

in hospital and profound long term health consequences. It charts a journey to a more effective model of treatment and self-management. This now sees her largely symptom free, on minimal lupus medication (blood pressure tablets) and leading an active personal and professional lifestyle.

Mary draws from her four decade experience to suggest a model of doctor - patient communication, collaboration and partnership that has implications for improving outcomes and quality of life for all lupus patients.

Methods

- Giving the patient a voice. Understanding the powerful psychological benefits with consequential direct and indirect physical benefits for the patient when they are regarded as an “equal partner”, an active as opposed to a passive participant in the treatment journey.
- Importance of information sharing with the patient, the treating immunologist and the general practitioner.
- Understanding that the fluctuating and multi-organ nature of lupus symptoms means that treating obvious presenting symptoms without understanding and treating the underlying auto-immune causes can and does lead to treatment errors and adverse patient outcomes.
- Addressing the whole patient, their physical, mental and emotional wellbeing, and the general hormonal system can greatly reduce ongoing symptoms and acute flares.

Results Improved patient outcomes.

Conclusions A more effective model of care.

146 THE ITALIAN SLE SURVEY BY WEB: INVESTIGATING PATIENTS' UNMET NEEDS WITH ONLINE SURVEY TOOLS

M falanga*. GRUPPO italiano LES - onlus, research, rome, Italy

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Background and aims Chronical illness perception and difficulties in everyday life due to disease and medications were explored by the first italian ONLINE SLE SURVEY, designed to assess chronic pain impact and health-care provision quality in Italy.

Methods Online questionnaire was created through Qualtrics, setting geographic data, disease duration, age at diagnosis, comorbidity, disability degree, care practices, treatments, subjective incidence and characteristics of pain. SLE patients were advertised by social media. Participation was voluntary and anonymous.

Results 550 SLE patients provided complete data; F 94.7%, M 5.3%; mean age 33 y. (14–82 y.); first SLE diagnosis at mean age 29 y.: 84% received SLE diagnosis between 18–42 y.; 36% comorbidity with other (1-6) autoimmune conditions. SLE impact on life is relevant, with specific problems and needs at different disease stage. Stress of life: relevant and worsening illness conditions; frequent relational problems. Need for psychological support: 54%. Osteoarticular pain is main symptom condition (83%), but only 54% use drugs for pain control. Physicians seem not responding to patients' request to take into account impact of pain. Women workers face many difficulties due to many combined factors which severely reduce access to proper care

Conclusions Health-care current model doesn't allow respect of SLE patients complex needs: most remain dissatisfied, affecting quality of life and doctor-patient concordance. SLE SURVEY highlights importance of competent clinical listening

by physicians and capacity to hold patient's crisis. GRUPPO ITALIANO LES – a volunteer patients' organisation - established ONLINE SLE SURVEY practice to explore current facts, development of patients' needs, and set social-health policies

147 A CASE OF DERMATOMYOSITIS WITH ELEVATED SERUM KL-6 LEVEL ASSOCIATED WITH OVARIAN CANCER

¹T Katagiri*, ¹H Ito, ¹Y Fujisawa, ¹K Mizushina, ¹S Takenaka, ¹H Ayako, ¹T Ogura, ²S Nagasaki, ²S Komiya, ³T Oharaseki, ¹H Kameda. ¹Division of Rheumatology-Department of Internal Medicine, Toho University Ohashi Medical Center, Meguro-ku, Japan; ²Department of Gynaecology, Toho University Ohashi Medical Center, Meguro-ku, Japan; ³Department of Pathology, Toho University Ohashi Medical Center, Meguro-ku, Japan

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Background and aims Elevated serum Krebs von den Lungen-6 (KL-6) is a biomarker of interstitial pneumonia and some types of cancers. Because patients with dermatomyositis (DM) may accompany interstitial pneumonia and malignancies, serum KL-6 level has been commonly examined for patients with DM in Japan.

Methods A 62-year-old woman developed myalgia in bilateral thighs in November 2014. She was admitted to our hospital in the following month because of progressive bilateral proximal muscle weakness and myalgia, elevated serum creatine kinase (CK: 5569 U/L), and Gottron's papule. Although muscle biopsy had not been done, the diagnosis as DM was further supported by muscle MRI, electromyogram and skin biopsy. The body CT revealed pelvic mass with ascites, but not interstitial pneumonia.

Results Although prednisolone 50 mg/day and intravenous immunoglobulin therapy against progressive muscle weakness including severe dysphagia only showed a partial response, the surgical resection of ovarian mass, identified as ovarian serous adenocarcinoma stage II c, followed by chemotherapy resulted in clinical remission of DM. Serum KL-6 level, as well as CA-125 decreased below the upper normal limit.

Conclusions The present case suggests that the measurement of serum KL-6 may be useful in the evaluation of patients with DM.

148 THE ENGAGEMENT OF SLE PATIENTS IN THEIR HEALTH CARE

¹D Mazzoni, ²A Cornet*, ²K Myllys, ²B van Leeuw, ¹E Cicognani. ¹University of Bologna, Department of Psychology, Bologna, Italy; ²Lupus Europe, Lupus Europe, Romford, UK

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Background and aims Patient engagement is recognised as a crucial component of high-quality healthcare services. Among rheumatic diseases, Systemic Lupus Erythematosus (SLE) appears particularly challenging for the engagement of patients in their own care. According to the Patient Health Engagement (PHE) model, patient engagement is a dynamic phenomenon that proceeds through four experiential positions (blackout, arousal, adhesion, and eudaimonic project). The aim of the present study was to describe the engagement process through the experiences of SLE patients.

Methods Ten in-depth interviews and four focus group were conducted with an international sample of SLE patients from different European countries. Interviews focused on several

aspect of patients' life with SLE and their relationship with the healthcare system. Transcripts were analysed through thematic content analysis.

Results The mean age of the participants to the study was 40.6 years (± 10.0). The average years since diagnosis were 15.5 ($SD=8.6$) with great variability in terms of disease manifestations. Findings showed that a fully engaged patient results from reframing emotional, cognitive, and behavioural dimensions. The advances along the process depends on how the patient succeeds in each position.

Conclusions PHE represents a appropriate model to understand the engagement process of SLE patients. In order to meet patients needs, healthcare providers should consider the specific position of SLE patients, providing adequate and tailored support.

149 LUPUS EXERCISE AND PERSONAL MEDICATION RECORD ON MOBILE APPLICATION TO HELP IMPROVE THE QUALITY OF LIFE OF PEOPLE WITH LUPUS

D Syarif. Bandung, Indonesia

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Background and aims Syamsi Dhuha (Morning Light) Foundation (SDF) has identified two major challenges among the lupus patients who are members of SDF:

- Those who have joint pain and muscle stiffness find it difficult to do their daily activities.
- Those who have to consult two or more doctors/physicians are having difficulties to combine and maintain their medical records in one place

The above challenges brought us to the current works as solutions to the problems

- To create "Lupus Exercise" (LE)
- To create "Lupie Diary Mobile Application" (LD App),

Methods SDF worked together with the Faculty of Sports Education and Health, Education University of Indonesia in developing LE. This LE is recorded and uploaded into YouTube, making it possible for lupus patients to follow the exercise.

SDF worked together with the School of Pharmacy at University of Surabaya, in developing the content for personal medication records. The App is available in Indonesia, English and Mandarin languages, and can be installed on android smartphones.

Results LE is a set of exercise suitable for people living with Lupus, as it:

- can ease joint pain and stiffness if done regularly
- can promote better general health conditions

LD App is a personal medication record application for smartphone users, intended to help lupus patients:

- record their personal medication history
- remind them to take medication and scheduled therapy
- save images of lab test results

Conclusions Both LE and LD App is expected to help people with lupus in coping with Lupus and in helping improve their quality of life.

SLE Complications and comorbidities

150 LOW PLASMA CONCENTRATIONS OF APOLIPOPROTEIN M CORRELATE TO DISEASE ACTIVITY AND ENDOTHELIAL DYSFUNCTION IN SLE

¹AA Bengtsson*, ¹H Tydén, ¹C Lood, ¹A Jönsen, ¹B Gullstrand, ²B Dahlbäck. ¹Lund University, Clinical Sciences Lund- Rheumatology, Lund, Sweden; ²Lund University, Laboratory Medicine Malmö- Clinical Chemistry, Malmö, Sweden

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Background and aims ApoM is an anti-atherogenic and vasculoprotective 25 kDa apolipoprotein suggested to play a role in keeping endothelial barrier integrity. The aims of the current study were to determine the impact of SLE disease activity on apoM levels and investigate if apoM levels reflect endothelial function in SLE.

Methods Plasma concentrations of apoM were measured with ELISA in two SLE cohorts, all patients fulfilling ≥ 4 American College of Rheumatology (ACR) classification criteria for SLE, and 100 healthy controls (HC). Patients in cohort I had active disease as evaluated with SLEDAI scores. In cohort II endothelial function was measured by EndoPAT 2000 and correlated to apoM levels. A low Reactive Hyperemia Index (RHI) value indicates endothelial dysfunction.

Results In cohort I, the plasma levels of apoM were found to be significantly decreased in SLE ($p < 0.0001$), and the apoM concentrations correlated inversely to disease activity (SLEDAI, $r = -0.29$, $p = 0.0063$). ApoM was also significantly lower in patients with active nephritis, leukopenia, anti-DNA antibodies or rash compared to patients without these manifestations.

In cohort II, using linear regression analysis, there was a positive correlation between apoM levels and the RHI value, indicating endothelial dysfunction, in the younger SLE patients: $\beta = 0.94$ CI 95% 0.22, 1.65 $r = 0.32$ $p = 0.011$.

Conclusions SLE related inflammation may have an impact on lower plasma apoM, which may affect the endothelium and the process towards cardiovascular disease.

151 HPV-RELATED PREMALIGNANT AND MALIGNANT LESIONS IN THE LOWER GENITAL AND ANAL TRACTS OF WOMEN WITH SLE

¹D Dubinsky*, ¹S Sapag Duran, ¹AM Sapag Duran, ¹G Nasswetter, ²V Maldonado, ²S Tatti, ²V Susuki, ³L Diaz, ³L Cardinal, ¹AM Beron. ¹Hospital de Clinicas Jose de San Martin, Reumatologia, Buenos Aires, Argentina; ²Hospital de Clinicas Jose de San Martin, Ginecologia, Buenos Aires, Argentina; ³Hospital de Clinicas Jose de San Martin, Patologia, Buenos Aires, Argentina

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Background and Aims Systemic Lupus Erythematosus (SLE) and its treatment predispose to infections such as human papillomavirus (HPV) that is a risk factor for the development of lower genital tract (LGT) and anal cancers.

To assess LGT- anal lesions, frequency of HPV lesions and premalignant and malignant lesions.

Methods Descriptive, cross-sectional design. Women with SLE (ACR 1997) of Argentina were consecutively sent to examination of the LGT and high-resolution anoscopy (2010–2015). Biopsies were performed according to gynaecological criteria and patient consent (Bethesda). Koilocytic cells were associated