



## COVID-19 pandemic and systemic autoinflammatory diseases management: a cross-sectional survey

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Since December 2019, coronavirus disease 2019 (COVID-19) caused by severe acute respiratory syndrome-coronavirus 2 (SARS-CoV-2) infection has spread all over the world. On 30th January 2020, World Health Organization (WHO) officially declared the COVID-19 epidemic as a public health emergency of international concern [1]. The pandemic has posed a challenge regarding the routine health care to patients with chronic diseases [2]. Systemic autoinflammatory diseases (SAIDs) are a group of rare disorders which have chronic trajectories and share characteristics of periodic inflammation, demanding long-term disease management [3]. We aim to investigate the impact of COVID-19 outbreak on real-world healthcare of patients with SAIDs in China.

From April 2020 to May 2020, we enrolled patients who were diagnosed with SAIDs and followed up in our tertiary medical center to finish the designed questionnaire. This study is approved by Ethics Committee of Peking Union Medical College Hospital. We sent out the link of the questionnaire to 122 SAIDs patients through E-mail and WeChat (a communication application similar to “WhatsApp”). If

without reply, we further contacted them through telephone for their answers to the questionnaire. Finally, a total of 86 SAIDs patients completed the questionnaire, and the response rate was 70.5% (86/122). These patients were from 22 provinces and municipalities, mainly in western, central, and northern China. Their demographic characteristics and clinical information are listed in Table 1.

First of all, COVID-19 was ruled out in our participants since they had no typical symptoms and with the negative results of SARS-CoV-2 via reverse transcription polymerase chain reaction testing. During COVID-19 pandemic, 17 (19.5%) patients with SAIDs had been hospitalized due to their disease activities. Some patients reported clinical symptoms of SAIDs, such as arthritis (40.7%), fever (39.5%), myalgia (27.9%), fatigue (18.6%), etc. Overall, 70 (80.5%) patients did not complete their follow-up since the COVID-19 outbreak. There were three (3.5%) patients who visited our center, seven (8.0%) patients received consultations via E-mails, and seven (8.0%) patients visited local outpatient clinics. Among those patients with no follow-up visits, 26 (37.1%) deemed the pandemic as a noteworthy factor to impact their hospital visits. Only 33 (37.9%) patients held the opinion that the pandemic did not pose a challenge to their disease treatment and follow-ups. In the meantime, the rest of these patients thought the pandemic did have an impact on their disease treatment and follow-ups to different extents: slightly (24/87, 27.6%), moderately (16/87, 18.4%), severely (10/87, 11.5%), and extremely (4/87, 4.6%). Given that fever is a characterized symptom of SAIDs, patients seldom visited hospital for the fear of being suspicious of COVID-19, which is also featured as fever. Besides, other concrete impacts included the failure of finishing their scheduled follow-ups, the difficulty to buy medicines.

We collected self-assessment scores from patients, ranging from 0 to 10, by which the patients were classified into three levels of disease severity: mild (0–3), moderate (4–7), and severe (8–10). The detailed proportion is shown in Table 1. The current crisis has led to a global phobia

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**Table 1** Characteristics of Chinese patients with SAIDs

Characteristics	Number (%)
Gender	
Male	50 (58.1%)
Female	36 (41.9%)
Age, median, yr (min–max)	32 (13–66)
Diagnosis	
Familial Mediterranean fever (FMF)	34 (39.5%)
NLRP12-associated autoinflammatory disease (NLRP12-AID)	11 (12.8%)
Periodic fever, aphthous stomatitis, pharyngitis, and cervical adenitis (PFAPA)	10 (11.6%)
NLRP3-associated autoinflammatory disease (NLRP3-AID)	9 (10.5%)
Tumor necrosis factor receptor-associated periodic syndrome (TRAPS)	6 (7.0%)
Others	16 (18.6%)
Symptoms	
Fever	34 (39.5%)
Fatigue or weight loss	16 (18.6%)
Arthritis	35 (40.7%)
Myalgia	24 (27.9%)
Cutaneous manifestations	20 (23.3%)
Eye inflammation	19 (22.1%)
Oral ulceration	22 (25.6%)
Self-assessment of disease severity	
Mild	55 (65.5%)
Moderate	22 (26.2%)
Sever	7 (8.3%)

yr years, *min* minimum, *max* maximum

called coronaphobia, raising concerns about mental health of the public [4]. With regard to psychological aspect, a total of 41 (47.7%) patients stayed calm, 28 patients (32.6%) felt worried, 4 (4.7%) patients were nervous, and 3 (3.5%) suffered from fear.

Although COVID-19 outbreak has been preliminarily controlled in China, the pandemic is still raging all over the world, raising grim problems. To the best of our knowledge, this is the first survey about the situation of disease management of patients with SAIDs in China since COVID-19 outbreak. Although the majority of our patients stay stable during the pandemic, some patients still had suffered from characteristic symptoms of SAIDs, such as fever and arthritis. Significantly, more than 60% of our SAIDs patients stated that their disease managements were impacted by the current crisis. Through this study, we found the low rate of follow-up was worthy of notice. Patients were more willing to complete follow-ups by visiting hospitals than through E-mails. Over half of these patients were affected psychologically, and were subjected to negative emotions. In conclusion, we suggest rheumatologists pay close attention to the unmet medical need for SAIDs patients in the unprecedented situation of COVID-19 pandemic.

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**Author contributions** All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by Na Wu, Mengzhu Zhao, and Min Shen. The first draft of the manuscript was written by Na Wu and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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## Declarations

**Conflict of interest** The authors declare that they have no competing interests.

**Ethics approval** This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Institutional Review Board of the Peking Union Medical College Hospital. (Date April 9th, 2020/No. S-K1148).

**Consent to participate** Informed consent was obtained from all individual participants included in the study.

**Disclosure** There was not any editing agency involved in editing and submission support.

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