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CHRONIC KIDNEY DISEASE PATIENTS’ EXPERIENCES IN THE DECISION MAKING PROCESS: THE RELATIONSHIP BETWEEN PERSONAL CHARACTERISTICS AND DECISIONAL SELF-EFFICACY ON DECISIONAL CONFLICT AND THE DIALYSIS DECISION IN PATIENTS WHO PARTICIPATED IN SHARED DECISION MAKING

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ABSTRACT

Patients with End Stage Renal Disease (ESRD) experience a complex and stressful decision making when comes to dialysis modality selection. There are pros and cons to both hemodialysis (HD) and peritoneal dialysis (PD). Patients are often uncertain as to which one is the best modality for them. This decisional conflict increases the likelihood of making a decision that is not based on the patient’s values or preferences and may result in undesirable post-decisional consequences.

Purpose

The purpose of this study was to explore Chronic Kidney Diseases (CKD) patients' experiences regarding their decision making process in selecting a dialysis modality. The study examined individual characteristics and explores the relationship between characteristics such as demographics, decisional self-efficacy, and decisional conflict on perceived participation in shared decision making in a sample of individuals with CKD.

Research Objective

The objective of this mixed-method study was twofold: (a) to provide a quantitative description of the sample of individuals with CKD who are currently considering any one of the treatment strategies or currently receiving treatment for CKD within the last three months of diagnosis; and (b) to explore relationships between individual characteristics and participation in shared decision making (SDM) as they predict their decisional conflict and satisfaction with the decision made.

Method

This study employed a mixed-methods approach with an exploratory and a descriptive correlation designed to evaluate constructs of individual characteristics that
may impact the decisions of individuals with CKD participating in shared decision making as described by the Ottawa Decisional Support Framework.

**Sample**

Study participants were recruited directly from the Kidney Solutions website (kidneysolutions.org). A recruitment flyer was sent out with the researcher’s contact information to Kidney Solutions along with the survey questionnaire using Google Forms. Kidney Solutions then sent out the link directly to all the patients who qualify for the study based on the inclusion criteria via email. No participants were contacted directly by the researcher. Participants were informed that their participation was voluntary, confidential, and that they could opt-out at any time.

**Procedure**

Data were collected after obtaining approval from Molloy College IRB. The survey was integrated into a single web-based set of questions using Google Forms. Completing the questionnaire indicated the subject's consent to participate. The online survey included four inclusion criteria questions: (a) 18 years of age and older; (b) individuals who self-identify as having CKD diagnosed by a healthcare provider; (c) individuals currently considering or within the last three months has decided on a treatment option for CKD; (d) individuals who can participate in English and have modest internet skills.

**Measures**

Suitable tools were selected after an intense literature review that would be useful in measuring the research concepts in shared decision making, and permission was obtained from the developers of the tool for the study. These instruments capture participants’ self-reported Decisional Self-Efficacy Scale (DSES), decisional conflict
(SURE test), shared decision making (9-item Shared Decision Making Questionnaire), and Satisfaction with Decision Instrument.

**Results**

Statistical analysis was performed to determine relationships between individual characteristics and concepts in shared decision making using *t* test, Chi-square, ANOVA and Pearson product-moment correlation coefficient and multiple linear regression. Participants were predominantly White (63.6%), male (54.5%), between 45-64 years old (45.5%), married or partnered (54.5%), college educated (60.0%), with most reporting CKD stage 5 (63.6%). There was a statistically significant difference at the *p* < .05 level in SDMQ9 scores for Decision making support (*t* = -2.582, *p* < .05) and use of a decisional aid in decision making (*t* = -2.357, *p* < .05). The study also found a statistically significant association between current treatment option (*p* = .021) and decisional conflict as measured by the SURE test. There was a statistically significant positive correlation between decisional self-efficacy (as measured by the DSES) and shared decision making (as measured by the 9-item Shared Decision Making Questionnaire) observed (*r* = .390, *n* = 55, *p* < .01). There was a significant relationship between participation in shared decision making and decisional conflict (*r* = -0.362, *p* < .01). The results indicated a negative correlation, which means as SDM increases, less decisional conflict is reported by the participants. There was a significant relationship between decisional self-efficacy and decisional conflict (*r* = -0.489, *p* < .001). The results indicated a negative correlation, which means as Decisional Self-Efficacy increases, less decisional conflict is reported by the participants. There was also a positive correlation between shared decision making and satisfaction with the decision, *r* = .701, *n* = 55, *p* < .01. There was also a positive
correlation between decisional self-efficacy and satisfaction with decision, \( r = .624, n = 55, p < .01. \)

Prediction for satisfaction with decision (SWD) is significant using a multiple linear regression model by combining decisional self-efficacy (DSES) and SDM, with \( n = 55, R = 0.797, R \text{ square} 0.636, \text{Adjusted } R \text{ square} = 0.622, F = 45.408. \) Prediction for decisional conflict (SURE) was significant using a multiple linear regression model by combining DSES and SDM, with \( n = 55, R = 0.523, R \text{ square} 0.273, \text{Adjusted } R \text{ square} = 0.245, F = 9.781. \) In this model, decisional self-efficacy predicts decisional conflict more than shared decision making. Shared decision making had a non-significant impact on the dependent variable decisional conflict alone, but it adds to the prediction when combined with decisional self-efficacy. Qualitative findings supported several quantitative findings, adding depth to understanding participants’ views.

**Conclusions**

The findings contribute to understanding the importance of increasing patient involvement in determining treatment when more than one treatment option exists based on the goals of care. Providers must approach their patients’ critical decision points in their illness trajectory with an openness of sharing in the plan of care. There is a significant need to move away from a “one-size-fits-all” approach to dialysis and provide more individualized care that incorporates patient goals and preferences while still maintaining best practices for quality and safety.
DEDICATION

This research work is dedicated to my family, particularly my understanding and loving husband, Jacob Jojan, and my loving children, David and Chris. If not for their patience, lasting encouragement, and support, I would not have achieved this dream. You have always inspired me to be the best in whatever role I take.
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CHAPTER 1: INTRODUCTION

The purpose of this study is to explore Chronic Kidney Diseases (CKD) patients' experiences regarding their decision making process. Choices can be difficult and stressful when making dialysis modality decisions for patients with end-stage renal diseases (ESRD); there are pros and cons to both hemodialysis (HD) and peritoneal dialysis (PD), as well as conservative care. The conservative management of ESRD involves shifting from efforts to prolong life to those focusing on care, quality of life, and symptom control. Multiple research studies have shown variances between the three treatment choices (Budhram et al., 2020). The current study is focused only on HD and PD as treatment choice.

Patients are often uncertain as to which treatment choice was the best alternative for them and may experience decisional conflict. This decisional conflict increases the likelihood of making a decision that is not based on the patient's values or preferences and may result in undesirable post-decisional consequences. To make the best treatment decision possible, clinicians should educate patients on all available treatment options, the risks and benefits of treatments, and the importance of an informed exploration of the patient's preferences and values. Due to a lack of timely information about all available treatment alternatives, HD may be the most frequently chosen therapy option for individuals with ESRD. The Decisional Conflict Scale (DCS), developed by Légaré and team (2006), has been widely used to evaluate patients' decisions regarding types of healthcare treatment, such as choices for various screening tests (Légaré et al., 2006).

Patients with ESRD may experience decisional conflict when they are unaware of the dangers and advantages of treatment options. As defined by the North American Nursing
Diagnosis Association, decisional conflict is a person's uncertainty and hesitancy regarding the optimal course of action when confronted with decisions that involve risk, regret, or challenges to their values and beliefs (Hu et al., 2021). Several variables that contribute to greater decisional conflict include a lack of clarity on personal values (what benefits, risks, and side effects are most important) and lack of support/guidance when choosing between treatment alternatives (Noble et al., 2017).

Addressing factors predisposing patients to decisional conflict helps to facilitate informed decision making and then to improve healthcare quality. Such decisions are value-laden so that patients require ample information on HD and PD and emotional support to help them discern and express their exact treatment preferences. Patients with ESRD may be more conflicted when they feel uninformed about treatment risks and benefits. Patients experiencing decisional conflict are more likely to oscillate between treatment options and postpone decision making. Several factors can influence patients' level of decisional conflict, including their level of knowledge about their treatment options, their clarity about the risks and benefits that are most important to them, and their sense of familial support when faced with a difficult decision about their kidney disease treatment (McPherson et al., 2017).

Background

For patients with chronic kidney disease (CKD) who are progressing to end-stage renal disease (ESRD), the decision about whether to undertake HD or PD becomes a critical component of the patient's journey. Over the last several decades, the importance of shared decision making (SDM) in healthcare has become increasingly recognized. Clinicians educate patients about all available options and assist them in identifying their preferences within the
context of their values. The American Cancer Society's guideline for colorectal cancer screening exemplifies the importance of involving patients in decision making in the face of uncertainty (Volk et al., 2018).

An integrated analysis conducted by Stacey et al. (2017) found that patients who received decision-support interventions had greater knowledge, less decisional conflict, and higher satisfaction than those who received standard care. As a result, it is critical to improve communication by involving patients and families in decision making through informed SDM; this can help alleviate decisional conflict if clinicians are aware of the patient's beliefs and preferences, increasing the patient's comfort with the decision. ESRD patients frequently postpone their decision to start long-term dialysis. These delays can aggravate the ESRD diagnosis and make it potentially fatal. Patients must weigh numerous factors before choosing dialysis treatment. For example, dialysis requires long-term dietary and hydration management, medication compliance, and discomfort during treatment. These limitations invariably have an effect on a patient's quality of life. Additionally, the range of available dialysis alternatives may contribute to delays in initiating dialysis. These delays are indicative of decisional conflict, particularly when ESRD patients are confronted with the hard decision of dialysis. Many medical decisions are fraught with uncertainty, causing patients to hesitate and experience decisional conflict. Given the known difficulty of making medical treatment decisions, and determining the scope of treatment along with identifying the factors that are best suited for interventions must be designed to reduce decisional conflict. Therefore, decision-makers’ experiences can be improved using tangible communication strategies that encourage patient and family engagement in the conversation, particularly for individuals with limited health literacy, which is critical in the
decision making process (Pecanac et al., 2020).

Two behavioral scientists, Janis and Mann (1977), found in their research that poor decision making will most likely occur in areas where the stress is so intense as to render the individual unable to function adequately. When patients are newly diagnosed with renal failure, it is most stressful, as it is a life-threatening and lifelong illness that coincides with the timing of when decisions need to be made. These researchers asserted that inadequate decision making will occur unless the patient is vigilant about the decision making process due to the increased stress. This study addressed patients with CKD who are progressing to ESRD. Deciding between two types dialysis (HD or PD) or conservative care is a critical component of the patient's journey, which is eased by using patient decision aids (PtDAs) in operationalizing SDM.

When treatment alternatives exist in a range of medical conditions, patients express preferences when informed and given the opportunity. For example, anticoagulation decisions should be made in individuals with nonvalvular atrial fibrillation using the CHA2DS2-VASc score, and primary prevention with a statin should be made using the patient's 10-year risk of cardiovascular disease (Fried, 2016). When doctors provide patients with accurate information about their treatment options, many patients are able to voice their preferences and align with clinicians' recommendations to make choices that are contradictory to their preferences.

Recent healthcare policy changes in the United States (The Advancing American Kidney Health Executive Order) have acknowledged existing barriers to home dialysis utilization and used a series of incentives to reduce in-center HD. From a health provider perspective, there are clear cost-related differences in the dialysis modalities, with home modalities being more cost effective than in-center dialysis delivery (Budhram et al., 2020; Walker et al., 2017).
A study conducted by Finderup et al. (2018) showed that only a small number of patients made the decision to start home dialysis, but after the patients were involved in SDM intervention, and based on clinical judgment of the healthcare provider, 80% of the patients chose dialysis at home. This was an increase by 23% of patients starting home dialysis, even though it was not their initial preference. Not all patients are able to choose their treatment option freely because of contraindications related to their medical condition. For example, if a patient prefers PD and the patient has uncontrolled diabetes, the nephrologist will not offer PD due to high glucose concentration in peritoneal dialysate. Instead, the patient is offered HD, as conventional PD fluid contains a high concentration of glucose (75-215 mmol/l) as the osmotic agent. Therefore, the dialysate is hyperosmolar in relation to serum, causing fluid removal (ultrafiltration) to occur (Farhat et al., 2008). Several approaches have been studied to improve SDM, such as educating clinicians on communication techniques, using a multidisciplinary medical team, incorporating trained decision coaches, and using PtDAs tools to support patients' decision making. These tools are commonly referred to as in operationalizing SDM.

“The process by which the optimal decision may be reached for a patient at a fateful health crossroads is called SDM and involves, at minimum, a clinician and the patient, although other members of the healthcare team or friends and family members may be invited to participate.” (Barry & Edgman-Levitan, 2012, p. 780) Both parties communicate information during SDM: the clinician presents options and outlines their associated risks and advantages, while the patient shares their preferences and values. When there are multiple viable treatments or screening options, healthcare professionals can facilitate SDM by encouraging patients to communicate their concerns to healthcare professionals and by providing decision aids that increase the patient's awareness and understanding of the
Despite decades of ethical, empirical, and policy support, SDM in healthcare in the United States has yet to become mainstream practice. Organizational and health system variables appear to have a role in the implementation challenges associated with SDM in routine care. The study by Scholl et al. (2020) identified that the overarching trend in the data gathered was concerned about a lack of revenue-generating, organizational, and individual profit margins of health professionals as a major impediment to SDM implementation. On an organizational level, leaders' support for SDM was deemed crucial for implementation. At the health system level, opinions varied on whether embedding tools within electronic health records, requiring SDM as a requirement for accreditation and certification, and passing legislation would facilitate SDM implementation. Achieving higher-quality healthcare at a lesser cost has piqued policymakers' interest in SDM. In the United States, programs are in place to promote SDM through legal and financial incentives, primarily through the implementation of PtDAs (Spatz et al., 2017).

In recent years, there has been a clear shift toward a more holistic, patient-centered approach in healthcare in which a strong clinician-patient relationship and the establishment of common ground are emphasized. Clinicians are expected to provide patients with the education and support they need to understand and integrate complex medical information to make informed decisions. This process evolved in the literature to this broader concept that expands patient involvement to an active SDM, which implies that medical decisions are made collaboratively according to the best available evidence provided by the clinician and the patient's values and preferences. In several studies of diseases with multiple treatment options such as prostate cancer and chronic pulmonary lung disease (Tiedje et al.,
2013), innovative tools have been introduced to assist patients in navigating the information and reflecting on personal choices to assist them in the decision process. While some of these PtDAs have been implemented and shown evidence of supporting patient-treatment choices that value their personal preferences for select diseases, there are few feasible mechanisms available for patients with kidney failure to easily navigate the process other than traditional information packets and brief conversations with providers. Even more importantly, there is little known about the precursors of using decision aids based on knowing the relationship between self-efficacy, decisional conflict, and how they may influence participation in SDM.

**Limitations in Patient Decision Aids**

The use of educational decision aids with patients experiencing decisional conflict may facilitate more in-depth provider-patient discussions about kidney transplantation and dialysis, and eventually reduce decisional conflict. In Stacey et al.'s (2017) systematic review of decision aids for patients facing treatment decisions, results from 115 studies led researchers to conclude that the use of decision aids improves patients' knowledge about their treatment options and lessens patients' level of decisional conflict. Clinicians play a critical role in assisting patients in making patient-centered decisions and may be supported by decision aids that improve decision making.

Decision aids that encourage people to be more actively involved in decision making and improve risk perceptions and congruence between the choice made and patient values is a necessary addition to clinical practice and ways to measure the quality of those choices (Noble, 2017). According to the International Patient Decision Aid Standards (2017), a PtDAs is intended to assist patients in making educated, value-based decisions.
PDAs must make the decision apparent by providing the required information and outlining the benefits and drawbacks. The objective is to achieve agreement between the choice and the decision maker's personal values and preferences. PDAs assist in resolving decisional issues. Although certain PDAs have been created for patients with chronic renal disease, there is limited research on their effects. When patients are confronted with medical decisions, providing them with decision aids can significantly assist them in making informed choices and improving their decision making (Therkildsen et al., 2019). For this study, understanding how patients’ personal characteristics influence their participation in SDM is fundamental to developing appropriate decision aids in the future.

Research in SDM has focused on the use of PtDAs to decrease decisional conflict; however, to this researcher’s knowledge, there have been no DAs rigorously tested in the CKD population that incorporate new therapeutic management options or consider individual characteristics and how these characteristics may impact engaging in decision making. Decisional aids assist the individual by incorporating personal values and preferences by describing the risks and benefits of equipoise treatment options. Research regarding PtDAs used by professionals in the encounter with the patient is limited (Finderup et al., 2018). In the meta-analysis by Stacey et al. (2017), only 16 studies evaluated PtDAs used in the encounter. An overview of nine PtDAs regarding dialysis choice is shown in Appendix A. Only five PtDAs have been used as a part of an intervention, including decision coaching, and only four of these have been evaluated. Decisional aids are intended to individualize patient care by decreasing decisional conflict and increasing knowledge; however, PtDAs have not considered individual characteristics such as sociodemographic, decisional self-efficacy, and how decisional conflict influences participating in SDM. A SDM process can be supported by PtDAs when better
understood. Decision aids are interventions that support patients by making their decisions explicit, providing information about options and associated benefits/harms, and helping clarify congruence between decisions and personal values, as defined by Stacey et al. (2017).

Involving the patient in making the decision on dialysis treatment choice has been recommended internationally for a decade. While there is evidence to support that PtDAs are effective interventions to increase patient involvement in making health decisions that facilitate SDM, how it impacts decisions or if the shared decision process results in positive outcomes for CKD patients is unknown, especially when patients must face complex clinical choices. In general, the literature suggests a lack of evidence regarding how best to implement PtDAs and SDM in clinical practice for patients with kidney failure who must decide the type of dialysis: HD or PD (Finderup et al., 2020). This study explored multiple factors that are part of the decision making process for patients with kidney failure who are on dialysis, having made clinical care choices over the course of their disease, and facing the transplant decision going forward. The findings can inform how to develop appropriate PtDAs that can best serve to accommodate the decisional conflict and participation in SDM that influence decisional satisfaction (i.e., the variables of this study).

Problem Statement

SDM for complex illness within routine clinical care remains a significant challenge. The inconsistency in education practices and evidence of patients not being involved in SDM indicate the need for research in this area. The present study examine patients with CKD characteristics that are progressing to ESRD and face the decision between two types of dialysis or as they may be progressing to another decision point, such as a renal transplant. It is a critical component of providers to fully understand the patient's journey through the decision processes, which may be
eased by using PtDAs in operationalizing SDM. This study extracted demographic, clinical, and personal characteristics such as self-efficacy to predict the satisfaction of the treatment decision and if SDM influenced the process. Additional descriptions in the patients' own words were elicited to describe their reflections on the facilitators and barriers to reaching the decision they made and the possible transplant decision they may be facing as the disease progresses.

**Significance of the Study**

More than 700,000 Americans suffer from ESRD. This life-limiting condition carries a high cost of healthcare utilization and significant life-altering burden and mortality (Singh et al., 2019). For a patient with CKD who is progressing to ESRD, deciding whether to undertake two types of dialysis is a critical component of the patient journey. As an ethical imperative of an individual's right to be informed, SDM in treatment options is recommended under professional organization guidelines and mandated under Centers for Medicare and Medicaid Services.

Barriers to CKD patient education are present at three levels. First, at the patient level, barriers include low health literacy levels, minimal awareness of kidney health in the general public, a low readiness to learn, and comorbidities. Second, at the clinician level, there are time and resource constraints, a lack of confidence in communicating the complexity of CKD, competing demands, and a lack of consensus on diagnosing and educating patients. Finally, at the systematic level, barriers include limited monetary incentives for education, lack of access to decision aids, inadequate multidisciplinary care teams, and a lack of role clarity and communication between different specialties (Cassidy, 2018).

SDM for a complex decision such as dialysis choices, transplant, or conservative care could be enhanced by a decision aid, a well-utilized practice in other disciplines but limited in nephrology (Fortnum et al., 2015). International renal guidelines recommend that all patients and
caregivers be adequately educated to make an informed decision (NICE guidelines, as cited in Fortnum et al., 2015). Informed SDM involves mutual dialogue between patient, family members, and the provider regarding treatment options, which helps accomplish true patient-centered care. Through multiple literature review searches, one can identify that, indeed, this gap in information exchange between the nephrology team and patient may be due to the provider's lack of awareness, communication skills, or time spent with the patient. Patients are not taught about PD as a viable option. The inconsistency in education practices, coupled with evidence of patients not being involved in SDM indicated the need for research in this area.

Research on SDM has focused on the use of decisional aids to decrease decisional conflict. SDM approaches integrating PtDAs, and decision coaching have not been fully developed for patients with ESRD. As a starting point, the Registered Nurses Association of Ontario (2009) produced a Best Practice Guideline for Decision Support for Adults Living with Chronic Kidney Disease that described a decision-coaching framework within which practitioners bring clinical expertise and patients share their personal preferences and values. SDM is a promising innovation to support the recalibration of approaches to care for patients living with ESRD. Early preparation can lower risks associated with urgent hospitalization or an unplanned start to dialysis.

A decision-support intervention can reduce the total DCS for a patient if that intervention provides sufficient information about choices (O' Connor, 1995). A decisional aid can be a useful tool for intervention to encourage active involvement in decision making and improve risk perceptions and congruence between the choice made and patient values. A patient-centered approach to decision making helps to clarify questions and reach an optimum treatment choice self-selected by the patient between HD, PD, and conservative management. Such an
intervention may also reduce emotional stress by enhancing the patient's sense of personal control over difficult situations. Sense of control will increase self-efficacy and empowerment and decrease anxiety (Zee et al., 2018).

HD and PD are the two common forms of dialysis therapy for ESRD. On one hand, HD is usually performed three times a week in an outpatient unit. Supervised by a medical team, the patient is connected to a blood purification system for four to five hours each session. Consequently, this is a passive treatment. The patient has to follow certain rules regarding diet and the correct medication. On the other hand, there is the option for PD, which can be performed at home by the patients themselves. Through an implanted PD catheter, dialysis fluid is filled into the abdominal cavity, with the peritoneum functioning as a membrane. PD patients treat themselves several times a day by replacing the dialysis fluid. Furthermore, outpatient consultations are necessary only every four to eight weeks, and there are few dietary restrictions (Robinski et al., 2016). The question of optimal choice of dialysis modality remains debatable. Numerous observational studies have investigated the mortality of ESRD patients treated with two different treatment modalities. Which dialysis modality performs better in prolonging life of ESRD patients is not clear; some studies showed superior outcomes with HD, whereas others demonstrated that PD was equivalent to HD or even better (Ratajczak et al., 2017; Zazzeroni et al., 2017). Based on research, one modality of dialysis is not uniquely better than the other. To offer the modality best suited to each patient’s everyday lifestyle, international guidelines recommend involving the individual patient in the decision making process, thus basing the decision on the patient’s preferences (Finderup et al., 2019). Young and employed patients are, in general, assigned to PD rather than HD. Initiation of HD often occurs as an urgent lifesaving action or as a bridging treatment while waiting for transplantation. In addition, assignment is
determined by characteristics of the consulting nephrologist, such as education or attitude toward PD (Robinski et al., 2016).

In-center HD remains the most common mode of Renal Replacement Therapy (RRT; U.S. Renal Data System, 2018). HD is a reasonable treatment choice for a large proportion of patients; however, it is uncertain how beneficial it may be for certain populations, including older adults or those with numerous comorbidities and limited life expectancy (Murtagh et al., 2016; Verberne et al., 2016). Mortality rates have improved for older patients on dialysis, but the rate is still disproportionately high. Compared to their non-dialysis counterparts, patients on dialysis 75 years or older have a four-fold greater mortality rate (U.S. Renal Data System, 2018). In their final 90 days of life, 83.4% of all Medicare beneficiaries with kidney failure were hospitalized with a median length of stay of 17 days. During this period, nearly two-thirds were admitted to the intensive or coronary care unit and 39% of these patients died in the hospital (U.S. Renal Data System, 2018). Current international guidelines, such as those from the Kidney Disease: Improving Global Outcomes (KDIGO, 2013) Working Group, encourage the incorporation of palliative care principles, including the discussion of conservative management of kidney failure (Cho et al., 2020). Conservative management has been described as “planned, holistic patient-centered care” for patients with kidney failure, which should include SDM, psychologic support, active symptom management, cultural and spiritual domains of care, without the use of dialysis (Murtagh et al., 2016, p. 1910). Patients with CKD must make a decision regarding their future dialysis mode: HD or PD. Patients may choose conservative care to manage their ESRD, if they do not wish to pursue dialysis as a treatment option for their ESRD, and their nephrologist should offer all three options. The Conservative Care option should be offered to patients “opting out” of dialysis initiation and those withdrawing from
dialysis. The discussion should be centered around the importance of symptom control and quality over quantity of life (Dhaun et al., 2013).

Retrospective observational studies comparing patients with kidney failure who choose dialysis (HD or PD) versus conservative management have generally demonstrated a survival benefit for those who choose dialysis; however, the magnitude of benefit diminishes with advanced age (80 years or older) and with a high number of comorbidities (Verberne et al., 2016). This study aimed to support patients in making decisions about specific future medical treatments once diagnosed with CKD 3. Also, it examined the degree of the patients' decisional conflict, their self-efficacy and SDM. SDM for complex illness within routine clinical care remains a significant challenge. The inconsistency in education practices coupled with evidence of patients not being involved in SDM indicated the need for research in this area.

**Purpose**

The purpose of this study was to explore CKD patients' experiences regarding their decision making process. The study examined individual characteristics including race/ethnicity and explored the relationship between characteristics such as demographics, decisional self-efficacy, and decisional conflict on perceived participation in SDM in a sample of individuals with CKD. Study findings provided insight into decision making preferences for patients with ESRD. To make an informed decision, patients should have adequate information and understanding of their health conditions, healthcare options, and the potential outcomes of these options. It is hoped that this study can add to the body of knowledge of SDM and decision making preferences of persons with CKD. Unfortunately, little research has been reported on the factors contributing to decisional conflict about dialysis modality choice. Therefore, the purpose of the study is to explore the factors related
to decisional conflict over dialysis modality choice in patients with ESRD currently in
dialysis and potentially facing a future decision regarding renal transplant or conservative
care.

Research Variables and Operational Definitions

Decisional Aid: Decision aids can improve the quality of decision making by providing relevant
information, helping set realistic expectations, and aligning choice with personal values (Stacey
et al., 2017).

Decisional Conflict: Decisional conflict is a measure of uncertainty concerned with
treatment choices and patients' confidence in making decisions. It is likely to arise when
there is outcome uncertainty and may impact the quality of the decision (Stacey et al.,
2017).

Decisional Process: Simon's model defines the decision process as a sequential and
iterative system for treatment information (Khechine, 2008).

Decisional Self-Efficacy: Self-efficacy is concerned with an individual's beliefs about his or
her ability to complete a specific action or obtain a certain goal (Bandura, 1997, as cited in
Wright, 2017).

Chronic Kidney Disease: CKD has five stages of disease progression, based on the
glomerular filtration rate, with stage 5 being ESRD. In addition, optimal timing of education
about treatment options should begin at stage 4 CKD to allow SDM before creating access
for dialysis (Stephenson & Bradshaw, 2018).

Hemodialysis (HD): HD is an extracorporeal blood-cleansing technique that is used to
remove metabolic waste products that accumulate in patients with ESRD (Ronco, 2018).

Peritoneal Dialysis (PD): A PD is a form of dialysis in which the lining of the abdomen is
used as a filter for dialysis, through which fluid and dissolved substances are exchanged with the blood. The dialysis fluid is introduced via a tube placed into the abdomen, called a peritoneal dialysis catheter (Cho, 2020).

**Satisfaction with the Decision:** Decision making resources patients use in making the decision to pursue treatment and how these affect their satisfaction with this Decision (Huang, 2020).

**Self-Efficacy:** Bandura described perceived self-efficacy as believing in one's capabilities to organize and execute the courses of action required to produce given attainments. Personal influences include motivation, thought processes, affective states, and actions. An individual's belief may influence the courses of actions people choose and how much effort they put forth in given endeavors (Wright, 2017).

**Shared Decision Making (SDM):** SDM is defined as a collaborative deliberation whereby patients and clinicians consider the potential harms and benefits of various medical options to come to a mutual agreement on how to proceed, accounting for the patient's values, goals, and preferences (Schoenfeld, 2018).

**Conservative Care:** Conservative kidney management is a treatment option for patients with end stage renal disease who, through SDM and holistic patient-centered care, emphasizes quality of life, active symptom management, and advanced care planning. It includes interventions to delay the progression of kidney disease, but it does not include dialysis (Davison et al., 2015).

**Research Questions**

The objective of this mixed-method study is twofold: (a) to provide a quantitative description of the sample of individuals with CKD who are currently considering any one of
the treatment strategies or currently receiving treatment for CKD within the last three months of diagnosis; and (b) to explore relationships between individual characteristics and participation in SDM, as these influence their decisional conflict and satisfaction with the decision made. Constructs to be measured are decisional self-efficacy, decisional conflict, involvement in SDM and if a decision has been made within the last three months, and satisfaction with the decision.

1. Research Question 1
   a. What are the sociodemographic characteristic (e.g., age, gender, educational attainment, partnership status) and participation with decision making in a CKD sample?

2. Research Question 2
   a. Is there a significant relationship between decisional self-efficacy and participation in shared decision making in a CKD sample?

3. Research Question 3
   a. Is there a correlation between participation in shared decision making and decisional conflict in a CKD sample? Is there a correlation between decision self-efficacy (DSE) and decisional conflict (SURE)?
   b. Is there a correlation between participation in shared decision making and satisfaction with the decision? Is there a correlation between participation in decision self-efficacy and satisfaction with the decision?
4. Research Question 4

   a. Is there a regression model that can predict satisfaction with the decision by the variables decisional self-efficacy and participation in shared decision making?

   b. Is there a regression model that can predict decisional conflict by the variables decisional self-efficacy and participation in shared decision making?

Four qualitative questions at the end of the questionnaire were open-ended and focused on how the participant describes in his or her own words the influencing factors about treatment choices.

“Please comments on the following questions.”

1. What information were you given by your provider, and what conversations did you have about dialysis options?

2. What factors did you feel could have influenced your choice regarding the type of dialysis you are currently on?

3. What kept you from deciding about other choices?

4. Describe if and how you were provided with decision aids or educational materials on dialysis options by your healthcare provider or other sources? How helpful were they in making your current treatment choice?

**Theoretical Framework**

*Theoretical framework using Janis and Mann's conflict theory of decision making model*

Decisional conflict is a state of uncertainty about the course of action to take. This state likely happens when making choices involving risk or uncertainty of outcomes. Choices can be difficult and stressful when a patient must plan for end-of-life medical care.
Such decisions are value-laden so that patients require ample information and emotional support to help them discern and express their true treatment preferences. Individuals experiencing moderate or high levels of decisional conflict may express difficulty in making choices and dealing with the possible undesired consequences of alternatives. They may be indecisive and postpone their decision (O'Connor, 1995). They may begin to question their values and beliefs, and they may show signs of distress while attempting to make the decision. According to O'Connor (1995), although decisional conflict is a common consequence of the difficulty inherent in making critical decisions, other factors cognitive, affective, and social can increase a person's perception of uncertainty. For example, a lack of information about alternatives and their consequences, unclear personal values, emotional stress, and perceived pressures from significant others can all exacerbate the difficulty of making a decision.

In the mid-1970s, Janis and Mann (1977) devised a decision making model that could be used for individuals who are actually confronting real-world choices that affect their lives. This model continue to be a part of behavioral research. Due to its applicability, a modified version of the Janis and Mann model was used as part of the theoretical framework for the present study. According to Janis and Mann (1977), inadequate decision making will inevitably occur when an individual does not consider all available alternatives fully and equally. Adequate decision making occurs when the individual attempts to understand and consider the various factors and alternatives that are available and continues to be receptive to new ideas until the time when a decision has been reached. There are seven criteria the decision-maker should meet to make a quality decision.
1. Accepts a realistic challenge involving alternatives.
2. Actively searches for and views a number of alternatives.
3. Considers advantages and disadvantages of each alternative.
4. Searches out new information.
5. Assimilates new information correctly, even if it does not support the preferred choice.
6. Reviews consequences of all alternatives.
7. Thoughtfully sets out to implement the chosen alternative but remains aware that contingency plans may be necessary.

Janis and Mann (1977) have also developed a conflict model of decision making, which is concerned with choosing between courses of action that have serious personal consequences. This model proposes five basic coping patterns used by individuals to cope with the stress that has been generated by any realistic challenge involving vital choices. A patient diagnosed with renal failure and progressing towards ESRD (challenge) have to decide what treatment to choose to treat their disease (vital choices) meets the criteria of decisional conflict as specified by the model. Their sense of control over events is challenged by their diagnosis. This dilemma can cause considerable anxiety and stress for these individuals, and coping patterns begin to emerge. Janis and Mann (1977) described five coping patterns in their model are unconflicted adherence, unconflicted change to a new course of action (complacency), defensive avoidance, hypervigilance (panic), and vigilance.
Figure 1.1 Decision map of Kidney Disease Pathways.

Source. Adapted from Winterbottom et al., 2020.

Figure 1.1 shows a hierarchy of nested decisions rather than a choice between discrete options. Decision making occurs in the context of managing a chronic illness, with patients and professionals discussing over months and years about therapy modifications as kidney function stabilizes or continues to decline. Additionally, patients may change or
discontinue therapies as treatments fail, their health deteriorates, or their life circumstances change (Murphy et al., 2014). This dynamic environment may explain why decision points are difficult to identify and discuss, and why patients may be unaware their kidney disease is deteriorating (Bristowe et al., 2019) or may be unprepared to make joint decisions with renal doctors regarding future treatment.

Janis and Mann (1977) argued that the five patterns are associated with different answers that the person gives to a series of questions (Demirtas, 2015).

1. If the decision maker feels there are no serious risks from his current decision, he/she will respond by unconflicted adherence.

2. If the decision maker feels there are risks in continuing, but none in adopting a new decision, he/she will change without experiencing conflict.

3. If the decision maker feels the current decision is failing, but no alternative is available, he/she will cope by defensive avoidance.

4. If the decision maker thinks there may be a good alternative but lacks time to search for it, he/she will be hypervigilant.

5. Vigilance occurs when the decision-maker searches for relevant information, assimilates it in an unbiased manner, and appraises alternatives carefully before making a choice. Such an approach is also referred to as analytical decision making behavior.

Janis and Mann (1977), acknowledged that the sequence is not “an ironclad law” but rather “a useful framework” (p. 178). This conflict model, as the authors call it, incorporates the first two stages of a five-stage model of decision making, the last stages being the weighing of the alternatives, deliberating about commitment, and adhering to the decision in
the face of setbacks as the decision maker progress through the decision-making process (p. 180).

The coping pattern of vigilance describes when the decision-maker meets all seven criteria for quality decision making. Janis and Mann's conflict theory concludes that vigilance is the only coping pattern that allows for sound and rational decision making. Therefore, the other patterns are maladaptive. Vigilance has been linked to positive outcomes (e.g., feeling a higher degree of decisional confidence and satisfaction), while decision conflict (e.g., non-vigilance) has been linked to delaying and avoidance. For the purpose of this study, the theoretical patterns by Janis and Mann (1977) underly the need to explore the patient's characteristics and demographics that are pre-cursors to how the person facing treatment options will navigate the decision. Janis and Mann (1977) assumed that the five coping patterns “are in the repertoire of every person when he or she functions as a decision-maker and that the use of one pattern rather than another is determined by mediating psychological conditions” (Janis, 1982, p. 52).

In the present study, the emotional distress the patient experiences when diagnosed with renal failure and the decisional conflict in selecting appropriate treatment options could be challenging. The use of a decisional aid in SDM is a useful mediating factor in choosing an appropriate patient-centered treatment option, but it is essential to understand the underlying characteristics of the patient as part of executing an intervention that will provide the CKD patient with an opportunity to enhance decision making information and assist patients in making informed choices in line with their values.
Summary

In recent years, there has been a clear shift toward a more patient-centered approach in healthcare. The UK Supreme Court recently ruled that the standard of risks, benefits, and alternative treatments provided by physicians are now to be determined by what a reasonable patient would deem important, rather than a reasonable physician; this has also been adopted by many states in the United States. This process, now referred to as “shared decision making” (SDM), implies that medical decisions are made collaboratively in accordance with the best available evidence provided by the clinician and the values and preferences of the patient (Spatz et al., 2016, as cited in Cassidy et al., 2018). However, the implementation of this concept can be challenging, as there is a current lack of understanding on the factors that influence patient involvement in the decision-making process and how individual characteristics (e.g., self-efficacy, decisional conflict) may influence an individual’s participation in SDM. Findings from this study may better inform the influencers of patient decision making needs and behaviors in the CKD patient population. To the researcher’s knowledge, this would be the first study considering multiple individual characteristics that may affect the perception of individuals with CKD and participation in shared medical decision making for dialysis modality selection. Frameworks to support the individual characteristics may explain relationships such as decisional self-efficacy (Ottawa Decisional Support Framework [ODSF]) & Bandura’s Self-Efficacy), decisional conflict (ODSF, & Janis and Mann Conflict Theory), and relationships on perceptions of participation in SDM in the context of CKD. The use of a theoretical framework provides more comprehensive and potential explanatory factors related to individual characteristics that influence decision making in patients’ selection of dialysis treatment choice.
Findings from this study may better inform providers and the influencers of patient decision making needs and behaviors in the CKD patient population.
CHAPTER 2: LITERATURE REVIEW

This chapter presents a review of literature that supports this study and examines related concepts. This section focuses on existing literature describing individual characteristics and the relationship to SDM for CKD patients. CKD is a global health issue associated with significant mortality and morbidity. Outcomes of CKD include kidney failure and complications from decreased kidney function. End-stage CKD is managed by dialysis, renal transplant, or conservative care. The focus of this research is on individuals with CKD who have recently or currently are considering HD or PD as the treatment option and the satisfaction with the decision made over the course of their disease, and explore patients' experiences regarding their decision making process.

Chronic Kidney Disease

CKD is the ninth leading cause of death in the United States. It is estimated that 695.5 million people worldwide are affected by kidney disease requiring dialysis (Bikbov et al., 2020) and 2 million people worldwide suffer from ESRD. The number of patients diagnosed with the disease continues to increase at a rate of 5% to 7% per year (UCSF, 2018). Chronic kidney disease is a progressive condition that advances through early stages and terminates in advanced kidney disease and kidney failure, requiring chronic dialysis treatment or kidney transplantation (Centers for Disease Control and Prevention, 2019). CKD is classified from Stage 1 through Stage 5, which eventually progresses into advanced kidney disease called End-Stage Renal Disease (ESRD; KDIGO, 2013). CKD has five stages of disease progression, based on the glomerular filtration rate, with stage 5 being ESRD. In addition, optimal timing of education about treatment options should begin at stage 4 CKD to allow SDM before creating access for dialysis (Stephenson & Bradshaw, 2018). ESRD is a serious public health problem, and its
incidence and prevalence are increasing globally (Ho et al., 2021).

Treatment options for ESRD include dialysis treatments, kidney transplant or conservative management. Dialysis treatments can be administered as HD available in an in-center or home setting, or PD, which is the most common home-based dialysis modality (Mathews, 2021). In the United States, 86.9% of patients began RRT with in-center HD, only 10.1% started with PD (USRDS, 2019). The existing gaps in kidney disease patients’ knowledge and lack of participation in SDM has resulted in selecting treatment modalities not based on patients’ values or preferences.

**Available Treatment Choices**

For patients with ESRD, treatment options include preemptive transplantation, PD, in-center HD, home HD, or supportive non-dialytic management also known as conservative care (Stephenson & Bradshaw, 2018). Kidney transplantation and conservative management, HD, and PD are currently the primary therapies for ESRD. However, these different treatment options will have a different effect on the patient's family, work, and social activities (Khan et al., 2019). Patients approaching ESRD are often required to make a shared decision about RRT. HD and PD are the two primary RRT for patients with ESRD.

HD patients are usually connected to an HD machine for 3 to 4 hours, three days a week. For PD, a person's peritoneum is used instead of dialyzers, and filters are used as the exchange membrane to remove waste products and excess fluid from the blood. In 2014, 86.7% of all prevalent dialysis cases worldwide were treated with HD, and 13.3% were being treated with PD (United States Renal Data System, 2016). Although HD continues to be the most common mode of dialysis, there is not enough evidence to support choosing one type of dialysis over another. In addition, both HD and PD showed similar outcomes in mortality and morbidity (Chen et al.,
In acknowledging that “as comorbidities go up, the survival advantage of starting renal replacement goes down. Survival between patients started on RRT, and those with conservative care become similar” (Peeters et al., 2016, p. 2), an observational study aimed to externally validate a risk stratification model utilizing the Renal Epidemiology Information Network (REIN) registry. Using the baseline comorbidity data, a final abbreviated REIN (aREIN) score was calculated. For those with aREIN score of $\leq 4$ or $\geq 9$, mortality at six months rose incrementally from 5.6% to 45.8%, respectively. Peeters et al. (2016) stated that the “aREIN score delivers meaningful discrimination between low and high-risk populations” (p. 1). The data conveyed helpful and realistic prognostic information during the SDM process: “As a clinically valid risk stratification tool, as crucial to assist evidence-based SDM on whether to start dialysis or opt for conservative care” (Peeters et al., 2016, p. 9). This tool will help to examine the personal care expectations tailored to realistic and achievable outcomes: “SDM may increase adherence to transplant treatment plans as patients recognize their active role in the decision making process” (Gordon et al., 2013, p. 1156, as cited in Stephenson & Bradshaw, 2018).

Patients with ESRD need to choose one of the RRT choices including kidney transplantation or dialysis (HD or PD), to survive and prevent uremia and other complications (Ghodsian et al., 2021). Among these treatments, HD is the most common treatment across the world. About 87% of patients with ESRD undergo HD and only 13% of them are on PD worldwide (Saran et al., 2017). Choosing the type of RRT based on the patient’s conditions is considered a challenge for CKD patients (Axelrod et al., 2018). Although kidney transplantation is the best choice for this disease, it cannot be performed for all patients due to the lack of easy access to donated kidneys, lack of information about transplanted kidneys, and taking into account the patient’s conditions (Farah et al., 2018). Therefore, most patients with CKD should
choose between home PD, in-center HD (IC-HD), and home HD (Home-HD). Home dialysis is currently underused in the United States compared with other industrialized countries. Not only is home dialysis less expensive from the standpoint of pure dialysis costs, but overall health system costs may be decreased by more subtle benefits, such as reduced transportation, improved quality of life, ability to return to part-time or full-time work and increased productivity. There is clinical, lifestyle, and financial advantages (Golper et al., 2013).

It is reported that there are multiple clinical advantages to dialyzing frequently at home over in-center dialysis treatments. The most obvious advantage includes better blood pressure regulation, regression of left ventricular hypertrophy, restoration of left ventricular ejection fraction, normalization of phosphate control, and certain aspects of quality of life related to kidney disease (Tennankore et al., 2014). Despite their significant benefits, home-based dialysis therapy including PD and home HD are underused dialysis modalities in the U.S. Low patient awareness and education regarding dialysis modalities has been identified as a major barrier to increasing the use of home dialysis in the U.S. (Chan et al., 2019).

Only few providers in the US provide patients with an opportunity for informed dialysis choice for their advanced CKD. As pre-ESRD education is provided infrequently, and when provided, it is done disparately among those with socio-economic advantage leading to limited and disparate home HD use. Thus, patients' lack of information about chronic kidney disease (CKD) and available dialysis therapy choices can considerably impair their decision of home HD. Recently, a number of research studies have shown that patients' awareness of CKD and its therapeutic options remains inadequate, even in the modern era. In light of these findings, the major professional renal associations, as well as the Center for Medicare and Medicaid Studies,
recommend that all patients with advanced CKD receive Comprehensive pre-ESRD Education to aid in making an informed dialysis decision (Shukla et al., 2019).

Choosing the best treatment for patients requires cooperation between the patient and the healthcare team, which is called SDM and is recognized as the gold standard for patient-centered care especially in chronic diseases. ESRD patients not receiving active RRT will die from kidney failure. Patients living with CKD face numerous decisions throughout their illness. At the same time, many patients want to participate in health-related decisions. However, they may experience decisional conflict when considering options and their importance to the pros and cons associated with those options. Modifiable factors such as knowledge gaps, uncertainty regarding outcomes, lack of clarity about what matters most, and feeling pressured to choose a particular option exacerbates the decisional conflict. Patients with unresolved decisional conflict are more likely to change their minds, delay decision making, have regret, or blame providers (Murray et al., 2008). Effective interventions to guide patients in decision making are decision aids and SDM. Patients exposed to decision aids are more likely to be informed, have realistic expectations of outcomes of options selected, participate actively in decision making, and feel lower decisional conflict. However, practitioners have identified time constraints, patient characteristics or clinical situations, perceived patient preferences for involvement in decision making, and disagreement with asking patients about their preferred role in decision making as barriers to using decision aids.

**Factors Influencing the Choice of Treatment**

The majority of ESRD patients are medically fit for either HD or PD. A well-informed patient should primarily decide on dialysis modality (HD or PD), considering a diversity of personal, social, and economic factors and the potential side effects of each approach (Chen et
al., 2018). However, this decision can be challenging, as either choice has pros and cons. Patients
are often uncertain about which one is the best alternative (Chen et al., 2018). This situation is
described as decisional conflict, affecting individual actions (e.g., delay), emotions (e.g., regret),
health outcomes, and proper use of health services. The dialysis modality selection should be
made by considering the patient's specific risks and benefits and their values and preferences.
Lack of knowledge about indications, contraindications, side effects, advantages, and
disadvantages of each type of dialysis may result in a higher level of decisional conflict.
Although pre-dialysis education is recommended for patients with advanced CKD (KDIGO,
2013), the information presented to patients is often incomplete and difficult to grasp.

The study conducted by Morton et al. (2010) concluded that factors influencing treatment
decisions included experiences of other patients, the problematic timing of information about
treatment options, simultaneous creation of vascular access, and a preference to maintain the
status quo. Based on the study's findings, reviewers presented that the formal incorporation of
peers (other patients) with CKD as mentors or educators into the orientation of new patients to
the renal unit greatly influenced decision making of patients and care givers. They also updated
clinical practice guidelines for the optimal timing of education about treatment options by
recommending they be given at stage 4 of the disease before creating dialysis access. Formal
care pathways should be developed for pre-emptive transplantation, home dialysis, and palliative
management for patients not wishing to dialyze to facilitate the provision of treatments more
aligned with patient preferences as cited in Stephenson and Bradshaw (2018).

Charles et al. (2004, as cited in Ho et al., 2021) pointed out that the patients' preparation
regarding the disease is one of the contributing factors for their participation in SDM. When
patients are not ready to face the disease, they will not participate in SDM (Charles et al., 2004,
as cited in Ho et al., 2021). In the social cognition theory of Bandura, it is mentioned that the three factors of people, behavior, and environment will interact to affect an individual's behavior. Personal beliefs and motives, often strongly and powerfully control and guide people's behaviors. Those behaviors and their results will, in turn, affect the content and emotional response of personal thinking (Bandura, 1977, as cited in Ho et al., 2021).

The trust relationship between patients and healthcare providers helped override patients' fears and concerns regarding dialysis (Griva et al., 2013) and encouraged patients to obtain medical information, for patients felt safer in engaging in discussions with healthcare providers. The study pointed out that trusting relationships were seen as crucial to active participation in clinical decisions. Patients felt more at ease and could confide in and share personal information with healthcare providers (Walker et al., 2017). The study conducted by Ho et al. (2021) suggested that mutual trust makes participants more willing to share their life experiences, values, preferences, strengthen the effective transmission of knowledge, and ease asking questions when discussing treatment options. Therefore, the trust relationship is indispensable during the decision process, especially in SDM. In this process, a sense of being respected, understood, and cared for is essential to forming the experiences of connection and trust. Therefore, establishing such trust should start even before the beginning of the SDM process. In addition, social support from family members has always been a powerful source of participant decision making. Although trust may enhance SDM, it may also foster a more passive patient role (Muscat et al., 2018). Patients who lack expertise often look for the opinion of professionals. Findings suggest that excessive trust in the healthcare providers can create passivity and hinder the patient from making decisions autonomously. However, Peek et al. (2013), as cited in Ho et al. (2021), pointed out that trust was also enhanced when patients felt HCPs encouraged them to
share information, which creates a good cycle, thereby balancing trust in professionals.

People often have decisional needs when faced with decisions that have more than one option, uncertain outcomes, or known outcomes that people value differently. They require assistance in making a high-quality decision, informed with the best available evidence and grounded in personal values for outcomes (O’Connor, 2018). The Ottawa Decision Support Framework (ODSF) has been used for 20 years to assess and address people’s decisional needs and evaluating decisional outcomes.

The first element of ODSF is decisional needs. Figure 2.1 clearly demonstrates how decisional needs can adversely affect the quality of a decision. The ODSF’s main premise is that decision support interventions that address decisional needs improve decision quality. Improved decision quality may favorably affect people’s actions. There is evidence demonstrating the benefits of addressing people’s decisional needs using patient decision aids, a decision support intervention (Hoefel et al., 2020).
Patient-Centered Care

Person-Centered care is a holistic approach in which a good therapeutic relationship is established between the patient and healthcare providers, with regard to patient’s needs and preference in their treatment decision. In fact, the patients play an active role in the treatment process (Blake & Brown, 2020). SDM is at the highest level of Person-Centered care and provide an opportunity for patients to engage in decisions and manage their health in an informed and effective way (Velez-Bermudez et al., 2019). To make an informed decision,
patients should have adequate information and understanding of their health conditions, healthcare options, and the potential outcomes of these options. In addition, patients' values and preferences should also be respected in making healthcare decisions (Vahdat et al., 2014, as cited in Chen et al., 2018). As international healthcare agencies transition from traditional disease models to contexts of patient-centered healthcare, the imperative to involve the patient in all stages of their care becomes more evident (WHO, 2016). However, acknowledging that simple information sharing does not constitute SDM (Thomas et al., 2016, as cited in Stephenson & Bradshaw, 2018), the decisive elements of evidence-based best practice and consideration of the patient's preferences will guide their active collaboration in healthcare decisions. SDM is viewed as fundamental to safe and effective healthcare. When there are reasonable options available to patients, it encapsulates a more patient-centric healthcare target (Joseph-Williams et al., 2014, as cited in Ho et al., 2021), which includes three stages: an information exchange, deliberation regarding the available treatment options, and reaching agreement on a final decision (Charles et al., 1999, as cited in Ho et al., 2021).

**Shared Decision Making in CKD**

Through SDM, patients can obtain information regarding different RRT and their impacts on their future daily lives, making appropriate choices. SDM allows a clinician and patient to participate jointly in making a health decision, taking into account the benefits and harms of all the options and considering the patient's values, preferences, and circumstances (Hoffman et al., 2014, as cited in Stephenson & Bradshaw, 2018). SDM has also been described “as a decision situation, in which at least two participants are involved, both share information and take steps to build a consensus about the preferred treatment, and where an agreement is reached on the treatment with joint responsibility” (Robinski et al., 2016, p. 563, as cited in Stephenson &
Despite the potential for SDM to improve patient-centered outcomes, the implementation of SDM in care has been limited because of clinician factors (such as limited time, lack of applicability to the patient situation), and patient factors including patient-provider power imbalance, health literacy, and denial about the health condition. However, facilitators of SDM include provider motivation to engage in SDM, healthcare provider training, patient-mediated interventions, provision of medical knowledge, validation of patient experiences, strong interpersonal skills, and provider availability (Yu, 2015). A study conducted by Moustakas et al. (2012, as cited in Stephenson & Bradshaw, 2018) sought to explore the needs of older persons with advanced CKD using four databases and reviewed eight quantitative and four qualitative papers to reveal three themes of importance: SDM, perception of quality of life, and educational resource requirements. The authors concluded, “there appeared to be a difference between what information a patient feels they need, to help them decide to have dialysis or not, compared to what the health professional thought they required” (Moustakas et al., 2012, p. 74, as cited in Stephenson & Bradshaw, 2018). A revised clinical practice guideline on SDM initiation and withdrawal from dialysis included 10 recommendations for adult patients with acute kidney injury (AKI), CKD, or ESRD (Moss, 2010, as cited in Stephenson & Bradshaw, 2018). The Renal Physicians Association in the United States recommended the following:

1. Develop a physician-patient relationship for shared decision making.
2. Fully inform AKI, stage 4 and 5 CKD, and ESRD patients’ patient-center diagnosis, prognosis, and all treatment options.
3. Give all patients with AKI, stage 5 CKD, or ESRD an estimate of prognosis specific to their overall condition.
4. Institute advance care planning.

5. If appropriate, forgo (withhold initiating or withdraw ongoing) dialysis for patients with AKI, CKD, or ESRD in certain, well-defined situations.

6. Consider forgoing dialysis for AKI, CKD, or ESRD patients who have a very poor prognosis or for whom dialysis cannot be provided safely.

7. Consider a time-limited trial of dialysis for patients requiring dialysis, but who have an uncertain prognosis, or for whom a consensus cannot be reached about providing dialysis.

8. Establish a systematic due process approach for conflict resolution if there is disagreement about what decision should be made concerning dialysis.

9. To improve patient-centered outcomes, offer palliative care services and interventions to all AKI, CKD, and ESRD patients who suffer from burdens of their disease.

10. Use a systematic approach to communicate about diagnosis, prognosis, treatment options, and goals of care (Moss, 2010, as cited in Stephenson & Bradshaw, 2018).

**Initiating the Shared Decision making Process**

Renal function in patients with CKD usually declines gradually, providing clinicians with multiple opportunities to discuss RRT and supportive care with patients and their families (Tuso, 2013, as cited in Stephenson & Bradshaw, 2018). The importance of initiating discussions about RRT or conservative care earlier in the disease progression has been highlighted, with SDM considered critical when the patient enters Stage 4 CKD. SDM is important when the patient is about to start RRT or when there is no evidence that further therapy will prolong life. Renal clinicians need to maintain communication with patients regarding prognosis and treatment options and participate in the process of SDM so patients and family members remain fully
informed (Tuso, 2013, as cited in Stephenson & Bradshaw, 2018). SDM as an approach is continually appropriate, at initiation, through the continuance of treatment, during sentinel instances, and stopping treatment/dialysis. In the SDM process, HCPs provide information regarding the risks and benefits of the different treatment options, whereas patients put forward their values and preferences. Both parties share information and then agree on the final implementation of treatment (Charles et al., 1997, as cited in Ho et al., 2021). The data shows that 30% of type 1 diabetes and 10% to 40% with type 2 diabetes will eventually suffer from kidney failure (Diabetes, 2020). A large proportion of studies to date indicate that PD is associated with worse outcomes than HD when performed in diabetic patients. In addition, a considerable number of studies have suggested that PD has possible advantages compared to HD in patients with underlying cardiac dysfunction in providing symptomatic relief (Koch et al., 2012, as cited in Kim et al., 2017). Studies have also shown that choice of PD as an initial modality includes lower cost than other RRTs (Saran et al., 2018) and it is more cost-effective than HD (Pike et al., 2017). Furthermore, previous studies have also revealed that PD leads to greater patient satisfaction as well as higher quality of life compared to HD (Goncalves et al., 2015, as cited in Ghodsian et al., 2021).

To involve patients in SDM regarding the type of dialysis treatment, patients and their caregivers should have a comprehensive understanding of the differences of dialysis methods and the impact of dialysis on their daily lives (Robinski et al., 2016, as cited in Ghodsian et al., 2021). SDM is a collaborative process in which patients, caregivers, family members, and even friends of the patient involved in healthcare decisions for patients and the final decision is made based on the patient’s values, preferences, and conditions by taking into account the advantages and disadvantages of each treatment (Zhang et al., 2017). The first step in this approach is to
encourage the patient to engage in SDM, and this happens when sufficient information about each of the treatment options is made available to the patients and their family in which the healthcare providers try to avoid imposing their opinions on patients’ choice. Nurses have the most direct contact time with patients and could influence patients’ knowledge and perception on SDM (Ahmadpour et al., 2021). Nephrology nurses could support patients’ decisions by providing education on modality selection. They can guide patients and their families in choosing the dialysis modality. Providing education by nurses as a healthcare team could help patients to better understand CKD, weigh available RRT, and decide on the modality. During the shared-decision process, nurses share the professional knowledge with the patients, and in turn, patients share their personal knowledge on their own daily life and healthcare. Finally, they discuss the choices and decide which dialysis modality (PD or HD) is best for the patients (Finderup et al., 2020).

The healthcare teams need to explain all modalities to the patients and the advantages and disadvantages of each modality. According to the literature review, many patients who have recently been diagnosed with ESRD do not have sufficient knowledge and information about RRT choices and are treated by one of RRT without even knowing its side effects (Farah et al., 2018). Furthermore, previous studies show that many patients are not prepared enough to start dialysis and do not play an active role in choosing the type of dialysis (Dahlerus et al., 2016). Moreover, many patients with emergency situations start RRT with HD and then continue on HD. In this regard, a study by Erlang et al., 2015 (as cited in Ghodsian et al., 2021) showed that PD was not introduced as one of RRTs for about 88% of dialysis patients and that PD leads to minimal disruption or change in the patient’s daily life and strengthens the patient’s self-care and independence. PD is also considered as the best type of dialysis for patients who are on the
waiting list for a kidney transplant (Gillespie et al., 2015, as cited in Ghodsian et al., 2021). However, PD has some limitations. This dialysis should be carried out every day and patients with PD has a greater risk of developing peritonitis, abdominal hernia, and disturbed body image. Furthermore, it is difficult to perform this type of dialysis in patients who have severe neurological problems and where there is no one to take care of patients with physical impairment or poor vision (Kao et al., 2013, as cited in Ghodsian et al., 2021). To involve patients in SDM regarding the type of dialysis treatment, patients and their caregivers should have a comprehensive understanding of the differences of dialysis methods and the impact of dialysis on their daily lives.

**Facilitators and Barriers of SDM**

SDM is accomplished by improving communication between clinician and patient. During pre-dialysis education, kidney professionals should provide information about renal replacement options, focusing on discussions about which options best fit into a patient's life, including HD and PD, with at-home or in-center options. In addition, conservative management is offered as an active option to manage symptoms arising from failing kidneys in patients meeting certain criteria (e.g., those under 75 years of age) with a high level of comorbidity and with a poor quality of life (Roderick et al., 2015). Clinicians should receive education about SDM and strategies to facilitate its successful implementation. Clinicians should also ensure that CKD patients are adequately informed of different treatment options and the associated impacts on lifestyle, giving them the ability to participate in SDM about treatment decisions. Incorporation of other patients with CKD as mentors or educators of new patients may be beneficial. Moss (2017), suggested it is imperative to address the importance of an integrated approach in determining supportive care principles for persons with advanced CKD, especially
in older patients with improved collaboration between nephrologists and supportive care specialists. Healthcare providers should involve patients with CKD and their families in dialysis-related decisions and this should be started in the early stage of CKD. Selecting a dialysis coordinator could improve the relationship between the patient and the medical team regarding the selection of dialysis modality (Ghodsian et al., 2021). This process warrants an understanding of how patients process information, look for guidance in decision making, and recognize the underlying characteristics of patients that influence their decisional conflict and ultimately the satisfaction in the decision made.

**Demographic Factors: in SDM**

The relationships among demographics, pre-dialysis education, dialysis knowledge, and decisional conflict have not been extensively studied. Thus, additional work is needed to investigate the influence of demographics, particularly family and cultural influences, pre-dialysis education, dialysis knowledge, decision self-efficacy, and social support on decisional conflict as to dialysis modality in patients with ESRD. To make an informed decision on dialysis modality, patients should receive structured education on dialysis options covering all modalities (Van den Bosch et al., as cited in Chen et al., 2018). A study conducted by Machowska et al. (2016) with the aim of determining predictive factors for patients receiving education, making a decision, and receiving their preferred modality choice authors acknowledge that 24% to 49% of patients begin dialysis in an unplanned(sudden) manner, and despite the need for rapid clinical decision making a modality choice is not routinely provided especially for the elderly. A qualitative descriptive study aimed to explore the experiences of persons under 70 years in the SDM process (Thomas et al., 2016). The authors acknowledged that various factors, including education, cultural/ethnic values, and age-related mental decline, may frequently cause patients
to defer to physician-directed care in decision making. Patients' decision making was influenced by the role of culture and language, patient-professional communication (trust and power distance), decisional awareness, and decision ability (Muscat et al., 2018). These factors provide valuable information; however, identifying the influencing factors of the choice of dialysis treatment did not convey the patient's personal experience in SDM.

Therefore, it is vital to understand what drives the patient's motivation for participation in decision making and improving ability and decision making awareness. Muscat et al. (2018) found that patients rely on family members for support throughout their dialysis decisions. Regardless of race, this kind of influence on the decision is consistent. The influence of family support is more significant, especially for the elderly. Even if young patients have the ability to make decisions, they rely on the support of their family members and consider the impacts and burdens of their decisions on other family members when making the decisions.

**Decisional Self-Efficacy**

Decisional self-efficacy, which refers to self-confidence or belief in one's ability in decisions making (O'Connor, 2002, as cited in Chen et al., 2018), has also been found to be negatively associated with decisional conflict and decisional regret in cancer treatment (Cuypers et al. 2014, as cited in Chen et al., 2018). Studies have shown that patients with higher decisional self-efficacy experienced more independence in decision making. In dialysis decision making, self-efficacy may be just as important as one's information processing ability for optimal decision making. Lack of support or resources can also make an inherently difficult decision even more difficult. Studies have shown that support from family, friends, or healthcare providers is important for patients making decisions about dialysis modality (Griva et al., 2013). Existing studies show that knowledge, decision self-efficacy, and social support are potentially
modifiable factors contributing to decisional conflict. When providing decisional support to pre-dialysis stage patients, practitioners need to increase patients' decision self-efficacy, provide PD and HD pre-dialysis education, increase dialysis knowledge, and provide professional support. Furthermore, self-efficacy theory-based interventions may offer the most promising result in supporting dialysis decision making, as self-efficacy was found to be the most important influencing factor of decisional conflict in the study done by Chen and team (2018). The ethical principle of autonomy is contingent upon patients having the choice to be involved. “Respect for patient autonomy means that patients are free to relinquish their decision making autonomy to providers” (Gordon et al., 2013, p. 1150, as cited in Stephenson & Bradshaw, 2018), and the choice to make decisions or be actively involved in their care is something not all persons are comfortable accepting. Yet, conversely, such should never be assumed. In fact, “the assumptions that some patients are not able or do not want to participate in decision making is inconsistent with both the evidence and contemporary models of care” (Politi et al., 2013, p. 1, as cited in Stephenson & Bradshaw, 2018). Therefore, it is pivotal to recognize that through successful and contextual discussion and ultimately commencement of the SDM process, determination of the patient's preferred level of involvement is made apparent.

The application of SDM for renal RRT is to assist CKD patients in making the appropriate choice of RRT and making the necessary preparations. Multiple researchers have focused on various SDM interventions, and the result of most studies have shown the effectiveness levels of the different interventions, including increased levels of knowledge and decision self-efficacy, as well as the ability to decrease decisional conflict (Bailey et al., 2016, as cited in Ho et al., 2021). Patients who play an active role in SDM not only pay more attention to recommendations made by physicians and medical staff but also have higher self-confidence
Moreover, SDM increases patient preparedness to overcoming the challenges of treatment-related problems and complications and reduces their worries (Ladin et al., 2017). Other advantages of the SDM approach include positive outcomes such as increasing the patients’ quality of life and maintaining patients’ independence.

**Decisional Conflict**

Addressing factors predisposing patients to decisional conflict helps to facilitate informed decision making and then improve healthcare quality. Unfortunately, little research has been reported on the factors contributing to decisional conflict about dialysis modality. Negative experiences during or after decision making can lead patients to have regrets about the choices that were made. Evidence suggests that decision regret is a common phenomenon in healthcare and can reach high levels for some medical decisions. For example, the study done by Becerra-Perez (2016) shows that decisional conflict is significantly associated with decision regret. Decisional conflict typically occurs when patients face difficult decisions for which multiple reasonable options exist and when patients feel unsupported in the decision making process. Decisions that are made in a context of uncertainty can lead to decision regret, especially when there is no preferable clinical option (Becerra-Perez, 2016). Decisional conflict can be defined as a state of uncertainty about a decision. This uncertainty increases the likelihood of making a decision not based on individual values or preferences and may result in undesirable post-decisional consequences (Vahdat et al., 2014, as cited in Chen et al., 2018). Therefore, addressing factors predisposing patients to the decisional conflict may help to facilitate informed decision making and relieve its related tension. For example, inadequate knowledge, unrealistic expectations, unclear values, social pressure, insufficient support or resources, and lack of
skills/self-confidence in making decisions may also predispose patients to decisional conflict. However, most of these studies focused on healthcare decisions other than dialysis. Therefore, there is little information on factors influencing decisional conflict over dialysis modality. Addressing factors predisposing patients to the decisional conflict may help to facilitate informed decision making and relieve its related tension. Knowledge on decisional conflict as to dialysis modality in patients with ESRD has been limited. Inadequate support and lack of self-confidence in making the decision may result in a higher level of decisional conflict. However, these relationships were mostly found in populations other than ESRD patients. Broader adoption of SDM strategies should help reduce the decision regret that some patients experience and help to address factors contributing to decisional conflicts, such as feeling uninformed about options and uncertain about the risks and benefits of available options. Decisional conflict during consultations can be addressed with effective decision support interventions to foster SDM, using patient decision aids. However, when the patient is not involved in clinical decision making and the choice of treatment is not selected based on the individual’s preferences and values, it may lead to conflict in decision-making (Vahdat et al., 2014, as cited in Ghodsian et al., 2021) and may result in unpleasant consequences such as decreased patient’s motivation needed for treatment adherence, feeling of regret and guilt, and even blaming of the medical staff by the patient (Tsang et al., 2016, as cited in Ghodsian et al., 2021).

**Satisfaction with Decision**

A retrospective survey \( n = 482 \) by Robinski et al. (2016) aimed to compare differences in SDM and treatment satisfaction (TS) between German patients undertaking HD or PD within 6–24 months of initiation of dialysis. The authors found strong patient reasoning behind their decisions to choose either modality, with positive correlations between SDM and TS \( (0.16 \leq r \leq \)
0.48; \( p \leq .0001 \). They suggested to initiate SDM at an early stage to screen patient preferences, add an awareness of consultation bias, careful use of terminology, and participation encouragement of passive patients is important. However, no comment was made in regard to conservative/supportive care options.

**Summary**

Patients with CKD have decision making needs across the trajectory of their illness. However, little is known about supporting patients with CKD decision making. Development of CKD-specific clinical practice guidelines that include decision support best practices could benefit CKD patients. The studies have mainly focused on the decisions patients with CKD faced around the choice of RRT and withholding/withdrawing dialysis. Also focused on healthcare professionals’ provision of information about the decision rather than identifying decisional conflict and supporting patients in decision making. No studies were found that identified the patient’s point of view about factors that might influence or inhibit quality decision making.
CHAPTER 3: METHODOLOGY

This chapter describes the setting, subjects, and procedures conducted in this study, including enrollment criteria, instruments for measurement, and method of analysis. In addition, the hypotheses for the data obtained from the quantitative measures were identified and tested in Chapter 4 using appropriate statistics.

Overview of Research Study Design

This study used a mixed-method approach with an exploratory and a descriptive correlation designed to evaluate constructs of individual characteristics that may impact individuals with CKD participating in SDM. Initially, the sociodemographic characteristics (i.e., gender, age, race/ethnicity, educational attainment, partnership status, and self-reported health status) of participants was studied for relationships between decisional self-efficacy, decisional conflict, and participation in SDM. Second an exploratory design examined the rates of self-reported SDM and SDM using the 9-items Shared Decision Making Questionnaire (SDMQ9). Third, relationships between decisional self-efficacy, decisional conflict, and SDM was investigated. Fourth, individuals who are currently on any one of the treatments were examined for their perception of participating in SDM with the CKD treatment options provided and their satisfaction with their decision being made using three open-ended questions. To examine patient-reported outcomes, an analysis examining a question on consequence of the decision and satisfaction with the decision was explored (see Figure 3.1). These questions were crafted in such a way to encourage responses, and these open-ended questions were analyzed using content analysis. Combining both research approaches, qualitative and quantitative, the results informed the study with a deeper exploration of the richness of the narratives and open-ended analysis of
comments. Combining these results provided triangulated information to enhance the quantitative findings while supplementing the limitations of the quantitative data.

Figure 3.1 Study Design

Research Procedures

This section discusses how the study was conducted from recruitment, selection, consenting, setting up data collection procedures and measures. Also, the processes for recruitment, screening, informed consent, and enrollment are included as well as detailed summaries of the selected measures for the variables of interest with associated validity and reliability.

Setting and Participants

Recruitment for this study began after receiving Institutional Review Board approval from Molloy College, Rockville Centre, New York. The primary method of recruitment was through an online network called Kidney Solutions, a support group that assists patients with kidney disease in their journey to find a living kidney donor. Kidney Solutions is a Texas-based,
501(c)3 non-profit organization established in 2018 to assist kidney patients in finding their living kidney donor (kidneysolutions.org). Working closely with patients and their families, the staff of Kidney Solutions provides education and mentoring throughout the entire pre- and post-transplant process and offers a wide range of services and programs to those navigating the many challenges of CKD. These programs and services educate and empower people living with kidney disease, from pre-dialysis to post-transplant, to live a healthy life. When diagnosed early patients are followed and encouraged to get a preemptive transplant. If patients are on dialysis, members work with them to seek a donor for transplant.

The Kidneysolutions.org website provides information about ESRD. Kidney Solutions is facilitated by transplant professionals, recipients, and living donors who desire to assist patients in finding a living kidney donor and help them and their families through the pre- and post-transplant processes. They have received the GuideStar Platinum Transparency of 2021. GuideStar is the world’s largest source of information on nonprofit organizations it is the platinum seal of transparency. When diagnosed early, patients are followed and encouraged to get a preemptive transplant. If patients are on dialysis, Kidney Solutions work with them to seek a donor for the transplant.

Sample

Study participants were recruited directly from the Kidney Solutions website (kidneysolutions.org). Permission was obtained from AAKP Board of Director and Vice President of Kidney Solutions. A recruitment flyer was sent out with the researcher’s contact information to Kidney Solutions along with the survey questionnaire using Google Forms. Kidney Solutions then sent out the link directly to all the patients who qualify for the study based on the inclusion criteria via email. No participants were contacted directly by the researcher
initially, but all consenting information was included in the forms provided by the researcher and sent to the willing recruited subjects who were invited by the vice president of Kidney Solutions. Participants were informed that their participation was voluntary, confidential, and they could opt out at any time. The setting for this study was an email/online survey created by the researcher called *Chronic Kidney Disease: Decision making Process in Selecting the Treatment Option*. Participants were offered an incentive for completing the survey and submitting it as instructed.

**Sample Size**

According to the Centers for Disease Control and Prevention’s (CDC) in 2021 CKD in United States with an estimate of current population of 37 million individuals nearly 2 in every 1,000 Americans suffer from ESRD, in which 71% are on dialysis and 29% are living with a kidney transplant (Chronic Kidney, 2021). However, the feasibility of recruiting an adequate representation of patients must be considered and acknowledge the challenges of finding large samples in any given area. To estimate the approximate participants required for this mixed-method study, a power analysis for the sample size was estimated using G power a priori that was conducted with a power of .80 and moderate effect size of .3 for correlation and regression analysis of the variables. Actual power was calculated on the actual sample obtained. The estimated potential sample from the kidney solutions referrals was approximately 50, which, although limited in power, clearly met eligibility criteria. Purposive sampling was chosen with a target sample size between 40 and 50. Additional subjects were invited via friends through social media like Twitter and recruitment ads on webpages.

Using data from multiple prior studies that used the Readiness to Transition Questionnaire (RTQ), power analysis was conducted. It was determined that 42 family caregiver–child dyads were needed to power the study (Speller-Brown et al., 2015). Varty and
colleagues (2022) examined the relationships between decision making involvement, self-efficacy, healthcare responsibility, and overall transition readiness in adolescents and young adults with sickle cell disease prior to transition to adult healthcare in a cross-sectional, correlational study with a sample of 50 caregivers.

Rose et al. (2019) used a mixed-method approach to measure the level of SDM within goal-setting in two intermediate-care settings. Forty elderly patients completed the MAPPIN'SDM questionnaire. Following that, 15 patients were interviewed in semi-structured interviews. This sample size was justified on the concept guided by information power since the aim for this phase was narrow and focused on the specific phenomenon of SDM in goal setting. The concept of information power was used to determine an appropriate sample size for qualitative research. This term refers to the fact that the more information a sample contains that is relevant to the particular study, the fewer participants are required.

Although an approximation of the sample size is crucial for planning, the sufficiency of the final sample size must be assessed continuously during the study process. The sample size cannot be predicted by formulae or by perceived redundancy. Tools for calculating a sufficient sample size should not be based on methods from a particular analysis approach but rather on accepted methodological principles for estimating an adequate sample size (Speller-Brown et al., 2015). The sample's information power was crucial for this study, since it focused on extremely unique to uncommon patient experiences regarding SDM in CKD patients. The study requires the fewest participants if the study objective is narrow, the participants are highly specific to the study objective, the study is backed by established theory, the interview dialogue is robust, and the analysis thoroughly explores the narrative details (Speller-Brown et al., 2015). The limitations on the number of eligible participants may provide the necessary information
concerning factors influencing their choice of treatment and the SDM experience in selecting the present treatment option for CKD. This study used a mixed-methods approach to blend the quantitative and qualitative strengths in one study. The combination of qualitative and quantitative findings adds richness to the data and enables a more nuanced interpretation of the responses.

**Inclusion Criteria**

The online survey began with these four inclusion criteria:

1. 18 years of age and older.
2. Individuals who self-identify as having chronic kidney disease diagnosed by a healthcare provider.
3. Individuals currently considering or within the last three months have decided on a treatment option for chronic kidney disease.
4. Individuals who can participate in English and have modest internet skills.

If participants responded “yes” to all four survey questions, they were considered enrolled in the study. A “no” response to any one of the four questions disqualified the intended participant. When disqualified, individuals were thanked for their time and an explanation was provided: “Thank you for your interest in this survey. We appreciate your willingness, but your participation is not needed. Again, we thank you for your interest.” The survey closed by reassuring the participant that he or she is still eligible for the drawing. The rationale for the three-month period inclusion criteria complied with the instructions for the use of the Satisfaction with Decision scale. This measure is recommended to be given at a point when a healthcare decision has been made and the consequences have not yet been experienced (Holmes-Rovner et al., 1996). Therefore, for the purposes of this study, an additional question
was added on the survey to include any potential consequences that could influence satisfaction with decision responses: “After making this decision on dialysis choice, did you have an event requiring a visit to a healthcare provider, emergency room or hospital related to your decision?” The response to this question was included in screening responses prior to analysis.

**Hypotheses Tested**

The following research hypotheses are written as separate sub-hypotheses of the research question as indicated. They are specified as the null (H0) and the alternative (H1) for each question on the sample of CKD participants in the study.

1. What is the sociodemographic characteristic (e.g., age, gender, race/ethnicity, educational attainment, partnership status, self-reported health status) and are these related to participation with SDM?

**Sub-hypotheses**

**Age**

**H0**: There is no difference or relationship between demographic variable age and participation with shared decision making.

**H1**: There is a difference or relationship between demographic variable age and participation with shared decision making.

**Gender**

**H0**: There is no difference among demographic variable gender and participation with shared decision making.

**H1**: There is a difference among demographic variable gender and participation with shared decision making.
Race

$H_0$: There is no difference between demographic variable race and participation with shared decision making.

$H_1$: There is a difference between demographic variable race and participation with shared decision making.

Education

$H_0$: There is no difference or relationship between demographic variable educational attainment with shared decision making.

$H_1$: There is a difference or relationship between demographic variable educational attainment with shared decision making.

Partnership

$H_0$: There is no difference between demographic variable partnership status with shared decision making.

$H_1$: There is a difference between demographic variable partnership status with shared decision making.

Health Status

$H_0$: There is no difference between demographic variable self-reported health status with shared decision making.

$H_1$: There is a difference between demographic variable self-reported health status with shared decision making.

2. Is there a significant relationship between decisional self-efficacy and participation in shared decision making in a CKD sample?

$H_0$: There is no significant relationship between decisional self-efficacy and participation
in shared decision making in a CKD sample.

**H₁**: There is a significant relationship between decisional self-efficacy and participation in shared decision making in a CKD sample.

3. **Research question 3**

   3a. Is there a correlation between participation in shared decision making (SDM) and decisional conflict in a CKD sample? Is there a correlation between decision self-efficacy (DSES) and decisional conflict (SURE)?

**Predictors of Decisional Conflict**

**H₀**: There is no significant relationship between participation in shared decision making (SDM) and decisional conflict.

**H₁**: There is a significant relationship between participation in shared decision making (SDM) and decisional conflict.

**Predictors of Decisional Conflict**

**H₀**: There is no significant relationship between decisional self-efficacy and decisional conflict.

**H₁**: There is a significant relationship between decisional self-efficacy and decisional conflict.

3b. Is there a correlation between participation in shared decision making and satisfaction with the decision? Is there a correlation between participation in decision self-efficacy and satisfaction with the decision?

**Predictors of Satisfaction with the Decision (SWD)**

**H₀**: There is no significant relationship between participation in shared decision making (SDM) and satisfaction with decision.
**H1:** There is a significant relationship between participation in shared decision making (SDM) and satisfaction with decision.

*Predictors of Satisfaction with the Decision (SWD)*

**H0:** There is no significant relationship between decisional self-efficacy and satisfaction with decision.

**H1:** There is a significant relationship between decisional self-efficacy and satisfaction with decision.

4. Research question 4

4a. Is there a regression model that can predict satisfaction with the decision by the variables decisional self-efficacy and participation in shared decision making?

**H0:** There is no significant contribution by the two variables shared decision making, and decisional self-efficacy, in the prediction of satisfaction with the decision.

**H1:** There is a significant contribution by the two variables shared decision making, and decisional self-efficacy in the prediction of satisfaction with the decision.

4b. Is there a regression model that can predict decisional conflict by the variables decisional self-efficacy and participation in shared decision making?

**H0:** There is no significant contribution by the two variables shared decision making and decisional self-efficacy in the prediction of decisional conflict.

**H1:** There is a significant contribution by the two variables shared decision making and decisional self-efficacy in the prediction of decisional conflict.

**Procedures**

Recruitment for this study began after receiving Institutional Review Board approval from Molloy College, Rockville Centre, New York. The data collection procedure included email
or online survey. Online data collection has been found to improve access to hard-to-reach
groups and participation from ethnic minorities (Joseph et al., 2013, as cited in Heath et al.,
2018), particularly those who are geographically diverse (Wilkerson et al., 2014, as cited in
Heath et al., 2018). Email interviews are being increasingly used by nurse researchers
(Hershberger & Kavanaugh, 2017). Email interviews have a number of strengths. They offer
low-cost interaction without the need to travel, do not require researcher or participant presence
at the same pre-specified time, and are potentially more acceptable to those who might decline or
be unable to participate in spoken interviews but willing to answer questions posted on their
computer screens. Studies have also found that online respondents might be less susceptible to
social desirability bias because of the lack of researcher presence (Duffy et al., 2005, as cited in
Heath et al., 2018).

The telephone interview was another option considered; however, it was ultimately
viewed as a less attractive alternative to the face-to-face interview (Novick, 2008, as cited in
Heath et al., 2018). Notable strengths include good geographical coverage and personal
interaction. More recent study findings reveal that interviewees feel comfortable with telephone
interviews when discussing intimate, sensitive, and personal issues in an open and honest
manner, and are less concerned about humiliation than when speaking face-to-face, perhaps due
to increased familiarity with telephones (Chapple, 1999, as cited in Heath et al., 2018).

With multiple options for interviewing available to researchers, when planning a study, it
is important that public involvement is utilized. Researchers have an important role in ensuring
that participants have an optimal research experience (Bartlett et al., 2019). Study participants
were recruited directly from the Kidney Solutions website (kidneysolutions.org). Permission was
obtained from AAKP Board of Director and Vice President of Kidney Solutions. A recruitment
flyer was sent out with the researcher’s contact information to Kidney Solutions along with the survey questionnaire using Google Forms. Kidney Solutions then sent out the link directly to all the patients who qualify for the study based on the inclusion criteria via email. No participants were contacted directly by the researcher initially, but all consenting information was included in the forms provided by the researcher and sent to the willing recruited subjects who were invited by the vice president of Kidney Solutions. Participants were informed that their participation was voluntary, confidential, and they could opt out at any time. The setting for this study was an email/online-survey created by the researcher. Factors suggested by Safdar and colleagues (2016) were used to mitigate low response rate, including review of clarity of instructions, minimizing survey questions to reflect what is being investigated, and providing a user-friendly survey format. All scales and instruments used in this survey were granted permission for use by developers.

**The Survey Questionnaire**

The surveys were integrated into a single web-based questionnaire used as an interview or via the internet. It began with instructions that make clear that participation is voluntary and, if using the web-based format, completing the questionnaire indicates the subject’s consent to participate. The subsequent survey items included three “eligibility/inclusion” questions that use the online structure to advance the subject or end the survey, sociodemographic questions, the eleven-item Decisional Self-Efficacy Instrument, four-item SURE test, nine-item Shared Decision Making Questionnaire, and then directed to the six-item Satisfaction with Decision Instrument. The survey ended with three additional open-ended question to elicit narrative responses from the participants describing the decision process and transplant consideration. The
total survey consisted of approximately 50 questions to minimize subject burden. Estimated time to take the survey was approximately 20 minutes (Appendix B).

**Measurements**

**Instrumentation**

The ODSF has been used for 20 years to assess and address people’s decisional needs and evaluate decisional outcomes. Care was taken in researching suitable tools in the literature that could be useful in measuring concepts in SDM. Several tools were identified, and all tools were given permission by developers (Appendix B, C, D, E).

**Socio-Demographic Questionnaire**

Participants questions related to CKD include duration of chronic kidney disease and time since treatment decision. Sociodemographic characteristics in the questionnaire include gender, ethnicity, race, age, education level, relationship status, social support during decision, and self-reported health status.

**Instruments/Interviews/Questions**

**Decisional Self-Efficacy Scale (DSES)**

Self-efficacy was measured using DSES. This is an 11-item scale in which participants rate their level of confidence in various aspects of the decision making process (Bunn & O’Connor, 1996). The Decision Self-Efficacy scale was developed by Annette O’Connor and based on Bandura’s (1977) concept of self-efficacy. Bandura described self-efficacy as a feeling of adequacy and efficiency in dealing with life situations. According to O’Connor, this measurement elicits clients’ appraisal of their abilities to engage in the task of obtaining information about treatment options, expressing their concern and views, and making an informed choice. This instrument assesses their social role in working with the health team.
O’Connor viewed self-efficacy as one’s perceived ability to engage in treatment-related behaviors, and the instrument was developed to measure self-confidence or beliefs in one’s abilities in decision making, including SDM (Bunn & O’Connor, 1996). The self-efficacy scale can be used over time, or before or after an intervention is provided (O’Connor, 2002). The DSES assesses participants’ self-confidence or belief in one’s abilities in decision making. In testing, the DSES internal reliability coefficient was .92, and the scale significantly discriminated between participants who did and did not make health-related decisions (O’Connor & Bunn, 1996, as cited in Bailey et. al, 2016). The DSES is summed and scored from 0 to 100, with 100 representing complete self-efficacy and 0 representing complete lack of self-efficacy. The tool begins with an introductory statement: How confident do or did you feel in making an informed choice in regard to your decision on CKD treatment choice by selecting the number on a scale for each item below as 0 = not confident at all to 4 = very confident (Appendix E).

**My confidence in making an informed decision**

Table 3.1 lists some statements involved in making an informed choice. Table measures how confident participant feel in doing these things by circling the number from 0 (not at all confident) to 4 (very confident) for each item listed below.

I feel confident that I can:

Table 3.1 Decisional self-efficacy scale

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Get the facts about the <strong>treatment options</strong> (original version: “medication choices”) available to me</td>
</tr>
<tr>
<td>2</td>
<td>Get the facts about the benefits of each choice</td>
</tr>
<tr>
<td>3</td>
<td>Get the facts about the risks and side effects of each choice</td>
</tr>
<tr>
<td>4</td>
<td>Understand the information enough to be able to make a choice</td>
</tr>
<tr>
<td>5</td>
<td>Ask questions without feeling dumb</td>
</tr>
<tr>
<td>6</td>
<td>Express my concerns about each choice</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>7.</td>
<td>Ask for advice</td>
</tr>
<tr>
<td>8.</td>
<td>Figure out the choice that best suits me</td>
</tr>
<tr>
<td>9.</td>
<td>Handle unwanted pressure from others in making my choice</td>
</tr>
<tr>
<td>10.</td>
<td>Let the <em>healthcare team</em> know what’s best for me (original version: Clinic Team)</td>
</tr>
<tr>
<td>11.</td>
<td>Delay my decision if I feel I need more time</td>
</tr>
</tbody>
</table>

**Scoring and Interpretation**

The Decision Self-Efficacy Scale, had five response categories (see sample tool in Table 3.1). The scale ranges from 0 to 100. The total score is summed, divided by 11 and multiplied by 25. Score range from 0 (*not at all confident*) to 100 (*very confident*). A score of 0 means “extremely low self-efficacy” and a score of 100 means “extremely high self-efficacy.”

**Decisional Conflict Using the SURE Test**

Decisional conflict refers to a patient’s uncertainty about the course of action to take when the choices involve risk, loss, regret, or a challenge to personal life values. Clinicians should assess individuals for decisional conflict to reduce the downstream effects of unresolved decisional conflict (Légaré et al., 2010). Therefore, screening for decisional conflict is an important competency in SDM (Ferron Parayre et al., 2014). The SURE test is a four item-two response category test that was developed for use in clinical practice (Légaré et al., 2010). For the purposes of this study, the 4-item SURE test (Appendix C) was administered to minimize cognitive burden related to the potential length of this study. Although this test should be performed before a decision is made, screening was performed for individuals continuing to contemplate a decision and retrospectively for those who have decided in the last three months. The SURE test was developed on the concepts of the ODSF, which accounts for all stages of decision making, feeling uncertain, feeling informed, feeling clear about values, and feeling
supported in decision making. The SURE test consists of two responses yes (score = 1) and no (score = 0), where the acronym SURE, stands for the following concepts (Légaré et al., 2010):

- **S** (Sure of myself) = Do you feel SURE about the best choice for you?
- **U** (Understand information) = Do you know about the benefits and risks of each option?
- **R** (Risk-benefit ratio) = Are clear about which benefits, and risks matter to you?
- **E** (encouragement) = Do you have enough support and advice to make a choice?

The total score of “uncertainty” can only be calculated if all items are answered. Therefore, for the purpose of the survey, all four questions on this instrument are noted as mandatory fields. The four items are summed, and scores range from 0 = *extremely high decisional conflict* to 4 = *no decisional conflict*. The SURE test has been used in patients with spinal stenosis, chronic back pain, prostate cancer, and breast cancer. The tool is available in English and French (O’Connor, 2010).

Ferron and colleagues (2014) evaluated the internal consistency of SURE using the Kuder-Richardson 20 coefficient (KR-20) and compared DCS and SURE scores using the Spearman correlation coefficient. Researchers assessed sensitivity and specificity of SURE scores (cut-off score 3 out of 4) by identifying patients with and without clinically significant decisional conflict (DCS score .37.5 on a scale of 0–100). SURE scores showed adequate internal consistency (KR-20 coefficient of 0.7). There was a significant correlation between DCS and SURE scores (Spearman’s $r = 0.45, p < .0001$). The prevalence of clinically significant decisional conflict as estimated by the DCS was 5.2% (95% CI, 3.7–7.3). The sensitivity and specificity of SURE were 94.1% (95% CI, 78.9–99.0) and 89.8% (95% CI, 87.1–92.0), respectively. SURE has the potential to be a useful screening tool for practitioners, responding to the growing need for detecting clinically significant decisional conflict in patients.
Table 3.2 shows the items measured in a SURE test.

Table 3.2 SURE test

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Do you feel sure about the best choice for you?</td>
<td>Yes/No</td>
</tr>
<tr>
<td>2.</td>
<td>Do you know the benefits and risk of each option?</td>
<td>Yes/No</td>
</tr>
<tr>
<td>3.</td>
<td>Are you clear about which benefits and risks matter most to you?</td>
<td>Yes/No</td>
</tr>
<tr>
<td>4.</td>
<td>Do you have enough support and advice to make a choice?</td>
<td>Yes/No</td>
</tr>
</tbody>
</table>

**Shared Decision Making**

The original 26-item German SDM-Q was developed building on Elwyn’s model of competencies for involving patients in decisions. With refinement the revised, SDM-Q-9 instrument represents the first psychometrically sound self-assessment tool measuring the process of SDM. The SDM-Q-9 was developed in a theory-driven manner and measures the extent to which patients are involved in the process of decision-making from the perspective of the patients. Over the last years, the SDM-Q-9 has become a frequently used instrument to measure SDM in clinical practice and has been translated into several languages, including English, Spanish, French, Italian, Chinese, Japanese, Korean, Persian, Hebrew, and Dutch (Rodenburg-Vandenbussche et al., 2015). The 9-item SDM Questionnaire has two versions: one assesses the perspective of a patient (SDM-Q-9) and another that assesses the perspective of a healthcare provider (SDM-Q-Doc). Both versions have demonstrated acceptable reliability and have factorial validity (Sepucha & Scholl, 2014). The patient version (SDM-Q-9) is a valid, reliable, and brief self-report questionnaire that assesses the patient’s view of the decision making process.

The SDM-Q-9 is used increasingly often to assess interventions aiming to improve SDM. This is likely due to its psychometric testing, acceptance, and feasibility of administration with only nine items. The SDM-Q-9 is a patient-reported measure that focuses on the decisional
process by rating physicians’ and patients’ behavior in medical encounters. The SDM-Q-9 showed good internal consistency ($\alpha = .94$) and high face and structural validity in its first psychometric testing in a large ($N = 2,351$) primary care sample. The SDM-Q-9 was translated into English (Kriston et al., 2010, as cited in Doherr et al., 2017), allowing for use in international research. The English version was tested in a stratified primary care sample ($N = 488$) in the U.S. and confirmed a unidimensional structure and high internal consistency (Scholl et al., 2011, as cited in Doherr et al., 2017). Further psychometric testing of the English version in a representative sample of the U.S. population ($N = 1,341$) revealed discriminating validity of the SDM-Q-9, which had not been tested before (Barr et al., 2014, as cited in Doherr et al., 2017). The availability of the measure in multiple languages with a relatively large amount of psychometric testing broadened the possibilities of its use in different healthcare systems. The 9-item questionnaire (SDMQ9) consists of each step describing one step of the SDM process as demonstrated in Table 3.3 (De Las Cuevas et al., 2013). The items are arranged in the survey instrument based on the steps of the SDM process:

Table 3.3 *SDM Q-9 and Steps in Shared Decision Making Process*

<table>
<thead>
<tr>
<th><strong>SDM-Q-9 Items Questions</strong></th>
<th><strong>Steps in the SDM Process</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>1) My doctor made clear that a decision needs to be made</td>
<td>1) Disclosure that a decision needs to be made</td>
</tr>
<tr>
<td>2) My doctor wanted to know exactly how I want to be involved in making the decision</td>
<td>2) Formulation of equality of partners</td>
</tr>
<tr>
<td>3) My doctor told me that there are different options for treating my medical condition</td>
<td>3) Equipoise Statement</td>
</tr>
<tr>
<td>4) My doctor precisely explained the advantages and disadvantages of the treatment options</td>
<td>4) Information patients of the benefits and risks of the options</td>
</tr>
<tr>
<td>5) My doctor helped me understand all the information</td>
<td>5) Investigation of the patient’s understanding and expectations</td>
</tr>
<tr>
<td>6) My doctor asked me which treatment option I prefer</td>
<td>6) Identification of preferences</td>
</tr>
<tr>
<td>------------------------------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>7) My doctor and I thoroughly weighed the different treatment options</td>
<td>7) Negotiation</td>
</tr>
<tr>
<td>8) My doctor and I selected a treatment option together</td>
<td>8) Shared decision</td>
</tr>
<tr>
<td>9) My doctor and I reached an agreement on how to proceed</td>
<td>9) Arrangement of follow-up</td>
</tr>
</tbody>
</table>

Source: Adapted from De Las Cuevas et al., 2013.

The 9-item SDM-Q9 Patient Version uses the structure of an introductory statement related to the patient’s recent decision with the following items see (Appendix B): Each statement is scored by means of scoring nine items on a 6-point Likert-type scale, ranging from 0 = *completely disagree* to 5 = *completely agree*. Summing up all items leads to a raw total score between 0 and 45, where 0 is the lowest possible level of SDM and 45 indicates the highest extent of SDM (De las Cuevas et al., 2015).

**Satisfaction with Medical Decision**

The Satisfaction with the Decision (SWD) scale was designed not to assume a good health outcome but to measure satisfaction with a healthcare decision. The SWD Instrument is a six-item instrument in which individuals rate the extent to which each statement is true at a point in time using a 1 to 5 point Likert type scale where 1 = *strongly disagree*, 2 = *disagree*, 3 = *neither agree nor disagree*, 4 = *agree* and 5 = *strongly agree*, where increase in score indicates more satisfaction with decision (Holmes-Rovner et al., 1996). Scores will range from 6 = *strongly disagree with satisfaction with decision* to 30 = *strongly agree satisfaction with decision providing a continuous variable*. Although there is no established cutoff for the satisfaction with decision total score, Hitz and colleagues (2013) used a pragmatic approach by considering the average of four points over the six questions as a reasonable cutoff. In a previous study of
patients seeking a new line of palliative treatment scores were dichotomized scores. The score of 24 or above were considered as high and scores below 24 as low SWD (Hitz et al., 2013). The six-item SWD measures satisfaction with a healthcare decision, not to assume that all decisions made will have a good health outcome as it is possible that death may be an individual’s choice for the “best” outcome.

For the purposes of this study, the SWD scale were obtained as continuous data as described by Best and colleagues (2018), where higher scores indicate greater satisfaction. Wills and Holmes-Rovner (2003) assessed the psychometric properties of a recently developed standardized outcome measure of patient decision making, the SWD scale for a sample of depressed primary care patients, against the original validation study results as reported in Holmes-Rovner et al. (1996). The SWD scale had good internal consistency reliability (alpha = 0.85).

**Satisfaction with the Medical Decision Made**

The instrument uses a structure that restating that the patient reflects on the recent decision made related to dialysis and poses the following questions using the numbers of 1 = *strongly disagree*, 2 = *disagree*, 3 = *neither agree nor disagree*, 4 = *agree*, 5 = *strongly agree* (Appendix D)

Table 3.4 *Satisfaction with the medical decision scale*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I am satisfied that I am adequately informed about the issues important to my decision.</td>
</tr>
<tr>
<td>2.</td>
<td>The decision I made was the best decision possible for me personally.</td>
</tr>
<tr>
<td>3.</td>
<td>I am satisfied that my decision was consistent with my personal values.</td>
</tr>
<tr>
<td>4.</td>
<td>I expect to successfully carry out (or continue to carry out) the decision I made.</td>
</tr>
<tr>
<td>5.</td>
<td>I am satisfied that this was my decision to make.</td>
</tr>
<tr>
<td>6.</td>
<td>I am satisfied with my decision.</td>
</tr>
</tbody>
</table>
After the Satisfaction with Decision Instrument was completed, participants were asked to answer one question related to experiences related to their decision as, “After making this decision on dialysis choice, did you have an event requiring a visit to a healthcare provider, emergency room or hospital related to your dialysis decision?” This was asked, as it may have influenced their satisfaction with decision responses.

Data Analysis (Closed-Ended surveys)

Data were collected after obtaining approval from Molloy College IRB (Appendix F). The data collected from the participants using Google Forms were exported into IBM SPSS Statistical package 25.0 for analysis. All questions were reviewed for completeness. There were no missing data. Cronbach’s alpha coefficient was calculated for the 11-item DSES, 9-item SDM Instrument, 6-item Satisfaction with Decision Instrument, and 4-item SURE test. Descriptive statistics (e.g., means, standard deviations, frequencies, and percentages) were summarized for all data, including questionnaire completion, participants’ characteristics, DSES, SURE test, SDMQ-9 and Satisfaction with Decision Scale. A 5% level of significance was used to assess predictive power of each individual concept. Cramer’s V measures the association between two categorical variables: 0 indicates no association and 1 indicates a perfect association between two variables and small effect, .30 for medium effect and, .50 for large effect were used to measure the relationship between two variables.

For the purpose of this study, the independent variables of SDM and DSES and dependent variables SWD and Decisional conflict (SURE) in the CKD sample were tested for their reliability of internal consistency with a Cronbach’s alpha coefficient on the SDM and DSES instruments. One-way analysis of variance (ANOVA) was conducted to explore the
differences for categorical variables of interest with continuous outcome variables, and the $t$ test was used to test the association between categorical variable with a two-category response (Response: Yes, No) and continuous variable. Chi-square was used to determine categorical variables of interest with categorical outcome variables.

A one-way ANOVA between-group analysis of variance and $t$ tests were conducted to explore the impact of demographics and clinical factors in CKD on levels of participation in SDM, as measured by the SDMQ-9. A one-way between-groups analysis of variance and $t$ tests were conducted to explore the differences among demographic characteristics and clinical factors in CKD with decisional self-efficacy as measured by DSES. A one-way ANOVA between-group analysis of variance and $t$ tests were conducted to explore the differences among sociodemographic and clinical factors in CKD with satisfaction with the decision measured by the SWD scale.

For the purposes of exploring relationships among categorical variables of interest with categorical outcome variables, a chi-square was used. A relationship between reported decisional self-efficacy (as measured by the DSES) and SDM (as measured by the SDMQ9) was investigated using Pearson product-moment correlation coefficient. The relationship between perceived participation in SDM (as measured by the SDMQ9) and satisfaction with decision (as measured by the SWD) on a continuous scale of 6 to 30, was investigated using Pearson product-moment correlation coefficient. Also explored the relationship between decisional self-efficacy measured by DSES scale and satisfaction with the decision measured by SWD scale. Multiple linear regression model was used to predict satisfaction with the decision by the variables decisional self-efficacy and participation in SDM and also to predict decisional conflict by the variables decisional self-efficacy and participation in shared decision making. The narrative
statements of the participants collected from the open-ended questionnaire was analyzed and grouped into categories and sub-categories. Content analysis was used to analyze the qualitative data.

**Feasibility**

Encouragement was offered to maximize participation through interpersonal contact by the vice president of Kidney Solutions. The researcher offered a participation incentive of a $300 Amazon gift card to be raffled to one of the participants who completed the survey and provided their email contact to be entered into the drawing.

**Data Analysis (Qualitative Component)**

The survey questionnaire included open-ended questions to elicit responses from the participants in their own words about the decision making process. These narrative responses were analyzed qualitatively using content analysis and constant-comparison methods developed by Glaser and Strauss (Leech & Onwuegbuize, 2011). This study applied the content analysis method because it is particularly useful for processing open-ended question responses obtained from a qualitative survey questionnaire. To explore CKD patients' experiences regarding their decision making process, the researcher ensured trustworthiness in the different stages of the research process by encompassing the qualities of credibility, dependability, confirmability, transferability, and authenticity. Credibility is addressed by maintaining consistency between respondents' views and the researcher's representation. Member checks are one of the most robust mechanisms of assuring credibility in qualitative inquiry; it involves seeking the participants' views on the honesty and consistency of the research findings (Lincoln & Guba, 1985). To achieve credibility from the initial recruitment phase, the researcher ensured that participants with experiences of the phenomenon were selected and could provide rich data. In
addition, participant selection was vital for the transferability of the findings and an accurate and rich description of the context. The researcher undertook a content analysis of the open-ended questions. The content analysis was carried out with the research committee through every step of the analysis process.

The goal was to identify responses from different participants who showed common characteristics and categorize them in the same place. All open-ended responses (i.e., raw data) were sorted first by questions. The supporting quotes from the original text were included in each category to ensure dependability. Two qualitative researchers undertook content analysis to identify topics of importance among respondents. Clear rules for differentiating between categories were established between the coders to eliminate researcher bias that could influence how the responses were perceived and interpreted. Including more than one researcher in the analysis is one way to address dependability, as researchers' interpretative repertoires can vary. A co-researcher can come up with alternative interpretations. Following ongoing discussions and numerous rereads, the researcher and the committee’s qualitative expert survey responses were iteratively refined into a set of primary and secondary categories. Rigor is necessary to enhance the consistency and quality of qualitative research. It is the framework for demonstrating the credibility and integrity of the qualitative research process. Rigor is achieved when the interpretation of the meaning of the experience is familiar, reasonable, and representative of the many dimensions of the experience. The written text must be readable and interesting, and it ought to be clear that the researcher has addressed all ethical considerations (Munhall, 2007). Methodological decisions regarding rigor can have implications for the findings' quality, integrity, and interpretability. Rigor, therefore, is a principle that should be present during all stages of the research study, from its inception to the writing of the final report. Indeed, without
rigor, there is a danger that research may become fictional journalism, worthless as contributing to knowledge (Caelli et al., 2003, as cited in McBrien, 2008). The criteria of reliability, internal and external validity, and objectivity used in the natural science approach are not applicable to the human sciences; instead, the criterion for this paradigm is trustworthiness. Trustworthiness is composed of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

Cavanagh (1997, as cited in McBrien, 2008) argued that the rigor of qualitative research findings can be judged using criteria and terminology constructed to test the validity of results from quantitative studies. The transferability of the findings was secured by generating detailed descriptions of the study methodology, sample selection criteria, data collection process, and context. Finally, the confirmability of the findings was also secured by checking the associated notes and text of the original data to ensure that personal opinions and biases did not influence the interpretations of the findings. Methodological rigor is necessary to enhance the consistency and quality of qualitative research.

The content analysis was driven by a deductive approach (i.e., hypothesis driven) also allowed an inductive approach to identify new topics brought up frequently in response to survey questions. The rich narrative information from the research question was extracted for analysis and manually coded. A codebook was developed, comprising categories and subcategories, and included a definition and an example quote from the responses. The goal of content analysis was to capture the many ways respondents discussed SDM in the context of CKD treatment options. Because most individual responses encompassed multiple topics of importance, metaphors and concepts within the text were identified and used as categories whenever appropriate. The researcher ensured the study's overall trustworthiness and that participants' voices were heard by
systematically organizing the data into a structured format to facilitate a deeper understanding of the CKD patients' experiences in making the treatment choice through SDM.

**Data Safety and Management**

Data were collected using Google Forms. It is a tool that allows to prepare a questionnaire, with which researcher can examine the respondents either directly or remotely. Available types of questions in Google Form include open ended questions that enable respondents to write a shorter or a longer statement, the single choice and multiple-choice questions, selecting the answer on the varying range scale (minimum range scale is from 1 to 2, and the maximum from 0 to 10). It also allows to choose the date, time and duration of the activity. The tool is capable to collect the responses also from people who do not have a Google account. Each question can be marked as mandatory to fill. If one skips a question, the tool does not allow the respondent to go to the next page or send the form as questionnaire is not completed. This makes the respondents carefully respond to questions. This can avoid dealing with the problem of missing data. The form of the text answer can also be set to the form of an e-mail address or a URL.

Answers are stored in a spreadsheet located in the author’s Google Drive after completing the questionnaire by each respondent. A complete database containing all answers is exported and saved on a hard drive. It saves automatically to the researcher’s Google Drive in the form of xls file by default. It can be moved to a disc or exported to ods format, which is an OpenOffice workbook file. The results form can also be saved in PDF file, not editable but versatile and in an easy-viewing format. The last option of saving is to store the results of the survey in the form of an archived web page (zip) (Romaniuk, 2015). Participants’ personal identification information (if provided) were separated from actual responses before exporting/sharing to keep their
anonymity. The researcher assumed responsibility for granting access to committee members if requested. When a file is created on google sheets, it is stored securely in Google world-class data centers. Data are encrypted in transit and at-rest. The Google account comes with built-in security designed to detect and block threats like spam, phishing and malware. The activity is stored using strong industry standards and practices. Google privacy policy states all surveys/forms/applications/questionnaires and any responses collected are private by default (except if the researcher has made them available via a public link).

Summary

The study used a descriptive, correlational design to identify CKD patients’ personal characteristics, if combined with experiencing SDM, which will influence their decisional conflict and satisfaction. Participants were recruited from a convenience sample of members from an online support group of patients with kidney disease who are currently on dialysis and may be waitlisted for a transplant. A web-based survey was emailed to eligible participants who agreed to participate. The mixed-methods approach included existing measures of the variables with established validity and reliability, and three open-ended questions eliciting from the participants, in their own words, what influenced their decisions.
CHAPTER 4: RESULTS

The purpose of this study was to explore CKD patients’ experiences regarding their decision making process in selecting a dialysis modality. The study examined individual characteristics and explored the relationship between characteristics such as demographics, decisional self-efficacy, and decisional conflict on perceived participation in SDM in a sample of individuals with CKD. This chapter presents a summary of the participants’ personal characteristics, a descriptive summary of general responses used to address the research questions. The findings are organized according to the research questions and tested with appropriate statistics for the quantitative hypotheses in the first section, and narrative responses are analyzed qualitatively for the open-ended questions. The summary of specific findings informed a regression model to describe the variables that are triangulated with the findings of the qualitative analysis. The study results are then summarized and represented graphically.

Sample

A total of 55 individuals completed the online CKD Survey \((n = 55)\). The survey was consisting of six sections: demographics, decisional self-efficacy, decisional conflict, SDM, satisfaction with decision, and four open-ended questions. All questions were answered and there were no missing data in the participants’ responses.

Research Question 1

What are the sociodemographic characteristics (e.g., age, gender, educational attainment, partnership status) and participation with decision making in the CKD sample?

Univariate Descriptive Analysis

The participant age distribution was young 23.6\% \((n = 13)\), middle age 45.5\% \((n = 25)\), and seniors 30.9\% \((n = 17)\). 30 (54.5\%) were males and 25 (45.5\%) were females. Participants’
identified race included, White/Caucasian (63.6%, n = 35) Black or African American (18.2%, n = 10), Asian or Asian American (14.5%, n = 8), and Multiple Race (3.6%, n = 2). The ethnicity responses included, 48 (87.3%) non-Hispanic and 7 (12.7%) Hispanic. The level of education reported by participants included, ≤ high school graduate (40%, n = 22), and ≥ college graduate (60%, n = 33). Their relationship status were reported as single (23.6%, n = 13), married/partnered (54.5%, n = 30), divorced/separated (14.5%, n = 8), and widowed (7.3%, n = 4) as show in Table 4.1.

Table 4.1 Demographics Characteristics – Univariate Descriptive Statistics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>25</td>
<td>45.5</td>
</tr>
<tr>
<td>Male</td>
<td>30</td>
<td>54.5</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100.0</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>7</td>
<td>12.7</td>
</tr>
<tr>
<td>Not Hispanic or Latino</td>
<td>48</td>
<td>87.3</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100.0</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian or Asian American</td>
<td>8</td>
<td>14.5</td>
</tr>
<tr>
<td>Black or African America</td>
<td>10</td>
<td>18.2</td>
</tr>
<tr>
<td>Multiple Race</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>35</td>
<td>63.6</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100.0</td>
</tr>
<tr>
<td>Age Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Young (18 to 44)</td>
<td>13</td>
<td>23.6</td>
</tr>
<tr>
<td>Middle Age (45 to 64)</td>
<td>25</td>
<td>45.5</td>
</tr>
<tr>
<td>Seniors (≤ 65)</td>
<td>17</td>
<td>30.9</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0.0</td>
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<tr>
<td>Total</td>
<td>55</td>
<td>100.0</td>
</tr>
<tr>
<td>Educational Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High School Graduate</td>
<td>22</td>
<td>40.0</td>
</tr>
<tr>
<td>≥ College Graduate</td>
<td>33</td>
<td>60.0</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100.0</td>
</tr>
<tr>
<td>Relationship Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>13</td>
<td>23.6</td>
</tr>
<tr>
<td>Married/Partnered</td>
<td>30</td>
<td>54.5</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>8</td>
<td>14.5</td>
</tr>
<tr>
<td>Widowed</td>
<td>4</td>
<td>7.3</td>
</tr>
</tbody>
</table>
The self-reported health status by the participants were as follows: Poor 3.6% \( (n = 2) \), Moderately healthy other than kidney disease 63.7% \( (n = 35) \), and Very healthy other than kidney disease 32.7% \( (n = 18) \). The survey included a question that asked participants who supported them in the decision-making process. For the sample of 55 participants, responses were collapsed into two groups: Decision with Provider 47.3% \( (n = 26) \), and Decision without Provider 52.7% \( (n = 29) \). For other questions with limited responses in some of the options, the variable was collapsed appropriately. For example, questions that focused on CKD: (1) participants identified their stage in CKD as Stage 1 to 3 (10.9%, \( n = 6 \)), Stage 4 (25.5%, \( n = 14 \)), and Stage 5 (63.6%, \( n = 35 \)); (2) Participants reported their CKD duration as: (1) \( \leq 3 \) Years 21.8% \( (n = 12) \), (2) 3 to 5 Years 29.1% \( (n = 16) \), and (3) \( > 5 \) Years 49.1% \( (n = 27) \). They also identified current treatment they are on as conservative care 9.1% \( (n = 5) \), HD 38.2% \( (n = 21) \), PD 23.6% \( (n = 13) \), and kidney transplant 29.1% \( (n = 16) \), as shown in Table 4.2.

Table 4.2 CKD Decisional Characteristics – Univariate Descriptive Statistics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Reported Health Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>Moderately healthy other than my kidney disease</td>
<td>35</td>
<td>63.7</td>
</tr>
<tr>
<td>Very healthy other than my kidney disease</td>
<td>18</td>
<td>32.7</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100.0</td>
</tr>
<tr>
<td>Individuals Supported Decision Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decision with Provider</td>
<td>26</td>
<td>47.3</td>
</tr>
<tr>
<td>Decision without Provider</td>
<td>29</td>
<td>52.7</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100.0</td>
</tr>
</tbody>
</table>
### Measures: Descriptive Statistics

#### Independent Variables

The predictor variables for Satisfaction with Decision and Decisional Conflict include SDM and DSES. Descriptive statistics include a mean score and standard deviation for SDM \((M = 4.071, SD = 11.268)\) and for DSES \((M = 3.613, SD = 5.988)\).

#### Questionnaire Psychometrics

The measures used for the study independent variables were established in the literature with reported validity and reliability. In testing, the DSES internal reliability coefficient was .92, and the scale significantly discriminated between subjects who did and did not make health-related decisions (O’Connor & Bunn, 1996 as cited in Bailey et al., 2016). The SDMQ-9 showed good internal consistency \((\alpha = .94)\) and high face and structural validity in its first psychometric study.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CKD Stages</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 1 to 3</td>
<td>6</td>
<td>10.9</td>
</tr>
<tr>
<td>Stage 4</td>
<td>14</td>
<td>25.5</td>
</tr>
<tr>
<td>Stage 5</td>
<td>35</td>
<td>63.6</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>CKD Duration</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\leq 3) Years</td>
<td>12</td>
<td>21.8</td>
</tr>
<tr>
<td>3 to 5 Years</td>
<td>16</td>
<td>29.1</td>
</tr>
<tr>
<td>&gt; 5 Years</td>
<td>27</td>
<td>49.1</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Current Treatment Options</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conservative</td>
<td>5</td>
<td>9.1</td>
</tr>
<tr>
<td>Hemodialysis</td>
<td>21</td>
<td>38.2</td>
</tr>
<tr>
<td>Peritoneal Dialysis</td>
<td>13</td>
<td>23.6</td>
</tr>
<tr>
<td>Transplant</td>
<td>16</td>
<td>29.1</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100.0</td>
</tr>
</tbody>
</table>
testing in a large \( n = 2,351 \) primary care sample. The SDMQ-9 was translated into English (Kriston et al., 2010, as cite in Doherr et al., 2017), allowing for use in international research.

For the purpose of this study, the independent variables of SDM and DSES in the CKD sample were tested for their reliability of internal consistency with a Cronbach’s alpha coefficient on the SDM and DSES instruments. An alpha coefficient of > 0.70 was considered an acceptable value of instrument reliability for this study. In this sample of individuals who completed all questions on survey to provide a total score the Cronbach’s alpha coefficients for continuous scales are reported as: SDM \((r = 0.964)\) and for DSES \((r = 0.934)\), shown in Table 4.3.

**Table 4.3 Reliability Testing for Shared Decision Making and Decisional Self-Efficacy Instrument**

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Range</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDM</td>
<td>4.071</td>
<td>11.268</td>
<td>0.582</td>
<td>0.964</td>
</tr>
<tr>
<td>DSES</td>
<td>3.613</td>
<td>05.988</td>
<td>0.345</td>
<td>0.934</td>
</tr>
</tbody>
</table>

**Dependent Variables**

The measures used for the dependent variables were reported with reliability and validity in the literature. Study conducted by Wills and Holmes-Rovner (2003) assess the psychometric properties of a recently developed standardized outcome measure of patient decision making, the SWD scale for a sample of depressed primary care patients, against the original validation study results as reported in Holmes-Rovner et al. (1996). The SWD scale had good internal consistency reliability \((alpha = 0.85)\). A previous cross-sectional study was conducted in four family medicine group practices in Quebec and one rural academic medical center in New Hampshire to assess the reliability and validity of the 4-item SURE screening test for decisional conflict in patients (Légaré et al., 2010). The study participants included 120 French-speaking pregnant women considering prenatal screening for Down syndrome and 1,474 English-speaking patients.
referred to watch video decision aids. The internal reliability of SURE test was moderate with a Cronbach’s alpha was 0.54 and 0.65. According to the literature, SURE is the only clinically oriented instrument that helps providers identify patients experiencing clinically significant decisional conflict, despite its less-than-desirable reliability.

For the purpose of this study, the dependent variables SWD and Decisional conflict (SURE) in the CKD sample were tested for their reliability of internal consistency with a Cronbach’s alpha coefficient. An alpha coefficient of >0.70 was considered an acceptable value of instrument reliability. In this sample of individuals who completed all questions on each survey, the Cronbach’s alpha coefficients for these measures on continuous scales were: SWD ($r = 0.966$) and SURE test ($r = 0.593$). Recognizing the limited reliability and to try to improve the SURE test reliability for this sample, the measure was tested again removing a recommended item to improve reliability. The result was not greatly improved. Therefore, it was decided to keep the measure intact as reported in the literature. Although the reliability would be questionable, the instrument was maintained as originally developed. The SURE test instrument was not changed from the original published test for this analysis despite lower reliability than expected (Table 4.3), but the coding was reversed to better correspond with the variable of Decisional Conflict.

The 4-item SURE test to measure the decisional conflict was developed as a core concept of the ODSF, which are relevant at all stages of decision making: feeling uncertain, feeling informed, feeling clear about values, and feeling supported in decision making. The questions are framed in a positive manner to match the acronym SURE. As per the established instrument instructions, the self-administered 4-item SURE test used 2 response categories: Yes (score = 1) and No (score = 0). A perfect score on the SURE test (4) would indicate that there was no
decisional conflict. For the purpose of this study, the response categories were reverse coded to Yes = 0 and No = 1 to inversely frame responses to indicate the maximum score (4) for the variables higher decisional conflict.

In this particular study on CKD patients, the less-than-optimal value of the tested Cronbach’s alpha may be due to the homogeneity of the participants in the study, but the measure may have value to be tested and therefore included as one of two dependent measures. For this reason, it was be important to interpret findings with caution, and future studies need to assess a diverse group of patients experiencing clinically significant decisional conflict (Table 4.4).

Table 4.4 Reliability Testing for Satisfaction with Decision and Decisional Conflict Scale

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Range</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>SWD</td>
<td>4.430</td>
<td>5.827</td>
<td>0.218</td>
<td>0.966</td>
</tr>
<tr>
<td>*SURE test</td>
<td>0.059</td>
<td>0.637</td>
<td>0.036</td>
<td>0.593*</td>
</tr>
</tbody>
</table>

*Note: Although the internal consistency was below .70 for this study, the reliability was comparable to that reported in the literature (Légaré et al., 2010) as .54 and .65.

Bivariate Analysis of Measures with Demographics

This study included a number of participants’ socio-demographic questions to be analyzed (e.g., birth sex, ethnicity, race, age group, educational level, relationship status) and clinical factors in CKD (e.g., health status, decision making support, decision aid, CKD duration stage, current treatment option). These characteristics were analyzed descriptively and tested to view any relationships among participant demographics and all other variables: Satisfaction With Decision (SWD), participation in shared decision making (SDMQ9), decisional self-efficacy (DSES), decisional conflict (SURE).

One-way analysis of variance (ANOVA) was conducted to explore the differences for categorical variables of interest with continuous outcome variables, and a \( t \) test was used to test the association between categorical variables with a two category response (Response: Yes, No)
and continuous variable. Chi-square was used to determine categorical variables of interest with
categorical outcome variables.

A one-way ANOVA between-group analysis of variance and \( t \) tests were conducted to
explore the impact of demographics and clinical factors in CKD on levels of participation in
SDM, as measured by the 9-item SDMQ9. There was a statistically significant difference at the \( p \)< .05 level in SDMQ9 scores for Decision making support (\( t = -2.582, p < .05 \)) and use of
Decisional aid in decision making (\( t = -2.357, p < .05 \)). Participation in shared decision making
was a statistically significant for both SDM and decision aid (\( p < .05 \)). SDM scores were
significantly higher with providers’ support compared to without providers’ support (\( M = 40.54, SD = 9.509 \) vs \( M = 33.14, SD = 11.719, p = .013 \)), SDM scores were significantly higher when
using decisional aids compared to no decision aid (\( M = 39.29, SD = 8.938 \) vs \( M = 30.71, SD = 13.774, p = .028 \)). No other demographics/clinical factors were significant for SDM (Table 4.5b and Table 4.5c).

Table 4.5a Independent Variable: Shared Decision Making (SDMQ9)

<table>
<thead>
<tr>
<th>Demographics / Clinical Factors</th>
<th>T</th>
<th>F</th>
<th>( p )</th>
<th>Bivariate Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Sex</td>
<td>-0.240</td>
<td>.811</td>
<td>NS</td>
<td>t-test</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>1.620</td>
<td>.111</td>
<td>NS</td>
<td>t-test</td>
</tr>
<tr>
<td>Race</td>
<td>0.307</td>
<td>.820</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Age Group</td>
<td>0.887</td>
<td>.418</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Educational level</td>
<td>1.298</td>
<td>.282</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Relationship status</td>
<td>0.957</td>
<td>.420</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Health status</td>
<td>2.842</td>
<td>.067</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td><strong>Decision making support</strong></td>
<td><strong>-2.582</strong></td>
<td><strong>.013</strong></td>
<td><strong>&lt;.05</strong></td>
<td>t-test</td>
</tr>
<tr>
<td><strong>Decision aid</strong></td>
<td><strong>-2.357</strong></td>
<td><strong>.028</strong></td>
<td><strong>&lt;.05</strong></td>
<td>t-test</td>
</tr>
<tr>
<td>CKD duration</td>
<td>0.307</td>
<td>.737</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>CKD stage</td>
<td>0.148</td>
<td>.863</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Current treatment option</td>
<td>0.668</td>
<td>.576</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
</tbody>
</table>
**Decision Support from Provider**

Participants were asked to identify if the current treatment decision was made with support from the healthcare provider or if the participant made the decision without support from the healthcare provider. Twenty-six (47.27%) individuals identified healthcare providers who supported them in making the current treatment decision. There were 29 (52.7%) individuals who did not identify healthcare provider in supporting them in the decisional process (Table 4.5b).

Table 4.5b *Decision support from Provider (T-Test) with Shared Decision Making (SDM-Q9)*

<table>
<thead>
<tr>
<th>Decision Support</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Without Provider</td>
<td>29</td>
<td>33.14</td>
<td>11.719</td>
<td>-2.58*</td>
<td>.013</td>
</tr>
<tr>
<td>With Provider</td>
<td>26</td>
<td>40.54</td>
<td>09.509</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < 0.05.

**Decision Aid**

Participants were asked to identify if they received an educational packet or decision aid pamphlet to assist in the decision process. There were 30.9% (*n* = 17) individuals who responded that “no packet or pamphlet” was received. However, 69.1% (*n* = 38) of individuals responded to having received some form of educational packet or educational brochure to assist in the decisional process (Table 4.5c).

Table 4.5c *Decision Aid (T-Test) with Shared Decision Making (SDM-Q9)*

<table>
<thead>
<tr>
<th>Decision Aid Used</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>17</td>
<td>30.71</td>
<td>13.774</td>
<td>-2.36*</td>
<td>.028</td>
</tr>
<tr>
<td>Some</td>
<td>38</td>
<td>39.29</td>
<td>08.938</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < 0.05.

A one-way between groups analysis of variance and t tests were conducted to explore the differences among demographic characteristics and clinical factors in CKD with decisional self-
efficacy as measured by DSES. There was no statistically significant difference at the p<.05 level observed in the findings (Table 4.6).

Table 4.6 Independent Variable: Decisional Self Efficacy Scale (DSES)

<table>
<thead>
<tr>
<th>Demographics / Clinical Factors</th>
<th>T</th>
<th>F</th>
<th>p</th>
<th>Bivariate Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Sex</td>
<td>-1.672</td>
<td>.101</td>
<td>NS</td>
<td>t-test</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>1.509</td>
<td>.179</td>
<td>NS</td>
<td>t-test</td>
</tr>
<tr>
<td>Race</td>
<td>2.377</td>
<td>.081</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Age Group</td>
<td>1.879</td>
<td>.163</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Educational level</td>
<td>1.112</td>
<td>.337</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Relationship status</td>
<td>1.720</td>
<td>.175</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Health status</td>
<td>2.622</td>
<td>.082</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Decision making support</td>
<td>-1.679</td>
<td>.099</td>
<td>NS</td>
<td>t-test</td>
</tr>
<tr>
<td>Decision aid</td>
<td>-0.419</td>
<td>.677</td>
<td>NS</td>
<td>t-test</td>
</tr>
<tr>
<td>CKD duration</td>
<td>0.799</td>
<td>.455</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>CKD stage</td>
<td>0.642</td>
<td>.531</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Current treatment option</td>
<td>1.117</td>
<td>.351</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
</tbody>
</table>

A one-way ANOVA between-group analysis of variance and t tests was conducted to explore the differences among sociodemographic and clinical factors in CKD with satisfaction with the decision measured by the SWD scale. There was no statistically significant difference at the p < .05 level in satisfaction with decision and reporting yes or no to consequence as a result of your decision (Table 4.7). It is important to note that the developers of the SWD commented that the SWD scale was designed not to assume a good health outcome but to measure satisfaction with a healthcare decision (Holmes-Rovner et al., 1996).

Table 4.7 Dependent Variable: Satisfaction With Decision (SWD)

<table>
<thead>
<tr>
<th>Demographics / Clinical Factors</th>
<th>T</th>
<th>F</th>
<th>p</th>
<th>Bivariate Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Sex</td>
<td>-1.235</td>
<td>.222</td>
<td>NS</td>
<td>t-test</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>1.479</td>
<td>.145</td>
<td>NS</td>
<td>t-test</td>
</tr>
<tr>
<td>Race</td>
<td>0.952</td>
<td>.423</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Age Group</td>
<td>1.471</td>
<td>.239</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Educational level</td>
<td>0.858</td>
<td>.430</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Relationship status</td>
<td>1.516</td>
<td>.221</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Health status</td>
<td>2.500</td>
<td>.092</td>
<td>NS</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Decision making support</td>
<td>-0.920</td>
<td>.362</td>
<td>NS</td>
<td>t-test</td>
</tr>
</tbody>
</table>
For the purposes of exploring relationships among categorical variables of interest with categorical outcome variables, a chi-square was used. There was a statistically significant association between current treatment option ($p = .021$) and decisional conflict as measured by the SURE test (Table 4.8a). It is important to note that the SURE test as a measure lacked optimum reliability, but as separated into the groups of presence or absence of conflict, the non-parametric measure produced a significant association (Table 4.8b and 4.8c).

**Table 4.8a Dependent Variable: Decisional Conflict Scale (SURE Test)**

<table>
<thead>
<tr>
<th>Demographics / Clinical Factors</th>
<th>$p$</th>
<th>Bivariate Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Sex</td>
<td>.400</td>
<td>NS</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>.568</td>
<td>NS</td>
</tr>
<tr>
<td>Race</td>
<td>.474</td>
<td>NS</td>
</tr>
<tr>
<td>Age Group</td>
<td>.303</td>
<td>NS</td>
</tr>
<tr>
<td>Educational level</td>
<td>.939</td>
<td>NS</td>
</tr>
<tr>
<td>Relationship status</td>
<td>.693</td>
<td>NS</td>
</tr>
<tr>
<td>Health status</td>
<td>.808</td>
<td>NS</td>
</tr>
<tr>
<td>Decision making support</td>
<td>.754</td>
<td>NS</td>
</tr>
<tr>
<td>Decision Aid</td>
<td>.256</td>
<td>NS</td>
</tr>
<tr>
<td>CKD duration</td>
<td>.222</td>
<td>NS</td>
</tr>
<tr>
<td>CKD stage</td>
<td>.935</td>
<td>NS</td>
</tr>
<tr>
<td><strong>Current treatment option</strong></td>
<td>.021</td>
<td><strong>p&lt;.05</strong></td>
</tr>
</tbody>
</table>

**Current treatment option and Decisional conflict (SURE test)**

Decisional conflict was assessed using the SURE test, which describes the presence of decisional conflict with the respondent score a maximum score of 4 and the absence of decisional conflict if the score is less than four ($<4$) in this particular study. A chi-square test for independence indicated a significant association between the current treatment option (4
categories) and dichotomous decisional conflict (presence vs. absence) as measured by the SURE test, $\chi^2 = 19.506, p = .021$, Phi = .596, Cramer’s V = .344. Selection of CKD treatment option is dependent on having conflict with decision making. The two variables have a significant relationship with each other, represented by a Phi of 0.596 and Cramer’s V of 0.344, with a moderate effect size. Decisional conflict plays a significant role in how participants select treatment options. Based on the study response, participants who selected PD as the treatment option had no decisional conflict compared to those who chose conservative care, HD, and kidney transplants (Table 4.8b and 4.8c).

Table 4.8b *Effect size*

<table>
<thead>
<tr>
<th>SURE Test/Treatment Options</th>
<th>Pearson Chi-square</th>
<th>$p$</th>
<th>Phi</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>19.506</td>
<td>0.021</td>
<td>0.596</td>
<td>0.344</td>
</tr>
</tbody>
</table>

Table 4.8c *Crosstabulation: SURE test * Current Treatment Options*

<table>
<thead>
<tr>
<th>SURE Test/Treatment Options</th>
<th>Conservative</th>
<th>Hemodialysis</th>
<th>Kidney Transplant</th>
<th>Peritoneal Dialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Conflict</td>
<td>60.0%</td>
<td>85.7%</td>
<td>76.9%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Some Conflict</td>
<td>40.0%</td>
<td>14.3%</td>
<td>23.1%</td>
<td>000.0%</td>
</tr>
</tbody>
</table>

**Research Question 2**

Is there a significant relationship between decisional self-efficacy and participation in shared decision making in a CKD sample?

A relationship between reported decisional self-efficacy (as measured by the DSES) and SDM (as measured by the SDMQ9) was investigated using Pearson product-moment correlation coefficient. There is a moderate, positive correlation between the two variables, $r = .390$, $n = 55$, $p < .01$, with high levels of decisional self-efficacy associated with higher levels of participation in shared decision making (SDMQ9, Table 4.9). Although decisional self-efficacy and shared
decision making are correlated, they are not measuring the same construct. Hence, they are two separate variables. They are not multicollinear. Therefore, decisional self-efficacy and SDM can be used in a multiple regression model.

Table 4.9 Bivariate test for Shared Decision Making (SDM Q9) and Decisional Self Efficacy Instrument (DSES)

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>N</th>
<th>r</th>
<th>p</th>
<th>Bivariate Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDM Q9</td>
<td>55</td>
<td>0.390</td>
<td>.003</td>
<td>p&lt;.01 Correlation</td>
</tr>
</tbody>
</table>

There were a few outliers in the scatterplot with the regression line represented. However, responses were used in subsequent analysis.

**Research Question 3a**

Is there a correlation between participation in shared decision making and decisional conflict in a CKD sample? Is there a correlation between decision self-efficacy (DSES) and decisional conflict (SURE)?
Main Effects on Dependent Variables

a. Predictors of Decisional Conflict

The 4-item SURE test is consistent with the ODSF, which is relevant at all stages of decision making: feeling uncertain, feeling informed, feeling clear about values, and feeling supported in decision making. Therefore, the screening for decisional conflict is an important competency in SDM. The DSES assesses participants’ self-confidence or belief in one’s abilities in decision making. Statistical analysis was performed to evaluate the relationship between SDM and Decisional Conflict using the SURE test and also evaluated relationship between Decisional Self efficacy with Decisional Conflict using the SURE test.

Hypotheses 3a

3a1: Shared Decision Making (SDM) is related to Decisional Conflict (SURE Test)

There is a significant relationship between participation in SDM and decisional conflict ($r = -0.362, p < .01$). The result indicates a negative correlation which means as SDM increases, less decisional conflict is reported by the participants (Table 4.10).

3a2: Decisional Self-Efficacy (DSES) is related to Decisional Conflict (SURE Test).

There is a significant relationship between decisional self-efficacy and decisional conflict ($r = -0.489, p<.001$). The result indicates a negative correlation, which means as Decisional Self Efficacy increases, less decisional conflict is reported by the participants (Table 4.10).

Table 4.10 Bivariate test for Shared Decision Making and Decisional Self-Efficacy Instrument with Decisional Conflict Scale

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>$r$</th>
<th>$p$</th>
<th>Bivariate Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDM Q9</td>
<td>-0.362</td>
<td>.007</td>
<td>$p&lt;.01$</td>
</tr>
<tr>
<td>DSES</td>
<td>-0.489</td>
<td>.000</td>
<td>$p&lt;.001$</td>
</tr>
</tbody>
</table>
Research Question 3b

Is there a correlation between participation in shared decision making and satisfaction with the decision? Is there a correlation between participation in decision self-efficacy and satisfaction with the decision?

Hypotheses 3b

3b1: Shared Decision Making (SDM) is related to Satisfaction with Decision (SWD).

There is a significant relationship between participation in SDM and SWD. The relationship between perceived participation in shared decision making (as measured by the 9-item SDMQ-9) and satisfaction with decision (as measured by the SDM Scale) on a continuous scale of 6 to 30, was investigated using Pearson product moment correlation coefficient ($n = 55$). There was a positive correlation between the two variables, $r = .701$, $n = 55$, $p<0.01$, with high levels of participation in SDM associated with higher levels of satisfaction with the decision (Table 4.11).

3b2: Decisional self-efficacy (DSES) is related to Satisfaction with Decision (SWD).

There is a significant relationship between decisional self-efficacy and satisfaction with decision. Pearson product-moment correlation coefficient was conducted to explore the relationship between Decisional self-efficacy measured by the DSES scale and satisfaction with the decision measured by SWD scale. There is a positive correlation between the two variables, $r = .624$, $n = 55$, $p<0.01$, with high levels of decisional self-efficacy is associated with higher levels of satisfaction with decision (Table 4.11).
Table 4.11 Bivariate test for Shared Decision Making and Decisional Self Efficacy Instrument with Satisfaction with Decision

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>r</th>
<th>p</th>
<th>Bivariate Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDM Q9</td>
<td>0.701</td>
<td>.000</td>
<td>p&lt;.001 Correlation</td>
</tr>
<tr>
<td>DSES</td>
<td>0.624</td>
<td>.000</td>
<td>p&lt;.001 Correlation</td>
</tr>
</tbody>
</table>

**Predictor Model Research Questions**

**Research Question 4a**

Is there a regression model that can predict satisfaction with the decision by the variables decisional self-efficacy and participation in shared decision making?

**Hypotheses Question 4a**

Prediction for SWD is significant using a multiple linear regression model by combining DSES and SDM (Figure 4.2):

![Figure 4.2 Regression Model](image)

The two variables SDM, and DSES contributed to satisfaction with the decision with \( n = 55 \), \( R = 0.797 \), \( R \) square, = 0.636, Adjusted \( R \) square = 0.622, \( F = 45.408 \). Almost two thirds of the adjusted variance is accounted for by the two variables, shared decision making, and decisional self-efficacy. In this model, SDM has a higher correlation with satisfaction with the decision making. The model is statistically significant (\( p = .000 \)). For this model, shared decision making is a higher predictor of satisfaction with the decision than decisional self-efficacy. Both
SDM and DSES are statistically significant with a corresponding \( p \) values < .05. The combined model is better than either simple regression models alone. Therefore, both SDM and DSES are individually contributing to the meaningful information in the prediction of satisfaction with the decision made. Having a good relationship with clinician and participating in SDM with healthcare provider can potentially increase satisfaction with the decision.

Table 4:12 *Multiple Regression Analysis of SDM and DSES on SWD*

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Unstandardized Coefficients B</th>
<th>Std. Error</th>
<th>Standard Coefficients Beta</th>
<th>T</th>
<th>Sig.</th>
<th>R</th>
<th>( R^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDM Q9</td>
<td>0.279</td>
<td>0.047</td>
<td>0.540</td>
<td>5.938</td>
<td>.000</td>
<td>0.797</td>
<td>0.636</td>
</tr>
<tr>
<td>DSES</td>
<td>0.177</td>
<td>0.039</td>
<td>0.413</td>
<td>4.548</td>
<td>.000</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Research Question 4b

Is there a regression model that can predict decisional conflict by the variables decisional self-efficacy and participation in shared decision making?

Hypothesis Question 4b

Prediction for decisional conflict (SURE) is significant using a multiple linear regression model by combining DSES and SDM (Figure 4.3):
The two variables SDM and DSES contributed to decisional conflict with \( n = 55, R = 0.523, \) \( R^2 = 0.273, \) Adjusted \( R^2 = 0.245, F = 9.781. \) The model is significant and accounts for 25% of the variance. The two variables, shared decision making, and decisional self-efficacy, accounted for almost a quarter of the adjusted variance. The model is statistically significant (\( p = .000 \)).

In this model, DSES predicts decisional conflict more than SDM. SDM has a non-significant impact on the dependent variable decisional conflict alone, but it adds to the prediction when combined with DSES, although it cannot be concluded with a reasonable degree of confidence that shared decision making negatively affects decisional conflict. SDM has a negative value for the unstandardized coefficient (-.011). In DSES, we have a negative value for the unstandardized coefficient (-.019), which supports the conclusion that decisional conflict decreases as decisional self-efficacy increases. One needs to interpret these findings cautiously as the SURE measure has a reliability that is less than optimal.

The SURE test as a dependent measure is only as good as reported in the literature. It may not measure the conflict in this study, and the finding may suggest that participants agree that they made the right decision. However, the study findings reveal that those currently on PD were not conflicted, and it did not matter how long ago the participants in the study made the decisions, it did not affect the measurement. This needs further study.

Table 4.13 *Multiple Regression Analysis of SDM and DSES on SURE*

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Unstandardized Coefficients</th>
<th>Standard Coefficients</th>
<th>( T )</th>
<th>Sig.</th>
<th>( R )</th>
<th>( R^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDM Q9</td>
<td>-0.011</td>
<td>0.007</td>
<td>-0.202</td>
<td>-1.53</td>
<td>.122</td>
<td></td>
</tr>
<tr>
<td>DSES</td>
<td>-0.019</td>
<td>0.006</td>
<td>-0.410</td>
<td>-3.193</td>
<td>.002</td>
<td>0.523</td>
</tr>
</tbody>
</table>
Summary of Regression Findings

The quantitative analysis and multiple regression models for the study on decision making yielded two strong prediction models that were more comprehensive than the simple correlations and individual regression models on the dependent variables of satisfaction with the decision and decisional conflict. These can be summarized as:

Summary of Quantitative Findings

- There was a statistically significant difference between SDMQ9 scores for decision making support and the use of decisional aid in decision making.
- Participation in SDM was statistically significant for decision making support and decision aid.
- SDM scores were significantly higher with providers. In addition, SDM scores were significantly higher when using decisional aids.
- There was no statistically significant difference among demographic characteristics and clinical factors in CKD with decisional self-efficacy as measured by DSES.
- There was no statistically significant difference among socio-demographic and clinical factors in CKD, with satisfaction with the decision measured by the SWD scale.
- There was a statistically significant association between the current treatment option and decisional conflict as measured by the SURE test.
- As measured by the SURE test, there is a significant association between the current treatment option and decisional conflict (presence vs. absence).
- The selection of CKD treatment options is dependent on conflict with decision making. Therefore, the decisional conflict plays a significant role in how participants
select treatment options. Based on the study response, participants who selected PD as the treatment option had no decisional conflict compared to those who chose conservative care, HD, and kidney transplants.

- There is a strong, positive correlation between the two variables, DSES and SDM.
- High levels of decisional self-efficacy are associated with higher participation in SDM (SDMQ9). Although DSES and SDM are correlated, they are not measuring the same construct. Hence, they are two separate variables. They are not multicollinear. Therefore, DSES and SDM can be used in a multiple regression model. There were a few outliers in the scatterplot with the regression line represented.
- There is a significant relationship between participation in SDM and decisional conflict. Furthermore, the result indicates a negative correlation, which means that as shared decision making increases, the participants reported less decisional conflict.
- There is a significant relationship between decisional self-efficacy and decisional conflict. The result indicates a negative correlation, which means that as Decisional Self Efficacy increases, the participants report less decisional conflict.
- There is a significant relationship between participation in SDM and satisfaction with Decisions. Furthermore, there was a positive correlation between the two variables, with high levels of participation in SDM associated with higher levels of satisfaction with the Decision.
- There is a significant relationship between decisional self-efficacy and satisfaction with decisions. Hence, there is a positive correlation between the two variables, with high levels of DSES associated with higher levels of SWD.
• The two variables, SDM and DSES significantly contributed to SWD. Almost two thirds of the adjusted variance is accounted for by the two variables, SDM, and DSES. In this model, SDM has a higher correlation with SWD making, also, a higher predictor of satisfaction with the decision than decisional self-efficacy.

• Both SDM and DSES are statistically significant. The combined model is better than either simple regression model alone. Therefore both SDM and DSES individually contribute to the meaningful information in predicting satisfaction with the Decision made. Having a good relationship with your clinician and participating in shared decision making with your healthcare provider can potentially increase SWD.

• The two variables, SDM and DSES significantly contributed to the decisional conflict. These two variables, accounted for almost a quarter of the adjusted variance. In this model, decisional self-efficacy predicts decisional conflict more than SDM, which has a non-significant impact on the dependent variable decisional conflict alone. Still, it adds to the prediction when combined with DSES. However, it cannot be concluded with a reasonable degree of confidence that SDM negatively affects decisional conflict.

• This supports the conclusion that decisional conflict decreases as DSES increases. One needs to interpret these findings cautiously, as the SURE measure has the reliability that is less than optimal.

• The SURE test as a dependent measure is only as good as reported in the literature. It may not measure the conflict in this study, and the finding may suggest that participants agree that they made the right decision. However, the study findings reveal that those currently on PD were not conflicted, and it did not matter how long
ago the participants in the study made the decisions, it did not affect the measurement. But the SURE test as a measure may have value to be tested and therefore included as one of two dependent measures. For this reason, it is important to interpret findings with caution, and future studies need to assess a diverse group of patients experiencing clinically significant decisional conflict.

**Qualitative Data Analysis**

This mixed-method study uses quantitative and qualitative approaches to provide a deeper exploration of participant’s experiences via the survey responses. Including open-ended responses enhance the quantitative findings while supplementing the limitations of the quantitative data. The researcher was interested in exploring what specific information was provided regarding RRT modalities, whether the healthcare provider provided decision aids, educational materials on dialysis options, or other sources; the extent to which SDM conversation were held; and what information was most helpful in making the current treatment choice. Content analysis is used to analyze qualitative data, mainly to focus on the subject and context and emphasize similarities and differences among responses. In addition, it analyze descriptive and interpretative content connected to the study participants and reveals meaning in the data using various degrees of interpretation.

The methodological approach used in the content analysis is both deductive and inductive. During the analysis, the researcher looked for similarities and differences in the data described in categories and subcategories. The text from individual participants was divided into meaningful units that were later condensed into primary categories and subcategories through reading, reflection, and discussion with a research committee member who is an expert in quantitative analysis.
The aim was to illuminate the experience of CKD patients' decision making treatment journey. Therefore, it is reported under four primary categories and multiple subcategories. The category includes what information were you given, decision making process, factors influencing choices, and information resources.

**Results**

A total of 55 participants responded to the survey. All participants responded to the open-ended questions. Four questions at the end of the main questionnaire were open-ended and focused on how the participant describes in his or her own words the influencing factors about treatment choice.

1. What information were you given by your provider, and what conversations did you have about dialysis options?
2. What factors did you feel could have influenced your choice regarding the type of dialysis you are currently on?
3. What kept you from deciding about other choices?
4. Describe if and how you were provided with decision aids or educational materials on dialysis options by your healthcare provider or others sources. How helpful were they in making your current treatment choice?

Responses to the open-ended survey questions are organized into four primary categories based on frequency. Within each primary category, the secondary categories are summarized below. In Table 4.14, which includes a few descriptive presentations of the category-relevant sample quotes taken from survey responses.
Table 4.14 *Content analysis table*

<table>
<thead>
<tr>
<th>Categories</th>
<th>Definition</th>
<th>Sample Text</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Category</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What information were you given?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sub Categories</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sufficient information provided</strong></td>
<td>Sufficient information and resources provided by the healthcare provider to select appropriate treatment option.</td>
<td>1. Pros and cons of each dialysis options. Amount of time and commitment that is required of me each day and how to coordinate my day around the dialysis option. 2. I was told about the types of dialysis available. And then it was explained to me the way each option was applied. And how they functioned. What time was involved and what training that would be available. 3. My doctor explain to me what dialysis means and most importantly why it was time for me to start dialysis.</td>
</tr>
<tr>
<td><strong>Insufficient Information provided</strong></td>
<td>Lack of information and resources provided by the doctor to select the appropriate treatment option</td>
<td>1. No aids were given to me. 2. Haven't received any educational materials as yet. 3. No choices were offered. I found out about transplant on my own.</td>
</tr>
<tr>
<td>Primary Category</td>
<td>4. I was not educated in choice.</td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>----------------------------------</td>
<td></td>
</tr>
<tr>
<td>Decision-Making Process</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sub Categories</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Shared Decision Making | Patient and clinician engaged in conversation to help patient understand treatment option and select the treatment best aligned to the patients’ values and goals of care. | 1. We discussed all options and ruled out some. I am currently on hemodialysis trying to get on the transplant list.  
2. My provider supplied me with enough info to make a solemn decision. I chose HD.  
3. I was given written material and verbal conversation about the different options for dialysis. I made the choice for hemodialysis.  
4. Doctor went over all my lab work and overall health condition and informed me of his recommendation for my health. I went over-all my concerns and made a decision for me and my family.  
| Paternalistic decision | Clinician decides treatment option for their patient, without giving patient an opportunity to weigh in. | 1. After treatment for couple of months, my doctor diagnosed and |
1. I had done hemodialysis, and chose to transition to peritoneal dialysis. I am waiting for a kidney transplant.
2. My provider was not involved in my decision.
3. With working and traveling frequently, PD seemed like the better choice.
4. I have CKD and knew I didn't want dialysis and I knew that for many years. I planned carefully, without really any help from my doctors, I opted for a preemptive kidney transplant.

<table>
<thead>
<tr>
<th>Patient-driven decision</th>
<th>That patient made a decision on their own.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Primary Category</th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Factors influencing choices</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Sub Categories</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Convenience</th>
<th>Opting for a particular treatment option to conserve time or effort due to busy schedule.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social support</strong></td>
<td>A person’s perception of the availability of help or support from others in their social network.</td>
</tr>
<tr>
<td>-------------------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1. Wanted to be with my kids’ activities and family time.</td>
<td></td>
</tr>
<tr>
<td>2. Better support from family.</td>
<td></td>
</tr>
<tr>
<td>3. Child care, transportation, scheduling and family support denial of transplant due to these issues.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Conservative care</strong></th>
<th>When a patient chooses to forego dialysis and shift from the effort from prolonging life to quality of life and symptom control.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ayurvedic and Homeopathic treatment. I was urinating and no swelling or water retention.</td>
<td></td>
</tr>
<tr>
<td>2. Maintaining a healthy diet, weight loss and exercise prevented me from needing dialysis.</td>
<td></td>
</tr>
<tr>
<td>3. I am not on dialysis and intend to stay off dialysis!</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Dependence on the healthcare provider</strong></th>
<th>Dependence on the availability of a trained provider at a dialysis location accessible to the patient.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I choose peritoneal because it was more convenient.</td>
<td></td>
</tr>
<tr>
<td>2. Would like to continue working full time.</td>
<td></td>
</tr>
<tr>
<td>3. My busy lifestyle, Peritoneal. Gives me freedom to be flexible, hemo did not.</td>
<td></td>
</tr>
<tr>
<td>4. With working and traveling frequently PD seemed like the better choice.</td>
<td></td>
</tr>
</tbody>
</table>
1. To have the best physical treatment and in a healthy environment. Going to dialysis center was the best choice because of the team: trained nurses, trained technicians and a manager. Doctors come through periodically as well.
2. Hemodialysis that time was my best option because they would do it to me in a specialized dialysis center.
3. I am on hemodialysis and I chose this because I want professional people taking care of me.

<table>
<thead>
<tr>
<th>Physiologic and Physical limitation</th>
<th>Limited in their bodily performance or due to physical structure limitation to arrange the dialysis equipment.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>1. At the time I wasn’t given an option because I was in a coma due to a seizure.</td>
<td></td>
</tr>
<tr>
<td>2. I'm a diabetic, so that rules out peritoneal dialysis. Having trouble get on the transplant list.</td>
<td></td>
</tr>
<tr>
<td>3. I was only on dialysis for two days for pre surgical reasons.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Satisfaction with the decision</th>
<th>Being satisfied by the outcome of the treatment decision made.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I made the right choice for me.</td>
<td></td>
</tr>
<tr>
<td>2. I am confident that my decision was good and I am moving forward toward a transplant!</td>
<td></td>
</tr>
<tr>
<td>3. I received a kidney transplant in July 2017 and I am doing very well.</td>
<td></td>
</tr>
</tbody>
</table>
### Classes

<table>
<thead>
<tr>
<th>Hands-on learning and treatment-related information by a trained healthcare professional.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The class I went to, I received hands on training on dialysis.</td>
</tr>
<tr>
<td>2. Two years ago, I was sent to a class to learn about dialysis, once I did the class, I made my decision.</td>
</tr>
<tr>
<td>3. Attended a class on PD and visit from home nurse.</td>
</tr>
<tr>
<td>4. I signed up for a dialysis class on my own. My doctors never really talked about it except to say Peritoneal might be better.</td>
</tr>
</tbody>
</table>

### Websites

<table>
<thead>
<tr>
<th>Publicly accessible, with a mix of text and other media to access educational content on disease and treatment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I was given lots of information on paper, and multiple websites with much information so I could process the gravity of my situation when I was able to!</td>
</tr>
<tr>
<td>2. Various doctors gave me websites and literature to do my own reference.</td>
</tr>
<tr>
<td>3. I was given basic details and told to research or YouTube it for more information. This part was stressful as it is hard to trust what is on the internet. I would have liked to be given a brochure with trusted sites on it.</td>
</tr>
</tbody>
</table>

### Brochures/pamphlets

<table>
<thead>
<tr>
<th>Printed materials to provide treatment information</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I was talked about different treatment and given pamphlets to read.</td>
</tr>
<tr>
<td>2. I was given lots of information on paper.</td>
</tr>
<tr>
<td><strong>Educational consultants</strong></td>
</tr>
<tr>
<td>-----------------------------</td>
</tr>
<tr>
<td><strong>Doctor referred for further information</strong></td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>My nurse and doctor discussed both options over the phone.</td>
</tr>
<tr>
<td>2.</td>
<td>My nephrologist and his staff along with the transplant team made sure that I had all the information needed.</td>
</tr>
<tr>
<td>3.</td>
<td>My doctor scheduled an appointment with a dialysis educator.</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>My doctor scheduled an appointment with a dialysis educator and surgeon to weigh my options on dialysis and gave me and discussed my options pertaining to transplant. I felt very prepared with the information and discussions I had with my doctor as well as my own personal research.</td>
</tr>
<tr>
<td>2.</td>
<td>The physician educated the risks and benefits of dialysis options. Arranged individual teaching section regarding dialysis with a dialysis educator.</td>
</tr>
<tr>
<td>3.</td>
<td>My doctor scheduled an appointment with a dialysis educator that spent 2 hours with myself, husband and mother. Who answered all our questions. She also scheduled an appointment with</td>
</tr>
</tbody>
</table>
a surgeon so I could understand what would go into getting ready for hemodialysis. All dialysis options were thoroughly discussed.

Descriptive Presentation of the Categories and Subcategories

During the analysis, the researcher looked for similarities and differences in the data described in categories and subcategories. The text from individual participants was divided into meaningful units that were later condensed into primary categories and subcategories through reading and reflection. Although the meaningful categories were predetermined after reading the comments multiple times, there were powerful statements that emerged after reading the narratives to the questions from the participants. Some were sentence fragments, and some were complete statements with a profound expression of emotional response to the question. This resulted in multiple subcategories, and the personal statements from the participants were encapsulated under subcategories.

Category 1: What information were you given?

Here, the researcher is looking for specific references about whether clinicians educated the patients to make the best treatment decision possible by providing information on all available treatment options, the risks and benefits of treatments, and the importance of an informed exploration of the patient’s preferences and values.

The participant’s responses varied in the perceptions and satisfaction concerning information and education offered by their healthcare provider on different treatment options. And their participation in the modality selection process varied. Many study participants reported receiving sufficient information on illness and treatment options, including the benefits and risks of each option. However, a substantial number of study participants reported receiving
insufficient information, they did not remember speaking with a healthcare provider on treatment
information nor receiving educational material to help them select appropriate treatment options.

**Subcategory 1a: Sufficient information provided**

Here, the researcher is looking to see if the healthcare provider provided sufficient
information and resources to select appropriate treatment options. The majority reported they had
received sufficient guidance and information from the healthcare team to make a decision and
had confidence in their doctor's advice on preferred treatment. An example from the participant's
response was, “Pros and cons of each dialysis option. Amount of time and commitment that is
required of me each day and how to coordinate my day around the dialysis option.”

However, a few participants acknowledged that limited time for decision making was
primarily due to the circumstances, such as their deteriorating health or kidney function. “My
doctor explained to me what dialysis means and, most importantly, why it was time for me to
start dialysis.” These personal comments were lengthy with deep meaning to the participant,
giving them confidence in their doctor's advice on preferred treatment and hope.

**Subcategory 1b: Insufficient information provided**

Here, the researcher is looking for specific references from the participants for the lack of
timely information received from the clinician about all available treatment alternatives, to select
the best treatment decision. However, those participants who experienced insufficient resources
and information mentioned that they “haven't received any educational materials yet.” A few
patients reported they barely received any treatment options: “No choices were offered.” “I
found out about transplants on my own.” “I was not educated on choice.” The participants who
reported negative experiences were especially those who had chosen HD. The above-mentioned
negative experience felt by the participants related to the lack of education and resources and the lack of shared decisions between the provider and patient.

**Category 2: Decision-making process**

Here, the researcher is looking for participants' experience during the treatment selection process with their clinicians and if patients and families felt engaged in the conversation and informed about their treatment options. There was variation in respondent perceptions. Most patients reported feeling engaged in conversation with the clinician by receiving verbal or written information on other treatment modalities and taking part in discussions in which providers presented treatment options, ruled out treatment options and, helped them to select the treatment best aligned to their values and goals of care. On the other hand, some participants felt that the clinician decided treatment options for them without allowing them to “weigh in” or educate them on possible choices. Finally, others felt that their provider was not involved in the decision making and they had to decide on their own. It appeared that participants who felt they had been involved in the modality-selection process were more likely to be very satisfied than those who had not been involved in the SDM. Also, they thought they made the choices based on their preference and values.

**Subcategory 2a: Shared Decision Making**

Here, the researcher is looking for participants’ specific references to see if both patient and clinician communicated information during SDM: where the clinician presented options and outlines their associated risks and advantages, while the patient shared their preferences and values. One group of patients reported to be satisfied with the SDM process and treatment decision related to timing and information related to the treatment options. They reported that the healthcare provider started counseling on a treatment plan at the right time and
that there had been enough time to decide with the family: “The doctor went over all my lab work and overall health condition and informed me of his recommendation for my health. I went over all my concerns and made a decision for my family and me” as well as “I was given written material and verbal conversation about the different options for dialysis. I made the choice for hemodialysis.”

Subcategory 2b: Paternalistic decision

Here, the researcher is looking for references made by the participants where they felt the clinician decided on the treatment option for them without allowing the patient to weigh in. In this situation the healthcare provider creates passivity and hinders the patient from making decisions autonomously. However, one-third of the patients who had chosen dialysis reported feeling forced to make a decision. For example, one patient reported, “My provider pushed me to do the home treatment, but I was not happy with all of the requirements that it imposed on my home life.” Those answering negatively would have preferred more time to consider their situation more extensively to prepare themselves better. For example, one of the participants reported, “After treatment for a couple of months, my doctor diagnosed and told me to start dialysis immediately.” Negative experiences were related to the timing, informing, and level of decision making being shared. Few other participants felt the decision was driven by their nephrologist's preference to start early dialysis initiation, including the dialysis fistula placement through surgery, as preparation for HD is still not needed many years later. Therefore, the stress about the experience of the potential initiation of dialysis treatment was unnecessary. For example, one of the participants stated, “Very little. Overzealous about ordering a fistula. At the time, I was railroaded into having a fistula placed in 2016 and have had no need for it. I was not educated in choice.” More patients who selected HD indicated to have felt forced to make a
decision. Few other participants felt a perceived lack of choice as the most common reason for selecting dialysis as the treatment option.

**Subcategory 2c: Patient-driven decision**

Here, the researcher is looking for specific references where the patient made the treatment decision on their own without receiving adequate information and understanding of their health conditions, healthcare options from the clinician, and the potential outcomes of these options. Few participants considered their opinion most important rather than their nephrologists' or relatives' opinions: “I have CKD and knew I didn't want dialysis, and I knew that for many years. I planned carefully, without really any help from my doctors, I opted for a preemptive kidney transplant.” A subset of patients who had chosen dialysis still doubted their treatment decision and want to transition to other treatment options. These patients were reconsidering their decision: “I had done hemodialysis and chose to transition to peritoneal dialysis. I am waiting for a kidney transplant.”

**Category 3: Factors influencing choices**

Here, the researcher is looking for specific references that inform participants were well-informed of treatment options considering a diversity of personal convenience, social factors, and health status, including the potential side effects of each approach. Most statements from the respondent were related to their perception of factors that influenced them to make the current treatment choice, mainly based on their convenience to conserve time or effort due to busy schedules. For some, it was based on the availability of support from others in their social network or social circumstances. For others, it was the dependence on healthcare providers and taking a passive role by having a trained provider at the dialysis location easily accessible. Few others wanted to take an active role by pursuing one's choices without external indulgence. A
selected few wanted to forego dialysis treatment and shift from the effort from prolonging life to quality of life and symptom control by selecting conservative care. A limited number of participants reported not being offered specific treatment options due to their limited bodily performance or physical or physiologic limitations to arrange dialysis equipment. Those who received information appreciated receiving information from the healthcare provider and were satisfied by the outcome of the treatment decision.

Subcategory 3a: Convenience

Here, the researcher is looking for specific references from the participant's personal factors that influence dialysis modality decisions, opting for one mode of treatment option over the other to conserve one's time or effort due to individuals' busy schedules and based on their individual preferences and lifestyle. “I choose peritoneal because it was more convenient,” “Would like to continue working full time,” “My busy lifestyle, Peritoneal,” “Gives me the freedom to be flexible, hemo did not,” “With working and traveling frequently, PD seemed like the better choice.”

Subcategory 3b: Social support.

Here, the researcher is looking for specific references from the participant's perception of the availability of help or support from others in their social network to proceed with the selected treatment option. Knowledge of the treatment options assisted participants in making a modality selection in the context of their life and the available social support. The availability of support in the home to assist with performing the dialysis and problem-solving was a key determinant for selecting the dialysis option. In addition, participants valued relationships: “Wanted to be with my kids' activities and family time,” “Better support from family.” Without sufficient support and resources, patients with CKD had limited choices in choosing dialysis for survival,
limitations for kidney transplantation, and persistent uncertainty on their preferred choice for kidney transplantation: “Child care, transportation, scheduling, and family support denial of transplant due to these issues.”

**Subcategory 3c: Conservative care**

Here, the researcher is looking for specific references from the participants who chose to forego dialysis and shift from the effort from prolonging life to quality of life and symptom control. Participants who had chosen conservative care most frequently mentioned the treatment burden of dialysis, its impact on their quality of life, and sense of life completion. Few participants described following the regimen to delay the progression of their kidney disease: “Maintaining a healthy diet, weight loss, and exercise prevented me from needing Dialysis” and “I am not on dialysis and intend to stay off dialysis!”

**Subcategory 3d: Dependence on healthcare provider**

Here, the researcher is looking for specific references to understand what factors drive the patient’s dependence on the availability of a trained provider to select the current treatment option and their level of participation in decision making, and their preparedness to overcome the challenges. Living with CKD requires following a burdensome regimen, including frequent medical appointments, bloodwork, injections, and blood pressure monitoring. Despite efforts to prevent the progression of their CKD, participants perceived the need for dialysis was beyond their control, and they were on the availability of a trained provider at a dialysis location. Here are a few personal narratives from the participants: “To have the best physical treatment and in a healthy environment. Going to the dialysis center was the best choice because of the team: trained nurses, trained technicians, and a manager. Doctors come through periodically as well,” “hemodialysis at that time was my best option because they would do it to me in a specialized
dialysis center,” and “I am on hemodialysis, and I chose this because I want professional people taking care of me.”

**Subcategory 3e: Physiologic and physical limitation**

Here, the researcher is looking for specific references to understand why the selected group of participants selected particular RRT to survive or prevent uremia and other complications, or limited bodily performance due to health conditions or physical limitations in arranging the dialysis equipment independently without assistance. All the participants made a choice for dialysis when needed, however, this choice was limited as a means for survival. They spoke about the possibility of dying from their kidney disease if they did not receive dialysis. Many participants described the need to start dialysis for survival, and these quotes are indicative of patterns reported: “At the time, I wasn't given an option because I was in a coma due to a seizure” and “I was only on dialysis for two days for pre-surgical reasons.” Participants were also hopeful that HD would be an opportunity to feel better and regain some quality of life, as other options were limited due to physical and physiologic context. Some mentioned receiving unclear advice from the nephrologist in regard to their transplant suitability: “I am a diabetic, so that rules out peritoneal dialysis. Having trouble get on the transplant list.”

**Subcategory 3f: Satisfaction with the decision**

Here, the researcher is looking to see the decision making resources participants used in deciding to pursue treatment and whether they are satisfied with the outcome of the treatment decision. The participants felt they made choices based on the modality best suited their preferences and lifestyle. These choices were very specific to each person and their life. Some participants were optimistic about their decision and reported high satisfaction: “I made the right
choice for me,” “I am confident that my decision was good and I am moving forward towards a transplant!” and “I received a kidney transplant in July 2017, and I am doing very well.”

Category 4: Information resources

Here, the researcher is looking to see specific information resources provided by the clinicians to assist the participants in reflecting on their personal choices to support patients' decision making using decisional aid, information packets, and a multidisciplinary medical team incorporating trained decision coaches. The participants varied in their responses on how and when they received the selected treatment option information. Some respondents received hands-on learning and treatment-related information from a trained healthcare professional in a classroom setting. Some participants were advised by their clinician to explore websites, literature, YouTube, and other social media to obtain information, which was reported as “stressful as it is hard to trust what is on the internet” and “hard to process the gravity of the situation.” Few participants received educational brochures and pamphlets to provide treatment information. Some respondents received information from their clinicians, who educated the risks and benefits of dialysis options. And the clinician arranged an individual teaching section regarding dialysis with a dialysis educator to provide additional information. Some participants were active information seekers who signed up for a dialysis class on their own to explore further information when they felt they were not satisfied with the information obtained from the provider. Participants in this study gave the most value to physicians and nurses as a source of information on kidney disease. They did not specify other patients as potential influencers in the decision making.
**Subcategory 4a: Classes**

Learning about their options was an important component of decision making. Many people with CKD found the classes and tours helpful: “The class I went to, I received hands-on training on dialysis,” “Two years ago, I was sent to a class to learn about dialysis, and once I did the class, I made my decision.”

**Subcategory 4b: Websites**

The educational websites provided information about their treatment options that they could place in the context of their own life to make modality choices. Participants' opinions were divided, some felt receiving lots of information on the websites led to more confusion and uncertainty in selecting an appropriate treatment option. “I was given basic details and told to research or YouTube it for more information. This part was stressful as it was hard to trust what was on the internet. I would have liked to be given a brochure with trusted sites on it.” For some, knowing the treatment options from various educational opportunities assisted participants in making a modality selection in the context of their life: “I was given lots of information on paper and multiple websites with much information so I could process the gravity of my situation when I was able to!” and “Various doctors gave me websites and literature to do my own reference.”

**Subcategory 4c: Brochures/pamphlets**

Some participants received printed materials such as pamphlets, fliers, and brochures. However, no one education method was superior: “I was talked about different treatments and given pamphlets to read,” “I was given lots of information on paper,” and “I was given written materials. Fliers, pamphlets, and brochures.”
Subcategory 4d: Educational consultants

The majority reported they had experienced sufficient guidance from the healthcare team during decision making. Most patients felt supported by their nephrologist and nurse in their decision: “My nurse and doctor discussed both options over the phone,” “My nephrologist and his staff, along with the transplant team, made sure that I had all the information needed,” and “My doctor scheduled an appointment with a dialysis educator.”

Subcategory 4e: Doctor referred for further information

The doctor referred the patient to gain additional information outside of the office and to understand the treatment environment to prepare for dialysis. Some participants in the survey reported they received sufficient support and resources from their doctor and felt well prepared: “My doctor scheduled an appointment with a dialysis educator and surgeon to weigh my options on dialysis and gave me and discussed my options pertaining to transplant. I felt very prepared with the information and discussions I had with my doctor as well as my own personal research,” “The physician educated the risks and benefits of dialysis options. Arranged individual teaching section regarding dialysis with a dialysis educator.”

Summary of Qualitative Analysis

The qualitative study determined participants' experiences and preferences for SDM on CKD treatment options. Most participants were satisfied with their SDM process and treatment decision. However, differences emerged between participants in their responses to the perceptions and satisfaction concerning information and education offered. Such negative experiences were related to the timing, amount of information provided, and level of decision making. Majority of survey participants reported being satisfied with their information they received on their disease and treatment, and also felt they had been involved in selecting their
treatment modality. There are participants reported receiving insufficient information, they did not remember speaking with a healthcare provider on treatment information nor receiving educational material to help them select appropriate treatment options.

It was found that a substantial subset of participants who had chosen HD still doubted their treatment decision. These findings show that despite high overall satisfaction, participants had contrasting experiences with SDM on HD versus PD or conservative care. The negative experiences illustrate important but modifiable barriers to an optimal SDM process. Therefore, it can be concluded that early initiation of decision making is needed in advanced care planning and that SDM should entail a dynamic process instead of a single point in time, including multiple interactions between patient, family and healthcare team about possible treatment and ongoing evaluation once a decision has been made.

The current study also shows that patients who chose HD doubted or regreted their decision, especially if the nephrologist's preference drove the decision primarily. The timing of shared decision making is essential, but there is an ongoing debate about what timing is best for decision making processes on dialysis (Rosansky et al., 2017). The current study is consistent with the previous research conducted by Bunn et al. (2018), which also indicates that decision making should be initiated earlier because a few of the participants in the survey felt unprepared or even forced to make a decision. The current study found that a few participants were unaware of the choices available during decision making. Information to facilitate the selection of alternative modalities seemed suboptimal. In addition, none of the participants reported receiving a decision aid in selecting the treatment choices. The study findings were also consistent with previous studies by Gilman et al. (2017). A few participants indicated their opinion as most important rather than their nephrologists. The clinician decided on a treatment option for the
patient without allowing the patient to “weigh in.” From this study, it appeared that all patients want to be informed. There should be an equal conversation between patient and healthcare worker, rather than just providing a unidirectional flow of information from the clinical perspective.

The study also recognized that multiple factors influence the choice of treatment selection. It was mainly based on their convenience to conserve time or effort due to busy schedules. For some, it was based on the availability of help or support from others in their social network. For others, it was the dependence on the healthcare provider. Few others wanted to take an active role by pursuing one's choices without external indulgence. Finally, a selected few wanted to forego dialysis treatment and focus on the quality of life and symptom control by selecting conservative care.

The study findings also reported how the participants had varied responses on how and when they received information on a selected treatment option. Some respondents received hands-on learning and treatment-related information from a trained healthcare professional in a classroom setting. Some participants were advised by their clinician to explore websites, literature, YouTube, and other social media to obtain information. Some participants were active information seekers who signed up for a dialysis class on their own to explore further information when they felt they were not satisfied with the information obtained from the provider. Those who received information appreciated receiving information from the healthcare provider as a valuable information source than websites or social media.
Conclusion

**Triangulating Quantitative and Qualitative findings**

Mixed-methods integration, an approach to meaningfully combining quantitative and qualitative data, is outlined. Researchers using this design collect and integrate quantitative and qualitative data in a single study to broaden the scope of observation. It works on the assumption that such a combination can generate a better understanding of the research problem than using a single approach. Researchers argue that mixed-methods research can offset the weaknesses and capitalize on the strengths of each method. This outcome is achieved by methodological triangulation, in which both methods are merged by combining quantitative and qualitative data (Ng, 2019). In this study, quantitative and qualitative findings are integrated to produce many informative, engaging, and reliable inferences. Sub-categories found in the qualitative component were matched to the relevant characteristics in the quantitative component.

**Quant**

There was a statistically significant difference between SDMQ9 scores for decision making support and the use of decisional aid in decision making.

**Qual**

The participants varied in their responses on how and when they received the selected treatment option information. Some respondents received hands-on learning from a trained healthcare professional in a classroom setting. Some participants were advised by their clinician to explore websites, literature, YouTube, and other social media to obtain information, which was reported as” stressful as it is hard to trust what is on the internet” and “hard to process the gravity of the situation.” Participants in this study gave the most value to physicians and nurses as a
source of information on kidney disease. None of the participants in the survey reported receiving decisional aid as an information source to support patients SDM.

**Quant**

The selection of CKD treatment options is dependent on conflict with decision making. Therefore, the decisional conflict plays a significant role in how participants select treatment options. Based on the study response, participants who selected PD as the treatment option had no decisional conflict compared to those who chose HD, conservative care, and kidney transplants.

**Qual**

Few participants felt a perceived lack of choice as the most common reason for selecting dialysis as the treatment option. Few others felt their provider was not involved in the decision making and had to decide independently. One-third of the patients who had chosen dialysis reported feeling forced to make a decision. Where the healthcare provider creates passivity and hinders the patient from making decisions autonomously. Participants who thought they had been involved in the modality selection process were more likely to be very satisfied than those who had not been involved in the shared decision making.

**Quant**

Both shared decision making and decisional self-efficacy are statistically significant with decisional satisfaction. The combined model is better than either simple regression model alone. Therefore both Shared decision making and Decisional Self efficacy individually contribute to the meaningful information in predicting satisfaction with the Decision made. Having a good relationship with your clinician and participating in shared decision making with your healthcare provider can potentially increase satisfaction with the Decision.
Qual

Most statements from the respondent were related to their perception of factors that influenced them to make the current treatment choice, mainly based on their convenience to conserve time due to busy schedules, giving them the confidence to select the treatment option best suited for their lifestyle. In addition, those who received information appreciated receiving information from the healthcare provider and were satisfied by the outcome of the treatment decision.

Quant

There is a significant relationship between participation in shared decision making and decisional conflict. Furthermore, the result indicates a negative correlation, which means that as shared decision making increases, the participants reported less decisional conflict.

Qual

Most survey participants reported being satisfied with their information on their disease and treatment and felt they had been involved in selecting their treatment modality. The participants felt they made choices based on the modality best suited their preferences and lifestyle. These choices were very specific to each person and their life. Some participants were optimistic about their decision and reported high satisfaction. However, others reported receiving insufficient information and not remembering speaking with a healthcare provider on treatment information or receiving educational material. Not being able to select appropriate treatment options leads to a lack of shared decision making between provider and patient, ultimately leading to uncertainty in their decision.

Quant
The two variables shared decision making, and decisional self-efficacy significantly contributed to the decisional conflict. In this model, decisional self-efficacy predicts decisional conflict more than shared decision making. Shared decision making has a non-significant impact on the dependent variable decisional conflict alone. Still, it adds to the prediction when combined with decisional self-efficacy.

**Qual**

There was variation in respondent perception. Most patients reported feeling engaged in conversation with the clinician by receiving verbal or written information on other treatment modalities. And also discussed all treatment options and ruled out a few, which helped them to select the treatment best aligned to their values and goals of care. On the other hand, some participants felt that the clinician decides treatment options for them without allowing them to “weigh in” or educate them on possible choices. Finally, others felt that their provider was not involved in the decision making and had to decide on their own. A patient-centered approach to decision making helps to clarify questions and guides to reach an optimum treatment choice self-selected by the patient between HD, PD, conservative management, and kidney transplant. Such an intervention may also reduce emotional stress by enhancing the patient's sense of personal control over difficult situations.
CHAPTER 5: DISCUSSION AND RECOMMENDATIONS

Clinical practice guidelines for treating kidney disease worldwide advocate providing information and education to patients as well as patient involvement in selecting a treatment modality. The ODSF supports the use of decisional aids to assist individuals in decision making. In addition, selecting appropriate renal replacement treatment is of utmost importance for patients with ESRD. Previous studies suggested that most ESRD patients want to be given information on different treatment options and participate in treatment selection (van Biesen et al., 2014). Still, the quality, comprehensibility, and completeness of information and education provided to kidney patients seem to be suboptimal. Receiving insufficient information may partly explain why some patients have little knowledge of their disease and limited awareness of their different treatment options. There are a limited number of studies to explore CKD patients' experiences regarding their decision making process and the factors contributing to decisional conflict about dialysis modality selection.

To address these issues, online surveys were developed and administered, comprising of both open-ended and closed-ended questions to explore CKD patients’ perceptions in their own words to describe their reflections on the facilitators and barriers to reaching the decision they made and the possible transplant decision they may be facing as the disease progresses. The study uses quantitative and qualitative approaches for deeper exploration of the richness of the narratives. The survey was intended to explore the factors related to decisional conflict over dialysis modality choice in patients with ESRD currently in dialysis and potentially facing a future decision regarding renal transplant or conservative care.
Treatment Choices

The present findings confirm previous research studies reporting patients perceiving a lack of choice when selecting a modality. In the last decade, there has been a shift in focus toward patient-centered and value-based healthcare. In the present study, one-third of the patients who had chosen dialysis reported feeling forced to make a decision. Those answering negatively would have preferred more time to consider their situation more extensively to prepare themselves better. Few other participants felt the decision was driven by their nephrologist's preference to start early dialysis initiation, including the dialysis fistula placement through surgery, as preparation for HD is still not needed many years later. Verberne et al. (2019) found early initiation of SDM is required in advanced care planning. The SDM should entail a dynamic process instead of a single point in time. Therefore, the stress about the experience of the potential initiation of dialysis treatment was unnecessary. More patients who selected HD indicated to have felt forced to make a decision. Few other participants felt a perceived lack of choice as the most common reason for selecting dialysis as the treatment option. This reflects the findings uncovered in the literature.

Shared Decision Making

Shared decision making is being defined “as a decision making process in which patient and healthcare provider discuss possible treatment options and come to a joint decision” (Härter et al., 2015, p. 672). On the other hand, asymmetric power relations between patients and physicians are also considered as major barriers to joint decision making (Zisman-Illani et al., 2021). A professional's role is crucial, but nephrologists are still found to differ in their approach to SDM and preferred level of patient involvement when choosing dialysis or other treatment modalities (Ladin et al., 2018). Therefore, it is important that patient involvement be
individualized, recognizing differences in patients' preferences for involvement (Wolff & Boyd, 2015). However, a minimum number of clinicians make their patients aware that patients' opinion is necessary when a decision is to be made. When the provider can encourage patients' communication by answering questions and concerns and utilizing educational material, this will increase the patient's awareness and understanding of the treatment options and possible outcomes.

Furthermore, the willingness and need that participants in the current study displayed to be involved in decision making add weight to the shift from the paternalistic healthcare model to the shared decision model. In addition, lack of information was also considered to limit patient choice, as patients sometimes felt they did not possess all the information about treatment. From this study, it appeared that all patients want to be informed. There should be an equal conversation between patient and healthcare worker, rather than just providing a unidirectional flow of information from the clinical perspective. Individuals' preferences for involvement in the decision making process may vary. Lee et al. (2019) reported that approximately 29% of CKD people did not complete the SDM process. They believed that this could be attributed to a lack of information on SDM, poor family support, and inappropriate initiation of SDM by the medical team. Receiving insufficient information may partly explain why some patients have little knowledge of their disease and limited awareness of their different treatment options. These study findings support Chanouzas and team's (2012) study, which emphasizes that providing pre-dialysis education is crucial in empowering patients to choose self-care therapies such as PD and home-based dialysis.
Factors Influencing Treatment Choices

Factors crucial in empowering patients to choose self-care therapies included the ability to cope, appropriate treatment with lifestyle, distance to the center, and provision of information about treatment. Lee and team’s (2019) study concluded that the treatment choice needs to have a greater focus on patients' preferences and lifestyles and a greater focus on pre-dialysis patients. None of the participants in the study reported receiving decisional aid as an information source by the provider for SDM. Fortnum et al.’s (2015) findings reflect this, stating that SDM for a complex decision such as dialysis choices, transplants, or conservative care could be enhanced by a decision aid, a well-utilized practice in other disciplines but limited in nephrology.

The study also recognized that multiple factors influence the choice of treatment selection. It was mainly based on their convenience to conserve time or effort due to busy schedules. For some, it was based on the availability of help or support from others in their social network. For others, the dependence on the healthcare provider was happy to leave these to health professionals. Similarly, Orsino et al.’s (2003) findings showed that less than one-quarter (23.9%) of participants wanted the healthcare team to decide for them. Few others wanted to take an active role by pursuing one's choices without external indulgence.

Information Sources in Decision Making

The participants’ responses varied in the perceptions and satisfaction concerning information and education offered by their healthcare provider on different treatment options. Their participation in the modality selection process also varied. Many study participants reported receiving sufficient information on illness and treatment options, including the benefits and risks of each option. However, a substantial number of study participants reported receiving insufficient information, they did not remember speaking with a healthcare provider on treatment
information nor receiving educational material to help them select appropriate treatment options. Those who received information appreciated receiving information from the healthcare provider and were satisfied by the outcome of the treatment decision. These findings reflect the previous findings by van Biesen et al. (2014) that CKD patients perceived information about access to a choice of treatment. Results showed that one-quarter of respondents did not remember receiving information about reduced kidney function before they started dialysis. Almost two-thirds stated that they felt they did not receive the education or information needed to help them deal with their condition concerning their everyday life. Over 40% identified doctors and nurses as their main sources of information.

Role in Decision Making

In findings by Lovell et al. (2017), patients choose dialysis for life prolongation and conservative care for the quality of life. It is reflective of the present study, selected few participants in the study wanted to forgo dialysis treatment and focus on the quality of life and symptom control by selecting conservative care. The findings from this survey are wide-ranging and cover many key areas, including diagnosis and treatment, information sources, decision making process, and factors influencing the choice of dialysis from provided information and knowledge. Findings also indicate that the clinician and nurse play a key role in providing information. This is similar to the findings by Guerraoui et al. (2022), where patients reported that the medical staff played an important role in improving the theoretical knowledge of home HD treatment and the nursing staff has a leading role in raising awareness and providing support in choosing the home HD technique.

The study findings conclude that even though a majority of patients feel fully informed and involved in the decision making processes of their CKD treatment options, not all patients
receive sufficient information to make an informed choice about their treatment. The findings were consistent with the key findings from Keeney and McKenna’s (2014) study where one-quarter of patients felt that they did not receive enough information about dialysis to allow them to make an informed choice. Patient involvement in decision making and making informed choices about dialysis and treatment are extremely important. There should be an equal conversation between a patient and healthcare worker, rather than just providing a unidirectional flow of information from the clinical perspective. Receiving insufficient information may partly explain why some patients have little knowledge of their disease and limited awareness of their different treatment options.

**Theoretical Framework Identified**

Janis and Mann (1977) found in their research that poor decision making will most likely occur in areas where the stress is so intense as to render the individual unable to function adequately. This stress is from an individual's internal conflict or uncertainty about what to do when a choice among competing actions involves risks, loss, regret, or challenge to personal life values. Findings from this study recognized that when patients are newly diagnosed with renal failure, it is most stressful as it is life-threatening, and that coincides with the timing of the medical decisions. Janis and Mann's model addressed five coping patterns: unconflicted inertia, unconflicted change, defensive avoidance, hypervigilance, and vigilance. The final coping pattern, 'vigilance,' occurs when a decision maker can complete a thorough search and evaluation of all alternatives without being rushed or limited by unacceptable choices. Researchers assert that inadequate decision making will occur unless the patient is vigilant about the decision making process due to the increased stress. This study addressed patients with CKD who are progressing to ESRD, to decide between two types of dialysis (HD or PD), kidney transplant or
conservative care is a critical component of the patient's journey. The selection of CKD treatment options is dependent on conflict with decision making. Therefore, the decisional conflict plays a significant role in how participants select treatment options. Participants who thought they had been involved in the modality selection process were more likely to be very satisfied with their decision than those who had not been involved. The study findings also revealed the decisional conflict can be eased by using PtDAs in operationalizing SDM.

**Clinical/Nursing Implications**

To fully implement SDM, patients need to be supported to participate in weighing potential outcomes. To enhance the novice nurse's experience working with clients suffering from CKD, the nurse needs specialized knowledge and training to provide dialysis patients care and shared decision coaching between patients and providers. Nurses need opportunities to develop and use new skills to be client-centered and responsive to patients' needs. Many still lack the knowledge, and skills to do so. Furthermore, practice environments, regulatory bodies, and educational systems can facilitate integrating shared decision coaching skills in practice and promoting policies that endorse nurses to provide patient decision support. Professional accreditation bodies can influence overcoming barriers to delivering shared decision coaching and creating supportive infrastructures.

Nurses can support patients to make significant differences in the quality of health decisions by facilitating access to patient decision aids, providing evidence-based information, clarifying concerns, monitoring and promoting patients' progress in decision making, and screening patients' self-efficacy and potential barriers impeding implementation. For nurses to be better facilitators in SDM, nurses need to be trained in decision support. Therefore nurses should be offered classes and workshops to enhance their decision-coaching skills. The training will
help nurses clarify patients' values associated with outcomes of options and prepare them to share their preferences with the nephrologist. Therefore, embedding decision support coaching for nurses as a usual practice among nursing professionals requires attention to key strategies such as competency development at licensure levels and related policy changes.

In addition, educational interventions should be designed to increase the exposure of nursing faculty members to patient decision support and enhance undergraduate nursing students' knowledge and skills to establish decision coaching competencies. Content related to integrating patient decision support competencies should be part of coursework and evaluation to assess students' performance in clinical settings. For example, a simulated patient program can be added to the nursing curriculum to support students' learning and evaluate the quality of their decision coaching, improving teaching-learning activity. And nursing colleges can collaborate with hospital executives in an academic and clinical practice partnership to introduce nursing students to dialysis nursing through a clinical experience.

Although practicing nurses have positive attitudes about supporting patient decision making, they have limited knowledge, skills, and confidence in providing decision coaching. However, nursing practice is often more strongly bound by organizational policies and structures. Therefore, for the sustainable implementation of decision coaching, administrative action at the organizational level will require evaluating the implementation of decision support by nurses within performance review indicators, job descriptions, and orientation programs as a standard of practice.

**Strength of Study**

Although the study sample size was small, the diversity of the sample, which consisted of patients of various ages and years on dialysis, added strength to the study. In addition, being a
relatively small sample, participants appeared to be representative of all different types of treatment modalities and captured a wide scale of patient perceptions. As a result, the results provide valuable pointers for selecting areas for future research.

Finally, the study gave insight into challenges faced and areas needing improvement from the patient's perspective and the need for early intervention in the detection, treatment, and training of CKD patients. The study findings validate the clinician's need for early intervention in educating patients holistically, possibly in group sessions, including patients and family members on one topic at a time, with reinforcement to accommodate life changes for better outcomes. As clinicians have the most direct contact time with patients, they can influence patients' knowledge and perception of the SDM process.

**Limitations of the Study**

A potential limitation of the study primarily centered on the participants; majority were volunteers from an online advocacy group. It was a small sample size for larger group comparisons, method of collecting data was self-reporting questionnaires through online media. Also, individuals were required to be English literate, have access to a computer, and have computer literacy skills. The observed discrepancy between patients' satisfaction and underlying negative experiences could be explained by socially desirable responses, as some of the patients may still be establishing trustworthy relationship with their clinician. Therefore true satisfaction might be lower. The relationship between the patient and nephrologist is vital to fruitful SDM. The study did not include the informed decision making barriers at the clinician level to effective education and SDM in the CKD patient.

Second, the findings reflect the experiences and preferences of a limited number of patients. The survey was conducted using a self-developed questionnaire by the researcher that
needs further validation and it was focused only on patients' perspectives. Although recognizing “vested interest” could be both a strength and limitation, participants may have a vested interest in this study as they were aware that the results of this study would assist clinicians in better understanding decisional needs, which could bias participants by responding in a socially desirable manner. Social desirability is a bias in self-report instruments created when participants tend to misrepresent their opinions in the direction of answers consistent with prevailing social norms (Polit & Beck, 2008). The study findings describe the special aspects of the sample that were also mostly well-educated and moderately healthy so it is not trying to “represent” a population of patients with CKD. This study was not an attempt to establish causality. Instead, it was designed to describe the associations among the decisional need variables and explore how such variables impact participation in SDM

**Recommendations**

The previous research findings and the study results may warrant future research to investigate to what extent modalities are being offered to kidney patients by their healthcare providers. In addition, patients progressing toward ESRD must decide among multiple treatment options with varying characteristics. Therefore, the clinician should adequately convey complex treatment information to patients, considering different educational backgrounds and informational needs. Decisions about treatment options also require family input, as families often participate in patients' treatment and support patients' decisions.

Furthermore, patients' poor access to adequate education about treatments has been linked to their abrupt initiation of dialysis and lack of access to other forms of RRT, such as kidney transplantation. Therefore, comprehensive decision aids are needed to help patients with kidney disease and their families make informed RRT selection decisions aligned with their
personal values. The decision aid should also address both positive and negative features of treatment options to help guide them through the decision making process with a range of health literacy and cognitive need. Future research should focus on developing decision aids for patients with CKD to accommodate patients with varying literacy and cognitive needs for engaging patients in informed decision making.

Conclusion

This study analyzed the participants’ narrative statement that receiving decisional aid or educational material from the healthcare provider has influenced their current decision making by qualitative content analysis. The findings suggested considerable inconsistency in providing educational material to the patients. The study revealed a greater understanding about how patients with CKD approach decision making when their illness has reached a point that requires treatment and when more than one treatment option exists. The findings contributed to understanding that with the goal of increasing patient involvement in determining the goals of care and treatment choice, providers must approach their patients’ critical decision points in their illness trajectory with an openness of sharing in the plan of care. There is a significant need to move away from a “one-size-fits-all” approach to dialysis and provide more individualized care that incorporates patient goals and preferences while still maintaining best practices for quality and safety. International renal guidelines recommend that all patients and caregivers be educated adequately to make an informed decision. None of the study participants mentioned receiving decisional aid from the healthcare provider to facilitate SDM for complex illnesses within routine clinical care, which remains a significant challenge. The inconsistency in education practices and evidence of patients not being involved in SDM indicated the need for research in this area. It can be concluded that early initiation of decision making is needed in advanced care
planning. That SDM should entail a dynamic process instead of a single point in time. Such an approach to SDM will help to achieve the overall goal of collaboratively deciding by patient and professional on a treatment pathway that fits best with the patient.
REFERENCES


Chanouzas, D., Ng, K. P., Fallouh, B., & Baharani, J. (2012). What influences patient choice of treatment modality at the pre-dialysis stage? Nephrology, dialysis, transplantation:


De Las Cuevas, C., Peñate, W., Perestelo-Pérez, L., & Serrano-Aguilar, P. (2013). Shared decision making in psychiatric practice and the primary care setting is unique, as measured using a 9-item shared decision making questionnaire (SDM-Q-9). *Neuropsychiatric Disease and Treatment, 9*, 1045-1052. doi:10.2147/NDT.S49021


Dhaun, N., Mackenzie, J., Goddard, J., & Whitworth, C. (2013). Prospective management of end-stage renal failure within a conservative care programme. *BMJ Quality Improvement Reports, 2*(1), u201182.w727–. https://doi.org/10.1136/bmjquality.u201182.w727


Finderup, J., Jensen, K. D., & Lomborg, K. (2018). Developing and pilot testing a shared
https://doi.org/10.1111/jorc.12241

choice, decision aid’: Supporting shared decision making. *Journal of Renal Care, 41*(2),
81-87. doi:10.1111/jorc.12100


Ghodsian, S., Ghafourifard, M., & Ghahramanian, A. (2021). Comparison of shared decision
making in patients undergoing hemodialysis and peritoneal dialysis for choosing a
02269-2

Gilman, E. A., Feely, M. A., Hildebrandt, D., Edakkanambeth Varayil, J., Chong, E. Y., Williams,
https://doi.org/10.5414/CN109030

https://doi.org/10.1111/sdi.12086

Griva, K., Li, Z. H., Lai, A. Y., Choong, M. C., & Foo, M. W. (2013). Perspectives of patients,
families, and healthcare professionals on decision making about dialysis modality—The
good, the bad, and the misunderstandings! *Peritoneal Dialysis International, 33*, 280–
289.


receipt of preferred dialysis modality in unplanned dialysis start patients. Patient Preference and Adherence, 10, 2229–2237.


https://doi.org/10.1136/bmj.c112


https://doi.org/10.1016/j.pec.2008.12.010


Noble, H. (2017). Clinician views of patient decisional conflict when deciding between dialysis and conservative management: Qualitative findings from the Palliative Care in chronic


Vélez-Bermúdez, M., Christensen, A. J., Kinner, E. M., Roche, A. I., & Fraer, M. (2019) Exploring the relationship between patient activation, treatment satisfaction, and


## APPENDIX A: DECISIONAL AIDS

<table>
<thead>
<tr>
<th>Name of the DA</th>
<th>Country</th>
<th>Format</th>
<th>Decision coaching</th>
<th>The design of evaluation</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney Failure: What Type of Dialysis Should I Have?&lt;sup&gt;a&lt;/sup&gt;</td>
<td>USA Healthwise</td>
<td>Internet based &amp; paper</td>
<td>None</td>
<td>None</td>
<td>–</td>
</tr>
<tr>
<td>My Life, My Dialysis Choice&lt;sup&gt;b&lt;/sup&gt;</td>
<td>USA</td>
<td>Internet based</td>
<td>None</td>
<td>None</td>
<td>–</td>
</tr>
<tr>
<td>Dialysis Making the Right Choices for You&lt;sup&gt;c&lt;/sup&gt;</td>
<td>UK Yorkshire</td>
<td>Leaflet</td>
<td>Yes</td>
<td>Prospective non-randomised comparison Self-developed questionnaires</td>
<td>Higher scores for understanding kidney disease, reasoning about options and feeling in control</td>
</tr>
<tr>
<td>My Kidneys, My Choice&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Australian New Zealand</td>
<td>Leaflet</td>
<td>Yes</td>
<td>Pre and post test Self-developed questionnaires</td>
<td>Increase knowledge, support shared decision-making and increase the number of choosing dialysis at home</td>
</tr>
<tr>
<td>Option Grid&lt;sup&gt;d&lt;/sup&gt;</td>
<td>UK</td>
<td>Decision overview Internet based &amp; paper</td>
<td>None</td>
<td>Pre and post test using DQM</td>
<td>Increased knowledge and increased readiness to make a decision</td>
</tr>
<tr>
<td>Shared Decision Making Process for RRT choice with Patient Decision Aids&lt;sup&gt;g&lt;/sup&gt;</td>
<td>Spain</td>
<td>Different tools</td>
<td>Yes</td>
<td>Observational prospective multicentre study</td>
<td>An increase in number of patient maintaining the decision and an increase in number of patient starting dialysis at home</td>
</tr>
<tr>
<td>Preparing for Kidney Treatment You Have a Choice&lt;sup&gt;h&lt;/sup&gt;</td>
<td>USA</td>
<td>Video Handbook Leaflet</td>
<td>None</td>
<td>None</td>
<td>–</td>
</tr>
<tr>
<td>OPTIONS&lt;sup&gt;i&lt;/sup&gt;</td>
<td>Baxter</td>
<td>Different tools</td>
<td>Yes</td>
<td>Prospective, multicentre observational study</td>
<td>Education and decision support allow patients to understand their options and choose dialysis modality</td>
</tr>
<tr>
<td>When dialysis is needed, what kind of dialysis do you prefer?&lt;sup&gt;j&lt;/sup&gt;</td>
<td>Canada</td>
<td>Leaflet</td>
<td>Yes</td>
<td>None</td>
<td>–</td>
</tr>
</tbody>
</table>

Table 1: Overview of decision aids regarding dialysis choice

<sup>a</sup>(Healthwise 2017), <sup>b</sup>(Schatell 2015), <sup>c</sup>(Winterbottom et al. 2016), <sup>d</sup>(Fortnum et al. 2015a), <sup>e</sup>(Fortnum et al. 2015b), <sup>f</sup>(Prichard & Thomas 2012), <sup>g</sup>(Prieto-Velasco et al. 2015), <sup>h</sup>(Armelino et al. 2012), <sup>i</sup>(Machowska et al. 2016), <sup>j</sup>(Loiselle et al. 2011).
APPENDIX B: USER MANUAL SHARED DECISION-MAKING QUESTIONNAIRE

PsycTESTS Citation:

Instrument Type:
Inventory/Questionnaire

Test Format:
This measure utilizes a 4-point scale: Strongly agree, Agree, Disagree, Strongly disagree.

Sources:

Permissions:
Test content may be reproduced and used for non-commercial research and educational purposes without seeking written permission. Distribution must be controlled, meaning only to the participants engaged in the research or enrolled in the educational activity. Any other type of reproduction or distribution of test content is not authorized without written permission from the author and publisher. Always include a credit line that contains the source citation and copyright owner when writing about or using any test.

PsycTESTS™ is a database of the American Psychological Association
**Shared Decision-Making Questionnaire**  
*SDM-Q*

<table>
<thead>
<tr>
<th>Items</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In the selection of the treatment method, my thoughts were taken into account just as much as the considerations of my doctor.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>2. There was enough time for questions.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>3. My doctor and I weighed up the different treatment options thoroughly.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>4. I was able to discuss the different treatment options with my doctor in detail.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>5. My doctor and I selected a treatment option together.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>6. I now know the advantages of the individual treatment options.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>7. I now know which treatment option is the best one for me.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>8. During the consultation, I felt included in the treatment decision.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>9. Through the consultation with the doctor, I felt jointly responsible for my further treatment.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>10. My doctor and I discussed the next steps of the treatment plan in detail.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>11. My doctor and I reached an agreement as to how we will proceed.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

**Note.** The validation study is based on data using the German version of the questionnaire. The translation into English was performed by two independent native speakers. Differences between these translations were identified, discussed and optimised by an expert panel consisting of three authors of this article (DS, AL, MH).

*PsycTESTS™* is a database of the American Psychological Association.
APPENDIX C: USER MANUAL DECISIONAL CONFLICT SCALE

User Manual – Decisional Conflict Scale

4.4 The SURE test version for clinical practice: 4 items 2 response categories

This version is recommended for use in everyday clinical practice.

Note: We always precede the DCS with an option preference question, which is not included in scoring.

[See item ‘A’ below].

4.4.1 Scale

A. Which [insert treatment/screening] option do you prefer? Please check ☐ one.

1. ☐ [Option 1]
2. ☐ [Option 2]
3. ☐ [Option 3]
4. ☐ Unsure

---

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sure of myself</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Understanding information</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Risk/benefits ratio</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Encouragement</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

---

<table>
<thead>
<tr>
<th>Question</th>
<th>Oui</th>
<th>Non</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sûr</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Utilité de l’information</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Risques-bénéfices à balancer</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Encouragement</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

---

4.4.2 Scoring and Interpretation

Items are given a score value of:

0 = ‘no’, 1 = ‘yes’.

TOTAL SCORE (UNCERTAINTY)

Can only be calculated if all items are answered.

The 3 items are summed.

Scores range from 0 [extremely high decisional conflict] to 4 [no decisional conflict].

A score of ≥ 3 indicates decisional conflict.
APPENDIX D: USER MANUAL SATISFACTION WITH DECISION INSTRUMENT

Satisfaction with Decision Instrument

You have been considering whether to consult your health care provider about hormone-replacement therapy. Answer the following questions about your decision. Please indicate to what extent each statement is true for you AT THIS TIME.

Use the following scale to answer the questions.
- 1 = strongly disagree
- 2 = disagree
- 3 = neither agree nor disagree
- 4 = agree
- 5 = strongly agree

1. I am satisfied that I am adequately informed about the issues important to my decision.

2. The decision I made was the best decision possible for me personally.

3. I am satisfied that my decision was consistent with my personal values.

4. I expect to successfully carry out (or continue to carry out) the decision I made.

5. I am satisfied that this was my decision to make.

6. I am satisfied with my decision.

The instrument vocabulary is at an eighth-grade reading level. As was true in the pilot study, the reliability of the SWD scale was good, Cronbach’s alpha = 0.86. The six-item SWD scale is a reliable and valid instrument that measures patient satisfaction with a healthcare decision. The brief scale provides an efficient measure that can be easily used in healthcare settings to evaluate decision-assisting technologies or patient-provider interactions aimed at involving patients in decision making.
APPENDIX E: USER MANUAL SELF EFFICACY SCALE

User Manual - Decision Self-Efficacy Scale

**Definition**

The ‘Decision Self-Efficacy Scale’ measures self-confidence or belief in one’s abilities in decision making, including shared decision making.

**Sample Tool**

**My confidence in making an informed choice**

Below are listed some things involved in making an informed choice. Please show how confident you feel in doing these things by circling the number from 0 (not at all confident) to 4 (very confident) for each item listed below.

I feel **confident** that I can:

1. Get the facts about the medication choices available to me
2. Get the facts about the benefits of each choice
3. Get the facts about the risks and side effects of each choice
4. Understand the information enough to be able to make a choice
5. Ask questions without feeling dumb
6. Express my concerns about each choice
7. Ask for advice
8. Figure out the choice that best suits me
9. Handle unwanted pressure from others in making my choice
10. Let the clinic team know what’s best for me
11. Delay my decision if I feel I need more time

Decision Self Efficacy Scale © AM O’Connor 1995
User Manual - Decision Self-Efficacy Scale

Directions for Use

In a short introductory statement, respondents are asked to reflect on how confident they feel in making an informed choice on a scale ranging from “Not at all confident” to “Very confident”. The scale can be used: a) over time; or b) before and/or after an intervention is provided.

Scoring and Interpretation

There are two versions of the Decision Self-Efficacy Scale, one with 5 response categories (see ‘Sample Tool’ above), and one with 3 response categories (see ‘Alternate Formats’).

To help others interpret the score more readily with scales ranging from 0 to 100, these scales can be converted to 0-100 scales.

TOTAL SCORE
For the original 5-point scale, items are: a) summed; b) divided by 11; and c) multiplied by 25.
Scores range from 0 [not at all confident] to 100 [very confident].
A score of 0 means ‘extremely low self efficacy’ and a score of 100 means ‘extremely high self efficacy’.

Psychometric Properties

Scale with 3 response categories
The Alpha coefficients are 0.86 [1,2]
The scale discriminates between those who made and delayed decisions about schizophrenia [1]. The scale is correlated [2] with: decisional conflict (r=.55), especially the sub-scales of feeling informed and supported; and knowledge (r=0.61).

Scale with 5 response categories
The Alpha coefficient [3] is 0.92
The scale is correlated [3] with: decisional conflict subscales of feeling informed (r=0.47) and supported (r=0.45)

Clinical Applications

The scale with 3 response categories has been used in a population of patients with schizophrenia [1] and osteoporosis [2].

The scale with 5 response categories is currently being used with women making decisions about osteoporosis treatment. [3]

Alternate Formats of this tool

Modified 3 point Decisional Self-Efficacy Scale
The following version of the Decision Self-Efficacy Scale was simplified for a population with Schizophrenia. This version of the scale might be suitable for a lower literacy population.
User Manual - Decision Self-Efficacy Scale

**Scoring and Interpretation**

For the 3-point scale, items are given a score value of:
4 = ‘A Lot Confident’, 2 = ‘A Little Confident’; 0 = ‘Not Confident’

**TOTAL SCORE**
11 items are: a) summed; b) divided by 11; and c) multiplied by 25.
Scores range from 0 [not confident] to 100 [extremely confident].

**Availability**

You may use any of these scales at no cost without permission.

These tools are protected by copyright but are freely available for you to use, provided you cite the reference in any questionnaires or publications.

**Suggested Citation**


**References**


APPENDIX F: IRB APPROVAL

DATE: March 8, 2022
TO: Lincy Jojan, NP
FROM: Molloy College IRB
PROJECT TITLE: [1875149-1] CHRONIC KIDNEY DISEASE PATIENTS’ EXPERIENCES IN THE DECISION-MAKING PROCESS: THE RELATIONSHIP BETWEEN PERSONAL CHARACTERISTICS AND DECISIONAL SELF-EFFICACY ON DECISIONAL CONFLICT AND THE DIALYSIS DECISION IN PATIENTS WHO PARTICIPATED IN SHARED DECISION MAKING.
REFERENCE #: New Project
SUBMISSION TYPE: New Project
ACTION: APPROVED
APPROVAL DATE: March 8, 2022
EXPIRATION DATE: March 7, 2023
REVIEW TYPE: Expedited Review
REVIEW CATEGORY: Expedited review category # 7

Thank you for your submission of New Project materials for this project. The Molloy College IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

YOU MAY PROCEED WITH YOUR PROJECT.

This submission has received Expedited Review based on applicable federal regulations.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UIRISOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.
This project has been determined to be a MINIMAL RISK project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of March 7, 2023.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact Patricia Eckardt at 516-323-3711 or peckardt@molloy.edu. Please include your project title and reference number in all correspondence with this committee.

Sincerely,

Patricia Eckardt, Ph.D., RN, FAAN
Chair, Molloy College Institutional Review Board

This letter has been issued in accordance with all applicable regulations, and a copy is retained within Molloy College IRB's records.
APPENDIX G: INFORMED CONSENT

Barbara H. Hagan School of Nursing
1000 Hempstead Ave
Rockville Centre, NY 11570
1-888-4-MOLLOY

Title of Study:
CKD PATIENTS’ EXPERIENCES IN THE DECISION-MAKING PROCESS:
THE RELATIONSHIP BETWEEN PERSONAL CHARACTERISTICS AND
DECISIONAL SELF-EFFICACY ON DECISIONAL CONFLICT AND THE
DIALYSIS DECISION IN PATIENTS WHO ParticiPATED IN SHARED
DECISION MAKING.

This study is being conducted by:
Lincy Jojan MS, NP
PhD Candidate at Barbara H. Hogan School of Nursing,
Molloy College, 1000 Hempstead Ave,
Rockville Center, New York, 11570
ljojan@molloy.edu
516-331-1773

Key Information about this study:
This consent form is designed to inform you about the study you are being asked to participate in. Here you will find a brief summary about the study; however you can find more detailed information later on in the form.

Research is on a sample of individuals with chronic kidney disease (CKD) who are currently considering any treatment strategies (Hemodialysis /Peritoneal dialysis/ kidney transplant) or now receiving any of the treatments for CKD within the last three or more months of being diagnosed. Researcher is seeking volunteers for a dissertation research study on decision-making experience. Therefore, researcher is reaching out to individuals 18 yrs. and older and who are willing to participate in the study.

Why am I being asked to take part in this study?

This research aims to explore experiences of patients with CKD regarding their decision-making process. This study is expected to improve the decision-making process for future CKD patients in selecting treatment options based on individual preference and values.

What will I be asked to do?
APPENDIX H: SURVEY INVITE

Did You Face a Complex Treatment Decision for Your CKD?

We are conducting research to find out how patients with CKD make decisions about treatment options.

- Are you in dialysis treatment for CKD?
- Are you contemplating or trying to decide if transplantation is the right choice for you?
- Are you able to read and understand English?
- Do you use a computer/mobile for connecting to internet?
- Can you recommend anyone who meets the above criteria and willing to participate?

We are recruiting participants for a web-based survey about decision-making experiences. If you complete the survey and provide your email, you will be automatically eligible for a $500 Amazon gift card lucky raffle draw at the end of the study. For more information, contact Melody at melody@molloy.edu

Molloy College IRB
Approval Date: March 8, 2022
Expiration Date: March 7, 2023
HELPING KIDNEY DISEASE PATIENTS

VOLUNTEERS NEEDED
If you take a survey, you may be lucky to get a $300 Amazon gift card

WE ARE CONDUCTING RESEARCH ON HOW KIDNEY DISEASE PATIENTS MAKE DECISIONS ON DIALYSIS.

We're looking for volunteers who can participate in a 20 minutes online survey.
http://survey.ckdresearch.org/

Contact: Lacey Jepson, Molloy College
516-331-1773
ljojanselions.molloy.edu
Ad · survey.ckdresearch.org

**Volunteers Needed | Do you have Kidney Disease? | Complex...**
Research: Chronic Kidney Disease Patients’ Experiences in the Decision-Making Process:. How patients with Ckd make...
Re: Requesting Permission

Linny Lian <linny@lines.mdig.com>

To: Margaret

Subject: Requesting Permission

Dear Dr. Holmes-Roner,

I am a Ph.D. student working on my dissertation. My area of interest is in the CHO population's participation in shared decision-making. Use of Decision Aid to Reduce Decisional Conflict Among Rural Patients in selecting appropriate treatment options that is best for them.

I am requesting permission to use your *Satisfaction with Decision Scale* for my dissertation.

Please let me know if permission is granted and if there is a fee involved.

Thank you for your consideration.

Linny Lian, M.S., R.N., P.N.
email@mdig.com
phone: (516) 950-5288
Ph.D. Candidate
Mount Sinai, Rockefeller Center
New York.

On Wed, Mar 16, 2021 at 3:58 PM Holmes-Roner, Margaret <moholmes@msu.edu> wrote:

You have my permission to use the Satisfaction With Decision Scale in your dissertation work. I am very interested in your topic, I would appreciate your sending me an abstract of your dissertation when you are done.

If I can be of any further assistance along the way, do not hesitate to be in touch with me. I would be happy to review any decision aids, and will protect your confidentiality.

Best,

Margaret

Margaret Holmes-Roner, PhD
Professor/Educator, Health Services Research
Michigan State University College of Human Medicine
Email: moholmes@msu.edu
Phone: (517) 353-2277

On Wed, Mar 16, 2021 at 9:30 PM Holmes-Roner, Margaret <moholmes@msu.edu> wrote:

You're welcome Linny! Let me know if you need any further assistance.

Best,

Margaret

Linny Lian <linny@lines.mdig.com>

Sent: Monday, March 15, 2021 1:29 PM

To: Holmes-Roner, Margaret <moholmes@msu.edu>

Subject: Requesting Permission

Dear Dr. Holmes-Roner,

I am a Ph.D. student working on my dissertation. My area of interest is in the CHO population's participation in shared decision-making. Use of Decision Aid to Reduce Decisional Conflict Among Rural Patients in selecting appropriate treatment options that is best for them.

I am requesting permission to use your *Satisfaction with Decision Scale* for my dissertation.

Please let me know if permission is granted and if there is a fee involved.

Thank you for your consideration.

Linny Lian, M.S., R.N., P.N.
email@mdig.com
phone: (516) 950-5288
Ph.D. Candidate
Mount Sinai, Rockefeller Center
New York.

APPENDIX I: PERMISSION LETTER
Re: Requesting Permission.

Linny Jojes (linnyj@lavoie.malaya.edu)

Thank you so much Dr.Lagare for your quick response and granting permission to use the decisional conflict scale for my dissertation.

Regards

Linny

On Mar, Mar 15, 2021 at 4:41 PM France Lagare &lt;france.lagare@med.ulaval.ca&gt; wrote:

Dear Linny Jojes,

I am very happy that you use the "SURE-Decisional conflict" for your dissertation.
I wish you well and don’t hesitate if you need anything else

With best regards,

France Lagare
MSc, PhD
Director of Research in Health Services and Emergency Medicine
Faculty of Medicine
Laval University (Québec)
Canada
Email: FR.LAGARE@ULaval.ca
http://www.recherche.ulaval.ca

De: Linny Jojes [mailto:linnyj@lavoie.malaya.edu]
Envoyé: 15 mars 2021 16:31
À: France Lagare &lt;france.lagare@med.ulaval.ca&gt;
Objet: Requesting Permission.

I am a Ph.D. student working on my dissertation. My area of interest is in the CKD population's participation in shared decision-making.
Use of Decisional Aid to Reduce Decisional Conflict Among Renal Patients in selecting appropriate treatment options that is best for them.

I am requesting permission to use your "SURE-Decisional conflict" for my dissertation.
Thanks for your email.

Please feel free to use our measure (and there is no fee). See the official statement below. Please remember to make any kind of adaptation transparent and in case of a publication, also cite the original source.

You are free to use the SDQ-I-9 and/or SDQ-II-9 in any non-commercial context (e.g., academic research, including validation studies), as long as you refer to its source (particularly, the original publication).

For authorized translations, adaptations and psychometric publications, visit [www.aimb.uni](http://www.aimb.uni).

The work is licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License.

To view a copy of the license, visit [http://creativecommons.org/licenses/by-nc-sa/4.0/](http://creativecommons.org/licenses/by-nc-sa/4.0/).

Please note that any adaptation of the instrument should be clearly shown in the report of your findings.

Good luck with your PhD and please contact me again in case of questions.

Best,

Stefan

Hartnische Grüße
Stefan Zeh

Stefan Zeh, M. Sc.
Psychologe, Wissenschaftlicher Mitarbeiter
Psychologik, Research Associate

Universitätsklinikum Hamburg-Eppendorf
Zentrum für Psychosomatik Medizin
Institut und Poliklinik für Medizinische Psychologie
University Medical Center Hamburg-Eppendorf
Department of Medical Psychology

Martinistraße 52
Gebäude 911, Raum 571
20246 Hamburg

Telefon/Fax: +49 (0) 40 7410 - 5200
Email: s.zeh@uke.de
Skype: s.zeh@uke.de

[www.uke.de/medizinpsychologie](http://www.uke.de/medizinpsychologie)
Chronic Kidney Disease (CKD) patients: Decision-Making experience.

Welcome to this survey on Chronic Kidney Disease (CKD) patients’ decision-making experience with your current treatment choice.

Thank you for considering participating in this survey. Participation in this study is voluntary. Your personal information will be kept confidential and will not disclose your identity. Your time and input are appreciated.

The purpose of this survey is to understand the CKD patients’ experience in the Decision-Making Process. These research findings might provide insight into decision-making preferences for patients with end-stage renal disease. This study is expected to improve the decision-making process for future CKD patients in selecting treatment options based on individual preferences and values.

You meet the eligibility criteria if you are 18yr or older and diagnosed with CKD in the last three months or more who are currently considering or receiving any of the treatment strategies (Hemodialysis /Peritoneal dialysis /kidney transplant).

Each individuals' response is important; therefore, you are asked to complete only one survey.

NOTE: You are giving consent by submitting this survey. You will be eligible for a $300 Amazon gift card lucky raffle draw at the end of the study if you provide your email address.
Chronic Kidney Disease (CKD) patients: Decision-Making experience.

Survey Questionnaire

Do you consent to participate in the study on CKD patients' experience in the decision-making process? By clicking "yes," you agree to participate.*

- No
- Yes

Are you 18 years and older? *

- No
- Yes

Has a health care provider diagnosed you as having CKD? *

- No
- Yes

What stage in CKD are you at? *

- Stage 3 Moderate CKD (GFR = 30-59 mL/min)
- Stage 1 with normal or high GFR (GFR > 90 mL/min)
- Stage 2 Mild CKD (GFR = 60-89 mL/min)
- Stage 5 End Stage CKD (GFR <15 mL/min)
- Stage 4 Severe CKD (GFR = 15-29 mL/min)
- I am unsure

How long have you had CKD? *

- Less than 1 year
- 3-5 years
- 1-2 years
- I am unsure
- greater than 5 years

Are you currently considering or have you made a decision regarding your treatment in the past three months or more? *

- Yes
- No

How long ago did you make the treatment decision for CKD? *

- More than three months
- I am currently considering a decision
- In the last three months

What treatment options are you currently considering or have made within the last 3 months regarding CKD? Choose all that apply.*

- Peritoneal dialysis
- Hemodialysis
- Kidney transplant
- Conservative care (No dialysis / No transplant)
- I am unsure

After making this decision on dialysis choice, did you have an event requiring a visit to a health care provider, emergency room or hospital related to your dialysis decision? *

- Yes
- No
### Demographic Questionnaire

**Birth sex**
- Male
- Female

**Ethnicity**
- Hispanic or Latino
- Not Hispanic or Latino

**Race**
- White or Caucasian
- Black or African American
- Asian or Asian American
- American Indian or Alaska Native
- Native Hawaiian or other Pacific Islander
- Multiple Race
- Other:

**What is your age?**
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85 or older

**What is your highest Education Level?**
- Grade School
- High School Graduate
- College Graduate
- Doctoral Degree
- Other:

**Relationship Status**
- Married/Partnered
- Single
- Divorced/Separated
- Widowed

**Self Reported Health Status**
- Very healthy other than my Kidney disease
- Moderately healthy other than my Kidney disease
- Average other than my Kidney disease
- Poor

**Did another individual support you during your decision? If so, please identify other individuals. Choose all that apply.**
- Not applicable
- Spouse
- Child
- Sibling
- Friend
- Healthcare provider (Physician/Nephrologist)
- Other:

**Did your healthcare provider share with you materials such as a decision aid packet or brochures to assist you in your decision-making for CKD treatment choice?**
- Yes
- No
### The decision making in CKD

Below are listed statements involved in making an informed choice. Please show how confident you feel in your decision on CKD treatment choice by selecting the number for each item below as 0 Not confident at all to 4 very confident. Respond to each item as.

I feel confident that I can .......

<table>
<thead>
<tr>
<th>Statement</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Not at all confident</th>
<th>Very confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get the facts about the treatment options available to me. *</td>
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<td>Get the facts about the benefits of each choice *</td>
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<td>Get the facts about the risks and side effects of each choice *</td>
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<td>Understand the information enough to be able to make a choice *</td>
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<td>Ask questions without feeling dumb *</td>
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<td>Express my concerns about each choice *</td>
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<td>Ask for advice</td>
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<td>Figure out the choice that best suites me *</td>
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<tr>
<td>Handle unwanted pressure from others in making my choice *</td>
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<tr>
<td>Let the health care team know what’s best for me *</td>
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<tr>
<td>Delay my decision if I feel I need more time *</td>
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</tbody>
</table>
Chronic Kidney Disease (CKD) patients: Decision-Making experience.

The decision making in CKD

Kindly choose the answer that reflects how you feel regarding the decision on CKD treatment choice you are currently considering or have made within the last three months related to your CKD.

Do you feel sure about the best choice for you? *
- Yes
- No

Do you know the benefits and risk of each option? *
- Yes
- No

Are you clear about which benefits, and risks matter most to you? *
- Yes
- No

Do you have enough support and advise to make a choice? *
- Yes
- No
Chronic Kidney Disease (CKD) patients: Decision-Making experience.

**The decision making in CKD**

Considering the current or recent decision on CKD treatment choice. Kindly complete the following questions using the scale below from completely disagree to completely agree.

1. My doctor made clear that a decision had to be made *
   
   - 0 1 2 3 4 5
   
   completely disagree  ○ ○ ○ ○ ○ ○ completely agree

2. My doctor wanted to know exactly how I wanted to be involved in making the decision *
   
   - 0 1 2 3 4 5
   
   completely disagree  ○ ○ ○ ○ ○ ○ completely agree

3. My doctor told me that there are different options for treating my medical condition *
   
   - 0 1 2 3 4 5
   
   completely disagree  ○ ○ ○ ○ ○ ○ completely agree

4. My doctor precisely explained the advantages and disadvantages of the treatment options *
   
   - 0 1 2 3 4 5
   
   completely disagree  ○ ○ ○ ○ ○ ○ completely agree

5. My doctor helped me understand all the information *
   
   - 0 1 2 3 4 5
   
   completely disagree  ○ ○ ○ ○ ○ ○ completely agree

6. My doctor asked me which treatment option I prefer *
   
   - 0 1 2 3 4 5
   
   completely disagree  ○ ○ ○ ○ ○ ○ completely agree

7. My doctor and I thoroughly weighted the different treatment options *
   
   - 0 1 2 3 4 5
   
   completely disagree  ○ ○ ○ ○ ○ ○ completely agree

8. My doctor and I selected a treatment option together *
   
   - 0 1 2 3 4 5
   
   completely disagree  ○ ○ ○ ○ ○ ○ completely agree

9. My doctor and I reached an agreement on how to proceed *
   
   - 0 1 2 3 4 5
   
   completely disagree  ○ ○ ○ ○ ○ ○ completely agree
Chronic Kidney Disease (CKD) patients: Decision-Making experience.

Satisfaction with Decision

After being made a decision for CKD, answer the following questions about your decision; please indicate to what extent each statement is true for you at this time.

I am satisfied that I am adequately informed about the issues important to my decision *

1 2 3 4 5

strongly disagree ○ ○ ○ ○ ○ strongly agree

The decision I made was the best decision possible for me personally *

1 2 3 4 5

strongly disagree ○ ○ ○ ○ ○ strongly agree

I am satisfied that my decision was consistent with my personal values *

1 2 3 4 5

strongly disagree ○ ○ ○ ○ ○ strongly agree

I expect to successfully carry out (or continue to carry out) the decision I made *

1 2 3 4 5

strongly disagree ○ ○ ○ ○ ○ strongly agree

I am satisfied that this was my decision to make *

1 2 3 4 5

strongly disagree ○ ○ ○ ○ ○ strongly agree

I am satisfied with my decision *

1 2 3 4 5

strongly disagree ○ ○ ○ ○ ○ strongly agree
Share your Experience

Please answer the following question in a few sentences about your experience in the decision-making process. Your experience is valuable.

What information were you given by your provider and what conversations did you have about dialysis options? *

Your answer

What factors did you feel could have influenced your choice regarding the type of dialysis you are currently on? *

Your answer

What kept you from deciding about other choices? *

Your answer

Describe if and how you were provided with decision aids or educational materials on dialysis options by your health care provider or others sources? How helpful were they in making your current treatment choice? *

Your answer

Thank you for your participation.

Thank you for participating in this survey.

Your input and personal experiences as an individual with CKD may influence future guidelines and recommendations for improving patient-centered outcomes.
APPENDIX K: LETTER OF SUPPORT

June 28, 2020

Lincy Jojan
PhD candidate, Molloy College
1000 Hempstead Ave,
Rockville Center
New York 11570

Reg: Letter of Support

Dear Lincy,

On behalf of Kidney Solutions (KS), a Texas-based, 501(c)3 non-profit organization established in 2018 to assist kidney patients in finding their living kidney donor. I assure my wholehearted support with your dissertation research in identifying CKD patients who will be willing to complete your research survey to share their Decision-making experience with CKD treatment options. The results of this study will help create a clearer understanding of the patient experience and help shape the future of kidney disease treatment and care. We can also help to communicate your excellent work once complete.

We offer a wide range of services and programs to those navigating the many challenges of chronic kidney disease. These programs and services educate and empower people living with kidney disease, from pre-dialysis to those with a transplant, to live a healthy life. After 30+ years of living with a transplanted kidney, I may not have seen it all, but I’ve seen and experienced enough to help others.

Sincerely,

Kent Bressler MA RN

Kent Bressler, MA RN,
KIDNEY SOLUTIONS: A Network of Transplant Experience
(830) 285-2140
Kent.bressler@kidneysolutions.org