

**A Discrete Choice Experiment Pilot Study: Understanding Patient  
Preferences for In-centre Hemodialysis**

by

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

Master of Science

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## Abstract

### Background:

End-stage kidney disease (ESKD) is the failure of functioning kidneys such that they no longer have the capacity to sustain life without intervention. While the incidence of ESKD has remained generally stable across all ages of Canadians since 2000, the prevalence of ESKD has been increasing. Kidney replacement therapy is required to sustain life, and options include dialysis or kidney transplant. Available dialysis modalities include hemodialysis (HD) and peritoneal dialysis (PD). HD is a procedure that filters toxins and solutes from blood through an artificial semipermeable membrane. PD is a procedure that utilizes the semipermeable peritoneal membrane in the abdominal cavity to remove toxins and solutes by regularly filling and draining the cavity with a dialysis solution. The majority of dialysis patients are treated with in-centre HD, which requires three to four hour HD treatments in a hemodialysis unit three times a week, imposing a significant burden of illness due to treatment time. The current prescription for hemodialysis has remained the same for all patients requiring initiation of kidney replacement therapy since its inception in 1985. Patient preference, in conjunction with the understanding that residual kidney function is dynamic has resulted in increasing interest in individualization of dialysis dosage. The individualized prescription often takes the form of an alternative dialysis dose by means of reduced duration, frequency, intensity of flow rates, as well as lifestyle modifications, including diet and fluid restriction. The purpose of this research is to determine and quantify patient preferences with respect to modifiable attributes of dialysis treatment.

**Methods:**

The study employed a qualitative description methodology which identified themes considered important to HD patients. The identified themes were used as attributes and assigned levels to construct a discrete choice experiment (DCE) pilot study to quantify patients' stated preferences of the attributes associated with dialysis in a binary option forced-choice survey.

**Results:**

In the qualitative study, eight people with ESKD participated in virtual interviews. Analysis of the semi structured interview data identified five main themes regarding patient preferences with respect to treatment: time on dialysis, recovery time post dialysis, schedule, diet restriction, and fluid restriction.

In the DCE, 20 kidney disease patients with a median age of 61 years (range 33-81), and a median dialysis treatment duration of 12 months (range 3-360) were presented a discrete choice experiment pilot study. Overall, 55% (12/20) chose their current treatment prescription and recovery period over the presented alternative dialysis treatment options. Participants choosing alternative treatment options preferred fewer weekly treatments of longer duration, increased flexibility in the choice of dialysis days, and preferred no further fluid restrictions or food restrictions. When comparing participants who picked the alternative treatment to participants who exclusively selected their current dialysis treatment, participants who picked alternative dialysis treatments were typically younger (median age 57 vs 63.5), more likely to drive themselves to dialysis (75% vs 25%), less likely to be retired (50% vs 67%), and less likely to have someone helping them manage their health at home (50% vs 75%).

**Conclusion:**

Inclusion of patient preferences concerning dialysis treatment prescriptions should be more thoroughly considered when making treatment decisions. This individualization of prescriptions should specifically aim to minimize fluid and food restrictions, while increasing schedule flexibility. These changes could be managed by altering dialysis duration and the number of treatments each week to suite specific patient preferences while balancing dialysis requirements. This approach is likely to benefit the health care system, patients, and providers by potentially decreasing costs to the system, incorporating patient preferences, and providing additional prescription options for health care providers to offer dialysis patients. This research highlights the need for increased patient preference consultation in dialysis prescriptions, and provides a foundation to continue quantifying patient preferences with respect to in-centre HD, as there is a range of patient preferences that deviate from the traditional HD prescription.

## **Preface**

This thesis is an original work by Jarom Stevenson. The research conducted in the qualitative pilot study forms phase 4 of the CanSOLVE 3.1 (Triple 1) pan-Canadian research collaboration led by Dr. Marcello Tonelli at the University of Calgary and Dr. Neesh Pannu at the University of Alberta.

Ethical approval for the Qualitative Pilot Study was received by the University of Alberta Health Research Ethics Board, Project Name “CanSOLVE 3.1 (Triple 1),” REB File # Pro00069939, March 9, 2020. The need for written informed consent was required prior to the interview.

Ethics approval for the Discrete Choice Experiment was received by the University of Alberta Health Research Ethics Board, Project Name “Understanding Patient Preferences for Dialysis Treatment using a Discrete Choice Experiment,” REB File # Pro00101641, February 25, 2021. The need for written informed consent was assumed by completion of the survey.

## **Acknowledgements**

### **Funding**

This study was funded through operating grant funds from the CIHR CANSOLVE network (PI – Dr. N Pannu).

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## 1.0 Introduction to End-Stage Kidney Disease and Dialysis

Chronic Kidney Disease (CKD) is a condition characterized by alterations in kidney function. This is measured as decreased glomerular filtration rate (GFR), and the presence of albumin protein in the urine. In individuals with normal kidney function, the GFR, generally calculated from serum creatinine measurement, ranges between 90 to 120 ml/min/1.73m<sup>2</sup> with no blood and protein identified in the urine. CKD is defined as a GFR less than 60 ml/min/1.73m<sup>2</sup> for greater than 3 months and/or the presence of albumin protein in the urine. Once defined, CKD severity is categorized into stages using laboratory measures of estimated glomerular filtration rate with mild kidney damage in Stage 1 to kidney failure in Stage 5 resulting in End-Stage Kidney Disease (ESKD).

CKD is a common condition amongst adults, with an estimated prevalence of approximately 11% in Canada.<sup>1</sup> The most common cause of CKD is diabetic kidney disease.<sup>2</sup> While most people with CKD can be medically managed, approximately 1-2% will progress to ESKD.<sup>2</sup> ESKD is the failure of functioning kidneys to the extent to which they no longer have the capacity to sustain life without intervention. ESKD is frequently complicated by with acid-base imbalances, electrolyte abnormalities, fluid overload, and uremic symptoms. The prevalence of ESKD in Canada is about 0.2%, which has been increasing over the last 20 years, with the largest increase identified in Canadians 75 years of age and older.<sup>2,3</sup> In Canadian adults the single greatest cause of ESKD is diabetes mellitus, with 30% of ESKD patients having diabetes as their primary diagnosis at the initiation of dialysis.<sup>4</sup>

Clinical symptoms of CKD and ESKD range from asymptomatic conditions which are only detectable via laboratory tests, to severe illness. Early stages of CKD typically do not cause symptoms as the body is able to cope with the reduced kidney function. In the later stages of

CKD, patients may experience edema, volume overload, muscle cramps, decreased appetite and weight loss. Symptoms of ESKD include fatigue, constipation, anorexia, anxiety, sleep disorders, restless leg syndrome, uremic pruritus (itchy skin), muscle cramps, nausea, and vomiting.<sup>5</sup>

## **1.1 ESKD Treatment Options**

Treatment options for ESKD include conservative management, kidney transplant, or kidney replacement therapy (dialysis). Conservative management is end of life care, with the purpose of providing comfort for the patient and medically managing complications. While kidney transplantation is associated with higher survival, the process is highly selective, and the need for donor kidneys greatly exceeds the available supply. Most patients with ESKD who required kidney replacement therapy are treated with dialysis.<sup>3</sup>

Dialysis is typically initiated when GFR is less than 9 ml/min/1.73m<sup>2</sup> and when symptoms or complications of ESKD become difficult to manage.<sup>6</sup> There are two types of dialysis available in Canada; peritoneal dialysis (PD) and hemodialysis (HD). PD is a procedure that utilizes the semipermeable peritoneal membrane in the abdominal cavity to remove toxins and solutes by regularly filling and draining the cavity with a dialysis solution. HD is a procedure that removes blood from the patient and filters out toxins and solutes from the blood through an artificial semipermeable membrane, before returning the blood to the patient.

Both HD and PD can be done at home with patient education and health care system support and is generally associated with better outcomes than in-centre treatments, although there are mixed results largely due to study design, bias, and confounding variables.<sup>7,8</sup> Home based dialysis is the preferred treatment option as it offers increased patient autonomy, flexibility in treatment schedule and duration, and is associated with higher quality of life as well as

decreased treatment costs.<sup>9</sup> However, in-centre hemodialysis treatments are used by more than 70% of ESKD patients receiving dialysis.<sup>2</sup> In-centre HD requires three treatments per week, and typically each treatment is three to four hours long separated by one or two days between sessions during which patients often spend the time recovering.<sup>10</sup> Therefore, treatments require patients to adhere to a strict schedule that once set is extremely difficult to change.

## **1.2 Hemodialysis Prescriptions**

Since dialysis inception, HD prescriptions have been established primarily from dialysis adequacy measures and econometrics.<sup>11</sup> Originally, dialysis was only offered to people with reversible acute kidney injury who were expected to recover. Once made available in the early 1960's to ESKD patients, treatment prescriptions originated as once weekly for 24 hours, which changed to twice weekly in the late 1960's to address uremic symptoms between treatments.<sup>12</sup> With poor control of peripheral neuropathy, the addition of a third dialysis session a week was introduced.<sup>11,12</sup> This was called "dialysis adequacy," and was defined as the amount of dialysis required to prevent peripheral neuropathy. Following the inclusion of dialysis into Medicare in 1973, thrice weekly sessions were adopted as the best way to deliver dialysis care to as many people as possible with the limited resources available.

Urea kinetics, a modelling system that focuses on urea removal as a marker of dialysis efficiency,<sup>13</sup> was developed in order to quantify dialysis dosage in relation to initial patients with uremic symptoms and peripheral neuropathy. With a focus on blood, urea, and nitrogen (BUN), the National Cooperative Dialysis Study (NCDS) found that HD should maintain BUN concentration within about 18-30 mmol/L using four and a half hour dialysis treatments.<sup>14</sup> In 1985, the BUN model was adjusted to the formula  $Kt/V$  (clearance mL/min multiplied by length

of dialysis in minutes and divided by urea distribution volume in mL) in order to calculate urea clearance to achieve dialysis adequacy while still using three treatments per week.<sup>15</sup> As a result, the current prescription for dialysis adequacy still uses the Kt/V model and has remained the same since its inception in 1985.<sup>16</sup> This approach restricts assessment of treatment adequacy to dialyzer urea clearance alone, and does not consider residual kidney function (RKF), which is a dynamic and important factor for incremental dialysis.

Incremental dialysis individualizes dialysis doses by considering residual kidney function (RKF).<sup>17</sup> Patients with substantial RKF may have a decreased HD dose as long as RKF is measured periodically to ensure adequate volume control, and solute clearance with incremental changes made to the dose as RKF declines.<sup>18</sup> Unfortunately, incremental dialysis is not available to all ESKD patients.<sup>17</sup> While there may be benefits to those who are eligible to receive incremental dialysis including preserved RKF,<sup>17</sup> there are no clear guidelines for the implementation and maintenance of incremental dialysis. Eligibility criteria have been proposed, based on data from observational studies, however these have not been prospectively validated or universally adopted.<sup>17,19-22</sup> Ongoing clinical trials are in the process of evaluating incremental dialysis effectiveness, incorporating RKF as a primary outcome measure, as well as clinical safety such as mortality, cardiovascular events, hospitalizations, and patient quality of life. These clinical trials will further delineate the standards of care for individualized incremental dialysis.

### **1.3 Dialysis Adequacy**

While Kt/V has been helpful in providing a standardized quantifiable measure of dialysis adequacy, it has several limitations.<sup>23</sup> Kt/V has been criticized for not being holistic enough to cover other essential aspects such as RKF, molecules other than urea, and patient related

outcomes, all of which should be considered in dialysis adequacy.<sup>23-25</sup> While RKF has long been understood to be important with respect to PD and patient outcomes, only more recently have the benefits of RKF been identified in HD.<sup>22,26,27</sup> However, HD studies evaluating treatment prescription have focused on dialysis delivery using a thrice weekly treatment while ignoring or not considering RKF, assuming static kidney function, and using historical Kt/V targets.<sup>18,25-32</sup> Taking RKF into consideration, there are likely many patients who could dialyze less each week and have similar outcomes, especially in the first year of dialysis.<sup>17</sup> An incremental start would provide patients with a more gradual transitional period from the initial dialysis session to full dose treatments which may mitigate the decreased quality of life experienced by ESKD patients upon starting dialysis.<sup>17</sup>

#### **1.4 Dialysis Patient Reported Experience and Outcomes**

Many of the existing studies in dialysis primarily focused on the “hard” clinical outcomes of mortality and morbidity, giving little attention to patient-oriented outcomes.<sup>14,28,29</sup> Patient reported outcome and experience measures provide a foundation upon which patient centred care can be built as they directly involve patients for what they consider to be important outcomes.<sup>33</sup> Given the extent to which dialysis treatments burden, and comorbidity decreases quality of life in ESKD patients, it is important to understand dialysis patient experiences.

In a review of seventeen qualitative studies with a total of 576 conventional dialysis patients Reid, Seymour, and Jones (2016) conducted a thematic synthesis of the patient experience of in-center HD.<sup>34</sup> This qualitative synthesis aimed to understand HD patient experiences and beliefs regarding HD. The study identified four analytical themes: a new dialysis-dependent self, a restricted life, regaining control, and relationships with health

professionals.<sup>34</sup> A similar qualitative meta-analysis also identified several negative associations that HD patients experience, such as social loss, sick role, and family burden among others.<sup>35</sup>

Aside from the impact of dialysis on health-related quality of life, dialysis patients experience a significant burden in terms of hidden costs associated with dialysis. A national survey of Canadian dialysis patients reported decreased annual income, with more than half of them reporting a decrease of 40% or more.<sup>36</sup> In addition, a conservative estimate of the average out-of-pocket costs necessitated by dialysis, such as transportation, parking, lost income, and others is between \$1400 to \$2500 per year. This is significant, as over half of the respondents had an annual income of less than \$35,000, and 21% of respondents reported going without basic necessities of life due to financial barriers they faced as a result of fulfilling their medical needs.<sup>36</sup>

As multiple qualitative studies have shown, there are many patient-oriented outcomes that are important for dialysis research consideration beyond mortality measures. In order to provide a framework to assist researchers, the SONG-HD collaborative identified a core set of standardized outcomes of importance to all stakeholders (patients and health care providers).<sup>37</sup> In this project, three tiers of outcomes were identified. Tier one included core outcomes that were critically important to all stakeholders and should be included in all trials, while tiers two and three were critically important outcomes to some stakeholders. Notably, outcomes such as fatigue, ability to work and travel, and dialysis adequacy were of identified as tier one and tier two to patients and providers.<sup>37</sup>



## 1.5 Dialysis Patient Preferences

Patient selection of dialysis modality is often determined by factors related to quality of life, such as number of hospital visits, flexibility of schedule, ability to travel, out-of-pocket costs, and social support.<sup>9,36,37</sup> Other factors vary between individuals such as life expectancy, anxiety of self-treatment, availability of nursing support, and overall well-being.<sup>9</sup>

In a systematic review of 18 qualitative studies investigating patient and care giver decision making around dialysis modality selection, 4 themes emerged; confronting mortality, lack of choice, gaining knowledge of options, and weighing alternatives.<sup>38</sup> Confronting mortality was associated with emotions related to life and death, becoming a burden on one's family, and existing in a state in which patients perceived they could not see an end to treatment. Lack of choice was a layered theme that covers a range of issues such as treatment education, constraints on resources including ability to pay, lack of knowledge about other modalities, and medical contraindications and physician preference. Gaining knowledge of options focused on the ways in which patients learned about the various dialysis options, which included peer influence and timing of that information.<sup>38</sup> The theme 'weighing alternatives' included the actual process in making a decision for a particular treatment, which was based on maintaining current lifestyles and was strongly influenced by family and friends. Once a decision was made and treatment was initiated, an interesting trend emerged, in which patients were reluctant to change modalities.<sup>38</sup> In summary, education about dialysis treatments and patient preferences in conjunction with the patients' life goals were identified as major drivers in choosing dialysis treatment. However, local resources and prescription patterns tend to override these drivers.<sup>16</sup>

## **1.6 Patient Preference Assessment**

As the patient-centered health model, meaning the patient is at the centre of their care to the extent that health outcomes are meaningful and valuable as defined by the patient,<sup>39</sup> has become the primary approach to individualized health, the incorporation of patient preferences into medical treatment plans has become increasingly important. A review of patient preference by Soekhai and colleagues determined this is done by either exploration or elicitation methods.<sup>40</sup> Exploration uses qualitative methods to collect descriptive data about phenomenon of interest, thereby gaining insight into the subjective experience of patients and how these patients make decisions which elucidates patient preferences.<sup>40</sup> Elicitation uses quantitative methodology to quantify patient preferences. The Medical Device Innovation Consortium Framework categorizes patient preference methods as structured weighting, health-state utility, revealed preference, and stated preference.<sup>41</sup> Stated-preference is a useful tool as it identifies patient preferences given a set of treatment options with their associated attributes and provides a method to quantify trade-off information elucidated during the process. This is often done using best-worst scaling, conjoint analysis, or discrete choice experiments (DCE).

## **1.7 Discrete Choice Experiments**

DCEs are beginning to be more integrated into healthcare research as they are a powerful tool to understand patient preferences. The primary function of a health-based DCE is to provide a valid and reliable method to quantify patients' preferences by capturing perceptions of treatment benefit and tolerance of possible risk.<sup>42</sup> Using DCEs to understand the preferences of patients with kidney disease for various topics such as preferred treatments for other conditions, transplants, dialysis, etc. is becoming more prevalent.<sup>43</sup> This is accomplished by providing the

patient with two or more discrete alternatives with differing attributes, such as time in the case of HD, that are layered with various levels, such as varying amounts of time, from which the patient is asked to choose which they prefer.<sup>44,45</sup> DCE analysis is particularly useful as it helps researchers know not only the preference of the discrete alternative, but what patients are willing to trade-off in terms of listed attributes and levels in order to obtain the preferred alternative. Therefore, a DCE provides more direct information on patient preferences and trade-offs compared to ranking or best-worst methods. This study is investigating which aspects of dialysis treatment are most important to dialysis patients, and what trade-offs they would be willing to make to have more or less of a certain attribute (e.g. duration of dialysis, dietary restrictions). Given the similar idea of multiple attributes to choose from, many researchers use conjoint analysis (CA) interchangeably with DCE as they appear similar. However, they come from unique theoretical foundations making them quite different analytically.

Unlike CA, DCE are founded in human choice behaviour theory called random utility theory (RUT).<sup>45</sup> Simply stated, RUT postulates people have a latent construct known as utility for each alternative that they see, which is not observable by the researcher. This utility is the sum of systematic or explainable components and random error or unexplainable components. In terms of patient preferences this is important, especially for treatments where it is impossible for clinicians to fully comprehend the experience of the patient as in dialysis treatments. As such, a DCE is a superior method of patient preference assessment because the unknown individual experience of treatment is a built-in error calculation.<sup>45</sup>

Attribute and level selection is critical for meaningful data to be generated in a DCE.<sup>44</sup> There are several considerations to be aware of including reality of attributes, cognitive ability of respondents vs. cognitive burden of the question, complexity, and number of combinations of

attributes and their varying levels. The frame in which the information is presented must be carefully considered such that it does not introduce bias into the study. This includes choice context, which is how the information is presented in terms of hypothetical or real life settings. Other items of consideration for respondent comprehension include literacy, numeracy, ability to understand graphs or other visual aids, and technological ability.<sup>46</sup> This is significant as most DCEs are typically delivered using internet technology such as email. However, given the range of technical literacy in local populations, other methods of survey dissemination are required. Providing in person assistance with survey completion has the added benefit of knowing that the participant understands the survey and is able to ask any clarifying questions.

Once the DCE is constructed, pretesting and pilot testing are considered to be important steps to refining the survey. Pretesting foremost helps researchers to confirm that their research question is understood by respondents in the intended way.<sup>46</sup> Pilot testing the survey in a small sample of the target population allows assessment of logistics, preliminary data analysis, completion timing rates, as well as respondent recruitment.<sup>46</sup> Issues from pilot testing are addressed and retested until the survey is ready for full deployment. Due to the need to do the survey in person, which is complicated by COVID-19 public health guidelines, we will complete the pilot test and prepare for large scale deployment when possible.

## **2.0 Methods**

The specific aim of this project was to identify what attributes of dialysis treatment that ESKD patients view as important and to quantify patient preferences of those attributes. This was done by elucidating important dialysis attributes using qualitative methodology. The discovered attributes were combined to construct a DCE with two alternatives for patients to choose from to quantify patient their preferences.

### **2.1 Qualitative Pilot Study**

A qualitative pilot study using qualitative description<sup>47,48</sup> was used to gain insight into the lived experience of people using HD to provide information to populate the attributes of a DCE. A male graduate student (University of Alberta), with previous experience interviewing who was unknown to all interviewees, conducted one-on-one virtual semi-structured interviews and administered a questionnaire which generated data for the study. The qualitative study followed the Standards for Reporting Qualitative Research reporting guidelines.<sup>49</sup>

#### **2.1.1 Ethics**

Ethics approval was obtained from the University of Alberta Human Research Ethics Board to interview participants virtually. REB File # Pro00069939

#### **2.1.2 Participants**

Eligible participants were defined as persons aged 18 years or older currently treated with in centre HD, who had initiated HD for ESKD at least three months earlier and living within the geographic boundaries of the Northern Alberta Renal Program. Participants not able to comprehend or speak in English, or not able to give informed consent were excluded from participating.

### **2.1.3 Participant Recruitment**

Eligible study participants throughout the Northern Alberta Renal Program were approached by nephrologists not associated with the research to introduce the participants to the study. Participants who expressed interest in participating in the virtual interviews were provided with a study invitation letter and a consent to contact form which was sent to principal investigator (PI). Potential participants were then contacted by the PI and provided information about the research project. For those who agreed to participate in the study, a time and date was set for the virtual interview to take place. The minimum number of participants to achieve meaning saturation, or the point at which issues were fully understood, with no further insight into issue dimension or additional nuances emerge during analysis,<sup>50</sup> were recruited, interviewed, and were administered the questionnaire.

### **2.1.4 Interview Structure**

The interview was semi-structured with both closed and open ended questions. The questions were adapted from a portion of a patient interview as part of a larger previous study<sup>51</sup> and was further developed by the principal investigator using an environmental scan and literature review followed by a patient advisor review and approval.<sup>52-55</sup> The final interview guide consisted of a mix of one trade-off, three closed, and 10 open-ended questions with additional probing questions for clarification if required. (See Interview guide in the appendix)

Due to the ongoing Covid-19 pandemic, all interviews were conducted telephone. During the interviews, current HD modality treatment selection and quality of life questions were explored. One open-ended question was asked to describe current HD modality, and three closed ended and nine open-ended questions were asked to ascertain current quality of life including personal schedule, independence, social support, travelling, working, cost of dialysis, mental

health, perceived self-image, recreation, and positive experiences resulting from dialysis. Participants were also asked a hypothetical life expectancy trade-off question. Consent to audio record the interviews was obtained from each participant. Participants were reminded that the interview was voluntary and that they could choose to not answer any question as well as end the interview early. Interview data was transcribed verbatim, with all collected data stored in password protected folders.

A pre interview questionnaire was used to collect demographic, quality of life, and comorbidity information as well as an assessment of treatment burden using the previously validated Illness Intrusive Ratings Scale (IIRS).<sup>55</sup> Originally developed to understand the impact of ESKD on patients,<sup>56</sup> it has been further validated for use to quantify psychosocial impacts from chronic diseases.<sup>55</sup> (See Interview Questionnaire in the appendix)

Self-reported demographic information captured included birth year, gender, age at kidney disease diagnosis, duration requiring HD, HD access, location of HD, types of kidney replacement therapies received, one way travel time to HD centre, postal code, method of transportation, number of HD sessions per week, as well as self-reported number of hours per HD session, time of HD session, preferred time of HD session, employment status, availability of caregivers, as well as participant comorbidities.

The IIRS was used to quantify how dialysis specifically impacted participant health, diet, work, active recreation, passive recreation, financial situation, relationship with spouse, sex life, family relations, other social relations, self-expression/improvement, religious expression, and community/civic involvement. This scale ranges from one to seven with seven being the maximally impacted.

### **2.1.5 Analysis**

#### **Interview:**

Data was analyzed using latent content analysis to provide participant contextualized themes.<sup>57</sup> Both the study PI and patient advisor (TG) independently coded the text for experiences regarding dialysis treatment that were important to the participant. The study PI discussed preliminary coding with TG. Common codes within the transcripts analyzed from both individuals were considered and categorized, from which themes emerged. The emergent themes were recorded and discussed with the project supervisor, from which select themes applicable to the research question were used to construct the DCE.

#### **Questionnaire:**

Questionnaire data was reported by frequency in aggregate to describe study participants. IIRS data was scored as individual summations (range 13 – 91) from which a group mean and standard deviation was calculated to describe intrusiveness of illness as a group. To determine if some areas of life are more impacted than others subscale scores for relationships and personal development (passive recreation, other social relations, self-expression/improvement, religious expression, and community/civic involvement), intimacy (relationship with spouse, sex life), and instrumental (health, diet, work, active recreation, financial situation) were calculated by subscale item means and standard deviations.

### **2.2 Discrete Choice Experiment Pilot Study**

A DCE pilot study was used for the determination and quantification of patient preferences with respect to patient centred modifiable attributes of dialysis treatment as discovered from the qualitative pilot study.



### 2.2.1 Ethics

Ethics approval was obtained from the University of Alberta Human Research Ethics Board to conduct the DCE with patients both virtually via email, mailed hard copy, as well as in person. The need for written informed consent was assumed by completion of the survey. (REB File # Pro00101641).

### 2.2.2 Participants

#### Eligibility

Eligible participants were 1) aged 18 years or older; 2) had CKD with an eGFR < 30 ml/min/1.73m<sup>2</sup> and receiving care in the multidisciplinary CKD clinic or were currently treated with in-centre HD and had initiated HD at least three months earlier; and 3) living within the geographic boundaries of the Northern Alberta Renal Program. Participants not able to comprehend or speak in English were excluded from participating. CKD participants were included in the DCE as they could have a preference about treatment alternatives presented to them even without having experienced dialysis but were excluded from the qualitative pilot study as they are not able to provide a lived experience of dialysis.

#### Sample Size Calculation

Using equation 1 (below) it was determined that 220 participants were required to achieve main effect statistical significance, which assumes a large population and aggregation of respondents such that each choice task by an individual is a single observation in the data.<sup>58</sup>

$$\frac{\# \text{ of participants} \times \# \text{ of tasks} \times \# \text{ of alternatives}}{\text{Largest \# of attributes for any attribute}} \geq 500 \quad \text{Equation 1}$$

### **2.2.3 Participant Recruitment**

Recruitment occurred at the University of Alberta Hospital where dialysis unit charge nurses/CKD clinic staff approached eligible participants during dialysis/virtual CKD clinic appointments to obtain consent to contact regarding participation in this research project.

Interested eligible participants who preferred a paper version were provided with a study packet and paid postage addressed return envelopes. CKD participants were only offered mailed out paper versions as they were not required to be physically present for clinic appointments due to COVID-19 health protocols. For participants who preferred to do the survey in person, a time was arranged for the PI to meet with them while they were on the dialysis unit undergoing dialysis treatment.

### **2.2.4 Pre and Post Survey Questionnaire**

The pre survey questionnaire was developed primarily from the qualitative pilot study to help survey participants to start thinking about their dialysis experience. The questions asked if the participant was currently using HD and for how long, as well as kidney care vintage, one way travel time to kidney care or dialysis centre clinic and their method of transportation.

The post survey questionnaire collected demographic information on participants including patient age, gender, employment status, information about caregiver support, as well as patient comorbidities, and a self-assessment of their current health. (See Pre/Post DCE Questionnaire in the appendix)

### **2.2.5 DCE Survey Development**

The DCE attribute selection was based on the most relevant themes identified from the qualitative pilot study. Relevance was determined by overlapping high IIRS scores and the most

prominent themes from interviews that were realistically modifiable with respect to dialysis treatment prescription alterations. This excluded themes such as “Lack of Information” from consideration as it was not modifiable through a change in dialysis prescription. (See Interview Themes in Appendix) To prevent participant cognitive overload during the choice task, the number of attributes was limited to six. The final list of attributes were discussed with and approved by the study patient advisor and principal investigator and were assigned levels in the context of dialysis treatments while maintaining realistic options. (See appendix for List of Attributes and Levels)

Ngene version 1.2.1 was used to construct the survey using an efficient design to limit the number of available but meaningless combinations. This was completed with an iterative process such that restrictions were incorporated to ensure realistic combinations of attribute levels, which were reviewed and improved until satisfactory. The final attributes and levels were constructed into a 32 question binary (option A or option B) forced-choice task survey with a static option A and a dynamic alternative option B. The static option A always had the same levels for each attribute, which was based on current/conventional dialysis prescriptions. The survey did not label option A as conventional/current treatment to prevent introduction of bias. The dynamic option B pivoted from option A with alternative treatment options by changing the various levels of some or all attributes.

The 32 questions were divided into four blocks with eight questions in each block to decrease the cognitive burden on participants completing the survey so each participant was only required to answer a total of eight questions. Each block had similar choice scenarios, albeit slightly different combinations. This enabled the participants to only answer eight questions individually while their collective answers would provide reliable data to draw conclusions from

the survey. Each question was framed as an individual page formatted as a table with column one containing the six selected attributes each in their own row, column two as the static option A (conventional treatment) with the set corresponding levels for each attribute, and column three containing the dynamic option B (alternative treatment) achieved by changing some or all of the levels of each attribute as compared to option A. There were three possible ways to answer the eight questions, one, only selecting option A (conventional treatment) for all eight questions, only selecting option B (alternative treatment) for all eight questions, and three, a mix of selecting either option A or B for the eight questions.

Option A levels were a darker shade of blue and the levels for option B that were the same as option A were the same shade of blue. Levels in option B that were different from option A were a lighter shade of blue to help denote that they were different. (See Table 1)

Table 1: Example of a DCE question.

<b>Example Question</b>	<b>Option A</b>	<b>Option B</b>
<b>Dialysis Schedule</b>	Dialysis Days Assigned	Dialysis Days Assigned
<b>Dialysis Duration</b>	4 hours/sessions	2 hours/session
<b>Dialysis Intensity (sessions/week)</b>	3 times/week	5 times/week
<b>Fluid Management</b>	Fluid managed by dialysis as usual	Fluid managed by dialysis as usual
<b>Food Consumption</b>	Your usual renal diet	Your usual renal diet
<b>Dialysis Recovery Period</b>	Your current/your normal amount of time to recover.	25% shorter than your current
<b>Your Choice (pick Option A or B)</b>		

The four blocks were pretested with 4 HD dialysis patient volunteers who were recruited by the study patient advisor and were contacted through the Kidney Foundation of Canada. Each patient answered all 32 questions to assess that the choice task was being perceived as intended, was framed neutrally to prevent bias, cognitively palatable, as well as the viability of the

attributes and their associated levels. Revisions to the survey were made in an iterative process until satisfactory based on feedback.

### 2.2.6 Analysis

Pre and post survey questionnaire data was collected and reported by frequency in aggregate to describe study participants using Microsoft Excel Version 16.35 (20030802).

The attributes Flexibility, Food, and Recovery Period were coded with dummy variables (0 for option A and 1 for option B if the level is different than option A), which is interpreted as the larger the absolute value the larger the utility or disutility, depending on the sign, positive or negative. The attributes identified as Duration, Intensity, and Fluid, were coded as number of hours, days, and as 100% or 50% respectively. Estimate values are interpreted with respect to how the levels were coded in the Apollo software. Therefore, a level with a higher numerical value would correspond to a greater marginal utility for that attribute. Significance is given by the t-ratio and robust t-ratio.

DCE data was analyzed with multinomial logit model (below) using Apollo for R, version 0.0.9.<sup>59</sup> DCE data analysis is based on the random utility model (RUM)<sup>60</sup> The RUM assumes utility  $U_{j,n,t}$  of individual  $n$  associated with alternative  $j$  in choice set  $t$  and has a systematic component  $V_{j,n,t}$  and an unobservable random error component  $\varepsilon_{j,n,t}$ .

$$U_{j,n,t} = V_{j,n,t} + \varepsilon_{j,n,t} \quad \text{Equation 2}$$

The functional form of the utility is approximated by a linear-in-parameters combination of treatment attributes.

$$V(\beta, x_{j,n,t}) = \beta_1 x_{j,n,t}^1 + \beta_2 x_{j,n,t}^2 + \beta_3 x_{j,n,t}^3 + \dots + \beta_n x_{j,n,t}^n \quad \text{Equation 3}$$

where  $x_{j,n,t}$  is the treatment attributes for individual  $i$  and alternative  $j$ , and  $\beta$  are the parameters to estimate. With  $\varepsilon_{j,n,t}$  being distributed identically and independently across individuals and choice scenarios following a type I extreme value distribution, an MNL model is obtained,<sup>61,62</sup> with the probability for alternative  $j$  in choice task  $t$  for person  $i$  given by:

$$P_{i,n,t}(\beta) = \frac{z_{avail,i,n,t} \cdot e^{V_{i,n,t}}}{\sum_{j=1}^J z_{avail,j,n,t} \cdot e^{V_{j,n,t}}} \quad \text{Equation 4}$$

where  $\beta$  is a vector combining all model parameters,  $V_{j,n,t}$  refers to the part of the utility functions in Equation 1 that excludes the error term  $\varepsilon_{j,n,t}$ , and where  $z_{avail,j,n,t}$  takes a value of 1 if alternative  $j$  is available in choice set  $t$  for person  $i$ , and 0 otherwise.

The raw probabilities from Equation 4 were then multiplied across individual choice observations for the same individual, thus recognising the repeated choice nature of our data.<sup>59</sup> When estimating a model the probability was computed for the chosen alternative using Equation 4. The contribution by person  $n$  to the likelihood function with a given value for the model parameters vector  $\beta$  is:

$$L_n(\beta) = \prod_{t=1}^{T_n} P_{j_n^*,t} \quad \text{Equation 5}$$

where  $T_n$  is the number of separate choice situations for person  $n$ .

Model estimations were then calculated using the maxLik package to calculate maximum likelihood.<sup>63</sup> The calculated estimates are measures of utility. The utility of choosing option A, coded as the Status Quo, is independent of the attributes and was captured by coding for the status quo utility parameter. Option B contains estimates of marginal utility for each of the

attributes used in the survey and are interpreted based on the absolute value and the sign of the estimate. Each attribute was analyzed while holding the others constant. An estimate with a larger positive value generally indicates a great utility and a larger negative value indicates a larger disutility, or vice-versa depending on the coding used. To measure significance T-ratio and robust T-ratio (when absolute value is greater than two the coefficient is statistically significant) was calculated.

### **3.0 Results**

#### **3.1 Qualitative Pilot Study**

##### **3.1.1 Qualitative Pilot Study Questionnaire**

###### **Participant Demographics and Comorbidities**

In total, 12 participants were recruited and eight completed the phone interview from February 2020 to July 2020 to achieve theoretical saturation, the point at which no new information emerges during analysis.<sup>64</sup> Participants were a median of 65.5 years old (range 39-81) and 50% were male. Median age at kidney disease diagnosis was 57 years (range 23-70) and a median of 60 years old (range 23-75) at HD initiation. Participants were predominantly urban with six participants who lived in greater Edmonton, one in Grand Prairie, and one from a rural community. Travel time to the HD centre was a median of 17.5 minutes (range 10-45 minutes).

The most common comorbidities were high blood pressure, and diabetes. (See Qualitative Pilot Study Tables 1-3 in the appendix)

###### **Illness Intrusive Ratings Scale**

Summary scores of the participants for each question are shown in Qualitative Pilot Study Table 4 in the appendix. Overall, the interviewed group had an average impact score of



46.7 ± 16.0. Subscale score means (a score of seven denotes most impacted) and standard deviations, used to determine which areas of the IIRS life are more or less impacted, were relationships and personal development; 2.7 ± 2.0, intimacy; 4.1 ± 2.3, and instrumental; 4.7 ± 2.1. Health, diet, work, active recreation, sex life, and community/civic involvement were identified as being most impacted by dialysis treatment.

### **3.1.2 Qualitative Pilot Study Findings**

Latent content analysis identified four main themes in describing the impact of dialysis on study participants: 1) time on dialysis, 2) schedule, 3) recovery post dialysis, and 4) dietary and fluid restrictions. All four themes negatively impacted the quality of life of each interviewee. Time on dialysis was described as similar to that of a part time job, the schedule of dialysis was described to be rigid, participants felt ill as they recovered from dialysis treatment, and fluid and food restrictions prevented participants from enjoying their favourite foods and drinks.

When asked the life expectancy trade-off question, participants indicated a willingness to trade years of current lived experience for a shorter life with better quality of life. Some participants simply stated they would make the trade but avoided quantifying how many years saying more information was required, while most others suggested a trade-off of a few years. One participant specifically answered that they would give up 10 years of the next 30 if that meant they felt normal compared to their current lived experience. Participants also had a desire for increased psychological/mental health support, more consistent standards of nursing techniques, better communication between health care workers and patients, and more transparency on the kidney transplant selection process.

Table 2: Themes surrounding dialysis patient experiences

<b>Time on Dialysis</b>	“No that is huge, what you're talking about for a guy like me is huge. I mean I can't say as much as I can with as much relevance as I can. That's valuable, that's relevant. That's my answer to you on that, is that, that particular thing, even from four, from three to two is massive.”
<b>Schedule</b>	“I’m tired, tired of their schedule I want to be on my own.”  “so I just work on the days between (dialysis), which is a very specific schedule”
<b>Recovery Post Dialysis</b>	“But now that your health deteriorates while you’re on dialysis your energy levels drops, and your momentum drops”  “I have to conserve my energy, I have to, if I expend it on things like that I just won’t have it for other things, like getting into dialysis”  “I feel like I’ve been surviving, and not living’
<b>Food &amp; Fluid</b>	“To have a little bit more freedom in terms of my fluid consumption”  “Everything I like I’m not allowed to have”  “...when you have 2 normal kidneys you can sit down for Christmas dinner and have mashed potatoes and gravy, and broccoli and asparagus right. Now you can’t have any of that.”

### 3.2 Discrete Choice Experiment Pilot Study

As a result of COVID-19 public health restrictions, access to dialysis centres and CKD clinics were curtailed. In order to determine the most appropriate method of survey dissemination, and to validate the content of the survey, we performed a pilot study. From January through April 2021 a total of 32 participants (10 CKD and 22 ESKD participants) were recruited to the DCE study. The DCE questionnaire was completed by 18 ESKD and two CKD participants. Of the 18 ESKD participants, eight completed the questionnaire with assistance of the study PI, with the remainder and the two CKD participants completing the questionnaire

independently on paper. The DCE survey was completed by 21 ESKD participants and one CKD participant. Of the 21 ESKD participants, eight were completed with assistance of the study PI, with the remainder completing the survey independently with 11 on paper and two by email. The one CKD participant completed the DCE survey independently on paper. One ESKD participant and eight CKD participants opted out of the study.

### **Participant Characteristics**

Participant demographics are provided in the Appendix under DCE Tables 1 and 2. Participants were a median of 61 years old (range 33-81) of which 64% were male. HD vintage was a median of 12 months (range 3-360). One way travel time to the HD centre was a median of 30 minutes (range 7.5-60) with 45% of participants driving themselves. 45% of participants specified that they did not have someone who helped manage their health at home and 55% participants were retired. Participant comorbidities are provided in the Appendix under DCE Table 3. The most common co-morbidities were high blood pressure (63% of participants) and diabetes (47% of participants).

### **DCE Findings**

Qualitative trends regarding the treatment preference estimates, which are measures of utility for the participants, are provided in Table 3. In our data set due to the small sample size (n=22), none of the estimates were statistically significant, although the attribute fluid was nearly significant, (robust t-ratio = 1.98) and the model assumes that each individual has the same preference.

The largest estimate (2.0154) represents the utility attained from the status quo, (option A) which correlates with the large proportion of participants who chose only option A.

The other estimates provide marginal utility or disutility measures (participant preferences) in terms of each attribute. Based on the signs of the other estimates, they trended towards longer dialysis duration with fewer days a week and a preference to choose dialysis days with fewer fluid restrictions or food restrictions. Based on the absolute value of the estimates, participants had a strong preference against further restrictions with food or fluid, with the fluid attribute being close to a significant finding. Recovery after dialysis did not appear to have a significant factor in decision making regarding dialysis treatment. Participants interested in alternative dialysis prescriptions preferred longer treatment duration with a lower intensity, however these are correlated findings as longer duration is constrained to lower intensity.

Table 3: Estimates of DCE using multinomial logit model. The values are not significant but do show trends. n=22

<b>Attribute</b>	<b>Estimate</b>	<b>Std Error</b>	<b>T ratio(0)</b>	<b>Robust Std Error</b>	<b>Robust T ratio</b>
<b>Status Quo</b>	2.1054	1.5542	1.35	1.2684	1.66
<b>Flexibility</b>	0.5079	0.4267	1.19	0.3433	1.48
<b>Duration</b>	0.3066	0.2005	1.53	0.2338	1.31
<b>Intensity</b>	-0.3198	0.2566	-1.25	0.1982	-1.61
<b>Fluid</b>	0.0133	0.0081	1.64	0.0067	1.98
<b>Food</b>	-0.9947	0.4188	-2.38	0.6426	-1.55
<b>Recovery Period</b>	-0.2146	0.4043	-0.53	0.3198	-0.67

Figure 1 shows the distribution of when either only conventional, only alternative, or a mixture of both was selected. When presented with the conventional in-centre dialysis option as compared to an alternative treatment, 55% (12/22) chose only conventional treatment, 40% (9/22) chose a variety of options, and one participant chose the alternative option consistently. Participants who picked option B (the alternative treatment) relative to participants who exclusively selected option A (current dialysis treatment), were younger (median age 57 vs 63.5), more likely to have independent transportation to and from treatment (75% vs 25%), more likely to be working (67% vs 50%), and less reliant on a caregiver (50% vs 75%). (See DCE Tables 1-2 in the appendix)

Figure 2 provides the distribution of the preferred treatment duration amongst the 30 times any question was answered by selecting the alternative treatment. Most participants preferred to have five hour long dialysis sessions each week (13/ 30 observations). It should be noted however, that those who chose fewer dialysis days were restricted to choosing longer dialysis duration.

Figure 3 provides the distribution of the selected intensity of treatment (number of dialysis treatments/week) when only looking at the results when the alternative treatment was chosen by the participant. The most prominent finding was that most HD participants preferred to have two dialysis sessions each week (19 out of 30 observations).

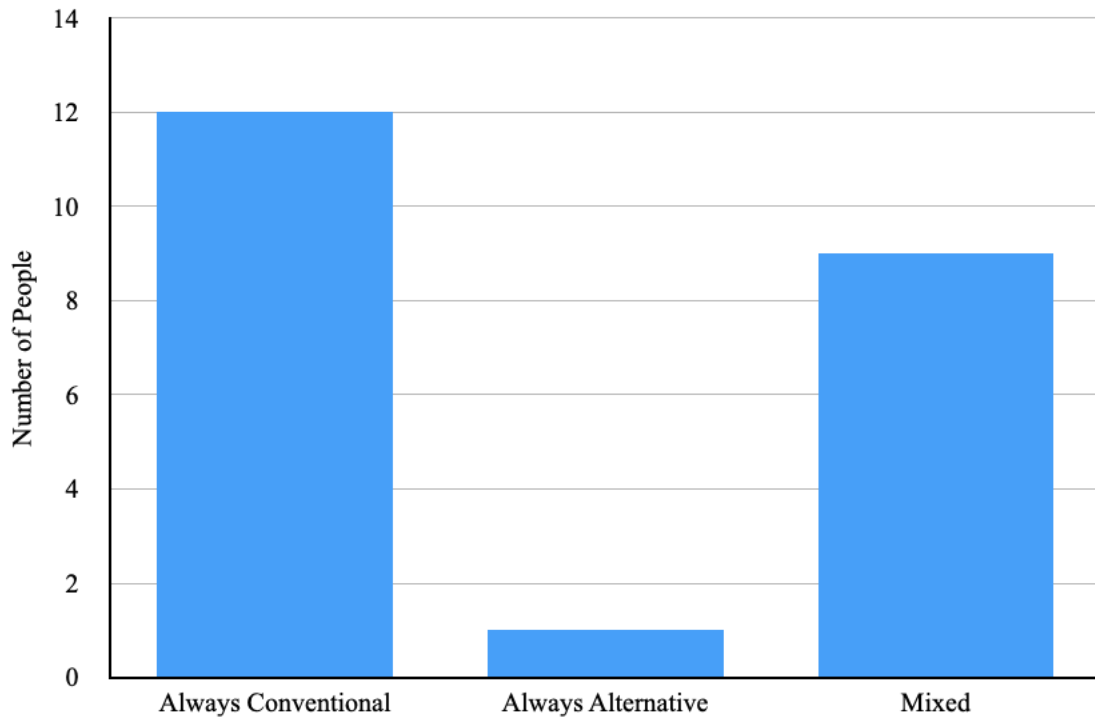


Figure 1: Patient answers to choice task. If during the survey the patient only chose conventional treatment they were marked as “Always Conventional”, if they only marked the Alternative they were marked as “Always Alternative”, if they made at least one alternative selection they were marked as “Mixed”. n=22

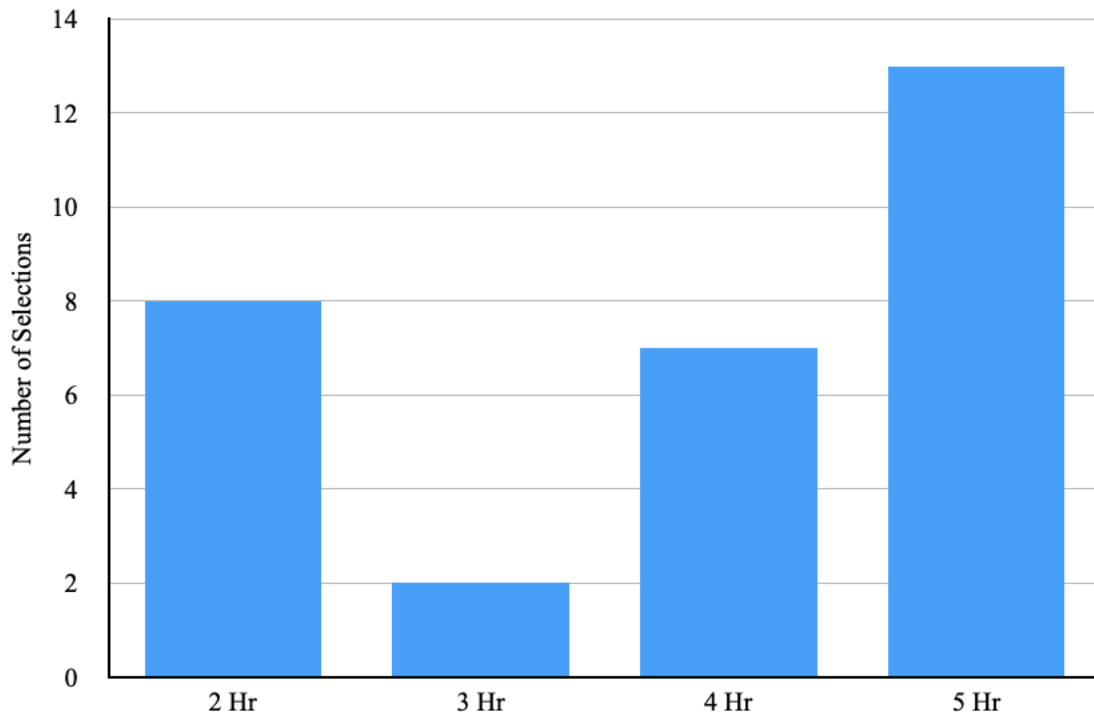


Figure 2: Number of times each level for dialysis duration was selected when the patient chose alternative treatment in the choice task. n=30

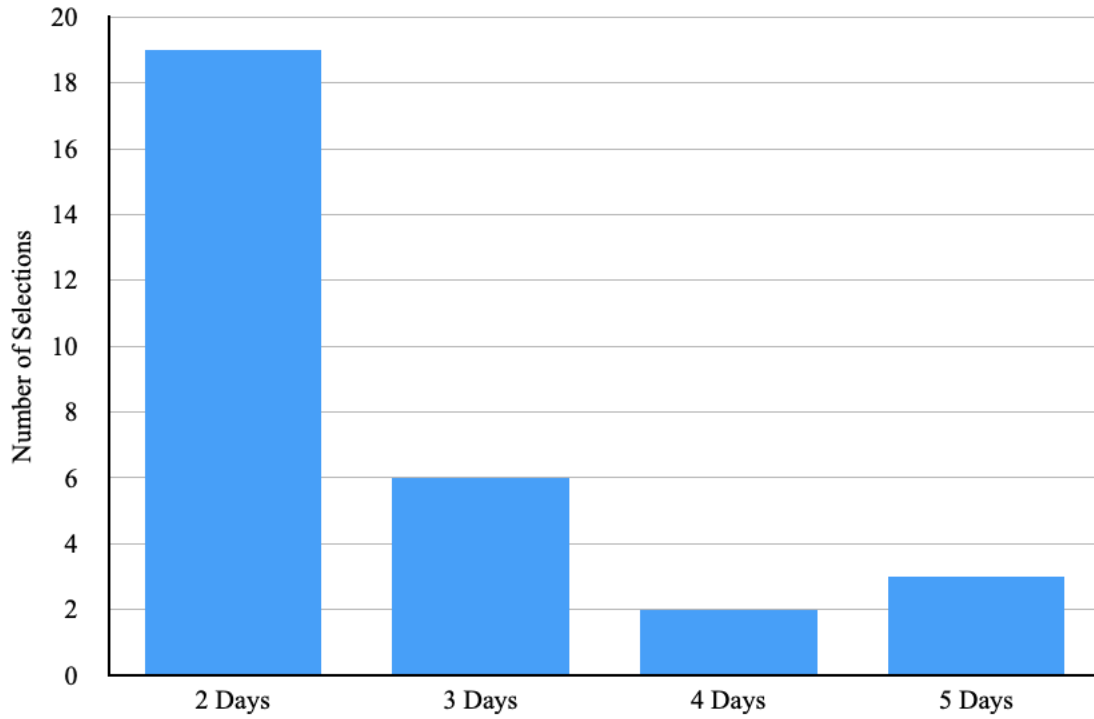


Figure 3: Number of times each level for dialysis intensity (# of days/ week) was selected when the patient chose alternative treatment in the choice task. n=30



## 4.0 Discussion

We present the results of a program of research designed to elicit and quantify patient preferences with respect to dialysis treatment, in persons with ESKD receiving in center dialysis. We identified four themes related to the impact of dialysis treatment on life style; time on dialysis, schedule, recovery post dialysis, and dietary and fluid restrictions. Preliminary data from our DCE suggest that fewer dialysis days each week with longer treatment duration to ensure dialysis adequacy are preferred by the majority participants who are willing to accept an alternative treatment from the conventional dialysis prescription of thrice weekly four hour sessions, that participants prefer to choose dialysis days providing them with increased flexibility in their daily schedules, and that they are not willing to accept additional fluid restrictions or food restrictions. Although our DCE was underpowered to adequately assess these preferences in a representative population, we identified a number of important aspects to consider in future evaluation of dialysis treatments including patient selection, specifically ESKD vs. CKD patients, patient age, location, employment status, and level of independence.

The themes identified in the patient interviews confirm those identified in previous work. Time on dialysis has been consistently identified as a major factor in treatment burden.<sup>65</sup> A qualitative study found the themes “killing time” and “wasting time” which corresponded to the long periods of time on treatment and time waiting before and after treatment respectfully, which throws patients repeatedly into states of boredom.<sup>66</sup> We found that amount of time on dialysis was concerning to all study participants and our findings suggest that participants prefer to spend less time on dialysis each week. This would provide increased dialysis-free time, which has been found in other studies to be invaluable to dialysis patients.<sup>37,67-69</sup>

The impact of treatment on sense of wellbeing on non-dialysis time has also been identified as a concern for ESKD patients.<sup>9,37,69</sup> Evangelidis and colleagues found that feeling washed out after dialysis were of greater concern to dialysis patients than healthcare providers.<sup>69</sup> In a DCE by Walker and colleagues, wellbeing was an important attribute in the dialysis modality decision-making process.<sup>9</sup> Dialysis patients experience more time feeling ill compared to the general population. Almost all of the interviewed patients noted how they didn't feel good, were 'low on energy', or felt 'zoned out'. Furthermore, the burden of the disease strongly impacts dialysis patients ability to work and to socialize.<sup>70</sup> As a result, most in-centre dialysis patients find working incompatible with their illness and lack the energy to socialize, both of which further isolate them. These findings are consistent within tier one and two core findings of the SONG-HD study.<sup>37</sup> The kidney diet for dialysis patients is highly restrictive, eliminating many foods that would in other circumstances be described as healthy. This can be confusing and frustrating for many patients, one interviewee explained "your vegetables your tomatoes carrots, you can't even have too much of those" largely due to potassium being in many vegetables.<sup>34</sup> Interestingly, fluid restrictions appeared to be of less concern relative to food restrictions.

Lack of autonomy and treatment flexibility have also been identified as important aspects of treatment. Claudia and colleagues reported that 47% of HD patients perceived they had no choice in what treatment they received, and found that flexibility in daily schedule was a top theme of importance to dialysis patients.<sup>52</sup> Our findings support these results with many of our interviewed patients also saying that in-centre HD was not a choice but the only option. In a DCE study of HD patients in Australia, Tong and colleagues found that not only was home HD significantly preferred when greater schedule flexibility was probable, but that patients were willing to accept an additional cost for dialysis of \$151 USD/month in exchange for increased

flexibility.<sup>9</sup> Our findings were consistent with this study, as our data trended towards participants preferring more flexibility in their dialysis schedule, however, we did not assess if a similar trade-off of willingness to accept additional monthly financial cost of dialysis is present in our study sample as we did not ask about cost.

Our study suggests that a one size treatment approach does not fit all patients. These findings provides further support for individualized dialysis prescriptions that include the input of patient preferences when considering what should be included in defining dialysis adequacy. While the majority of participants were interested in fewer dialysis sessions each week with longer duration times, there was heterogeneity in the results indicative that some participants, albeit fewer, preferred more dialysis sessions that are shorter each week. This suggests that patient considerations for dialysis treatment prescriptions should include patient preferences such as flexibility of schedule, intensity, and duration of treatment. This information is valuable to clinicians who can use it as a guide in providing additional options when considering dialysis prescriptions with patients. Furthermore, healthcare system policy makers can incorporate this information when allocating resources into dialysis units by considering how to allow for more flexibility in scheduling treatment times.

This study was significantly limited by the public health restrictions in place due to the COVID-19 pandemic. One-on-one virtual interviews were sufficient to gather qualitative data, however, a certain depth of that data that would have been obtained from body language was missed. Additionally, focus groups would have been effective in providing a richer discussion. The small sample size of the DCE is a substantial weakness which prevented statistical significance in our findings as well as our ability to examine interaction effects, particularly from sociodemographic information. The public health restrictions in place due to the COVID-19

pandemic prevented large scale in-person surveys to be collected. While tablets have been found to be acceptable means of completing surveys in HD patients by Wong and colleagues, they had research assistants present to help their study participants with clarifying or explaining survey content, which was more likely to be required in people older than 70, and in people with lower health literacy.<sup>71</sup> Given this, and considering our survey target population, in-person surveys are preferred to complete the DCE survey. Also as a result of the COVID-19 pandemic, we expect there is a possible bias in the sample that was used for the DCE. As all ESKD and CKD participants surveyed were recruited at the University of Alberta Hospital, our sample is not representative of the Northern Alberta Renal Program patient population. We also wondered if some patients were at dialysis less frequently than they otherwise would have been to minimize their contact with other people to prevent potential infection from COVID-19.

Other limitations with respect to the DCE survey methods and design are worth discussion. While the stated preference provided by a DCE is a strong tool, it still falls short of what the actual choice of participants would be given a real decision. We also were compelled to incorporate design restrictions to ensure clinically realistic combinations that allow for correlation of the attributes. The results of which taken alone, make interpretation of the data challenging, i.e., do patients prefer fewer days of dialysis treatment per week or longer duration of dialysis session. Although, in context of the literature and our interview data we can assume that dialysis-free time is a factor in the decision making process, therefore the decision is likely based on both attributes maximize dialysis-free time while achieving adequate dialysis. Additionally, we also must entertain the unobservable random component of the RUM and recognise that the participants may have been making their stated preference based on information that we did not present to them and do not know.

With respect to survey dissemination, we suspect that mailed surveys may be of lesser quality than that of surveys completed with the assistance of the PI, we also expected there to be a difference in the responses to the survey between ESKD and CKD participants. In example, both CKD participants completed the DCE questionnaire but only one completed the DCE survey. The CKD patient who did not complete the survey made a note on the page stating they could not complete the survey because they were not using dialysis. If they had been assisted by the PI it would have been explained to them that they can still have a preference on dialysis treatment, which would provide valuable information for what CKD preferences are before dialysis commences given that it may possibly change based on the experience of using dialysis when that occurred. We also wondered if there was a cognitive burden that was dampened with the presence of the PI for participants who had assistance with completing the DCE survey compared to those who completed the survey independently. However in both cases we lack sufficient power to assess these differences with certainty. As such, moving forward we would consider not using mail as a method of survey dissemination and will recruit more CKD participants.

Future work will be done to increase the number of people surveyed from a greater number of dialysis units and CKD clinics including rural and regional locations which will provide more generalizable statistically significant results. We will collect postal codes to ensure a representative sample from both urban and rural communities. We will also alter questions in the DCE survey to be more clear, as well as rewording some of the attributes to be more familiar to participants. Specifically, we will frame the post dialysis recovery attribute to be more suggestive of feeling fatigue after dialysis. The attributes intensity and duration will be combined

to avoid correlating results, and the levels will be carefully selected to provide possible combinations to assess the heterogeneity in the findings of the intensity and duration attributes.

## **5.0 Conclusion**

Inclusion of patient preferences concerning dialysis treatment prescriptions should be more thoroughly considered when making treatment decisions. This individualization of prescriptions should specifically aim to minimize fluid and food restrictions, while increasing schedule flexibility. These changes could be managed by altering dialysis duration and the number of treatments each week to suite specific patient preferences while balancing dialysis requirements. This approach is likely to benefit the health care system, patients, and providers by potentially decreasing costs to the system, incorporating patient preferences, and providing additional prescription options for health care providers to offer dialysis patients. This research highlights the need for increased patient preference consultation in dialysis prescriptions, and provides a foundation to continue quantifying patient preferences with respect to in-centre HD, as there is a range of patient preferences that deviate from the traditional HD prescription.

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## 7.0 Appendix

### Appendix: Interview Guide

Ask informant to sign consent form and fill out demographic questionnaire. Explain consent form.

My name is \_\_\_\_\_. I'm a researcher from the University of Alberta.

We wanted to interview you because of your experience with hemodialysis. Please think about both positive experiences and challenges with dialysis. We would like to understand what guides your everyday decisions with respect to the type of treatment you have chosen, as well as what you value and consider important when making those decisions.

If it's ok, we're going to record this interview so we don't miss anything. \_\_\_\_\_ is here as well to take some notes for us in case something happens with the recorder.

All your responses will be kept confidential. And any identifying information will be removed before we analyze what you tell us.

Your participation today is completely voluntary, which means you can stop the interview at any point or to decline to answer any questions. What you say will not impact the level or type of care you receive.

I'll be asking you about a couple of things today: your current experiences with hemodialysis, both positive and any challenges; and your values and opinions on what is important to you when making health care decisions.

#### **Lets start with your treatment.**

1. Why did you choose the treatment option that you did?
  - a. What do you think the benefits were to this?
  - b. What are the disadvantages or risks?
  - c. Did you feel like you had a choice - why?
  - d. What other treatment options are you aware of?
    - i. What prevented you from other treatment options?

#### **We are now going to ask you about Quality of Life.**

1. What is important to you in terms of quality of life?
2. Describe how your daily schedule has been changed as a result of your treatment?
3. How has your treatment affected your independence?
4. How has your treatment changed your social support?
  - Do you feel like you need more support? How do you think that could be improved?
  - How has it affected your current relationships, family, partners, etc.?
  - How has dialysis altered how you feel you fit into society?

- Do you feel socially excluded, not normal, always in a ‘sick’ role, etc.? What are some ways that we could implement that would help you fit in better?
  - Social gatherings are often focused around eating and drinking. How does this impact your decisions on attending these types of gatherings?
    - If another treatment was available that allowed more flexibility in your diet, for example allowed you to drink an additional 500 mL per day, to what extent would you pursue it?
5. What is important to you in terms of life expectancy?
    - If you switched treatments, would life expectancy affect which treatment you choose?
    - Consider this hypothetical scenario: A new dialysis treatment is offered to you but it means you will give up 20% of the amount of life that you would like to have left. For example, if you wanted to live for another 10 years, the new treatment would mean you only live for 8 more years. The benefit is you have a significantly better quality of life. If you could choose 2 factors that would increase your quality of life, what would they be and why?
      - How would your answer change if it was 30%?
      - How would your answer change if it was 3 factors that you could choose to increase your quality of life?
  6. Is travelling important to you to see family, for work, or to go on vacations? Explain how dialysis has impacted this.
    - Probe if important: to what extent are you willing to travel while still dialyzing?
  7. How has treatment affected your ability to work?
    - Is having a job an important part of your identity, explain why?
    - Do you/would you tell your coworkers about dialysis? Why?
    - How have you been treated differently because you are dialysis patient?
  8. What would you say is the most expensive part of your treatment?
    - How concerned are you about your financial situation?
    - If you could make a change to decrease the cost while still receiving treatment, where would that change take place?
  9. How has your mental health been affected?
    - Do you think that your mental health is sufficiently addressed?
    - Who do you consider to be in your circle of support for mental health?
  10. How concerned are you about the way you look, or the way others see you?
    - How important is body image to you when choosing a treatment method?
  11. Has dialysis impacted your religious expression? Can you explain that more?
  12. How have your recreational activities changed as a result of your dialysis?
    - Was that something you were concerned about when you started treatment?
    - Has that changed now that you have been dialyzing for as long as you have been?
  13. What has been the most positive thing you have experienced as a result of dialysis?

When we're done, we're going to create a short 1 or 2 page report highlighting some of our findings. You'll have the opportunity to comment on it as well if you wish. Would you like to receive a copy? What would be the best way to get that to you?

Thank you

## Appendix: Interview Questionnaire

### Participant Questionnaire: Person with kidney disease

#### A. Clinical Characteristics

1. Approximately how long have you been receiving kidney care?  
\_\_\_\_ years and \_\_\_\_ months
  
2. What was your approximate age at the time of diagnosis of kidney disease?  
\_\_\_\_\_
  
3. What was your approximate age when you started hemodialysis?  
\_\_\_\_\_
  
4. What is your hemodialysis access?  
 Fistula                       Graft                       Central venous catheter
  
5. What type of hemodialysis do you currently receive?  
 In-centre               Home
  
6. What is the approximate duration of your current type of dialysis?  
\_\_\_\_ years and \_\_\_\_ months
  
  
  
  
  
  
  
  
  
  
7. What type of kidney replacement treatment(s) did you receive prior to your current type of treatment (please select all that apply)?  
 In-centre hemodialysis                       Transplant from a living donor



- Home hemodialysis
- Peritoneal dialysis
- Transplant from the waiting list
- No previous kidney replacement therapy

8. If you receive in-centre hemodialysis, approximate one-way travel time to dialysis centre: \_\_\_\_\_

9. How do you get to dialysis in-centre?

- DATS
- Drive yourself
- Receive a ride
- LRT/Bus
- Other: \_\_\_\_\_

10. How many times a week do you dialyse?

\_\_\_\_\_ days a week

11. How often do you come off earlier than your prescribed dialysis treatment in a month?

12. On average, how many hours of hemodialysis do you receive in each session?

\_\_\_\_\_ hours

13. Generally, when is your hemodialysis session (please check one option only)?

- Morning
- Afternoon
- Evening
- Night

14. Please circle your preferred session time. (please check one option only)?

- Morning
- Afternoon
- Evening
- Night

15. Do you have any other health issues?

- Diabetes
- Cancer
- Cardiovascular (Heart) Disease
- Asthma
- Lupus
- High Blood Pressure
- Mobility Issues
- Other: \_\_\_\_\_

16. Your employment status:

- Full-time
- Part-time or casual
- Student
- Disabled
- Not employed
- Retired
- Other: \_\_\_\_\_

17. Do you have someone at home who helps you manage your health conditions?

- No
- Yes

- If yes, relationship to you:
- Spouse/partner
  - Parent
  - Child
  - Other: \_\_\_\_\_

18. Year of birth: \_\_\_\_\_

19. Your gender:
- Male
  - Female
  - Other: \_\_\_\_\_

## B. Quality of Life Characteristics

The following items ask about how much your illness and/or its treatment interfere with different aspects of your life. PLEASE CIRCLE THE ONE NUMBER THAT BEST

DESCRIBES YOUR CURRENT LIFE SITUATION. If an item is not applicable, please circle the number one (1) to indicate that this aspect of your life is not affected very much. Please do not leave any item unanswered. Thank you.

How much does your illness and/or its treatment interfere with your:

Health

Not Very Much    1    2    3    4    5    6    7    Very Much

Diet

Not Very Much    1    2    3    4    5    6    7    Very Much

Work

Not Very Much    1    2    3    4    5    6    7    Very Much

Active Recreation (participating in sports, hiking, cycling, etc.)

Not Very Much    1    2    3    4    5    6    7    Very Much

Passive Recreation (reading, listening to music, going to movies, etc.)

Not Very Much    1    2    3    4    5    6    7    Very Much

Financial Situation

Not Very Much    1    2    3    4    5    6    7    Very Much

Relationship With your Spouse

Not Very Much    1    2    3    4    5    6    7    Very Much

Sex Life

Not Very Much    1    2    3    4    5    6    7    Very Much

Family Relations

Not Very Much    1    2    3    4    5    6    7    Very Much

Other Social Relations

Not Very Much    1    2    3    4    5    6    7    Very Much

Self-Expression/Self-Improvement

Not Very Much    1    2    3    4    5    6    7    Very Much

Religious Expression

Not Very Much    1    2    3    4    5    6    7    Very Much

Community and Civic Involvement

Not Very Much    1    2    3    4    5    6    7    Very Much

***Thank you!!***

*Please return completed questionnaire to your facilitator*

## Appendix: DCE Pre-Survey Questionnaire

### Pre-Survey Questionnaire

Before you begin the survey, we want to ask you a few questions about your current kidney care.

1. Are you currently using hemodialysis as your main source of dialysis?  
 Yes  
 No (if no please go to question 4)
  
2. (If yes to Question 1) Approximately when did you start dialysis? \_\_\_\_\_
  
3. (If yes to Question 1) If you had the choice, would you make any changes to your dialysis treatment plan such as duration, location, lifestyle restrictions, etc.?  
 Yes  
 No
  
4. (If no to Question 1) Approximately when did you start receiving kidney care?  
\_\_\_\_\_
  
5. How long does it take you to travel one-way to the dialysis centre or kidney care clinic: \_\_\_\_\_
  
6. How do you get to dialysis or kidney care clinic?  
 Accessible Public Transit       Drive yourself       Receive a ride  
 Standard Public Transit       Other

## Appendix: DCE Post-Survey Questionnaire

### Post-Survey Questionnaire

1. What is your age? \_\_\_\_\_ years
  
2. Do you have any other health issues?
  - Diabetes
  - Cancer
  - Cardiovascular (Heart) Disease
  - Asthma
  - Lupus
  - High Blood Pressure
  - Mobility Issues
  - Other predisposed kidney disease
  - Other
  
3. Your employment status:
  - Full-time
  - Part-time or casual
  - Student
  - On Disability Leave
  - Not employed
  - Retired
  - Other
  - Prefer not to say
  
4. Is there someone who helps you manage your health?
  - No
  - YesIf yes, relationship to you:
  - Spouse/partner
  - Parent
  - Child
  - Extended Family Member
  - Friend
  - Assisted Living Staff
  - Other
  
5. Select one of the following in response to the following:  
I am in the best health of my life
  - Strongly Disagree
  - Disagree
  - Neutral
  - Agree
  - Strongly Agree
  
6. Your gender:
  - Male
  - Female
  - Non-binary
  - Other

## Appendix: Interview Themes

**Table 1: Interview themes, categories, and codes**

Themes	Examples of Categories	Examples of Codes
Post Dialysis Recovery	feelings after dialysis	fatigue, flu-like, tired, zoned out, achy, not myself, needs distraction to cope,
Schedule	rigid, in-flexible, 3x/week	someone else's, trapped, want to change, not ideal
Time on Dialysis	hours, minutes	ruins the day, time to travel, waiting rooms, setting up machine, 4 hours,
Food/Fluids	eating, drinking	more fluid freedom, can't have my favourite foods, thirsty, potassium
Social Support	other people	people don't understand, isolated, hard to participate
Healthcare Workers	nurses	lacking consistency, some good, some bad, techniques vary, seem afraid to ask each other for help
Mental Health	crying, emotional	Need follow up on questionnaires, more psychological support, mandatory classes
Limited Resources	cost	can't do home hemo, parking, traveling, lost income from less working or forced early retirement
Quality vs Quantity of Life	years of life	would trade years of current lived experience for a life with better quality

## Appendix: List of Attributes and Levels

### List of Characteristics and Associated Levels

#### Dialysis Schedule

Levels to choose from:

Dialysis days are assigned

Dialysis days are chosen

#### Duration of Treatment

Levels to choose from:

2 - 5 Hours per session

#### Intensity of Treatment (number of dialysis sessions each week)

Levels to choose from:

2 - 5 Days a week

**Fluid Management:** For many people dialysis treatment is the primary way to remove water from the body. If dialysis treatment is reduced this means that patients may have to restrict their fluid intake, and/or take medications to increase urine output.

Levels to choose from:

Fluid managed by dialysis as usual.

Additional fluid restrictions and oral medications.

**Food Consumption:** Dialysis treatment removes salt, potassium and phosphate. However, many people starting dialysis may still have some urine output which may allow them to dialyze less. Those that choose shorter or less frequent dialysis may have to restrict consumption of foods containing potassium, sodium, and phosphate, or use more medication to control them.

Levels to choose from:

Usual renal diet

Restricted renal diet and use of medications to control potassium/phosphate.

**Post Dialysis Recovery Period:** The period of time after dialysis during which people often feel nausea, tiredness, and generally feel sick. This period of time is unique to each person, but can be altered by adjusting length of treatment and filtration rate.

Levels to choose from:

Current/normal recovery time

25% shorter than your current/normal time



## Appendix: Qualitative Data Table 1

Table 1: Qualitative Study General Demographic Data

Patient	Age	Gender	Years of Kidney Care Received	Age at Diagnosis of Kidney Disease	Age at HD Initiation	One-way Travel to HD (min)	Method of Transport	Employment Status	Who Helps Manage Health at Home
1	60	Male	2	57	59	30	Drives self	Other	Spouse
2	81	Female	10	70	75	20	DATS	Retired	N/A
3	70	Female	9	61	61	10	Receives a ride	Retired Not employed	Spouse
4	49	Female	2	23	23	45	Receives a ride	employed	Brother
5	39	Male	4	34	34	10	Transit	Casual	N/A
6	72	Male	15	57	67	25	DATS	Retired	Spouse
7	64	Female	34	28	28	15	Receives a ride	Disability leave	N/A
8	67	Male	10	57	64	10	Drives self	Retired	Spouse

## Appendix: Qualitative Data Table 2

Table 2: Qualitative Study Patient Current HD Information

Patient	Access	Type	Duration of HD (years)	Number of HD Sessions per Week	HD Session Duration	HD Session Time of Day	Preferred HD Session Time of Day	How Often Patient Comes Off Treatment Early per Month	Previous HD Modalities
1	fistula	in-centre	0.25	3	4	afternoon	not known	rarely	none
2	central venous catheter	in-centre	6	3	4	morning	morning	rarely	PD
3	central venous catheter	in-centre	9	3	4	morning	morning	less than once	none
4	central venous catheter	in-centre	2	3	4	morning	morning	3-4 times	PD, living donor Tx
5	fistula	in-centre	4	3	3.5	morning	morning	rarely	PD
6	Graft	in-centre	5	4	4	morning	morning	never	none
7	central venous catheter	in-centre	6	3	4	morning	morning	1	PD, deceased donor Tx
8	fistula	in-centre	1	3	4	morning	morning	never	living donor Tx

### Appendix: Qualitative Data Table 3

Table 3: Qualitative Study Self-reported percent of patients who have other health problems. n=19

<b>Patient</b>	<b>Diabetes</b>	<b>Cancer</b>	<b>CVD</b>	<b>Asthma</b>	<b>Lupus</b>	<b>High Blood Pressure</b>	<b>Mobility Issues</b>	<b>Other</b>
<b>Overall</b>	63%	25%	50%	0%	0%	63%	75%	50%

### Appendix: Qualitative Data Table 4

Table 4: Qualitative Study IIRS. Scored 1-7 with 1 least and 7 most impacted by dialysis.

<b>Patient</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>Health</b>	4	1	7	6	5	7	4	7
<b>Diet</b>	2	7	5	6	2	5	2	7
<b>Work</b>	5	1	7	6	5	1	4	7
<b>Active Recreation</b>	5	1	7	7	5	7	4	6
<b>Passive Recreation</b>	1	1	4	2	1	1	1	3
<b>Financial Situation</b>	4	1	6	7	5	1	3	4
<b>Relationship with Spouse</b>	1	1	7	2	4	3	7	2
<b>Sex Life</b>	4	1	7	5	3	6	7	6
<b>Family Relations</b>	1	1	3	1	1	1	2	5
<b>Other Social Relations</b>	3	1	4	1	2	2	2	5
<b>Self-Expression/Self-Improvement</b>	4	1	6	2	3	7	2	7
<b>Religious Expression</b>	1	1	4	1	1	1	2	3
<b>Community &amp; Civic Involvement</b>	2	7	6	1	1	7	4	6
<b>Total Score</b>	37	25	73	47	38	49	44	68

## Appendix: DCE Table 1

Table 1: DCE Study median and ranges of patient characteristics who chose only conventional treatment vs. those who made at least one alternative choice.

Patient Characteristics	Conventional Treatment Only n=12		Alternative Treatment n=10		Overall n=22	
	Median	Range	Median	Range	Median	Range
Age (Years)	63.5	33-81	57	38 - 78	61	33-81
Months of Dialysis	10.5	3-108	19.5	10-360	12	3-360
CKD Years of Kidney Care Received (Months)	13	5--21	204	9-399	15	5-399
Age at Diagnosis of Kidney Disease (Years)	57	23-70	57	23-70	57	23-70
One-way Travel to HD (min)	30	15-60	32.5	7.5-60	30	7.5-60

## Appendix: DCE Table 2

Table 2: DCE Study percentages of patient characteristics who chose only conventional treatment vs. those who made at least one alternative choice.

<b>Patient Characteristics</b>	<b>Alternative n=8</b>	<b>Conventional n=12</b>	<b>Overall n=20</b>
<b>Male (%)</b>	71	75	64
<b>Drives Self to Clinic (%)</b>	75	25	45
<b>Retired (%)</b>	50	67	55
<b>Someone Helps Manage Health at Home (%)</b>	50	75	45

## Appendix: DCE Table 3

Table 3: DCE pilot study Self-reported percent of patients who have other health problems. n=19

<b>Patient Treatment Group</b>	<b>Diabetes</b>	<b>Cancer</b>	<b>CVD</b>	<b>Asthma</b>	<b>Lupus</b>	<b>High Blood Pressure</b>	<b>Mobility Issues</b>	<b>Other</b>
<b>Overall</b>	47%	11%	21%	0%	0%	63%	26%	21%
<b>Conventional</b>	45%	18%	27%	0%	0%	64%	18%	9%
<b>Alternative</b>	43%	0%	14%	0%	0%	71%	43%	43%