EXPERIENCES DURING THE COVID-19 PANDEMIC AMONG PEOPLE WITH INFLAMMATORY ARTHRITIS. “IT WAS LIKE BEING UNDER A HARDER THAN LOCK-DOWN” - A QUALITATIVE INVESTIGATIVE STUDY

L. Lund1, M. Lowe1, O. Hendrichs2, K. Schreiber2, B. Glintborg2, R. Petersen2, C. Plischke1, W. Fisk1, J. Primdahl1,2,1. University College UC SYD, Esbjerg, Denmark, Research Center of Applied Health Science (SuPra), UC SYD, Esbjerg, Denmark, Esbjerg, Denmark, Esbjerg, Denmark 2. Danish Hospital for Rheumatic Diseases, University Hospital of Southern Denmark, Sønderborg, Denmark, Department of Regional Health Research, University of Southern Denmark, Odense, Denmark, Sønderborg, Denmark; DABIO and Copenhagen Rheumatoid Diseases, Centre of Head and Orthopedics, University Hospital of Copenhagen Rigshospitalet, Glostrup, Denmark, Department of Clinical Medicine, Faculty of health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark, Copenhagen, Denmark; 3. Danish Hospital for Rheumatic Diseases, University Hospital of Southern Denmark, Sønderborg, Denmark, Patient Research Partner, Sønderborg, Denmark; 4. University Hospital of Southern Denmark, Aabenraa, Denmark, Sygehus Sønderjylland, Aabenraa, Denmark, Aabenraa, Denmark

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 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 timing 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 the 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 and a sense of taking 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

1. “...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...”

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

PATIENT ASSESSMENT CHRONIC ILLNESS CARE (PACIC) AND ITS ASSOCIATIONS WITH QUALITY OF LIFE AMONG SWISS PATIENTS WITH SYSTEMIC SCLEROSIS – A MIXED METHODS STUDY

A. Kocher1,2, M. Simon1,2, A. A. Dwyer3,4, C. Blatter1, J. Bogdanovic1, P. Künzler-Heule1,5, P. Villiger6, D. Dan7, O. Distler8, U. Walker9, D. Nicca1,10,11

1. Institute of Nursing Science (INS), University of Basel, Basel, Switzerland; 2. Biostatistics and Prevention, University of Zurich, Department of Global and Public Health, Zurich, Switzerland

Background: Variable disease presentation and symptom burden in patients living with systemic sclerosis (SSc) require a chronic care approach including competent, coordinated, multidisciplinary collaboration as well as self-management support targeting individual patient needs. The Chronic Care Model (CCM) is a longstanding and widely adopted model guiding chronic illness management. Little is known about how CCM elements are implemented in SSc care or how patients’ care experiences relate to health-related quality of life (HRQoL).

Objectives: First, to describe current SSc care in Switzerland according to the CCM from the patient perspective and examine relationships with HRQoL. Second, to explain these results by patients’ illness and care experiences.

Methods: We employed an exploratory sequential mixed methods design (Figure 1). First, we conducted a cross-sectional quantitative survey (n=101 Swiss patients) using the Patient Assessment of Chronic Illness Care (PACIC)-20 and Systemic Sclerosis Quality of Life (SScQoL) questionnaires. Because PACIC has not been used in the context of SSc, we used the Mokken model to test the construct validity of the PACIC scale and its subscales. After excluding five problematic items, H coefficients were strong for the subscales and the global scale (0.52) suggesting a robust unidimensional scale.

Table 2. Evaluation of PACIC and SScQoL scores

Figure 1. Schematic of the explanatory, sequential mixed methods design

Next, we used data from individual patient interviews (n=4) and one patient focus group (n=4) to further explore care experiences of people living with SSc according to the PACIC model and PACIC dimensions.

Results: The mean overall PACIC-15 score was 3.0 / 5.0 (95% CI; 2.8–3.2), n=4, indicating care was neither ‘generally not’ aligned with the CCM. Lowest subscale scores related to ‘goal setting/tailoring’ (mean = 2.5, 95% CI: 2.2–2.7) and ‘problem solving/contextual counselling’ (mean = 2.9, 95% CI: 2.7–3.2) (Table 1). No significant associations were identified between the mean PACIC-15 and SScQoL scores.

REFERENCES: