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 CID 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-ste-roidal 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 (rheumatologic 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 FPP information, pointing to a need for healthcare professionals to provide adequate or inconsistent information.1

Background: Danish CID patients of reproductive age have concerns related both to their disease and to FPP, which affects their decisions around family planning. The majority of patients responding to this survey reported limited access to FPP information, pointing to a need for healthcare professionals to provide adequate or inconsistent information.1

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References:


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

<table>
<thead>
<tr>
<th>Age</th>
<th>Rheumatological diagnosis N (%)</th>
<th>Dermatological diagnosis N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>18–29 yrs</td>
<td>19 (49)</td>
<td>14 (74)</td>
</tr>
<tr>
<td>30–39 yrs</td>
<td>61 (56)</td>
<td>16 (73)</td>
</tr>
<tr>
<td>40–50 yrs</td>
<td>134 (60)</td>
<td>34 (63)</td>
</tr>
</tbody>
</table>

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References:

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 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 ranked-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 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 were important to track for their condition at baseline via the ArthritisPower app. 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 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 survey has identified gaps in the IAT procedures, such as a lack of patient control over the procedure, lack of informed consent, and lack of clear communication between the patient and the healthcare provider. The survey results also highlight the need for more research to understand the long-term effects of IAT on patient outcomes.


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