



Putting patients at the center of kidney care transitions: PREPARE NOW, a cluster randomized controlled trial

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Abbreviations: CKD, Chronic kidney disease; EHR, Electronic health record.

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ABSTRACT

Care for patients transitioning from chronic kidney disease to kidney failure often falls short of meeting patients' needs. The PREPARE NOW study is a cluster randomized controlled trial studying the effectiveness of a pragmatic health system intervention, 'Patient Centered Kidney Transition Care,' a multi-component health system intervention designed to improve patients' preparation for kidney failure treatment. Patient-Centered Kidney Transition Care provides a suite of new electronic health information tools (including a disease registry and risk prediction tools) to help providers recognize patients in need of Kidney Transitions Care and focus their attention on patients' values and treatment preferences. Patient-Centered Kidney Transition Care also adds a 'Kidney Transitions Specialist' to the nephrology health care team to facilitate patients' self-management empowerment, shared-decision making, psychosocial support, care navigation, and health care team communication. The PREPARE NOW study is conducted among eight [8] outpatient nephrology clinics at Geisinger, a large integrated health system in rural Pennsylvania. Four randomly selected nephrology clinics employ the Patient Centered Kidney Transitions Care intervention while four clinics employ usual nephrology care. To assess intervention effectiveness, patient reported, biomedical, and health system outcomes are collected annually over a period of 36 months via telephone questionnaires and electronic health records. The PREPARE NOW Study may provide needed evidence on the effectiveness of patient-centered health system interventions to improve nephrology patients' experiences, capabilities, and clinical outcomes, and it will guide the implementation of similar interventions elsewhere.

Trial registration: [NCT02722382](https://clinicaltrials.gov/ct2/show/study/NCT02722382)

1. Introduction

Over 115,000 patients develop kidney failure each year [1]. Patients with kidney failure have high rates of mortality [2–4] and must receive treatment to replace their kidney function, such as dialysis or a kidney transplant, to survive. Due to the morbidity of kidney disease and the demands of kidney failure treatments, patients with kidney failure often experience drastic changes in their physical and mental health that are often devastating not only for patients but also for their families [5–12]. Ideally, patients should receive substantial advance preparation before initiating kidney failure treatments. Optimal treatment preparation involves educating patients regarding numerous treatment options, assisting patients in treatment decision-making, and ensuring patients receive a number of preparatory clinical evaluations, including evaluations for vascular surgery, kidney transplantation, or home dialysis treatments.

Unfortunately, many patients are unprepared for kidney failure treatments—even when they have been under nephrology specialty care for years [13–15]. A number of factors contribute to patients' poor preparation. For instance, nephrologists are often unable to predict with precision the timing of when patients' kidney failure will occur, as many patients with advanced kidney disease never progress to kidney failure [16]. As a result, nephrologists may feel hesitant to discuss kidney failure with patients too early. However, some patients with advanced kidney disease experience very rapid declines in their kidney function. Most of these patients have no symptoms, and their kidney disease may progress so rapidly that nephrologists have little time to help patients prepare in advance. As a result, many patients experience unplanned, chaotic, and psychologically traumatic treatment initiation [17–21]. Even when patients are aware of their declining kidney function in advance of treatment, they may fail to obtain recommended consultations to facilitate their advance preparation for dialysis or transplantation [22–25].

Hence, interventions are needed to improve the identification of patients in need of advance preparation, educate patients on their treatment options, help patients navigate multiple preparatory clinical evaluations for kidney failure treatment, and help patients obtain adequate psychosocial support for potentially traumatic kidney care transitions.

Efficacious interventions exist to help patients experience better kidney transitions, but their effectiveness in the real world may be limited by their disjointed or piecemeal implementation. For instance, risk prediction tools are now available to help physicians recognize when patients are at risk of kidney failure and could most benefit from kidney transitions care [26–29]. Further, randomized trials have shown that patients who receive education and psychosocial support for their kidney disease experience 43% fewer hospitalizations and prolonged time to kidney failure [30–32]. Randomized trials in patients at risk of kidney disease have also shown that when patients learn skills to overcome problems they feel empowered and better manage their kidney disease risks [33,34]. Studies also suggest that when patients receive assistance to make decisions and navigate complex care plans, they are up to 30% more likely to pursue self-care treatment options such as kidney transplantation or peritoneal dialysis [31,35]. To date, these promising interventions have not been implemented in a coordinated fashion to improve patients' care experiences and outcomes in a comprehensive manner.

2. Materials and methods

2.1. Overview

The PREPARE NOW study is a pragmatic cluster randomized controlled trial designed to quantify the effectiveness of integrated health system interventions to improve patients' preparation for kidney failure treatments. Based in Geisinger health system and working with

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