

## Editorial

# Sjögren's syndrome: disease activity indexes! Do they make us better clinicians or technicians?

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Sjögren's syndrome (SS) is a slowly progressive autoimmune disorder with a wide clinico-laboratory spectrum. SS usually runs a quiescent course with infrequent exacerbations. Two main clinical phenotypes of the syndrome can be identified from the first patient evaluation: type I which includes patients programmed to evolve from benign to malignant B-lymphocyte proliferation and type II which is a benign disease that can potentially affect, in addition to exocrine glands, parenchymal organs such as the kidneys, the lungs and the liver (1). In all affected organs the invasive auto-reactive lymphocytes are localised around epithelial cells, a finding which prompted us to coin for SS the term "Autoimmune Epithelitis" (2). Over the last decade the European as well as the international scientific community, in order to acquire a relatively objective tool for clinical and therapeutic studies, have placed significant effort, time and money to define and validate Disease Activity Indexes for SS (3-5). Two disease activity indexes were developed: the EULAR SS Patients Reported Index (ESSPRI), and the EULAR SS Disease Activity Index (ESSDAI). The scores of the two indexes did not correlate with each other and appeared to be complementary. The ESSDAI, evaluates disease activity primarily of SS patients with systemic (extra-glandular) disease, in other words the index is useful only for one third of SS patients. Furthermore, different SS disease components with completely different prevalence, course and prognosis are lumped together (6, 7). It is surprising that infrequent manifestations (*e.g.* peripheral neuropathy) are pooled together with relatively frequent ones (*e.g.* parotid gland enlargement) to develop the ESSDAI score. In this effort of "index-

ing" could the forest be missed for the trees? We believe yes!

ESSDAI cannot evaluate disease activity in the majority of SS patients in which the disorder is expressed only with sicca manifestations. The grading of salivary or lacrimal gland dysfunction, as attested by measuring salivary gland flow and by staining the eye conjunctiva and cornea epithelia, are not included in the index. Furthermore, is it fair to place in the same therapeutic protocol two patients with similar scores but with diverse disease clinical phenotypes, the one presenting with arthralgias, persistent cough and erythema multiforme and the other with moderate renal involvement? In addition, the allocated time to complete forms in order to define ESSDAI, will be taken away from the necessary time to holistically evaluate the patient, answer questions, and alleviate disease related anxieties and fears. The proponents of the indexes will argue that the patient's metrics can be done by a physician's assistant or a clinical nurse. This however is not in favour of an effective doctor-patient communication. Wouldn't it be better instead of investing time and money for the development of indexes to focus on disease pathogenesis?

In the modern era of practicing medicine, in which the art and skill of taking a detailed medical history and performing complete physical examination coupled with complementary laboratory evaluation, have been replaced by excessive use of unnecessary laboratory tests and imaging techniques, patient's evaluation by metrics may be another way of medical practice. If however, the patient's approach is mechanistic, then appreciation of distinct clinical expression is lost as well as the humanistic component of our science.

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