Got CKD? There’s an App for That!

Joel M. Topf1 and Swapnil Hiremath2


On January 9, 2007, Steve Jobs reached into his pocket and pulled out a revolution. The first iPhone was expensive and only available on a handful of cell-phone networks, but over the next few years, the iPhone became progressively cheaper and more available. Fifteen months after the first iPhone went on sale, Google’s Android system made its commercial debut with the T-Mobile G1 phone. Subsequently, these two operating systems overtook and dispatched Windows, Blackberry, and Symbian to become the two dominant operating systems on the most widespread implementation of computing, the smartphone. The fuel that drove the smartphone revolution was applications, aptly abbreviated to “apps.” Developed sometimes by Apple or Google but more often, by independent players, apps are programs that extend the reach and capabilities of the device far beyond communication into games, traveling, shopping, eating, dating, and fitness among many other purposes; 194 billion apps were downloaded in 2018, up 35% from 2016, with two thirds coming from emerging markets. Spending on and within apps topped $100 billion in 2018 (1).

From the perspective of a nephrologist, however, the app revolution has been remarkably unexciting. Very few patients share apps with doctors, and when they do, they are little more than glorified notepads to track BPs, body weight, or blood sugars. Some of the invisibility may be due to patient reluctance to share health app data with their physician—only 18% of individuals tracking health tell their physician (2). However, another reason nephrologists are not seeing their patients using apps is that the apps are not very good.

In this issue of the Clinical Journal of the American Society of Nephrology, Singh et al. (3) share a systematic review of the apps available for patients with CKD. The authors searched the Google Play Store and the Apple App Store to find all of the apps that matched a specified search strategy focused on patients with CKD, including dialysis or transplant. The top 50 apps (as rated on the respective stores) for each category were then chosen. From a universe with 318,000 health-related apps, the investigators search strategy uncovered 339 apps, of which 28 unique kidney-related and patient-facing apps qualified for the detailed evaluation. Each app was evaluated by a nephrologist, a patient, and a research staff member, and they evaluated various measures, including usability (from the patient perspective) and safety (from the nephrologist perspective). Overall, very few apps were rated to be of a high quality by all groups. For most apps, there were safety concerns (only two of seven apps with tracking functions alerted users on entry of extremely abnormal values). A core finding was that patients did not agree with the quality assessment of nephrologists. There was similar disagreement between the app store scores and the patient scores. The authors identify a number of study limitations, but the most concerning is a search strategy that required apps to be specifically about kidney disease. Many aspects of good CKD self-management are impossible to separate from good health maintenance in general. Many apps are tools that can be made to serve a wide variety of purposes. As an example, Twitter is now often chosen to be the most useful app to remain up to date on medical literature, something that is not its primary purpose and not a feature that the vast majority of Twitter users will need or appreciate (4). In this case, an excellent BP, weight, or diet tracking app that did not self-identify as being for patients with kidney disease would be missed by this search. Moreover, ratings for apps within the ecosystems are fickle, and the top 50 apps within those categories would generate a different set of apps today. Thus, these results are internally valid, but one should be cautious about its generalizability to all health-related apps.

These dismal results are somewhat unsurprising. In an analysis from Australia of 21 apps focused on diets for CKD, over one half of the apps did not contain accurate, evidence-based information (5). In another systematic review, studies using an app (but not an analysis of the apps themselves) reported a high rate of nonadherence (6). This suggests that health literacy and the willingness to use an app should be accounted for during app evaluation and that the patient evaluations and perceptions of usability are important (7). It is also possible that high ratings may in part be driven by free apps that were downloaded but were not used at all or for long. CKD is a disease that demands an engaged patient to monitor BP, diet, and a complex medical regimen. It seems like a disease that should benefit dramatically from a program that could track vital signs, remind people to take medications, provide dietary consultation, and facilitate communication with physicians. The reality, however, is quite different. In this systematic review of dietary apps, none of the five apps were able to produce significant changes in nutrient intake, biochemical markers, or intradialytic weight gain (8). Interestingly, the only

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1Department of Medicine, Oakland University William Beaumont School of Medicine, Detroit, Michigan; and 2Division of Nephrology, Department of Medicine, University of Ottawa, Ottawa, Ontario, Canada

Correspondence: Dr. Swapnil Hiremath, Division of Nephrology, Department of Medicine, University of Ottawa, 1967 Riverside Drive, Ottawa, ON K1H7W9, Canada. Email: shiremath@toh.ca
app that was rated highly by nephrologists and patients in the study by Singh et al. (3) (Transplant Hero) is geared toward medication reminders.

What is the way forward given the state of the medical app world? We argue that it should be perceived as an opportunity rather than a debacle. Wisdom of the crowds is fine in principle, but the passive ranking of apps does not seem to have worked well so far. The most important findings of the study by Singh et al. (3) were that the apps chosen were patient facing and that there was a mismatch between patient and nephrologist ratings, with the patient ratings being a bit more generous. The small sample size of raters means that these findings may not be robust or generalizable, but if confirmed, then there is an important gap in how patients can even find reliable and safe apps. Could there be a “verified” review to supplement app store ratings that certifies that an app is approved by legitimate stakeholders? Is this a role for the professional organizations, such as the American Society of Nephrology, the American Association of Kidney Patients, and the National Kidney Foundation? Apps that the nephrology community finds accurate, evidence based, and easy to use could be disseminated using websites, newsletters, and social media. The general lack of quality and poor upkeep of apps should not be surprising, because most of the apps in the study by Singh et al. (3) were not created by large health groups, universities, or electronic medical records companies, but rather, they were created by individual developers and free to download (which may explain their popularity). This space sounds like one occupied by hobbyists rather than well resourced and committed companies. It also results in scenarios where apps are sending personal health information to other organizations for creation of focused advertising and marketing purposes, which is as clear of an infringement of privacy as could be (9).

We live in an era with supercomputers in our pockets and purses, continuously connected to a ubiquitous computer network. Asking them to track postdialysis weights and a few manually entered BPs is a pedestrian endeavor. Perhaps the apps are not being used, because they lack the ambition to move the needle. We spend time in the clinic giving your medications and a few questions about symptoms, such as "are you dizzy with standing?" to make personalized medication changes to get BPs to goal safely and effectively.

Finally, the hope for anything we do is to improve the health of our patients living with kidney disease. Unlike most other interventions, apps do not lend themselves to randomized, controlled trials (RCTs) easily for a variety of reasons. There are constant upgrades and updates, which will make a static app obsolete in the time that it takes conduct a traditional RCT. As we have seen, adherence in a broad unselected population is likely to be poor, and an intention to treatment analysis would very likely show a null result. At the same time, choosing only a motivated and health-literate patient population would give us data that are impossible to generalize. Most importantly, outcomes that would be easy to monitor with an app, such as nutritional targets (like phosphorus and total carbon dioxide) or vital signs (like BP), are increasingly out of step in a patient-oriented outcome world. Perhaps we should lower our eyes from the RCT and focus on whether an app provides helpful advice when needed, gives greater confidence and comfort in self-care, or helps complete simple tasks, such as tracking and reminding patients about medication timing.

With the advent of wearables, we are seeing big technology move into this space. The latest Apple watch has fall detection, regularly monitors heart rate and notifies users of abnormalities, and even has an integrated single-lead electrocardiogram that can screen for atrial fibrillation. Nephrology is ripe for the professionalization of health apps. It is time to close out amateur hour.

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See related Patient Voice, "Patient Perspective of Smartphone-Based Apps for CKD Self-Care," and article, "Patients* and Nephrologists’ Evaluation of Patient-Facing Smartphone Apps for CKD," on pages 483–484 and 523–529, respectively.