APPLICATION OF THE EULAR SYSTEMIC SCLEROSIS IMPACT OF DISEASE (SCLEROID) QUESTIONNAIRE IN AN ITALIAN COHORT OF PATIENTS WITH SYSTEMIC SCLEROSIS: ANALYSIS OF PATIENT-REPORTED OUTCOMES AND THEIR ASSOCIATION WITH MAIN DISEASE FEATURES

Keywords: Patient reported outcomes, Outcome measures, Systemic sclerosis

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Background: Systemic sclerosis (SSc) is characterized by a chronic and frequently progressive course and by a high patient-to-patient variability. Due to the lack of disease-specific, patient-reported outcome measures for use in clinical trials and in clinical practice, EULAR recently validated the Systemic Sclerosis Impact of Disease (ScleroID) questionnaire, calculated as a composite score of 10 different health dimensions with Numeric Rating Scales (NRS) from 0 to 10 (from best to worst)(Figure 1). For each dimension, the NRS score is multiplied by the specific weight for its item and the weighted scores are summed up.

Objectives: The aim of this study was to apply ScleroID questionnaire to an Italian cohort of patients affected by SSc and to find any possible association with their main demographical, clinical and serological features.

Methods: 55 consecutive patients with SSc (defined by 2013 ACR/EULAR criteria) were enrolled, ScleroID was administered. Socio-demographic variables and clinical features were recorded. Data were analyzed using GraphPad Prism 8 software. Wilcoxon nonparametric test was used to compare data. Spearman’s rank correlation coefficient was used and Linear regression analysis (r correlation coefficient) was employed to identify significant correlations, defined by a p value <0.05.

Results: The main demographic, clinical and serological features of the study population are shown in table 1. ScleroID total score median value of our patients was 42 (IQR 21-57). Significant associations were found among the presence of DU and higher values in the domains of Raynaud’s phenomenon (p 0.03), impaired hand function (IHF)(p 0.005), pain (p 0.013), life choices (LC)(p 0.03) and body mobility (BM)(p 0.01). Anti-SCL70 positivity was associated with higher DU domain score (p 0.01). Diffuse SSC form was associated with higher values of IFH (p 0.006), pain (p 0.02), LC (p 0.002), BM (p 0.0005) and DU domains (p 0.003). Moreover, a positive correlation was found between mRSS and IHF (p 0.02), LC (p 0.006), BM (p 0.02) and DU (p 0.04), as well as between lower gastrointestinal symptoms domain and age (p 0.02). A higher ScleroID global score was associated with the diffuse SSC form (p 0.002), the use of immunosuppressive therapy (p 0.01) and the presence of DU (p>0.0001). Finally, this last result was confirmed on multivariate analysis (p<0.007).

Conclusion: Our results confirm the reliability of ScleroID questionnaire in the real life of ScS patients, highlighting the impact of an extensive cutaneous involvement and the presence of DU in several health quality dimensions. Thus ScleroID appears to be a valid and easy to perform tool, able to assess the disease activity by a patient reported outcome.

REFERENCES:


Table 1. Main features of n55 patients

<table>
<thead>
<tr>
<th>Feature</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE (median-IQR)</td>
<td>57 (49-56)</td>
</tr>
<tr>
<td>Female (%)</td>
<td>54 (98)</td>
</tr>
<tr>
<td>Disease duration in years (median-IQR)</td>
<td>8 (4-14)</td>
</tr>
<tr>
<td>Scl70+</td>
<td>20 (36)</td>
</tr>
<tr>
<td>dSSc (%)</td>
<td>19 (34)</td>
</tr>
<tr>
<td>mRSS (median-IQR)</td>
<td>4 (0-10)</td>
</tr>
<tr>
<td>NVC Scleroderma pattern</td>
<td>45 (81)</td>
</tr>
<tr>
<td>Digital Ulcers(%)</td>
<td>30 (55)</td>
</tr>
<tr>
<td>Calcinosis (%)</td>
<td>7 (12)</td>
</tr>
<tr>
<td>ILD (%)</td>
<td>11 (20)</td>
</tr>
<tr>
<td>Gl involvement (%)</td>
<td>33 (60)</td>
</tr>
<tr>
<td>CV involvement (%)</td>
<td>5 (9)</td>
</tr>
<tr>
<td>Arthritis (%)</td>
<td>19 (34)</td>
</tr>
</tbody>
</table>

Figure 1. Protein-protein interaction network (PPI)

Figure 2. Molecular function and Pathway analysis

Conclusion: Cytokines related to “Inflamming” shown significant relationship with arterial stiffness parameters measured in RA patients and IL-10 in OA group. These representative nodes/proteins were related with cellular adhesion, MAPK activation pathway and proinflammatory responses showing that those are key processes in arterial stiffness and rheumatoid arthritis.

REFERENCES: NIL.

Acknowledgements: NIL.

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The IMPACT OF FASTER DIAGNOSIS THROUGH ARTIFICIAL INTELLIGENCE ON THE QUALITY OF LIFE OF PATIENTS WITH RARE DISEASES

Keywords: Quality of life, Descriptive Studies, Artificial Intelligence

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Background: Diseases that affect fewer than 2000 people in the general population are defined as rare diseases [1]. The rarity and the associated limited experience with these diseases, but also the large number of about 8000 rare diseases [2], pose a major diagnostic challenge for physicians. On average, affected patients need 5.6 to 7.6 years until they receive a diagnosis and thus the correct therapy [3]. These diagnostic odysseys place a heavy financial, health, and psychological burden both on patients and their families. Diagnostic decision support systems (DDSS) have great potential to assist physicians in diagnostic decision-making and can indicate the presence of a rare disease much earlier. An exploratory study conducted at the Outpatient Clinic for Rare Inflammatory Systemic Diseases with Renal Involvement at Hannover Medical School showed that the diagnostic process can be shortened by a DDSS. The median lead between diagnosis and the hypothetical time of diagnosis by a DDSS was three months [4]. A follow-up study showed that health economic savings were also possible by making the diagnosis so early [5]. The study showed how much a correct diagnosis affects the diagnostic odysseys and thus improved patients’ QOL at an earlier stage.

Methods: To determine the potential for improving QOL through artificial intelligence (AI), 71 patients from the patient cohort of the previous studies were surveyed [4][5]. The questionnaire was composed of established questionnaires such as the WHO HPQ and the SF-36. In five interview sessions from the onset of the disease, the time of professional diagnosis, to the current time, the development of QOL was retrospectively recorded. To analyze the development of QOL during the disease, but also to show the influence of the DDSS on QOL, data were also collected for the time points at which the DDSS would have indicated the correct diagnosis as the first suggestion or among the first five suggestions.

Results: The study showed that the QOL of most patients improved with a correct diagnosis. The graphically depicted progression of the patients’ health perception are shown in Figure 1: with the onset of the first symptoms, 65% of the patients found their state of health to be less good or bad, in course of disease, this number increased to 70%. At the current time, the time of the interviews, the number declined to 28%. Originally, no patient was in excellent health, but at the current condition after the diagnostic odyssey, 10% were able to describe their state of health as excellent. The interviews show an overall decline in well-being during the diagnostic odyssey, which slowly increases with the correct diagnosis.

Conclusion: The study showed how much a correct diagnosis affects the patients’ QOL. The use of a DDSS would have significantly shortened the diagnostic odysseys and thus improved patients’ QOL at an earlier stage.

References:

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Disclosure of Interests: None Declared.

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HPR Epidemiology and public health (including prevention)

DOCUMENT SEARCH IN LARGE RHEUMATOLOGY DATABASES: ADVANCED KEYWORD QUERIES TO SELECT HOMOGENEOUS PHENOTYPES

Keywords: Artificial Intelligence, Systemic lupus erythematosus, Systemic sclerosis

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Background: Natural language processing tools are powerful for mining rheumatology databases, extracting patient information directly from clinical notes. However, these algorithms come with a high computational cost and are often not applicable at the scale of very large databases in the temporality of clinical practice.

Methods: To determine the potential for improving QOL through artificial intelligence (AI), 71 patients from the patient cohort of the previous studies were surveyed [4][5]. The questionnaire was composed of established questionnaires such as the WHO HPQ and the SF-36. In five interview sessions from the onset of the disease, the time of professional diagnosis, to the current time, the development of QOL was retrospectively recorded. To analyze the development of QOL during the disease, but also to show the influence of the DDSS on QOL, data were also collected for the time points at which the DDSS would have indicated the correct diagnosis as the first suggestion or among the first five suggestions.

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References:

Acknowledgements: NIL.

Disclosure of Interests: None Declared.

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Figure 1. Retrospective development of health perception over the course of the disease among the study participants (n=71). Displayed are the results as an extract of the SF-36.

Figure 1. The EULAR Scleroderma Impact of Disease Score (Sclerosis). How much have the different aspects of systemic sclerosis affected you during the last week? Please mark your responses on the scale by choosing the appropriate number for each of the following dimensions:

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sclerodematous phenomenon</td>
<td>4-10</td>
</tr>
<tr>
<td>Hard-function</td>
<td>4-10</td>
</tr>
<tr>
<td>Fatigue</td>
<td>4-10</td>
</tr>
<tr>
<td>Lower gastrointestinal tract symptoms (e.g., bloating, diarrhea, constipation, anal/rectal bleeding)</td>
<td>4-10</td>
</tr>
<tr>
<td>Health status</td>
<td>1-7</td>
</tr>
<tr>
<td>Clinical course</td>
<td>1-7</td>
</tr>
<tr>
<td>Body-mobility</td>
<td>1-7</td>
</tr>
</tbody>
</table>

The graphically depicted progression of the patients’ health perception over the course of the disease is shown in Figure 1. The study showed how much a correct diagnosis affects the patients’ QOL. The use of a DDSS would have significantly shortened the diagnostic odysseys and thus improved patients’ QOL at an earlier stage.