Patient Views on Telehealth for Kidney Disease Care

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I have had CKD (lupus nephritis) for more than 3 decades and have been on dialysis multiple times. There have been many times in my past when a telehealth visit would have been incredibly helpful. I commend the authors of “Video-Based Telemedicine for Kidney Disease Care: A Scoping Review,” published in this issue of CJASN, for choosing this topic for their study (1).

My first experience with telehealth was 15 years ago with my mother. She had a neurology evaluation with Johns Hopkins for a second opinion on a potential diagnosis of Parkinson’s Disease. She was able to be viewed performing routine neurologic tests through video. It was a good experience and a glimpse into the future of telehealth, which I would later deal with myself.

When I was going into kidney failure, I was very ill. Gathering the strength to get dressed and drive to my doctor’s office was a monumental feat. Over the years, I was a peritoneal dialysis patient (briefly), an in-center patient for a year, a transplant patient for 17 years, and a NXStage patient (home hemodialysis) for 16 months, and I have now been in-center again for 4 years. I am close to completing my workup for transplant number 2.

In April 2020, I was an in-center hemodialysis patient in need of a fistulagram. My pre-op was a telehealth appointment. I took my blood pressure and weighed myself at home. Because I was an established patient with my vascular surgeon, we discussed my prolonged bleeding at the end of my dialysis treatment. It was agreed that I was having the same symptoms that I had had in the past, and a fistulagram was needed. Now if I had not been an established patient, telehealth might not have been the best option. I would have needed to physically be in the office to receive an ultrasound of my fistula. But, in this case, telehealth worked for me.

Upside of Telehealth

During the first few months of 2020, my Medicare Advantage Plan notified me that all telehealth appointments were free. This was good news. Cost savings are helpful to any patient, and a telehealth appointment saves money on gas and parking. Having a doctor’s appointment in your home also saves time. Telehealth is a definite advantage for people who have kidney disease who are working or have young kids to care for at home.

Those in rural communities can certainly benefit from telehealth, as it eliminates the stress of a long drive to a doctor’s office. Many patients at my center are amputees and have other mobility issues and would greatly benefit from telehealth. When patients are at home, appointments are not missed and follow-up is more accessible.

The last 19 months with coronavirus disease 2019 (COVID-19) have been especially scary for me and my peers who are chronically ill and/or immunocompromised. Knowing that we can receive care from the comfort of our home helps us feel safer. Patients who have recently had a transplant certainly feel safer with telehealth as it limits the time spent in a health care setting, which was nerve-racking without a pandemic but now with COVID-19 can be terrifying.

Telehealth should be an option for in-center dialysis patients as well. For some reason, rounds in my center are conducted at the end of treatment, when most patients are tired. I personally feel weak and washed out. If my plan of care meeting was set for later, at home on nondialysis days when I feel stronger and sharper, it would be a great benefit.

When I was a home dialysis patient, my nurse came to my home many times. Telehealth would be perfect for these visits as well. Troubleshooting access problems or issues with my machine could have been done remotely and would have saved her the drive to my home.

Furthermore, I think patient engagement is improved with telehealth as it lets patients be in the comfort of their own home. Family members can be better engaged as well, as they can easily listen in to learn more about our plan of care.

Downside of Telehealth

Of course, there is value in hands-on care. Some situations just cannot be handled with telehealth. For example, touching a patient’s legs or abdomen for edema must be done in person.

There are times when physically going into a doctor’s office or imaging facility is necessary. I know patients who have not had any routine medical tests, e.g., a mammogram, for fear of catching COVID-19.

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Unfortunately, many types of medical tests must be done outside of the home.

Another consideration is that not all patients have the money to buy a computer or have the funds for internet service, and a basic phone call might not work quite as well. Some older patients are not technologically savvy. These populations might be better served in person.

Although so many people have been able to use video-conference software easily, I have had several hiccups with my telehealth appointments. Over the last year and a half, several appointments that started out as Zoom calls ended up being just a phone call because of technical issues.

Still, there are many other times when telehealth is a beneficial option. The quality of care is very similar to what you would get in a doctor’s office. Patients who are employed, less mobile, have children at home, are immunocompromised, or live far from their care providers can save significant money, time, and energy with telehealth. Stress levels tend to go down along with expenses when you are in the comfort of your home. The high patient satisfaction and acceptable clinical outcomes cited in the CJASN study (1) should encourage continued telehealth support and options.

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