

National Kidney Foundation 2016 Spring Clinical Meetings Abstracts April 27 – May 1, 2016

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Kevin A. Ceckowski¹, Dustin J. Little¹, Joseph R. Merighi², Teri Browne³, Christina M. Yuan¹. ¹Walter Reed National Military Medical Center, Bethesda, MD, USA; ²University of Minnesota–Twin Cities, St. Paul, MN, USA; ³University of South Carolina, Columbia, SC, USA
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- 1 RESULTS OF A NEPHROLOGIST END-OF-LIFE PRACTICE SURVEY:** Kevin A. Ceckowski¹, Dustin J. Little¹, Joseph R. Merighi², Teri Browne³, Christina M. Yuan¹
¹Walter Reed National Military Medical Center, Bethesda, MD, USA; ²University of Minnesota—Twin Cities, St. Paul, MN, USA; ³University of South Carolina, Columbia, SC, USA

There has been increasing focus on training nephrologists to recognize and refer end-stage renal disease (ESRD) patients likely to benefit from palliative and hospice care. We assessed barriers and facilitators associated with end-of-life (EOL) discussion and referral among current Walter Reed Nephrology Fellowship Program faculty and program graduates since 1980.

A 17-item anonymous on-line survey was administered from July and October 2015, and 57/93 surveys were received (61% response rate). The majority practiced clinical nephrology (95%), 64% had been in practice >10 years, and 65% resided in the Southern US.

Ninety-two percent indicated that they felt comfortable discussing EOL care, and no significant difference was found between those with ≤10 years and those with >10 years of practice experience (p=0.28). Thirty-one percent reported referring ESRD patients to EOL care “somewhat” or “much less often” than indicated. The most frequently chosen barriers preventing EOL referral were: time-consuming nature of EOL discussions (27%); difficulty in accurately determining prognosis for <6 month survival (35%); patient (63%) and family member (71%) unwillingness; and patient (69%) and family member (73%) misconceptions. Half (51%) indicated they would refer more patients if dialysis or ultrafiltration could be made available during hospice care. Some observed that local palliative care resources (12%) and local hospice resources (6%) were insufficient.

Surveyed clinical nephrologists were comfortable with EOL care discussion and referral. However, considerable patient, family and system barriers exist, and many nephrologists reported less than indicated rates of referral for EOL care. Additional efforts are needed to overcome familial and structural barriers to facilitate timely referral for EOL care and services.

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.

- 3 TRANSITIONING FOR YOUNG ADULTS ON DIALYSIS**
 IPRO/ESRD Network of NY Transition Working Group
 Noghrey, B; Smith, E.(IPRO); Doyle, M. H.(CHAM); Amaral, S.(CHOP); Fernandez, H. E.(CUMC); Kaskel, F. (CHAM)
Background: The transition to adult-oriented care is a crucial element of healthcare for youth with CKD and ESRD. Approximately 2000 individuals <18 are receiving dialysis in the U.S, awaiting a first transplant or after graft loss. Despite improving survival rates of adolescents with ESRD, and the existence of transitioning guidelines, evidence suggests poor health outcomes and mortality (related to cardiovascular and infection-related causes, as well as psychosocial factors) are associated with the transition out of pediatric care for young adult dialysis patients.
Method: The IPRO/ESRD Network of NY has developed a survey of NYS dialysis providers to assess preparation for transition, the typical age of transfer, and the assumption of care by dialysis providers and units traditionally serving an older adult population. The group is exploring ways to utilize historical CMS data to assess transition outcomes for young adult ESRD patients over the last 5-10 years.
Findings: Out 263 dialysis facilities across NY State, 38 facilities care for 110 patients <21. An additional 600 patients ages 21-30 are cared for at 194 facilities. Survey will be sent to administrators of dialysis facilities caring for patients under the age of 25 across NY State, to capture data about the transitioning practices and outcomes in pediatric- and adult-oriented facilities.
Implications: This pilot investigation may provide a model and markers for assessment and quality improvement of transitioning practices in dialysis for other states and on a national basis.

- 2 A MULTIDISCIPLINARY AND PEER MENTOR APPROACH TO EDUCATING CKD PATIENTS ALONG THE CONTINUUM**
 Karen Crampton, Terri Holewinski, Therese Adamowski, University of Michigan Dialysis, Ann Arbor, MI

Many studies have shown that patients with the skills, ability, and willingness to manage their own health and health care, experience better health outcomes at a lower cost. As a result, a program was developed at University of Michigan Health System to educate patients by a multidisciplinary team (nurse, dietitian and social worker) and peer mentor. The education is done monthly in two sessions, lasting 2 hours. The referral sources include internal nephrologists as well as nephrologists in the community. The first session summarizes how kidneys work, the causes of kidney disease, enhanced nutrition to slow progression, and adjusting to chronic illness while using a motivational interviewing approach. The second session focuses on treatment options for kidney failure, optimal nutrition and adjusting to chronic illness. This session includes a peer mentor that shares their experiences as a chronic kidney disease/dialysis patient. The entire process empowers patients to know as much as they can about their disease, diet and treatment while also learning how to cope with the various challenges related to kidney disease and dialysis. The multidisciplinary team and peer mentor approach help patients and families understand their illness and treatment plans. It also engages patients and families in shared decision-making as promoted in patient and family centered care.

- 4 EMPLOYMENT STATUS AMONG END-STAGE RENAL DISEASE PATIENTS BY DIALYSIS TREATMENT MODALITY:**
 Duane Dunn,¹ Deborah Evans,¹ Rich Mutell,² Caroline Hann,¹ Deborah Benner¹

¹DaVita HealthCare Partners Inc, Denver, CO; ²Apex Health Innovations, Simi Valley, CA

Patients with end-stage renal disease (ESRD) receiving dialysis who are employed have been shown to have higher quality-of-life scores than those who are unemployed. Patients on peritoneal dialysis (PD) and home hemodialysis (HHD) are often younger than patients receiving in-center hemodialysis (HD) and may additionally have greater flexibility to work. To inform the development of initiatives to help patients remain in employment or return to work, we sought to characterize patient employment status by treatment modality among patients of a large dialysis organization (LDO) in the United States.

Data on patient employment status and treatment modality were derived from LDO electronic health records. Employment status information is collected by LDO social workers every 6 months for patients of age < 60 years and at least annually for patients of age ≥ 60 years during the course of routine care.

There were 156,524 active patients in the LDO dataset as of 15 November 2015. Of these, 23.7% (n=37,160) were unemployed, 12.8% (n=20,084) were employed (full-time, part-time, or per diem), and 41.2% (n=64,427) were retired. The proportion of patients classified as employed was lower for patients on HD than for those on PD and HHD (11.0% vs 25.1% and 27.8%) and, conversely, the proportion classified as retired was higher for patients on HD than for those on PD and HHD (42.5% vs 33.0% and 25.8%), reflecting the differing age distributions for patients on each modality. However, the proportion of patients who were unemployed was largely consistent across modality types (24.2%, 20.3%, and 22.0% for HD, PD, and HHD, respectively).

Patients on PD and HHD are more likely to be employed and less likely to be retired than those receiving HD. However, unemployment rates are high across all dialysis modalities. Initiatives designed to support patients who choose to continue working or return to employment should therefore target patients across all modalities.

- 5 BARRIERS TO EMPLOYMENT AMONG END-STAGE RENAL DISEASE PATIENTS RECEIVING DIALYSIS:** Deborah Evans,¹ Duane Dunn,¹ Rich Mutell,² Elizabeth Jones,¹ Deborah Benner¹
¹DaVita HealthCare Partners Inc, Denver, CO; ²Apex Health Innovations, Simi Valley, CA
- Patients with end-stage renal disease (ESRD) receiving dialysis who are employed have been shown to have higher quality-of-life scores than those who are unemployed. Despite this, unemployment rates are very high among the ESRD patient population and we sought to assess the barriers to returning to work perceived by unemployed patients of a large dialysis organization (LDO) in the United States.
- Patient employment status and patient-reported barriers to employment were derived from LDO electronic health records. Employment status information is collected by LDO social workers every 6 months for patients of age < 60 years and at least annually for patients of age ≥ 60 years during the course of routine care.
- Of 156,524 active patients identified in the dataset as of 15 November 2015, 23.7% (n=37,160) were classified as unemployed; of these, 21.3% (n=7902) reported being interested in working. In this subset of patients, the most frequently cited barrier to employment was “I don’t have enough energy and/or feel too ill to work” (34.4%), followed by “I have a disability and don’t think I should be working” (11.1%) and “I need job training to return to employment” (7.7%). Stratification of patients by age revealed that while lack of energy/feeling too ill was consistently reported as the leading barrier to employment across all age categories, disability was identified more frequently by older patients. Need for job training and issues relating to childcare and transportation were more frequently listed as barriers by younger patients.
- Among unemployed dialysis patients interested in working, lack of energy/feeling too ill was the most frequently identified barrier to employment; the relative significance of other factors varied based on patient age. To be most effective, initiatives designed to support patients returning to work should target the specific issues that may prevent patients from working and should take into account the differences across age groups.
- 6 RE-FRAMING THE GIFT OF LIFE: A COMPARISON OF FACTORS INVOLVED IN NON-DIRECTED KIDNEY DONOR MOTIVATION FOR SOCIAL WORKERS AND NURSES** Harry Humphries, Browyn Conrad, Cheryl Giefer, Amy Hite, Kristen Humphrey and Kathryn Potter, Department of History, Philosophy and Social Sciences and Irene Ransom Bradley School of Nursing, Pittsburg State University, Pittsburg, KS, USA.
- The purpose of this study examines donor motivations using a research design from earlier investigations evaluating the persuasiveness of the National Kidney Foundation’s (NKF) altruistic “gift of life” frame. Earlier studies produced mixed results, in particular, showing substantially more support for material incentives among an international sample of nursing professionals as compared to a convenience sample of college students.
- The method for this study compared practitioners in the fields of nursing and social work and their motivation for donating a kidney. A total of 159 social workers and nurses participated in a survey that addressed not only the relationship between material incentives, social distance and motivation to donate but also work-related burnout and compassion fatigue as structural factors that might reduce donor motivation.
- The results show a significant negative relationship between altruism and donor motivation as measured by social distance between donor and recipient and a strong lack of support for direct cash incentives as a complement to living kidney donation. The results also show a little to no compassion fatigue than could potentially account for either of these results. Final conclusions show that social workers are somewhat more altruistic than nurses and both groups support some material incentives but the differences between the two groups are not meaningful.
- 7 ASSOCIATION BETWEEN SLEEP QUALITY AND HEALTH RELATED QUALITY OF LIFE IN HEMODIALYSIS PATIENTS ENROLLED IN A SOCIAL WORKER QUALITY IMPROVEMENT PROGRAM:** Nien-Chen Li, Stephanie Johnstone, Felicia Speed, Dugan Maddux, John Larkin, Len Usvyat, Peter Kotanko, Franklin W Maddux, Fresenius Medical Care North America, Waltham, MA, USA, Renal Research Institute, New York, NY, USA
- As part of a social worker (SW) quality improvement program, we investigated if low self-reported sleep quality (SQ) is associated with worsened outcomes in the 5 summarized KDQoL-36 domains in hemodialysis (HD) patients (Pts).
- Data was collected from 737 HD Pts at Fresenius Medical Care North America clinics that were enrolled into the SW program due to HD treatment non-adherence between 7/1/13 and 2/28/14. A 5-item SQ assessment (each scaled from 1-10) was surveyed at baseline. The 5 SQ items were placed into 3 domains by indications of factor analysis; these were difficulty sleeping (DS), difficulty awakening (DA), and restless legs (RL) during sleep. For each domain (DS, DA, & RL), the SQ was defined as “low” for scores greater than the median (worse SQ scores). Mean of KDQoL measures were calculated and compared between 2 SQ groups using t-tests. Associations of KDQoL and SQ were analyzed by multivariate regression with KDQoL as dependent variable, SQ (better vs. low) as independent variable, adjusted for age, gender, race, diabetes, coronary artery disease, and congestive heart failure. Effect sizes (Cohen’s d, regression estimates divided by standard deviations of domain scores) were calculated.
- Pts Mean age was 53.4 (±13.6) years, 51% males, 59.6% white, and 54% with diabetes. The mean SQ scores (range 1-10) for the three factors were DS=4.5, DA=2.4, and RL=3.2. All 5 KDQoL measures were adversely associated with DS (p<0.0001), with effect sizes ranging from 0.46 to 0.65. Mental Component Scores, Symptoms, and Effects of kidney disease were adversely associated with DA (p<0.01), with effect sizes ranging from 0.14 to 0.31. All 5 KDQoL domains were adversely associated with RL (p<0.05), with effect sizes ranging from 0.20 to 0.25.
- This study indicates that low SQ scores are adversely associated with all 5 measures of KDQoL scores in non-adherent HD Pts.
- 8 PREDICTORS OF LOW SLEEP QUALITY IN HEMODIALYSIS PATIENTS ENROLLED IN A SOCIAL WORKER QUALITY IMPROVEMENT PROGRAM:** Nien-Chen Li, Stephanie Johnstone, Felicia Speed, Dugan Maddux, John Larkin, Len Usvyat, Peter Kotanko, Franklin W Maddux, Fresenius Medical Care North America, Waltham, MA, USA, Renal Research Institute, New York, NY, USA
- It is not established if poor sleep quality (SQ) is associated with psychological conditions in hemodialysis (HD) patients (Pts). As part of a social worker (SW) quality improvement program, we investigated if low self-reported SQ is associated with depressive symptoms and perceived pain and psychological stress in enrolled HD Pts.
- Data was collected from 737 HD Pts at Fresenius Medical Care North America clinics that were enrolled into the SW program due to HD treatment nonadherence between 7/1/13 and 2/28/14. A 5-item SQ assessment (each scaled from 1-10) was recorded at baseline. The 5 SQ items were reduced into 3 measures by way of factor analysis: difficulty sleeping (DS), difficulty awakening (DA), and restless legs (RL) during sleep. For each of three measures, SQ was defined as “low” for scores greater than the median. The CESD-10 questionnaire, components of a Comfort Barriers Screening Tool (back pain, arthritis/bone pain, and pain or tingling in feet/legs/hands), and a Psychological Stressor Screening Tool (stress related to financial/insurance, family/relationships, health symptoms, loss/grief, and others) were used to determine the level of depressive symptoms, perceived pain, and psychological stress respectively.
- Pt demographics were: age 53.4 ±13.6 years, 51% males; 59.6% white, and 54% with diabetes. The mean SQ scores (range 0-10) for the three factors were DS=4.5, DA=2.3, and RL=3.2. Predictors of low SQ were: CESD scores >5 (for DS, DA & RL; p<0.01); comfort barrier of back pain (for DS & RL; p<0.01); comfort barrier of arthritis/bone pain (vs DS; p=0.04); comfort barrier of pain or tingling in feet/legs/hands (for RL; p<0.001); Stressors related to financial/insurance, family/relationships, health symptoms, and loss/grief (for DS, DA & RL; p≤0.01); Stressor related to other (for DS & DA; p≤0.01).
- This study indicates that low SQ is associated with depressive symptoms, perceived pain, and psychological stress in nonadherent HD Pts. Further studies of the impact of the SW interventions are needed.

9 DIALYSIS PROVIDERS' PERCEPTIONS OF TRANSPLANT BARRIERS FOR MINORITY AND LOW-INCOME PATIENTS ALONG LEVELS OF THE SOCIO-ECOLOGICAL MODEL

Anna-Michelle M. McSorley¹, Cynthia Gonzalez^{1,2}, John D. Peiper¹, Keith C. Norris¹, Christina J. Goalby¹, Leanne J. Peace³, Patricia A. Lutz³, Amy D. Waterman¹, 1. University of California, Los Angeles, Los Angeles, CA, USA, 2. Charles R. Drew University of Medicine and Science, Los Angeles, CA, USA, 3. Missouri Kidney Program, University of Missouri, Columbia, MO, USA

To explore racial/ethnic minority and low-income disparities in transplant pursuit, we conducted a mixed-methods study with 4 focus groups (n=48) and surveys (n=68), categorizing dialysis providers' perceptions of transplant barriers using the Socio-Ecological Model (SEM). The SEM considers how intra-personal (individual), interpersonal (social relationships), institutional (organizational), community, and public policy (national laws) factors impact behavior. Respondents were predominately social workers and nurses within Midwestern states. Two coders identified common focus group themes, with mean responses and frequencies for survey items calculated.

Providers strongly agreed that transplant would improve the quality of life for all patients (81%), including minority/low-income patients (79%). While they reported the presence of transplant-related barriers at every SEM level, they felt that minority/low-income patients had a greater focus on day-to-day survival (intra-), less social support to pursue transplant (inter-) and greater concerns about health insurance loss after transplant (public policy). For example, one provider stated, "I had patients that said nope, not going to get a transplant because I'd lose my Medicare after 3 years." Providers also reported that 40% of these patients struggle with reading at a 6th grade level, with one stating, "when they're so uneducated...you really have to sit down and talk with them." However, with >50% of providers reporting having limited time to offer transplant education, their perception of the greater levels of barriers may cause generalizations and failures to comprehensively educate or refer patients from these groups to transplant. Future work should seek input from patients, family, and community members to fully understand all perceptions and develop solutions that reduce barriers at all SEM-levels.

11 MATURE ADULT ATTITUDES AND PRACTICES TOWARD ORGAN AND TISSUE DONATION

Allyce Haney Smith¹, Ann Andrews¹, Caitlin Loughery¹, Remonia Chapman², Jerry Yee³, Ken Resnicow⁴
NKF of Michigan¹, Ann Arbor, MI, USA, Gift of Life Michigan², Detroit, MI, USA, Henry Ford Health System³, Detroit, MI, USA, School of Public Health, University of Michigan⁴, Ann Arbor, MI, USA

Sixty-five percent of the U.S. transplant waiting list is comprised of individuals over age 50 years. However, in 2013, only about 35% of deceased donors were over age 50. Many mature adults are supportive of donation but mistakenly believe that their age or health conditions preclude them from donating organs or tissues after death. In fact, anyone of any age or health status can join the Donor Registry and donate.

The NKF of Michigan, Gift of Life Michigan, and the University of Michigan have partnered on multiple cluster randomized design controlled intervention studies reaching mature adults over age 50 years. In a collaboration with Henry Ford Health System, dialysis patients at twelve dialysis units in Southeast Michigan, 51% of whom were over age 60 years, participated in a study to determine the impact of peer mentors discussing donation with patients on registrations to the state's Donor Registry. The consortium is currently utilizing organ transplant recipients to deliver a one-hour donation education session to participants in evidence-based health programs (EBP); 93% of participants in this study are over age 50 years. Participants in both studies were surveyed about their attitudes toward organ donation.

In the dialysis center study, the odds of signing up for organ donation among those who talked with a peer mentor were 2.34 times the odds in the control group (p-value =0.0046). The EBP baseline study data reveals that 30% self-report having signed up on the Donor Registry and 52% indicated high intent to sign up. Predictors and correlates of attitudes toward donation will be reported.

10 DEVELOPING PATIENT CENTERED COMMUNICATION: THE KEY TO IMPROVING OUTCOMES

Mary Rzeszut, North Shore/LIJ Dept. of Kidney Diseases, Great Neck, NY, USA.

Health care providers that care for chronic kidney disease patients deliver difficult information from relating initial diagnosis to discussing renal replacement therapy. Communicating this information and having a patient follow recommended treatment is challenging for all members of the interdisciplinary team.

Effective communication is an integral part of excellent patient care. It is more than being honest and courteous. Patient centered communication creates an understanding of the patient's individual needs, perspectives and values. Evidence demonstrates that patient centered communication builds trust; improves patient understanding and adherence to medical regimens; decreases hospital readmissions; promotes patient and provider satisfaction; and improves clinical outcomes.

Developing patient centered communication requires a specific set of communication skills that can be learned and improved with practice. These include fostering healing relationships; exchanging information to understand patients' wants and needs; responding to patients' emotions; engaging in shared decision making and enabling patient self-management.

Patients are often labeled difficult or in denial when healthcare providers do not know how to help them. Improving communication skills increases the likelihood of developing a deeper understanding of patients' behavior and health outcomes.

12 VIOLENCE IN THE DIALYSIS SETTING: A NATIONAL SURVEY

Mathias Stricherz, Jane Kwatcher, Michaela Kretzner. Montezuma, NM, Claremont, CA, Sacramento, CA

Although there is anecdotal information regarding threats and actual occurrences of violence in dialysis settings, reported events are protected by risk managers. To quantify occurrence, an independent national survey was conducted on the nature and extent of violence within dialysis settings. Survey respondents, N=272, represent the spectrum of US dialysis facility employees.

At least one incident of violence in the facility was reported by 74% of the respondents (58% reported ≥2 incidents), and 51% reported personal experiences of workplace violence.

Threats to direct care personnel come from, in descending order, patients, persons known to patients, staff, and strangers. Respondents (64%) report patients have initiated physical violence toward staff. Telephone harassment from patients to staff is reported by 21% of respondents. The most common physical assaults are from hitting and kicking, followed by assaults with body fluids. Incidents with weapons of opportunity (14%), knives (9%), and guns (7%) were also reported. 36% reported patient to patient violence. Death threats to staff were reported by 27% of respondents, and death threats to patients were reported by 6% of the respondents. Incidents of facility lockdown (39%) and police responses to facility were both reported (56%).

Only 23% of facilities have security or on-site law-enforcement, 25% have an emergency response system, 35% of the respondents report having a system or policy to notify employees within minutes of a threat. Training in defensive strategies is not provided to the majority of respondents. In addition, 26% of victims reported experiencing psychological trauma.

Due to the high number of respondents reporting workplace violence and the identified gaps, opportunities exist for improving security measures for dialysis facilities.

13 COACH4LIFE APP® A LIFESTYLE CHANGE TOOL FOR KIDNEY PATIENTS: Theodór Vogels, Máxima Medisch Centrum, Veldhoven, N.B., The Netherlands.

Patient education and empowerment has entered new territories by the increased availability of appliances like smart phones and tablets. The widespread popularity of computer games has evolved into applications for healthcare purposes in basic practical tasks like pedometers and medication reminders. Thus a group of kidney patients representing the Dutch renal patient Association and health care professionals consisting of nephrologist, a nephrology nurse practitioner, nephrology dietitian and a nephrology social worker; teamed up with technical experts in the development of Serious Games. The development of a Serious Game consists obviously in knowledge state of the art ICT technology but requires deep insight in psychological learning principles and adaptive methods.

The Dutch Kidney Foundation was supported in this project by a grant of the “Vrienden Loterij” to explore the possibility of patient empowerment by the use of an applied Serious Game. In March 2013 a multidisciplinary advisory committee was formed to help develop a Serious Game for kidney patients. The aim at the start of the development was to increase prevention of stages CKD 3-4 combining patient education and support lifestyle change. The use of a Serious Game concept made available through an App for use in both smart phone and tablet was to be a basic requirement. Earlier successful examples of the use of Serious Games, for instance in children oncology in had led to better medication adherence, increase of knowledge of the diseases and self-efficacy levels of young cancer patients.

The game would incorporate setting a goal chosen by the individual patient, a variable medication alert tool, feedback system to support the patient with advice to enhance self-efficacy and motivational aspects, a quiz and a button for email support and a dedicated social media group. The developed App was named Coach4Life®, demonstrating its purpose to support patients to strategies which could help increase their level of coping and self-management and was uploaded 1000+. It is obvious that the use of Serious Games in support of patients will evolve through new research and attuning to specific user-groups. Also it seems eminent that patient associations, together with health care professionals are aware of this new, and increasing field of patient support and are willing to incorporate the motivational support to patients to make use of them. Social workers can contribute to their development and promote the use amongst patients. We are awaiting the results of a qualitative study on the use and impact on the current users, but further research and development will be needed in the near future.

14 CREATING A RELIABLE TRANSPORTATION PROGRAM FOR OUTPATIENT DIALYSIS TREATMENT: Julie Wilcke, Troyce Cruchiola, Ride Connection, Yasuyo Tsunemine, Fresenius, Portland, OR, USA

An inclusionary planning and evaluation process that supports the identification of challenges related to transportation to and from hemodialysis treatment and how these challenges impacted patient health. The strategies, best practices and community resource ideas that came from the dialysis community in this process were numerous and resulted in positive change for patients. The results to-date offer promising practices that can be replicated throughout the nation.

The methods used involved the creation of an advisory committee, conducting focus groups, administering a patient survey and a caregiver/healthcare provider survey, one-on-one patient interviews and holding public workshops. Each of these steps helped to identify transportation challenges and informed specific changes that would not only improve the quality of *transportation services*, but ultimately would improve the *health outcomes* of patients receiving dialysis treatment. Social workers were involved in developing and implementing the education component and pilot project.

The planning process resulted in several solutions; a transportation pilot project to test the concepts developed, a volunteer driver program to transport patients, a driver training program developed to equip the driver with techniques for better transport as well as empathy, and an educational video that could be used to educate, supplement the driver training curriculum, or be used as a recruitment tool. All strategies and concepts implemented were patient developed and approved.

The transportation pilot project has been underway since February 2015 with 28 patients participating. Feedback from patients is overwhelmingly positive and patients are now reporting less stress in relation to transportation to/from treatment. A combination of utilizing multiple partners with paid and volunteer drivers has proven successful. The education program has been very well received by all. Participants report a 92.5% rating in effectiveness of the training. Drivers feel more prepared and comfortable supporting their riders.