Q & A: Possible Consequences of a Shortage of Hydroxychloroquine for Lupus Patients Amid the COVID-19 Pandemic

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Dr. Earl Silverman (ES): Hi, I'm Earl Silverman, editor-in-chief of The Journal of Rheumatology. I hope you're all doing well during the ever-changing situation in our medical community.

Today, I'm pleased to have my guest Dr. Christine Peschken from University of Manitoba, who is the Associate Editor for Systemic Lupus Erythematosus at The Journal of Rheumatology. She's being interviewed today because she's the author of the editorial entitled, "Possible Consequences of a Shortage of Hydroxychloroquine for Lupus Patients Amid the COVID-19 Pandemic."

This editorial is now available as an open access article at our website at jrheum.org.

We will be discussing Dr. Peschken's article on the implications of the COVID-19 pandemic for patients with SLE and physicians taking care of these patients.

Christine, first of all, I'd like to thank you for writing an excellent editorial discussing the potential implications of the COVID-19 epidemic for patients with SLE and physicians caring for them. I also want to thank you for joining me and agreeing to discuss your editorial.

If I could ask you please to briefly summarize the issues that you believe are important implications as a result of the coronavirus pandemic to both patients with SLE and physicians.

Dr.Christine Peschken (CP): Thanks, Earl, for inviting me to talk about this. There's a lot of things that are coming together for lupus patients and physicians who look after them in this epidemic.

First, lupus patients are already thought to be at high risk of poor outcomes with COVID-19 because of their underlying lupus, as well as the immunosuppressive medications that many of them are taking, combined with comorbidity including organ damage from lupus, such as heart disease, chronic kidney disease, or diabetes that they may have as well.

At the same time, medical care is disrupted. We're seeing our patients less often. We're seeing them either by phone or over video instead of in person. Many visits have been delayed or deferred, and investigations are being deferred as well. Patients are reluctant to come in, even when they're sick, because they're frightened of attending clinics or labs, or for investigations.

And now on top of that, we have this possible shortage of hydroxychloroquine. This is a drug that is considered crucial for people with lupus. It's really the only medication that we have that is not immunosuppressive and it's known to be protective for lupus patients.

So now we've got patients concerned and physicians concerned not just about bad disease and bad outcomes, but worse disease because of this shortage, and concern that [they] won't be able to access the drug, because it's being used to treat other people for COVID-19.

ES: Thank you for that good summary. I have a few questions to ask you.

In your editorial you had a very long discussion, an excellent discussion, about the possible shortage of hydroxychloroquine. For those in the audience, I'm going to refer to just hydroxychloroquine, because we're Canadian and in Canada at this moment, you can only get hydroxychloroquine and not chloroquine, but of course it would follow for chloroquine also.

So you said the result of the shortage, as it has been advocated by the presidents of both Brazil and the United States, that you should treat and/or prevent the SARS-CoV-2 infection with an antimalarial. You stated that it will result in and create worry, anxiety, and illness uncertainty.

Could you please discuss a little bit of the significance of this issue and the implications?

CP: Sure. Uncertainty — the unpredictability of lupus — has always been one of the hardest parts for patients to cope with.

The disease, of course, comes out of the blue and we don't know why it starts, but by nature, it is a disease that flares and then settles down again, and patients never know what to expect next.

When will it flare? How will it flare? And they are always worried in the background about this disruption to their life. Will it interrupt their education, their family life, their career, what's going to happen next?

That's a chronic problem for lupus patients and has a huge impact in terms of symptoms and quality of life.

And now, on top of that, it's magnified by all the concerns that I mentioned about COVID-19, about having a bad outcome, about not being able to access the drug that is supposed to be stabilizing their disease.

And, of course, lupus patients share the same worries about job security and income that the entire world is concerned about right now.

So, that's a huge increase in background worry for lupus patients. And we are learning that this sort of chronic stress and uncertainty actually can increase anxiety and cause increased disease activity down the road for people with lupus.

So, there is actually the possibility that we might see increased flares of lupus in the months ahead, simply because of increased anxiety and uncertainty about COVID-19 and the hydroxychloroquine shortage, without actually having a shortage.

And, of course, it comes as we're going into spring and summer, and in Canada, at least, we often see flares as spring and summer approach because of the increased UV exposure.

So that might be happening.

ES: Guess we'll have to see. Hopefully, we will be studying this. But a few questions regarding these issues. You mentioned that patients may have difficulty obtaining hydroxychloroquine. Have any of your patients said that to you?

CP: Yes, we've had quite a few calls to the clinic from worried patients saying they went to the drugstore and could not fill the entire month that they were looking for, could only get a few days' worth, couldn't get it at all, had to wait. I think that that is improving in the last few weeks.

Here, at least in Manitoba this week, we had what is called a practice direction, stating that any prescribing for hydroxychloroquine when in relation to COVID-19 should only be done in the context of a clinical trial.

And the week or so prior to that, we had a similar communication from our local regulatory body, the College of Physicians and Surgeons, really telling us that we are not allowed to just prescribe this for ourselves, for office supply that was being done, or randomly for possible COVID. It really needed to be done in an inappropriate setting.

And it looks like that is having an impact, because I'm getting a lot less of those calls here in clinic. At least I hope so.

ES: So, along those lines, is your center part of any trials?

CP: Yes, we are. We are part of the trial, I think it's a multicenter Canadian and American trial. It's a pragmatic randomized trial looking at hydroxychloroquine in high-risk people, that's in those who are positive or family members or contacts of positive people, or in healthcare workers with high-risk contacts. We're part of that trial and I believe we're also participating in the convalescent sera trial that is just coming up. So, we do have ongoing trials here at the center.

ES: Well, that's great, and I certainly agree 100% that prescribing should be restricted to trials for non-rheumatic disease patients, or other people already on the drug.

CP: Yes.

ES: Flipping the other way, have people stopped it, have any of your patients stopped it? I don't know why, but you never know with people; they want to stop medications during when they're worried.

CP: You know, we had that at the very beginning of the COVID outbreak and such. We had patients phoning, asking if they should stop their medications, including hydroxychloroquine. And we answered

no to that, and then, it turned around after Trump's comments. Of course, it turned around that they couldn't get it.

And certainly, when I do my virtual follow-ups now, patients are well aware of this touted benefit and they are concerned that if they haven't had trouble filling their prescriptions, they're asking about it.

The other interesting thing is, I've had quite a number of patients who have not filled it in quite a long time and suddenly I'm getting refill requests. Or they were, "we stopped the drug because it wasn't thought needed years ago," and suddenly it's, "Well, maybe I should start taking it again." So, we've had that, as well.

ES: Yeah, you commented on one the potential upsides of this is that people going to take it more regularly and I must admit, I had the same experience when you go back and all of a sudden they say, I don't have hydroxychloroquine, and you see no wonder, it hasn't been filled for years.

Last question, along those lines is, as you commented on the excellent trials, withdrawal trials showing that certainly patients are at a risk for flaring, could you comment on your feeling of what the time frame when they flare?

CP: So, the time frame is generally thought to be about three months or so, sometimes, as long as six.

There are also, for those patients who are on quite a low dose, there are some instances where the time frame is less than that. If they're already on a very low dose, it's possible that they're reaching a threshold in two months or less. For most patients, though, it's somewhere around three months that we're seeing that.

ES: I presume you haven't seen any flares that you were convinced at this point would be related.

CP: No, I don't think we've seen anything related to COVID-19. I mean, we've all sadly, I think, seen lots of flares in our careers related to stopping hydroxychloroquine, some of them with very serious and tragic outcomes, so this is a legitimate concern if this were to go forward, and if our patients couldn't access the drug.

ES: Thank you. Well, you really answered my last question. Do you think there is anything we missed that you want to highlight for the listeners?

CP: No, I think the only thing is important is that I'm really glad that the Canadian approach has been to use hydroxychloroquine through clinical trials for COVID, because that's not what's being done in other

countries. I mean, my understanding is that it's kind of become standard of care in many of the European countries, as well as possibly the States; I'm not quite sure what they're doing there.

And that they are experiencing very real shortages for lupus patients because of it. And certainly we would here too if everybody who was a COVID suspect or a COVID patient was getting it.

So I'm really glad that Canada's taking the approach that we'll use it through clinical trials, then we'll really know whether it works. And if it does, then that'll give us time to ramp up production so that anybody who needs it, can get it.

ES: Great. For those who are listening who treat lupus patients, we would be very interested on what the policies are in your countries. You know what Canada's basically is, you know what the president said. We're now going to be divided into red and blue States on the use of it, as most things are.

If [there are] any people from other countries, I would encourage, if possible, please write a letter to the editor of what is going on in their country.

On that note, I want thank Dr. Peschken for I think was both a fascinating and informative editorial, as well as our conversation to putting implications into perspective.

I ask all the listeners to please read the full-length editorial entitled, "Possible Consequences of a Shortage of Hydroxychloroquine for Lupus Patients amid the COVID-19 Pandemic" by Dr. Peschken.

I also want to highlight that we have three other special editorials about SARS-CoV-2 infection and COVID-19 and its effects and implications for rheumatologists and rheumatology practice. This is available at http://www.jrheum.org/covid19.

If you have any questions, concerns, please respond via Twitter @jrheum or e-mail us at manuscript@jrheum.com, and I encourage any letters to the editor to be sent to mc.manuscriptcentral.com/jrheum.

On that note, I'd like to thank you for joining us and please continue to follow the guidelines of your regional and national health authorities and be sure to maintain social distancing as we are in this conversation. She is in Manitoba, I am in Toronto, and that is pretty far, not by Canadian standards, but by world standards, and I hope everyone stay safe out there.

Thank you.