

## Work-related disability in Behçet's syndrome: a British case series

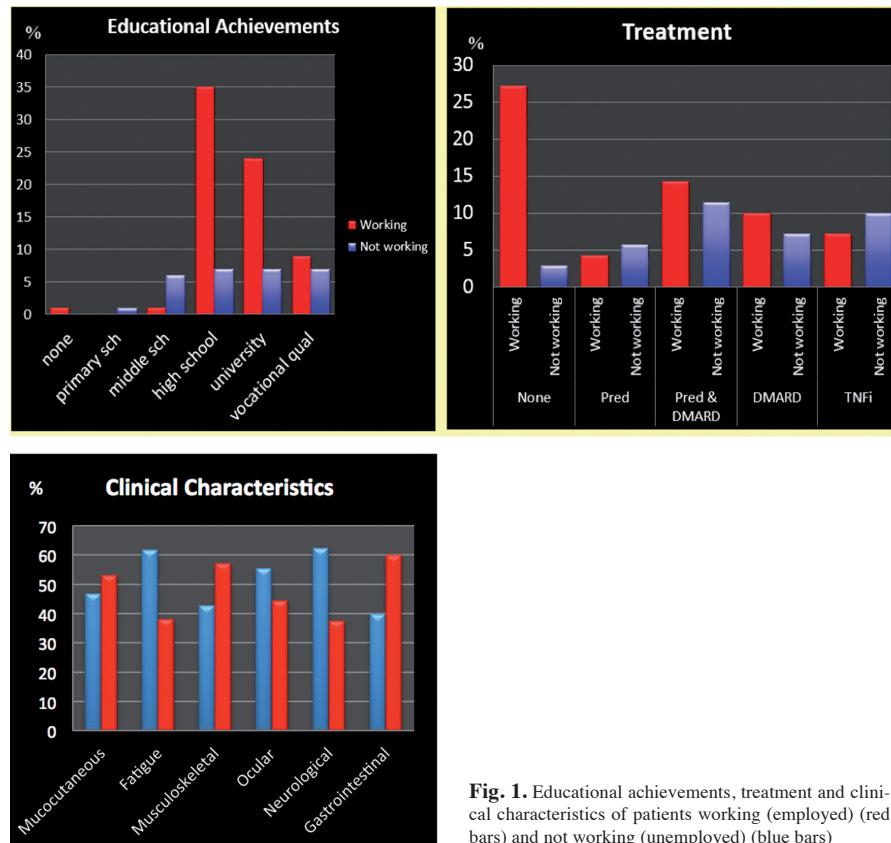
Sirs,

Behçet's syndrome (BS) is a heterogeneous multi-system inflammatory condition in which orogenital ulceration is a central characteristic. BS affects males and females equally, but males are more likely to have serious complications involving the eye, nervous system and vasculature. BS typically presents in late adolescence-early adulthood and is most active early in the disease course, with symptom severity declining over time. Thus, BS is most active during working years, and may affect productivity. A number of studies have demonstrated the impact of BS on quality of life (1) and a cost-analysis study from Turkey illustrated the economic burden that BS exerts in Turkey (2). To our knowledge, however, work-related disability in BS has not been addressed in the UK. We aimed to survey the frequency of and reasons for work-related disability among patients attending our tertiary referral BS centre in the UK and also the effect of work on symptoms of Behçet's syndrome.

The proposal was discussed with the Behçet's Syndrome Society, which is a national patient organisation. Ethical approval was obtained from the National Research Ethics committee. A postal questionnaire (on line supplement) survey together with a cover letter, information sheet and pre-paid envelope were sent to 200 adult patients (above 18 years), with a confirmed diagnosis of BS. Consent was implied by return of the questionnaire.

We received 70 responses. 54% (n=38) patients were female and 77% (n=54) were Caucasian British. The median age was 47 years (range 18–71 years). 41% (n=29) had high-school education, 31% (n=22) university degrees and 16% (n=11) vocational qualifications. 7% (n=5) considered themselves to have significant co-morbidities. 19% were taking no medication, 49% corticosteroids, 61% steroid-sparing immunosuppressants and 17% TNF inhibitors (Fig. 1). The most common organ manifestation of BS was mucocutaneous involvement 91% (n=64), followed by fatigue in 79% (n=55), musculoskeletal involvement in 50% (n=35), ocular involvement in 39% (n=27), neurological involvement (excluding headaches) in 11% (n=8), vascular involvement in 10% (n=7) and gastrointestinal involvement with ulceration in 7% (n=5) (Table I).

21% (n=15) patients were retired, of which 73% (n=11) had taken early retirement on medical grounds. 13% (n=9) were homemakers and 3% (n=2) students. The remaining 44 patients were eligible to work, 64% (n=28) were currently working / employed



**Fig. 1.** Educational achievements, treatment and clinical characteristics of patients working (employed) (red bars) and not working (unemployed) (blue bars)

and 36% (n=16) were not currently working (*i.e.* unemployed). 94% (n=15) of the 16 patients not currently working, had been working before BS was diagnosed. 87% (n=13) of these patients cited BS as their reason for not being able to work. The most common reasons for being unable to work due to BS were the effects of oral ulceration on speech (52%) and fatigue (39%). Only 31% (n=5) patients felt their BS symptoms had improved after stopping work. Of the 64% (n=28) currently working, 61% (n=17) were full-time workers and 39% (n=11) part-time. 54% (n=15) had made changes to their work because of BS – reduced hours (n=6; 40%), part-time work in a different job (n=5; 33%) and changing job (n=4; 25%). 67% (n=10) felt their BS had improved after these changes. Of those working, the mean annual number of sick days was 18, with 13 days (72%) attributed to BS. The mean visual analogue scale assessment (out of 10) for the effect of BS on productivity at work was 7/10, the effect of BS on activities of daily living was 4/10 and the effect of work on BS was 6/10.

The socioeconomic impact of BS in the UK is not well-described. BS is rare with an estimated UK prevalence of 0.64 per 100,000, but disease activity is most severe in working-age populations. Previous studies have demonstrated the impact of BS on overall quality of life (1) and with relation to specific organ manifestations (cutaneous (3), ocular (4), oral ulceration (5, 6) and

disease activity (7). In Turkey, a high unemployment rate has been observed in BS (8). A cost-analysis study in 119 Turkish patients with BS, found that 43% reported lost workdays due to BS, with mean number of sick days per annum of 119 days and 12 days for patients and their household carers respectively (2). Workday loss was highest in patients with neurological disease (60%) and lowest in patients with mucocutaneous disease (22%) (2). This is in contrast to our study, where oral ulceration and the subsequent effects on speech was the most common reason for being unable to work. As expected, mucocutaneous involvement was a very common manifestation of BS in our cohort, affecting 64 of 70 patients (91%). Interestingly the prevalence of mucocutaneous features (oral ulceration) between those working (47%; n=30) and not working (53%; n=34) was very similar, despite this being the most cited reason for being unable to work. A possible explanation for this observation is that patients with oral ulceration that limited their ability to work may have had more severe or resistant mucocutaneous manifestations or occupations involving language and communication skills, such as teaching. A study comparing oral health in BS patients from the UK and Turkey found that the number of oral ulcers and their activity under immunosuppression was higher in patients from the UK compared with those in Turkey, although the oral quality of life status

was similar (6). Intriguingly, fatigue was more frequently cited by those working (62%; n=32) compared to those not working (38%; n=21), which potentially may be related to the effect of work on BS.

Mucocutaneous involvement is almost universal in BS. Oral aphthous ulcers are frequently the first symptom and may precede other manifestations by years. Ulcers occur in crops on the buccal mucosa but can also occur on the tongue, palate and in the pharynx. Ulcers do not typically form on the outer lips. Ulcers may sometimes be managed topically, with steroid formulations *e.g.* with beclomethasone inhalers, triamcinolone acetonide in an adhesive base or hydrocortisone lozenges. Many patients will require systemic treatment, and colchicine may be effective for limited mucocutaneous disease. Most patients report an excellent response to stronger DMARDs such as azathioprine, mycophenolate or anti-TNF $\alpha$  therapy.

Our survey shows that work-related disability in BS is high and under-appreciated. A considerable number of patients give up work or change their work practice because

of BS, particularly the effects of oral ulceration on speech. Effects of BS on ability to work, particularly the effects of mucocutaneous involvement, need to be factored in to treatment decisions.

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P. MEHTA  
N. AMBROSE  
D.O. HASKARD

*Department of Rheumatology, Imperial College Healthcare NHS Trust, London, United Kingdom.*

*Please address correspondence to:  
Prof. Dorian Haskard,  
Department of Rheumatology,  
Imperial College Healthcare NHS Trust,  
Du Cane Road, W3 6QB London,  
United Kingdom.*

*E-mail: d.haskard@imperial.ac.uk*

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