Background: People with inflammatory arthritis (IA) treated with conventional or biological immunosuppressive disease-modifying anti rheumatic drugs (DMARDs), were initially considered to have an increased risk of severe illness from SARS-CoV-19 (COVID-19) infection compared to the general population. Although recent studies have not confirmed this, people with IA have reported high level of anxiety and self-isolation during the pandemic (1). Only few studies have qualitatively explored how people with IA experience the impact of the COVID-19 pandemic and the SARS-CoV-19 vaccinations.

Objectives: To explore how people with IA experienced restrictions during the COVID-19 pandemic and the possible impact of vaccination on their protection against COVID-19 and their everyday lives.

Methods: Semi-structured in-depth interviews were conducted via telephone or video with 19 people with IA in May – August 2021, shortly after they were enrolled in the national COVID-19 vaccination programme (all Danish citizens >18 years of age invited for SARS-CoV-19 vaccination, free of charge, with timimg depending on age and comorbidities). At the same time, society gradually reopened after a complete lock-down. Qualitative content analysis, inspired by Graneheim and Lundman (2), was applied to analyse the data. Two patient research partners were involved in development of the study protocol, an interview guide and in the interpretation of findings.

Results: The participants’ age ranged from 21 to 64 years, median 50 years. 7 male and 12 female, all diagnosed with IA (Psoriatic arthritis n=4, Axial Spondyloarthropathy n=4, Rheumatoid arthritis n=9, and Juvenile arthritis n=2) and 14 were treated with DMARDs. Two had not accepted vaccination.

The analysis derived five themes: 1. “Changing and divergent information”: The participants experienced there was an overload of general information to the public, while targeted information on the specific risk for people with IA was lacking; 2. “Individual interpretation of own risk”: reflecting that participants had to find their own level of daily-life restrictions, a task they found to be very difficult; 3. “Impact on everyday life”: They took self-imposed precautions to protect themselves and their families from attracting COVID-19; 4. “Position in society and the vaccination programme”: emphasizing that participants were affected by the inconsistent announcements from authorities whether they were considered to be in particular risk or not, and some expressed concerns regarding the DMARDs influence on the effect of the vaccine and 5: “Reopening is somehow harder than lock-down”: A societal spirit of being “in this together” emerged through the lock-down and some were concerned that fewer restrictions during reopening of the society would put them in higher risk of a COVID-19 infection and force them to continue self-isolation.

Table 1. Quotation to illustrate the findings

<table>
<thead>
<tr>
<th>Quotation</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...you felt like one in the crowd and then everything is easier. Even though it was difficult. But then it was difficult for all of us. It had nothing to do with my rheumatic disease...we were in this together...But it was harder when the reopening started. Because it’s like: I’m back on the platform and can’t just jump on the train, can’t go anywhere, that is...I’m just not quite ready to jump into society like everyone else...”</td>
<td>Changing and divergent information</td>
</tr>
<tr>
<td>“...I feel like I’m not quite ready to jump into society like everyone else...”</td>
<td>Impact on everyday life</td>
</tr>
</tbody>
</table>

Conclusion: The COVID-19 pandemic affected the everyday lives of people with IA due to the authorities’ restrictions and further self-imposed precautions throughout lock down and reopening of society. People with IA experienced a lack of consistent information and felt alone to assess their own SARS-Cov-19 infection risk.

REFERENCES:

DISCLOSURE OF INTERESTS: None declared

Table 1. Summary of scores (n=101) for the 15-item PACIC scale (adapted version of the original 20-item scale)

<table>
<thead>
<tr>
<th>PACIC mean scores</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Patient activation (mean of items 1–3)</td>
<td>3.0 (2.8–3.2)</td>
</tr>
<tr>
<td>2: Delivery system design/ Decision Support (items 4–6)</td>
<td>3.4 (3.1–3.6)</td>
</tr>
<tr>
<td>3: Goal setting/ Tailoring (items 7–9)</td>
<td>3.2 (3.0–3.4)</td>
</tr>
<tr>
<td>4: Problem solving/ Contextual Counselling (items 12–15)</td>
<td>2.9 (2.7–3.2)</td>
</tr>
<tr>
<td>5: Follow-up/ Coordination (items 19–20)</td>
<td>3.3 (3.0–3.5)</td>
</tr>
</tbody>
</table>

Note: CI=Confidence interval; PACIC=Patient Assessment of Chronic Illness Care

Interviews revealed patients frequently encounter major shortcomings in care including experiencing organized care with limited participation, knowing which strategies are effective or harmful and feeling left alone with disease and psychosocial consequences. Patients often responded to challenges by dealing with the illness in tailored measure, taking over complex coordination of care and relying on an accessible and trustworthy team.

Conclusion: The low PACIC mean overall score is comparable to findings in patients with common chronic diseases. Key elements of the CCM have yet to be systematically implemented in Swiss SSC management. Identified gaps in care related to lack of shared decision-making, goal-setting and individual counseling –aspects that are essential for supporting patient self-management skills. Furthermore, there appears to be a lack of complex care coordination tailored to individual patient needs.

REFERENCES:

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Table 1. Recommendation Level of evidence Degree of agreement

Before starting treatment with a jakinib, it should be confirmed that the patient has no contraindications. 5 100%

The patient's efficacy and outcome expectations for the drug should be explored and those that need to be adjusted. 5 85%

It should be indicated that a double dose should not be taken if one is missed. 4 100%

As with other DMARDS, the patient should be instructed that close management will follow. 5 99%

The use of contraception and discontinuation of the drug is recommended in case of gestational desire or unplanned pregnancy. 1a 100%

It is recommended to explain the warning signs of infection: fever, blisters, burning pain in the ribs, itching when urinating, productive cough, diarrhoea, pus-filled wounds, phlegmon. 1a 89%

It is recommended to instruct the patient on preventive measures for infectious diseases (dental and hand hygiene, HPV, social distance, etc.). 1a 89%

Vaccination against common germs in immunocompromised persons and shingles with the current vaccine is recommended. 1a 93%

CV risk factors should be monitored, and the patient trained for signs of thrombosis, HF or ischaemic heart disease. 1a 93%

Close monitoring of elderly patients (CV risk, infections) is recommended. 2 100%

Emphasis on adherence is recommended for jakinibs to be effective. 3 100%

Before surgery, discontinuation of jakinibs should be scheduled depending on the type of surgery and comorbidities. 3 89%

Conclusion: These recommendations will allow a practical approach to the management of jakinibs by nurses and enjoy an adequate consensus among potential users.

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