Facilitating a Patient-Centered Transition From Kidney Disease to Kidney Failure: Can Digital Tools Help?



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Guiding patients through the transition from advanced chronic kidney disease (CKD) to kidney failure is a hallmark of nephrology care. The process is inherently multidisciplinary, spanning domains of patient education

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about the etiology of their kidney disease and treatment options, exploring individual preferences and values to identify the most appropriate therapy, obtaining dialysis access at the right time, and optimizing dietary and medical management to preserve the remaining kidney function while minimizing symptoms and metabolic derangements.¹ Despite decades of work to improve this transition, there is clear room for improvement at each step along the way. In 2018, nearly half of patients transitioning to dialysis did so in the inpatient setting, and catheter use at the initiation of hemodialysis was 81%.² Most patients still initiate kidney replacement therapy without a clear understanding of their kidney disease or treatment options, including transplant and conservative management. The complexity of the aforementioned steps involved and the potential for delays in every step in the process likely contribute to suboptimal transitions to kidney failure treatment.³

Digital tools to systematically identify individuals who need additional resources for a complex transition and health navigators that help patients access health care resources have individually been shown to improve chronic care management. Their combination promises to render the transition to kidney failure more efficient, effective, and patient-centered. Green and colleagues⁴ are testing this hypothesis in the ongoing PREPARE NOW study, a pragmatic cluster-randomized controlled trial that tests whether a suite of digital tools leveraging the electronic health record (EHR) augmented by trained nurse case managers can address the many challenges patients and clinicians face in preparing for the transition to kidney failure. In a recent issue of Kidney Medicine, Green and colleagues⁵ describe the year-1 implementation experience of this trial, offering early insights into the promise and challenges of navigation programs augmented by digital technology.

The "Patient-Centered Kidney Transitions Care" intervention consists of 4 distinct but interrelated elements. The CKD registry and risk prediction tool identifies patients in nephrology care at high risk of developing kidney failure, defined as CKD G3aA3, G3bA2-A3, and all G4-G5, and

facilitates scheduling a nephrology follow-up if a high-risk patient has not had a nephrology appointment in the preceding year. In addition, patients on the registry with the highest kidney failure risk (>10% within 2 years), computed using the Kidney Failure Risk Equation, are prioritized for enrollment in a nurse case management program with a Kidney Transitions Specialist who engages patients in shared decision making and ensures the completion of steps necessary for them to receive their preferred kidney replacement therapy option.⁶ Kidney Transitions Specialists leverage an electronic patient values clarification tool that formalizes the ascertainment of patient preferences to guide shared decision making in alignment with patients' individual values. They also use a care navigation and tracking tool that creates a dedicated section within the EHR for tracking the status of steps in kidney failure planning (eg, referral to a transplant center, discussion of treatment options, and patient indication of preferred therapy). The fourth element is a treatment preferences broadcast that displays patients' preferred kidney failure treatment in the EHR problem list. Taken together, this suite of tools provides an integrated system for identifying and directing resources toward patients at the highest risk of kidney failure, systematically tracking patients through the necessary steps in preparation for the management of kidney failure, and clearly communicating patients' treatment preferences in the EHR.

The authors examined the uptake and acceptability of these tools in the first year of implementation in 4 CKD clinics within the Geisinger health system, a large integrated system in rural and suburban Pennsylvania and New Jersey. Over a 12-month period, 1,032 patients were identified as meeting the registry criteria. Of the 243 registry patients identified as high-risk (>10% 2-year kidney failure risk) and therefore eligible for case management, approximately half were enrolled in the case management program with Kidney Transitions Specialists. Of those enrolled, 28% received kidney failure modality education, and nearly all completed the values clarification tool. The care navigation and treatment preferences broadcast tools demonstrated high uptake (100% and 87%, respectively) among enrolled the patients, and the 2 Kidney Transitions Specialists rated the tools highly for ease of use and helpfulness.

A Strength of this work includes the simultaneous implementation of multiple tools designed to achieve a shared objective, namely, to facilitate a smooth, timely, individualized transition to kidney failure therapy. The

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high uptake and favorable acceptability reported are promising early signs—particularly because a frequent challenge of implementation studies is incomplete uptake of the intervention, resulting in reduced power to detect differences compared with usual care.

Previous interventions to improve care in the transition to kidney failure have involved multidisciplinary care and educational programs for patients with advanced CKD, reporting improvements in various outcomes, including greater uptake of home dialysis modalities, outpatient dialysis starts, and reduced hospitalization.⁷⁻¹⁰ However, multidisciplinary care programs are cost- and personnelintensive, and directing these resources toward the right patients is challenging. For example, interventions based in dedicated "predialysis" clinics do not capture patients at high risk of kidney failure who have not been referred to such a clinic. Meanwhile, applying intensive resources to all patients with CKD G4 may capture many patients whose kidney function will remain stable for years as well as those who will die before developing kidney failure. By leveraging the EHR to create a CKD registry and applying an algorithm to predict each patient's risk of kidney failure, Green and colleagues⁴ are able to direct case managers and transitions resources to the patients who need it most.

Although the initial results about intervention uptake and acceptability are promising, they do raise interesting questions related to dissemination should the intervention prove successful. Digital tools can be a powerful way to efficiently identify and allocate care resources. However, it is critical to understand their "blind spots": where and how patients might fall through the cracks of the algorithm. For example, it will be important to understand why only 28% of patients enrolled in the transitions program received modality education. Possible explanations may be the short, 1-year time frame of the study; that despite being a higher-risk population, some patients were still considered too far from kidney failure to receive modality education; or that enrolled patients did not wish to receive modality education in the way it was presented. Remarkably, a few patients required assistance with the electronic patient values clarification tool, and language and health literacy were not reported to be barriers. It would be helpful to see more granular sociodemographic characteristics of the study population, as the experience with the patient values clarification tool will likely be difficult to achieve for health systems that care for populations with low levels of literacy (including digital literacy) and limited English proficiency.

Furthermore, the implementation of automated risk prediction within the EHR is a nontrivial undertaking. In this study, the authors predicted the 2-year risk of kidney failure using the 8-variable Kidney Failure Risk Equation, which requires data regarding age, sex, estimated glomerular filtration rate, urine albumin-creatinine ratio, and measures of serum albumin, serum bicarbonate, serum phosphorus, and serum calcium. A practical challenge is

that risk prediction relies on the availability of inputs, which is especially problematic for parameters infrequently obtained in routine clinical practice. For example, widespread implementation of the Kidney Failure Risk Equation is likely to be hindered by broad underutilization of albuminuria testing—in 2018, only 38% of Medicare beneficiaries with CKD had albuminuria or proteinuria tested.² Although allowing for a longer lookback period to ascertain laboratory results may increase the proportion of patients having complete data for risk prediction, the usefulness of predictions becomes more uncertain as it is based on increasingly remote data.^{11,12} Although very few registry participants (29/1032; 2.8%) in this study had a missing risk score, the utility of prediction algorithms such as the Kidney Failure Risk Equation may be reduced if transported to less-resourced, nonintegrated health systems with less data availability. In these more fragmented care delivery settings, which often provide care for racially, ethnically, and linguistically diverse populations of low socioeconomic status, it will be crucial to verify that missingness does not systematically withhold care from high-risk patient populations who may be less likely to be tested due to suboptimal access to care. Future iterations of the transitions intervention may include a mechanism for stimulating laboratory testing among registry patients to ensure that risk predictions are accurate and up-to-date.

In summary, Green and colleagues⁵ have demonstrated high uptake and acceptability of a suite of digital tools for facilitating patient-centered transitions to kidney failure in a large, integrated health system. We look forward with great anticipation to the findings of the PREPARE NOW study that is examining the effect of these interventions on clinical and patient-reported outcomes. If successful, future work will need to focus on the thoughtful adaptation of these tools to care delivery settings with different resource levels, diverse patient populations, and greater fragmentation of care.

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REFERENCES

- Evans M, Lopau K. The transition clinic in chronic kidney disease care. *Nephrol Dial Transplant*. 2020;35(suppl 2):ii4-ii10. doi:10.1093/ndt/gfaa022
- United States Renal Data System. 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2020.
- Hughes SA, Mendelssohn JG, Tobe SW, McFarlane PA, Mendelssohn DC. Factors associated with suboptimal initiation of dialysis despite early nephrologist referral. *Nephrol Dial Transplant*. 2013;28(2):392-397. doi:10.1093/ndt/ gfs431
- Green JA, Ephraim PL, Hill-Briggs FF, et al. Putting patients at the center of kidney care transitions: PREPARE NOW, a cluster randomized controlled trial. *Contemp Clin Trials*. 2018;73:98-110. doi:10.1016/j.cct.2018.09.004
- Green JA, Ephraim PL, Hill-Briggs F, et al. Integrated digital health system tools to support decision making and treatment preparation in CKD: the PREPARE NOW study. *Kidney Med.* 2021;3(4):565-575.e1. doi:10.1016/j.xkme.2021.03.009

- Tangri N, Stevens LA, Griffith J, et al. A predictive model for progression of chronic kidney disease to kidney failure. *JAMA*. 2011;305(15):1553-1559. doi:10.1001/jama.2011.451
- Fishbane S, Agoritsas S, Bellucci A, et al. Augmented nurse care management in CKD stages 4 to 5: a randomized trial. *Am J Kidney Dis.* 2017;70(4):498-505. doi:10.1053/j.ajkd.2017. 02.366
- Peeters MJ, van Zuilen AD, van den Brand JAJG, et al. Nurse practitioner care improves renal outcome in patients with CKD. *J Am Soc Nephrol.* 2014;25(2):390-398. doi:10.1681/ASN. 2012121222
- Manns BJ, Taub K, VanderStraeten C, et al. The impact of education on chronic kidney disease patients' plans to initiate dialysis with self-care dialysis: a randomized trial. *Kidney Int.* 2005;68(4):1777-1783. doi:10.1111/j.1523-1755.2005.00594.x
- Kaiser P, Pipitone O, Franklin A, et al. A virtual multidisciplinary care program for management of advanced chronic kidney disease: matched cohort study. J Med Internet Res. 2020;22(2):e17194. doi:10.2196/17194
- Stempniewicz N, Vassalotti JA, Cuddeback JK, et al. Chronic kidney disease testing among primary care patients with type 2 diabetes across 24 US health care organizations. *Diabetes Care*. 2021;44(9):2000-2009. doi:10.2337/dc20-2715
- Naranjo FS, Sang Y, Ballew SH, et al. Estimating kidney failure risk using electronic medical records. *Kidney*360. 2021;2(3): 415-424. doi:10.34067/KID.0005592020