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

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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 survey[2] 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)

	Answers received (n)			Average anxiety (SD)			% of very anxious patients		
Country	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.

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