

National Kidney Foundation

2017 Spring Clinical Meetings Abstracts

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CKD-ESRD – Other

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Kathryn Aebel-Groesch, Duane Dunn, Nancy Culkun, Angie Major, Sean Mayes, Deborah Benner.
DaVita Inc, Denver, CO, USA
- 2 **Putting Patients at the Center of Kidney Care Transitions: A Partnership Model for Kidney Disease Patients, Family Members and Community Stakeholders in Patient Centered Outcomes Research**
Prepare Now Workgroup: Teri Browne¹, Brian Bankes², Shakur Bolden³, Kelli Collins⁴, Patty Danielson⁵, Gary Green⁶, Katina Lang-Lindsey⁷, Diane Littlewood⁸, Jennifer Martin⁴, Suzanne Ruff⁹, Jennifer St. Clair Russell¹⁰, Dori Schatell¹¹, Lana Schmidt¹², Dale Singer¹³, Stephanie Stewart¹⁴, Amy Swoboda¹⁵, Brandy Vinson¹⁶, Peter Woods¹⁷, Jamie Green⁸, Patti Ephraim¹⁸, Tara Strigo¹⁰, L. Ebony Boulware¹⁰. ¹University of South Carolina, Columbia, SC, USA; ²Patient, Bloomsburg, PA, USA; ³Patient, Jacksonville, FL, USA; ⁴National Kidney Foundation, New York, NY, USA; ⁵Adventist Health, Portland, OR, USA; ⁶American Association of Kidney Patients, Tampa, FL, USA; ⁷Patient, Montgomery, AL, USA; ⁸Geisinger Health System, Danville, PA, USA; ⁹Family Member, Mooresville, NC, USA; ¹⁰Duke University School of Medicine, Durham, NC, USA; ¹¹Medical Education Institute, Inc., Madison, WI, USA; ¹²Patient, Liberty, IL, USA; ¹³Renal Physicians Association, Rockville, MD, USA; ¹⁴Council of Nephrology Social Workers, NY, NY, USA; ¹⁵Family Member, Edgewater, MD, USA; ¹⁶Mid-Atlantic Renal Coalition, Richmond, VA, USA; ¹⁷Patient, Hartsdale, NY, USA; ¹⁸Johns Hopkins University, Baltimore, MD, USA
- 3 **Clinical Social Work End-of-Life (EOL) Survey**
Kevin A. Ceckowski¹, Dustin J. Little¹, Joseph R. Merighi², Teri Browne³, Marie Salimbeni¹, Elizabeth I. Jones⁴, Christina M. Yuan¹. ¹Walter Reed National Military Medical Center, Bethesda, MD; ²University of Minnesota-Twin Cities, St Paul, MN; ³University of South Carolina, Columbia SC; ⁴DaVita Sterling, Sterling, VA, USA

Transplantation

- 4 **Factors Affecting Interest in Transplant among End-Stage Renal Disease Patients Receiving Dialysis**
Deborah Evans,¹ Duane Dunn,¹ Rich Mutell,² Paul Broughton,² Deborah Benner¹. ¹DaVita Inc, Denver, CO, USA; ²Apex Health Innovations, Simi Valley, CA, USA

Other

- 5 **Shared Contracting in a Pediatric Dialysis Center**
Connie Perkins. Levine Children's Hospital, Charlotte, NC, USA
- 6 **The Thrills and Ills of Encouraging Employment Amongst ESRD Patients**
Wendy Tan, Wei Bin Chua, Job Loei, Srikanthan Rajagopalan, Crystal Goh. National Kidney Foundation, Singapore

1. **INCIDENCE OF PAIN AND DEPRESSION AMONG PATIENTS WITH END-STAGE RENAL DISEASE:** Kathryn Aebel-Groesch, Duane Dunn, Nancy Culkin, Angie Major, Sean Mayes, Deborah Benner; DaVita Inc, Denver, CO, USA

Chronic pain and depression can impact quality of life and adherence to treatment regimen among patients with end-stage renal disease (ESRD). Previous research has demonstrated that patients with ESRD experience pain and depression more frequently than the general population. From 2016, CMS has required that all eligible ESRD patients are evaluated regularly for pain and depressive symptoms.

We assessed pain and depression symptom scores among patients of a large dialysis organization (LDO) over the period Mar-Oct 2016. Pain is assessed monthly by LDO nurses using the Wong-Baker pain scale (0-10). Depression screenings are conducted biannually by LDO social workers using the PHQ-2 (scale 0-6) and exclude patients with existing diagnosis of depression or bipolar disorder, cognitive impairment or language barrier, and those who were hospitalized or refused screening.

A total of 688,346 pain responses from 160,626 individual patients and 223,421 depression screening responses from 158,172 patients were considered. A score of 0 (no pain) was reported for 83.5% of pain responses and 65.7% of patients had a 0 score in all pain assessments. A score of 10 (most severe pain) was reported at least once during the study period by 3.0% of patients. Patients with a pain score of 10 were more frequently female (55%) and patients on peritoneal dialysis were less likely to have a pain score of 10 than those on other modalities. A depression score of 0 (patient answered "Not at all" to both "Little interest or pleasure in doing things" and "Feeling down, depressed, or hopeless") was reported for 69.1% of all responses and 62.6% of patients had a 0 score in all assessments; 1.8% of patients had at least one score of 6 (patient responded "Nearly every day" to both questions) and 9.7% had at least one score of 3 or more.

The majority of ESRD patients did not report pain symptoms and, among those not excluded from screening due to an existing diagnosis or other reason, the majority did not report symptoms of depression. However, routine assessment of pain and depression enables the timely identification of new or increased symptoms, thus allowing earlier implementation of interventions that may improve patient experience.

2. **PUTTING PATIENTS AT THE CENTER OF KIDNEY CARE TRANSITIONS: A PARTNERSHIP MODEL FOR KIDNEY DISEASE PATIENTS, FAMILY MEMBERS AND COMMUNITY STAKEHOLDERS IN PATIENT CENTERED OUTCOMES RESEARCH:** PREPARE NOW Workgroup, Durham, NC, USA

Patients, family members & community stakeholders are often peripherally engaged in patient centered outcomes research (PCOR). Our novel model includes patients & family members as Co-Investigators & community stakeholders as research partners in a currently funded clinical trial. Seven patients, 2 family members & 7 kidney stakeholder organizations partnered with researchers to develop an intervention, establish outcomes & write a proposal. We transcribed our meeting discussions, identified common themes, & refined our ideas prior to funding. Patients & family members were leading participants in all pre-award discussions & contributed to more than 5 major study design revisions.

Together, we created solutions to collaboration barriers (knowledge sharing, topic selection, time commitment, compensation). Patients & family members identified their most important research outcomes: control, empowerment, acceptance, grief, anxiety, depression & CKD knowledge. Patients & family members are Co-Investigators on this project, provide feedback on all components of the study protocol, revise all recruitment & communications materials, & ensure all aspects of the intervention respond to patient & family members' needs. Stakeholders are active participants in all of our project work groups, make recommendations related to project sustainability & dissemination, & along with the patient & family member Co-Is meet at least monthly with the team. Patients, family members & stakeholders can be fully engaged in research projects, thereby substantially improving the relevance & quality of PCOR studies. Our example could serve as a model to improve kidney disease PCOR studies & patient care.

3. **CLINICAL SOCIAL WORK END-OF-LIFE (EOL) SURVEY** Kevin A. Ceckowski¹, Dustin J. Little¹, Joseph R. Merighi², Teri Browne³, Marie Salimbeni¹, Elizabeth I. Jones⁴, Christina M. Yuan¹. ¹Walter Reed National Military Medical Center, Bethesda, MD; ²University of Minnesota-Twin Cities, St Paul, MN; ³University of South Carolina, Columbia SC; ⁴DaVita Sterling, Sterling, VA, USA.

Clinical medical surgical social workers (CMSSW), mental health (CMHSW), and nephrology SW (CNSW) are critical to assisting nephrologists in conversations about Advance Directives (AD)/Medical Orders for Life-Sustaining Treatment (MOLST). We surveyed 221 clinical SW about EOL care, with a 49-item, anonymous on-line survey (Oct-Nov 2016). Response rate was 38%; 80% were CNSW, 13% CMSSW, and 7% CMHSW. Responses: 73% had caseloads >60 patients, averaging 15 deaths/year; 74% reported <25% of deaths were surprising/unanticipated; 68% reported ≤10% of patients were in hospice at the time of death; 45% reported ≤25% of patients had an AD/MOLST. Among SWs, 36% had a fully executed AD/MOLST; 52% had assisted a family member to complete an AD/MOLST. SWs with an AD were significantly more likely to have assisted a family member (p<0.001). In 51%, a life event had changed their opinion of EOL care. Only 42% stated that physicians discuss EOL care with patients, and 52% disagreed that physicians discuss AD with patients. The most frequent EOL referral barriers were physician discomfort discussing palliative care (63%) and hospice insurance (68%). About half agreed that they discuss hospice benefits with patients. In summary, SWs were comfortable having patient EOL discussions, but observe that many physicians do not discuss AD, and are uncomfortable discussing palliative care/hospice insurance issues.

The views expressed in this report are those of the authors, and do not reflect the official policy of the Department of the Army, the Department of the Navy, the Department of Defense, or the United States Government.

4. **FACTORS AFFECTING INTEREST IN TRANSPLANT AMONG END-STAGE RENAL DISEASE PATIENTS RECEIVING DIALYSIS:** Deborah Evans,¹ Duane Dunn,¹ Rich Mutell,² Paul Broughton,² Deborah Benner¹; ¹DaVita Inc, Denver, CO, USA; ²Apex Health Innovations, Simi Valley, CA, USA

For patients with end-stage renal disease (ESRD) receiving dialysis, receipt of a transplant offers the best possible long-term treatment option. The process of qualification for transplant involves many steps, beginning with the patient's statement of interest. We sought to characterize transplant interest among patients of a large dialysis organization (LDO) in the US and to explore reasons identified by patients for lack of interest in transplant.

Data on patient transplant status were derived from LDO electronic health records; this information is collected by LDO social workers during the course of routine care. Transplant status categories considered were: active, delisted, denied, in work-up, inactive, not interested, on hold, and pending patient follow-up. Reasons for lack of interest were assessed among patients not interested in transplant and characteristics of patients not interested in transplant were compared to those of patients with transplant status listed as active.

As of November 2016, there were 182,906 patients with available transplant status information in the LDO database. Of these, 58,057 (31.7%) expressed that they were not interested in transplant. Among patients not interested in transplant, the most frequently identified reasons for lack of interest were "advanced age" (25.7%), "perceived poor health" (12.0%), "comfortable with current modality" (12.0%), and "uninterested in further surgeries" (11.9%). Compared to patients with transplant status listed as active, those not interested in transplant were older (21.4% < 60 years vs 64.6%), more likely to be female (47.7% vs 36.6%); more likely to be white (43.9% vs 30.4%) and less likely to be Hispanic (14.7% vs 22.2%); more likely to be receiving in-center hemodialysis (92.0% vs 73.7%); and more likely to have Medicare as primary insurance (91.3% vs 77.3%).

Transplant education should respect the specific needs and choices of individual patients. Further research is needed to evaluate whether education and referral to a transplant center could provide patients with greater insight into transplant as an alternative to their current modality.

5. SHARED CONTRACTING IN A PEDIATRIC DIALYSIS

CENTER: Connie Perkins, Levine Children's Hospital, Charlotte, NC, USA

Adherence to medical plans is crucial to optimizing successful outcomes for patients facing ESRD/dialysis. Formulating an *Understanding of Expectations* that includes patient/family input in developing the contract, outlining shared expectations, promotes buy-in and empowers the patient/family.

Patients/families identified by a healthcare professional as having difficulty adhering to their medications, treatments, appointments or meeting other behavioral expectations, were asked to meet with the medical team to share in problem solving the issue. Concerns and possible barriers to adherence were identified. Each participant clarified their expectations and responsibilities in helping the patient/family meet with success. The discussion resulted in a shared agreement of expectations.

Seven patients participated in the shared contracting from 1/2015 – 10/2016. The average patient age was 9.28±8.49 years. Of those, 71% of patients were on hemodialysis and 29% were on peritoneal dialysis. 71% of patients were female. The issues addressed included: treatment related (43%); fluids (29%); medication (14%); and appointments (14%). One month following the review and signing of the *Understanding of Expectations* contract, expectations were met in all areas with the exception of the adherence to dietary fluid allowance. Those improvements were inconsistent over the subsequent months. Expectations were reviewed during monthly care meetings and adjusted as needed.

Involving patients/families in developing *Understanding of Expectations* contracts and working as a team to address areas of concern enhances relationships and improves patient engagement. Including responsibilities for the healthcare team reduces the punitive perception of contracting and reinforces a team approach to healthcare. Continuous education, positive reinforcement and inclusiveness may positively impact patient adherence.

6. THE THRILLS AND ILLS OF ENCOURAGING

EMPLOYMENT AMONGST ESRD PATIENTS: Wendy Tan, Wei Bin Chua, Job Loei, Srikanthan Rajagopalan, Crystal Goh, National Kidney Foundation, Singapore

In National Kidney Foundation Singapore (NKFS), we have over 4,000 needy patients receiving subsidised dialysis treatment. Regular dialysis and prolonged treatment impairs the physical and emotional state of End Stage Renal Disease (ESRD) patients. These patients opine that their current state of health limits their ability to perform certain job roles which are considerably physically demanding, such as being a driver, food & beverage/retail assistant, construction/ engineering positions etc. Coupled with age and long-standing diabetic conditions, these factors further impede patients' functional status — i.e. level of clear vision, mobility independence, cognitive and alertness status, and heavy lifting ability. Formative research is conducted to explore and guide the aspects of motivation and resilience in ESRD patients. This research will gain insight into effective programme planning, develop better support systems for patients and how to optimise their rehabilitative outcome. It will also help in problem identification and solving through the provision of employment assistance. The research outcome will allow multi-disciplinary teams to better understand the patients' psychological well-being, suitable work conditions and employment needs for their patient clients. NKFS seeks to understand a patients' experience under this new initiative. Through this study, we would like to identify areas that patients were successfully supported and highlight the potential aspects that are important to further address. Through this formative study, NKFS also seeks to determine the sufficiency of the programme to meet patients' needs and capabilities. This qualitative study aims to document patients' experience of seeking and attaining employment. Through Interpretative Phenomenological Analysis (IPA), this study adopts semi-structured interviews to document patients' experience. Analysis is conducted after interviews to highlight patients' experience, areas that were successful as well as to identify areas for support enhancement. Formative research — 12 Focus group discussions with the target group comprises of patient employees of NKFS and patient job seekers. 6 In-depth interviews on attitudes, norms experiences, behavioural responses in seeking employment, and satisfaction reviews from the employers.