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Brazilian Sjogren's Syndrome Registry (BRASS): a large Brazilian multicentric cohort of primary Sjogren's syndrome

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BACKGROUND

Primary Sjögren's syndrome (pSS) is an orphan systemic autoimmune disease with no treatment based on evidence. There is an international effort for multicentric registries for getting information about phenotypes, complication, response of treatment, and biobank consortium.

MATERIALS AND METHODS

BRASS is supported by Brazilian Committee on Sjögren's syndrome of Brazilian Society of Rheumatology (SBR) and is including patients from all regions of the country. Recruitment started in 2018 and is due to be completed in 2024. We are including patients with pSS according to AECG 2002 or ACR-EULAR 2016 classification criteria. All patients are being assessed for disease activity (Sjögren's Syndrome Disease Activity Index, ESSDAI), disease damage (Sjögren's Syndrome Disease Damage Index, SSDDI), symptoms (Sjögren's Syndrome Patient Reported Index, ESSPRI), fatigue (Functional Assessment of Chronic Illness Therapy Fatigue Subscale, FACIT-Fatigue), anxiety depression (Hospital Anxiety and Depression Scale, HAD), sleepiness (Epworth Sleepiness Scale, ESE), physical activity (International Physical Activity Questionnaire short form, IPAQ-SF) and quality of life (EuroQOL, EQ-5D). In addition, demographics, immunological tests, unstimulated whole salivary flow (UWSF), salivary gland biopsy (SGB), comorbidities, treatment and complications such as cancer and cardiovascular risk assessment are being collected.

RESULTS

There are currently 10 centers across the Brazil and 248 patients were evaluated until now. Most patients were female, white (45%) or mixed (38,3%), with disease duration mean of 8 years, ESSDAI at baseline was 6.62 ± 6.37 and currently was 4.21±5.16 ($p<0.05$), SSDDI 2.16±1.6 and ESSPRI mean of 8.38±6.88. SGB was positive in 81,5% and focus score was 1.58±1.30. Schirmer test I was positive in 72.6%, van Bijsterveld in 70.9% and UWSF in 84,8%. About classification criteria, 91,9% fulfilled AECG 2002 and 94% ACR/EULAR 2016. Anti-Ro and anti-La were positive in 70.8% and 35.5%, respectively. Forty three percent RF, 88.5% ANA, 93,1% low C3, 89,3% low C4, 34,9% high IgG, Nineteen percent were using prednisone, 40.4%

immunosuppressant, 53.6% antimalarial and 17.6% biological therapy. Prevalence of cardiovascular event was 7.5%, hypertension 43.3%, diabetes 13.3%, dyslipidemia 31.5%, smoking 5.8% and cancer 7.5%.

CONCLUSION

ESSDAI has decreased over time and more than half of patients are on hydroxychloroquine, immunosuppressant or biological therapy. Further analysis is needed to understand whether the reduction in ESSDAI reflects the natural course of the disease or greater access to treatment. BRASS Registry will be important to enhance research and to develop public health planning.