

# The impact of the COVID-19 pandemic on patients with Behçet's syndrome within the framework of Maslow's hierarchy of needs: implications for patient empowerment in national or global emergencies

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## Abstract

### Objective

The aim of this online survey was to assess the impact of the COVID-19 pandemic on patients with Behçet's syndrome (BS) using Maslow's hierarchy of needs.

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### Methods

Sixty-eight BS patients from the UK completed an online questionnaire that covered three components of Maslow's hierarchy of needs regarding Physiological needs (sleep, food, mobility), Safety needs (employment, health), Social needs (relationships), personal precautions and main concerns regarding COVID-19.

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### Results

The patients received a letter from the NHS (66.2%) advising shielding. Health concerns were addressed using Tele-medicine by telephone consultations and e-mails to access BS specialists during lockdown (44.1%; 27.9%). In addition, patients also obtained information through official government and Behçet corporate health web pages related to Behçet's disease for self-empowerment. During lockdown, their weekly working hours were reduced ( $26.65 \pm 13.86$  vs.  $20.79 \pm 17.94$ ) ( $p=0.017$ ) and the employment rate was decreased (32.6% vs. 26.7%) in comparison to pre-lockdown. Moreover, the reduction in frequency of exercise per week ( $4.39 \pm 1.94$  vs.  $3.71 \pm 2.26$ ) and healthy food consumption (73.5 % vs. 47.1%) per week were also reported ( $p=0.007$ ;  $p=0.001$ , respectively). Furthermore, patients experienced sleeping less (54.4%) and feeling lonely (66.1%).

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### Conclusion

Using Maslow's hierarchy of needs provided a framework for reviewing the quality of basic needs in patients' life during lockdown. These needs are required for healthy social lives and the deprivation should be considered while considering healthcare planning. Since lockdown appeared to have a negative influence on patients' lives and disease management in the framework of patient-centred, the empowerment of patients gained importance at this point.

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### Key words

Behçet's syndrome, COVID-19, lockdown, Maslow's hierarchy of needs, empowerment

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## Introduction

The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), causing the COVID-19 pandemic, has a major effect on human lives, and affects healthcare system, health policies, social life and economic security of populations, globally (1, 2). Mild to severe pneumonia, flu-like symptoms, tissue damage and multiple organ failure with exaggerated inflammatory reaction and mortality are caused by the rapidly spreading virus. Since individuals of all age groups and patient populations are affected by this fast-spreading virus, personal and nationwide protective precautions such as lockdown are initiated to prevent increasing infection and spread of the pandemic effects (1, 3).

The physical isolation imposed by lockdown affected and transformed daily life, educational activities, working conditions and social life. These changes of circumstances lead to psychological stress, economic damage and have negative impacts on basic human needs (4, 5). Maslow's hierarchy of needs provides a perspective to understand the effects of lockdown on human needs.

The model describes five components:

1. *Physiological needs* (breathing, water, sleep, food, mobility),
2. *Safety needs* (employment, health, stability, security),
3. *Social needs* (family, friends, relationships),
4. *Esteem needs* (respect, achievement, self-confident),
5. *Self-actualisation* (creativity, acceptance of facts, morality, problem solving) (6).

The possible outcomes of lockdown are defined as less mobility and less food access for *Psychological needs*, health problems and unemployment for *Safety needs*, limited access to family and friends for *Social needs*, an uncertain future for *Esteem needs*, and limited or unknown impact on *Self-actualisation* in the COVID-19 pandemic (4, 6, 7). However, being able to meet these needs are associated with the empowerment of patients with their chronic disease management (8, 9).

Behçet's syndrome (BS) as a chronic multi-systemic inflammatory disorder presents with mucocutaneous manifes-

tations and involvement of musculoskeletal, vascular, ocular, central nervous and gastrointestinal systems. Infectious agents, immune dysregulation, hormonal and genetic background are implicated in the aetiopathogenesis of BS (10-13). The clinical manifestations in BS patients with positive COVID-19 test results (PCR) were evaluated. BS patients have fatigue, anosmia, fever, arthralgia, loss of taste, cough and headache (3, 12, 14-17).

However, the COVID-19 infection does not appear to induce severe complications in BS patients (14-17). Comorbidities, glucocorticoid use, older age and male gender are essential factors for poor prognosis in rheumatic diseases (3, 18, 19).

Although these clinical data provide essential information for disease management, the outcomes of the pandemic and lockdown need to be evaluated from the patient's perspective. Consequently, the aim of this online survey was to assess and evaluate the outcomes and needs of patients with BS during lockdown using Maslow's hierarchy of needs.

## Methods

An online cross-sectional survey was conducted by during the first wave of COVID-19 during the lockdown period in the UK. The COVID 2020 online survey was prepared by London Behçet's Centre together with the Behçet's Society. The Behçet's Patients Support designed as a digital/online form (digitisation J. Mather). Ethical approval was obtained from the Queen Mary Research Ethics Committee; City Research Ethical Committee (COREC) approved study "Immune-regulation at the mucosal barrier" (P/03/122) at Barts Health NHS Trust in full compliance with the Helsinki Declaration (20).

The survey links are:

<https://www.survevgizmo.eu/s3/90209097/2020-BEHSETS-CQVID-SURVEY>  
<http://sgiz.eu/s3/2020-BEHSETS-COVID-SURVEY>  
<https://behcetpatients.org.uk/>  
<https://apps.talktalk.co.uk/appsuite/>  
Participants pressed the "agree button" to indicate that they had read the instructions and information sheet e.g. were voluntarily agreeing to partici-

pate, and were at least 18 years old. Patients who had difficulty understanding English, or replied with minimal information were excluded. One reminder was sent to increase the response rate. The main inclusion criterion was giving consent to participate in the study. Incomplete forms were excluded from the database. Although 121 patients with BS gave informed consent and started to complete the online survey, only 68 patients were included in the study due to incomplete data.

Data were collected from November 2020 to March 2021 using the online questionnaire that covered three parts.

1. Socio-demographic profile, ethnicity, living conditions (alone vs. with others), having children, and treatment protocols were included in the first part of the questionnaire.
2. The second part covered variables according to the first three levels of Maslow's hierarchy of needs (6). *Physiological needs* (sleep, food, mobility), *Safety needs* (employment, health), *Social needs* (family, friends, and relationships) were used to evaluate the patient's needs during lockdown.

Variables were working status (employment; working hours per day), frequency of healthy food consumption, access to healthcare (tele-health; face-to-face; no access; no need to access), precautions and main concerns regarding COVID-19. The outcomes of lockdown were experience of fatigue (decreased; same; increased), sleeping status (less; no change; more), feeling lonely (always; most of the time; sometimes; never).

Additionally, health-related habits were evaluated based on alcohol use/per week, smoking status (current smoker vs. non-smoker/previous smoker; the number of cigarette smoked per day) and frequency of exercise per week.

Weekly alcohol consumption was evaluated according to units determined as a pint of beer/lager/cide r=2 units, alcopop or can of beer = 1.5 units, single measure of spirits = 1 unit, glass of wine (175mls) = 2 units, bottle of wine = 9 units.

3. The third part examined patients' empowerment and the ability to ac-

**Table I.** The profile of patients with Behçet's syndrome.

|   | n  | %    |
|---|----|------|
| <b>Gender</b>   |    |      |
| Male  | 9  | 13.2 |
| Female  | 55 | 80.9 |
| No response   | 4  | 5.9  |
| <b>Age groups</b>   |    |      |
| < 30 years  | 7  | 9.4  |
| 30-39 years   | 10 | 14.7 |
| 40-49 years   | 22 | 32.4 |
| 50-59 years   | 17 | 25   |
| ≥60 years   | 8  | 11.8 |
| No response   | 4  | 5.9  |
| <b>Living conditions</b>                                    |    |      |
| Living alone  | 9  | 13.2 |
| Living with others (spouse/parent/partner/friend/children)  | 53 | 77.9 |
| No response   | 6  | 8.9  |
| <b>Ethnicity</b>  |    |      |
| English/Welsh/Scottish/British                              | 53 | 77.9 |
| Irish   | 2  | 2.9  |
| Others (White, Asian, White and Asian, other ethnic groups) | 13 | 19.2 |
| <b>Treatment protocols</b>                                  |    |      |
| Colchicine  | 28 | 41.2 |
| Prednisolone  | 27 | 39.7 |
| Triorazol/Triple mouthwash                                  | 22 | 32.4 |
| Azathioprine  | 16 | 23.5 |
| Mycophenolate mofetil                                       | 11 | 16.2 |
| Adalimumab/Infliximab/Interferon alpha                      | 14 | 20.6 |
| Cyclosporine  | 1  | 1.5  |
| <b>COVID-19 test results</b>                                |    |      |
| COVID-19 test positive-BD patients                          | 2  | 2.9  |
| COVID-19 test positive-household                            | 5  | 7.4  |

cess sources to obtain information about the COVID-19 pandemic including the shielding letter from the National Health Services (NHS).

#### Statistical analysis

The data was analysed using SPSS Statistics software (version 28; IBM Corporation, USA) and R-studio (<https://shiny.rstudio.com/>). Chi-square test for categorical data and Mann-Whitney U-test for continuous data were performed in the study. A *p*-value less than 0.05 was accepted as statistically significant.

#### Results

Sixty-eight patients with BS took part in the online survey. Most of the patients were female (80.9%), British/English/Scottish (77.9%), >40 years old (75.9%) and living with others at home (77.9%; spouse/child/parent/friend/partner: n=53) (Table I). Almost one-third (n=19; 27.9%) of patients had children under 18. They were mainly treated with colchicine (41.2%) and prednisolone (39.7%). One-third of

patients were using triple mouthwash (Triorazol) (32.4%).

Some patients were also taking azathioprine (23.5%), adalimumab/humira/infliximab/interferon alpha (20.6%) and mycophenolate mofetil (16.2%) (Table I).

#### Working status and educational activities

Less than one-fifth (17.4%; n=15) were noted to be key workers. In addition, 27.9% (n=24) did not work and 24.4% (n=21) worked from home, whereas 2.3% (n=2) went out to work and 3.5% (n=3) were furloughed workers during lockdown.

Weekly working hours were reduced during lockdown (20.79±17.94) compared to before lockdown (26.65±13.86) (*p*=0.017) (Table II). The employment rate decreased from 32.6% prior to lockdown to 26.7% currently. During the pandemic, the rates of unemployment (5.8%) and retirement (9.3%) increased (11.6% vs. 10.7%). Working conditions as a part of *Safety needs* were badly affected in patients with BS.

Very few patients were currently in full-time (n=4) and part-time education (n=2). They did not attend school/university physically. Social contact was maintained by online video calls (Zoom/Teams), e-mails and telephone.

*Health-related factors and access to healthcare*

An increase in alcohol use (7.42±6.17 vs. 10.14±10.88), as well as a decrease in the frequency of exercise (4.39±1.94 vs. 3.71±2.26) and healthy food consumption (73.5% vs. 47.1%), were observed during the pandemic compared to before lockdown (p=0.014; p=0.007; p=0.001, respectively). However, smoking habits were not affected by the pandemic (12.12±8.2 vs. 11.5±5.52) (p=0.705) (Table II). In the last week, 82.35% (n=56) cooked their own food 4.67±2.57 times during the last week. Lockdown changed patients' habits in the direction of unhealthy food consumption and less mobility as a part of *Physiological needs*.

During lockdown, patients used the telephone to access their GP (63.2%), BS specialist (44.1%) and non-BS hospital specialists (29.4%). In addition, e-mail was the other communication method preferred by patients to access BS specialists (27.9%). Telephone consultation was commonly used by patients' BS specialist (64.7%) during COVID-19. However, patients also did face-to-face interviews with Behçet's Centre staff (13.2%) (Table III). Moreover, 82.4% (n=56) accessed their prescriptions whereas only 4 patients (5.9%) did not. One patient answered that they did not need them. The others (n=7) did not give any information regarding medication use or compliance. A decrease in access to healthcare as a part of *Safety needs* was supported by tele-health/tele-medicine according to these results. During lockdown, fatigue increased (61.8%), sleeping less (54.4%) as *Physiological needs* and feeling lonely as *Social needs*, (always: 22%; sometimes: 44.1%) were experienced by patients (Fig. 1).

In the setting of *Social needs*, over one-third of the group (n=24, 35.3%) received more support during the COVID-19 outbreak. Furthermore,

**Table II.** Physiological (food, exercise) and safety needs (employment and health) during lockdown according to Maslow's hierarchy of needs model in the COVID-19 pandemic.

|  | Prior to lockdown |       | During lockdown |       |
|--|-------------------|-------|-----------------|-------|
|  | Mean              | SD    | Mean            | SD    |
| Working hours (weekly) *   | 26.65             | 13.86 | 20.79           | 17.94 |
| <i>Health related habits</i>                                     |                   |       |                 |       |
| • Alcohol use (unit/weekly) (n=28) <sup>a</sup>                  | 7.42              | 6.17  | 10.14           | 10.88 |
| • The number of cigarette consumption/per day (n=8) <sup>b</sup> | 12.12             | 8.2   | 11.5            | 5.52  |
| • Frequency of exercise/per week <sup>c</sup>                    | 4.39              | 1.94  | 3.71            | 2.26  |
|  | n                 | %     | n               | %     |
| <i>Healthy food consumption<sup>d</sup></i>                      |                   |       |                 |       |
| • Always/most of time  | 50                | 73.5  | 32              | 47.1  |
| • Some of time/never   | 12                | 17.6  | 30              | 42.6  |

\*p=0.017, <sup>a</sup>p=0.014, <sup>b</sup>p=0.705 (n=8 prior to lockdown and during lockdown), <sup>c</sup>p=0.007 (n=41 prior to lockdown, n=35 during lockdown), <sup>d</sup>p=0.001.

**Table III.** The empowerment of patients through tele-medicine services during lockdown and the COVID-19 outbreak.

|                                 | BS specialist consultation |      | Non-BS specialist consultation |      |
|---------------------------------|----------------------------|------|--------------------------------|------|
|                                 | n                          | %    | n                              | %    |
| <b>During lockdown</b>          |                            |      |                                |      |
| Face to face consultation       | 9                          | 13.2 | 9                              | 13.2 |
| Video consultation              | 2                          | 2.9  | 1                              | 1.5  |
| E-mail consultation             | 19                         | 27.9 | 2                              | 2.9  |
| Telephone consultation          | 30                         | 44.1 | 20                             | 29.4 |
| No access                       | 8                          | 11.8 | 13                             | 19.1 |
| No need to access               | 11                         | 16.2 | 20                             | 29.4 |
| <b>During COVID-19 outbreak</b> |                            |      |                                |      |
| Cancelled                       | 8                          | 11.8 | 21                             | 30.9 |
| Telephone consultation instead  | 44                         | 64.7 | 21                             | 30.9 |
| Video consultation instead      |                            |      | 2                              | 2.9  |
| Carried out as planned          | 7                          | 10.3 | 9                              | 13.2 |
| None planned                    | 3                          | 4.4  | 9                              | 13.2 |
| No response                     | 6                          | 8.8  | 6                              | 8.8  |

55.9% (n=38) received help or support (shopping/childcare/hospital visit/collecting medication/personal care) from family, friends and neighbours who did not live in the same household as the BS patient during lockdown. Few patients (n=4, 5.9%) received home visits (personal care/help with medication/cooking/cleaning/dressing/injections) in both periods. Moreover, a limited number of patients (n=7, 8.1%) received mental health support prior to lockdown (face to face: n=4; telephone n=1; group session n=2) and during the lockdown (face to face: n=1; telephone n=5; group session n=1, respectively).

*Precautions in the COVID-19 pandemic*

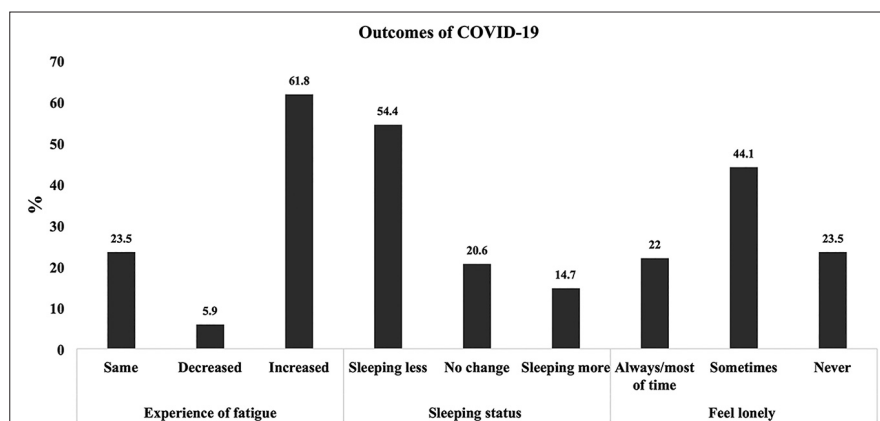
In the group, 66.2% of patients (n=45) received a letter from the NHS about shielding at the start of the pandemic. Although the rate of shielding was 38.2% (n=26) prior to lockdown, it in-

creased to 76.5 % (n=52) at the start of lockdown. Over half of the group (n=43, 63.2%) were still shielding (Table IV). Patients mainly protected themselves by washing hands, using hand sanitiser and masks (material or surgical) outside the home (Fig. 2). These precautions were taken by patients to protect themselves from the virus which was reflected by the *Safety needs* of patients with BS.

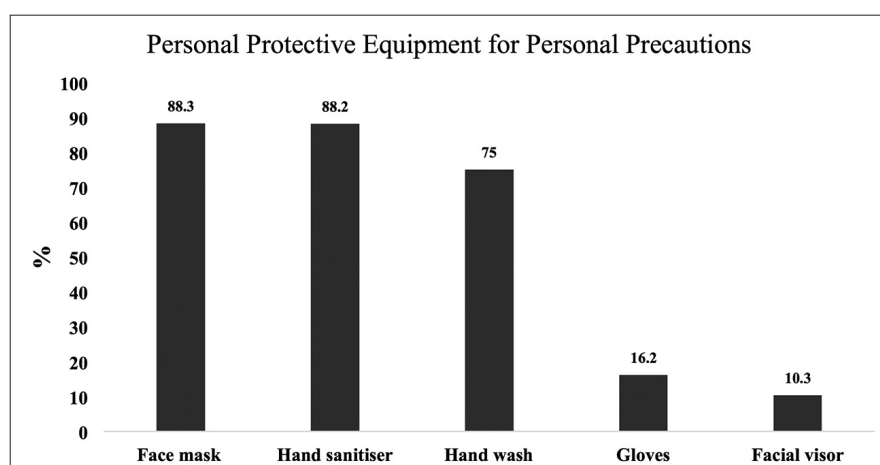
The primary concern for COVID-19 was associated with catching the virus (70.6%), health (69.1%) and family (60.3%) in the group. Almost one-third of the group worried about finance (29.9%), career (27.9%), getting medication (23.5%) and isolating (22.1%) (Fig. 3). Concurring with BS patient responses, *Social needs* and *Safety needs* were essential for them.

*Use of information and communication technologies*

Mobile technologies (mobile phone:



**Fig. 1.** Physiological need (sleep), safety need (health), social need (family, friends, relationships) during the lockdown according to Maslow's hierarchy of needs model in the COVID-19 pandemic.



**Fig. 2.** Self-protection in safety needs (health) during the lockdown according to Maslow's hierarchy of needs model in COVID-19 pandemic.

**Table IV.** The empowerment of patients through shielding and information resources during the COVID-19 pandemic.

|  | n  | %    |
|--|----|------|
| <b>Shielding</b>   |    |      |
| Receive a letter from NHS about shielding at the start of lockdown | 45 | 66.2 |
| Shielding prior to lockdown  | 26 | 38.2 |
| Shielding at the start of lockdown                                 | 52 | 76.5 |
| Still shielding  | 43 | 63.2 |
| <b>Websites to obtain information</b>                              |    |      |
| Behçet's UK.org (www.behcetsuk.org)                                | 38 | 55.9 |
| Facebook groups  | 29 | 42.6 |
| NHS.UK (www.nhs.uk)  | 26 | 38.2 |
| GOV.UK (www.gov.uk)  | 26 | 38.2 |
| Behçet's Patients Support (behcetspatients.org.uk)                 | 10 | 14.7 |
| Health Unlocked (healthunlocked.com)                               | 7  | 10.3 |

n=62, 91.2%; tablet: n=41, 60.3%; laptop computer n=48, 70.6%) were commonly used by patients in this period. Over the half of them (n=41, 60.3%) used these devices to access Behçet's support. In addition to Facebook groups (n=29, 42.6%), Behçet's UK (n=38,

55.9%), and NHS.UK and GOV.UK (n=26, 38.2%) were commonly visited websites for this purpose (Table IV). Finally, strategies for patient empowerment helped to decrease the impact of the pandemic based on Maslow's hierarchy of needs in BS (Fig. 4).

*The profile of patients with COVID-19 test positive*

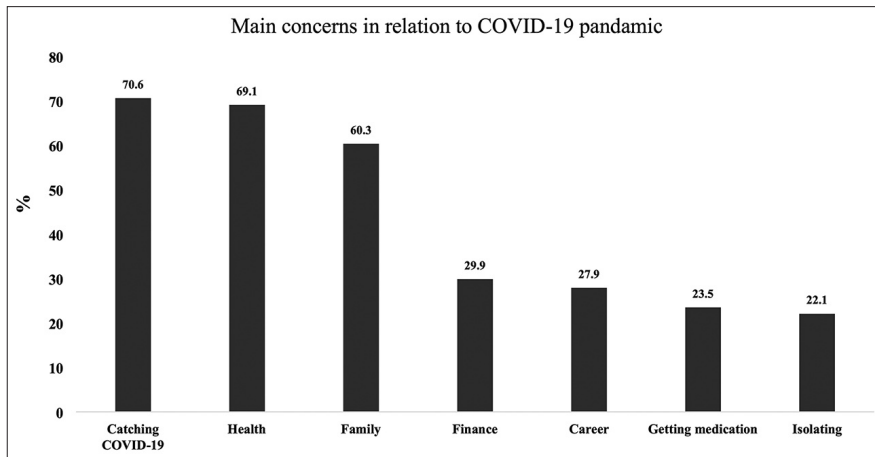
Although almost one-third of patients declared COVID-19 like symptoms during pandemic (Supplementary Table S1), a very limited number of patients (F/M: 1/1) and their households (n=5) had positive COVID-19 test results (Table I). These two patients were young, English (Patient-1), or White Asian (Patient-2), travelled abroad, employed (Patient-1), or self-employed (Patient-2). Hypothyroidism and Lichen sclerosis for Patient-1 each, and deafness for Patient-2 were other health problems. Additionally, these patients did not have any symptoms of COVID-19 when they received the positive test results (Suppl. Table S2).

**Discussion**

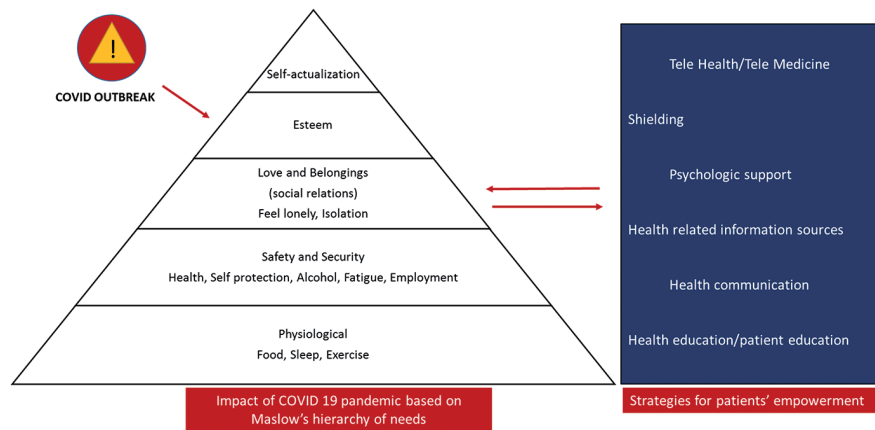
Patients with chronic diseases encounter many challenges including access to healthcare, obtaining medication during the pandemic. Therefore, within the frame of health systems, countries have taken numerous precautions to improve health conditions on the behalf of patients with chronic diseases (2, 21). In BS, patients' lives are negatively affected by exacerbation and remission of symptoms. Consequently, regular visits and effective treatment protocols are important reasons for reducing mortality and morbidity risks in BS (22).

Maslow's hierarchy of needs is a motivation theory concerning 5 levels of human needs regarding Physiological needs, Safety and security, Love and belonging, Esteem and Selfactualisation. Individuals satisfy their lower-level needs before moving forward to meet their higher-level needs (4, 6, 7). Assessing patients' needs and empowering patients in the management of chronic disease require focusing on the disease and patients' capabilities to promote their health (23). Consequently, this study aimed to understand patients' needs during lockdown using the first three levels in Maslow's hierarchy of needs.

Decrease in consumption of healthy food and frequency of exercise and sleeping less were seen in *Physiological needs* at lockdown. Adequate sleep (24, 25), access to a healthy diet and the frequency of exercise are essential



**Fig. 3.** Main concerns regarding safety (employment and health) and social (family, friends' relations) needs during the lockdown in relation to Maslow's hierarchy of needs model in the COVID-19 pandemic.



**Fig. 4.** Patient's needs vs. strategies for patient's empowerment during COVID-19 lockdown.

components of physical health (26). Although the recommended sleep times are 7–9 hours for young adults, 7–8 hours for older adults according to the National Sleep Foundation (24), patients reported sleeping less in lockdown. A decrease in the frequency of exercise is a risk factor for healthy life, physical and mental well-being (7). A minimum of 30 minutes 5 days per week is recommended by the American Heart Association (26). In addition, physical exercise can also modulate the inflammatory response (27). A healthy lifestyle depends on a balanced diet and healthy food, and both dietary and lifestyle issues affect the homeostasis of the immune system in BS (28). The inflammatory response is activated by dysbiosis of the gut microbiota through the decrease in butyrate production in BS (29-32). Consequently, healthy food consumption as an im-

portant supplemental effect is always recommended for BS. This was compounded by insufficient sleep and unhealthy food consumption, a decrease in the frequency of exercise increases the risk factor for BS patients during enforced social isolation. For *Safety needs*, smoking habit was stable during lockdown whereas an increase in alcohol consumption was the main problem during this period. It is known that both smoking habits and alcohol consumption are major risk factors for chronic diseases, mortality and morbidity. Besides, increased quit attempts and cessation are associated with COVID-19 lockdown among past-year smokers. In high-risk drinkers, lockdown is associated with alcohol reduction attempts (33). Interestingly, the mean units of alcohol consumption per week fell whereas the number of drinking days were almost the same in lock-

down (34). Consequently, health education programmes and webinars with a multidisciplinary approach would be helpful to manage the problems. In addition, improving preventive strategies should provide ways to increase patient empowerment in future national and/or global health emergencies (9). A decrease in working hours and an increase in the unemployment rate, concern for finance and career were the other items in *Safety needs*. Working conditions and the business environment rapidly changed during the pandemic (35, 36). Both unemployed workers (36) and workers with reduced incomes together with changes in working hours are consequences of the pandemic (35). Although the monitoring of workers' health, safety protocols and providing a healthy workplace are crucial points for occupational health services, the home became the new workplace for most workers during the outbreak (35). Our results were in agreement with these global changes. In the present study, a decrease in access to healthcare as a part of *Safety needs* was supported by tele-health applications by the Behçet's centres during lockdown. Due to the nature of BS, patients required multiple specialists' opinions. They used tele-health/tele-medicine applications that were mainly done using telephone consultations and e-mail queries to obtain expert opinions. Tele-medicine provided a practical option for supporting patients' needs. All patients' queries were answered during the lockdown period providing reliable and accurate information, as well as obtaining professional guidance. This made it possible to provide disease management and continued support of patients' needs during lockdown. Tele-medicine is an essential component of patient-centred care for chronic disease management during the pandemic (9, 37, 38). At the beginning of lockdown, many patients preferred this form of communication. As the pandemic continued, many patients and professionals found this suboptimal to face-to-face appointments as clinical evaluation of patients could not be performed effectively by health professionals in the Behçet's Centres. Tele-medicine may

result in undiagnosed clinical manifestations, unmanaged diseases and delays in access to healthcare, which progressively increases the burden of disease (9). In addition, the success of tele-medicine applications depends on the readiness of health professionals/health care institutions/health systems, health literacy of patients, technical infrastructure and technical difficulties (37). However, during pandemics or national/global health emergencies, the initial or emergency consultation should take place with a multidisciplinary health professional team in specified Centres. As envisaged, social isolation resulted in some patients requiring mental health support during the lockdown period. Isolation and feelings of loneliness were evaluated using *Social needs* of Maslow's hierarchy. For these reasons, face-to-face, clinical appointments continued for patients during the pandemic in the Behçet's Centres of Excellence in the UK, as supportive psychological care is essential for anxiety, stress, depression, sleep problems which all increased as the pandemic and lockdown continued (5, 39-42).

The official and corporate web pages as Behçet's UK.org, NHS.UK, and GOV.UK provide information flow about outbreak in the study. As expected, patients used Facebook groups as social networks and communicated patient's organisations. These approaches have helped patients to cope with difficulties they experienced during lockdown and the COVID-19 outbreak. Social media is commonly used to satisfy the needs of communication and information. Access to timely and reliable information has benefits for patients whereas unapproved information from health professionals lead to failure to protect from virus (43). Behçet's Syndrome Centres of Excellence with multidisciplinary clinics has provided tele-medicine services, prepared leaflets to give detailed information about the pandemic including vaccine information in several languages to aid BS patients psychologically to increase self-empowerment (44).

In this study, the main concerns of patients were contracting COVID-19, providing health status stability, their family and obtaining their medication.

In addition to isolating, the personal protective precautions taken by patients were the use of facemasks, hand sanitizer and hand washing. As associated with *Safety needs*, the use of masks, and good hygiene procedures are essential personal precautions performed by individuals and patients (45, 46).

The crucial factor during the outbreaks of infection in epidemics and a pandemic was household transmission. Asymptomatic individuals are more likely to infect the other members of the household (47). Over three quarters of patients with BS were living with family or friends when the study was carried out. Most of the patients and households has experienced COVID-19-like symptoms with only 2 patients and 5 households having positive test results at this phase of the pandemic.

During the first wave of COVID-19, 2.2 million people were classified as clinically extremely vulnerable (CEV) by the NHS (39). Over half of the group received a letter from the NHS recommending shielding and around 75% of the group started shielding with lockdown. The low number of positive tests during the first wave in the UK in BS patients may be partially explained by isolating and effective self-protection (48). Furthermore, this NHS letter regarding isolating had a positive safety effect on the empowerment of patients during the pandemic. Patient empowerment is a well-known outcome using health education programmes (49). The education initiatives have three important objectives. These are: improvement of personal health awareness, environmental health awareness, and improving the quality of life. These objectives are achieved by providing health literature which is a crucial aspect for the accomplishment of the self-management programmes, especially in chronic diseases (50). Patient empowerment as a component of chronic disease management may also be accomplished in diverse ways, e.g. tele-medicine applications, improvement of physician-patient communication, advising and or informing, e.g. a letter on shielding and giving information about the pandemic and personal precautions (9).

The study provided crucial information

regarding unmet needs of BS patients using Maslow's hierarchy of needs and gave clues regarding patient empowerment for the next pandemic, national/global health emergencies. However, the study had some limitations, First, the study did not have diseased and healthy control groups. The study results were not specific for BS whereas patients with chronic diseases could have similar problems during lock-down. Secondly, the study group was mainly composed of female patients. We did not have a chance to do gender balance in the online questionnaire. Thirdly, the sample size was small and the number of incomplete questionnaires was high. This could be associated with the length of the questionnaire or the patient's technical skills. In addition, loss of valuable data from groups who do not use the internet and do not fill in questionnaires include a vulnerable cohort of those most susceptible to severe outcomes associated with COVID. For this reason, continuing to run a face-to-face service during COVID was vital. Finally, a detailed clinical assessment of clinical signs could not be evidenced using an online survey.

Therefore, the results of the study cannot be generalised to all BS patients in the UK, since they are only specific to the participants. Since lockdown appeared to have a negative influence on patients' lives and disease management within the framework of patient-centred care, patient empowerment is essential to assist in helping patients achieve a better quality of life. Using Maslow's hierarchy of needs provided a framework for reviewing the quality of basic needs in patients' lives during lockdown, needs which are required for healthy social lives. Consequently, careful consideration of these deprivations should be considered during the process of health planning at all levels, local, national and global to help communities live useful healthy physical and psychosocial lives in beneficial environments.

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