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NATIONAL KIDNEY FOUNDATION
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1. DIALYSIS CENTER STAFF KNOWLEDGE AND ATTITUDES REGARDING ORGAN AND TISSUE DONATION

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Individuals often look to their health care professionals for guidance when making health care decisions, including the decision of whether or not to be an organ donor. To date, studies have looked at the organ donation attitudes and knowledge of staff in ICUs and EDs; however, few studies have surveyed staff in dialysis centers. Dialysis center employees work directly with patients who are both waiting for a transplant and have the potential to be organ donors. Any individual, of any age or health status, may sign up on the Donor Registry.

A consortium consisting of the NKF of Michigan (NKFM), Greenfield Health Systems (GHS), Henry Ford Health System, Gift of Life Michigan, and the University of Michigan surveyed 210 GHS staff, including administrative staff, dialysis technicians, dietitians, nurses, reuse staff, and social workers, regarding their donation attitudes and knowledge. Staff at twelve GHS dialysis units in Southeast Michigan received a one-hour education session about organ donation as part of a larger study to determine the effectiveness of a Peer Mentor intervention to increase knowledge and awareness among dialysis patients about their option to become organ donors.

At baseline, 48% of staff reported already signing up on the Donor Registry; among those not currently signed up, 38.4% indicated high intent to do so. No significant differences in mean attitude scores were found between type of staff on most items. Overall f-test shows significant difference in mean scores between type of staff on "Peer mentors can encourage patients to sign up as donors"; no difference in pairwise comparisons. Exploratory factor analysis data will be reported.

3. ENVIRONMENTAL SCAN OF KIDNEY TRANSPLANT REFERRAL PRACTICES IN THE SOUTH EASTERN UNITED STATES

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The Southeastern United States has the lowest kidney transplant (KTx) rates in the country; this may be due in part to dialysis facility referral practices. Our aim was to identify the attitudes, common practices, and perceived barriers dialysis professionals in this region have to KTx. Every dialysis unit in ESRD Network 6 (n=586) was invited to participate in a survey regarding dialysis facility practices in KTx; the completion rate was 93.2%. Data were analyzed with descriptive statistics to determine trends in responses and provide foundational information for bivariate and multivariate analyses.

Completed surveys were analyzed for GA (47.5%), NC (31.9%) and SC (20.6%) dialysis facilities by nurse managers (51.0%) or social workers (26.3%). Almost all (98.4%) reported that they were comfortable discussing KTx with patients, and over 80% have a protocol in place for KTx education. Most staff reported that more than 50% of their patients were either ineligible or not interested in transplant (X^2 p-value<0.0001). Eighty-eight percent of staff believed that less than half of their patients referred for transplant completed the evaluation process and were placed on the waitlist.

More than one quarter of GA staff agreed that patient interest was a barrier to KTx, compared to NC (23.2%) and SC (23.9%) (X^2 p-value=0.023). Other patient-level barriers identified were: lack of patient education materials (34%), insufficient patient social support (61%), patient transportation (74%), and patient financial status (89%).

This is the first study in the Southeastern United States to survey dialysis professionals to determine barriers and attitudes about KTx. This study may help formulate research and program development in order to eliminate identified barriers and improve dialysis patient outcomes related to KTx.

2. TREATING DEPRESSION IN THE DIALYSIS SETTING: VALIDATING SYMPTOM TARGETED INTERVENTION

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Approximately 25% of all end-stage renal disease dialysis patients are depressed, which increases risk of infections and missed dialysis sessions, leading to increased hospitalizations and mortality rates (Boulware et al: *Clin J Am Soc Nephrol* 2003;1(3):496-504 and Weiner et al: *Soc Work Health Care* 2010;49(6):513-25). In 2011, 46 nephrology social workers participated in a nationwide Practice Outcome Evaluation (POE) to determine if symptom targeted intervention (STI) would improve the Kidney Disease Quality of Life (KDQOL-36) and Center for Epidemiologic Studies Depression Scale (CES-D 10) scores of patients involved in the project (Sledge et al, *Nephrol News Issues* 2011;25(7):24-25,28-31). Following STI counseling patients' KDQOL-36 and CES-D 10 scores were improved over baseline; however, mean patient-level score improvements did not reach statistical significance.

In 2013, 89 social workers in a large dialysis organization replicated the STI POE. Statistical Package for Social Sciences software was used to determine if changes in patient scores were statistically significant (pre- and post-dependent T test). Social workers received weekly training via WebEx and conference calls prior to and throughout the 6-week intervention period.

KDQOL-36 and CES-D 10 questionnaires were completed by each participating in-center hemodialysis patient (N = 91) prior to and after completion of the 6-week intervention period. Statistically significant improvement occurred in KDQOL-36 Mental Component scores (p < 0.001), Physical Component scores (p = 0.042), as well as Burden (p < 0.001) and Effects (p = 0.001) domain scores.

The results indicate that nephrology social workers can use STI to help in-center hemodialysis patients improve their quality of life scores and positively impact their level of depression.

4. KIDNEY TRANSPLANT CANDIDACY OF LONG TERM CARE RESIDENTS- A NATIONAL SURVEY

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Due to an increasingly healthier older adult population and advances in medical treatments for many chronic illnesses and serious injuries, kidney transplant centers are now receiving a greater number of referrals for patients in end-stage organ failure that live in long-term care settings (LTC). To build the literature related to kidney transplantation of long term care residents, we conducted a national online survey of kidney transplant social workers, physicians and surgeons to assess best practices in this area.

126 transplant professionals completed the survey in 2013. Almost 50% of those (47%) reported that their center has transplanted someone who resided in LTC, 27% had not, and 27% did not know if they had. The following reasons were given for not approving a LTC resident for a kidney transplant: risk of infection (43%); poor use of scarce resources (34%); likelihood of medical comorbidities (66%) and no improvement in patient quality of life (69%).

Respondents were given hypothetical patient scenarios to assess the transplant candidacy of LTC residents with poor social support, moderate mental retardation, and a stable neurological condition (such as Parkinson's disease). There was no significant majority consensus on any of the scenarios of the transplant consideration of the LTC residents as described. Exactly half of the professionals said that they would (50%) or would not (50%) transplant a LTC resident with poor social support. 53% reported that they would provide a LTC resident with moderate mental retardation (47% would not), and 54% would transplant a LTC resident with a stable neurological condition (46% would not).

The results of this national survey suggest that there is currently no best practice consensus among kidney transplant centers related to providing transplants long term care residents. Further research is needed in this area to help transplant centers provide services to LTC residents.

5. **PATIENT IDENTIFIED BARRIERS AND FACILITATORS TO KIDNEY TRANSPLANTATION**

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Purpose: Barriers in the access to kidney transplantation are a significant problem in the United States, and are most pronounced in the Southeastern region. To determine perceived barriers and facilitators to kidney transplantation in the Southeastern United States, we conducted patient focus groups in Georgia, North Carolina and South Carolina.

Methods: In 2012, we conducted three focus groups of kidney disease patients. Each focus group was 90 minutes in length; participants also completed a brief companion survey. An interview guide was used by the group facilitators to explore patient interest and personal experience related to kidney transplantation, perceived barriers and facilitators related to getting a kidney transplant, and ideas regarding how dialysis unit medical professionals can help patients receive a kidney transplant. A constant comparative method was used to identify themes that emerged from a line-by-line review of the focus group transcripts.

Results: Of the 40 participants, 14 (35%) were male, 25 (63%) were African American; 46% were on dialysis for more than two years. Participants described five main barriers to receiving a kidney transplant: financial, medical, informational, attitudinal, and the composition and behaviors of the dialysis team, medical providers, and others in their social networks. They identified finances, younger age, information, attitudes and beliefs, and helpful medical professionals and others as facilitators for getting a kidney transplant.

Conclusions: This study is the first of its kind to explore the barriers and facilitators of getting a kidney transplant in the Southeastern United States. The study findings provide the basis for responding to patient needs by the development of targeted interventions that can improve kidney transplant rates in a way that is patient-centered.

7. **SOCIAL WORKER DRIVEN PROGRAM TO REDUCE HEMODIALYSIS THERAPY NON-ADHERENCE:**

Stephanie Johnstone, Nien-Chen Li, Franklin Maddux, Eduardo Lacson, Fresenius Medical Care, North America, Waltham, MA, USA

Missed hemodialysis (HD) treatments associate with poor outcomes. As a quality improvement project, a social worker (SW) initiated intensive intervention program was implemented to improve treatment adherence and we report preliminary findings from the initial 93 participating Fresenius Medical Care North America facilities.

One hundred fifty-one (151) patients with ≥ 1 missed treatments per 12 week period underwent the 8-session intervention between March 1 and July 31, 2013. A session was attempted every 1 to 2 weeks. The intervention included patient-empowerment education and counseling designed to address potential root causes of non-adherent behavior as well as aggravating factors from 4 surveys: KDQOL-36, CESD-10, a Sleep Quality Screen, and a Stressors Screen. Pre- and Post-intervention survey scores were compared and the rate of missed treatments from the pre-intervention baseline was compared to the rate over the 3-months immediately after the intervention concluded.

The patients' mean age was 52.7 years, with 48% males; 58% white/31% black; 60% had diabetes mellitus. The baseline missed treatment rate (per 12 weeks) was 1.8 vs. 1.2 post-intervention ($p < 0.0001$). The survey results indicated significant improvement (all $p < 0.01$) of pre- to post-intervention scores for: CESD-10 depression scores (9.1 vs. 6.7), Family/Relationship Stressors (5.0 vs. 3.8), Financial/Insurance Stressors (5.2 vs. 4.3), Difficulty Falling Asleep (4.1 vs. 3.5), Difficulty Staying Asleep (4.4 vs. 3.8), Interrupted Sleep (4.3 vs. 3.5), and Difficulty Awakening (2.4 vs. 1.9). There was also improvement in perception of Kidney Disease Effects (66.5 vs. 73.6), Burden (42.5 vs. 49.6), Symptoms (71.9 vs. 75.2), and MCS (45.7 vs. 47.6). There was no significant difference in PCS, Restless Legs, and Stressors related to Health Symptoms or Loss/Grief.

Preliminary results indicated that an intensive SW-initiated intervention program was able to reduce missed treatments in the short term (3 months). Furthermore, indicators of quality of life and well-being that potentially contributed to the non-adherent behavior also improved, which may help sustain the favorable results over the long term. This study is ongoing and updated outcomes will subsequently be reported.

6. **DIALYSIS PATIENT ATTITUDES AND KNOWLEDGE ABOUT ORGAN AND TISSUE DONATION**

Denise Cyzman,¹ Allyce Smith¹, Sheri Stav², Ann Andrews¹, Holly Jenkins-Riley², Remonia Chapman³, Nanhua Zhang⁴, Jerry Yee^{2,5}, Ken Resnicow⁶

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The need for more organ donors is great, yet misconceptions about organ donation deter eligible individuals from signing up on donor registries. Inaccurate information about donation and chronic disease may lead to low consent rates among those living with end stage renal disease (ESRD). Many may believe that, due to kidney disease, they are ineligible to sign up on the Michigan Organ Donor Registry. However, anyone of any health status may sign up to donate their organs after death. ESRD patients are eligible to donate and may obtain a sense of empowerment in knowing they can give back. More information is needed both on the unique perspectives of dialysis patients on organ donation, as well as interventions to increase awareness among the dialysis community about donation.

A consortium consisting of the NKF of Michigan (NKF), Greenfield Health Systems (GHS), Henry Ford Health System, Gift of Life Michigan, and the University of Michigan surveyed 554 dialysis patients about their attitudes and knowledge regarding donation. Patients at 12 GHS dialysis units in Southeast Michigan received education about donation as part of a larger study is to determine the effectiveness of a Peer Mentor intervention to increase knowledge and awareness among dialysis patients about their option to become donors.

Baseline data shows that 54.5% of those participating indicated high intent to sign up. We report on the psychometric properties and correlates of a measure of organ donation attitudes and practices. We created two new a priori scales – Dialysis Barriers (alpha .78) and Dialysis Benefits (alpha .70). We will report the association of these scale scores with donation intention.

8. **ROOT CAUSES OF LACK OF ADHERENCE TO MINERAL BONE DISEASE (MBD) MEDICATION IN ESRD PATIENTS**

Maureen McKinley

DaVita Healthcare Partners Inc., Irvine, California, USA

Adherence with MBD medications amongst ESRD patients is estimated to be only 50%. Dietitians managing MBD in hemodialysis patients are challenged to determine accurate root causes of missed doses and to perform interventions that improve adherence.

Fifty patients across 17 hemodialysis clinics were interviewed on a weekly basis over a 12-week period to determine the root causes for missed MBD medication doses. Social workers and dietitians alternated meeting with patients, using a "Patient Encounter Tool" to identify root causes for missed doses. Interventions specific to each root cause were performed and recorded on the tool.

The most frequently cited reason for missing doses was "Forgot to take" at 41%. The second most frequent reason was "Ill and not eating as many meals" at 10%. Patients reported having financial barriers to obtaining their medications only 3% of the time. Of the patients in the study, 24% reported never forgetting to take their medications, while 66% reported forgetting 5 times or less. Only 10% of patients reported forgetting 5 times or more. The phosphorus values of 58% of the patients improved during the 3 months of the study.

Adherence with MBD medications is a problem in the ESRD population. In this study, the major reason reported for non-adherence was forgetfulness. Interventions focused on helping patients remember to take their pills, like placing pills in an area where they are readily visible, setting an alarm, or carrying pills with them. Both dietitians and social workers found collaboration around medication adherence to be valuable, although 30% of social workers reported having difficulty working this additional task into their schedules.

9. **NON-ADHERENCE IN INDIVIDUALS ON HEMODIALYSIS: A DISCUSSION OF THREE THEORIES TO IMPROVE ADHERENCE:** R. Lee Phillips, The University of Georgia, Athens, GA, USA
- Adherence continues to prove challenging in work with Hemodialysis patients. This presentation explores three theories that can guide practice when working to improve compliance with individuals on hemodialysis. The Theory of Planned Behavior (TPB), the Common-Sense Model (CSM), and Motivational Interviewing (MI) each offer insight into behavioral change and the internal processes of individuals. Each theory seeks to empower the individual and sees client involvement as critical to patient care and improved health related outcomes. Understanding the tenants of these three theories can guide social work practice beyond education and the dissemination of health related information in order to improve compliance.

10. **MEDICATION SELF-MANAGEMENT AND ESRD: ASCERTAINING A FUNDAMENTAL CAUSE**

Tamara Estes Savage

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Poor medication self-management leads to increased risk for morbidity and mortality in ESRD patients. Much research also has shown that there are poor rates of medication self-management in the ESRD population. In addition, there is research that race/ethnicity is associated with unsuccessful medication self-management. Specifically African Americans have poorer rates of medication self-management when compared to Whites. However, the reasons for this racial inequity are not understood beyond the identified proximal risk factors. This is particularly troubling since ESRD patients who do not adhere suffer decreased quality of life, increased morbidity, and death. Hence medication nonadherence is an important health inequity that is worthy of further investigation.

As a first step in exploring beyond the proximal risk factors, poor medication self-management as it relates to the health inequity, a literature review was conducted to examine the broader social conditions, fundamental causes, that contribute to this lack of parity in the ESRD population. An online search was conducted from August 2013 to December 2013 using MEDLINE, PubMed, Ovid, CINAHL, and PsychLIT databases to identify research and summarize findings from meta-analyses, systematic reviews, clinical reviews, and clinical trials published in English between January 1985 and December 2013, as they relate to fundamental causes of patient medication self-management. The results of this literature search suggest that there are indeed social conditions such as racism and structural racism which may be fundamental causes of the problem of parity as it is related to medication self-management in the ESRD population. Many barriers are explicated in the extant literature; however, little pertain to the unique circumstances of minority groups living in a society where racism is prevalent. Therefore, further research needs to be conducted to ascertain the unique factors related to unsuccessful medication self-management in minority ESRD patients.