Results: A total of 260 patients took part in the survey; mean age of the respondents was 60 years IQR (54-66), 93% were female. In July 2020 88% of patients had accessed a telemedicine-based and 12% a face-to-face rheumatology consultation; only 3.5% of patients reported having been less adherent to pharmacological therapy due to information received through media or social networks. Regarding the prevention measures taken during the pandemic, 98% reported to have stayed in their houses since the lockdown was established in Colombia, and have implemented or increased hand washing from one or none to more than three times per day. Also 8% of respondents lived with people who were at bigger risk of having SARS-CoV-2 (i.e. health care professionals, workers at public transportation, and supermarkets among others), the main measurement taken was to be completely separate from the person at risk to avoid contagion and maintaining hygiene measures and physical distancing (Fig 1). Only one patient was positive for SARS-CoV-2, due to a possible contagion from a relative at home and reported only flu-like symptoms without any complications. Patients highlighted the necessity to return to the educational on RA program agreeing to attend to an online modality. Patients highlighted the need for educational sessions focused on the relationship between rheumatoid arthritis, its treatment, and Covid-19.

Figure 1. Behaviors, practices, and its changes due to Covid-19 pandemic

Conclusion: An educational on RA program shows to be helpful tool to maintain high adherence rates to the RA treatment despite of the new challenges associated to the pandemic and despite being incomplete due to lack of time; patient-centered education programs should continue to address the patient's concerns and beliefs about their disease and the Covid-19 issues.

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AB0922-PARE OSTEOPOROSIS AWARENESS LEVEL AS A METHOD FOR IMPROVING PRIMARY PREVENTION

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Background: Having complete information about osteoporosis is a prerequisite for preventive behavior, which determines the conscious adherence to the principles of a healthy lifestyle.

Objectives: To assess the level of awareness of osteoporosis among women.

Methods: A survey was conducted of 750 female respondents aged 15 to 55 years in the Chuvash Republic. The survey was conducted from January to December 2019. The questionnaire consisted of 30 questions. One point was awarded for each correct answer. The minimum score for passing the test was 75% correct answers. The questions addressed both general knowledge about osteoporosis and the relationship between disease onset and diet, physical activity, vitamin D, cigarette smoking, excessive alcohol consumption, and being overweight. The respondents were divided into two groups: group A (n = 375) - females from 15 to 35 years old and group B (n = 375) - females from 36 to

55 years old. Survey data was processed in Statistical Analysis Software 15.0. Statistical significance was calculated using Analysis of Variation.

Results: We obtained the following results for the Main Aspects of the survey: 1. Osteoporosis is a rare condition that occurs primarily in women (Awareness level: Group A - 47%; Group B - 67,5%; Analysis of Variation > 0,05). 2. Postmenopausal women are more at risk of osteoporosis (Awareness level: Group A - 73,5%; Group B - 70,4%; Analysis of Variation > 0,05). 3. Prevention of osteoporosis is impossible (Awareness level: Group A - 78,8%; Group B - 89%; Analysis of Variation > 0,05). 4. Vitamin D is synthesized by direct exposure to UV radiation on the skin (Awareness level: Group A - 53,1 %; Group B - 69,1%; Analysis of Variation > 0,05). 5. Effective prevention of osteoporosis are: I. Balanced diet; II. Absence of bad habits; III. Occupation with health-improving physical culture. IV. Reduction of excess body weight (Awareness level: Group A - 69,2%; Group B - 47,1%; Analysis of Variation > 0,05). 6. Increased consumption of table salt, sugar and excessive consumption of protein foods, vegetarianism negatively affects the quality of bone tissue (Awareness level: Group A - 56,7%; Group B - 70,4%; Analysis of Variation > 0,05).

Conclusion: The conducted survey shows that the level of awareness of osteoporosis and its prevention is low among women in different age groups. In some cases, it is even a cause for concern. We believe that respondents' statements that osteoporosis cannot be effectively prevented are the most important findings of our study. Starting from adolescence, women should be well aware of the main risk factors for the development of osteoporosis, the mechanisms of its development and its consequences. This knowledge will help substantiate why it is necessary to lead a healthy lifestyle, which will help to prevent the development of this disease in the future. The concept of prevention of osteoporosis should include the following recommendations for the general population: to maintain a physically active lifestyle and to spend sufficient time under the influence of sunlight, avoid smoking and drinking large amounts of alcohol, ensure that dietary calcium intake is in line with the recommended level in the area, and maintain an appropriate body weight.

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Building patient led organisations

AB0923-PARE WHAT IS THE IMPACT ON THE QUALITY OF LIFE (QOL) OF PEOPLE LIVING WITH SPONDYLOARTHRITIS (SPA)*?

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Background: SpA describes a group of chronic inflammatory arthritic diseases with common features including inflammation of the spine, eyes, skin and gastrointestinal tract. These conditions can be painful and debilitating for many. Delayed diagnosis and treatment can lead to irreversible damage to the spine and other joints. Diagnosis of these conditions can take, on average, 7 years or more. We don't know what causes SpA and there is no cure. The onset of symptoms can be in early childhood and expands throughout one's lifespan. It affects children, women and men worldwide.

Objectives: To understand how living with SpA impacts QOL (including relationships, work and day-to-day life) and what is important to patients in order to help the CSA** prioritize advocacy focus and resource development.

Methods: The CSA surveyed the community virtually from 11/19/19 to 01/21/20. The results of 838 respondents were analyzed after the survey closed.

Results: 66% of respondents had been diagnosed with Ankylosing Spondylitis and 24% with Psoriatic Arthritis. 22% were diagnosed with more than one form of SpA.

Over 70% reported their day-to-day life was negatively impacted by SpA. Only 7% indicated no impact on their daily life and 22% said it was somewhat impacted. Ability to remain in the workplace was impacted and 16% reported being on long-term disability and 4% on short-term disability. There were 7% who retired early due to their disease.

Sleep loss/interruption was reported by 89% and 74% said they avoid social events. 41% of participants are highly restricted by SpA when it comes to tasks like outdoor yard work. Other highly restricted tasks include exercise (36%) and cleaning (31%). Tasks of medium restriction include preparing meals (31%) and engaging in intimate relations (30%).

Upon diagnosis and disease progression, many reported less frequent participation in exercise, travel, intimate relationships, social outings and family activities. Some even said they stopped participating in these all together.

When asked to rank what was most important regarding QOL, most ranked living with no/reduced pain as most important, followed by improved sleep/no fatigue. The least important were returning to work and going out with friends.

Conclusion: SpA conditions have a negative impact on QOL and are a burden causing patients to constantly assess their situation, worry about tomorrow and adjust different aspects of their lives. Results confirmed every aspect of life is impacted, both physically and mentally, leaving people feeling hopeless and without a purpose. Many can no longer work or do their favorite hobbies which leads to emotional and mental difficulties. People struggle with maintaining social and intimate relationships, intensifying social isolation and low self-confidence. Many indicated that their loved ones have difficulties understanding chronic pain and illness, making patients feel like a burden. This may be attributed to general lack of knowledge about SpA. The unpredictability of the disease impacts QOL leaving patients hesitant to make social plans in advance. Even those who are undergoing successful treatment and have improved QOL worry about the future. QOL can be improved with proper treatment, management and support.

Many expressed frustrations of being limited by their disease and indicated that it is often the chronic pain that causes these limits. It is clear that by living with less pain, patients can improve all aspects of their lives and be happier.

The CSA is committed to educating, supporting and advocating on behalf of Canadians impacted by SpA to improve health outcomes and QOL.

It doesn't have to be visible to be real. Together we are stronger!

Footnotes:

*SpA conditions include: Ankylosing Spondylitis, Psoriatic Arthritis, non-radial SpA, Axial and Peripheral Spondyloarthritis, Enteropathic Arthritis, Reactive Arthritis and Juvenile Onset Arthritis

**The Canadian Spondylitis Association (CSA) is a national non-profit patient association supporting and advocating for those living with SpA.

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Arthritis research

AB0924-PARE

EXPERIENCES AND PERCEPTIONS OF PATIENTS WITH PSORIATIC ARTHRITIS PARTICIPATING IN A TRIAL OF FAECAL MICROBIOTA TRANSPLANTATION: A NESTED QUALITATIVE STUDY

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Background: Patients' first-hand experiences of faecal microbiota transplantation (FMT) performed in a rheumatological care-setting have yet to be elucidated. **Objectives:** The objectives were to explore participants' perceptions of being part of an FMT trial thereby identifying potential trial participation effects and enlightening the patient perspective on the outlook for future FMT trials in rheumatic diseases.

Methods: In a qualitative study nested within a double-blind, randomised, placebo-controlled trial (RCT) testing FMT as a potential new anti-rheumatic treatment,¹ semi-structured telephone interviews were conducted following the trial participants' final 26-week visit. The RCT was conducted at a Danish rheumatology university outpatient clinic with nationwide inclusion. The qualitative study included ten patients with psoriatic arthritis (PsA) who completed the final 26-week trial visit and were unaware of their treatment allocation (one gastroscopic-guided FMT or sham transplantation into the duodenum), see table 1. Qualitative researchers, who did not take part in the RCT, performed the interviews and the primary analysis. The experiences explored related to the conduct of the RCT and changes in the participants' everyday life. The analysis was carried out using a thematic approach. There was sufficient repetition of ideas in data to conclude data saturation.

Table 1. Characteristics of the participants.

Characteristic	Total (n = 10)
Female sex, no. (%)	7 (70%)
Age, yr.	53.9 (11.3)
Time since diagnosis, yr. ^a	7.4 (4.2, 12.8)
Rheumatoid factor IgM negative, no. (%)	10 (100%)
Anti-citrullinated peptide antibody negative, no. (%)	10 (100%)
HLA-B27 negative, no. (%)	8 (80%)
C-reactive protein, mg/L	4.5 (3.6)
HAQ-DI ^b	1.09 (0.40)
Swollen joint 66 count	7.4 (3.8)
Tender joint 68 count	22.8 (7.9)
SPARCC enthesitis index ^c	
Score ≥1, no. (%)	10 (100%)
Score in patients with a score ≥1	8.7 (4.0)

Data are mean (SD) or n (%) unless otherwise stated. ^a Time since diagnosis of psoriatic arthritis is presented as median and interquartile range (IQR). ^b Scores on the Health Assessment Questionnaire Disability Index (HAQ-DI) range from 0 to 3, with higher scores indicating greater disability. ^c Spondyloarthritis Research Consortium of Canada (SPARCC) Enthesitis Index range from 0 to 16, with higher scores indicating more severe disease.

Results: Participation in the RCT influenced the patients' understanding of PsA and induced positive changes in their everyday life. Renewed hopes for the future in addition to a feeling of enhanced care contributed to significant trial participation effects.² We identified several factors related to the RCT that may have promoted these effects (figure 1). FMT was deemed acceptable and safe, and all participants supported more research into the field of microbiota-targeted interventions in rheumatic diseases.

Figure 1. Factors related to the RCT that may have promoted trial participation effects.

Conclusion: Discrepancies between the clinical and the research setting should be considered when discussing the clinical relevance of the results of the RCT. Overall, patients with PsA who have participated in an RCT testing FMT find the treatment acceptable and safe encouraging more research into the field of microbiota-targeted interventions in rheumatic diseases. Further research into the potential beneficial and adverse effects of FMT in addition to exploring the magnitude and mechanisms behind FMT trial participation effects in the rheumatological setting are highly needed.

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