feelings of dryness at the base of the penis, around the testicles, under the foreskin, around the glans of the penis and in the anus. Discussions were also had about changes in the volume and consistency of seminal fluid released either prior to or during ejaculation. Another conversation theme revolved around how the symptoms they experienced affected their ability to engage in sexual intercourse. Forum users discussed how pain and dryness made sexual intercourse painful, resulting in them withdrawing from sexual activity indefinitely. Discussions were also had about the lack of information available to help understand and manage sexual dysfunction. Forum users discussed how feelings of embarrassment about the nature of the symptoms and the stigma of it being "a woman's disease" kept them from seeking medical assistance. Those who had sought medical assistance shared their belief that health professionals (HPs) were misdiagnosing their symptoms and were prescribing ineffective treatments. They also reported that their HPs were dismissive of symptoms and unwilling to assist further.

Conclusion: Utilising conversations from an internet forum was an effective method to use to gain insight into some of the issues that males with SS experience with sexual functioning. The absence of accessible information and lack of support from HPs for males with SS is hinted at in this research. Future research should focus on identifying issues surrounding male sexual functioning as this will both guide future intervention strategies and allow HPs to publish material to better support males with SS.

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SAT0634-HPR PATIENT-REPORTED OUTCOMES REGARDING TWO FORMS OF METHOTREXATE AUTOINJECTORS IN RHEUMATOID ARTHRITIS: AN INTERNATIONAL CROSS-OVER SURVEY.

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Background: Several types of methotrexate (MTX) autoinjectors (AI) are currently marketed in rheumatoid arthritis (RA), yet comparative data are scarce.

Objectives: Investigate respective perceptions of patients regarding two marketed forms of MTX AI via a survey conducted by a global market research company.

Methods: Patients with moderate to severe RA treated by one of the two forms of MTX AI were recruited. In each participating country (France, Ireland, United-Kingdom, Spain), the respective proportions of recruited patients were approximately aligned on local market shares. The two investigated devices were: A-AI/ The first MTX AI marketed in Europe: bigger size, with an activation button, without double injection sound-control, with a larger window; B-AI/ The second MTX AI commercialized in Europe: smaller and thinner size, without activation button, with double injection sound-control and a smaller window. Each patient was interviewed during 30 minutes on his or her satisfaction level with the currently used device. Then, they were presented the alternative AI and they could test it on skin-mimicking pads. After this step, the patients were interviewed on the alternative device.

Results: 100 patients were enrolled over one-month period (A-AI users, n=65; B-AI users, n=35). Overall, 61% of A-AI users reported that B-AI was "better" or "much better" whereas 43% of B-AI users judged A-AI as "better" or "much better." When B-AI users were asked to evaluate convenience elements of A-AI, recognition of injection ending, general design and ease of use were the indicators that were the most poorly judged (60%, 54%, and 46% respectively). When A-AI users were cross-tested for B-AI, injection mode, general feeling, and ease of use were the three items providing the greatest satisfaction (80%, 77%, and 75%, respectively). When they were asked about the characteristics of their usual device, the button, the design of the device and discomfort associated with the injection were the most dissatisfactory elements (30%, 31%, 34% respectively). Also, 73% of A-AI users reported being interested in trying B-AI while 26% of B-AI users replied being so. Last, 95% of B-AI users declared being "very satisfied" or "totally satisfied", with ease of use and recognition of injection ending being the most attractive items (94% and 95% of high or full satisfaction respectively).

Conclusion: In this international cross-over survey, the newest autoinjector on the market, B-AI has shown to exhibit better reported outcomes with respect to ease of use and recognition of the end of the injection and other tested indicators.

Treatment of patients with RA should aim at the best care and must be based on a shared decision between the patient and the rheumatologist.¹ In this scope, the shared decision making is permitted when the patient agrees with the choice of

treatment (medication, administration route, device, etc.). Patient's involvement in decision making is assumed to lead to improvement in health outcomes such as a better adherence to the treatment.²

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SAT0635-HPR THE BURDEN OF SCLERODERMA FROM PATIENTS' PERSPECTIVE

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Background: Scleroderma can significantly impair daily functioning by leading to multi-organ involvement and profound fatigue. Recent studies suggest that objective measures of the disease severity may not necessarily correspond with the patients' perception¹.

Objectives: To evaluate the degree of disability and fatigue in patients with scleroderma, distinguish the most troublesome activities and assess which clinical symptoms had mostly impact on daily functioning.

Methods: An online questionnaire was created and distributed to English-speaking patients with scleroderma by means of online support groups. The questionnaire contained inquiries about demographical data, clinical symptoms as well as the Scleroderma Health Assessment Questionnaire (SHAQ, comprised of HAQ-DI and specific VAS scales) and Functional Assessment of Chronic Illness Therapy – Fatigue (FACIT-F). Standard and Alternative Disability Indexes (SDI and ADI) were counted based on answers in HAQ-DI part. Degrees of disability and fatigue, reflected by SDI, ADI and FACIT-F scores, were compared between subgroup of patients with and without particular clinical symptoms. Responses were analysed statistically.

Results: Questionnaire was completed by 85 responders (mean age 48,93±14,4; 98,82% were female). Mean SDI was 1.09±0.66 with 41.18% of patients fulfilling the criteria of mild to moderate difficulty (SDI<1), 50.59% classified as moderate to severe disability (1≤SDI<2) and 8.24% being severely or very severely disabled (SDI≥2). Mean value of ADI was 0.93±0.61. 56.47 % of responders needed aid of the caregivers while gripping/opening, 31.76% while reaching and 29.41% while running errands and chores. Most frequently used facilitating devices included devices for gripping/opening (32.94%) and for maintaining hygiene (21.18%). Mean value of overall disease severity was estimated by VAS as 52.06±0.66. The mean values of VAS assessing the impact on daily living were respectively 48.16±29.28 for pain related to the disease, 43.34±34.94 for Raynaud's, 41.86±34.59 for gastrointestinal problems, 31.60±31.38 for breathing difficulties and 20.85±33.47 for finger ulcers. Mean FACIT-F score was 23.62±11.88 yet 71.76% of patients fulfilled the criteria of severe fatigue. Both SDI and ADI correlated with FACIT-F score (respectively r=-0.5684, p<0.0001 and r=-0.5711, p<0.0001). SDI, ADI and FACIT-F correlated with VAS scores for overall disease severity, pain, gastrointestinal and breathing problems. Patients with symptoms such as arthralgia, muscle weakness, dysphagia, blurred vision, hair loss, unintentional weight loss and hoarseness were statistically more disabled and fatigued as compared to patients without such symptoms. Responders with skin ulcers/non-healing wounds (other than finger ulcers), Raynaud's or erythema/rash were more disabled than responders without such symptoms, yet no differences were observed in the degree of fatigue.

Conclusion: Majority of patients with scleroderma are moderately to severely disabled yet cope with the impairments with the widespread use of facilitating devices or aid of caregivers. Profound fatigue, observed in the majority of patients, may contribute to the high overall perception of disease severity.

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SAT0636-HPR PATIENT EXPERIENCE WITH THE PRESCRIPTION, INFORMATION AND USE OF METHOTREXATE

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Background: Methotrexate (MTX) is currently a mainstream drug in the treatment of rheumatic diseases. However, the response to MTX is not universal and

may be conditioned by a number of factors, among which adherence could be crucial.

Objectives: The aim of this study is to explore adherence to MTX in patients with rheumatic diseases, facilitators and perceived when taking and maintaining the prescription.

Methods: A qualitative study of content analysis was performed. Focus groups with patients taking either oral or subcutaneous MTX (being the main or coadjutant treatment) for any rheumatic disease was performed. The groups were moderated by a rheumatologist that was unknown for the patients. The speech was recorded and transcribed. Subsequently, an inductive coding was performed with the help of Atlas.ti and main themes and sub-themes were extracted, with examples of verbatim anonymized speech.

Results: Three focus groups were conducted, with a total of 12 participants, of whom eight were women, seven had rheumatoid arthritis, three had psoriatic arthritis, one had spondyloarthritis, and one had systemic lupus erythematosus. All patients reported an adequate adherence to treatment. The barriers identified were: information in the leaflet, technical language in the consults, difficult access to doctor's appointment, social environment, side effects and the subcutaneous device. As facilitators, the following aspects were discussed: good predisposition of the physician, reliable graphic information, role of associations and partners support.

The unmet needs detected were: problems with travelling, protocols for eventualities, absence of a plan of care, neglect of "non-physical" symptoms, disinformation on side effects and training in complementary aspects.

Conclusion: Getting reliable information was the main barrier identified. The environment and side effects may also negatively impact on adherence. Shared decision making is a goal to be achieved in the future in these patients.

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SAT0637-HPR IMPAIRED HEALTH-RELATED QUALITY OF LIFE AND PHYSICAL FUNCTION IN NORWEGIAN PATIENTS WITH TAKAYASU ARTERITIS.

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Background: Takayasu arteritis (TAK) is a rare vasculitis of large vessels in young women. We have previously reported a point prevalence of 25.6/10⁶. The disease most prevalently limited to the aortic arch and its branches (Type 1) among North Europeans.

Early symptoms of TAK include fever, myalgia and loss of appetite. Later, the inflammation of blood vessel may lead to irreversible vascular damage and ischemic symptoms with claudication of the extremities. We have recently found that TAK may reduce life expectancy, mainly due to cardiovascular complications. The median age among those deceased was only 58 years. These findings clearly indicate that TAK may have severe impact on the wellbeing of the patients and their physical capacity.

It is widely accepted to include patients' perspectives related to their health condition and treatment to better understand the burden of the disease and the impact on their daily life activities. However, studies of health-related quality of life (HRQoL) in TAK has rarely been undertaken, and we are not aware of any studies from the Northern part of Europe.

Objectives: (i) To compare HRQoL in Norwegian TAK with age- and sex matched Norwegian normative data. (ii) To assess patients reported disease symptoms (iii). To evaluate the impact of disease symptoms on HRQoL and functional status.

Methods: Patients with TAK from "The Norwegian Systemic Connective Tissue Disease and Vasculitis Registry" (NOSVAR) were included. All patients had to fulfill the American College of Rheumatology classification criteria and/or the modified Ishikawa diagnostic criteria for TAK and return three sets of questionnaires:

1) The SF 36 was applied to measure HRQL. Age- and sex-matched normative data were obtained from a former study and consisted of 2471 randomly selected Norwegian citizens (1162 women) who were >20 yrs. of age. 2) Questions from the Modified Health Assessment Questionnaire (MHAQ). 3) Patients answered questionnaires regarding disease symptoms, employment and assessment of general health status Disease duration was defined as the time from diagnosis to date of registration. Pearson correlation tests were used to explore associations between disease symptoms and HRQL.

Results: A total of 33 female patients were included. Their mean age at diagnosis was 32 yrs. and they had a disease duration of median, 8.9 yrs. at inclusion. The SF-36 results adjusted for age, indicated significantly impaired HRQoL in the patients compared with normative data on 6 of eight subscales, with the largest

differences observed for role physical (51 vs. 80, p < 0.001) and general health (51 vs. 78, p < 0.001) (Fig. 1). Symptoms of claudication in legs correlated strongly to moderately with activities as running or jogging 3 km (.538, p<0.001), walking outdoor on flat ground (.542, p=0.002), climbing stairs (.564, p=0.001) and run errands and shop (.417, p=0.016) assessed by MHAQ. The most frequently reported symptoms were dyspnea at physical exertion (67%), claudication of arms (63%) and myalgia (55%). A moderate correlation was found between claudication of legs (-.572, p<0.001), pain (VAS) (-.585, p<0.001), fatigue (-.493 P<0.002), dyspnea (-.471, p<0.002) and physical function as reported in SF36. Similarly, a moderate negative correlation was present between pain (VAS) (-.553, p<0.001), fatigue (VAS) (-.482, p<0.002) and mental health in SF36.

At the time of diagnosis, 89 % were employed, compared to only 21% at registration. Patients self-perceived health status was reported in 39 %, compared to 79% in a share of the Norwegian population aged 16 or over (The data from the EU Statistics on Income and Living Conditions(EU SILC)).

Conclusion: Patients with TAK reported reduced QoL compared to data from our general population. The most frequently reported disease symptoms were dyspnea at exertion, claudication of arms and myalgia. Pain, fatigue and dyspnea at exertion had a significant impact on HRQoL. Claudication of legs correlated significantly with impaired walking activities reported in MHAQ.

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SAT0638-HPR CHARACTERIZING THE IMPACT OF AXIAL SPONDYLOARTHRITIS ON DAILY LIFE: GENDER AND PATIENT-REPORTED OUTCOMES ASSOCIATED WITH FUNCTIONAL LIMITATION IN CANADA. RESULTS FROM THE IMAS SURVEY

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Background: Understanding the most limiting daily activities reported by patients is important for a holistic healthcare approach.

Objectives: To evaluate the degree of functional limitation on daily activities and its association with PROs in Canada.

Methods: The International Map of Axial Spondyloarthritis (IMAS) is a cross-sectional online survey of non-selected patients with self-reported axSpA conducted in 22 countries and endorsed by the Axial Spondyloarthritis International Federation. IMAS captures the patients' perspective of the burden of axSpA. The Canadian adaptation included a review of the survey by an advisory board of axSpA patients and a national steering committee composed of the Canadian Spondylitis Association, rheumatologists and axSpA patients. Canadian participants were recruited from 2018 to 2019. Socio-demographics variables, BASDAI and mental health (GHQ-12) data were collected. Degree of functional limitation in 18 daily activities was evaluated using a 3-point Likert scale. Bivariate analysis was performed to assess activities associated with poorer BASDAI and mental health status.

Table 1. BASDAI and mental health (GHQ-12)- impact on daily activities (N = 542)

	BASDAI Mean ± SD			GHQ-12 Mean ± SD		
	Low limitation	Medium + High Limitation	p-value	Low limitation	Medium + High Limitation	p-value
Dressing / undressing	5.5 ± 2.0	6.4 ± 4.4	<.001*	4.4 ± 3.8	5.7 ± 4.0	.007*
Washing / personal grooming	5.6 ± 2.0	6.3 ± 2.0	.002*	4.7 ± 4.1	5.6 ± 4.1	.099
Taking a bath / shower	5.6 ± 2.0	6.6 ± 1.8	<.001*	4.2 ± 4.0	5.9 ± 4.0	.002*
Tying shoe laces	5.4 ± 2.0	6.1 ± 2.0	.005*	4.3 ± 3.8	5.2 ± 4.1	.044*
Walking / getting around the house	5.5 ± 2.0	6.4 ± 1.9	<.001*	4.2 ± 3.9	5.6 ± 4.1	.005*
Stair climbing	5.1 ± 1.9	6.3 ± 1.8	<.001*	3.4 ± 3.4	5.4 ± 4.0	<.001*
Lying down / getting up from bed	5.2 ± 2.0	6.3 ± 1.9	<.001*	3.6 ± 3.6	5.5 ± 4.1	<.001*
Going to the toilet	5.4 ± 2.0	6.7 ± 1.9	<.001*	4.3 ± 4.2	5.6 ± 3.9	.024*
Shopping	5.6 ± 1.8	6.2 ± 1.9	.003*	4.1 ± 3.7	5.3 ± 4.1	.025*
Cooking	5.6 ± 1.9	6.3 ± 1.8	.008*	3.7 ± 3.6	5.8 ± 4.2	<.001*
Eating	5.9 ± 2.1	6.9 ± 1.9	.024*	5.0 ± 4.4	5.8 ± 3.9	.282
Housework / cleaning	4.9 ± 2.0	6.0 ± 1.8	<.001*	3.7 ± 3.6	4.8 ± 4.0	.021*
Walking down the street	5.4 ± 1.9	6.1 ± 2.0	.005*	4.4 ± 3.8	5.1 ± 4.1	.228