

# Contextualizing the COVID-19 Induced Hydroxychloroquine Shortage in Sub-Saharan Africa and How It Impacted Adult Systemic Lupus Erythematosus Patients



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## Introduction:

Systemic Lupus Erythematosus (SLE) is a complex, incurable, and uncommon autoimmune disease that can impact any organ or tissue in the body. In 2020, two of the main SLE treatments, the antimalarials hydroxychloroquine (HCQ) and chloroquine, were announced as potential treatments and prophylaxes for COVID-19. This initiated a global medication shortage that left many SLE patients unable to access their essential medication and vulnerable to undesirable socio-cultural and health effects.

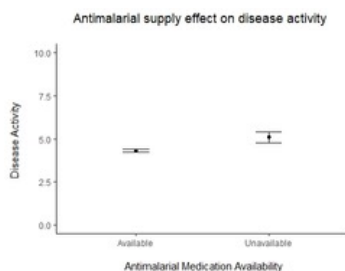
## Study Objective:

This study aims to contextualize the hydroxychloroquine shortage in Sub-Saharan Africa and look at how patients were socially, physically, and emotionally impacted. Since around 90% of SLE patients are women, there is a particular emphasis on the female experience. This study is meant to compliment medically oriented studies and humanize the shortage beyond its biological impact.

## Background:

- A Global Rheumatology Alliance survey showed that patients in Africa had the most difficult time accessing HCQ and that a lack of medication access led to worse mental and physical outcomes. (Siroitch et al., 2020)
- A 2021 study out of Italy demonstrated a significant correlation between disease flares and medication discontinuation for SLE patients. (Zucchi et al., 2021)
- When looking at general drug shortages, they are often associated with increased costs, stress, poor outcomes, and overall health complaints. (Phuong et al., 2019)

This chart from the Global Rheumatology Alliance Survey demonstrates the negative impact of the HCQ shortage on autoimmune disease activity (Siroitch et al., 2020)



## Methods:

Participants:

- The target populations for this study are SLE patients and advocates across Sub-Saharan Africa.
- There is a large overlap in these categories, as many advocates are also SLE patients.

Data Collection:

- Data was collected via interviews over Zoom. Questions were open-ended. So far, there have been 8 interviews in 4 countries. 7 are patients and advocates, and one is an advocate.

Data Analysis:

- Interviews were recorded and listened to after to capture key concepts and quotes.
- Interview content was compared to identify trends and common themes.

## Results:

### Emotional Impacts

- Every interviewee indicated large amounts of fear and anxiety surrounding the pandemic and actual or potential drug withdraw. Several cited the uncertainty of the situation and inaccessible care as additional contributors the stress.
- Many participants stated that the patients they interact with or themselves were afraid of imminently dying without their medication or getting COVID-19 since so little information was known early in the pandemic.

### Physical Impacts

- Patients indicated that increases in SLE flares were common. They attributed them to a mix of stress and a lack of medication, as stress is a major disease trigger as well.
- Patients rationing medication if they were low on supply was a frequent occurrence. Prices were often so high it was not feasible to purchase more if it was even available.

### Social Impacts

- Social isolation was highlighted in multiple interviews as one of the most common precautionary measures taken by SLE patients during the pandemic. The HCQ shortage and the associated uncertainty increased patients' drive to isolate, which often left them without access to community or loved ones.

### SLE Community-Based Issues and Solutions

- Two interviewees reported SLE patients pooling HCQ together to share amongst themselves to ensure all had some level of access, even if the patients sharing were low themselves.
- SLE organizations have been interrupted in their normal and routine patient-oriented services and support groups.

## Discussion & Additional Trends:

- The initial results from the interviews indicate that SLE patients faced challenges on multiple fronts during the pandemic and the drug shortage.
- Interviewees said they often felt invisible and unheard in some way during the pandemic as the medications they relied on were becoming scarce due to, as participants stated it, overprescribing and hoarding.
- When asked about what we can learn from this moving forward, interviewees stated that as a society, we can learn to better plan and distribute medications for pandemics, as this will likely occur again and could be a different drug for a different disease next time.
- On a positive note, several interviewees agreed that the pandemic and HCQ shortage has brought more awareness and name recognition to SLE from the press and media coverage.
- Almost every participant pointed to the press conferences held by Donald Trump in late March 2020 where he promoted HCQ as the starting point for the shortage surrounding the drug.
- As of late last summer, the hydroxychloroquine shortage has largely eased.

## Works Cited

- Phuong, J. M., Penn, J., Chaar, B., Oldfield, L. D., & Moles, R. (2019). The impacts of medication shortages on patient outcomes: A scoping review. *PLOS ONE*, 14(5), e0215837. <https://doi.org/10.1371/journal.pone.0215837>
- Siroitch, E., Kennedy, K., Surangiwal, S., Semalulu, Larche, M., Liew, J., Wallace, Z., Robinson, P., Grainger, R., Sparks, J., Simard, J., Yazdany, J., Gore-Massy, M., Howard, R., Levin, M., & Hausmann, J. (2020, November). *Antimalarial Drug Shortages During the COVID-19 Pandemic: Results from the Global Rheumatology Alliance Patient Experience Survey*. American College of Rheumatology. <https://acrabstracts.org/abstract/antimalarial-drug-shortages-during-the-covid-19-pandemic-results-from-the-global-rheumatology-alliance-patient-experience-survey/>
- Zucchi, D., Tani, C., Elefante, E., Stagnaro, C., Carli, L., Signorini, V., Ferro, F., Trentin, F., Fulvio, G., Cardelli, C., Di Battista, M., Governato, G., Figliomeni, A., & Mosca, M. (2021). Impact of first wave of SARS-CoV-2 infection in patients with Systemic Lupus Erythematosus: Weighting the risk of infection and flare. *PLOS ONE*, 16(1), e0245274. <https://doi.org/10.1371/journal.pone.0245274>

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