Patient Impact of a Kidney Disease Patient-Centered Outcomes Research Study

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Organizational Predictors of High-Quality Performance in Medicare’s Comprehensive End-Stage Renal Disease Care Initiative

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Engagement and Experiences in a Kidney Disease Patient-Centered Outcomes Research Study During COVID-19

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Everyday Racial Discrimination and Medication Adherence: A Qualitative Study

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Patient and Decision Partner Shared Decision-Making in Dialysis

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Female Sexual Function in an Inner-City Population of Chronic Kidney Disease (CKD), Dialysis and Kidney Transplant (KTx) Patients

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Treatments and Trauma

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

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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 decrease 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:

Shantika Long1, Teri Browne1, Ashley Cabacungan2, Tara Strigo3, Patti Ephraim4, Jamie Green5, Katina Lang-Lindsey6, Shaker Bolden7, Amy Swoboda8, Suzanne Ruff9, Patty Danielson10, Lana Schmidt11, Brian Banke11, Peter Woods12, Kelli Collins12, Diana Clynes13, Diane Littlewood13, Dori Schell14, Dale Singer15, Stephanie Stewart12, Brandi Vinson16, Felicia Hill-Briggs16, L. Ebony Boulware17, University of South Carolina, Columbia, SC, United States; 2University of South Carolina, Columbia, SC, United States; 3University of South Carolina, Columbus, SC, United States; 4Duke University School of Medicine, Durham, NC, United States; 5Johns Hopkins, Baltimore, MD, United States; 6Patient Co-Investigator, Durham, United States; 7Family 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. Seven 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 prescription medications, free medication samples given to White patients but not African American patients, patients 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 Sladek1,2, Driae Meyer1, Max Zobalskiy1, Kate Haider-Roozbe1, Marie Philippe1,2,3, Teri Brown1,2,3, Medical Education Institute, Madison, IL, United States; 1Saint Louis University School of Medicine, Saint Louis, MO, United States; 2University 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.

Dyads making modality decisions are attuned to patient autonomy while managing bodily integrity with relational autonomy; and activities honoring the ultimate responsibility of the dyad across treatment trajectory; balancing exercise habits, or diagnosis of HTN or diabetes. FSFI was not correlated with PHQ9, SSS, PSS, SEAR, and analyzed using ASA-24. There were no differences between the three groups, so data were pooled. Associations were calculated using Pearson’s $r$.

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 Estvez-Inoa, Basim Ahmad, Mariana Markell, SUNY 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, PHQ, SSS, 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 dysfunction 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 mentally, 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 in increase in positive self-management.