

**NATIONAL KIDNEY FOUNDATION
2013 SPRING CLINICAL MEETINGS
APRIL 2–6, 2013**

CKD-ESRD: Vascular Access

- 3 Motivational Interviewing to Overcome Barriers to Placement or Cannulation of Permanent Access**
Sharon Essick, Shaun Boyd, Alison Dunklee, Scott Franklin, Dawn Burton, Carolina Gilbert, Jamece Mckinley, Stephanie Best. DaVita, Inc., Denver, CO, USA

CKD-ESRD: Other

- 2 Incidence of Missed and Shortened Hemodialysis Treatments in a Large Urban Hemodialysis Unit. Effect on Mortality. Impact of QUAPI Derived Multidisciplinary Protocol on Outcomes**
John D'Avella, Stephanie Antonelli, Mary Jane Porado, Donna Kelly. Hartford Hospital Dialysis, Hartford, CT, USA
- 4 Quality of Life Issues for Children with Kidney Disease: Lessons Learned and Recommendations for Professionals**
Keenan Fisher. University of South Carolina, Columbia, SC, USA
- 7 Increasing Patient Awareness of an Advance Care Planning Guide Using a Multimedia Approach**
Kelly Rivers, Anita Vidic, Donna Belmore. York Region Chronic Kidney Disease Program, Mackenzie Health, Richmond Hill, Ontario, Canada
- 8 Impact of In-Home Education Programs on the Graduation Rate of Young Adults with Kidney Disease**
Lori Sanderson¹, Lee Anne Gridley¹, Peter Yorgin². ¹Loma Linda University Children's Hospital, San Bernardino, CA, USA; ²Rady Children's Hospital, San Diego, CA, USA

Home Dialysis: Home Hemodialysis Peritoneal Dialysis

- 10 Characteristics of Selected KDQOL Survey Results with Home Dialysis Patients**
Dodie M. Stein¹, Janet L. Welch², Michael A. Kraus¹. ¹Indiana University Health, Indianapolis, IN, USA; ²Indiana University School of Nursing, Indianapolis, IN, USA

Transplantation

- 1 Patient Navigation: A Promising Intervention to Promote Kidney Transplant Parity**
Teri Browne¹, Avrum Gillespie², Tamara Savage¹, Alison Brown¹, L. Ebony Boulware³. ¹University of South Carolina, Columbia, SC, USA; ²Temple University, Philadelphia, PA, USA; ³Johns Hopkins University, Baltimore, MD, USA
- 5 "We're Not Going to Say it's Suffering, We're Going to Say it's an Experience." The Lived Experience of Mothers of Children Who Have Undergone Kidney Transplantation**
Andrew Mantulak. King's University College at Western University, London, Ontario, Canada

Other

- 6 Phosphate Binder Self-Management in Dialysis Patients: A Qualitative Study**
Joseph Merighi¹, Teri Browne², Tamara Savage², Karen Ryals³, Kerri Cavanaugh⁴. ¹Boston University School of Social Work, Boston, MA, USA; ²University of South Carolina College of Social Work, Columbia, SC, USA; ³American Association of Kidney Patients, Tampa, FL, USA; ⁴Vanderbilt University Medical Center, Nashville, TN, USA
- 9 ESRD: Medication Self-Management and Parity**
Tamara Savage. University of South Carolina, Columbia, SC, USA
- 11 Relationship Between MSW Time Spent in Clinical Tasks and Facility Quality Scores and Patient Satisfaction Ratings**
Leslie Wilfong. Fresenius Medical Care, Franklin, IN, USA

1. **PATIENT NAVIGATION: A PROMISING INTERVENTION TO PROMOTE KIDNEY TRANSPLANT PARITY**

Teri Browne,¹ Avrum Gillespie,² Tamara Savage,¹ Alison Brown,¹ & L. Ebony Boulware³

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Patient navigation is an intervention that has shown significant promise in improving cancer and other chronic illness outcomes. Patient navigation was created to help ameliorate health disparities and uses a professional or lay “patient navigator” to help patients navigate through different barriers to treatment. Despite frequent use of patient navigation in other chronic illnesses, the kidney disease community has not widely embraced this intervention as of 2012. As a first step in exploring the use of patient navigation by social workers with kidney disease patients, particularly as a possible way to promote kidney transplant parity, a literature review was conducted to examine the use of patient navigation in kidney disease and other chronic illnesses. An online search was conducted from January 2012 to October 2012 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 October 2012, as they relate to patient navigation in kidney disease and other chronically ill populations. The results of this literature search suggest that patient navigation is a promising intervention that may help improve kidney disease outcomes, including kidney transplant parity. This poster will also discuss recommendations for the use of patient navigation to promote kidney disease and kidney transplant.

3. **MOTIVATIONAL INTERVIEWING TO OVERCOME BARRIERS TO PLACEMENT OR CANNULATION OF PERMANENT ACCESS**

Sharon Essick, Shaun Boyd, Alison Dunklee, Scott Franklin, Dawn Burton, Carolina Gilbert, Jamece Mckinley; Stephanie Best
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Introduction: Despite the risks associated with Central Venous Catheters (CVC), some patients refuse permanent access for non-medical reasons. We engaged patients who were refusing permanent access, or cannulation of permanent access, for non medical reasons in Motivational Interviewing (MI) to see if these patients would obtain permanent access, or cannulation of permanent access, by the end of the study period.

There were four patients in the study from three dialysis centers in a large dialysis organization. The project team consisted of five social workers, one RN, and one Patient Care Technician. The project team participated in weekly calls for two months to become familiar with MI techniques. MI interventions began the first week of January 2012 and ended the last week of March 2012. Weekly calls continued throughout the study period to review patients’ status, and to offer suggestions on how to help the patients move through the stages of change. Project team members met with patients an average of three times a month.

Results: By the end of the study period three out of the four (75%) patients either obtained permanent access or allowed cannulation of permanent access. The fourth patient dropped out of the project when he traveled to another country for two months during the study period.

Conclusion: The project results lend themselves to a broader study.

2. **INCIDENCE OF MISSED AND SHORTENED HEMODIALYSIS TREATMENTS IN A LARGE URBAN HEMODIALYSIS UNIT. EFFECT ON MORTALITY. IMPACT OF QUAPI DERIVED MULTIDISCIPLINARY PROTOCOL ON OUTCOMES**

John D’Avella, Stephanie Antonelli, Mary Jane Porado, Donna Kelly, Hartford Hospital Dialysis, Hartford, CT, United States.

There is no recent data on the incidence of missed or shortened hemodialysis treatments in a large urban setting. We tracked missed and shortened treatments as a quality indicator. When the incidence of missed and shortened treatments was noted, a QUAPI project was undertaken to study why and to design a protocol to correct it. Patients were interviewed and a root cause analysis was done. A protocol was developed involving a multidisciplinary approach to address missed and shortened treatments. Barriers to treatments were addressed and patients were educated about the risks. If patients missed more than 3 treatments per quarter, a multidisciplinary meeting with the patient and family was facilitated. The unit delivers approximately 26,208 treatments per year. In 2010, 640 treatments were missed (2.4%). Patients who missed 4 or more treatments had a mortality risk of 31% vs unit mortality of 19.6%. With the protocol in 2011, missed treatments fell to 516 (decreased 19%) and in 2012 1st quarter data annualized to 392(decrease 39%). This will result in added revenue of \$55,056. Shortened treatments did not initially change 198/199 2010/2011 (they were included in the protocol). Since inclusion, the annualized rate for 2012 is 172 (decrease of 14%). The most common reason for missed/shortened treatments was not feeling well and cramping. Missed treatments have a negative impact on patient mortality and unit revenue. Through a protocol which discovers reasons for missed/shortened treatments; relies on patient and family education and involves all members of the health care team; it is possible to reverse this trend.

4. **QUALITY OF LIFE ISSUES FOR CHILDREN WITH KIDNEY DISEASE: LESSONS LEARNED AND RECOMMENDATIONS FOR PROFESSIONALS**

Keenan Fisher, University of South Carolina, Columbia, SC, USA

Kidney disease and its treatments result in unique quality of life stressors for children under the age of 18. Dialysis and transplant social workers and interdisciplinary professionals need distinct interventions to help minimize the burden of kidney disease on pediatric patients and their family members. Before testing different interventions which could potentially maximize pediatric quality of life (QOL), a literature review was completed to research the particular facilitators and barriers to QOL for this specific population. Also, a search on the current interventions which relate to pediatric kidney disease patient QOL was conducted. The literature search was conducted October 2012 to November 2012 and included findings from different databases including, PubMed, Academic Search Complete, AltHealthWatch, Applied Social Sciences Index and Abstracts, Social Work Abstracts, and Social Service Abstracts. The databases were used to help identify and summarize the findings from clinical trials, articles and journals, and reviews specifically related to QOL of pediatric patients with kidney disease. These were all published in English from January 1990 to November 2012. The results provide evidence that the pediatric kidney disease community needs particular interventions to improve QOL for not only the patient, but their families as well. The literature suggests that a variety of social determinants of health strongly contribute to patient QOL. An overview of measurements for pediatric QOL will be provided, including recommendations for professionals which can help this specific population’s outcomes.

5. *"WE'RE NOT GOING TO SAY IT'S SUFFERING, WE'RE GOING TO SAY IT'S AN EXPERIENCE."* THE LIVED EXPERIENCE OF MOTHERS OF CHILDREN WHO HAVE UNDERGONE KIDNEY TRANSPLANTATION
Andrew Mantulak King's University College at Western University, London, Ontario, Canada
- Advances in the surgical and immunological aspects of organ transplantation have resulted in significant improvements in the long term outcome and survival rates, making kidney transplantation the optimal therapy for children with end stage kidney disease. The goal of transplantation is no longer just graft survival and getting children to an acceptable level of physical health, but to improve their overall quality of life. In the limited literature available, however, there continues to be a negative impact reported on overall family functioning despite the reported good health and quality of life for the transplanted child. Specifically, the stressors of the burden of care experienced by mothers (who are socially ascribed the caregiving role for chronically ill children) is notable. This research utilizes a hermeneutic phenomenological approach to examine the lived experience of mothers of children who had undergone kidney transplantation. A sample of 7 mothers from southwestern Ontario (Canada) volunteered to participate in a process of in depth interviewing. Findings of the study illuminate that the experience of mothering in the context of pediatric kidney transplantation are reflected in (1) the significance of relationships to the experience of self, (2) the lived experience of time (3) the lived experience of space, and (4) opportunity for the growth and personal development. This research identifies that while mothering a child with a kidney transplant is fraught with physical, social and emotional challenges, there are opportunities for the development of skills and personal growth within the experience.
7. INCREASING PATIENT AWARENESS OF AN ADVANCE CARE PLANNING GUIDE USING A MULTIMEDIA APPROACH
Kelly Rivers, Anita Vidic, Donna Belmore, York Region Chronic Kidney Disease Program, Mackenzie Health, Richmond Hill, Ontario, Canada.
- A common challenge experienced within dialysis programs is how to disseminate advance care planning (ACP) information to patients, while respecting the sensitive nature of this topic and being mindful of the amount of time already devoted to hemodialysis (HD) treatments. Various formats to determine the best approach of addressing the ACP needs of the patients were explored.
- A focus group was held with both HD staff and patients requiring HD to determine essential information to include in an ACP guide and how to effectively disseminate this information. The ACP guide, in the form of a booklet, titled "It's My Decision" was created to help patients facilitate discussions with their family members and trusted friends about their wishes for future health and personal care decisions. The ACP guide includes a section on frequently asked questions, definitions, and a detachable portion that patients can complete to document their wishes and Powers of Attorney (POA).
- During initial Social Work assessments and on a case-by-case basis, patients requiring HD were made aware of ACP and the availability of "It's My Decision". In addition, various formats, including: education sessions, handouts, and bulletin board postings were used. To further increase patient awareness of the ACP guide, a DVD presentation was created. The DVD was available to view on the patient televisions, on designated channels, in all four HD units while they were receiving treatments. Following the implementation of the DVD, a patient survey was distributed to obtain their feedback.
- With the addition of the DVD, this multimedia approach has resulted in over 4.5 times (from 12 to 67) more patients requesting "It's My Decision". In addition, 87% of patient survey responses indicated that the information in the DVD was useful to them. This multimedia approach has helped to increase patient awareness about the importance of discussing ACP and completing POA for Personal Care and Property.
6. PHOSPHATE BINDER SELF-MANAGEMENT IN DIALYSIS PATIENTS: A QUALITATIVE STUDY
Joseph Merighi¹, Teri Browne², Tamara Savage², Karen Ryals³, Kerri Cavanaugh⁴
- Boston University School of Social Work, Boston, MA¹; University of South Carolina College of Social Work, Columbia, SC²; American Association of Kidney Patients, Tampa, FL³; Vanderbilt University Medical Center, Nashville, TN⁴
- Phosphate binder medication use reduces serum phosphorus and is associated with improved bone and mineral disorders and cardiovascular mortality in dialysis patients. The main study aim is to understand factors that facilitate and prevent phosphate binder self-management, so that innovative and culturally relevant interventions can be developed to promote long-term medication use.
- Primary data were gathered from five, 90-minute, small-group interviews with hemodialysis patients ($N = 17$) in Atlanta, GA. The sample profile is: 12 women, 13 African American, mean age = 53 ($SD=10.9$), dialysis vintage = 87 months ($SD=59$), and total pills consumed per day = 16 ($SD=13$). A constant comparative method was used to identify themes that emerged from a line-by-line review of the interview transcripts.
- Participants described three key factors that facilitated phosphate binder use: family, peer, and provider support; placing binders in multiple locations; and seeing images that depict health consequences associated with high serum phosphorus. Further, they identified several salient barriers to using binders as prescribed: cost, preserving privacy by not taking pills in public, and regimen complexity.
- The study findings provide the basis for the development of targeted interventions that can reduce health disparities by bolstering patient self-management, improving health outcomes, and reducing costs associated with medication non-adherence in the end-stage renal disease population, as well as in other chronically ill populations.
8. **IMPACT OF IN-HOME EDUCATION PROGRAMS ON THE GRADUATION RATE OF YOUNG ADULTS WITH KIDNEY DISEASE**
Lori Sanderson, Lee Anne Gridley, Peter Yorgin
- Kidney transplant recipients (KTXP) and young adults with chronic kidney disease (CKD) have many academic and physical challenges as a result of their illness. Most school systems can provide home schooling with self-paced learning material and in some cases a tutor or credentialed teacher for children with chronic disease.
- A retrospective analysis of high school graduation rates (before their 19th birthday) for KTXP and CKD patients was performed. There were 54 participants in the study sample. High school graduation positively correlated with traditional school (OR: 3.778, $p < 0.001$), parents who attended college and no state or federal aid. Participation in home education programs was positively correlated with working parents, kidney transplantation, Hispanic ethnicity, English language spoken at home, and parents who were not college educated.
- Limitations of the study included the retrospective design of the study, and lack of information detailing educational and motivational support at home. The ability to generalize study findings to the general population may be hampered by the unique patient population, which consisted of those who were predominately low-income and Hispanic.
- In-home education programs for patients with kidney transplants and chronic kidney disease were associated with lower graduation rates. Close monitoring of patients who are enrolled in home education programs by multidisciplinary medical teams may be warranted.

9. **ESRD: MEDICATION SELF-MANAGEMENT AND PARITY**

Tamara 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. As a first step in exploring poor medication self-management as it relates to parity, a literature review was conducted to examine the factors 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 factors associated with patient medication self-management and parity. The results of this literature search suggest that there is indeed a 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 group 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.

10. **CHARACTERISTICS OF SELECTED KDQOL SURVEY RESULTS WITH HOME DIALYSIS PATIENTS**

Dodie M. Stein¹, Janet L. Welch², Michael A. Kraus¹

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The *Kidney Disease Quality of Life* (KDQOL) survey is mandated by the Centers for Medicare & Medicaid Services as part of the social worker's comprehensive assessment of dialysis patients. Current normative data overwhelmingly represent in-center patients. There has been no large study reported to date of health-related quality of life for home dialysis patients. A better understanding of the health-related quality of life of home dialysis patients would assist social workers and other staff in helping patients improve their quality of life.

The purpose of the current study was to describe health-related quality of life for both daily home hemodialysis and peritoneal dialysis patients from a single, large unit and explore differences between the home dialysis modalities. Specifically, the Physical Component Summary (PCS) score and the Mental Component Summary (MCS) score of the KDQOL, thought to be significant predictors of hospitalization and/or death, were used for primary comparisons. Descriptive data will be reported from the most recent administration of the KDQOL-Complete survey for the calendar year 2012. Data will be compared for demographic (age, gender, race, home dialysis modality) and illness (diabetic status, length of time on home dialysis, type of access, dialysis adequacy, albumin, incidence of hospitalization) characteristics. Preliminary analyses suggests substantial differences for both demographic and illness characteristics.

Implications for social worker and staff follow-up with patients will be presented.

11. **RELATIONSHIP BETWEEN MSW TIME SPENT IN CLINICAL TASKS AND FACILITY QUALITY SCORES AND PATIENT SATISFACTION RATINGS.** Leslie Wilfong, Fresenius Medical Care, Franklin, Indiana, USA

. Purpose: The researcher intended to discover if the percent of work time the Renal MSW spends providing clinical services has an impact on the facility's quality scores (Ultrascore) or if it has an impact on patients' satisfaction with the MSW's social work services provided in the facility.

. Methods: The NKF-CNSW Time Study tool was completed by 26 MSW's employed with Fresenius Medical Care in the Indiana Region for one month between September 2011 and December 2011. The results were summarized on a spreadsheet, specifying percent of time spent in Clinical tasks (Assessments, Care plans, Quality of Life Surveys, Counseling, Patient Education), Administrative/Clerical Tasks, Insurance tasks and 'Other' (time off, breaks, travel). These results were correlated with the quality scores of the social worker's facilities. (The quality score, or Ultrascore, is derived from facility performance on key indicators such as adequacy, albumin, and hospitalization.). Additionally patients' ratings of satisfaction with Social Work services was compared with the percent of clinical time, the amount of time spent driving during work hours and amount of time spent making arrangements for traveling patients. No statistical analysis was applied, only straightforward observation of trends.

. Results: The facilities of the five MSWs with the greatest percent of clinical time had higher quality scores, as a group, than the facilities of the MSWs with the lowest amount. The patients in facilities with a higher percent of MSW clinical time rated their satisfaction with the MSW higher. Facilities which had less clinical time or more driving and patient travel related tasks had lower satisfaction ratings.

. Conclusion: MSW time spent with clinical tasks has a positive impact with both quality and satisfaction in the sample studied.



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