

Behçet's Syndrome Society

Symptoms of Behçet's Syndrome in a representative group of adults in the UK.

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Introduction

The report provides epidemiological data that reflects the needs of adults with Behçet's Syndrome living in the UK. The findings will help (i) commission and manage treatment demands based on sound epidemiological data; (ii) develop health care strategies targeting relevant symptoms and (iii) provide cost-effective care services.

Method

Type of Study: Questionnaire to the 650 members of the Behçet's Syndrome Society in the UK.

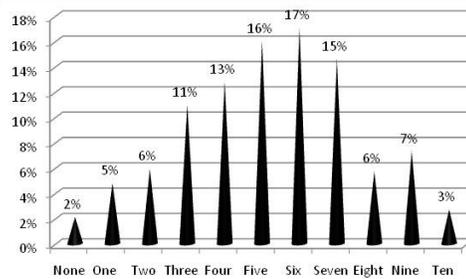
Patient Inclusion Criteria: Member of Society and over 18 years
Statistical Analysis: Data manually entered into MS Excel; then ported to the "Statistical Package for Social Sciences" for evaluation

Objective of the Study

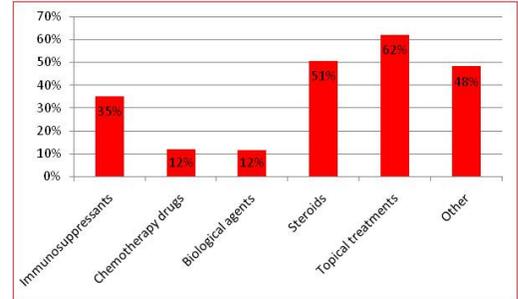
To assess the prevalence of symptoms of Behçet's Syndrome in members of the Behçet's Syndrome Society and the effect this has on patients.

Symptoms Experienced	
Mouth ulcers	95.1%
Joint Problems	86.5%
Fatigue	85.7%
Genital ulcers	83.4%
Headaches	65.9%
Skin Lesions	65.5%
Eye problems	61.2%
Stomach / bowel problems	59.9%
Other Neuro problems	38.1%
Pathergy reaction	26.0%

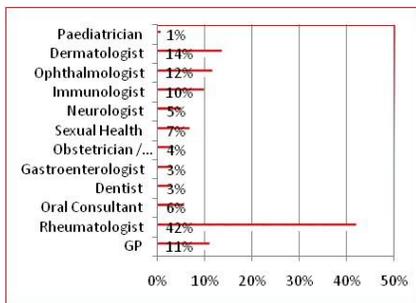
No of Symptoms



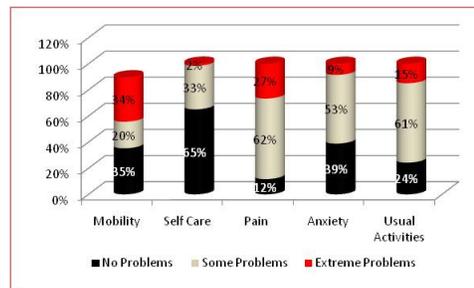
Current Medication



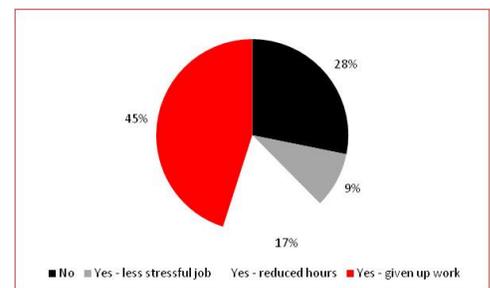
Diagnosing Doctor



Problems currently faced



Effects on Career



Findings

- 5 The average time to diagnosis was approx 12 years during which time the patient received incorrect diagnosis and treatment.
- 5 Patients report mouth ulcers, joint problems and fatigue as the most common symptoms, but the only symptoms the majority do not report are neurological issues and a pathergy reaction.
- 5 The mean number of active symptoms was 5.3
- 5 The average number of doctors each patient visits regularly is 2.72
- 5 The results indicate that a collaborative, multidisciplinary health care team and the administration of multiple medications are necessary to take care of patients with Behçet's Syndrome.

Further Study

- 5 This survey will be followed by a subsequent survey to further analyse the impact on the Quality of Life experienced by Behçet's patients
- 5 The survey will also be used in the application for Nationally Commissioned Centres to provide multi-disciplinary teams to care for patients with Behçet's Syndrome
- 5 It is envisaged that this survey will be repeated to assess whether the situation in the UK improves for patients over time.