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Implementation of an Advance Care Planning Discussion for Patients with Chronic Kidney Disease

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Running head: ADVANCE CARE PLANNING

Implementation of an Advance Care Planning Discussion for Patients with Chronic
Kidney Disease

BY

Chelsea Hinders

A paper submitted in partial fulfillment of the requirements for the degree

Doctor of Nursing Practice

South Dakota State University

2017

Implementation of an Advance Care Planning Discussion for Patients with Chronic
Kidney Disease

This Doctor of Nursing Practice (DNP) Project is approved as a credible and independent investigation by a candidate for the DNP degree and is acceptable for meeting the project requirements for this degree. Acceptance of this DNP Project does not imply that the conclusions reached by the candidate are necessarily the conclusions of the major department.

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Abstract

Implementation of an Advance Care Planning Discussion for Patients with Chronic

Kidney Disease

Chelsea Hinders

2017

Clinical practice guidelines (CPGs) support the need for providers to engage patients in a discussion of goals and priorities regarding end-of-life care through the use of advance care planning (ACP) (Agency for Healthcare Research and Quality [AHRQ], 2014). However, current data demonstrated a lack of implementation specific to patients with chronic kidney disease (CKD). A five question standardized tool developed from current guidelines served as the discussion guide for this intervention. Despite the great need for this project, patients who were eligible for the intervention were not willing to be active participants in an ACP discussion. The clinical significance, most notably the increased awareness of the nephrology Nurse Practitioner (NP) and other clinic providers, demonstrated ACP can be successful. Further research is needed to transform the topic of ACP in both research and practice.

Keywords: advance care planning, advance directive, chronic kidney disease

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List of Abbreviations

ACP	Advance care planning
AD	Advance directive
AHRQ	Agency for Healthcare Research and Quality
APRN	Advance Practice Registered Nurse
CKD	Chronic kidney disease
CPG	Clinical practice guideline
DNP	Doctor of Nursing Practice
DNR	Do-not-resuscitate
ESRD	End-stage renal disease
GFR	Glomerular filtration rate
HIPAA	Health Insurance Portability and Accountability Act
ICU	Intensive care unit
NIH	National Institutes of Health
NP	Nurse Practitioner
RCT	Randomized controlled trial
TTM	Transtheoretical Model
USPSTF	United States Preventive Services Task Force

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Chapter 1

Introduction

Introduction

The kidneys are a paired organ system that filter, reabsorb, and excrete solutes, water, and harmful toxins from the body. Fluids, electrolytes, and acid-base balance are closely regulated by this organ system as well as the production of vitamin D and erythropoietin (Chisholm-Burns et al., 2013). When part or all of these functions are lost for a time period of greater than three months, chronic kidney disease (CKD) develops. Those who are plagued with CKD experience a progressive loss of kidney function that can occur over months to years. This decline is often irreversible and may result in end-stage renal disease (ESRD) at which point dialysis or another form of renal replacement therapy may be required (Chisholm-Burns et al., 2013).

A large number of individuals may be unaware they are living with CKD making it challenging to successfully treat this condition. In addition, patients with CKD are older, usually have multiple comorbid conditions, and face death earlier than the average individual (Wasylynuk & Davison, 2015). This raises the need for advance care planning (ACP) in this patient population. Defined more thoroughly, ACP is a process involving reflection, discussion, and structured communication between a patient, family member, caregiver, close friend, and/or a health care provider that helps to clarify an individual's health status, prognosis, values, goals, and treatment preferences for end-of-life care (Davison, 2012). However, ACP is not part of the routine care of patients with CKD, despite the chronic and debilitating nature of the condition (Wasylynuk & Davison, 2015).

Significance of the Problem

CKD exists along a continuum of stages one to five based on glomerular filtration rate (GFR). Kidney damage is present at stage two and ESRD exists at stage five (Chisholm-Burns et al., 2013). Today, CKD plagues nearly 26 million Americans and millions of others may be at risk for this diagnosis (National Kidney Foundation, 2016). Five years ago, one in 10 American adults was living with some form of CKD (U.S. Department of Health and Human Services, National Institutes of Health [NIH], 2012). In addition, the incidence of CKD was greatest among those 65 years of age and older, with this rate more than doubling between 2000 and 2008 (NIH, 2012). Alarming, these numbers continued to grow by about 10% per year (Harrison & Watson, 2011).

Mortality is much higher in those with ESRD than in the general population. In 2009, the number of deaths from ESRD totaled over 90,000, as compared to just over 10,000 in 1980 (NIH, 2012). Patients who were referred to a nephrologist or who started dialysis later in the disease process had significantly poorer survival rates and were at risk for an earlier death as compared to their healthier counterparts. The later stages of CKD, such as stages four and five, are often accompanied by a less than optimal health state, less residual kidney function, and longer periods of acute hospitalizations (Wasylynuk & Davison, 2015).

Failure to establish an individual's own goals of care, such as what occurs during ACP, often resulted in unnecessary admissions to the hospital, invasive procedures, and more aggressive care than individually desired for patients with CKD (Davison, 2012). CKD may seem like an easy disease to control and manage, but an individual's CKD progression is largely unpredictable and no definitive prognosis can be effectively made

(Wasylynuk & Davison, 2015). These facts together stress the need for an early discussion about a patient's wants, goals, and desires should they near the end-of-life quicker than imagined.

Those without an advance directive (AD) lack specific goals of care for their end-of-life. In a time of a health crisis, those nearest to the patient, such as family members, close friends, or even health care providers, must make decisions regarding a patient's treatment. This can result in unnecessary stress for these persons and uncertainty in their decision making since a discussion about what should and should not be done in this situation has never been discussed with the patient. These treatments can go against what the patients would want for themselves without an exact document stating their wishes. The end result may hover between two ends of the spectrum, prolonging life unnecessarily or allowing patients to die despite their desire to continue with aggressive treatment. However, a successfully implemented ACP discussion allows patients to enjoy their last few days giving them time to reflect on their prior life experiences with self-worth. Having a developed AD prior to experiencing a health crisis or the end-of-life often ensures these crucial matters have been voiced with those closest to them.

The concept of ACP focuses on the early identification of individual needs, wants, and desires should a patient become incapable of making his or her own decisions. It involves naming a surrogate decision maker, discussing individual goals of care with family members, close friends, or health care providers, and making critical decisions as to what is desired at or near the end-of-life (Wasylynuk & Davison, 2015). The development of an advance care plan is often a continuous process, revisited by the patient, family member, and health care provider at many successive visits once the

initial topic had been brought forth (Davison, 2012). Widespread use of ACP enhances communication between patients and providers, improves quality of life for patients and family members, reduces unnecessary and unwanted hospitalizations, and decreases health care costs (Rietjens et al., 2016). Nicholas, Langa, Iwashyna, and Weir's (2011) study showed Medicare beneficiaries with treatment-limiting ADs spent up to \$380,200 on end-of-life care as compared to those without ADs, whose costs were \$522,754. Life-sustaining treatment differences between the two groups were statistically significant for those with an AD using less than half of the resources required by those without an AD (Nicholas et al., 2011). While the necessity of ACP has been stressed in multiple settings, this work flow continues to be underutilized today, despite a great patient desire to partake in these conversations (Goff et al., 2015).

Those who reported previously using ACP described increased control over medical situations, relief of burdens on loved ones, and strengthened relationships with family members (Holley, 2012). However, specifically for patients with CKD, nearly half of all patients living with ESRD have some form of cognitive impairment and are unable to participate in decision making at the end-of-life (Feely et al., 2016). Moderate to severe cognitive impairment was common in over 70% of dialysis patients, despite having no history of former changes in mental status (Davison, 2012). This change is thought to occur due to blood vessel disease and resulting hypoperfusion, or decrease in blood flow, to the brain cells. Brain imaging of these patients commonly showed areas of damaged tissue and an increased risk of stroke due to this decrease in blood flow (Tamura & Yaffe, 2011). In addition, depression was common and often unrecognized among those with CKD, both before and during dialysis therapy (Davison, 2012). Death,

hospitalization, and disability rates were higher among those with this condition in conjunction with CKD (Tamura & Yaffe, 2011). The above issues contribute negatively to ACP and hinder a patient's ability to actively participate in end-of-life decision making once the disease has progressed. These psychiatric conditions make it more difficult to formulate an advance care plan or AD document with this patient population.

ACP is a fluid process, not a single act, that should first occur with the patient and his or her family members. One of the most beneficial times for ACP to occur in patients with CKD is when dialysis or other conservative options are first presented to the patient and/or family members. After this topic is first presented to the patient, it is then brought up at successive office visits and is revisited on a regular basis to ensure the patient's care plan remains consistent with one's wants, goals, and desires for their end-of-life care (Davison, 2012). ACP focuses on an individual's broad goals of care and helps serve as a facilitator of discussion among patients, families, and health care providers. In this population, specific goals to be addressed through ACP include the decision to start or stop dialysis or to pursue other forms of renal replacement therapy. However, a lack of knowledge of the ACP process among this patient population is a major barrier to its current use.

ADs are also an important component of ACP. In 1991, the Patient Self Determination Act stressed the necessity of ensuring patients enact ADs to guarantee their goals for end-of-life care are honored at a very critical point in their lives. However, this law did little to increase the use and completion of ADs, as only 36% of the United States population had documented their wishes for end-of-life care in 2011 (Pecanac, Repenshek, Tennenbaum, & Hammes, 2014). Encouraging patients to have these crucial

conversations and to engage in ACP is not only essential to good end-of-life care but provides patients with this chronic condition some control over one part of their lives.

The high prevalence of CKD, its unpredictable course, and the relatively small number of individuals who had completed ADs or participated in the unique process of ACP stressed the impetus to explore this concern further through this Doctor of Nursing Practice (DNP) Project. Given the compounding factors listed above, matching individual goals of care with the care received as the disease progresses is critical for patients with CKD (Goff et al., 2015). In communication with an Advance Practice Registered Nurse (APRN), ACP specific to patients with CKD is not a routine and consistent process implemented in an urban Midwestern nephrology clinic (K. Jerke, personal communication, May 19, 2016). As health care providers, the implementation and consistent use of ACP can result in more informed and prepared patients and family members. The purpose of this DNP Project was to help patients identify their personal goals of care in the CKD disease process, decide for themselves what it is they want for their last few months, and promote a more dignified dying process.

Population of Interest

The population of interest included adult patients who were in CKD stages four and five based on GFR without an existing AD document. GFR is defined as the amount of blood filtered across the capillary of the kidney, or the glomerulus, per unit time, based on serum creatinine level, age, sex, and race (Harrison & Watson, 2011). A normal GFR is more than 90 mL/min/1.73 m². Age-related declines in kidney function are common; however, one does not normally progress to stages four and five without persistent kidney

damage. Stage four CKD is defined as a GFR between 15-29 mL/min/1.73 m² and stage five is a GFR less than 15 mL/min/1.73 m² (Chisholm-Burns et al., 2013).

Other risk factors associated with CKD include low kidney mass, low birth weight, being of a racial or ethnic minority, having a family history of kidney disease, and having a low income or low education level (Chisholm-Burns et al., 2013). Diabetes is the most common cause of CKD while hypertension is a close second, especially when these conditions are uncontrolled. Together, these two illnesses account for roughly two-thirds of all cases of impaired kidney function (National Kidney Foundation, 2016). Other diseases, such as autoimmune diseases, polycystic kidney disease, urinary tract infections, and elevated cholesterol levels can all contribute to an increased incidence of CKD. Often, once sustained damage has occurred to an individual's kidneys, it is impossible to regain prior function (Chisholm-Burns et al., 2013).

Patients with CKD stages four and five were chosen for the project sample due to the chronicity of this health condition. Once a patient reaches these stages, kidney damage is irreversible and ESRD is most likely to result. A thorough discussion of dialysis and other forms of renal replacement therapy takes place between the patient and health care provider once a patient reaches these advanced stages of kidney disease. An individual's prognosis and the limited treatment options can be addressed with ACP. Informed health care consumers can make more realistic choices and will have the potential to experience a quality of life they are satisfied with, even with a diagnosis of an incurable health care condition.

A large group of patients are likely to benefit from the implementation of ACP. This includes patients with CKD who have decided to manage their health conservatively

without dialysis or other forms of renal replacement therapy, those whom a trained health care provider knows have a poor prognosis or are near death, and those who are considering withdrawing from dialysis therapy. Patients who have difficulty determining simple goals of care, those who have experienced great functional decline within the last year, and those who have experienced an acute change in health, such as a debilitating stroke or heart attack, may also be appropriate for a structured use of ACP (Davison, 2012). However, it is essential to understand that any patient with CKD can benefit from the process of ACP. As it has been developed today, ACP can and should be used with any patient at any time.

Clinical Question

The clinical question for this DNP Project was asked in PICOT format. P stands for patient population, I stands for intervention, C stands for comparison intervention, O stands for outcome, and T stands for time frame (Melnyk & Fineout-Overholt, 2011).

(P) In adult patients with CKD stages four and five in an urban Midwestern nephrology clinic, does **(I)** implementation of an ACP discussion **(C)** compared to usual care **(O)** increase patient knowledge of ACP and increase completion of ADs **(T)** over a three month time period?

For the last six years, the DNP Project coordinator's clinical practice has focused on the care of patients with CKD. Oftentimes, it was stressful health situations, unexpected illnesses, or tragic situations that triggered ACP to occur in patients of this type. These patients failed to acknowledge the extent of their situation and refused to prepare for their final days. Family members routinely felt unprepared to make these difficult decisions and were often uncertain about what it was the patient desired.

Desperate measures, such as ventilator support, use of feeding tubes, and long surgical procedures were initiated and death became a painful process for all involved, including the health care providers and staff caring for these patients. A gap existed in a patient's knowledge of preparing for the end-of-life and actually partaking in these processes.

This DNP Project hoped to enable ACP to become an integral part of the care of patients with CKD and as such, allowed each patient to achieve his or her goals and desires at the end-of-life.

Purpose of the Project

The purpose of this DNP Project was to implement a standardized process of ACP specific to patients with CKD stages four and five in an urban Midwestern nephrology clinic. The usual care in this setting was while rooming a patient, the nursing staff asked the patient if he or she had an AD document completed. If the patient did not, he or she was then asked if he or she would like information on completing one. Information on forming an advance care plan was sometimes provided but it was not specific to the care of patients with CKD. No further steps were identified in regards to ACP or the completion of ADs. The usual care was replaced with an ACP process specific to patients with CKD. Implementation of this intervention aimed to introduce patients to the process of ACP and enabled eligible patients to see the necessity of an ACP discussion. It was a goal of this project to increase patient knowledge of the process of ACP after the completion of the intervention. In addition, patients would be enabled to complete an AD document and it was the desire that they would be more easily able to state their wishes for their end-of-life care with their family members and health care providers after participating in this consistent ACP intervention.

This project aimed to allow ACP to become a routine, dynamic practice in the care of all patients with CKD at this outpatient clinic. Over time, it is the goal that patients will experience a greater quality of life at the end-of-life, patient wishes will be more easily honored at the end-of-life with the use of and increase in the completion of AD documents, and family members can be assured they are following their loved ones wishes as he or she approaches the end-of-life. In addition, health care costs may decrease as patients who partake in ACP often choose less life-sustaining treatment measures and experience fewer unnecessary hospitalizations at the end-of-life (Rietjens et al., 2016).

Definitions

Adult – a person who is fully grown or of age

Advance care planning (ACP) – a crucial process of thought and communication in which a cognitively sound person makes future health and/or personal care decisions in the event that they become incapable of making these decisions (Wasylynuk & Davison, 2015). Advance care planning is a continuous process that occurs over many office visits and should be revisited with the patient on a regular basis (Davison, 2012).

Advance directive (AD) – a document prepared by a competent adult that provides views, wishes, and directions on the steps to be taken on matters pertaining to health and medical treatment at a time when an individual is unable to make those decisions (Pandya, 2015). These tangible documents are sometimes referred to as written instructional directives. ADs are a distinct part of the process of ACP (White et al., 2014).

Chronic kidney disease (CKD), also known as chronic renal insufficiency or progressive kidney disease – presence of kidney damage that is present for a time period of three months or more and is generally a progressive, irreversible loss of kidney function. CKD exists along a continuum of stages from one to five. Kidney damage exists at stage two and dialysis typically begins at stage five (Chisholm-Burns et al., 2013).

Do-not-resuscitate (DNR), also known as a no code – a medical term that allows a patient to die naturally. Often used for a patient who has a terminal or chronic health condition. When a patient's heart stops beating or a patient stops breathing, no unnecessary or life-sustaining measures are undertaken to prolong the patient's life (Santonocito, Ristagno, Gullo, & Weil, 2013).

End stage renal disease (ESRD), which is also known as CKD stage five – an individual's GFR is below 15 mL/min/1.73 m² and dialysis or another form of renal replacement therapy may be required to sustain life (Chisholm-Burns et al., 2013).

Glomerular filtration rate (GFR) – the amount of blood filtered across the capillary of the kidney, or the glomerulus, per unit time, based on serum creatinine level, age, sex, and race (Harrison & Watson, 2011). A normal GFR is more than 90 mL/min/1.73 m² (Chisholm-Burns et al., 2013).

Nephrologist – a health care provider who studies and deals with the anatomy, management, physiology, and pathology of the kidneys (Nephrology, n.d.).

Renal replacement therapy – a type of medical therapy that takes the place of the normal function of the kidneys. Hemodialysis, peritoneal dialysis, and kidney

transplantation are the three known types of renal replacement therapy (Chisholm-Burns et al., 2013).

Surrogate decision maker – an individual entrusted to make health care decisions on a person's behalf if they are unable to do so. This person should have the most knowledge about what a person does and does not want in regards to his or her health and end-of-life care (Wasylynuk & Davison, 2016).

Usual care – asking a patient if he or she has an AD document completed. If not, the patient is then asked if he or she would like information on one. Information on forming an advance care plan is sometimes provided, but it is not specific to the care of patients with CKD. No further steps are identified in regards to ACP or the completion of ADs.

Chapter 2

Literature Review

Introduction

Current clinical practice guidelines (CPGs) supported the need for providers to engage patients in a discussion of goals, preferences, and priorities regarding end-of-life care through the use of ACP (Agency for Healthcare Research and Quality [AHRQ], 2014). Even in those with CKD, ACP should be targeted to address specific issues that occur throughout the course of the disease, including initiating, withdrawing, or withholding dialysis therapy (Renal Physicians Association & American Society of Nephrology, 1999; AHRQ, 2015). A review of the literature also supported the need for this intervention as a routine process in the care of all patients with CKD. However, current data demonstrated a lack of implementation specific to those with this condition despite the known benefits for all involved.

A literature review was conducted using the Cochrane Library, CINAHL, EBSCOhost, MEDLINE/PubMed, and Ovid. Search terms included: *advance care planning, advance directive, chronic kidney disease, culture, dialysis, end-stage renal disease, kidney failure, Native American, renal, and renal insufficiency*. Databases were searched from the years 2011 to 2016. The United States Preventive Services Task Force (USPSTF) and the Agency for Healthcare Research and Quality (AHRQ) were searched for relevant CPGs. Search terms included: *advance care planning, chronic, dialysis, and renal*. Relevant guidelines were searched from the years 2011 to 2016.

Inclusion criteria for the research studies and CPGs for this literature review included peer-reviewed articles, written in the English language, consisted of patients 18

years of age and older, and involved an ACP intervention to determine the effect on patient and family outcomes and/or the completion of ADs. Articles and CPGs were excluded if they studied the effects of an intervention targeted to health care providers or persons younger than the age of 18, utilized a computer-based intervention, were a study protocol, and were not research based. Together, the combined searches yielded 568 articles that was limited to 20 documents based on the specific exclusion criteria that answered the PICOT question listed above. Appendix F lists the literature review methods table.

All retained articles were appraised using the John Hopkins Research Evidence Appraisal Tool (Dearholt & Dang, 2012). This model assigns a level of evidence, level I – V, to each article based on study design. The level of evidence assigned to an article is synonymous with the strength of the article. The highest level of evidence, level I articles, include randomized controlled trials (RCT) and systematic reviews of RCTs, both with and without meta-analyses. Level II evidence consists of quasi-experimental studies. Next, level III is composed of non-experimental studies and qualitative studies. Level IV contains expert opinion included in CPGs and consensus panels. Finally, level V is literature reviews, quality improvement projects, and case reports (Dearholt & Dang, 2012).

The John Hopkins Research Evidence Appraisal Tool also assigns each article a quality grade, in letters A – C (Dearholt & Dang, 2012). Grade A articles are of the highest quality and contain consistent and generalizable results, a sufficient sample size for the study design, adequate control, definite conclusions, and consistent recommendations. Grade B articles, good quality, are defined by reasonably consistent

results, sufficient sample size based on study design, some level of control, fairly definite conclusions, and reasonably consistent recommendations. Finally, grade C articles, low or major flaw, consist of little evidence with inconsistent results, insufficient sample size for the study design, and no definitive conclusions (Dearholt & Dang, 2012).

CPGs were appraised using the Agree II Instrument (Agree Enterprise, n.d.). The Agree II Instrument assesses for variability in CPGs, evaluates the quality of CPGs, and provides a strategy for the development of these guidelines. This tool consists of 23 items categorized into six domains: scope and purpose, stakeholder involvement, rigour of development, clarity of presentation, applicability, and editorial independence. Finally, two assessment questions are asked of the appraiser to rate the ability to use the CPG in practice. This instrument aims to greatly improve the quality of health care through the rigorous appraisal of CPGs (Agree Enterprise, n.d.). An evidence table was developed to display the level and quality of evidence, sample, setting, participants, type of study design, intervention, results, strengths, and limitations (see Appendix G).

Evidence Findings

This literature review focused on an ACP intervention for patients with CKD stages four and five. Based on the developed PICOT question and the inclusion and exclusion criteria listed above, outcomes desired included an increase in knowledge of the ACP process, an increase in ACP discussions with patients and family members/caregivers, and an increase in the frequency of AD completion. Literature found focused largely on qualitative and descriptive outcomes with this population, which strengthened the need for both a quantitative and qualitative focus for this DNP Project.

The 20 chosen studies were reviewed and critically appraised to determine the level of evidence. The John Hopkins Research Evidence Appraisal Tool classified the articles as three in level I, three in level II, 11 in level III, two in level IV, and one in level V. Two studies were appraised as low quality or C evidence. One of these studies was included due to the nature of the study design (quasi-experimental) and the lack of the availability of this type of results with this topic. This study never discussed the reliability and validity of the study instruments, which decreased the potential quality of the findings (Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2012). The second article was included due to the type of study group and the ability to show the benefit of ACP in a number of different patient populations (Colombian, Mexican, and Puerto Rican women) (Carrion, Nedjat-Haiem, Martinez-Tyson, & Casteñeda, 2013).

Two CPGs were appraised using the Agree II Instrument. Based on the results, both were of high quality, 4/7 and 5/7 respectively, and were appropriate for use in practice (Renal Physicians Association & American Society of Nephrology, 1999; AHRQ, 2014; AHRQ, 2015). One of the original CPGs found for this project was developed in 1999 by the Renal Physicians Association and the American Society of Nephrology. This document has subsequently been updated in 2010 and re-affirmed for practice in 2013. Both documents were used in this literature review and throughout the DNP Project (Renal Physicians Association & American Society of Nephrology, 1999; AHRQ, 2015). The specific findings are grouped and synthesized below.

Efficacy of ACP. The AHRQ CPG (2014) recommended using a structured ACP process in patients with conditions for which death within the next year would not be unlikely, any patient with a chronic illness, and any patient over the age of 55. It is easy

to see that a patient with CKD, the population component of the PICOT question, fits many of these requirements. However, even if their death is not likely within the next year, ACP can and still is a beneficial process for these patients. The findings of two meta-syntheses stressed the necessity of answering the developed clinical question with both structure and communication. It was less important the type of intervention utilized but more or less that an intervention targeted to ACP took place (Luckett et al., 2014; Oczkowski, Chung, Havney, Mbughaw & You, 2016). Developed CPG recommendations provided a valid and reliable starting point for intervention tools that enhanced the efficacy and use of ACP today and resulted in positive outcomes, even in patients with CKD (Renal Physicians Association & American Society of Nephrology, 1999; AHRQ, 2015).

ACP is a process that cannot be successfully completed in one single office visit. White et al. (2014) stressed this concept by reinforcing that ACP was an all-encompassing process that should consist of an ongoing conversation between a competent adult, his or her family, and health care professionals about one's future goals of care. Opportunities to enhance and increase the use of ACP exist at every office visit and should be addressed at each point of contact in the health care system. Harrison & Watson (2011) implemented a nurse-led palliative care clinic that involved meetings with the patient and/or family members in a series of sessions over a one year time frame. Patients were exposed to end-of-life issues earlier in the disease process, explored fears about the future, and were given opportunities to make necessary decisions with their family or caregivers. Family members felt more in control, had a better idea of the disease progression, felt more prepared for the future, and were less anxious about the

end-of-life process after these series of meetings (Harrison & Watson, 2011). At the very least, an ACP discussion should be implemented annually with those with a chronic condition or when a patient transitions to the next stage of CKD (AHRQ, 2014; Bristowe et al., 2015; Goff et al., 2015).

Completion of ADs. The AHRQ (2014) encouraged all patients to complete an AD. The dialysis center setting was an appropriate time and place to participate in an ACP discussion in patients who received hemodialysis. Those who participated generally did not see any problems completing these end-of-life documents and were more willing to do so and to participate in a palliative medicine consultation if needed after an ACP discussion (Amro, Ramasamy, Strom, Weiner, & Jaber, 2016; Felly et al., 2016).

When searching to determine what would be best to answer the PICOT question, the type of ACP intervention did not matter. The use of structure, communication, and actual implementation of ACP resulted in positive outcomes. Completion of ADs was greatly increased, patients were more satisfied with their care, end-of-life care was congruent with their wishes, and costs were decreased at the end-of-life with the implementation of ACP (Nicholas et al., 2011; Luckett et al., 2014; Oczkowski et al., 2016). Overall care of patients with CKD will be greatly enhanced with the long-term and successful implementation of an ACP discussion.

The patient population of those with CKD varies in both race and ethnicity. It was important to consider the factors those other than Caucasian or Northern European descent may have in regards to participating in this intervention that may result in fewer AD documents completed. African American patients, patients from Australia, and Hispanic women were less likely to want to complete an AD document. Knowledge of

what these actual documents were and what an AD meant was the biggest barrier to their completion (Bullock, 2011; Carrion et al., 2013; White et al., 2014).

Patient benefits. The over-arching purpose of this DNP Project was to provide patients with an avenue to discuss end-of-life goals before ever needing to make these critical decisions. A simple intervention of an ACP discussion, similar to the intervention proposed with this project, showed an improved ability for patients to state their end-of-life wishes, enhanced their capacity to partake in an ACP discussion, reduced patient conflict, provided better congruence with his or her goals of care, and allowed these decisions to be more easily handed over to family members (Luckett et al., 2014; Song et al., 2015; Oczkowski et al., 2016). Wishes were explored earlier in life, future fears were put to rest, and professional support was provided in a non-threatening environment (Harrison & Watson, 2011). Essentially, patients were more satisfied with the care received from their health care providers both during and after participating in an ACP discussion. These studies support the long-term effects of this PICOT question and the routine use of ACP in this patient population.

When completed, ADs usually place a great limit on treatment preferences of the patient. Advance care plans and ADs allow the patient to exactly state what he or she does not want at the end of his or her life. Congruence of care, again, was another long-range goal of this project but was one that could provide great benefit to all involved. Kirchhoff et al. (2012) and Amro et al. (2016) showed a large increase in the number of patients choosing a do-not-resuscitate (DNR) status after the implementation of an ACP discussion. When patients make that choice, they are more likely to be supported as their

disease progresses. ACP allowed patients to be informed and satisfied individuals with a written, fluid document stating their preferred goals and wishes.

Family/caregiver benefits. Family and caregiver benefits were not a direct outcome of this PICOT question. However, the long-range benefits of this project would greatly serve to benefit these populations. A simple intervention of ACP resulted in family members who were more prepared and who easily transitioned through the end-of-life process with their ill family members (Song et al., 2015). Communication was enhanced with all involved, continuity of care was improved, anxiety was decreased, and overall knowledge of the entire process increased with the use of an ACP intervention (Luckett et al., 2014; Oczkowski et al., 2016). Many of these outcomes were similar to patient benefits from an ACP discussion. Even though these were not direct indicators that were measured through this project, it was necessary to understand how helpful this process can be for all involved. The involvement of family members should be stressed when working with this clinical question.

Culture and health literacy barriers. Both culture and health literacy are important factors to consider when discussing ACP. Waite et al. (2013) showed African Americans were less likely to complete an AD. African Americans are a fairly large population served by the outpatient clinic in this DNP Project. It was necessary to understand this barrier prior to the implementation of this intervention.

ADs are lacking throughout the world (Bullock, 2011; Kataoka-Yahior, Yancura, Page, & Inouye, 2011; Carrion et al., 2013; Waite et al., 2013; White et al., 2014). The large number of individuals with CKD stressed the need to intervene with structured ACP discussions. In addition, this project was targeted to all individuals to ensure those of

different races and ethnicities were included in this intervention. Several studies focused on a lack of patient and provider knowledge of the ACP process as the major barrier to participating in this intervention throughout the world, including persons in Australia, Ireland, Thailand, and those of Asian Islander and Hispanic descent who were living in the United States (Artsanthia, Mawn, Chaiphibalsarisdi, Nityasuddhhi, & Triamchaisri, 2011; Kataoka-Yahior et al., 2011; Carrion et al., 2013; Collins & Lehane, 2013; White et al., 2014).

One's culture affects many aspects of health care, including the illness experience, the response to illness, access to health care services, utilization of health care services, and interaction and communication with health care providers. The Native American population is plagued with CKD almost twice as often as the Caucasian population (Walton, 2011). Similar to other racial and ethnic minorities, cultural awareness is essential when caring for this population. Family is an important aspect of the Native American population and this stressed the need to involve family members or caregivers in the ACP process. Discovering the narrative story of the patient may also help further divulge into his or her illness course. Spirituality, prayer, and the community are common components of health care of this population and should be integrated into care plans whenever possible. Each individual is different in regards to what one wants and does not want at the end-of-life. Oftentimes, it is demonstrating an open and honest lack of understanding of the culture that will enable the patient to express his or her wishes. Walton (2011) showed increased exposure to the cultural group was the best way to understand one's thoughts and feelings. The use of prayer, spirituality, and traditional

health ceremonies should be encouraged with the Native American culture if at all possible (Walton, 2011).

Health literacy directly relates to the knowledge a person has of his or her disease, its progression, its treatment options, and the ACP process. The health care professional must be aware of how much a patient does and does not understand in regards to his or her health and condition in order to successfully answer the PICOT question and in order to modify the intervention to fit each individual. The health literacy of the sample population was not directly assessed in this study. However, it was important to address how much each patient understood at the time of the intervention and to take the time to address all questions a patient had in regards to the CKD disease process. The intervention tools used in this project were at a high readability level and this stressed the need to devote adequate time to help each patient understand the process of ACP.

Waite et al. (2013) identified that those with a higher health literacy had higher rates of AD completion. The intervention to answer this PICOT question was implemented on an individualized level. A person's health literacy was more deeply understood at the time of the intervention. Using health literacy, an ACP discussion can be personalized to the patient's level of knowledge if necessary. Understanding the key characteristics of culture and health literacy enabled this PICOT question to be more deeply understood and successful conclusions to be reached.

Health care resource utilization. Health care costs and the admission for use of health care facilities were not direct outcomes that were measured with this clinical question. However, a long-range goal of a structured ACP discussion and an increase in the number of developed ADs could result in a decrease in both of these concepts. ADs

and participation in an ACP discussion, when developed and utilized appropriately, usually placed a limit on the care a patient desired to receive at the end-of-life. This resulted in an overall decrease in health care costs, hospitalizations, and even usage of emergency room services (Nicholas et al., 2011; Oczkowski et al., 2016).

Suggestions to improve ACP. ACP was an inconsistently used process in the care of all patients with a chronic health condition (Artsanthia et al., 2011; Bullock, 2011; Carrion et al., 2013; White et al., 2014; Bristowe et al., 2015). An intervention targeted to ACP aimed to improve the usual care provided and helped to address and solve the developed clinical question. Frequent outpatient appointments become the standard of care for patients with a chronic health condition such as CKD. These visits allow trust to be developed and a relationship to be established between the patient and the health care provider. A conversation initiated early on in the disease process, such as at the time of diagnosis, and initiated by a person the patient can speak freely with, such as a nephrology Nurse Practitioner (NP), resulted in the most achievable outcomes for this project. A close, supportive, and trusting relationship with a health care provider was one of the most stressed and necessary aspects of successful ACP. An active ACP discussion benefited the patient by enhancing satisfaction with the overall care provided and also allowed the provider to honor the patient's wishes at the end-of-life (Bristowe et al., 2015; Goff et al., 2015).

Usual care of patients with CKD in this outpatient clinic did not routinely involve an ACP discussion. For this reason, both patients and health care providers were unaware of the potential effects ACP could have for this patient population. This alone may have made them unwilling to participate in this project (Artsanthia et al., 2011).

Knowledge deficits were a major barrier to the use of ACP, even with family members of patients with CKD. Community awareness was raised and health care providers were trained to help focus on this necessary process by implementing an intervention focused on ACP (White et al., 2014). This DNP Project firmly stressed the implementation of ACP in patients with CKD brought about by a trusting health care provider.

A standardized, validated, and reliable process of implementing ACP resulted in the most achievable outcomes for patients. A well-developed CPG states five questions that should be asked routinely in the ACP process of all patients with CKD:

1. If you become unable to make decisions for yourself, whom do you want to make decisions for you?
2. If you had to choose between being kept alive as long as possible regardless of personal suffering or living a shorter time frame to avoid suffering and medical procedures such as breathing machines and feeding tubes, which would you pick?
3. Under what circumstances, if any, would you want to stop dialysis?
4. Under what circumstances, if any, would you not want to be kept alive with medical means such as cardiopulmonary resuscitation, a feeding tube, or mechanical ventilation?
5. Where do you prefer to die and whom do you wish to be with you when you die? (Renal Physicians Association & American Society of Nephrology, 1999; AHRQ, 2015, pp. 47)

Evidence Summary (Recommendations for Practice)

One of the most common themes obtained from the literature review was an overall lack of knowledge of the ACP process for many cultures, ethnicities, and health

care diagnoses. An increase in knowledge greatly enhanced both patient and family use of this service (Artsanthia et al., 2011). Patients, and even family members, were generally willing to partake in ACP once offered but it must be delivered by a health care provider or person he or she can rely upon in a culturally competent manner (Goff et al., 2015). Patients with CKD stages four and five have a chronic health condition with obvious treatments, goals, and plans of care. Although the literature was certainly lacking in regards to this specific diagnosis, the needs of these patients should be addressed with a structured ACP process which includes an individual trusted by the patient, the patient, and a family member or close friend.

In summary, an ACP process specific to this group of patients with CKD is necessary to address their end-of-life goals, future decisions, and health-related issues consistent with this condition. ACP should be a routine process in the care of all patients with CKD. Finally, ACP should involve a family member or trusting individual and be communicated with a health care provider.

Gaps in the Evidence

Several gaps were identified in this literature search despite the above research findings. First and foremost, a tool used during implementation of an ACP discussion was very difficult to find. Many studies discussed an intervention was utilized but never provided a means of re-producing their study. This literature review was unsuccessful in finding any specific intervention tools or project protocols that could have been used as the basis for or as a guide to this DNP Project. Next, in all of the literature found, few studies directly studied the effects of ACP specific to those of the CKD population. A majority of the data found was in the form of qualitative data and this was a slightly

different approach than was desired for this DNP Project. While these results were still beneficial to this patient population, it was difficult to correlate an effect to a project that hoped to achieve both significant quantitative and qualitative results. In addition, CKD patients are unique in regards to their end-of-life needs. Treatment options for this chronic condition, such as dialysis or transplantation, are very limited and are often only approached with this group of patients when the disease progresses. Withdrawal or continuation of this treatment can be the difference between life and death for these patients. Patients without this chronic condition may never have to consider these options and these topics should be removed from their ACP process unless it is truly needed. For this reason, it was important to implement an intervention specific to this group discussing dialysis and other forms of renal replacement therapy. A lack of these interventions was found despite the great need that exists for this population. A standardized process to better implement ACP was lacking in all groups and this was easily seen in the above literature review.

Evidence-Based Practice Model

The Iowa Model of Evidence-Based Practice to Promote Quality Care was the basis for this DNP Project. This model has been revised a number of times with the most recent update in 2015 (see Figure 1). The University of Iowa Hospital & Clinics model provides a guideline for implementing research into nursing practice. Nurses and other health care staff can make meaningful decisions that result in improved patient outcomes. The model is not a one step process but instead consists of multiple phases with several feedback loops. Today, current evidence helps to guide nursing actions. The Iowa

Model stresses the use of the best evidence throughout its multi-step process (Titler et al., 2001).

The Iowa Model was the evidence-based practice change model used at the health care institution where this DNP Project was implemented. This factor allowed the project to be more easily accepted and disseminated into practice. This model was chosen for its ease of use, its practicality when addressing a clinical problem, and its effectiveness with problems of similar interest. An identified need existed to routinely adopt the use of ACP in patients with CKD stages four and five. The steps of the Iowa Model allowed this change to be addressed and implemented successfully in an effective problem-solving process.

The steps of the Iowa Model are detailed below. First, the practice question must be developed by identifying trigger issues and opportunities (Titler et al., 2001). CKD is a highly prevalent condition yet few individuals had participated in the unique process of ACP or had formulated an AD document stating their preferred wishes for the end-of-life. Discussion with nephrology health care providers and personal experience of the DNP Project coordinator triggered the development of this project to enhance continuity and quality of care at the end-of-life and to decrease stress for both patients and family members. A gap existed in the routine care of patients with chronic health conditions. ACP is a standard of care that all patients should undergo, especially those with CKD.

Next, the question or purpose of the change must be developed to help guide the project towards its goal. If the identified issue is a priority, the process can continue on. If not, other trigger issues must be considered (Titler et al., 2001). The guiding PICOT question was developed at this point in the project. This question served as the basis for

the remainder of the project, listed the detailed specifics of the project, and identified the over-arching goal of the project. Then, a team was developed to help focus the clinical question, evaluate evidence, and design and evaluate the practice change (Titler et al., 2001). Stakeholders are necessary to help implement a successful change. The key stakeholder in this DNP Project was a nephrology NP. This individual agreed with the identified need to target patients with CKD stages four and five with an ACP discussion and agreed to help implement this project in the clinic setting. The nephrology NP was not specifically trained in the process of ACP but she did have a long-standing history of working with the CKD population and was well-versed in motivational interviewing and conversation with patients of all ages. As this project progressed, this person was able to help determine if and when changes needed to be made to the intervention and helped evaluate the effectiveness of the practice change.

A literature review is the next step to undertake in the Iowa Model. This is done to help assemble, appraise, and synthesize the body of evidence. If there is sufficient evidence, the change can continue. If not, feedback loops exist to redesign the change or formulate another, more important practice change (Titler et al., 2001). A literature review was described in detail. Using several databases, information was gathered to assess for the effectiveness of ACP in patients with CKD. However, a gap was found in regards to available evidence in this category. While this may represent a great barrier to implementing this change, it was identified that a large body of research exists in regards to ACP with other patient populations. This sufficient evidence strengthened the need for this project and helped to provide a basis for this practice change. The change continued and the intervention was implemented.

The change is designed and piloted after it has been evaluated. Based on the data collected, a determination is made regarding the project. A conclusion is reached whether the change is appropriate for adoption into clinical practice. On-going evaluation and revisions take place as necessary throughout the process to help sustain the change and ensure effective results are achieved (Titler et al., 2001). Chapter three lists the detailed methods, procedures, tools, and statistical approach that were used with this project. Data was collected and assessed for statistical significance after the intervention had been implemented for a time period of three months. Based on these results, conclusions were reached as to whether ACP was effective in patients with CKD. This DNP Project's purpose was to achieve a clinically significant change in the knowledge of the ACP process, in the number of patients and/or family members participating in ACP discussions, and in the number of AD documents completed with the sample population.

The last important step is dissemination into practice to share the findings and help others implement the same change, despite the results (Titler et al., 2001). Chapter four of this project discusses the exact findings and chapter five forms conclusions for future practice. It was the goal of this project to provide others with valid data and results that guided ACP as a standard of care in the management of patients with CKD. Just as this project was guided by research and data not specific to those with this condition, this project also served as the basis for the care of all patients.

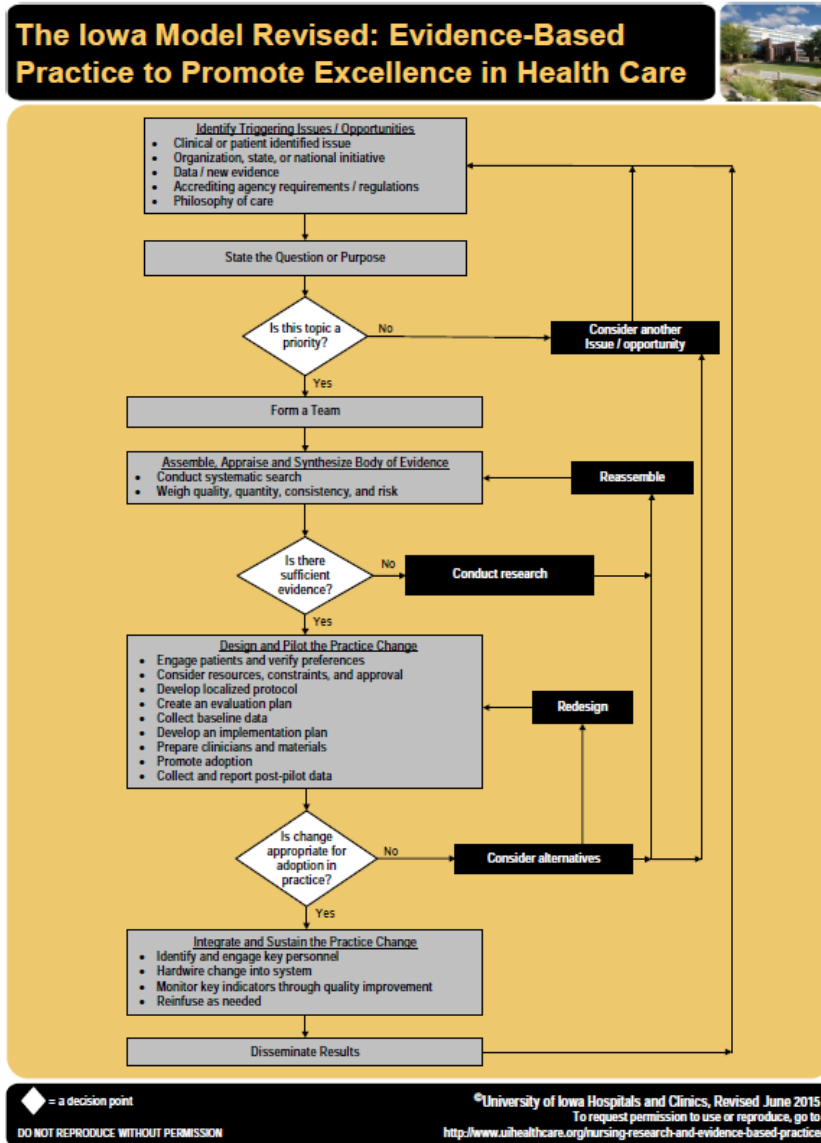


Figure 1. The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care. Used/reprinted with permission from the University of Iowa Hospitals and Clinics. Copyright 2015.

Theoretical Approach

Viktor Frankl's Theory of Meaning (1938) guided the theoretical approach to this DNP Project. Essential to human nature is the question: Why am I here? This question is necessary but should be answered by the individual alone. Even in patients who have been diagnosed with a chronic disease, there remains a will to live in each and every individual. The Theory of Meaning hopes to divulge this meaning and determine what

can be done to help the patient achieve meaning in life. Internal conflict is a normal, natural process and is also part of this theory. Four recommendations exist in this theory: a person's search for meaning is the primary motivation of life; a person is responsible for the meaning of life; a person may find meaning in life even in the face of a hopeless circumstance; a life offers meaning in every moment (see Figure 2). This theory has been used successfully in many other areas of health care and is often the basis for working with those with chronic illnesses (Frankl, 1984).

The most unique reason why this theory fits into this DNP Project is at any point in life, the individual's meaning of life may change (Frankl, 1984). Those with any chronic disease, but especially CKD, can benefit from discovering their true meaning in life. Herein lies the necessity to partake in an ACP discussion and complete an AD. Starting this discussion and involving family members or close friends allows the patient to truly ponder what it is he or she wants for his or her life. Long-term goals can be more realistically set without other unnecessary stressors, such as a major health crisis, influencing his or her decision. The ultimate purpose of this DNP Project was to clarify the desires, wants, needs, and goals for patients with CKD and to avoid difficult decisions and a death incompatible with their wants and goals. The patient's true meaning of life was discovered and their individualized treatment plans were developed from this meaning through an ACP discussion. As was discussed in the literature review, the ACP process needs to occur over the course of several office visits and should also be revisited on a regular basis. Having an open and honest discussion with the patient was the first step and this was where ACP fell into place with these patients.

Life purpose is the ultimate goal to be achieved with the Theory of Meaning (Frankl, 1984). This allows a person to feel called and dedicated to what one does. Essentially, it is helping making the world a better place through actions. An individual's life purpose is unique and must be explored before any complicated and stressful decisions can be successfully made (Frankl, 1984). When implementing an ACP discussion, a health care provider will need to help the individual determine what it is they want to live for and what it is they want to accomplish. Patients with CKD are vulnerable due to the irreversible nature of the condition but it was still necessary to help them divulge the true meaning of their life. A trusted health care professional remains the most competent individual to start this discussion. This necessitated the need for this project to be undertaken in the outpatient setting.

Freedom to choose is the second main component of the Theory of Meaning (Frankl, 1984). The freedom to choose exemplifies the process of choosing which options a person has control over. It clearly explains when a person is presented with two options, why one person chooses a certain option (Frankl, 1984). Again, this is a very individualized process and is based on one's attitude. An individual's life purpose can be more easily met in an ACP discussion by helping the patient explore those attitudes and choose what he or she wants for his or her last few days of life. A patient who feels in control of his or her actions is more likely to trust the health care provider who supports this practice and remain consistent with his or her goals and wishes at the end-of-life.

Human suffering is the final component of Frankl's theory (Frankl, 1984). In line with each of the other components of this theory, what causes suffering for one person is very different from another. Suffering is an all-consuming experience, comprising an

array of emotions. However, unique to suffering is not the exact meaning of the experience but how one responds to the situation that helps the individual progress through the Theory of Meaning (Frankl, 1984). CKD is a diagnosis that triggers suffering in any individual. In many cases, the suffering is prolonged and the patient is instead confronted with an array of issues when a health crisis occurs. Discovering what causes suffering in a patient is essential and this is a key component of an ACP discussion. The cause of suffering can be eliminated and the patient can be allowed to respond how he or she chooses. Together with life purpose and a freedom to choose, an ACP discussion stimulated these concepts to be brought forth and the patient was allowed to experience a greater quality of life consistent with his or her goals and wishes. The Theory of Meaning is an all-encompassing process that successfully brought forth the real need for ACP in patients with CKD.

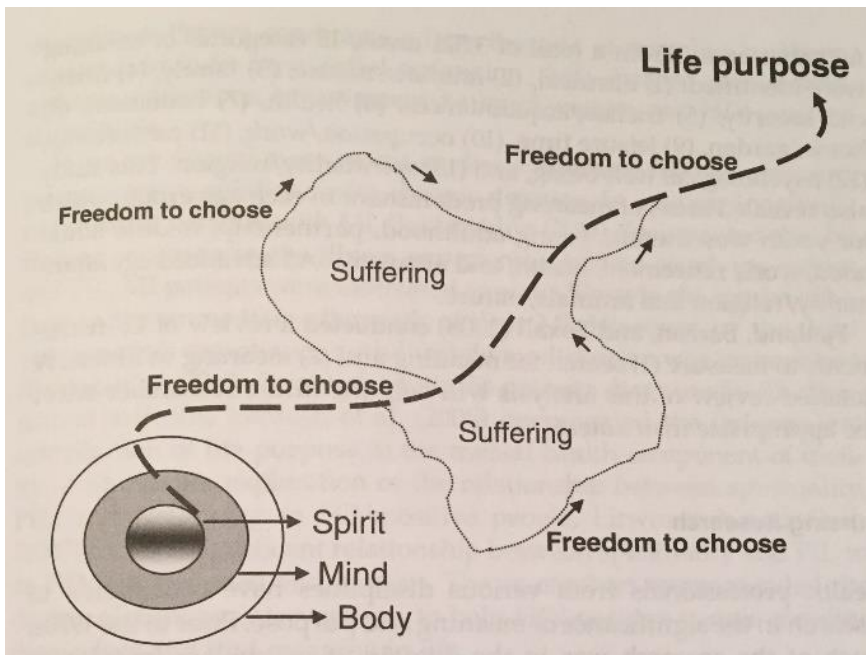


Figure 2. The Theory of Meaning. (Smith & Liehr, 2014, p. 97)

Change Theory

James Prochaska's and Carlo Di Clemente's Transtheoretical Model (TTM) served as the guiding change theory for this DNP Project. The principle behind this model is an individual progresses through five specific stages when attempting to change a behavior, regardless of what the behavior is. The five stages of changes are: precontemplation, contemplation, preparation, action, and maintenance. Transitioning from one stage to another helps an individual achieve a successful behavior change but it is also common for a person to go back and forth between these stages, such as is depicted in the spiral model in Figure 3 (Prochaska, DiClemente, & Norcross, 1992). Key concepts from psychotherapy and previous works in behavior change helped Prochaska and Di Clemente to invent this theory in the early 1980s. This theory was initially derived while helping individuals quit smoking. Since that time, the TTM has been used successfully in helping others adopt change in many health related behaviors, such as alcohol use, anxiety and depression, eating disorders and obesity, and medication compliance (Prochaska, Redding, & Evers, 2008).

The TTM was utilized when attempting to elicit a behavior and knowledge change from patients with CKD in regards to ACP. End-of-life decision making is a complex process and can involve a fluctuation between the individual stages included in the TTM. As health care providers come to understand the process of behavior change and determine what stage each individual is in, specific strategies and interventions can be utilized to help the patients reach the latter phases of action and maintenance. The use of the TTM in regards to the process of ACP is described below.

The first stage of the TTM is precontemplation. An individual in the precontemplation stage has no intention to change the behavior in the foreseeable future. Essentially, they are unaware that a problem exists (Prochaska et al., 1992). Patients with CKD without an AD or those who have never participated in ACP before have no knowledge of the benefit this process could have on their end-of-life goals. This could occur for many reasons, such as a lack of knowledge of the ACP process or a lack of knowledge of the correct use of ADs. However, whatever the reason as to why the patient was in the precontemplation stage, it did need to be brought to the patient's attention what the behavior to change was and why it was beneficial to change. This stage of the TTM focused on education of the individual during the office visit with the nephrology NP and other support persons to enhance a patient's overall knowledge. This brought the idea of a behavior change to the forefront of the person's mind.

The second stage of this model is the contemplation stage. This stage involves an individual who is aware that a problem exists. This person is seriously thinking about making the identified change but has yet to make a commitment to act. The contemplation stage involves a person weighing the pros and cons of changing the identified behavior and the proposed solution (Prochaska et al., 1992). Education of the process of ACP and the completion of ADs resulted in a person who was aware of the process and actively thinking about participating in this intervention. Internally, the individual needed to think about what they wanted to experience at the end-of-life, who they wanted to have this discussion with, and if they were ready to partake. A person can remain in this stage for any period of time, heavily weighing the pros and cons of the proposed behavior change. Similar to the first phase of this model, this phase also

focused on individual education with the nephrology NP and allowed the individual adequate time to make the commitment to change.

The third stage of the TTM is preparation. This stage combines components of intention and behavior. Persons in this stage are intending to take action within the next month but have not previously made this same change within the past year (Prochaska et al., 1992). An individual was made more aware and more knowledgeable of the process of ACP with the intervention tool, which helped the patients to progress to this stage. During successive office visits that involve ACP, the patient can continue to strive to reach this stage and be able to state exactly what his or her wants, needs, and desires for his or her end-of-life care are. An individual in the preparation phase of ACP formulated their own AD document and discovered their true meaning in life, as is in line with Frankl's Theory of Meaning. Persons in this stage understood the importance of the behavior change and were willing to reach the next stage.

The next stage involves action. Action is the stage that involves the actual behavior change. Individuals here modify their behavior or environment in order to overcome their problems. This stage is where visible actions occur but this is not reached without a great amount of time, dedication, and energy from the individual (Prochaska et al., 1992). The action stage of this intervention involved completing the intervention tool and having a thorough discussion with one's family members, close friends, or health care providers. Action was acknowledging that a behavior change was needed and actually carrying out that change. This stage was not easily reached but was one with the greatest reward for the patient as a person determined what it was he or she wanted for his or her end-of-life care.

Finally, the maintenance stage is reached. This stage involves a person working to prevent relapse. Oftentimes, this stage is never ending and an individual must continually work to sustain the behavior change (Prochaska et al., 1992). The individual completed the intervention tool, had a discussion with the nephrology NP and/or his or her family members, and upheld his or her decisions in his or her daily life. The static process of ACP allowed for an individual to go back and forth between the various phases, as is an important component of the TTM. If, throughout future office visits or if a major change in life occurs, a person can go back to the preparation phase, determine what he or she wants to change, and then successfully move through the action and maintenance phases as necessary. It is important to understand that this model relies heavily on education in order to help a person adopt a successful and long lasting behavior change.

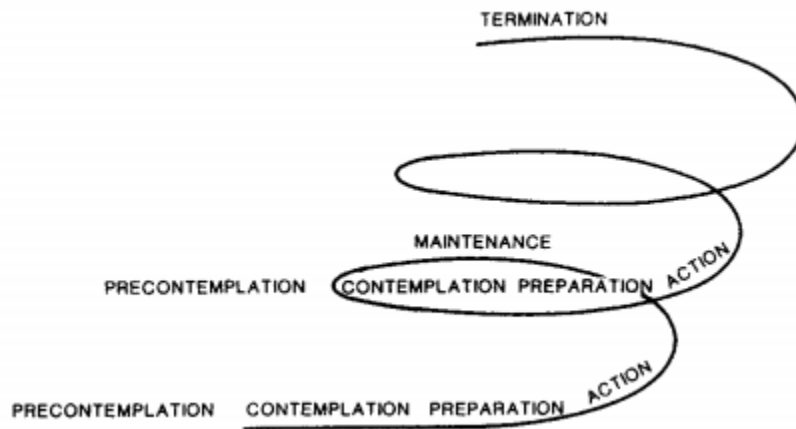


Figure 3. Transtheoretical Model. (Prochaska et al., 1992, p. 1104)

Chapter 3

Method and Procedures

Introduction

This DNP Project was developed to address the aforementioned proposed PICOT question utilizing a quality improvement approach in the design phase of the Iowa Model. Based on the needs of the health care institution and the DNP Project coordinator experience, the setting and sample were chosen. A five question validated and appraised CPG was utilized as the main intervention and served as the ACP discussion guide throughout this project. Changes in patient knowledge of the ACP process were also assessed utilizing a six question pre-test and post-test document. Below is a detailed structure of the procedure and analysis, based on various potential impacts, considerations, barriers, and stakeholders.

Design/Approach

This project was focused as a quality improvement project. Quality improvement projects are based on an organized, evidence-based, systematic process designed to ensure patients are provided care that is addressed in a reliable manner. Quality of care provided to patients is enhanced due to current evidence that has been implemented into practice throughout other projects such as this. A working hypothesis is necessary in a quality improvement project. Projects of this type are usually low risk to a patient and are becoming more routine in today's clinical practice (Melynk & Fineout-Overholt, 2011).

The literature review completed showed the necessity of integrating ACP into routine health care practices. Several studies have shown the effectiveness this process

has had on patients with other chronic conditions but data was lacking in regards to those with CKD. Using successful interventions and validated CPGs, ACP was used to improve the care of patients with CKD. A clinical hypothesis or PICOT question guided this quality improvement project. This process has the potential to translate to other areas of health care as a more routine and effective process.

This quality improvement project involved a retrospective chart review. The retrospective chart review served as the comparison group for this DNP Project. The population who received the intervention was a non-randomized convenience sample of patients with CKD stages four and five who were seen in the clinic setting by a nephrology NP. Both samples were similar in characteristics yet were a different group of individuals. A detailed discussion of the tools and procedures this project involved is described below.

Setting

The project setting was an urban Midwestern nephrology clinic located in a town of approximately 180,000 people (U.S. Department of Commerce, 2015). The clinic was attached to a main hospital campus. Specialized nephrology care was provided to adult patients 18 years of age and older who came from both rural and urban backgrounds. Many patients traveled over 100 miles to be seen in this clinic. Time of travel for patients averaged between two and four hours; however, some patients drove up to six hours to be seen in this clinic. Patients also traveled from various surrounding states, including Iowa, Minnesota, and Nebraska, to utilize the services provided in this setting. Telemedicine services were provided to remotely access patients in rural settings in both South Dakota and Minnesota. Most patients were middle class but income levels varied

from the very poor to the very wealthy. Those with both acute and chronic renal issues were seen in this clinic (A. Saeger, personal communication, June 21, 2016).

This clinic was staffed by four physicians (including three Medical Doctors and one Doctor of Osteopathy), two NPs, four registered nurses, one licensed practical nurse, and two schedulers/receptionists. No interdisciplinary team members were employed in this clinic. A social worker and dietician were available by telephone but they did not routinely see patients in the clinic setting unless a specific need was identified by a provider. A clinic manager was available to provide notary services at the time of AD completion.

Combined, the six health care providers had more than 40 years of experience in the nephrology setting, including patients on both hemodialysis and peritoneal dialysis. A specialized area of interest of all providers was hypertension management. Most providers were educated in urban areas with a focus on nephrology management. Nine exam rooms were utilized between the six providers. Approximately 60-80 patients were seen each week by all of the providers. The key stakeholder, one nephrology NP, in this project saw approximately 10-20 patients in the clinic setting each week. Appointment times varied based on patient diagnosis. New patient appointments averaged 40 minutes in length while follow-up visits were routinely 20 minutes. Laboratory and x-ray services were not provided in this clinic. However, a laboratory facility was located in the basement of the same building and x-ray services were provided at the main hospital campus (A. Saeger, personal communication, June 21, 2016; K. Jerke, personal communication, July 5, 2016).

Sample

The sample for this project was a non-randomized convenience sample of patients with CKD stages four and five without an existing AD document who were seen in the clinic by one nephrology NP. Inclusion criteria for the intervention sample included adult patients over 18 years of age. Patients of all ethnicities and races were included in the project sample, as well as those of all genders. While English was the major language spoken among the patients in this clinic, those who were non-English speaking were also included in the sample. Translator services by the use of phone, iPad, or live interpreter were available and provided to these patients. One iPad used for translator services only was available from the clinic receptionist staff. If a trained medical interpreter was needed, the nursing staff arranged for this service prior to the patient's scheduled appointment. The informal letter of invitation, informed consent form, knowledge assessment, and intervention tool were not translated into individual languages. It was necessary to go through each document with the interpreter service, patient, and family members to ensure they were knowledgeable of the process, willing to participate, and were able to actively engage in the ACP discussion. A large majority of the population seen in this clinic was Caucasian, followed by persons of Native American and African American descent (A. Saeger, personal communication, June 21, 2016). Cultural differences were addressed on an individual level. It was the aim of this project to help an individual incorporate ACP into his or her medical care while also respecting the cultural beliefs and values one may have. It was hoped that all genders were equally represented in this DNP Project.

Due to the many coexisting conditions that occur with CKD, those who received the intervention had an array of comorbid conditions. Hypertension, diabetes, and peripheral vascular disease were a few of the most common comorbid health conditions this sample had. Those with conditions that impair brain functioning and/or limit decision making capacity (such as dementia and Alzheimer's disease), however, were excluded from this sample due to the nature of the intervention and the great need for adequate decision making capacity to state one's goals and desires for their end-of-life care. This was determined based on past medical history or discussion with family members or caregivers. In addition, patients who already had an AD document were excluded from the project sample per the health care institution's request. These factors were the only exclusion criteria utilized in the intervention.

The comparison sample was patients from one year ago at the time of project implementation with CKD stages four and five who were seen in the clinic setting by the same nephrology NP. Patients who were part of the comparison sample were not included in the project sample. A thorough chart review ensured the comparison sample and intervention sample did not overlap. Comparison sample data was gathered and reviewed from January 1, 2016 to March 31, 2016. All patients reviewed were similar in characteristics to the intervention sample. The inclusion criteria for the comparison sample was the same as that listed for the intervention group. Comparing these two groups at the time frame of one year ago limited the influence of extraneous variables and other biases that may have occurred with one sample and not another, thereby providing the most accurate results for this DNP Project. The estimated sample size of this project was $n = 20-30$.

Development of Intervention/Tools

The intervention for this DNP Project was the implementation of a standardized ACP discussion tool. This intervention replaced the usual care currently received and allowed patients with CKD to focus on goals of care specific to this patient population. Five specific questions were recommended by the Renal Physicians Association and the American Society of Nephrology as being critical to implement in ACP in patients with CKD (Renal Physicians Association & American Society of Nephrology, 1999; AHRQ, 2015). The five questions were:

1. If you become unable to make decisions for yourself, whom do you want to make decisions for you?
 2. If you had to choose between being kept alive as long as possible regardless of personal suffering or living a shorter time to avoid suffering and medical procedures such as breathing machines and feeding tubes, which would you pick?
 3. Under what circumstances, if any, would you want to stop dialysis?
 4. Under what circumstances, if any, would you not want to be kept alive with medical means such as cardiopulmonary resuscitation, a feeding tube, or mechanical ventilation?
 5. Where do you prefer to die and whom do you wish to be with when you die?
- (Renal Physicians Association & American Society of Nephrology, 1999; AHRQ, 2015, pp. 47)

From these questions, a one-page document was developed to use as the intervention and primary tool for this project. The Renal Physicians Association granted permission to use

this document as part of this DNP Project (see Appendix I). Appendix L shows the specific document used.

The Agree II tool was used by the project coordinator and three other DNP students to appraise the CPG (Agree Enterprise, n.d.). All persons were familiar with and had experience using this tool. The CPG was recommended for use by all four individuals and was rated, on average, a 5.75/7. This demonstrated the high quality of the CPG and showed how necessary it was to implement into current practice. In addition to the overall high average rating received, the overall objectives of the guideline were clearly stated, systematic methods were used to search for available evidence, key recommendations were easily identifiable, and the recommendations were specific and unambiguous (Agree Enterprise, n.d.). The CPG discussed methods used for data extraction that greatly strengthened the validity of the project and discussed congruence of the CPG with several nephrology physicians, which also increased the reliability of the document (Renal Physicians Association & American Society of Nephrology, 1999; AHRQ, 2015).

A six question pre- and post-intervention knowledge assessment was given to patients to determine their increase in knowledge about ACP and ADs after the implementation of the intervention. These questions were adapted from a RCT that assessed change in knowledge of medical students of the ACP process after a computerized intervention. These questions were developed through a thorough literature review and both face and content validity were verified prior to their implementation (Green & Levi, 2011). Both multiple choice and true/false questions were included. The six questions were:

1. An advance directive is a document that:
 - Expresses an individual's medical wishes when that person is unable to speak for him- or herself
 - Determines who will handle one's financial affairs after death
 - Explains one's rights as a patient
 - I don't know
2. Advance directives go into effect if an individual:
 - Gets admitted to the hospital
 - Has a terminal medical condition
 - Can no longer communicate his or her health care decisions
 - I don't know
3. In general, the best person to serve as an individual's health care surrogate is the person who:
 - Has the most knowledge
 - Is best able to represent the individual's views
 - Has known the individual the longest
 - I don't know
4. Of the following, which is least important for a patient to do regarding advance care planning?
 - Discuss their values and wishes regarding end-of-life care with trusted family members and friends
 - Create an advance directive that explains their goals of care
 - Provide their physician(s) with the advance directive
 - Use a state-specific living will form
5. Advance care planning is a one-time process and does not need to be revisited during the course of a patient's life.
 - True
 - False
6. If an individual has decision-making capacity and can still speak for him- or herself, an advance directive does NOT determine which medical treatments they will receive.
 - True
 - False (Adapted from Green & Levi, 2011, pp. 88-90)

From these questions, a one-page document was used to assess a patient's baseline knowledge prior to the intervention. The same questions were used to assess a patient's change in knowledge following the completion of the intervention. Appendices J and K show the specific documents used.

Project Procedure

This project transitioned into the implementation phase after obtaining both the health care organization and university's Institutional Review Board approval. A retrospective chart review was completed from one year ago at the time of implementation to gather information on the comparison sample. The actual chart review process was conducted during the first week of this DNP Project implementation period. A chart review was done to determine the number of patients with CKD stages four and five who were seen by the same nephrology NP who had a documented ACP discussion and the number of patients who had a completed AD document in their electronic medical record. These baseline numbers helped to determine the amount of change that occurred with this project in a similar patient sample seen at the same time of the year and who were seen by the same provider in the same clinic setting.

One to two weeks prior to project implementation, a meeting was held with the nephrology NP, clinic manager, members of the nursing staff, and the clinic receptionists to review the informal letter of invitation, informed consent form, intervention tool, and pre- and post-intervention knowledge assessment document. A routine process of implementing all parts of the intervention were discussed. These staff members were provided with an algorithm document to assist in the process of completing all of the steps of the intervention (see Appendix O).

Each working day during the three month intervention period, the nephrology NP, clinic nurses, and receptionists determined from the scheduled patients those who were eligible to receive the intervention. An asterisk was made next to each eligible patient on a printed clinic schedule that was placed at the front desk. The nephrology NP and the

other involved stakeholders were knowledgeable of who was to receive the informal letter of invitation, informed consent form, pre- and post-intervention knowledge assessment document, and intervention tool for that day and fulfilled their role in the intervention as detailed below. The DNP Project coordinator was not readily available in the clinic setting during the implementation period but checked-in with the nephrology NP on a weekly basis and was available by telephone if questions or concerns arose.

The clinic receptionists gave each eligible patient an informal letter of invitation from the DNP Project coordinator (see Appendix M). While waiting to see the nephrology NP, the patient had time to formulate any questions in regards to the details of the project. The nursing staff answered these questions while rooming the patient. The patient then selected one option on the bottom of the informal letter of invitation, either I agree to participate or I decline to participate. The completed informal letter of invitation was given to the nurse. All forms, even if the patient declined, were kept in a locked filing cabinet, only accessible by nursing staff, the key stakeholder, and the project coordinator. After this step, the nurse then asked the patient if he or she had an AD document. If the patient did, usual care ensued and the patient was not eligible for the intervention. The office visit went on as originally scheduled. If the patient did not and agreed to participate, the intervention would have continued, in addition to the scheduled office visit for that day.

If the patient did not have an AD document and would have agreed to participate, the nurse would have provided the patient with the informed consent form (see Appendix N). The nursing staff would have collected the completed informed consent form from the patient during the rooming process. These forms would have been stored in a locked

filing cabinet only accessible by nursing staff, the key stakeholder, and the project coordinator. After the nurse completed her rooming procedure, the patients who consented to the intervention would have been given the pre-intervention knowledge assessment document to gather baseline data of patient knowledge in regards to ACP and ADs. The assessment tool would have been returned to the nursing staff or nephrology NP. These assessments would have been stored in the locked filing cabinet only accessible by the nursing staff, the key stakeholder, and the project coordinator. The nephrology NP would have then provided the intervention to the eligible and consenting patients using the developed intervention tool.

The nephrology NP would have had a discussion with the patient and/or individual(s) who were present at the time of the appointment using the developed intervention tool. This intervention would have replaced usual care. The patient would have been encouraged to complete the form at the time of the visit, discuss his or her wishes with the nephrology NP, or take the form home to discuss with family members and fill out at a later date. If the intervention tool would have been completed at the time of the office visit, the clinic manager would have served as the notary to witness the signing of the AD document. The nephrology NP would have then given the document to a member of the nursing staff who would have ensured the document was scanned into the patient's electronic medical record. A copy would have been sent to the medical records department and the original document would have been kept in the locked filing cabinet in the clinic. These forms would have been only accessible by the nursing staff, the key stakeholder, and the project coordinator.

Finally, the same knowledge assessment tool would have been given to the patient in the form of a post-intervention knowledge assessment document. This would have been given to the patient by either the nephrology NP or any member of the nursing staff. The patient would have given the completed assessment to either the nephrology NP or any member of the nursing staff. As similar to the pre-assessment, the post-intervention knowledge assessment documents would have been kept in the same locked filing cabinet only accessible by the nursing staff, the key stakeholder, and the project coordinator.

The nephrology NP would have given each eligible and consenting patient an identifying patient number. This number would have been placed onto the patient's informal letter of invitation, informed consent form, intervention tool, and pre- and post-intervention knowledge assessment documents. This would have allowed all completed forms for each patient to be grouped together for a more streamlined approach to data collection after the completion of the intervention.

The nephrology NP would have been encouraged to document the ACP discussion in the patient's progress note in the electronic medical record. If the patient did not complete the intervention tool at the time of the clinic visit, he or she would have been encouraged to return the form to a clinic staff member as soon as he or she felt ready. The same procedure for medical record documentation would have occurred any time during the implementation period when a patient returned the intervention tool to the clinic staff members, including scanning the form into the electronic medical record, sending a copy to the medical records department, and keeping the original form in the locked filing cabinet only accessible by the nursing staff, the key stakeholder, and the project coordinator.

At the end of the three month time period, the patient sample was reviewed to determine the number of ACP discussions completed and the number of intervention tools received to help determine the change this intervention had on the sample. In addition, the change in knowledge from the pre-intervention knowledge assessment would have been measured against the post-intervention knowledge assessment to determine the amount of knowledge the patients obtained from participating in this intervention. As similar to the comparison sample, the same demographic data (age range of the patient, gender of the patient, race of the patient, and stage of CKD) were collected with the intervention sample to aid in determining factors which promoted or hindered this change. Weekly check-ins and discussions with the stakeholders by the DNP Project coordinator were a necessary process to help identify any changes that needed to occur, discuss any barriers the nephrology NP or other staff members were encountering, and review any successes or set-backs the project was experiencing.

Ethical Considerations

This DNP Project was proposed to the health care institution's Institutional Review Board and Nursing Research Council for approval (see Appendices B and C). Once approval was obtained, the project was submitted for approval to the DNP Project coordinator's university Institutional Review Board (see Appendix A).

The retrospective chart review data included demographic data as well as the number of patients who had completed an ACP discussion and the number of documented ADs. This information was stored in the same locked filing cabinet only accessible by the nursing staff, the key stakeholder, and the project coordinator. The intervention tools, pre-intervention knowledge assessments, and post-intervention

knowledge assessments would have been collected and stored in the same manner following informed consent. All data was collected electronically and was de-identified.

This project placed a patient at a low risk from an ethical standpoint. An ACP discussion collects information about sensitive end-of-life issues and asks questions that could possibly cause psychological distress, discomfort, and anxiety beyond what is experienced in daily conversation. This project was a necessary component of the care of patients with a chronic condition, such as CKD, despite the known risk. A patient was able to withdraw from the project at any time. If this did occur, usual care ensued from the nursing staff and nephrology NP and the appointment went on as previously scheduled. There were no repercussions to the patient for withdrawing from the project.

If information needed to be stored for the DNP Project coordinator, it was kept in the locked filing cabinet in the clinic. This information will be kept for a total of six years in order to comply with university Institutional Review Board requirements. Electronic ACP and AD documentation will be accessible by anyone directly caring for the patient, including nursing staff, health care providers, and the project coordinator. Health Insurance Portability and Accountability Act (HIPAA) and electronic medical record accessibility was maintained for this reason.

Projected Analysis

Demographic data collected included the age range of the patient, gender of the patient, race of the patient, and stage of CKD. This data was analyzed using frequencies and percentages and aggregate demographic data was displayed. Data was gathered to assess for the change in the number of patients who participated in an ACP discussion and/or who had an AD document completed after the intervention. Due to the nature of

this part of the project and the different comparison group used for analysis, an independent, or unpaired, *t*-test would have been used to assess for a statistically significant change after the completion of the intervention. The two groups were independent of one another and were different in regards to sample size; hence the use of the independent *t*-test. An independent *t*-test compares the means of two groups of data, which was the overall objective of this DNP Project. The level of significance, or *p*-value, was set at $p < 0.05$. This specific *p*-value was chosen over a *p*-value of 0.1 to provide more significant data that a true difference was detected in the actual data gathered.

Data was also analyzed to assess for a change in the level of knowledge patients have of the ACP process and the use of ADs after the intervention. Due to nature of this part of the project and the same comparison group used for analysis, a dependent, or paired, *t*-test would have been used to assess for a statistically significant change in knowledge after the completion of the intervention. The two groups were dependent of each other; hence the use of the dependent *t*-test. A dependent *t*-test compares the means of the same two groups of data, which was also another overall goal of this DNP Project. The level of significance, or *p*-value, was set at $p < 0.05$. This specific *p*-value was chosen over a *p*-value of 0.1 to provide more significant data that a true difference was detected in the actual data gathered.

Environmental and Organizational Context

The vision of this health care institution is dedicated to improving the human condition. ACP is a process that can easily help improve the human condition. Helping patients identify what their goals and wishes are for end-of-life care before a change in

health occurs, before the patient is unable to make his or her own decisions, or before the thought even crosses the patient's mind is necessary to improve and promote a higher quality of life near the end-of-life. Making patients aware of and presenting them with their treatment options gives them the necessary tools to consider their wants, needs, and desires for their last few months. In the end, quality of life is greatly enhanced, all in line with the goal of improving the human condition.

Courage, passion, and family are three core values of this organization and are also necessary to consider when implementing this DNP Project. An ACP discussion is one that few providers undertake today. This conversation involves feelings and emotions and is oftentimes not what the patient or family members want to hear. It is a challenging topic to address with patients and often leaves patients, families, and providers feeling unsettled. Many providers may be unsure of how to bring about this discussion and instead leave it unaddressed with their patients. Courage is necessary to present the truth in a caring and compassionate manner. Passion about the topic of early ACP and the use of ADs is also necessary to implement this project successfully. Passion is shown by focusing on the patient and/or family during an ACP discussion and helping the patient identify his or her wants, needs, and desires for end-of-life care. An open, honest, and trusting relationship between the involved parties is also essential and embodies passion from all of those involved. Finally, family is another key value to consider when implementing ACP. Many patients are close to their family members and are concerned about leaving them with difficult decisions to make. This process helps eliminate stress and anxiety of those other individuals and also promotes a greater view of the dying process in light of ACP.

Discussions with the nephrology NP and the clinic manager provided this DNP Project coordinator with overwhelming support (K. Jerke, personal communication, May 19, 2016; A. Saeger, personal communication, June 4, 2016). This organization's Nursing Research Council also supported this project. The Council identified a lack of a current work flow, a lack of AD documentation in the outpatient setting, and a lack of a standardized process of ACP specific to this patient population. This DNP Project's purpose was to address and improve all of these concerns, in addition to enhancing overall patient knowledge of the process of ACP. As this project was implemented, support from the first two individuals was necessary and also helped to overcome any barriers that were experienced. This project could not have been implemented alone, and as a team, successful changes were reached that could then be implemented as a routine practice throughout the entire clinic and health care organization.

Stakeholders/Facilitators

The key stakeholder for this project was one nephrology NP. She served as the primary implementer of the intervention tool and helped complete the chart review to determine changes in ACP discussion rates and AD completion rates. This individual had a well-rounded experience working with patients with CKD and comprehended the necessity of this intervention and project. Another stakeholder in this project was the clinic manager. This individual, again, realized the necessity of this intervention and was willing to help pilot this project in the clinic setting. This person also served as the notary to witness the signing of the AD documents if completed in the clinic setting. The help of these two individuals allowed patients with CKD to achieve improved and more consistent outcomes with the implementation of ACP.

The members of the nursing staff and the clinic receptionists were also stakeholders to this DNP Project. Together, these individuals helped identify patients who were eligible for the intervention each day. The clinic receptionists gave each eligible patient an informal letter of invitation at the time of appointment registration. Then, while rooming the patient, the nursing staff answered any questions the eligible patients had and collected the informal letter of invitation. These individuals would have given the informed consent form to the consenting patients, would have gathered the signed informed consent form, would have completed the steps of usual care, would have administered the pre- and post-intervention knowledge assessment tool to the appropriate patients, and then communicated with the nephrology NP whether or not the patient consented and if he or she had an existing AD document. The nursing staff would have helped gather the completed intervention and assessment tools. They also would have ensured the completed intervention documents were placed into the patient's electronic medical record. The DNP Project coordinator worked closely with these individuals to ensure they understood their scope of the project and answered any questions as they arose.

As this project continued to move forward, the other providers in the clinic helped to serve as stakeholders of this project. As the nephrology NP began to have these conversations with the patients she was seeing, the patients of other providers began to ask about these critical conversations. Through word of mouth and realizing what a difference this intervention could have on their patients, the interest of the other providers increased and it is hoped that they will begin to adopt this into their own practice. In addition, these individuals had personal experiences and ideas or suggestions to improve

this project. The vast array of knowledge and personal experience of these providers served to help this DNP Project move forward and achieve successful results.

Finally, the health care institution at which this project was implemented was a stakeholder to the success of this intervention. The Nursing Research Council of this organization allowed this project to move forward. The Council hoped for great results to be achieved that can then be translated to other areas of this organization. A clinical nurse leader stressed the necessity of the project to the DNP Project coordinator and was instrumental in launching the idea of this project. The vision of this institution and three key values, courage, passion, and family, were achieved with this project.

Potential Barriers

Barriers have a potential to occur with any project. Time was a great barrier with this specific DNP Project. This intervention was implemented for the time frame of three months, which may not have provided some patients with enough time to make these sensitive decisions or to identify all of their wants, needs, and desires. As was discussed in chapter two, ACP is not a one-step process but instead needs to be revisited with each patient over several office visits. The topics discussed with the five question intervention tool were a lot for a patient to process in one short office visit. This was another valid reason why a greater period of time may have been more beneficial to the ACP process. A longer time period, such as one year, may result in more patients completing the intervention tools. This may also result in more significant results and as such, would have a larger impact on this patient population. Due to the time constraints of this project, that was not feasible. The time frame chosen still allowed for successful results

to be achieved. Based on these results, it would then be implemented for a longer time frame and with a larger sample of patients.

The informal letter of invitation, informed consent form, pre- and post-intervention knowledge assessment document, and discussion tool all had a very high readability level, around the 12th grade for all documents. ACP and ADs bring about very challenging issues, and as such, do require a somewhat higher level of thinking in order to complete them successfully. For some persons, it may be quite difficult to read and complete the tools and actively participate in the intervention for this reason. The nephrology NP completing the intervention needed to consider this aspect during the implementation. In addition, it was important to also understand that patients may need some extra time to read and comprehend all parts of the intervention.

This project had multiple steps and processes that required time and attention from nursing staff. There was a great possibility that steps were missed in the process. Establishing a buy-in and providing an algorithm of the processes this project entailed helped prevent any aspects of the project from being missed. Detailed meetings and discussions both before the start of the implementation period and also during the three month time frame helped to ensure all steps were being followed and all staff members were aware of what the expectations were.

The nephrology NP, chosen as the key stakeholder for this project, routinely rounds on patients in the hospital setting while also seeing patients in the clinic. This fact served as a barrier as the sample of patients may be somewhat smaller as opposed to a provider that only sees patients in the clinic setting. In addition, this nephrology NP may have needed to spend more time with patients implementing the ACP discussion and this

may have decreased the total number of patients she was able to spend time with in the clinic setting. Overall, the productivity of the clinic could decline slightly, but the increase in long-term patient outcomes will override these productivity losses. The clinic manager was aware of this barrier prior to the implementation of the intervention but was still willing to help the patients reach better and more consistent outcomes with ACP.

Turnover in the clinic with both nursing and various support staff could also serve as a barrier to this project. Changes in nursing staff and clinic receptionists during the course of the project may result in fewer patients being enrolled in the project and less significant results achieved. In addition, more time may be required to train new staff in the process of this project and this may also result in fewer patients who are targeted with the ACP intervention. Again, it was hoped that if this DNP Project was successful in the outpatient setting, this process could then be implemented in the inpatient setting. Having a provider who provided care in both settings helped to round out this project and will allow for easier translation in other settings and with other patient populations.

Finally, as with any project, a lack of patient participation and a lack of patient buy-in to the necessity of the project was a major barrier that could be encountered. As was shown in the literature review, many patients lacked knowledge of ACP and did not see the necessity of completing an AD document. Education is an essential component of this intervention in order to engage patients to participate and to help them see the necessity of this project. As the nephrology NP implemented the project with each patient, questions were answered and the use of ACP and AD documents was addressed. Fully informed patients are more likely to participate with a trusting health care provider. However, if a trusting relationship is not first established between these two individuals,

the project will not be successful. New patients to the clinic undoubtedly require more time to establish this relationship with the nephrology NP. Nevertheless, these individuals were not excluded from the sample. The nephrology NP used motivational interviewing and effective communication skills to establish a rapport with the patients. The ACP discussion could be undertaken and success could be achieved after this had been established. These barriers provided potential set-backs to this DNP Project. However, once they were overcome, significant results could be achieved.

Impact on:

Organization. This DNP Project was directly in line with the vision of the health care institution at which it was implemented, as was discussed above. ACP helps to promote the human condition and directly achieves the three values of courage, passion, and family. Two stakeholders at the participating organization saw the necessity of this project and were willing to pilot it in one outpatient clinic. As this project progressed, it was important to involve several key organizational members to engage in and enable project dissemination. It was hoped that significant results will be achieved to more easily allow this topic to be translated to other areas of health care. Stressing the necessity of this project with all involved, educating patients, and involving health care staff may allow ACP to become a routine process in the care of all patients throughout this health care organization.

Finances. Costs were incurred to print the informal letter of invitation, informed consent form, intervention tool, and knowledge assessments but were minimal when completed in large quantities. A major cost that could occur with this DNP Project was the increased time the health care provider spent with the patients having the ACP

discussion. This may have resulted in less reimbursement received from insurance companies and federal organizations in addition to less time available to see other patients. However, the cost savings of an ACP intervention greatly outweighs the costs incurred. Individuals who participated in ACP and those who developed ADs more often choose treatment-limiting options. Essentially, a higher quality of life may be experienced at the end-of-life with fewer invasive treatments, hospitalizations, intensive care unit (ICU) stays, emergency room visits, and medications needed to promote a sustainable life.

Diagnosis codes used for Medicare patients are available for initial ACP discussions as well as each additional 30 minutes spent with a patient in this type of intervention (Centers for Medicare and Medicaid Services, 2016). ACP is a reimbursable service for providers yet it was not a routine process in this outpatient clinic. This fact stressed the need to make ACP a more consistent practice. Providers do understand more time is necessary to participate in ACP. However, if it is a billable service and they are reimbursed for their time spent with patients, providers should be more willing to participate and integrate this practice into the routine care of their patients, especially in those with CKD.

Policy decisions. If this project is successful at showing the impact ACP can have on a small sample of patients with CKD, ACP will need to become a routine practice in the care of all patients with a chronic health condition. For that reason, strict policies and procedures will need to be developed to guide an ACP discussion if it is shown to be successful. Key organizational leaders will need to be involved in this process in order to engage and promote dissemination into health care practices.

Quality of health care. The greatest impact of this DNP Project rests on the improved quality of care that can be experienced with ACP. Patients will benefit the most from an intervention of this type. Their benefits include a higher quality of care experienced at the end-of-life, a care that is congruent with their wishes at the end-of-life, lower cost of care at the end-of-life, fewer hospitalizations and emergency department visits, and an enhanced relationship with their health care provider. However, family members can experience a wide array of benefits from the use of ACP. Family members can have less stress and anxiety about end-of-life decision making and feel more confident caring for their family member who has developed an AD or participated in ACP.

Health care providers implementing the practice also benefit from choosing to use ACP with their patients. They will have a greater connection with their individual patients and increased satisfaction in taking care of patients who are fully informed, satisfied, and aware of their diagnosis, prognosis, and treatment options. Finally, as was discussed in the cost section, a cost savings and a smaller use of resources will result for the health care institution. In the end, ACP is envisioned to be a routine process for the health care institution at large. Policy making and changes after this project will ensure ACP is an expectation for both providers and patients at this organization. Patients will expect to be asked these questions, to engage themselves in end-of-life decision making, and to develop goals and desires for their disease process.

Rural or underserved populations. This outpatient clinic served a wide-range of patients, including those who came from many small rural communities. Those who live in a rural environment have less access to health care and less health care resources

to utilize. Individualized patient goals can be tailored based on what treatments are available in the community or what would be most accessible to the patient. Rural patients would benefit by having an increased awareness of services and options, which makes their end-of-life care more congruent with their goals and wants on an individual basis. The educational component of ACP is essential with all patients, but especially those coming from a rural setting. A higher quality of life is experienced for these patients with the help of ACP, even if access to health care and resources is less.

Those with CKD are medically underserved for many reasons, such as a lack of available dialysis facilities, a lack of successful long-term treatment options, and a high cost of procedures and medications that only prolong their life for a short period of time. The use of ACP and the completion of ADs served to help limit these factors. Patients increased their awareness of all of their treatment options but also chose to forgo such expensive, extensive, or invasive procedures having the full knowledge of what it all entails. Again, the educational component of an ACP intervention was necessary to ensure this process was successful. Patients with CKD who are more informed, educated, and satisfied experience a quality of life congruent with their wants, needs, desires, and treatment prognosis. ACP helps to even the playing field for this underserved population and enhances quality of life without going through any unnecessary procedures, should the patient desire.

Non-English speaking patients are also an underserved population. These persons lack knowledge and literacy of health and health care and often do not seek health care due to the language barrier that exists. Often times, when health care is sought, it is in emergency situations. Health care providers do not have the knowledge of what a patient

would want at the end-of-life if he or she has not sought health care before. Language barriers should not be a reason to not implement ACP in this patient population. These patients need more time to understand the components of end-of-life care but it is essential to provide them with this service. ACP with this patient population may result in more informed and educated patients who are able to access the health care system at all stages of life, even during the end-of-life.

Summary

This DNP Project had the ability to reap great rewards for all of those involved. Utilizing a quality improvement approach with a retrospective chart review and the experience of a nephrology NP, patients with CKD stages four and five were given a valid and reliable ACP tool based on recommendations from a CPG. It was the goal that the number of patients participating in an active ACP discussion and those completing an AD document would increase with this one-on-one individualized intervention. Overall knowledge of the ACP process will be increased with the implementation of this intervention. Patients will experience a greater quality of life at the end-of-life, care congruent with their wishes, and a more dignified dying process with ACP. Patients with CKD will feel more prepared for the road that lies ahead and will be able to decide for themselves what they want for their last few days. This health care organization's values of courage, passion, and family were met with the implementation of an ACP intervention specific to those with CKD.

Chapter 4

Findings

Introduction

All data collected for this project was gathered electronically and was de-identified to maintain patient confidentiality. Comparison data was collected from January 1, 2016 to March 31, 2016. The comparison sample included patients with CKD stages four and five who were seen by the nephrology NP during this time period. The intervention detailed above was implemented from January 1, 2017 to March 31, 2017. Despite the great need identified in the literature review for this project, patients who were eligible for the intervention were not willing to actively participate in an ACP discussion. Demographic data were collected on patients with CKD stages four and five who were seen in the clinic setting by the same nephrology NP who met project criteria to receive the intervention. Demographic data is discussed below and detailed in pie chart images. The greatest area demonstrating change with this intervention was clinical significance and this will be discussed in detail below.

Demographics

Various demographic data were collected on both the comparison sample and eligible intervention sample populations. These included age range of the patient, gender of the patient, race of the patient, and stage of CKD. Age ranges were divided into 18-29 years, 30-49 years, 50-69 years, 70-89 years, and 90+ years. Possible gender choices were male or female. Races sampled included African American, Caucasian, and Native American. Finally, eligible stages of CKD were stages four and five based on GFR.

Information on whether the patient had an existing AD document was also collected for both the comparison sample and eligible intervention sample.

Comparison data. The comparison sample consisted of 10 patients. One patient was between 30-49 years of age, four patients were between 50-69 years of age, three patients were between 70-89 years of age, and one patient was older than 90 years of age.

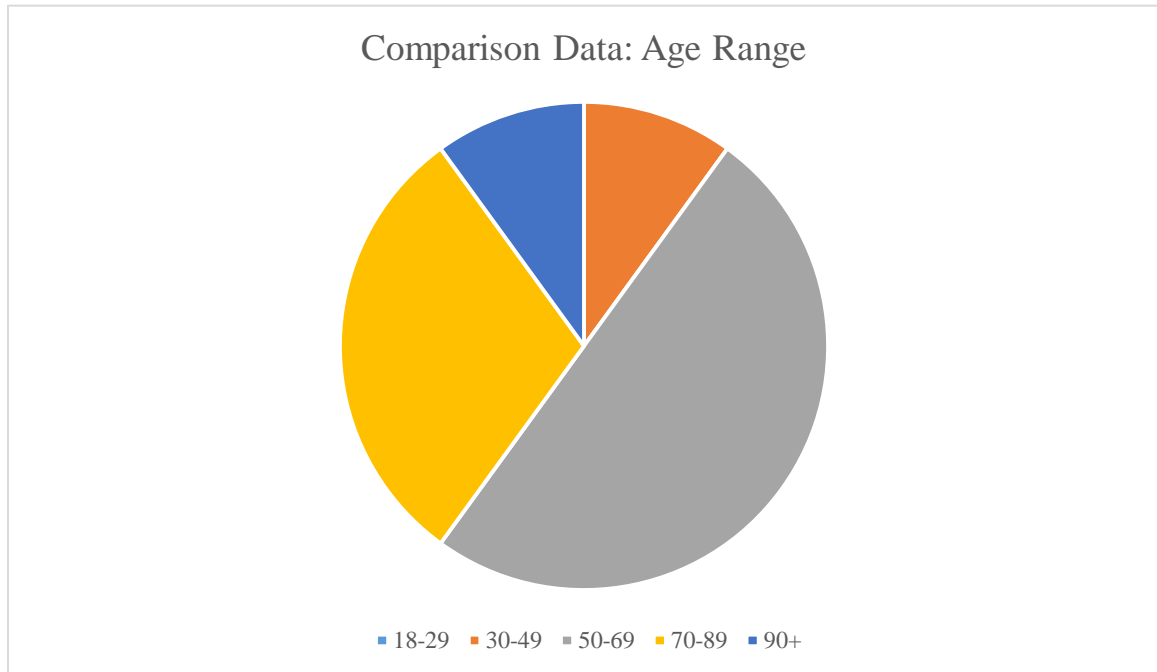


Figure 4. Age range of comparison sample of patients seen in the clinic setting by the nephrology NP between January 1, 2016 to March 31, 2016.

Both males and females were equally represented in the comparison sample. Five males and five females with CKD stages four and five were seen in the clinic setting by the nephrology NP between January 1, 2016 to March 31, 2016.

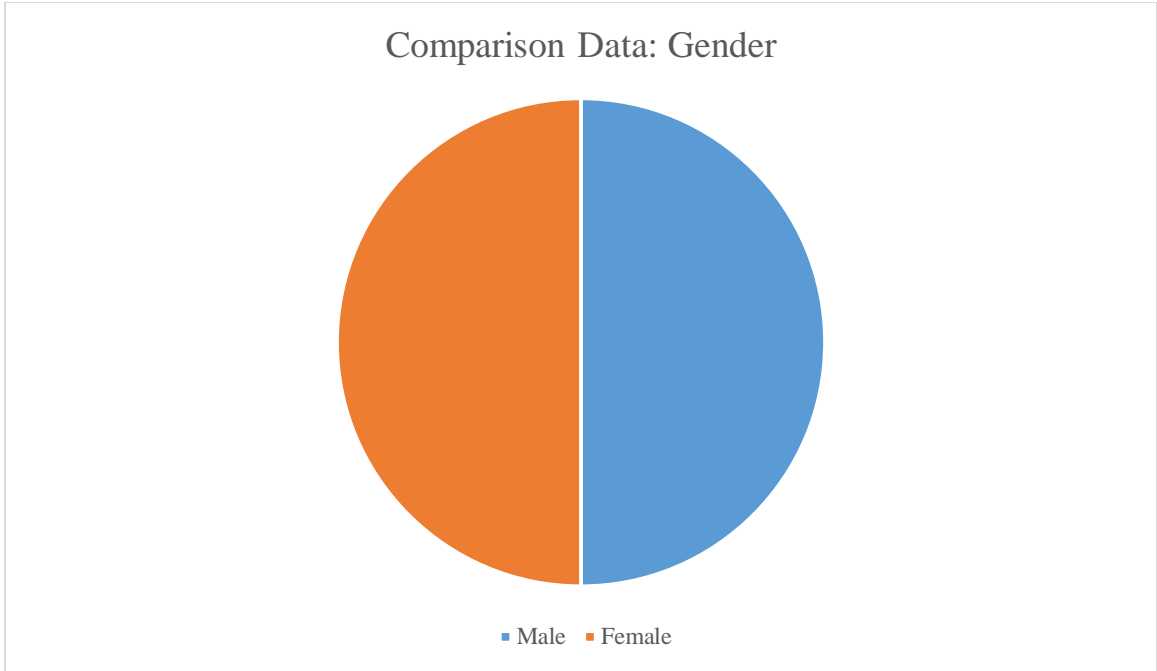


Figure 5. Gender of comparison sample of patients seen in the clinic setting by the nephrology NP between January 1, 2016 to March 31, 2016.

All of the comparison sample patients were of the Caucasian race.

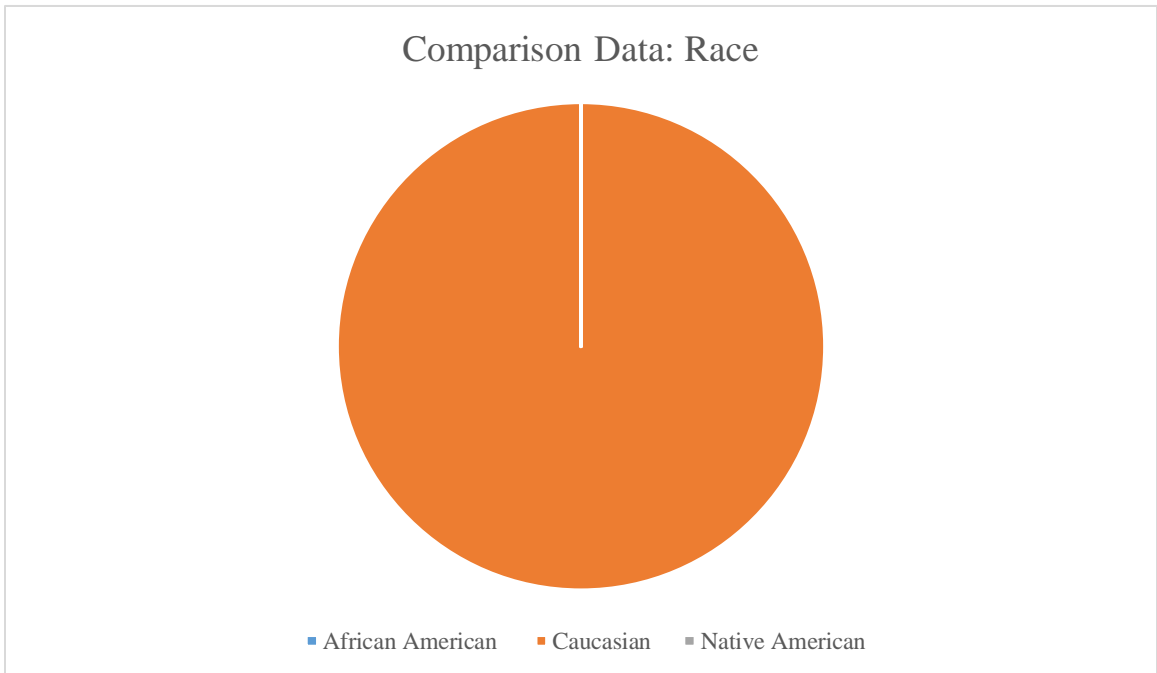


Figure 6. Race of comparison sample of patients seen in the clinic setting by the nephrology NP between January 1, 2016 to March 31, 2016.

The comparison sample included patients with CKD stages four and five. CKD stage four was more common with seven patients. CKD stage five was less common with three patients.

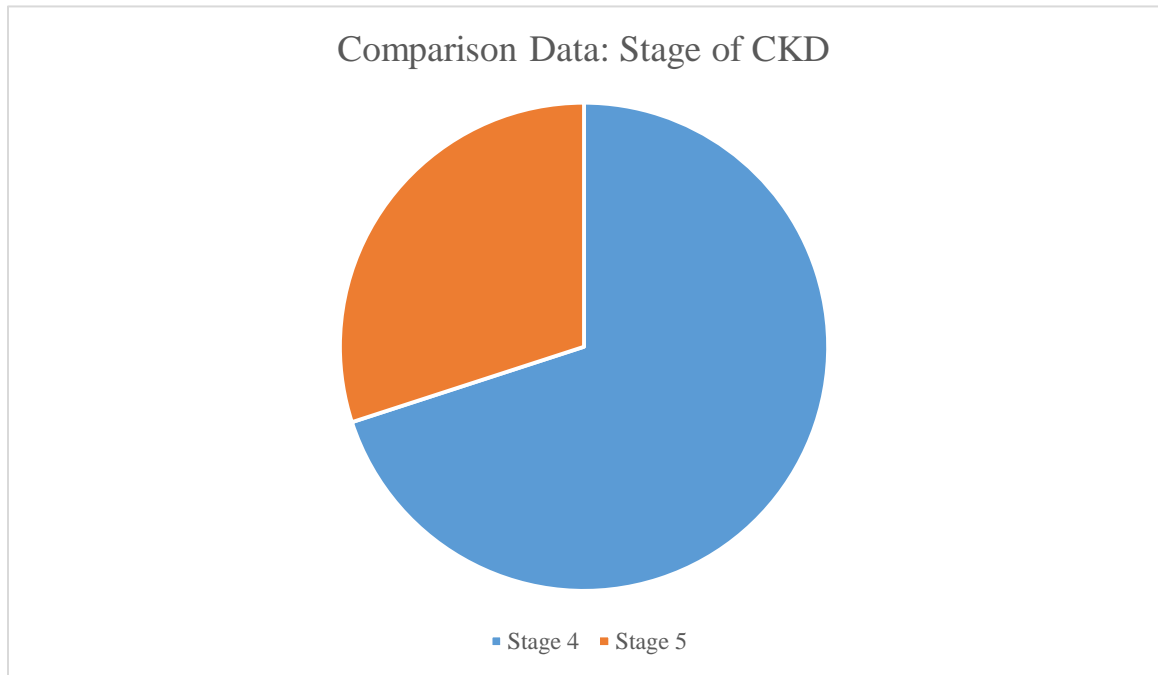


Figure 7. Stage of CKD of comparison sample of patients seen in the clinic setting by the nephrology NP between January 1, 2016 to March 31, 2016.

The comparison sample patients included both those with and without an existing AD document. Five patients had an existing AD document and five did not.

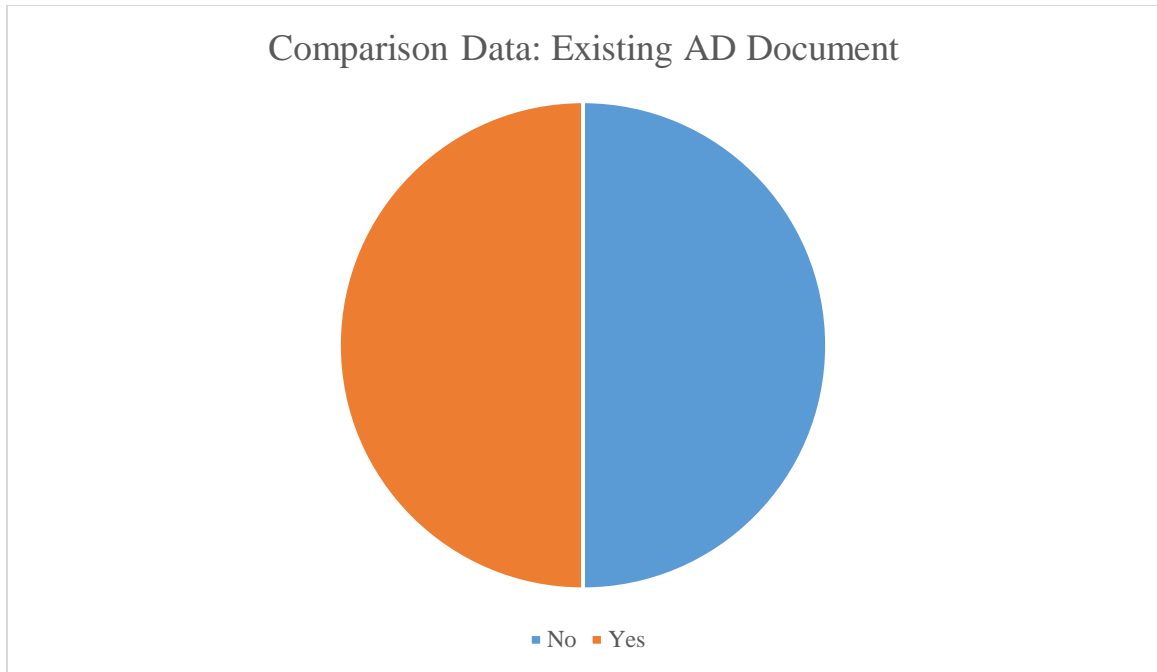


Figure 8. Patients of comparison sample with an existing AD document who were seen in the clinic setting by the nephrology NP between January 1, 2016 to March 31, 2016.

None of the patients who were part of the comparison sample had a documented ACP discussion in their electronic medical record.

Intervention data. The intervention sample consisted of 14 patients who were identified as having CKD stages four or five and by having a scheduled appointment with the nephrology NP between the time period of January 1, 2017 to March 31, 2017. Two patients were between 30-49 years of age, five patients were between 50-69 years of age, and seven patients were between 70-89 years of age.

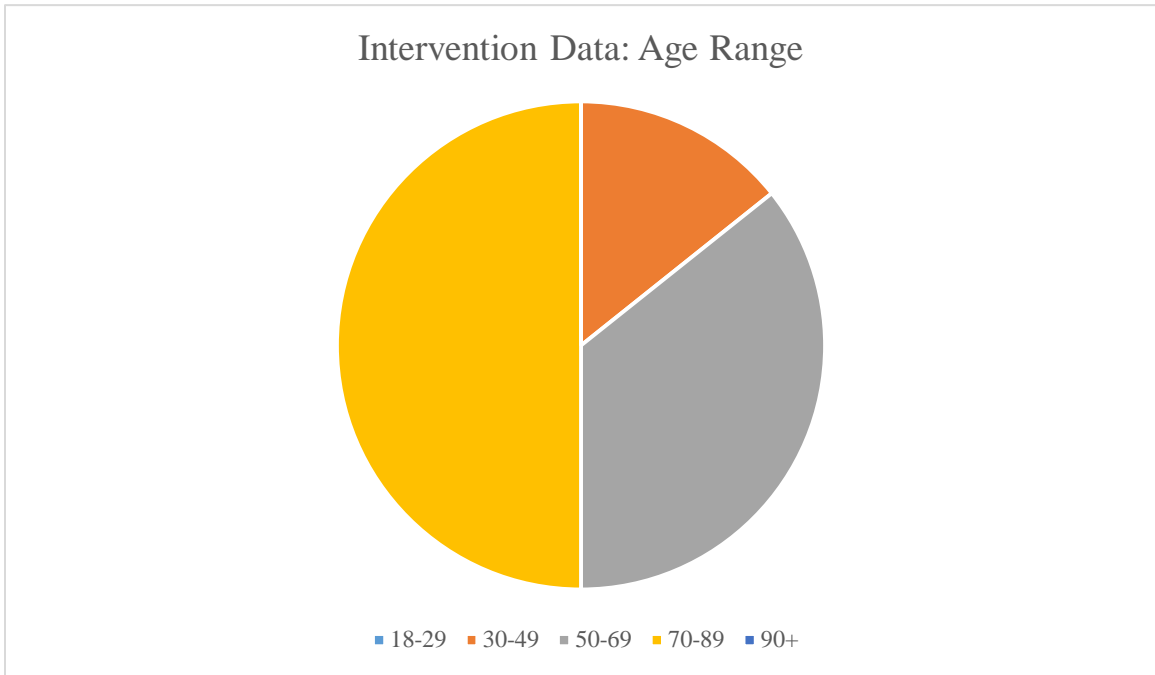


Figure 9. Age range of patients eligible for the intervention sample seen in the clinic setting by the nephrology NP between January 1, 2017 to March 31, 2017.

The intervention sample consisted of seven males and seven females.

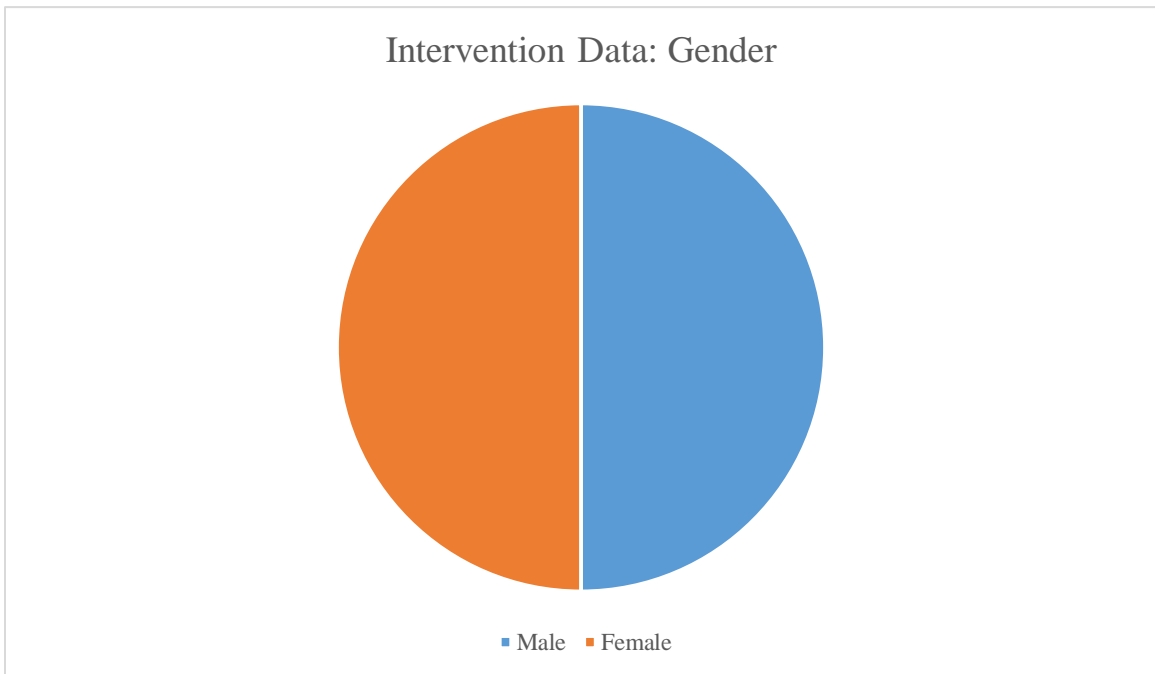


Figure 10. Gender of patients eligible for the intervention sample seen in the clinic setting by the nephrology NP between January 1, 2017 to March 31, 2017.

A wide variety of races was represented in those eligible for the intervention sample. A majority of the sample were Caucasian (11 patients), two patients were Native American, and one patient was African American.

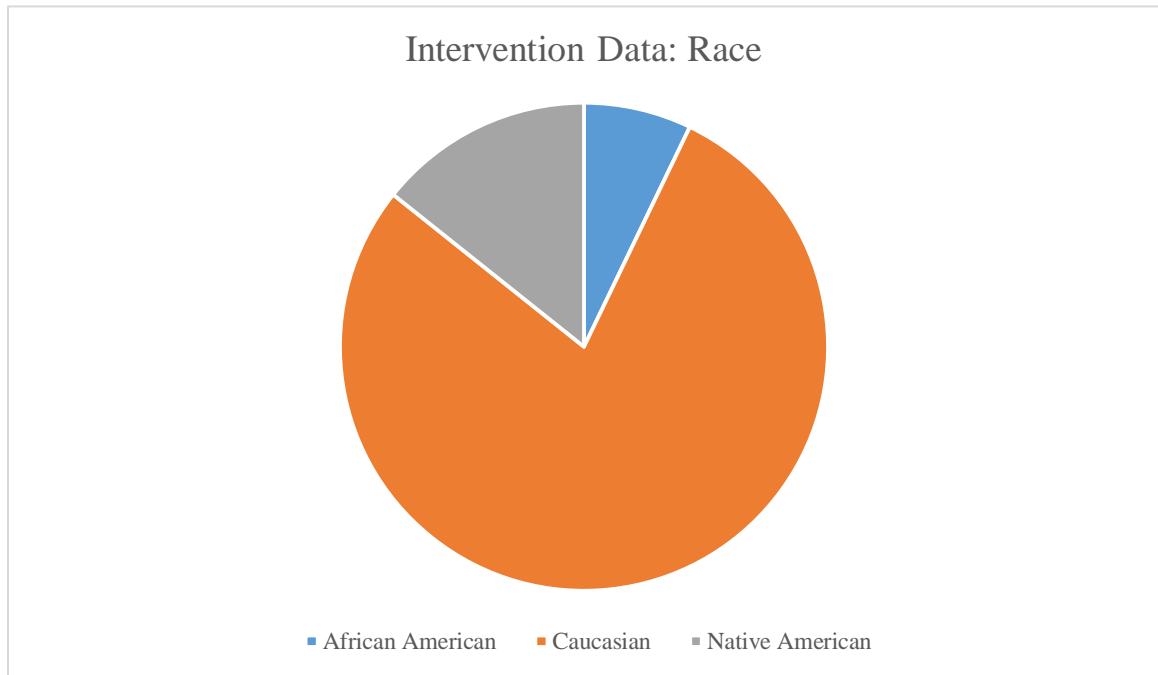


Figure 11. Race of patients eligible for the intervention sample seen in the clinic setting by the nephrology NP between January 1, 2017 to March 31, 2017.

CKD stages four and five were both represented in those eligible for the intervention sample. Ten patients were identified as having CKD stage four. Four patients had CKD stage five.

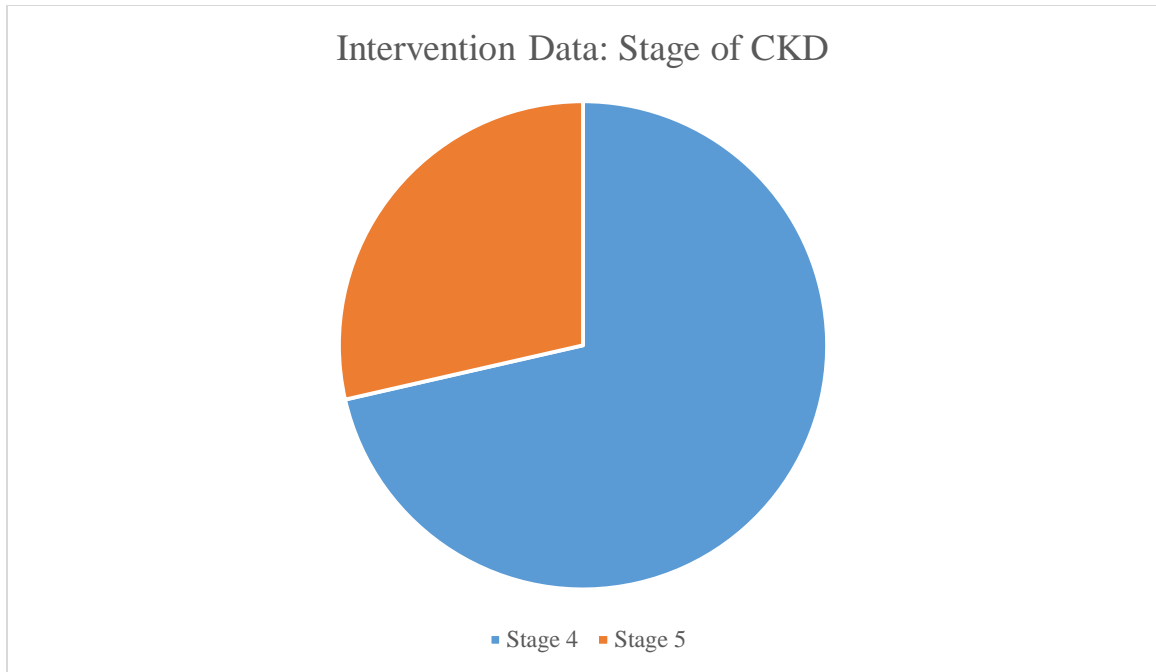


Figure 12. Stage of CKD of patients eligible for the intervention sample seen in the clinic setting by the nephrology NP between January 1, 2017 to March 31, 2017.

Finally, of the patients with CKD stages four and five who were seen in the clinic setting by the nephrology NP during the intervention period between January 1, 2017 to March 31, 2017, seven had an existing AD document and seven did not. However, these seven individuals without an existing AD document declined to participate in the intervention for reasons discussed below.

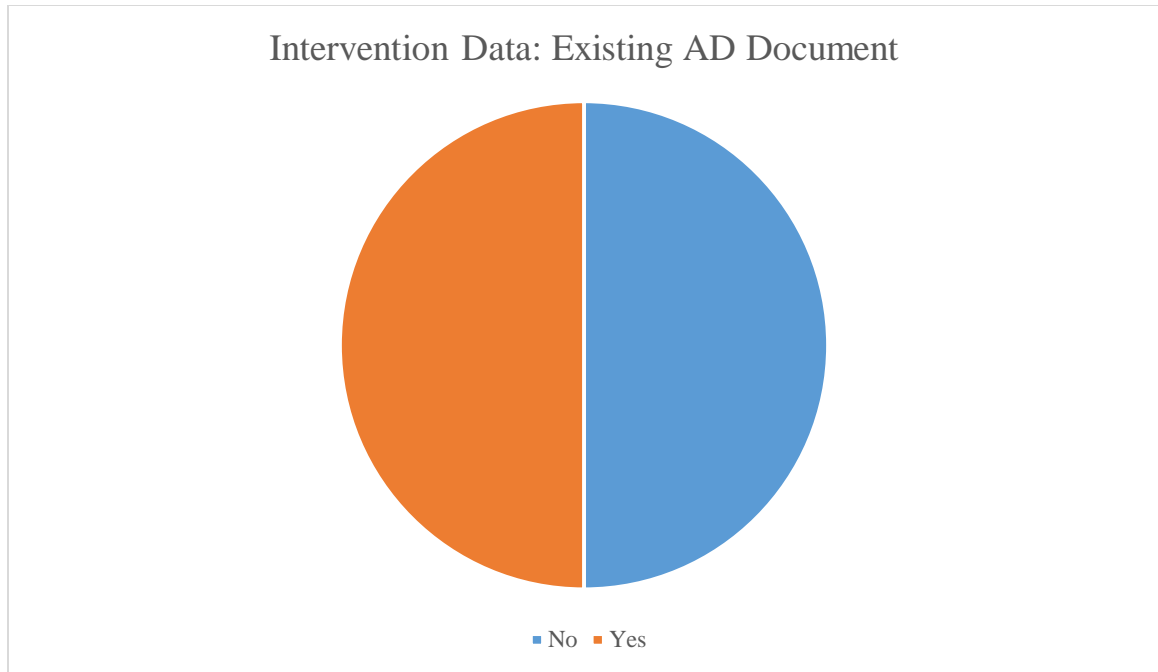


Figure 13. Patients eligible for the intervention sample who were seen in the clinic setting by the nephrology NP who had an existing AD document between January 1, 2017 to March 31, 2017.

Results

Clinical significance. The greatest impact of this project rests in its clinical significance. The DNP Project coordinator conducted regular check-ins with the nephrology NP and other members of the clinic staff throughout the course of the project. Halfway into the intervention period, despite the inability to successfully recruit patients to participate in the project, the nephrology NP identified her approach to her clinical practice was changing. The nephrology NP had been taking time in her routine office visits to verify that a patient had an existing AD document, even though this was already completed by the nursing staff. Although half of the patients the nephrology NP saw with CKD stages four and five during the intervention period had an existing AD document, she was able to take a few minutes to discuss with the patients and individuals present at the time of the appointment what the process of ACP was, why it was

important, and also why it is considered to be a process that is never truly completed. The nephrology NP encouraged all patients, both those with and without an AD document, to think about addressing their end-of-life needs with those who are closest to them. If a patient had developed an AD document a few years ago, the nephrology NP also stressed the necessity of revisiting this document on a regular basis, ensuring what he or she wanted at the end-of-life was still accurate and consistent with his or her health and disease process. Although patient knowledge was unable to be directly assessed with this intervention due to a lack of active patient participation, many patients were provided with basic knowledge of the ACP process. This is only projected to increase as the number of providers who are exposed to this process increases and as patients are offered more ACP education.

The nephrology NP discussed this project with several of the other providers in the practice throughout the three month intervention period. Most of the other providers have realized the necessity of this intervention and do want to be able to integrate ACP into the care of all of their patients but have not adopted this practice routinely. The nephrology NP had provided education to other providers on ways to bring up these sensitive topics with patients and key points patients with CKD need to consider in their end-of-life care using the intervention tool developed for this DNP Project. This project did not show statistical significance. However, the clinical significance and the knowledge gained by the nephrology NP and other clinic providers demonstrated how beneficial ACP is and how patients will routinely be exposed to and offered ACP at all of their office visits with each of their providers.

Statistical significance. Fourteen patients were identified as having CKD stages four and five during the intervention period and were scheduled to be seen by the nephrology NP during the implementation of this DNP Project. Half (seven) of these patients had an existing AD document and per the institution request, were ineligible to receive the developed intervention. The other seven patients declined to participate in the intervention for a variety of reasons. Discussion with the nephrology NP highlighted a few of these reasons, including not seeing the need to develop an AD document, having never heard of ACP, and also not wishing to discuss this sensitive issue at the appointment. The unpaired and paired *t*-tests and detailed statistical analysis were unable to be completed with the lack of patient participation in the developed intervention. It was also noted all patients that were identified to have CKD stages four and five who were scheduled to see the nephrology NP had never participated in an ACP discussion. This demonstrates the need to continue to introduce these patients to ACP and to educate these patients about the necessity of a continuous ACP discussion with health care providers and family members.

Summary

A lack of eligible and consenting patients was a major barrier to achieving statistically significant results with this DNP Project. However, the clinical significance, most notably the increased awareness of the nephrology NP and other clinic providers and the initial education of the process of ACP with patients with CKD stages four and five, was the greatest success of this project. Together, these two areas will help to further transform the topic of ACP in research and practice and will provide health care providers with a way to address ACP with their patients.

Chapter 5

Conclusions

Discussion of Outcomes

This project aspired to achieve many outcomes, including increasing the number of patients participating in an ACP discussion, increasing the number of patients completing the intervention tool, and increasing knowledge of the ACP process. These outcomes were unable to be directly assessed due to not having any participants in the intervention sample. Statistical analysis could not be run with this project and these results were not achieved.

The clinical significance of this project, however, indicates this intervention was successful in other areas. The development of a standardized intervention that enabled all providers to adopt this process into their practice and also an increase in overall provider knowledge were two outcomes achieved with this project. The nephrology NP for this project has now made it a routine practice in all of her clinic visits to ask patients whether or not they have an AD document, even if this was already completed by the nursing staff. The clinical practice of the nephrology NP has greatly changed since the beginning of this project and this practice has continued despite the end of the project. Today, in addition to asking each patient if they have an AD document, the nephrology NP is also asking the patients when this document was last updated, if they have had any major changes to their health since this time, and if they are satisfied with the choices they made previously. Each patient is educated on the necessity of revisiting this document on a regular basis and discussing what is listed in this document with those who are closest to them to ensure their wishes at the end-of-life are carried out as they desire.

Other providers in the same clinic setting are also beginning to use ACP with many of their patients, regardless of the patients' stage of CKD. The nephrology NP has been a great resource for all of the other providers and has started to have discussions with each of them as to how her own clinical practice is changing and how she is slowly beginning to see a change in the attitude of her patients. Even though this project did not show the great need to continue ACP in this patient population, the changing practice of the providers shows how this practice can be incorporated into the care of all patients with CKD. This intervention provides a written starting point for all providers in all patient care settings. This process may be utilized more often and may produce achievable and significant results as more patients are exposed to the process of ACP and are asked about their AD document on a regular basis.

Limitations

The lack of patients included in this project sample was the biggest limitation for this project and greatly hindered the ability to achieve statistically significant results. It was identified by the DNP Project coordinator and the nephrology NP that there were no participants in the intervention sample halfway through the intervention period. The DNP Project coordinator contacted the Nursing Research Council of the health care institution at which this project was implemented under the guidance of the DNP Project advisor. This was done because prior to implementation of the DNP Project, the Nursing Research Council requested that the intervention sample did not include patients who already had an existing AD document. Information was provided to the Nursing Research Council regarding the lack of eligible participants and the desire to include patients with pre-existing AD documents. The Nursing Research Council approved the

request to continue the intervention and to include those with existing AD documents for the remainder of the intervention period. Together, the DNP Project coordinator, the DNP Project advisor, and the nephrology NP decided to include those patients with CKD stages four and five with an existing AD document in the last three weeks of the pre-determined implementation period. Even despite these changes, patients did not agree to participate in the intervention. The nephrology NP was very flexible in the implementation of this project and enabled the clinical significance to be achieved. This project could have easily become stagnant and changes could not have occurred during the three month intervention period without the nephrology NP. The nephrology NP's willingness and desire to incorporate ACP into the routine care of patients with CKD allowed clinical significance to occur.

The informal letter of invitation, informed consent form, pre- and post-intervention knowledge assessment document, and discussion tool all had a very high readability level. If these documents were to have been used, this would have been a great limitation to this project. For some persons, it may have been difficult to read and complete the documents and actively participate in the intervention for this reason. More time would have been necessary to ensure the patients could understand what they were being asked to decide upon. This limitation would have need to have been considered when working with patients with a lower education level. Reading the documents and questions to the patient by the nephrology NP or a family member would have been one way to overcome this and still allow the patient to decide upon accurate goals for his or her end-of-life care.

Other than the initial meeting held prior to the beginning of the project, the DNP Project coordinator had little interaction with the nursing staff. The individuals rooming the patients were not trained in the use of ACP and in ways to approach this topic with this patient population. This fact could have limited the number of willing participants. This is an important factor to consider in future projects of this type.

This exact project is not continuing at this clinical practice site at this time but all of the providers, especially the nephrology NP, are aware of the need for this practice and are routinely investigating the AD status of each patient and also continuing to educate each patient on the need to revisit and address these documents on a regular basis. The process of ACP is not a one-time process but instead is continuous and must be revisited on a regular basis, as was supported in the literature review. The TTM would help to guide providers implementing this intervention to help them identify what stage of change the patient is in. Patients in the precontemplation stage should be targeted with education about the process of ACP and why it is important to one's end-of-life care. Once the patient has transitioned to the contemplation and preparation stages, the actual process of ACP can then be implemented. This project confirms this evidence and with a longer time frame for this project, more significant results could be achieved and patients could agree to participate in the intervention.

Impact on:

Organization. The clinical significance achieved with this project was in line with the vision and three core values of the health care institution where this project was implemented. The clinical practice of the nephrology NP has been expanded to include a review of the AD status of each patient seen in the clinic setting. The nephrology NP

believes this process will continue in her personal practice. Both courage and passion are qualities she has embodied since this project began. It is necessary to be willing to step outside one's comfort zone as a provider utilizing courage and passion to provide well-rounded care for patients with a chronic disease. The family value of this organization is also met while talking with patients who already have an AD document and determining if it is recent or if the patient would like to make changes to it.

Various organizational members were not enlisted to help disseminate these results due to the lack of patient participation in this DNP Project. Once results are obtained that show the statistical significance of this project, these persons will help gather the support of other providers and patients in other settings. Education should continue and providers should revisit developed ADs with their individual patient populations as changes are made. The more routine the process becomes, the more results that can be achieved.

Finances. The nephrology NP did spend a few more minutes with each patient than she would have normally making sure each patient with CKD stages four and five had an existing AD document and changes were not needed, even though intervention tools and ADs were not completed during the implementation period of this project. There were no direct cost increases with this initial project. However, as future projects are completed and more patients and providers are enlisted to participate in ACP, more time may be required to spend with the patients completing the intervention tool. The financial impact should continue to be addressed with the use of any type of ACP discussion. Providers should continue to be made aware of the ability to provide this service to all Medicare patients and to use the diagnoses codes that are also available.

Medicare and other insurance companies do see the necessity of ACP and it should be translated to all health care areas and all patient populations.

If patients would have participated in the intervention and in the long run, a great financial savings would have occurred for the health care institution. Nicholas et al. (2011) showed those with ADs spent over \$100,000 less on end-of-life care. This cost savings could override any increased costs that may occur with the implementation of this program, such as increased provider time spent with patients actively participating in an ACP discussion. This would be an important factor to consider when choosing to implement an ACP discussion in future settings and with other patient populations.

Policy decisions. The number of individuals participating in this project was less than anticipated. Currently, changes in policies or procedures have not occurred in this health care institution. The need for this change may be great as more providers are made aware of the clinical significance of this project and the need for all individuals with CKD to participate in ACP. Key organizational leaders will need to be enlisted to help adopt and implement this change throughout the entire organization, including both the inpatient and outpatient settings, once this project has shown to be successful with increased participation and with statistical significance.

Quality of health care. It was hypothesized that patients with CKD would benefit the most from an intervention of this type. However, this did not occur due to a lack of patient participation. The nephrology NP had the greatest amount of change in clinical practice and is now implementing an AD discussion with each of her clinic patients. The provider is still talking with the patient and determining when the last updates were made and what the patients' desire is for his or her end-of-life care even if

the patient has an existing AD document. This discussion, despite not using the developed intervention tool, did help to establish a better connection between the patients and family members who partook in this process. Its use will only continue to expand, cost savings may result for the health care institution, and policy changes can be made as more providers and patients are made aware of this process.

Direct patient and family member benefits were not able to be successfully measured with this project. This should be the focus of future research and similar projects. It is still anticipated patients will benefit from a higher quality of care experienced at the end-of-life, a care that is congruent with their wishes at the end-of-life, lower cost of care at the end-of-life, fewer hospitalizations and emergency department visits, and an enhanced relationship with their health care provider. Family member benefits may include less stress and anxiety about end-of-life decision making and increased confidence caring for his or her family member who has developed an AD or participated in ACP.

Rural or underserved populations. This project enabled patients from a variety of settings the opportunity to participate in ACP. Regardless of what community the patient lived in or how far he or she traveled to be seen in this outpatient clinic, each patient meeting the inclusion criteria was offered the ability to complete the intervention tool and formulate an advance care plan with the help of his or her family members, caregivers, or the nephrology NP. Patients from a rural setting will experience an enhanced awareness of services and options and can formulate an AD document stating their exact wishes and desires for their end-of-life care as adjustments are made to this project and as it continues to move forward.

Again, as more patients participate and are allowed to formulate an advance care plan, informed patients may choose to forgo more expensive, extensive, or invasive procedures knowing many of these options may be unsuccessful long-term and may result in unnecessary and higher medical costs. Education of eligible and consenting patients remains a key component of the essential use of ACP. It is hoped that as ACP continues to be utilized in all patients with chronic disease, those of rural and underserved populations will experience an enhanced quality of life.

It was anticipated that non-English speaking patients would be included as part of this project's sample. However, non-English speaking patients were not seen during the three month implementation period. Language barriers should not be a reason to forgo implementing ACP in this population. It is still essential to provide these patients with this service, even though more time will be needed to allow for translation and to ensure adequate understanding of the process of ACP. ACP, even in non-English speaking patients, will result in informed and educated patients who are able to access the health care system successfully at the end-of-life.

New Evidence Generated for Practice

The literature review completed identified several gaps that were addressed with this DNP Project. A lack of eligible and consenting patients with CKD stages four and five did, however, greatly limit the amount of sustainable and effective results that could be achieved with this project. The greatest barrier in developing this DNP Project was the lack of an available intervention to use in patients with CKD. Therefore, a new, effective intervention was developed for this project. It does cover some of the most basic questions for a patient with CKD who is nearing the more advanced stages and

provides a starting point for an ACP discussion. This document can be used by others and provides health care providers a starting point for these difficult discussions.

More tangible evidence is needed outside of this project to support the use of ACP in this patient population. ACP has shown to be successful in a wide range of patients with other chronic diseases but further research still needs to focus on those with CKD. Combined with this specific intervention and specific group of patients, a more standardized process of communicating and discussing end-of-life issues, needs, and treatment options can be addressed in a meaningful manner.

Recommendations for Future Projects

The major limitation to this project was the lack of eligible patients included in the project sample. Future research should focus on expanding the number of patients who are eligible to partake in an ACP discussion. This could be done in many ways, such as including patients in lower stages of CKD, such as stages two or three, or having more providers implement the process of ACP in their clinic settings. An NP in a specialty practice setting, such as nephrology, often sees the less critical or seriously ill patients. Including a physician in addition to a NP or other advance practice provider may continue to expand the number of patients who would be eligible to receive this intervention. If, with the help of these changes, patients who are seen in the clinic setting with CKD are shown to benefit from the process of ACP, this intervention could then be expanded to include patients in the hospital setting and patients with other chronic diseases. The intervention used for this project has not shown to be unsuccessful and should be continued.

The length of time of project implementation should also be expanded in future projects. Three months is a relatively short time frame to expect patients to make and discuss their end-of-life decisions with their family members, caregivers, or health care providers. A project involving ACP should last a minimum of six months but one year would allow for true and successful results to be achieved. The process of ACP should involve a continuous discussion between the patient and health care provider at each office visit encountered in the health care system. The providers who have currently been exposed to ACP should continue to use this practice in their daily patient interactions, even in those who do not have a chronic health condition.

Other than the initial meeting before the project implementation, the nursing staff rooming the patients received no education in regards to this specific project. The DNP Project coordinator also never witnessed the rooming of a patient and this per chance was a limitation to this project as actions and attitudes of the nursing staff in regards to ACP were never directly assessed. As such, future projects should focus on education of the all involved parties to ensure these extraneous variables or personal biases are accounted for.

This project showed a great need to gather qualitative data in regards to why patients were declining to participate in the process of ACP. The literature review completed for this project showed a lack of patient knowledge of the process of ACP and this was one of the most cited reasons for choosing not to participate in this specific intervention. Patients also suggested they did not see the need to develop an AD document or were not ready to make these decisions during their appointment. These reasons did serve as barriers to the developed intervention. However, this qualitative data

also serves to enhance future research in the area of ACP. This project shows education about ACP must be implemented by providers prior to discussing end-of-life issues.

Once this process of education is completed, the patients will have a better understanding of the necessity of ACP and will be more willing to participate in an intervention. Other research projects focusing on ACP should also begin with education in order to achieve the greatest outcomes. This type of data stresses the need to continuously engage patients in an ACP discussion, as was also discussed in the literature review. An advance care plan or AD is not something that can be developed in a short time frame and should instead be discussed with patients during successive office visits and at each point of contact in the health care system. The end result of improved education and enhanced knowledge will greatly enhance patient care at the end-of-life.

ACP needs to be included early on in the care of a patient with a chronic disease, despite the lack of patient participation and the lack of statistical results achieved with this project. All health care providers will need to help prepare their patients for the end-of-life and support them as they participate in this endeavor as the research continues to grow with ACP and as patients continue to be exposed to ACP. It is the hope that ACP will become a routine topic of discussion between health care providers, patients, and family members or close friends.

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Appendix A: SDSU IRB Form



Office of Research Assurance
and Sponsored Programs

Box 2201, SAD 200
SDSU
Brookings, SD 57007-1998
Phone: 605-688-6696
FAX: 605-688-5530

Dianne.Nagy@sdstate.edu

To: Chelsea Hinders and Nicole Gibson, College of Nursing

Date: November 17, 2016

Project Title: Implementation of an Advance Care Planning Discussion for Patients with
Chronic Kidney Disease

Approval #: IRB-1611017-EXM

Thank you for bringing your project to the Human Subjects Committee. Your project is approved as exempt from the Common Rule. The basis for your exempt status (from 45 CFR 46.101 (b)) is:

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:
(i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

If there are any unanticipated problems involving risks to subjects or others or changes in procedures during the study, please contact the SDSU Research Compliance Coordinator. At the end of the project please inform the committee that your project is complete.

If I can be of any assistance, don't hesitate to let me know.

Sincerely,

Dianne Nagy
Acting IRB Coordinator

Appendix B: Organization IRB Form



NOT HUMAN RESEARCH

November 8, 2016

Dear Chelsea Hinders:

The IRB reviewed the following submission:

Type of Review:	Initial Study
Title of Study:	Implementation of an Advance Care Planning Discussion for Patients with Chronic Kidney Disease
Investigator:	Chelsea Hinders
IRB ID:	STUDY00000837
Finalized Documents this review:	None

The IRB determined that the proposed activity is not human research. Sanford IRB review and approval is not required.

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are being considered and there are questions about whether IRB review is needed, please submit a study modification to the IRB for a determination. You can create a modification by clicking **Create Modification / CR** within the study.

For questions please contact the IRB Office: eIRB@sanfordhealth.org.

Appendix C: Nursing Research Council Approval Letter

From: Jensen, Gwen
Sent: Monday, September 19, 2016 10:56 AM
To: Hinders, Chelsea
Cc: Jensen, Gwen
Subject: Review from Nurs Res Council

Chelsea – The Council agreed you have a very strong proposal. There were a few questions/clarifications that you may find helpful. Overall, they approved your proposal to move forward here at Sanford. Congratulations!!!! Really great job!

Gwenneth A. Jensen PhD RN CNS
Sanford Health
1305 W. 18th Str
Stow Falls, SD 57105
gwenneth.jensen@sanfordhealth.org
605-328-4223

Confidentiality Notice: This e-mail message, including any attachments, is for the sole use of the intended recipient(s) and may contain privileged and confidential information. Any unauthorized review, use, disclosure or distribution is prohibited. If you are not the intended recipient, please contact the sender by reply e-mail and destroy all copies of the original message.

Appendix D: Organization Letter of Agreement

1305 W 18th Street
PO Box 5079
Sioux Falls, SD 57117-2029

Ph: 6051393-1000
sanfordhealth.org

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December 12, 2016

Re: Letter of Agreement for Onsite Research/IRB - Sanford Sioux Falls

This is to confirm that we agree to collaborate with South Dakota State University on an EBP project entitled *Implementation of an Advance Care Planning Discussion for Patients with Chronic Kidney Disease*, conducted by South Dakota State University graduate student Chelsea Hinders.

We are aware that the procedures used in this project have been reviewed by Sanford Human Research Protections (IRB) and deemed not human research. Procedures for this study include:

a) A retrospective chart review will be completed from one year ago at the time of implementation to determine the number of patients with chronic kidney disease stages four and five who were seen by the nephrology nurse practitioner who had a documented advance care planning discussion and the number of patients who had completed an advance directive document in their electronic medical record. b) During the project implementation period, the nephrology nurse practitioner, clinic nurses, and receptionists will determine from the scheduled patients who are eligible to receive the intervention each working day. An asterisk will be made next to each eligible patient on a printed clinic schedule that will be placed at the front desk. c) The clinic receptionist will give each eligible patient an informal letter of invitation from the DNP project coordinator. The nursing staff will answer any questions while rooming the patient. The patient will then select one option on the bottom of the informal letter of invitation, either I agree to participate or I decline to participate. The completed informal letter of invitation will be given to the nurse. d) All forms, even if the patient declines to participate, will be kept in a locked filing cabinet, only accessible by the nursing staff, the key stakeholder, and the project coordinator. e) The nursing staff will then ask the patient if he or she has an advance directive document. If the patient does, usual care will ensue and the patient will not be eligible for the intervention. If the patient does not and has agreed to participate, the intervention will continue. f) If the patient agrees to participate and does not have an advance directive document, the nurse will provide the patient with the informed consent form. The nursing staff will also collect the completed informed consent forms from the patient during the rooming process. These forms will be stored in the same locked filing cabinet. g) After the nurse has completed the rooming procedure, the patients who consent to the intervention will be given the pre-intervention knowledge assessment to gather baseline data of patient knowledge of advance care planning and advance directives. The assessment tool will be returned to the nursing staff or nephrology nurse practitioner. These will also be stored in the same locked filing cabinet. h) The nephrology nurse practitioner will have a discussion with the patient and/or individuals who are present at the time of the appointment using the developed intervention tool. The patient will be encouraged to complete the form at the time of the visit, discuss their wishes with the provider, or take the form home to discuss with family members and fill out at a later date. i) If the intervention tool is completed at the time of the office visit, the clinic manager will serve as the notary to witness the signing of the advance directive document. j) The nurse practitioner will then give the document to a member of the nursing staff who will then ensure the document is scanned into the patient's electronic medical record. A copy will then be sent to the medical records department and the original document will be retained in the clinic setting. k) The same knowledge assessment tool will be given to the patient in the form of a post-assessment document. This can be given to the patient by either the nephrology nurse practitioner or any member of the nursing staff. The patient will be given the completed document to any member of the clinic staff. This form will also be kept in the same locked filing cabinet. l) The nurse practitioner will be encouraged to document the advance care planning discussion in her progress note in the electronic medical record. m) If the patient does not complete the document at the time of the clinic visit, they will be encouraged to return the form

Our Mission:
Dedicated to the work of
health and healing

1335 W 10th Street
PO Box 5029
Sioux Falls, SD 57117-3029

Ph: (605) 333-1000
sanfordhealth.org

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HEALTH

to a clinic staff member as soon as they feel ready. The same procedure for medical record documentation will occur at any time during the implementation period when a patient returns the form to a clinic staff member. n) At the end of the three month time period, the patient sample will be reviewed to determine the number of active advance care planning discussions completed and the number of intervention tools received to help determine the change this intervention had on this sample. In addition, the change in knowledge from the pre-intervention assessment will be measured against the post-intervention assessment to determine the amount of knowledge the patients obtained from participating in this intervention. Precautions are in place so that information will not be identifiable.

We understand that any protected health information, such as names, addresses, social security numbers, medical record numbers, account numbers, birthdates, or admission and discharge dates, that is abstracted from medical records for research purposes will be collected electronically and de-identified. The retrospective chart review data will include demographic data as well as the number of patients who have completed an advance care planning discussion and the number of documented advance directives. This information will be stored in a locked filing cabinet in the clinic only accessible by the nursing staff, the key stakeholder, and the project coordinator. The intervention information will be collected and stored in the same manner following informed consent. All documents obtained, including informal letters of invitation, informed consent forms, intervention tools, pre-knowledge assessments, and post-knowledge assessments, will also be stored in the same locked filing cabinet only accessible by nursing staff, the key stakeholder, and the project coordinator. Analysis will be done on inaccessible, password protected computers, and original identifiers will be deleted by the PI within 72 months after completion of the study. Aggregate Sanford Health clinical data will remain confidential and will not be shared outside of the organization without specific authorization.

This letter confirms that we are aware of the conduct of this project in Sanford Nephrology Clinic and agree to collaborate with the researcher and the project entitled *Implementation of an Advance Care Planning Discussion for Patients with Chronic Kidney Disease*.

Sincerely,

Amanda Saeger
Clinic Director Sanford Nephrology

Lisa Hoyle DNP, RN
Chief Nurse Executive

Date _____

Date _____

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health and healing

Appendix E: Stakeholder Agreement

DNP Project Stakeholder Agreement

I agree to serve as the DNP Project Stakeholder to the DNP student named in this agreement.

Name of Stakeholder:

Signature of Stakeholder:

Name of DNP student:

Signature of DNP student:

Date:

Appendix F: Literature Review Methods Table

Database(s) Searched	Search Terms	Number of Results	Number Retained
Cochrane Library	advance care planning AND CKD, advance care planning AND renal, advance care planning AND dialysis, Native American AND culture beliefs	2	1
CINAHL, EBSCOhost	advance care planning AND CKD, advance care planning AND dialysis, advance care planning OR advance directive AND kidney failure OR renal insufficiency OR dialysis patient OR nephrology nursing, Native American AND culture beliefs	24	10
MEDLINE/PubMed	advance care planning AND CKD, advance care planning AND renal	59	6
Ovid	advance care planning OR advance directive AND kidney OR renal OR chronic or end-stage	16	1
USPSTF	advance care planning	0	0
AHRQ	advance care planning, chronic, dialysis, renal	467	2
Total		568	20

Appendix G: Evidence Table

Citation	Level of Evidence	Sample/Setting	Participants (n)	Study Design/Purpose	Intervention	Results	Comments; strengths and limitations
Agency for Healthcare Research and Quality. (2014).	IVB	Sources were extracted through database searches (PubMed, Google, Respecting Choices Website, POLST website) from January 2012-December 2013.	Not listed in the CPG	CPG developed to help achieve improvements in ACP through development of evidence-based guidelines, to assist practitioners in engaging patients in ACP discussions, to recommend interventions to address ACP, and to focus on key components of ACP	NA	Recommendations: implement a standardized ACP process, assist patients to use a reliable and valid ACP tool, help a patient revise his or her ACP at least annually or with a significant health change, and document the patient's goals in their medical record.	<p>CPG appraised using the Agree II tool – quality rating of 4/7. Updated version of a previous guideline. Not specific to patients with CKD. Supports use of ACP in a variety of adult patients.</p> <p>Strengths: Multiple key recommendations listed. Multiple databases searched.</p> <p>Limitations: Number of extracted sources or number of</p>

							participants was not listed. Not listed if views of public opinion have been sought. Few resource implications discussed. No update procedure provided.
Agency for Healthcare Research and Quality. (2015); Renal Physicians Association & American Society of Nephrology. (1999).	IVB	1,062 articles synthesized for systematic review extracted through database searches	Not listed in this CPG	CPG developed to provide clinicians, patients, and family members information in regards to benefits and burdens of dialysis, to systematically allow the health care provider to make individual decisions for special health care circumstances, to synthesize	NA	Recommendations: develop a patient-physician relationship for shared decision making, fully inform patients of their diagnosis, prognosis, and all treatment options, institute ACP, if appropriate, withhold dialysis in individual patients, and offer palliative care services to appropriate patients (early on in the disease process).	CPG appraised using the Agree II tool - quality rating of 5/7. Specific to patients with CKD. Not specific to only ACP interventions. Supports use of ACP in patients with CKD. Updated version of a previous guideline – reaffirmed 1999 guideline from the Renal

				available research, to provide a way to make ethically sound health care decisions, and to enhance understanding of processes used to initiate or withdraw dialysis therapy			<p>Physicians Association and American Society of Nephrology.</p> <p>Strengths: In-depth literature search completed. In-depth methodology listed.</p> <p>Limitations: Conflicts of interest not addressed. Few costs implications addressed. Not discussed whether public opinion was sought.</p>
Amro, O. W., Ramasamy, M., Strom, J. A.,	VB	Two outpatient dialysis facilities in Boston, MA from June	201 patients with ESRD receiving outpatient hemodialysis	Quality improvement project to help develop an AD method that is	Patients identified by a nephrologist as having a short life	An additional 12 patients opted for a DNR order (p = 0.01). An increase from 10% to 90%	Specific to patients with CKD. Shows importance of a face-to-face

<p>Weiner, D. E., & Jaber, B. L. (2016).</p>		<p>2013 to July 2014</p>		<p>practical, widely applicable, and comprehensive</p>	<p>expectancy were invited to participate in a focus group encounter dedicated to ACP. Face-to-face encounter was held during a routine dialysis run and lasted from 15 to 60 minutes.</p>	<p>was seen after the intervention in regards to completion of an AD form ($p < 0.001$).</p>	<p>encounter on improving AD rates.</p> <p>Strengths: Large sample size. Statistically significant results. Study conducted at a time convenient for all participants. Two different dialysis settings were used.</p> <p>Limitations: No control group used for comparison. Sample size too small to determine impact of culture or religion on AD completion or DNR orders.</p>
<p>Artsanthia, J., Mawn,</p>	<p>IIIB</p>	<p>Purposive sample of older</p>	<p>30 Thai adults with</p>	<p>Mixed methods focus group</p>	<p>Focus groups were held</p>	<p>Four major themes developed:</p>	<p>Specific to those with CKD.</p>

<p>B. E., Chaiphiba- lsarisdi, P., Nityasu- ddhi, D., & Triam- chaisri, S. K. (2011).</p>		<p>adults living with ESRD and their family members. Patients were between the ages of 50 and 80 years and were followed at a hemodialysis clinic in a Bangkok Hospital. Family members were adults older than 20 that provided care to a person with ESRD, were relatives of a person with ESRD, or were identified as community leaders.</p>	<p>ESRD and 30 family members</p>	<p>study focusing primarily on qualitative methods to explore the needs of palliative care implemented with individuals with ESRD living in Bangkok, Thailand</p>	<p>using a qualitative interview guide to explore the physical, emotional, and spiritual needs of patients with ESRD and associated family members</p>	<p>tremendous suffering, economic consequences, inadequate community support, and concern for the future. These four themes display the wide range of issues facing these patients. Reveals the need for an in-depth palliative care approach with these patients that addresses all of these issues.</p>	<p>Shows the importance of integrating palliative care with patients with ESRD. Reinforced cultural importance of palliative care with CKD patients.</p> <p>Strengths: Small focus groups but adequate sample size for study design.</p> <p>Limitations: Use of purposive sampling. Only one country/dialysis center was used in the study. Need for further research to develop themes/</p>
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							quantitative data more with this population and intervention.
Bristowe, K., Horsley, H. L., Shepherd, K., Brown, H., Carey, I., Matthews, B., . . . Murtagh, F. E. M. (2015).	IIIB	Two large London renal centers that service approximately 1000 hemodialysis patients at two main and 10 geographically dispersed satellite units. Participants were sampled by age (<65, 65 and over), time spent on dialysis (<12 months, 12-36 months, >36 months), and symptom burden and from November	20 hemodialysis patients, 11 participants were female, 9 participants were male	Qualitative grounded theory design that aimed to explore the experiences of people living with ESRD regarding starting dialysis, its impact on quality of life, and their preferences for future care and to explore the ACP needs of this population and the timing of this support	Semi-structured qualitative interview that occurred during a routine dialysis treatment. Recruitment occurred until data saturation was reached.	Participants had a variety of unmet and unaddressed ACP needs, including fear, grief, denial, shortage of information regarding illness and prognosis, and a lack of opportunity to discuss concerns, prognosis, and future care.	Specific to patients with CKD. Supports the need for earlier ACP in patients with CKD/ESRD. Strengths: Convenient location/time for all participants. Data saturation was reached. Limitations: Use of purposive sampling. Four patients died during the study. Need for greater research (longitudinal studies) to show importance of ACP and how

		2011 – February 2012					outcomes change with a specific intervention.
Bullock, K. (2011).	IIIA	Focus groups gathered from Black and white community-dwelling residents	202 participants (black participants n = 102, white participants n = 100)	Qualitative focus group grounded theory design to promote cultural competency in end-of-life care that included extended family networks	Focus groups responded to guided questions about preferences for or against end-of-life care, control and autonomy, attitudes and beliefs about death and dying, and questions in regards to ADs	Caucasians were more likely than African Americans to have completed an AD, wanted to make their end-of-life care decisions independent of family members' influence, and viewed hospice care more positively. White older adults tended to value individualism, independence, self-reliance, and future orientation. African Americans tended to value collectivism, interdependence, interconnectedness, and present orientation.	Not specific to those with CKD. Discussed impact culture has on ACP and differences between African Americans and Caucasians. Strengths: Discussed reliability of cultural beliefs scale. Theoretical saturation was reached. In-depth statistical analysis was completed. Limitations: Setting of study was never listed making it hard to generalize the

							results or apply to another situation.
Carrion, I. V., Nedjat-Haiem, F. R., Martinez-Tyson, D., & Castañeda, H. (2013).	IIC	Purposive sampling used to recruit Latina women who self-identified as Colombian, Mexican, or Puerto Rican and resided in Central Florida. Participants were recruited from community health clinics, churches, cultural centers, and cancer support groups.	45 Latina women	Qualitative grounded theory design to address the lack of literature regarding ACP and decision making patterns among Colombian, Mexican, and Puerto Rican women. This study explored cultural perceptions and identified factors that facilitated ACP completion within this specific population.	60-90 minute in-depth, semi-structured interviews composed of broad and open-ended questions. Interviews were conducted at locations that were convenient for the women.	Four themes developed: lack of knowledge of ACP, a shared decision making approach, lack of information and informal ACP, and a key concern of decision making. While there is a disconnect between knowledge regarding the term ACP among these women, discussions regarding this topic still occurred. These women need the influence of family in their decisions and this highlights the need for further research involving their family members. Higher levels of education point to a larger	Not specific to CKD. Discusses great cultural barriers to using and implementing ACP in a culturally diverse population. Stresses need to continue to educate this group to improve knowledge and AD completion. Strengths: Data analysis was completed in both English and Spanish. Research team consisted of both English and Spanish individuals.

						percentage of completion of ADs and ACP conversations. The number of years one has been in the United States also influences their ability to complete an AD.	Limitations: Use of purposive sampling. Specific to Colombian, Mexican, and Puerto Rican women with cancer which greatly limits the generalizability of the results. Data saturation never discussed. Validity and reliability of research methods were not discussed.
Collins, M., & Lehane, E. (2013).	IIIB	Convenience sample of adult patients receiving hemodialysis that attended a dialysis unit at an acute hospital in Ireland. Had received	50 participants.	Non-experimental descriptive cross-sectional study design to determine the views of Irish patients receiving hemodialysis on	Pre-defined questionnaire using closed-ended questions with a 5-point Likert scale response	In regards to ACP, patients wanted honest opinions from their doctors. Patients wanted some involvement in decision making at the end-of-life; however, they also wanted medical interventions to keep	Specific to CKD. Stresses necessity of ACP and giving patients honest opinions near the end-of-life. Family is important to these patients as they near the end-of-life.

		hemodialysis for a minimum of three months, had to be able to read and understand English, and were 18 years of age and older		death, dying, and ACP		them around as long as possible. Family members play an important role in the patient's lives, but they are not necessarily comfortable discussing end-of-life issues with them.	<p>Strengths: Descriptive statistics used to summarize results.</p> <p>Limitations: Results limited to one dialysis unit. Results limited to patients from Ireland. Further statistical analysis is needed to determine the significance of the results. Reliability and validity of study questionnaire not discussed.</p>
Feely, M. A. Swetz, K. M., Zavaleta, K., Thorstein-	IIA	Adult patients 18 years of age and older who received hemodialysis at a single outpatient	91 patients participated in specialist palliative medicine consults	Quasi-experimental study to determine the feasibility of embedding palliative	Specialist palliative medicine consultations performed by two board-certified	Patients were well-receiving of these discussions and preferred to complete them during dialysis. After intervention,	Specific to those with CKD. Shows importance of palliative medicine consults.

sdottir, B., Albright, R. C., & Williams, A. W. (2016).		center between January 1, 2012 and June 30, 2012		medicine consultations into the outpatient hemodialysis setting and to determine the impact of this intervention on ACP and symptom management	physicians and occurred during a routine hemodialysis run. A chart review was completed both before and after the intervention to determine documented ADs, code status, and goals of care.	54 patients had a documented goals of care discussion ($p < 0.0001$). Number of patients electing a full code status increased after the intervention ($p < 0.0001$).	<p>Effective if implemented during hemodialysis treatments.</p> <p>Strengths: Large sample size. In-depth statistical analysis completed. Discussed validity and reliability of measures used.</p> <p>Limitations: Purposive sample used. Study took place at only one hemodialysis center. No control group. Lack of randomization.</p>
Goff, S. L., Eneanya, N. D., Feinberg, R.,	IIIB	Purposive sampling from dialysis units in Massachusetts	13 patients and 9 family or friends were interviewed	Qualitative grounded theory design to investigate how dialysis teams	Interviews conducted by study team members. Interviews	Three emerging themes: prior experiences with ACP, factors that may affect	Specific to CKD. Involved both patients and family members. Study identified a

<p>Germain, M. J., Marr, L., Berzoff, J., . . . Unruh, M. (2015).</p>		<p>and New Mexico. Participants were invited to bring up to two family members or close friends to also participate.</p>	<p>during 15 sessions</p>	<p>should discuss ACP</p>	<p>were conducted until theoretical saturation was reached.</p>	<p>perspectives with ACP, and recommendations for ACP. Themes revealed that ACP discussions rarely occur yet most patients and families desire them, patients desire a better connection with their nephrology team, and that health care providers should lead ACP discussions at least annually.</p>	<p>need for an interview guide specific to dialysis patients or those with CKD.</p> <p>Strengths: Interviews were conducted until theoretical saturation was reached. Validity of interview guide was assessed prior to implementation.</p> <p>Limitations: Although theoretical saturation was reached, the small sample size might have prevented additional themes from being exposed. Interviews were</p>
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							conducted in only two states, which may limit the generalizability of these results.
Harrison, K., & Watson, S. (2011).	IIB	Recruited from a nephrology clinic. Patients had previously chosen conservative management for CKD or were in need of decision-making support. Clinic took place in a renal satellite hospice unit during October 2008 – October 2009.	18 patients were seen for a total of 50 consultations over the time period of one year	Quasi experimental design to investigate the effects of a nurse-led palliative care clinic on patients with CKD stage five and their carers	Nurse-led monthly educational palliative care clinic (led by a hospice nurse and a renal palliative care nurse) aimed to provide optimal symptom management, empower patients to make their own choices, and to support them in ACP	Patients found the clinic to be helpful to help appropriately manage the underlying condition and symptoms with a continuity of care. Patients were exposed to palliative care earlier on in the disease process than commonly occurs. Patients felt supported, had an opportunity to make ACP decisions with family present. Family caregivers reported a better understanding of the disease, felt more prepared for the future, and less anxious.	Specific to CKD. Generally the clinic was well-evaluated. Involved patients both before dialysis initiation and while receiving dialysis therapy. Involved patients and family members. Strengths: 75% of surveys were completed after the intervention. Limitations: Small sample size. Six patients died during the course of the

							study. Statistical analysis of study results not shown or discussed. Validity and reliability of intervention and post-survey not discussed.
Kataoka-Yahiro, M. R., Yancura, L. A., Page, V., & Inouye, J. (2011).	IIIB	Purposive sample of Asian-Pacific Islanders recruited from a dialysis center located in Oahu, HI. Had to be family caregivers for patients receiving hemodialysis for CKD stage four and stage five. Data was collected between May 2009 and	14 Asian-Pacific Islander family caregivers of persons receiving hemodialysis	Qualitative grounded theory study design to describe the attitudes, subjective norms, and perceived behavioral control among Asian-Pacific Islander family caregivers of those receiving hemodialysis for CKD stage four and stage five	Four focus group sessions held at the dialysis center that lasted one hour to 90 minutes.	Completion of ACP and ADs are associated with peace of mind and ease of making future decisions. It also prevents burden, minimizes family disputes, and allows family members to see problems ahead of time. Most family members desired to feel comfortable with ACP and ADs so that they were able to carry out patient wishes and not be a burden to his or her family.	Specific to CKD. Discussed benefits of ACP on family members. Shows necessity of involving family members in ACP and end-of-life care, especially in the Asian-Pacific Islander population. Strengths: Data was collected until theoretical saturation was reached. Two authors read and

		September 2009.				Family is first and primary in decision making.	analyzed focus group transcripts. Limitations: Purposive sample used from one dialysis center. Sample taken from one state. Need for more quantitative research in this area to determine true cultural barriers and resource implications. Validity and reliability of focus group questions not discussed.
Kirchhoff, K. T., Hammes, B. J., Kehl, K. A., Briggs, L. A., &	IIC	Two health centers in Wisconsin with associated clinics and dialysis units	153 participants in the control group (64 with ESRD, 90 with CHF). 160 participants	Quasi experimental post-test only design to compare patient preferences for end-of-life care with care	Patient centered ACP interview with patient and family members lasting between one	In CPR, 43.5% of the intervention patients had outcomes matching their initial preferences. However, almost one-third of patients	Study not specific to patients with CKD. Involved patients and family members. Results indicate that intervention

<p>Brown, R. L. (2012).</p>			<p>in the intervention group (70 with ESRD, 90 with CHF). Patients and family members were recruited as pairs.</p>	<p>received at the end-of-life</p>	<p>and one and a half hours.</p>	<p>changed their mind about CPR preferences. For patients with ESRD, more intervention patients than control (37.7% versus 17%) chose to withdraw from dialysis.</p>	<p>patients may choose fewer life-sustaining interventions near the end-of-life, but the differences were not shown to be statistically significant.</p> <p>Strengths: Study looked at patients with two common chronic illnesses. Post-test only study design used to determine effect of intervention.</p> <p>Limitations: Potential effects of the study could have been reduced due to patient death (110 patients died before the end of the study).</p>
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							Study was completed only in one state and involved only those with ESRD and CHF (great limit on generalizability). Statistical analysis of study results not shown or discussed. Validity and reliability of intervention not discussed.
Luckett, T., Sellars, M., Tieman, J., Pollock, C. A., Silvester, W., Butow, P. N., . . . Clayton, J. M. (2014).	IB	55 articles reporting on 51 discrete samples included (7 intervention records, 48 other records). Sample included adults with CKD and/or families caring for this group of	Not listed in the meta-synthesis	Meta-synthesis using both quantitative and qualitative designs to identify what interventions have been developed, piloted, and evaluated in regards to ACP in patients with CKD, to identify	Studies used a variety of methods – teaching sessions, videos, telephone interviews, printed materials, and face-to-face education with physicians.	Two studies found ACP to have a significant effect on both patient-clinician communication and interaction. One study increased AD completion rates. In one study, 76% of nephrologists were in favor of an ACP intervention while 70% of patients	Specific to CKD. Both qualitative and quantitative studies were included in this review. This study was the first meta-synthesis to focus on ACP in those with CKD. Findings were not found to be

		<p>patients (44 articles involved patients with CKD and 6 articles involved families/care-givers). All patient samples included people with CKD stage 5 and 2 articles included patients with CKD stage 4. 5 articles took place in the inpatient setting while 24 articles involved the outpatient setting. 35 articles took place in the United States.</p>		<p>what measures have been used in intervention and other research studies, to establish evidence for the efficacy of interventions, and to inform understanding of barriers and facilitators to implementation of ACP.</p>		<p>found an AD pamphlet helpful. No studies found a significant effect for patient/surrogate decisional conflict. However, two studies found a significant effect for congruence between patient wishes and surrogate knowledge of those wishes after an ACP intervention.</p>	<p>significant across multiple studies.</p> <p>Strengths: Comprehensive approach to ACP that focused on patient, caregiver, and system related factors. Most research in regards to ACP and CKD has been descriptive in nature and this meta-synthesis followed this.</p> <p>Limitations: Key search terms were not listed in the study description. Data extraction was completed by only one researcher. No studies included measured</p>
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							compliance with patient wishes for end-of-life care. Only one intervention study demonstrated the effect on patient and family outcomes. None of the intervention studies looked at the effect of ACP on bereaved family members.
Nicholas, L. H., Langa, K. M., Iwashyna, T. J., & Weir, D. R. (2011).	IIIA	Health and Retirements Study respondents who died between 1998 and 2007 at age 65 years or older after qualifying through Medicare through disability or	3302 decedents	Non-experimental descriptive cohort study to examine the relationship of ADs with the cost and aggressiveness of end-of-life treatment in the United States	Post-mortem interview conducted with next-of-kin. Asked about the decedent's experience at the end-of-life, including the nature and type of their AD. Chart review	Those with treatment-limiting ADs had lower rates of life-sustaining treatments (p = 0.02), lower rates of in-hospital death (p < 0.01), and higher rates of hospice use (p < 0.01). Those with ADs were more likely to be white, affluent, and highly educated. Decedents	Not specific to CKD but does discuss those with ESRD. Strengths: Large sample size. Studied Medicare decedents throughout the United States. Large amount of statistical analysis.

		ESRD. Had to be enrolled in fee-for-service Medicare during the last six months of life			calculated Medicare spending in the last six months of life across all care settings	residing in low-spending regions were more likely to have treatment limiting ADs ($p < 0.01$). End-of-life spending was lower for decedents in low-spending regions than those in higher spending regions.	Limitations: Non-experimental design limits ability to determine casual effect.
Oczkowski, S. J., Chung, H., Hanvey, L., Mbuagbaw, M., & You, J. J. (2016).	IA	67 articles obtained from studies conducted in the ambulatory setting (included 47 qualitative only studies for future review, 19 ICU-based studies, 18 inpatient, non-ICU studies, and 20 educational studies)	Not listed in this meta-synthesis	Meta-synthesis using both qualitative and quantitative study designs to determine the effect of structured communication tools for end-of-life decision making on completion of ADs in the ambulatory care setting	Variety of interventions examined: verbal discussion alone, paper tools alone, verbal discussion combined with paper tool, and computer programs	Interventions were associated with a statistically significant increase in frequency of ACP discussions ($p = 0.007$) and frequency of completion of ADs ($p < 0.001$). For patients who died throughout the course of the studies, the communication tools were associated with a statistically significant increase in the congruence of	Not specific to patients with CKD. Showed great benefits of using structured communication tools to improve frequency of ACP and acceptability of these discussions with patients and family members. Looked at the effect of ACP with family members.

						<p>care desired by patients ($p = 0.004$). Communication tools reduced patient's desire for life-sustaining treatments but was not statistically significant ($p = 0.02$). Knowledge of family members was enhanced with the use of structured communication tools ($p < 0.001$). All studies found communication tools to be equally or more acceptable than usual care.</p>	<p>Strengths: Involved both qualitative and quantitative studies targeted to ACP. Showed importance of ACP for patients with cancer, lung disease, heart disease, neurologic disease, and renal disease. In-depth description of study methodology and data extraction methods. Two separate authors were used to screen studies. Discussed a wide variety of interventions to use as communication tools.</p>
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							<p>Limitations: Studies limited to those in ambulatory settings. Even despite statistically significant findings, many studies were found to be of low-quality when appraised.</p>
<p>Song, M., Ward, S. E., Fine, J. P., Hanson, L. C., Lin, F., Hladik, G. A., . . . Bridgman, J. C. (2015).</p>	<p>IB</p>	<p>Recruited from 20 outpatient dialysis centers in 8 counties in North Carolina between March 2010-December 2012</p>	<p>420 participants from 20 dialysis centers. Patient and family members were recruited as pairs (intervention group n = 109, control group n = 101)</p>	<p>RCT that examined the efficacy of an ACP intervention on preparation for end-of-life decision making for dialysis patients and surrogates and for surrogate's bereavement outcomes</p>	<p>Intervention group took part in a psycho-educational intervention (Sharing Patient's Illness Representations to Increase Trust [SPIRIT]). SPIRIT consists of two sessions. All sessions</p>	<p>Congruence in goals of care for both patients and surrogates was higher in those who participated in the SPIRIT intervention at two and six months, but the effect was not significant across all time points. Patient decisional conflict decreased over time in those who participated in SPIRIT (p = 0.01).</p>	<p>Specific to CKD. Involved both patients and family members. Results show that patient and surrogate congruence may not be sustained over time, which shows the need for ongoing intervention with this group.</p> <p>Strengths: This is the first trial to</p>

					<p>included both patient and family members.</p>	<p>Surrogate decision making confidence scale scores were high at all time points. The SPIRIT intervention effects on congruence and surrogate decision making confidence score were statistically significant at $p = 0.03$ and $p = 0.03$ respectively. However, the effect of dyad congruence was significantly decreased at 12 months ($p = 0.04$) for those in the intervention group. Depression scores in those who were part of the SPIRIT intervention were significantly lower at 3 months and 6 months ($p = 0.01$).</p>	<p>show effects of bereavement outcomes of surrogates of patients with ESRD. This is the only RCT to demonstrate positive effects in a sample with African Americans.</p> <p>Limitations: 45 persons died during the study. Study was conducted in a single United States region. Data collection methods were not clearly described in the article. Validity or reliability of the instruments used was not fully discussed.</p>
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<p>Waite, K. R., Federman, A. D., McCarthy, D. M., Sudore, R., Curtis, L. M., Baker, D. W., . . . Paasche-Orlow, M. K. (2013).</p>	<p>IIIA</p>	<p>Adults aged 55 to 74 were recruited from an internal medicine clinic or one of four federal health centers in Chicago between August 2008 and November 2010.</p>	<p>784 adults were included in analysis (two-thirds of the participants were female)</p>	<p>Non-experimental descriptive correlational study design to examine the effect of the relationship between literacy and other individual-level factors on having an AD</p>	<p>Face-to-face structured interviews with a trained interviewer, completed for 4 hours divided over 2 days</p>	<p>Literacy skills were strongly associated with having an AD – 12.4% with low literacy, 26.6% with marginal literacy, and 49.5% with adequate literacy ($p < 0.001$). Race was also associated with having an AD – African Americans 22.9%, white 57.2% ($p < 0.001$). Other factors associated with AD completion include older age, higher education, higher income, part-time employment, and fewer chronic health conditions.</p>	<p>Study not specific to patients with CKD. Strong statistically significant correlation between health literacy and having an AD. Suggests need to target the population of patients with a lower health literacy.</p> <p>Strengths: In-depth statistical analysis completed. Large sample size. Looked at multiple variables other than just health literacy.</p> <p>Limitations: No reliability or</p>
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							validity of interview questions discussed. Participants in this study were mainly African American and Caucasian.
Walton, J. (2011).	IIIB	Non-randomized convenience sample of college students. Participants were primarily Caucasian; ages ranged from 18 to 45 with a majority of the participants ages 22 years and female	95 college students (65 were enrolled in a health science course from a liberal arts college in the rural Northwest; 30 student nurses attending a Montana nursing association conference)	Mixed methods design involving quantitative and qualitative study designs. Quantitative component involved a pre- and post-survey to assess if there was a statistically significant difference in the knowledge and cultural awareness of students following an educational intervention by a	60 minute educational presentation based on research findings from a study entitled <i>Prayer Warriors: A Grounded Theory Study of American Indians Receiving Hemodialysis</i>	Students can learn cultural awareness to Native Americans receiving dialysis and apply cultural interventions following an educational session. Five themes emerged from the case study findings: approaching the patient with an open mind, assessing beliefs and culture, educating and re-educating with the patient and family, convincing the patient to begin	Specific to Native Americans with CKD. Shows importance of cultural awareness when working with the Native American culture. Shows a brief educational period can enhance the relationship between a patient of another culture and a health care provider. Strengths: Sufficient sample

				<p>nephrology nurse. Qualitative component involved students writing a reflection paper of a case study of a young Native American patient with CKD.</p>		<p>dialysis, and creating a sacred space.</p>	<p>size for the study design. Involved two methods of assessing cultural barriers to providing care to the Native American population. Intervention was based off of a prior research study.</p> <p>Limitations: Sample population was a non-randomized convenience sample of students from two different settings. Sample was primarily female and around the same age. Pre- and post-survey was developed from the findings of</p>
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							another research article. Reliability and validity of this instrument was never discussed.
White, B., Tilse, C., Wilson, J., Rosenman, L., Strub, T., Feeney, R. & Silvester, W. (2014).	IIIB	National sample of the Australian adult population (aged 18 and above) conducted between August and September 2012	2405 individuals agreed to be interviewed with 50% being female	Non-experimental cross-sectional descriptive prevalence study to determine the prevalence of ADs in the Australian population	National telephone survey	Only 14% of respondents had prepared an AD. Respondents with a financial EPA were almost nine times more likely to have an AD than those without. Respondents with a living will were 2.5 times more likely than those without to have an AD. Respondents who were either single or not in a legally recognized relationship were 1.7 times more likely than those who were married to have an AD.	Results not specific to those with CKD. Strengths: Equal representation of males and females. Diverse age of sample. In-depth statistical analysis was completed. Limitations: Study was completed in only one country. Low response rate to telephone survey. Small sample size in comparison to entire population.

							Only discussed ADs and not other legal documents.
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Appendix H: Approval Letter to Use Iowa Model

Permission to Use and/or Reproduce The Iowa Model (2015)



Jordan, Kimberly (Nursing) <kimberly-jordan@uiowa.edu>

Today 12:16 PM

Hinders, Chelsea Ann - SDSU Student ✕



Reply all | ▾



Action Items



You have permission, as requested today, to review/use *The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care (The Iowa Model Collaborative. (In review). The Iowa Model Revised: Development and Validation.*) Click the link below to open the model.

Copyright of *The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care* will be retained by The University of Iowa Hospitals and Clinics.

Permission is not granted for placing the Iowa Model on the internet.

[The Iowa Model - 2015](#)

In written material, please add the following statement:

- *Used/Reprinted with permission from the University of Iowa Hospitals and Clinics. Copyright 2015. For permission to use or reproduce the model, please contact the University of Iowa Hospitals and Clinics at (319)384-9098.*



If you have questions, please contact Kimberly Jordan at 319-384-9098 or kimberly-jordan@uiowa.edu.

Appendix I: Approval Letter to Use Renal Physicians Association Guideline

RE: Use of Clinical Practice Guideline in DNP Project



Shalice Smedley <ssmedley@renalmd.org>
Tue 4:05 PM
Hinders, Chelsea Ann - SDSU Student

  Reply all | 

Inbox

Good afternoon Ms. Hinders.

Our director, Dale Singer, has granted permission to use the questions from the RPA publication **Shared Decision-Making in the Appropriate Initiation of and Withdrawal of Dialysis**. We ask that RPA is cited properly in your project.

If you have any questions, please do not hesitate to contact our director at 301-468-3515 ext. 11.

Thank you.

Shalice Smedley
Administrative Coordinator
Renal Physicians Association
1700 Rockville Pike, Suite 220
Rockville, MD 20852
P – 301-468-3515 ext. 10
F – 301-468-3511
E – ssmedley@renalmd.org

Appendix J: Pre-Intervention Knowledge Assessment

Advance Care Planning for Patients with Chronic Kidney Disease

Answer the following questions below before your discussion with the health care provider.

1. An advance directive is a document that:
 - Expresses an individual's medical wishes when that person is unable to speak for him- or herself
 - Determines who will handle one's financial affairs after death
 - Explains one's rights as a patient
 - I don't know

2. Advance directives go into effect if an individual:
 - Gets admitted to the hospital
 - Has a terminal medical condition
 - Can no longer communicate his or her health care decisions
 - I don't know

3. In general, the best person to serve as an individual's health care surrogate is the person who:
 - Has the most knowledge
 - Is best able to represent the individual's views
 - Has known the individual the longest
 - I don't know

4. Of the following, which is least important for a patient to do regarding advance care planning?
 - Discuss their values and wishes regarding end-of-life care with trusted family members and friends
 - Create an advance directive that explains their goals of care
 - Provide their physician(s) with the advance directive
 - Use a state-specific living will form

5. Advance care planning is a one-time process and does not need to be revisited during the course of a patient's life.
 - True
 - False

6. If an individual has decision-making capacity and can still speak for him- or herself, an advance directive does NOT determine which medical treatments they will receive.
 - True
 - False

(Adapted from Green & Levi, 2011)

Appendix K: Post-Intervention Knowledge Assessment

Advance Care Planning for Patients with Chronic Kidney Disease

Answer the following questions below after your discussion with the health care provider.

1. An advance directive is a document that:
 - Expresses an individual's medical wishes when that person is unable to speak for him- or herself
 - Determines who will handle one's financial affairs after death
 - Explains one's rights as a patient
 - I don't know

2. Advance directives go into effect if an individual:
 - Gets admitted to the hospital
 - Has a terminal medical condition
 - Can no longer communicate his or her health care decisions
 - I don't know

3. In general, the best person to serve as an individual's health care surrogate is the person who:
 - Has the most knowledge
 - Is best able to represent the individual's views
 - Has known the individual the longest
 - I don't know

4. Of the following, which is least important for a patient to do regarding advance care planning?
 - Discuss their values and wishes regarding end-of-life care with trusted family members and friends
 - Create an advance directive that explains their goals of care
 - Provide their physician(s) with the advance directive
 - Use a state-specific living will form

5. Advance care planning is a one-time process and does not need to be revisited during the course of a patient's life.
 - True
 - False

6. If an individual has decision-making capacity and can still speak for him- or herself, an advance directive does NOT determine which medical treatments they will receive.
 - True
 - False

(Adapted from Green & Levi, 2011)

Appendix L: Intervention Tool

Advance Care Planning for Patients with Chronic Kidney Disease

Advance care planning is a communication process that takes place between the patient, family member or close friend, and/or the health care provider. The patient’s preferences for future medical care is decided. Read and discuss the questions below with a family member, close friend, or health care provider. Write your wishes on the lines below. Keep a copy for your records and return the completed form to a clinic staff member.

- If you become unable to make decisions for yourself, whom do you want to make decisions for you?

- If you had to choose between being kept alive as long as possible regardless of personal suffering or living a shorter time to avoid suffering and medical procedures such as breathing machines and feeding tubes, which would you pick?

- Under what circumstances, if any, would you want to stop dialysis?

- Under what circumstances, if any, would you not want to be kept alive with medical means such as cardiopulmonary resuscitation, a feeding tube, or mechanical ventilation?

- Where do you prefer to die and whom do you wish to be with you when you die?

(Renal Physicians Association & American Society of Nephrology, 1999; AHRQ, 2015)

Patient Signature: _____ Date: _____

Notary Signature: _____ Date: _____

Appendix M: Informal Letter of Invitation

Dear patient:

I, Chelsea Hinders, am conducting a project entitled "*Implementation of an Advance Care Planning Discussion for Patients with Chronic Kidney Disease*" as part of a Doctor of Nursing Practice project at South Dakota State University. The purpose of the project is to implement a standardized process of advance care planning specific to patients with chronic kidney disease stages four and five in an urban outpatient setting.

You as a patient are invited to participate in the project by actively participating in a discussion during your office visit with a nephrology Nurse Practitioner and completing a test before and after the discussion. We realize that your time is valuable and have attempted to keep the requested information as brief and concise as possible. It will take you approximately 30 to 40 minutes of your time. Your participation in this project is voluntary. You may withdraw from the project at any time without consequence.

There is minimal risk to you for participating in this study. An advance care planning discussion collects information about sensitive goals of care issues and asks questions that could possibly cause psychological distress, discomfort, and anxiety beyond what is experienced in daily conversation. As a participant, you will have the option of not answering any questions which you find upsetting.

The benefits to you include having a document that states your exact wishes for your goals of care in your medical record. Your health care provider and family members or caregivers will also be made known of your wishes and will be able to carry out your desires should the time arise. Your responses are strictly confidential. When the data and analysis are presented, you will not be linked to the data by your name, title or any other identifying item. Please assist us in our project and participate in the discussion with the nephrology Nurse Practitioner and complete a test before and after the discussion.

Sincerely,

Chelsea Hinders
nephrologyacp@gmail.com
605-610-9039

- I agree to participate
- I decline to participate

Appendix N: Informed Consent Form

**Sanford Health
Consent to Participate in a Study**

Title: *Implementation of an Advance Care Planning Discussion for Patients with Chronic Kidney Disease*

Principal Investigator: Chelsea Hinders

What is the purpose of this study?

The purpose of this study is to implement a standardized process of advance care planning specific to patients with chronic kidney disease stages four and five in an urban outpatient setting.

What will happen during this study?

As a participant in the study, you will participate in a discussion regarding end-of-life wishes and care with a Nurse Practitioner. Your family members and/or those who are with you today will also be asked to participate in the conversation. Five specific questions will be used to guide the conversation. Your answers will be written down and placed into your electronic medical record to reference at future appointments and during future hospitalizations. Your answers can be changed at any time and the questions can be answered at a future date. This study will serve as a facilitator of end-of-life discussions and will help guide your future health care.

Your participation in the study will last during this office visit only. No return appointments specific to this study will be required. Participation in the study will take approximately 30 to 40 minutes of your time.

What are the risks of the study?

There may be some risk from being in this study but any risk for participating is not expected to be more than risk experienced in everyday life. An advance care planning discussion collects information about sensitive goals of care issues and asks questions that could possibly cause psychological distress, discomfort, and anxiety beyond what is experienced in daily conversation. As a participant, you will have the option of not answering any questions which you find upsetting.

What are the benefits of this study?

You may not benefit personally from being in this study. However, we hope that, in the future, other people might benefit from this study by having exact end-of-life wishes documented clearly in an electronic medical record. Care at the end-of-life will be enhanced and individual patient wishes will be upheld during this difficult time.

What are the alternatives to participating in this study?

The alternative is to not participate in this study.

Are my records confidential?

While we cannot guarantee absolute confidentiality, we will use all available security measures to minimize the risk that this information would be given to someone outside of the study. Your study record may be reviewed by the Sanford Institutional Review Board (IRB) and Sanford Research Compliance.

If we write a report or article about this study, we will describe the study results in a summarized manner so that you cannot be identified. Confidentiality will be maintained by means of de-identifying personal data. Any personal information collected will be stored in a locked filing cabinet in the clinic only accessible by the project coordinator, the nursing staff, and the Nurse Practitioner.

An Electronic Medical Record (EMR) is an electronic version of the record of your care within a health system. An EMR is simply a computerized version of a paper medical record. If you are receiving care or have received care at Sanford (outpatient or inpatient) and are participating in a Sanford study, results of related procedures (i.e. laboratory tests, imaging studies and clinical procedures) may be placed in your existing EMR maintained by Sanford. The completed advance care plans will be placed into your EMR to be accessible by health care providers and staff during future office visits and hospitalizations.

Is this study voluntary?

Your participation is voluntary. You can choose not to participate or you may stop your participation at any time without penalty or loss of benefits to which you are otherwise entitled.

Your decision whether or not to participate will not affect your current or future relations with Sanford Health.

Who can I talk to?

You may ask any questions you have now or later.

If you have questions, concerns, or complaints, or think the study has hurt you, talk to the team at (605) 610-9039 or nephrologyacp@gmail.com

For this study you must be 18 years of age older to consent to participate in this study.

Your signature documents your permission to take part in this study.

 Signature of subject

 Date

 Printed name of subject

Signature of person obtaining consent

Date

Printed name of person obtaining consent

Appendix O: Project Procedure Algorithm

Advance Care Planning Procedure Algorithm

RN/LPN to print NP schedule each AM



RN/LPN and NP determine which patients are eligible to receive the intervention (CKD stages four and five, GFR less than 30 mL/min/1.73 m²). Place an asterisk on the printed schedule next to each who is eligible to receive the intervention. Place printed schedule by the clinic receptionist.



Clinic receptionist to give each eligible patient an informal letter of invitation at the time of registration



While rooming the patient, RN/LPN collect informal letter of invitation from all patients with marked response (I agree to participate or I decline to participate). If patient agrees to participate, RN will then ask patient if he or she has an advance directive document. If patient does not, then give and collect informed consent form from patient. Administer pre-assessment knowledge test to patient after completing rooming activities. Keep all forms in collected in locked filing cabinet.

(Continue through care as usual if patient already has an advance directive.)



RN/LPN report off to NP whether patient has an advance directive document. NP to implement intervention using the five question tool if patient does not have an advance directive. NP collect form from patient if completed during the clinic visit and give to RN/LPN. Clinic manager to notarize document. Copy completed document. Scan to medical records. Send copy to medical records. Keep original in locked filing cabinet. RN to administer post-assessment knowledge test to patient after the discussion. Keep assessment documents in locked filing cabinet. NP to document in clinic note regarding discussion.

** (If intervention tool is returned at a later date, follow same instructions above for scanning to medical records.) **