

National Kidney Foundation
NKF 2021 Spring Clinical Meetings Abstracts
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CKD/ESRD—Other

- 1 **Patient Impact of a Kidney Disease Patient-Centered Outcomes Research Study**
Teri Browne¹, Jamie Green², Christina Yule², Sara Kwiecien², Patti Ephraim³, Ashley Cabacungan⁴, Sherri Wydra², Tara Strigo⁴, Katina Lang-Lindsey⁵, Patty Danielson⁶, Lana Schmidt⁶, Amy Swoboda⁷, Brian Bankes⁶, Suzanne Ruff⁷, Shakur Bolden⁶, Peter Woods⁶, George Jackson⁴, Felicia Hill-Briggs³, L. Ebony Boulware⁴. ¹University of South Carolina, Columbia, SC, United States; ²Geisinger Health System, Danville, PA, United States; ³Johns Hopkins University, Baltimore, MD, United States; ⁴Duke University School of Medicine, Durham, NC, United States; ⁵Alabama A&M University, Huntsville, AL, United States; ⁶Patient Co-Investigator, Durham, NC, United States; ⁷Family Member Co-Investigator, Durham, NC, United States
- 2 **Organizational Predictors of High-Quality Performance in Medicare’s Comprehensive End-Stage Renal Disease Care Initiative**
Kelsey Drewry, Adam Wilk. Emory University, Atlanta, GA, United States
- 3 **Engagement and Experiences in a Kidney Disease Patient-Centered Outcomes Research Study During COVID-19**
Shamika Jones², Teri Browne¹, Ashley Cabacungan³, Tara Strigo³, Patti Ephraim⁴, Jamie Green⁵, Katina Lang-Lindsey⁶, Shakur Bolden¹⁴, Amy Swoboda¹⁵, Suzanne Ruff¹⁵, Patty Danielson¹⁴, Lana Schmidt¹⁴, Brian Bankes¹⁴, Peter Woods¹⁴, Kelli Collins⁷, Diana Clynes⁸, Diane Littlewood⁹, Dori Schatell¹⁰, Dale Singer¹¹, Stephanie Stewart¹², Brandy Vinson¹³, Felicia Hill-Briggs⁴, L. Ebony Boulware³. ¹University of South Carolina, Columbia, SC, United States; ²University of South Carolina, Columbia, SC, United States; ³Duke University School of Medicine, Durham, NC, United States; ⁴Johns Hopkins, Baltimore, MD, United States; ⁵Geisinger Health System, Danville, PA, United States; ⁶Alabama A&M University, Huntsville, AL, United States; ⁷National Kidney Foundation, New York, United States; ⁸American Association of Kidney Patients, Tampa, FL, United States; ⁹Pennsylvania Medical Society, Harrisburg, PA, United States; ¹⁰Medical Education Institute, Madison, WI, United States; ¹¹Renal Physicians Association, Rockville, MD, United States; ¹²Mayo Clinic, Mankato, MN, United States; ¹³Quality Insights Renal Network 5, Richmond, VA, United States; ¹⁴Patient Co-Investigator, Durham, NC, United States; ¹⁵Family Member Co-Investigator, Durham, NC, United States
- 4 **Everyday Racial Discrimination and Medication Adherence: A Qualitative Study**
Tamara Estes Savage. University of North Carolina - Pembroke, Pembroke, NC, United States

Other

- 5 **Patient and Decision Partner Shared Decision-Making in Dialysis**
Renata Sledge^{1,2}, Dixie Meyer², Max Zubatsky², Kaite Heiden-Rootes², Marie Philipneri², Teri Browne³. ¹Medical Education Institute, Madison, IL, United States; ²Saint Louis University School of Medicine, Saint Louis, MO, United States; ³University of South Carolina, Columbia, SC, United States
- 6 **Female Sexual Function in an Inner-City Population of Chronic Kidney Disease (CKD), Dialysis and Kidney Transplant (KTx) Patients**
Tatyana Yatsenko, Stefan Hamaway, Michael Goldberg, Gabrielle Estevez-Inoa, Basim Ahmad, Mariana Markell. SUNY Downstate Health Sciences University, Brooklyn, NY, United States
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Sonya-Lee Zezza. Fresenius, Palatka, FL, United States

1. PATIENT IMPACT OF A KIDNEY DISEASE PATIENT-CENTERED OUTCOMES RESEARCH STUDY:

Teri Browne¹, Jamie Green², Christina Yule³, Sara Kwiecien², Patti Ephraim³, Ashley Cabacungan⁴, Sherri Wydra², Tara Strigo⁴, Katina Lang-Lindsey⁵, Patty Danielson⁶, Lana Schmidt⁶, Amy Swoboda⁷, Brian Bankes⁶, Suzanne Ruff⁷, Shakur Bolden⁸, Peter Woods⁹, George Jackson⁴, Felicia Hill-Briggs³, L. Ebony Boulware⁴. ¹University of South Carolina, Columbia, SC, United States; ²Geisinger Health System, Danville, PA, United States; ³Johns Hopkins University, Baltimore, MD, United States; ⁴Duke University School of Medicine, Durham, NC, United States; ⁵Alabama A & M University, Huntsville, AL, United States; ⁶Patient Co-Investigator, Durham, United States; ⁷Family Member Co-Investigator, Durham, United States

Introduction

PREPARE NOW is a 5-year patient-centered outcomes research study testing a health system intervention to change kidney disease care. Patients received kidney care transitions services including nurse case management, classes, & referrals to peer mentors, behavioral health and dietitians. We conducted a study to examine the patient impact of the interventions.

40 patients were randomly selected for phone interviews. Patient & family Co-Investigators collaborated to design the interview guide. Transcripts were analyzed using MaxQDA software. First-cycle coding was performed using provisional codes derived from interview prompts. Second-cycle axial coding was then performed to differentiate and organize codes used to identify the most salient themes.

The PREPARE NOW interventions helped patients make shared decisions about their ESKD treatment choice, empowered patients, helped patients accept their kidney disease and provided emotional support to patients. Patients appreciated both in-person and virtual classes. Patients who chose not to do intervention components (peer mentor, dietitian, behavioral health) did so because they did not feel they needed that help or were too busy with other medical appointments.

Overall, most patients were highly satisfied with the PREPARE NOW project and thought that both the nurse case management and classes on ESKD treatment choices and living with kidney disease were very valuable. Although infrequently used by patients, referrals for peer mentors, dietitians and behavioral health were valued by those who used these services.

2. ORGANIZATIONAL PREDICTORS OF HIGH-QUALITY PERFORMANCE IN MEDICARE'S COMPREHENSIVE END-STAGE RENAL DISEASE CARE INITIATIVE:

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Introduction

Medicare is increasing the prevalence of alternative payment models in nephrology to improve the quality and value of care for beneficiaries with CKD and ESRD. Previously, Medicare implemented the analogous ESRD Seamless Care Organization (ESCO) program, through which provider groups (ESCOs) that provided high-quality care and reduced spending for ESRD patients could share in Medicare's savings. This study analyzed the relationship between ESCO organizational and staffing characteristics and quality performance.

We captured key information for all 37 ESCOs during 2015-2018 using data from CMS reports and the National Provider Identification registry. We performed bivariate and generalized logistic regression analyses of ESCOs with above vs. below median quality scores, focusing on measures potentially related to ESCO organization and staffing and controlling for community characteristics at the county level. Statistical significance was evaluated at the 5% level with Bonferroni corrections to account for multiple comparisons.

ESCO composition and quality performance varied widely (e.g., eye exam 0-95%; depression screening 60-99%; dialysis care rating 53-72%). Logistic regression models suggested that high performance on clinical process quality measures (eye and foot exams, depression screenings) was negatively associated with increasing ESCO size (+10 affiliated practices associated with 5-7 percentage point (pp) *decreases* in likelihood of achieving high performance on eye/foot exams and depression screenings [p=0.002, p<0.001, & p=0.028, respectively]). Patient information and dialysis care ratings were positively associated with ESCO size (+10 affiliated practices associated with 5 pp *increase* in likelihood of high performance [p=0.001 for both outcomes]), but were significantly negatively associated with increasing non-physician clinician staffing.

During 3 years of Medicare's ESCO program, the measures of care quality delivered by ESCOs varied greatly. We found that ESCO size was the most consistent predictor of performance on a variety of quality measures: larger ESCOs were less likely to achieve high performance on clinical process quality measures but more likely to achieve high performance on patient information and dialysis care ratings. This study provides crucial evidence to inform the decisions of provider groups participating in Medicare's new nephrology-focused payment models.

3. ENGAGEMENT AND EXPERIENCES IN A KIDNEY DISEASE PATIENT-CENTERED OUTCOMES RESEARCH STUDY DURING COVID-19:

Shamika Jones², Teri Browne¹, Ashley Cabacungan³, Tara Strigo³, Patti Ephraim⁴, Jamie Green⁵, Katina Lang-Lindsey⁶, Shakur Bolden¹⁴, Amy Swoboda¹⁵, Suzanne Ruff¹⁵, Patty Danielson¹⁴, Lana Schmidt¹⁴, Brian Bankes¹⁴, Peter Woods¹⁴, Kelli Collins⁷, Diana Clynes⁸, Diane Littlewood⁹, Dori Schatell¹⁰, Dale Singer¹¹, Stephanie Stewart¹², Brandy Vinson¹³, Felicia Hill-Briggs⁴, L. Ebony Boulware³. ¹University of South Carolina, Columbia, SC, United States; ²University of South Carolina, Columbia, SC, United States; ³Duke University School of Medicine, Durham, NC, United States; ⁴Johns Hopkins, Baltimore, MD, United States; ⁵Geisinger Health System, Danville, PA, United States; ⁶Alabama A & M University, Huntsville, AL, United States; ⁷National Kidney Foundation, New York, United States; ⁸American Association of Kidney Patients, Tampa, FL, United States; ⁹Pennsylvania Medical Society, Harrisburg, PA, United States; ¹⁰Medical Education Institute, Madison, WI, United States; ¹¹Renal Physicians Association, Rockville, MD, United States; ¹²Mayo Clinic, Mankato, MN, United States; ¹³Quality Insights Renal Network 5, Richmond, VA, United States; ¹⁴Patient Co-Investigator, Durham, United States; ¹⁵Family Member Co-Investigator, Durham, United States

Introduction

PREPARE NOW is a patient-centered outcomes research study testing a health system intervention to change kidney disease care. We conducted a qualitative study to examine the impact of COVID-19 on patient-centered engagement in research.

7 patient and family Co-Investigators & 8 kidney disease stakeholders were interviewed. Transcripts were analyzed to differentiate and organize codes used to identify the most salient themes.

COVID-19 has impacted patients by restricting travel, requiring isolation, increasing mortality concerns & the use of telehealth. COVID-19 has increased anxiety & fear among patient and family members, but it has not affected their ability to participate in virtual PCOR research activities.

PREPARE NOW team members were highly engaged in research. Problems that may occur when participating on research teams during COVID-19 include technology knowledge, limitations of virtual meetings, and internet bandwidth. Suggestions for PCOR research in general & during COVID-19 include frequent communication and technical assistance. The virtual engagement approaches of the PREPARE NOW project can serve as a model for the PCOR community.

4. EVERYDAY RACIAL DISCRIMINATION AND MEDICATION ADHERENCE: A QUALITATIVE STUDY:

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Introduction

Poor medication adherence leads to increased risk for morbidity and mortality in dialysis patients. African American dialysis patients have poorer rates of medication adherence when compared to Whites. Studies have not investigated the impact of broader social issues such as everyday racial discrimination on this disparity. It is critically important to understand how everyday racial discriminatory acts within the healthcare system contribute to this disparity in medication adherence. Thus, a qualitative study was conducted.

Primary data were gathered from five in-depth interviews with African American ESRD patients (N = 5). Each interview was 1 to 1.5 hours in duration. Participants were recruited from attendees at a National Kidney Foundation Patient Empowerment Meeting. The interviews were transcribed verbatim. Grounded theory was used to identify themes that emerged from a line-by-line review of the interview transcripts.

Participants stated that health providers assumed that participants could not pay for prescriptions, free medication samples given to White patients but not African American patients, participants treated unkindly or ignored by medical staff, participants treated as a "typical" African American, and information about medication and lab results were withheld or given to participants without further consultation. In contrast, White patients received in-depth consultations.

These findings provide the basis for development of future research concerning the impact of everyday racial discrimination on medication adherence in the African American dialysis population. Such research could lead to antiracist strategies, and targeted interventions that can address the medication adherence health disparity.

5. PATIENT AND DECISION PARTNER SHARED DECISION-MAKING IN DIALYSIS:

Renata Sledge^{1,2}, Dixie Meyer³, Max Zubatsky², Kaitie Heiden-Rootes², Marie Philipperi², Teri Browne³. ¹Medical Education Institute, Madison, IL, United States; ²Saint Louis University School of Medicine, Saint Louis, MO, United States; ³University of South Carolina, Columbia, SC, United States

Introduction

Caregiver and family involvement by medical professionals in decisions vary over the dialysis treatment trajectory, yet family preferences are important considerations for patients starting dialysis. Existing literature has not explored the experience of patient and decision partner shared decision-making. Consequently, dialysis providers focus on education about expected benefits of dialysis, rather than personalizing the dialysis decision discussions.

This interpretive phenomenology study explores how dialysis patients and their partners experience dialysis decisions. A purposive sample of 13 patient-decision partner dyads were recruited from dialysis clinics and on-line dialysis patient groups and participated in semi-structured interviews. Eligible participants were over 18 years old, English speaking, involved with their treatment teams for at least 6 months, and the patient was currently on dialysis. Decision-partners included those who have participated in decision-making with the patient. Crist and Tanner's (2003) five-step iterative process of data analysis occurred concurrently with data collection.

Thirteen dyads (26 participants) were interviewed with patients on ICHD (n=6), PD (n=3) and HDD (n=4). Decision partner relationships included romantic partner (n=9), parent (n=2), sibling (n=1), and friend (n=1). Fifty-seven percent of participants were White; 46% of patients were women; and 76% of decision partners were women. Emerging patterns include a shifting focus of the dyad across treatment trajectory; balancing bodily integrity with relational autonomy; and activities honoring the ultimate responsibility of decision by the patient with their shared responsibility to the family.

Dyads making modality decisions are attuned to patient autonomy while managing the collateral effects of dialysis. Shifting the paradigm of dialysis treatment decisions from promoting patient autonomy to dialogues exploring relational autonomy will help providers to balance the competing demands of incentivized standards to promote home dialysis with the realities of patients and their decision partners.

6. FEMALE SEXUAL FUNCTION IN AN INNER-CITY POPULATION OF CHRONIC KIDNEY DISEASE (CKD), DIALYSIS AND KIDNEY TRANSPLANT (KTX) PATIENTS:

Tatyana Yatsenko¹, Stefan Hamaway¹, Michael Goldberg¹, Gabrielle Estevez-Inoa¹, Basim Ahmad¹, Mariana Markell¹. ¹SUNY Downstate Health Sciences University, Brooklyn, NY, United States

Introduction

Sexual dysfunction (SD) can greatly affect quality of life, but most studies of SD in kidney disease are limited to men. We studied trends in psychosocial factors, beliefs, and lifestyle habits in relation to Female Sexual Function Index scores (FSFI) in an inner-city population with kidney disease.

A random sample of female CKD (7), dialysis (4), and transplant (8) pts were surveyed by telephone using the PSS (Perceived Stress Scale), PHQ9, SSS (Stress and Social Support), SEAR (Self Esteem and Relationships), Lubben Social Network and BIAAQ (Body Image Acceptance and Action) questionnaires. 24 hour diet intake was recorded and analyzed using ASA-24. There were no differences between the three groups, so data were pooled. Associations were calculated using Pearson's r.

Mean age was 57± 10. 63% of patients were Black, 11% Hispanic, 5% white, 5% other, and 16% unreported. 74% of patients had FSFI scores consistent with sexual dysfunction (mean 14±12, out of 36). FSFI was not correlated with PHQ9, SSS, PSS, SEAR, Lubben Social Network, or BIAAQ-5 scores. FSFI was also not correlated with age, exercise habits, or diagnosis of HTN or diabetes. FSFI was correlated with intake of sugar (r=0.6, p<0.05), fiber (r=0.7, p<0.01), and 4-week herbal supplement history (r=0.6, p=0.01), and inversely associated with total fat intake (r=-0.7, p=0.01) and sodium (r=-0.6, p=0.04). 26% and 16% of patients discussed sexual dysfunction with a physician after any chronic disease diagnosis and within the last year, respectively. Pts who had discussed sexual dysfunction reported more sexual activity within the past 4-weeks (r=0.5, p<0.05). 11% had discussed treatment for sexual dysfunction. Two patients commented on physician inattention and discomfort when discussing sexual health and one patient also noted insufficient education related to kidney disease and sexual dysfunction.

In our population: 1. Female sexual dysfunction was reported by almost three quarters of patients surveyed. 2. Sexual dysfunction did not correlate with age, comorbidities, or psychosocial factors. 3. Sexual dysfunction was associated with diet that featured less sugar and fiber and more sodium and fat. 4. Patients with better sexual function were more likely to have taken herbal supplements. 5. Sexual function is likely multifactorial and is an important component of overall health. Three quarters of pts had never discussed it with their healthcare provider and several noted that their physician was uncomfortable discussing the topic. 6. More attention should be paid to this important issue in order to improve quality of life for our female patients with kidney disease.

7. TREATMENTS AND TRAUMA:

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Introduction

There is very little research on medical self-management in adulthood dialysis treatments and the links to childhood abuse. However, by utilizing the Adverse Childhood Experiences (ACE) study and what is known about affect dysregulation in traumatized people we can start to see a relationship between childhood trauma and self-management treatment among adult dialysis patients and attending their treatments.

Methods: We conducted a literature review into the relationship between childhood trauma and the self-management of treatment on adults on dialysis. The ACE study along with affect dysregulation patterns were used to gather information. Affect dysregulation behaviors include being self-destructive due to traumatizing experiences such as different types of abuse. The ACE study had over 17,000 participants which had questions on several types of abuse and family stressors. Two other studies used parts of the ACE questions to formulate their research. One was on general health and childhood trauma where they studied 272 adults with 5 measurements of childhood trauma and lastly, a study on trauma and low-income country where there were 468 participants.

Results: The ACE's study revealed that childhood trauma significantly impacted more than 60% of adults physically and mentally. Studies within HIV in General Health Care and in the Trauma History and Depression Predict Incomplete Adherence to Antiretroviral Therapies in a Low-Income Country in adults reveal that the higher the ACE score and the more frequent medical treatments the less they are to participate in self-managed treatments, therefore engaging in affect dysregulation.

Conclusion: It is known that the most common ways for traumatized people to cope are through self-destructive/affect dysregulation behaviors leading the adult dialysis patient to poorly manage their treatment. Self-destructive behaviors can be seen as a way to control their environment and medical treatments. With early detection of childhood trauma and expanding mental health services to the dialysis patient, dialysis centers would see an increase in positive self-management.