Madrid, Spain

Background: Intra-articular therapy (IAT) is routinely used in rheumatic and musculoskeletal diseases (RMDs). In order to improve the effectiveness and safety of IAT, it is essential to understand patients' perceptions and needs.

Objectives: To assess the perspective of persons who have experienced IAT, including perceptions on benefits and safety.

Methods: A steering committee (including a patient research partner) prepared a 44-item questionnaire based on the information needs of a Taskforce on IAT in adult patients with RMDs. The questionnaire was translated into 11 languages and disseminated via EULAR PARE associations and social media. Persons who had experienced at least two IAT procedures were eligible for the survey. Descriptive statistics were used to summarise results as well as inductive codification of open-ended questions.

Results: The survey was answered by 200 individuals diagnosed with rheumatoid arthritis (66%), osteoarthritis (21%), spondyloarthritis (10%), psoriatic arthritis (9%), and others (16%). The mean number of IATs received was 7 (SD 8), mainly in the knee (66%), shoulder (42%), and wrist (28%), and primarily with corticosteroids (83%) or hyaluronic acid (16%). Twenty-seven percent had not been informed about benefits or potential complications of IAT, and 73% had not been asked whether they wanted local anaesthetic. Consent was deemed necessary by 82 (41%). Most (65%) had never received an ultrasound (US)-guided injection, and of those who had experienced blinded and guided injections, 42 (63%) preferred US-guided because of increased perceived accuracy and confidence in the procedure. Only 50% reported a clear benefit of IAT, mainly in terms of reduced pain and increased joint mobility, but also perceived reduced inflammation, with effect from immediate to 36 hours or even 3 weeks post-injection, and that lasted from as little as less than one week to years. Regarding safety, 40 (20%) had experienced some complications from IAT, including but not limited to increased pain, impaired mobility, rashes, or swelling.

Finally, the respondents suggested improvements in the procedure, including: (1) wider availability; (2) less painful procedures; (3) greater efficacy, faster and longer-lasting; (4) fewer side effects; (5) a clear diagnosis beforehand; (6) better shared decision-making, including better information; (7) follow-up, (8) better accuracy; and (9) more expertise.

Conclusion: The survey has identified gaps in the IAT procedures, such as a need for clearer information. Patients perceive IAT as relatively safe, though painful, and with varying effect. Suggestions for improving the procedure, including more expertise, should be relayed to professionals and relevant organisations.

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