

Patient Perspective of Smartphone-Based Apps for CKD Self-Care

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As a professional and a 38-year patient dealing with kidney disease, I was thrilled when the editorial team from the *Clinical Journal of the American Society of Nephrology* invited me to share my perspectives on the findings of the study entitled “Patients’ and nephrologists’ evaluation of patient-facing smartphone apps for CKD” (1). Over this past year, I have broadened my understanding of kidney disease by reading the new Patient Voice editorials and the accompanying articles on innovations and treatments across the United States and the world.

My perspectives on the efficacy of smartphone applications (apps) are informed by my own experiences as a patient and my belief that I have a responsibility to be an active participant in my own care.

I am 50 years old and have an extensive medical history, which includes a diagnosis of type 1 diabetes since age 12. I developed hypertension in my early 20s, and by age 32, I found myself requiring dialysis. Beyond the multitude of complications that accompany chronic disease, I have lived through treatments, including two kidney transplants and a pancreas transplant. Today, I am continually searching for new solutions for myself and other patients that allow better management of quality of life and clinical outcomes. I have become a strong patient advocate and an Ambassador for the American Association of Kidney Patients (AAKP), an independent organization founded for patients by patients.

Living with CKD from its earliest stages and through transplant requires education and dedication to self-managed care. Understanding laboratory values, BP, blood sugar, weight, body mass index, and dietary and medicine requirements is a critical component to maintaining a long and healthy life. I think that many patients would love to have their physicians monitor all of these factors, but most realize that is impractical. Instead, we rely on channels of communication that we have established with our doctors to effectively perform these critical tasks ourselves.

It is my belief that patients increasingly find themselves burdened with confusion when attempting to manage their care using smartphone apps. Last year, I beta tested a mockup of a nutrition app for veterans developed under a partnership between the American Society of Nephrology (ASN) and the

Veterans Administration. I was encouraged to be candid, and I respectfully indicated that the user interface was so cumbersome, buggy, and ill conceived that it could have only been designed by a pair of 20-year-old amateur coders camped out in their mom’s basement with a good idea and an internet connection. That is the beauty of involving patient consumers in app development—candor means that the final product will be better aligned toward and more widely used by the target audience.

Other apps that I have tried suffer not from poor design and/or user experience but from a lack of shared coherent purpose and outcomes among doctors and patients. Some are designed by medical professionals, and they produce data that have never been part of a prior doctor/patient dialogue and are outside basic patient understanding. In nearly every instance, poor user interface design and seemingly esoteric data undermined the goal of creating patient-centric health solutions.

What some physicians and probably, most smart app designers fail to realize is that, as patients, we do want to manage our care. However, kidney disease means that sometimes we can barely muster the strength to wrap a BP cuff around our arm. Therefore, the prospect of using an app with a clunky interface or the burdensome challenge of deciphering cryptic purpose is too difficult.

Currently, there are 174 apps on the market, but I have not heard any nephrologist say that there are apps deemed “the best.” I certainly do not hear of a highly favored cluster of apps discussed among patients with kidney disease. This is astonishing at a time when >75% of Americans own a smartphone or device. As patients, we want apps that offer clear, concise controls with an intuitive interface and helpful feedback in plain language.

So, with an interested patient with kidney disease consumer market and demand for workable apps, where do we go from here? The study itself is timely, detailed, and statistics laden. Whether by design or default, the authors have shined a brilliant light on the elephant not in the room—patients. Developers need to collaborate with kidney consumers and design apps that works for both nephrologists and patients. Patients add value and help define the product, and when a usable app arrives, patients themselves will drive the updates.

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I know that it can be done! As an AAKP Ambassador, I have participated in and witnessed amazing efforts by industry, researchers, and government officials to involve patients to solve hard problems across the product development lifecycle for diagnostics, devices, and biologics. Clearly, the ASN and the Veterans Administration sought out patients as collaborators before their app launched. The time is now for all app developers to replicate this model and harness the value of our life experiences.

Acknowledgments

D.R. serves as a National Ambassador from the state of Idaho for the American Association of Kidney Patients. He also serves Kootenai Health as a member of both the Patient Advisory Council and the Patient Education Committee.

Disclosures

None.

References

1. Singh K, Diamantidis CJ, Ramani S, Bhavsar NA, Mara P, Warner J, Rodriguez J, Wang T, Wright-Nunes J: Patients' and nephrologists' evaluation of patient-facing smartphone apps for CKD. *Clin J Am Soc Nephrol* 14: 523–529, 2019

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See related editorial, "Got CKD? There's an App for That!," and article, "Patients' and Nephrologists' Evaluation of Patient-Facing Smartphone Apps for CKD," on pages 491–492 and 523–529, respectively.