My Telehealth

Q&A | With Emily Kramer-Golinkoff

CYSTIC FIBROSIS PATIENT

Q: How has telehealth helped you manage your disease?

I have advanced-stage cystic fibrosis, so I haven't stepped foot in a public space – except for the hospital – since March 2020. Any virus, especially the coronavirus, could trigger severe, life-threatening lung infections for me.

Being able to attend appointments from home has been a huge deal. Cutting the commute and wait time is great because it limits my exposure. It's also a more efficient use of my time.

Q: What is a typical virtual visit like for you?

It depends on the specialty, but it's mostly talking and sharing what I'm dealing with and discussing where I need help. I sometimes do at-home tests and then share the results via video chat so my provider and I can discuss next steps together.

Telehealth doesn't impact the quality of the visits. Because of my experience as a patient, I'm close with many of my providers and can have just as good, or better, conversations via video chat. Every patient may have different preferences, though.

Tel•e•health

noun

A way for vulnerable patients to seek care without sacrificing safety

Q: How do you balance virtual and in-person visits?

There is value to both, and I take a case-by-case approach. When there's a reason to go to an office, like a medical test or an important physical exam, I go. When there isn't and the appointment is mostly focused on discussion, virtual visits are often preferable.

> "I get precious hours of my life back."

Q: What misconceptions about telehealth do you see?

Some people minimize the value of saving a patient's time. They see that as a trivial benefit. But for someone in my situation, it's an enormous burden and disruption to life just staying up to date with your doctors. I spend four hours a day in treatment, and that's when I'm healthy. The efficiency of telehealth means I get precious hours of my life back.

Q: Have you experienced access challenges?

The only issue I have encountered has been with providers who don't want to do telehealth. They're either used to in-person, or don't have a mechanism for telehealth. I usually give a strong pitch and try to persuade them. Most of them have been accommodating because of my condition.

Q: How can telehealth be improved?

From the perspective of a person with cystic fibrosis, we need better at-home testing devices. I do a lot of home monitoring, and there's space for innovation there.

We also need policies that allow a patient and a provider to decide together the best format for their meeting, without the decision being impacted by reimbursement. Having telehealth as an option is a game-changer, so long as it's deployed thoughtfully — at the right time, for the right patient.

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