


Consequences of medication unavailability on patient anxiety: the example of the 2020 hydroxychloroquine availability crisis for patients with SLE – 18 months later

Alain Cornet ¹, Jeanette Andersen,¹ Chiara Tani,² Marta Mosca,³ for LUPUS EUROPE

To cite: Cornet A, Andersen J, Tani C, *et al.* Consequences of medication unavailability on patient anxiety: the example of the 2020 hydroxychloroquine availability crisis for patients with SLE – 18 months later. *Lupus Science & Medicine* 2023;**10**:e000895. doi:10.1136/lupus-2023-000895

Received 3 January 2023
Accepted 13 January 2023



© Author(s) (or their employer(s)) 2023. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹Lupus Europe, Brussels, Belgium

²Clinical and Experimental Medicine, Rheumatology Unit, University of Pisa, Pisa, Italy

³Department of Clinical and Experimental Medicine, University of Pisa, Pisa, Italy

Correspondence to

Alain Cornet; secretariat@lupus-europe.org

During the early phases of the COVID-19 pandemic in 2020, based on limited in vitro and anecdotal clinical data in case series, hydroxychloroquine sulfate (HCQ) has been recommended for treatment of patients with COVID-19 in several countries;¹ soon after HCQ was confirmed to be in short supply in several countries raising significant concerns for those who use HCQ for chronic diseases including SLE.²

In April 2020, Lupus Europe (the European federation of lupus patient organisations) launched a survey² to quantify this access gap, as well as the anxiety expressed by patients confronted with this outage. A total of 2422 European patients with self-declared lupus diagnosis and usage of HCQ responded confirming that 48.3% of them could not obtain HCQ in their usual pharmacy when asking, and an average level of 6.45 on a Likert scale of 0 (not at all) to 10 (extremely) was registered on the question ‘How anxious are you about not being able to have access to hydroxychloroquine?’. A follow-up survey (August–September 2020, 1854 patients) confirmed restored access (only 13.5% with access issue), and anxiety significantly reduced to an average of 4.15. Survey methodology is described at length in *Lupus Science & Medicine* 2021 Apr;**8**:e000496.²

The present study re-evaluated patients' experience and state of mind 18 months after supply was restored, and to objectify emerging signals of new shortages in Poland.

In November 2021, a second online follow-up survey was launched using the same method and format as the two prior ones including questions on the current access to

HCQ and anxiety with regard to not being able to have access to HCQ (Likert scale from 0 (‘not at all’) to 10 (‘extremely’)).

A total of 2511 valid answers from European patients with self-declared lupus diagnosis were gathered from 29 November 2021 to 13 February 2022. Of these, 2255 included answers about the level of anxiety with regard to not being able to have access to HCQ and have been included in this analysis. The survey confirmed a largely restored access, with 90.6% of patients obtaining their medication at first request from their usual pharmacy and 1.1% unable to find it in normal supply channels. It confirmed the existence of significant shortages in Poland starting about 1 month prior to the survey. It also showed a further reduction of anxiety, as self-defined and assessed by patients, to an average of 3.54 on a scale of 10.

However, with the exception of Finland and Portugal, a core group of 6.2%–13.7% of patients remains extremely anxious (defined by the researchers as scoring 9 or 10) about supply of their medication. In Portugal and Finland, the two countries where supply remained fair (ie, more than 95% of patients declared being able to get HCQ supply from pharmacies) at the heat of the crisis, that percentage is substantially lower at 0% and 3.5%, respectively.

In Poland, anxiety had reduced from 9.02 to 6.31 when supply improved in September 2020, but then came back at record levels (9.09) due to a deterioration of supply at the end of 2021. It is important to stress the speed of this reincrease of anxiety, as the supply disruption has been at the time of analysis, of a maximum 1-month duration, and 40%

Table 1 Country-by-country average anxiety and proportion of patients very anxious (score 9 or 10) about their supply of hydroxychloroquine sulfate at the heat of the crisis (April 2020), soon after resolution (August–September 2020) and 18 months later (December 2021–February 2022)

Country	Answers received (n)			Average anxiety (SD)			% of very anxious patients		
	April 2020	August–September 2020	December 2021–February 2022	April 2020	August–September 2020	December 2021–February 2022	April 2020	August–September 2020	December 2021–February 2022
Finland	66	23	86	5.39 (2.71)	*	2.41 (2.46)	9.1	*	3.5
Portugal	66	2	46	4.03 (2.70)	*	1.22 (2.13)	3.0	*	0.0
Belgium	95	54	112	6.23 (3.13)	3.83 (3.41)	3.77 (3.35)	26.3	16.7	12.5
Denmark	36	21	85	5.86 (2.66)	*	4.09 (3.20)	16.7	*	9.4
France	422	285	100	6.46 (2.67)	3.93 (3.13)	3.14 (3.14)	23.7	8.8	8.0
Germany	254	10	102	7.50 (2.48)	*	4.15 (3.62)	40.9	*	13.7
Italy	249	495	226	6.14 (2.84)	4.26 (3.04)	3.24 (3.07)	22.9	9.1	6.2
Lithuania	29	21	91	8.10 (2.73)	*	3.53 (3.36)	62.1	*	9.9
Netherlands	62	24	37	6.00 (2.82)	*	4.24 (3.36)	21.0	*	10.8
Slovakia	53	33	22	5.87 (2.91)	3.48 (3.13)	2.27 (2.18)	20.8	12.1	*
Spain	205	186	359	6.06 (3.07)	4.19 (3.13)	3.66 (3.49)	21.5	8.6	9.7
Switzerland	47	83	3	6.28 (2.55)	3.89 (2.80)	*	23.4	7.2	*
UK	343	287	567	6.84 (2.76)	4.49 (3.40)	3.66 (3.43)	31.2	13.9	12.3
Bulgaria	181	126	219	9.71 (1.02)	8.69 (2.18)	8.29 (2.73)	92.8	71.4	64.4
Poland	43	26	115	9.02 (1.87)	6.31 (3.28)	9.09 (1.72)	76.7	30.8	73.9

*Averages and SDs only calculated where more than 25 answers were received.

of the patients obtained their medication on the spot or from their usual pharmacy, possibly with a minor delay.

In Bulgaria, anxiety remains very high at an average 8.29 on a scale of 10, down from an initial 9.71 in April 2020, and trending in parallel with the slight improvement in supply.

Data per country are represented in [table 1](#).

In conclusion, in countries where shortages were resolved in mid-2020, the patient-reported anxiety about the possible lack of access to HCQ appeared to gradually improve. The confidential aspect of the surveys did not allow linking of responses of the same individual in each of the three consecutive surveys and hence validation if the current anxiety levels correlates with the initial individual experience of shortages in supply back in April 2020. Rather, the numbers provide a trend in a similar population, but from different samples of patients.

However, while supply of HCQ is back to normal levels, the experience of the past shortages is leaving traces in patient anxiety level, with 3%–13% more patients still being very anxious about not being able to access their medication compared with countries where the shortages were not significant.

The case of Poland indicates that, when a new supply issue occurs, even 18 months later, the anxiety level almost immediately jumps back to historical levels, with a high ‘contagion’ effect, with even those not experiencing current shortfalls reporting extreme anxiety relating to the availability of their medication.

Thus, shortages of medicine create an anxiety that can be long-lasting. Even when supply is re-established, the fear remains. For this reason, establishing an effective communication system is necessary to reassure patients when short-term shortages are taking place and is key to

avoid fast-spreading anxiety relating to this concern. In this process, patient associations, physicians, industries and all the stakeholders should be involved.

Contributors AC and JA designed, reviewed and coordinated the online questionnaire together with the LUPUS EUROPE Patient Advisory Network, and animated the PAN on identifying statements to be submitted for voting. AC analysed the data and performed statistical analyses. AC, JA and CT wrote the manuscript. MM supervised the process and provided guidance and support at each step. All authors discussed the results.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None of the authors has direct conflict of Interest. However, LUPUS EUROPE is funded mostly by grants or donations from Pharmaceutical Companies (Astra Zeneca, Bayer, Biogen, BMS, Boehringer-Ingelheim, Galapagos, GSK, Idorsia, Janssen, Lilly, Merck, Novartis, Roche and UCB), none of which exceeds 25% of total funds collected, and none having a say on the content of our studies.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Alain Cornet <http://orcid.org/0000-0001-7344-7258>

REFERENCES

- 1 Hinton DM. Request for emergency use authorization for use of chloroquine phosphate or hydroxychloroquine sulfate supplied from the strategic national stockpile for treatment of 2019 coronavirus disease. 2020. Available: <https://www.fda.gov/media/136534/download> [Accessed 31 Mar 2020].
- 2 Cornet A, Andersen J, Tani C, *et al.* Hydroxychloroquine availability during COVID-19 crisis and its effect on patient anxiety. *Lupus Sci Med* 2021;8:e000496.