Objectives: To analyse experiences, facilitators and barriers of telemonitoring the pulmonary function in SSC-ILD patients.

Methods: This study was embedded in a longitudinal study on the validity of detecting progressive ILD with weekly home spirometry in adult SSC patients, fulfilling the ACR-EULAR criteria with a disease-duration ≤ 5 years and a maximum of immunosuppressive treatment of 8 weeks. Using a Bluetooth-enabled handheld spirometer, measurements are collected via a mobile application for smart devices with results being visible, as graphs and bar charts, for both physician and patient. The weekly measurements are evaluated by a physician and an extra hospital check-up will be scheduled if results decrease. This system has proven to be feasible in SSC patients in our pilot study [3].

In patients, who used home spirometry for at least 3 months, semi-structured interviews were conducted and audio-records were transcribed. Patients were selected using purposive sampling based on age, treatment for ILD and course of pulmonary function in telemonitoring (>5% decline/stable) till data-saturation was achieved (i.e. no new codes in the last 2 interviews). Interviews were coded by 2 researchers independently using inductive thematic analysis.

Results: In total 13 patients (8 female/5 male) were interviewed from whom 3 patients had > 5% decrease in pulmonary function during the observation period. The age ranged from 36-75 with a median of 58 year. Five main themes were extracted: telemonitoring routine, impact of telemonitoring, trust in telemonitoring, contextual factors and implementation in regular healthcare (Figure 1). Most patients perceived it as reassuring to see stable results weekly, though the moment itself might be tensive. Moreover, the possibility to detect progressive disease earlier was appreciated. One patient, however, preferred disease activity being monitored by the physician instead.

Some patients placed fluctuations of measurement within limits of normal in perspective, while others experienced negative feelings in case of a decreased value. Experienced advantages of telemonitoring were being in the lead, insight in disease course (for some resulting in less confronting hospital visit), increased trust in health, decreased fear of progression, and reduced dependence on hospital visits. Most patients trusted the results of telemonitoring, although some trusted the hospital measurements more, because of external guidance from an analyst (leading to more motivation and unbiased results), and the manner of measurement (during breathing cycle in hospital vs. single breath at home). Understanding the rationale behind telemonitoring is an important facilitator, whereas possible barriers to perform weekly home spirometry are excessive saliva production (as it hinders proper function of the spirometer), confrontation with the disease, and older age. Most patients advocated to implement telemonitoring in healthcare and appreciated an accompanied reduction in hospital visits, although others viewed the regular physical contacts and control of other disease features as important. It was recommended to provide information about limits of normal values or regular feedback.

REFERENCES:

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Disclosure of Interests: Arthiha Velathapillai: None declared, Gwyn Schepers: None declared, Madelon Vonk Speakers bureau: Boehringer Ingelheim, Bristol-Myers Squibb, GSK, Janssen, MSD, Novartis and Roche, Consultant of: Boehringer Ingelheim and Janssen, Grant/research support from: Research grants from Boehringer Ingelheim, Janssen,Ferrer and Galapagos, Cornelia van den Ende: None declared.

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Figure 1. Overview of general dimension, first-, and second-order themes.

Conclusion: In SSC telemonitoring the pulmonary function can contribute to patient empowerment, however it might not be suitable for every patients, as it might elicit negative feelings.
REFERENCES:

Acknowledgements: NIL.
Disclosure of Interests: None Declared.
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**POSI190-HPR**

**WHY LUPUS? – PATIENTS’ THOUGHTS OF TRIGGERS OF SYSTEMIC LUPUS ERYTHEMATOSUS AND PERCEIVED HEALTH**

Keywords: Systemic lupus erythematosus, Patient information and education

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Background: It is well known that genetic factors and environmental triggers contribute to the inflammatory process and onset of systemic lupus erythematosus (SLE). Yet, other contributors may still be unknown, and few studies have to date systematically explored patients’ views on what caused SLE onset. In a longer perspective, we also need to pay more attention to health literacy, and to patients’ understanding of their disease since these aspects are important for treatment compliance, patients’ perceptions of health and patient education.

Objectives: To explore patients’ thoughts of the cause of SLE and to analyse their reports in relation to perceived health and quality of life.

Methods: Adult patients with SLE (≥ 4 ACR criteria) recruited to a cohort study in tertiary care. The participants answered the written question “Do you have any thoughts of why you got SLE?” and additional questions of perceived SLE activity during the last three months (score 0-10, 0= no activity), SLE health last week (score 0-100, 0=good SLE health) and current general health (score 0-100, 100=full health). The participants’ free written answers were categorized according to the content. We explored if patients’ age, educational level, disease duration as well as perceived health differed between the categories.

Results: 375 patients were included. The main question regarding their thoughts of why they got SLE was answered by 290 patients (77%), mean age 48 years, range 18-87, mean disease duration 15 ±14 years. The replies on the health scales ranged from minimum till maximum. SLE activity was low to moderate (mean 4.2 ±3), perceived SLE health mean 34.7 ±25.9 and current general health mean 63.1 ±21.0. The highest reported level of education was university education for 47% and high school for 36%. Among the patients who answered the main question (n=290), 33% (n=95) answered that they had no idea/thoughts of why they got SLE. Men (p=0.041) and persons with lower educational level (p=0.038) were more common in this group, also reporting slightly better general health (p=0.050) than the group that had explicit thoughts of why they got SLE. Age, disease duration or perceived SLE parameters did not differ between the two groups. The answers of patients’ thoughts of why they got SLE were sorted into categories: genetics (n=82), stress/trauma (n=65), infections/immunization (n=96), hormones/treatment (n=28), lifestyle behavior (n=28), treatment/disease other than SLE (n=26) and environmental factors (n=5). A majority (n=135, 69%) wrote one potential factor of why they got SLE, two factors were reported by 149 patients (25%), three factors by 20 patients (3%), and four factors by 15 patients (2%). It was exclusively answers from women that could be categorized as “hormones/treatment” or “treatment/diseases other than SLE” and only one man wrote a statement of stress/trauma as potential trigger of SLE. Patients in the category “hormones/treatment” had shorter disease duration (p=0.029), higher perceived SLE activity (p=0.011) and worse general health (p=0.002) compared to those that had no statement that could be sorted into the category. Only five patients reported environmental triggers and these perceived worse SLE health (p=0.022) and worse general health (p=0.038). Patients who reported stress/trauma as potential trigger of SLE onset had in a larger extent university education (p=0.027) than those who did not report stress/trauma as a trigger.

Conclusion: Beside genetic factors, a prominent number of patients in this study reported stress/trauma or hormones as important triggers for developing SLE. In these groups perceived health and educational levels had different patterns. Additionally, infections/immunization were perceived as triggers for SLE but without the same difference in perceived health or educational level. Further studies should extend these results and investigate patients’ perceptions of triggers for SLE flares, and high disease activity, information which can enhance our understanding of factors that may contribute to important aspects of SLE and patients’ perceptions of health.

Table 1. Description of inflammatory activity by ultrasound in metatarsophalangeal joints of 36 patients with SLE.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Grade 1 Synovitis</th>
<th>Grade 2 Synovitis</th>
<th>Grade 3 Synovitis</th>
<th>Doppler 1</th>
<th>Doppler 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right Foot</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1° MTF</td>
<td>3 (8.3%)</td>
<td>13 (36.1%)</td>
<td>2 (5.6%)</td>
<td>1 (2.8%)</td>
<td></td>
</tr>
<tr>
<td>2° MTF</td>
<td>8 (22.2%)</td>
<td>6 (16.7%)</td>
<td>1 (2.8%)</td>
<td>2 (5.6%)</td>
<td></td>
</tr>
<tr>
<td>3° MTF</td>
<td>11 (30.6%)</td>
<td>3 (8.3%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4° MTF</td>
<td>3 (8.3%)</td>
<td>4 (11.1%)</td>
<td>1 (2.8%)</td>
<td>1 (2.8%)</td>
<td></td>
</tr>
<tr>
<td>5° MTF</td>
<td>7 (19.4%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left Foot</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1° MTF</td>
<td>6 (16.7%)</td>
<td>9 (25%)</td>
<td></td>
<td>1 (2.8%)</td>
<td></td>
</tr>
<tr>
<td>2° MTF</td>
<td>10 (27.8%)</td>
<td>9 (25%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3° MTF</td>
<td>14 (38.9%)</td>
<td>2 (5.6%)</td>
<td>1 (2.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4° MTF</td>
<td>3 (8.3%)</td>
<td>6 (16.7%)</td>
<td>1 (2.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5° MTF</td>
<td>3 (8.3%)</td>
<td>1 (2.8%)</td>
<td></td>
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</tr>
</tbody>
</table>

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Disclosure of Interests: None Declared.
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**POSI191-HPR**

**ULTRASONOGRAPHIC AND FUNCTIONAL CORRELATION OF THE FEET IN PATIENTS WITH SYSTEMIC LUPUS ERYTHEMATOSUS**

Keywords: Ultrasound, Systemic lupus erythematosus

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Background: Systemic lupus erythematosus (SLE) is a chronic immune-mediated disease with involvement of various organs[1,2]. El 95% of patients with SLE have musculoskeletal involvement[1], most often in the form of arthralgia or non-erosive arthritis affecting mostly the hands and knees. A subgroup of patients with SLE, which is seen with increasing frequency, late develops a deforming arthropathy as a result of laxity of ligaments and perilunous apparatus resulting in joint subluxations and tendon ruptures which is part of the accumulated damage of the disease. The foot is a heavily affected structure that may initially go unnoticed, but results in significant disability.

Objectives: To determine the relationship between inflammatory activity measured by ultrasound in metatarsophalangeal joint (MTF) and questionnaires of functionality, hand deformities and SLE activity.

Methods: A cross-sectional study was performed. Thirty-six subjects with a diagnosis of SLE in the Rheumatology Unit were consecutively recruited between March and June 2022. Inclusion criteria were: patients with SLE diagnosis according to EULAR/ACR 2019 criteria, with at least one year of evolution and age equal or older than 18 years. A Rheumatology nurse collected information on socio-demographic data, questionnaires and ultrasound scans. The SLE activity questionnaires completed were: SLEDAI and SLICC, quality of life: EQ-5D, foot function: FFI (Foot Function Index), FAAM (Foot and Ankle Ability Measures). The FFI Posture Index (FFI). As for hand malformations collected were: Jaccoud arthropathy, non-reducible arthritis, z-finger, grommet finger, non-reducible arthritis, burst finger and gooseneck finger. A descriptive, bivariate and R-Pearson correlation analysis was performed.

Results: Thirty-six SLE patients (97.2% female) with a mean (SD) age of 49.31 (11.4) years with a range 23-66 years participated. A total of 30 patients (83.3%) showed at least one MTF synovitis, the most frequent being 2nd MTF left (58.3%) and right (44.4%), followed by 1st MTF right and left (41.7%). The number of patients with and without ultrasound synovitis, as well as the degree of synovitis and Doppler signal in each joint are shown in Table 1. A significant direct correlation was observed between inflammatory activity with Doppler in the 1st MTF of the right foot with the SLICC (r=0.439; p=0.007) and SLEDAI (r=0.608; p<0.001) questionnaire, as well as an inverse relationship between synovitis in the 1st toe of the right foot with the FPI questionnaire of the right foot (r =0.340; p=0.040) (Table 2). Likewise, a significant relationship was observed between deformity in the hands with the synovitis of 5 right (p=0.042) and left (p=0.005) MTFs.

Conclusion: Ultrasound synovitis in MTFs is common in SLE patients and is associated with disease activity, some deformities and functionality.