

Sarcoidosis is a systemic, granulomatous disease which can be acute or chronic. It affects people with a mean age of 41 years old and causes symptoms of fatigue, dry cough, pain, dyspnoea and depressive symptoms, among others. It is a genetically based illness where prevalence, incidence as well as presentation vary between different ethnic groups. There is always an antigen involved which can be mycobacteria or propionibacteria, fungi, dust or mould, among others.

Apart from propionibacteria and mycobacteria, the presence of *P.acnes* seems to lead to a high association with sarcoidosis. In this regard, the CLEAR regime (antimycobacterial agents) has been investigated in the treatment of the chronic form of pulmonary sarcoidosis.

Quality of life is often affected and to assess this I've followed 30 Belgian pulmonary sarcoidosis patients over the course of two years, using the King's Sarcoidosis Questionnaire (KSQ) and the Fatigue Assessment Scale (FAS). The KSQ uses five modules (general health status, lung, medication, skin and eyes). The FAS questionnaire assesses fatigue where scores of >21 represent fatigue and >35 is seen as considerable fatigue. As depressive symptoms can be one of the symptoms of sarcoidosis, these symptoms seem to be partly linked to exhaustion.

Introduction: Sarcoidosis has been found to have a variable presentation. Prior studies of the disease on quality of life (QoL) have mostly been at a single time point and changes in QoL versus other aspects of the disease are poorly understood.

Aims and objectives: We set out to investigate in detail how the quality of life of sarcoidosis patients was affected over time.

Methods: Thirty Belgian patients were included in the retrospective study and followed-up for a period of 2 years. One patient was excluded from the study because of high age and a variety of concurrent diagnoses that would have interfered with symptoms of diagnosis. One patient left the study after one year. Participants received two questionnaires, the King's Sarcoidosis Questionnaire every 3, 6 or 12 months. Other information collected included pulmonary function tests, weight, height, age, sex, drugs, comorbidities, smokers, non-smokers or ex-smokers, time of diagnosis, other types of sarcoidosis, first or second opinion, race, persistent disease or not, symptomatic or asymptomatic disease.

Results: There were significant correlations between FAS and FEV1% (forced expiratory volume in the first second) and FVC% (forced vital capacity) predicted (Spearman correlation coefficient FEV1%: -0,334, FVC%: -0,359, DLCO% (diffusing capacity of the lungs for carbon monoxide): -0,198 with significant level P values of 0,0021 and 0,001 and 0,0777 respectively). However, there was no significant correlation between change in FAS and PFTs (pulmonary function tests) (although FEV1% was borderline). Fatigue is an omnipresent fact in sarcoidosis patients as this was seen in the responses in the FAS questionnaire. For example, on the questions included in the study 'physically, I feel exhausted' 25% responded 'often' and on the question 'mentally, I feel exhausted' 16,3% responded 'regularly', respectively.

Conclusion: In this prospective study of sarcoidosis patients seen over 1 year period, there was a correlation between FAS and spirometric values. However, changes in FAS did not correlate with changes in PFTs.

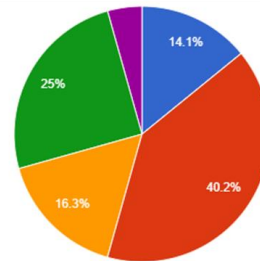


Fig. 1 Responses to the question 'Physically, I feel exhausted'. From the FAS questionnaire and RedCap as accessed on 10 August 2021.

Blue: Never (14,1%).
 Red: Sometimes (40,2%)
 Orange: Regularly (16,3%).
 Green: Often (25%).
 Purple: Always (4,3%).

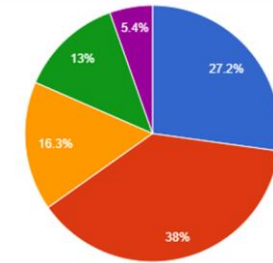


Fig. 2 Responses to the question 'Mentally, I feel exhausted'. From the FAS questionnaire and RedCap as accessed on 10 August 2021.

Blue: Never (27,2%).
 Red: Sometimes (38%).
 Orange: Regularly (16,3%).
 Green: Often (13%).
 Purple: Always (5,4%).

Quality of life, in the form of severe fatigue leading to depressive symptoms and anxiety, is often disturbed in patients with pulmonary sarcoidosis. As seen in this study, decreased spirometric values affect QoL. Additionally, 55% of patients feel misunderstood because of lack of awareness of this disease. Therefore, it is important that, besides medication and rest, extra support is provided in the form of mindfulness, meditation, psychological support and exercise. It follows that several specialists should provide support in the care of the sarcoidosis patient. These should be pneumologists but also psychologists and/or psychiatrists, among others.