Program, Albuquerque, United States of America; "University of Wisconsin-River Falls, Young Patients' Autoimmune Research & Empowerment Alliance, River Falls, United States of America; "University of New Mexico, Occupational Therapy Graduate Program, Albuquerque, United States of America; "Arthritis Research Canada, Research, Richmond, Canada; "University of British Columbia, Rheumatology, Vancouver, Canada

Background: Systemic sclerosis (SSc) severely limits one's ability to participate in paid employment, which may threaten an individual's economic, social, physical, or mental well-being. No programs and very little resources exist to help people with SSc remain in the work force despite the high prevalence of work disability. The few programs that do exist were developed for patients with other rheumatic conditions. One evidence-based program, Making it Work™ (MIW), has the potential to be adapted to meet the specific work related problems faced by people with SSc.

Objectives: This study identified challenges in the work environment and supports received or desired by persons with SSc as a preliminary step to identify adaptations that could make the MIW™ more relevant to people with SSc.

Methods: Participants were recruited through virtual communication from the National Scleroderma Foundation and word of mouth to participate in one 2-hour virtual focus group. Participants were >18 years of age, currently employed or stopped work in the past 5 years, United States residents, English-speaking, and self-reported a diagnosis of SSc and that SSc affected their work ability. Participants were first asked about difficulties working with SSc. The facilitator created a list of challenges based on initial discussion, then participants identified the top five most important challenges according to their experience. Participants were then asked about supports received or desired to help maintain employment. Focus group notes and transcripts were analyzed to determine challenges and supports that must be addressed in an employment intervention for people with SSc.

Results: The sample included 14 participants (85.7% women, mean age 48.6±10.1 years, mean disease duration 7.7±7.4 years; 78.6% had diffuse SSc). 71.4% had college degrees and 71.4% were employed full time. 42.9% described their jobs as having mostly mental demands while 35.7% had both physical and mental demands. Important challenges prioritized by the most participants were: 1) challenges with physical tasks, particularly related to hand use [11, 78.6%]; “My hands are always messed up; typing is a challenge”; 2) fatigue [9, 64.3%]; “When you say fatigue, people are like, ‘Well, go take a power nap,’ but that’s not what it is. I could sleep 12-hours and still be exhausted”; 3) mental and emotional health, related to coping with how the unpredictability of SSc affects the body, identity, and employment [8, 57.1%]; “This disease does not just knock us down one time or challenge us on one level. It’s like onebody system after another.”

You have to deal with the issues of your self-esteem, feeling like you’re different than everybody else, mourning that loss of ability or career or work ethic that you had prior to your diagnosis. Participants identified a variety of individualized strategies that enabled them to overcome challenges with SSc at work, including ways to plan ahead, adaptive equipment, and strategies to adapt job tasks. However, participants emphasized that in order to use these tools, it is most helpful to: 1) have the knowledge and advocacy skills to know what to ask for; 2) feel confident that asking for support or accommodations in the workplace will lead to a beneficial change; and 3) be able to problem solve with others (e.g., clinicians, work-related program, therapists, support group).

Conclusion: This study identified the prominent barriers and supports to employment from the perspectives of patients with SSc. While there is some overlap with issues reported by persons with other rheumatic conditions, there are also SSc-specific concerns. This information will be used to adapt the MIW™ intervention, and warrants further consideration for how to incorporate better supports in healthcare, workplaces, and vocational counseling for people with SSc.

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POS1400-HPR

ONLINE SCHOOL AS A METHOD OF INCREASING THE MEDICAL LITERACY OF PATIENTS WITH RHEUMATIC DISEASES

Keywords: Patient information and education

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Background: Today, most of the population of Kazakhstan have access to the Internet. Due to this fact, the use of online schools for patients with rheumatic diseases seems to be a promising direction [1, 2].

Objectives: The purpose of the study is to analyze whether online rheumatology schools can be used as one of the methods to improve the medical literacy of patients with rheumatic diseases.

Methods: A survey was conducted with 90 patients in the city of Astana attending an online school on RH from September 2021 to September 2022 after graduation. The online questionnaire included 20 questions (part A and part B). The questions in Part A concerned the age of patients, gender, bad habits, heredity, sources of information about the school, and the desire to study at an online school. In part B, the questions concerned the novelty and quality of the information received. Patients had to choose one/several of the presented answer options. In some questions, a differentiated assessment was used on a 5-point scale, where 0 points is the minimum, and 5 is the maximum positive assessment.

The lecture course consisted of 36 lectures and 6 practical exercises on rheumatological diseases. The questionnaire data were processed in Statistical Analysis System Software 15.0. Statistical significance was handled using Analysis of variance. Results: Part A. The number of patients under the age of 39 was 9 (10%) respondents, 31-40 years old - 41 (45.6%) respondents, 41-50 years old - 12 (13.3%) respondents, 51-60 years old - 17 (18.9%) respondents, over 60 years old - 11 (12.2%) respondents. 75 (83.3%) patients were women. 26 (28.8%) patients had bad habits. 17 patients (18.8%) knew about rheumatic diseases FROM relatives. Most of the participants received information about the online school from the clinic staff - 42 (46.7%) or FROM the clinic website - 27 (30.0%), from other sources - 21 (23.3%) respondents, 72 (80%) respondents noted their desire to attend such classes in the future. These data indicates on the interest of respondents of different age groups in improving the level of medical literacy in rheumatic diseases. Part B. 77 (85.5%) and 82 (91.1%) respondents learned about new risk factors for RD (the role of infection and stress), respectively. 39 (43.3%) patients understood the need to correct their lifestyle. A total of 26 (28.8%) respondents realized that they could independently control treatment. 92% of respondents rated the quality of the information received by the maximum score.

Conclusion: The online school can be used as one of the methods to improve the medical literacy of patients with rheumatic diseases.

REFERENCES:

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significantly more physically active compared to individuals with RA (p<0.005). Body awareness, kinesiophobia, pain catastrophizing and psychosocial status were similar between groups (p>0.05). In addition, disease activity was moderately correlated with body awareness, pain catastrophizing and kinesiophobia, with associations between AS and RA being similar.

**Conclusion:** Treatment of RA and AS is similar, but there are key differences. According to our results, individuals with AS is more physically active than individuals with RA regardless of disease duration and disease activity. Health professionals can also focus on correlation between disease activity and higher body awareness, pain catastrophizing and kinesiophobia in individuals with AS.

**REFERENCES:**


**Table 1. Characteristics of patients and outcome measures**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>RA (n=48)</th>
<th>AS (n=30)</th>
<th>p*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (year); mean ± SD</td>
<td>51.34 ± 11.0</td>
<td>40.27 ± 10.38</td>
<td>0.000*</td>
</tr>
<tr>
<td>BMI (kg/m²); mean ± SD</td>
<td>28.21 ± 4.47</td>
<td>26.66 ± 5.78</td>
<td>0.101</td>
</tr>
<tr>
<td>Gender (n, %) Female</td>
<td>41 (85.4%)</td>
<td>7 (23.3%)</td>
<td>0.000*</td>
</tr>
<tr>
<td>Duration of disease (year); mean ± SD</td>
<td>7.20 ± 9.39</td>
<td>5.91 ± 7.28</td>
<td>0.488</td>
</tr>
<tr>
<td>ESR (mm/h)</td>
<td>12 (2-58)</td>
<td>9 (2-54)</td>
<td>0.115</td>
</tr>
<tr>
<td>CRP (mg/dl)</td>
<td>3.65 (0.18-37.70)</td>
<td>5.2 (0.60-49.06)</td>
<td>0.300</td>
</tr>
<tr>
<td>BASDAI (0-10)</td>
<td>Active disease</td>
<td>18 (60)</td>
<td>12 (40)</td>
</tr>
<tr>
<td>n (%)</td>
<td>36 (75.0%)</td>
<td>24 (80.0%)</td>
<td>0.740</td>
</tr>
<tr>
<td>DAS28 Remission</td>
<td>24 (50)</td>
<td>24 (50)</td>
<td>1.000</td>
</tr>
<tr>
<td>n (%)</td>
<td>Low activity</td>
<td>12 (25)</td>
<td>12 (25)</td>
</tr>
<tr>
<td>Moderate activity</td>
<td>12 (25)</td>
<td>12 (25)</td>
<td>1.000</td>
</tr>
</tbody>
</table>

**Outcome measures**

- **RA: Rheumatoid arthritis; AS: Ankylosing spondylitis; SD: Standard deviation; BMI: Body mass index; ESR: Erythrocyte sedimentation rate; CRP: C reactive protein; Bath Ankylosing Spondylitis Disease Activity Index, BDI: Beck Depression Inventory; IPAQ-SF: International Physical Activity Questionnaire-Short Form; PCS: Pain Catastrophizing Scale; TSK: Tampa Scale for Kinesiophobia; BAIQ: Body Awareness Questionnaire.**

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**POST1402-HPR**

**LIVED EDUCATIONAL EXPERIENCE OF YOUNG ADULTS WITH CHILDHOOD- AND ADULT-ONSET SYSTEMIC LUPUS ERYTHEMATOSUS: A MULTI-CENTER CANADIAN QUALITATIVE STUDY**

**Keywords:** Qualitative research methods, Systemic lupus erythematosus, Work-related issues

**Methods:** YASLE were recruited from two Lupus clinics in Toronto and Winnipeg. Semi-structured qualitative interviews were conducted individually via secure video conferencing. As this study was conducted during the coronavirus pandemic, participants were also asked about the pandemic impacts on their educational experiences. All interviews were transcribed verbatim, double-coded and analysed using a reflexive thematic approach.

**Results:** Twelve participants (2 males), 9 of childhood- and 3 adult-onset SLE (cSLE, aSLE) were interviewed. Nine participants (82%) were <25 years old. Five also worked while studying. Five were Asians, 5 were White, 2 of other ethnicities. Half have severe disease (central nervous system or renal involvement). Median duration of disease was 4.0 (25%-75% percentile, 1.8-5.3) years. The impacts of SLE on their education experience emerged in 5 themes:

1. **Challenges imposed by SLE:** Difficulties adjusting to the diagnosis, physical and cognitive symptoms of SLE. While most participants disclosed their diagnosis to their schools, some expressed hesitation.

2. **Changes in aspirations:** Education/career goals were modified by reducing course load or shifting to more sedentary or less cognitively demanding careers.

3. **Coping and acceptance:** More adaptive than maladaptive coping strategies were used to manage their SLE, including self-acceptance, pacing, planning and avoidance. All strove to do well in their studies despite SLE and were hopeful for their futures.

4. **Facilitating factors for education success:** Family and friends social support, individualized accommodations from school and parental financial support were identified.

5. **Pandemic impacts:** Virtual learning and flexible schedules enabled participants to adapt their schedules according to their physical conditions (e.g. pain, fatigue). However, fewer opportunities to interact in-person were viewed as challenges. Participants want hybrid options to continue even after the pandemic.

**Conclusion:** SLE affected students’ performance through physical symptoms, fatigue and cognitive dysfunction. Ongoing school and social supports help to support them. Maintaining the remote learning options may increase accessibility for them. These results identified opportunities for developing future supportive interventions for YASLE patients in their schooling which then better prepare them for future employment.

**REFERENCES:**


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