

# Using Existing Mobile Technology to Monitor Disease Activity: An Example in Childhood Nephrotic Syndrome



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*Kidney Int Rep* (2019) 4, 1037–1039; <https://doi.org/10.1016/j.ekir.2019.06.006>

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Most US adults and adolescents representing a range of socioeconomic backgrounds now own or have access to cell phones or smartphones.<sup>1,2</sup> Mobile devices are no longer limited to simply making voice calls and have been integrated into nearly all aspects of our daily lives (e.g., work, education, shopping, entertainment). Given the success in using mobile technology to revolutionize the delivery of services in other domains, mobile health (mHealth), defined as the use of mobile devices to support medical and public health practice,<sup>3</sup> is a natural next step. mHealth has the potential to transform how we provide patient health care services and improve patient outcomes on a large scale by reducing barriers to accessing care and delivering interventions to nearly anyone with a mobile phone.

However, the most efficacious and practical means for using mobile technology to improve patient health often seems elusive. Building the

technology to support mHealth solutions may be daunting to providers with little to no training in computer coding and user design or experience partnering with technology companies. Moreover, mHealth ventures often fail because of limited funds to develop the technology and cover long-term operating and maintenance costs.<sup>4</sup> There are numerous mHealth apps available to consumers that aim to address a range of health-related concerns (e.g., symptom tracking, fitness, nutrition, sleep, stress management, medical adherence). Yet, major critiques of many existing mHealth interventions are that they do not have adequate empirical support for their efficacy, were not designed for efficient implementation, and use unreliable outcome measures,<sup>3</sup> which further limits their potential for successful clinical application. Specific to nephrology, a recent review of smartphone apps for people with chronic kidney disease identified safety as a major concern, given that most apps did not alert users about abnormal values.<sup>5</sup> Thus raises the question, “How may nephrology providers (and other specialists) realistically use mHealth in practice

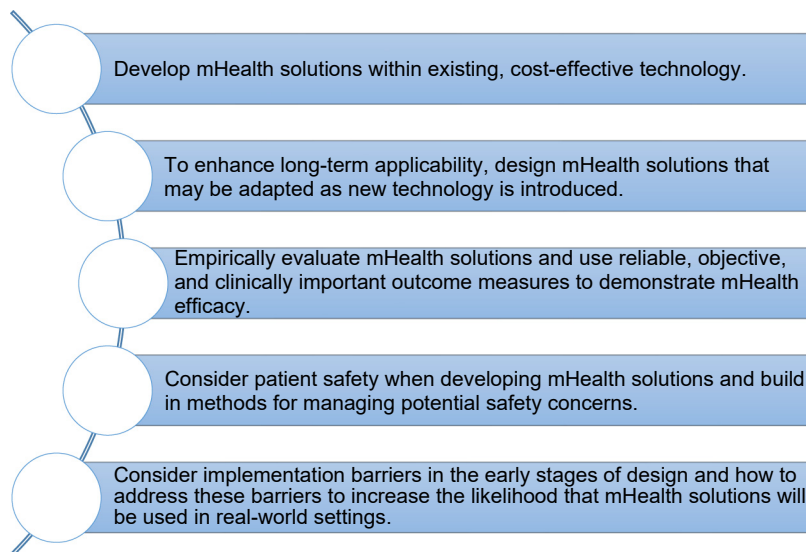
to actually improve patient care and health outcomes?”

## An mHealth Disease Monitoring System for Childhood Nephrotic Syndrome

Wang and colleagues<sup>6</sup> developed and tested a text message–based disease monitoring system for children and adolescents with nephrotic syndrome and their caregivers. This monitoring system is an example of how noted concerns regarding the clinical use of mHealth approaches in health care generally, and specifically nephrology, may begin to be addressed (Figure 1). Strengths of this monitoring system are its use of existing, low-cost technology. Text messaging is an easy-to-use, inexpensive service that is a standard feature on nearly all current cell phones (i.e., no need to build or maintain new technology to implement the system). Text messaging is the most commonly used smartphone feature in the United States, ahead of voice/video calls and e-mail,<sup>7</sup> and is popular internationally, even in emerging nations.<sup>8</sup> Reflecting these data on text messaging usage, enrollment, retention, and engagement rates for the monitoring system were high, suggesting that participants were likely comfortable using text messaging on a regular basis and open to using it for pediatric health purposes.

Wang and colleagues<sup>6</sup> prospectively evaluated their monitoring system over 1 year, providing preliminary results to build support for its efficacy in characterizing childhood nephrotic syndrome disease activity. To summarize, caregivers of children with nephrotic syndrome and adolescents with nephrotic syndrome were sent daily (first 90 days) or weekly (remainder of study period) study team–initiated text message prompts to respond with home urine test results, edema status

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**Figure 1.** Addressing barriers to mHealth use in practice. mHealth, mobile health.

updates, and other caregiver- or patient-reported information. Study team members were alerted when concerning health information was captured through the monitoring system and were prompted to follow up directly with the patient and/or caregiver. Although the study design was uncontrolled, initial results were promising: the text message-based monitoring system detected significantly higher numbers of relapse events and demonstrated shorter time-to-remission estimates compared with in-person clinic visits. These findings suggest that text message-based disease monitoring systems integrated within pediatric nephrology care may have sustained impacts on important patient health outcomes.

Implementing mHealth solutions within clinical settings may be challenging because of staffing demands for managing mHealth systems on top of existing clinical and administrative duties and investing resources in rapidly changing technology. However, the study team-initiated text messages were reportedly automated and the back-end managing system automatically alerted study teams to clinical concerns captured with the monitoring system, which may alleviate staff burden. This built-in alert system

also may address previously noted concerns with patient safety when using mHealth in nephrology care.<sup>5</sup> Most text messaging platforms are low cost and clinics may already have text message systems in place for other purposes (e.g., confirming appointments). Disease monitoring systems that use automated, provider-initiated prompts delivered to respondents' own mobile devices may be integrated within new technology if short message service text messaging is eventually supplanted with other forms of mobile communication.

### Why Did Wang and Colleagues' mHealth Approach Work? Communication Is Key

Further research is needed to identify the mechanisms of action for how this monitoring system affected patient health outcomes (e.g., how did investigators respond when disease relapses were identified?). However, one hypothesis is that the text message-based monitoring system facilitated more consistent patient and caregiver communication with providers about home urine test results, edema status, and other disease information via text messaging, a familiar and accessible technology. The system captured daily or weekly patient health data, which may have

resulted in greater opportunities for providers to act on relapse concerns as they occurred. Text messages may have served as reminders that increased adherence to home urine testing. Given the ubiquity of text messaging in daily life,<sup>1,7,8</sup> the monitoring system may have been less subject to barriers associated with other communication methods (e.g., not available to answer or initiate voice calls, does not regularly check voicemail or e-mail or log in to patient portals, unable to attend regular in-person clinic visits).

### What's Next?

Wang and colleagues<sup>6</sup> have appropriately noted limitations of their study and future directions include evaluating their monitoring system in a randomized controlled trial and determining the optimal frequency of text messaging needed to obtain high-quality data from respondents. Text message frequency may be tailored to respondents based on individual factors, such as how consistently they respond to text messages and the patient's disease activity (e.g., more frequent text messages during periods of lower responding or greater disease severity). The role of cultural factors in responding behavior deserves further investigation, as study results indicated that participants identifying as Hispanic or non-English primary speakers exhibited lower response rates when text message frequencies changed from daily to weekly. It is possible that these individuals may have benefited from more frequent text message contact throughout the study to encourage responding.

This monitoring system relied on self-reported urine test results and edema status, although data captured via text messaging were compared with same-day in-person study visit results and demonstrated excellent concordance. Most current mobile devices can take and send

photographs and photo monitoring of urine dipstick results may enhance confidence in the validity of information sent to providers. The system obtained patient- and caregiver proxy-reported medication adherence, which is known to be unreliable in pediatric nephrology samples and other disease groups.<sup>9</sup> Ideally, objectively measured adherence, such as electronic monitoring, will be incorporated in adaptations of this monitoring system, especially because it was designed to alert study teams to reported non-adherence. Reliance on self-report may result in missing a significant portion of individuals who do not regularly take their medicine.

When capturing data through relatively passive modalities such as text messaging, some individuals may not provide requested information, despite prompts. There may be utility in developing and implementing a protocol to improve response rates for individuals who less consistently respond to text message prompts (e.g., problem solve barriers to responding, set realistic response goals, address motivational factors that may contribute to low response rates).

Given that very few adolescents participated in the study, further research is needed to better characterize adolescents' engagement with and acceptance of this monitoring system. Adolescents who may be responsible for completing home urine testing and other health management tasks independent of caregivers may be especially receptive to text message-based disease monitoring systems. Reasons why individuals declined to enroll in or withdrew from the study are unknown, but these data may inform how the monitoring system may be adapted to enhance its acceptability. For example, it is possible individuals who declined enrollment or withdrew may have been receptive to providing

requested health information via e-mail or voice call. Further evaluation of caregivers', adolescents', and providers' experiences with the monitoring system may offer greater insight into how it may be modified to be even more user-friendly and clinically useful. Financial data on operating costs would further inform how sustainable this monitoring system may be a real-world setting. If text message-based disease monitoring systems become part of regular clinical care, policies will need to be adopted to enhance patient privacy and ensure compliance with the Health Insurance Portability and Accountability Act.

There are several important conclusions to draw from this study: (i) it is feasible to use a text message-based disease monitoring system for childhood nephrotic syndrome, (ii) caregivers and adolescents are likely open to reporting certain types of health information in the context of pediatric nephrology care via text messaging, and (iii) text message-based disease monitoring may enhance providers' abilities to capture childhood nephrotic syndrome disease activity over time and manage patients' health concerns. Although Wang and colleagues<sup>6</sup> disease monitoring system is early stage, it may serve as a blueprint for how to practically use text messaging to effectively monitor disease activity outside of in-person clinical encounters and improve patient health outcomes in other areas of nephrology.

## DISCLOSURE

The author declared no competing interests.

## ACKNOWLEDGMENTS

This work was supported by the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, Ruth L. Kirschstein National Research Service Award

(NRSA) Individual Postdoctoral Fellowship (F32DK118988 to CKE) and the Society of Pediatric Psychology Drotar-Crawford Postdoctoral Fellowship Research Grant in Pediatric Psychology (to CKE). The content is solely the responsibility of the author and does not necessarily represent the official view of the National Institutes of Health or the Society of Pediatric Psychology.

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