



SYSTEMIC LUPUS ERYTHEMATOUS OUTCOME CONCERNS: IDENTIFYING DIFFUSE PAIN AND THROMBOSIS AS MAJOR DISCREPANCIES BETWEEN RHEUMATOLOGISTS AND PATIENTS

GLAUCIA FERREIRA ABRAHAO (Hospital das Clinicas HCFMUSP, Faculdade de Medicina, Universidade de Sao Paulo, SAO PAULO, SP, Brasil), ISABELA MARIA BERTOGLIO (Hospital das Clinicas HCFMUSP, Faculdade de Medicina, Universidade de Sao Paulo, SAO PAULO, SP, Brasil), MICHELLE REMIÃO UGOLINI-LOPES (Hospital das Clinicas HCFMUSP, Faculdade de Medicina, Universidade de Sao Paulo, SAO PAULO, SP, Brasil), LUCIANA PARENTE COSTA SEGURO (Hospital das Clinicas HCFMUSP, Faculdade de Medicina, Universidade de Sao Paulo, SAO PAULO, SP, Brasil), ELOISA SILVA DUTRA DE OLIVEIRA BONFA (Hospital das Clinicas HCFMUSP, Faculdade de Medicina, Universidade de Sao Paulo, SAO PAULO, SP, Brasil)

BACKGROUND

There is a growing trend of switching to a more patient-centered healthcare system, with a widespread use of patient-reported outcomes (PROs). However, most of PROs-questionnaires are designed by physicians and patients are underrepresented in this development. Therefore, the purposes of this research were: a) to assess the concerns of patients with systemic lupus erythematosus (SLE) during follow-up and compare them to the rheumatologist's concerns; b) to gather patient's and physician's concerns to develop a SLE outcome standard set.

MATERIALS AND METHODS

97 SLE patients and 42 rheumatologists from a tertiary center were invited to answer a standardized questionnaire about outcomes for SLE. Initially, an open questionnaire was applied in order to assess unbiased concerns of both groups. Thereby, the top 10 answers were selected and applied in a multiple-choice questionnaire, inquiring the top 5 major concerns. Answers of each group were plotted into charts and frequencies were compared. The agreement rate was calculated. Concerns were gathered in a SLE outcome standard set, following the methodology proposed by the International Consortium for Health Outcomes Measurement.

RESULTS

The top five concerns raised among the patients were: to avoid damage (79%), followed by quality of life (61%), renal function (55%), diffuse pain (47%) and preventing thrombosis (40%). And by rheumatologists were: quality of life (87%), Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) (70%), adherence to treatment (61%), organ damage (50%), prednisone dose (54%). The agreement rate between both groups was 39% (mostly due to proteinuria control). The main discordances between patients and rheumatologists were diffuse pain and thrombosis. Some associations between concerns and clinical features were found: patients concerned with dialysis had higher SLEDAI ($p=0.02$), those concerned with fatigue had higher obesity frequency ($p=0.008$), and those concerned with quality of life had higher inflammatory activity labs (PCR $p=0.012$ /VHS $p=0.01$). It is also important to mention that patients concerned with diffuse pain had no association anxiety/depression ($p=0.78$) neither with fibromyalgia ($p=0.06$), and patients concerned with thrombosis had not previous thrombosis ($p=0.30$). The developed SLE standard set included: SLEDAI, Systemic Lupus International Collaborating Clinics Damage Index (SLICC), EuroQol (EQ5D), diffuse pain VAS, prednisone dose and proteinuria.

CONCLUSION

We identified that there are different outcome concerns between patients and rheumatologists for lupus treatment. Patients consider that controlling diffuse pain is an important outcome as well as preventing thrombosis. Improving physician's awareness of patient's outcome concerns may provide a better assistance and ensure treatment adherence.