

Effecting Palliative Care for Chronic Kidney Disease Patients by Increasing Provider Knowledge

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Abstract

Chronic kidney disease affects over 30 million Americans. In addition, thousands of patients advance from chronic kidney disease to end stage renal disease annually, which can become fatal without renal replacement therapy such as dialysis. Advance care planning and palliative care consultation can meet the needs of many patients with incurable illness by decreasing symptom burden and improving quality of life. Unfortunately, many nephrology providers focus patient care on dialysis and are not comfortable discussing advance care planning or palliative care. The project purpose was enhancing nephrology providers' knowledge of the Renal Physician Association guidelines on *Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis* to increase advance care planning and palliative care referral to improve the quality of life of renal patients. The guidelines offer tools for providers in determining patient prognosis, facilitating advance care plans and appropriate palliative care referral. The project design was an evidence based quality initiative, not-human subjects research. Thirteen nephrology providers and nurses in the Midwest received the educational intervention in autumn 2017. Post-intervention outcomes included four renal palliative care referrals and 22 Advance Care Plans over four-months from a baseline of zero/unknown. Palliative care provides symptom relief related to renal disease and other chronic conditions, allowing patients comfort and improved quality of life. Benefits of this project to nursing and society are vast, minimizing burden on caregivers, nursing staff, and the health care system.

Keywords: renal palliative care, dialysis, chronic kidney disease, advance care planning, end of life, dialysis cost, quality of life, shared decision-making

Effecting Palliative Care for Chronic Kidney Disease Patients by Increasing Provider Knowledge

Chronic kidney disease (CKD) affects over 30 million Americans (National Kidney Foundation [NKF], 2017). CKD leads to end stage renal disease (ESRD) in over 600,000 patients annually (United States Renal Data Systems [USRDS], 2016). Unfortunately, ESRD patients suffer from chronic, incurable renal dysfunction, requiring dialysis to prolong life (NKF, 2014). The hemodialysis process initially requires a surgical procedure to create vascular access followed by an average of three dialysis treatments per week in an outpatient facility (NKF, 2014). Many renal patients express the need for improved symptom management related to renal failure, such as pain, pruritus, and fatigue, as well as those related to other comorbid health conditions (Davison, 2010, 2012; Grubbs et al., 2014; Weisbord et al., 2005).

Background

Significance

For many CKD patients, the decision to pursue dialysis is often difficult, as quality of life (QOL) is affected by symptoms, surgeries, and the demanding dialysis process (Davison, 2012; Verberne et al., 2016). Despite decades of recommendations from many national organizations, shared decision-making, advance care planning, and palliative care referral are underutilized in the CKD population (American Nephrology Nurses' Association [ANNA], 2008, 2011; Grubbs et al., 2014; National Institutes of Health [NIH], 2013; National Institutes of Nursing Research [NINR], 2014; National Institute of Medicine, 2014; NKF, 2014; RPA, 2010).

The phenomenon of concern is increased utilization of palliative care (Davison, 2010, 2012; Grubbs et al., 2014). The premise is that nephrology providers lack knowledge regarding the guidelines on *Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis* (Davison, 2012; Grubbs et al., 2014). Lack of shared decision-making for this

population leads to poor QOL (Davison, 2012; Grubbs et al., 2014). Based on low utilization and late referral to palliative care, it is believed that nephrology providers demonstrate the need for increased knowledge and awareness of the Renal Physician Association (RPA) guidelines so that advance care planning, appropriate palliative care referral, and symptom management may be achieved, thereby improving patient quality of life (Grubbs et al., 2014).

Economic significance. Nationally, ESRD places a huge economic burden on the healthcare system. As of 2014, there were over 600,000 dialysis patients nationwide, and with the increased prevalence of obesity, diabetes, hypertension, and advanced age that number is expected to rise (NKF, 2014). The annual costs of dialysis treatments are also increasing with an average cost per dialysis patient of just over \$87,000, with over 38% spent on inpatient care (USRDS, 2016). Dialysis patients often require frequent hospital admission for infection, cardiac related illness, vascular access issues, and hemodynamic instability (hypotension) at a rate of twice per year (NKF, 2014; USRDS, 2016). Dialysis related direct costs in 2011 exceeded \$34 billion for approximately 600,000 patients (USRDS, 2016).

With appropriate palliative care referral, symptom management and social support will be available for patients resulting in decreased hospital admissions (Coalition for the Supportive Care of Kidney Patients, 2017). Inpatient palliative care referral has been shown to decrease daily costs by approximately \$500 per person due to the less invasive nature of care provided (Penrod et al., 2010). The Institute of Medicine's (IOM) *The Future of Nursing* supports palliative care referral to improve overall care plan discussions between patients and their caregivers, improving patient QOL, and decreasing health care costs (IOM, 2010).

Policy and health system significance. Chronic kidney disease not only holds a significant financial burden, but the number of patients requiring dialysis, admissions, and

surgeries tasks the already overworked healthcare system (Penrod et al., 2010). For decades, national institutions such as the American Nephrology Nurses Association (ANNA), RPA, and the Robert Wood Johnson Foundation have encouraged standardized policies surrounding shared decision-making and renal palliative care (ANNA, 2008; Moss & Dillon, 1997; RPA, 1997, 2010). The supportive benefits of this project to nursing and society are vast, minimizing nursing, health system, and caregiver burden. (Smith, Potts, Wellard, & Penney, 2015).

Local Issue

In 2014, there were 15,435 established dialysis patients in the Heartland Kidney Network-12 (Missouri, Kansas, Nebraska, and Iowa). In 2014, in the state of Missouri alone, there were 7,881 established dialysis patients among which 2,139 were newly diagnosed (Heartland Kidney Network, 2015). The costs of dialysis for Missouri patients at approximately \$87,000 per patient year, equals \$600,000,000 in total annual expense. In 2014, the Heartland Kidney Network reported 2,944 deaths in dialysis patients, among which 1,490 were in Missouri alone (Heartland Kidney Network, 2015).

Diversity Considerations

Two inner urban Midwest nephrology practices were included in the project. Each facility brings uniqueness to the patient population served, caring for insured, underinsured, and uninsured populations. Jackson County has a diverse population of Caucasian, African American, Asian, and Middle Eastern descent (Jackson County, 2017). According to data from the United States Renal Data System (USRDS) ESRD prevalence in African Americans was 3.7 times greater than Caucasians (2016).

Problem and Purpose

Problem Statement

The problem statement related to this evidence based quality initiative (EBQI) project was: Shared decision-making, advance care planning, and palliative care referral are underutilized in Chronic Kidney Disease Stage 4 and 5 patients.

Intended Improvement with Purpose

The purpose of this EBQI was to bring awareness and increase knowledge of clinical practice guidelines on *Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis* (RPA, 2010). The intended improvement was nephrology provider involvement of chronic kidney disease stage 4 and 5 patients in the shared decision-making process. This includes discussing all renal replacement options such as hemodialysis, peritoneal dialysis, renal transplant, as well as conservative management with palliative care referral when indicated (Davison, 2012; RPA, 2010). Advance care planning can assist in determining patient wishes and should be completed early in CKD (Grubbs et al., 2014). Utilizing the guideline's "surprise" question, *Will I be surprised if this patient died in the next 12 months?* can assist in prognosis and appropriate PC referral (RPA,2010). Patients with multiple comorbid conditions, age greater than 70, and those who simply choose not to pursue dialysis should be offered PC referral with or without dialysis therapy (Davison, 2010; Grubbs et al., 2014).

Facilitators and Barriers

Facilitators included the facilities' palliative care teams, social workers, and nephrology nurse practitioner (NP). Additional support was provided by the project preceptors. The practice directors were instrumental in assisting in scheduling luncheon times for the interventions. One nephrologist was unable to attend the educational session due to family emergency; however, they were aware of the project from the invitation and verbalized interest with discussion and attempted to refer more patients to palliative care.

Barriers included nephrology provider time and willingness to attend the educational sessions. Of the twenty providers invited to the educational sessions, thirteen attended. Potential barriers also included potential bias regarding previous experience with palliative care referrals. The student investigator (SI) collaborated with the nephrology NPs and clinic managers at the participating practices and encouraged continued participation in the project. There was expected support of the multidisciplinary team members during the project to maintain sustainability. Additionally, sustainability was addressed with monthly emails, providing feedback and engagement in the PC referral process. Each email contained the original PowerPoint, ACP forms, and update on referrals. No participants resigned from either of the participating practices, so additional training for their replacements was not needed.

Review of the Evidence

PICOTS

Among nephrology providers caring for renal patients, can providing education and increasing knowledge of the RPA guidelines on the *Shared Decision-Making in the Appropriate Initiation of the Withdrawal from Dialysis* increase the number of patients referred to PC by at least 10 percent of baseline, over a 4-month span of time at two urban nephrology practices in the Midwest?

Search Strategies

An integrated literature search was conducted using Cumulative Index to Nursing and Allied Health (CINAHL), PubMed, Medline, and PsycINFO databases; and the search engine Google Scholar from 2006 to 2017. Key words included renal palliative care, dialysis, chronic kidney disease, end of life, palliative care knowledge, dialysis cost, quality of life, and shared decision-making. Inclusion criteria involved palliative care, chronic kidney disease, conservative

management versus survival on dialysis, advance care planning, and quality of life for renal patients. Over 8,461 articles were initially found utilizing those key words. Exclusion criteria included children, renal artery obstruction, uncompensated care, religious beliefs, acute kidney injury/failure, non-English articles, and healthcare errors. Applying the exclusion criteria, 189 articles were reviewed and twenty-eight articles felt best for inclusion. Appendix C represents the synthesis of evidence table.

Results of the literature search indicated 12 quantitative designs, including experimental, non-experimental, cross sectional surveys, prospective observational studies, and systematic reviews. The quantitative studies were reviewed for their level of evidence, finding two evidence based practice guidelines (Level 1), nine Level 2 studies, one Level 3 study, and two Level 4 studies (Melnik & Fineout-Overholt, 2015, adapted). Fifteen qualitative studies provided relevant information to the PICOT question, including eleven systematic reviews of the literature (Level 5), three studies were Level 6, and one study was an expert opinion publication at evidence Level 7 (Melnik & Fineout-Overholt, 2015, adapted).

Synthesis of Evidence

The following paragraphs discuss four common themes revealed during the integrated review of the literature. Those themes are as follows with the corresponding number of studies related to each:

1. Lack of knowledge among nephrology providers (12)
2. Improved quality of life and symptom burden (9)
3. Underutilization of advance care planning and shared decision-making (5)
4. Survival analysis between conservative management (CM) and renal replacement therapy (RRT) (3)

Lack of knowledge among nephrology providers. The first theme indicates the need for improving nephrology providers' knowledge of the RPA guidelines on *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* (Davison, 2012; RPA & ASN, 2010) to increase palliative care referral and improve QOL for renal patients. The extensive literature review focused on nephrology provider awareness, education, knowledge, and barriers of end of life guidelines and QOL for renal patients (Cohen, Ruthazer, Moss, & Germain, 2010; Combs et al., 2015; Davison, 2010, 2012; Davison, Jhangri, Holley, & Moss, 2006; Fassett et al., 2011; Germain, Davison, & Moss, 2011; Grubbs et al., 2014; Moss & Dillon, 1997; Moss, Stocking, Sachs, & Siegler, 1993; NKF, 2014; Parvez, Abdel-Kader, Pankratz, Song, & Unruh, 2016; Patten, Ojeda, & Lindgren, 2016; Robinson et al., 2004; Robinson & Port, 2010; RPA, 1997; RPA, 2010; Schell, Green, Tulskey, & Arnold, 2013; Smith, Potts, Wellard, & Penney, 2015; Verberne et al., 2016; Yamamoto, Kizawa, Nakasawa, & Morita, 2013; Yard, 2010).

The estimated number of nephrologists involved in the studies was greater than 1,000, with many studies sampling over 300 participants each (Davison et al., 2006; Patten, Ojeda, & Lindgren, 2016; Robinson, Bieber, Pisoni, & Port, 2012; Yamamoto, Kizawa, Nakasawa, & Morita, 2013). The results indicate the need for improved education for nephrology providers in shared decision-making, addressing ethical considerations for patients, and referral for palliative care support (Davison et al., 2006; Patten, Ojeda, & Lindgren, 2016; Robinson, Bieber, Pisoni, & Port, 2012).

Barriers contributing to underutilization of nephrology referrals to PC include discomfort with the topic, lack of knowledge and training, and provider uncertainty about patient wishes (Combs et al., 2015; Davison, 2010, 2012; Davison, Jhangri, Holley, & Moss, 2006; Fassett et

al., 2011; Grubbs et al., 2014; Moss & Dillon, 1997; NKF, 2014; Patten, Ojeda, & Lindgren, 2016; Smith, Potts, Wellard, & Penney, 2015). Overcoming those barriers include utilizing the RPA and ASN guidelines as a resource for appropriate CM and PC referral, engaging patients in shared decision-making, and increasing the practice of ACP with all CKD patients (Davison, Jhangri, Holley, & Moss, 2006; Germain et al., 2011; Graham et al., 2006; Grubbs et al., 2014; Moss et al., 1993; Robinson et al., 2004).

Improved quality of life and symptom burden. The literature indicates QOL and symptom burden for renal patients improves with PC referral and support (Russell, Lupu, Seliger, & Moss, 2016; Somma, Trillini, Kasa, & Gentile, 2013). Fassett and colleagues (2011) advocate for improved QOL by offering a PC approach for all renal patients enhancing symptom management, alleviating pain and suffering, providing social and spiritual support, and ultimately improving QOL. Studies of renal patients, including questionnaires, surveys, mortality and hospitalization rates, support the need for CKD patients to be better informed about the dialysis process and the effect on QOL for an informed decision regarding all treatment options (Arulkumaran, Szawarski, & Philips, 2012; Berger, Jaikaransingh, & Hedayati, 2016; Brown et al., 2015; Ordille, 2016; Rayner et al., 2014; Somma et al., 2013; Weisbord et al., 2005).

In 1997, the Robert Wood Johnson Foundation created a nephrology task force to facilitate improvement in end of life care for renal patients addressing: Quality of Life, Quality of Dying, and Education (Moss & Dillon, 1997). They also determined additional education was needed for patients and providers to enhance their understanding of PC (Moss & Dillon, 1997). Providers of CKD patients should also consider the most appropriate laboratory testing, studies, and invasive procedures renal patients receive as each causes a physical and financial burden (Williams et al., 2012).

A prospective cohort study by Rayner and colleagues (2014) surveyed 6,040 dialysis patients in the United States reviewing mortality rates, hospitalizations, and subjective patient recovery time to best health status after dialysis therapy. The results showed longer recovery time was associated with comorbidities such as diabetes, psychiatric illness, and older age (Rayner et al., 2014). These should be taken into consideration when discussing RRT versus CM with renal patients nearing ESRD (Rayner et al., 2014).

Moss and Dillon (1997) conducted a novel qualitative study two decades ago assessing renal patients' QOL. Several valid and reliable QOL questionnaires were disseminated to renal patients ($n = 165$) including the McGill QOL Questionnaire, the Satisfaction with Life Scale, the Patient Satisfaction Scale, and the Kidney Disease QOL Instrument. The results indicated renal patients request support for symptom management and psychosocial issues (Moss & Dillon, 1997).

The philosophy of science is phenomenology as it relates to quality of life for the renal patient and knowledge translation for nephrology providers. Phenomenology is described as a subjective view, or the lived personal experience (Ordille, 2016), such as the symptoms renal patients experience. Wojnar and Swanson (2007) provide a thorough review of phenomenology as it relates to nursing science and theoretical development for increased knowledge application.

Underutilization of advance care planning and shared decision-making. Advance care planning and shared decision-making are under discussed and underutilized yet necessary to determine patient wishes (Davison, 2010, 2012; Goff et al., 2015; Grubbs et al., 2014; Swartz & Perry, 2009). Advance care planning encompasses advanced directives and living wills, outlining health care wishes and persons in charge of health care decisions (RPA, 2010). The Coalition for Supportive Care of Kidney Patients released new recommendations and tools to assist in ACP for

renal patients in 2017. This new curriculum was incorporated into the DNP project as a resource guide for the providers.

The results of this sub-topic include nine qualitative and quantitative studies involving hundreds of nephrology providers and 598 dialysis patients at chronic dialysis units. Sinuff and colleagues (2015) defined quality indicators in a conceptual framework which allow health care providers to evaluate and improve the quality of end-of-life communication and decision-making in renal patients. Interdisciplinary team members including nurses, physicians, and social workers developed the framework (Sinuff et al., 2015). Many participants of one qualitative survey preferred increased communication with their dialysis team and nephrologists regarding QOL and symptom management (Goff et al., 2015).

Discussing end of life brings about many ethical considerations (Davison, 2012). The RPA and ASN guidelines address these ethical considerations including offering a dialysis trial for patients who are uncertain whether to proceed with dialysis or conservative management (2010). Reiterating PC along with dialysis, or as an option for patients who choose to withdrawal from dialysis, is recommended as best practice for nephrology providers (Davison, 2012; RPA, 1997). Many national organizations encourage respecting patients' wishes regarding their health care decisions, including ACP through shared decision-making (ANNA, 2008; NIH, 2013; NIM, 2014; NINR, 2014; RPA, 2010).

Survival analysis between conservative management and renal replacement therapy in renal patients. Many elderly patients with comorbid conditions may have shorter life expectancy but improved QOL without dialysis (Chandna et al., 2011). A recent dialysis in-center observational study utilizing the Davies comorbidity score ($n = 311$) found no statistical difference between longevity in patients greater than 80 years old who opted for CM versus

those who chose dialysis (Verberne et al., 2016). The results of the study also indicated patients with increased comorbid conditions did not do any better with dialysis treatment and may have an improved QOL with CM (Verberne et al., 2016).

Through a retrospective quantitative review of 379 dialysis patient charts over a ten-year period, Mayo Clinic (2013) found that half of dialysis patients over 75 years old passed away within one year. Mayo Clinic supports a shared decision-making process for CKD and ESRD patients facing RRT or already on dialysis (Mayo Clinic, 2013).

Additional reasons for ACP and PC referral include high hospital admission rates for symptoms management (769.9/1000 over 85 years old and 558.4/1000 ages 66 to 69), and high mortality rates due to cardiovascular disease (USRDS, 2016). Dialysis patients are admitted to the hospital at least twice per year, with incidence of readmission over 33% within the first 30 days of discharge (USRDS, 2016). According to the USRDS (2016), the main reasons for hospital admissions are vascular access issues, cardiovascular events, and infection. The mortality rate is nearly 50% during the first year of dialysis for patients with multiple risk factors and comorbidities (Cohen, Ruthazer, Moss, & Germain, 2010). Those comorbidities include cardiovascular disease, vascular disease, malnutrition, and advanced age; however, throughout the literature, authors recommend discussing PC with all nephrology patients for symptom management and support, and transition to hospice for end of life care (Cohen et al., 2010; Misra, Oreopoulos, & Vonesh, 2008; Smith et al., 2015; Yard, 2010). Mortality rates and hospitalizations should be considered when discussing renal replacement options with patients with multiple comorbid conditions and advanced age (Brown et al., 2015; Russell et al., 2016).

Theoretical Framework

The Knowledge to Action (KTA) Framework was chosen as the most suitable theoretical approach (Canadian Institutes of Health Research [CIHR], n.d.). KTA is a reliable, easy to use framework for increasing knowledge of guidelines to improve outcomes across disciplines (CIHR, n.d.; Graham et al., 2006; Logan & Graham, 1998, Straus, Tetroe & Graham, 2009; Sudsawad, 2007). Appendix D depicts the KTA theoretical framework as applied. The framework is utilized by the World Health Organization (WHO) as a model for educational programs focusing on evidence based guideline review (WHO, n.d.).

Theoretical Concepts

The concepts include nephrology providers' insufficient knowledge regarding end-of-life guidelines and quality of life for nephrology patients (Davison, 2010, 2012; Davison, Jhangri, Holley, & Moss, 2006; Fassett et al., 2011; Grubbs et al., 2014; Kidney Supportive Care, 2016; RPA, 2010; Smith, Potts, Wellard, & Penney, 2015). The rationale for the chosen concepts is that nephrology providers need additional knowledge related to the EBP guidelines (Davison, 2012). Furthermore, renal patients suffer chronic symptoms related to renal disease and other comorbid conditions, often more severe than cancer patients (Davison, 2010, 2012; Grubbs et al., 2014).

Methods

Institutional Review Board

Site approval and Institutional Review Board. Site approval was obtained from the two participating nephrology practices. The student investigator completed Collaborative Institutional Training Initiative (CITI) in June 2017. An IRB (Institutional Review Board) Authorization Agreement between the nephrology practices and the University of Missouri-Kansas City (UMKC) was finalized prior to project implementation. The evidence based practice proposal was submitted to the University of Missouri-Kansas City Social Sciences Institutional

Review Board for review on July 7, 2017. Approval for not-human subjects evidence based quality improvement was granted on July 25, 2017 (see IRB Approval, Appendix M).

Ethical issues. Ethical considerations such as beneficence, patient privacy, confidentiality, and informed consent were high priority for the project (Melnik & Fineout-Overholt, 2015). Privacy and protection of the participants as well as the retrospective chart review were maintained according to the Health Insurance Portability and Accountability Act (HIPAA) (Terry, 2015). Confidentiality was maintained as no identifying factors were disclosed in the project (Moran, Burson & Conrad, 2014; Terry, 2015). There was no harm to humans in this project. There were no student investigator (SI) conflicts of interest. Data was entered into SPSS and kept private and confidential.

Funding. Expenses included folders, pens, handouts, and lunch for the participants. Budgeted indirect and direct cost was \$1,870 with actual costs of \$12,718. Indirect costs include time for SI email communication, project implementation and coordination, and personal computer use for development of educational presentation and materials.

The itemized budget is in Appendix A. Funding was provided through the Barbara Prowant Research Grant from the American Nephrology Nurses Association in the amount of \$5,000, and the University of Missouri Women's Graduate Assistance Fund in the amount of \$1,500 (Appendix L).

Setting and participants. The setting for the EBQI project included two urban academic medical centers' nephrology practices in the Midwest. Both institutions offer services to a variety of patients in the community including insured, underinsured, and uninsured of various cultures and ethnicities offering a representative sample of the surrounding area.

Inclusion criteria. Participants in the educational intervention were nephrology providers including physicians, NPs, and nurses at the nephrology practices. These providers manage patients in the outpatient nephrology clinics and educate patients regarding their renal replacement options. Convenience sampling included all providers and nurses at the two practices ($n = 25$). Although twenty-five were invited, thirteen attended and participated.

Exclusion criteria. Nurses caring for patients in the chronic dialysis setting were excluded, focusing instead on advanced CKD in the outpatient setting. Future studies should focus on ACP and PC initiation in the chronic dialysis setting. Additional exclusions were primary care providers caring for renal patients, as the current focus was on nephrology providers and nurses.

Evidence Based Practice Intervention

The EBQI project intervention involved educating nephrology providers and nurses of the guidelines supporting shared decision-making, ACP, and appropriate PC referral. This EBQI project supported the research recommendations in educating nephrology providers on the RPA (2010) guidelines with the end result of improved renal patient QOL. The independent variable was a lunch presentation updating the providers on the guidelines (Melnyk & Fineout-Overholt, 2015). According to Berling (2013), adult learners learn best by having input on their learning schedule, practice relevancy, and written or verbal feedback. Through literature review and presentation, the SI imparted the importance of the project to the participants. Participants were provided handouts regarding ACP as well as a copy of the guidelines. Additionally, a pocket card was provided as a resource tool. The dependent variable was the increased number of ACPs and PC referrals over four months from baseline data (Melnyk & Fineout-Overholt, 2015). A retrospective chart review of ACP and PC referrals for patients with advanced CKD Stage 4 or 5

with estimated Glomerular Filtration Rate (eGFR) less than 29cc/min was performed pre-and post-intervention. The premise was that advance care plans and renal palliative care referrals by nephrology providers would increase post educational intervention by at least 10% compared to baseline data.

Intervention steps. The EBQI project began in June 2017, with the SI attending CITI training and completing the IRB application process through UMKC and the nephrology practices. After approval, the SI performed the retrospective chart review of ACP and PC referrals from July 2016 to December 2016. This timeframe was chosen to minimize bias as the project was developing. In July 2017, the SI met with the practices' clinic managers to determine best times and educational offerings for the intervention such as luncheon, journal club, or monthly meeting. In August 2017, after the dates were determined, the SI developed and emailed formal invitations to the participants (Appendix I). An invitation confirmation occurred at the local NKF Renal Roundtable event in September 2017 for those in attendance. Reminder emails and phone calls also took place to ensure attendance. The interventional sessions took place in late September and early October 2017. The sessions started with introductions, verbal consent, and a discussion of the EBQI project including pre-intervention data. A review of the RPA guidelines and discussion then occurred (2010). Additionally, the new Coalition for Supportive Care of Kidney Patients (2017) ACP tools were introduced as a resource (Appendix H). The guidelines and tools are web-based available and free for download, without permission. At one-month intervals after the educational session, a retrospective chart review by the SI occurred, collecting the same data as in the pre-intervention query. Feedback was disseminated to the participants via email for their review on a monthly basis (Berling, 2013). Data analysis utilizing descriptive statistics was completed in early 2018.

The Evidence Based Practice Model, Change Process

The Model for Evidence-Based Practice Change. The Model for Evidence-Based Practice Change was chosen as the most appropriate EBP and change model to guide the EBQI project (Melnik & Fineout-Overholt, 2015). It has been utilized in EBP change since its origination in 1999 (Melnik & Fineout-Overholt, 2015). The model includes six implementation steps including: needs assessment, evidence synthesis, evidence analysis, practice change, implementing and evaluating the practice change, and finally integrating and maintaining the practice change (Melnik & Fineout-Overholt, 2015). The last step includes maintaining practice change, or sustainability of the change, which is the long-term goal of the EBQI project.

Study Design

The project was an evidence based quality improvement initiative, not-human subjects research. The intervention was dissemination of knowledge of the RPA (2010) guidelines to nephrology providers and nurses at two urban Midwest nephrology practices to increase knowledge/awareness of shared decision-making, ACP, and PC referrals for CKD patients. The evidence indicates need for improved symptom management, and PC referral can address patient needs from emotional, spiritual, and physical standpoints (Yard, 2010). The overall goal of the project was to enhance renal patient quality of life.

Validity

Internal validity. Convenience sampling was utilized for this EBQI. There was concern for the small sample size of participants; however, the sampling is representative of the nephrology practices in the area. Additional confounding variables include provider awareness and education of ACP and PC referrals from other sources, such as newly published research or seminars. Post intervention occurred during the winter months, when minimal national seminars

are held, minimizing this risk. Renal palliative care referrals may also occur from primary care providers or other sub-specialties, which may affect the internal validity of the study. The referring provider was noted during the chart review to alleviate this threat.

External validity. There were concerns for small sample size and utilization of convenience sample method. The larger the sample size, the better generalizability to other populations (Terry, 2015). The nephrology practices' physicians, nurses, and NPs were invited to participate in the EBQI project. Utilization of both the KTA theoretical model (CIHR, n.d.) and the Model for Evidence Based Practice Change (Melnik & Fineout-Overholt, 2015) to guide this EBQI project made it easily generalizable to other nephrology practices. The intervention steps and results of this EBQI project will also be generalizable to other urban core academic medical centers with culturally diverse populations.

Outcomes Measured

The primary outcome to be measured in this EBQI project was the number of PC referrals for patients with CKD Stage 4 and 5. This was determined through retrospective chart review of the number of palliative care referrals for renal patients over a four-month span of time post-intervention, compared to the number of referrals over a six-month span of time pre-intervention. Secondary outcomes included the number of ACPs completed during the same timeframe. The retrospective chart review query included patient demographics such as age, gender, race, comorbid conditions (diabetes, hypertension, vascular disease, congestive heart failure, and/or dementia), ACP completion, code status, insurance, living situation, and marital status. Clinical parameters included the number of admissions over six months, eGlomerular Filtration Rate (eGFR), protein/creatinine ratio, and serum albumin. Additionally, for those patients who chose PC, treatment modality (HD versus CM), admission rates, and date of death,

if occurred, was included. The patient demographics and clinical data strengthen the project to determine patient parameters for PC referral and ACP, and evaluate for future research (Appendix J).

Measurement Instruments

The measurement instrument was the retrospective chart review of palliative care referrals over six months pre-intervention, and four months post-intervention. The demographic survey from the nephrology providers included age, gender, degree, practice years, awareness of the guidelines, and use of the guidelines. Appendix J depicts the data set as shown in SPSS.

Quality of Data

The SI invited 100% of two Kansas City, Missouri nephrology practices' providers and nurses ($n = 25$) as project participants, therefore a power analysis was not calculated for the participant sample. At baseline, the participants were asked if they utilize the guidelines in current practice. This data is subjective, and therefore, may affect the quality of the data collection.

The patient retrospective chart review data was collected from the electronic medical record (EMR), and was reliable, objective data (Appendix J). The potential variables in the chart review included patient marital status and living situation, as these may change within the timeframe of the study should there be a decline in health status. The recent quantitative study by Parvez et al., (2016), assessed nephrology provider knowledge regarding patients with advanced CKD and was used as a resource for project development.

Analysis Plan

Descriptive statistics was the analytical method for the retrospective chart review (Moran, Burson, & Conrad, 2014). Outcome data projections were an increase in awareness of the EBPG

from baseline after educational intervention. Additionally, analysis was performed on the number of PC referrals and ACPs from baseline for advanced CKD patients. Several clinical parameters were collected and reviewed, therefore, the t-test was expected to be utilized for normal variables, Mann-Whitney U was expected to be utilized for ordinal variables (mean ranks), and Chi Squared was expected to be the statistical analyses applied for nominal variables. (See Appendix K for the statistical analysis templates). Statistical significance was set at $p=0.05$ (Moran, Burson, & Conrad, 2014).

Results

Setting and Participants

The project setting was two inner-city, academic medical centers' nephrology practices in the Midwest. Each offers a representative sample of both providers and participants. Of twenty-five nephrologists, nurses, and NPs invited to participate in the project, thirteen attended the intervention presentation and participated in the project over four months post-intervention. Participant data included six physicians, four NPs, and three registered nurses. According to the participant survey, four stated they were aware of the EBPG and three utilized the guidelines in current practice (See Appendix K).

Intervention Course

The EBQI project began in June 2017, with CITI training, IRB application and approval process through UMKC and the nephrology practices. After IRB approval, the SI performed the retrospective chart review of ACP and PC referrals from July 2016 to December 2016. This timeframe was chosen to minimize bias as the project and intervention details were finalized. In July 2017, the SI engaged clinic staff in scheduling the intervention. In August 2017, the SI developed and emailed formal invitations to the participants (Appendix I). An invitation

confirmation occurred at the local NKF Renal Roundtable event in September 2017. Reminder emails and phone calls also took place to ensure attendance, one week and the day prior to the events.

The interventions took place at one practice on September 29, 2017 and October 13, 2017 and at the other on October 25, 2017. Each lunch session started with introductions, verbal consent, and participant demographic completion. Participant demographic information included practice years, age, degree, awareness of the guidelines, and utilization of the guidelines. No identifiers were collected. Participants were then provided reference handouts regarding evidence review, PowerPoint (including case study), ACP, and a copy of the guidelines in a folder. Additionally, a laminated pocket card of the guidelines was provided as a resource tool. The SI delivered the PowerPoint presentation and discussed the EBQI project, including pre-intervention data, literature review, and the RPA guideline review (2010). The new Coalition for Supportive Care of Kidney Patients (2017) ACP tools were introduced as a resource (Appendix H). The guidelines and tools are web-based available and free for download, without permission. The luncheon intervention sessions lasted approximately one hour, including time for questions and discussion.

At monthly intervals over four months, after the educational sessions, a retrospective chart review by the SI occurred, collecting the same data as in the pre-intervention query. Feedback and electronic resources (utilized at the intervention) were disseminated to the participants via email for their review on a monthly basis (Berling, 2013). Data analysis was performed with simple descriptive statistics, given baseline data which revealed unknown/zero ACPs and zero PC referrals. (See Appendix K).

Outcome Data

Pre-intervention data collection occurred during July to December 2016 and revealed zero outpatient palliative care referrals at either organization by nephrology providers in the outpatient setting. Post-intervention data collection from mid-October 2017 to mid-February 2018 revealed four outpatient PC referrals. The patient clinical parameter data is described in Appendix K. Unfortunately, two nephrology providers (one MD and one NP) could not recall the names of the patients they referred to PC, so data was not collected on those two patients. The office was unable to extract that information electronically. During the same pre-intervention period, no outpatient ACPs were completed at one organization, and at another, they were unable to determine if ACP were completed in their EMR during that timeframe. Post intervention ACP completions totaled 19 (21 including those referred to PC) in the outpatient setting, performed primarily by the practices' NPs.

Discussion

Successes

The participants expressed interest in the topic as well as palliative care in general. Many mentioned the ethical issues related to patient family wishes versus patient wishes and how to proceed. This discussion led to the importance of ACP in meeting patient needs and wishes and therefore should be completed early in CKD (Kidney Supportive Care, 2016).

Increased awareness of the value of palliative care services led one nephrology NP to seek palliative care consultation for her brother's severe chronic obstructive pulmonary disease. Further, a palliative care physician who manages approximately 100 CKD patients in long term care settings, has requested that the SI be consulted for nephrology management of these individuals. Awareness of the project has also been discussed with the chair of the family medicine department within one participating organization. The SI and palliative care nurse

practitioner have been invited to discuss renal palliative care with the residents and medical students at the academic medical center. This will assist in meeting the requests of the national organizations, encouraging PC discussion in medical school and residency programs.

Study Strengths

Study strengths included participants from a representative sample of nephrology providers practicing in the Midwest. The patients at each location were also representative of urban settings, including culturally diverse, insured, uninsured, and underinsured. Following the theoretical framework, the educational intervention was successful in answering the PICOT question. Awareness of PC and ACP for CKD patients was achieved by review of the RPA guidelines through PowerPoint presentation and supplemental resources of pocket guide and ACP. Support for the intervention was provided by the nephrology and palliative care NPs, social workers, and the office managers at both locations. They were instrumental in facilitating dates for the interventions as well as providing input on data collection. The interventions were provided by the SI, a board Certified Nephrology Nurse-NP (CNN-NP) with nearly 20 years of nephrology experience.

Results compared to Literature

Compared to the extensive literature review, the results of this project indicate the majority of nephrology participants were not aware of the RPA (2010) clinical practice guidelines for shared decision making. Of the 13 participants, only four (30.8%) were aware, and of those, three (23.1%) stated they utilized the guidelines in their practice. Additionally, this EBQI project indicated the need for education/increased knowledge regarding ACP and renal PC referrals, similar to the literature review (Ceccarelli, Castner & Haras, 2008; Cohen, Ruthazer, Moss, & Germain, 2010; Combs et al., 2015; Davison, 2010, 2012; Davison, Jhangri, Holley, &

Moss, 2006; Fassett et al., 2011; Germain, Davison, & Moss, 2011; Grubbs et al., 2014; Haras, Astroth, Woith, & Kossman, 2015; Moss & Dillon, 1997; Moss, Stocking, Sachs, & Siegler, 1993; NKF, 2014; Parvez, Abdel-Kader, Pankratz, Song, & Unruh, 2016; Patten, Ojeda, & Lindgren, 2016; Robinson et al., 2004; Robinson & Port, 2010; RPA, 1997; RPA, 2010; Schell, Green, Tulskey, & Arnold, 2013; Smith, Potts, Wellard, & Penney, 2015; Verberne et al., 2016; Yamamoto, Kizawa, Nakasawa, & Morita, 2013; Yard, 2010). In contrast to the prior studies, this EBQI project utilized an educational intervention to inform nephrology providers of the RPA guidelines (2010) to increase ACP and PC referrals to enhance renal patient quality of life.

Limitations

Internal validity effects. Limitations to internal validity included convenience sampling methods, which may include bias. Additional confounding variables included provider awareness and education of ACP and PC referrals from other sources. There was concern for renal palliative care referrals from primary care providers or other sub-specialties.

External validity effects. Limitations to this project are nephrology providers' subjective perceptions of palliative care, bias related to end-of-life care and personal experience with end-of-life care for both patients and nephrology providers (Berger, 2012; Grubbs, 2014; Robinson, 2004; Swartz, 2009). Generalizability was affected by small sample size of 13 participants. Larger sample size equates to greater generalizability among other healthcare populations (Terry, 2015).

Sustainability of effects and plans to maintain effects. Sustainability post educational intervention was addressed through four email communications delivered at monthly intervals to nephrology providers, updating them on the number of PC referrals, answering questions, and reiterating availability of electronic resources. Future plans to maintain effects could include

organizational awareness of palliative care for renal patients through in-service trainings for nurses, physicians and students. Other methods include supplying QOL questionnaires and ACP during CKD education sessions, prior to renal replacement therapy such as dialysis. The latter is already in place at both organizations since the inception of the project.

Efforts to minimize study limitations. Measures were taken to minimize limitations. All nephrology providers and nurses from both organizations were invited to participate in the project. Advance Care Planning was discussed in a nephrology journal published during the same timeframe as the EBQI project, but the nephrologists denied having read the article. Primary care provider and inpatient PC referrals were excluded from the EBQI project.

Interpretation

Expected and actual outcomes. Expected outcome was an increase in PC referrals by at least 10% of baseline. Actual outcome was an increase in PC referrals by 400% of baseline, as baseline revealed zero referrals and post-intervention garnered four referrals. Post intervention, the number of ACPs increased to 21 compared to zero/unknown at baseline.

Interventions effectiveness. Using simple descriptive statistics, the percentage increase of ACP and PC referrals demonstrates that the intervention was effective. Additionally, the request for nephrology consultation for some 100 patients with CKD residing in long term care demonstrates an emerging relationship in the community between nephrology and palliative care experts who, by working together, have an opportunity to improve the quality of life for these vulnerable patients. It is anticipated that this collaborative model of care will continue to grow in the coming months, and should be viewed as one of the greatest successes of the EBQI. Awareness of the guidelines was evident throughout the four months post intervention period with questions regarding PC referrals and the increased number of ACPs by the participants.

Intervention revision. For future interventions, collection of patient clinical parameters and data analysis in real time could potentially support the project. This was a weakness of this EBQI project as one of the nephrology practices' electronic medical record did not support retrospective data collection of ACP and PC referrals. The information was obtained manually, and two patients' data was missed due to human error. Additionally, focusing the intervention on providers who manage and provide CKD education to renal patients would facilitate even greater results.

Expected and actual impact to health system, costs, and policy. The expected impact to health systems, cost, and policy are infinite. Palliative care offers symptom support for patients, regardless of life expectancy. Symptoms such as pain, pruritus, swelling, shortness of breath, and neuropathy affect renal patients in various ways contributing to frequent hospital admissions (USRDS, 2016). According to the USRDS (2016), in addition to symptom management, hospital admissions for vascular access issues, cardiovascular events, and infection are also high. A mortality rate of nearly 50% during the first year of dialysis for patients with multiple risk factors and comorbidities should prompt ACP and PC referrals for advanced CKD patients (Cohen, Ruthazer, Moss, & Germain, 2010). Adding ACPs in the outpatient clinic setting allows patients the opportunity to determine whether dialysis or other life-saving measures are preferred. Making these decisions prior to failing health or mental status are important aspects of plans of care. With dialysis costs exceeding \$87,000 annually, patients choosing not to pursue dialysis and opting for symptom support from PC providers directly impacts the overall healthcare expenditures related to CKD and ESRD (USRDS, 2016).

The overall direct and indirect costs related to this project are minimal compared to the overall system costs of CKD and ESRD patient care. The direct costs were around \$550 for the

luncheon intervention and resources. The SI time for project development and implementation is included in the budget. The itemized budget is in Appendix A. This EBQI project is a cost-effective method of increasing awareness of evidence based practice guidelines, ACP, and importance of appropriate PC referrals for renal patients. Funding was provided through the University of Missouri Women's Graduate Assistance Fund in the amount of \$1,500 to cover SI indirect costs, and the American Nephrology Nurses Association Grant in the amount of \$5,000 (Appendix L).

Healthcare policy should include ACP discussion and completion for all advanced CKD patients (Stage 4 and 5 or GFR less than 29cc/min). This project intervention brought awareness of the importance of ACPs, specifically in chronic kidney disease education classes where advance directives were then included in educational packets for completion during the course. The majority of the ACPs discussed and completed during this project were during CKD education classes by nephrology NPs. Additionally, CMS has allowed ACP education services as a billable option (CMS, 2017).

Conclusion

Despite recommendations by national organizations over past decades, shared decision-making along with ACP and PC referrals are underutilized in renal patients (American Nephrology Nurses' Association 2008, 2011; Grubbs et al., 2014; NKF, 2014; NIH, 2013; NINR, 2014; NIM, 2014; RPA, 2010). Based upon the extensive literature review, this EBQI project improved knowledge of the RPA guidelines on *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* (2010) meeting national recommendations and patient requests. Long term practice change includes shared decision-making for all advanced CKD and ESRD patients, respecting patient wishes on their health care

delivery with or without dialysis, as well as their wishes for dying (Davison, 2012). Effecting palliative care for chronic kidney disease patients is possible by increasing provider knowledge of the clinical practice guidelines, thereby increasing ACP discussion and completion, and PC referral if indicated.

Literature synthesis supports minimizing renal patient symptom burden and improving QOL with PC referral through shared decision-making (Russell, Lupu, Seliger, & Moss, 2016; RPA, 2010; Somma, Trillini, Kasa, & Gentile, 2013). Additionally, synthesis also suggests increasing awareness and knowledge regarding shared decision-making and end-of-life decision-making is imperative for nephrology providers (Moss & Dillon, 1997; RPA, 2010). As such, the weight of the evidence clearly supported the SI's evidence-based project to enhance knowledge of these ethical issues among nephrology providers.

Future research should focus on the need for structured renal palliative care programs across the nation, working collaboratively with palliative care and nephrology providers (Brown et al., 2015; Cohen, Ruthazer, Moss, & Germain, 2010). This project has connected renal and palliative care providers, recognizing needs for this vulnerable population. The SI plans to continue to develop this relationship and provide nephrology care for the long term residents, already receiving PC support. Future research can be obtained from this study, including CKD patient QOL.

Additionally, patient education regarding the differences between palliative care and hospice should be considered (Cohen, Ruthazer, Moss, & Germain, 2010). Through successful project development and data collection and analyses, this project can be used as a guideline for all nephrology practices (Cohen et al., 2010; RPA, 2010; Smith et al., 2015; Yard, 2010). The EBQI project results will be disseminated at the local level through monthly nephrology

meetings and resident seminars, and nationally, in peer reviewed journals, such as the American Nephrology Nurses Association's *Nephrology Nursing Journal*, once approved. Additionally, the project will be presented at the 2019 American Nephrology Nurses Association National Symposium.

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Appendix A

Cost Table

Direct Costs	Dollar Terms	Student Investigator Costs	Total Cost of Time
Materials Folders, pens, etc.	Budgeted \$200.00 Actual \$40.29	Email communication for project implementation and coordination	Budgeted 6 hours x \$60.00/hour = \$360.00 Actual 53.25 hours x \$60/hr = \$3195
Printing guidelines, ppt materials, surveys, pocket guide of guidelines	Budgeted \$60.00 Actual \$238.68	Personal Computer for development of educational presentation and materials	Budgeted 6 hours x \$60.00/hour = \$360.00 Actual 62 hours x \$60/hr = \$3720
Postage for invitations	Budgeted \$10.00 Actual \$0-did not use paper mail	Personal telephone or in person communication for project implementation and coordination	Budgeted 1 hour x \$60.00/hour = \$60.00 Actual 50.5 hours x \$60/hr = \$3030
Lunch for Nephrology Providers and nurses	Budgeted \$10 x 25=250.00 Actual Presentation #1- \$104.38 #2-\$47.61 #3-\$92.86 Actual Total: \$244.85		
		In-kind SI: IRB, data collection, data entry, and statistical analysis	Budgeted 10 hours x \$60.00/hour=\$600 Actual 37.5 x \$60/hr = \$2250
Budgeted	\$520.00		\$1,380.00
Actual	\$523.82		\$12,195

Total Budgeted Costs \$1820.00

Total Actual Costs \$ 12,718.82

Justification: Each attendee was provided a resource packet including a copy of presentation PowerPoint, the guidelines, a pocket guide of the guidelines, palliative care resources and the RPA ACP toolkit. The intervention presentation occurred over lunch, so lunch was provided for the attendees. The SI costs were based upon time spent in coordination, development, and implementation of the intervention, as well as data collection.

Appendix B

Definition of Terms

Advance Care Planning: Includes education regarding disease management, establishing goals of care, and determining durable power of attorney (RPA, 2010).

Chronic Kidney Disease: Damage to the kidneys which limits their ability to filter waste, remove fluids, and regulate electrolytes and hormones (NKF, 2017).

End Stage Renal Disease: Occurrence of signs and symptoms of kidney failure; eGFR less than 15cc/min (NKF, 2017).

Palliative Care: An improvement in QOL of patients, families, and their caregivers. Patients referred to PC most often have life-threatening, chronic disease and benefit from symptom management, social and spiritual support (WHO, 2017).

Hospice Care: Supportive care for patients and their families offered at the end of life, with prognosis less than six months (WHO, 2017).

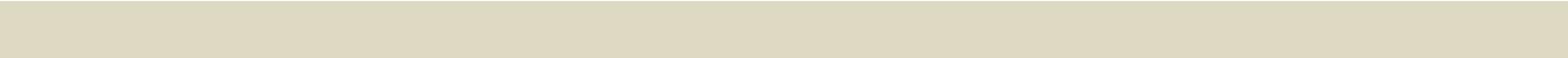
Shared Decision-Making: Including patients, providers, and caregivers in decisions related to patient care, such as renal replacement therapy, including risk/benefit of options, and addressing patient preferences (RPA, 2010).

Appendix C: Synthesis of Evidence Table

First author, Year, Title, Journal	Purpose	Research Design ¹ , Evidence Level ² & Variables	Sample & Sampling, Setting	Measures & Reliability (if reported)	Results & Analysis Used	Limitation & Usefulness
Lack of knowledge among nephrology providers						
Patten (2016). An assessment of palliative care beliefs and knowledge: the healthcare provider’s perspective. International Journal of Palliative Nursing.	Determine the difference between perceived competency and knowledge of (PC) between providers who participated in PC training and those who did not.	Quantitative, non-experimental. Level 3. Variables of PC knowledge, personal history.	N=388 health care providers (physicians, NPs, and PAs) 129 took the PC training course, 259 did not. Study took place in an acute care hospital in Southeastern US. Excluded PC providers.	2 validated and well utilized assessment tools were used: PCQN & S-EOL. Data were collected using: Demographic survey, EPCS, PCS instruments.	Testing was done using IBM SPSS stats software. $\alpha=0.05$. Mann Whitney U-- to determine whether those who participated in training obtained total EPCS or PCS scores that were significantly different from those who did not. P <0.001 is statistical sig difference.	Acute Care setting. Realistic use-- proves more PC education needed for providers.
Parvez (2016). Provider Knowledge, Attitudes, and Practices Surrounding Conservative Management for Patients with	Determine nephrology provider knowledge regarding CM for renal patients.	Quantitative. Survey. Level 6	Nephrologists and primary care providers from the AMA database.	Survey questionnaire was developed.	52.8% versus 36.2%. Statistically Sig differences in nephrologists knowledge between pts who could benefit from CM and	Limitations—study questionnaire. Applicable and useful to DNP project.

Advanced CKD.
Clinical Journal of the
American Society of
Nephrology.

those who would not
with PCP uncertain
about survival rates
with CM.



Combs (2015). Update on end-of-life care training during nephrology fellowship: A cross- sectional national survey of fellows	Determine nephrology fellows' thoughts on PC and end of life in 2013, compared to a 2003 survey.	Quantitative Cross Sectional online survey Level 2	104 Nephrology Fellowship program in US in 2013.	Surveys of preparedness of end of life care.	204 fellows, 65% replied). Statistical sig difference from 2003 to 2013 in attitudes toward end of life training. (95% vs 54%; $P < 0.001$). Fellows also requested a PC rotation.	Limitations: Fellows' subjective perceptions. Applicable to DNP project and useful.
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Yamamoto (2013). The palliative care knowledge questionnaire for PEACE: reliability and validity of an instrument to measure palliative care knowledge among physicians. Journal of Palliative Medicine.	To validate a measurement tool to quantify physicians' knowledge level of PC.	Quantitative Cross sectional anonymous survey Level 2 Variables included physician prior biases with PC.	N=434 sampled physicians	Test-retest reliability/ Intra-class correlation coefficients, known- group validity	33 items across 9 domains: addressing physical and social aspects. Intra-class correlation was 0.84 and the Kuder- Richardson Formula 20 (KR-20) test of internal consistency was 0.87. Validation was a success.	Limitations are that the PEACE-Q was thought to be used for primary palliative care vs renal palliative care. Useful to guide knowledge pre and posttest
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Robinson (2012). Identifying Best Practices and Outcomes in the DOPPS: Caring for Dialysis Patients: International Insights from the Dialysis Outcomes and Practice Patterns Study (DOPPS). Seminars in Dialysis.	Review of the DOPPS as it relates to renal patients	Qualitative SR Level 7-opinion	Renal Patients US	NA	NA	Limitations: Opinion Useful as it relates to renal patients.
Germain (2011). When enough is enough: The nephrologist's responsibility in ordering dialysis treatments. American Journal of Kidney Diseases.	Authors encourage shared decision making prior to dialysis, and "aggressive" CM if dialysis is declined.	Qualitative, SR No variables Level 5	Nephrology providers	NA	NA	No limitations listed. Very relative to current project.
Renal Physicians Association (2010). Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis, Second Edition. RPA	Clinical Practice Guideline for shared-decision making in choosing or withdrawal from dialysis.	EBPG Level 1	Education for all nephrology providers caring for renal patients.	NA	NA	No Limitations. Relative and very useful for all nephrology providers.

Yard (2010) Nephrologists expand the use of palliative care in ESRD. Renal and Urology News.	Determine which patients should benefit from dialysis versus PC.	Qualitative, SR, review of clinical guidelines. Also includes authors' opinions Level 5	NA	NA	Each patient should have shared decision making and may not be the best dialysis candidate	Opinion Useful for project.
Davison (2006). Nephrologists' Reported Preparedness for End-of-Life Decision-Making. Clinical Journal of the American Society of Nephrology	Determine nephrologists' education and comfort in end of life discussion.	Quantitative, online surveys, non-experimental, Level 2 Variables include personal perception, past history of PC or hospice with family.	360 Nephrologists in US and Canada, members of the ASN and Canadian Society of Nephrology in 2005	Questionnaire	X2 test, <i>t</i> test, Awareness of the ASN and RPA Guidelines was a positive predictor for nephrologists' reporting preparedness for end-of-life discussion and decision making, as did longevity of practice, and personal history. 50% of participants knew of the Guidelines ($p < 0.001$).	Older study, but believed to be still relevant today. Useful and quite applicable to current DNP project and nephrology practice.

Graham (2006). Lost in knowledge translation: Time for a map. The Journal of Continuing Education in the Health Professions.	Determine concepts and framework related to knowledge to action and knowledge translation	SR Qualitative Level 5 No variables specified.	NA	Systematic Review of years of knowledge translation usage	NA	No limitations noted. Useful for framework to guide project.
Robinson (2004). Assessment of the Education for Physicians on End-of-Life Care (EPEC™) Project. Journal of Palliative Medicine.	Increase physicians' knowledge on palliative care using the EPEC curriculum using a train the trainer approach, and evaluating this.	2 step qualitative and quantitative design. Level 5	200 physicians who used the EPEC education program	Survey evaluation of the EPEC program to determine the amount of knowledge gained and ease of use.	Results showed a positive result of using the EPEC program to increase palliative care knowledge.	Limitations, prior palliative care knowledge. Useful to current project in showing providers need additional education on PC, however, providing an entire curriculum is not feasible.
Moss (1993) Variation in the attitudes of dialysis unit medical directors toward decisions to withhold and withdraw dialysis. CJASN.	Determine what decisions and attitudes dialysis medical directors have toward patients who want to stop treatment.	Quantitative Level 2 Variables include prior experience with PC, training in fellowship programs.	318 nephrology medical directors of adult chronic dialysis units in US.	Study showed statistically significant variation among dialysis medical directors in their attitudes toward withholding or withdrawing	94% felt prepared 92% listed practice experience, 57% listed training in fellowship. 49% self study	Older study Relevant to today's patient population and DNP project.

dialysis.

Improve quality of life and symptom burden

Ordille (2016). Phenomenology in End-of-Life Care: Implications for Philosophy and Clinical Practice. Clinical Social Work Journal	Determine an understanding of phenomenology in end of life care from a SW perspective.	Qualitative, Case study design. Level 5. No variables	Patients at end of life.	NA	Phenomenology has significance in end of life care due its subjective nature	Limitations related to patient involvement and acceptance. Relevant to DNP project and end of life care.
Russell (2016). Providing supportive care to patients with kidney disease. Nephrology News & Issues	SR of the QOL of renal patients and need for supportive care.	Qualitative SR, Level 5 No variables	Renal patients	NA	National organization, Coalition for Supportive Care of Kidney Patients, providing tools for providers to care for renal patients to improve QOL.	No limitations. Found useful and relevant to DNP project and all nephrology providers.
Brown (2015). CKD in Elderly Patients Managed without Dialysis: Survival, Symptoms, and Quality of Life. Clinical Journal of the American Society of	Determine the QOL, survival and symptoms of elderly patients managed with CM versus dialysis.	Quantitative: single- center prospective observational study Level 2	N=467 renal patients from 2009 to 2013. Australia.	t-test and Mann Whitney U. Data collected after patients chose their therapy.	Older patients with CKD 4-5 managed with CM vs those managed with dialysis--survived a median of 16 months with a 53% 1-year	Limitations: Not a RCT. Bias toward poorer survival in the CM group. There was short follow-up (for a survival study).

Nephrology.

No variables

survival from the time of referral.
Mean eGFR 16cc/min

Very useful

Most patients had symptom improvement with PC referral

Rayner (2014). Recovery Time, Quality of Life, and Mortality in Hemodialysis Patients: The Dialysis Outcomes and Practice Patterns Study (DOPPS). American Journal of Kidney Diseases.

Determine how long patients need to recover from dialysis treatments.

Quantitative. Prospective cohort study.

Level 4.

No Variables specified.

6040 dialysis patients in the DOPPS study. US

Cross-sectional and longitudinal comparisons between recovery time on dialysis. Pt demographics and QOL assessment included.

Recovery time < 2 hours: 32%
2-6 hours: 41%
7-12 hours: 17%
>12 hours: 10%

Males employed full time, with high albumin had shortest recovery tim.

Older patients, patients who had been on HD longer, with comorbidities had longer recovery time.

Patients with increased fluid gains had longer recovery.

Limitations include subjective answers.

Useful in that patients QOL is affected with dialysis treatments, and older patients, comorbid conditions lead to longer recovery after treatment.

Somma (2013). Managing End Stage Renal Disease in the Elderly. Aging Health.	Overview of factors affecting elderly renal patients: nutrition, comorbid conditions, etc.	Qualitative SR Level 5 No variables specified	Patients over 60 years old. Review of patients across the US.	NA	Nephrology providers should consider each patient and their QOL	Limitations: None Useful
Arulkumaran (2012). End-of-life care in patients with end-stage renal disease. Nephrology Dialysis Transplantation	SR of renal patients during end of life and completion of Advanced Care Planning.	Qualitative SR. Level 5.	CKD and ESRD patients in nephrology clinics UK	NA	SR indicates need for improved communication with renal patients on end of life treatment options including palliative care and completion of ACP.	No limitations. Useful and relevant to DNP project.
Williams (2012). Critical and Honest Conversations: The Evidence Behind the "Choosing Wisely" Campaign Recommendations by the American Society of Nephrology	Determine the best tests/studies renal patients should receive.	SR of Quantitative studies resulting in recommendations Level 2	Nephrology providers	A total of 45 recommendations were included in the results.	Recommendations were specific, including minimizing invasive procedures, cancer screenings, and permanent accesses in certain groups.	No limitations. Relative to current practice in nephrology. #5 recommendation is a Shared Decision Making process for renal patients prior to starting RRT/dialysis

Swartz (2009). Chapter 38: End of Life and Decision Making in Elderly Persons With Kidney Failure. American Society of Nephrology.	Determine end of life preferences for elderly patients with kidney failure.	Qualitative, SR, Case study review. Level 5.	Elderly patients nearing or on dialysis.	SR of multiple studies from up to 20 years prior to article.	Patients, families, and caregivers need shared decision-making	Limitations: Older study and case review. Useful
Weisbord (2005). Prevalence, Severity, and Importance of Physical and Emotional Symptoms in Chronic Hemodialysis Patients. Journal of the American Society of Nephrology.	Determine the QOL and symptoms of dialysis patients.	Quantitative. Level 4 Variables include patients who have just started dialysis, those who may have been on dialysis for a while.	N=162 Dialysis patients from 3 dialysis units in Pittsburgh, PA.	Dialysis Symptom Index questionnaire was used. Once completed, multivariable linear regression was used to assess the associations of overall symptom burden and overall symptom severity with HRQoL and depression adjusting for demographic and clinical covariates Mann Whitney U was used to compare symptom burden.	Patients reported an average of 9 symptoms. There was noted depression, severe symptoms, and the results were reviewed according to age, sex, and ethnicity using a multivariate analysis.	Limitations: Nutrition, adequacy of dialysis, or overall comorbid conditions were not measured or reviewed. Even though the study is over 10 years old, and the above limitations were noted, the study could be usable in reviewing the importance of symptom management in dialysis patients.

Underutilization of advance care planning and shared decision-making

Goff (2015). Advance Care Planning: A Qualitative Study of Dialysis Patients and Families. Clinical Journal of the American Society of Nephrology.	Determine an understanding of dialysis patients and their families' needs, for advanced care planning.	Qualitative Study Level 6 Variables of subjective answers during the interview.	N=13 dialysis patients and their families. 2 chronic dialysis units in Massachusetts.	NA	Recorded interviews of patients and families on dialysis. Many desired improved communication with their nephrologist and/or their dialysis team	Small study with limited numbers. If larger study, would be found useful.
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Sinuff (2015). Improving End-of-Life Communication and Decision Making: The Development of a Conceptual Framework and Quality Indicators. Journal of Pain and Symptom Management.	Development of conceptual framework and quality indicators for improving end of life communication, ACP, decisions.	Qualitative. Level 5. Variables include participants of different teams.	Interdisciplinary team members participated to develop the framework and quality indicators.	NA	The authors developed a conceptual framework that can be used by providers to improve EOL communication and decision-making. Delphi Method	No limitations. Generalizable. Applicable to current project.
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Grubbs (2014). A Palliative Approach to Dialysis Care: A Patient Centered Transition to the End of Life. Clinical Journal of the American Society of Nephrology.	Determine the potential and appropriate use of Palliative Care for dialysis patients.	SR Qualitative. Level 5 No Variables	Nephrology providers	NA	SR of many qualitative and quantitative studies as well as recommendations from national organizations such as CMS.	No limitations. Useful for nephrology providers.
Davison (2012). The ethics of end -of-life care for patients with ESRD. CJASN.	Determine patient QOL, ethics of not starting dialysis, which patients would benefit from PC referral.	Qualitative SR conceptual framework for renal palliative care Level 4	Nephrology providers and renal patients	NA	The nephrology team is responsible for caring for ESRD patients and treating their symptoms.	No limitations. Useful for project.
Davison (2010). End-of-life care preferences and needs: Perceptions of patients with Chronic Kidney Disease. CJASN.	To evaluate end-of-life care preferences of CKD patients to help identify gaps between current end-of-life care practice and patients' preferences and to help prioritize and guide future innovation in end-	Quantitative SR Level 2 Variables include patient ability to complete surveys, literacy, perceptions of QOL.	N=585 Stage 4&5 renal patients in 2008. Alberta, Canada	Questionnaires Surveys.	Regretted starting HD-61% Preferred to die at home or inpatient hospice-6.1% Percent of patients who had EOL discussion-<10%	Limitations--use of questionnaires and subjective. Very useful for project.

of-life care policy.

Survival analysis between conservative management (CM) and renal replacement therapy (RRT) in renal patients						
Verberne (2016). Comparative Survival among Older Adults with Advanced Kidney Disease Managed Conservatively Versus with Dialysis. Clinical Journal of the American Society of Nephrology.	Determine survival between older patients who choose RRT or CM.	Qualitative, single-center retrospective cohort study occurred from October 31, 2004 to October 31, 2014. Level 2 Variables include patients who changed their mind on modality or passed away prior to starting dialysis. Excluded AKI.	N= 311 patients with advanced CKD deciding between renal replacement therapy (RRT) or Conservative Management (CM).	The t test, chi-squared and Mann-Whitney U tests are reliable.	CM n=107 RRT n= 204 Overall results in the cohort study of patients >70 years choosing RRT had better survival than CM group (2 vs 1 year). For patients > 80 years old, CM may be a better option.	Limitations-unable to adjust for cofounders It is an applicable and useful study for this DNP project.
Mayo Clinic (2013). Dialysis for the elderly: New evidence from Mayo Clinic to guide shared decision-making. Science Daily.	Study shows half of elderly patients who opt for HD pass away within a year—patients need shared decision-making.	Quantitative, single study reviewed Level 6	N=379 dialysis patients over 75 when they started dialysis. Rochester, MN, Mayo Clinic	Records review and analysis	Study shows half of elderly patients who opt for HD pass away within a year	Limitations: Review of the study. Useful to DNP project, encouraging shared decision making.

Cohen (2010). Predicting six month mortality for patients who are on maintenance hemodialysis. CJASN	The purpose of was to develop and validate a tool to determine patients who have a shortened life expectancy on HD.	Quantitative Level 2 Variables include decline in pt status and nutrition, age, and other factors.	N=514 patients from 8 hemodialysis clinics in Massachusetts	In a Cox multivariate analysis early mortality for HD patients are associated with: Older age Dementia Vascular disease Decreased albumin	Neither (the SQ or CCI) instrument is sufficiently sensitive and specific alone to use in this study, per the authors.	Insufficient number of nephrologists in the study, and the SQ instrument. Useful in using the SQ and CCI as prognostic tools, however, the CCI was found to be more sensitive than the SQ
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Appendix D

Theory to Application Diagram

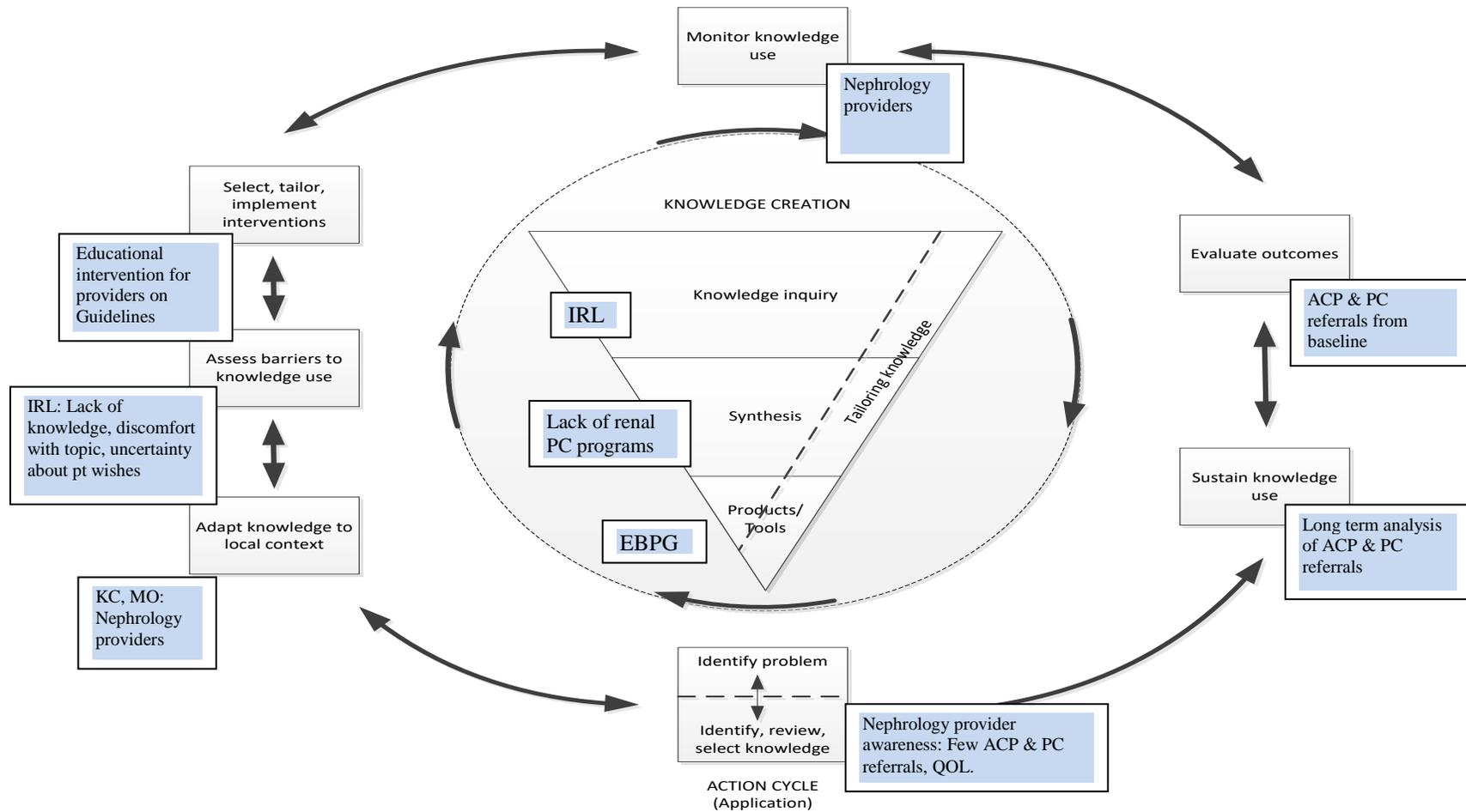


Figure 1. Knowledge-to-Action Cycle, adapted. (Graham et al., 2006).

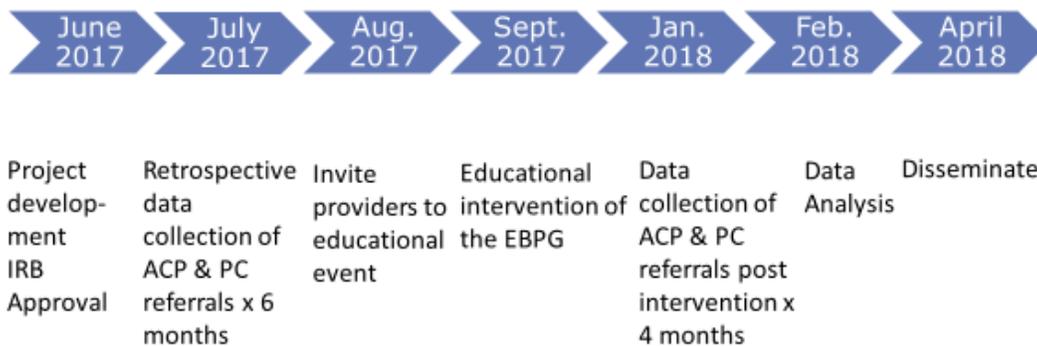
Appendix E Logic Model

Inputs	Intervention(s) Outputs		Outcomes -- Impact		
	Activities	Participation	Short	Medium	Long
<p>Evidence, sub-topics Lack of knowledge among nephrology providers (12)</p> <p>Improve quality of life and symptom burden (9)</p> <p>Underutilization of advance care planning and shared decision-making (5)</p> <p>Survival analysis between conservative management and renal replacement therapy (3).</p> <p>Major Facilitators or Contributors 1. DNP Advisor 2. Nephrology APRNs 3. Palliative Care team 4. Social Workers</p> <p>Major Barriers or Challenges 1. Nephrology provider lack of knowledge of guidelines and PC 2. Inadequate training 3. Trained in Curing versus Palliation 4. Unsure of patient wishes 5. Time for intervention</p>	<p>EBP intervention which is supported by the evidence in the Input column Improving nephrology provider knowledge on RPA guidelines will increase ACP, palliative care referrals and shared decision-making, improving QOL</p> <p>Major steps of the intervention 1. Obtain IRB/Baseline data of PC referrals over 6 months 2. Provider verbal consent and demographics survey 3. Education of guidelines/PC luncheon 5. Obtain number of PC referrals monthly over 4 months 6. Compare pre intervention and post intervention data and disseminate.</p>	<p>The participants (subjects) Nephrology Providers (NPs & MDs) and nurses in 2 KC urban Nephrology Practices</p> <p>Site Practice locations/hospitals</p> <p>Time Frame 1 year</p> <p>Consent or assent Needed Provider verbal consent to participate, IRB</p> <p>Other person(s) collecting data Yes-SI</p> <p>Others directly involved in consent or data collection Yes, Palliative Care APRNs and/or Social Workers</p>	<p>(Completed during DNP Project)</p> <p>Outcome(s) to be measured Primary: Number of palliative care referrals for renal patients, pre-post intervention. Secondary: The number of ACPs pre and post intervention</p> <p>Measurement tool(s) Retrospective chart review of ACP and PC referrals</p> <p>Statistical analyses to be used 1. Mann Whitney <i>U</i> 2. Chi Squared 3. <i>t</i>-test</p>	<p>(after student DNP)</p> <p>Outcomes to be measured 1) Determine knowledge of guidelines for students, residents, and fellows 2) Review numbers of patients with palliative care referrals at 6 months and 1 year. 3) Add QOL questionnaires for renal patients. 4) Cost analysis of renal palliative care program.</p>	<p>(after student DNP)</p> <p>Outcomes that are potentials 1) Development of a Renal Palliative Care Program in Kansas City. 2) Decrease admission rates of renal patients with PC referral 3) Improved QOL and symptom management of renal patients with PC referral 4) Decreased healthcare costs with renal PC referral 5) Nephrology provider satisfaction of knowledge of end of life guidelines 6) Increased patient satisfaction with PC referral</p>

Appendix F

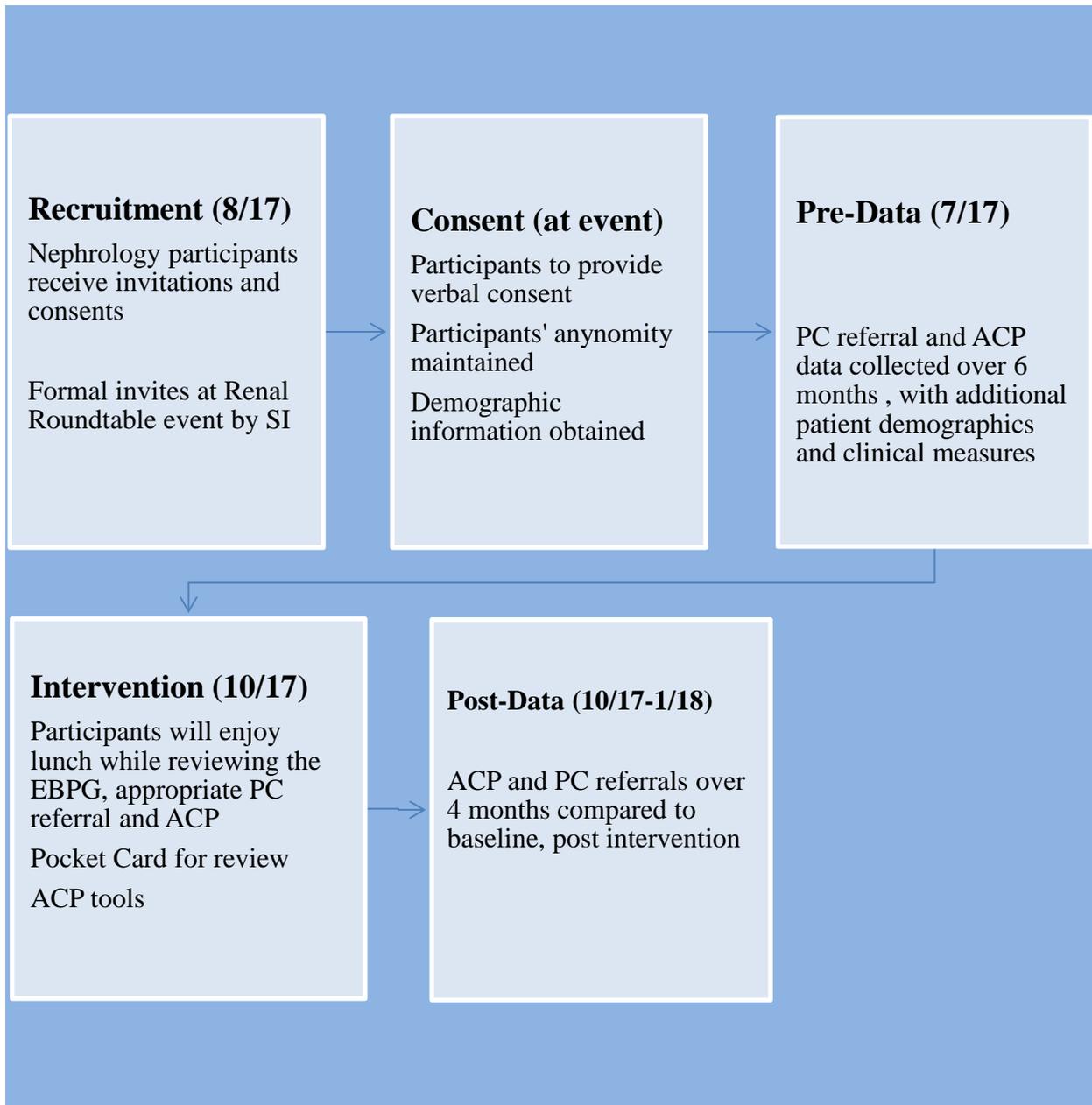
Project Timeline

Project Timeline



Appendix G

Intervention Flow Diagram



Appendix H

Intervention Content

Information Lunch Sessions with Nephrology Providers and Nurses

- I. Introductions
- II. Verbal Consent
- III. Demographic Survey
- IV. Background
- V. Significance
- VI. Local Issue
- VII. Problem and Purpose
- VIII. Evidence by Subtopics
- IX. Practice Change Methods: Tools for Success
 - a. Renal Physician Association Review (and pocket guide) of the Clinical Practice Guidelines: Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis:
 - i. https://c.ymcdn.com/sites/www.renalmd.org/resource/resmgr/Store/Shared_Decision_Making_Recom.pdf
 - b. Renal Physician Association Advance Care Planning Tool:
 - i. <https://www.renalmd.org/?page=AdvancedCare>
 - c. Kidney Supportive Care Advance Care Planning Guide:
 - i. <http://www.kidneysupportivecare.org/Files/CurriculumGuideAdvanceCarePlan3-2017.aspx>
 - d. Centers for Medicare & Medicaid Services Advance Care Planning:
 - i. <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf>
 - e. Renal Physician Association App:

Shared Decision Making App Webinar

Introduction

This complimentary webinar guides you through the use of the RPA Shared Decision Making (SDM) App. The RPA SDM App translates the Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis clinical practice guideline into an interactive, workflow-driven aid for nephrology and palliative care practitioners.

- Easy to use evidence-based tools include a validated prognosis calculator for dialysis patients, pain and symptom assessment scoring systems, and links to relevant web-based resources.
- Step-by-step approach to guide decision making for initiating, withholding and withdrawing dialysis for adult and pediatric patients and families at the point of care.

The RPA SDM is available free of charge for iPad on [iTunes](#).

RPA's *Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis, 2nd Edition*, clinical practice guideline is available for download in the [RPA Store](#).

If you have not already set up your eLearning account, please use your RPA renalmd.org login credentials when doing so.

Appendix I

Recruitment Materials

EFFECTING PALLIATIVE CARE FOR CHRONIC KIDNEY DISEASE PATIENTS



The purpose of this Evidence Based Practice Quality Initiative is to:

- Bring awareness and increase knowledge of clinical practice guidelines on *Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis* (RPA & ASN, 2010).
- Involve chronic kidney disease stage 4 and 5 patients in the shared decision-making process
- Review Advance Care Planning for renal patients
- Improve quality of life for renal patients
- Increase Palliative Care referrals and Advance Care Planning

Date and Time

Participation involves:
A time commitment of 1 hour during lunch (provided).
Participants include:
Physicians, APRNs, and Nephrology Nurses



CHRISTINE CORBETT, APRN, FNP-BC, CNN-NP, FNKF
DNP STUDENT

816-805-4557
Christine.Corbett@umkcmed.org
PI: Dr. Janet Wood

Participant Results

Variable	Total (n)	Control (n)	Intervention (n)	Statistical Significance
Gender				
Female				
Male				
Practice Years				
0-5				
6-10				
11-15				
16-20				
21-30				
> 30				
Age				
21-30				
31-40				
41-50				
51-60				
61-70				
>70				
Awareness of Guidelines				
No				
Yes				
Utilization of Guidelines				
No				

Yes				
Degree				
NP				
RN				
MD				
DO				

Patient Results

Variable	Total (n)	Control (n)	Intervention (n)	Statistical Significance
Patient/GROUP				
Age Will complete once data collected				
Ethnicity Caucasian African American Asian/Pacific Islander Hispanic Middle Eastern				
Gender Female Male				
Code Status Full Code DNR				
Advance Care Plan Completed No Yes				
Marital Status Married or live in partner Single				
Living Status				

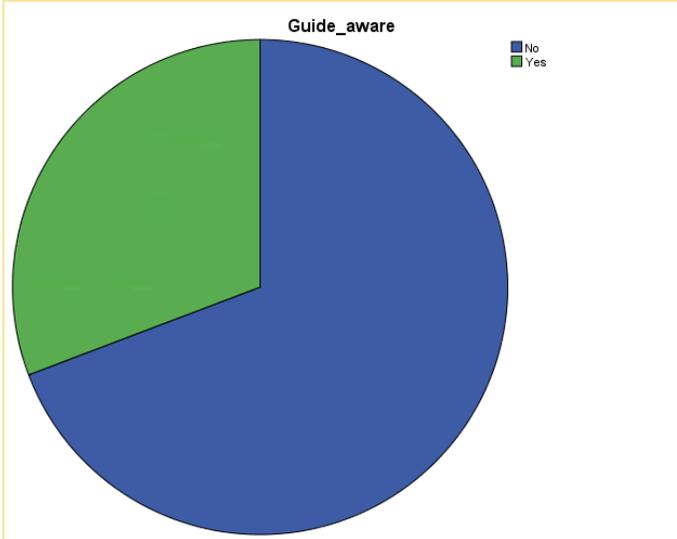
Home				
SNF				
NH				
Homeless				
Insurance				
Medicaid				
Medicare				
Uninsured				
Commercial				
Admissions				
0				
1				
2				
3				
4				
5				
GFR				
0-5				
6-10				
11-15				
16-20				
21-25				
26-29				
PCR				
> 3.5gm				
< 3.5gm				
Albumin				

>4				
3-4				
2-3				
Dialysis				
Yes				
No				
Referral Source				
APRN				
MD				
DO				
RN				
LPN				
Diabetes				
Yes				
No				
HTN				
Yes				
No				
CHF				
Yes				
No				
PVD				
Yes				
No				
Dementia				
Yes				
No				

Appendix K

Statistical Analysis Tables

Pie Chart Depiction of Participants' Awareness of the EBP Guidelines



Appendix L

Project Proposal Approval Letter



July 7, 2017

Members of Institutional Review Board
Truman Medical Centers, Kansas City Kidney Consultants and the University of Missouri-
Kansas City
Kansas City, Missouri

IRB Members,

This letter serves to provide documentation regarding Christine M. Corbett's Doctor of Nursing Practice (DNP) Project proposal. Ms. Corbett obtained approval for her project proposal, *Effecting Palliative Care for Chronic Kidney Disease Patients by Increasing Provider Knowledge* from the School of Nursing DNP faculty committee on July 7, 2017.

If I can provide any further information, please feel free to contact me.
Sincerely,

A handwritten signature in cursive script that reads "Susan J. Kimble". The signature is contained within a thin black rectangular border.

Susan J. Kimble, DNP, RN, ANP-BC, FAANP
Clinical Associate Professor
DNP Programs Director
UMKC School of Nursing and Health Studies
816-235-5962
kimbles@umkc.edu

Appendix M
IRB Approval Letter



UMKC
5319 Rockhill Road
Kansas City, MO 64110
TEL: (816) 235-5927
FAX: (816) 235-5602

NOT HUMAN SUBJECTS RESEARCH DETERMINATION

Principal Investigator: Ms. Janet Wood
6372 S. Farm Rd. 119
Brookline Station, MO 65619

Protocol Number: 17-253
Protocol Title: Effecting Palliative Care for Chronic Kidney Disease Patients by Increasing Provider Knowledge
Type of Review: Not Human Subjects Determination

Date of Determination: 07/25/2017

Dear Ms. Wood,

The above referenced study, and your participation as a principal investigator, was reviewed and determined to be Not Human Subjects Research (NHSR). As such, your activity falls outside the parameters of IRB review. You may conduct your study, without additional obligation to the IRB, as described in your application.

The NHSR Determination is based upon the following Federally provided definitions:

"Research" is defined by these regulations as "a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge."

The regulations define a **"Human Subject"** as "a living individual about whom an investigator (whether professional or student) conducting research obtains: data through intervention or interaction with the individual, or identifiable private information."

Attachments include the following:

Attachments

All Human Subjects Research must be submitted to the IRB. If your study changes in such a way that it becomes Human Subjects Research, please contact the Research Compliance office immediately for the appropriate course of action.

Please contact the Research Compliance Office (email: umkcirb@umkc.edu; phone: (816)235-5927) if you have questions or require further information.

Thank you,

A handwritten signature in black ink, appearing to read 'Crystal Simonis', is written over a light blue horizontal line.

Crystal Simonis
UMKC IRB Administrative Office