

**National Kidney Foundation
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1. ENHANCED CARE QUALITY AND IMPROVED EXPERIENCE FOR DIALYSIS PATIENTS:

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The concept of patient engagement has gained increasing importance as a promising pathway toward better quality, more efficient health care, and improved population health.^{1,2} Engagement establishes a culture of care requiring an authentic partnership between the care team and patient in improving health care and reducing harm. A recent study affirmed that while many healthcare teams believe they use patient engagement practices, they have limited understanding of these approaches.² To increase understanding of patient engagement and its application, ESRD Network 5 developed the ENGAGE program to assist dialysis providers in engaging patients through self-assessment, improved practice, and sharing of best practices.

The ENGAGE program was a requirement of 345 dialysis facilities enrolled in the Network's 2019 quality improvement activities, impacting approximately 27,832 patients. With the use of pre- and post-surveys, dialysis providers were asked to self-assess their implementation of patient engagement across three levels of engagement: patient, facility, and governance. Between surveys, dialysis facilities were required to complete an educational module.

Comparison of pre- and post-survey responses revealed statistically significant increases in patient engagement at the patient- and governance-levels. Incremental improvement occurred at the facility-level despite lack of statistical significance. The ENGAGE program promoted increased application of patient engagement approaches.

2. THE INFLUENCE OF SPIRITUALITY AMONG AFRICAN AMERICAN ESRD PATIENTS ON END-OF-LIFE TREATMENT PREFERENCES:

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Kidney disease among African Americans represent more than 30% of end-stage renal disease cases among a population that accounts for 15% overall in the United States (Harding et al., 2017). African Americans are three times as likely to require renal replacement therapy as their non-Hispanic White counterparts (Laster et al., 2018). Most patients have a five-year mortality rate (Grubbs, 2018). During the last month of life, ESRD patients age 65+ are hospitalized, admitted to intensive care units, experience medical procedures & death more than patients with cancer, CVA, & CHF (Mandel et al., 2017).

Systematic Literature Review

Keywords: spirituality, religiosity, end of life, treatment preferences, African American, cultural humility, ESRD, CKD, hospice and palliative care. The search yielded 86 peer reviewed journal articles. ProQuest, EBSCOHost, Web of Science & PubMed databases were used. Final clean sample resulted in 27 qualitative studies. Sample sizes ranged from 1 to 345 participants. Inclusion criteria >18 yrs.old, African American, ESRD pt. Studies held at academic & medical centers, faith institutions, dialysis centers, and medical record review. 26 thematic statements were initially identified and reduced to 7 recurrent themes.

Individual culture will influence how patients make sense of their illness as well as how they make end of life decisions (Smith et al., 2008). Decision making is most often a family decision that includes faith and spirituality (Moss et al. 2016).

Engagement by the medical team in treatment of the whole person, including a spirituality assessment is a significant initial step in addressing end of life concerns among African Americans. The introduction of palliative care and hospice care earlier in the disease process is warranted. A positive relationship between African Americans and faith institutions was found. Medical care providers may collaborate with faith-based community outreach organizations.

3. USING SMALL TESTS OF CHANGE TO IMPROVE ADVANCE CARE PLANNING IN CHRONIC KIDNEY DISEASE:

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Dallas Nephrology Associates (DNA) realized a need to improve advance care planning (ACP) across its large nephrology practice. In so doing, the opportunity to partner with the Pathways Project was accepted. This poster speaks to improving serious illness conversations with chronic kidney disease (CKD) patients while another part of DNA was working on improving ACP in dialysis.

To promote improvement in CKD, the following was implemented:

1. a needs assessment of nephrologists
2. provider education on ACP through Serious Illness Conversations and Care Project (SICP)
3. implementation of serious illness conversations
4. auditing and implementing small tests of change

At one office practice location, social worker worked with nephrologist to identify and audit CKD Stage 4/5 patients over age 65. Twenty-four patients were identified with the SICP provided. In this same setting, the physician trainer provided SICP training to 15 of 18 providers at the location. While not all trained providers provided goals of care conversations, referral to the Supportive Care Team (SCT) follow up increased.

Opportunities for continued change include ongoing follow up with identified patients with the goal being to identify a health proxy that is included in a goals of care conversation so that what matters most to the patient is supported by their loved ones and health care team. Additionally, the team has identified that use of documents from PREPARE for your Care (Sudore) are helpful in educating patients/families, identifying and documenting what matters most and documenting a health proxy.

To increase awareness, sympathy cards were developed for company wide distribution after an improvement activity identified that the office practices may not always know when a patient died. Additionally, the SCT Team gained support to have all employees review a module from the Center to Advance Palliative Care "Delivering Serious News" as a part of yearly compliance training.

Using small tests of change can spark continuous improvement in advance care planning. Finding a way to maintain gains takes continued perseverance.

4. NEPHROLOGY SOCIAL WORKERS' OPINIONS ON THE USE OF ACCEPTABLE HUMOR IN CONVERSATIONS WITH ADVANCED ILLNESS PATIENTS:

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Nephrology social workers frequently encounter patients with advanced illness, assessing them for depression, anxiety, pain and suicidality. Death is frequent and may contribute to social worker burnout. Humor—enjoying a good laugh, joking, smiling—is part of being human, and no less important for those with advanced illness. Humor has been shown to improve patient quality of life and overall well-being. In multiple studies on the use of humor in palliative care, humor appears to allow providers, patients and caregivers to better connect, provide joy and hope, enhance relaxation, and improve perspective. Acceptable humor can be a "powerful resource" for providers to manage the "negative effects of the strain of death and dying." By using acceptable humor, do nephrology social workers perceive less burden in their own lives and that of their patients? Do they believe humor can alleviate perceived pain and discomfort in advanced illness? Is acceptable humor appropriate for their practice, their gender and their particular culture? Do they believe that acceptable humor ameliorates burnout?

Cross-sectional, 33-item anonymous online survey to be administered in spring 2020. No identifiable information will be collected. All questions will be optional. The survey may be taken only once. The survey link will be emailed to the 18 End Stage Renal Disease (ESRD) Network representatives at the Centers for Medicare and Medicaid (CMS). They will be asked to send the survey link to their network social workers using their confidential network email list and tell the investigator the number of surveys they forwarded. This will determine response rate.

Opinion sample of nephrology social workers from all CMS ESRD Networks. Conversations using acceptable humor with advanced illness patients have been shown to decrease the perception of pain, create a suitable distraction from illness, and benefit patients and providers. We anticipate that our survey will add information regarding its effect in ESRD patients.

The views expressed in this article are those of the author and do not reflect the official policy of the Department of Army/Navy/Air Force, Department of Defense, or U.S. Government.

5. THE BENEFITS OF EXERCISE DURING HEMODIALYSIS TREATMENT:

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With dialysis patients, regular exercise is a difficult struggle. Common reasons for this are fatigue, lack of motivation, and minimal knowledge about its benefits. Exercising during hemodialysis is an effective and realistic way to improve treatment efficiency. Besides typical health benefits: studies show that doing it during treatments results in better dialysis. Patients are receiving double the benefit because it is working on both their fitness level and treatment efficiency.

Four key studies were used that were each tailored to the patients' treatment position and fitness level. Since patients either sit or lie down during hemodialysis; cycle ergometers or mini steppers allowed them to exercise while in the chair. Exercise ranged from 15 to 60 minutes total during the first 2 hours of treatment. Fitness levels and blood labs were tested before, during, and after the studies to measure changes and improvements.

The removal of urea is a standard way to measure dialysis efficiency; and is labeled as spKt/V. This substance normally comes out in urine; but dialysis patients do not produce enough to get rid of it. Exercise increases blood flow to the muscle, which leads to greater movement of urea and other toxins from the dialyzer such as creatinine and potassium. The spKt/V increased 11% after the first month and remained there throughout one study; and another showed a 38% improvement in spKt/V. One measure utilized was the 6 Minute Walk Test (6MWT). Distance increased to almost 30% for some; and all participants had some gain. Patients also showed growth in lower muscle strength and balance. This reduces their risk of falls and bone breakage.

Implementing in-clinic exercise is a safe and efficient way to promote exercise benefits. Exercise during hemodialysis can bring great improvement to patients' health quality and overall clinic outcomes.

6. PERITONEAL DIALYSIS AND PREEMPTIVE KIDNEY TRANSPLANT UPTAKE FOLLOWING MULTIDISCIPLINARY MODALITY EDUCATION:

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Pre-dialysis education can increase the proportion of patients who select peritoneal dialysis (PD) as a modality option. One goal of the recent "Advancing American Kidney Health" executive order is to have 80% of new ESRD patients either receiving dialysis at home or a kidney transplant. We examined rates of PD and preemptive transplant following a multidisciplinary dialysis modality education session.

Patients with CKD stage IV who attended a 2-hr education session led by a nephrologist, social worker, dietician and PD patient were followed until renal replacement therapy started to determine their modality preference and actual modality used (March 2014-September 2019). We determined the proportion of PD initiation among patients whose preference was for PD as well as combined preemptive transplant and PD initiation.

Of 210 participants, the mean age was 65.6 years, 80.2% were white, 53.7% women, and 47.5% had diabetes. Mean follow up from date of class to renal replacement therapy or end of study was 15.7 months. Modality preferences were: 39.9% PD, 40.9% HD, 3.4% palliative care, 2.5% planned pre-emptive transplant and 12.8% no/unknown preference. Of the 100 patients who started renal replacement therapy, 51% initiated HD, 35% PD, and 14% were preemptively transplanted before dialysis. Among the 40 patients who preferred PD and started dialysis, 85% actually initiated PD as their first modality.

Multidisciplinary modality education was associated with a 49% uptake of PD and preemptive kidney transplant. Most patients were able to start with their preferred modality, but additional interventions will be needed to achieve higher rates of PD and preemptive transplantation.

7. ADVANCING ADULT LEADERSHIP IN CYSTINOSIS ADVOCACY:

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Cystinosis is a rare metabolic disease with particular impact on kidneys, eyes, and muscles. Improved treatment has extended the lifespan with cystinosis from adolescence into adulthood,^{1,2} but challenges remain. Patients with cystinosis are taking an active role in advocacy, done by caregivers in the past.

Following 10 years of research and advocacy related to the transition to adulthood, the Cystinosis Research Network (CRN) convened its Adult Leadership Advisory Board (A L A B) as a formal way of empowering patients. A L A B's intention is to nurture patients who have cystinosis, and provide advice, support, and companionship along the disease process.

The goal of all A L A B projects is to use newer communication technologies to reach crucial young adult and adult constituents with cystinosis. For 2019-2020, A L A B projects include video conferencing, podcasts on issues such as mental health, relationships, and regimen adherence; and teen-oriented photo updates highlighting community members' challenges and successes. Survey instruments will be created and disseminated by email to assess satisfaction and impact of these projects. New projects will be developed over time as A L A B leadership rotates and new concerns arise.

Recipients of A L A B content will strengthen their knowledge of cystinosis (i.e., treatment options, adherence); education, employment, and relationships; navigating the healthcare system; and overall problem-solving. Those creating A L A B project content will gain teaching and leadership skills, and motivation for their own disease management and coping. A L A B members want healthcare providers and researchers to recognize that cystinosis patients are well-versed in their own disease and can clearly speak about how it impacts their lives.

8. PROVIDER PERCEPTIONS OF THE MY WAY INTERVENTION: IMPLEMENTING ADVANCED CARE PLANNING IN CKD CLINICS:

Alice Lee¹, Annette Aldous¹, Liz Anderson², Dale Lupu¹. ¹George Washington University, Washington, DC, United States; ²Western Carolina University, Cullowhee, NC, United States

Patients with chronic kidney disease (CKD) benefit from integration of advance care planning (ACP) into their care, and many patients report wishing they had engaged in ACP before the dialysis decision. The MY WAY trial randomized participants from four CKD clinics in the eastern United States to receive printed ACP materials or printed materials plus an ACP coaching session that used motivational interviewing. We interviewed providers at each site to gain insights into the impact of the intervention on clinic workflows and patient outcomes as well as challenges and facilitators to implementation.

Telephone interviews were conducted with clinical providers and research staff at each intervention site. We invited principal investigators, ACP coaches, and research staff. The semi-structured interview used open-ended questions to elicit personal impressions as well as perceptions of clinic-wide responses, changes in workflow, and intentions for future use of the intervention. Interviews were audio recorded, transcribed, and analyzed using Dedoose software. Grounded theory was used to identify patterns and discover core concepts and categories.

12 participants were interviewed between September 2019 and November 2019. Participants from all four clinical sites included three nephrologists, one palliative care doctor, three ACP coaches (two social workers, one nurse practitioner), and five research staff. The intervention was well-received; providers were overwhelmingly in favor of integrating ACP into CKD care. The interviews revealed themes as to what inhibited or encouraged integration. Some major obstacles were lack of time, provider discomfort/lack of training, and a need for dedicated staff for ACP. Despite varied perceptions of issues with recruitment, providers reported positive patient reception of the MY WAY intervention.

Interviews with clinical providers revealed positive reactions to an ACP coaching intervention at diverse sites. Qualitative analysis provided insight into the possible future implementation of aspects of the MY WAY intervention as part of ACP integration into CKD care. The themes revealed in this analysis can guide conversations within CKD providers about how to resolve obstacles to integrating ACP into care.

9. HEMODIALYSIS PATIENT CHARACTERISTICS AND THEIR EFFECT ON KDQOL-36 SCORES:

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The quality of life for those on dialysis is challenged daily by the disease and treatment regimens. Quality of life has been linked to health outcomes and the Center for Medicare and Medicaid Services (CMS) has identified the Kidney Disease Quality of Life 36 (KDQOL-36) as the preferred health-related quality of life survey for use with dialysis patients.

The purpose of this study was to identify possible relationships between patient attributes and KDQOL-36 scores. Data consisted of patient attributes and KDQOL-36 scores for 116 hemodialysis patients and was analyzed using Chi-square and One-way ANOVA. Relationships between KDQOL-36 subscales was analyzed using Pearson correlation for continuous scores and Chi Square for categorical scores (below average, average, above average).

Key findings include relationships between physical activity level and BMI with the Physical Component Summary, between the Mental Component Summary and each of the disease specific subscales, and between each of the disease specific subscales.

Encouraging physical activity, managing symptoms, and maintaining mental well-being appears critical in quality of life among dialysis patients and for positive health outcomes.

10. STAFF PERCEPTION OF NEEDS FOR IN-CENTER DIALYSIS CLIENTS: A PARTICIPATORY ACTION RESEARCH PROJECT:

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Chronic kidney disease impacts the quality of life of dialysis clients. Poor quality of life can have a negative impact on mental health and clients with a poor quality of life may have problems adjusting to kidney disease. This project explored dialysis staff's perceptions of client needs and potential services that could address those needs and improve client quality of life.

Participatory action research was used to identify in-center hemodialysis client needs and services. Fourteen interviews were conducted with dialysis staff about the needs of dialysis clients. Six dialysis staff participated in a focus group to discuss services that could address the needs identified and improve client quality of life. The responses were audio recorded and transcribed verbatim and then qualitatively analyzed using a thematic analysis.

Dialysis staff observed clients having various mental health concerns, such as depression. It was recommended that staff receive training on how to interact with clients that have mental health issues. It was suggested that therapeutic services be provided to clients to address these concerns. Needs, such as transportation and financial barriers to services, were also observed by multiple dialysis staff.

This project was instrumental in identifying needs of dialysis clients that can impact their quality of life. Dialysis staff identified mental health concerns as a primary issue and want more information on how to best address the identified needs. Dialysis staff were provided mental health training to learn how to provide better care for clients.

11. COPING WITH AN ESRD DIAGNOSIS: DIFFERENCES AMONG PATIENTS ACCORDING TO PRESENCE OF PRE-ESRD NEPHROLOGY CARE:

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More than one third of patients with end-stage renal disease (ESRD) had not been under the care of a nephrologist when they received the diagnosis. The aim of this study was to explore the coping styles and strategies used at the time of ESRD diagnosis among patients with varying amounts of pre-ESRD nephrology care.

A mixed-methods design was used, and semi-structured interviews were conducted with patients with varying amounts of pre-ESRD nephrology care, exploring their coping styles and strategies as it related to their ESRD diagnosis and renal replacement therapy (RRT) initiation. Participants were grouped according to amount of pre-ESRD nephrology care. Interviews conducted to date were analyzed using applied thematic analysis and codes were created deductively and inductively. Two members of the research team independently coded each interview transcript. Relevant sociodemographic data were also collected, and three coping-related validated measures were administered. Data collection is ongoing.

Thus far, 40 patients with varying amounts of pre-ESRD nephrology care participated. Interim analyses reveal that coping styles and strategies vary according to amount of pre-ESRD nephrology care and the following qualitative themes have emerged: (1) psychological distress; (2) adjustment to illness issues; (3) influences on primary appraisal of the stressor; and (4) secondary appraisal of the stressor. Mean scores on the Denial, Acceptance, and Active Planning subscales of the Brief COPE measure and on the Coping Strategies Index-Short Form Emotion-Focused Disengagement subscale vary between groups, with higher mean scores seen among patients with no history of pre-ESRD nephrology care.

The qualitative and quantitative differences in coping with the ESRD diagnosis and RRT initiation according to amount of pre-ESRD care suggest further exploratory and targeted intervention research is necessary to help all patients optimally adjust to this life-altering illness.

12. "I WAS JUST BLINDSIDED" – THE DIAGNOSIS AND RENAL REPLACEMENT INITIATION EXPERIENCES OF PATIENTS NEWLY DIAGNOSED WITH ESRD WITH VARYING AMOUNTS OF PRE-ESRD NEPHROLOGY CARE:

Megan Urbanski¹, Levent Dumenci¹, Crystal Gadegbeku², Laura Siminoff³, Amy Waterman³, Heather Gardiner¹. ¹Temple University, Philadelphia, PA, United States; ²Lewis Katz School of Medicine, Temple University, Philadelphia, PA, United States; ³UCLA, Los Angeles, United States

According to recent data, more than a third of new cases of end-stage renal disease (ESRD) in the U.S. had no or minimal pre-ESRD nephrology care. Little is known about the ESRD diagnosis experiences of this patient group, how they initiate renal replacement therapy (RRT), or how their experiences compare to patients with a history of pre-ESRD nephrology care.

Using a mixed-methods design, semi-structured interviews were conducted with patients with varying amounts of pre-ESRD nephrology care, exploring their ESRD diagnosis experiences and RRT initiations. Participants were grouped by amount of pre-ESRD nephrology care. Applied thematic analysis was used and codes were created deductively and inductively. Two members of the research team independently coded each interview. Sociodemographic data were also collected, and 7 validated measures were administered. Data collection is ongoing.

To date, 40 patients have participated. Preliminary analyses reveal that the diagnosis experience is similar across participant groups and the following themes have emerged: (1) diagnosis occurs on a spectrum of emergency; (2) diagnosis communication environment; (3) emotional reaction to the news; (4) characteristics of the first dialysis treatment; and (5) perception that the disease could have been avoided. A majority of participants (n=37; 92.5%) had an inpatient RRT initiation and initiated to hemodialysis (n=39; 97.5%). Most participants without pre-ESRD nephrology care blamed themselves for their disease development, and this was reflected in corresponding quantitative measure scores.

ESRD diagnosis does not occur as a dichotomous phenomenon in the U.S. but occurs on a continuum of suboptimal and often occurs as an emergency, irrespective of amount of pre-ESRD nephrology care. Further research is needed to improve the patient experience and reduce the burden on the healthcare system at the time of ESRD diagnosis.

13. LOWER PREVALENCE OF KIDNEY TRANSPLANT WAITLISTING IN MICROPOLITAN AREAS, SMALL TOWNS, AND RURAL AREAS:

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The Percentage of Prevalent Patients Waitlisted (PPPW) measures the percentage of patients at a dialysis facility who were on the kidney or kidney-pancreas transplant waitlist. This measure joined the End Stage Renal Disease Quality Incentive Program in performance year 2020, with a weight of 4%. PPPW is adjusted for age, but not for other factors. Physical distance between residence and transplant center may influence PPPW. As an indirect test of this hypothesis, we assessed whether PPPW was associated with rural-urban commuting area (RUCA) levels.

We analyzed data in Dialysis Facility Compare (DFC), as of October 30, 2019. DFC included PPPW values that quantified wait-listing prevalence during 2018. According to ZIP code, we classified the location of each dialysis facility as metropolitan (RUCA values, 1-3), micropolitan (4-6), small town (7-9), or rural (10). We estimated weighted mean PPPW values in each location class, with the weight of each facility equal to the number of patients contributing to PPPW. We fit a linear regression model to test differences in PPPW values between the location classes.

PPPW values were reported in 7086 (94%) of 7566 dialysis facilities, and RUCA values were identified in 6999 (99%) of 7086 facilities. The weighted mean PPPW value among all facilities was 17.5%. There were 5363 (77%) facilities in metropolitan areas, 954 (14%) in micropolitan areas, 550 (8%) in small towns, and 132 (2%) in rural areas. By location class, weighted mean PPPW values were 18.5% in metropolitan areas, 12.8% in micropolitan areas, 12.1% in small towns, and 10.8% in rural areas. Relative to the mean PPPW value in metropolitan areas, mean PPPW values were 5.8, 6.5, and 7.7 percentage points lower in micropolitan areas, small towns, and rural areas, respectively ($P < 0.01$ for each).

The PPPW measure takes significantly lower values in dialysis facilities located in micropolitan areas, small towns, and rural areas, relative to metropolitan areas. The physical distance between residence and transplant center may preclude many patients in non-metropolitan areas from completing the process of kidney transplant evaluation. New processes are needed to improve access to transplantation in outlying areas.

14. NATIONAL ESTIMATES OF MENTAL HEALTH NEEDS AMONG PATIENTS WITH CHRONIC KIDNEY DISEASE:

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The Advancing American Kidney Health initiative encourages greater use of transplant and home dialysis among patients with new-onset end-stage kidney disease (ESKD). Poorly controlled mental health (MH) disorders are a contraindication to these preferred treatments, yet national estimates of the MH needs of patients with chronic kidney disease (CKD) are not available.

We used 2015-17 data from the National Survey of Drug Use and Health to identify three nationally representative populations of adults (age ≥ 22) with: (1) no identifiable chronic conditions ("healthy"), (2) hypertension or diabetes but not CKD ("HTN/DM"), or (3) CKD. Outcome measures assessed self-reported MH and use of MH services in the prior year, and were compared across the three populations in unadjusted descriptive analyses and regression analyses, adjusted for other respondent characteristics (age, sex, race/ethnicity, insurance, education, family income).

We identified $n=70,530$ individuals with no chronic conditions, $n=19,417$ with diabetes or hypertension but not CKD, and $n=1,508$ with CKD in our data. CKD patients were more likely than HTN/DM or healthy patients to report having a mental illness in the past year (30.9% vs. 23.4% or 18.6%, respectively, $p<0.01$), any psychological distress in the past year (17.3% vs. 13.4% or 12.0%, respectively, $p<0.01$), and any suicidal thoughts in the past year (7.2% vs. 5.1% or 4.1%, respectively, $p<0.01$). CKD patients were also more likely than HTN/DM or healthy patients to have received MH services in the past year (any outpatient: 12.1% vs. 9.6% or 6.3%, respectively, $p<0.01$; any prescription medication: 21.1% vs. 18.2% or 10.1%, respectively, $p<0.01$) and yet were still more likely to report having unmet MH needs (7.8% vs. 6.4% or 5.6% respectively, $p<0.01$). These differences persisted in regression models.

In the U.S., patients with CKD have greater levels of unmet MH need than healthy or HTN/DM patients despite greater use of MH services. More effective management of CKD patients' MH care needs will be needed to advance goals of treating greater numbers of patients with ESKD with transplant and home dialysis.