

In Conversation

A Physician Discusses
COVID-19 & Rare Disease



A discussion with **DINESH KALRA, MD**

Q How has COVID-19 impacted your patients with rare diseases?

Dr. K: At first, patient visits slipped to nearly 25% of what we normally have. Now that we're seeing some of these patients again, either in person or through telemedicine, it's clear that the gap adversely impacted care.

There also was a definite mental health impact, especially for older patients. Some people wouldn't go outside and limited interactions to one family member - or no one at all. A lot of them got depressed, constantly wondering, "What happens if I get sick with COVID?"

Q What role has telemedicine played?

Dr. K: It helped. I could say to the patient, "Show me your ankles," and then I could see if there was swelling that indicated heart failure. Some patients had a blood pressure cuff at home and would take their blood pressure before our visits. And I could ask those basic important questions, "Are you taking your medications? What's your average day like?"

With virtual visits I miss some of the subtleties that make in-person visits valuable. For instance, I can't see patients walk down the hall to the exam room, and I can't listen to their lungs or heart. But given the circumstances, telemedicine was valuable.

Q Has telemedicine increased access to specialists for rare disease patients?

Dr. K: In some instances. For example, I'm based in Chicago, but I had a guy from Fairbanks, Alaska do a video visit for a rare lipid disorder. There was no lipid clinic where he lived. I can see how, as telemedicine continues to grow, it may help geographically isolated patients who need a specialist.

Q What has been the biggest challenge?

Dr. K: Patients not reporting symptoms. Some patients don't want to "bother" their doctor because they assume he's working with COVID patients. So they don't report that they're more short of breath or that their ankles are swelling or that they couldn't get their blood thinners for three weeks.

As a result, many of my patients with amyloidosis have had their condition worsen. Patients need to realize how important it is to stay in contact and let the doctor know what's going on.

Q Do you anticipate a wave of delayed care for rare disease patients?

Dr. K: Absolutely. In my clinic now, 80-90% of patients are back for in-person visits, but all the providers are super booked. Now it may take a patient six weeks to see a specialist that used to take just two weeks to book. Eventually we'll get it straightened out, but it's going to be a challenge.



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