The development of the dialysis decisions patient education program: an evidence-based nursing practice quality improvement project

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The Development of the Dialysis Decisions Patient Education Program

An Evidence-Based Nursing Practice Quality Improvement Project

Trish Carter

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Abstract

Chronic illness is one of the biggest challenges in health care today. Chronic Kidney Disease (CKD) is a worldwide health problem and is escalating at an alarming rate in the United States. CKD affects 26 million people or one in nine adults in the US. There is growing evidence in the literature that early recognition and treatment of CKD helps in the prevention and progression of this devastating disease. Globally as well as in the US, this condition remains under-diagnosed and under-treated resulting in lost opportunity for early intervention and prevention. This evidence based practice quality improvement project has identified a need within a university medical center setting for CKD education which will result in a business plan for the creation and implementation of a comprehensive modality education program. The Corbin and Strauss chronic illness trajectory model, a framework for understanding the pervasive effects of this disease on patients’ lives, has guided how the program was developed and presented. The anticipated outcome of the educational program is to provide the knowledge needed for the patient to make an informed decision regarding modality options. A decision tool was used to assist in evaluating the patients’ perception of the modality decision making process.
The Development of the Dialysis Decisions Patient Education Program

Introduction

Performance Improvement & Evidence-Based Practice

Performance improvement (PI) and evidence based practice (EBP) are two of the most important strategies for improving clinical performance of healthcare systems (Brown, 2006). EBP is the use of current research evidence combined with clinical expertise and patient values to formulate sound interventions (DiCenso, Guyatt, Clinska, 2005). The use of EBP closes the gap between research outcomes and practice and improves the quality of patient care (Newhouse, Dearbolt, Poe, Pugh, & White, 2005).

This EBP project utilized the FOCUS-PDCA performance improvement process to impact a problem identified at a university medical center. Performance improvement is defined as a continuous process of ongoing measurement and evaluation with the intended goal to improve quality care (Redick, 1999). FOCUS-PDCA was developed to provide a model for improving processes and is used to identify, measure, and address problem areas and implement improvements. This structured model is research-based and has been proven in many settings within healthcare and outside industries. The model’s name is an acronym that describes the basic components of the improvement process. The steps include:

F - Find a process to improve
O - Organize an effort to work on improvement
C - Clarify current knowledge of the process
U - Understand process variation and capability
S - Select a strategy for continued improvement
PDCA is an acronym for Plan, Do, Check and Act (Bader, Palmer, Stalcup, & Shaver, 2002). The PDCA cycle is a way of continuously checking progress throughout the PI process. Using this model, along with other tools, outcomes were monitored and improvements in processes and care were documented.

Find

Identify the Problem

The optimal course for patients as they are approaching End Stage Renal Disease (ESRD) is early Nephrology referral, ideally several months in advance of renal replacement therapies which include referral for renal transplantation, hemodialysis and peritoneal dialysis. Early referral allows for selection of dialysis modality and access placement prior to the start of therapy. At the initiation of this program, there was no formal process utilized at a university medical center for identifying non-nephrology referred individuals prior to the commencement of dialysis and no formal process to provide education to individuals at the appropriate time in their disease trajectory. In order to identify patients not yet followed by the nephrology service, General Internal Medicine practitioners as well as other specialty services that follow individuals at high risk for developing CKD, such as cardiology and endocrine services, were targeted as potential referral sources. Utilizing Corbin and Strauss’ Chronic Illness Trajectory Nursing Model (Corbin & Strauss, 1988) and decision support, a dialysis education business plan for the Dialysis Decisions Patient Education Program was developed and implemented. An Internal Review Board (IRB) assessment was not required to initiate this project. The Dialysis Decisions Patient Education Program project was selected to meet a recognized need within a university medical center to target colleagues for early referrals and partner with individuals in CKD Stage 4 to provide education as they traverse their illness path.
The Corbin and Strauss Chronic Illness Trajectory Nursing Model

The theoretical model for this CKD Education Program includes a comprehensive chronic illness management approach focused on the patient and their family. This program reflects the diversity, multiplicity, and complexity of the problems of CKD across the illness continuum while focusing on CKD Stage 4. Corbin and Strauss’ model is formed on the premise that the course of a chronic condition is variable and is altered over time (Corbin & Strauss, 1991).

Corbin and Strauss’ (1991) chronic illness trajectory nursing model is a middle-range theory that considers the situations of those with chronic diseases and the nursing management of their conditions. Corbin and Strauss’ model promotes a holistic nursing process through its design of stages and phases. It embraces the patient’s biography or life story as well as their social environment as he or she navigates the course of chronic illness. Through health, prevention, disease and rehabilitation, the patient is identified and supported as an active partner. This premise is a central focus of the CKD education program as self-management is promoted.

The goal of nursing care for the patient in chronicity is for the individual to participate in shaping the illness course while maintaining quality of life, independence and normalcy. This is accomplished through supportive assistance (Corbin, 1998). In the absence of cure, supportive assistance is another form of trajectory that shifts in sync with the fluctuations in the client’s illness and subsequent impact on family, health and environment. The nurses’ role in chronic illness management includes not only delivery of care, but also initiating, building upon, directing, transcending and supplementing the efforts of the patient, family, and interdisciplinary team members (Corbin). Doctoral prepared nurses possess the skills, knowledge and vision to
organize and provide for the comprehensive and technologically complex care that chronically ill patients require.

Corbin and Strauss' (1991) multi-dimensional framework facilitates an understanding of how a chronic illness unfolds and the impact and effect on individuals and those around them in every facet of life (Robinson, Bevil, Arcangelo, Reifsnyder, Rothman, & Smeltzer, 1993). Within the framework of everyday living circumstances, the trajectory model focuses on the dynamic role that individuals play in determining the course of their illnesses. The term trajectory indicates the illness course which includes not only the potential physiological development of an illness, but also the measures involved in its management and the changes in the lives of persons and their families (Corbin & Strauss, 1991). The three dimensions of trajectory are symptoms, disability and outcomes which in turn impact the management of the illness. The complexity of shaping and managing the illness course requires the cooperative efforts of multiple individuals of which the patient and patient’s family is paramount.

Progression of CKD into Stage 4 and the preparation necessary to educate and support individuals as they adjust to the reality of renal replacement therapy describes this stage. The extent that CKD is integrated into everyday life demonstrates acceptance of this chronic illness.

Shaping, in the sense of altering the illness course direction for CKD, encompasses preventing deterioration and extending stability of renal function and symptom control through appropriate management and fostering patient involvement in self-care. Chronic Kidney Disease (the illness) and dialysis modalities (technology) used to manage this condition have consequences for both the physical well-being and identity of the patient over time. Corbin and Strauss (1991) refer to this as biographical fulfillment. Individual biographical needs impact daily life activities and illness management choices which ultimately affects the illness course or
trajectory. Examples of how this relates to CKD education includes identifying potentially modifiable risk factors for the development and progression of CKD and including how the patient can be an active partner in controlling them. Risk factors include: lack of knowledge about CKD, proteinuria, hypertension, dyslipidemia, hyperglycemia, anemia, nutritional factors, thrombogenic factors, oxidative stress, elevated homocysteine, smoking, infection and inflammation, uremic toxins, depression, poor physical functioning, vocational disability, and poor social functioning (National Kidney Foundation Dialysis Outcomes Quality Initiatives, 2002). Patients who comprehend the significance of these measures in preserving renal function are more likely to participate in adhering to medication and diet as well as other recommendations.

Multiple properties of trajectories are recognized in Corbin and Strauss’s’ Trajectory Model (1991), such as trajectory phasing and subphasing, trajectory projection, trajectory scheme, conditions influencing management, trajectory management, reciprocal impact, and nursing care (Cooley, 1999). Chronic condition changes in status over the course of the illness are identified as phasing. The eight phases include:

- Pretrajectory – the preventative phase, no signs or symptoms present, before the illness course begins
- Trajectory onset – signs and symptoms are present, includes diagnostic period
- Crisis – life threatening situation requiring emergency or critical care
- Acute – active illness or complications that require hospitalization for management
- Stable – illness course/symptoms controlled by regimen
- Unstable – illness course/symptoms not controlled by regimen but not requiring hospitalization
- Downward – progressive deterioration in physical/mental status characterized by increasing disability/symptoms
- Dying – immediate weeks, days, hours preceding death (Corbin and Strauss, 1991, p. 163).

Additionally, within each phase exist fluctuations and periods of the illness called subphases. Subphases are characterized as existing in reversal, plateau, upward movement or drop (Corbin & Strauss, 1991). The pretrajectory phase correlates with CKD Stages 1-3. Trajectory onset would be CKD Stage 4. The phases of crisis, acute, stable, unstable and downward will be entered and exited numerous times throughout the course of this chronic illness.

Trajectory projection identifies the illness course vision and includes five dimensions which are: meaning of the illness, meaning of symptoms, meaning of disability, meaning for biography, and time (Cooley, 1999). The patient’s perception may motivate and inspire them to be proactive or deter them to the point of withdrawal from care. All persons involved with illness and its management including the physician, nurse, patient and their family formulates their own trajectory projection and how it should be shaped. This decision is typically founded on knowledge, experience, hearsay, and beliefs (Thorne & Robinson, 1988). It is critical to establish dialogue with patients and their families to know and understand their trajectory projection. Ideally, this phase is where decision support would be beneficial to dispel uncertainty and identify a decisive course of action.
Trajectory scheme refers to the plan of care and action. According to Corbin and Strauss (1991), “the plan is designed to shape the overall illness course, control any immediate symptoms, and handle disability” (p. 163). Included with the medical treatment plan, the trajectory scheme encompasses non-traditional, alternative forms of care such as “herbal therapy, acupuncture, unapproved drugs, controversial diets, prayer, meditation, positive thinking, and other strategies” (Forsyth, Delaney, & Gresham, 1984, p. 184).

Influencing management is comprised of numerous dimensions, some of which include resources, experience, motivation, setting, life style and beliefs, interactions and relationships, type of chronic illness, physiologic involvement, and political and economic climates. These are not all inclusive and may be expanded as care is tailored to specific patient needs. Controlling symptoms, handling crises, preventing complications, and handling disabilities comprise the four dimensions of trajectory management (Cooley, 1999). The notion of reciprocal impact refers to the impact the illness and its management has on the patient. The two dimensions of reciprocal impact are biography and everyday activities (Cooley). Nursing care consists of two dimensions, prevention of illness and proper management of chronic illness. Six specific nursing action dimensions are identified and include direct care, teaching, counseling, making referral, making arrangements, and monitoring (Cooley). These nursing care dimensions are crucial to the education process and were utilized throughout the program.

Progression through the phases does not occur linearly and may fluctuate amongst and between the phases. Additionally, individuals frequently react to their illness on different levels. To understand the actions and experiences of individuals confronting the various phases of chronic illness requires the identification of several key concepts within the trajectory model. Corbin and Strauss (1988) use the term biography to refer to the person's life course. When
chronic illness appears, the individual’s self-perceptions become discontinuous where they perceive who they are now is different from whom they were in the past, and hoped to be in the future (Corbin & Strauss). Individuals with CKD often suffer varying degrees and types of body system changes and body image disturbances with resulting limitations of actions which potentially affect their self-concept. Patients must come to terms with the physical and social limitations imposed upon them by the nature of their disease. Previous concepts of body, self, interactions, events, and relationships must be replaced with new definitions.

The practical application of Corbin and Strauss’ chronic illness trajectory model can be utilized in CKD management (Appendix A). The model depicts the CKD population and provides insight, generalizability and understandability across the continuum of the disease process. The Corbin and Strauss model provides the practitioner with the foundation or framework to manage the structure and process of circumstances as they change over time while fostering and encouraging patient participation. The Corbin and Strauss model was helpful in guiding and supporting patients as they progress through the Dialysis Decisions Patient Education Program.

Organize

Initiate an Action Plan

The action plan for this project was to develop and initiate a business plan that resulted in the implementation of a comprehensive education program for individuals with CKD Stage 4. Preliminary discussions took place with Nursing Administration and Hospital Finance in the facility where the framework of this project is now implemented (Appendix B).

The current healthcare environment mandates high quality, cost-effective, patient and family focused care. A unique, holistic approach to this type of patient care is accomplished by
The Advanced Practice Nephrology Nurse (APNN) (Easom & Allbritton, 2000). The APNN is trained, educated and certified to competently coordinate and provide care for the complex renal patient population. Additionally, the APNN is able to direct care on health promotion and patient well being that spans the chronic kidney disease continuum by preventing or delaying disease and its ensuing complications. The APNN is an integral member of the healthcare team and collaboratively works to assure the highest standards of quality care.

The American Nephrology Nurses' Association (ANNA) identifies competencies of the APNN to include the ability to:

- provide expert nursing care to individuals with varying degrees of renal impairment
- assess the healthcare needs of individuals, families, groups and communities
- use the nursing process to diagnose, plan, implement, and manage care as well as to evaluate the outcomes of that care
- focus on care that promotes health and prevents renal disease and disability
- assist patients and families with modality choices (including hemodialysis, peritoneal dialysis, transplant, and conservative management)
- support the palliative care needs of patients and their families
- provide and coordinate care for complex patient, family, and community populations
- manage acute and chronic renal disease in a variety of healthcare settings
- prescribe, administer, and evaluate pharmacologic and therapeutic treatment regimens
- explore, test, and advance scientific theories upon which nursing practice is based
- identify, study and solve complex problems in the areas of nephrology
- independently assess, conceptualize, and diagnose complex health problems
• provide leadership within the area of nephrology through consultation, clinical practice, education, and research
• contribute to the generation of the knowledge base for nursing and specifically nephrology nursing
• provide leadership for practice changes
• provide leadership for nephrology nursing to be an integral part of disease management proposals
• contribute to the advancement of the profession as a whole (Counts, 2008, p. 3).

Proposed Team

This project was completed by an APNN with guidance and instruction by advisers Dianne Smolen, PhD, CNE, RN-BC, CNS, Christopher Bork, PhD, EMT-B, FASAHP, Sherrill Smith, RN, PhD, CNL and Shobha Ratnam, MD, PhD.

Nursing administration and the Department of Finance were involved to discuss the program need and appropriate hours to be devoted to this project. Their contribution was in determining the full-time equivalent (FTE) needed to create a position and identify clinic-related and educational materials costs. The position created is filled by an APNN currently employed as a Disease Manager for End Stage Renal Disease who previously was a non revenue generator for the institution. The APNN will independently bill for the education sessions. The Centers for Medicare and Medicaid Services reimbursement is $108.00 for each of six sessions, which is additional revenue for the organization. Nephrology clinic nursing staff have been provided with an informational in-service outlining the objectives and goals of this project. Currently, clinic nursing staff are not involved with patients scheduled for these education session appointments.
Clarify

Review of Literature to Determine Evidence

An evaluation of the literature was completed using the U.S. Preventive Services Task Force (USPSTF, 2006) rating scale in regards to overall evidence quality and level of effectiveness (Appendix C). Evidence quality is rated on a three point scale as follows: Good – evidence includes consistent results from well-designed, well-conducted studies in representative populations that directly assess effects on health outcomes; Fair – evidence is sufficient to determine effects on health outcomes, but the strength of the evidence is limited by the number, quality, or consistency of the individual studies, generalizability to routine practice, or indirect nature of the evidence on health outcomes; Poor – evidence is insufficient to assess the effects on health outcomes because of limited number or power of studies, important flaws in their design or conduct, gaps in the chain of evidence, or lack of information on important health outcomes (United States Preventive Services Task Force, 2006). The USPTF scale is recognized as a well-defined, overt methodology for evaluating scientific evidence (Mengel, Holleman, & Fields, 2002).

Another critical appraisal of evidence is the level of effectiveness which considers the research design and result strengths of the study. The USPSTF identifies five categories (A, B, C, D, I) that reflect the evidence strength and extent of benefit minus harm. These are described as: A – strongly recommends that clinicians provide the service to eligible patients. Good evidence found that the service improved important health outcomes and benefits substantially outweigh harms; B – recommends that clinicians provide the service to eligible patients. Fair evidence found that the service improved important health outcomes and benefits outweigh harms; C – no recommendation for or against routine provision of the service. Fair evidence that
the service can improve health outcomes but concludes that the balance of benefits and harm is too close to justify a general recommendation; D – Recommends against routinely providing the service to asymptomatic patients. At least fair evidence that the service is ineffective or that harm outweighs benefits; I – evidence is insufficient to recommend for or against routinely providing service. Evidence that service is effective, is lacking, of poor quality, or conflicting and the balance of benefits and harms cannot be determined (United States Preventive Services Task Force, 2006).

The literature review included a topic search of CKD, decision support, APN education programs, self-management, evidence-based, chronic illness, dialysis education programs, disease prevention and decisional conflict. Of the sources reviewed, there were four clinical guidelines; six systematic literature reviews; two randomized control trials; three evidence-based practice papers; and three qualitative studies. The overall quality of evidence was good to fair and the levels of evidence were rated as strongly recommends or recommends, based on the USPSTF rating scales. Synthesis of the literature supports early referral for modality education, demonstrates how progression to CKD Stage 5 can be delayed with self-management strategies, describes the benefits of decision support in the decision making process, illustrates how decisional conflict delays the decision making process, explains how modality education facilitates modality selection, supports appropriate access placement prior to renal replacement initiation and provides additional benefits of patient education to the patient and the organization. Each of these areas will be described in further detail.

**Chronic Illness**

Recently, there has been a nationally recognized shift away from acute care management to health promotion and prevention of chronic illness/conditions. According to health care
professionals, one of the biggest challenges in health care today is chronic illness (Vickers, 2001). A chronic illness is an illness that lasts for a long time, or that last longer than acute illnesses, which are brief and do not linger. Chronic illnesses are treated but usually not entirely alleviated. The Institute for Health and Aging (1996) defines a chronic condition as a medical illness or impairment with duration of greater than three months. Royer (1998) writes, "The term 'chronic illness' refers to those disease categories for which there is no known 'cure,' to conditions that are ineradicable and usually progressive" (p. 1). The magnitude and significance of chronic illness is evident by these disquieting facts: nearly 1 in 2 Americans (133 million) has a chronic condition, (Chronic Care in America, 2004); by 2020, about 157 million Americans will be afflicted by chronic illness; that number is projected to increase by more than one percent per year by 2030, resulting in an estimated chronically ill population of 171 million (Chronic Care in America); four in five health care dollars (78%) are spent on behalf of people with chronic conditions (Anderson, 2004); 60% of the chronically ill are between the ages of 18 and 64 (Chronic Care in America); 90% of seniors have at least one chronic disease and 77% have two or more chronic diseases (Anderson); about one-fourth of people with chronic conditions have one or more daily activity limitations (Anderson); and seven out of 10 deaths among Americans each year are from chronic diseases (Kung, Hoyert, Xu, Murphy, 2008).

Among the plethora of devastating, pervasive, yet manageable chronic illnesses is chronic kidney disease (CKD). This EBP QI project will examine and discuss CKD, identify a problem that exists at an academic medical center in the Midwest, and outline strategies implemented to impact the identified deficit.
Chronic Kidney Disease

The National Kidney Foundation operationally defines chronic kidney disease (CKD) as: kidney damage for ≥3 months as defined by structural or functional abnormalities of the kidney, with or without decreased glomerular filtration rate (GFR), manifest by either pathological abnormalities or markers of kidney damage, including abnormalities in the composition of the blood or urine, or abnormalities in imaging tests or GFR <60 mL/min/1.73 m² for ≥3 months, with or without kidney damage (2010, p3).

Table 1.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
<th>GFR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal kidney function</td>
<td>Healthy kidneys</td>
<td>≥ 90 ml/min</td>
</tr>
<tr>
<td>Stage 1</td>
<td>Kidney damage with normal or high GFR</td>
<td>90 ml/min or more</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Kidney damage with mild decrease in GFR</td>
<td>60 to 89 ml/min</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Moderate decrease in GFR</td>
<td>30 to 59 ml/min</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Severe decrease in GFR</td>
<td>15 to 29 ml/min</td>
</tr>
<tr>
<td>Stage 5</td>
<td>Kidney failure</td>
<td>Less than 15 ml/min</td>
</tr>
</tbody>
</table>

CKD is classified according to stages as kidney function declines over time (Table 1.) The Kidney Foundation also has identified actions for CKD risk reduction that are associated with each stage which are as follows: Stage 1, diagnosis and treatment, treatment of comorbid conditions, slowing progression and cardiovascular risk reduction; Stage 2, estimating progression; Stage 3, evaluating and treating complications; Stage 4, preparation for kidney replacement therapy; and Stage 5, replacement therapy (National Kidney Foundation, 2010).
CKD is a worldwide health problem and a growing issue in the United States. According to the National Kidney Foundation (2010), 26 million Americans, or one in nine adults, have CKD and millions of others are at increased risk for this disease. High risk groups include individuals with diabetes, the leading cause of renal failure, followed by hypertension, the second leading cause, and a family history of kidney disease. Additionally, ethnic minorities, particularly African Americans, Hispanics, Native Americans and people of Asian ancestry are at higher risk. African Americans are close to four times as likely to develop kidney failure as Caucasian Americans, American Indians have almost three times the risk compared to Caucasians, and Hispanic Americans have nearly twice the risk as non-Hispanic Caucasians (National Institute of Diabetes and Digestive and Kidney Diseases, 2005). Seniors are another population at increased risk (National Kidney Foundation).

A rising incidence and prevalence of kidney failure is seen in the United States with poor outcomes and high costs. The number of people with kidney failure requiring dialysis or transplantation has been increasing exponentially and currently is estimated at 700,000 (National Institute of Diabetes and Digestive and Kidney Diseases, 2009). The associated cost of treating kidney failure in the United States exceeds a staggering $20 billion annually. Kidney failure is only a part of the picture. Twenty million Americans are estimated by experts to have significantly reduced kidney function. It has been identified that even a small loss of kidney function can double a person's risk of developing cardiovascular disease (National Institute of Diabetes and Digestive and Kidney Diseases). Many of these people will experience heart attacks or strokes before they are even aware they have kidney disease.
Impact of Early Referral and Education Programs

A significant number of patients, estimated to be 30% to 50% of those starting dialysis, experience delayed nephrology referrals as a result of unrecognized CKD in the early stages (Arora, et al., 1999). It is documented that nephrology referrals that result in commencement of dialysis for the patient in less than four months after the initial visit (defined as a late referral) are associated with poor pre ESRD care (Watson, 2008). These patients are likely to experience abnormal blood values related to renal failure that include low serum albumin, high phosphorus, low calcium, low hemoglobin and high parathyroid hormone (Dogan, Erkoc, Sayarliouglu, Durmus, & Topal, 2005). Additionally, these individuals are less likely to be on erythropoietin-stimulating agents or phosphate binders and have a higher incidence of central venous catheter use at the time of hemodialysis initiation (Watson, 2008). This group is shown to experience worse outcomes including poor early survival, increased hospitalization rates, inadequate access placement and lower quality of life (Owen, et al., 2006).

In recent decades, increased evidence has accumulated that identify complications of CKD such as kidney failure, cardiovascular disease and premature death that can be prevented or delayed (National Kidney Foundation Dialysis Outcomes Quality Initiatives, 2002). It is now recognized that CKD treatment in the early stages is effective in slowing progression toward kidney failure. Treatment for cardiovascular risk factors at earlier stages of CKD can be effective in reducing cardiovascular disease events both before and after the onset of kidney failure (National Kidney Foundation Dialysis Outcomes Quality Initiatives). Unfortunately, in the United States, CKD is both under-diagnosed and under-treated which results in lost prevention opportunities.
Identified as a time of emotional upheaval and uncertainty, the pre-dialysis stage affects all aspects of a patient’s life (Murray, et al, 2009). It is during this time of insecurity that modality selection needs to be decided. Dialysis modality education programs have been shown to decrease anxiety, enhance self-care strategies, promote autonomy and decision making, reduce healthcare costs, delay initiation of renal replacement therapy, increase starting dialysis with a self-care modality and impact morbidity and mortality (Pagels, Wang, & Wengstrom, 2008).

**Understand**

**Appraisal and Synthesis of the Evidence**

Chronic Kidney Disease (CKD) Stage 5, also referred to as end stage renal disease (ESRD), occurs when renal function has declined to a glomerular filtration rate (GFR) <15 mL/min/1.73 m² and requires renal replacement therapy for survival (Tweed & Ceaser, 2005). Renal replacement treatment modalities include hemodialysis, either in-center, nocturnal or at home; peritoneal dialysis, either continuous automated peritoneal dialysis (CAPD); or continuous ambulatory peritoneal dialysis (CAPD), transplantation, and no treatment initiation. The sequela at this stage of renal illness imposes numerous restrictions that result in life altering adjustments; therefore, referral for the provision of disease specific education, ideally early in CKD Stage 4 (GFR 29-15 mL/min/1.73 m²), prior to the necessity of renal replacement therapy, should occur.

According to Tones and Tilford (1994), disease specific education is a process of critical consciousness rising. Patients need to understand the circumstances of their disease and that they possess the ability to influence these circumstances. The goal of education, therefore, is to empower and facilitate choice, not persuade and sustain.
Patient preference surveys identify that patients desire to be involved in decision making regarding their personal health care (Tweed & Ceaser, 2005). It has been documented that: pre-dialysis education leads to increased participation by patients in their own care; that it can impact morbidity and mortality; that it lowers the cost of care to the patients, organization and government; and that it reduces stress for both patients and their families (Heatley, 2006, p. 171).

The introduction of structured pre-dialysis education programs has demonstrated extended wellness in individuals who have participated. In addition, patient adherence to education recommendations geared toward health promotion such as to control glucose levels, blood pressure, cholesterol and smoking cessation have been shown to slow the progression of renal decline, which ultimately delays the start of renal replacement therapy (Watson, 2008). Many participants described a greater sense of "taking control of their health" that results in increased confidence in their self management skills (Hain, Calvin & Simmons, 2009). Also recognized as a result of pre-dialysis education is the selection of self-care and home replacement modalities (Goovaerts, Jadoul & Goffin, 2005). In general, patients who experience an unplanned modality initiation of hemodialysis, due to urgency in initiating a therapy, without pre-dialysis education, rarely convert to an alternative therapy (Tweed & Ceaser, 2005).

Some important factors identified in the selection of a renal replacement modality include information on survival, morbidity and quality of life (Mazzuchi, Fernanzezi-Cean, & Carbonell, 2000). A Canadian study surveyed patients attending a nephrology clinic for the first time. The results identified that 97% of the patients investigated would want life-expectancy information. They preferred the physician to approach the subject without being prompted and a majority
responded that they would want as much information as possible, both good and bad (Fine, Fontaine, Kraushar & Rich, 2004).

Suitability of treatment modality for an individual should be analyzed with consideration to comorbid conditions, non-medical reasons and demographics since no one treatment modality is best suited for all patients. Advantages and disadvantages of each modality and potential complications would be presented as well as absolute and variable contraindications. Additional factors identified in the decision process include “clinical status, patient age, patient preference, psychological stability, etiology of ESRD, comorbidity, suitable living-related donor, economic factors and social circumstances” (Mazzuchi, et al., 2000, p. S-136). The goals of CKD education should offer problem-solving skills and strategies that enhance patient self-confidence to carry out the desired behavior(s). Chronic Kidney Disease education that considers and values the uniqueness of individuals as they strive for physical, mental, and social well-being should be provided.

**Decision Support**

An evolving movement in chronic illness and an educational strategy to be utilized in this program is decision support (DS). Decision support promotes informed decision making by assisting and supporting the patient in identifying all the data required to make a decision, gathering it together, organizing it as meaningful information, understanding the effects of all alternatives, and recognizing the best choice based on knowledge, circumstances and preference (Stacy, Murray, Légaré, Dunn, Menard, & O’Connor, 2008). Patient-centered care is fostered in DS by involving the patient and family in decision making and providing structured decision support to facilitate patient decisions. The Institute of Medicine (2001) identifies patient-centered
care as “providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions” (p.28).

Increasingly, patients as health consumers are advocating for more information on the subject of their illnesses and treatment options and are seeking autonomy in medical decision making. Decision support fosters decision making and, according to Stacey, Taljaard, Drake and O’Connor (2008), decision support is a “process of assessing patients’ decision making needs, providing support tailored to their needs, and evaluating progress in decision making” (p. 519.) Decision support systems should be evidence based and be evidence adaptive to reflect the most recent advances in clinical science and local practice knowledge (Purcell, 2005).

The aim of decision support is to achieve a valued decision that is reached based on current evidence and founded on personal values (Stacey et al., 2008). Potential benefits associated with patient participation in medical decision making include: “decreased incidence of anxiety and depression, enhanced sense of hope, increased feelings of control over their illness, improved self-efficacy, a better understanding of and commitment to their treatment, better compliance, and increased satisfaction with their physician” (Orsino, Cameron, Seidl, Mendelssohn & Stewart, 2003, p.324).

Patients with CKD face the challenge of multiple decisions throughout their illness. Chronic disease management decisions encountered by these individuals will focus on ways to monitor their condition, set priorities for making changes, and implement approaches to better manage the impact of their condition as it relates to their physical, emotional, and social life (Stacey, Murray, Légaré, Dunn, Menard, & O’Connor, 2008). A systematic review of factors influencing decision-making in adults with CKD identified the following patient-level factors that impact decision making:
Interpersonal relationships
- Knowing others’ experiences; provider/patient interactions; self-perceived burden to family; trust in providers

Preservation of current well being
- Normality and quality of life; maintaining current lifestyle

Need for control
- Managing the situation; maintaining individuality; being personally responsible

Personal weightings for benefit/risk ratios
- Willingness to take chances; fear if things do not go well; potential for disappointment (Stacy, et al., 2008, p. 155).

Decisional Conflict

Despite the desire to participate in health related decision making, many patients may experience uncertainty or decisional conflict when considering treatment options and the positive and negative factors associated with each option. Decisional conflict is defined as the “uncertainty about which a course of action is to be taken when choice among competing actions involves risk, loss, regret, or challenge to personal life values” (Nelson, Han, Fagerlin, Stefanek, & Ubel, 2007, p. 613). Evidence of decisional conflict includes “verbalizing uncertainty, expressing concern about undesired outcomes, wavering between choices, delaying decisions, questioning personal values, being preoccupied with decision, and feeling emotionally distressed by the decision” (Nelson, et. al., p. 613). In the literature, decisional conflict is described as an objectionable state since it reflects anxiety and distress related to uncertainty or indecision (Nelson, et. al.). There is an increased likelihood that an “effective decision” will be reached when decisional conflict is reduced (Nelson, et. al.). Modifiable factors that exacerbate
decisional conflict include knowledge gaps, uncertainty regarding outcomes, lack of clarity about what matters most, and feeling unsupported in the decision making process or pressured to choose a particular option (Murray, et al., 2009; Stacy, Taljaard, Drake & O’Connor, 2008). Decision aids and shared decision making are effective interventions to guide patients through the decision making process.

**Decision Aids**

Decision aids and shared decision making are effective interventions to guide patients through the decision making process and reduce decisional conflict (Murray et al., 2009). Decision aids and shared decision making is utilized in the modality selection portion of the Dialysis Decisions Patient Education Program. Medical decision making in ESRD in regards to the mode of renal replacement therapy significantly impacts compliance, quality of life, and ultimately, survival (Orsino, Cameron, Seidl, Mendelssohn & Stewart, 2003). Modality selection of the various therapies that includes hemodialysis, peritoneal dialysis and transplantation, have associated differences that impact lifestyle, their own set of limitations and disadvantages, and medical and rehabilitative outcomes. Additionally, each treatment has varying levels of participation that range from totally independent to a passive role. Evidence-based decision making recognizes that patients are the experts in judging their personal values which impacts their decisional outcome (O’Connor, 2001).

The function of decision aids is to assist the preparation of patients in making informed health decisions that are aligned with the patients’ personal values. Evidence-based decision aids provide information in a format that facilitates the patients’ understanding of the plausible consequences of available options, reflects on the personal values linked to the consequences, and supports active involvement in selecting the best option for them (O’Connor, 2001).
The Cochrane definition of decision aids is: interventions designed to help people make specific and deliberative choices among options by providing information about the options and outcomes that are relevant to a person’s health status. Additional strategies may include information on the disease or condition, probabilities of outcomes tailored to a person’s health risk factors, an explicit values-clarification exercise, information on others’ opinions, and guidance or coaching in the steps of decision making and communicating with others (O’Connor, Feist, et al., 1999, p. 67).

Systematic evaluation studies from a Cochrane overview of trials and general analysis recognize that decision aids improve patients’ decision making. This is demonstrated by a decrease in the number of individuals experiencing uncertainty with their choice; increased knowledge of the problem, options, and outcomes; creation of practical and realistic expectations of outcomes; improvement in the concord between choice and values; reduction in various components of decisional conflict such as feeling uninformed, uncertain, unclear about values, or unsupported in decision making; and increased participation in decision making without anxiety (O’Connor, 2001).

O’Connor and Jacobson (2007) reviewed several randomized controlled trials that verified decision aids as being preferable to standard care in terms of “increasing participation in decision making without increasing anxiety, improving decision quality by improving knowledge of options, benefits, and harms, providing more realistic expectations of the probabilities of benefits and harms and enhanced matching between personal values and choices. Decision aids are also found to be beneficial in lowering decisional conflict and helping undecided people to decide” (p. 14).

Additional randomized controlled trials and systematic reviews identify evidence that
further demonstrates the utility of decision aids. Decision aids are shown to “increase patients’ desire to participate meaningfully in decision-making, encourage question asking, promote information seeking behaviors, and improve knowledge about available treatment options” (Harrison, et al., 2009, p. 120). Murray et al. (2009) noted that patients exposed to decision aids are more likely to be informed, have realistic expectations of outcomes of options, participate actively in decision making, and feel lower decisional conflict.

An assortment of media can be used with decision aids that include decision boards, interactive videos or compact discs (CD’s), personal computers, audiotapes, audio-guided workbooks, pamphlets, and group presentations (O’Connor, 2001). Passive informed consent materials, educational interventions not geared to a specific decision, or interventions designed to promote compliance with a recommended option rather than a choice based on personal values are not considered decision aids.

Nine objectives of decision aids have been identified and include:

- Improve knowledge of the clinical problem, options, outcomes, and variation in patient or practitioner opinions and practices
- Create realistic expectations of outcomes, consistent with available evidence
- Clarify personal values for outcomes and promote congruence between patient’s values and choice
- Reduce patients’ and practitioners’ decisional conflict (uncertainty) about the course of action to take
- Promote implementation of choices
- Improve patients’ or practitioners’ satisfaction with decision making
- Promote patients’ persistence with choice
• Reduce patients’ distress from the consequences of decisions
• Improve patients’ health-related quality of life and promote informed use of resources by patients and practitioners (Nelson, Han, Fagerlin, Stefanek, & Ubel, 2007, p.616).

Decision-making needs are faced by patients with CKD across the trajectory of their illness. Murray, et al. (2009) identifies that decisional conflict is likely to be experienced in patients with CKD related to the decisions they are expected to face. Defined as a state of uncertainty about a course of action, decisional conflict “is experienced when two or more clinically reasonable options have benefits and harms that patient’s value differently (NANDA International, 2005).

**Decision Coach**

The Dialysis Decisions Patient Education Program nurse educator will be identified as a decision coach. A decision coach recognizes patients in decisional conflict and intercedes by leading them through the decision making process with the ultimate goal of reaching an informed decision outcome (Stacy et. al., 2008). The decision coach role encompasses: assessing decisional needs including decisional conflict, knowledge, values clarity and support; providing decision support tailored to needs through the use of evidence-based patient decision aids and coaching; monitoring and facilitating progress in resolving needs and decision quality; and screening for implementation needs (Stacy et al., p. 27). Additional principles that may be used to guide the decision coach include: verifying understanding, clarifying values, building skills in deliberation, communication, and accessing support; monitoring and facilitating patients’ progress in decision making; and screening for factors influencing decision implementation that includes patients’ motivation and self-efficacy, and other potential barriers impending implementation (Stacy et al., p. 28).
Evaluation

Decision making when a chronic or terminal disease is involved is a complex, challenging and difficult task for many patients. Therefore, a critical step in informed decision making is in evaluating the effectiveness of the process of facilitating an informed decision outcome. This can be accomplished by measuring the patient’s perceived involvement in the decision.

A tool designed for use in evaluating the decision-making process is the Generic Decisional Conflict Scale (DCS). This instrument measures the level of decisional conflict experienced by patients while making health care decisions (O’Connor, 2001). The DCS is a 16-item tool using a Likert type, five-point response design that includes: completely agree, agree, neither agree nor disagree, disagree, and completely disagree. Three subscales comprise the DCS. Three items determine the first subscale, “Uncertainty.” This refers to the patients’ perceived level of uncertainty concerning a specific healthcare decision. “Factors contributing” is the second subscale and contains nine items. The extent to which certain factors contribute to decision uncertainty is measured in this portion. Examples include lack of information about alternative treatments, unclear values, and emotional distress. The third subscale, “Effective decision making”, consists of 3 items. The extent to which a patient perceives the decision as effective and based on information consistent with personal values and having implemented on these values is measured in this subscale (Koedoot, et al., 2001).

The DCS has utility in measuring decision uncertainty which results in decision delay and has demonstrated reliability, validity, and sensitivity to change for groups making different health decisions. In Canada, populations tested by this tool include individuals making decisions concerning immunizations, hormone replacement therapy, breast cancer screening, and treatment
for schizophrenia (Koedoot, et al., 2001). Test-retest and internal consistency coefficients of the three subscales ranged from 0.78 to 0.89, and the test-retest reliability indices exceeded 0.80 (Koedoot et al.). DCS validity was scrutinized by contrasting group analysis and differentiated significantly ($p<0.001$) (Koedoot, et al.). The DCS has been utilized in a number of clinical research trials measuring decisional conflict. This tool is reported to have “acceptable psychometric properties and has been used both as an outcome measure of decision-making effectiveness and as a predictor variable in numerous studies of decision aids (Nelson, et al., 2007, p. 614).

Quantification of modifiable factors that contribute to uncertainty can be identified both during the process of deliberation and following the choice. The DCS’s utility is revealed by evaluating the impact of decision support interventions and modifying the program in order to tailor it to individual patient’s needs (O’Connor, 2001). The DCS instrument (Appendix D) was be utilized by the APNN as an evaluation tool to identify if the patient is experiencing decisional conflict at the time of their modality decision. Patient responses of strongly agree or agree would confirm confidence in their decision. Responses of neither agree nor disagree, disagree, or strongly disagreed would denote uncertainty and decisional conflict which will cause the APNN to alter and adjust the methods of content presentation, refine decision support tools, confirm with the patient their confidence level at the time of their decision, assess for patient stressors or emotional distress, and strengthen clarification of any misconceptions.

Additional program evaluation will include tracking the number of patients who complete the program, type of modality selections made, access placement at time of modality initiation, revenue generated, the number of nephrology (within and outside of a University Medical Center) and non-nephrology physician referrals, patient satisfaction with the program as
identified by the Kidney Foundation Evaluation Tool provided with each session, APNN hours and program expenses.

The Kidney Foundation evaluation tools are numbered and titled to identify each of the six individual sessions. Titled How Would You Rate this Workshop, there is an area to note the date, presenter and location. Questions asked include: How satisfied were you with this workshop? Check box answers include very satisfied, satisfied or not satisfied. Would you recommend that other people with chronic kidney disease and their families attend this workshop is the next question. Answers include yes or no. If no is checked, there is a space and request to please explain. The next question asks: Did this workshop make you aware of any changes you could make to improve your health? Answer options are yes, what kind or no, why not? How likely are you to attend more workshops in this program is the final question. Very likely, not sure or unlikely are the choices. An area for comments is also provided.

Medicare Improvement for Patients and Providers Act (MIPPA)

In effect since January 2010, Section 152(b) of The Medicare Improvement for Patients and Providers Act (MIPPA) of 2008 provides a new coverage provision for people on Medicare with Stage 4 CKD to receive individualized kidney education training. This legislation requires Medicare to fund kidney education services that will help beneficiaries manage the superfluity of health problems that accompanies this disease, prevent additional complications, and understand their dialysis options. Qualified health care providers for this education benefit have been identified as physicians, physician assistants, nurse practitioners and clinical nurse specialists (MIPPA, 2008). Individuals with Stage 4 CKD face important decisions about their treatment as they progress to CKD Stage 5, also called kidney failure or ESRD. In this stage, renal replacement therapy of dialysis or kidney transplant is initiated. Making an informed decision
requires knowledge of available treatment options and potential complications (National Kidney and Urologic Diseases Information Clearinghouse, 2009).

The Centers for Medicare and Medicaid Services (CMS) have identified two G codes for the six, individual, 60 minute education sessions. One code denotes individual education sessions and another identifies a group setting format. Beneficiary eligibility for this new benefit is defined by CMS as Stage 4 CKD: kidney damage with a severe decrease in GFR defined quantitatively as GFR of 15-29ml/min/1.73 m2 using the Modification of Diet in Renal Disease Study formula (MIPPA). A CMS requirement is that the education be provided face-to-face.

Content has been established by CMS for the provision of comprehensive information regarding the management of co-morbidities including how it relates to delaying the need for dialysis, prevention of uremic complications, and each available option for renal replacement therapy (hemodialysis, home hemodialysis, peritoneal dialysis, and renal transplantation) and vascular access to ensure the individual’s participation in choice of therapy tailored to meet their specific needs (United States Department of Health and Human Services, 2009).

The Dialysis Decisions Patient Education Program meets the CMS requirements for reimbursement and provides patients the opportunity to actively participate in their decision of modality selection while providing personalized information and instruction. Following CMS guidelines, the sessions will include management of co-morbidities, with the goal of delaying the need for dialysis and discussion on the treatment options available for renal replacement therapy.

Select

Education Program

An important component of an education program and crucial role in a patient’s recovery is receiving clear, appropriate advice, information and support. Clinicians should relay specific messages that can be translated into actual self-care behaviors (Braun, Curtin, Mapes, Schatell,
Burrows-Hudson, 2005). The result is reduced distress and increased satisfaction in patients and their families (Iles-Smith, 2005). Successful program elements include “physician support, designated nurse coordinator, multidisciplinary team, patient referral system, positive patient experience, early treatment of comorbidities, and improved patient outcomes” (Compton, Provenzano, & Johnson, 2002). This program, titled Dialysis Decisions Patient Education Program, includes these essential points and is provided in a one-on-one, intimate, informal setting at a university medical center. The Corbin and Strauss model helps guide the APNN and patient as they partner to navigate the impact of CKD on their lives through this educational journey. The six session topics presented as identified by MIPPA include:

- Chronic Kidney Disease: What You Need to Know
- Chronic Kidney Disease: What You Can Do
- Choosing Transplantation
- Choosing Dialysis
- Choosing the “No Treatment” Option
- Living Well With Your Choices (National Kidney Foundation)

An outline of the session topics is included in Appendix E.

The National Kidney Foundation developed a CKD modality specific curriculum that satisfies the MIPPA Kidney Disease Education Benefit. The content is specific to CKD Stage 4 patients and describes how to manage their disease, prevent uremic complications, make good treatment choices, and other relevant and important information (National Kidney Foundation, 2010). The program is designed to accommodate different styles of adult learning and encourage patient and family interaction and participation. The materials have been developed to facilitate participant reflection on topics covered and to gain a sense of empowerment to make decisions
based on personal choice and benefit. To achieve this, handouts, self-assessment quizzes, take
home exercises, and other materials are provided for each of the six separate, one hour session
topics. Specific components and descriptions for each session include:

- **PowerPoint Slides and Speaker Notes** – Fully scripted slide presentation
- **Slide Handout for Participants** – 2 large size font slides per page with room for notes.
  This allows the participant to follow along with each presentation
- **Lesson Plan** – Separate lesson plans describe the learning objectives, content to be
covered, and desired outcomes for each workshop
- **Take Home Exercises** – Helps participants think about and apply what they have learned
- **Check Yourself** – An educational self-assessment quiz in a variety of “fun” formats such
  as word games, puzzles and quizzes that helps participants think about key information
  from each session
- **Resources** – A bibliography of relevant titles, websites, and other resources for
  participants who want more information
- **How Would You Rate This Workshop?** – An evaluation form to evaluate each session
- **Certificate of Attendance** – Certifies that the participant has completed the session

**Forms and Documentation Tools include:**

- **Record of Participation** – Form is completed with participant’s name and date each
  session is completed. The purpose of this form is to document attendance in the medical
  record.
- **Educational Checklist** – Allows participants to keep track of sessions attended and decide
  on the order sessions are presented.
• Workshop Summary – Used to record participant’s responses to session evaluation forms to evaluate the overall effectiveness of the sessions.

• Tell Us How You Are Doing! – A follow up survey used to collect patient data for an outcome report. Designed to be given to participants three months after completion of the six sessions.

• Summary of the “Tell Us How You Are Doing!” Survey – Can be used to summarize the results from the “Tell Us How You Are Doing!” survey to organize an outcomes report (National Kidney Foundation).

This educational program utilizes principles of adult learning. Recognized characteristics of adult learners include that they are autonomous and self directed, have accumulated a foundation of life experiences and knowledge to draw upon, are goal-oriented, relevancy-oriented, practical, and need to be shown respect (Lieb, 1991). Patients are afforded the opportunity to be self-directed and choose their preference regarding the order of the modality specific sessions. In addition, the four critical elements of learning are addressed. These include motivation, reinforcement, retention, and transference (Lieb). Motivation is evident by the patients’ continued attendance at each of the subsequent sessions. Information is reviewed and restated to support reinforcement. Retention is measured at the end of each session by completion of the Check Yourself educational self-assessment quiz included in the Kidney Foundation workshop materials. Through the use of this “fun” format that includes word games, puzzles and quizzes, the participant is prompted to recall key information from each workshop. The answers are reviewed informally with the patient and scored to identify areas of reinforcement needed. Transference is evident by the patient’s ability to complete the modality decision process based on the information presented.
The key stakeholders of this Dialysis Decisions Patient Education Program are: the patients; Chair, Division of Nephrology and Associate Professors of Nephrology; referring physicians; business customers; nursing and hospital administration; and an advanced practice nephrology nurse educator.

The advanced practice nephrology nurse educator, engaged in interactive dialogue with the patient, provides two benefits. The first is for the patient to exchange experiences and information so that they can choose how best to manage their CKD and its effects on their daily lives with the most favorable outcomes to their circumstances and lifestyle. Secondly, the patient will become empowered to actively participate in the decision making process regarding their preferred treatment modality.

Plan

**Business Plan Market Analysis: Introduction**

Market analysis, “the actual assessment of the target population, competition and needs for marketing that product or service” (Conduct a Market Analysis, 2004, ¶6), is the first step in initiating a new product or service. The benefits of a market analysis include validating the market need for your service, confirming the need for the development of a marketing plan, and gathering market information that will assist in promoting the service. (Conduct a Market Analysis). To determine the need for the Dialysis Decisions Education Program, a market analysis was performed using a SWOT Analysis.

A SWOT analysis is a deliberate method utilized to assess the Strengths, Weaknesses, Opportunities, and Threats involved in a project or business venture (SWOT Analysis, 2008). Necessary steps include ascertaining the objective of the business venture or project and identification of the internal and external factors that are favorable and unfavorable to achieve
that objective (SWOT Analysis). Providing clarification and summarizing key issues and opportunities available to a new business enterprise are some of the benefits of a SWOT analysis.

**Population**

Two types of customers will benefit from this program, the individual customer and the business customer. The individual customer will consist of patients who have CKD Stage 4 (GFR 15-29 mL/min/1.73 m²). These individuals will be recognized as currently being followed by the Division of Nephrology at a university medical center, individuals identified within the organization and those referred by other services within and outside of the organization. The business customer is the primary care physician, diabetic nurse educator, and other health care professionals that support the program through referrals. Each customer population will be further explored.

**Individual Customer**

Demographically, the individual or patient customers will be similar to those currently receiving dialysis. According to the United States Renal Data System (2007), the median age is 58.6 years with minimal variation by race or ethnicity. Additionally, there are more males than females and African Americans and Hispanics have a higher incidence of CKD Stage 5 than Caucasians (United States Renal Data System). The four primary diagnoses in order of prevalence are diabetes, hypertension, glomerulonephritis, and cystic kidney disease (United States Renal Data System).

Of 39 patients initiating treatment modality at a university medical center for a one year time span beginning January 1, 2009, there were 18 males and 21 females. The median age was 60.2 years. Twenty three were African American, 14 Caucasian and two Hispanic. The geographical area served by this university medical center does not have a prominent Hispanic
population. Primary diagnosis identification included 16 with diabetes, 22 with hypertension, no glomerulonephritis and one with polycystic kidney disease.

**Business Customer**

The business customers will be referring physicians, consult services and clinic providers within a university medical center. The APNN cultivates relationships for referrals through personal contacts, formal and informal educational programs, and informational program introduction letter mailings. Services and departments targeted will be locations that individuals with primary diagnoses that contribute to renal decline would be followed, primarily areas that treat diabetes and hypertension. A partnering relationship with various departments will be nurtured to promote mutually beneficial services to the patient. Referral for participation in the Dialysis Decisions Patient Education Program will be made directly to the APNN.

**Do**

**SWOT Framework**

The SWOT Analysis framework was a useful tool for evaluating the Dialysis Decisions Patient Education Program due to its simplistic format and visual ease in identification of positive and negative strategies within the internal and external environment to assist in the formulation of program viability conclusions. The following SWOT Analysis was performed to determine the need for the Dialysis Decisions Patient Education Program (Appendix F).

**Strengths:**

- Certified adult educator (APNN, Doctor of Nursing Practice student)
- University Medical Center location with vast resources
- Convenient location
- Need identified for program
• Division of Nephrology support
• Hospital Administration support
• Innovative ideas (logic models, modality stations, current patient interviews)

Weakness:
• No current program
• New program with no history to determine potential success
• Referral base unknown
• Time constraints for patients
• Financial resource constraints

Opportunities:
• No cost for facility
• Division of Nephrology will financially support educational materials
• Accessibility to educational material
• Availability of audiovisual equipment
• May be able to publish and/or present data
• Future promotion of program
• Network with other services (social work, dietitian, billing department, drug reps, transplant department, etc.)
• Promote the university medical center
• Status of being first to develop a CKD education program in the region

Threats:
• Another area program may be initiated
• May not get referrals
• May not be successful
• Referred patients don’t attend

Mission, Goals, Objectives

The mission statement at a university medical center is to improve the human condition. This concept is carried through the Dialysis Decisions Patient Education Program, where the mission statement is to provide CKD education to patients and their families in a safe, supportive environment that promotes self-management, collaboration, knowledge and decision-making. Eligible Medicare beneficiaries with Stage 4 CKD are supported, encouraged and empowered to manage their disease, prevent uremic complications, and provided the tools necessary to foster informed decisions. The program goals are to delay the progression of CKD, improve the health of CKD patients through management of coexisting diseases, facilitate vascular access placement prior to initiation of renal replacement therapy, increase home modality choice, optimize patient education and empowerment through decision-support strategies, and reduce health care costs. The objectives are to have every Medicare eligible patient identified in CKD Stage 4 attend six separate one hour CKD classes over a six to eight week period, decrease fear and anxiety, facilitate an informed modality option decision by improving the patient’s level of knowledge regarding CKD Stage 5 modality options, and evaluation of a decision support analysis tool. The program slogan is: Putting the pieces of life-on-dialysis together, one piece at a time (Appendix G). A CKD acronym for this program is Collaboration, Knowledge, and Decisions.

Defined Market

The market for this program is individuals in Northwest Ohio within commuting distance to a university medical center. Currently, over 2,500 individuals receive dialysis in the Northwest Ohio geographical area (United States Renal Data System, 2007). It is reasonable to
extrapolate that a larger number than those currently on dialysis are in earlier stages of CKD who will eventually reach the need for renal replacement therapy.

This growing market is supported by evidence that approximately 19.5 million or one in nine adults in the United States are affected by CKD (Rasu, Manley, Crawford & Baldrishnan, 2007). Furthermore, the incidence of individuals with CKD is on the rise due to the epidemic of obesity and diabetes and the aging baby boomer generation.

**Current Services**

Prior to the development of this program, no formal pre-dialysis education was offered at a university medical center and no programs have been identified in Northwest Ohio. A variety of corporate dialysis facilities provide education after initiation of therapy; however, by this time, the option of informed modality selection has been lost. In lieu of this, the market was identified as wide open.

All areas of CKD care are under scrutiny to determine how to improve care management, reduce the progression of renal disease, and reduce associated costs with CKD care. Once individuals have initiated treatment, numerous performance indicators are reported to the Centers for Medicare and Medicaid Services. There was a deficit identified in the provision of formal pre-dialysis education which has been shown to improve patient outcomes, and is now supported by CMS. Once the true benefit of this education is realized, CMS may mandate this educational benefit in the future.

**Check**

**Customer Expectations**

A recent informal survey was conducted by this APNN Doctor of Nursing Practice student at an outpatient dialysis facility in Northwest Ohio. The demographics of the individuals
participating included: n=30; 18 men and 12 women; mean age for men was 46.2 years of age; mean age for women was 58.1 years of age; 20 were African-American; 10 were Caucasian; all have been receiving dialysis treatments for less than one year. The purpose of the survey was to recall the patient’s perception of educational needs at the time of treatment initiation. Five general questions about dialysis education were asked. It was explained that they should recollect the time period prior to initiating therapy. The survey results showed: 21 (70%) did not receive any modality education, 30 (100%) stated they would have attended and felt they would have benefited from an education program prior to therapy initiation. Thirty (100%) reported having a general lack of knowledge about renal disease, 20 (67%) could not name alternative modalities to hemodialysis, and 30 (100%) identified experiencing fear of the unknown and anxiety at the initiation of hemodialysis.

**Program Development**

Customers of an education program expect convenient hours, easy to understand information in multiple formats and appropriate length of time for each session. A clinic setting environment provides a comfortable temperature, has adequate lighting, convenient parking that is easy to access, and handicap accessibility. Time is provided during the education session for interaction, questions, reflection, and reinforcement. The atmosphere is informal, accepting and supportive. Family is welcomed and encouraged to attend. The length of the sessions is one hour and builds content retention with frequent reinforcement and restating of information using a variety of methods. All of these factors were considered when the educational program was developed.
A SWOT analysis (Appendix F) was performed to determine if the Dialysis Decisions Patient Education Program was needed. The population to be served was identified as both individual and business customers. The mission statement, goals and objectives have been stated. The market for this program was recognized as well as current services and customer expectations. Based on the market assessment, a need existed for a dialysis decision patient education program at a university medical center. An evaluation of the SWOT analysis revealed that the Strengths and Opportunities outweighed the Weaknesses and Threats; therefore, the prospect of this program being successful is supported by the evaluation.

Program Implementation: Patient Enrollment

The Dialysis Decisions Education Program was initiated at a university medical center in October, 2010. Four patients have been enrolled in the program. Two have completed all six sessions. One patient withdrew after completion of three sessions due to an acute rise in creatinine post arteriogram that required subsequent tunneled catheter placement for urgent dialysis initiation. The second patient withdrew after completion of two sessions due to progression to CKD Stage 5 before completing all sessions and required tunneled catheter and AVF placement with consequential initiation of dialysis. Inability to complete the program due to progression of kidney disease to Stage 5 within a six to eight week time period confirms that referrals remain delayed and education to physicians needs be reinforced to encourage early identification of CKD and timely referral for modality education.

Program Implementation: Physician Education

Physician education regarding the Dialysis Decisions Modality Education Program was begun. Following informal face to face interactions, three internists at a university medical center
and one private practice nephrologist have agreed to refer their CKD Stage 4 patients to this program. A PowerPoint presentation has been developed to present to residents and medical staff in the future during Core Curriculum didactics where a presentation on CKD staging and management will be presented by Dr. Ratnam, Associate Professor, Division of Nephrology. The APNN will end the session with the introduction and explanation of the Dialysis Decisions Modality Education Program and request for referrals.

**Program Implementation: Program Reimbursement**

It was determined by the Department of Finance that the APNN should bill as an independent practitioner. Since the APNN was not a revenue generator in her current roll, provider status is lacking. Applications have been completed and submitted by the APNN for an NPI, Medicare and Medicaid number. Consequently, at this time, due to this previously unrecognized billing issue, patients currently enrolled in the program are not being billed through Medicare and are not required to be Medicare beneficiaries. The decision to open enrollment and delay billing was initiated by Hospital Administration and the Department of Finance. The APNN’s time for each session averages approximately two hours and 15 minutes for each session completed and includes copying handouts, scheduling and calling patient for appointment dates and reminders, education session, and documentation. It is expected that as the number of sessions increases, efficiency will improve. When appropriate, the billing process will be included.

**Check**

**Program Evaluation**

Of the two patients completing the program, both selected in-center hemodialysis. The age of both patients is > 64 years and one is male and one female. Both patients have physical
disabilities that they feel influenced their decision against a home modality option. Due to this low number, the age and comorbid conditions of these patients, their modality option selection are not significant and it is believed that home modality selection will increase with future enrollment. All patients answered post session satisfaction questionnaires favorably and none offered suggestions for program improvement. All patients answered very satisfied with the workshop; yes, they would recommend the session; yes, the session made them aware of changes to improve their health, and three of the four answered very likely to attend future workshops. One patient marked not sure to the question how likely are you to attend more workshops in this program and listed transportation issues as the reason. Items listed to the question: did this workshop make you aware of any changes you could make to improve your health, answers included: take my pills, watch my sugar, and eat better food for me.

From the two patients completing the program, answers to the Decisional Conflict Scale were agree or strongly agree which, as previously described, represents confidence in their modality decision. Results to the Decisional Conflict Scare are as follows:

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<tbody>
<tr>
<td>1. This decision is easy for me to make.</td>
<td>1 - Strongly agree</td>
<td>1 - Agree</td>
</tr>
<tr>
<td>2. I’m sure what to do in this decision.</td>
<td>2 - Strongly agree</td>
<td>0 - Agree</td>
</tr>
<tr>
<td>3. It’s clear what choice is best for me.</td>
<td>2 - Strongly agree</td>
<td>0 - Agree</td>
</tr>
<tr>
<td>4. I’m aware of the options I have in this decision.</td>
<td>2 - Strongly agree</td>
<td>0 - Agree</td>
</tr>
<tr>
<td>5. I feel I know the pros of each option.</td>
<td>2 - Strongly agree</td>
<td>0 - Agree</td>
</tr>
<tr>
<td>6. I feel I know the cons of each option.</td>
<td>2 - Strongly agree</td>
<td>0 - Agree</td>
</tr>
<tr>
<td>7. I am clear about how important the pros are to me in this decision.</td>
<td>2 - Strongly agree</td>
<td>0 - Agree</td>
</tr>
<tr>
<td>8. I am clear about how important the cons are to me in this decision.</td>
<td>1 - Strongly agree</td>
<td>1 - Agree</td>
</tr>
<tr>
<td>9. For the main option I am considering, I am clear about which is more important to me (the pros or the cons)</td>
<td>1 - Strongly agree</td>
<td>1 - Agree</td>
</tr>
<tr>
<td>10. I am making this choice without any pressure from others.</td>
<td>1 - Strongly agree</td>
<td>1 - Agree</td>
</tr>
</tbody>
</table>
11. I have the right amount of support from others in making this choice. | 1 - Strongly agree | 1 - Agree  
12. I have enough advice about the options. | 2 - Strongly agree | 0 - Agree  
13. I feel I have made an informed choice. | 2 - Strongly agree | 0 - Agree  
14. My decision shows what is important to me. | 2 - Strongly agree | 0 - Agree  
15. I expect to stick with my decision. | 2 - Strongly agree | 0 - Agree  
16. I am satisfied with my decision. | 2 - Strongly agree | 0 - Agree  

One of the patients completing the program was referred to vascular surgery and has had timely creation of an AVF. Access placement at initiation of dialysis remains undetermined since for one patient, access creation is not yet appropriate. All four patients enrolled were referred to the program through the Division of Nephrology, so at this time, no non-nephrology physician referrals were realized. At this time, no revenue has been generated due to the APNN unrecognized billing issue. Program expenses to this point have been absorbed by the Division of Nephrology for patient handouts and other educational materials. In the future, as the program grows, materials may be developed and printed with the program logo through the university medical center’s marketing department with funding provided by the university medical center.

**Summary**

The progression of renal disease that culminates in the necessity of renal replacement therapy is identified as well as the prerequisite need for disease specific education, specifically pre-dialysis modality education. The education program content is congruent with MIPPA’s criteria for Medicare benefit reimbursement. A problem was recognized that identified no formal process at an academic medical center for identifying non-nephrology referred individuals prior to the initiation of dialysis. Also, no formal process to offer education to individuals at the appropriate time in their disease progression was previously provided. Pre-dialysis education, utilizing decision aids, decision support and a decision coach demonstrate improved patient
outcomes. The Decisional Conflict Scale is used as an evaluation tool to assess the patients’ perception of the decision making process. A successful EBP QI project was developed and initiated for the Dialysis Decisions Patient Education Program at an academic medical center.

Some important factors identified by patients in the selection of a renal replacement modality include information on survival, morbidity and quality of life. No one treatment modality is best suited for all patients and choices should be analyzed individually with consideration to comorbid conditions, non-medical reasons and demographics. Advantages and disadvantages of each modality and potential complications will be presented to the patients as well as absolute and variable contraindications.

In the future, the implementation of the Dialysis Decisions Patient Education Program will demonstrate having an impact on patients, practice and administration. The patient benefits include increased knowledge, implementation of conservative medical management that may retard or prevent progression of renal failure which extends time to dialysis therapy, improved quality of life, supporting an active role in care management and ultimately the selection of a treatment modality. Practice is impacted by gaining administrative support to develop and manage an advanced practice nurse led education program. As an advocate for patients, practice will be affected through CKD education to other specialty services and support of legislation that promotes improved patient outcomes. Administratively, through education of primary care physicians, referrals should result allowing patients to obtain the education they need to manage their disease. This Dialysis Decisions Patient Education Program can be promoted in the Northwest Ohio geographic area as the only modality education program supported by CMS and fiscally, that the APNN role has transitioned to a revenue generating position.
Barriers

Potential barriers to this project include the potential for physicians to decline referral of patients to this service despite being informed of the program availability and benefits to patients. Patients may have strongly ingrained preconceived perceptions of renal replacement therapy options or outcomes that prohibit them from being able to make an educated, informed modality decision. Patients may not attend all sessions available or suddenly progress to CKD Stage 5 and require urgent or unplanned initiation of dialysis treatments. The program may grow to the point where individual sessions will need to transition to group sessions. Lastly, the ability to initiate a revenue stream is currently delayed due to the lack of Medicare provider status.

Based on the Corbin and Straus (1991) Chronic Illness Trajectory Model, recommendations have been identified to address these potential barriers. Supportive assistance is a form of trajectory that shifts in sync with the illness. This trajectory will be employed to encourage and support patients to complete all sessions by reinforcing the impact self-management can have on delaying progression of their illness course. Trajectory projection, which includes meaning of symptoms, illness, and disability will be utilized to present information in a clear, concise, easy to understand format that will supply the patient with information that may impact their beliefs and allow them to be open to the information presented. Corbin (1998) identifies the nurses’ role as building upon and supplementing efforts of the interdisciplinary team members. This would be utilized to continue to reach out to non-nephrology physicians to reinforce the need for early referral that will prevent unplanned modality initiation as well as highlight the benefits of this program both as it relates to the patient and the physician. An additional emphasis to garner physician buy-in will occur through understanding the benefits of shaping. Shaping encompasses preventing deterioration and
extending stability of renal function and symptom control through education, management, and patient involvement in self-care. In the event the program expands to necessitate group sessions, the trajectory of influencing management will be utilized which includes experience, motivation, resources, setting, interactions and relationships. A group setting format may foster sharing, connections, and interactions that prove mutually beneficial to the attendees as they forge relationships and bonds with each other through their illness connection.
Appendix A

The Nine Concepts of Corbin and Strauss’ Trajectory Theory of Chronic Illness Management and CKD

Trajectory: Course of chronic disease in its different stages and phases

Five Stages of CKD
- Stage 1 with normal or high GFR (GFR > 90 ml/min)
- Stage 2 Mild CKD (GFR = 60-89 ml/min)
- **Stage 3** Moderate CKD (GFR = 30-59 ml/min)
- **Stage 4** Severe CKD (GFR = 15-29 ml/min)
- **Stage 5** End Stage CKD (GFR <15 ml/min)

3 Dimensions
- Symptoms
- Disability
- Outcomes

Trajectory Projection
- 5 Dimensions
  - Meaning of Symptoms
  - Illness
  - Disability
  - Biography
  - Time

Trajectory Scheme
- 3 Dimensions
  - Plan to shape overall illness
  - Plan to control any immediate symptoms
  - Plan to handle disability

Conditions Influencing Management
- Resources
- Experience
- Motivation
- Setting
- Life style and beliefs
- Interactions and relationships
- Type of chronic illness
- Physiologic involvement
- Political and economic climate

Reciprocal Impact
- 2 Dimensions
  - Biography
  - Everyday activities

Specific Nursing Actions
- 6 Dimensions
  - Direct care
  - Teaching
  - Counseling
  - Making referral
  - Making arrangements
  - Monitoring

8 Concepts of Trajectory Phasing
- Pretrajectory
- Trajectory onset
- Crisis
- Acute
- Stable
- Unstable
- Downward
- Dying

Subphasing
- 4 Dimensions
  - Reversal
  - Plateau
  - Upward
  - Drop
**Appendix B**

**Action Plan Table**

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Activities to be Completed</th>
<th>Person Responsible</th>
<th>Timeline Projected</th>
<th>Timeline Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify topic</td>
<td>Define project. Steps to accomplish goals.</td>
<td>Trish, Dr. Smolen</td>
<td>2/2010</td>
<td>2/2010</td>
</tr>
<tr>
<td>Form team</td>
<td>Identify stakeholders. Norma Tomlinson, Dr. Malhotra, Ron Goedde</td>
<td>Trish</td>
<td>2/2010</td>
<td>2/2010</td>
</tr>
<tr>
<td>Determine potential internal patient population</td>
<td>Determine patients admitted in last year with dx CKD Stage 4. Identify # pts currently within Division of Nephrology practice.</td>
<td>Trish</td>
<td>6/2010</td>
<td>6/2010</td>
</tr>
<tr>
<td>Identify potential outside referral sources</td>
<td>Network with GIM physicians at UTMC. Develop relationship with Nephrologists in area to determine interest in referral.</td>
<td>Trish</td>
<td>7/2010</td>
<td>7/2010</td>
</tr>
<tr>
<td>Defend Proposal</td>
<td>Defend Proposal to committee.</td>
<td>Trish, Dr. Smolen</td>
<td>9/2010</td>
<td></td>
</tr>
<tr>
<td>Meet with N. Adm and Finance</td>
<td>Determine FTEs needed for position and number of clinic days needed. Determine reimbursement arrangement with Division of Nephrology. Identify space and available dates for education sessions in Medicine Clinic.</td>
<td>Trish, Norma Tomlinson, Ron Goedde</td>
<td>9/2010</td>
<td></td>
</tr>
<tr>
<td>Identify decision support analysis tool</td>
<td>Decision support tool.</td>
<td>Trish</td>
<td>9/2010</td>
<td></td>
</tr>
<tr>
<td>Define education objectives</td>
<td>Define education objectives.</td>
<td>Trish</td>
<td>10/2010</td>
<td></td>
</tr>
<tr>
<td>Identify clinical practice guidelines</td>
<td>Identify NKF-KDOQI clinical practice guidelines/core indicators.</td>
<td>Trish</td>
<td>10/2010</td>
<td></td>
</tr>
<tr>
<td>Develop curriculum</td>
<td>Develop curriculum.</td>
<td>Trish</td>
<td>10/2010</td>
<td></td>
</tr>
<tr>
<td>Objectives</td>
<td>Activities to be Completed</td>
<td>Person Responsible</td>
<td>Timeline Projected</td>
<td>Timeline Actual</td>
</tr>
<tr>
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</tr>
<tr>
<td>Behavioral Change Action Plans</td>
<td>Develop structured action plan to target specific behaviors.</td>
<td>Trish</td>
<td>11/2010</td>
<td></td>
</tr>
<tr>
<td>Zones for management handouts</td>
<td>Develop handouts with lab values and behaviors in green, yellow and red categories and what action to take in each level.</td>
<td>Trish</td>
<td>11/2010</td>
<td></td>
</tr>
<tr>
<td>Reveal Business Plan and Reimbursement Proposal</td>
<td>Meet with Dr. Malhtora to discuss business plan and reimbursement proposal.</td>
<td>Trish Dr. Malhotra Ron Goedde</td>
<td>12/2010</td>
<td></td>
</tr>
</tbody>
</table>
## Evaluation of the Evidence

<table>
<thead>
<tr>
<th>Source/ Year</th>
<th>Purpose</th>
<th>Sample/ Setting</th>
<th>Results</th>
<th>Implications</th>
<th>Quality of Evidence</th>
<th>Level of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advances in Chronic Kidney Disease, 2008</td>
<td>Explore association between patient’s perceived self-efficacy &amp; self-mgt</td>
<td>N=174</td>
<td>5 types of self-mgt behaviors studied</td>
<td>Fostering self-mgt by supporting patient self-efficacy may have long term benefits associated with positive patient outcomes</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>American Family Physicians, 2005</td>
<td>Identify steps to support self-management in patients with chronic illness</td>
<td>N/A</td>
<td>Self-mgt resources (support tools) are available and personal action plans produce + outcomes</td>
<td>Personal action plans facilitate learning new behaviors and help develop self-care strategies</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>American Journal of Nursing, 2005</td>
<td>Identify nursing strategies to help patient transition through CKD with self-mgt</td>
<td>N/A</td>
<td>Behavior change action plans facilitate behavior changes</td>
<td>Patient is the principal illness manager and needs tools and proficiency in skills and knowledge for this role</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Annals of Internal Medicine, 2008</td>
<td>Clinical Guidelines for CKD</td>
<td>N/A</td>
<td>Defines and provides 5-stage classification of CKD, recommendations for early detection</td>
<td>Due to high prevalence of early stages CKD in general population, important to general internists and specialists</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Bioethics, 2007</td>
<td>Ethics of self-mgt of chronic disease</td>
<td>N/A</td>
<td>4 central ethical issues identified</td>
<td>Conditions must be in place to optimize the benefits of self-mgt while controlling potential harm</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
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<tr>
<td>British Journal of Medicine, 2008</td>
<td>To discuss importance of patient engagement in decision making</td>
<td>Systematic review of 7 papers on coaching</td>
<td>Coaching needs to be tailored to individuals</td>
<td>Coaching can improve patient’s participation and facilitate decision making as well as improve health outcomes</td>
<td>Fair</td>
<td>B</td>
</tr>
<tr>
<td>CANNT Journal, 2006</td>
<td>Explore concepts of compliance, adherence and self-mgmt in CKD</td>
<td>N/A</td>
<td>Nursing interventions are crucial to enhancing patients lives</td>
<td>Nurses are in best position to impact patient’s behavior</td>
<td>Fair</td>
<td>A</td>
</tr>
<tr>
<td>CANNT Journal, 2008</td>
<td>APN education program for patients emergently started on dialysis “Home Dialysis First”</td>
<td>N=233</td>
<td>First 26 months of program, HD decreased from 87% to 33%, home hemo increased from 13% to 67%</td>
<td>APN led education program for patients emergently starting HD can impact modality selection to home dialysis</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Decisional Conflict Scale, 1997</td>
<td>Tool developed to evaluate perceived effectiveness of decision maker’s decision process</td>
<td>N/A</td>
<td>Scale’s construction, conceptual framework, reliability and validity discussed</td>
<td>Scale’s usefulness in evaluation of the decision making process</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Dialysis &amp; Transplantation</td>
<td>Comprehensive CKD program</td>
<td>N/A</td>
<td>SHAPE UP easy to use</td>
<td>Has potential to improve care of CKD patients</td>
<td>Fair</td>
<td>B</td>
</tr>
<tr>
<td>Disease Management, 2006</td>
<td>Identify improved management of CKD</td>
<td>N/A</td>
<td>Reducing burden of CKD on healthcare systems needs to be addressed with early diagnosis and interventions</td>
<td>Associated costs, morbidity and mortality unacceptable. Decrease in incidence may be possible with collaboration of PCP and nephrology</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Evidence Based Medicine Notebook, 2001</td>
<td>Evaluation of evidence based decision aids</td>
<td>Review of literature</td>
<td>Terms and uses defined and outlined</td>
<td>Decision aids are useful for patient’s facing decisions based on personal values and judgments</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
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<tr>
<td>General Hospital Psychiatry, 2003</td>
<td>Examine health information needs and decision making in patients with CKD</td>
<td>N=197 Self-report survey</td>
<td>Participation in levels in decision making were not in agreement with preferred degree of participation</td>
<td>Patients want high levels of information and greater participation in decision making</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Health Education Behavior, 2003</td>
<td>Literature review between social support and chronic illness</td>
<td>N=29 articles 22 quantitative 7 qualitative</td>
<td>Negative social influences identified. Family responsibilities take precedence over disease mgt</td>
<td>Patient’s social environment must be part of plan of care. Social influence can be positive or negative</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>International Journal of Nursing Studies, 2009</td>
<td>Evaluation of a nurse-led disease management program for CKD</td>
<td>Randomized control trial N=120</td>
<td>Evidence supports effective CKD management using nurse led model</td>
<td>Specialty nurse found to be key within this model</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>International Journal of Nursing Studies, 2005</td>
<td>Development of a nurse-delivered dialysis education program using cognitive behavioral therapy for self-care</td>
<td>N=150</td>
<td>Behavioral therapy is an intervention to influence pt behavior</td>
<td>Self-mgt interventions have a beneficial effect on well-being of pts and increase self-efficacy</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Journal of Advanced Nursing, 2007</td>
<td>Review of theoretical and empirical literature review on patient autonomy</td>
<td>N/A</td>
<td>Autonomy is identified in positive and negative freedom</td>
<td>In-depth knowledge of autonomy is needed to interact with patients and facilitate their expression of autonomy</td>
<td>Fair</td>
<td>B</td>
</tr>
<tr>
<td>Journal of the American Academy of Nurse Practitioners, 2007</td>
<td>Present a theory of illness useful in clinical practice promoting self-care</td>
<td>N/A</td>
<td>NP can use this model to establish interventions and action plans to decrease distress in management of symptoms</td>
<td>Useful framework to identify cognitive and emotional illness representations to establish interventions and action plans</td>
<td>Fair</td>
<td>B</td>
</tr>
<tr>
<td>Source/Year</td>
<td>Purpose</td>
<td>Sample/Setting</td>
<td>Results</td>
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<tr>
<td>Journal of General Internal Medicine, 2007</td>
<td>Self-mgt in chronic disease is explored</td>
<td>Case study</td>
<td>Intervention effectiveness in areas of prevention, addiction, and self-mgt of chronic disease</td>
<td>Implications for research are discussed as well as how to engage patients in behavior change</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Journal of Lancaster General Hospital, 2007</td>
<td>Guideline commentary</td>
<td>N/A</td>
<td>Importance of Albuminuria in early stages of CKD reviewed due to likelyhood of disease progression</td>
<td>Heightened awareness and partnering with PCP essential in retarding progression of CKD</td>
<td>Fair</td>
<td>A</td>
</tr>
<tr>
<td>Journal of Nursing Care Quality, 2006</td>
<td>Convey importance of evidence based practice and theory-driven care</td>
<td>N/A</td>
<td>Leadership strategy based on evidence based practice</td>
<td>This framework is versatile and relevant for translating evidence into practice</td>
<td>Fair</td>
<td>A</td>
</tr>
<tr>
<td>Journal of Renal Care, 2005</td>
<td>Identify perceptions and experiences of pre-dialysis patients</td>
<td>Qualitative study N=10</td>
<td>Patients had no clear perceptions or expectations of treatment prior to therapy initiation</td>
<td>Patients lack of knowledge due to lack of formal and informal education</td>
<td>Fair</td>
<td>A</td>
</tr>
<tr>
<td>Journal of Renal Care, 2006</td>
<td>Identify quality of life tools</td>
<td>N/A</td>
<td>QOL tools compared</td>
<td>QOL tools provide nurses with important information. Instrument must be valid and reliable</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Journal of Renal Care, 2008</td>
<td>Develop a self-management packet for diabetic patients at risk of CKD</td>
<td>Interviews and education N=370</td>
<td>Patients were not aware of risk of CKD</td>
<td>Educational packages addressed deficits in knowledge</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Kidney International, 2007</td>
<td>Identification of patient needs of pre ESRD education</td>
<td>N/A</td>
<td>Patients are not making informed modality choices</td>
<td>Improvement in pre ESRD education is needed</td>
<td>Fair</td>
<td>B</td>
</tr>
<tr>
<td>Source/Year</td>
<td>Purpose</td>
<td>Sample/Setting</td>
<td>Results</td>
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</tr>
<tr>
<td>Managed Care, 2003</td>
<td>Managed Care Organizations targeting CKD Stage 3 &amp; 4 for Disease Mgt</td>
<td>N/A</td>
<td>Aggressive mgt of CKD will impact progression</td>
<td>Financial as well as health benefit possibilities</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Medical Decision Making, 2007</td>
<td>Evaluate 2 criteria of decision aids, values clarification and reduction of decisional conflict</td>
<td>N/A</td>
<td>Value clarification is difficult to measure or assess. For many decisions, uncertainty is reality and should be supported</td>
<td>Decision aids have potential to be valuable adjuncts to patient decision making</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Medical Informatics and Decision Making, 2006</td>
<td>Systematic review of computerized decision support systems (CDSS)</td>
<td>Systematic review of randomized control trials using CDSS</td>
<td>Many CDSS programs have failed for various reasons</td>
<td>Use of decision tools is important and should not focus on technology. Use best tool for each problem and patient</td>
<td>Fair</td>
<td>B</td>
</tr>
<tr>
<td>National Kidney Foundation, 2002</td>
<td>Clinical practice guidelines for CKD</td>
<td>N/A</td>
<td>Evidence based guidelines</td>
<td>Improve outcomes</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Nephrology, Dialysis and Transplantation, 2008</td>
<td>Introduction of an algorithm-based, primary care CKD disease mgt program</td>
<td>N=483</td>
<td>Significant improvements after nine months compared to baseline</td>
<td>Chronic disease management is an effective method of identifying and managing patients with CKD</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Nephrology, Dialysis and Transplantation, 2008</td>
<td>Commentary of “epidemic” of CKD</td>
<td>N/A</td>
<td>Disparities in diagnosis of CKD by race and sex</td>
<td>Need to follow NKF-KDOQI guidelines</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Source/Year</td>
<td>Purpose</td>
<td>Sample/Setting</td>
<td>Results</td>
<td>Implications</td>
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</tr>
<tr>
<td>Nephrology News and Issues, 2008</td>
<td>Understanding motivation can improve patient behaviors</td>
<td>N/A</td>
<td>Practitioner support of patient autonomy will increase motivation</td>
<td>Supporting patients and</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Nephrology Nursing Journal, 2008</td>
<td>Identify the impact of a nurse-led clinic on self-care ability, disease-specific knowledge and home dialysis modality</td>
<td>N=70</td>
<td>59% chose self-care dialysis in nurse led group compared to 33% in control group</td>
<td>Nurse –led clinic offered increased access to care, increased opportunities for education and information, facilitated learning</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Nephrology Nursing Journal, 2008</td>
<td>Explore how pts with CKD describe liminal experience with CKD &amp; treatment</td>
<td>Qualitative design N=100</td>
<td>Diverse liminal spaces identified in CKD</td>
<td>Acknowledging liminal spaces provides support and hope for patients</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Nephrology Nursing Journal, 2008</td>
<td>To explore, describe, and stimulate interest in self-mgmt in pts with CKD</td>
<td>Qualitative design N=14</td>
<td>Patients learned to renegotiate life with CKD education</td>
<td>Collaborative partnership of self-management can fill current void in early CKD patients</td>
<td>Fair</td>
<td>A</td>
</tr>
<tr>
<td>Nephrology Nursing Journal, 2007</td>
<td>Identify how to use motivational interviewing successfully</td>
<td>N/A</td>
<td>Coaching and motivating are successful strategies for changing behavior</td>
<td>Knowledge of stages of change can facilitate behavior changes in patients</td>
<td>Fair</td>
<td>B</td>
</tr>
<tr>
<td>Nursing Outlook, 2006</td>
<td>Understand, develop and test new interventions to enhance self and family mgt in chronic conditions</td>
<td>N/A</td>
<td>Improved outcomes such as higher self-efficacy, empowerment, better adherence to tx, improved QOL</td>
<td>Growing emphasis on self-management, gaps in literature, need more nursing research in this area</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Source/ Year</td>
<td>Purpose</td>
<td>Sample/ Setting</td>
<td>Results</td>
<td>Implications</td>
<td>Quality of Evidence</td>
<td>Level of Evidence</td>
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<tr>
<td>Patient Education and Counseling, 2008</td>
<td>Evaluate the DSAT-10 tool</td>
<td>76 encounters</td>
<td>Tool was effective and easy to use.</td>
<td>Inter-rater reliability was confirmed.</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Patient Education and Counseling, 2009</td>
<td>Identify factors influencing patient involvement in decision making</td>
<td>Systematic review of literature 40 studies</td>
<td>Four influential factors identified in CKD patient’s decision making</td>
<td>More studies are needed to help patients with CKD make decisions</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Patient Education and Counseling, 2009</td>
<td>Determine feasibility of implementing 3 decision support tools</td>
<td>N=20</td>
<td>Tools were identified as useful and should be used during consultation</td>
<td>Decision support tools are useful tools that can help ensure patients are involved, informed and supported during decision making</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Patient Education and Counseling, 2010</td>
<td>To develop an instrument that assesses extent that patients are involved in decision making</td>
<td>N/A</td>
<td>Instrument was developed and tested</td>
<td>Tool is available to evaluate patient participation in decision making.</td>
<td>Fair</td>
<td>B</td>
</tr>
<tr>
<td>Quality in Health Care, 2000</td>
<td>Decrease progression of CKD in diabetic patients</td>
<td>Randomized control trial N=1148</td>
<td>Tight BP control group had less microvascular disease</td>
<td>Promotion of self-management programs can impact rate of progression of CKD</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Queensland Government, Princess Alexandra Hospital, Australia, 2009</td>
<td>Health management protocol for CKD</td>
<td>N/A</td>
<td>Clinical Practice Guidelines Developed</td>
<td>Promotion of health, mgt of complications, delay of progression, multidisciplinary management of CKD</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Renal Physicians Association, 2009</td>
<td>Development of a CKD clinic</td>
<td>N/A</td>
<td>Guidelines</td>
<td>Steps provided in process of clinic development to develop and implement a comprehensive action plan</td>
<td>Good</td>
<td>A</td>
</tr>
<tr>
<td>Source/Year</td>
<td>Purpose</td>
<td>Sample/Setting</td>
<td>Results</td>
<td>Implications</td>
<td>Quality of Evidence</td>
<td>Level of Evidence</td>
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</tr>
<tr>
<td>Worldviews on Evidence-Based Nursing, 2008</td>
<td>To offer an evidence-based decision coaching framework</td>
<td>Review of Literature</td>
<td>Nursing interventions can assist patients in the decision making process</td>
<td>Providing options, screening for decisional conflict, and educating and supporting decisions impacts patient participation</td>
<td>Good</td>
<td>A</td>
</tr>
</tbody>
</table>
### The Generic Decisional Conflict Scale

<p>| | | | | | |</p>
<table>
<thead>
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</thead>
<tbody>
<tr>
<td>17. This decision is easy for me to make.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>18. I’m sure what to do in this decision.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>19. It’s clear what choice is best for me.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>20. I’m aware of the options I have in this decision.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>21. I feel I know the pros of each option.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>22. I feel I know the cons of each option.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>23. I am clear about <em>how important</em> the pros are to me in this decision.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>24. I am clear about <em>how important</em> the cons are to me in this decision.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>25. For the main option I am considering, I am clear about which is <em>more</em> important to me (the pros or the cons)</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>26. I am making this choice without any pressure from others.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>27. I have the right amount of support from others in making this choice.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>28. I have enough advice about the options.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>29. I feel I have made an informed choice.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>30. My decision shows what is important to me.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>31. I expect to stick with my decision.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
<tr>
<td>32. I am satisfied with my decision.</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither Agree Nor Disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
</tbody>
</table>

(O’Connor, 1997, p. 15-16)
Appendix E

Session Topic Outline

Session 1. Chronic Kidney Disease: What You Need to Know
- Why you should learn about chronic kidney disease (CKD)
- What are kidneys and how do they maintain health?
- What is chronic kidney disease (CKD)?
- Understanding the complications of CKD
  - Anemia
  - Mineral and bone disorders
  - Malnutrition
  - Cardiovascular disease (CVD)
- What causes CKD and why?
  - Diabetes
  - High Blood Pressure
  - Other common conditions
- How CKD is diagnosed
- The different stages of CKD
- The symptoms of CKD
- Treatment for CKD (Stage 4)
  - Goal of treatment
  - Diet and fluids
  - Medications
  - Exercise
- What kidney failure is and how it is treated
- Participant/professional role in Stages 4 and 5
- How to pay for treatment
- Questions & Answers

Session 2. Chronic Kidney Disease: What You Can Do
- What you will learn today
- Understanding how CKD can affect your body
  - Heart and blood vessel problems
    - High blood pressure, abnormal cholesterol, heart attack, stroke
  - Anemia
  - Bone disorders
  - Malnutrition
  - Buildup of toxins (called uremia)
  - Depression
- Working with your health care professional to create a plan of care
  - Control of blood pressure
  - Lower high cholesterol
  - Treat anemia
  - Lower risk of bone disorders
  - Prevent malnutrition
• Preserve kidney function
• Manage depression

Questions & Answers

Session 3. Choosing Transplantation
• What you will learn today
• What is a kidney transplant?
• Understanding how the process to get a transplant works
  o Who can get a transplant
  o Early transplant/Living donor
  o The transplant team
  o Advantages and disadvantages of kidney transplantation
  o How to meet transplant costs
  o Types of donors/Evaluation of donors
  o Transplant tourism
  o The transplant waiting list
• What happens when a kidney is available?
  o The operation, in-hospital care and potential longer-term problems
• Transplant medicines and why they’re important
• Transplant rejection and what you can do about it
• How to live well with a transplant
  o Work, exercise, nutrition, pregnancy
• Questions & Answers

Session 4. Choosing Dialysis
• What you will learn today
• Understanding dialysis
  o What dialysis is
  o What dialysis can and cannot do
  o How dialysis works
• Peritoneal Dialysis
  o How it works
  o Equipment/Technique
  o Access
  o The pros and cons of peritoneal dialysis
• Hemodialysis
  o How it works
  o Access
  o Home therapy
  o In-center therapy
  o The pros and cons of hemodialysis
• Dietary recommendations for people on dialysis
• Traveling while on dialysis
• Working while on dialysis
• Questions & Answers

Session 5. Choosing the “No Treatment” Option
• What you will learn today
• Choice is a participant right
• Making the choice for “No Treatment”
• What an Advance Directive is and why it’s important
• Family, legal and financial matters
• Understanding support services (hospice, end-of-life-care, palliative care, spiritual support, psychosocial support, symptom control/adjunct therapy)
• Questions & Answers

Session 6. Living Well With Your Choices
• What you will learn today
• Psychosocial well being
  o Common worries and emotions
  o Coping strategies
  o Who can help
• What you can do to feel your best
  o Being informed
  o Maintaining family and social support
  o Watching for depression (prevention and early detection)
  o Maintaining psychological health (keeping a positive attitude, having a sense of humor, setting realistic goals, maintaining spiritual beliefs, etc.)
  o Following your treatment plan
  o Exercise
  o The benefit of meaningful activities (hobbies, work/employment, travel, etc.)
• Finances
• Questions & Answers

(National Kidney Foundation)
Appendix F

SWOT Analysis

SWOT ANALYSIS

Helpful
Harmful
in achieving the objective
in achieving the objective

Strengths
Weaknesses

Opportunities
Threats

(SWOT Analysis, 2008)
Appendix G
Dialysis Decisions Education Program Logo

Dialysis Decisions
Putting the pieces of life-on-dialysis together, one decision at a time

Dialysis Decisions Education Program CKD Acronym

Collaboration
Knowledge
Decisions
References


1842-1847.


