

**POS1567-PARE** **ASSESSMENT OF ADHERENCE AMONG GREEK PATIENTS WITH RHEUMATIC DISEASES DURING THE COVID-19 ERA**

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**Background:** Patient's (pts) adherence is a EULAR important recommendation for an optimal disease course and outcome. COVID-19 pandemic has globally challenged the issue of adherence. As relevant Greek data are lacking, the Pan-Hellenic Federation "Rheumazein" (i.e., co-living with a Rheumatic Disease) conducted a survey among their members to assess adherence and a possible COVID-related negative impact.

**Objectives:** The main endpoint of the study aimed to capture the degree of pt adherence to treatment, either with conventional synthetic or/and biologic DMARDs (csDMARDs, bDMARDs). The secondary endpoints were: a. To record pts'-physicians' interactive communication to assess the level of shared disease making (SDM). b. The emerged barriers to medication access during the pandemic and consequent restrictive measures. c. To record pt perceptions on the usefulness of mobile reminder applications towards an uninterrupted regimen.

**Methods:** A 29-item quantitative questionnaire was uploaded in the social media of the Federation and its associations, in order to register pts' responses on the aforementioned sections. The questionnaire was accessible for a 58-day period (21/09/2021-17/11/2021).

**Results:** Participants' characteristics: The responses of 303 adults with RD (M:F 63:240), aged (in yrs) 18-44: 35%, 45-54: 26%, >55: 38% respectively, were available for analysis. The RD types were RA 33%, AS 18%, PsA 13%, SLE 18%, Juvenile Arthritis 5% and Other RD 13%, respectively. The education level was low/moderate 39%, high 30%, post-graduate 31%, respectively. Receivers of a monotherapy with either cs- or bDMARDs were 93(31%) and 83(27%), of a combined regimen cs+bDMARDs 114(38%) and off treatment 13 (4%). bDMARD receivers were mostly AS pts (93%) while the least, SLE pts (48%). The route of bDMARD administration (sc vs iv did not significantly differ (57% vs. 43%). Since diagnosis, the mean disease trajectory was 7.6 yrs, the mean time on medication 6.9 yrs, while the mean duration on the current regimen 3 yrs, respectively. Adherence: At least one skipped dose during the last trimester was reported, significantly more often by pts under csDMARDs than by those under bDMARDs, (60% vs. 40%, p<0.001) with a mean number of 2.7 vs. 1.8 skipped doses, respectively. Additionally, the main reasons of non-adherence under csDMARDs and bDMARDs significantly differed only in respect to pt responsibility (56% vs.19% p<0.001), but not for COVID-related reasons, namely fear either of getting infected, or due to a performed COVID vaccination (35% vs 42%), or due to physician recommendations (22% vs. 32%). Regarding the pt-physician interactive discussions on emerging new treatments, 90% of the pts reported this policy, but only 40% of them in a rather frequent to more frequent rate. In respect to satisfaction, 67% expressed a moderate to high satisfaction regarding the level of provided information, while the degree of their satisfaction was positively related with the frequency of these discussions. The main topics focused on the route and frequency of the medication, especially with bDMARD receivers. Of note, 80% of the bDMARD group participated in the SDM before commencing this therapy, but just 20% in the selection of the brand name. Only a minority of pts (17%) were aware of the existence of mobile applications, reminding the scheduled drug administration; however, they rated these programs as very useful (4.3 according to a 0-5 scale). Despite the difference source of supply of cs and bDMARDs on pt access to treatment, the impact of COVID-19 and consequent restrictive measures had not impaired it (1.5/5 and 1.7/5 by the above scale, respectively).

**Conclusion:** A significant percentage of pts skip scheduled DMARD administrations, especially those (60%) under csDMARDs. The relationship with the physician was considered relatively satisfactory. Most of the pts did not have any mobile phone reminder application regarding their dose. Finally, the COVID-19 pandemic appeared to have had little effect on pts' access to both cs- and bDMARDs and consequently, adherence to their treatments.

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**POS1568-PARE** **THE BRIEF-ILLNESS PERCEPTION QUESTIONNAIRE: A METHOD FOR ASSESSING THE COGNITIVE REPRESENTATION OF RHEUMATIC DISEASE**

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**Background:** The common-sense model proposes that illness perception (IP), is how patients make sense of their illness and respond emotionally to it, influencing the way they cope with the illness and subsequently illness outcomes. This proposition has gained considerable empirical support, and the relevance of IP in understanding illness-related behaviors or outcomes has also been supported in patients with rheumatic diseases (RD). The Brief Illness Perception Questionnaire (B-IPQ) was designed to provide a simple and rapid assessment of IP. This questionnaire has been widely used in diverse ages, illness types, countries, and languages.

**Objectives:** This study aimed to examine the construct of IP as measured by the B-IPQ in patients with RD.

**Methods:** A cross-sectional study was conducted at a Tunisian rheumatology department on 80 patients with RD. Sociodemographic, disease-related variables were reported. Participants completed a questionnaire on illness beliefs (B-IPQ).

**Results:** Subjects were aged 22-74 years (mean 51 years), 61.6 % were female. Diagnoses included Rheumatoid arthritis (RA) (63%), axial spondylarthritis (AS) (37%). The mean disease duration was 11 years and 7 years for RA and AS respectively. The proportion of physical comorbidities was higher in RA patients (36%) versus AS patients (11%). Disease activity was low in 28.8% of patients. All patients were on medications for their rheumatic disease, and 34.6 % were on biological therapy.

In both diseases, the participants perceived their rheumatic illness as a chronic condition (9.4) that could be controlled by treatment (6.6) but not strongly influenced by personal actions (4.3). Overall, Rheumatic disease was seen as having an important impact on their life (7.9) without significant difference between patients with low or high activity disease (p=0.23). The majority believe that they have a moderate understanding of their illness (6.6). The frequency of symptoms was highly evaluated in RA patients than AS patients (7.3 vs 5.6) (p=0.01). In RA patients, 76% were extremely affected emotionally by their disease, however, the majority of AS patients were moderately affected emotionally with a significant difference (p=0.02). In addition, RA patients considered their disease mainly a result of psychological factors (66.8%). On the other hand, AS patients (73%) attributed their illness to various risk factors (especially physical overexertion).

**Conclusion:** High scores of B-IPQ shown in our studies, encourage the design of psychotherapeutic trials targeting disease-related cognitions in AS and RA in an attempt to improve patients' reported outcomes and disease outcomes.

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## Building patient led organisations

**POS1569-PARE** **TESTING A NEW APPROACH TO IDENTIFY AND ASSESS PATIENT-VALUED TREATMENT GOALS IN RHEUMATOID ARTHRITIS (RA): A PATIENT-ENGAGED HEALTHCARE VALUATION STRATEGY**

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**Background:** Common approaches to valuing health technologies often fail to capture outcomes that matter to patients and families. The treatment goals of people living with rheumatoid arthritis (RA) include common trial endpoints but also include other facets of disease impact. Identifying a feasible and rigorous approach to inclusion of the patient perspective is needed as trialists increasingly seek to incorporate patient-important outcomes in trial design and as varied patient-centered value assessment frameworks emerge. No standard approach is available to systemically identify and quantify patient-important outcomes, nor to include those outcomes in deliberative decision-making. We developed the Patient-Engaged Healthcare Valuation strategy, using principles of goal attainment scaling to frame survey-based goal collection directly from adults.

**Table 1. Top Goals based on rating as "Very Important" by >70% of subjects, from set of 36. "My goals for living with RA are to..."**

| Goals   | Not Important | Somewhat Important | Important | Very Important |
|---|---------------|--------------------|-----------|----------------|
| <b>Symptom Management</b>                               |               |                    |           |                |
| improve the quality of my life with RA                  | 0% (0)        | 0% (0)             | 23% (11)  | 77% (36)       |
| manage my RA pain                                       | 0% (0)        | 2% (1)             | 11% (5)   | 87% (41)       |
| reduce how my RA pain interferes with my life           | 0% (0)        | 9% (4)             | 17% (8)   | 74% (35)       |
| <b>Life Impact</b>                                      |               |                    |           |                |
| reduce the ways in which RA interferes with my life     | 0% (0)        | 2% (1)             | 21% (10)  | 77% (36)       |
| be independent in my daily functioning                  | 0% (0)        | 4% (1)             | 15% (4)   | 81% (22)       |
| <b>Managing my RA</b>                                   |               |                    |           |                |
| feel like I can manage my RA                            | 0% (0)        | 2% (1)             | 26% (12)  | 72% (34)       |
| <b>Treatment Features</b>                               |               |                    |           |                |
| understand my RA treatment options                      | 0% (0)        | 4% (2)             | 21% (10)  | 74% (35)       |
| have the information I need to make treatment decisions | 0% (0)        | 0% (0)             | 19% (9)   | 81% (38)       |
| know what to expect with my RA treatment                | 0% (0)        | 2% (1)             | 23% (11)  | 74% (35)       |
| find treatments that are effective                      | 0% (0)        | 0% (0)             | 6% (3)    | 94% (44)       |

**Objectives:** To develop and test a goal-based method for collecting RA patient input for use in clinical trials and value assessment and evaluating the feasibility of this approach in people with RA.

**Methods:** Patient goals and domains were identified from (1) a literature review (2010-2020) of patient outcomes, goals, and preferences in RA, and (2) discussions with patients and clinicians during two meetings with a steering committee (SC) consisting of clinicians, outcomes researchers, patients/advocates, and health economists. These goals informed the development of a draft survey. Adults with RA were recruited from online patient networks to rate goal importance and suggest additional goals. SC members reviewed the survey findings and assessed feasibility of scaling up goal collection for HTA.

**Results:** Of 135 articles identified, 17 were retained. An inductive and iterative approach was used to identify and thematically group the final set of 36 goals into 4 domains. The draft survey was cognitively debriefed with 4 adults with RA. The first survey was administered to 20 participants; results informed item revisions and additions for the second round of data collection (n=27).

The 47 respondents were mostly White (87%), college-educated (72%) women (93%) living with RA for an average of 15 years; 75% rated their RA as moderate to severe. Free-text goals added in round 1 include: 1) finding specialists who listen to patient input on symptoms; 2) addressing loneliness or isolation; and 3) finding support from or helping others with RA. All Symptom and Life Impact goals were rated as *Important* or *Very Important* by ≥85% of participants; endorsement for Management and Treatment goals was somewhat more variable, with ≥85% endorsing these as *Somewhat* to *Very Important*. Results suggested that domains match key goals. Steering committee ratings supported the feasibility of this method.

**Conclusion:** Goals relevant for RA treatment evaluation can be efficiently identified and rated for importance by patients. Patient-important goals can be incorporated into deliberative healthcare valuation using this method to permit "crowd-sourced" input from people living with RA and to capture heterogeneous patient perspectives in healthcare valuation.

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**Methods:** An online survey was developed, translated into multiple languages and shared via social media and patient organisations, targeted at parents of children and young people with rheumatic, autoimmune and autoinflammatory conditions. Fieldwork took place in April 2021 in Europe and May 2021 in Canada. Consent was provided during enrollment.

**Results:** A total of 290 responses were received (133 Europe; 157 Canada). Of these, 73% were female, median age 12.

Over half of respondents (53%) in Europe reported travelling over an hour to in-person appointments with their paediatric rheumatologist, compared to a significantly higher proportion of respondents in Canada (87%). Consequently, in-person appointments represent a greater time burden amongst Canadian caregivers, though both groups report appointments taking over three hours in total (51% Europe, 69% Canada).

Prior to COVID-19, most had never had a telemedicine appointment (92% Europe, 95% Canada). Since March 2020, the majority (71% Europe, 82% Canada) had at least one telemedicine appointment.

**Table 1. Shows the scores (1 worst, 5 best) given by parents about their telemedicine experience. Overall, most aspects scored positively (p<.05). However, parents felt telemedicine was not as good as in-person appointments.**

|                                 | Europe               | Canada               | P |
|---------------------------------|----------------------|----------------------|---|
| Easy to schedule                | 3.50 (3.18, 3.82) *  | 4.33 (4.14, 4.52) *  | † |
| On time                         | 3.22 (2.89, 3.55)    | 4.07 (3.85, 4.28) *  | † |
| Enough time with doctor         | 3.51 (3.19, 3.83) *  | 4.24 (4.02, 4.45) *  | † |
| As good as in-person visit      | 2.21 (1.96, 2.46) ** | 2.66 (2.42, 2.90) ** | † |
| Easier to see doctor            | 2.84 (2.55, 3.13)    | 3.51 (3.25, 3.77) *  | † |
| Easy to sign-in                 | 3.52 (3.22, 3.82) *  | 4.25 (4.06, 4.43) *  | † |
| Quality of video                | 3.23 (2.93, 3.53)    | 3.87 (3.66, 4.07) *  | † |
| Quality of sound                | 3.54 (3.26, 3.81) *  | 3.94 (3.75, 4.14) *  | † |
| Able to speak freely            | 3.61 (3.34, 3.88) *  | 4.05 (3.85, 4.24) *  | † |
| Able to understand doctor       | 3.61 (3.32, 3.90) *  | 4.09 (3.90, 4.28) *  | † |
| Quality of care provided        | 3.43 (3.12, 3.73) *  | 3.78 (3.56, 4.00) *  | † |
| Overall telemedicine experience | 3.23 (2.91, 3.55)    | 3.78 (3.57, 3.99) *  | † |

Table 1. Mean scores for a range of aspects of telemedicine (1-worst; 5-best). \* Positive score (p<.05) \*\* Negative score (p<.05) † Difference between Canadian and European cohorts is statistically significant (p<.05), chi-square.

When asked about aspects of telemedicine, a greater proportion of respondents from Canada answered favourably compared to those from Europe with the majority reporting telemedicine appointments had saved them time, enabled them to have an appointment and that it made the appointment safer. However, most felt that their consultant could not properly assess their child (72% Europe, 78% Canada, P<.05).

Overall respondents said they would prefer the next appointment to be in-person (82% Europe, 62% Canada, p<.05), although 31% from Canada were amenable to a combination of in-person and telemedicine-based care.

**Conclusion:** There are advantages to telemedicine, notably saving time and making appointments accessible. Families from Canada tended to view telemedicine more favourably than those from Europe, although the majority from both cohorts reported concerns about the ability to assess their child. There may be value in providing training to parents to enhance the accuracy of home-based assessments, particularly when the disease is stable. However, parents continue to report the value of in-person appointments.

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## Arthritis research

### POS1570-PARE A PATIENT-LED SURVEY INTO THE BENEFITS AND LIMITATIONS OF TELEMEDICINE APPOINTMENTS FOR ASSESSING CHILDREN AND YOUNG PEOPLE WITH RHEUMATIC CONDITIONS: COMPARING EUROPEAN AND CANADIAN COHORTS

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**Background:** During the COVID-19 (coronavirus) pandemic, some provision of healthcare shifted to remote, technology-assisted appointments (telemedicine). Whilst parents/carers of children and young people with rheumatic conditions have reported benefits of telemedicine, concerns remain.

**Objectives:** This patient and parent-led project sought to understand the views of parents/carers about telemedicine, identifying the benefits and limitations of remote technology-assisted appointments, and comparing views between Canadian and European cohorts.