

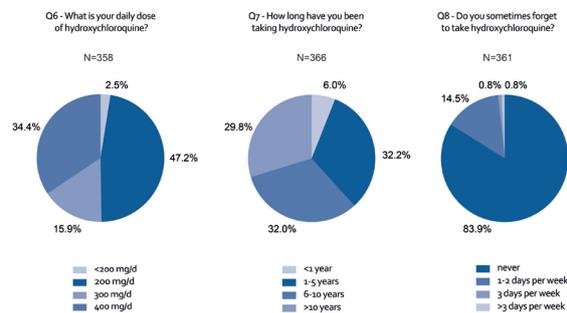
Concerns and needs of patients with systemic lupus erythematosus regarding hydroxychloroquine supplies during the COVID-19 pandemic: results from a patient-centred survey

We read the letter by Mathian *et al* with great interest.¹ In their paper, the authors report on the course of COVID-19 in 17 patients with systemic lupus erythematosus (SLE). The data suggest that patients with SLE on hydroxychloroquine (HCQ) are not protected from COVID-19 infection but have a high level of comorbidities, which potentially renders them more susceptible to a severe course. HCQ, an essential drug for patients with SLE,² has been advocated for prophylaxis and treatment of COVID-19 by many. Subsequently, drug shortages have ensued, which has led to discussions on scientific reporting³ and ethics of treatment allocation⁴ because withdrawing HCQ in SLE is associated with flares.⁵ Rheumatologists are involved in this pandemic as counsellors for physicians unfamiliar with repurposed antirheumatic drugs used in COVID-19 but also face the concerns and needs of their chronically ill patients. These

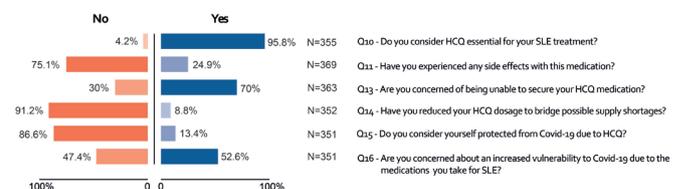
Table 1 Self-reported survey respondents' characteristics	
	N (%)
Demographic characteristics	
Age	
18–30	45 (12.2%)
31–40	87 (23.6%)
41–50	99 (26.9%)
51–60	90 (24.5%)
60–70	33 (9%)
>70	14 (3.8%)
Gender	
Female	347 (94%)
Male	22 (6%)
Organ manifestations	
Arthritis	225 (61%)
Skin	120 (32.5%)
Lupusnephritis	127 (34.4%)
Pulmonary involvement	51 (13.8%)
Heart	54 (14.6%)
Serositis	55 (14.9%)
NPSLE	57 (15.4%)
Haematological	94 (25.5%)
Other	*
Concomitant medications	
Prednisone	197 (53.4%)
MTX	40 (10.8%)
AZA	74 (20%)
MMF	47 (12.7%)
Cyclosporine	6 (1.6%)
Tacrolimus	6 (1.6%)
Belimumab	40 (10.8%)
Cyclophosphamide	2 (0.5%)

*Other organ manifestations: antiphospholipid antibody syndrome (APS), n=8 (2.1%); myalgia, n=7 (1.9%); fatigue, n=3 (0.8%)
AZA, azathioprine; MMF, mycophenolate mofetil; MTX, methotrexate; NPSLE, neuropsychiatric lupus erythematosus.

A Dosage, treatment duration and adherence to HCQ



B Patients' opinions and beliefs towards HCQ for SLE and Covid-19



C Q12 - Have you experienced problems securing HCQ during the Covid-19 pandemic?

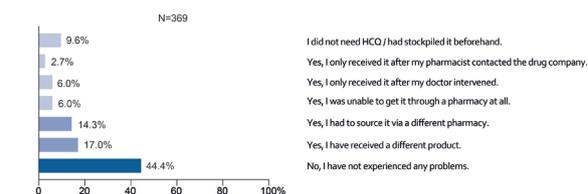


Figure 1 Survey results of 369 respondents with complete results. (A) Self-reported dosage, treatment duration and adherence to hydroxychloroquine (HCQ) are reported. (B) Patients' general opinions and beliefs concerning HCQ in systemic lupus erythematosus (SLE) and COVID-19. (C) Potential supply issues reported by the patients. Q, question number.

discussions also need to involve patients' views. In SLE, this is particularly important.

To gain insights into supply chains of HCQ, we conducted a survey (online supplementary table S1) to investigate the current situation among patients with SLE in Germany. We received 554 responses; 185 were excluded based on prespecified answers to questions 1 and 5 or incomplete data. The self-reported characteristics of the respondents are shown in table 1. In short, 347 (94%) were women, and 75% of the respondents were between 31 and 60 years of age. SLE manifestations included arthritis (n=225, 61%), nephritis (n=127, 34.3%), skin (n=120, 32.5%) or haematological abnormalities (n=94, 25.5%), among others. Medications included prednisone (n=197, 53.4%), azathioprine (n=74, 20%), mycophenolate mofetil (n=47, 12.7%), methotrexate or belimumab (n=40, 10.8%, respectively).

The survey questions relating to dose, treatment duration and adherence to HCQ (figure 1A) revealed that almost half (47.4%) of respondents reported a daily intake of 200 mg. Treatment duration was 1–5 years, 6–10 years and more than 10 years in about a third each. The vast majority (83.9%) stated they never forget their intake. Furthermore, 95.8% of patients considered HCQ essential for their SLE treatment (figure 1B). 70% expressed concerns about being unable to receive prescriptions; 8.8% reduced their daily dose to overcome potential supply issues. Importantly, 86.6% saw no benefit regarding an impending

COVID-19 infection, while half of the patients expressed concerns of increased vulnerability because of their SLE. One question specifically addressed supply issues (figure 1C): here, about 45% reported different types of supply issues, 44.4% had not experienced any problems at all and almost 10% had stockpiled HCQ beforehand.

Overall, our data represent the first surveyed report in patients with SLE regarding HCQ supplies during the COVID-19 pandemic. Our cohort showed a typical distribution of organ manifestations and treatment profiles, which support their representativeness.

On 3 April 2020, the German Federal Institute for Drugs and Medical Devices issued a statement for the security and reliability of HCQ supplies.⁶ It reiterates that any off-label use should only be conducted in clinical trials. In practical terms, prescriptions of HCQ in Germany have to include an in-label diagnosis justifying its use. This potentially ensures continued supplies for patients who depend on the drug and prevents off-label use, including for COVID-19. Nevertheless, supply issues were reported commonly in our survey.

Patients with SLE and caregivers are facing challenges with the improper use of essential drugs, and healthcare policies need to take this into account. As politics differ regionally, it may prove informative to investigate patients' concerns globally and put emphasis on their needs. Ultimately, even during global crises, vulnerable populations need to be protected. The data reported by Mathian *et al* and our presented survey data suggest that patients with SLE are particularly vulnerable.

Marlene Plüß ,¹ Gamal Chehab ,² Peter Korsten ¹

¹Department of Nephrology and Rheumatology, University Medical Center Göttingen, Göttingen, Germany

²Department of Rheumatology & Hiller-Research Unit Rheumatology, Heinrich-Heine University, Duesseldorf, Germany

Correspondence to Dr Peter Korsten, Department of Nephrology and Rheumatology, University Medical Center Göttingen, Robert-Koch-Str. 40, 37075 Göttingen, Germany; peter.korsten@med.uni-goettingen.de

Twitter Peter Korsten @pekor002

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details. The survey link was distributed through communication channels (eg, mailing list) of the German SLE self-help organisation (Lupus Erythematoses Selbsthilfegemeinschaft e. V.).

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ORCID iDs

Marlene Plüß <http://orcid.org/0000-0003-4956-9401>

Gamal Chehab <http://orcid.org/0000-0001-7309-2370>

Peter Korsten <http://orcid.org/0000-0001-6065-5680>

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