Title

From Referral to the Evaluation: A Narrative Study on Factors Associated with Patients “Lost to Follow-up” in Kidney Transplant

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From Referral to the Evaluation: A Narrative Study on Factors Associated with Patients “Lost to Follow-up” in Kidney Transplant

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Nursing

by

Jill Kathleen Scherrey

2023

ABSTRACT OF THE DISSERTATION

From Referral to the Evaluation: A Narrative Study on Factors Associated with Patients “Lost to Follow-up” in Kidney Transplant

by

Jill Kathleen Scherrey
Doctor of Philosophy in Nursing
University of California, Los Angeles, 2023
Professor Carol L. Pavlish, Chair

Many patients diagnosed with kidney failure and referred for kidney transplant do not proceed towards medical evaluation for transplant and are considered “Lost to Follow-Up.” The reasons patients do not pursue kidney transplant are not well understood by providers and kidney transplant centers. To expand and deepen understanding about the “Lost to Follow-Up” population, this study sought to explore the lived experiences of patients who are referred for renal transplant but do not initiate or complete transplant evaluation. The goal was to listen to their stories about living with life-threatening kidney disease, their perspectives about the referral process, and their considerations about renal failure treatments.

Using the Narrative Inquiry method of qualitative research, the PI conducted semi-structured phone interviews with ten patients labeled “Lost to Follow-Up” by their kidney transplant center. Interviews were digitally recorded and immediately transcribed for analysis. Multi-level coding was performed and the themes that emerged included a metanarrative entitled “The Struggling Self” and four themes that appear to describe the “Lost to Follow-up” patient designation. The themes reveal that participants (1) wanted meaningful information, (2) experienced both internal and external barriers as they put off the kidney transplant referral, (3) needed improved provider communication, and (4) needed help to shoulder the burden of renal failure and subsequent treatment. The study findings revealed that patients do not see themselves as “Lost to Follow-Up” but rather as “nowhere”, “prisoners”, “trapped”, “stuck”, “scarred”, “on-hold”, “not worth it”, “wrecked”, “complicated”, “home alone” and “pretty happy”.

The study findings reveal opportunities for provider actions that align with the four thematic categories including (1) increase upstream screening and early, meaningful patient education and engagement regarding kidney health; (2) enhance provider communication training; (3) perform ongoing patient assessment for internal and external barriers to follow-up and (4) align care with patient goals and consider the utilization of conservative care as a treatment option in kidney disease.

The dissertation of Jill Kathleen Scherrey is approved.

Felicia S. Hodge

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2023

DEDICATION PAGE

To my husband John for his tireless support, love and understanding, and my son Vincent for believing in his mom.

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ABBREVIATIONS

AA, African American

AVF, Arterial Venous Fistula

CKD, Chronic Kidney Disease

CFKTC, Connie Frank Kidney Transplant Center

CVC, Central Venous Catheter

DDKT, Deceased Donor Kidney Transplant

ESRD, End Stage Renal Disease

HD, Hemodialysis

KF, Kidney Failure

KT, Kidney Transplant

KTC, Kidney Transplant Center

LDKT, Living Donor Kidney Transplant

PD, Peritoneal Dialysis

PKD, Polycystic Kidney Disease

SES, Socio Economic Status

SOC, Standard of Care

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Thank you to Calder Foundation for granting me permission to share images of the Calder mobile.

Curriculum Vitae

Education

2018-2023, PhD. candidate in Nursing, University of California Los Angeles, School of Nursing
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Teaching Experience (selected most recent)

2014-2020: UCLA Health Patient Education Annual Symposium planner and facilitator
2018-2020: Optimizing Patient Education for Renal Transplant Coordinators Content expert and presenter
2017-2020: Patient engagement & education co-facilitator of quarterly system champion meetings, 2016-2020: Simulation instructor for clinical new hires and Nurse Residents
2015-2020: Preceptor Development: Learning styles, Adult Learning Theory, teach back, content expert and presenter

Education Related Activities (selected recent activities)

2020-2022: COVID-19 related patient education development and dissemination
2019-2022: Consultant and patient education lead developer Oncology, Hodgkin, and Non-Hodgkin lymphoma content
2018-2021: Consultant and patient education subject matter expert on Renal Transplant Patient Education Restructure initiative
2016-2022: Lead planner, content expert and presenter at the annual UCLA Patient Education Symposium

Leadership Experience (selected recent activities)

2020-2022: Lead, UCLA Health Cancer Care Patient Education Development Project
2020-2022: Founder and Chair of Consumer/Patient Education Development Team, UCLA Center for Nursing Excellence
2019-2022: Co-Chair Patient Education Interprofessional Workgroup, UCLA Health
2016-2018: Lead planner Nurses Week and Nursing Awards Ceremony, UCLA Health

CHAPTER ONE: INTRODUCTION

Background

For patients suffering with kidney failure, choosing a course of treatment can be fraught with challenges. Obtaining a kidney transplant (KT) continues to be considered the standard of care for End Stage Renal Disease (ESRD) but achieving that outcome can be an overwhelming journey for many patients. Typically, the journey begins with a referral made by a primary MD or nephrologist to a kidney transplant center (KTC) closest in proximity to where the patient resides. Once referred to a KTC the patient must successfully complete the evaluation process to determine eligibility for KT before becoming waitlisted, which is a required step on the journey to KT. The evaluation process may take up to a year to complete, depending on the KTC's requirements, and the patient's underlying health conditions. Only a "successfully" evaluated patient will be placed on the KT waitlist.

The "waitlist" is a list of eligible KT candidates, used by the Organ Procurement and Transplant Network (OPTN) to track and distribute deceased donor kidneys to patients nearest to the top of the list. For an ESRD patient, becoming waitlisted demonstrates one's current eligibility to receive a Deceased Donor Kidney Transplant (DDKT), however, a change in health status such as an infection can cause a waitlisted patient to be removed from the list until they are cleared by the KTC. For patients initially waitlisted in 2013, the median wait-time for KT was 49.2 months (United States Renal Data Service, [USRDS] 2021). The average number of months waiting for a KT for Whites is 37.3; Hispanic 56.5; Asian 57.7; Native Hawaiian/ Pacific Islander 62.4; Blacks 63.8; Native American 65.1 (USRDS, 2021). Wait times are also affected by the patient's blood type, antibody status, overall health, and deceased donor kidneys availability in the geographic region (USRDS, 2022). Blood Type O kidneys are universally accepted by all other blood types, commonly causing ESRD patients with O+ blood type longer wait times, averaging 89 months on the KT waitlist (Glander et al., 2010). At the end of 2020, 75,747 ESRD patients in the U.S. were waitlisted and therefore, waiting for a kidney to become available for transplant (USRDS, 2022).

Disease Burden

Each year, kidney failure (KF), also known as ESRD, affects 786,000 people and takes the lives of 45,000 in the U.S. alone (Centers for Disease Control and Prevention, 2022). While the adjusted all-cause mortality among ESRD patients dropped 13% over 2010-2019 per thousand person years, it rose sharply in 2019-2020 due to the pandemic (USRDS, 2022). The incidence of chronic kidney disease (CKD) and ESRD continue to rise around the globe, and in the U.S., by as much as 7% annually with 38.3% of kidney failure attributed to diabetes in 2020, up from 29.7 % in 2010 (Lentine et al., 2022; National Kidney Foundation, 2021; USRDS, 2022). Kidney failure attributable to hypertension was lower in 2020 at 20.9%, down from 25.4% in 2010 (Lentine et al., 2022).

Kidney failure, diagnosed by measuring an individual’s kidney function, correlates to the kidney’s ability to filter waste from the body’s blood. The rate at which the kidneys filter the blood is defined as the Glomerular Filtration Rate (GFR). The GFR is the measure of how efficiently the kidney’s glomeruli filter waste from the blood each minute. There are five stages of CKD, which are based on the GFR (Table 1). When kidney function drops to a GFR of 15% or less the patient is diagnosed as having ESRD or KF, and renal replacement treatment, dialysis and/or KT, is strongly advised to reduce the risk of dying (CDC, 2022).

Table 1: Stage of ESRD and percentage of kidney function

CKD/ESRD Stage	Description of kidney function	Glomerular Filtration Rate (GFR)	Percentage of kidney function
Stage 1	Kidney damage with normal kidney function	90%	90-100%
Stage 2	Kidney damage with mild loss of kidney function	89-60%	89-60%
Stage 3a	Mild to moderate loss of kidney function	59-45%	59-45%
Stage 3b	Moderate to severe loss of kidney function	44-30%	44-30%
Stage 4	Severe loss of kidney function	29-15%	29-15%
Stage 5	Kidney failure	<15%	<15%

Hemodialysis offers a five-year survival rate of just 35% while KT offers patients a five-year survival rate of 78% and 88% for deceased donor and living donor transplants respectively (USRDS, 2022). Not only does KT have better five-year survival rates than dialysis, KT also offers patients a better quality of life than dialysis and costs less than dialysis treatment (National Kidney Foundation, 2022). Since 1972, Medicare has covered the cost of dialysis and kidney transplantation for those in the U.S. with irreversible kidney failure (Nissenson & Rettig, 1999).

In 2020, the average Medicare expenditure for one individual on hemodialysis was $95,932 for 12 months of treatment. That same year the cost of kidney transplant surgery was $39,264 and the annual cost of anti-rejection medication required post-transplant was approximately $25,000 per person (Axelrod et al., 2018; USRDS, 2022). Excluding the year of surgery, KT as treatment for ESRD, yields an annual cost savings to Medicare of approximately $70,000 per patient per year when compared to dialysis (Axelrod et al., 2018; USRDS, 2022). Since the 1970s KT has been considered the gold standard in the treatment of KF.

Economic and Ethnic Disparities in Kidney Transplant

Renal disease in the U.S. disproportionately affects people of color and those of lower socio-economic status (Browne et al., 2016; Rodrigue et al., 2012; USRDS, 2022; Waterman et al., 2012). African Americans are three times more likely, and Hispanics are twice as likely as Caucasians to be diagnosed with ESRD and are less likely to receive a kidney transplant (CDC, 2019; HHS, 2018; Saran et al., 2018; USRDS, 2022). These well documented disparities in kidney transplant are thought to stem in part from a lack of information about kidney disease and transplant (Saran et al., 2018; Waterman et al., 2013), as well as medical mistrust and fear of kidney transplant surgery (Wachterman, McCarthy & Marcantonio, 2018). Regardless of ethnicity, patients of lower socioeconomic status are less likely to obtain a Deceased Donor KT (DDKT) or a Living Donor KT (LDKT) with women receiving fewer transplants than men overall

(Axelrod et al., 2010; USRDS, 2022). In 2021, of the 22,669 kidney transplants in the U.S. Whites/non-Hispanics received 42.1% of all KTs and 62.1% of the LDKTs; Blacks received 28.7% of all KTs and 13% of LDKTs; Hispanic/Latino received 20.1% of all KTs and 17.1% of LDKTs; Asians received 7.1 % of all KTs and 6.2% of LDKTs; American Indian/Alaskan Natives received 0.7% of all KTs and 0.6% of LDKTs; and Pacific Islander 0.5% of KTs and Multiracial 0.8% of KTs and 02% of LDKTs. Men received 61.1% of all KTs and 62.7% of LDKTs, and women received 38.9% of all KTs and 37.3% of LDKTs (OPTN, 2021).

National Goals

The Department of Health and Human Services (HHS) OPTN has ongoing goals to increase the number of kidney transplants performed each year, improve transplant outcomes, and improve communication and education geared towards reducing barriers to living donation (HHS, 2019). The Healthy People 2020 and 2030 goals also include reducing kidney transplant wait times (HHS, 2020). A 2019 U.S. Executive Order on Advancing American Kidney Health outlined a national strategy to improve the health of ESRD patients, including a plan to reduce financial barriers to living kidney donation (HHS, 2019). The U.S. goals demonstrate the focus and direction the nation has promoted regarding KT and those goals include removing the barriers patients face in obtaining a KT (HHS, 2020).

Research Problem

For many patients, obtaining a referral to a Kidney Transplant Center (KTC) does not ensure a spot on the KT waitlist. One significant barrier in obtaining a kidney transplant is a lack of knowledge about ESRD and renal replacement treatment options (Cooper et al., 2019; Rodrigue, 2008; Waterman et al., 2015). Patients with modifiable risk characteristics, such as a lack of knowledge about the disease and treatment options, are less likely to successfully complete transplant evaluation than those who are fully informed and engaged in the transplant evaluation process (Brown et al., 2016; Kazley et al., 2012; Waterman et al., 2013). Providing comprehensive information about ESRD treatment options to dialysis patients has been shown to increase the number of patients starting and completing the transplant evaluation for kidney transplant (Rodrigue, 2008; Waterman et al., 2015). Engaging and educating patients about renal replacement treatment options can increase knowledge and self-efficacy which has been shown to help patients complete the steps needed to obtain a transplant (Boulware et al., 2013; Rodrigue, 2008; Waterman et al., 2015).

Early exposure to educational content and discussions about renal replacement treatments increases a patient’s awareness of their options including the pursuit of LDKT (Brown et al., 2016; Kazley et al., 2012; Vilme et al., 2018). However, some of the key barriers include a lack of effective standardized patient education processes, lack of dialysis staff accountability in engaging patients in education, and failure to account for patient’s literacy and numeracy levels at dialysis centers. (Boulware et al., 2013; Moodley et al., 2021; Rodrigue, 2015; Waterman et al., 2015; Venkataraman & Kendrick, 2020).

While knowledge about renal replacement treatment options has been shown to increase the number of kidney transplants performed among ESRD patients, knowledge alone is not always enough. For reasons including medical, psychological, and social barriers, many patients referred to a KTC for transplant do not complete the evaluation process and therefore cannot proceed to transplant. Non-modifiable risk factors such as medical conditions including cancer within the last five years and uncontrolled diabetes or hypertension, which are the number one and two causes of kidney failure in the U.S. (CDC, 2022) are common medical disqualifiers to KT.

Barriers to becoming waitlisted can also stem from the burden the evaluation process places on the individual and their support system. Frequent doctor visits, transportation, childcare, elder care, required weight loss, diabetes management, and a willing caregiver to help with care for months after KT surgery are some barriers many patients cannot overcome

(Brown et al., 2016; Sullivan et al., 2012). To better understand the derailers that patients in the Los Angeles region experience, this study focused on patients 'perspectives of the KT evaluation process and the psychological, social, and medical barriers to kidney transplant.

Much of the research regarding KT has identified the need for improved patient knowledge and social support regarding ESRD treatment and the journey to KT (Axelrod, Waterman, Browne et al., 2021). What is lacking in the literature is a clear understanding of how patients experience the KT referral and evaluation processes and the factors that are considered and matter to patients during the treatment decision making process.

In 2020, of the 954 patients referred for KT to the Connie Frank Kidney Transplant Center (CFKTC) at the University of California, Los Angeles (UCLA), Medical Center only 350 or 36% successfully completed the evaluation process and advanced to the KT waitlist (M. Dunbar, personal communication, 2021). The evaluation process can be arduous for many patients. Co-morbidities, including a BMI > 35, a common disqualifier for KT, can feel like insurmountable barriers to completing the evaluation process. It is at the post-referral juncture in care that some patients withdraw from the process or are labeled “Lost to Follow Up” (M. Dunbar, personal communication, June 2021).

“ Lost to Follow-Up” Concept

The “Lost to Follow-Up” label or designation is not unique to kidney transplant and has been in use for decades among providers and health care institutions that consider a patient unreachable. The concept analysis of the label “Lost to Follow-Up” has been described by Ojukwa et al. (2021):

> The attributes of the concept [“Lost to Follow-Up”] include a clinical starter event suffered by a patient that requires ongoing evaluation by an event tracker at a given location and frequency. However, despite a mutual agreement between the patient and the event tracker, the evaluation suffers a hiatus due to several modifiable and nonmodifiable risk

factors (antecedents of the concept), consequences which might include morbidity and death. Early identification and intervention are critical to avoid the occurrence of being lost to follow-up, and nurses need to be cognizant of such knowledge.

This study explored patients' perspectives, insights, preferences, and feelings about the referral and evaluation processes, the barriers they encountered, and their decision-making process regarding renal replacement treatment (RRT), which includes dialysis and KT. The nurse scientist leading this study interviewed patients from the CFKTC who were considered "Lost to Follow Up" by the KTC.

A narrative approach was used to develop a deeper understanding about the patient experience leading up to the referral for KT, the referral process, considerations of KT options, and any barriers experienced during the evaluation process. Through this study, the study Principal Investigator (PI) learned what ESRD patients experienced, both positive and negative, as they approached and considered KT as treatment for their kidney disease.

Specific Aims

1. Explore the trajectory of kidney disease from the perspective of patients diagnosed with ESRD and referred to the kidney transplant center.
2. Examine patient perceptions of the treatment referral process and the available treatment options presented to them.
3. Describe factors affecting patient decision-making in the pursuit of renal transplant after being referred to a transplant center.

Implications for Nursing Practice and Future Research Direction

Nursing practice includes the task of caring for and educating patients about health conditions and treatment related topics. According to the Model of Professional Role, penned by Maria O'Rourke (1997), one distinct role of the registered nurse is referred to as "transferor of knowledge" or patient educator. This nursing role is commonly undervalued in the age of ever advancing technology and the medical model that dominates healthcare (Yiull, Crinson, & Duncan, 2010). However, patients continue to rely on the registered nurse to advise them and help make sense of healthcare information and instructions. Patient education can range from nutritional and physical-activity guidance and instruction; medication information; signs and symptoms to report, and any other health related topic. Among patients with kidney failure, the registered nurse as patient educator can help inform and motivate ESRD patients to seek a KT by providing meaningful and timely information and encouragement (Arriola et al., 2014). However, adult learning theory posits that adult learners are unique and there is no "one size fits all" approach to effectively engage and educate adult learners/patients about their health and healthcare needs (Knowles, 1978). Understanding how patients think, feel, and experience the KT referral and evaluation process can inform providers to better care for and meet the needs of ESRD patients throughout their health care journey, regardless of their treatment choice.

Through patient-centric studies, nursing science can better understand and contribute to the care of patients through enhanced patient education. By garnering understanding and knowledge about the needs and preferences of unique patient populations, nurses are positioned to create more impactful patient education content and deliver more patient-centered care. Additionally, understanding patient experiences including factors that affect treatment decision making early along the care continuum can benefit patients faced with difficult health decisions such as KT (Arriola et al., 2014).

Summary

Historically, barriers to KT have been strongly associated with ethnicity, gender, and socio-economic status (SES) (Axelrod et al., 2017; Kutner et al., 2012; Rodrigue et al., 2012; Waterman et al., 2015). African Americans (AA), women, and those of lower SES, are less likely to take the steps required to be considered for KT (Axelrod et al., 2017; OPTN 2019; Rodrigue et al., 2012; USRDS, 2019; Waterman et al., 2015). Patients who know the available treatment options when they begin the KT evaluation process are more likely to be successfully transplanted than patients who lack the knowledge needed or experience other barriers when faced with making an informed decision about ESRD treatment. How patients experience the KT referral and evaluation processes have not been well studied qualitatively, leaving healthcare providers unsure of the derailers patients experience in this portion of their KT journey. This study explored the stories of patients who did not complete the KT evaluation process after receiving a referral and did not make it to the KT waitlist. The goal was to provide a better understanding of the barriers ESRD patients encounter and, by doing so, find potential solutions to the problems patients face when making these important treatment decisions.

CHAPTER TWO: LITERATURE REVIEW

Background

Kidney transplant (KT) is commonly considered the gold standard for treating End Stage Renal Disease (ESRD), with a 76% five-year survival rate for Deceased Donor Kidney Transplant (DDKT) and an 86% five-year survival rate for Living Donor Kidney Transplant (LDKT) (National Kidney Foundation, 2019; United States Renal Disease System (USRDS), 2019). Hemodialysis, the ESRD treatment currently used by nearly 700,000 people in the U.S. offers a 40-50% lower five-year survival rate than DDKT and LDKT, respectively (USRDS, 2019). Considering the KT survival rates, the national support for increasing access to KT, and the number of KT candidates, not pursuing a KT following a referral is of interest especially for transplant centers experiencing this phenomenon among those patients considered “Lost to Follow-up” (M. Dunbar, personal communication, August 3, 2021).

A patient referral is typically made by the patient’s nephrologist prior to the required evaluation for KT by the transplant center team. The referral period is of unique interest since patients at this early juncture in care can easily be “Lost to Follow-Up” by the transplant center and very little is known about patients who do not to pursue a KT at this stage (M. Dunbar, personal communication, August 3, 2021).

Referral Process

Two types of patients are generally referred for KT evaluation. Patients with ESRD referred to a transplant center for KT are generally receiving dialysis as treatment for kidney failure (USRDS, 2020). Patients with CKD who have not yet progressed to ESRD are also referred to a transplant center for KT evaluation; these patients are most commonly under the age of 30 and may not be receiving dialysis. This type of “preemptive” or “prior to kidney failure” transplant is typically reserved for children and young adults with renal disease (USRDS, 2020).

Once a patient is referred to a transplant center, the center contacts the patient to schedule an appointment to begin the evaluation process. It is the responsibility of the patient to respond to the center's communication, make the appointment, establish the patient-provider relationship, and begin the evaluation process. If the patient does not initiate contact, the center attempts to contact the patient by phone for two weeks, including at least one phone call to the patient's emergency contact number on record if the patient cannot be reached. If the patient is interested in pursuing KT, he or she must respond to the transplant center's phone call and allow a relationship with the transplant center to be established. If the appointment is scheduled, but the patient does not attend the entire appointment, the transplant center attempts to reschedule the appointment using the same methods of communication.

After communication and scheduling attempts are exhausted, the transplant center considers the patient "Lost to Follow-Up." In this circumstance, the transplant center informs the patient's dialysis unit social worker (SW) about the patient's status. If the patient is "preemptive" and not on dialysis, the center notifies the patient's nephrologist's office of the status. At that point, the patient's chart is closed unless the patient contacts the center and requests another appointment. If the patient wants to pursue KT, the center reschedules the appointment and if the patient is a "no show" not due to illness, the SW is be informed that no further appointments will be made until the patient communicates with SW that he or she is ready to attend the full transplant center appointment, which can last four hours. The reasons patients are "Lost to Follow-Up" are not well understood as this phenomenon in KT is not well studied.

The literature review in this study examines the state of the science regarding the lived experience of End Stage Renal Disease (ESRD) patients who do not pursue a KT following a referral to a transplant center. Specifically, this literature review seeks to explore studies on how and why ESRD patients do not pursue a KT after a referral to a transplant center.

Method

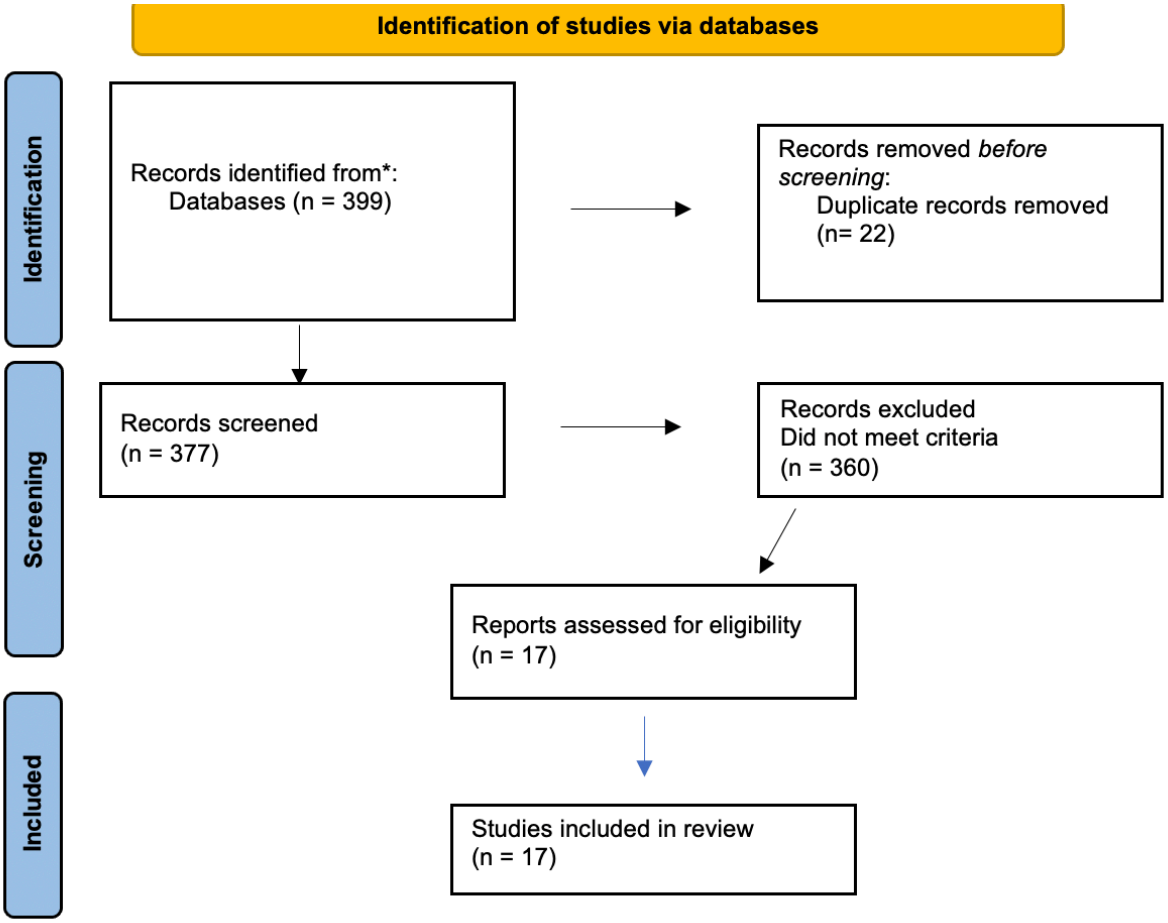
An extensive literature search was conducted using the databases of PubMed and Web of Science during the fall of 2021. The focus of the search was to identify factors that influence decisions about KT, and in particular to identify qualitative studies that explore the lived experience of kidney disease patients prior to the evaluation stage for KT. Published research related to adult patient experiences during this preliminary KT period was sought, including research regarding patients who did not to pursue a KT before evaluation.

Article inclusion criteria were set as: (a) adult patients; (b) patients referred for KT; (c) patients lost to follow-up or did not choose to pursue KT for a non-medical reason; (d) articles written in English; and (e) barriers to KT. Article exclusion criteria included: (a) pediatric patients; (b) patients who had already received one or more kidney transplants; and (c) articles not written in English. A total of 399 articles resulted from this search, with 17 articles meeting the inclusion criteria from Pub Med and Web of Science. The Table of Evidence includes 17 articles from recent searches, described above (Appendix 1).

Search Results

Overall, 17 peer-reviewed articles comprised the review. Research designs for the 17 articles were as follows: 4 (24%) randomized control trials, 9 (53%) quasi-experimental / pre-post design, 3 (18%) qualitative design, and 1 (5%) mixed methods design. One article specifically addressed the population of “Lost to Follow-Up” during the referral stage (Kazley et al., 2012) and one other article describing survey responses of patients who did not attend evaluation after referral were found in the literature review (Dageforde et al., 2015). A few articles describe problems with the referral system such as delayed referrals (Browne et al., 2016; USRDS, 2020; Waterman et al., 2015). All other articles used in this review address factors that influence decisions about KT, especially those factors considered patient derailers at stages prior to the “waitlist stage” for KT.

Figure 1: PRISMA



(McKenzie et al., 2020)

“Lost to Follow-Up” in ESRD

A study of 83 ESRD patients representing different ethnicities who had been referred to a medical center but did not follow up on the evaluation workup were surveyed regarding reasons for not following up after referral (Kazley et al., 2012). The most frequent responses included patients who assumed they would not qualify, were fearful of the transplant surgery, could not afford the transplant, and would not have sufficient help with follow up care. In another study, investigators reached out via phone survey to patients (matched by race) and followed up with those who did not attend the KT evaluation process after referral and found that most patients in both groups reported financial concerns; those who were absent (compared to those who attended) reported currently being on dialysis (p=0.008) and some previous experience with KT evaluation (p=0.029) (Dageforde et al., 2015). Both studies were conducted on small samples at single sites limiting generalizability of findings.

Lack or Delay of Referral to a Kidney Transplant Clinic

Typically, a patient referral for KT is initiated by a nephrologist working with a dialysis clinic. The clinic nephrologist would manage the weekly hemodialysis (HD) orders for patients receiving treatment at that clinic. As of February 2020, there were 7,566 dialysis centers in the U.S., 82% of which are privately owned (Levin, Lingam & Janiga, 2020). The majority of dialysis clinics in the U.S. are for-profit businesses, with Davita Kidney Care operating 2,271 or 37% of clinics and Fresenius Medical Care operating 2,634 clinics or 35% of the market share of clinics in the U.S. (Levin, Lingam & Janiga, 2020). In 2020, 79% of DaVita’s revenue came from clinic-based hemodialysis (HD), with 88% of Fresenius revenue generated by clinic-based HD treatment (Levin, Lingam & Janiga, 2020). When an ESRD patient receives a KT, there ceases to be a need for ongoing dialysis treatment, which can contribute to a conflict of interest in clinics that wish to retain their patients.

A delay in or absence of referrals made for KT has been shown to reduce the number of patients waitlisted each year (Browne et al., 2016; USRDS, 2020; Waterman et al., 2015). Patients most commonly experiencing a delay or absence of a referral for KT are African Americans (Hamoda et al., 2019; Lockwood, Bidwell, Werner, & Lee, 2016), Native Americans (Keddis et al., 2018), those with lower levels of completed education, and those living in lower socioeconomic groups (Waterman et al., 2013).

Factors Influencing Kidney Transplant

Navigating the journey to KT can be challenging for ESRD patients. Factors that influence decisions about KT have been identified in four categories: 1) socioeconomic factors including: referral status, lower SES, insurance status, and the financial burden of transplant (Schold et al., 2011), education level, and geographical location (Axelrod et al., 2008; Devitt et al., 2017; Hamoda et al., 2018; Waterman et al., 2015); (2) social support described as family or friends of the patient willing and able to provide emotional support and assistance with health care related decisions and activities such as driving to medical appointments, surgical after care (at least one and preferably two, full-time patient caregiver(s) required for at least 60 days post-transplant), child care, grocery shopping, and food preparation (Kazley, Simpson, Chavin, & Baliga, 2012; Wachterman, McCarthy, Marcantonio, & Ersek, 2015); (3) perceived discrimination and medical mistrust was described by some minority groups (Browne et al., 2016; Devitt et al., 2017; Hamoda et al., 2019; Wachterman et al., 2015); (4) knowledge factors include low literacy, low health literacy and numeracy, lack of knowledge about transplant, and a lack of clarity within patient/provider communication (Axelrod et al., 2017; Boulware et al., 2013; Browne et al., 2016; Grubbs, Gregorich, Perez-Stable, & Hsu, 2009; Rodrigue et al., 2008; Wachterman et al., 2015; Waterman et al., 2015). These factors are explained in greater detail below.

Socioeconomic Status

Regardless of ethnicity, patients of lower SES are less likely to obtain a kidney transplant, and up to 75% less likely to obtain a living donor KT (Axelrod et al., 2010). Schold et al. (2011) surveyed 3,029 adult ESRD patients in South Carolina and identified older age, public or government-provided insurance status, and lower median income as highly significant patient-identified factors that decreased the possibility of progressing to KT evaluation and waitlist. Concerns about affordability of KT were expressed in other studies that explored patient perceptions about pursuing the KT evaluation process (Browne et al., 2016; Brown et al., 2021; Dageford, Box, Feurer & Cavanaugh, 2015).

In a study using a secondary dataset and patient medical records, the Kidney Transplant Derailers Index was evaluated for validation among 753 adults ESRD patients. Patient data were assessed for individual level SES barriers to transplant with the largest indicators of derailment including not having fulltime employment, not having private insurance, having Medicaid insurance, and reporting financial insecurity (Peipert et al., 2019). Researchers found that socioeconomic impediments such as patients ’limited income, insurance issues, and transportation concerns were frequently described among both patient and provider participants.

Social Support

Social network factors have been shown to affect ESRD patients ’interest in pursuing KT (Browne, 2011; Brown et al., 2016; Brown et al., 2021). Among 228 African American dialysis patients in Chicago, KT referrals and appointments for KT evaluations increased significantly (p= 0.001) when a dialysis center and informational social network were available for patients (Browne, 2011). Additionally, for every $15,000 increase in income and holding the social support constant, patients were 40% more likely to attend a transplant center appointment (Browne, 2011).

In Hart et al. (2019), qualitative data were collected from 28 KT candidates using both individual interviews and focus groups. Findings demonstrated that patients relied heavily on family and friends to help make sense of medical information and aid in decision making regarding treatment options. Among 742 White and Black ESRD patients receiving hemodialysis, patients with “instrumental support networks” (multiple friends or family members to assist with daily activities) were significantly more likely to complete the referral and evaluation for KT (p <0.001) than patients without “instrumental support networks” or less than two supportive friends (Clark et al., 2008). Among patients with higher levels of instrumental support, defined as the number of friends or family available to assist with daily life, black women ($p < .05$), white women ($p < .05$), and white men ($p < .05$), had higher rates of completed evaluations for KT (Clark et al., 2008).

In a qualitative study, 40 adult ESRD patients in three southeastern states identified patient-level barriers and facilitators to acquiring a KT (Browne et al., 2016). Findings revealed patients were more likely to begin and complete the KT evaluation process with the support of a social worker, compared to without the help of a social worker. As one patient stated, “Everybody needs a cheerleader to get a kidney transplant.” The quote, used in the article title, indicated that every patient needs to have an advocate and a guide to help the patient achieve the goal of KT (Browne et al., 2016).

Medical Mistrust and Discrimination

Perceived racism, discrimination experiences, and medical mistrust were significantly associated with ESRD patients not initiating the evaluation for KT stage in a survey study of 528 ESRD patients (Hamoda et al., 2019). Researchers surveyed Black and White race adult ESRD patients between 2014-2016 and found that patients who experienced a higher level of medical mistrust ($p = <0.01$) and greater perceived racism ($p = <0.01$) were less likely to complete evaluation for KT than patients with less medical mistrust and less perceived racism (Hamoda et al., 2018). In addition, patients with grade school or less education were less likely to initiate evaluation for KT compared with patients with more years of education ($p = <.01$) (Hamoda et al., 2018).

In a qualitative study with 16 African Americans on chronic hemodialysis, authors found that participants expressed a “tone of mistrust” when describing barriers to completing the KT evaluation process including mistrust about equity in organ allocation (Wachterman et al., 2015, p. 243). Another concern pertained to lack of communication and lack of a good relationship with the nephrologist and transplant team. Some participants believed they were being “overlooked” during the evaluation process because of the limited time they had with clinic staff;

several patients expressed a need to establish a good relationship with providers before considering KT.

A qualitative study among 146 indigenous patients with ESRD in Australia revealed that participants had a high interest in learning about KT but described themselves as being poorly informed, and therefore believed they could not make a good decision (Dewitt et al., 2017). Not only did participants describe information overload but also inadequate time with physicians that participants perceived was needed but not provided. Several participants described feeling overpowered by assertive healthcare professionals. One patient stated “They [staff] don’t give it [information] the right way. Instead of like trying to teach them, they come across like they know everything, and they don’t compromise on that, hey? When they come across like that, everyone’s too scared to ask them questions, why, so then they just shut up and think, well I’ve been told this, so that must be it’” (Devitt et al., 2017 p.20).

Medical mistrust was also evident as some participants described clinic staff using their “greater power to restrict patient access to information” (Devitt et al., 2017 p. 8). More information is needed about patient experiences during the referral phase that could subtly but profoundly influence patients ’decisions on whether to pursue the evaluation process for a KT such as those described in this study.

In a 2-phase grounded theory study, 30 Black or African American ESRD patients and 24 patient care providers in Virginia participated in semi-structured interviews and focus groups (Nonterah & Gardiner, 2020). The study explored patients ’and providers ’perspectives on barriers and motivators to completing the KT evaluation process. Both groups also identified medical mistrust as an impediment to successfully completing the required evaluation for KT. Remarkably, eight (44.5%) patient participants interviewed had inaccurately believed they had been listed for KT when they had not been placed on the waitlist (Nonterah & Gardiner, 2020). Similarly, among 83 adult ESRD patients surveyed in a South Carolina dialysis center, 42 patients (50.6%) stated they were listed for transplant when only 26 (31.3%) were actually waitlisted for a KT (Gillespie et al., 2011). This finding together with patient's describing a lack of clear communication with their providers, suggests a gap exists in patient centered education (Gillespie et al., 2021; Nonterah & Gardiner, 2020).

Level of Knowledge

A lack of knowledge about renal replacement treatment options is considered a primary barrier to KT (Axelrod et al., 2017; Boulware et al., 2013; Browne et al., 2016; Rodrigue et al., 2008; Waterman et al. 2015). This lack of knowledge includes but is not limited to: (a) available treatment options for chronic kidney disease (CKD) and ESRD; (b) patient and caregiver responsibilities in KT; (c) cost and payment options for KT; and (d) available resources for KT patients (Boulware et al., 2013; Rodrigue et al., 2008; Waterman et al. 2015). Any of these issues and related gaps in knowledge or understanding can make obtaining a KT difficult, and this is especially true for African American, Latino, and Native American patients and those of lower socioeconomic status (Boulware et al., 2013; Rodrigue et al., 2008; Sakpal, Donahue, Ness & Santella, 2020; Waterman et al., 2015). In a randomized controlled intervention study of 802 adult ESRD patients of mixed ethnicity, patients receiving the "Your Path to Transplant" education were significantly more interested and ready to pursue KT ($p < .001$) than patients receiving less education about treatment options (Waterman et al., 2021). The intervention produced a significantly higher rate of waitlisted or transplanted patients regardless of race or ethnicity ($p = .003$) (Waterman et al., 2021).

In a randomized control trial, 133 adult ESRD patients were randomly assigned to one of two groups: the control group was given standard of care (SOC) clinic KT patient education and the intervention group was offered SOC and home-based (HB) education follow-up regarding KT and living donor KT (LDKT). The group given both SOC and HB had more knowledge about LDKT ($p < .0001$), fewer concerns ($p < .0001$) and a greater willingness to discuss LDKT with others than the control group which received the SOC alone ($p<.0001$) (Rodrigue et al., 2007). Without adequate knowledge, patients may be unable to make informed decisions regarding treatment options (Hart et al., 2019).

Education/Assessment Provided by Dialysis Centers

Due to the well-established benefits of KT, dialysis centers are required by federal law to provide patient education regarding ESRD treatment options including DDKT and LDKT within 45 days of the initiation of dialysis treatment for ESRD (Centers for Medicare and Medicaid Services, 2008; USRDS, 2022). A lack of dialysis center compliance with the law and oversight by the Centers for Medicare and Medicaid Services contribute to lower referral rates especially among African Americans and patients of lower SES (Boulware et al., 2013; Rodrigue et al., 2008; Waterman et al., 2015).

National data demonstrates that 30% of dialysis center patients are not provided information about KT by dialysis center staff (Balhara, Kucirka, Jaar, & Segev, 2012). The most common reason given by nephrologists for inadequate patient education about KT was that the patient was “not assessed” meaning the patient may have been eligible for KT but was not evaluated for a number of reasons, including provider-level short staffing and time constraints (Balhara, Kucirka, Jaar, & Segev, 2012). Unassessed patients showed a 46% lower rate of KT than patients who have been assessed (Balhara, Kucirka, Jaar, & Segev, 2012). Assessment for KT includes the delivery of patient education regarding KT as a treatment option for ESRD. Without assessment for KT and the required patient education, the patient may lack the information needed to make an informed decision about treatment options (Balhara, Kucirka, Jaar, & Segev, 2012; Waterman et al., 2013).

Synthesis and Discussion

The factors that influence patients 'decision making about KT are shown to overlap and interact. For example, a delayed or absent referral by a nephrologist can contribute to a patient not being given required education related to KT as a treatment option for ESRD (Levin, Lingam & Janiga, 2020). Inadequate patient education can lead to an increase in medical mistrust and patient fear related to KT. Mistrust of the medical system and lack of communication with providers also contributed to lack of knowledge and delays in decision making (Devitt et al., 2017; Hamoda et al., 2019; Wachterman et al., 2015). A lack of knowledge regarding treatment options and many of the other factors have been shown to contribute to a patient not pursuing KT for ESRD (Axelrod et al., 2017; Boulware et al., 2013; Browne et al., 2016; Grubbs et al., 2009; Rodrigue et al., 2008; Waterman et al., 2015).

The term "Lost to Follow-Up" in KT has been associated with patient and system-level barriers. Historically, barriers to kidney transplant have been strongly associated with race/ethnicity, gender and socio-economic status which can contribute to being "Lost to Follow-Up" at any point in a patient's health care journey and especially in the early stages (Axelrod et al., 2017; Kutner et al., 2012; Rodrigue, et al., 2012; Waterman et al., 2015). African Americans, women, and those of lower SES, are less likely than other patients to achieve the required steps needed to be considered for a KT (Axelrod et al., 2017; Rodrigue et al., 2012; USRDS, 2019; Waterman et al., 2015). Patients referred for KT, who enter transplant evaluation knowledgeable of available treatment options, are more likely to be successfully transplanted (Waterman et al., 2013).

The majority of studies found in this literature review relied on surveys and other quantitative measures to examine factors that impact ESRD patients 'decision-making about treatment options. The person-centered reasons why ESRD patients are "Lost to Follow-Up" are unique to each patient, and to this researcher's knowledge, no narrative study has sought to uncover the patient's lived experiences and perspectives in choosing not to follow-up with the transplant center after referral to a KT center and before beginning the KT evaluation process. Understanding the unique and collective narrative shared by those who lived the referral experience may help shed some light on the early phases of care and specifically what impedes decision-making and treatment.

Conclusion

The purpose of the literature review was to explore the referral process for KT including the factors that influence ESRD patient decision-making and how they experience the referral process if they do not to pursue KT or are "Lost to Follow-Up." Patients "Lost to Follow-Up" at the referral stage are not well studied and there is no national patient-level tracking of referred patients prior to the waitlist phase (Harding et al., 2021). The data pertaining to referral for KT is maintained at the transplant center to which the patient is referred, and in the patient's electronic health record (EHR) and is not found in the national database (USRDS, 2021). The body of literature in this review identified patient and system level factors that appear to influence patients 'decisions about pursuing KT evaluation and KT. Many of these factors pose barriers that have been shown to significantly reduce KT referrals, and successful KT evaluations. Patient-level factors included: (a) socioeconomic, (b) social support, (c) medical mistrust and discrimination, and (d) knowledge about ESRD treatment options including KT. System-level factors found in the literature included: (a) delayed transplant referrals, (b) disparities in care delivery, (c) insurance and financial concerns, (d) the conflict-of-interest potential when dialysis centers provide most of the patient education on ESRD treatment options. None of these factors appear in isolation. They are frequently seen in groupings and appear to potentiate one another.

Through understanding the lived experience of ESRD patients previously interested in KT and "Lost to Follow Up" before beginning or completing the evaluation stage, clinicians will gain insight into what is occurring and what matters most to patients on the journey to KT. Encouraging patients to describe the meaningful events, relationships, and factors that influenced their decisions and ability to pursue the KT evaluation process will allow clinicians the opportunity to improve the healthcare systems and processes patients must navigate.

CHAPTER THREE: NARRATIVE INQUIRY

Within qualitative research there are five classically recognized methods of inquiry which include case study, ethnography, grounded theory, narrative, and phenomenology. In the narrative method of inquiry, the story of the narrator is the data, allowing the subjective voice of the participant to present meaning and context to the subject or phenomena (Butina, 2015; Wang & Geale, 2015). In Narrative Inquiry (NI), each participant's story is analyzed individually (within each data text) and then analyzed collectively (across all participants 'data text), allowing the researcher to gain a deep understanding of the meaning of the phenomenon being studied and context being relayed. This method of inquiry helps to explain, understand, and illuminate the participant's lived experience of the research topic, allowing the meaning of the experience or phenomena to take shape in union with the researcher (Riessman, 2008). The NI method, which studies human experiences is well suited for nursing science, as it helps the nurse scientist understand the patient's perspective and identify how nursing can support and enhance the patient experience and health outcomes (Clandinin, 2006; Wang & Geale, 2015).

Narrative Theory

Narrative theory has evolved from a mixture of Aristotle's theory of plot, Augustine's theory of time, Ricouer's theory of the mimetic function of the narrative, and Dewey's theory of human experience. Aristotle described plot as the primary principal of Greek tragedy. Plot is the arrangement of incidents and events that occur within a story, in how the author describes the events to affect the audience. Plot possesses an ordering of events with a beginning, middle and a consequential end. This ordering of events creates a unified plot creating an emotional connection with fear, hope, dread, and the unexpected that captivate the audience (Riessman, 2008). Plot, with its introduction, rising action, climax, falling action and resolution is like a story, which can be described as both narrative and plot, offering a sequential ordering of events, rupture or climax leading to a resolution (De Fina, 2003 as cited in Riessman, 2008).

Augustine’s theory of time posits that the perception of time as past, present, and future exist and are measured in the mind as part of human consciousness (Hernandez, 2016). The past lives on as far as we remember, while the future lives in expectation (Hernandez, 2016). The sequential arrangement of events and actions gives structure to human experiences as described across time, and this allows the storyteller to anchor his or her experience as stories within the narrative. The passing of time and a sense of duration can be measured in relation to rhythms of life, such as day and night, four seasons, holidays, and one’s circadian rhythm (Barreau, 2004). Augustine’s theory of time demonstrates how an experience can be shared from memory, laid out sequentially against the backdrop of time, which is described by the narrator (Barreau, 2004).

Ricouer has written extensively on the concept of the narrative and defines mimetic function as the narrative’s ability to imitate and represent oneself. Ricouer posits that narrative is integral to identity and promotes understanding of self and one’s existence in time and over time (Ricouer,1984). It is the weaving together of the events over time through narrative that helps individuals make sense of their lives (Bruner, 1990; McAdams, 1993; Polkinghorne, 1988; Sarbin, 1986 as cited in Richardson, 2015). In narrative theory, time is the central construct of human existence, and Ricouer posits that narrative is the merging of past and future into the present and offers insight into a narrator’s identity (Ricouer, 1980, as cited in Richardson, 2015). Narrative is made-up of events, experiences, and actions that are connected to the culture of the narrator. Within narrative, a storyteller will describe types of autonomous or “agentic” actions that are set in time and influenced by cultural context, personal identity, and social context (Richardson, 2015).

Dewey’s theory of experience (Dewey, 1938 as cited in Lindsey & Schwind, 2016) highlights the inquirer’s experiential role in the narrative, as well as how human experience intersects in time, place, and social context. Dewey posits that experience is the crux of learning, and that narration or the telling of the experience reinforces the knowledge gained from the experience (Connelly & Clandinin, 1990; Dewey, 1938 as cited in Lindsey & Schwind, 2016). Dewey's belief was that to understand an individual, one had to examine how that individual interacted with people and society in time: past, present, and future (Wang & Geale, 2015). It is at these intersections that the inquirer is able to analyze and construct the overarching narrative experience (Clandinin, 2006).

Connelly and Clandinin, (1990) posit that it is equally correct to say "inquiry into narrative" as it is "narrative inquiry" meaning that NI is both phenomenon and method. Drawing from Dewey, Connelly and Clandinin (1990) first described narrative inquiry as three dimensional, including continuity, interaction, and situation. Clandinin and Connelly's most recent framework (2000) describes the constructs of narrative as temporality, sociality, and spatiality. In NI, temporality denotes how one may write and rewrite stories over time, and how the narrator's story may change over time and be experienced and rewritten to improve some outcome in the future. The narrator changes over time and therefore what and how the story is remembered and retold may change too (Clandinin & Connelly, 2000). Sociality refers to how the narrator delivers a story to a particular audience at a particular time. The narrator's relationships may change over time influencing how the story is delivered and to whom. The researcher seeks to understand the social relationships affecting the narrator and the story they tell (Clandinin & Connelly, 2000). Spatiality denotes the physical space that contains the story, where the story takes place and how context and location affect the story (Clandinin & Connelly, 2000).

From these three constructs, Clandinin and Connelly, (2000) describe four directions from which to approach analysis of narrative data: inside, outside, backwards, and forwards. Inside represents the narrator's emotion and feelings within the story. Outside represents the effects of society and external influences on the narrator and how and why those influences affect the story. Backwards and forwards describe what emotions and experiences change over time and how these changes influence the narrator's perspectives on past and present experiences and future expectations. These changes in perspective allow the inquirer an opportunity to consider what factors and circumstances influence the stories being told (Clandinin & Connelly, 2000).

Narrative Inquiry as Research Method

It has been said that narrative is everywhere, but not everything is narrative (Riessman, 2008). To the displeasure of many qualitative researchers, the term "narrative" has become common vernacular among postmodernists in all walks of life (Riessman, 2008). For clarity, the current cultural meaning of "narrative" commonly used in media, is loosely structured and may be applied to a single idea or topic, without adhering to the discipline and structure traditionally used in NI research (Atkinson & Silverman, 1997; Gubrium & Holstein, 2002; Riesmann, 2008).

Broadly interpreted, NI embodies meaning found in a wide array of expressions including written or spoken story, interview, dialogue, art piece, music, or performance (Riessman, 2008). In most expressions, the narrative shares the commonalities of contingency and connecting ideas or events over time (Riessman, 2008). Meaning revealed through NI is constructed from the data found in participant interviews and stories, the interpretation of the researcher along with the perspective of the reader (Riessman, 2008). By creating and telling the narrative the storyteller is given the opportunity to construct meaning and share her or his own understanding of the research phenomenon being studied (Mishler, 1986).

The researcher in NI has a unique role in that their experience, beliefs, social context, and reference may play a part in the inquiry and understanding of the narrative, and therefore bias must be rigorously addressed (Wang & Geale, 2015). The goal of the researcher in NI is to generate rich accounts of experiences with participants, through open-ended, non-leading questions and dialogue, which promote the retrospective telling of the experience from the participant’s perspective (Mishler, 1986). The use of the interview structure, without interruptions by the researcher during the flow of the narrative, allows the participant’s account to be a more authentic narrative about the topic being studied (Mishler, 1986). The less the researcher interrupts during the interview the greater the potential for meaningful participant narrative (Mishler, 1986; Riessman, 2008).

The semi-structured interview is very different from the structured interview or surveys. Allowing participants the opportunity to freely construct the narrative in response to an opening question reduces the suppression of the respondent’s story seen in more rigid formats of inquiry (Mishler, 1986; Riessman, 2008). This method of interview, however, can be more difficult to analyze but has been shown to yield rich narrative data (Mishler, 1986; Riessman, 2008). Additionally, seeking opportunities to explore meaning with participants within the interview allows for co-construction of meaning and decreases the risk of researchers misinterpreting participant meanings during data analysis.

Narrative Analysis

Analyzing NI data or Narrative Analysis (NA) can be accomplished in multiple ways and is dependent on the study’s overall purpose, specific objectives, and context. Data may include a topical story, a personal narrative, or an entire life story such as a biography. In some settings, visual depictions of personal experiences may be more conducive to analysis than relying on language alone. There are typically four ways to analyze narrative data which include:

1. Narrative thematic analysis in which participants ’descriptions of a particular human experience or research phenomenon is the primary focus of the inquiry.
2. Structural analysis which focuses on the way participants construct and describe their stories and experiences. This could include analyzing the use of language (linguistics) and story plots that develop over time and within a particular place.

3. Dialogic/performance analysis which focuses on how the interviewee and interviewer engage to explore the context of stories (for example, cultural, community, and/or political context) in order to understand the construction of participants' narratives.
4. Visual narrative analysis which focuses on how images and language work together to provide meaning in the text.

This study used narrative thematic analysis; however, all four types of narrative analysis are briefly explained.

Narrative Thematic Analysis

Thematic analysis (TA) is frequently used type of narrative analysis and relies on what is "told" by the narrator or storyteller and not the "telling" (Mishler, 1995). Therefore, this type of analysis seeks rich descriptions of meaningful events or participants 'experiences that are told in a series of stories that pertain to the research phenomenon.

Narratives can be identified from entrance and exit signals, which are phrases individuals use to start or end a description of an event or experience. For example, entrance into a description of an event or experience could start with the phrase "well it started with" and completion of the description could be signified with "that's how it went". This method of identifying story snippets can help to identify analytic units and point to themes as well.

A complete narrated story generally includes six elements: an abstract or opening; orientation to an event, experience, or situation; complicating action, usually with a crisis or turning point; evaluation, where the narrator comments on meaning; resolution; and a coda, or an ending to the story. Not all stories contain all the elements listed, and the elements may occur in varying order (Riessman, 2008). However, the researcher keeps these elements in mind to encourage participants to provide as complete a narrated story as possible.

Inductive and Descriptive Approach to Narrative Thematic Analysis

In this method of analyzing data, the researcher breaks up participants 'descriptions of events and experiences into separate stories and compares the narratives, helping to develop core categories and themes based on participants 'descriptions. Inductive thematic analysis of narrative data may be broken into five steps including: a) organizing data, b) obtaining an overall sense of the data, c) coding or attaching descriptive labels to accurately represent data segments, d) arranging similar codes into data patterns or categories, and e) assimilating categories into meaningful themes that can be supported with participants 'quotes and other references to the participants 'narrative data. The researcher avoids using her or his own experiences or pre-established theories to interpret participants 'descriptions.

Deductive and Interpretive Approach to Narrative Thematic Analysis

In a deductive and interpretive approach to Narrative Thematic Analysis, the researcher applies a framework of concepts or theoretical constructs over the entire narrative to help interpret data provided by participants and formulate meaning and themes based on the theoretical constructs. This method is generally informed by a literature review of the topic or theoretical perspective that emerged from previous research. For example, as described by Riessman (2008), Gareth Williams (1984) used the deductive method of NA to further develop narrative reconstructionism, which illustrates how human beings construct or reconstruct misfortune to create an explanation that helps them process the negative experience. Riessman (2008) described how Williams interviewed 30 rheumatoid arthritis patients and asked the question “Why do you think you got arthritis?” Williams focused his research on the subjects that did not accept the medical explanation of their arthritis such as a genetic predisposition. Alternative explanations reflected unique beliefs about why participants suffered with arthritis, such as being job related. This type of interpretive NA uses a priori theory and participant narratives to fulfill the outcome of interest (Riessman, 2008).

Structural Analysis

This second type of narrative analysis focuses on how the story is constructed. In this type of analysis, the "telling" is just as important as what is "told". Riessman (2008) exemplifies structural analysis as seen in a classroom study of children and storytelling. How the stories were told by the children and how the teachers responded to the stories and the children, not the stories themselves, were the focus of data collection and analysis. In participant interviews and recordings, the cadence of speech and pitch of the spoken word can reveal the storyteller's focus (Gee, 1991). According to Gee, a social linguist (1991), roughly each four lines of an interviewee's monologue are equal to a poetic stanza. When using this process of parsing out the spoken word for analysis, confusing content can take shape and become clearer for the researcher. This method is especially helpful with long monologues which are often observed in health science interviews (Riessman, 2008).

Dialogic Performance Analysis

If thematic and structural approaches interrogate "what" is spoken and "how" the story is constructed and spoken, the dialogic/performance analysis asks "who," "when," and "why," that is, for what purposes? This broad approach often used on ethnographic data, focuses on the dialogic process between the teller and listener. Dialogic/performance looks beyond what is consciously intended and views stories as social artifacts, revealing meaning about society and culture in addition to person and/or a group. Dialogic investigation, which is well suited for large groups in dialogue, includes the listener's role as being significant, including their physical position, voice, and effect on the audience (Riessman, 2008). For example, a dramatic performance that sparks meaningful group dialogue on a selected topic can be a rich source of data for narrative researchers.

Visual Narrative Analysis

This approach incorporates images into narrative analysis alongside written text and integrates words and images such as photos, paintings, video, collage, etc. Riessman suggests that this type of analysis needs the story of the production of the image, the image itself and how it can be read. Forms of communication such as gesture, body movement, sound, and images are older and more universally understood than language. This type of analysis may be performed by a researcher as photographer, or film maker, using images to speak the way words speak in thematic narrative. This “deep look” at visuals helps the viewer (such as the research participant) move beyond a quick interpretation of an image and instead to see what the image is saying. In visual narrative analysis one reads the image in detail and responds (Becker 1986; Riessman, 2008). The narrative that results can be rich descriptions of human experiences within a particular focus and sociocultural context. According to Becker (1986), the image makes a statement and shows the viewer details that contribute to seeing and describing the mood, moral point of view and causal connections within a particular lived experience.

Gillian Rose (2001) posits there are three sites to note for visual narrative analysis: (a) the story of the image; (b) the image itself; and (c) the viewer or audience (Miyazaki, 2004). When participants and the researcher view images such as photographs, the researcher works with participants to create a description of the images by adding text or captions to help draw connections with a human experience. Often what is missing from the image or text can often reveal a powerful narrative (Riessman, 2008).

These four types of data analysis in narrative inquiry provide researchers with an array of analytic techniques to elicit participants ’stories of their lived experiences. These stories can reveal important themes that deepen the researcher’s understandings of a selected research phenomenon. In particular, this study will use narrative thematic analysis to explore the lived experience of ESRD patients referred for KT. This study proposes to understand why patients who have been referred to a transplant center for evaluation for KT decide not to move forward in the process. Understanding this gap and the patient's experience may shed some light on why patients chose to withdraw from the evaluation process and therefore do not become waitlisted.

Narrative Inquiry in Nursing Research

Within the practice of nursing there exists a dynamic relationship between the nurse and the patient in their care. The creative structure and application of NI is uniquely appropriate for research among the vulnerable patient populations, who may not recount events in a purely "western" manner (Lee, Fawcett & DiMarco, 2016). Storytelling has been shown to enhance the health-related communication and uncover sociocultural elements that affect health outcomes among participant populations (Lee, Fawcett & DeMarco, 2015). This appears to make NI particularly relevant among the ESRD population and those who do not pursue the "gold-standard" treatment of kidney transplant. (Lee, Fawcett & DiMarco, 2016; Reissman, 2008).

Addressing the Gap with Narrative Inquiry

The NI method of qualitative research was used in this study to help investigate and expose the lived experience and decision-making process of ESRD patients following the referral to the KT center at UCLA. The NI method was well suited for the gap identified in the literature among this patient population. The narratives (stories) obtained from study participants through semi-structured interviews will reveal their experiences during the KT referral process. The use of this qualitative research method allowed the participants and the researcher the opportunity to share and reflect on the KT referral process and subsequent decision-making experience and construct meaning about these experiences.

Summary

Research is situated in its scientific discipline. Within the discipline of nursing, there must be room for the narrative voice of the patient. Allowing the patient to co-construct the meaning of their lived experience is necessary for the patient, the provider and society. As nursing seeks to be more person-centric, equitable and inclusive, how and what patients are saying *and* meaning is of growing importance as we seek to improve health care. Uncovering the lived experience of ESRD patients referred for KT helps inform providers and others on how to better serve the needs of that patient population.

CHAPTER FOUR: RESEARCH DESIGN AND METHODS

The purpose of this Narrative Inquiry (NI) study was to explore the lived experience of ESRD patients labeled “Lost to Follow-Up” for KT at a large transplant center in Southern California. Narrative Inquiry was used as the qualitative research method in this study to allow the patient’s voices and viewpoints to be heard and their narratives to be analyzed for prevalent themes. Quantitative methods have proven to be inadequate in capturing and understanding the reasons why patients in treatment for ESRD do not advance towards obtaining a KT, which offers significantly better survival rates and quality of life (QOL) than hemodialysis (Kostro et al., 2016; Wang & Geale, 2015).

Current science in KT has demonstrated a preliminary examination of the ESRD population who do not pursue and/or obtain a KT. The term “Lost to Follow-Up” describes patients who drop off the patient roll after they were referred to a KT center. The reason why patients are “Lost to Follow-Up” is not well understood and very few qualitative studies have examined the lived experience of these patients to better understand this phenomenon, which occurs at a relatively constant rate nationwide (Kazley et al., 2012).

The aims of this study were to: (1) explore the trajectory of kidney disease from the perspective of patients diagnosed with ESRD and referred to the transplant center; (2) examine patient perceptions of the treatment referral process and the available treatment options presented to them; (3) describe factors affecting patient decision-making regarding kidney transplant after being referred for treatment.

Rationale for Narrative Inquiry Methodology

A qualitative NI approach was used in this study to allow the words and meanings of ESRD patients to inform the topic of treatment decision-making and factors that influenced treatment choices. The NI method was used to analyze the unique and intact stories that patients shared, which differs from the Grounded Theory approach of theorizing across cases

(Riessman, 2008). The NI analysis helped provide some clarity and understanding about what KT patients experience during the referral period. The NI tradition within the study of health sciences has been defined as (1) an extended account of a speaker's story; (2) A bound segment of an interview or text; (3) A bound segment of a document; and (3) A life story of the speaker (Riessman, 2008).

The NI method allows participants the opportunity to construct meaning out of their personal experiences which they provide in semi-structured interviews. The process of patient/participant storytelling helped to illuminate the patient decision-making process regarding KT. Unlike structured interviews and surveys commonly used in quantitative methods, NI invites participants to construct meaning from his or her own perspective, influenced by his or her own experience of temporality, sociality, and spatiality (Clandinin & Connelly, 2000). Given the gap in understanding the patient population labeled "Lost to Follow-Up" after receiving a KT referral, and the lack of qualitative research on treatment decision-making processes when presented with renal failure treatment options, NI allowed this nurse scientist the opportunity to co-construct a deeper understanding of the ESRD patient experience and may help to inform care for this patient population.

Study Procedures

Study Setting

The CFKTC at UCLA is one of the largest transplant centers in the U.S., performing more than 350 KT surgeries each year. Since 1965 UCLA has transplanted more than 8,000 kidneys, including Deceased Donor Kidney Transplants (DDKT) and Living Donor Kidney Transplants (LDKT), utilizing kidney exchange, voucher, non-compatible blood types, HIV and Hepatitis C-positive transplants. Patients treated at the CFKTC come from across the southern California community, the United States, and many countries around the world. Due to COVID-

19 precautions, the study was performed remotely. Individual participant interviews took place by phone and lasted between 40-55 minutes.

Study Participants

For this study, ESRD and CKD patients referred and labeled “Lost to Follow-Up” at the Connie Frank Kidney Transplant Center (CFKTC) at University of California, Los Angeles (UCLA) were recruited for participation. The Transplant Center considers patients who have been referred for KT but have not contacted or responded to calls from the Transplant Center within 30 days as “Lost to Follow-up.” Approval from the Office of the Human Research Protection Program at UCLA was obtained for human subject participation in this study. A list of patients designated as “Lost to Follow-Up” was provided by the CFKTC at UCLA for possible recruitment in the study. These patients were referred for KT by a nephrologist, but according to medical records did not begin or complete evaluation for KT at the transplant center.

Inclusion and Exclusion Criteria

Using inclusion criteria similar to other studies conducted among the adult ESRD patient population, participants for the study were English speaking adults, >18 years and diagnosed with either CKD or ESRD. Pediatric patients were not studied due to the age-related causes of CKD and ESRD, the differences in disease trajectory children and adults face, and parental involvement in treatment choice among children. Additional inclusion criteria included patients who were referred for KT within the previous 24 months to the CFKTC at UCLA and were able to recall and describe the KT referral process, including the reason for their “Lost to Follow-Up” designation. A KT referral obtained within the prior 24 months was used to create a recruitment pool of patients who were probably not planning to pursue KT and were not merely delayed in contacting the KT center. Due to recruitment findings the inclusion criteria were amended to include participants who had or would potentially pursue the evaluation for KT process in the future. Patients who had a previous KT or were being seen at another transplant center were excluded from the study.

Recruitment Process

With the CFKTC nurse manager’s assistance, adult patients, over 18, who had not followed up within a month of referral to the transplant center were identified using the UCLA electronic health record monthly reports. A list of 488 “Lost to Follow-Up” patient names with medical record numbers was provided by the CFKTC at UCLA and shared with this Principal Investigator (PI) using a secure password-protected Box folder. The same list was shared with a Clinical Translational Science Institute (CTSI) associate for the sole purpose of obtaining patient recruitment information. The UCLA CTSI associate provided the email addresses and phone numbers for the “Lost to Follow-Up” patients and uploaded the file to the secure Box folder for the purposes of this study.

The list of 488 patients provided 235 email addresses which were used, and 102 phone calls were made, providing 12 patients interested in participating and meeting inclusion criteria for the study. Two of the 12 identified would later be unreachable by phone and were not included in the study. During recruitment one IRB amendment was sought and obtained to include participants who had or would pursue the evaluation for KT process. This amendment was considered necessary due to findings that some patients were delayed in participating or completing the evaluation process but were unsure of their plans regarding future participation.

During recruitment patients who were interested in participating in the study were screened by phone for meeting inclusion criteria. Those who met the inclusion criteria were invited to participate in the study and the phone interview was scheduled. The Study Information Form was delivered to all participants via email during the recruitment process. During the first few minutes of the scheduled interview the research information sheet was reviewed, and the participant was verbally consented for the study.

Data Collection

Data for this NI study was provided by the study participants during the ten semi-structured interviews, conducted privately by the PI and recorded using the NoNotes secure iPhone app. A Semi-Structured Interview Guide (SSIG) (Appendix 2) was used to facilitate participants sharing their experiences with kidney disease and the kidney transplant referral process (Appendix 2). The PI's goal in this study was to allow participants to recall and share their thoughts, feelings, and experiences regarding the topic, without interjecting the interviewer's personal ideas or assessment (Butina, 2015). Open-ended questions were used throughout the interview and follow-up questions were used judiciously to guide the participant if he or she was speaking for an extended time on a tangential subject.

All 10 recorded interviews were transcribed verbatim by the PI using voice to text in Word. The digital audio recorded interviews were each reviewed by the PI at length to verify transcription accuracy. After removing all identifying information such as names of people and places, the PI uploaded the transcribed interviews into to a secure Box folder shared with this PI's UCLA, School of Nursing (SON), Dissertation Committee Chair, Carol Pavlish PhD. Working paper copies of the transcripts were kept in a locked drawer in the PI's private home office.

For data organization and management, the transcripts were uploaded into qualitative data management program N-Vivo, stored on the PI's password protected computer file and uploaded into a secure study BOX folder shared with Dr. Pavlish. Transcribed interviews were reviewed and analyzed shortly after each interview, field notes and the study audit trail were uploaded into the secure study Box folder and updated frequently. Field notes and journal entries allowed the PI to keep a detailed written record of the unspoken portion of the interview data, such as the PI's own impressions and thoughts about each interview and participant including unrecorded information such as prescreening conversations. The study audit trail provided calendar entries for all study activities beginning with IRB approval.

Thematic Data Analysis

In this method of narrative analysis, the researcher analyzes the meaningful events and experiences of the narrators. Stories are first compared within each narrative and then across all narratives, helping to develop central themes based on participants 'descriptions. The thematic analysis of the narrative data in this study was inductive. Meaning was drawn from the data, and no hypothesis about the findings was held. Data analysis was systematically organized to obtain a sense of repetitive themes and the overarching narrative. Coding, categorizing, and labeling were applied to the data segments, and critical events and patterns were identified. Specific techniques that were used during narrative analysis are further described.

Level I Analysis: Line-by-Line, Detail Coding

The transcripts were deidentified and each one read thoroughly for an overview of the interview. Establishing familiarity with the data provided a landscape upon which coding began. The PI inductively coded the interviews line-by-line with a focus on describing the meaning being expressed. In qualitative analysis, coding represents the process of providing "a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute" (or code) to a section of data (Saldana, 2016, p. 3). The unit of data being coded may vary from a single word, a phrase, a full sentence, or a couple of sentences. During narrative analysis in this study, line-by-line coding focused on data units that described human experiences such as meaningful actions, events, relationships, time-points, and feelings. These data segments were assigned descriptive codes to capture the essence of the data unit being analyzed (Saldana, 2013). This type of detail coding allowed the researcher to dive deeply into the data and study its meaning and messages.

Development of a Codebook

Creating a codebook was an essential aspect of the data analysis since codes quickly accumulated during the coding process. The codebook served as a separate record that assisted the PI in condensing the large dataset into more manageable units that were compared across the narratives. Each code was briefly described along with a brief data example and reference to the text location (Saldana, 2016). This codebook evolved during data analysis as new codes emerged, code sorting and merging occurred, and categories were developed.

Level II Analysis: Pattern Coding and Categorizing

Once all detail coding was complete, the PI compared and contrasted detail codes within and across all research participants. First, within each transcript, similar codes were sorted and clustered into more expansive and abstract categories that described the group of codes. Once all transcripts were coded and arranged into meaningful categories, the PI again compared and contrasted codes and categories across all narratives and began to merge codes and categories. Through this process, some resorting and re-labeling of codes and categories occurred so that codes were merged into sub-categories which were then sorted into higher level categories (Saldana, 2013). Codes, subcategories, and categories were supported with direct quotes from each of the participants. Finally, diagramming was used to visualize how the subcategories and categories related to one another and yielded conceptual themes.

Development of Conceptual Themes: Capturing the Heart of the Data

The PI and the committee chair coded separately to validate accuracy and differences in coding were discussed and reconciled. The PI and committee chair studied the categorical structure with its codes, sub-categories and supporting quotes. From there, the PI developed conceptual themes that were grounded in the data and best described the important meaning being expressed within the narratives. Themes that emerged were the outcome of Levels I and II coding and categorizing, the visual depiction, and a reflective analytic process which was captured in the audit trail and the field notes (Saldana, 2013). Conceptual themes are described as findings and supported using participants 'quotes and references from the data.

Assuring Rigor and Trustworthiness in Narrative Inquiry

The traditional positivist term and method of “validity” which relies on “measurable and objectivist assumptions” does not apply within NI (Riessman, 1993 as citied in Mertova & Webster, 2020 p. 74). A storyteller’s “truth” is not universal nor generalizable. Individual narratives and personal stories used in NI are unique, influenced by context and life circumstances of each account. Storytelling consistency can be assessed using “critical events”, “like events”, and “other events” which the storyteller themselves corroborate with “like” and “other” events recalled in the participant’s life (Mertova & Webster, 2020). However, it is not the individual’s lived experience alone that is evaluated for “truth” but the method and rigor in analyzing the data. It is the researcher’s role in NI to produce the rigor of “validation” through meaningful qualitative methods of study design, execution, and analysis (Mertova & Webster, 2020; Riessman, 2008). It is the job of the researcher to present narrative data in a genuine manner, ensuring “analytic interpretations are reasonable, plausible and convincing” (Riessman, 2008, p. 191). Applying a framework of validating constructs to a study remains standard practice for evaluating rigor and trustworthiness (Riessman, 2008).

Standards and Techniques for Trustworthiness

The following table describes a common framework used in qualitative research, including NI for assuring a rigorous method and trustworthy findings (Lincoln & Guba, 1985; Loh, 2013). These standards yield specific techniques that guided data collection and analysis during study implementation.

Table 2: Techniques for Trustworthiness

Standard	Description	Techniques Applied During the Study
Confirmability (Objectivity)	Study follows rigorous procedures and is conducted from a neutral stance, free of researcher values and biases. Findings can be confirmed by raw data.	• Clear explanation of study procedures with rationale provided. • Field Notes and an Audit Trail of all participant and data encounters with reflexive notations to acknowledge, manage and minimize researcher bias. • Participant quotes used to support all themes and findings
Dependability (Internal consistency)	Study follows rigorous procedures and are consistently adhered to throughout implementation. Findings can be corroborated.	• Peer review and debriefing of data analysis with committee chair. • Triangulation – 2 coders (PI and Committee Chair) with consensus easily reached. • Enough participants to reach saturation
Credibility (Authenticity)	Findings flow logically and truthfully from the raw data.	• Findings are clear, context-rich with “thick descriptions” and supported with quotes • Peer review of codebook • Audit trail with analytic decisions recorded throughout data analysis
Utility	Findings are useful and applicable to future action.	• Implications for practice flow logically from study findings • Findings are worthwhile with recommendations for further study.

Reliability

Within NI the definition of reliability is not a statistical measure, but a measure of data (narrative) accuracy (Mertova & Webster, 2020; Riessman, 2008). A SSIG was used in this study to draw out a personal narrative from participants. Using the same SSIG including open-ended questions and prompts designed to answer the specific aims of the study offered a measure of consistency throughout the study. Each participant was asked the same questions and probes as needed and given the time to respond without unnecessary interruption.

Additionally, two researchers coded transcripts separately, compared detailed codes, and discussed and reconciled differences before creating the study Codebook.

Reflexivity

Reflexivity is a necessary and ongoing self-assessment in NI which allowed researchers to examine their own beliefs, values, and attitudes regarding the topic and population being studied and how those beliefs might affect the study. Reflexivity is represented by taking "two steps back to reflect on the reflection" which is considered by qualitative researchers as mirroring of the self (Foley, 2002 p 473 as cited in Kim, 2016). The reflexivity practice is foundational to NI and allows the researcher to view themselves as other (Mertova & Webster, 2020). The technique of analytic memoing was used to journal the PI's judgments, assumptions, biases, and values. These reflexive notations were recorded in the Audit Trail throughout the data collection and analysis processes in this study.

Transferability

Narrative inquiry findings are not necessarily generalizable although they can be transferable (Mertova & Webster, 2020). If enough is known regarding the study population, setting, and methods, the reader may be able to assess the study's applicability and value and apply its findings across populations and settings (Meyrick, 2006).

Study Integrity in Narrative Inquiry: Intersubjectivity

This refers to sharing the meaning of the narrative with a storyteller. This can occur when the storyteller and researcher share meaning, and the researcher interprets the narrative from a shared subjective state of meaning (Clandinin & Connelly, 2000). For the PI it was crucial to remain objective as both narrative inquirer and critic throughout the data analysis period.

Smoothing

This occurs when the researcher smooths out the wrinkles of the narratives to create a the perfect "Hollywood plot" where everything works out in the end (Clandinin & Connelly, 2000). The NI researcher must refrain from adjusting the narrative and the analysis to make the story “better”. The PI made choices about analyzing and drawing from the data in this study, but decisions were not based on creating a happier or more interesting ending, but on remaining true to the voice of the study participants.

Ethical Considerations

In NI, participant stories are the data and therefore the trustworthiness of the researcher and the participants was imperative to the study. Participants may want to be off the record regarding certain topics and/or remain anonymous, which was accommodated to establish and maintain a trusting relationship. During the first 15 minutes of the interview call the PI reviewed the Research Information sheet and discussed the possibility of off the record topics and anonymity procedures which included the use of a participant pseudonym and the redaction of all provider names shared in the interview. The inquirer must maintain the highest standards with the stories shared, working with the data to express the meaning of the participants and not another agenda. Participant interviews were held in private, and recordings and notes from all interviews, including the coding manual were kept by the PI on a password protected computer in the PI’s locked office. Each participant was identified by a pseudonym in all references.

Psychological Risk

A study exploring the lived experience among ESRD patients runs the risk of opening or exacerbating unpleasant thoughts and feelings regarding kidney disease and experiences related to the disease and treatment. In response to this risk, participants were asked about negative feelings related to the interview and the referral process and given time to reflect and discuss their feelings. None of the participants verbalized strong or unpleasant feelings about the topic and no one was referred for follow-up with health professional. During the recruitment period, two individuals on the “Lost to Follow-up” patient list stated they had questions about their status for KT and requested assistance in contacting the CFKTC. As planned for, the PI contacted the nurse manager at the CFKTC with the patient names, medical record numbers and the nature of their inquiry. The nurse manager informed the PI that she would contact the patients herself to answer their questions.

Summary

As nurse researchers seek to understand the challenges patients face, NI can provide the patient perspective of their lived experiences which is so frequently absent within quantitative health studies. This study aimed to explore the lived experience of patients with ESRD referred for KT but who did not pursue a KT as treatment for kidney failure. By better understanding why patients labeled “Lost to Follow-Up” did not complete KT evaluation, providers will have an opportunity to address the reasons and barriers that were insurmountable for some patients. Understanding the lived experience of patients allows providers an invaluable perspective, one in which the patient’s voice is heard speaking about what does and does not work for them in the referral for KT evaluation process. This opportunity also offers providers and scientists a view of the upstream community needs regarding kidney care, kidney health screenings, early diagnosing and interventions. As we seek to better meet the needs of all patients within our diverse community, understanding what patients are saying about their health and the care they receive allows care providers to better meet the needs of those they serve.

CHAPTER FIVE: STUDY RESULTS

Ten patients referred for KT at the UCLA CFKTC and designated “Lost to Follow-Up” by the center, met inclusion criteria and agreed to participate in the study. The participants consisted of seven men and three women between 40 and 73 years of age (median age 57); four participants were African American (AA), five were Caucasian (Cauc), and one was Hispanic (Hisp). Multi-level coding was performed by the study PI and committee chair Dr. Carol Pavlish. Pseudonyms have been used to protect the participant’s anonymity.

Table 3: Participant Overview

Pseudo Nym	Gender	Age	Ethnicity	Participant Background	Self-Statements and Interview Field Notes
Shawn	M	40	AA	Type 1 Diabetic, 12 surgeries, foot ulcers, nerve damage, eye damage. Began HD in Jan 2021. Completed evaluation for KT in San Diego but lacks transportation and support to continue there. Hopes to begin evaluation closer to home. Plans to seek KT.	“I don’t want to stress myself out or worry about something…” “…this [referral for KT] was like just taking on another challenge.” **PI Notes:** Prefers to not dwell on the negatives. Regards KF as one more diabetes-related illness/challenge.
Janice	F	56	AA	Delay in any treatment for ESRD due to her role as full-time caregiver for parents, now deceased. All 5 members of immediate family with ESRD requiring HD, none have had a KT. History of cardiac issues. Unsure if she will seek KT.	“It's like your body is just full of scars now.” “I’m not recovered from that mentally.” **PI Notes:** Sorrowful, feelings and scars related to surgeries and fistula, and the death of her parents. Ambivalent about KT.

Pseudo Nym	Gender	Age	Ethnicity	Participant Background	Self-Statements and Interview Field Notes
Kristen	F	58	Cauc	History of cancer treatment and “too many illnesses” “too sick for HD” and “too sick” to complete evaluation for KT. Complex medical issues. Unsure if she will seek KT.	“I’m definitely sick enough, I’m too sick…” “It’s like I’m not worth it.” **PI Notes:** Talkative, social, self-described health is very complex. Feels hurt and frustrated that none of her providers have been able to help her more.
Warren	M	73	Cauc	Needs liver, kidney, and heart transplant. Receives HD at home, wife is caregiver. Health care managed by Hospital Extensivist team. Overall health too fragile for KT now.	“I have all the confidence in the world in my doctors.” “The longer I live the more problems I have.” **PI Notes:** Has faith in his health care team and his wife to manage his health to the best of their abilities.
Marcus	M	46	Hisp	Suffered debilitating stroke due to HTN in 2017. Denied KT evaluation after stroke due to weakness. Second evaluation for KT delayed currently due to valley fever. Plans to seek KT	“I want to know how it works.” “You gotta roll with it [what comes your way].” “I have to look at this [KT] like realistically.” **PI Notes:** Self-Advocate, provides support to other ESRD patients online. Deals with challenges, problem solver.
Shelli	F	72	Cauc	History of kidney cancer and single nephrectomy. Denied KT after nephrectomy due to cardiac status.	“I’m stuck...I’m trapped.” “It wrecked me.” “It’s horrible, horrible.” **PI Notes:** Frustrated and angry she agreed to nephrectomy and was then denied a KT at multiple KTCs.

Pseudo Nym	Gender	Age	Ethnicity	Participant Background	Self-Statements and Interview Field Notes
Kevin	M	54	Cauc	Family history of primary kidney disease. Father died 2 days post KT. Lost to follow-up due to busy work schedule and "poor preparation"	"I'm hopeful...I'm focusing on what I can control... I have a baby on the way...I'm in a strong position." **PI Notes:** Self-described realist-optimist, shared-values with provider made the difference in him pursuing a KT.
Frank	M	69	Cauc	History of liver transplant 2005, KF due to immunosuppression medication. Lost to follow-up due to pulmonary infection requiring long term treatment. Plans to seek KT	"I feel like a prisoner." "I wouldn't know what to ask anyway." **PI Notes:** Stated the surgical recovery is the hardest part of KT. Tries not to "over think" the process.
Mike	M	73	AA	Ex-military, KF due to type 2 diabetes. On HD for 10 years, lacks caregiver. Sees HD as manageable. Unsure if he will seek KT.	"I'm home alone." "Every year I get a little better." **PI Notes:** Feels okay with status quo, and the social aspect of HD. Still considers KT an option, but states he doesn't have all the answers he might need to pursue KT. Ambivalent about KT.
Josh	M	44	AA	Ex-military, twelve-year history of HTN with intermittent treatment. HD initiated emergently during HTN related hospitalization. Divorced father with four kids, managing HD. Unsure if he will seek KT.	"How can I do this when I don't have anyone to count on?" "They all say you're one of the healthiest people we see." **PI Notes:** Not convinced a KT would help that much. Ambivalent about KT.

Using the inductive process for thematic narrative analysis, four themes were identified from the interview data, including one metanarrative titled “My Story-Living the Struggle.” Each theme will be discussed using illustrative quotes.

Metanarrative: My Story-Living the Struggle

Narrative Inquiry is the exploration of the individual as “self”. Within the stories we tell ourselves and others, lies our beliefs and understandings about who we are in relation to others, society, and culture, across time (Holloway & Freshwater, 2007). In this qualitative study the use of phone interviews between the PI and each of the 10 participants provided the narrative stories of patients labeled “Lost to Follow-Up” by providers at a KTC.

Each narrative provided rich details and a unique perspective of the self, as it was revealed in the participant’s self-talk and the beliefs they expressed. How the participants viewed themselves alone and in relationship to others including their health care provider, deeply affected how they viewed the evaluation process and the health care that intersected their lives. Additionally, the experience that each participant had with their diagnosis and health care team seemed to impact how they viewed themselves. Table 1: Participant Overview provides an abbreviated collection of each participant’s self-statements, which captures a glimpse into the identity from which they speak and construct their narrative.

Theme 1: Wanting Meaningful Information

Knowledge in KT shows up early in the stories of participants, and usually in the form of a gap in knowledge or understanding. Whether it is a participant’s knowledge of their renal condition prior to diagnosis with KF or knowledge of the treatment options available in ESRD, what participants know and when they know it showed up in the data as a significant issue. The stories and quotes that the participants shared will be used to highlight their personal experience.

"I wouldn't know what to ask anyway"

Kidney disease has been called "the silent disease" because patients often do not experience any symptoms when their kidneys are failing. Josh, (see Table 1) recounted a twelve-year history of medical care, beginning when he was discharged from the military at the age of 32. Josh described health care that lacked information regarding his risk for kidney disease as an AA male, a clear diagnosis, planning and treatment. He said he had never experienced a blood pressure (BP) check during his military service and was diagnosed with hypertension (HTN) as a civilian the year he was discharged. He explained "That was the first time in life that I had high blood pressure." Six years after being diagnosed with HTN he was placed on blood pressure medication for the first time, but no one ever mentioned his kidney health until he was hospitalized for HTN in 2020. At that time, four years after being placed on BP medication he began seeing a nephrologist and was even referred to the transplant center, but later the referring nephrologist told Josh he did not need a transplant because his kidneys looked good.

In 2021, Josh was again hospitalized for HTN and headaches. He was also COVID positive upon admission. As an in-patient, Josh was emergently placed on hemodialysis (HD) via an intravenous catheter. He remained an in-patient for seven more days and continued to use the same intravenous catheter for dialysis for seven months before receiving an arterio-venous (AV) fistula in his arm.

Similarly, another veteran, Mike, discovered he had diabetes mellitus (DM) and ESRD one month after being discharged from the military at age 39. He recalled "Getting out of the military after 20 years, I thought I was an iron man back then." He did not remember having any health check-ups during his time in military service. He explained that because he was diagnosed within 12 months of discharge from the military, his condition is considered a service-related condition and the Veterans Administration (VA) pays for a portion of his ongoing care. During the preliminary screening phone call with Mike, he responded to an inquiry regarding being waitlisted for kidney transplant with “I’m not sure what waitlisted means.” During the interview, Mike explained that he has been on dialysis for 10 years and he said “…every year I get a little better and my blood gets cleaned up a little better.” Both statements demonstrate a lack of knowledge and understanding related to the waitlist and the risks and benefits of hemodialysis.

Even when a diagnosis and referral is expected as in the case of Kevin whose father received a KT for Primary Kidney Disease (PKD) at age 70, being prepared by the provider for the “evaluation” could have helped him with the process. Kevin, who admittedly works long hours at a demanding job was “Lost to Follow-Up” after weeks of phone tag and trying to connect with the transplant center. He explained the situation would have been more ideal if the “nephrologist did more prep work in getting me psychologically ready” for the evaluation process.

> No one prepares you for evaluation. It happened very quickly, and it was almost like writing a prescription, there was no real discussion or dialogue around it. It was just like you really need to get a transplant I’m going to refer you blah blah blah…

As Kevin considered how the evaluation process could have been improved, he recommended “Have conversations and talk it through and kind of explain the process a little more so that I’m better prepared to engage.” He explained he was frustrated with the back and forth he experienced with the KTC. He described the tone of the phone messages he received from a clinician at the KTC as sounding “annoyed.”

> I can honestly say I don’t feel like they were that interested you know in making it work…I’m not sure I could have done more, but I think priming me a little more I might have, you know been able to give them my wife’s phone number.

“I was overwhelmed honestly”

Multiple participants told stories of encountering an overwhelming amount of information and often all at once from a dialysis center and/or the KTC. Josh recounted his experience:

> I read up on it [KT], it’s just a lot of information and like I don’t think people know how much information it is. It’s pretty intense…the thing is that even before I started dialysis, I didn’t know I was getting a catheter put in, it’s just I was getting dialysis. I didn’t know I would have this thing in my chest [for seven months]. I didn’t know it was going to be three appointments a week for 3 ½ hours [HD]. I didn’t know, so when you get all this information from the kidney transplant people and they’re talking about all these medications and all the other points they’re talking about…It’s a lot and pretty overwhelming…It’s just information overload.

Janice recounted “I was new to dialysis so um I didn’t have much thought because this was just a new thing to me, everything was like new to me, so it was overwhelming you know.” Marcus, who had suffered a stroke in 2017 recounted beginning dialysis and hearing about KT at the dialysis center:

> You’re rushed into everything, like right away, and they’re throwing all this information at you at one time and it’s hard to take in when you have something going on [dialysis], you’re not ready…they’re throwing like all this information, like you need to make decisions like right now, right now!

Knowing they were risk for KF did not specifically prepare participants for the diagnosis. Janice shared “I knew it was inevitable for me…” and yet she explained that other factors in her life, such as caring for her aging parents, took precedence over her own health and actions. She explained “That’s what my life was and how a typical caregiver is doing everything for them and not taking care of myself.” She went on the describe the inevitability and conflict she felt:

> Kidney disease was prominent in my family. All five members of my immediate family have it; my brother, my mother and my father have passed away. But they were on dialysis, and my sister and I are on dialysis…I had been having symptoms… I knew that it was inevitable for me, but I was holding on because I was my dad's caregiver...I wasn't seeing the doctor regularly because I didn't want him to put me on dialysis.

A family history of illness can increase one's awareness of risk but can be perceived as a death sentence for patients anticipating a diagnosis, and fear may perpetuate avoidance. Kevin explained his father received a pre-emptive (not yet on dialysis) KT for Polycystic Kidney Disease (PKD) and died from sepsis two days post-op. "In my mid 30's I was officially diagnosed, that was that. I was kind of expecting it even though nothing really prepares you." He went on "It was a big shock. I mean I went home, and I cried. I was like okay, so I have this thing." He explained that his diagnosis came with a few handouts about kidney diets. "That was pretty much it…and I knew that little by little it's [kidney function] gonna go down."

Janice described her delay in seeking care for ESRD:

> I felt horrible especially towards the end of 2020. I started getting infections and my legs were starting to swell, so yeah, I knew it was time to do it [seek treatment]. I knew I had to go to dialysis, but I was holding off because I didn't know what would become of them [her parents]. But they passed away and maybe two or three weeks later I was in the hospital because my doctor told me to go to Emergency…I went to the hospital, and they kept me and they told me you can't put this off anymore, and so I was on dialysis by the end of that month.

Shawn explained that he was told by a provider that because of his Type-1 Diabetes his kidneys would fail at some point. "They were gonna fail regardless because of the medical [problems] that I had, you know…I just speeded up the process of damage that I was doing as far as the drinking and smoking cigarettes…and the sugar intake." Shawn was diagnosed with Type-1 Diabetes at the age of three and was told by a provider his kidneys would eventually fail, but that inevitable diagnosis did not help him manage his health or deal with the diagnosis when it came. “In the past I wasn’t going to the doctors. I wasn’t following-up with my appointments…I didn’t take this serious until I started falling apart - it [information] didn’t stick.”

“I didn’t even want to think about it.”

A lack of knowledge and understanding can leave patients with a diagnosis of CKD or ESRD in fear. Kevin described learning about KT and dialysis online. He stated he read “…horror stories from the internet…during my initial stage of discovery…I found myself depressed all the time from all the negative information…I didn’t even want to think about it.” He described the pictures of dialysis fistulas online of the “worst case scenarios…of grotesque veins…distorted and infected.” He also sought information from dialysis chat groups online but found them full of people dealing with suffering. “It wasn’t positive, like how to cope and live with this, it was just a lot of people you know dealing with their suffering.”

Josh described his understanding of the KT survival statistics he had learned. “One of the scary things is when they gave you the outlook, like this adds up to so many years, and this adds up to so many years. One of the shocking things is it seems to me that having a transplant truly didn’t add that much.” This statement about survival demonstrates an inadequate understanding of the cumulative number of years potentially gained from KT following the years spent on dialysis.

Theme 2: Putting Off the Next Step

For many labeled “Lost to Follow-Up” KT was not their top priority at the time of the referral. Some participants saw themselves as too busy to connect with the KTC to begin the KT evaluation process, which can take many weeks or months to complete depending on the tests and procedures required by the KTC. Janice described taking care of her elderly parents full-time at the expense of her own health. “That’s how my life was, a typical caregiver you know, doing everything for them and not taking care of myself.” Kevin explained he was working 12-

14-hour days at a demanding job and playing phone tag with the TC for 2 weeks "Once the transplant center stopped calling, I just threw myself into my work."

"It was so much going on at the time"

Janice explained her role as a caregiver was her priority, and that was in direct conflict with her referral for KT. "I don't think if my parents hadn't died, I would've taken care of it" referencing taking care of herself and seeing her nephrologist. Janice was referred for KT soon after beginning dialysis weeks after her parents died. Josh explained his daughter needed surgery before he could consider going through evaluation. "I had a lot going on in my family...I think I had told them [KTC] that my daughter is having surgery in November, and I want to get her to that and then reconnect with them after that." He explained "I was stressed at the time [of the referral]. I had just suddenly found myself in the middle of a divorce so there was a lot going on."

Janice spoke softly, slowly, and carefully as she described her KT referral experience two months after her parents died during the pandemic:

> …they [her parents] were in their 80s so it [COVID] hit them hard. So, it was all awful, and you know I still I'm not recovered from that mentally (she paused) because I feel like my dad, he was in the late stages of Alzheimer's I didn't expect him to live because he wasn't walking, he wasn't doing much you know. I did expect him to die, but my mom even though she was in her 80s she, I do think she was cheated by COVID, because she had a few years to live I believe.

"I'm nowhere because I have…."

For many participants, health concerns, conditions and priorities interfered with the referral process schedule. Warren explained "Kidney transplant is off the table now due to all the other [health] issues going on with me." Marcus, who suffered a stroke in 2017 was placed on hold for KT evaluation the second time in 2022 due to a respiratory infection, "I'm nowhere since I've got Valley Fever." Prior to the Valley Fever infection Marcus was referred and denied evaluation for KT at a different KTC due to leg weakness following his stroke.

Kristen described a long medical history of illness including thyroid and ovarian cancer for which she received treatment, as well as autoimmune issues. Regarding her status as "Lost to Follow-Up" for KT, she repeatedly described herself as "too sick" and explained that she is either "too sick or not sick enough to go down there" when she had been scheduled to attend evaluation for KT. "I am in this fine-line position, I have to be like… okay I can go right now today! It's kind of like I should get pregnant today, you know, like come on, right now! I mean it's that kind of situation." She laughed at the irony as she described how this situation made her feel.

> It's like I'm never going to be at that sweet spot, it's never going to happen because I'm always too sick and you know it's always going to be a factor. It's always going to be a problem… and every single one of my doctors has said I'm the most complicated case.

She explained that her son agreed that she is the most complicated case "I don't know if I should take that as a compliment or not at this point."

Janice described her many medical conditions and how they affect her desire and ability to attend evaluation for KT.

> I had a quadruple bypass in 2016. I have heart disease, I have neuropathy, I mean I have a lot of things going on with me and dialysis is really challenging for me, and I would love to be free. I would love to have a kidney transplant, but I look at it realistically with my health… I don't know if that's, you know…I have seen a couple of people die from that [transplant] and I know people die from dialysis too…I'm not saying I won't revisit it [KT] but it's not for me right now.

This type of ambivalent response, which was echoed by other participants, demonstrated the decisional back and forth that many patients experience concerning their desire to pursue KT. Kristen explained that she chose not to receive the COVID vaccination, which is required for KT at most KT centers. “Why would I take something I think killed my daughter?” “Without the shot I’m not going down there [KTC]…but COVID is the least of my worries when it comes to that…because I will never be in that sweet spot.” During the interview Kristen spoke at length about her daughter’s recent unexpected death after receiving a COVID vaccine.

Two other “Lost to Follow-Up” patients, screened for participation in the study, explained they had refused the COVID vaccine and were therefore denied the opportunity to be evaluated for KT by the KTC. One of these two patients who had responded to a recruitment email, wrote that it was her decision to not get the vaccine knowing she could be denied treatment, and that was all the information she wanted to share with the PI. The other unvaccinated patient who had called in response to the first recruitment email, was eligible and interested in participating in the study, but was later unreachable after multiple attempts to make contact.

Theme 3: Relating to My Providers

Stories about the participant’s relationship with their health-care providers (including all those providing care such as physicians, nurses, social workers, clinic, and dialysis staff) occurred in eight of the 10 interviews. Three of the eight participants indicated a strong relationship with their provider, however five participants recounted negative encounters with healthcare providers. Both types of relationships will be described with supporting quotes.

“There are people out there who really care about your wellbeing”

Warren, who was denied KT due to his fragile health was interviewed together with his wife who is his full-time caregiver. When asked about his feelings regarding his complex health issues he responded, “I’m very confident in the team I have” and during the interview he repeatedly expressed his confidence in his medical “extensivist” team of providers who manage his health care. He did however describe an experience with a former provider in the past as “very frustrating” due to a lack of clear communication from the provider.

Kevin had recently relocated in the state and was referred to a new nephrologist by a co-worker. He described his new provider:

> He's a wonderful guy, really funny, he does this rap about being a nephrologist and a kidney doctor and…it was refreshing because he's just such a good guy and you know that positive mindset… I really appreciate that. This [new nephrologist] is a very different experience.

Josh shared that his physicians provide him a great deal of support. "There are people out there that actually care about your well-being and your health" referring to his care team.

"He doesn't give two rips about me"

Shelli described the nephrologist she saw during the COVID pandemic, when she was asked to come in to the KTC to begin the preliminary tests of the evaluation process. "He was very negative, and he had a cold and he said he got stuck working because no one else would work because it was the pandemic." Kristen described her relationship with her nephrologist "…my nephrologist is kind of sucky right now, I mean he's not really paying a whole lot of attention to me" Later she explained, "I'm frustrated with my doctor (nephrologist) because I realized he doesn't give 2 rips about me." She explained that neither she nor her primary physician have been able to reach her nephrologist, which she says is why she recently changed nephrologists. "I have a real loyalty to him, and it hurt me so deeply" referring to his non-responsiveness. "He's grown from you know like a three-person office to like 20-person office and he's got these teeny boppers in the front office, and they don't care." She said she realized that this nephrologist was not her advocate. "…I realized that if I don't advocate for myself no one is going to."

Many patients expressed their provider did not consider their values, nor did they confirm their understanding of discussions or any educational content they received. During her interview, Shelli shared a lengthy medical history delivered chronologically that included the names of many physicians and medical centers she had encountered over the years. She described how she felt her interactions with some physicians, and their personal feelings about her, contributed to her being denied a KT. She stated "…he [nephrologist] held a grudge because right after that [after she changed doctors] they wouldn't put me on the transplant list." She described another physician who really listened to her and would adjust her steroid medication weekly to manage her symptoms more effectively saying, "He's a good doctor…I really had a good life while I was with him."

During Shelli's interview she recounted at least 20 different providers that she had seen over the years for different health issues, including lupus nephritis which caused her KF. Her thoughts and feelings about those providers ran the gamut; from pleased, hopeful, to frustrated, disappointed and angry. On three occasions Shelli stated she was "dropped" by a physician who retired or moved their practice, and each time Shelli sought a KT she described how she "climbed the ladder" of evaluation at another KTC, only to be denied repeatedly due to be a series of unfortunate events. She explained, "They [KTC] took out one of my kidneys because [after transplant] they [nephrology] will give you high doses of immunosuppression drugs, so you can't have cancer cells in your body, or you could die from cancer." The KTC that insisted she have a nephrectomy assured Shelli that she would have a new kidney in few months, and in fact Shelli's son was a match for a living donor transplant, and he wanted to donate his kidney to her. However, soon after having the nephrectomy and being worked up for KT she was told by the KTC team that she needed cardiac bypass surgery before she could receive a KT. The cardiac surgery team however said she didn't need the surgery, but they agreed to operate if it was the only way she could receive a KT.

Shelli explained that the cardiac bypass surgery "seemed like a bigger surgery than the KT", and she went to another cardiologist for a second opinion. The second cardiologist diagnosed her with atrial fibrillation and told her she needed to be on blood thinners before she could undergo the coronary bypass surgery. After all this, Shelli explained, "I don't want to take blood thinners because they are bad for me, because my husband can't get the bleeding stopped in my dialysis catheter now, so if I take blood thinners, I won't have a chance." During the interview Shelli expressed deep frustration with some of her providers and her health care overall.

Marcus, who had sustained a stroke in 2017, described an interaction with a KTC staff member during preliminary tests for his initial KT evaluation. He described how the KTC staff member had ended a treadmill test early, stating initially it was stopped due to an equipment failure, but later insisted the test could not be conducted due to Marcus 'weakness. Marcus said he realized early on "It's better not to argue with people like that, you're not going to win."

Janice described the social worker at her dialysis center as not being available or helpful. "The other social worker [who no longer worked at the clinic] would take the time to talk with me and see how things were going. This new one is totally different. It's almost like you have to seek her out…" Marcus also commented on the social worker at his dialysis center. "…if you're not really 'good 'with them, they don't really talk to you about anything."

"That's not what I was told"

A crucial element in the patient-provider relationship is the level of trust and confidence the patient has for their provider. Marcus described his experience when his scheduled treadmill stress test was stopped abruptly, and the clinicians at that KTC contradicted one another as to the reason:

> I said that's not what I was told, and she kind of got a little attitude about the whole deal so I was like (he paused briefly and did not finish this sentence)…and then two weeks later I got a letter in the mail listing all the reasons why they would deny me and one was if you walk with any kind of assistance like a cane or a walker, but none of that was explained in the beginning…If they knew they were going to deny me why put me through all that?

Marcus explained that there was significant travel involved with getting to the KTC and on multiple occasions he and his wife were asked to come in for a single one-hour appointment prior to the evaluation denial. These factors made his initial evaluation for KT burdensome and motivated Marcus to research the KT evaluation process on his own. Marcus described:

> They [dialysis center] made it sound like I had to make a decision on where to go [for KT] and that place [KTC] was going to be the only place for me. But as time went on and I started reading stuff...I realized that they were not the only place, and not the best place for me like they made it out to be.

After Marcus' denial for KT, he contacted a second KTC and was able to schedule another evaluation appointment, which is pending due to his Valley Fever. Marcus described the provider at the second KTC "When I got there, the lady was super nice and understanding, and I didn't get that feeling I got from the first kidney transplant center." He also noted that he was also more knowledgeable [about the KT evaluation] the second time and that helped make the experience more comfortable. "Now that I've done some research and talked to people, I know a little bit more so I'm able to make better decisions on where I want to go."

"He told me the most ridiculous thing"

Shelli described the great disappointment and frustration she experienced over being denied a KT at multiple transplant centers after agreeing to have a nephrectomy on the advice of her oncologist. Shelli explained her decision to get a nephrectomy in advance of a KT, which was later denied, she said "Everyone was saying that [get a nephrectomy], so we just had to do it and now my husband really regrets it. It's the worst thing we ever did, so I'm stuck on dialysis with no hope of ever getting a transplant."

Shelli explained that she has seen many barriers to being waitlisted for KT. "They have a lot of criteria for not letting you get listed… and you get to a certain age, and they won't do it (waitlist you)." She shared her experience with trying to travel as a dialysis patient. "…You can't trust them. They say they have a chair (dialysis) and then they cancel you." She also recounted that after her nephrectomy she required dialysis, and her nephrologist became unreachable. "Once I started dialysis with her, she never answered my phone calls" When Shelli attended a preliminary evaluation appointment at one KTC, she recounted that a nephrologist cautioned her that she would likely lose both feet due to her impaired circulation. “He said I would have my feet cut off if I had a kidney transplant…we went back to the doctor who did the circulation testing and he said that was a ridiculous statement.” She then explained she was denied at that KTC and tried another center. She shared “We think, my friends think they ran me through the mill with all these places to get the money from the insurance for all this testing. You know it’s thousands and thousands of dollars over the years.”

Kevin shared that he was encouraged by a friend to seek a KT outside the US. “I am deeply concerned about the ethics of that...maybe some of those kidneys were harvested from Chinese prisoners. Mike described how the dialysis social worker gave him inaccurate information regarding being “listed.” “…I thought I couldn’t get a kidney transplant. The previous social worker [at dialysis] said we "will put you on the list” but I never heard about it.” A social worker at a dialysis center can help a patient receive a referral to a KTC, but the transplant team at the KTC will decide if the patient can be listed for transplant.

Theme 4: Shouldering the Burden

As participants shared their experiences, they each expressed the importance of having someone to help shoulder the burden of kidney disease and treatment. Not having support made it difficult for respondents to imagine how they could be successful in KT.

“You kind of need someone to help you”

Needing support was one the strongest themes present in the data. Josh described how his divorce affected his outlook. "I was suddenly in the middle of a divorce... and the person that when push came to shove, that was my lifeline, that option was no longer there...How can I do this when I don’t have anyone to count on?” The importance of having someone to count on and someone to help with the daily needs, such as appointments, driving, medications was seen in each interview. Shawn explained “It was too far [to drive] and I didn’t have this support because you have to get back and forth to the kidney transplant center.” During the screening phone call Shawn had alluded to his housing insecurity and during the interview he stated he had relocated to low-income housing. He was figuring out transportation with his sister who was quitting her job to care for their mother full time, and his sister would be able to drive him to the KTC in the future. Mike described his lack of support as a primary reason for not attending the evaluation for KT. “I really don’t have anyone, my wife passed away four years ago and you kind of need someone to help you.” He went on about support:

> I would probably say save that kidney for someone else. I would like to be independent you know, being able to go when I want to go do, but sometimes I feel like I forget, and you can’t never forget to take that medicine. You got to be on time every day and you got to have it set-up, so you know when you are taking that. And I don’t have anybody to work with me cause I’m home most of the day by myself. My daughter works and she’s at school and she’s not here now. I am home alone.

Warren’s wife explained her role as caregiver “We‘ve been together 40 years, whether it was for me to take care of him, I don’t know”. Shelli described her husband throughout the interview as a constant support “If it wasn’t for my husband I wouldn’t go through it, and I told him that too.” She went on “I tell him, if it wasn’t for you… if it’s ever too much for me too much for you just let me know because I’ll quit because it’s a horrible, horrible life.” Jason, who is divorced and has custody of his four children, described his relationship with them and how much he relied on them emotionally. “My kids are really a lifeline that support me.” Frank, who is unable to participate in evaluation for KT due to a long-term pulmonary infection explained that his wife and adult children are his support system. “My wife Is amazing, and she is the only one locally who helps me.” Kevin described his wife who is expecting their first child. “She’s very optimistic and I’m a little more realistic…I think from my perspective she’s in it for the fight…and she chooses to focus on the positive and I appreciate that about her, it keeps me focused on positive things too.”

Marcus, who is part of an online mentoring group for ESRD patients shared his recommendations for mental health support:

> I've talked to a lot of people, not just locally but anywhere in the world…we all get together and talk whether by phone calls, email, or video calls and…I personally think patients should have to go to therapy because if they say it doesn't affect them mentally, it does, and you see that when you see them. A lot of people - they just look defeated. They just give up. Unless you have a support system it's gonna get to you. There's got to be some kind mental emotional assistance for patients, where they can get some help besides the physical help for their health, because that will ensure mental health too.

"With God anything is possible"

Many participants described how their faith in God helped them stay positive during difficult times. Marcus described how his faith gives him the strength he needs. "I have never ever felt sorry for myself, or like why me, so, I just thought if this happens, I'll get past it, you know. A lot of it is our faith and now this is what I have go through and I'll make it past it." Mike explained he feels settled in his faith. "I read my bible and I thank God for what I got…I'm 71 if I get 10 more years, 20 more or five, whatever it is, I'll thank God for it and I'll move on to the next transition." Josh explained his illness and the journey he's been on with diabetes and ESRD has deepened his faith and his reliance on God. "it's a lot, but I'm dealing with it, and it actually brought me, within myself closer to God. So that's where I'm getting my strength and my faith…With God anything is possible, everything is possible" Warren's wife shared that she believed God was involved in her being able to care for her husband all these years. "God has got a path for all of us some way."

CHAPTER SIX: DISCUSSION AND CONCLUSION

This qualitative study used Narrative Inquiry (NI) and Thematic Narrative Analysis (TNA) to explore the lived experience of ESRD patients referred for KT but considered “Lost to Follow-Up.” This study aimed to explore participants ’perspectives about living with CKD, their experiences being referred to a Kidney Transplant Center (KTC) for evaluation, and the factors that affect their treatment decision making. From the stories that participants shared, an overarching metanarrative of My Story-Living the Struggle was apparent. The statements and the language shared by participants in the interviews reveal 10 unique self-perspectives with some common themes across narratives. The descriptive themes that illustrate “Living the Struggle” included: Theme One) Wanting Meaningful Information; Theme Two) Putting Off the Next Step; Theme Three) Relating to My Providers; Theme Four) Shouldering the Burden (Appendix 8).

The themes identified in the narrative stories represent the experiences that study participants had with their kidney disease and treatment choices. The themes are separate, and yet not mutually exclusive, and each theme may affect and contribute to another, as the individual incorporates CKD into their identity, lives their struggle, interacts with multiple providers, their families, friends, and their faith - all within the very complex healthcare and social systems.

How participants see themselves is constructed by the telling and retelling of their unique stories, relevant to their struggle of living with kidney disease, the possibility of KT and other health conditions that often accompany CKD. For a few participants, the narratives were like a monologue, carefully chronicled, in time and space, recited as if reliving their experiences, and without much room for questions from the PI. Some participants told stories that emphasized a repeated pattern of illness and the failure of providers to correctly diagnose and treat them. For a few others, the “struggling self” was more veiled within the stories they shared about hope in the future, faith in a healthcare team and the suggested treatment.

Patients in this study were labeled by providers as “Lost to Follow-Up”; however, these patient-participants did not appear to see themselves as intentionally abandoning their provider or their healthcare treatment. Instead, according to the data, participants viewed themselves as “nowhere”, “prisoners”, “trapped”, “stuck”, “scarred”, “on-hold”, “not worth it”, “wrecked”, “complicated”, “home alone” and “pretty happy”. The language that participants used to describe themselves in their stories differed starkly from the label “Lost to Follow-Up” which reflects the provider’s point of view, not the patient perspective. The reasons these patients were “Lost to Follow-Up” were revealed in the stories they told about themselves and their struggles to cope with difficult internal and external barriers experienced while living with the complexities of CKD and the referral process.

Given the study participants were considered “Lost to Follow-Up” by the KTC, study findings are not unexpected. Previous research regarding ESRD patients and KT has shown similar concerns in obtaining treatment for KF, including the patient’s perceived knowledge, and understanding (Crenesse-Cozien et al., 2019), needed support (Crenesse-Cozien et al., 2019), and trust in the provider (Wachterman et al., 2016). The rich narrative data from participants in this study are consistent with other research among this population, adding texture and nuance where non-narrative approaches may fall short.

Discussion of Study Themes

Wanting ‘Meaningful’ Information

Regardless of the self-described cause, the data revealed some common issues among this non-waitlisted KF population, such as not receiving the right kind of information (i.e., what they wanted or needed) at the right time or the information was not delivered in a way they could understand. In a study among CKD patients at stages 3-5, Waterman et al., (2020) noted that patients desired more information earlier in their care, including how to avoid a KT, how to become waitlisted, and education for a patient’s family and others in their support network. Additionally, in Waterman et al., (2019) researchers found that health literacy, numeracy, and culturally sensitive and tailored patient education (together considered best practice) that was delivered over an eight-month period of time increased patient knowledge and readiness to pursue KT including the percentage of patients successfully completing KT evaluation and being waitlisted for KT.

Participants in the current study claimed they felt overwhelmed by the volume of information they received when they began hemodialysis, were referred for KT, or started the evaluation process for KT. This situation seemed to result when it was their first encounter with unfamiliar educational content. Feeling overwhelmed could also indicate the difficulty of incorporating a significant amount of information into their own stories in a meaningful way.

The current study narratives presented several attributes associated with the type of patient education participants alluded to but did not typically receive. When these attributes were combined, they seemed to describe more ‘meaningful ’patient education. Not seen in other research, ‘meaningful ’patient education, as seen by this PI is more effective in communicating valuable information to the patient/learner at the appropriate time, allowing for more timely and informed decision-making regarding treatment choices.

From the perspective of this PI, the key to ***‘meaningful’*** patient education is the personalization of both content and delivery including: (1) timeliness of delivery of content, which is linked to the patients ’situation, condition, goals, and preferences; (2) frequent ‘non-shaming assessment of the learners ’comprehension and understanding of content, and revisiting topics as needed; (3) early access to tailored educational content; (4) the utilization of literacy, numeracy, and cultural best practices in all educational content.

Patients encountering a large volume of “overwhelming” educational material was noted in other studies examining KT derailers (Brown et al., 2016; Waterman et al., 2019), citing a lack of knowledge and understanding as a significant barrier to being waitlisted for transplant (Koch-Weser et al., 2021; Patzer et al., 2012). In Jones et al., (2018) 167 hemodialysis patients were surveyed regarding their KT knowledge, evaluation experience and attitude. The primary reasons participants in that study gave for not pursuing KT were (1) not being referred for KT evaluation; (2) not knowing how to proceed after referral; (3) not understanding the benefits of KT. Jones et al. (2018) posited that without timely and tailored patient education patients will adhere to preconceptions that may dissuade them from pursuing KT.

The idea that most participants in the current study claimed they lacked adequate meaningful information and understanding, and yet felt overwhelmed by what they did receive, demonstrates a tension experienced by patients during the referral process. This tension speaks to the educational materials, education process, specific techniques that providers use, and other potentially modifiable methods of patient education and engagement used by providers and clinicians during patient encounters.

When a patient cannot connect with personal meaning in the information provided and feels overwhelmed, several reasons may exist. For example, poorly designed educational tools or processes may be contributing factors, hindering the learner's ability to understand and retain information. In a study conducted by Koch-Weser et al. (2021) when "Standard of Care" (SOC) education was used among ESRD patients at four separate dialysis locations, it was often initiated following a late referral for education, lacked health literacy best practices and was not tailored to the learner. This type of patient education has been found to be less effective at improving patient knowledge and readiness for KT. Conversely, utilizing health literacy, numeracy, and cultural sensitivity best practices in patient education, tailoring, and initiating education early and continuing over time has been found to be more effective in improving knowledge and readiness for KT (Waterman et al., 2021).

In a longitudinal RCT, Waterman et al., (2021) evaluated the effect of tailored, modular patient education designed using best practices, delivered online to ESRD patients over time, compared to the SOC education in use. The SOC patient education in this case included a power point presentation and a standardized patient binder of written content, both lacking educational best practices. Tailoring education to meet the patient's needs was found to be significantly more effective than the SOC education in increasing knowledge and understanding and increasing KT “readiness” among participants. Additionally, inconsistent, or inaccurate messaging (Crenesse-Cozien et al., 2019), poor timing for the learner experiencing a high level of stress (Crenesse-Cozien et al., 2019), and/or low health literacy or numeracy (Waterman et al., 2013) have all been found to reduce knowledge retention and patient satisfaction with education.

The tension, expressed by wanting more information, yet being overwhelmed by the information presented, was experienced in some form by all participants in the current study. For individuals facing a life-altering decision to pursue KT, this type of tension may exacerbate patient anxiety and decisional conflict, potentially contributing to “Putting Off the Next Step,” which delays decision making and increases the number of referred patients being labeled “Lost to Follow-Up.”

As evidenced by the narratives in the current study, patients may respond to a lack of adequate, timely or meaningful information by researching treatments on the internet or seeking information from others who have had a similar experience with renal failure. As seen in Farsi et al., (2022), when patients lack adequate information and understanding about their CKD, they commonly use online resources and social media to help find answers to their questions. However, independent research from online sources can exacerbate a patient’s fears, as information may not be accurate for that individual (Farsi et al., 2022).

As one study participant stated, “I wouldn’t know what to ask” signifying his lack of understanding and confidence relative to his KD, treatment and medical care. This statement likely demonstrates this patient’s reliance on the provider to accurately facilitate meaningful education, which is a common patient expectation and perspective (Nicholas et al., 2022).

Putting Off the Next Step: Not Prepared to Advance

Many participants described delaying or avoiding the next step in KT evaluation. There were some common reasons provided. First, some participants ’narratives described the sudden and often surprising diagnosis of ESRD or other conditions that affected renal function. This lack of preparation regarding a chronic disease trajectory seems to reflect a gap in care. For example, Josh explained that he felt unprepared for every medical intervention he experienced, including the central venous catheter insertion and long-term usage, dialysis, and the significant amount of time dialysis required each week. His ongoing lack of preparation, which include a hypertension diagnosis accompanied by inconsistent medical treatment may contribute to Josh’s ambivalence to the idea of KT.

Because ESRD takes years to develop, the United States Renal Data Service (USRDS) tracks and reports on the types of vascular access used to initiate hemodialysis (HD) in KF annually as a marker in care. Using a “mature” Arterial-Venous Fistula (AVF) at the initiation of HD is considered best practice, and maturity occurs at approximately 9 months post insertion. The use of a central venous catheter (CVC), which can be used for HD on the day of insertion is not considered best practice, since a CVC increases infection risk for the duration of its use. Initiating emergency hemodialysis on a patient who is unaware of a CKD diagnosis, represents a lack of adequate monitoring and proactive patient education. Nee et al. (2023) points out that proactive patient education contributes to better patient outcomes in CKD, citing well documented barriers among patients and providers in achieving optimal patient education and engagement.

Providing patient education may meet the “Standard of Care” but confirming a patient’s comprehension and understanding of that educational content is not typically required and is frequently overlooked by providers struggling against the time constraints of medical practice (Moodley et al., 2020). The suboptimal patient preparation and education regarding KT evaluation with the goal of becoming waitlisted for transplant, has been identified as a primary reason KF patients do not successfully complete KT evaluation and become waitlisted for KT (Nee et al., 2023; Waterman et al., 2013). A lack of preparation is especially significant among

AAs and patients of lower SES (Brown et al., 2016: Crenesse-Cozien et al., 2019; Waterman et al., 2013).

A second reason that some participants delayed KT evaluation was the perception that they were too busy to participate in the process. Busyness was described in the form of work (e.g., Kevin) and family caregiving (e.g., Janice). However, being too busy was never the only barrier participants described. For example, Janice described her caregiving role for her parents as all-consuming and revealed she avoided her doctors because she knew they would initiate dialysis.

The deeper thoughts and feelings Janice held may be found in the self-reflective statements she made regarding her mental and physical state. “It’s like your body is just full of scars now” and “I’m not recovered from that mentally.” These statements were made in reference to her heart surgery scars, dialysis fistula scars and the emotional scars that remain after both parents died from COVID in 2021. Her statements carried the weight of her grief and the internal barrier she experienced as she faced KT referral.

In a qualitative study by Cassidy et al. (2017), patients expressed feelings of frustration, anger, regret, fear, denial, and shock regarding their KF diagnosis and needing dialysis. Patients described that their emotions impacted their decision making and how they processed information. In the current study, this PI uncovered what appeared to be the potentiating effects of beliefs and feelings on the participant’s resolve to pursue KT in the face of external barriers.

In the case of Kevin, his work schedule and busyness (external barrier) may have been potentiated by ***internal barriers*** such as his fear of an uncertain outcome, due to his father’s death after KT. The disheartening interactions with the KTC seemed to compound this uncertainty and contributed to this ***internal barrier.*** Interestingly, Janice explained her caregiving responsibilities (external barrier) led to an emptiness of being ***(internal barrier)***, which intensified her aversion to initiating dialysis even though she was experiencing worsening symptoms of KF. A year and a half after the death of her parents, Janice expressed that she continued to have strong feelings of loss and grief ***(internal barriers),*** which might also contribute to her continued delay and ambivalence to follow-up. The presence of both external barriers (Cassidy et al., 2017) and internal barriers found in the narratives of this current study, may demonstrate the symbiotic nature of the struggles that individuals often experience in the course of their illness, decision-making and treatment.

These strong emotions seem to represent internal barriers that contribute to delayed decision-making. Although not found in other literature on barriers to KT evaluation these strong feelings seemed prevalent in the narratives of the current study. Internal barriers seemed to represent the internal struggle and dialogue participants had with themselves regarding feelings, expectations and preconceptions related to their health and innate value. The data alluded to how the more hidden, yet present internal barriers potentiated the external barriers that participants experienced. For example, as Kristen described herself as “complicated” and “too sick” to attend evaluation or get a KT, she explained “It’s like I’m not worth it. It’s like there’s not a doctor out there anymore that takes the time…to say you’re worth our time…” This statement may reveal Kristen’s internal struggle with her sense of worth and value as it is mirrored through her health care providers.

Feelings such as grief (Cassidy et al., 2017); depression (Cassidy et al., 2017); fear (Moodley et al., 2020); mistrust (Wachterman et al., 2018); or the effects of poor or absent communication with a provider (Crenesse-Cozien, 2018) may become internal barriers that impede or obstruct action, leading to avoidance. It may be that busyness was another way of communicating a participants ’ambivalence towards KT. “Putting Off the Next Step” might have been the manifestation of that ambivalence, compounded or potentiated by other barriers such as a lack of support from family, friends, or health care providers.

Finally, a third reason that six of the participants described as a significant barrier to attending KT evaluation was “other” health issues. “I’m nowhere since I’ve got…” is a partial phrase that reflects perceptions about health conditions that could or actually do disqualify or delay six participants from being evaluated for KT. The health concerns that some participants described included Valley Fever, pulmonary infection, and cardiac conditions. These health conditions appeared to be external barriers that prevented their movement forward since they could not meet the criteria for KT evaluation. However, other health conditions, which were not necessarily primary causes but contributed to the participant not wanting to begin or attend KT evaluation included “I’m too sick” and “I have too many things going on with me [my health] right now” or “I had a lot going on with my family and my marriage at the time”. The statements some participants raised as a sort of defense of their delay in follow-up could have represented their unstated internal barriers to taking the next step.

Kazley et al. (2012) examined the “Lost to Follow-Up” phenomenon among ESRD patients and found that 56.6% of study respondents (n=71) had not taken steps to pursue KT after referral. The reasons given by participants in the study by Kazley et al. (2012) included concern regarding not passing medical tests; fear of KT; fear of financial burden of KT; dialysis was not seen as that bad; did not know how to proceed, and some did not understand the benefits of KT. Additionally, some of the respondents in Kazley et al. (2012) wrote narrative comments regarding their frustration with a provider, and fear of organ failure after transplant. These findings reveal some similar reasons for “Putting off the Next Step” and the tension participant’s experienced regarding the barriers they faced during referral.

The deep-seated reasons participants were not proceeding with the evaluation for KT may not be readily apparent, but avoidance behavior such as not returning phone calls or missing appointments at the KTC may demonstrate how internal barriers such as an individual’s emotional state can potentiate an external barrier such as work, caregiving, or other health priority. The often silent or hidden interaction between internal and external barriers was evident in several participants ’stories and appeared to create an insurmountable hurdle in moving forward toward KT evaluation.

Relating to My Provider

A lack of clear communication, presence of mixed messages, or lack of caring attention from providers in dialysis, primary care and/or nephrology was evident in the narratives. Eight participants indicated that poor provider communication strained the patient-provider relationship at some point in the participant's struggles to live with ESRD.

Kevin, described above, explained that when he received the referral from his nephrologist, it was as if he were receiving a prescription. The referral came without any discussion regarding what to expect or anticipate. Kevin, who was already apprehensive about KT, felt this lack of communication did not set him up for a successful referral or KT evaluation. Interestingly, after relocating and connecting to a new nephrologist, Kevin capitulated and indicated that his second referral experience differed completely from the first. His shared values and meaningful communication with the nephrologist seemed to make the difference for Kevin to move forward with KT evaluation, prioritizing his own health needs with newfound confidence.

Other studies (Cassidy et al., 2017) have also found that patient-provider relationships and communication are key to patient engagement and shared decision-making regarding treatment. The relationship that Kevin's new nephrologist established with him seemed to increase his confidence and readiness to proceed with the evaluation process. Researchers have found shared values among patients and their providers can enhance communication and shared decision-making regarding treatment (Vandenberg et al., 2019).

Even though Warren described his current care as “very good,” he spoke about a former care provider who abruptly informed Warren that his liver was “dead” and he would need a transplant. Warren and his wife explained they had no idea Warren had liver disease, which preceded his KF. They explained that if they had known about Warren's liver disease earlier, they could have made lifestyle changes such as going to a plant-based diet earlier, which they began when he was diagnosed with ESRD.

Providers ’lack of adequate communication with patients was found in similar studies (Koch-Weser et al., 2021; Moodley et al., 2021). As reasons, authors suggest that clinicians and providers may not feel comfortable having discussions preparing for KT (Koch-Weser et al., 2021), may lack the time needed to thoroughly explain relevant topics (Moodley et al., 2021), or the information they share with the patient does not match the patient’s experience and therefore goes unheeded (Koch-Weser et al., 2021; Moodley et al., 2021).

Patients receiving mixed messages during provider communication was also evident in the data of the current study. Mixed messages which were described in six of the narratives, referred to hearing two different messages from the same provider or contrasting messages from separate providers. This was demonstrated clearly by Marcus when he described failing a treadmill stress test as he began the KT evaluation process. At first the clinician told him the test was stopped abruptly due to an equipment failure, but later he was told he failed the test due to his muscle weakness. Shelli described being told conflicting information by providers relative to her ability to obtain a KT without it necessitating a bilateral lower extremity amputation. The uncertainty caused by mixed or partial messages was also evident in the patient voices heard in Cassidy et al. (2017), where patients described conflicting messages violated their autonomy. Clear messaging and a trusting relationship with the nephrologist enhance a patient’s sense of control, value, and respect. The result of receiving mixed messages can increase the patient’s apprehension and reduce the likelihood of shared decision-making regarding treatment (Cassidy et al., 2017).

Some participants also described provider communication that they perceived as uncaring. For example, Shelly, Marcus, and Kristen recounted times when they perceived that they did not matter to their healthcare providers. The concept of mattering has emerged as a key component of self-concept which influences a person’s identity and adaptation to challenges. In Flett et al. (2022) “mattering” is described as a modifiable psychological construct that when present is motivational and protective against negativity, and therefore influences ones ’actions. Mattering denotes a sense of importance and significance to another and can be understood as a highly important element of self-concept for patients facing a chronic and/or life-threatening illness such as KF.

Inadequate, poor, or uncaring communication can erode patients ’trust and faith in their provider or the clinicians who provide care for them (Moodley et al., 2021). This erosion of trust can have short and long-term repercussions. For example, patient mistrust for health care institutions and providers can lead to inadequate knowledge or understanding about treatment options (Crenesse-Crozien et al., 2018; Wachterman et al., 2018), and therefore, influences their decision-making and subsequent actions. The effect of pre-existing mistrust in healthcare systems has been particularly well documented among AA patients in KT (Wachterman et al., 2018) and may compound a patient’s avoidance and ambivalence towards follow up or treatment (Wachterman et al., 2018).

Shouldering the Burden

The 2016 qualitative study by Browne et al., eloquently expressed “Everybody Needs a Cheerleader” on the journey to KT. That patient’s voice was echoed in this data, along with the voices of others struggling to manage their kidney disease and the health care system that offers them hope with a possible KT. Treatment for kidney failure places significant demands on an individual. It can involve significant dietary changes, 12-16 hours of weekly dialysis, and a possible KT requiring lifelong adherence to immunosuppression medications. KTC providers expect patients pursuing a KT to have one primary and one back-up caregiver available to assist the organ recipient full-time for one to two months post-transplant. Caregiving responsibilities include all driving, shopping, cooking, help at home with medications and all daily activities.

Each of the study participants spoke of their need for the support of family and friends to help manage their disease, treatment, and decision-making. Support came in the form of a spouse, adult and school-age children, friends, and co-workers. Having support was described as a “lifeline” “necessary” and “you’ve gotta have it.” Not having the necessary support prevented progress toward KT evaluation and ultimately KT. For example, Mike, age 72, a retired veteran on dialysis for 10 years, says he lives alone and does not have the support he would need to manage a KT, so he does not consider transplant a good option. Finding someone available 24 hours a day, seven days a week willing and able to provide caregiving support is not a simple task for many ESRD patients.

Support described as “Faith in God” came up numerous times in the narratives. For some “Faith in God” was rekindled through their struggle with disease and for others their “Faith in God” gave their struggle greater meaning. For all who spoke of faith, their belief and trust in God provided them courage and comfort as they faced the daily challenges of their disease, treatment, and inevitable death.

Themes as Kinetic Imagery

Broadly interpreted, Narrative Inquiry embodies meaning found in a wide array of expressions including written or spoken story, interview, dialogue, art piece, music, or performance (Riessman, 2008). In considering this, one might imagine the themes identified in the participants’ narratives are interconnected like pieces of a mobile. At the center of the art piece lies the self, a constant yet dynamic entity that occupies space in time and is subject to influencing forces. Suspended elements protrude outward from the self, balancing untouched in stillness, interacting with any movement, separate and yet interrelated, dependent on one another and influenced by forces outside itself. (Appendix 9).

When viewed as such, one may see the themes and their related subthemes are linked to the struggling self as well as connected to one another. For example, “Wanting Meaningful Information” seems connected to “Relating to My Provider” since the self (within the struggle of living with ESRD) seems to need more information, that is uniquely meaningful to the individual. In turn, patients appear to view information as more trusted and reliable when shared within a strong relationship with the provider. “Putting Off the Next Step” appears to be connected to

“Shouldering the Burden: Needing Help” since participants described scenarios wherein help and support was needed and wanted to assist them forward on the path towards KT. When support was not immediately available or the self was too absorbed in other demands such as family illnesses or work, the tendency was to put off their own struggles with ESRD treatment and prioritize other more external struggles. For the individual, these elements do not appear to exist in isolation but in a confluence upon the struggling self, which may be directly linked to self-perception and experiences within the four themes.

As providers caring for and educating patients, study findings may be meaningful in that everything done or not done on behalf of the patient may affect the patient outcome in one way or another. The provider’s actions, lack of action, or uncaring communication may directly affect the patient and their decision to pursue treatment or their desire to avoid care altogether. In the case of “Wanting meaningful Information”, participants indicated they needed the opportunity to learn the right educational content, at the right time, delivered in a meaningful way for that individual. However, patient education content is typically delivered to a patient at the provider’s discretion. It is the provider who decides what, when and how to deliver educational content to each patient, and in this way the “Relating to My Provider” and “Wanting Meaningful Information” are inextricably linked. The relationship among themes identified in the narratives, highlights the provider’s role in potentially modifying the referral process to assess and meet the patients ’needs, which could reduce the number of patients labeled "Lost to Follow-Up” (Brown et al., 2016; Kazley et al., 2012; Moodley et al., 2020; Waterman et al., 2020)

Clinical Implications of Findings

The themes presented in the narrative data reveal opportunities for clinicians and healthcare organizations including dialysis centers to improve care for ESRD patients. Practice implications include: (1) increase the timely and effective delivery of ‘meaningful’/personalized patient education as discussed on page 67; (2) improve patient-provider relationships through attentive listening and caring communication; (3) assess patients journey to KT concerning conflicting life priorities and other barriers that exist; and (4) increase support to meet personal and social needs, including mental health support in the form of routine patient counseling to help manage feelings of anxiety, frustration and depression.

Patient Education

One constant in KT is the need for proactive patient education to prepare patients and their families for what lies ahead on the journey to organ transplant. Like other solid organ transplants, the patient education process generally starts when the organ begins to fail and continues throughout the transplant and post-operative period (Waterman et al., 2020). Study participants found the education process to be insufficient, overwhelming, not meaningful and/or inconsistent.

A unique feature of findings in the current study is participants' emphasis on the need for meaningful information that is helpful in understanding how the information fits within their specific situation. The need for a kidney transplant appears to necessitate a major adjustment in each person's life, and therefore, participants appeared to seek assistance with managing their individual challenges including navigating the many steps involved in the pursuit of KT. Therefore, healthcare providers need to assess patient perspectives and their unique struggles in order to provide educational content that helps patients find meaning in the information provided.

Patient education, including the modifiable factors of knowledge and understanding associated with a particular disease, treatment, and prognosis, is achieved through a partnership between the patient/learner and provider/clinician facilitator. The patient must be ready, willing, and able to learn and make an effort to understand new and possibly difficult information, which may require the support of a patient advocate. The provider is tasked with delivering the educational content to a wide variety of learners at different stages of readiness, which requires skill, effort, time, and willingness to teach and discuss relevant health topics to patients (Nicholas et al., 2022; Waterman et al., 2013).

In recognizing patient education outcomes are linked to both patient/learner needs and goals, and the providers ’knowledge, skills, and demands, as demonstrated in the kinetic imagery of the mobile, the issue of inadequate patient knowledge can be seen as a shared hurdle. The provider or clinician initiates the process and is responsible for providing the right content, at the right time, and according to the patient’s preference and unique situation. When providers share the responsibility of patient education with the patient/learner, considering the patient’s values and readiness, they may appreciate the importance of confirming the learner/patient’s comprehension at important markers like the referral to KT event (Cassidy et al., 2017). Additionally, confirming a patient understands the information they receive is crucial to complete the process of patient education and is often overlooked in a busy health care setting.

Communication and Patient-Provider Relationship

Studies on improving clinician communication (Boisey et al., 2016), enhancing patient-centered care (Newall & Jordan, 2015), and improving patient satisfaction and shared decision making are well documented in the literature (Brett et al., 2018; Campbell-Montalvo, 2022) and appeared to be important in the current study. Researchers have noted non-verbal as well as verbal communication is crucial in sending patient-centered messaging to patients and their families (Henry et al., 2012). Greater clinician warmth and empathy, and less nurse and physician negativity were also associated with increased patient satisfaction with care (Henry et al., 2012). Participants in the current study emphasized that their relationship with providers mattered to them all along the ESRD journey.

Patient Barriers to Kidney Transplant

The data showed the external and internal barriers participants faced were rarely assessed or discussed with providers, leaving patients alone to navigate personal and system level hurdles without support. In Patient Centered Care providers and clinicians caring for patients are tasked with the ongoing assessment of the patient’s well-being holistically, physically, mentally, and emotionally. To assess only one aspect of the mind, body or spirit interaction would be insufficient and could hinder the individual’s pursuit of wellness. As taught by Florence Nightingale (1898) a patient is more than one ailment, and it is the role of the nurse [clinician and/or provider] to assess what burdens could impair patient healing and restoration. As seen in the data, the ESRD patient may be confronting various personal, social, or societal barriers on their KT journey. It is the role of the healthcare team, providers, and clinicians to holistically assess for barriers and alleviate suffering to the best of the clinicians ’ability.

Patient Journey Support

Every study participant commented on his or her need for support on the ESRD journey, and most named a particular family member who provided frequent help with dialysis, transportation, and activities of daily living. To uncover any gaps in patient support, providers and clinicians may need to perform a patient needs assessment early and routinely during care to help determine what type of support may be needed.

Another area of support that came up in five of the narratives was living donor kidney transplant (LDKT). The benefits of LDKT were generally unknown by participants, apart from the shortened wait time to transplant, however the participants shared a concern over asking someone to donate an organ. The reluctance the participants voiced seemed to stem from not wanting to burden a family member or friend with such a ‘heavy” and “overwhelming” request.

Josh explained that his younger brother had offered to donate his kidney; however, Josh stated he would rather stay on dialysis than take someone’s kidney, which felt overwhelming. Mike said he worried that his adult children would have the same genetic risk that he carried. Kevin worried about the ethics of living donation and said he was adamantly opposed to the idea of taking someone’s organ. The tension these participants expressed regarding LDKT could denote how alone they felt in their struggle, unable to receive the type of support that was promoted by the KTC in LDKT.

Recommendations

Six recommendations emerge from the patient narratives. First, providing earlier identification and intervention of increased-risk individuals including AA, Hispanic, hypertensive, diabetic, prediabetic through routine screenings. Obtaining serum creatinine and/or low-cost urine albumin screenings and monitoring for at-risk and early-stage CKD individuals, could allow patients more time to learn ways to reduce risk and slow or reverse kidney damage (Nicely et al., 2021; Komenda et al., 2013; Shilpak et al., 2021).

Screening paired with upstream patient education provided to at-risk patients diagnosed with diabetes and/or HTN or a family history of CKD or ESRD may also help improve decision-making and survivability among the ESRD population (Brown et al., 2016; Komenda et al., 2013; Patzer et al., 2017; Waterman et al., 2013). As in the case of Josh, an AA male with HTN, considered high risk, early screenings and education may have helped Josh and his provider identify and address Josh's risk factors and potentially slow or halt the progression of his renal disease.

Second, providing meaningful patient education earlier and more often during patient encounters seems essential. At-risk and CKD patients should be provided with health literacy, numeracy and culturally sensitive patient education with corresponding knowledge and comprehension assessments performed by the provider. Early and continued access to meaningful information including guidance to free and reliable online resources, establishes a meaningful foundation of knowledge on which to build, and potentially slows or interrupts the progression of KD.

Additionally, confirming a patient understands the information they receive is crucial to complete the process of patient education and is often overlooked in a busy health care setting. Confirming a learner's understanding and comprehension of educational materials and what it personally means to them is necessary to allow for informed decision-making in advance of treatment and is imperative when patients may have lower heath literacy or numeracy, which is prevalent among the CKD and ESRD population (Cassidy et al., 2018; Jain & Green, 2016; Wittink & Oosterhaven, 2018). A few participants shared ideas for improving the patient experience during ESRD treatment, including mental health support for patients, and the addition of former KT recipients serving as patient educators and/or navigators.

Third, enhanced provider training in patient-centered communication and patient education best practices has been shown to improve patient satisfaction and trust, which may help reduce decisional conflict among patients faced with a life changing treatment such as KT (Boissy et al., 2016). Providing psychological support, including education and counseling for family caregivers of ESRD patients has been shown to be helpful in reducing stress and caregiver burden among this population (Chan et al., 2016). Communication training was also shown to reduce provider burn-out, which is a bonus to any training (Boissy et al., 2016). Providing trained patient care navigators and patient advocates within dialysis clinics, nephrology care and KTCs to help patients and families navigate the journey to KT seems important (Sullivan et al., 2012; Waterman et al., 2020).

Fourth, assess CKD and ESRD patients for potential internal and external barriers to decision-making about treatment. For example, a dialysis social worker or other healthcare team member may have helped Janice overcome the inertia she experienced as she faced her caregiving responsibilities and subsequent grief. Providers and clinicians who encounter CKD patients routinely need to assess patients for witnessed or more hidden barriers to care.

Fifth, patients deemed “Lost to Follow-Up” could benefit greatly from “Conservative Care.” Conservative Care seeks to manage symptoms and delay the progression of CKD without dialysis and KT. This topic did not come up in the data and according to Hamroun et al., (2022) only 5 % of patients (n=1404), >75 years of age had heard of conservative care for KF. However, when providing patient centered care, topics such as Conservative Care should be addressed with all patients, especially when patients are facing insurmountable health barriers and a denial for KT. Patient centered care that includes a more holistic approach should include Conservative Care education and guidance, which could be triggered by the nephrologist and/or KTC to better meet the physical and emotional needs of patients and families unable to advance to evaluation or the waitlist for KT.

Finally, further research regarding (1) internal and external barriers and their effects on decision-making and treatment choice; (2) what comprises “meaningful” information for patients considering KT and how to tailor education accordingly; (3) effects of providing meaningful information on patients ’subsequent decision- making, outcomes, and satisfaction; (4) effects of communication training for healthcare providers on patient decision-making about pursuing KT and (5) effects of including a patient navigator or decision coach to the KTC care team. Each of these research topics may help providers improve person-centered care in ESRD and reduce the number of patients labeled “Lost to Follow-Up.”

Strengths and Limitations

One of the study strengths included the rich and lengthy narratives that participants graciously provided the PI during the interviews. Participants were open and genuinely interested in sharing their struggles with ESRD and treatment choices. The limitations of this study include a small sample size from a single KT center. Recruitment was difficult among a population labeled “Lost to Follow-Up”. There is also the possibility of recall bias on the part of the participants, although the narratives appeared to reflect participants ’honest perceptions of events. Qualitative study findings are not typically generalizable. However, findings do contribute deeper and more expansive insights to the literature on patients CKD journey, the KT referral and evaluation process, and participant’s reasoning about treatment.

Conclusion

The voices of patients heard in the narrative data have spoken and have echoed patients in similar studies, requesting assistance with the burden of KT access. Many of the barriers they discussed could be overcome with the help of providers, clinicians, and health systems willing and able to make necessary adjustments in care.

Meeting the holistic needs of the patient, regardless of the barrier they face is truly the goal of providing patient-centered care. This study revealed that an opportunity exists for providers to partner with their patients who may be struggling to meet the expectations of a KTC following a KT referral. The narrative data in this study, more than the commonly acquired survey data used among this population, has revealed the nuanced patient perceptions regarding the KT referral process, including aspects of the participants' overall health care experience. Improving some identified aspects of care could be achieved through KTC quality improvement work focusing on enhanced patient education, provider communication skills and patient navigation through the KT referral and evaluation.

Epilogue

This NI study revealed the delicate humanity of the participants. Found within the stories of patients with chronic disease was the struggling self, seeking to regain balance or homeostasis. As the PI pondered the experiences of humankind faced with chronic illness, the imagery of the mobile took on deeper meaning and grew to represent the participants' need to adapt to their life circumstance. The mobile video transcript was rewritten to capture the beauty, artistry, and uniqueness of the patients in the care of a nurse. The rewrite replaced words of art or sculpture with words of personhood and experience.

We tend to think of a person as a very static being, someone that exists in one condition and we move around them and observe them, but when we see them as a person, we observe them in a new way. The person represented by the mobile, can be moved simply by a gentle *touch of the hand or by a conversation as they experience each interaction like leaves fluttering in the wind.*

The constellations of thoughts and feelings are ingeniously balancing within the self. As the person before us moves through space and time, they change, and we see the person never remains the same. As we observe and interact with this person and reflect on their ever-changing being, we may marvel at the wonder of the universe and creation. An individual so delicately constructed that our very presence affects their internal balance and perspective.

There are big movements as a person's life is impacted by conditions of change such as illness, and there are subsidiary movements within the person who is seeking to find balance again. The individual is designed so uniquely, so carefully, that the shadows of their being and the elements in their movement become a sort of secondary work of art, leaving a lasting impression of the audience. Yet, the movement of their being in its grace, tells its own story with or without our audience.

In contrast to life's busyness, the expression of the individual as a mobile art piece, causes one to slow down to appreciate a person's beauty, activity, and responsiveness. From this vantage point, as care provider we may witness that they are turning, they are behaving, they are reacting to their environment and their experiences. There is no way to fully experience another person without spending time with them and allowing them to hold our attention for a time. Anytime you can step out of time and be with another, it is a gift for both.

Appreciating the beauty and humanity of our patients is a privilege. As expressed by Koloroutis & Trout (2012) as we hold space for our patients (and each other), we share in their beauty and dignity.

Appendix 1: Table of Evidence

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
Alansari, H., Almalki, A., Sadagah, L., & Alharthi, M. (2017). Hemodialysis Patients' Willingness to Undergo Kidney Transplantation: An Observational Study. Transplantation proceedings, 49(9), 2025–2030. https://doi.org/10.1016/j.transproceed.2017.09.016	To estimate HD patients' willingness to undergo kidney transplantation and to explore its underlying determinants.	N=248 HD adults patients mean age 55 from King Abdulaziz Medical City and King Abdullah dialysis center	An observational cross-sectional study using a pre-tested questionnaire.	61% of respondents described inadequate knowledge about KT. 69% chose "willingness" for KT (proportion, 0.69; 95% confidence interval [CI], 0.64–0.75). The main reasons against willingness for KT was being too old for transplantation (61%) and fear of surgery (26%). Less willingness was shown with age ≥60 years (adjusted odds ratio [AOR], 0.2; 95% CI, 0.11–0.36; *P* < .001), duration on 0.89; *P* = .021), and being non-married (AOR, 0.47; 95% CI, 0.24–0.93; *P* = .03)	Willingness was negatively associated with older age, lack of spouse, and longer duration on HD. The majority of HD patients reported poor knowledge about kidney transplantation
Alobaidi, S., Dwid, N., Salem, N., Mehdawi, F., Kashgary, A., Alhozali, H., Nablawi, R., Alsolami, E., Shaheen, F., & Akl, A. (2021). Barriers to Kidney	To assess the main barriers to the low KT rate in the Saudi community within Saudi Arabia (SA) Saudi	N=321 hemodialysis (HD) and peritoneal dialysis (PD) (on APD) outpatients. 97.2% were undergoing HD	Cross-sectional self-designed questionnaire study. Data were obtained by direct interviewing using a specifically pre-coded and pre-tested online questionnaire.	HD ≥5 years (AOR, 0.47; 95% CI, 0.25– P <0.05 was considered statistically significant. Barriers to KT: Marital status, singleness p=0.016 Higher or lower education	In Saudi Arabia, patients have a free access to all government transplant centers and financial concerns related to KT were not significant among this population.

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
Transplantation among Adults on Maintenance Dialysis in Western Region Saudi Arabia: A Cross-Sectional Study. Saudi Journal of Kidney Diseases and Transplantation: An Official Publication of the Saudi Center for Organ Transplantation, Saudi Arabia, 32(1), 49–59. https://doi.org/10.4103/1319-2442.318548				P=0.003 Satisfaction with dialysis P=0.0012 Univariate analysis >60 years P=0.027 Widow P=0.0028 Unknown ESRD etiology P=0.002 77.3% of participants were aware that KT is a treatment of choice for ESRD but only 12.5% were aware of KT benefits before they began HD	Access to KT is correlated to referral for KT, 55.5% of participants had been referred for KT evaluation. Among participants preferring a living donor KT a donor was the biggest barrier. Other barriers included knowledge, age and marital status.
Browne T. Amamoo A., Patzer R.E. Krishner J., Well H. Gander J., Pastan S.O. (2016). Everybody needs a cheerleader to get a kidney transplant. A qualitative study of the patient barriers and facilitators to kidney transplantation in the southeastern	To identify barriers to obtaining kidney transplant in the Southeastern region of the country	N=29 adult patients in 5 focus groups. Participants were recruited through National Kidney Association events held in 5 regions.	Qualitative study design with 29 participants. Focus groups of 6-12 in size with one or two trained moderators leading the discussions. Discussion participation was controlled by	Patient identified barriers revealed two prominent themes: (1) The dialysis center approach to transplant is not encouraging or active. (2) Patients remained unsure of treatment options and the cost of treatment. Fear of health care mistreatment or would	Anonymity may have helped to encourage sharing in focus groups. • Limitations: Sample size, this was a convenience sample from 3 states. Dialysis centers as a primary source

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
United States. BMC Nephrology (17). 108. DOI 10.1186/s12882-016-0326-3			allowing only one person to speak at a time and having the moderators ask the same questions to each group in the same order.	not provide them with organs. Barriers to KT are actual and perceived, including knowledge of treatment options, mistrust financial barriers, transportation, distance to the transplant center.	for KT education is not reliable due to variability in training and the financial conflict of interest the dialysis faces in directing patients to get transplanted.
Crenesse-Cozien N, Dolph B, Said M, Feeley TH, Kayler LK. Kidney Transplant Evaluation: Inferences from Qualitative Interviews with African American Patients and their Providers. J Racial Ethnic Health Disparities. 2019 Oct;6(5):917-925. Doi: 10.1007/s40615-019-00592-x. Epub 2019 Apr 24. PMID: 31020606.	To identify both facilitators and barriers for patients to complete the waitlisting process is necessary for KT	N= 24 AA mean age 51.8 years, listed or transplanted patients including with their caregivers if available Plus N=14 transplant	Semi-structured qualitative focus groups and interviews with AA patients, caregivers and, providers to explore thoughts, feelings, and assumptions about transplant evaluation.	Three themes emerged from thematic analysis: (1) transplant center support in navigating steps to wait-listing, (2) provider attitude and messaging (3) education about evaluation and the waiting list. Facilitating factors included staff assistance provided with completing testing, frequent communication positive staff messaging. Barriers were staff inaccessibility, scheduling difficulties, misunderstanding/misinformation regarding the role of the transplant	Findings demonstrated how patients gained the knowledge and self-efficacy to successfully complete transplant evaluation. The primary factor in completing the KT work-up in the evaluation stage, were help from the transplant center with testing, and communication with transplant center staff regarding patient responsibilities and status in the

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
				coordinator, requirements for listing.	evaluation process. Patients who knew their KT coordinator and understood the coordinator's role were more empowered and successful in their journey. Patients needed to know more about what mattered to them and not what the staff felt was important to tell them, demonstrating the inadequate communication patients experienced. As a qualitative study, findings may not be fully generalizable.
Dageforde, L. A., Box, A., Feurer, I. D., & Cavanaugh, K. L. (2015). Understanding Patient Barriers to Kidney	To compare demographic, socio-economic, psychological factors between evaluation visit	N= 104 adults participated (61% male, 46% Caucasian,	Convenience sample of patients referred and scheduled for kidney transplant evaluation at a	Financial concerns were the most prevalent (67.3% affording medication, 64.1% affording operation).	Barriers to follow up and listing for KT are the result of mis-understanding,

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
Transplant Evaluation. Transplantation, 99(7), 1463–1469. https://doi.org/10.1097/TP.0000000000000543	attendees and absentees.	52±12 years).	single center from November 2012 to December 2013 Participants surveyed phone	Prior evaluation at a different transplant center (p=0.029) and being on dialysis (p=0.008) were significantly associated with absence. Attendance was associated with concerns about finding a living donor (p=0.038) and higher perceived general knowledge about transplantation (p ≤0.001). No differences were appreciated in demographic, socioeconomic or health literacy factors between groups.	misinformation, or fear. Additional outreach and education for these patients at an appropriate health literacy level may reduce these barriers by providing accurate information in ways the patients can understand.
Devitt, J., Anderson, K., Cunningham, J., Preece, C., Snelling, P., & Cass, A. (2017). Difficult conversations: Australian Indigenous patients' views on kidney transplantation. BMC nephrology, 18(1), 310.	The Improving Access to Kidney Transplants (IMPAKT) research program: To investigate barriers to kidney transplantation for Indigenous Australian	N=146 Indigenous patients, including views on transplant. Interviews were conducted at 26 Australian hospital and transplant units and	A Narrative Inquiry, interview study, conducted in 2005–2006. Patients were invited to describe what had happened to them over their course of their illness, how it had affected them, and their	Four themes were identified: 90% of respondents of positive interest in transplantation; experienced a range of communication difficulties: felt uninformed about transplant; family involvement was difficult due to lack of information, patients held	A majority of Australian Indigenous patients must move away from rural areas and home to obtain life-saving HD. This makes KT more desirable for many struggling with being away from family and

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
https://doi.org/10.1186/s12882-017-0726-z		dialysis treatment centers	understanding of their current options.	cultural and social sensitivities to the topic.	friends when on HD.
Gander, J. C., Zhang, X., Plantinga, L., Paul, S., Basu, M., Pastan, S. O., Gibney, E., Hartmann, E., Mulloy, L., Zayas, C., & Patzer, R. E. (2018). Racial disparities in preemptive referral for kidney transplantation in Georgia. Clinical transplantation, 32(9), e13380. https://doi.org/10.1111/ctr.13380	Identify and describe racial disparities in preemptive referral for kidney transplantation evaluation in Georgia	n=1,580 referred for pre-emptive transplant evaluation at three transplant centers in Georgia	Patient level data obtained from the transplant centers, Georgia state data from the USRDS, and Georgia census data to determine neighborhood poverty level data available for patient zip codes was used.	The odds of African Americans being preemptively referred for transplant evaluation were 37% (OR=0.63; (95% CI: 0.55 0.71)) lower than whites. Among preemptively referred patients, there was no racial difference (African Americans compared to whites HR=0.96; (95% CI 0.88, 1.04) in waitlisting. Among all patients referred, there was a significant difference between insurance status (Chi-sq=148.5; p<0.001), In multivariable logistic regression adjusted for patient demographics, and clinical factors, socioeconomic characteristics, and neighborhood poverty, African Americans had lower odds (OR=0.63; (95% CI: 0.55, 0.71)) of	The study shows that while African Americans (AA) are being referred at equal percentages as whites among these 3 KT centers, AA patients are not being referred for preemptive KT as often. Having a preemptive KT reduces time spent on dialysis and increases survival rates. More needs to be done among AA patients in terms of preemptive KT education, earlier and at the onset of CKD LDKT is the least common KT among AA ESRD patients.

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
				being preemptively referred compared to whites. 40.4% of preemptively referred patients were White and 40.0% were African American patients were waitlisted over the study period (p=0.70), 10.9% of white patients received a living donor transplant vs. 3.1% of African Americans (p<0.001).	
Hamoda, R. E., Gander, J. C., McPherson, L. J., Arriola, K. J., Cobb. L., Pastan, S. O., Plantinga, L., Browne, T., Hartmann, E., Mulloy, L., Zayas, C., Krisher. J., Patzer, R. E., (2018). Process evaluation of the RaDIANT community study: a dialysis facility-level intervention to increase referral for kidney transplantation. BMC Nephrology,	To test the effectiveness of a 1-year education intervention in increasing referral for kidney transplant evaluation among selected Georgia dialysis facilities.	N=26 Dialysis facilities in Georgia	Facility-level randomized trial testing 20-item survey to the staff involved with transplant education in 67 dialysis facilities	Staff from 65 of the 67 dialysis facilities completed the questionnaire, identifying patient barriers as perceived by staff. (1) socioeconomic status (73.9%), (2) inability to afford medications after transplant (72.3%), (3) patient perceived fundraising requirements (60.0%). Additional barriers listed by staff include lack of transportation to a	Researchers assessed participant staff member's perceived barriers that may have prevented referred patients receiving intervention materials from beginning or completing the kidney transplant evaluation. Staff recommend earlier discussions with

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
(1):13. Doi: 10.1186/s12882-017-0807-z. PMID: 29334900; PMCID: PMC5769303				transplant center (56.9%), contentment with existing dialysis treatment (53.9%), and loss of interest in continuing the evaluation process once referred (53.9%)	patients about evaluation requirements and financial advisement education and training.
Hart, A., Bruin, M., Chu, S., Matas, A., Partin, M. R., & Israni, A. K. (2019). Decision support needs of kidney transplant candidates regarding the deceased donor waiting list: A qualitative study and conceptual framework. Clinical transplantation, 33(5), e13530. https://doi.org/10.1111/ctr.13530	Researchers sought to understand knowledge needs and decision support needs with KT outcomes and treatment options.	N=28 adult kidney transplant candidates from 2 centers in Minnesota	Grounded theory approach, semi-structured interviews were conducted between March 2016 and August 2016 which informed the four focus groups from October 2016 and April 2017	Themes identified (1) candidates lack a thorough understanding of ESRD treatment options and demonstrate a lack of understanding about the KT waiting list, KT outcomes and prognosis. (2) candidates want frank discussions about outcomes and personalized prognosis. (3) informed decisions are affected by emotional factors. (4) participants rely on family and friends to help process information, many patients want the health care professionals to speak with his or her family and friends to help make medical decisions.	KT candidates have limited understanding regarding treatment options and possible outcomes on the KT waiting list. Personalized risk information and education helps patients process risk and treatment options. that recognize how patients process information and balance competing risks may improve informed decision making.

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
Hwang, S. J., Tan, N. C., Yoon, S., Ramakrishnan, C., Paulpandi, M., Gun, S., Lee, J. Y., Chang, Z. Y., & Jafar, T. H. (2020). Perceived barriers and facilitators to chronic kidney disease care among patients in Singapore: a qualitative study. BMJ open, 10(10), e041788. https://doi.org/10.1136/bmjopen-2020-041788	To outline the facilitators and barriers to patients' self-management of pre-dialysis chronic kidney disease (CKD). Design Qualitative. Setting	N=20 patients >40 years with Diabetes, Stage 3 & 4 CKD Three polyclinics in a public primary care institution in Singapore. Participants	Qualitative interviews. The combined use of grounded theory and deductive analysis	Key barriers to the management of pre-dialysis CKD: A lack of knowledge and awareness of CKD among patients, passivity toward self-management and poor communication between doctor and patient in the primary care setting in Singapore. Strong interpersonal relationships with doctors and family members were main facilitators to self-management in these patients.	Patients with a high level of ownership of their health did much better with self-management while others relied heavily on family to manage their health care. many female patients declined to participate which led to an imbalance in the gender distribution. Only English-speaking diabetic patients participated.
Kazley, A. S., Simpson, K. N., Chavin, K. D., & Baliga, P. (2012). Barriers facing patients referred for kidney transplant cause loss to follow-up. Kidney international, 82(9), 1018–1023.	To identify barriers to kidney transplant for patients who have been referred by a physician for KT.	N=83 adults vascular access (dialysis) clinic patients at an academic medical center in South Carolina	Survey design of patients in the vascular clinic who met inclusion criteria. Nurses within the clinic would survey patients.	Study results reveal the most common barriers to follow up and listing for KT among patients who have been referred are misunderstanding, misinformation or fear.	The most common reasons for not completing the referral appointments were patients did not think they would pass the medical tests, were afraid of KT surgery, could not afford the medicine or

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
https://doi.org/10.1038/ki.2012.255		patients, 79% African American, 59% female mean age 53.5 referred and met selection criteria by not completing an evaluation for transplant.			surgery. Outcomes are both real and perceived barriers and can be contributed to unclear provider communication, misinformation received from non-medical friends and family, limited health literacy and or health decision making ability.
Knight, R. J., Teeter, L. D., Graviss, E. A., Patel, S. J., DeVos, J. M., Moore, L. W., & Gaber, A. O. (2015). Barriers to preemptive renal transplantation: a single center questionnaire study. Transplantation, 99(3), 576–579. https://doi.org/10.1097/TP.0000000000000357	To determine factors that hinder or favor referral for transplantation before dialysis is initiated.	N=197 participants at Houston Methodist Hospital Transplant Clinic.	Survey questionnaire was administered to prospective kidney transplant recipients.	The primary barrier to renal transplantation referral before dialysis was patient education regarding the option of preemptive transplantation. Factors significantly associated with referral before dialysis were the diagnosis of polycystic kidney disease, white recipient race, referral by a transplant nephrologist, and employed status. One hundred six subjects (54%) had not been informed of the option of	Knowledge of treatment options before beginning dialysis is highly associated with referral and KT. Other significant factors effecting preemptive KT include polycystic kidney disease, white recipient race, referral by a transplant nephrologist, and employed status. Greater effort should be applied to patient

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
				transplantation until after initiating dialysis.	education regarding preemptive transplantation early after the diagnosis of end-stage renal disease.
Lockwood, M. B., Saunders, M. R., Nass, R., McGivern, C. L., Cunningham, P. N., Chon, W. J., Josephson, M. A., Becker, Y. T., & Lee, C. S. (2017). Patient-Reported Barriers to the Prekidney Transplant Evaluation in an At-Risk Population in the United States. Progress in transplantation (Aliso Viejo, Calif.), 27(2), 131–138. https://doi.org/10.1177/1526924817699957	To assess and understand barriers to KT evaluation among urban "at risk" patients. Patient-reported barriers to the pre-kidney transplant medical evaluation in populations largely at-risk for evaluation failure.	N=100 adults were enrolled at an urban, Midwestern transplant center.	Questionnaire 90-days after evaluation for KT. A prospective Cohort study of pre-kidney transplant patients at one urban Midwestern transplant center	Statistically significant barriers Race/ethnicity of Hispanic, Asian or Pacific Islander P=0.004 Co-morbidity Index p=0.024 Income <$40,000 per year p= 0.025	Researchers identified 19 patient-reported barriers to completing evaluation for KT - grouped into 5 categories including: communication, physical health, socioeconomic psychosocial, and access. Poor communication between patients and providers, being the most prominent patient-reported barrier identified. The majority of HD patients reported

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
					poor knowledge about kidney transplantation.
Patzer, R. E., McPherson, L., Wang, Z., Plantinga, L. C., Paul, S., Ellis, M., DuBay, D. A., Wolf, J., Reeves-Daniel, A., Jones, H., Zayas, C., Mulloy, L., & Pastan, S. O. (2020). Dialysis facility referral and start of evaluation for kidney transplantation among patients treated with dialysis in the Southeastern United States. American journal of Transplantation: Official Journal of the American Society of Transplantation and the American Society of Transplant Surgeons, 20(8), 2113–2125. https://doi.org/10.1111/ajt.15791	To examine possible barriers to referral and evaluation in KT	N=34 857 ESRD patients mean age of 59.5 years, from 690 dialysis in Georgia, North Carolina, or South Carolina between January 1, 2012 and August 31, 2016	Two primary outcomes were measured: referral and evaluation start. Referral date was defined as the date when one of the nine transplant centers received a referral form for a kidney transplant evaluation. Patient- and dialysis facility-level characteristics were obtained from CMS-and the USRDS database	11 862 (34.0%) of patients were referred within 1 year of starting dialysis, 5716 (48.3%) were evaluated within 6 months of referral. The mean age among those referred within a year of dialysis start, was 54.0 (95% CI: 53.8-54.2) and lower among those who started the evaluation within 6 months of referral (52.5 years; 95% CI: 52.2-52.9). 85.1% of all dialysis patients were treated at for-profit dialysis facilities. Among the 9 transplant centers included, the median time from ESKD start to referral was 245 days and to evaluation start was 91 days. The median proportion of patients who start the evaluation among those	Among the 690 dialysis facilities there was a great deal of variation in referrals for KT among ESRD patients. the median number of those referred to KT within 12 months was 33.7%, and 16.1% of those patients referred began evaluation for KT within 6 months. This suggests there are barriers between referral and evaluation that affect KT access and shows there is an opportunity to increase the conversion of referrals to evaluations.

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
				referred at the transplant center level was 55.1%	
Schold, J. D., Gregg, J. A., Harman, J. S., Hall, A. G., Patton, P. R., & Meier-Kriesche, H. U. (2011). Barriers to evaluation and wait listing for kidney transplantation. Clinical journal of the American Society of Nephrology: CJASN, 6(7), 1760–1767. https://doi.org/10.2215/CJN.08620910	To evaluate factors and patient characteristics associated with successful KT journey.	N=3029 Cohort of adult patients referred for kidney transplantation to the University of Florida from January 2003 to July 2008	Data were derived from an internal database. Primary outcomes of the study were patient likelihood to receive an evaluation, waitlisted, receive a transplant from the time of referral. Demographics derived from medical records.	Older age, lower median income, and public insurance were associated with decreased likelihood in obtaining a KT	Race/ethnicity, age, insurance status, and income are highly associated with patient progress to transplantation Disparities of Race/ethnicity may be largely explained by insurance status and income despite Medicare entitlement for ESRD and KT.
Waterman, A. D., & Peipert, J. D. (2018). An Explore Transplant Group Randomized Controlled Education Trial to Increase Dialysis Patients' Decision-Making and Pursuit of Transplantation. Progress in transplantation (Aliso	To study whether the Explore Transplant education program increased patients' readiness to pursue transplant, transplant knowledge, informed transplant decision-making, discussions about	N=253 patients in 20 dialysis centers St Louis, Missouri	Randomized controlled trial, pre- to post intervention survey. Patients at participating dialysis centers were randomized to receive either (1) Explore Transplant education	Compared to standard-of-care group, patients who received the intervention were more likely to increase in their stage of readiness for LDKT (odds ratio: 2.50; 95% confidence interval: 1.10-5.66), had greater transplant knowledge (P < .001), and were more likely to begin or restart	The education program was effective in increasing KT. Purposeful education helps patients and especially AA patients with decision making and follow-through with KT steps.

Citation	Purpose	Sample / Setting	Methods Design, Measures	Results	Discussion Limitations
Viejo, Calif.), 28(2), 174–183. https://doi.org/10.1177/1526924818765815	transplant with potential living donors, pursuit and receipt of living or deceased donor transplant, and whether these effects varied by race.		program, (2) standard-of-care transplant education. Changes in transplant knowledge, self-efficacy, and perceived benefits and disadvantages to DDKT and LDKT were measured using linear regression.	transplant evaluation (38% vs 24%, P = .006). Black patients were more likely to take action toward KT compared to whites. Print and video education had the greatest affect in patients discussing LDKT with MDs (P = .05) and completing KT evaluation (P = .04)	Limitation: Only white and black dialysis patients were part of the study population used was not generalizable

Appendix 2: Semi Structured Interview Guide questions

Introduction : Five minutes

- a. Welcome the participant and thank each person for participating.
- b. State that the interview is being recorded for the study.
- c. Ensure anonymity.
- d. State the interview is approximately one hour and state the finish time, ensure the stated time is acceptable.
- e. Discuss gift card of $50 for one hour interview, including when and how payment will be delivered. Verify mailing address or email address to deliver payment of gift card.
- f. Ask if they have questions. Answer any questions participant may have.
- g. Using common language briefly inform the participant of the types of questions you will be asking them to discuss in the interview.

Questions: Complete in fifty-five minutes

1) Would you please tell me about your kidney disease?
2. How did you learn about your kidney disease (kidney failure)?
    - a. When was that and how was that experience for you?
    - b. What did you learn about why you have kidney disease?
    - c. What treatments have you had since being diagnosed with kidney disease?
    - d. What has it been like to live with kidney disease – and its treatments? Can you think of a specific time when it was particularly difficult? How did you manage that?
3. Can you tell me what you know about kidney transplant?
    - a. When and how did you learn about kidney transplant?
    - b. How was that for you?
4. Can you tell me about being referred for KT?
    - a. What was the referral process like for you?
        - i. What happened during the referral time kidney transplant?
        - ii. How were you feeling about being referred to the transplant center?
        - iii. What did you know about transplant before you got the referral?
        - iv. What would you have changed about the referral process?
        - v. What was helpful to you during the process?
        - vi. What could be improved about the process?
5. What did you think about / feel about pursuing a kidney transplant?
    - a. Can you talk about when you were making the decision?
        - i. What was that like?
        - ii. What do you think influenced you as you were thinking about the decision to either pursue or not pursue a kidney transplant?
        - iii. What are your current thoughts about treatment options such as kidney transplant?
        - iv. What did your family think about you getting kidney transplant?
        - v. What do they think now?
    - b. What else did you consider as you were thinking about your treatment options, including a kidney transplant?
    - c. How is that for you?
6. What do you know about the “evaluation for kidney transplant” process?
7. What do you know about being “waitlisted” for kidney transplant?
    - a. What do think about being “waitlisted for kidney transplant”?
    - b. How do you feel about the idea of being “waitlisted”
    - c. How do you feel about the idea of NOT being “waitlisted”
8. How do you feel about your health now?

9. Of all the topics we have talked about today, what do you think matters the most?
10. Is there anything about your kidney disease or your medical care that you want to talk about?

Closure of interview

   a. Thank the participant for his or her time and for sharing their story
   b. Confirm if a follow-up interview is needed or could be possible

Appendix 3: SCREENING CONSENT

Thank you for calling Jill Scherrey regarding the study From Referral to the Evaluation: A Narrative Study on Factors Associated with Patients “Lost to Follow-up” in Kidney Transplant.

I would like to ask you a few questions to determine whether you may be eligible for this research study. Before I begin the screening, I would like to tell you a little bit about the research.

This is a study designed to explore the experiences of patients referred for kidney transplant at UCLA who did not begin or complete the evaluation for kidney transplant process, not due to medical reasons. Patients who meet our inclusion criteria will be interviewed and asked about their experience with their referral process. The interviews themselves will provide the data that will be analyzed.

Would you like to continue with the screening? The screening will take about 10 minutes.
I will ask you about your referral for kidney transplant.
You do not have to answer any questions you do not wish to answer or are uncomfortable answering, and you may stop at any time.
Your participation in the screening is voluntary.

Your answers will be confidential. No one will know your answers except for the research team. Your answers will be typed into my (Jill’s) computer which is password protected and remains in locked home office. If you do not meet our inclusion criteria your answers will be deleted.

If you meet our inclusion criteria your answers will remain on my (Jill’s) password protected computer in her locked home office, along with all research notes, interviews, and transcriptions.

Would you like to continue with the screening?
If no, thank the person and hang-up
If yes, continue with the screening by asking the following questions:

1. Have you ever received a kidney transplant?
2. Are you currently or were you ever “waitlisted” for a kidney transplant?
3. Were you referred to the kidney transplant center at UCLA for a kidney transplant?
4. Do you remember the circumstances of your referral for kidney transplant well enough to share them with me?
5. Did you begin the “evaluation for kidney transplant” process at UCLA or elsewhere?
6. If yes, did you complete the evaluation process for kidney transplant process at UCLA or elsewhere?
    a. If NO, was it your decision not to complete the evaluation process?
7. If you did not begin the evaluation for kidney transplant process, was that your decision?
8. Were you ever told you were ineligible for a kidney transplant?
    a. If yes when and by whom?

Thank you for answering the screening questions. [Indicate whether the person is eligible, requires additional screening, or is not eligible and explain why.]

Do you have any questions about the screening or the research? I am going to give you a couple of telephone numbers to call if you have any questions later. Do you have a pen? If you have questions about the research screening, you may call me (Jill) and I will answer your questions.

If you have questions about your rights as a research subject or if you wish to voice any problems or concerns you may have about the study to someone other than the researchers, please call the UCLA Office of the Human Research Protection Program at (310) 825-7122.

Thank you again for your willingness to answer our questions.

Appendix 4 : RESEARCH INFORMATION SHEET

A Study on Factors That Patients Consider After Being Referred to the Clinic for Kidney Transplant

INTRODUCTION

Jill Scherrey, MSN, RN, and Dr. Carol Pavlish PhD, RN from the School of Nursing at the University of California, Los Angeles are conducting a research study. You were selected as a possible participant in this study because you were referred to the Connie Frank Kidney Transplant Center at UCLA for a kidney transplant. Your participation in this research study is voluntary.

WHAT SHOULD I KNOW ABOUT A RESEARCH STUDY?

- Someone will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

WHY IS THIS RESEARCH BEING DONE?

This study is being conducted to help nurse researchers understand your experience with the referral process for kidney transplant. We want to understand the factors that influenced your decision making about whether to get a kidney transplant.

HOW LONG WILL THE RESEARCH LAST AND WHAT WILL I NEED TO DO?

Participation will take 45-60 minutes of your time for a video or phone interview. You may also be asked to volunteer to participate in a shorter (30 minute) follow-up phone interview.

If you volunteer to participate in this study, the researcher will ask you to do the following:

- Speak by video or phone for about 1 hour with the investigator.
- Describe what it is like to live with kidney disease.
- Discuss your experience with being referred for a kidney transplant.
- Describe your thoughts and feelings about kidney transplant.
- Discuss what factors influenced your decision about kidney transplant.

ARE THERE ANY RISKS IF I PARTICIPATE?

- There are no anticipated physical risks or discomforts associated with this study.
- You may experience uncomfortable feelings when speaking about your kidney health history and your decision making with kidney transplant.
- You will be asked to speak privately on video or the phone during the interview. If you do not speak privately with the researcher, others may overhear what you say during the interview.

ARE THERE ANY BENEFITS IF I PARTICIPATE?

You may benefit from the study by better understanding your decisions regarding kidney transplant.

The results of the research may help health care providers better understand the experiences of patients who were referred for kidney transplant and did not continue to evaluation or become waitlisted for kidney transplant.

You may freely choose not to participate in this research study.

HOW WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?

The researchers will do their best to make sure that your private information is kept confidential. Information about you will be handled as confidentially as possible but participating in research may involve a loss of privacy and the potential for a breach in confidentiality. Study data will be physically and electronically secured. As with any use of electronic means to store data, there is a risk of breach of data security.

Use of personal information that can identify you:
Your interview will be anonymous, and your name will not be recorded. A number will be assigned to your interview and all reference to names will be eliminated from the research text.

How information about you will be stored:
The audio recording of your interview will be transcribed, and both the audio recording and the transcribed interview will be stored on the researcher's password protected computer in a locked office.

People and agencies that will have access to your information:
Your anonymous interview transcript will be read by the two researchers during the analysis phase of the study.

The research team, and authorized UCLA personnel, may have access to study data and records to monitor the study. However, University employees are bound by strict rules of confidentiality. Publications and/or presentations that result from this study will not identify you or any participants by name.

USE OF DATA FOR FUTURE RESEARCH

Your de-identified data may be kept for use in future research.

WILL I BE PAID FOR MY PARTICIPATION?

You will receive a $50 gift card for a one-hour phone interview.

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The research team: Jill Scherrey, Dr. Carol Pavlish

If you have any questions, comments, or concerns about the research, you can talk to the one of the researchers. Please contact: The primary investigator Jill Scherrey XXX@XXX.XXX or Faculty Advisor Dr. Carol Pavlish PhD. XXX@XXX.XXX .

UCLA Office of the Human Research Protection Program (OHRPP):

If you have questions about your rights as a research subject, or you have concerns or suggestions and you want to talk to someone other than the researchers, you may contact the UCLA OHRPP by phone: XXX-XXX-XXXX; by email: XXX@XXX.XXX or by mail: Box 951406, Los Angeles, CA 90095-1406.

WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?

- You can choose whether you want to be in this study, and you may withdraw your consent and discontinue participation at any time.
- Whatever decision you make, there will be no penalty to you, and no loss of benefits to which you were otherwise entitled.
- You may refuse to answer any questions that you do not want to answer and remain in the study.

You will be given a copy of this information to keep for your records.

Appendix 5 : Oral Consent for Study Participants

Hello, I am calling from UCLA School of Nursing, may I speak with insert name?

Hello, insert name, my name is Jill Scherrey, and I am a graduate student in the UCLA School of Nursing, and I am calling to invite you to be a part of a research study I am conducting about the kidney transplant referral process at the kidney transplant center at UCLA.

May I tell you about the study?

- The purpose of the research study is to understand your experience with the referral for kidney transplant process.
- Your participation in this study is voluntary.
- If you agree to participate, I would like to arrange a time to interview you by phone about your experience with kidney disease, about being referred for kidney transplant, and how you made your decision. We hope to improve our communication with patients and how we can support them as they are referred to the transplant center.
- Our interview will be private and will last approximately one hour.
- I will compensate you for your time with a $50 gift card for approximately 45–60-minute interview.
- With your permission, I will audio record your interview so I can study it later. We are hoping to include about 10-16 patients in this study.
- I will keep your name anonymous, and I will keep your interview recording and my interview notes on my computer, which is password protected and locked in my home office.

- Would you be interested in participating in this study?
  Yes /No
    - If yes, can we schedule your interview now? When would you be available for your phone interview?
    - If no, thank you very much for your time. Goodbye
    - If maybe, do you have questions I can answer that would help you decide?
    - Would you like me call back another time to discuss the study with you further?

- If you have any questions, you can reach me by phone or email.
- EmailXXXX@XXXX, cell XXX-XXX-XXXX

Appendix 6: Email script

Hello,

My name is Jill Scherrey, and I am a doctoral student in the School of Nursing at UCLA. I would like to invite you to participate in a research study that I am conducting through the UCLA School of Nursing. If you were referred to the kidney transplant center at UCLA for a kidney transplant, I would like the opportunity to speak with you by phone to assess your eligibility for this study.

As a patient referred to the kidney transplant center at UCLA you can help us understand the factors involved in your decision-making regarding transplant. This information is important to us as we seek to improve patient care for all patients at UCLA.

I specifically want to speak with patients who were referred to the transplant center but did not begin the evaluation for transplant process. If this sounds like your experience, and you are eligible and want to be a part of the study, I will compensate you for your time with a $50 gift card for a one-hour phone interview about your experience.

This study will help us understand your experience and may improve the care we provide kidney patients. If you are eligible, interested in participating in this study and being provided a gift card for your time, please reply to this email and tell me the best way to contact you by phone or call me at XXX-XXX-XXXX. If I am unable to take your call, please leave a message and I will call you back within 24 hours.

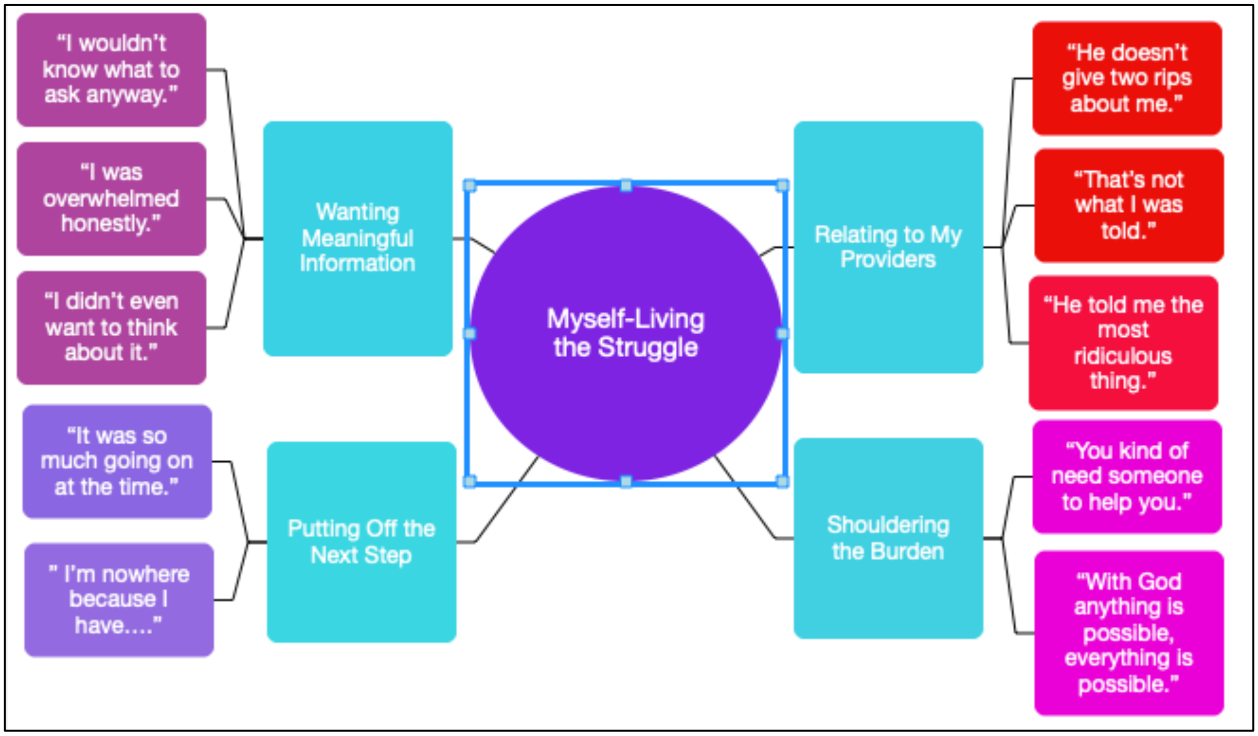
Thank you very much!
Jill Scherrey MSN, RN

Appendix 7: Phone script

Hello,
My name is Jill Scherrey, and I am a nurse and doctoral student at UCLA. I am calling from the UCLA School of Nursing, and I am calling to speak with NAME.
Hello NAME, how are you today? Thank you for taking my call.
I am calling to speak with you about participating in a research study that we are conducting about the kidney transplant referral process at UCLA. Do you have 5 minutes to talk with me about this study?
(If yes, proceed with script. If no, ask to arrange a different time to inform them about the study – or if not interested at all, then thank them and conclude the call).
I would appreciate an opportunity to interview you by phone and learn about your experience with being referred for kidney transplant at UCLA.
As a patient referred for a kidney transplant, you can help us understand the factors involved in your decision-making about getting a kidney transplant.
I specifically want to speak with patients who were referred to the transplant center for kidney transplant but did not begin or complete the evaluation for transplant process.
Was that your experience?
If you are interested and eligible to be a part of the study, I will compensate you for your time with a $50 gift card for a one-hour phone interview about your experience.
This study will help us understand your experience and may help us improve the care we provide our kidney patients.
Does this sound like something you would be interested in doing?
If no, thank you for your time.
If potential participant is wavering or uncertain, ask “Can I send you more information about the study by email or postal mail?”
If yes, great! Would be alright with you if I asked a few questions now about your eligibility, and then we can set up another time for your phone or video interview. I would like to send you more information about the study. What is the best way to send you this information?
If no, okay when would be a good time for me to call you back?
If yes,

1) Have you ever had a kidney transplant or are you listed for KT at another transplant center? [If yes to either, say thanks and let them know you are only looking to interview patients who have never been listed nor had a KT. Thank them for their time and say goodbye.]
2) Do you remember your experience of being referred to kidney transplant center at UCLA?
3) Are you willing to speak with me by phone for about an hour to talk about your experiences with being referred for a kidney transplant?
4) What day and time can we schedule your interview?
5) After scheduling a follow up call or interview verify their phone number and email address and thank them for their time. Provide your phone number to potential participant in case they have follow up questions.

Appendix 8: Theme Map



Appendix 9: Mobile Metaphor Images

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