

THE IMPACT OF A PRE-END STAGE RENAL DISEASE EDUCATION INTERVENTION  
ON CENTRAL VENOUS CATHETER PLACEMENT IN THOSE INITIATING DIALYSIS:  
A QUALITY IMPROVEMENT PROJECT

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## ABSTRACT

Heather Boykin: The Impacts of a Pre-End Stage Renal Disease Education Intervention on Central Venous Catheter Placement in Those Initiating Dialysis: A Quality Improvement Project  
(Under the direction of Meg Zomorodi)

Chronic kidney disease (CKD) continues to be a growing public health problem. Education focused on time-sensitive objectives, specifically vascular access preparation for dialysis, must be addressed to avoid unnecessary complications and poor outcomes. Therefore, the purpose of this project was to study the potential impact of a patient education intervention to decrease the placement of central venous catheters in patients initiating dialysis. The project focused specifically on informing and encouraging patients, through education, to plan for and obtain optimal methods of vascular access in advance of the need for hemodialysis.

Ten adult patients with CKD in stage four or five were recruited through an outpatient nephrology office. Individuals participated in a face-to-face, one hour, pre-established education session provided by an expert nurse practitioner, and structured based upon the Centers for Medicare and Medicaid standards. Interview-style questionnaires were administered pre-session, immediately after, and four weeks following the education. Outcomes related to the effectiveness of the session and vascular placement were obtained.

All participants found the session either ‘helpful’ or ‘the reason’ for decision making regarding dialysis modality choice and access planning. Half commented that the session specifically addressed their knowledge of kidney disease, its progression and treatment options, and risks associated with central venous catheter use. Of the 10 patients, 2 indicated that they had

non-catheter access placed prior to the education class; 4 patients were referred for vascular access placement; and 2 patients elected peritoneal dialysis and therefore did not need vascular access placement.

A timely, pre-ESRD education session focused on dialysis modality selection and vascular access planning has the potential to reduce central venous catheter placement in those initiating dialysis. Future exploration is needed, on a larger scale, to identify the impact of an education session on patient outcomes.

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## LIST OF ABBREVIATIONS

AVF	Arteriovenous fistula
AVG	Arteriovenous graft
CKD	Chronic kidney disease
CMS	Centers for Medicare & Medicaid Services
CVC	Central Venous Catheter
ESRD	End-stage renal disease
GFR	Glomerular filtration rate
HBM	Health belief model
MIPPA	Medicare Improvement for Patients and Providers Act
NKDEP	National Kidney Disease Education Program
NKF	National Kidney Foundation
NKUDIC	National Kidney and Urologic Diseases Information Clearinghouse
RRT	Renal replacement therapy
TOPS	Treatment Options Program classes
USRDS	United States Renal Data System

## INTRODUCTION

Chronic kidney disease (CKD) patients approaching end stage renal disease (ESRD) are often not completely informed of, or educated on their disease severity, likelihood of disease progression, and treatment options (Branson, 2007). This absence of early education has been implicated as a cause of significant psychological trauma for patients and families, which additionally adds to the burden of their disease and contributes to poor and potentially fatal health outcomes (2007). Consequently, patients with less knowledge about the treatment options for ESRD may be more likely to initiate dialysis with less than optimal vascular access such as a central venous catheter (CVC) (2007).

The National Kidney Foundation (NKF) has established practice guidelines regarding the stage of disease during which education regarding treatment and vascular access options should be offered. Additionally, Centers for Medicare Medicaid Services (CMS) has published guidelines that specify who can provide the kidney disease education, when it should be offered, and what topics the education session must cover in order to be gain reimbursement for services utilizing CMS billing codes. Despite detailed guidelines and recommendations, pre-ESRD education is still not consistently part of every patient's care plan. Due to the lack of pre-ESRD education, these patients are more likely to be less informed about their modality choices, as well as vascular access options, and thus more likely to initiate dialysis with a catheter. Practice patterns that are lacking in preparatory patient education may be contributing to the high rate of catheter use; a reality that unfortunately is associated with poor outcomes for patients.

A 2006 study published in the American Journal of Kidney Disease found those who initiate dialysis with a catheter had a three times greater risk of mortality than those who dialyze with a fistula or graft (Allon et al., 2006). More specifically, patients using CVCs for dialysis access experience a 38% increased risk of a major cardiac event and more than double the risk of fatal infection (Ravani et al., 2013). The highest morbidity and mortality exists in hemodialysis patients dialyzing with CVCs when compared with arteriovenous fistulas (AVF) and arteriovenous grafts (AVG) (Asif, Merrill, Leon, Ellis, & Pennell, 2006).

In addition to the medical complications associated with CVCs, there is significant cost attributed to the care that one requires for the treatment of these complications. The average cost to the healthcare system for catheter related bloodstream infections is \$4,000 to over \$80,000 per incident, per patient (Bakke, 2010). Catheter related bloodstream infections are significant health problems which lead to increased hospitalizations, mortality and morbidity, as well as the previously mentioned financial burden on the healthcare system (2010). Furthermore, infection related complications caused by catheters may also lead to deterioration or decline in other medical conditions, which leads to additional healthcare costs.

An intensified approach to reduce catheter use began in 2003 as a joint effort between the Centers for Medicare & Medicaid Services and various ESRD networks. As an outcome of this joint effort, the Fistula First Initiative was born which called for timely evaluation and placement of AVFs. A primary goal of this initiative was to exceed the initial standards set forth by the NKF, specifically related to increasing the placement of AVFs for primary vascular access (Lok, 2007; NKF, 1997). Despite the successes of this initiative, there continues to exist a disproportionately high number of patients initiating dialysis with CVCs. Thus, CVCs continue to be the focus of many policymakers, healthcare executives and national renal disease networks.

CVC use is proven to be associated with exponentially higher risks of blood stream infections, cardiovascular complications and even death, as well as higher utilization of healthcare services and increased costs. Due to the costs and complications associated with CVCs, providers should focus more on preemptive patient education and planning to facilitate patient obtainment of more stable options for vascular access and thus avoid the use of CVCs.

It is hypothesized that pre-ESRD education has the potential to reduce the burdens of disease progression and improve health outcomes (Branson, 2007). More so, vascular access options education is potentially one of the most important tools in assisting patients to understand the benefits and potential consequences of the choices for access (Asif et al., 2006). In order to understand these benefits and consequences, people with advanced disease need early, frequent, focused education and planning for dialysis modality selection and vascular access planning. Pre end-stage renal disease education can facilitate this planning and thus potentially improve outcomes related to increased patient satisfaction with care and modality selection, and also decrease patient experience of negative outcomes and medical complications related to catheter use. Therefore the purpose of this quality improvement project was to explore the effect of a pre-ESRD patient education intervention focused on dialysis modality selection and vascular access planning and the incidence of central venous catheter placement for those making the transition to ESRD and dialysis.

## CHAPTER 1

### BACKGROUND & SIGNIFICANCE

CKD is a public health problem fraught with poor outcomes and astounding healthcare costs (Narva et al., 2010). Furthermore, the statistics regarding life expectancy, disease related complications, quality of life and healthcare dollars consumed are deeply shocking. According to the NKF (2013), 26 million Americans have some form of kidney disease. These estimates further conclude that 1 in 10 American adults are estimated to have CKD (USRDS, 2013). A large portion of people may not know that they have CKD, and others may not be aware of their risk for the disease (NKF, 2013).

The risks for CKD are greater when particular comorbidities are present. Various epidemiological studies have validated the increased risk for CKD in those with autoimmune disease, a history of certain environmental or pharmacological exposures, neoplasia, systemic infections, urinary tract infections, diabetes and hypertension, for example (NKF, 2013).

Diabetes and hypertension are the two most common causes of CKD in the United States, and are responsible for 72% of new cases of kidney disease (CDC, 2014). In fact, 1 in 3 adults with diabetes and 1 in 5 adults with hypertension have CKD (2014).

Along with comorbidities, certain demographics such as race and age are correlated with an increased risk. With regards to race, people of African American, Native American, Asian and Hispanic decent are associated with an increased incidence of CKD (NKDEP, 2014). Advancing age also significantly increases the risk for CKD (2014). The incidence is increasing most

rapidly in those who are 65 years of age or older (NKUDIC, 2012). The incidence of CKD has doubled from the year 2000 to 2008 in those aged 65 years or older (2012). For all populations affected by this disease, an insurmountable increase in the death toll has been realized secondary to the rising incidence and health related effects of this disease.

In order to gauge the severity and progression of the disease, formulas are used to estimate the glomerular filtration rate (GFR); or percentage of kidney function which remains. There are 5 progressive stages of CKD (NKF, 2000). During stages 1 through 4, the focus of treatment is on slowing disease progress and on management of comorbidities. The patient is often managed by the primary care provider, ideally in concert with yearly nephrology follow up, during these initial stages.

There is typically no discussion or planning for vascular access during stages 1 through 4 unless the patient is progressing quickly toward stage 5 or end-stage disease, where GFR is 15ml/min or less. This current model of practice goes against the recommendations by the NKF Kidney Disease Outcomes Quality Initiative (NKF, 2013) which states that education on dialysis modalities and permanent dialysis access should occur for those with a GFR less than 30ml/min. Therefore, practice patterns must change, specifically as they relate to earlier education, beginning at stage 4 disease when the GFR is 30ml/min or less. Furthermore, education should continue to focus on slowing disease progression but also should focus earlier on preparation for end stage disease, treatment options and access planning. Unfortunately the literature demonstrates that the window of opportunity for planning and education in stage 4 CKD is not consistently utilized due to a number of proposed barriers.

Barriers to education in the CKD community included time constraints and economic pressures that are placed on nephrologists in today's healthcare system (Branson, 2007).

Additional barriers include lack of skill to educate patients and a shortage of staff and time to support educational efforts (Wright-Nunes, 2013). A lack of motivation to teach, lack of space and privacy to teach, an absence in reimbursement for patient education, and the perception that education is not effective are also identified as barriers (Branson, 2007).

Beyond understanding the clinical markers of kidney disease and its progression, illness trajectories of chronic organ disease are helpful and important in understanding how the disease unfolds, and especially the physical and psychosocial impacts on the patient and those otherwise involved in the patient's life. The trajectory of illness for those with CKD is similar to that of other chronic organ diseases (Lunney, Lynn, & Hogan, 2002). Lunney, Lynn and Hogan (2002) offer four trajectory descriptors that are pertinent in the context of describing CKD and its relative course of progression beyond the clinical stages described previously. The description of this chronic organ disease trajectory is interwoven with the clinical stages of CKD in order to offer both a clinical, physiological and psychosocial perspective on the stages of progression.

In the first trajectory, sudden death occurs without prior diagnosis or symptoms (Lunney et al., 2002). This trajectory is representative of the portion of CKD patients who are undiagnosed or lost to follow up. Many may not have timely access to health care or the financial means to be evaluated; others may simply remain unaware that an underlying condition is inflicting great havoc on their bodies. Another portion of patients may not have been screened or diagnosed by their attending providers, as CKD is known to be overlooked in the early stages (Snyder & Pendergraph, 2005). In fact, approximately 30% to 50% of patients initiating dialysis were thought to have unrecognized kidney disease, specifically early disease, and thus experienced late referral to a nephrology specialist (Arora et al., 1999).

The second trajectory encompasses the diagnosis of chronic kidney disease, and is followed by a period of medical treatment and lifestyle modifications to preserve health related quality of life and functional status (Lunney et al., 2002). Within this trajectory, which may include stages 1 through 4 of chronic kidney disease, it may be likely or rather ideal that the patient is closely followed by a nephrology specialist. A patient may be educated on their diagnosis, prognosis and treatment options at this time. The focus of care is typically on controlling comorbidities such as hypertension and diabetes. The secondary disease trajectory concludes with rapid decline in function in the advancing stages of CKD.

The third disease trajectory is characterized by repeated acute episodes of illness, requiring hospitalization and is inclusive of a significant, progressive decline in functional status with each episode (Lunney et al., 2002). This trajectory represents further progression of disease, usually the clinical kidney disease stage 4 and approaching stage 5, which signals that end-stage kidney disease is nearing. The progressive and often unpredictable trajectory of CKD requires that thorough education and planning should occur between the transition from Stage 4 to Stage 5, in order to ready the patient for likely transition to dialysis (Villano, Scourick, & Williams, 2001).

Specifically at this time, a focus on vascular access options for hemodialysis is imperative (Villano et al., 2001). Thus, this project focuses on providing patient education during Stage 4 of this trajectory of illness. As mentioned previously, the NKF guidelines also recommend education and planning when GFR < 30 mL/min., however actual practice habits have been found to differ greatly. In addition to education and planning, the patient and provider are likely preparing for modification in living arrangements to meet the patient's needs, such as an increased level of care, or a planned transition to dialysis, transplant, or palliative

care/hospice. This third trajectory should be understood to include also the final stages of CKD which represents the transition to end-stage disease and dialysis. Stage 5 or ESRD is the expected outcome of CKD.

Many patients in Stage 5 with ESRD may emergently initiate renal replacement therapy (RRT) in an acute hospital setting. Often in this scenario, the patient is suffering from life-threatening conditions such as fluid volume overload and uremia. In this situation, patients commonly rely on temporary means for dialysis access, a CVC, rather than more stable options such as an AVF or AVG (Cavanaugh, Wingard, Hakim, Elasy, & Ikizler, 2009); the issue of which remains a primary focus of this project and its education intervention.

Although this final trajectory does not include a transition to dialysis, this fourth chronic organ disease trajectory represents a clinical picture that is more typical of older persons who are already in a poor state of function (Lunney et al., 2002). Gradual, yet progressive, decline towards death is characteristic of this trajectory (2002). This decline may represent clinical cases where dialysis or transplant have been deemed as options which are not likely to improve the patient's quality of life and/or functional status, nor are these options considered to be safe options for an older person in an already declining state. Preparation for end of life care, palliative care and advanced directives are often a central focus in this trajectory. Since palliative care should also be an option offered to patients, the patient education offered during this project included discussion on the offers a focus on the option of 'no treatment' as it relates to dialysis, along with discussion on the benefits of palliative and/or hospice care.

As discussion related to access options is of the greatest need for patients with CKD, the primary focus of the education component of this quality improvement project was to provide clarification to patients about their treatment options, with specific focus on the strengths and

weaknesses of each access option in order for the patient to make an informed decision about their treatment plan.

### ACCESS OPTIONS

The optimal standard for vascular access for those pursuing hemodialysis is an AVF (Allon et al., 2006; Lacson, Lazarus, Himmelfarb, Ikizler, & Hakim, 2007; NKF, 2000). This type of access requires a surgical procedure during which time a surgeon will join a vein to an artery inside the patient's arm. The naturally high rate of blood flow through the artery carries increased blood flow to the adjoined vein, which causes strengthening and enlargement of the vein. After an average of 2 to 3 months for healing or maturation of the AVF, the now stronger and enlarged vein, functions as an optimal site for needle access for hemodialysis (NKUDIC, 2012). Two needles are placed in to the patient's arm; one needle which carries blood from the patient to the dialysis machine to be cleaned and depleted of extraneous fluid volume; the other needle which carries the cleaned blood back to the patient (NKDEP, 2014; NKF, 2013; NKUDIC, 2012). Use of an AVF for dialysis access affords the patient a longer lasting access, which is associated with multiple benefits and reduced risks of clotting or infection (Asif et al., 2006; Lacson et al., 2007)

Another potential option for vascular access is very similar to the AVF, but involves a prosthetic tube which is surgically placed as the connection between an artery and vein within the patient's arm. The product of the installation of this plastic tube is called an AVG; a vascular access option which is deemed appropriate for a patient who does not possess the appropriate or ideal vascular anatomy for an AVF. AVGs are associated with an increased risk of clotting and infection compared to AVFs (NKUDIC, 2012). AVGs also do not provide the same longevity in years of repeated use, however if properly cared for AVGs can function as a reliable dialysis

access for many years (2012). As previously mentioned, there are very time sensitive factors when referring a patient for an AVF or AVG, as there is an unavoidable period of time which is required for adequate healing of the access before it may be used. Due to the sensitivity of this timeframe and other confounding variables such as inadequate patient follow up with the nephrologist, patients may find they are without an AVF or AVG at the initiation of hemodialysis, and instead may be reliant on a CVC for dialysis access. This overall lack of preparation and absence of reliable vascular access for dialysis represents a suboptimal transition to the next phase of care, and a significant risk to the patient's health and well-being; which again reinforces the need for early treatment options education and vascular access planning. Regardless of the reason for CVC placement, the potential complications associated with CVC use are nothing less than serious and may often prove fatal. Part of the complications that CVCs pose is related to their placement location.

A CVC is a long, flexible, synthetic tube inserted through the skin and tunneled under the tissue. CVCs are placed in a large vein in the chest, neck or groin. Commonly, in a case which the CVC is placed in the chest, the tip of the catheter tubing terminates in the right atrium of the heart. As a portion of the CVC remains external, there exists a convenient pathway of travel for problematic bacteria to enter the central circulation, potentially becoming resident vegetation on cardiac valves. The literature provides varying statistics describing how many people initiate dialysis with a catheter, but ultimately, even when under the care of a nephrologist, more than 40% of patients began dialysis with a CVC (Arramreddy, Zheng, Saxena, Liebman, & Wong, 2014). Ideally, patients should obtain more reliable and less risky options for vascular access than the CVC; an outcome that pre-ESRD education and access planning aims to produce.

Patients using CVCs for access to their blood for hemodialysis have the highest risk for death, infections and cardiovascular complications when compared to patients who are not using CVCs (Asif et al., 2006; Ravani et al., 2013; USRDS, 2013). In addition, CVCs are associated with lower blood flow rates, poorer toxin removal during dialysis, endocarditis, spinal complications leading to paralysis, and the development of central venous stenosis and frequent episodes of thrombosis (2006). Considering benefits of AVFs and AVGs versus the serious risks associated with CVCs, many may wonder why catheter use continues and in such a large number of those initiating dialysis.

Dr. Allen Nissenson, Chief Medical Officer for a nationwide dialysis organization, succinctly identifies the common reasons why patients may start dialysis with a catheter, which include: inadequate care during the early stages of renal disease, resistance by patients to vascular access planning and placement, inadequate surgical results, and insufficient focus by nephrology providers for AVF or AVG placement (Nissenson, 2013; Zumoff, 2013). Pre-ESRD patient education should bridge the gap in care by exploring the patient's perception of their disease, addressing their beliefs and background knowledge of their disease, and offering a quality, timely and tailored education program which informs them and encourages them to be active in their decision making and their care plan. Therefore the purpose of this project will focus on the education that is provided on the transition to dialysis, treatment options and related vascular access options and planning.

## CURRENT PRACTICE PATTERNS

### PRE-ESRD EDUCATION

As a result of an extensive review of the literature focused on educational programs for pre-ESRD care, it is clear that a scant amount of evidence is available to support the design of such programs. However, CKD care programs, in addition to improving pre-ESRD care, have

proven to significantly reduce medical services utilization and associated healthcare costs (Wei et al., 2010). A study published by Cavanaugh and colleagues (2009) in the Clinical Journal of the American Society of Nephrology suggests that greater patient knowledge about dialysis is associated with increased likelihood that they will use an AVF or AVG when initiating dialysis. Furthermore, Asif and colleagues (2006) underscore that vascular access options education is potentially one of the most important tools in assisting patients to understand the benefits and potential consequences of the choices for access.

Programs with the most success in CKD education are implemented early in the trajectory of CKD. Fresenius Medical Care, North America reports success with their Treatment Options Program (TOPs) (Mollicone, Pulliam, & Lacson, 2013). Fresenius Medical Care developed their TOPs program in response to consistent observations that a large number of patients initiating dialysis were mostly unaware of their treatment options (2013). The TOPs program is a face-to-face meeting offered to patients with stage 3 and stage 4 CKD. The program focuses on dialysis modality choices and options for vascular access and offers this education at pre-specified intervals where the repeated education can be tailored to the patient needs (2013). Although the program is sustainable, reliable, and reports positive outcomes for patients, the major barrier to its complete success is late referral of patients to the program (2013). Therefore it was imperative, prior to and throughout this project, to gain and maintain the understanding, buy-in and enthusiasm of all stakeholders in the practice, such that referrals for the program would be made and would occur at an earlier stage of disease which is more amenable to affecting future outcomes.

Subsidiary companies such as WellBound in California offers pre-dialysis and CKD education programs with a focus directed toward educating patients to elect 'self-care dialysis'

otherwise known as home dialysis therapy (Branson, 2007) rather than focusing specifically on selection of a modality and planning for access options. A limitation of this type of education program is that it is focused on the company product and service rather than a non-biased focus on all of the renal replacement therapies and related vascular access. In order to truly educate patients, one must provide a non-biased approach and offer all available options.

The literature fails to address how CKD care programs affect patient satisfaction, as there has been little to no focus on collecting patient satisfaction data. Few studies have collected data on patient satisfaction regarding dialysis modality choice, and even fewer have focused efforts to evaluate the impact of CKD education programs on overall patient satisfaction with their care. The literature only speculates that CKD education programs have the potential to improve patient satisfaction, but there have been insufficient efforts made to move beyond speculation.

#### EARLY REFERRAL PRECEDES EDUCATION

As an adjunct to patient education, another part of the solution may also depend upon timely patient referral by primary care providers to nephrology care providers (Finkelstein et al, 2008). According to the United States Renal Data System's annual data report (2013), 42% of patients who began dialysis in 2011 were not seen by a nephrologist prior to initiation of dialysis. Of those not seen by a nephrologist, over 50% began dialysis with a catheter (2013). Despite late referral to a nephrology provider, patient education regarding vascular access options and their associated risks must still be provided (Asif et al., 2006). Early referral to nephrologists by primary care providers and a subsequent early referral to vascular surgeons for fistula placement are felt to be some of the most important interventions to avoid CVC use (Haddad, Van Cleef, & Agarwal, 2012). Therefore, a focus of this intervention was to encourage the nephrology stakeholders practicing at this project site, to engage in timely referral of new and established

patients to receive the pre-ESRD education intervention. Furthermore, an additional focus of this project was to determine if patients had previously been referred to a vascular surgeon or already had an access placed, and to guide patients in their decision making of these services.

Present findings suggest that even in patients seen by nephrologists, the levels of patient perception of knowledge about CKD and therapeutic options for ESRD are still limited (Finkelstein et al., 2008). A very limited number of studies have found particular, brief, physician-delivered education interventions to be endorsed by CKD patients (Wright-Nunes, 2013), however there is little to no focus on the patient view of and desires for their CKD and pre-ESRD care. Therefore, it is important to encourage patients to talk about their desires for vascular access and to discuss preferences for access from their own perspectives; all of which is characteristic of the pre-ESRD education intervention offering within this project.

Further investigation of the benefits of education in pre-ESRD care is needed, as well as focused investigation on timing, frequency and format of education initiatives. This project focused specifically on the potential benefits of pre-ESRD education and its impact on reducing CVC use by encouraging patients to plan for and obtain less complicated and risky types of vascular access in advance of the need for hemodialysis. Furthermore, this education intervention and related efforts aim at reducing the incidence of complications and even fatal outcomes associated with CVC use in those initiating hemodialysis.

While pre-ESRD education has the potential to offer many advantages to the patient and additionally reduce medical complications, costs and utilization, there is little implementation of these patient education programs. The literature suggests this lack of implementation is due to certain barriers to effective education such as time constraints and economic pressures placed on nephrologists in today's healthcare system (Branson, 2007). Less of an emphasis is being placed

on quality patient education along with the time required to provide such an important service. Additional barriers identified in the literature include lack of skill to educate patients and a shortage of staff and time to support educational efforts (Wright-Nunes, 2013). In addition, lack of motivation to teach, lack of space and privacy to teach, an absence in reimbursement for patient education, and the perception that education is not effective are also identified as barriers (Branson, 2007). The barriers to pre-ESRD education and the gaps which have been identified in the literature were of priority consideration, especially as they relate to the design, plausibility and applicability of the education module.

## CHAPTER 2

### CONCEPTUAL FRAMEWORK

The health belief model was chosen to guide this education intervention and project because it uniquely addresses why patients choose to adopt or reject health behaviors or aspects of a plan of care. The application of this model to pre-ESRD education allows for the exploration of a patient's motivation for change, need for information or knowledge, and particular aspects of decision making which may facilitate behavior change. Advanced practice nurses, as educators, utilize the health belief model to guide teaching, tailor the education to the patient's unique needs and thus appropriately guide patients for change.

#### ASSUMPTIONS, CONCEPTS AND CONSTRUCTS

The health belief model is commonly found in the literature as it pertains to patient compliance and education. Assumptions of the HBM are based on the belief that an individual will take action on their health if they:

1. Feel that they can avoid a negative condition
2. Believe that by taking a recommended action for their health, they can actually avoid a negative condition
3. Believes that they actually can succeed in completing a recommended health action (Twente, 2014).

There are four major constructs of the health belief model, which represent patient perceptions; constructs which are intricately interwoven into the education of pre-ESRD patients (Roth, 1984). Roth (1984) examines how the health belief model can be specifically used to

address the patient perceptions of CKD and suggests how each construct can be addressed to aid patient education and ultimately in slowing disease progression:

- Perceived susceptibility—perception of personal vulnerability to kidney disease. According to Roth (1984), helping patients to understand that they have a realistic probability of progressing is key.
- Perceived severity—evaluation of medical and social consequences. It is important for patients to understand that their disease has consequences that will affect their health and social life. However, in some cases even when patients over-estimate the likelihood of their kidney disease to progress, they still do not change their behaviors. Furthermore, there is no evidence to suggest that increasing fear is an effective strategy in motivating patients to change their behavior. Roth (1984) concludes that it is necessary but not sufficient for patients to be simply aware of the impact on their health and social life, but rather, the risks need to be presented in a way that raises awareness, but does not paralyze the patient.
- Perceived benefits of action—perception of feasibility and efficacy of adopting preventative and more appropriate health related behaviors to slow the progression of their CKD.
- Perceived barriers—perceptions of action / health related behavior as expensive, dangerous, unpleasant, inconvenient, or time-consuming.

#### LIMITATIONS

A particular criticism of the health belief model is that it cannot easily be tested, nor is it quantifiable; leading to difficulty in providing a direct link to health beliefs and behaviors

(Rankin & Stallings, 1996). The model does, however, continue to serve as a valuable guide to practitioners in planning their health education programs (Narva, 2009), as it guides practitioners to understand why patients maintain certain health related behaviors.

Due to the lack of research focused on the topic of patient education in pre-ESRD, there is also little in the way of theoretical framework discussion as it relates to the education rationale. However, there are theories related to patient education in chronic disease management which are relevant although not of obvious focus in the pre-ESRD education literature. Especially as they relate to chronic disease, the health behavior theories, specifically the health belief model, are important bases for education in health behavior change (Butts & Rich, 2011).

#### USE OF THE HBM FOR CKD PATIENTS

The HBM can guide future education, planning and coordination regarding the types of behavior change necessary to slow the progression from CKD to ESRD (Roth, 1984). Additionally, use of the health belief model in the context of pre-ESRD education may be used to empower patients regarding treatment options decision-making (1984). By systematically utilizing the four constructs of the model, providers may more appropriately develop an approach to working with patients who are at risk for ESRD by first understanding the important and often pivotal perceptions that patients hold and the barriers that they believe are in the way of their progress (Roth, 1984).

Theory-based strategies for patient education will improve the effectiveness of the provider as an educator and keep the CKD patient at the center of the process, thus decreasing ambivalence and resistance to decision-making (Porter, Watson, & Bargman, 2013). A crucial part of this project is the use of the health belief model to identify and address the patient's perceptions of their disease, and to guide behavior which allows for avoidance of serious

complications specifically related to vascular access planning for dialysis. Furthermore, the use of the health belief model within this education intervention will facilitate the identification of barriers and misconceptions related to treatment options and planning. Rather than delivering information and opinion to the patient and directing them to make treatment related decisions which are based solely on the provider's perspective, the health belief model guides the provider in a way that maintains the patient at the center of learning and decision making.

## CHAPTER 3

### RESEARCH METHODOLOGY

The overall purpose of this project was to explore the impact of pre-ESRD patient education on decreasing the rate of central venous catheters in those patients initiating dialysis. Ten adult patients with CKD in stage 4 or 5 were recruited for this study through an outpatient nephrology office. Individuals participated in a face-to-face, one hour, pre-established education class. The education was created and provided by a nurse practitioner with expertise in the field, and structured based upon the CMS standards for CKD education. The education was inclusive of various topics related to kidney disease, as well as treatment and vascular access options. An interview style questionnaire, based upon the HBM, was completed at the beginning of the session and afterwards. The medical record was reviewed to determine if surgical referral or vascular access placement was achieved. Participants were interviewed by phone 4 weeks after their education session to discuss their desire for access options and to evaluate the impact of the education session on their decision-making.

#### EDUCATION MODULE AND QUESTIONNAIRE CREATION

The education module was created by a nurse practitioner with over 15 years of experience in nephrology, who also works at the implementation site. The structure and content of the education module was based upon the CMS standards for CKD education for beneficiaries of Medicare, and is presented as a PowerPoint presentation. CMS requires that the education program be offered during a face-to-face meeting, and must be provided by a qualified provider. CMS identifies qualified providers of this education to be physicians, physician assistants, nurse

practitioners or clinical nurse specialists (CMS, 2009). Furthermore, the education program must cover the topics of disease management, methods for preserving renal function and delaying the need for dialysis, prevention of complications related to uremic toxicity, all options for renal replacement therapy, as well as vascular access options (2009). Although these standards apply specifically to the education for Medicare patients, the structure and provision of this education module is certainly useful for all patients with CKD, not just Medicare beneficiaries.

An interview-style questionnaire was completed with the patient prior to, immediately after and 4 weeks post education session. Prior to its use and after content validity testing, the questionnaire was revised for improved readability and understanding based on the experts' feedback. The interview questionnaire was based upon the HBM, and the questions were aimed at gathering information about the patient's perceptions of their illness, their understanding of their disease as well as their education needs; all of which was aimed at optimally tailoring the pre-ESRD education to the patient's needs.

#### CONTENT VALIDITY TESTING OF QUESTIONNAIRE

To determine if the questionnaire addressed all of the components of the HBM as well as aspects of decision making in CKD, content validity was tested. Participants were recruited from academic medical center settings as well as an outpatient nephrology practice in order to provide a heterogeneous sample of experts. A total of 4 experts were recruited and participated in this phase of the study. The panel consisted of two currently practicing nephrology nurse practitioners, a PhD prepared researcher and nursing faculty member, and a PhD prepared nurse faculty with expertise in academic and patient education. The questionnaire was sent via email in a content validity format where a score could be selected for each question based upon the perceived level of validity. The experts were asked to review each set of questions, score them

for content validity and include detailed feedback. The expert panel returned the questionnaire via email within one week of receipt. An average score was calculated and the resulting score determined that the questionnaires met standards for content validity and relevance. Based on the recommendations of the content experts, the questionnaire was revised for use in the implementation phase of this study. All of the questions were modified to simplify language, remove complex or abstract terminology, improve readability and add terms which implied a focus on the patient, their disease and baseline knowledge of their disease, rather than a focus on general knowledge or perceptions of kidney disease. No questions were deleted from the questionnaire. The final questionnaire is presented as Appendices 1 through 3.

#### SETTING

The implementation of this project took place in a private, outpatient nephrology clinic in the Eastern United States. The nephrology practice holds a physician staff of 11, as well as 5 nurse practitioners and 1 physician assistant. The practice provides comprehensive, inpatient and outpatient care and treatment of kidney disease and hypertension. The practice also provides care for patients requiring renal replacement therapies such as peritoneal dialysis, hemodialysis and renal transplant. The practice sees approximately 1000 patients per month with a variety of CKD stages. To the benefit of the patients of this nephrology clinic and also to the aims of this project, a pre-ESRD education program was already well established in this clinic. An education schedule also existed, prior to project implementation, in which patient appointments were already arranged. Patients were referred and scheduled secondary to order by the attending nephrology physician.

## SAMPLE

A convenience sample of 15 patients was intended for this project. No recruitment strategies were needed as the patient sample had been referred, as part of their standard care plan, to receive the education session. Pre and post session interview style questions and 4 week post education follow up were also standard of care, therefore requiring no recruitment or consent for participation. Inclusion criteria included: diagnosis of stage 4 CKD, participation in a face-to-face, one hour education class completed by a nephrology nurse practitioner; and completion of a pre/post and 4 week post, interview-style questionnaire. Exclusion criteria included non-English speaking patients without family or associates available to translate, as translation service or personnel are not currently available at the practice site. No identifiable patient information was recorded for use outside of the electronic health record.

## CHAPTER 4

### RESULTS

Out of the 10 patients seen during the 10 week implementation and data collection period, 8 patients were of African American descent, 1 patient was of Hispanic descent, and 1 patient was Caucasian. There were 3 females and 7 males in this sample with ages ranging from 35 to 76 years. It is important to underscore the fact that a majority of the sample was of African American descent. Although the African American population is known to have an increased risk for developing kidney disease, what is not well known is specific implications for pre-ESRD education in this population; representing a fully recognized need for further study.

Pre-education survey results showed that upon their initial diagnosis of kidney disease: 3 patients spoke with relatives about their diagnosis, 1 patient completed an internet search on topics related to kidney disease, 1 patient spoke with a friend on dialysis, and the remaining 5 patients reported that they did not seek information from any person or resource upon their initial diagnosis. When asked about their education needs regarding their kidney disease, 9 patients reported that they needed information on everything related to their disease, and more specifically desired information on how they would feel on dialysis and if travel would be possible. One patient reported that she had questions related to the material she had researched on her own, specifically related to transplant. She reported that she did not desire further information on dialysis options as her primary goal was to receive a renal transplant. However, a family member accompanying the patient to the education session did request a full review of the dialysis options, and this was completed by the nurse practitioner. When asked who assists the patient in making medical

decisions, 9 out of 10 patients reported that family assists with decision making. One patient reported that she makes all decisions on her own and without consultation with other persons. When the patients were asked about their understanding of their kidney disease, 8 out of 10 patients reported that diabetes and high blood pressure had damaged their kidneys. Two patients reported that they didn't understand how or why their disease occurred. Upon review of the medical record, documentation was reviewed which detailed than an explanation of the etiology of the patients' disease had been presented by the physician upon initial diagnosis. Furthermore, it appeared that continued discussion had occurred during follow up appointments. Re-education specific to the causes of kidney disease in these patients was completed by the nurse practitioner during the education session.

During the education session, patients and families listened to the education presentation and frequently asked questions throughout the presentation. While explaining the objectives of the education session, the nurse practitioner informed the patient and family members that they should feel free to interject or ask questions as they arise. Patient and families asked questions regarding their current laboratory values, current stage of kidney disease and also estimated time to requiring dialysis. They also commonly inquired as to the types of symptoms which may be experienced as kidney function declines. Family members or caregivers frequently asked about signs which would indicate that the patient may need emergency attention or hospitalization. All of the attendees remained very engaged in the education module, asked questions and commented on their experiences living with kidney disease.

As part of the post-education survey, all patients were asked how many additional education sessions they desired, and 8 out of 10 patients declined additional sessions. Two out of the 10 patients reported that additional education would be helpful, specifically to include

additional family members that were not present during the session. When asked about their treatment options preference, 8 out of 10 patients stated they would elect to have dialysis. Three patients reported peritoneal dialysis as their modality of choice. Interestingly, 1 of the 3 patients choosing peritoneal dialysis had previously elected to have hemodialysis and had also obtained a permanent access prior to the session. The participant reported that peritoneal dialysis had not been discussed as an option, and stated that the information received during the education session had been the impetus to changing their modality choice due to peritoneal dialysis allowing for more independence and the preference for no needles. The remaining 5 patients selected hemodialysis as their preferred modality choice. At the conclusion of the data collection period, 2 patients remained undecided on their choice for treatment, both stated that they needed more time to consider the options and declined further education sessions. Patients were also asked what had helped them to choose a dialysis modality and to pursue vascular access placement. All 10 patients responded that the education session had been either 'helpful' or was 'the reason' for decision making regarding dialysis modality choice and access planning. Five of the ten patients specifically commented that the information presented improved their understanding of kidney disease, its progression and treatment options, as well as the risks associated with CVC use. When asked about their understanding of the risks associated with central venous catheters, all 10 patients reported that catheters cause infection and death. Eight of the ten patients specifically stated that they wanted to avoid the complications associated with catheters.

At the four week follow-up, 3 patients had a vascular access placed and 1 patient was awaiting surgery. Two patients had vascular access placed prior to the education session. Two patients had selected peritoneal dialysis as a modality and therefore did not require vascular access. Two patients remained undecided as to the treatment options choices. One patient who had,

previous to the education session, decided upon hemodialysis had changed her mind to consider peritoneal dialysis as an option. No other patients changed their minds regarding modality choice or vascular access plan.

Forty percent of patients received non-catheter vascular access placement subsequent to completion of the education session; the conclusion of which clearly shows that 40% of patients completing the education session are more likely to initiate hemodialysis without a central venous catheter and instead with an AVF or AVG. These results suggest and even demonstrate the potential of a pre-ESRD education session to decrease the rate of central venous catheter placement in those initiating dialysis.

## CHAPTER 5

### DISCUSSION

The primary purpose of this project was to study the potential impact of this patient education intervention to decrease the placement of central venous catheters in patients initiating dialysis. The education session covered a range of topics, however the project focused specifically on informing and encouraging patients to plan for and obtain less complicated and risky methods of vascular access in advance of the need for hemodialysis.

The literature has emphasized the wide ranging benefits of patient education in general, and specifically suggests the potential of pre-ESRD patient education to decrease the rate of CVC use in those initiating dialysis. However, the literature is largely void of evidence which aims to demonstrate the benefit of pre-ESRD education. The theoretical frameworks which are foundational to patient education speak to the power of assessing and addressing the patient perception of their disease and their susceptibility to complications, and providing timely, and comprehensive education. Yet, widespread, publicized initiatives to change practice patterns are lacking.

By directing the patient toward a treatment choice or desired behavior without comprehensive and focused consultation and education, the provider has neglected to put the patient at the center of the decision making process and has essentially excluded the patient from the conversation; all of which translates to a frank denial of the patient's rights. By placing the patient at the center of their care and decision making, and focusing on improving their understanding of the disease, medications, complications and behaviors, barriers are removed,

reducing the likelihood of treatment related complications and adherence issues. The HBM also supports the preceding statement. As a result of this project, the benefits, impacts and potential of pre-ESRD education in reducing CVC placement has further validated the need for more patient centered education in the clinical setting. This project has also substantiated the plausibility of offering a dedicated education program in the outpatient, private practice setting.

### IMPLICATIONS FOR PRACTICE

Nurse practitioners can be instrumental in changing the current practice patterns related to the education of CKD patients by incorporating this pre-ESRD education in to their practice. The nurse practitioner has the training to assess the patient's knowledge deficits, perceptions, readiness for change, abilities and needs, environment, personality, and lifestyle. Thus, nurse practitioners are capable of providing patient-centered information which is delivered in a way that is specifically tailored to the patient's preferred method of learning; a delivery approach that may ultimately empower patients for medical decision making (Key, 2008). As the nurse practitioner guides the patient through education to becoming a more active problem-solver, it changes the role of the provider from a controller to more of an advisor or coach (Rankin & Stallings, 1996). The Doctorate of Nursing Practice (DNP) advanced practice nurse is uniquely prepared for translating evidence in to practice, gaining collegial support for change, and in transforming the business logistics of the practice environment to incorporate new services which are beneficial to patients. It should be considered the ethical duty of the advanced practice nurse to review the evidence as it relates to pre-ESRD education, be aware of the guidelines and move forward with determination and intention to mandate this education within his or her practice environment.

Furthermore, nurse practitioners fully recognize the worth and importance of diverse perspective and efforts of the multidisciplinary team in taking care of patients, and thus eagerly request the participation of our physician colleagues, social workers, dieticians and clinician staff to provide high quality education and care. It will be as a team that we accomplish the positive outcomes which our patients so desperately need and desire.

#### LIMITATIONS

Limitations of this project include convenience sampling, small sample size and an abbreviated implementation and data collection period. Additionally, there were patient cancellations and no-shows for the education session which further affected the size of the sample. The education session was only offered once weekly which may have also contributed to sample size. Physician referral to the education program was also not ideal; the reasons for which will require further exploration, as this was the standard of care. Furthermore, there were no translation services available for non-English speaking patients which presented a challenge for their inclusion. Non-English speaking patients were therefore required to have family or associates who were able and willing to provide translation.

#### FUTURE WORK

In consideration of the implications for future exploration of this topic, it will be preferable to have the luxury of an extended implementation and data collection period, which may potentially span months to years and include follow up of patients after their transition to dialysis. Follow-up extending beyond dialysis initiation may provide evidence that the benefits of pre-ESRD education extend well beyond stage 4 CKD. A larger and more diversified sample size may also certainly improve the validity of this project's conclusion. Future work should focus on a comparison between patients who did and did not receive pre-ESRD education,

especially with regards to vascular access at the time of dialysis initiation. Further exploration of methods to increase physician stakeholder buy-in and patient referral to the program may also be a highly productive focus. A crucial need for future exploration of the implications for pre-ESRD education in the African American and Hispanic population has also been fully recognized. Furthermore, a system for providing education for non-English speaking patients will certainly require extensive focus.

Additional implications for future research include the exploration of factors which influence patient and family attendance for the education session, as well as investigation of potential barriers to offering this education in the practice setting. Additional areas to explore would be the reason behind cancellations and patients who did not reschedule. Future work will be dedicated to learning more about the barriers that patients face when it comes to attending this education session. In the future, call ahead appointment reminders by the nurse practitioner may help to reinforce to the patients and families the importance of the meeting. This pre-appointment contact may also provide time for introductions and time to inform and clarify the basic objectives of the session. To additionally assist in improving attendance, consideration will be given to providing food or snacks prior to or during the session. Furthermore, particular interest in barriers unique to age, race and gender will also drive future research pertaining to pre-ESRD education.

It may also prove beneficial to explore opportunities for chronic kidney disease education in the primary care setting, in an effort to educate patients earlier in their disease trajectory prior to nephrology referral. Further exploration of the roles of advanced practice nurses in affecting change in practice patterns, especially as they relate to pre-ESRD patient education, would likely provide useful insight to how the discipline may further utilize the advanced skill set of the DNP

nurse practitioner to increase awareness of the issue; potentially spawning nursing research and encouraging nurse led authorship related to this issue.

Exploration of innovative technologies to provide patient education is also needed to potentially expand the methods by which education may be offered. What also remains is the need for research, which focuses on CKD patient learning needs and desires, as well as perceptions of CKD education, and the outcomes of such interventions. Again, further investigation on a larger, more in-depth scale is paramount to changing practice; resulting in evidence which is required to adequately understand the relationship between pre-ESRD education and the placement of vascular access versus CVC use.

In conclusion, a timely, pre-end stage renal disease, education class focused on dialysis modality selection and vascular access planning has demonstrated the potential to reduce central venous catheter placement in those initiating dialysis, by encouraging preminent placement of an arteriovenous fistula or graft. The tremendous benefits of this education are clear and far reaching. Nephrology providers should be aware of the benefits of this education and increase practice-wide and specialty-wide initiatives to set standards for education and exceed them.

APPENDIX 1: PRE EDUCATION QUESTIONS

<b>Please evaluate the following interview questions by selecting a content relevance score:</b>	
<b>Pre Education Questions</b>	Content Relevance (circle your choice)
<p>After receiving the news that you have kidney disease, did you search for more information about it? Where did you search or with whom did you talk for more information? Family, friend, pastor, internet, library, other? Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>
<p>What type of information do you feel that you need to help you understand more about kidney disease? Lifestyle, lab numbers, diet information, treatment options, vascular access, life expectancy, complications, kidney function, keywords, what to do next... Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>
<p>Who assists you in making medical decisions? Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>
<p>What is your understanding of kidney disease? Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>

## APPENDIX 2: POST EDUCATION QUESTIONS

<b>Post Education Questions</b>	Content Relevance (circle your choice)
<p>What type of information do you feel that you still need to help you understand more about the disease? Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>
<p>How many additional education sessions do you think you need? Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>
<p>After completing this education session, are you leaning more toward a certain type of dialysis and/or a certain type of vascular access for dialysis (graft, fistula, and catheter)? Tell me more about what has helped you to make this choice? Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>
<p>What is your understanding of the complications and risks associated with catheters used for hemodialysis? Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>

APPENDIX 3: 4 WEEK FOLLOW UP QUESTIONS

<b>4 Week Follow Up Questions</b>	Content Relevance (circle your choice)
<p>Have you changed your mind about your decision to have dialysis? Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>
<p>Have you changed your mind about the type of dialysis that you selected? If so, tell me more about what influenced you to change your mind. Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>
<p>How has the education session influenced your decision making? Suggestions for changes:</p>	<p>1 = Not relevant 2 = Unable to assess or in need of so much revision that it would no longer be relevant 3 = Relevant but needs minor revision (suggestions please) 4 = Very relevant and succinct</p>

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