STARS

Electronic Theses and Dissertations, 2020-

2020

Transplant Center Criteria and Inequalities Within Transplant Wait Listing Process

Melanie Bergeron
University of Central Florida

TRANSPLANT CENTER CRITERIA AND INEQUALITIES
WITHIN TRANSPLANT WAITLISTING PROCESS

by

MELANIE E. BERGERON
B.A. Rhode Island College, 2002
B.S.W. Rhode Island College, 2002
M.S.W. University of Central Florida, 2014

A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in the Doctoral Program in Public Affairs
in the College of Community Innovation and Education
at the University of Central Florida
Orlando, Florida

Summer Term
2020

Major Professor: Mary Ann Burg

ABSTRACT

More than 650,000 people per year in the United States are affected by End Stage Renal Disease (ESRD) (US Renal Data System, 2013). This diagnosis affects many areas of the patient's life and patients have limited options for treatment. Kidney transplantation for patients with ESRD continues to be noted as the most optimal treatment (Rubin & Weir, 2015; Maggiore, et al., 2014; Patzer, Platinga, Krisher, & Pastan, 2014). However, despite this information, utilization of transplantation remains inconsistent and variable in the population.

There are many areas of disparities regarding the kidney transplant waitlist including wait times, gaining access to the wait list, and being changed to inactive status. This paper will discuss the reasons identified in the literature for these inequalities and will also explore the impact that the demographics of the patient play a role in their ability attempt to better to be waitlisted. Transplant recipients will be surveyed and also interviewed to gather more information on the transplant wait list process and possible reasons for the inequalities.

Keywords: kidney transplant, transplant wait list, inequalities, access, end stage renal disease

For my children, Cody, Abby and Madison, and for my husband Joe

ACKNOWLEDGMENTS

There are so many people to thank for getting me to this point. I cannot thank everyone enough for their support, encouragement and kind words. Without all of you I would not have been able to make it through.

I first want to thank my wonderful chair, Dr. Burg who never stopped believing in me and never stopped advocating for me. The time and energy you put into me will forever be cherished as you are one of the reasons I was able to make it this far. You never gave up on me even when I was not at my best and you stuck by me when I had other obstacles in life to overcome. I learned so much from you in the classroom, conversations and during our meetings.

To my amazing committee who provided helpful feedback and who stuck by even when this process took me a bit longer than I had planned. I could not have anticipated some of the obstacles I hit along the way but I appreciate you all sticking with me to the end.

To my wonderful family for putting up with all the times I had to stay late at work or school to focus on this paper. For all the practices, dinners, tournaments and events I missed to get through the program, I hope you understand that it was all for a purpose and will be worth it in the end. I appreciate the flexibility of my beautiful children and especially my husband. Even when feeling sick or exhausted, you never hesitated to get the children to all their practices and rehearsals so that I could focus on my paper. Thank you for putting up with my exhaustion and late nights at the computer screen.

Lastly but definitely not least, I would love to thank some amazing friends and colleagues throughout this program as you all played special roles throughout different parts of the program.

Thank you, Gary Grimes, Lisa Macri, Colleen Cicale, Brie Haupt, Amanda Terry and Anya Miller along with all of my classmates and coworkers. You all took a special interest in helping me and providing the strength and push I needed to get through the program whether it be providing support when my husband was sick or just being my cheerleader. You never gave up and I am forever grateful for that.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

xviii

CHAPTER ONE: INTRODUCTION

More than 650,000 people per year in the United States are affected by End Stage Renal Disease (ESRD) (US Renal Data System, 2013). Patients with this diagnosis have limited options for treatment. Some patients may choose to delay treatment, not pursue treatment at all or choose between either dialysis or kidney transplantation. Kidney transplantation for patients with ESRD continues to be noted as the most optimal treatment (Rubin & Weir, 2015; Maggiore, et al., 2014; Patzer, Platinga, Krisher, & Pastan, 2014). Compared to dialysis, transplantation offers patients increased quality of life and decreased mortality (Davis, et al., 2014). However despite this information, utilization of transplantation remains inconsistent and variable in the population.

Article 25 of the Universal Declaration of Human Rights states that "everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control" (United Nations, 1948). In the U.S. there is evidence that many disparities persist in regard to access to needed health care. These disparities are also evident in the area of kidney transplantation and access to kidney transplantation waitlists.

Research has shown that organ transplantation access is problematic for many people in the United States. As of January 2016, "there are currently 121,678 people waiting for lifesaving organ transplants in the U.S. Of these, 100,791 await kidney transplants" (National Kidney Foundation, 2016, para 1). Many attempts have been made to improve the organ transplantation

process. This research will focus specifically on one of these methods, the kidney transplant waitlist, and specifically sources of variability in access to the waitlist.

The organization of this thesis starts with an explanation of kidney disease including the criteria required for diagnosis at each stage of the disease. The treatment options for each stage will also be discussed along with the steps in the transplant process, including access to transplant waitlists. Evidence of disparities in all areas of the transplantation process will be identified and discussed in order to inform the central research question and to identify the reasons for disparities in access to transplant waitlists. Fundamental cause theory will be discussed as it relates to kidney transplant waitlist variability and will guide the construct of the research questions. The focus of this study is specifically on what factors contribute to race and ethnic differences in the transplant list, which ultimately affects the likelihood of receiving a transplant (Eggar, 2009).

CHAPTER TWO: LITERATURE REVIEW

Kidney Disease

When discussing the transplant waitlist, it is important to first give an overview of kidney disease, symptoms, possible interventions and explain how a person may find themselves in need of a transplant. Chronic kidney disease is a public health problem with an estimated 26 million people diagnosed in the United States (National Kidney Foundation, 2016; Levey, et al., 2005). Unfortunately, most people who have this disease may not even know they have it because, many times, it goes undetected (National Kidney Foundation, 2016). This may be due to not receiving regular, routine health checkups. It may also be due to lack of health insurance, lack of transportation, lack of health literacy, income, or lack of resources to afford necessary medical procedures (National Coalition for the Homeless, 2009). Kidney disease that goes undetected can cause many other medical issues such as heart disease and can result in permanent kidney failure and ESRD (National Kidney Foundation, 2015).

Symptoms of kidney disease differ at each stage of the diagnosis and symptoms may present differently in different patients (American Kidney Fund, 2016). In the early stages of kidney disease, some of the symptoms may include itching, difficulty catching your breath,, swelling, loss of appetite, high blood pressure, changes in urine function, difficulty sleeping, nausea and vomiting and muscle cramps (American Kidney Fund, 2016; Mayo Clinic, 2016; National Kidney Foundation, 2016).

Acute Kidney Injury (AKI) is defined as "a syndrome that results in a sudden decrease in kidney function or kidney damage within a few hours or few days" (National Kidney Foundation, 2016a, para 1). This diagnosis tends to be more common for patients already in the

hospital setting and consists of waste buildup in the blood resulting in difficulties for the kidneys ability to control fluid in the body (National Kidney Foundation, 2016a). AKI can lead to Chronic Kidney Disease (CKD) or even End Stage Renal Disease (ESRD).

Chronic Kidney Disease has been classified into five stages by the National Kidney Foundation (2016b); these stages are utilized to best identify the patient's diagnosis in order to provide the best plan of care. In order to test a person's kidney function and to calculate their stage of illness, the Glomerular Filtration Rate (GFR) is calculated (Davita, 2016). The "GFR number tells how much kidney function you have" (National Kidney Foundation, 2016c, para 2). This test consists of a mathematical formula that is utilized with information including the person's age, body size, race, gender and their level of serum creatinine (Davita, 2016; National Kidney Foundation, 2016c). Creatinine is defined as "a waste product in your blood that comes from muscle activity…when kidney function slows down, the creatinine level rises" (National Kidney Foundation, 2016b, para 2).

Healthy kidneys are able to remove creatinine from the blood; failing kidneys are less able to remove creatinine and the GFR goes down as kidney disease progresses. Kidney damage is identified by a certain protein called albumin in the patient's urine (National Kidney Foundation, 2016c). Having albumin in the urine can be an early sign of kidney disease and patients with a large amount of this protein "are at an increased risk of having chronic kidney disease progress to kidney failure" (National Kidney Foundation, 2016c, para 5). The figure below displays the amount of risk for the patient in each stage of CKD with the albumin level categories.

				Albuminuria categories		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
	G1	Normal or high	$\geq$ 90	*	**	***
	G2	Mildly decreased	60-90	*	**	***
GFR Stages	G3a	Mildly to moderately decreased	45-59	**	***	+
	G3b	Moderately to severely decreased	30-44	***	+	+
	G4	Severely decreased	15-29	+	+	++
	G5	Kidney Failure	<15	++	++	++

*Low Risk   +Very High Risk

**Moderately Increased Risk   ++ Highest Risk

*** High Risk

Figure 1:Albumin Levels.

Stages of CKD

Stage 1 of CKD includes patients with a normal GFR or high level greater than 90 ml/min (Davita, 2016; Cash & Glass, 2010). Stage 2 of CKD includes patients with a GFR between 60 and 89 ml/min (Davita, 2016; Cash & Glass, 2010). Patients typically do not even realize there has been a loss in kidney function in either of these two stages and there may not be any symptoms of kidney damage at this stage. Hypertension, however, is usually present in early stages of kidney disease (Cash & Glass, 2010). Davita (2016) states that patients in these stages

may only be diagnosed when getting testing done for other illnesses including diabetes and high blood pressure. These two conditions have been noted to be the two leading causes of kidney disease (Davita, 2016; American Kidney Fund, 2016; Mayo Clinic, 2016; National Kidney Foundation, 2016).

A person with Stage 3 of CKD would be considered to have moderate kidney damage (Davita, 2016; The Renal Association, 2013; Mayo Clinic, 2016). Stage 3 has been split into two separate categories; Stage 3A and Stage 3B. Stage 3A consists of patients with GFR between 45-59 mL/min and Stage 3B consists of patients with GFR between 30-44 mL/min (Davita, 2016; The Renal Association, 2013). The reason that this stage is divided into two categories is due to the increased risk of cardiovascular disease and CKD progression with the lower GFRs (Henry Ford Health System, 2011). As stated previously, as the kidney function declines, the waste products continue to build up in the blood (Cash & Glass, 2010).

A person with Stage 4 CKD would be considered to have advanced kidney damage (Davita, 2016; The Renal Association, 2013). In this stage, the GFR falls to a more severe level between 15-30 ml/min. This is the stage where options such as dialysis, or future transplant discussions become necessary (Davita, 2016; Mayo Clinic, 2016 American Kidney Fund, 2016; National Kidney Foundation, 2016). Many other symptoms and conditions become evident in this stage due to the increased waste buildup in the blood. Davita (2016) notes some of these conditions to be heart and cardiovascular diseases, high blood pressure, bone disease and anemia.

The last stage of CKD is Stage 5. When a person finds themselves at this stage, they are identified as having End Stage Renal Disease (ESRD). This is when the GFR falls at or below 15 ml/min (Davita, 2016; The Renal Association, 2013). The kidneys have now been severely affected and can no longer function effectively. They lose the ability to filter out the waste in the

bloodstream which then begins to build up. They also begin to lose the ability to regulate blood

pressure. The person will begin feeling ill with symptoms such as nausea, vomiting, less urine

production or no urine production, muscle cramps, etc. (Davita, 2016; Mayo Clinic, 2016

American Kidney Fund, 2016; National Kidney Foundation, 2016). Below is a table

summarizing the stages of CKD and the GFR levels associated with each stage.

Table 1. Stages if CKD and GFR Levels

CKD Stages	Description	GFR Levels
At increased risk	Risk factors for kidney disease*	More than 90
1	Kidney damage with normal kidney function	90 or above
2	Kidney damage with mild loss of kidney function	89 to 60
3a	Mild to moderate loss of kidney function	59 to 44
3b	Moderate to severe loss of kidney function	44 to 30
4	Severe loss of kidney function	29 to 15
5	Kidney failure	Less than 15

*(e.g., diabetes, high blood pressure, family history, older age, ethnic group)

It is important to note the population differences in the diagnosis of ESRD. In January

2016, there were about 660,000 people documented as having ESRD (National Kidney

Foundation, 2016). Of these patients about 57% (378,185) were male and about 43% (281,604)

were female (National Kidney Foundation, 2016).   ESRD occurs disproportionately in African

Americans, with 30.68% of patients diagnosed with ESRD as black/African American, 61.73%

of these patients identified as white, 16.91 % Hispanic, 5.58% Asian, and 1.09% American

Indians (National Kidney Foundation, 2016). Patients with family history of kidney failure or

comorbidities such as diabetes or heart disease are more at risk of developing ESRD (National

Kidney Foundation, 2016).

Treatment Options

In stages 1 and 2 of CKD, the treatment options usually include emphasis on a healthy diet plan. This diet consists of foods high in protein, low in sodium and saturated fats, and includes fruits, vegetables and grains. Davita (2016) also notes the importance of keeping blood pressure at healthy levels in these stages. When diagnosed with Stage 3 CKD, treatment options also include discussion of diet but this stage also includes working with a dietitian as well as a nephrologist. The nephrologist can order lab tests to monitor the patient and the dietitian can utilize the results of this lab work to assist with developing an appropriate diet plan to extend the life of the kidney (Davita, 2016).

When diagnosed with either Stage 4 or 5 of CKD, more intense treatment options are necessary. The discussion of dialysis (described in detail below) as a treatment option begins when a patient is diagnosed with Stage 4 CKD (Davita, 2016). Following up with a nephrologist and having routine lab tests are imperative. Patients with Stage 5 CKD or ESRD, will need to begin dialysis and discussion of eligibility for transplant options and waitlisting should occur as well (Davita, 2016 American Kidney Fund, 2016; Mayo Clinic, 2016; National Kidney Foundation, 2016).

Dialysis

Dialysis is the medical procedure necessary for patients with kidney failure. Dialysis is the artificial system for cleaning the patient's blood (Emory Healthcare, 2016). Some patients with acute kidney injury (AKI) may only need dialysis for a short period of time and then their

kidneys return to normal functioning (Levy, Brown, & Lawrence, 2015). For others, when

kidney failure is chronic (ESRD), the kidneys will never return back to normal functioning

(Davita, 2016). These patients will either be on dialysis for the remainder of their lives or they

will be on dialysis until they are able to obtain a kidney transplant.

The unfortunate thing about dialysis is that it is not a long term, lifesaving intervention.

The average life expectancy while on dialysis some say is 3 to 5 years, therefore transplantation

is necessary for survival (Stokes, 2011). Figure 1 displays the differences among treatment

modality in ESRD patients (National Institute of Diabetes and Digestive and Kidney Diseases,

NIDDK, 2012).

Number of ESRD Patients by Treatment Modality

Dialysis Patients
- Other or uncertain dialysis (1,262)
- Continuous cycler-assisted peritoneal dialysis (18,064)
- Continuous ambulatory peritoneal dialysis (9,458)
- Home HD (4,511)
- In-center HD (365,566)

Transplant Patients (172,553)
Dialysis Patients (398,861)
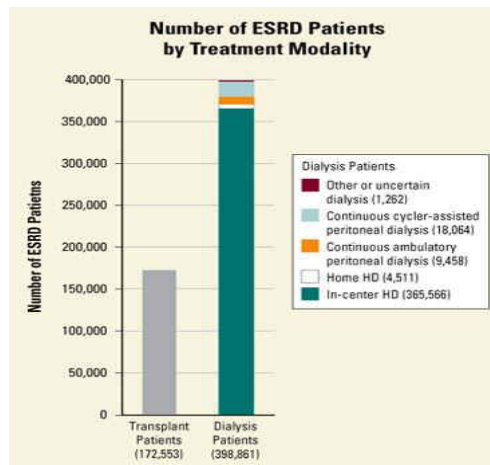
Figure 2: Number of ESRD Patients by Treatment Modality.

There are two different dialysis modalities, hemodialysis (In-center or at home) and

peritoneal dialysis (continuous cycler-assisted or continuous ambulatory).

Hemodialysis

Hemodialysis is the treatment modality consisting of a dialysis filtering system which removes small quantities of the patient's blood in order to filter out the toxins and then the filtered blood is returned to the patient's body (Davita, 2016). Hemodialysis requires the patient have an access point where two needles connected to tubing are inserted. One needle takes the blood from the patient and the other needle returns it (Emory Healthcare, 2016; Davita, 2016).

This type of dialysis requires patients to have these treatments three times per week for anywhere from two and a half hours to four hours per treatment (Emory Healthcare, 2016). Typically this treatment is done in a dialysis center but patients also have the option of having the treatments at home which provides the patient with the opportunity to adjust treatment to their schedule. For in home hemodialysis, the patient and a caretaker are properly trained on treatment requirements (Emory Healthcare, 2016).

Peritoneal Dialysis

Peritoneal Dialysis is similar to hemodialysis in that the blood is cleansed however, with this treatment, a tube in placed in the abdomen (specifically in the peritoneal cavity) and a special solution is added in (Emory Healthcare, 2016). The solution absorbs the waste product and is then drained from the body after a prescribed amount of time (Mayo Clinic, 2016). This treatment is needed four to five times per day (Emory Healthcare, 2016). This type of treatment may not be appropriate for all patients as the patient would need to be able to take care of themselves or would need the assistance of a reliable caregiver if they were unable to do so themselves (Mayo Clinic, 2016).

Prevalence of Dialysis Modalities by Population Subgroups

Out of all dialysis modalities 57% were male patients and 43% were females in 2015 (USRDS, 2015). In terms of race, out of all dialysis modalities, 57% of the patients were white, 35% were black, 18% identified as Hispanic, 1% identified at Native American, 6% were Asian, and about .5% were labeled as other/unknown (USRDS, 2015).

In the table below, the differences amongst dialysis modalities by race and gender are depicted (USRDS, 2015). There is only small variability in dialysis type by gender, race and ethnicity.

Table 2: Dialysis Treatment Modalities

Type of Dialysis	Male	Female	White	Black	Native	Asian	Hispanic
Peritoneal	10%	10%	11%	7%	8%	13%	9%
Hemodialyis	90%	89.4%	88%	93%	92%	87%	91%
All Dialysis	57%	43%	57%	35%	1%	6%	18%

Burdens of Dialysis

Patients on any dialysis modality face many difficult challenges that can cause burden on the patient as well as their caregiver. These challenges may differ by patient, caregiver, as well as the dialysis treatment modality. The burden of dialysis can range from health, financial, employment, social supports, as well as overall quality of life (Browne, 2006).

Financial and Employment Burdens

One of the challenges noted in the literature is the ability to hold employment and preserve their socioeconomic status (Nakayama, et al., 2015). The type of dialysis was identified as a factor in maintaining employment. "The odds of unemployment after dialysis inception were 5.02 fold higher in those on in center hemodialysis compared to those on peritoneal dialysis, after adjusting for covariates" (Nakayama, et al., 2015, p. 523). Patients on peritoneal dialysis were also shown to have a greater ability to maintain employment and also tend to have a greater income than those patients on in-home dialysis (Nakayama, et al., 2015).

A study by Walker, et al. (2016) uncovered themes related to the economic considerations when discussing patients on dialysis. The three themes they identified were: productivity losses due to changes in employment, the need for subsidization of home dialysis expenses and the role of economic disadvantage as a barrier to home dialysis (Walker, et al., 2016). Home dialysis, while convenient, can also be costly to patients due to insurance coverage limits leaving out of pocket costs for the patient and patient's family (Johnson, 2014). The main advantage of a patient choosing home dialysis is that of flexibility. This flexibility offered time for the patient to continue to work due to the convenience of being able to receive their treatments at home (Walker, et al., 2016). In center dialysis can make it difficult to commit to a sufficient work schedule.

Life Changes

Those who choose in-center dialysis are required to go to a dialysis center typically three times per week for hours at a time (Davita, 2015). Cantekin, Kavurmaci, and Tan (2016) found

that patients who are dependent on having to be at the hospitals or facilities on specific days for an allotted amount of time may begin to feel the burden with the changes it makes to their lives. These patients may see a decrease in physical activities, decrease in work labor, as well as financial loss due to the strain of the treatment (Cantekin, Kavurmaci, & Tan, 2016). The long-term effects may involve divorce or difficulty in relationships, difficulties with family members and many other psychosocial problems related to the treatment including less participation in social activities (Cantekin, Kavurmaci, & Tan, 2016).

<u>Physical Issues</u>

ESRD and the treatment options all involve physical changes to the patient's body (Muringai, Noble, McGowan, & Chamney, 2008). As stated previously, peritoneal dialysis requires the insertion of a catheter and with hemodialysis access is normally created with a fistula or catheter in the arm, neck, leg or other femoral area (Muringai, Noble, McGowan, & Chamney, 2008). These changes can cause the patient to have difficulty with their body image. This is also true post-transplant as transplantation leaves a scar. Partridge and Robertson (2011) express the need for patient education regarding body image changes that will occur with different treatment modalities.

Besides body image, Öyekçin, Gülpek, Sahin, & Mete (2012) discovered that patients on dialysis also had difficulty with depression, anxiety and sexual ability. They noted that "in hemodialysis group, as depression and anxiety levels increased, body image was disturbed. In both groups, long-term dialysis disturbed body image" (Öyekçin, Gülpek, Sahin, & Mete, 2012, p. 235). In peritoneal dialysis group, as depression and anxiety levels increased, body image

changed and sexual satisfaction decreased" (Öyekçin, Gülpek, Sahin, & Mete, 2012). Murtagh, Addington-Hall and Higginson (2004) found that 1 in 2 dialysis patients reported feelings of fatigue, constipation, pain and extreme itching. They also noted sleep disturbance, depression, anxiety and difficulty breathing (Murtagh, Addington-Hall & Higginson, 2004).

Sleep Disorders

Sleep disorders are common in dialysis, with insomnia being reported by 19-71% of those dialysed and 30-80% are affected by sleep apnea (Merlino Gigli & Valente, 2008; Hanly, Pierratos, Mucsi, & Novak, 2016). Some risk factors for insomnia include patients in the older age group, restless legs syndrome, sleep apnea and other common sleep disorders (Merlino Gigli & Valente,2008; Hanly, Pierratos, Mucsi, & Novak, 2016). Patients on dialysis also report excessive sleepiness during the daytime (Merlino, Gigli, & Valente, 2008).

Hanly, Pierratos, Mucsi, and Novak (2016) found that the type of dialysis was not a factor in sleep disorder as patients reported insomnia on either hemodialysis or peritoneal dialysis. Insomnia has been linked with increased mortality amongst patients with ESRD (Hanly, Pierratos, Mucsi, & Novak, 2016). Agarwal and Light (2011) found that patients on hemodialysis had more severe sleep disruption and patients with CKD who were not on dialysis also reported more sleep disruption than people without kidney disease. They also found that patients who are non-compliant with dialysis treatments, either missing treatments or shortening the length of their assigned treatments, reported greater burden of sleep disturbance (Agarwal & Light, 2011).

Merlino, Gigli, and Valente (2008) explain that several sleep disturbances such as restless leg syndrome, sleep apnea syndrome, excessive daytime sleepiness, may be treated and if they are left untreated, it is possible that they may impair health status and increase the risk of mortality. Risk of obstructive and central respiratory events are increased by renal failure and dialysis therapy (Merlino, Gigli, & Valente, 2008). Many studies suggest that the concern of sleep disorders in this population are often not discussed (Merlino, Gigli, & Valente, 2008; Agarwal & Light, 2011; Hanly, Pierratos, Mucsi, & Novak, 2016).

Fertility and Sexual Function

Eid, et al. (2013) studied female patients with kidney disease and found that as the duration of dialysis increased, the patient's rating of their sexual function decreased. When discussing sexual function, many areas were examined such as sexual desire, arousal, lubrication, and orgasm (Eid, et al., 2013). Holley, and Schmidt (2003) explained that ESRD results in low rates of pregnancy in women and Eckersten, Giwercman, and Christensson (2015) reported impaired male reproductive function with ESRD. While infertility has been noted in patients with kidney disease, fertility has been noted to be restored when the patient receives a successful kidney transplant (Holley, & Schmidt, 2013).

Social Supports

Caregivers and social supports are integral for patients with ESRD in many stages of the disease. Patients on dialysis and awaiting a transplant need a good support network to assist them with navigating the transplant system, caring for themselves and their daily living needs,

medication management as well as coping support (Ghai, et al., 2014). Support can be divided into two categories: perceived and received support (Cangro, 2014). Perceived social support refers to the perception that the person is cared for, is valued, and is part of a group (Uchino, 2009). Received support is described as a situational response to a difficult or stressful situation (Ochino, 2009). Overall, perceived social support has been shown to predict positive health outcomes better than received social support (Uchino, 2009). Both types of support demonstrated benefits when it comes to chronic illnesses such as CKD (Cangro, 2014).

When interviewing caregivers, Ghai, et al. (2014) discovered that caregivers identified as feeling as though they are suffering a financial as well as a psychological burden. They noted participating less in social activities as well as disruption in their family and work lives (Cantekin, Kavurmaci, & Tan, 2016). Some risk factors for caregiver burden were unemployment, having to be a caregiver for more than 12 months, low income, being the female spouse, and the patient waiting longer than 12 months on the transplant waitlist (Ghai, et al., 2014). Families of ESRD patients are insufficiently knowledgeable of the disease, medical complications, treatment options and how the disease may impact the patient and family (Browne, 2006).

Perceived support from the transplant team can lessen stress, anxiety and depression. Received support leads to graft survival and treatment compliance (Cangro, 2014). Supports should be readdressed during treatment and progression of the disease as support systems may change throughout the progression of the disease (Cangro, 2014; Urchino, 2009).

Quality of Life

 "Ill health can adversely affect an individual's quality of life, particularly if caused by

long-term (chronic) conditions, such as chronic kidney disease—in the United States alone, 23

million people have chronic kidney disease, of whom 570,000 are treated with dialysis or kidney

transplantation" (Wyld, et al, 2012, p. 12). Quality of life, in particular health related quality of

life is defined as the subjective assessment of the impact of disease and its treatment across all

domains of functioning and well-being (Pagels, et al., 2012). Quality of life in patients with

various stages of renal disease has been shown to have significant effects on the clinical

outcomes of these patients (Stratta, & Coppo, 2008).

Health related quality of life (HR-QOL) within dialysis patients has been shown to be

poor on average (Chiu, et al., 2009).   While quality of life appears to improve with

transplantation, it still remains lower for these patients than people without this diagnosis

(Stratta, & Coppo, 2008). Some reasons for this were identified the patient's quality of life still

being shown to be "affected by uncertainty about the final result, fear of having to go back on

dialysis, or anger about unexpected complications" (Stratta, & Coppo, 2009, p. 48). Poor quality

of life "in ESRD is significantly linked to patient outcomes: decreased functional status,

decreased well-being, increased hospitalizations, increased morbidity and higher mortality

(Browne, 2006).

Transplantation Process

"For the >600, 000 patients in the United States with end stage renal disease (ESRD)

kidney transplantation represents the optimal treatment for most patients, providing longer

survival, better quality of life, lower hospitalization rates and substantial cost savings compared

with dialysis" (Patzer, Plantinga, Krisher, & Pastan, 2014, p. 1562). There are two options for

transplantation; live kidney donation or deceased kidney donation (Rudow, et al., 2015). Rudow

et al. (2015) states that live kidney transplantation is ideal in that it improves quality of life,

patient survival, graft survival and are more cost effective overall.

Despite all the positive outcomes of transplantation, many patients have difficulty in

completing the pre-transplant evaluation, or may find themselves lost in the follow up procedures

necessary for wait listing (Kazley, et al., 2014). In order to receive a kidney transplant, one must

first be placed on a kidney transplant waitlist which is not an easy task (see Figure 3 below).
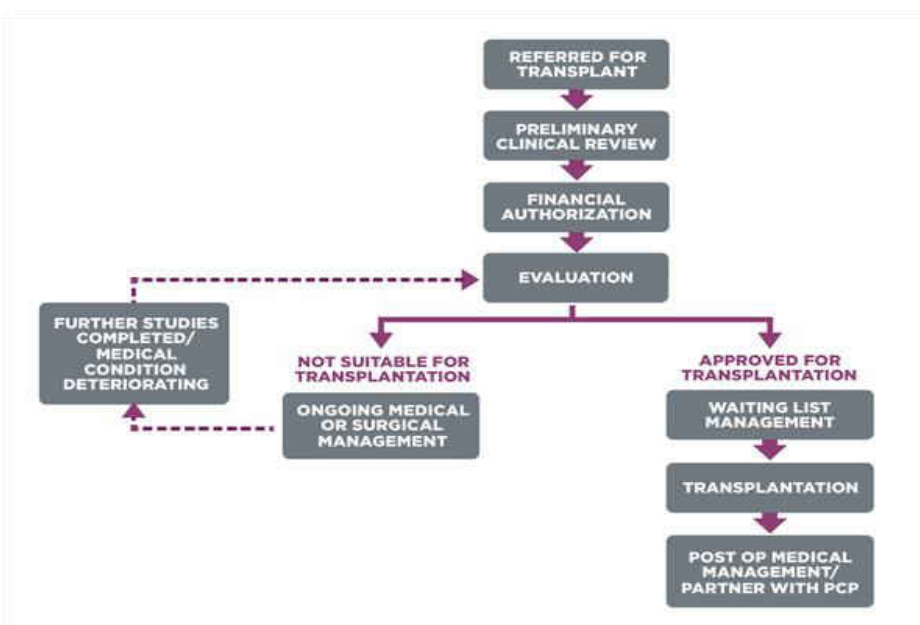
Figure 3: Flowchart of Transplant Process.

To get onto the national waitlist, the first step is for the patient to be referred by their

physician or nephrologist (UNOS, 2016). It is then the patient's responsibility to contact a

transplant hospital of their choice to learn more about them to determine if their program fits

their specific needs, especially in areas such as location, finances, acceptable insurance (UNOS,

2016; National Kidney Foundation, 2016). The patient must then schedule an appointment for evaluation at the transplant center which includes an in-person interview, medical testing, lab work, psychosocial evaluation, working with the multidisciplinary team and gaining financial clearance through insurance (Tampa General Hospital, 2017; Gill, Hendren, Dong, Johnston, & Gill, 2014).

Calestani, et al.(2014) explains that it is difficult for medical personnel to agree on which patients are best for wait listing. Due to this, the waitlist criteria and how the criteria is utilized varies greatly (Calestani, et al., 2014; Tong et al., 2014). In the UK, even though national guidelines are present and describe which patients would be suitable for transplant the variation of who is waitlisted is also present (Calestani, et al., 2014). The testing required in the clinical evaluation also varies amongst the centers (UNOS, 2016; Tampa General Hospital, 2016).

Clinical Evaluation

Testing, lab work and assessments are necessary in the evaluation process for transplantation (Gill, Hendren, Dong, Johnston, & Gill, 2014). A psychosocial assessment to evaluate the psychosocial factors that have been identified as risk factors for transplantation is a requirement for all potential transplant patients (Cangro, 2014). "Risk for nonadherence, the need for social support, and a realistic assessment of the cost of renal transplantation should be the cornerstone of the pre-transplant psychosocial evaluation" (Cangro, 2014, p. 173). Behaviors identified as risk factors such as smoking, alcohol use, drug use, obesity, noncompliance with dialysis and noncompliance with follow up appointments become evident in these assessments (Cangro, 2014).

Some transplant centers provide information on the specific medical testing factored into their evaluation process and not all centers require the same types of testing (UNOS, 2016; Cangro, 2014). For example, Tampa General Hospital (2017) requires tests such as kidney ultrasound, cardiac stress test, and a colonoscopy. UCDAVIS (2016) for instance, requires pulmonary function tests to check the function of your lungs, colonoscopy, cardiac testing, a dental exam as well as a test called a VCUG to test to see if the patient's urinary tract is functioning normally. Beth Israel Deaconess Medical Center (2017) requires blood tests, chest x-rays, cardiac testing, vascular studies, and cardiac catheterization if the patient has coronary artery disease. They also require colonoscopies but only for men over 50 and they discuss mammograms and pap smears for women (Beth Israel Deaconess Medical Center, 2017).

Testing for preexisting conditions is part of the overall pre-transplant evaluation. Patients are tested for diabetes, cardiac concerns, disease, respiratory, and ability to survive the surgery (Cangro, 2014). Patients with diagnoses such as cancer or cardiac disease may be asked to follow up with an outside specialist for evaluation and then return to the transplant center for reevaluation (Hricik, 2008). Some centers may require a patient with a cancer diagnosis to be cancer free for 2-5 years before being considered for the transplant waitlist (Hricik, 2008).

Tampa General Hospital (2016) lists what they call "absolute contradictions" meaning reasons that the patient would not be considered for transplant. Some of this "contradictions" include patients over the age of 80, patients with active cancer, HIV positive patients, active substance abuse, BMI greater than 40, active mental health disorders, to name a few (Tampa General Hospital, 2016). UCSF Medical Center (2016) lists some restrictions as patients who have recently had a heart attack, cancer, substance abuse or active infection. They also discuss

that patients over 60 will be considered on a case to case basis (UCSF Medical Center, 2016).

Transplant center policies such as these may make it more difficult for patients with a co-existing

condition to be able to navigate their way to completion of the evaluation process.

During the patient's evaluation, it is important for the patient to ask questions to better

educate them about the process at each center. Not only does each center differ in the testing

required during the evaluation stage, but each center also differs in the waitlist criteria utilized to

determine if the patient will be accepted (UNOS, 2016; National Kidney Foundation, 2016).

The determination of which patients are eligible for transplantation is a complex and

varies across transplant centers (Patzer, et al., 2015). Each transplant center may have different

wait list criteria (Patzer, et al., 2015; UNOS, 2015; National Kidney Foundation, 2016). Patients

should have an understanding of these differences in order to better determine which transplant

center to wait list with (National Kidney Foundation, 2016). Some transplant centers such as

Tampa General Transplant Center will accept patients that may be considered more high risk

whereas other centers may be stricter with their criteria (Tampa General Hospital, 2016).

Many factors come into play when it comes to identifying potential renal transplant

recipients however there does not appear to be any one federal or standardized process for

choosing the appropriate transplant candidates (UNOS, 2016; National Kidney Foundation,

2015). The medical decisions regarding wait listing are made based upon a patient's chances of

surviving the surgery and not being adversely effected by lifelong immunosuppressive therapy

(Cangro, 2014). "Clinical practice guidelines on wait listing for kidney transplantation are based

on comorbidities, psychosocial and lifestyle factors vary in their recommendations, scope and

how criteria are defined" (Batabyal, et al., 2012, p.). Some centers may also have restrictions

based on age, lack of proper insurance coverage, lack of social supports and medical compliance

issues (National Kidney Foundation, 2016; Tampa General Hospital, 2016; UCSF, 2016).

It is also important that the patients are aware they are able to wait list at multiple centers

if they so choose (UNOS, 2016; Tampa General Hospital, 2016). Multiple listing is defined as a

patient being placed on the transplant waitlist at more than one hospital simultaneously (UNOS,

2016). Some studies suggest that patients who list at multiple hospitals will have a shorter wait

time for transplant, however there is no guarantee (UNOS, 2016; University of Wisconsin,

2017). It is also important to note that in order to be listed at multiple centers, the patient must

complete the specific evaluation and testing required by each specific center (UNOS, 2016).

Also some centers may not be willing to accept patients who are listed at multiple centers

and they may set specific criteria for these patients or may refuse to accept these patients at all

(UNOS, 2016; Tampa General Hospital, 2016; University of Wisconsin, 2017). Medical

insurance restrictions may also limit the number of centers the patient is allowed to be waitlisted

with (National Kidney Foundation, 2016). Madhavan, et al. (2014) identify the option of

developing some uniform selection criteria within each transplant center in order to allow a fairer

evaluation of the patient. With some uniform selection criteria, it may lessen the opportunity for

provider bias and may lessen the inequalities in accessibility overall (Madhavan, et al., 2014).

As demonstrated above, gaining access to the kidney transplant list and staying on are not

easy tasks. Some patients may receive assistance from the interdisciplinary health care team

while others who are in need of a transplant may never even make it onto the list (Grams,

Massie, Schold, Chen, & Segev, 2013). A policy change in 2003 allows for what is known as an

inactive status on the transplant waitlist (Grams, et al, 2013). A patient may be labeled as

inactive status for various reasons and is "sometimes used as a placeholder for reasons other than a candidate's medical fitness—until completion of the transplant work-up, for example, or achievement of a threshold body mass index (BMI) for surgery" (Grams, et al., 2013, p. 1012).

Patients labeled as inactive are still able to accrue waiting time but will not be offered a kidney transplant once their number comes up (Gram, et al, 2013). Patients can be initially placed on the waitlist as inactive and these patients are known as continuously inactive patients. Gram, et al. (2013) identified disparities in this continuously inactive group. They noted that patients in this group were more likely to be African American, female, have diabetes, higher BMI, comorbidities and poor status (Gram, et al., 2013). These patients have higher mortality rate and lower rate of getting to active status on the list. It was also noted that the continuously active (never placed as inactive status) group was younger and generally had less comorbidity (Gram, et al., 2013).

Patient Education

Education for patients regarding transplantation has been identified as an area in need of reform and may account for some of the disparities identified in the transplant evaluation (Patzer, et al., 2012). Patients have reported the lack of information regarding transplantation in every stage of the process (Calestani, et al., 2014). Some of these areas include patients being unaware of pre-emptive transplantation options, the listing process, patients not knowing they had been removed from the waitlist, and not knowing why they had been excluded from the list from the start (Calestani, et al., 2014).

Proper education can increase a patient's health literacy which allows the patient and their caregivers to be able to better understand the information in order to make informed decisions regarding their care (Kazley, et al., 2014). Increased literacy may offer patients the ability to feel they are able to navigate the transplant process and are more likely to actually complete the process and receive a transplant (Kazley, et al., 2014). The patients in one study were more likely to complete the transplant evaluation when an education program was implemented (Patzer, et al., 2012). Kutner, et al. (2012) identified an association between early transplant education and earlier wait listing for patients.

Tong et al. (2014) discusses that nephrologists believe that transplant education should be more than 20 minutes in length. With that said, they found that only 43% of nephrologists reported actually enforcing this in their practice (Tong, et al., 2014). Balhara et al. (2012) noted that for profit centers were less likely to spend more than 20 minutes on patient education and were less likely to include the patient's family in the education process.

Patient education should also occur early on in the diagnosis in order to allow the patient to feel informed before even beginning with dialysis (Madhavan, et al., 2014). "Ongoing support and education about kidney transplantation for patients after dialysis start could help to build on early education and foster greater quality improvement in patient outcomes" (Kutner, et al., 2012, p. 1017).

The education should occur across the interdisciplinary team and Madhavan, et al. (2014) suggests also involving primary care providers in the education process. Rudow, et al. (2015) also explains that in order to improve disparities, education should be available in the patient's primary language and the staff should be required to engage in cultural competence trainings. Other reasons patients received less transplant education were identified as patients being

uninsured or having Medicaid, being in a for-profit center, patient refusal, or other medical issues such as obesity (Kurcika, et al., 2012). This entire transplant process, as stated above, is quite lengthy and disparities (discussed below) are evident at every stage, beginning with referral.

Source of Racial and Ethnic Disparities in the Transplantation Process

Disparities are relevant in many areas leading up to transplant and these disparities have been recognized in many different populations which will be discussed below. Some of the factors associated with transplant disparities include: education, race, socioeconomic status, gender, and health literacy (Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016; Tong, et al., 2012). The literature has also noted some organizational factors for transplant disparities such as transplant waitlist criteria as well as university based centers vs. private centers (Ramos, et al., 1995).

Race and Ethnic Disparities

Despite similar prevalence rates for early stages of CKD, racial/ethnic minorities have poorer outcomes such as the diagnosis progressing to ESRD (Garcia-Garcia, & Jha, 2015). According to National Center for Chronic Disease Prevention (2014), Blacks and Hispanics are more likely to develop ESRD relative to Whites. Consequently, racial/ethnic minorities have experienced higher incidences of ESRD compared to Whites (Garcia-Garcia, & Jha, 2015). These statistics may be in part due to the fact that minority groups tend to experience a delay in

referral to the nephrologist which is an important factor to prevent the progression of the disease (Patzer & McClellan, 2014).

This delay in referral can also increase morbidity, mortality, and cost due to the progression to ESRD (Patzer & McClellan, 2014). CKD within minority populations also often goes unnoticed and undiagnosed until symptoms present themselves (Garcia-Garcia, & Jha, 2015). "Worse dialysis outcomes and reduced access to transplantation have also been associated with neighborhood factors such as poverty, urbanicity, and the proportion of African-Americans residing in the neighborhood" (Saunders, et al., 2014, p. 291).

The Black population has a higher incidence of comorbity with diagnoses such as diabetes, high blood pressure and hypertension (Wachetman, et al., 2015). Patients who identify as Black who have diabetes are 3.5 times more likely than white patients to get kidney disease (American Kidney Fund, 2016). Hypertension and diabetes have been identified as accounting for over 60% of ESRD diagnosis (Patzer & McClellan, 2014). These diagnoses are more evident in minority populations (Patzer & McClellan, 2014).

It has been noted that Black patients are less likely to receive dialysis at a high-quality facility due to the evidence of ongoing residential segregation (Saunders, et al., 2014). This is due to the fact that there may not be high quality dialysis centers located in the neighborhoods they reside (Saunders, et al., 2014). The literature has shown that there are differences between for profit and nonprofit dialysis centers such as referral rates, hospitaladmissions, successfully transplanted patients, and mortality rates (Lee, Chertow, & Zenios, 2010). Prakashet, et al. (2010) also indicated that when the percentage of black individuals increases within a neighborhood, the likelihood of individuals in this neighborhood to gain access to nephrology

care decreased. Transplant recipients residing in Black communities are noted to have inferior outcomes post-transplant than any other race or ethnicity (Gordon, Ladner, Caicedo, & Franklin, 2010).

Sources of Racial and Ethnic Disparities in Transplant Waitlists

The focus of this current study is specifically on what factors contribute to race and ethnic differences in the transplant list, which ultimately affects the likelihood of receiving a transplant (Egger, 2009). In the initial steps of wait listing, minority patients tend to have a lower rate of referral to a transplant center despite their desire for transplant (Higgins & Fishman, 2006). Black, Hispanic and Native American patients continue to be underrepresented on kidney waiting lists (Higgins & Fishman, 2006). Black and Hispanic patients had significantly longer times from starting dialysis to wait listing, which may be related to their lower socioeconomic status and less preemptive wait listing (Shivam, et al., 2013).

During 2014, 11,570 patients who received a deceased donor transplant, 42% were white compared to the 31% that were black (National Kidney Foundation, 2016). This gap increases among patients who received a transplant from a live donor, with 67% of White patients receiving a transplant relative to 12% of black patients (National Kidney Foundation, 2016). Other factors come into play when discussing the racial disparities at each level of the transplantation process: lower socioeconomic status, less access to follow up care, lack of resources, higher levels of discrimination by healthcare professionals, and lack of proper health insurance (Schold, et al., 2011).

Patient-Level Variables in Wait Listing

<u>Education</u>

Literature to date on the barriers for minorities at the individual level are attributed to health literacy (discussed previously), attitudes about transplant, concerns regarding risks, and concerns about cost (Purnell, Hall, & Bourware, 2013). Purnell, Hall and Bourware (2013) identify that African Americans and Hispanic patients in particular, have been shown to have poor understanding and education about the risks and benefits of kidney transplant. This lack of education may deter the patient from ever completing the evaluation process.

<u>Socioeconomic Factors</u>

When discussing socioeconomic status (SES), it is important to understand that poverty can affect the patient's accessibility to proper medical care including transplant wait listing (Srinivas, 2014). When discussing a patient's accessibility to proper medical care, it is important to discuss insurance issues. According to the Kidney Foundation (2017), patients with ESRD are automatically eligible for Medicare. With that said, the patient must be knowledgeable of this information and also must complete the application process. If the patient does in fact apply and get approved for Medicare, this insurance covers only 80% of costs for dialysis treatment and only 80% of the cost of immunosuppressant medications needed after transplant which leaves the patient responsible for any amount remaining (Kidney Foundation, 2017). The patient could also apply for Medicaid to cover the excess costs, but again, the patient must be knowledgeable of

this process, complete the online application, turn in all necessary paperwork and be approved based upon their situation (Kidney Foundation, 2017).

Low SES as noted to be a barrier to the transplantation list (Tong, et al., 2014). "Low SES is associated with increased incidence of chronic kidney disease, progression to end-stage renal disease, inadequate dialysis treatment, reduced access to kidney transplantation, and poor health outcomes" (Patzer & McClellan, 2012, p. 1). This could be due to many reasons such as lower education, inadequate or no insurance which leads to a lack of preventative care and early detection (Patzer & McClellan, 2012).

In a study by Patzer, et al. (2012) one third of the racial differences between black patients and Caucasian patients in transplant rates could be explained by SES. Lower SES patients and minority groups also experience a delay in referral to the nephrologist in the early stages of diagnosis which lead to worse outcomes (Patzer & McClellan, 2014). Shivam, et al. (2013) discussed how patients living in a zip code associated with an impoverished neighborhood along with other variables such as insurance type, being a non-US citizen, and race (specifically black) were associated with longer average times from starting dialysis to waitlisting. They also found an association between these variables and less preemptive waitlisting for patients in this population (Shivam, et al., 2013). Similar to Patzer, et al. (2012), Shivam, et al. (2013) also found that the effects for patients identifying as black were mostly associated with their lower socioeconomic status. It was also noted that poorer outcomes for Hispanics versus Caucasian were also associated with lower socioeconomic status and non-US citizenship (Shivam, et al., 2013).

Insurance Type

There have been many changes at the policy level when it comes to Medicare's ESRD program and in 2010 when the ESRD Quality Incentive Program was created, Medicare changed to "pay-for-performance" (Lee, & Zenios, 2012). This new program was developed with the hopes of implementing more standardized care focusing on best practices (Lee, & Zenios, 2012). However, lack of appropriate insurance continues to be identified in the literature as an area where inequality is evident.

Patients with CKD who require either dialysis or transplantation are considered disabled and are automatically eligible for Medicare (Rettig, 2011). In order to be able to receive the insurance coverage, the patient would have had to have paid into the system for a long enough amount of time (Rettig, 2011). It is important to note that there are initial waiting periods for the coverage and once a transplant is received, the insurance ends after three months (Rettig, 2011).

When Johansen, et al. (2012) adjusted for race and ethnicity, insurance status was identified as a reason in which a patient would not be assessed for possible transplant. Patients without insurance at all were the most disadvantaged followed by patients with Medicare, Medicaid or other insurance (Johansen, et al., 2012). "Patients with Medicaid or without insurance were 11 to 14% more likely to be unassessed, respectively" (Kuricka, et al., 2012, p. 351). Non-private insurance along with the patient identifying as black lowered their chances of being waitlisted within the first 2 years of referral (Johansen, et al., 2012). "Insurance status was strongly associated with transplant assessment, with privately insured patients substantially less likely to be not assessed" (Johansen, et al., 2012, p. 1495). Once waitlisted, patients who did not have private insurance were more likely to be removed from the waitlist (Schold, et al., 2016).

Another area where insurance and socioeconomic status come into play occurs during post-transplant when the patient is required to remain on many immunosuppressive medications that can be costly for the patient. Patients typically only receive coverage for these medications for a short time even though the medications will need to be taken for the remainder of the patient's life (Gill & Tonelli, 2012). Medicare currently covers the medications for only 3 years post-transplant unless the patient has a work-related disability or is 65 years old or older (Gill & Tonellie, 2012; Rettig, 2011).

"Ensuring lifetime access to these medications for all Americans with kidney transplants would save lives as well as reduce the cost of treating patients with ESRD" (Gill & Tonelli, 2012, p. 587). In a survey in 2010, it was noted that more than 70% of kidney-transplant programs identified their patients having an extremely difficult time paying for the medications and 68% reported patient deaths and transplant failure due to non-adherence to medication attributed to costs (Gill & Tonelli, 2012).

Age

Wong et al. (2012) stated that "if there were an unlimited supply of organs and no waiting time, transplanting the younger, and healthier individuals saves the most number of life years and is cost-saving, whereas transplanting the middle-age to older patients still achieves substantial incremental gains in life expectancy compared to being on dialysis" (p. 1). In older patients, non-assessment for transplant was noted to occur due to either being labeled medically unfit or unsuitable for transplant due to age (Johansen, et al., 2012). Younger patients were also more likely to receive care from a nephrologist before ever beginning the dialysis treatments

(Johansen, et al., 2012). Mackelaite, et al. (2014) noted that even patients who are 70 years of age or older can still benefit from transplantation.

Bayat et al. (2015) discussed that in France they show similar issues with the association of age and waitlist status as in the U.S. Patients ages 70 and older were 97.5% less likely to be waitlisted in France than patients between the ages of 18 and 39 (Bayat, et al., 2015). Kurika et al. (2012) found older patients were less likely to be educated about transplant.

Much like younger patients, elderly patients also experience improved quality of life with transplant versus dialysis (Tso, 2014). Tso (2014) discussed the clinical guidelines set by the American Society of Transplantation in 2001 which states that "there shall be no absolute upper limit for excluding patients whose overall health and life situation suggest that transplantation will be beneficial" (p. 10).

Physicians' Evaluation of Patient

Health care providers' perceptions of the patient is an important factor in the probability of a patient getting on a waitlist (Purnell, Hall, & Bourware, 2013). The idea of how the health care provider perceives the patient as motivated for transplant is an important part of the clinical decision making for determining a patient's appropriateness for transplant. African Americans have a lower transplant rate than whites and this difference has been attributed to misconceptions by health care providers that African Americans are not interested in transplantation (Wachterman, McCarthy, Marcantonio, & Ersek, 2015). Minority patients were less likely to be recommended for the waitlist as they were seen as being more at risk (Tong, et al., 2014). Patzer, et al. (2009) noted that "patient ethnicity may influence physician's beliefs about a

patient's risky behaviors and likelihood of treatment adherence" (p. 1337). This, along with the lack of formal wait list evaluation standards, could lead to physician referral bias.

Wachetman, et al. (2015) discovered, however, that providers' beliefs about patient motivation were not the relevant factor, but instead found that lack of communication between the patient and the health care provider was the most relevant factor in lower transplantation rates among African Americans in this study. Nephrologists were less likely to refer black patients as they felt survival rate would be better in white patients (Tong, et al., 2012).

Another reason for racial disparities in referral was identified as physician's views of perceived patient preference (Ayanian, et al., 2004). As far as patient's attitude about transplant, Patzer, et al. (2009) noted studies have suggested that black patients were less likely to desire a transplant. Ayanian, et al. (2004) discussed that physicians viewed black patients as less likely to prefer to pursue transplantation and would therefore not refer them. Minority patients continue to experience low referral rates even when they have expressed interest in transplantation (Higgins & Fishman, 2006).

Donor Service Area Location

OPTN (2016) demonstrates how the United States is divided into 11 UNOS transplant regions consisting of 58 donor service areas (DSA). "Kidney allocation policy currently allocates a donated kidney first to patients in the same DSA of procurement (local allocation), then if necessary to patients in the same UNOS region of procurement (regional allocation) and ultimately nationally (national allocation)" (OPTN, 2010 as cited in Davis et al., 2014, p.1). With this allocation system in mind, with local allocation being the first disbursement of donor

organs, patients who are more financially stable may actually relocate in order to have an

increased opportunity for a shorter wait time (Davis, et al., 2014).

According to Davis, et al. (2014b), each DSA has their own waitlist. Patients are able to

list on DSAs not in their home area which can cause variations in wait times and the differences

in wait times amongst some DSAs has increased to 4.72 years (Davis, et al., 2014a). The figure

below provides a depiction of the length of waiting times, the prevalence of waitlisting in those

areas, prevalence of ESRD and the prevalence of deceased donor kidney transplant (Davis, et al.,

2014a).
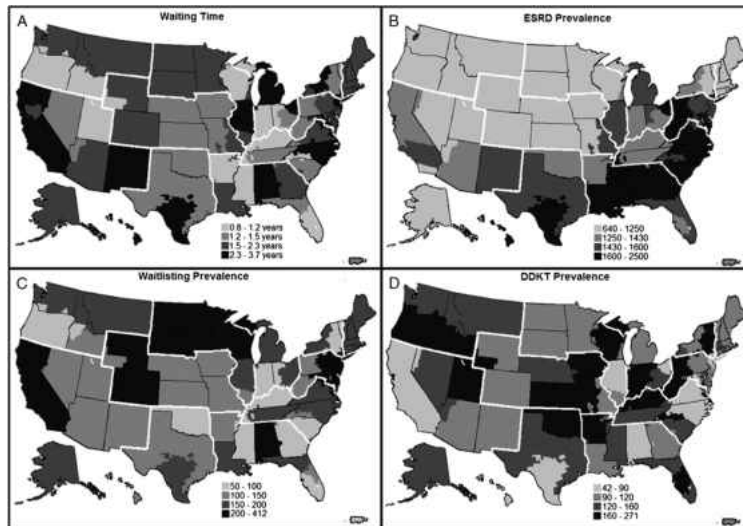
Figure 4: Waitlist Wait times and Prevalence.

The Southeast United States (identified as Region #3) has been identified as the

geographic area with the lowest rates of patients on the transplant waitlist (Kazley, et al., 2014).

Patzer, et al. (2012) discuss that race and the patient's SES play roles in this as they found that

patients who were black and who resided in lower income neighborhoods were noted to be 67%

less likely to be placed on the deceased donor transplant wait list when compared to whites in

lower income neighborhoods. Georgia in particular has the lowest referral rate in this region

with only about 28% being referred for transplant after a year of dialysis (Patzer, et al. 2015).
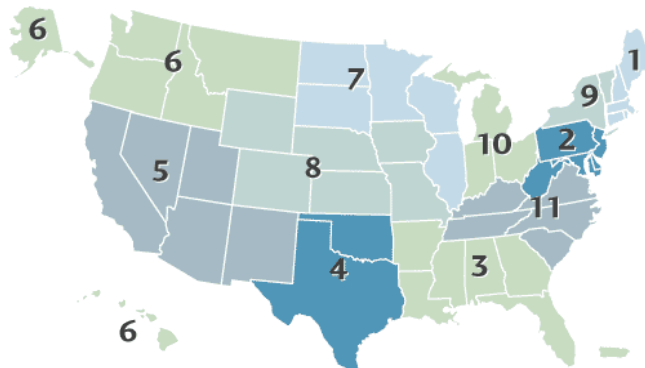
Figure 5: Transplant Regional Map.

The Final Rule is a mandate created by the US Department of Health and Human

Services in 1998 specifying that kidney allocations within the United States must prove to be

equal geographically and it consists of many elements (Davis, et al., 2014). It states that "organ

allocation shall be based on many variables including (1) sound medical judgement; (2) the best

use of donated organs; (3) [to be] specific for each organ type or combination of organs to be

transplanted into a specific candidate; (4) [to be] designed to avoid wasting organs, to avoid

futile transplants, to promote patient access to transplantation, and to promote efficient

management of organ placement; and (5) shall not be based on the candidate's place of residence

or place of listing, except to the extent required by items previously listed" (Reed, et al., 2015).

The Final Rule was implemented in attempts to eliminate geographic inequalities in organ

allocation for transplantation (Davis, et al., 2014).

Davis, et al. (2014) argue that the variation in wait times (in some cases, 4-year variation)

for transplantation across the United States, violates this mandate. Supply and demand in each

DSA can vary greatly causing variations in wait times as well (Lewis, Sankar & Pittman, 2014).

A good example was provided by Lewis, Sankar & Pittman (2014) which showed that patients listing in Alabama waiting on average greater than 72 months for transplant and during that same 5-year time frame from 2004-2009 patients in Oregon waited on average only about 19 months (SRTR, 2010).

Dialysis Centers

Patzer and Pastan (2014) discuss how the type of dialysis center can also play an important role in the transplantation process. Some reasons for the variability among the dialysis centers could be that the patients receiving treatment at the specific center are not eligible but also patients may not be referred to the transplant centers, or that patients that are referred may not complete the evaluation process (Patzer, & Pastan, 2014). Some interesting findings were that as the number of staff in the center increased the patient's access to transplantation also increased (Patzer & Pastan, 2014). It was also noted that the decrease in staffing will increase patient caseloads across the multidisciplinary team which may result in decreased quality of education for the patients (Patzer & Pastan, 2014).

Disparities were also noted in the literature between for-profit and not for profit centers where for profit centers have lower transplant rates (Patzer & Pastan, 2014; Bayat, et al., 2015). In the United States, about 85% of the dialysis centers are identified as for-profit and these centers tend to employ less staff members (Palomino, 2015). These for-profit centers also tend to have fewer resources to offer the patients and have higher mortality rates overall than non-profit centers (Palomino, 2015).

Zhang et al. (2014) explained that 85% of for profit dialysis centers are affiliated with a chain organization or multicenter enterprise and 33% of non-profits are affiliated with a chain organization as well. The change from independent dialysis centers into big corporation raises concerns for quality of care (Zhang, et al, 2014). Patients from the for-profit chain centers were 13% less likely to be waitlisted (Zhang, et al., 2014).

 It may also be that dialysis center staff members need more training on which patients should receive referrals for transplant (Patzer, et al., 2015). However, the national guidelines of the Organ Procurement Transplantation Network (OPTN, 2014) explain that if the healthcare team has any questions about whether a patient should be referred or not, the patient should actually be referred anyway. This way the patient has the opportunity to complete all the pre-transplant evaluation to determine if they are eligible for wait listing (OPTN, 2014).

Patient Preferences

Patient preferences in their health care can also play a role in the transplant waitlist process. Some studies suggest that "African American dialysis patients are less likely than whites to desire transplant" (Wachterman, et al., 2015, p.240). Wachterman, et al. (2015) found that it was not that they did not desire transplant but rather that they had many concerns and misunderstandings regarding transplant. Some of their concerns were centered around trust in many areas such as trust in physicians, donors, and in the equality of the waitlist process itself.

Salter, et al. (2016) found that Black patients raised concerns about the increased burden of the medication regimen, fears in regard to risks of surgery and possible organ rejection when discussion transplantation. These patients also expressed feelings of being treated poorly by the

medical professional and also not receiving proper education about ESRD and the treatment options available to them. Salter, et al. (2016) also found that Black patients reported receiving inadequate information from their doctor and the expressed their lack of trust with medical decisions that were made. The Black patients in this study did show reluctance to pursue transplant but the researchers attributed this to their satisfactions with their level of activity while on dialysis.

Robinson, et al. (2015), when researching kidney donations, found that "(1) Lack of knowledge and awareness of the topic of donation and transplantation; (2) Religious myths, misperceptions and superstitions; (3) Fear of premature death; (4) Concerns about racism/classism and transplant system inequities; and (5) lack of trust in healthcare systems" were all identified with Black patients (p.42).

Patient Referral

Many areas of the transplant process have been studied in detail but literature regarding areas of pre-wait listing such as patient referral is scarce. It is important to note that "dialysis facilities function as gatekeepers between kidney patients and new organs" (Palomino, 2015, p.2). "Unfortunately, there are no standard measures for kidney transplant eligibility or kidney transplant referral processes in dialysis centers" (Browne, et al., 2016). It is important for patients with CKD to be referred to a nephrologist early to a nephrologist before the disease progresses to ESRD (Cass, Cunningham, Snelling, & Ayanian, 2003). Later referrals are associated with decreased survival rates and morbidity (Cass, Cunningham, Snelling, & Ayanian, 2003).

Patzer, et al. (2015) looked into the patient referral rates within dialysis centers in Georgia which has been labeled the state with the lowest transplant rates. Out of the 308 dialysis facilities, they identified there were 15 facilities that did not refer any of the patients within their first year of dialysis treatment while some facilities that had a 75% referral rate (Patzer, et al., 2015). Rubin and Weir (2015) found that patients were more likely to be referred for transplant if the dialysis staff members had positive attitudes about transplant. The authors explored factors associated with referral rates and found that the lower referring facilities were "more likely to be non-profit, to be hospital-based, to have more patients, to treat patients living in high poverty neighborhoods, and to have a high patient to social worker ratio compared with facilities with the highest referral" (Patzer, et al., 2015, p. 587). Palomino (2015) found that when looking into the dialysis centers in Georgia, 9 out of 10 facilities were performing below the national average for referral between 2007-2010.

"Interestingly, socioeconomic factors seemed to be significant modifiers of the differences between African Americans and Caucasians for the propensity to be placed on the waiting list in our population" (Schold, et al., 2011, p. 1763). It is important to note the in a study by Patzer, et al. (2012) when they adjusted for SES, black patients still had a 59% lower rate of transplantation than whites. Higgins and Fishman (2006) noted that referral rates are lower for minorities both at initial evaluation of transplantation as well as at placement on transplant list. The lack of communication identified from physicians raised concerns amongst this population creating misconceptions about risk/benefit of transplantation and mistrust about equitable allocation of organs (Wachetman, et al., 2015).

Patzer, et al. (2009) "found that black patients were less likely than whites to be placed on the kidney transplant waiting list, and this disparity was not associated with the distance to the

nearest transplant center. Furthermore, we observed that neighborhood poverty was associated with waitlist placement and we report for the first time that racial disparities differ as neighborhood poverty increases" (p. 1334). Once on the wait list, the Hispanic population was shown to be removed from the wait list at a disproportionally higher rate (Schold, et al., 2016).

Interdisciplinary Team Processes and the Transplant Waitlist

The importance of interdisciplinary teams in health care outcomes has been an area mentioned often in the literature. The process of transplantation from original diagnosis to actual transplant includes many different actors. Many different disciplines must work effectively together in order to achieve improved outcomes in the transplant realm. An effective, patient-focused team can assist in improving the patient's quality of life (Nissenson, 2013). "Medicare's Final Rule of the Conditions for Coverage (April 2008) define the medical director of the dialysis center as the leader of the interdisciplinary team and the person ultimately accountable for quality, safety and care provided in the center" (Schiller, 2015, p. 493). These directors are part of the collaborative team consisting of physicians, nephrologists, social workers, nurses and dietitians (Schiller, 2015).

As part of the interdisciplinary team, nephrology social workers also play a role throughout the transplant process. The Centers for Medicare and Medicaid Services (CMS) require qualified, master's level nephrology social workers to be part of the interdisciplinary team in both transplant centers as well as within dialysis centers (Avery, 2014; Nephrology News and Issues, 2014; Browne, 2006). "This is very unique to the nephrology field only, and is the sole Medicare provision of its kind that recognizes that an illness like CKD carries with it

such psychosocial issues that only a master's-level social worker an competently address with patients and their families (Browne, 2006, p. 11). Quality Assessment and Performance Improvement (QAPI) Committees are required to continuously monitor and evaluate the transplant programs (Nephrology News and Issues, 2015). The committee meets on a regular basis and is comprised of members of the interdisciplinary team (Nephrology News & Issues, 2015).

The role of the social worker in dialysis centers is to serve as a support system for the patient and patient's families at the times of diagnosis, adjusting to the diagnosis and understanding the disease (Avery, 2014). The social worker also serves as an advocate and assists in bridging the communication gap between the interdisciplinary team and the patient. Some areas of this assessment include: financial and insurance information, medical history, preference in treatment modality, family and support systems, mental health or substance abuse concerns (Avery, 2014).

Social workers are also responsible for collecting information on the patient's quality of life based via an annual survey they must administer to patients (Avery, 2014). This information can assess areas in which the patient needs more support and to also identify how the patient views his/her situation. Some of the responsibilities of the social worker that are relevant to the transplant wait list process include: providing education and referrals to appropriate resources, assisting with obtaining and keeping insurance coverage, educated patients on the importance of their participation in their own care, and assisting patients with their rights and responsibilities (Avery, 2014).

The nephrology social workers are responsible for completing psychosocial evaluations for the patient to assist in determining if they meet the transplant center's psychosocial criteria

41

(Nephrology News & Issues, 2014; Miller, 2016; Browne, 2006). The psychosocial assessment includes areas such as: cultural and language factors, plans for post-transplant medication adherence, ensuring the patient understands the risks and benefits of transplant, mental health and substance abuse history, and the ability to commit to a treatment regiment, just to name a few (Nephrology News & Issues, 2014; Miller, 2016; Browne, 2006).

"The psychosocial patient selection criteria and psychosocial evaluation address psychosocial issues that affect patient and graft survival outcomes, similar to the medical patient selection criteria emphasis on the medical issues and how they affect patient and graft survival and outcomes" (Nephrology News & Issues, 2014, para 4). There are many areas of psychosocial issues, discussed previously, that are specific to patients with ESRD (Browne, 2006). The information based on these assessments is presented to the interdisciplinary team to assist with determining if the patient is suitable for transplant and transplant wait listing.

Synthesis of the Literature

The literature overwhelmingly identifies the benefits of transplantation such as cost, life expectancy and quality of life (Bayat, et al., 2015). However, even with transplant as the best option for patient with ESRD, inequalities exist within access to the kidney transplant waitlist (Srinivas, 2014; Kutner, et al., 2012; Kucirka, et al., 2012; Garcia, Harden, & Chapman, 2012; Mackelaite, Gaweda, Muhs, & Ouseph, 2014; Bayat, et al., 2015). The inequalities are evident within each area of the process from early access to healthcare, treatment options such as dialysis, referral for transplant, as well as achieving waitlist status (Kucirka, et al., 2012; Garcia,

Harden, & Chapman, 2012; Mackelaite, Gaweda, Muhs, & Ouseph, 2014; Bayat, et al., 2015; Patzer, Plantinga, Krisher, Pastan, 2014).

With a diagnosis such as ESRD, early education about the disease and treatment options was shown to be an area of importance (Kutner, et al., 2012). According to Kutner, et al. (2012) early education can increase the number of waitlisted patients. The literature also discusses the concern that some patients do not receive any education at all regarding transplant as an option (Kucirka, et al., 2012; Mackelaite, Gaweda, Muhs, & Ouseph, 2014; Calestani, et al., 2014). Racial differences were also evident when discussing early education where whites were identified as receiving early education more often (Kutner, et al., 2012).

Additionally, the evidence supports that the areas of inequalities present include the patient's age, gender, ethnicity, geographic location, SES, lack of proper insurance and education level (Srinivas, 2014; Pussell, Bendorf, & Kerridge, 2012; Kutner, et al., 2012; Kucirka, et al., 2012; Mackelaite, Gaweda, Muhs, & Ouseph, 2014; Bayat, et al., 2015; Patzer, Plantinga, Krisher, Pastan, 2014; Davis, et al., 2014; Axelrod, et al., 2014). Calestani, et al. (2014) found that patients disclosed the distress they felt due to being excluded from the kidney transplant list because of their age and comorbidity and patients also discussed feelings of inequity regarding the waitlist process. Patzer, et al. (2014) found that centers with lower transplant rates had a greater number of black patients, patients without proper medical insurance, and patients with diabetes.

Davis, et al. (2014) found that longer wait times were in areas where more patients were black, had lower education and were less likely to waitlist outside of their area. Mackelaite, Gaweda, Muhs, and Ouseph (2014) discussed how younger, healthier and wealthier patients have a better opportunity of getting on the transplant wait list. They also found that female patients,

older adults, non-Caucasian patients and those with lower SES are less likely to obtain a kidney transplant (Mackelaite, Gaweda, Muhs, & Ouseph, 2014). Kucirka, et al. (2012) discovered that patients who were older, obese, uninsured or patients with Medicaid as well as patients at for-profit centers were more likely to remain unassessed for transplant.

Reasons noted as possible reasons for the inequalities were the physician's or patient's preference (Tong, et al., 2014; Watcherman, McCarthy, Marcantonio, & Ersek, 2015). Stereotypes exist amongst minority populations, one of which includes the stereotype which suggests that African American patients are less likely to desire transplantation (Watcherman, McCarthy, Marcantonio, & Ersek, 2015). When discussing physician's preference, Tong, et al. (2014) stated that nephrologists were less likely to recommend a patient for the waitlist who has comorbidities, was nonadherent, older adults, minority patients, lower SES, patients with diabetes, obese patients, patients with cardiovascular disease or those patients who smoke or have abused alcohol. These preferences are thought to be accounted for due to the physician wanting to ensure the maximum efficiency of the transplant process (Tong, et al., 2014).

The literature also discusses the process for transplant centers when evaluating patients who are possible candidates for transplant (Tampa General Hospital, 2017; Gill, Hendren, Dong, Johnston, & Gill, 2014). There does not appear to be any one federal or standardized process for choosing the appropriate transplant candidates which leaves these decisions up to the transplant centers (UNOS, 2016; National Kidney Foundation, 2015; Bayat, et al., 2015). The testing and lab work required in the clinical evaluation also varies amongst the centers (UNOS, 2016; Tampa General Hospital, 2016; Gill, Hendren, Dong, Johnston, & Gill, 2014). The psychosocial evaluation is also part of the transplant candidate evaluation and the literature emphasizes the importance of including psychosocial factors in the evaluation (Cangro, 2014). These factors,

including social support, coping skills and access to resources can help to determine the patient's transplant success (Cangro, 2014).

Thus, although the literature provides ample evidence that racial and ethnic disparities exist in the process of ESRD patients getting on transplant waitlists, this evidence begs the question of why these process differences occur. To date, the literature does not include research that adequately answers this important question. It is clearly difficult to answer this question through existing data which only allows for the analysis of associations between patient race/ethnicity and waitlists. The process preceding the placement of a patient on a transplant waitlist has not been adequately detailed, and it may be quite variable from dialysis center to dialysis center.

Theoretical Framework

Equal access to resources and healthcare has been a topic of discussion for quite some time. Many definitions of what equality and equal access means are discussed in the literature. For the purposes of this paper, we will utilize the definition by Gutman (1983) which states that "a principle of equal access to health care demands that every person who shares the same type and degree of health need be given an equally effective chance of receiving appropriate treatment of equal quality so long as that treatment is available to anyone" (p. 44). Yet disparities, as previously discussed, continue to exist in access to healthcare therefore first understanding the possible cause of these disparities becomes important.

Theory of Fundamental Causes

The Theory of Fundamental Causes attempts to account for the reasons socioeconomic and racial disparities persist in specific causes of mortality in spite of a variety of efforts to eliminate them and despite multiple risk pathways in the course of disease that change over time (Phelan, & Link, 2005). Phelan and Link (2005) identify that while there have been many advances in medicine, and improvements have been made in population health, certain populations continue to benefit more than others, and this is due to "key resources" that can be deployed by certain populations thereby influencing disease outcomes. "The fundamental cause explanation focuses attention on flexible resources of knowledge, money, power, prestige, and beneficial social connections that can be used to harness advantages and avoid disadvantages in changing circumstances" (Phelan, & Link, 2005, p. S33).

Link and Phelan (1995) also discuss that the patient's flexible resources operate at not only the individual level but the contextual level as well. At the individual level, the resources shape the patient's access to finances and social support for accessing the best treatment (Link & Phelan, 1995). At the contextual level of flexible resources lies the idea that patients with flexible resources obtain the advantage of health enhancing circumstances such as better neighborhoods and quality health care resources (Link & Phelan, 1995).

In the area of access to the kidney transplant list, disparities as previously stated can be identified despite advances in the treatment of the disease. While transplant is identified as the ideal treatment for ESRD both medically as well as financially, access to transplant continues to be associated with inequalities. Kidney transplant is acknowledged as a major advance in the

medical field as it improves the longevity and quality of life for patients diagnosed with ESRD (Garcia, Harden, & Chapman, 2012).

The overall cost of transplantation has also been noted to be less than annual dialysis treatment costs. Hemodialysis can have an annual average cost of $72, 000 per patient in the United States (U.S. Renal Data System, 2014). Peritoneal dialysis can have an average annual cost of $53, 000 per patient (U.S. Renal Data System, 2014). While the average cost of a kidney transplant is about $32, 000 for the actual transplant surgery and then an annual post-surgery cost of $25, 000 (U.S. Renal Data System, 2014).

Link and Phelan (1995) suggest that a fundamental social cause of health inequalities has four essential features. These features are: 1) The cause influences various diseases, 2) it affects the outcome of the disease with multiple risk factors, 3) it affects access to resources that can be used to either avoid risk or lessen consequences of the disease, and 4) the association between a fundamental cause and health is reproduced over time via the replacement of intervening mechanisms.

The first feature of fundamental cause theory is that these causes, such as low SES and lack of education, can be utilized when discussing different diseases such as cardiac disease, communicable diseases and chronic diseases (Phelan, Link, & Theranifar, 2010). Rubin, Colen, & Link (2010) used this theory to identify inequalities evident in mortality of HIV/AIDS patients. They found that the introduction of a life-extending treatment actually increased the inequalities evident in areas of SES and race (Rubin, Colen, & Link, 2010).

Polonijo and Carpiano (2012) discussed fundamental cause theory as it relates to inequalities associated with the Human Papilloma Virus (HPV) vaccine. They discovered that patients with minority parents or low SES were less likely to be knowledgeable about the

vaccine's benefits and were less likely to have received a physician referral for the vaccine (Polonijo& Carpiano, 2012). Phelan, Link, & Tehranifar (2010) referred to this theory when looking at two separate diabetes clinics and they found that the clinic treating higher SES patients provided better continuity of care and the patients were noted to be more knowledgeable about their treatment. For the purposes of this paper, we will be using fundamental cause theory to frame disparities in treatment in ESRD.

The second feature of this theory is that socioeconomic status can affect the outcome of the disease with multiple risk factors. This feature is evident within ESRD and access to treatment options such as access to the transplant list (Axelrod, et al., 2010; Srinivas, 2014; Patzer, et al. 2012). Srinivas (2014) states that the southeast United States has the lowest health status attainment than any other area. This region also has poor access to health care and some of the lowest transplant rates. Socioeconomic status accounts for the high rate of poverty in this area and may also account for the high prevalence of ESRD, poor access to healthcare and lower transplant rates (Srinivas, 2014).

Axelrod, et al. (2010) found that patients with higher SES had better access to receiving a transplant and noted that they were 76% more likely to receive an organ from a live donor. Patients in the lower SES had higher incidence of death while on the waitlist as well as mortality post-transplant (Axelrod, et al., 2010). As discussed earlier, patients have the option of wait listing at multiple centers which may be more feasible for patients in the higher SES and these patients have the ability to travel across donor service areas to increase their access to donor organs (Axelrod, et al., 2010). Discussion of clinical advantages related higher SES leads directly into the discussion of the next feature of this theory which is access to resources.

The third feature involves access to resources that can be utilized to either avoid risk or to less the consequences of the disease (Phelan, Link, & Theranifar, 2010). The key resources are identified as knowledge, money, power, prestige, and beneficial social connections (Phelan, Link, & Theranifar, 2010). Jain and Green (2016) discuss the importance of knowledge, identified as health literacy at every stage of chronic kidney disease from diagnosis to dialysis to transplant. Education on the transplant practices, policies, referral and evaluation are all important pieces of knowledge that would enhance a patient's ability to lessen the consequence of the disease (Davis, et al., 2014). Health literacy is also important when discussing dialysis (Green, et al., 2013). Green, et al. (2013) identified that limited health literacy regarding dialysis was associated with increased non-compliance and an increase in missed treatment appointments. This also led to more hospitalizations and more emergency room visits for these patients (Green, et al., 2013). Without transplantation, as discussed previously, the patient would have to remain on dialysis and their life expectancy shortens greatly.

The areas of money, power and prestige all seem to relate to one another and can be identified by differences in SES and minority status. Those patients with lower socioeconomic status, as discussed previously tend to have less power and prestige and tend to have a more difficult time navigating through the transplant system (Axelrod, et al., 2010; Srivinas, 2012). The race/ethnicity of the patient also plays a role here in that patients who identified as black were 28% more likely to have limited health literacy whereas 5% of patients who identified as white were said to have limited health literacy regarding chronic kidney disease (Jain & Green, 2016). This is increasingly important as the American Kidney Fund (2015) explains that there are certain racial and ethnic groups who are more at risk for having kidney failure. When it comes to diagnosis of kidney failure, "compared to whites, the risk for African Americans is

almost 4 times high, Native Americans is 1.5 times higher, Asians is 1.4 times higher"

(American Kidney Fund, 2015, p.1).

Phelan, Link and Theranifar (2010) define what they refer to as flexible resources as

resources that can be utilized in different ways as needed in different situations. These resources

are noted as operating at either the individual and contextual levels (Phelan, Link, & Theranifar,

2010). Flexible resources for certain individuals accumulate because of the context they live in

(Phelan, Link, & Theranifar, 2010). Persons with higher SES live in neighborhoods with better

quality health care, for example and the geographic differences in wait listing may be accounted

to some degree by this factor. Early detection of kidney failure can be effective in ensuring the

patient receives proper treatments to prevent the disease from worsening (Phelan, Link, &

Theranifar, 2010). It is important for the patient to have the resources to be able to obtain these

early screenings. If resources are available, this flexibility of resources provides the patient with

options at each stage of their disease.

For instance, in the early stages of kidney disease, resources may be utilized to avoid risk

of the disease progressing into ESRD. Some of the emphasis for treatment options in the early

stages of the disease are healthy diet, and lower blood pressure which are more accessible to

those individuals by virtue of SES levels (Davita, 2016; Mayo Clinic, 2016 American Kidney

Fund, 2016; National Kidney Foundation, 2016). Similarly, when the disease progresses to

Stage 3 CKD, the patient would need to have resources such as health insurance, access to

transportation, access to a nephrologist as well as a dietitian as these are all recommended to

lessen the risk of progression at this stage (Davita, 2016; Mayo Clinic, 2016 American Kidney

Fund, 2016; National Kidney Foundation, 2016).

As far as social connections in the patient population, a strong social support network is of great importance. As discussed previously, during the evaluation process for the transplant list, the patient meets with the transplant social worker to uncover any biopsychosocial concerns (Nephrology News & Issues, 2014; Miller, 2016; Browne, 2006). Social supports are identified as protective factors and the patient has lower risk factors such as medication adherence when there is evidence of a support system (Danovich, 2009). Patel, Peterson, and Kimmel (2005) discuss the importance of social support with chronic diagnoses such as CKD. They found that social supports can be beneficial in many areas such as treatment and medication compliance, increased access to health care, enhanced psychosocial and nutritional status and immune function, and having support has been shown to decrease stress levels (Patel, Peterson, & Kimmel, 2005).

The last feature of the Fundamental Cause theory is the association between a fundamental cause and health outcomes over time (Link & Phelan, 1995). In other words, a way to prove a particular fundamental cause exists is if this cause continues to be a powerful predictor of poor outcomes through time. This is evident in the racial and socioeconomic disparities identified in obtaining a transplant (Patzer, et al., 2015). The literature has shown that disparities due to the patient's socioeconomic status and the patient's race have existed for a long time. For instance, in a study by Gaylin, et al. (1993) found that previous reports of lower transplant rates for lower income, nonwhite patients were confirmed in their study. Held, et al. (1988) looked at a random sample of new dialysis patients from each year between 1981 and 1985 and the fundamental causes were evident then as well. They found that young, male white patients within the high-income bracket were more likely to receive a transplant (Held, et al., 1988). Socioeconomic status and the race and ethnicity of the patient have been powerful predictors of

poorer transplant outcomes over time (Patzer, et al., 2015; Gaylin, et al., 1993; Held, et al., 1988).

If the fundamental causes are the persistent reasons for inequality, it appears that identifying ways to lessen these causes may provide a better chance to ensure equal opportunity for wait listing. A discussion of Rawls Theory of Social Justice along with Daniels' Theory of Health Care Justice is below. The Theory of Health Care Justice discusses health and healthcare as being thought of as a basic need and therefore the access to treatment should organizationally be more equal.

Rawls and Daniel's Theory of Justice

It would appear that a theory focused on social justice would be suitable when discussing the disparities of the kidney transplant list. Rawls Theory of Social Justice has many features that are pertinent to this topic. Rawls discussed the two principles of justice: 1) justice requires a liberal democratic political position to make sure that the citizens' basic need for goods are met; 2) justice includes regulation on institutions to assure that the - First, Rawls (2009) explains that per the "equal opportunity principle," inequalities are acceptable if every person in society has a reasonable chance of obtaining the positions that lead to the inequalities. According to Rawls' theory, there is inevitably going to be disparities and he identifies the need for what is known as the difference principle to address these disparities (Rawls, 2009).

The difference principle infers that "social and economic equalities…. are to be to the greatest benefit of the least advantaged members of society" (Rhodes, Battin & Silver, 2013, p.3). This accounts for the policies that are unequal in the distribute goods and services as long

as the end result is the benefit of the least well off in the population (Rhodes, Battin, & Silver, 2013). Rawls did not apply his theory specifically to healthcare and this is where Daniel's Theory of Healthcare Justice (2001) comes into play.

Daniel's (2001) interpretation of Rawls' theory as it applies to healthcare can be a good fit when discussing the transplant waitlist process.   Daniel's (2001) explained that a theory of justice for healthcare should be designed to answer three important questions. The first of these questions is "Is healthcare special?" which was addressed by Daniels (2001) when he argued that healthcare should be considered a basic need since healthcare works to maintain a person's normal functioning. When relating this to ESRD, dialysis and transplantation can be seen as working to bring a patient's health back to normal functioning.

With the second question, "When are health inequalities considered unjust?", it takes into account social standing and the underlying inequalities already embedded in society (Daniels, 2001). This is particularly important in the discussion of access to the transplant list as the inequalities are not just evident in the availability of healthcare but also within the social inequalities such as poverty and racism that have been identified in this population. Lastly, with the question, "How can the competing healthcare needs be met under resource constraints?" Daniels (2001) identifies the difficulty working with limited resources. This is relatable to the kidney transplant wait list as the demands for kidney transplants far outweigh the supply of donations (The Kidney Fund, 2015). This is where the allocation of organs is important to ensure that the available organs are provided in a fair and equitable manner. The difficulty is that there is no true agreement on what distributive justice with healthcare should look like (Daniels, 2001). The same can be said about the allocation of organs as changes have been made over the years in hopes of improving the distribution but yet disparities still exist.

"From Daniels point of view…the allocation of healthcare resources should be aimed at equalizing social opportunity" (Rhodes, Battin, & Silver, 2013, p. 61). According to Rhodes, Battin and Silver (2013) Daniel's argument extends further using Rawls' difference principle idea to state that due to social inequalities, health care should then be provided to those who are the most disadvantaged in terms of their health, which in the case of patients with chronic disease such as ESRD, this may be applied. Daniels would argue that this population would not have what he calls "normal species function" until transplant is complete due to the limitations the disease places on the individual (Rhodes, Battin, & Silver, 2013).

The differences in the wait list criteria amongst the transplant centers may be an area in need of review as there are currently no set mandates on this criterion. This allows the transplant centers to be able to choose which patients they feel are appropriate for the wait list at their center (UNOS, 2016; National Kidney Foundation, 2015). Each transplant center has their own multidisciplinary transplant committee who meet regularly to discuss each patient and ultimately decide if the patient meets their criteria (UNOS, 2016; National Kidney Foundation, 2015; Tampa General Hospital, 2016).

Critical Race Theory

Due to the variations in waitlist criteria and disparities noted in the literature in regard to the waitlist process, Critical Race Theory (CRT) can be useful as a theoretical framework and will be integrated into the Anderson model for the purposes of this study. Ford, Collins, and Airhihenbuwa (2010) explain that the Anderson model discusses race in terms of being a

characteristic that can innately cause inequalities but states that when combined with CRT, the socially constructed component of race is also addressed.

According to Stovall (2005), CRT examines racism at all levels including the individual and group levels. It also attempts to identify any institutional or systematic reasons that promote the function of racism (Stovall, 2005). Another important component of CRT is that it "recognizes the complex relationships and intersections that reside within race, class, gender and sexuality differences and feature prominently in the social world of ethnic minorities" (Graham, et al., 2011, p. 82).

Ford, Collins, and Airhihenbuwa (2010) discuss the four features of CRT they have identified, which include: race consciousness, contemporary orientation, centering the margins rather than in the mainstream and praxis. Race consciousness is identified as the person's awareness and understanding of the presence of racism in their personal life and how it affects them (Ford, Collins, & Airhihenbuwa, 2010). For example, in terms of kidney transplant patients, Cuevas and O'Brien (2017) identified that the patient's racial identity was an important component of the patient's experience in terms of receiving equitable health care.

The second feature of CRT, contemporary orientation has to do with understanding race at the system level. This feature explains racism as an ordinary component of society (Ford, Collins, & Airhihenbuwa, 2010). This concept provides an explanation for why some people may begin to either ignore racism or become hypervigilant as it has become a regular component of their everyday life. When discussing the kidney transplant waitlist and patient's behaviors in the early steps of the process, this ordinariness may have some influence as to whether a patient pursues transplant. Cuevas, O'Brien, and Saha (2017) explained that "although African Americans perceive discrimination in health care settings, experience higher levels of medical

mistrust compared with European Americans, and experience poorer communication with health

care providers" (p. 987).

The third feature of centering the margins has to do with lessening some of the innate

biases between the researcher and the minority group (Ford, Collins, & Airhihenbuwa, 2010).

The "outsiders within" approach has been noted to be a valuable component of this feature as the

minority's perspective of their experiences are taken into account which allows for greater

understanding. This approach will also be valuable in the kidney transplant arena as patients

have expressed discrimination in health care providers and in their communication with minority

patients (Hausmann, et al., 2011).

The last feature of CRT that will be discussed is known as praxis. Praxis can guide the

research by focusing on the information provided by those within the marginalized communities

(Ford, Collins, & Airhihenbuwa, 2010). The kidney transplant patients themselves will be

surveyed in this study to provide more meaningful data about their personal experiences

navigating through the transplant waitlist system and this will provide insight into how race may

play a role in this process.

Anderson's Behavioral Health Model of Health Services Use

The Behavioral Model of Health Services Use was originally created to help develop an

understanding of why families utilize health services, to determine a way to define and measure

access to healthcare, and to assist in policy development to promote equitable access (Anderson,

1995). The reason the family was the original focus was because Anderson (1995) identified that

the social and economic characteristics of a family can indicate the type of medical care the

patient receives. This model was since changed to focus more on the individual patient which is the model that will be utilized for the purposes of this paper.

The Anderson Model was used to organize the examination of factors that impact the likelihood of a patient moving onto a transplant waitlist. This model coincides with fundamental cause theory regarding resources operating at the individual and organizational levels that result in variance in health care utilization, in this case in inclusion on the transplant waitlist. The Anderson Model posits predisposing characteristics (or causes) including demographics, social structure and health beliefs play a role in the patient's use and access to healthcare. The model also includes enabling resources, which much like the flexible resources in Phelan and Link's (1995) theory are identified as being necessary and these resources must be present for the patient to be able to access healthcare services (Anderson, 1995). This model also takes into account the patient's need for medical services which Anderson (1995) divides amongst perceived health need versus evaluated needs for health services. The patient's predisposing characteristics as well as their enabling resources can play an integral part in identifying the patient's need as well as their ability to access proper healthcare.

The figure below depicts the behavioral model as it relates to patients with ESRD and these areas will also be addressed in the survey measurement tool. Starting with the predisposing characteristics of the patient, this is broken down into: demographics, social structure and health beliefs (Anderson, 1995). In terms of demographics, the focus is on the patient's age and gender which have been shown in the literature to play a role in the patient's access to the kidney transplant wait list (Patzer, et al., 2014). When discussing social structure, it is composed of the patient's ethnicity, education, and employment. As discussed previously, all of these components play a role in the patient's ability to gain access to the transplant wait list as well as

57

the inequalities evident in the process. Finally, in the area of health beliefs, the patient's

knowledge about kidney disease, attitudes about transplantation as well as health literacy are

taken into account.

Predisposing Characteristics Resources		Enabling Resources		Need		Use of Health

Demographics	Personal/Family Resources	Perceived Health
Age	Social Support	Patient's View of Health
Gender	Insurance Type	Patient's Perception of Condition
Race	Socioeconomic Status	
	Perceived barrier to care	

Social	Community Resources	Evaluated Health
Ethnicity	Geographic Residence	Physician's Evaluation of Patient
Education	Region	Physician Perception of Patient
Employment	Transplant Center Location	Transplant Center Evaluation of pt.
	Transplant Center Type	

Health Beliefs

Knowledge about kidney disease
Attitudes about transplantation
Health Literacy

Figure 6: The Anderson Behavioral Health Model of Patients with ESRD.

Application of Theories

The literature discussed previously provides evidence of the disparities that exist in

kidney transplant wait listing (CITE). The theories identified above can be utilized to identify

and explain the areas of inequalities. These theories will also be utilized to explore associations

between the region the transplant center is located, the differences amongst transplant center wait list criteria and the patient access inequalities that exist in these centers. Fundamental causes of these inequalities will also become evident with the use of the theory.

Daniels' Theory of Justice focuses on patient's equal access to healthcare. This theory provides a perspective that can be used when looking at the lack of standardization for transplant wait list criteria. Daniels (2001), much like Rawls discusses the difference principle which accounts for any unequal distribution so long as it benefits the least advantaged members of society. However, the literature has shown that this is not necessarily true when discussing the transplant wait as there are many disadvantaged patients who have difficulty accessing the transplant list. Daniels believes that the citizens have equal opportunity to the goods and services (Rhodes, Battin, & Silvers, 2013). While it is known that inequalities exist when discussing the transplant list, however it is not clear as to whether the wait list criteria designated at each transplant center may be a systematic reason for the inequalities. This study will be using this theory when looking into the differences amongst transplant wait list criteria.

Fundamental Cause Theory provides a framework for identifying the reasons why inequalities exist and also demonstrates that these causes have been evident for years. Link and Phelan (1995)'s notion that flexible resources influence racial disparities in health care outcomes and can operate at the individual level and the contextual level. At the individual level, the resources shape the patient's access to finances and social support for accessing the best treatment (Link & Phelan, 1995). At the contextual level of flexible resources Link & Phelan posit that the opportunity for equitable health outcomes is dependent on the resources existing in the external context, including primarily the level of neighborhood socioeconomic development vs. level of poverty. Furthermore, it is reasonable to assume that neighborhood socioeconomic

59

status acts as a proxy for the flexibility of resources in the macro-context, including the quality of health care resources, rates of insured vs. uninsured, and the density of minorities. The fundamental causes that will be addressed in this study are socioeconomic status of the county within which the respondents' dialysis centers reside.

Link and Phelan (1995) explain that patients with flexible resources available to them, may be better able to gain access to quality healthcare, have the financial and social support necessary for accessing the best treatment option and may reside in more advantageous neighborhoods. These resources are necessary for patients to be able to navigate through the transplant evaluation process and to successfully complete the transplant process. This study will assess how the patient's flexible resources may play a role in their ability to access the wait list.

Anderson's Behavioral Health Model will be utilized to classify the potential sources of variation in kidney transplant wait listing (predisposing, enabling, etc.). The predisposing factors that will be included in the model specific to transplant wait listing include the patient's age, gender, ethnicity, education level, employment status, as well as the patient's health literacy. The enabling resources that will be addressed in this study include social support, insurance type, SES, geographic location including the patient's geographic region, as well as the availability of resources. The last component of the model includes the patient's perceived health and evaluated health which includes areas such as the transplant center's evaluation of the patient including waitlist criteria, the physician's perception of the patient as well as the patient's view in these areas.

Research Questions and Hypotheses

Due to the differences in patients who gain access to the kidney transplant waitlist as well as differences in transplant center criteria regarding wait list practices, this study focuses on gaining a better understanding of the factors that may play a role in variations in patients' experiences in accessing the transplant list. Ideally, in order to understand what affects racial disparities in transplant waitlists one would attempt to specify a model wherein the outcome variable measured the likelihood of Black ESRD patients getting on a waitlist and then regressed the variables from the Anderson Model on that outcome. However, numbers and racial characteristics of patients ending up on waitlists versus those who do not end up on a waitlist are difficult to obtain. For this reason, we must look to find informants who have been through the process, who can help to indicate which factors from the theoretical model they see as influential in the waitlist decision making process in their center. Patients who have received a transplant will serve as expert informants to the factors affecting the process of wait-listing, since these individuals have been involved in the wait listing process through completing all necessary evaluations and by navigating through the transplant process.

We surveyed kidney transplant recipients to find out their level of endorsement of the importance of the predisposing, enabling and need variables from the Anderson model in the transplant waitlist process. We then looked at whether the factors endorsed by the transplant recipients as important in wait listing vary by contextual factors including organizational factors of the waitlist sites (type of transplant center, rural or urban location, or university vs. hospital-based center). We also asked transplant recipients to estimate the time from learning that they needed a transplant until the time they were put on a waitlist, and then the time from first being

put on a waitlist until they received the transplant. These time factors will also be explored as a function of the recipients' characteristics and their responses to the two discrimination indexes in the survey. Lastly, in depth interviews were conducted with some respondents to explore nuances present in the wait list process and to gain a better understanding from the patient's perspective.

Research Questions

The research questions in this section were explored through a survey of transplant recipients. Anderson's Model of Health Behavior and CRT served as the framework for specification of the first three research questions in this analysis. This data was collected via a cross-sectional survey of members of kidney transplant support groups (see below for details of survey recruitment). The survey included Likert-scaled questions to measure the recipients' perceptions of the impact of each of the variables from the Anderson Model on the process of getting on transplant waitlists. This data offered a descriptive analysis of transplant recipients' perceptions of the factors that affect the process of getting on transplant waitlist (see RQ1 and RQ2).

R1 – To what degree do transplant recipients perceive the role of their predisposing characteristics (race/ethnicity, age, gender, education level) as important in the process of getting on the kidney transplant waitlist?

> H1a-Respondents will report that they perceive their race/ethnicity as important in the process of getting waitlisted.
> H1b- Respondents will report that they perceive their age as important in the process of getting waitlisted.

H1c- Respondents will report that they perceive their sex as important in the
process of getting waitlisted.

H1d- Respondents will report that they perceive their education level as important
in the process of getting waitlisted.

R2- To what degree do transplant recipients and perceive the role of their enabling resources (patients' SES, health insurance type, support system, transplant center type and location) as important in the process of getting on the kidney transplant waitlist?

H2a- Respondents will report that they perceive their income level as important in
the process of getting waitlisted.

H2b- Respondents will report that they perceive their health insurance type as
important in the process of getting waitlisted.

H2c- Respondents will report that they perceive their support system as important
in the process of getting waitlisted.

The literature review also indicates that there are potential external influences on the process of wait listing, including characteristics of the Donor Service Area (DSA) region the transplant center is located in (length of waiting times, the prevalence of wait listing in those areas, prevalence of ESRD and the prevalence of deceased donor kidney transplant), organizational differences in transplant centers (type of transplant center and transplant center location type). Data for these external factors was sourced in several ways. First, the transplant recipients were asked questions about the location of the transplant center and organizational characteristics of their center. Data from the cross-sectional surveys was stratified by these organizational variables in order to explore differences in survey responses across organizational strata.

63

R3. To what degree do transplant recipients' perceived discrimination differ amongst their predisposing characteristics (age, race, sex, educational achievement) and enabling resources (insurance type, transplant center type and income level)?

> H3a-Higher mean scores on the Discrimination in Medical Settings will be found in respondents in the older age groups
>
> H3b- Higher mean scores on the Discrimination in Medical Settings will be found in respondents in non-white racial groups
>
> H3c- Higher mean scores on the Discrimination in Medical Settings will be found in female respondents
>
> H3d- Higher mean scores on the Discrimination in Medical Settings will be found in respondents with lower educational achievement
>
> H3e- Higher mean scores on the Discrimination in Medical Settings will be found in respondents in the lower income groups.
>
> H3f-Higher mean scores on the Discrimination in Medical Settings will be found in respondents with non-private insurance.
>
> H3g- Higher mean scores on the Discrimination in Medical Settings will be found in respondents in rural transplant centers.

R4. To what degree do transplant recipients' perceived trust of the interdisciplinary team differ amongst their predisposing characteristics (age, race, sex, educational achievement) and enabling resources (insurance type, transplant center type and income level)?

> H4a-Higher mean scores on the Medical Mistrust Scale will be found in respondents in the older age groups
>
> H4b- Higher mean scores on the Medical Mistrust Scale will be found in respondents in non-white racial groups
>
> H4c- Higher mean scores on the Medical Mistrust Scale will be found in female respondents
>
> H4d- Higher mean scores on the Medical Mistrust Scale will be found in respondents with lower educational achievement

H4e- Higher mean scores on the Medical Mistrust Scale will be found in
respondents in the lower income groups.

H4f-Higher mean scores on the Medical Mistrust Scale will be found in
respondents with non-private insurance.

H4g-Higher mean scores on the Medical Mistrust Scale will be found in
respondents in rural transplant centers.

Respondents were asked to identify characteristics related to the sites they received their

transplants, including proprietary status and location in order to explore associations between

treatment context and respondents' perceptions of the waitlist process. Trends in transplant

recipients' responses to the Anderson model categories were further explored by examining

correlations and interactions with organizational characteristics of the transplant center type and

location type.

**R5. Are reported kidney transplant wait times (pre and post) associated with the
recipients' predisposing characteristics (age, race, sex, educational achievement), enabling
resources (insurance type, transplant center type and income level) or with their perceived
discrimination or mistrust?**

H5a-Longer reported wait times will be found in respondents in the older age
groups

H5b- Longer reported wait times will be found in respondents in non-white racial
groups

H5c- Longer reported wait times will be found in female respondents

H5d- Longer reported wait times will be found in respondents with lower
educational achievement

H5e- Longer reported wait times will be found in respondents in the lower income
groups.

H5f-Longer reported wait times will be found in respondents in rural transplant
centers.

H5g- Longer reported wait times will be found in respondents with higher scores on the MMS scale.

H5h- Longer reported wait times will be found in respondents with higher scores on the DMS scale.

Detailed descriptions of these survey items and measures are described in Chapter 3 in the Measurement Section. Demographic information was also collected on respondents to explore trends in process factors and perceived discrimination by age, gender, SES, race and ethnicity. The survey also included some open-ended questions to allow respondents the opportunity to provide more detail and anecdotal information on their own experience in the waitlist process.

Finally, in order to more deeply explore possible sources of racial and ethnic based differences in the process of wait listing for kidney transplants and in order to triangulate the data in the analysis, there was a qualitative arm of the study. Specifically, in-depth interviews were conducted with ten transplant recipients who completed the survey and agreed to provide contact information for a follow-up interview. Ideally, this process will yield a sufficiently diverse set of interviewees in order to more fully compare the waitlisting experience across race and ethnicity. A more in-depth description of the interview process is provided later.

CHAPTER THREE: RESEARCH METHODOLOGY

Sample Recruitment

Originally, the intended recruitment plan for the sample was to attempt to survey kidney transplant recipients from kidney transplant support groups solely in the state of Florida. When researching the kidney transplant support groups, an online search was started via Google with the keywords "transplant support groups" which brought up a broad range of groups which included many different types of organ transplants such as: kidney, heart, lung and liver. Through this search, it was noted that UNOS Transplant Living (2018) provided a list of 348 support groups across the United States, 19 of which were listed as being located in Florida and only five of these groups in Florida focused on kidney transplantation.

In order to identify more groups for survey recruitment, the search was modified via Google by entering the key words "*kidney* transplant support groups in *Florida*" into the search engine. With this search in addition to the five groups from the previous search, the total number of kidney transplant support groups identified in Florida was now 19 groups.

The group leader listed for each group was contacted via email and a brief description of the study purpose was provided. Group leaders' email responses provided information about their group and information on which groups were willing to allow participants to participate in the survey. The responses from group leaders varied and are listed below.

- Some group leaders had stated that their groups no longer meet face to face due to lack of attendance (n=2).
- Some leaders stated that the group no longer exists (n=3).
- Some group leaders did not respond at all (n=5).

- Some of the contact information for the group had numbers or emails that were no longer valid (n= 5).

Due to the small number of kidney transplant support groups in the state of Florida that meet face to face (n=4), a new IRB addendum was submitted to open the sample to online kidney transplant support groups as well. The IRB addendum was approved on September 26, 2018.

Once approved by IRB, the statement "online kidney transplant support groups" was entered into the Google search engine. From this, eleven online forums and support groups were identified. The group leader listed for each of these groups was contacted via email and a brief description of the study purpose was provided and is shown below.

Hello Everyone,

I am the wife of a kidney transplant recipient and I am also working on my PhD at University of Central Florida where my focus is on the Disparities in Kidney Transplant Waitlisting and I would love to hear about your experience.

· Are you over 21 years old?

· Have you received a kidney transplant within the last 10 years?

If you answered YES to these questions then we would love for you to share your kidney transplant waitlist experiences with us.

The purpose of this research study is to explore transplant patients' experiences with getting on the kidney transplant waitlist, and will also examine how patients' characteristics are associated with these experiences and attitudes related to the process of getting on a transplant waitlist.

All you have to do is complete a survey online which should take approximately 30 minutes of your time. You will also have the option to volunteer to participate in a phone survey at a later date if you so choose.

Once a response from the group leader was received, the plan for how to properly disperse the surveys to the group was identified. If the group leader felt the survey was best

completed in electronic format, then that was available to them and a paper form was also available for groups that felt this was a better option. The eligibility criteria were only that the participant has to be an adult kidney transplant recipient (age 21 or older) who received a transplant within the last 10 years. Patients who are still on the waitlist or on dialysis awaiting a transplant were not included in the study. Finally, for the support groups that met face to face, their leaders were given the option for the researcher to come to the support group and distribute surveys in person to the members.

Out of the four face to face groups, the group leaders offered to disperse the surveys either via email to their participants or in person when they attended group. The group leaders had stated that they are not always sure how many participants will show up to the groups each time they meet. One group leader even offered to post the information about the study in their weekly newsletter.

Online groups leaders' responses were quite similar to each other. Many group leaders offered for the researcher to post the description of the study (same as described previously) along with a link for the survey for their members to access easily.

If the group leader's plan was to have the survey dispersed via email or by posting online, the following process took place to ensure a good response rate. In order to gain a better response rate, Schaefer and Dillman (1998) recommend personalizing the email if the survey is sent via email. The transplant recipients may receive many emails and online posts in a single day so research has shown that sending a mass email or post without any personalized information may result in decreased response rates (Schaefer & Dillman, 1998). With this in mind, each email survey was sent with a personalized message in attempts to increase the response rate. This was also true for posts in online groups or forums.

According to Schaefer and Dillman (1998), another way to increase response rates of emailed surveys, multiple contacts must be made. Therefore, two weeks after the surveys had been sent out, a reminder email/post was sent to those participants who had not yet responded. Two weeks following the reminder email/post another reminder was sent, and another two weeks later, one final reminder email/post was sent in hopes of increasing the response rate. Schaefer and Dillman (1998) mentioned that the response rate with only one contact is about 28% and increases to 41% with two contacts and then increases even more to 57% for three or more contacts which is why more than three contact attempts were made.

Since the recruitment letter was posted on each forum or support group site, along with link for the survey, it was decided that it may be beneficial to be able to determine which groups the responses were coming from. Specific links for each recruitment group were created through Qualtrics in order to determine which group the respondents belonged to. The survey was identical on all links but were labeled with a letter to be able to distinguish which group the answers were coming from. For example, Survey form A, B, C etc.

Once the responses began coming in, it was noted that many of the responses were coming in from the online support groups and forums (n=129). It was also noted that from these responses, many of the participants completing the survey did not receive their transplant in Florida (n=120). This may be due to the availability of online support groups to reach many people all over the world, however it is unclear as to exactly why this may have occurred. In order to increase the number of survey responses to be included in the data analysis an addendum to the IRB approval was submitted and approved which authorized the use of the data from any of the responses nationally, not limiting them to just the state of Florida. An application for IRB

70

approval was submitted and approved as Exempt Human Research after all addendums on December 4, 2018.

To ensure that the final sample used in the analysis was large enough for results to have external validity, a power analysis was conducted to determine minimum necessary sample size. As a function of effect size, alpha and statistical power, a power analysis indicates that with a 5% margin of error and a 95% confidence level, and $\alpha=.0.05$, the target sample size required approximately 150 kidney transplant recipients to create an acceptable sample size for the study (Calculator, 2015).

Measurement

The survey consists of a total of 60 questions which are either likert-scale, open ended or multiple-choice questions. Within the survey are two scales, The Discrimination in Medical Settings Scale and the Medical Mistrust Scale. There is also a qualitative component to the data collection which consisted of phone interviews. The survey and qualitative interviews are described in detail below.

Survey

The first item on the survey ensured that all participants in the study were kidney transplant recipients by simply asking, "Are you a kidney transplant recipient?". Items 2-6 covered individual predisposing characteristics (demographics) by asking the participants to indicate their age, sex, describe their race, income level, and educational level. Items 7-10 included information relating to enabling resources, in particular, geographic location and region

of the transplant center and patient's residence. Items 11-18 provided information on the patient's experience on the kidney transplant waitlist including:

What age were you first told you needed a transplant?

What year did you receive your transplant?

What was the approximate time from knowing and getting on the list?

What was the approximate time from waitlisted to getting transplant?

Were you ever removed or labeled inactive status on the list?

If so, how many times were you removed and why?

What year did you receive your transplant?

Questions 19-22 included questions about support the patient may have including questions about if a social worker assisted them in the waitlist process, how important was the social worker, what did they do to support them, and what types of support or assistance do they wish they had throughout the process. The next ten questions (22-33) were Likert scaled questions (strongly agree (5), agree (4), neutral (3), disagree (2) and strongly disagree (1)) to look into the patient's feelings about each of the predisposing characteristics, enabling resources and perceived need. Out of these, questions 23-27 included the questions about: age, ethnicity, race and gender and were worded as: *I feel that my _____ had a negative effect on my waitlist experience.* Questions 28-33 were worded a bit differently. For example: *I feel that if I had better (health insurance, paying job, support system, education, information) the wait list process would have been easier.*

Hausmann, et al. (2008) focused on race-based discrimination in health care settings and they explained that "there is strong evidence suggesting that people who perceive more discrimination directed at themselves or other members of their group are at greater risk for

reduced mental and physical health status" (p.905). Peek, et al. (2011) also discussed perceived

racial discrimination in health care as it was associated with lower patient satisfaction, less

adherence to treatment, poor communication between patient and provider, as well as less use of

preventative services.

Table 3. Study Variables

Study Variables	Variable	Survey Question	RQ	Hypo
Outcome Variables	Pre Wait-Times	14	R5	H5a-H5h
	Post-Wait Times	15	R5	H5a-H5h
	Medical Mistrust Scale	34-40	R4	H4a-H4g
	Discrimination in Medical Settings Scale	41-57	R3	H3a-H3g
Level One: Predisposing Characteristics	Age	2	R1	H1b
	Sex	3	R1	H1c
	Race	4	R1	H1a
	Income	5	R2	H2a
	Education	6	R1	H1d
Level Two: Enabling Resources	Social Supports	30	R2	H2c
	Insurance Type	13	R2	H2b
	Socioeconomic Status	5	R2	H2a
	Geographic Residence	7	------	-------
	Region of Residence	7	-------	-------
Level Three: Need	Patient's Perception	MMI, DMS & 23-33	R3 & R4	H3a-H3g H4a-H4g
	Perceived Discrimination	DMS	R3	H3a-H3g
	Perceived Mistrust	MMI	R4	H4a-H4g
External Variables	Center Location (rural, suburban, etc)	9	R5	H5f
	Center Type (hospital or university based)	8	-------	--------

Because much of the data collection includes Likert-scale data, nominal data and interval level data, care must be taken to utilize analytic techniques appropriate to each measurement type. Analysis of Likert-scale data has been said to be problematic for several reasons and these issues will be considered here. First there is the problem of data distortion. First depending on the nature of the question sets and to some degree the subjective lens of the respondents, there may be low likelihood of utilizing the extreme ends of the Likert scale (i.e., 1 or 5) which is referred to as "central tendency bias, acquiescence bias and/ or social desirability bias.

To minimize these sources of potential bias, the survey instrument was designed to balance the Likert scale items with negative and positive statements, which is the best solution for acquiescence bias. In order to reduce the risk of central tendency bias, the survey directions urged the respondents to utilize the full scale in their responses. And to minimize social desirability bias respondents were urged to understand the critical nature of the problem the survey is investigating and how important it is to provide the most accurate responses possible in order to achieve the most accurate results.

As stated previously, two scales were included in the survey, The Discrimination in Medical Settings Scale and the Medical Mistrust Index 2.1, to provide more information in these areas. Below is a description of the scales utilized in this study.

Discrimination in Medical Settings Scale

The Discrimination in Medical Settings Scale was utilized to provide information on the patient's experiences of mistreatment in healthcare (in this case during the transplant process)

due to the patient's race. This is a 7-item (items 34-40 in the survey) scale used by Bird, et al. (2001) that had been modified from the original Everyday Discrimination Scale (EDS) which had "high levels of internal consistency, convergent validity and divergent validity among African American men and women" (Peek, et al., 2011, p.3). This scale has been utilized in many other studies with different populations with different medical diagnoses.

For instance, this scale was used by Cloyes, and Rivera (2015) with LGBT older adults to look into their perceptions of discrimination in the medical setting as there were LGBT older adults who reported fearing discrimination by health care providers. The scale was used to determine if their sexual orientation predicted their score on this scale as this is important to know as this may prevent members of this population from getting the medical care they need. Bisexuals in this study reportedly had significantly lower scores (Cloyes & Rivera, 2015) which is also important to know so that further studies can be conducted to look into why this population tends to have lower scores which in turn means, less perceived discrimination.

Lopez-Cervallos and Harvey (2016) used the Discrimination in Medical Settings Scale with a group of young adult Latinos. They discussed how health care discrimination is causing barriers to health care services in many minority groups including the Latino population. The statement on the scale they mentioned with the lower score for this population was "A doctor or a nurse acts as if he or she is afraid of you" (Lopez-Cervallos & Henry, 2016) which is important to note as patients may be less likely to see medical care if they feel the health care provider is afraid of them. Rivera, et al. (2016) used this scale in female to male transgender patients to evaluate times they perceived discrimination in the medical setting. They found that participants scored higher 2.45 on the statement "I felt I was treated with less respect than other patients".

Rivera, et al. (2016) noted that the majority of this population surveyed had reported that discrimination occurs sometimes.

Lastly the study by Peek, et al. (2011) used the scale with African American patients and it was noted that the patients with diabetes who reported health care discrimination had more health complications and worse control of their control. The scores in this study had an overall mean of 1.71 and the highest mean 1.91 was with the statement "you feel like a doctor or nurse is not listening to what you are saying" (Peek, et al., 2011). The statement with the lowest mean 1.33 was "A doctor or nurse acts as if he or she is afraid of you" (Peek, et al., 2011). This finding was similar to Lopez-Cervallos, & Henry (2016).

The participant's responses were assessed on a 5-point scale (1-never, 2-rarely, 3-sometimes, 4-most of the time, 5-always) and the mean score on each statement was calculated. The higher the mean score, the more perceived discrimination.

Medical Mistrust Scale 2.1

LaVeist, Nickerson, and Bowie (2000) found that African American patients were more likely to perceive racism and also more likely to report mistrust with the medical system. They found that this perceived racism and mistrust played a role in patient satisfaction. The Medical Mistrust Scale 2.1 was also utilized in the survey to provide more information about how patients feel about trust in the medical setting. This scale consists of 17 items (statements 41-57 in the survey) and include statements such as "patients should always follow the advice given to them at healthcare organizations" and "healthcare organizations put the patient's health first". Participants are asked to rate these statements with either: 5-strongly agree, 4-agree, 3-neutral, 2-

disagree or 1-strongly disagree. As in previous studies, the mean score on each statement was

calculated. The higher the mean score, the more perceived medical mistrust.

LaVeist (n.d) discussed the importance of understanding the trust needed when

navigating through a health care system. He explains that trust is evident in many areas such as

doctor/patient relationships, trust in the pharmaceutical companies, trust in competence of the

health care team, and trust in the education received and appropriate decision making in regard to

the diagnosis (LaVeist, n.d.). This is true in the kidney transplant process as there are many

steps to the waitlisting process and this begins with trusting that the patient will receive a referral

to begin the process.

Qualitative Interviews

Survey respondents were also asked if they would volunteer to be contacted at a later date

to participate in a phone interview. They were told that this interview would allow for a more in

depth look into the transplant recipients experience overall as it relates to the focus of this paper,

that each interview would consist of eight open ended questions to allow the respondent to

answer freely without being limited by multiple choice options or likert scale response options.

The eight interview questions are listed below. These questions were designed to allow the

respondent to identify any areas of the waitlist process that were particularly difficult as well as

areas they find to have been easy to navigate which will provide more information directly from

the patients who have had to experience this process.

Survey respondents who indicated they were willing to be recruited for an in-depth

telephone interview provided their names and a contact email and telephone number on their

surveys. Because a key research question is the role of patient race in waitlisting experiences, I

attempted to recruit five African American respondents and Caucasian respondents for

interviews. I emailed ten potential interview recruits, reminded them of the purpose of the study

and asked if they were still willing to be interviewed and open to having their interview

audiotaped over the phone to please respond to my email and to provide potential days and times

in the next month that they could be interviewed.

These interviews were conducted by phone and were semi-structured with the intent of

exploring further each respondents' wait list experiences. A list of the interview questions is

provided below.

- *Please discuss the steps of the transplant waitlist process and approximately how long each step took for you.*
- *Please describe some of the obstacles you experienced when trying to get wait listed.*
- *Please describe any areas of the waitlist process that you found to be easy to navigate.*
- *Please discuss any people in particular that were helpful during the transplant waitlist process.*
- *Please discuss any times where you felt discriminated against for any reason during the waitlist process.*
- *Describe anything about yourself or your personal situation that, if you had the ability to change it, would have made the transplant waitlist process easier.*
- *Is there any advice you would give to other patients trying to get onto the transplant waitlist?*
- *Please discuss any areas that you feel could have been improved in order to make wait listing easier for you.*

CHAPTER FOUR: RESULTS

The survey was entered into Qualtrics to be able to provide a link for the online version of the survey for the support groups and forums that meet online and for the support group leaders who requested to disperse the survey via email. The data was collected in Qualtrics, cleaned and stored in the password-protected database accessible by the researcher and then analyzed using the Statistical Product and Service Solutions (SPSS) software version 25 (IBM Corporation, 2012). Once surveys were completed and the survey was closed, frequency distributions were run on all demographic data to better understand the sample of the population that completed the survey. This data was analyzed and is described in detail in the subsequent section under sample.

Data Analysis

This chapter discusses the results of data analysis, including a descriptive outline of the respondents' demographics including age, race, sex, educational level, income level and insurance type, relationship and prediction. The dependent variables in the analysis are reported wait times, mean scores on the Medical Mistrust Scale, and mean scores on the Discrimination in Medical Settings Scale. Descriptive analysis includes examination of measures of central tendency and variability in all the independent and dependent variables. The survey items, previously described, include mainly Likert-scale questions and several nominal response items which were first examined with descriptive statistics. Each Likert item was analyzed separately in univariate analysis including percentage distribution of responses in each of the five Likert response categories and measures of central tendency including the mean.

As in previous studies, the mean scores from the Discrimination in Medical Settings Scale and the Medical Mistrust Index were also computed for each respondent. Descriptive approaches were used to begin to explore the trends in mean scores across different moderator variables including: respondent gender, age-group, race/ethnicity; respondent's organization characteristics including region, location of the center (rural or urban) and the type of center (university or hospital based).

Although there are some debates about the use of averages from Likert response data in parametric analyses, in this analysis of the two standardized scales, since groups of Likert response items were coded and mean scores were calculated, the mean scores can be defended as an approximation of interval data. Thus, an analysis of variance was used as the primary methods for exploring the relationships between the study variables and the scale scores. Analysis of variance was also employed to explore how relationships of the three dimensions of the Anderson Model of Health Behavior (predisposing, enabling and need scores) and transplant center organization variables varied significantly across the reported waitimes.

With the Medical Mistrust Scale and Discrimination in Medical Settings Scale, the mean scores on the scale were compared by predisposing characteristics and enabling resources. A one-way ANOVA was used for the medical mistrust scale (categorical independent variable, continuous dependent variable) and the Discrimination in Medical Settings Scale. An ANOVA was run for each demographic variable, the post-hoc (in the hopes of significant results) and graphs showing the mean plots for all variables.

Qualitative Analysis of Interviews

Ten in-depth interviews were conducted by phone with kidney transplant recipients. Interview data was audio recorded and transcribed verbatim. A team of two doctoral students coded the data. They employed an iterative coding process that applied techniques of grounded theory (Strauss & Corbin, 1998) and directed content analysis (Hsieh & Shannon, 2005). Specifically, to initiate team-based codebook development, coders independently reviewed the first two interview transcripts with the intention of coding descriptive labels for responses to each of the open-ended questions.

Using the constant comparison method (Strauss & Corbin, 1998) coders grouped and named common concepts as a means to generate their version of a coding grid that included each concept's name, working definition, coding criteria and notes, and illustrative examples (MacQueen, 1998). The primary researcher (Bergeron) reviewed and compiled the two-coder's initial coding grid into one team-based codebook in an Excel file (MacQueen, 1998). The two coders then returned to the initial transcript and reach consensus on coding utilizing this coding grid, as well as make any agreed changes to the coding grid. They then independently coded the remaining interview transcripts and met regularly to discuss emergent codebook and coding issues (e.g., unclear coding definitions, overlap among codes, challenging survey responses).

Descriptive Analysis

Survey Respondents. The survey respondents consisted of kidney transplant recipients from kidney transplant support groups. As stated previously, in order to distinguish which group each survey response came from to be able to understand the types of groups were represented in

81

the data, identical forms of the survey were created and each was labeled with a different letter to distinguish which group the respondent was a member of. Subsequently, in order to protect respondent identities, specific group names were removed from the data and only the group IDs were kept and referred to in the analysis.

Five of the support groups the respondents were from were online support groups, one of the groups was an online forum and four groups were face to face support groups. The type of support group that yielded the most responses was the online support group.

Table 4. Respondent Groups

	Frequency	Percent	Cumulative Percent
Online	115	83.4%	83.9%
Forum	14	10.2%	94.2%
Face to face	8	5.8%	100%
Total	137	100.0	

Once all of the survey data was collected and the survey was closed, the data was reviewed and cleaned. Upon reviewing the Qualtrics data set, it originally consisted of 163 surveys. Out of this total, it was noted that five surveys had no responses at all, therefore these five were removed from the analysis leaving 158 total surveys for analysis. The focus of this study was on kidney transplant recipients and there were two subjects that did not meet this criteria and their responses were also removed from the final data set leaving 156 total responses. One of which answered "no" to the first question on the survey which asked if the participant was a kidney transplant recipient and the other also answered "no" to the first question but completed the survey stated they had received a liver not kidney transplant.

With the first question of the survey, there were also seven respondents who did not put a response for this question at all. These participant's responses for the rest of the survey were then reviewed. Six of the seven surveys were left in the data set even though the first question's response was blank because the respondent had answered all the other questions including year of the transplant and information about the transplant center they had received the transplant at. The one that was removed was because not only did the person leave the first question blank but they had also left the year they received their transplant blank bringing the total to 155 total.

The last reason that data was removed was due to the respondent's location. This research is focused on patients in the United States therefore 18 responses were removed due to the patient residing and receiving their transplant outside of the United States. Two of these respondents were from Australia, three were from South Africa, four from India, five from Canada, one from Norway, one from Qatar, one from DiDo (unknown origin) and one from Germany. This left a total of 137 responses to be analyzed for this study.

Table 5. Survey Deletions

# Surveys Deleted	Reason for Deletion
5	No responses to any of the survey questions
1	Answered "no" to being a transplant recipient
1	Received a liver not kidney transplant
1	Unable to identify if they are a kidney transplant pt. as they left question 1 blank
18	Resided outside of the US and the study focus is US recipients

Dependent Variables

Wait Times

As previously discussed, wait times can vary not only once a patient is on the transplant list but may also vary during the time the patient is waiting to get onto the list after they begin the process. The frequency table below shows the length of time, in months, the survey respondents reported they had to wait to get onto the list once they were notified they needed a transplant.

Table 6. Pre-Wait Times

	Frequency	Percent	Valid Percent	Cumulative Percent
0	8	5.8	6.0	6.0
1	8	5.8	6.0	11.9
2	5	3.6	3.7	15.7
3	19	13.9	14.2	29.9
4	6	4.4	4.5	34.3
5	6	4.4	4.5	38.8
6	17	12.4	12.7	51.5
7	3	2.2	2.2	53.7
8	2	1.5	1.5	55.2
9	2	1.5	1.5	56.7
10	2	1.5	1.5	58.2
11	5	3.6	3.7	61.9
12	10	7.3	7.5	69.4
13	1	.7	.7	70.1
14	1	.7	.7	70.9
15	2	1.5	1.5	72.4
18	3	2.2	2.2	74.6
20	1	.7	.7	75.4
23	1	.7	.7	76.1
24	10	7.3	7.5	83.6

	Frequency	Percent	Valid Percent	Cumulative Percent
30	1	.7	.7	84.3
36	6	4.4	4.5	88.8
37	1	.7	.7	89.6
40	1	.7	.7	90.3
48	4	2.9	3.0	93.3
50	1	.7	.7	94.0
72	1	.7	.7	94.8
78	1	.7	.7	95.5
84	1	.7	.7	96.3
93	1	.7	.7	97.0
120	2	1.5	1.5	98.5
168	1	.7	.7	99.3
324	1	.7	.7	100.0
Total	134	97.8	100.0	
Missing	3	2.2		

As you can see from the table above, 51.5% of the respondents reported waiting 6 months or less to get onto the waitlist. 69.4% of the respondents reported waiting a year or less whereas 83.6% reported waiting 2 years or less to get onto the waitlist. The least amount of time was reported by eight respondents who reported they were able to get onto the list in less than a month and the longest time reported was 324 months by one respondent.

Post Wait Time

The frequency table below shows the length of time, in months, the survey respondents reported they had to wait for a transplant once they were on the wait list.

Table 7. Post-Wait Times

	Frequency	Percent	Valid Percent	Cumulative Percent
0	7	2.8	5.4	5.4
1	6	2.4	4.6	10.0
2	2	.8	1.5	11.5
3	9	3.6	6.9	18.5
4	4	1.6	3.1	21.5
5	5	2.0	3.8	25.4
6	9	3.6	6.9	32.3
7	2	.8	1.5	33.8
8	6	2.4	4.6	38.5
9	2	.8	1.5	40.0
10	3	1.2	2.3	42.3
11	2	.8	1.5	43.8
12	7	2.8	5.4	49.2
13	4	1.6	3.1	52.3
14	3	1.2	2.3	54.6
17	1	.4	.8	55.4
18	5	2.0	3.8	59.2
19	2	.8	1.5	60.8
21	1	.4	.8	61.5
24	7	2.8	5.4	66.9
26	2	.8	1.5	68.5
28	1	.4	.8	69.2
30	3	1.2	2.3	71.5
32	1	.4	.8	72.3
36	5	2.0	3.8	76.2
37	1	.4	.8	76.9
38	1	.4	.8	77.7
40	1	.4	.8	78.5
42	2	.8	1.5	80.0
43	1	.4	.8	80.8
45	1	.4	.8	81.5
46	1	.4	.8	82.3

	Frequency	Percent	Valid Percent	Cumulative Percent
48	1	.4	.8	83.1
54	3	1.2	2.3	85.4
57	1	.4	.8	86.2
60	4	1.6	3.1	89.2
72	3	1.2	2.3	91.5
73	1	.4	.8	92.3
78	1	.4	.8	93.1
84	2	.8	1.5	94.6
85	1	.4	.8	95.4
100	1	.4	.8	96.2
120	1	.4	.8	96.9
144	1	.4	.8	97.7
168	3	1.2	2.3	100.0
Total	130	51.6	100.0	
System	122	48.4		
	252	100.0		

As you can see from the table above, only about 32% of the respondents reported waiting 6 months or less to get onto the waitlist. 49% of the respondents reported waiting a year or less whereas about 67% reported waiting 2 years or less to get onto the waitlist. The least amount of time was reported by seven respondents who reported they were able to get onto the list in less than a month and the longest time reported was 168 months by three respondents.

Discrimination in Medical Setting Scale

Respondents with this scale were asked: *During your kidney transplant experience, have you ever had any of the following things happen to you?* (all statements are shown in the table below). A large percentage of the respondents indicated that they have never: had a doctor or

nurse act as though they were afraid of them (86%), had a doctor or nurse act as though they thought they were not smart (66%), had a doctor or nurse act as if they were better than them (65%), feel they were treated with less courtesy than others (81%), received poorer services than others (82%), felt treated with less respect (83%) or felt like a doctor or nurse was not listening to what they were saying (55%).

The Likert scaled items were assigned a numerical value and the mean score was derived from these values. The response, "most of the time"(4), "sometimes" (3), "rarely" (2) and "never" (1). The higher the average score for each statement, the higher the perceived discrimination. All of the mean scores were below 2 so there was not much perceived discrimination in the medical setting in this sample. The highest mean (1.85) was on the statement about not feeling like a doctor or nurse was listening to what they were saying and this mean was still in the "rarely/never" category. The lowest mean (1.21) was on the statement, "I had a doctor or nurse act as though they were afraid of me".

With this said, the responses overall did not yield much evidence of perceived discrimination in this process. The scores in our study were similar to those in the study by Peek, et al. (2011). They had an overall mean of 1.71 where our overall mean was 1.44. The highest mean in their study was 1.91 with the statement "you feel like a doctor or nurse is not listening to what you are saying" (Peek, et al., 2011). The statement with the lowest mean 1.33 was "A doctor or nurse acts as if he or she is afraid of you" (Peek, et al., 2011). This finding was also similar to Lopez-Cervallos, & Henry (2016).

Table 8. Discrimination in Medical Settings Scale

	Most of the Time	Sometimes	Rarely	Never	Mean
I had a doctor or nurse act as though they were afraid of me	0 %	6.6%	7.3%	85.4%	1.21
I had a doctor or nurse act as though they thought I was not smart	3.7%	14.6%	15.3%	65.7%	1.56
I had a doctor or nurse act as if he or she was better than me	4.4%	17.5%	12.4%	65%	1.61
I felt I was treated with less courtesy than other people	1.5%	5.8%	10.9%	79.6%	1.28
I felt I received poorer services than other people	2.9%	4.4%	10.2%	81.8%	1.28
I felt as though I was treated with less respect than other people	2.2%	5.1%	9.5%	82.5%	1.26
I felt like a doctor or nurse was not listening to what I was saying	8.8%	22.6%	13.1%	54.7%	1.85

Medical Mistrust Scale

The survey then asked a few questions about how respondents feel about any healthcare organization where they received their healthcare throughout their ESRD treatments all the way through transplant. These statements are shown in the table below.

Similar to the previous scale, the Likert scaled items were assigned a numerical value and the mean score was derived from these values. The response, "strongly agree"(5), "agree" (4), "neither" (3),"disagree" (2), and "strongly disagree" (1). As stated previously, to minimize any sources of potential bias, the survey instrument was designed to balance the Likert scale items with negative and positive statements, which is the best solution for acquiescence bias. This scale does just that and when looking at the table below, the first ten statements are negative statements and the last seven statements (shown highlighted darker in the table) are positive

statements. Therefore, for the positive statements, the scoring scale was reversed where the responses were scored as"strongly agree"(5), "agree" (4), "neither" (3),"disagree" (2), and "strongly disagree" (1).

For the negative statements, most were a mean of three or less, therefore there was not much evidence of perceived mistrust. For the positive statements, the means were similar to the negative statements with means below 3.45. The lowest mean overall was 2.35 which was on the statement "I trust that the healthcare organizations keep up with the latest medical information". The highest mean overall was 3.45 for the statement "I trust that healthcare organizations will tell me if mistake is made about my treatment". Other than that, the means remained less than three which indicates that there is little evidence of perceived medical mistrust.

Table 9. Medical Mistrust Scale

Statements	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	Mean
You better be cautious when dealing with healthcare organizations	5.8%	23%	32%	19%	18.2%	2.79
Patients have sometimes been deceived or mislead by healthcare organizations	6.6%	29%	27.7%	19.7%	16%	2.90
I trust that healthcare organizations will tell me if a mistake is made about my treatment	.7%	24%	24.8%	29%	20.4%	3.45
Healthcare organizations often want to know more about your business than they need to know.	15.3%	16%	41.6%	17.5%	5%	3.20
When healthcare organizations make mistakes they usually cover it up	9.5%	25.5%	41.6%	17.5%	5%	3.17
Healthcare organizations have sometimes done harmful experiments on patients without their knowledge	5.8%	10.9%	40.9%	27.7%	13.9%	2.67
The patient's medical needs come before other considerations at healthcare organizations	7.3%	36.5%	35.8%	16.8%	2.9%	2.76
Healthcare organizations are more concerned about making money than taking care of people	5%	25.5%	30.7%	27.7%	10.2%	3.06
Healthcare organizations put the patient's health first	9.5%	34.3%	32%	19.7%	3.6%	2.71
Healthcare organizations don't always keep your information totally private	11.7%	32%	32%	19%	2.9%	2.88
Patients should always follow the advice given to them at healthcare organizations	6.6%	44.5%	35.8%	8.8%	2.2%	2.74
I typically get a second opinion when I am told something about my health	3.6%	43.8%	40%	9.5%	.7%	3.31
I trust that healthcare organizations check their staff's credentials to make sure they are hiring the best people	5.8%	26.3%	36.5%	21.2%	8%	2.54
They know what they are doing at healthcare organizations	5.8%	39.4%	35%	17.5%	.7%	2.59
Sometimes I wonder if healthcare organizations really know what they are doing	13%	52.6%	18.2%	12.4%	1.5%	3.04
Mistakes are common in healthcare organization	7.3%	36.5%	35.8%	16.8%	2.9%	3.33
I trust that healthcare organizations keep up with the latest medical information	5%	25.5%	30.7%	27.7%	10.2%	2.35

There was a large percentage of respondents who chose the neither agree or disagree answer and remained neutral on these subjects. Thirty-two respondents agreed that you need to be cautious when dealing with healthcare organizations whereas twenty-five respondents

strongly disagreed with this statement. Forty respondents agreed that patients have sometimes

been deceived or mislead by healthcare organizations and twenty-two respondents strongly

disagreed with this statement.

Table 10. Dependent Variable Descriptives

DV	Mean	SD	Range
Pre-Wait Times	18.65 months	36.58	324 months
Post Wait Times	26.8 months	34.18	168 months
DMS	1.44	0.24	0.64
MMS	2.91	0.31	1.10

Independent Variables

Predisposing Characteristics

<u>Age</u>

The largest age group was the 55-64 year old age group (28.5%). The survey resulted in

respondents from younger age groups younger than this group were the 21-35 year old group

(24%), 35-44 year old group (19%) and 45-54 year old group (21.9%). The largest respondent

age group category was the 55-64 year old respondents (28.6%). There were 17 respondents

(12.4%) in the oldest group of 65 and older.

Table 11. Respondent's Age

	Frequency	Percent	Cumulative Percent
21-35	24	17.5	17.5
35-44	27	19.7	37.2
45-54	30	21.9	59.1
55-64	39	28.5	87.6
65 or older	17	12.4	100.0
Total	137	100.0	

Respondent's Gender

Out of the 137 respondents, 77.4% (106 respondents) identified themselves as female and 22.6% (31 respondents) identified as male. The distribution of the respondent's gender is shown in the table below. The reason for the large difference in respondent's gender is difficult to determine but will be discussed later.

Table 12. Respondent's Sex

	Frequency	Percent	Cumulative Percent
Female	106	77.4	77.4
Male	31	22.6	100.0
Total	137	100.0	

Respondent's Race/Ethnicity

In terms of race, only one respondent did not disclose their race. The rest of the respondents' answers varied and their answers in their original form are depicted in the table below.

Table 13. Respondent's Race/Ethnicity (Original Version)

	Frequency	Percent	Cumulative Percent
Missing	1	.7	.7
Asian	2	1.5	2.2
Asian, Native Hawaiian or Pacific Islander, Filipino	1	.7	2.9
Asian, Vietnamese, Other	1	.7	3.6
Black, African American	14	10.2	13.9
Chinese	1	.7	14.6
Hispanic	4	2.9	17.5
Korean	1	.7	18.2
Mexican	1	.7	18.9
Other	2	1.5	28.4
White	105	76.6	97.1
White, Asian	1	.7	97.8
White, Cuban	1	.7	98.5
White, Other	1	.7	99.3
White, Puerto Rican, American Indian, or Alaskan Native	1	.7	100
Total	137	100	100

This list was then recoded into the following 6 collapsed categories: missing, Asian, Black/African American, Hispanic, White or Other/Mixed. The Asian category is comprised of respondents who identified themselves as: Asian, Asian Native Hawaiian or Pacific Islander, Asian Other, Asian Vietnamese, Chinese or Korean. The Black/African American Category included respondents who identified as Black or African American. Unfortunately, only 10% of the respondents were in this category, which limits our ability to draw conclusions about race differences in transplant wait times. The Hispanic category included Hispanic and respondents who identified as Mexican. The White category was the largest ethnicity category (76.6%). The last category, Other/Mixed included individuals who identified as other, or identified as more than one race such as White along with Puerto Rican, American Indian and Alaskan Native or

White other, White Asian or White Puerto. These collapsed categories are shown in the table

below.

Table 14. Respondent's Race/Ethnicity (cleaned version)

	Frequency	Percent	Cumulative Percent
Missing	1	.7%	.7
Asian	6	4.4%	5.1
Black, African American	14	10%	15.1
Hispanic	5	3.6%	18.7
White	105	76.6%	95.3
Other/Mixed	6	4.4%	100
Total	137	100%	

Education

One respondent reported having less than a high school diploma and 28 (20.4%)

identified themselves as being a high school graduate. Forty-one respondents (24.8%) reported

having some college education and 74 respondents (29.9%) reported having a college degree or

a graduate or professional degree (24.1%)**.**

Table 15. Respondent's Education

	Frequency	Percent	Cumulative Percent
Less than high school diploma	1	.7	75.2
High school graduate	28	20.4	74.5
Some college	34	24.8	100.0
College degree	41	29.9	29.9
Graduate or professional degree	33	24.1	54.0
Total	137	100.0	100.0

Enabling Resources

Socioeconomic Status

Respondents were also asked about their current household income and four respondents

left this question blank and are labeled as missing on the table below. There were 27

respondents who reported a household income less than $24,999 and 14 of these respondents

reported making less than $15,000 per year. There were 33 respondents who reported making

between $25,000 and $54,999. There were another 38 respondents who reported making

between $55,000 and $94,999. The last group of 35 respondents reported a current annual

household income of greater than $95,000. The amount of people represented within the

household for each respondent is unknown

Table 16. Respondent's Income

	Frequency	Percent	Cumulative Percent
Missing	4	2.9	2.9
Less than $15, 000	14	10.2	13.1
$15,000-$24,999	13	9.5	22.6
$25,000-$34,999	12	8.8	31.4
$35,000-$44,999	12	8.8	40.2
$45,000-$54,999	9	6.6	46.8
$55,000-$64,999	6	4.4	51.2
$65,000-$74,999	14	10.2	61.4
$75,000-$84,999	12	8.8	70.2
$85,000-$94,999	6	4.4	74.6
greater than $95,000	35	25.5	100
Total	137	100.0	100.0

Health Insurance

Having proper medical insurance can be essential when needing a kidney transplant. The

survey asked respondents about the insurance they had and also left a text box in case someone

had an insurance that was not on the list. The original version of the insurances that recipients'

listed is shown below.

Table 17. Respondent's Insurance (original version)

	Frequency	Percentage	Cumulative Percent
Medicaid	7	5.1	5.1
Medicaid,Medicare	19	13.9	19.0
Medicare	11	8	27.0
Medicare,Other	12	8.8	35.8
Other	6	4.4	40.1
Private	40	29.2	69.3
Private,Medicaid	1	.7	70.1
Private,Medicaid,Medicare	3	2.2	72.3
Private,Medicare	35	25.5	97.8
Private,Medicare,Other	1	.7	98.5
Private,Medicare,VA insurance	1	.7	99.3
Private,Other	1	.7	100.0
Total	137		

This list of insurances was then cleaned into a more concise table which is shown below.

The first category identified as Medicaid includes the 26 respondents who identified as having

Medicaid or Medicaid and Medicare combined. The next category was Medicare which included

23 respondents who stated they had either "Medicare" or "Medicare Other". The category listed

as Private includes 40 total respondents who answered as having "private" insurance. The

category listed as Private+ includes the respondents who identified as having private insurance

along with another insurance which totaled 42 respondents. This group includes "private

Medicaid", "private Medicaid Medicare", "Private Medicare", "Private Medicare Other" "Private

Other" and "Private Medicare VA insurance". The last category is named "Other" which

included anyone who identified by checking the box for other. This category included six

respondents.

Table 18. Respondent's Insurance (cleaned version)

		Percent	Cumulative Percent
Medicaid	26	18.98	18.98
Medicare	23	16.77	35.75
Other	6	4.4	40.15
Private	40	29.20	69.35
Private+	42	30.65	100.00
	137	100.0	100

Organizational Characteristics

Transplant Centers

As stated previously, UNOS has divided the country into transplant regions and some

regions have been shown to be more successful when it comes to kidney transplantation (OPTN,

2016). Patients are allowed to be waitlisted in multiple centers, multiple states and multiple

transplant regions. Respondents were asked about the state they reside as well as the state they

received their transplant in. These answers were in open text and then were recoded by region

number which has been identified by UNOS (OPTN, 2016).

Region of Residence vs. Region of Transplant

The table below depicts the states included in each region.

Table 19. States in each Transplant Region

1	Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Eastern Vermont
2	Delaware, District of Columbia, Maryland, New Jersey, Pennsylvania, West Virginia, Northern Virginia
3	Alabama, Arkansas, Florida, Georgia, Louisiana, Mississippi, Puerto Rico
4	Oklahoma, Texas
5	Arizona, California, Nevada, New Mexico, Utah
6	Alaska, Hawaii, Idaho, Montana, Oregon, Washington
7	Illinois, Minnesota, North Dakota, South Dakota, Wisconsin
8	Colorado, Iowa, Kansas, Missouri, Nebraska, Wyoming
9	New York, Western Vermont
10	Indiana, Michigan, Ohio
11	Kentucky, North Carolina, South Carolina, Tennessee, Virginia

There were two respondents which could not be coded as one was unidentifiable and one respondent only entered US for place of residence but did not indicate which state. Out of the surveys that were recoded, the most responses were from Region 3 (29 responses or 21.2%) which includes Florida, Georgia, Alabama, Arkansas, Louisiana, Mississippi and Puerto Rico Region 2 which includes states in the Northeast was the next largest with a total of 19 responses (13.2%) and then Region 7, midwestern states, with 18 responses (13.1%). The region with the least amount of responses was Region 9 (6 responses, or 4.4%).

Table 20. Respondents' UNOS Regions

Transplant Region	Frequency	Percent	Cumulative Percent
	6	3.7	3.7
1	12	7.4	11.0
2	19	11.7	33.1
3	25	15.3	48.5
4	9	5.5	54.0
5	11	6.7	60.7
6	9	5.5	66.3
7	18	11.0	77.3
8	10	6.1	83.4
9	8	4.9	88.3
10	10	6.1	17.2
11	7	4.3	21.5

Similar to the information above, respondents were asked to identify where their transplant center was located. This answer was also open text and the answers were recoded into the UNOS regions. There were a total of twelve respondents (8.8%) who reported having their transplant in a different region than their residence.

Survey respondents were then asked which type of area the center was located. A large portion of the respondents (70.1%) stated that they received their transplant in a transplant center located in an urban area. Twenty-five respondents (18.2%) stated their center was located in a suburban area and nine respondents (6.6%) stated their center was in a rural location. The rest of the respondents either marked other (3.6%) or did not answer this question (1.5%).

Table 21. Respondent's Transplant Center Location

	Frequency	Percent	Cumulative Percent
Missing	2	1.5	1.5
Other	5	3.6	5.1
Rural	9	6.6	11.7
Suburban	25	18.2	29.9
Urban	96	70.1	100.0
Total	137	100.0	

In regard to the type of transplant center setting that patients received their transplant, 83 respondents (60.6%) identified their center as a University or University Affiliated Center. Thirty-six respondents (26.3%) identified their center as a Private Hospital Transplant Center. Some respondents (6.6%) were unsure of the type of setting, eight respondents checked "other" and one respondent did not answer the question and was recoded as missing.

Table 22. Transplant Center Type

	Frequency	Percent	Cumulative Percent
Missing	1	.7	.7
Other	8	5.8	6.6
Private Hospital	36	26.3	32.8
University or University Affiliated	83	60.6	93.4
Unsure	9	6.6	100.0
Total	137	100.0	

<u>Inactively Waitlisted</u>

One of the difficult parts of the transplant waitlist is that there are sometimes when a patient may be on the waitlist but may then be labeled as inactive which means they still have a

placehold on the list but they are unable to receive a transplant even if it is their turn and a kidney is available. The transplant recipients responded that 34 of them or 24.8% had been labeled as inactive at some point in their time on the waitlist. Five respondents were unsure if they had ever been labeled as inactive. Over 70% (98) of the respondents indicated that they had never been removed or labeled as inactive on the waitlist at any point.

Table 23. Waitlist Inactivity

		Frequency	Percent	Cumulative Percent
Valid	No	98	71.5	71.5
	Not Sure	5	3.6	75.2
	Yes	34	24.8	100.0
	Total	137	100.0	

When asked if the patient had been removed from the waitlist, there was also an open text box which allowed for those who had been removed to state what it was that made them inactive or removed from the list. The qualitative responses were categorized by the reason for removal and they were entered into the table below.

102

Table 24. Inactivity Reasons

Category	Qualitative Response
Number of removals	Once (n=11)
	Twice (n=2)
Received Transplant	Son donated kidney
Issues with Weight	I was inactive until I met BMI requirement
	First time because I gained weight
	I was inactive accruing time due to weight issues
Non-Compliance	Non-compliance with medication and appointments
Insurance	Waiting on Medicaid and Medicare to go through
Lab work/testing issues	Creatinine went down temporarily
	Once, labs stable
	Once for high antibiotics
	Test results not received from another Dr.
	False pregnancy test
	Was told pap wasn't current (it was), and irregular echo
Organ issues	Septic shock, lung surgery
	Once due to lung surgery
	Triple bypass
	Once. I had a coronary stent placed in 2018
	I was having issues with diverticulitis and had a colon resection
	I was placed on hold for 2 months
	1 time for approximately 4 mths while they were looking at growths in my lungs
	2 times, second time because I was diagnosed with breast cancer
	Once, due to having developed Cardiomyopathy
	I was only removed when the first one failed and had to do the evaluation again after I recovered. I have been active since
Infection	Once due to severe abdominal infection
	Inactive more times than I count from countless infections
	Was removed because of infections
Improved function	Inactive once because gfr went up
	Once, improved function and no need for dialysis for 7 years
Moved	Yes. Moved out of state

Research Questions

Research Question 1: To what degree do transplant recipients perceive the role of their

predisposing characteristics (race/ethnicity, age, gender, education level) as important in the

process of getting on the kidney transplant waitlist**?**

Frequency Distributions were run on the Likert scale responses to the questions

regarding the respondents' perception of the role their race, age, sex, or educational level had on

their transplant waitlist experience. The Likert scale responses were coded: strongly agree (5), agree (4), neutral (3), disagree (2) and strongly disagree (1). The tables below depicts the responses. The participants were asked how much they agree that each of these predisposing characteristics played a negative role in their ability to get waitlisted.

Respondents Beliefs About Impacts on Waitlisting

The survey respondents were asked how they felt their predisposing characteristics: race, ethnicity, education, employment, age, gender and health literacy impacted their waitlist experience. They were also asked how they feel their enabling resources: insurance, social support, geographic location and socioeconomic status impacted their waitlist experience. The responses to all of these questions are shown on the table below.

All questions for the first four categories: age, ethnicity, race and gender were worded as: *I feel that my _____ had a negative effect on my waitlist experience.* The largest percentage of respondents indicated that they strongly disagreed that their race (62%), ethnicity (61.3%), age (56.2%) or gender (63.5%) had a negative effect on their waitlist experience. No respondents reported that they felt their gender had a negative effect on their waitlist experience and only one respondent strongly agreed that their race and ethnicity had a negative effect on their waitlist experience. Two respondents strongly agreed that age had a negative effect as well.

The questions for the next four categories were worded a bit differently. For example: *I feel that if I had better (health insurance, paying job, support system, education) the wait list process would have been easier.* The survey showed that 71 respondents (51.8%) strongly disagreed that if they had better health insurance, the waitlist process would have been easier for them. Similar results were found in terms of having a better paying job (48.2%), better social supports (45.3%) and better education (51.8%) as these respondents also strongly disagreed that

104

the waitlist process would have been easier. There were, however, three respondents (2.2%) that strongly agreed that better insurance would have made the process easier. Six respondents (4.4%) strongly agreed that having a better paying job would have helped, five respondents (3.6%) felt that having a better support system would have helped and one respondent (.7%) strongly agreed that the waitlist process would have been easier had they had a better education.

The last two categories referred to the information communicated to the patient. The statements on the survey for these categories were: *I feel that I was not provided enough information about the waitlist process and I feel I was not provided enough information about my kidney disease which made it more difficult to pursue transplant.* In terms of information provided on the waitlist process, 50 (36.5%) of respondents strongly disagreed that they were not provided enough information and only 5 respondents (3.6%) strongly agreed with this statement. In terms of information provided on kidney disease itself, 72 respondents (52.6%) strongly disagreed with this statement while four respondents (2.9%) strongly agreed.

Table 25. Factors Perceived As Impacting Waitlisting

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Mean
Race	1 (.7%)	5 (3.6%)	19 (13.9%)	27 (19.7%)	86(62%)	1.61
Ethnicity	1 (.7%)	4 (2.9%)	18 (13.1%)	29 (21.2%)	84 (61.3%)	2.02
Age	2 (1.5%)	6 (4.4%)	20 (14.6%)	31 (22.6%)	77 (56.2%)	1.71
Gender	0	0	19 (13.9%)	30 (21.9%)	87 (63.5%)	1.5
Insurance	3 (2.2%)	6 (4.4%)	23 (16.8%)	34 (24.8%)	71 (51.8%)	1.8
Job/$	6 (4.4%)	7 (5.1%)	23 (16.8%)	34 (24.8%)	66 (48.2%)	1.64
Support	5 (3.6%)	13 (9.5%)	20 (14.6%)	36 (26.3%)	62 (45.3%)	1.99
Education	1 (.7%)	5 (3.6%)	22 (16.1%)	37 (27%)	71 (51.8%)	1.74
Waitlist Info	5 (3.6%)	21 (15.3%)	18 (13.1%)	43 (29.2%)	50 (36.5%)	2.18
CKD Info	4 (2.9%)	5 (3.6%)	17 (12.4%)	38 (27.7%)	72 (52.6%)	1.76

In terms of race, participants were provided with the statement: *I feel that my race had a negative effect on my waitlist experience* and were asked to rate their responses on a 5 point Likert Scale ranging from Strongly Agree to Strongly Disagree. Table 26 below provides the information from the frequency distribution for the characteristic of race. 86 respondents (62.8%) stated that they strongly disagree that their race had a negative effect on their waitlist experience. Whereas one person reported that they strongly agreed with this statement (.7%) and five reported they agreed (3.6%).

Table 26. Perceived Impact of Race on Waitlist Experience

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly Disagree	86	62.8	62.8	62.8
Disagree	27	19.7	19.7	82.5
Neutral	18	13.1	13.1	95.6
Agree	5	3.6	3.6	99.3
Strongly Agree	1	.7	.7	100.0
Total	137	100.0	100.0	

In terms of ethnicity, participants were provided with the statement: *I feel that my ethnicity had a negative effect on my waitlist experience* and were asked to rate their responses on a 5 point Likert Scale ranging from Strongly Agree to Strongly Disagree. The table below provides the information from the frequency distribution for the characteristic of ethnicity. Similar findings were identified such as 85 respondents (62%) stated that they strongly disagree that their ethnicity had a negative effect on their waitlist experience. Whereas one person reported that they strongly agreed with this statement (.7%) and four reported they agreed (2.9%).

Table 27. Perceived Impact of Ethnicity on Waitlist Experience

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly Disagree	85	62.0	62.5	62.5
Disagree	29	21.2	21.3	83.8
Neutral	17	12.4	12.5	96.3
Agree	4	2.9	2.9	99.3
Strongly Agree	1	.7	.7	100.0
Total	136	99.3	100.0	
Missing	1	.7		
Total	137	100.0		

In terms of age participants were provided with the statement: *I feel that my age had a negative effect on my waitlist experience* and were asked to rate their responses on a 5 point Likert Scale ranging from Strongly Agree to Strongly Disagree. The table below provides the information from the frequency distribution for the characteristic of age. 78 respondents (56.9%) stated that they strongly disagree that their age had a negative effect on their waitlist experience. Whereas two people reported that they strongly agreed (1.5%) with this statement and six reported they agreed (4.4%).

Table 28. Perceived Impact of Age on Waitlist Experience

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly Disagree	78	56.9	56.9	56.9
Disagree	32	23.4	23.4	80.3
Neutral	19	13.9	13.9	94.2
Agree	6	4.4	4.4	98.5
Strongly Agree	2	1.5	1.5	100.0
Total	137	100.0	100.0	

In terms of their sex, participants were provided with the statement: *I feel that my sex had a negative effect on my waitlist experience* and were asked to rate their responses on a 5 point Likert Scale ranging from Strongly Agree to Strongly Disagree. The table below provides the information from the frequency distribution for the characteristic of sex. Similar to race and ethnicity, 85 respondents (62%) stated that they strongly disagree that their age had a negative effect on their waitlist experience. Whereas two people reported they agreed (1.5%) and no one reported strongly disagreeing with this statement.

Table 29. Perceived Impact of Sex on Waitlist Experience

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly Disagree	85	62.0	62.0	62.0
Disagree	32	23.4	23.4	85.4
Neutral	18	13.1	13.1	98.5
Agree	2	1.5	1.5	100.0
Strongly Agree	0	0	0	100.0
Total	137	100.0	100.0	

In terms of educational level, participants were provided with the statement: *I feel that if I had a better education, the waitlist process would have been easier* and were asked to rate their responses on a 5 point Likert Scale ranging from Strongly Agree to Strongly Disagree. The table below provides the information from the frequency distribution for the characteristic of age. 72 respondents (52.6%) stated that they strongly disagree that their educational level needed to be better to make the waitlist experience easier. Whereas, similar to race and ethnicity, one person reported that they strongly agreed (.7%) with this statement and six reported they agreed (4.4%).

Table 30. Perceived Impact of Education Level on Waitlist Experience

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly Disagree	72	52.6	52.6	52.6
Disagree	36	26.3	26.3	78.8
Neutral	22	16.1	16.1	94.9
Agree	6	4.4	4.4	99.3
Strongly Agree	1	.7	.7	100.0
Total	137	100.0	100.0	

<u>**Research Question 2**</u>- To what degree do transplant recipients and perceive the role of their enabling resources (patients' SES, health insurance type, support system) as important in the process of getting on the kidney transplant waitlist?

Frequency Distributions were run on the Likert scale responses to the questions regarding the respondents' perception of the role their SES (measured in income level), health insurance and support system had on their transplant waitlist experience. The Likert scale responses were coded: strongly agree (5), agree (4), neutral (3), disagree (2) and strongly disagree (1). The tables below depicts the responses. The participants were asked how much they agree that each of these predisposing characteristics played a negative role in their ability to get waitlisted.

In terms of income, participants were provided with the statement: *I feel that if I had a better paying job making more money, the waitlist process would have been easier* and were asked to rate their responses on a 5 point Likert Scale ranging from Strongly Agree to Strongly Disagree. The table below provides the information from the frequency distribution for the characteristic of income. 67 respondents (48.9%) stated that they strongly disagree that with a

better paying job the waitlist experience would have been easier. Whereas six people reported that they strongly agreed with this statement (4.4%) and seven reported they agreed (5.1%).

Table 31. Perceived Impact of Income on Waitlist Experience

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly Disagree	67	48.9	48.9	48.9
Disagree	35	25.5	25.5	74.5
Neutral	22	16.1	16.1	90.5
Agree	7	5.1	5.1	95.6
Strongly Agree	6	4.4	4.4	100.0
Total	137	100.0	100.0	

In terms of health insurance, participants were provided with the statement: *I feel that if I had a better health insurance, the waitlist process would have been easier* and were asked to rate their responses on a 5 point Likert Scale ranging from Strongly Agree to Strongly Disagree. The table below provides the information from the frequency distribution for the characteristic of health insurance. 71 respondents (51.8 %) stated that they strongly disagree that with a better insurance the waitlist experience would have been easier. Whereas three people reported that they strongly agreed with this statement (2.2%) and six reported they agreed (4.4%).

Table 32. Perceived Impact of Health Insurance on Waitlist Experience

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly Disagree	71	51.8	51.8	51.8
Disagree	35	25.5	25.5	77.4
Neutral	22	16.1	16.1	93.4
Agree	6	4.4	4.4	97.8
Strongly Agree	3	2.2	2.2	100.0
Total	137	100.0	100.0	

In terms of support systems, participants were provided with the statement: *I feel that if I had a better support system, the waitlist process would have been easier* and were asked to rate their responses on a 5 point Likert Scale ranging from Strongly Agree to Strongly Disagree. The table below provides the information from the frequency distribution for the characteristic of support system. 61 respondents (44.5%) stated that they strongly disagree that with a better support system the waitlist experience would have been easier. Whereas five people reported that they strongly agreed with this statement (3.6%) and thirteen reported they agreed (9.5%).

Table 33. Perceived Impact of Support System on Waitlist Experience

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly Disagree	61	44.5	44.5	44.5
Disagree	38	27.7	27.7	72.3
Neutral	20	14.6	14.6	86.9
Agree	13	9.5	9.5	96.4
Strongly Agree	5	3.6	3.6	100.0
Total	137	100.0	100.0	

Research Question 3. To what degree do transplant recipients' perceived discrimination differ amongst their predisposing characteristics (age, race, sex, educational achievement) and enabling resources (insurance type, transplant center type and income level)?

ANOVA-Comparing Mean Scores on the Discrimination in Medical Settings Scale and respondents predisposing characteristics/enabling resources.

Assumption #1

The one way ANOVA assumes that the dependent variable is either interval or ratio level data. This assumption has been met as the survey asks the participants to rate their responses on a 5-point Likert Scale where the mean scores were computed. This assumption was met.

111

<u>Assumption #2</u>

The independent variable must consist of two or more categorical, independent groups. In the case of this study, the independent variables are the predisposing characteristics and enabling resources. These include age, race, sex, educational level, and income level. The organizational characteristics also meet the assumption requirements as they are rural, urban, hospital or university-based transplant centers. This assumption was met.

<u>Assumption #3</u>

This assumption states that there must be independence of observations, meaning there is no relationship between each group. The participants in this study identified the group they fit in based on the demographic information they provided therefore no respondent was in more than one group. This assumption was met.

<u>Assumption #4</u>

This assumption states that there should be no significant outliers. To test this, box plots were run to identify any outliers and to determine if these outliers are effecting the data set. The box plots for each category for each question are shown below.

When evaluating the box plots for each question within each category, there was one question that had no outliers (question 7 in the categories of age and sex). This was assessed by inspection of the boxplot for values greater than 1.5 box-lengths from the edge of the box (Laerd Statistics, 2019). The questions showing the most outliers were in questions 1, 4, 5 and 6. The data was reviewed to ensure it was entered properly and it was noted that the answers to these questions due vary quite a bit amongst respondents but the data was entered correctly. It was decided that the outliers will remain in the data set and the ANOVA will be run with and without them to determine if they effect the analysis significantly or not.

<u>Assumption #5</u>

This assumption is regarding the dependent variable being approximately normally distributed (Laerd Statistics, 2019). To test for the normal distribution, the Shapiro-Wilk test of normality was completed. The results of this test for each variable is displayed below.

As you can see in the table in the Appendix, there are some questions where the scores were normally distributed (they are highlighted in gray as p>.05). The other areas do not indicate normal distribution, however the data will be run due to the "robust" nature of an ANOVA. "In conclusion, non-normality does not affect Type I error rate substantially and the one-way ANOVA can be considered robust to non-normality" (Laerd Statistics, 2019, p.10)

<u>Assumption #6</u>

The one way ANOVA assumes homogeneity of variances and this assumption was tested using Levene's test of equality of variances to see if the variances between the groups for the dependent variable are equal (Laerd Statistics, 2019). The table below shows the results of this test. There was homogeneity of variances, as assessed by Levene's test for equality of variances (p>.05) for all of the questions for this scale when compared with respondent's age.

ANOVA

Now that all of the assumptions have been addressed, the ANOVA was run to look at differences in total mean scores of the Discrimination in Medical Settings Scale across each variable, beginning with the respondent's age. Then the ANOVA was run to look at differences in mean scores of each individual question across each variable. The results are shown in the table and graphs below.

Table 34. ANOVA-Age and DMS Score

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	.761	4	.190	.484	.747
Within Groups	51.458	131	.393		
Total	52.219	135			

Table 35. ANOVA Descriptives by Age

	N	Mean	SD	Std. Error	95% Confidence Interval for Mean Lower Bound	95% Confidence Interval for Mean Upper Bound	Minimum	Maximum
21-35	25	1.5772	.67032	.13406	1.3005	1.8539	1.00	3.43
35-44	27	1.4659	.57055	.10980	1.2402	1.6916	1.00	3.14
45-54	30	1.3913	.67156	.12261	1.1406	1.6421	1.00	3.57
55-64	38	1.3979	.58814	.09541	1.2046	1.5912	1.00	3.14
65 +	16	1.3481	.64976	.16244	1.0019	1.6944	1.00	3.14
Total	136	1.4371	.62194	.05333	1.3316	1.5425	1.00	3.57

In terms of the respondent's age, there was no statistically significant difference in the total mean score on the Discrimination in Medical Settings Scale between the different age groups.

Total Mean Score	$F_{(4, 131)}=.484, p=.747$

Next the ANOVA was run to look at differences in mean scores on each question on the Discrimination in Medical Settings Scale across the respondent's age groups.

114

Table 36. ANOVA-Individual DMS Question Means by Age

		Sum of Squares	df	Mean Square	F	Sig.
Q_1	Between Groups	.515	4	.129	.425	.790
	Within Groups	39.720	131	.303		
	Total	40.235	135			
Q_2	Between Groups	1.038	4	.259	.332	.856
	Within Groups	102.492	131	.782		
	Total	103.529	135			
Q_3	Between Groups	3.188	4	.797	.923	.453
	Within Groups	113.157	131	.864		
	Total	116.346	135			
Q_4	Between Groups	1.160	4	.290	.698	.595
	Within Groups	53.623	129	.416		
	Total	54.784	133			
Q_5	Between Groups	.865	4	.216	.450	.772
	Within Groups	62.951	131	.481		
	Total	63.816	135			
Q_6	Between Groups	.274	4	.068	.153	.961
	Within Groups	58.660	131	.448		
	Total	58.934	135			
Q_7	Between Groups	3.978	4	.995	.886	.474
	Within Groups	147.080	131	1.123		
	Total	151.059	135			

In terms of the respondent's age, there were no statistically significant differences in mean scores on each question of the Discrimination in Medical Settings Scale between the different age groups.

Sex

Next the ANOVA was run to look at difference in total mean scores on the Discrimination in Medical Settings Scale across the respondent's sex groups and the results are displayed in the table below.

Table 37. ANOVA-Sex and DMS Score.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	.858	1	.858	2.238	.137
Within Groups	51.361	134	.383		
Total	52.219	135			

In terms of the respondent's sex, there was no statistically significant difference in total mean score on the Discrimination in Medical Settings Scale between the different sex groups.

Table 38. Mean DMS Score by Sex.

Total Mean Score	F(1, 134)=2.238, p=.137

The ANOVA was then run to look at differences in mean scores on each question on the Discrimination in Medical Settings Scale across the respondent's sex groups.

Table 39. ANOVA- Individual DMS Question Means by Sex.

		Sum of Squares	Df	Mean Square	F	Sig.
Q_1	Between Groups	.142	1	.142	.475	.492
	Within Groups	40.093	134	.299		
	Total	40.235	135			
Q_2	Between Groups	1.172	1	1.172	1.535	.218
	Within Groups	102.357	134	.764		
	Total	103.529	135			
Q_3	Between Groups	1.385	1	1.385	1.615	.206
	Within Groups	114.960	134	.858		
	Total	116.346	135			
Q_4	Between Groups	.317	1	.317	.768	.382
	Within Groups	54.467	132	.413		
	Total	54.784	133			
Q_5	Between Groups	1.246	1	1.246	2.668	.105
	Within Groups	62.570	134	.467		
	Total	63.816	135			
Q_6	Between Groups	1.001	1	1.001	2.316	.130
	Within Groups	57.933	134	.432		
	Total	58.934	135			
Q_7	Between Groups	1.253	1	1.253	1.120	.292
	Within Groups	149.806	134	1.118		
	Total	151.059	135			

In terms of the respondent's sex, there were no statistically significant differences in mean scores on each question of the Discrimination in Medical Settings Scale between the male or female respondents.

Table 40. Results of DMS Question Means by Sex

Question 1	F(1,134)=.475, p=.492
Question 2	F(1, 134)=1.535, p=.218
Question 3	F(1, 134)=1.615, p=.206
Question 4	F(1, 132)=.768, p=.382
Question 5	F(1, 134)=.2.668, p=.105
Question 6	F(1, 134)=2.316, p=.130
Question 7	F(1, 134)=1.120, p=.292

Race

Next the ANOVA was run to look at differences in total mean scores on the

Discrimination in Medical Settings Scale across the respondent's race groups.

Table 41. Descriptives-Race and DMS Scores

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Asian	6	1.1917	.23353	.09534	.9466	1.4367	1.00	1.57
Black	14	1.7043	.84641	.22621	1.2156	2.1930	1.00	3.57
Hispanic	5	1.6000	.81841	.36601	.5838	2.6162	1.00	2.86
Mixed	6	1.5000	.33604	.13719	1.1474	1.8526	1.00	1.86
White	104	1.4080	.60413	.05924	1.2905	1.5255	1.00	3.43
Total	135	1.4403	.62310	.05363	1.3342	1.5464	1.00	3.57

Table 42. ANOVA-Race and DMS Scores

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1.604	4	.401	1.034	.392
Within Groups	50.422	130	.388		
Total	52.026	134			

In terms of the respondent's race, there was no statistically significant difference in the total mean score on the Discrimination in Medical Settings Scale between the different race groups.

Table 43. Mean DMS and Race.

Total Mean Score	$F(4, 130)=1.034, p=.392$

Next the ANOVA was run to look at differences in mean scores on each question on the Discrimination in Medical Settings Scale across the respondent's race groups.

Table 44. ANOVA-Individual DMS Question Mean Scores by Race.

		Sum of Squares	df	Mean Square	F	Sig.
Q_1	Between Groups	1.019	4	.255	.845	.499
	Within Groups	39.174	130	.301		
	Total	40.193	134			
Q_2	Between Groups	2.367	4	.592	.763	.551
	Within Groups	100.848	130	.776		
	Total	103.215	134			
Q_3	Between Groups	4.220	4	1.055	1.227	.302
	Within Groups	111.750	130	.860		
	Total	115.970	134			
Q_4	Between Groups	3.301	4	.825	2.055	.091
	Within Groups	51.406	128	.402		
	Total	54.707	132			
Q_5	Between Groups	3.514	4	.879	1.897	.115
	Within Groups	60.219	130	.463		
	Total	63.733	134			
Q_6	Between Groups	3.702	4	.926	2.181	.075
	Within Groups	55.157	130	.424		
	Total	58.859	134			
Q_7	Between Groups	3.321	4	.830	.734	.570
	Within Groups	147.005	130	1.131		
	Total	150.326	134			

In terms of the respondent's race, there were no statistically significant differences in mean scores on the Discrimination in Medical Settings Scale due to respondent's race.

Table 45. Results of DMS Question Means by Race.

Question 1	F(4,130)=.845, p=.499
Question 2	F(4, 130)=.763, p=.551
Question 3	F(4, 130)=1.227, p=.302
Question 4	F(4, 128)=2.055, p=.091
Question 5	F(4, 130)=1.897, p=.115
Question 6	F(4, 130)=2.181, p=.075
Question 7	F(4, 130)=.734, p=.570

Income

The ANOVA was then run to look at differences in total mean scores on the Discrimination in Medical Settings Scale across the respondent's income groups.

Table 46. ANOVA-Descriptives by Income Level.

	N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
less than $15,000	11	1.3782	.46729	.14089	1.0643	1.6921	1.00	2.29
$15,000-$24,999	12	1.5708	.68078	.19652	1.1383	2.0034	1.00	3.14
$25,000-$34,999	12	1.1317	.15620	.04509	1.0324	1.2309	1.00	1.43
$35,000-$44,999	10	1.8140	.90138	.28504	1.1692	2.4588	1.00	3.43
$45,000-$54,999	6	1.3083	.34161	.13946	.9498	1.6668	1.00	1.71
$55,000-$64,999	14	1.8071	.85127	.22751	1.3156	2.2987	1.00	3.57
$65,000-$74,999	12	1.3917	.54881	.15843	1.0430	1.7404	1.00	2.57
$75,000-$84,999	6	1.2850	.31220	.12746	.9574	1.6126	1.00	1.57
$85,000-$94,999	35	1.3637	.63635	.10756	1.1451	1.5823	1.00	3.14
greater than $95,000	14	1.3464	.54849	.14659	1.0297	1.6631	1.00	2.57
Total	132	1.4384	.62775	.05464	1.3303	1.5465	1.00	3.57

Table 47. ANOVA-Income Level and DMS Score.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	5.276	9	.586	1.543	.140
Within Groups	46.346	122	.380		
Total	51.622	131			

In terms of the respondent's income, there was no statistically significant difference in the total mean score on the Discrimination in Medical Settings Scale between the different income levels.

Table 48. Mean DMS and Income

Total Mean Score	F(9, 122)=1.543, p=.140

Next the ANOVA was run to look at differences in mean scores on each question on the Discrimination in Medical Settings Scale across the respondent's income groups.

Table 49. ANOVA-Individual DMS Question Mean Scores by Income Level.

		Sum of Squares	df	Mean Square	F	Sig.
Q_1	Between Groups	3.032	9	.337	1.110	.361
	Within Groups	37.028	122	.304		
	Total	40.061	131			
Q_2	Between Groups	11.470	9	1.274	1.708	.094
	Within Groups	91.045	122	.746		
	Total	102.515	131			
Q_3	Between Groups	7.976	9	.886	1.027	.423
	Within Groups	105.319	122	.863		
	Total	113.295	131			
Q_4	Between Groups	6.059	9	.673	1.684	.100
	Within Groups	47.972	120	.400		
	Total	54.031	129			
Q_5	Between Groups	6.228	9	.692	1.485	.161
	Within Groups	56.833	122	.466		
	Total	63.061	131			
Q_6	Between Groups	4.878	9	.542	1.230	.283
	Within Groups	53.751	122	.441		
	Total	58.629	131			
Q_7	Between Groups	9.187	9	1.021	.899	.528
	Within Groups	138.472	122	1.135		
	Total	147.659	131			

In terms of the respondent's income level, there were no statistically significant differences in mean scores on the Discrimination in Medical Settings Scale questions due to respondent's income level.

Table 50. Results of DMS Question Means by Income Level.

Question 1	F(9,122)=1.110, p=.361
Question 2	F(9,122)=1.708, p=.094
Question 3	F(9,122)=.1.027, p=.423
Question 4	F(9,122)=1.684, p=.100
Question 5	F(9,122)=.1.485, p=.161
Question 6	F(9,122)=1.230, p=.283
Question 7	F(9,122)=.899, p=.528

Education

The ANOVA was then run to look at differences in total mean scores on the Discrimination in Medical Settings Scale across the respondent's education groups.

Table 51. ANOVA-Descriptives by Education Level.

	N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
High School	42	1.6157	.68159	.10517	1.4033	1.8281	1.00	3.43
Some College	33	1.5115	.65684	.11434	1.2786	1.7444	1.00	3.14
College	27	1.0848	.20359	.03918	1.0043	1.1654	1.00	1.86
Graduate or Professional degree	33	1.4367	.64282	.11190	1.2087	1.6646	1.00	3.57
Total	135	1.4403	.62310	.05363	1.3342	1.5464	1.00	3.57

124

Table 52. ANOVA-Education Level and DMS Score.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	4.872	3	1.624	4.512	.005
Within Groups	47.154	131	.360		
Total	52.026	134			

In terms of the respondent's education, there was a statistically significant difference in the total mean score on the Discrimination in Medical Settings Scale between the different education groups. Participants who had a high school educational level reported having the highest average score (1.62) on the Discrimination in Medical Settings Scale. The participants who identified as having a college education reported the lowest average score (1.08).

Table 53. Mean DMS and Education

Total Mean Score	$F(3, 131)=4.512, p=.005$

Next the ANOVA was run to look at differences in mean scores on each question on the Discrimination in Medical Settings Scale across the respondent's education groups.

Table 54. ANOVA-Descriptives Individual DMS Mean Scores by Education Level

Descriptives

		N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
Q_1	College	42	1.38	.697	.108	1.16	1.60	1	3
	Graduate or professional degree	32	1.28	.634	.112	1.05	1.51	1	3
	High school	26	1.00	.000	.000	1.00	1.00	1	1
	some college	33	1.09	.384	.067	.95	1.23	1	3
	Total	133	1.21	.551	.048	1.12	1.31	1	3
Q_2	College	42	1.69	.924	.143	1.40	1.98	1	4
	Graduate or professional degree	32	1.78	1.070	.189	1.40	2.17	1	4
	High school	26	1.19	.402	.079	1.03	1.35	1	2
	some college	33	1.52	.834	.145	1.22	1.81	1	4
	Total	133	1.57	.882	.076	1.42	1.72	1	4
Q_3	College	42	1.81	.994	.153	1.50	2.12	1	4
	Graduate or professional degree	32	1.72	.958	.169	1.37	2.06	1	4
	High school	26	1.12	.326	.064	.98	1.25	1	2
	some college	33	1.70	1.045	.182	1.33	2.07	1	4
	Total	133	1.62	.934	.081	1.46	1.78	1	4
Q_4	College	42	1.40	.828	.128	1.15	1.66	1	4
	Graduate or professional degree	32	1.34	.602	.106	1.13	1.56	1	3
	High school	26	1.00	.000	.000	1.00	1.00	1	1
	some college	33	1.27	.626	.109	1.05	1.49	1	4
	Total	133	1.28	.644	.056	1.17	1.39	1	4
Q_5	College	42	1.40	.828	.128	1.15	1.66	1	4
	Graduate or professional degree	32	1.34	.745	.132	1.08	1.61	1	4
	High school	26	1.04	.196	.038	.96	1.12	1	2
	some college	33	1.30	.684	.119	1.06	1.55	1	4
	Total	133	1.29	.694	.060	1.17	1.41	1	4
Q_6	College	42	1.38	.795	.123	1.13	1.63	1	4
	Graduate or professional degree	32	1.28	.634	.112	1.05	1.51	1	3
	High school	26	1.04	.196	.038	.96	1.12	1	2
	some college	33	1.33	.736	.128	1.07	1.59	1	4
	Total	133	1.28	.667	.058	1.16	1.39	1	4
Q_7	College	42	2.24	1.165	.180	1.88	2.60	1	4
	Graduate or professional degree	32	1.94	1.045	.185	1.56	2.31	1	4
	High school	26	1.23	.587	.115	.99	1.47	1	3
	some college	33	1.85	1.034	.180	1.48	2.22	1	4
	Total	133	1.87	1.062	.092	1.69	2.05	1	4

Table 55. ANOVA-Individual DMS Question Mean Scores by Education Level

		Sum of Squares	df	Mean Square	F	Sig.
Q_1	Between Groups	3.015	3	1.005	3.541	.017
	Within Groups	37.177	131	.284		
	Total	40.193	134			
Q_2	Between Groups	5.862	3	1.954	2.629	.053
	Within Groups	97.353	131	.743		
	Total	103.215	134			
Q_3	Between Groups	8.888	3	2.963	3.624	.015
	Within Groups	107.082	131	.817		
	Total	115.970	134			
Q_4	Between Groups	2.824	3	.941	2.340	.076
	Within Groups	51.883	129	.402		
	Total	54.707	132			
Q_5	Between Groups	2.348	3	.783	1.670	.176
	Within Groups	61.385	131	.469		
	Total	63.733	134			
Q_6	Between Groups	2.113	3	.704	1.626	.186
	Within Groups	56.747	131	.433		
	Total	58.859	134			
Q_7	Between Groups	17.071	3	5.690	5.594	.001
	Within Groups	133.255	131	1.017		
	Total	150.326	134			

In terms of the respondent's education level, there were three questions that showed statistically significant differences in mean scores (Q1, 3, and 7) on the Discrimination in Medical Settings Scale. One statement showing a significant difference in mean score amongst respondents' education level was: *I had a doctor or nurse act as though they were afraid of me.* Respondents with a college education had the highest mean (1.38) and those with a high school diploma had the lowest mean (1.00). For question 3: *I had a doctor or nurse act as if he or she was better than me*, respondents with a college education again had the highest mean (1.81) and

those with a high school diploma again had the lowest mean (1.12). Question 7: *I felt like a doctor or nurse was not listening to what I was saying* had similar results as the respondents with a college education had the highest mean (2.24) and those with a high school diploma had the lowest mean (1.23).

Table 56. Results of DMS Question Means by Education Level.

Question 1	F(3, 131)=3.541, p=.017
Question 2	F(3, 131)=2.629, p=.053
Question 3	F(3, 131)=3.624, p=.015
Question 4	F(3, 129)=2.340, p=.076
Question 5	F(3, 131)=1.670, p=.176
Question 6	F(3, 131)=1.626, p=.186
Question 7	F(3, 131)=5.594, p=.001

Insurance Type

Next the ANOVA was run to look at differences in total mean scores on the Discrimination in Medical Settings Scale across the respondent's insurance type.

Table 57. ANOVA-Descriptives by Insurance Type.

	N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Medicaid	25	1.3084	.60027	.12005	1.0606	1.5562	1.00	3.43
Medicare	22	1.5132	.53125	.11326	1.2776	1.7487	1.00	2.86
Other	7	1.6114	.85167	.32190	.8238	2.3991	1.00	3.14
Private	41	1.2898	.46565	.07272	1.1428	1.4367	1.00	3.14
Private+	41	1.5922	.74143	.11579	1.3582	1.8262	1.00	3.57
Total	136	1.4371	.62194	.05333	1.3316	1.5425	1.00	3.57

Table 58. Insurance Type and DMS Score.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	2.631	4	.658	1.737	.146
Within Groups	49.588	131	.379		
Total	52.219	135			

In terms of the respondent's insurance type, there was no statistically significant difference in the total mean score on the Discrimination in Medical Settings Scale between the different insurance groups.

Table 59. DMS and Insurance Type

Total Mean Score	F(4, 131)=1.737, p=.146

.

The ANOVA was then run to look at differences in mean scores on each question on the Discrimination in Medical Settings Scale across the respondent's insurance groups.

Table 60. ANOVA-Descriptives Individual DMS

Descriptives

		N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
Q_1	Medicaid	25	1.08	.400	.080	.91	1.25	1	3
	Medicare	20	1.40	.681	.152	1.08	1.72	1	3
	Other	7	1.57	.976	.369	.67	2.47	1	3
	Private	41	1.05	.312	.049	.95	1.15	1	3
	Private+	41	1.29	.602	.094	1.10	1.48	1	3
	Total	134	1.21	.549	.047	1.12	1.30	1	3
Q_2	Medicaid	25	1.48	.770	.154	1.16	1.80	1	3
	Medicare	20	1.85	.933	.209	1.41	2.29	1	4
	Other	7	2.00	1.291	.488	.81	3.19	1	4
	Private	41	1.32	.687	.107	1.10	1.53	1	3
	Private+	41	1.66	.965	.151	1.35	1.96	1	4
	Total	134	1.57	.880	.076	1.42	1.72	1	4
Q_3	Medicaid	25	1.36	.757	.151	1.05	1.67	1	4
	Medicare	20	1.95	.945	.211	1.51	2.39	1	3
	Other	7	1.71	1.254	.474	.55	2.87	1	4
	Private	41	1.37	.662	.103	1.16	1.57	1	3
	Private+	41	1.85	1.108	.173	1.50	2.20	1	4
	Total	134	1.62	.932	.081	1.46	1.78	1	4
Q_4	Medicaid	25	1.20	.645	.129	.93	1.47	1	4
	Medicare	20	1.20	.410	.092	1.01	1.39	1	2
	Other	7	1.43	.787	.297	.70	2.16	1	3
	Private	41	1.10	.374	.058	.98	1.22	1	3
	Private+	41	1.51	.840	.131	1.25	1.78	1	4
	Total	134	1.28	.642	.055	1.17	1.39	1	4
Q_5	Medicaid	25	1.20	.645	.129	.93	1.47	1	4
	Medicare	20	1.25	.716	.160	.91	1.59	1	4
	Other	7	1.43	.787	.297	.70	2.16	1	3
	Private	41	1.20	.511	.080	1.03	1.36	1	3
	Private+	41	1.44	.838	.131	1.17	1.70	1	4
	Total	134	1.29	.692	.060	1.17	1.41	1	4
Q_6	Medicaid	25	1.20	.645	.129	.93	1.47	1	4
	Medicare	20	1.35	.587	.131	1.08	1.62	1	3
	Other	7	1.29	.756	.286	.59	1.98	1	3
	Private	41	1.20	.511	.080	1.03	1.36	1	3
	Private+	41	1.37	.829	.130	1.10	1.63	1	4
	Total	134	1.28	.665	.057	1.16	1.39	1	4
Q_7	Medicaid	25	1.64	1.036	.207	1.21	2.07	1	4
	Medicare	20	1.95	1.050	.235	1.46	2.44	1	4
	Other	7	1.86	.900	.340	1.03	2.69	1	3
	Private	41	1.80	1.005	.157	1.49	2.12	1	4
	Private+	41	2.02	1.172	.183	1.65	2.39	1	4
	Total	134	1.87	1.061	.092	1.68	2.05	1	4

130

Table 61. ANOVA-Individual DMS Question Mean Scores by Insurance Type.

		Sum of Squares	df	Mean Square	F	Sig.
Q_1	Between Groups	3.200	4	.800	2.830	.027
	Within Groups	37.035	131	.283		
	Total	40.235	135			
Q_2	Between Groups	5.328	4	1.332	1.777	.137
	Within Groups	98.201	131	.750		
	Total	103.529	135			
Q_3	Between Groups	7.932	4	1.983	2.396	.054
	Within Groups	108.414	131	.828		
	Total	116.346	135			
Q_4	Between Groups	4.016	4	1.004	2.551	.042
	Within Groups	50.768	129	.394		
	Total	54.784	133			
Q_5	Between Groups	1.702	4	.425	.897	.468
	Within Groups	62.115	131	.474		
	Total	63.816	135			
Q_6	Between Groups	.781	4	.195	.440	.779
	Within Groups	58.153	131	.444		
	Total	58.934	135			
Q_7	Between Groups	2.436	4	.609	.537	.709
	Within Groups	148.623	131	1.135		
	Total	151.059	135			

In terms of the respondent's insurance type, there were three questions that showed statistically significant differences in mean scores (Q1, Q3 and Q4) on the Discrimination in Medical Settings Scale due to respondent's insurance type. The first statement that showed statistically significance was: *I had a doctor or nurse act as though they were afraid of me.* Respondents who marked other as their insurance type had the highest mean (1.57) and those with private insurance had the lowest mean (1.05). For statement 3: *I had a doctor or nurse act as if they were better than me* the respondents with Medicare had the highest mean (1.95) and those with Medicaid had the lowest mean (1.36). For the last statement: *I felt I was treated with*

less courtesy than other people, respondents who marked Private + insurance had the highest

mean score (1.51) and those with Private insurance had the lowest score (1.10).

***Research Question 4*: To what degree do transplant recipients' perceived trust of the
interdisciplinary team differ amongst their predisposing characteristics (age, race, sex,
educational achievement) and enabling resources (insurance type, transplant center type
and income level)?**

The Medical Mistrust Index 2.1

**ANOVA-Comparing Mean Scores on the Medical Mistrust Scale and respondents
predisposing characteristics/enabling resources.**

ANOVA

All assumption testing was completed and once all of the assumptions were addressed,

the ANOVA was run to look at differences in total mean scores of the Medical Mistrust Scale

across each variable, beginning with the respondent's age. Then the ANOVA was run to look at

differences in mean scores of each individual question across each variable.   The results are

shown in the table and graphs below.

Age

Table 62. ANOVA-Descriptives MMS by Age.

	N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
21-35	25	2.8720	.23198	.04640	2.7762	2.9678	2.29	3.41
35-44	27	2.7656	.22640	.04357	2.6760	2.8551	2.35	3.24
45-54	29	2.8662	.24436	.04538	2.7733	2.9592	2.35	3.29
55-64	38	2.7776	.32855	.05330	2.6696	2.8856	1.89	3.35
65+	17	2.7400	.29732	.07211	2.5871	2.8929	2.06	3.24
Total	136	2.8068	.27308	.02342	2.7605	2.8531	1.89	3.41

Table 63. ANOVA-MMS Score and Age.

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	.363	4	.091	1.224	.304
Within Groups	9.704	131	.074		
Total	10.067	135			

In terms of the respondent's age, there was no statistically significant difference in the total mean score on the Medical Mistrust Scale between the different age groups.

Table 64. Mean MMS and Age

Total Mean Score	$F(4, 131)=1.224$, p=.304

The ANOVA was then run to look at differences in mean scores on each question on the Medical Mistrust Scale across the respondent's age groups.

Table 375. ANOVA-Descriptives Individual MMS Mean Scores by Age

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Minimum	Maximum
Q_1_t41	21-35	25	3.08	1.038	.208	2.65	3.51	1	5
	35-44	26	2.54	1.174	.230	2.06	3.01	1	5
	45-54	30	2.67	1.124	.205	2.25	3.09	1	5
	55-64	38	2.95	1.184	.192	2.56	3.34	1	5
	65+	17	2.47	1.375	.333	1.76	3.18	1	5
	Total	136	2.77	1.174	.101	2.57	2.97	1	5
Q_2_t42	21-35	25	3.52	1.005	.201	3.11	3.93	1	5
	35-44	27	2.67	1.209	.233	2.19	3.14	1	5
	45-54	30	2.93	1.143	.209	2.51	3.36	1	5
	55-64	38	2.79	1.166	.189	2.41	3.17	1	5
	65+	17	2.59	1.278	.310	1.93	3.25	1	5
	Total	137	2.91	1.181	.101	2.71	3.10	1	5
Q_3_t43	21-35	25	2.88	1.092	.218	2.43	3.33	1	5
	35-44	27	2.52	1.189	.229	2.05	2.99	1	4
	45-54	30	2.50	1.137	.208	2.08	2.92	1	4
	55-64	38	2.45	1.005	.163	2.12	2.78	1	4
	65+	17	2.71	1.263	.306	2.06	3.36	1	5
	Total	137	2.58	1.116	.095	2.40	2.77	1	5
Q_4_t44	21-35	25	2.64	1.075	.215	2.20	3.08	1	5
	35-44	27	2.74	1.095	.211	2.31	3.17	1	5
	45-54	30	2.83	.986	.180	2.47	3.20	1	5
	55-64	38	2.50	1.109	.180	2.14	2.86	1	5
	65+	17	2.41	.870	.211	1.96	2.86	1	4
	Total	137	2.64	1.042	.089	2.46	2.81	1	5
Q_5_t45	21-35	25	3.24	.970	.194	2.84	3.64	1	5
	35-44	27	3.11	.934	.180	2.74	3.48	1	5
	45-54	30	3.27	1.048	.191	2.88	3.66	1	5
	55-64	38	2.97	1.026	.166	2.64	3.31	1	5
	65+	17	3.24	1.091	.265	2.67	3.80	1	5
	Total	137	3.15	1.004	.086	2.98	3.32	1	5
Q_6_t46	21-35	25	2.40	.957	.191	2.00	2.80	1	4
	35-44	27	2.85	.989	.190	2.46	3.24	1	5
	45-54	30	2.87	1.167	.213	2.43	3.30	1	5

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Minimum	Maximum
	55-64	38	2.45	1.032	.167	2.11	2.79	1	5
	65+	17	2.76	1.091	.265	2.20	3.33	1	5
	Total	137	2.65	1.054	.090	2.47	2.83	1	5
Q_7_t47	21-35	25	3.36	.860	.172	3.00	3.72	2	5
	35-44	27	3.11	1.188	.229	2.64	3.58	1	5
	45-54	30	2.93	1.081	.197	2.53	3.34	1	5
	55-64	38	3.29	1.088	.177	2.93	3.65	1	5
	65+	17	3.35	1.222	.296	2.72	3.98	1	5
	Total	137	3.20	1.084	.093	3.01	3.38	1	5
Q_8_t48	21-35	25	3.16	1.068	.214	2.72	3.60	1	5
	35-44	27	3.22	1.013	.195	2.82	3.62	1	5
	45-54	29	3.10	1.113	.207	2.68	3.53	1	5
	55-64	38	2.82	1.182	.192	2.43	3.20	1	5
	65+	17	2.88	1.111	.270	2.31	3.45	1	5
	Total	136	3.03	1.102	.094	2.84	3.22	1	5
Q_9_t49	21-35	25	3.20	.707	.141	2.91	3.49	2	5
	35-44	27	3.11	1.013	.195	2.71	3.51	1	5
	45-54	30	3.27	.944	.172	2.91	3.62	2	5
	55-64	38	3.37	.942	.153	3.06	3.68	2	5
	65+	17	3.71	1.105	.268	3.14	4.27	1	5
	Total	137	3.31	.944	.081	3.15	3.47	1	5
Q_10_t50	21-35	25	3.00	1.041	.208	2.57	3.43	1	4
	35-44	27	2.63	1.006	.194	2.23	3.03	1	5
	45-54	30	3.07	1.143	.209	2.64	3.49	1	5
	55-64	38	2.71	1.037	.168	2.37	3.05	1	5
	65+	17	2.88	1.111	.270	2.31	3.45	1	5
	Total	137	2.85	1.063	.091	2.67	3.03	1	5
Q_11_t51	21-35	25	2.92	1.115	.223	2.46	3.38	1	5
	35-44	27	2.67	1.038	.200	2.26	3.08	1	5
	45-54	30	2.90	.923	.168	2.56	3.24	1	5
	55-64	38	2.92	1.024	.166	2.58	3.26	1	5
	65+	17	2.47	1.125	.273	1.89	3.05	1	5
	Total	137	2.81	1.033	.088	2.64	2.98	1	5
Q_12_t52	21-35	25	2.52	1.122	.224	2.06	2.98	1	5
	35-44	27	2.74	.859	.165	2.40	3.08	2	5

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Minimum	Maximum
	45-54	29	2.69	.967	.180	2.32	3.06	1	4
	55-64	37	2.89	1.075	.177	2.53	3.25	1	5
	65+	17	2.41	.939	.228	1.93	2.89	1	4
	Total	135	2.69	1.003	.086	2.52	2.86	1	5
Q_13_t53	21-35	25	2.48	1.005	.201	2.07	2.89	1	5
	35-44	27	2.59	.844	.162	2.26	2.93	1	5
	45-54	29	2.69	.712	.132	2.42	2.96	2	4
	55-64	37	2.49	.932	.153	2.18	2.80	1	5
	65+	17	2.41	.618	.150	2.09	2.73	1	3
	Total	135	2.54	.844	.073	2.40	2.68	1	5
Q_14_t54	21-35	25	2.44	.768	.154	2.12	2.76	1	4
	35-44	27	2.56	.892	.172	2.20	2.91	1	5
	45-54	29	2.69	.660	.123	2.44	2.94	2	4
	55-64	37	2.59	.725	.119	2.35	2.84	1	4
	65+	16	2.63	.719	.180	2.24	3.01	2	4
	Total	134	2.58	.749	.065	2.45	2.71	1	5
Q_15_t55	21-35	25	3.04	1.136	.227	2.57	3.51	1	5
	35-44	27	2.96	.980	.189	2.58	3.35	2	5
	45-54	29	2.97	.906	.168	2.62	3.31	1	5
	55-64	38	3.08	1.050	.170	2.73	3.42	1	5
	65+	16	2.94	1.124	.281	2.34	3.54	1	5
	Total	135	3.01	1.018	.088	2.83	3.18	1	5
Q_16_t56	21-35	25	2.68	.852	.170	2.33	3.03	1	4
	35-44	27	2.67	.877	.169	2.32	3.01	1	5
	45-54	29	2.76	.872	.162	2.43	3.09	1	4
	55-64	38	2.68	.842	.137	2.41	2.96	1	4
	65+	17	2.59	1.004	.243	2.07	3.10	1	4
	Total	136	2.68	.867	.074	2.54	2.83	1	5
Q_17_t57	21-35	25	2.28	.936	.187	1.89	2.67	1	4
	35-44	27	2.33	.832	.160	2.00	2.66	1	5
	45-54	29	2.55	.827	.154	2.24	2.87	2	4
	55-64	37	2.22	1.031	.170	1.87	2.56	1	5
	65+	17	2.35	.996	.242	1.84	2.87	1	4
	Total	135	2.34	.924	.079	2.18	2.50	1	5

Table 66. ANOVA-Individual MMS Question Mean Scores by Age.

		Sum of Squares	Df	Mean Square	F	Sig.
Q_1_t41	Between Groups	6.836	4	1.709	1.250	.293
	Within Groups	179.098	131	1.367		
	Total	185.934	135			
Q_2_t42	Between Groups	13.226	4	3.307	2.472	.048
	Within Groups	176.540	132	1.337		
	Total	189.766	136			
Q_3_t43	Between Groups	3.480	4	.870	.693	.598
	Within Groups	165.805	132	1.256		
	Total	169.285	136			
Q_4_t44	Between Groups	3.022	4	.756	.689	.601
	Within Groups	144.729	132	1.096		
	Total	147.752	136			
Q_5_t45	Between Groups	1.954	4	.489	.477	.752
	Within Groups	135.126	132	1.024		
	Total	137.080	136			
Q_6_t46	Between Groups	5.855	4	1.464	1.329	.262
	Within Groups	145.328	132	1.101		
	Total	151.182	136			
Q_7_t47	Between Groups	3.687	4	.922	.780	.540
	Within Groups	155.991	132	1.182		
	Total	159.679	136			
Q_8_t48	Between Groups	3.691	4	.923	.755	.557
	Within Groups	160.192	131	1.223		
	Total	163.882	135			
Q_9_t49	Between Groups	4.219	4	1.055	1.191	.318
	Within Groups	116.905	132	.886		
	Total	121.124	136			
Q_10_t50	Between Groups	4.038	4	1.009	.890	.472
	Within Groups	149.743	132	1.134		
	Total	153.781	136			
Q_11_t51	Between Groups	3.527	4	.882	.822	.513
	Within Groups	141.538	132	1.072		
	Total	145.066	136			
Q_12_t52	Between Groups	3.616	4	.904	.895	.469

		Sum of Squares	Df	Mean Square	F	Sig.
	Within Groups	131.317	130	1.010		
	Total	134.933	134			
Q_13_t53	Between Groups	1.200	4	.300	.413	.799
	Within Groups	94.326	130	.726		
	Total	95.526	134			
Q_14_t54	Between Groups	.895	4	.224	.391	.814
	Within Groups	73.702	129	.571		
	Total	74.597	133			
Q_15_t55	Between Groups	.403	4	.101	.095	.984
	Within Groups	138.589	130	1.066		
	Total	138.993	134			
Q_16_t56	Between Groups	.326	4	.081	.106	.980
	Within Groups	101.079	131	.772		
	Total	101.404	135			
Q_17_t57	Between Groups	1.961	4	.490	.567	.687
	Within Groups	112.365	130	.864		
	Total	114.326	134			

In terms of the respondent's age, there was only one question (Q2) that was statistically significant in mean scores on the Medical Mistrust Scale between the different age groups. The statement on the scale for this question was that*: Patients have sometimes been deceived or mislead by healthcare organizations.* For this statement, the youngest respondent group (ages 21-35) had the highest mean (3.52) whereas the oldest group (65+) had the lowest mean score (2.59).

Table 67. Results of MMS Question Means by Age.

Question 1	$F_{(4, 131)}=1.250$, $p=.293$
Question 2	$F_{(4, 132)}=2.472$, $p=.048$
Question 3	$F_{(4, 132)}=.693$, $p=.598$
Question 4	$F_{(4, 132)}=.689$, $p=.601$
Question 5	$F_{(4, 132)}=.477$, $p=.752$
Question 6	$F_{(4, 132)}=1.329$, $p=.262$
Question 7	$F_{(4, 132)}=.780$, $p=.540$
Question 8	$F_{(4, 131)}=.755$, $p=.557$
Question 9	$F_{(4, 132)}=1.191$, $p=.318$
Question 10	$F_{(4, 132)}=.890$, $p=.472$
Question 11	$F_{(4, 131)}=.822$, $p=.513$
Question 12	$F_{(4, 130)}=.895$, $p=.469$
Question 13	$F_{(4, 130)}=.413$, $p=.799$
Question 14	$F_{(4, 129)}=.391$, $p=.894$
Question 15	$F_{(4, 130)}=.095$, $p=.984$
Question 16	$F_{(4, 131)}=.106$, $p=.980$
Question 17	$F_{(4, 130)}=.567$, $p=.687$

Sex

Next the ANOVA was run to look at differences in total mean scores on the Medical

Mistrust Scale across the respondent's sex groups.

Table 68. ANOVA-Descriptives MMS by Sex.

	N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Male	30	2.8357	.28574	.05217	2.7290	2.9424	2.24	3.29
Female	106	2.7986	.27023	.02625	2.7465	2.8506	1.89	3.41
Total	136	2.8068	.27308	.02342	2.7605	2.8531	1.89	3.41

Table 69. ANOVA-MMS Score and Respondent's Sex.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	.032	1	.032	.429	.513
Within Groups	10.035	134	.075		
Total	10.067	135			

In terms of the respondent's sex, there was no statistically significant difference in the total mean score on the Medical Mistrust Scale between the different groups.

Table 70. MMS and Patient's Sex

Total Mean Score	F(1, 134)=.429, p=.513

The ANOVA was then run to look at differences in mean scores on each question on the Medical Mistrust Scale across the respondent's sex groups.

Table 71. ANOVA-Descriptives Individual MMS Mean Scores by Sex

		N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
Q_1_t41	Male	30	2.97	1.066	.195	2.57	3.36	1	5
	Female	106	2.72	1.201	.117	2.49	2.95	1	5
	Total	136	2.77	1.174	.101	2.57	2.97	1	5
Q_2_t42	Male	30	2.77	1.251	.228	2.30	3.23	1	5
	Female	107	2.94	1.164	.113	2.72	3.17	1	5
	Total	137	2.91	1.181	.101	2.71	3.10	1	5
Q_3_t43	Male	30	2.63	1.066	.195	2.24	3.03	1	4
	Female	107	2.57	1.134	.110	2.35	2.79	1	5
	Total	137	2.58	1.116	.095	2.40	2.77	1	5
Q_4_t44	Male	30	2.63	1.033	.189	2.25	3.02	1	4
	Female	107	2.64	1.050	.101	2.43	2.84	1	5
	Total	137	2.64	1.042	.089	2.46	2.81	1	5
Q_5_t45	Male	30	3.23	1.040	.190	2.84	3.62	1	5
	Female	107	3.12	.997	.096	2.93	3.31	1	5
	Total	137	3.15	1.004	.086	2.98	3.32	1	5
Q_6_t46	Male	30	2.57	1.006	.184	2.19	2.94	1	5
	Female	107	2.67	1.071	.104	2.47	2.88	1	5
	Total	137	2.65	1.054	.090	2.47	2.83	1	5
Q_7_t47	Male	30	3.37	.964	.176	3.01	3.73	1	5
	Female	107	3.15	1.114	.108	2.94	3.36	1	5
	Total	137	3.20	1.084	.093	3.01	3.38	1	5
Q_8_t48	Male	30	3.07	1.048	.191	2.68	3.46	1	5
	Female	106	3.02	1.121	.109	2.80	3.23	1	5
	Total	136	3.03	1.102	.094	2.84	3.22	1	5
Q_9_t49	Male	30	3.43	.728	.133	3.16	3.71	2	5
	Female	107	3.27	.996	.096	3.08	3.46	1	5
	Total	137	3.31	.944	.081	3.15	3.47	1	5
Q_10_t50	Male	30	2.83	1.177	.215	2.39	3.27	1	5
	Female	107	2.85	1.035	.100	2.65	3.05	1	5
	Total	137	2.85	1.063	.091	2.67	3.03	1	5
Q_11_t51	Male	30	2.60	1.003	.183	2.23	2.97	1	4
	Female	107	2.87	1.038	.100	2.67	3.07	1	5

141

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Minimum	Maximum
	Total	137	2.81	1.033	.088	2.64	2.98	1	5
Q_12_t52	Male	30	2.77	.858	.157	2.45	3.09	1	4
	Female	105	2.67	1.044	.102	2.46	2.87	1	5
	Total	135	2.69	1.003	.086	2.52	2.86	1	5
Q_13_t53	Male	30	2.57	.728	.133	2.29	2.84	1	4
	Female	105	2.53	.878	.086	2.36	2.70	1	5
	Total	135	2.54	.844	.073	2.40	2.68	1	5
Q_14_t54	Male	30	2.53	.681	.124	2.28	2.79	1	4
	Female	104	2.60	.770	.075	2.45	2.75	1	5
	Total	134	2.58	.749	.065	2.45	2.71	1	5
Q_15_t55	Male	30	3.10	1.094	.200	2.69	3.51	1	5
	Female	105	2.98	1.000	.098	2.79	3.17	1	5
	Total	135	3.01	1.018	.088	2.83	3.18	1	5
Q_16_t56	Male	30	2.70	.794	.145	2.40	3.00	1	4
	Female	106	2.68	.890	.086	2.51	2.85	1	5
	Total	136	2.68	.867	.074	2.54	2.83	1	5
Q_17_t57	Male	30	2.43	1.073	.196	2.03	2.83	1	4
	Female	105	2.31	.880	.086	2.14	2.48	1	5
	Total	135	2.34	.924	.079	2.18	2.50	1	5

Table 72. ANOVA-Individual MMS Question Mean Scores by Sex.

		Sum of Squares	Df	Mean Square	F	Sig.
Q_1_t41	Between Groups	1.458	1	1.458	1.059	.305
	Within Groups	184.476	134	1.377		
	Total	185.934	135			
Q_2_t42	Between Groups	.736	1	.736	.526	.470
	Within Groups	189.030	135	1.400		
	Total	189.766	136			
Q_3_t43	Between Groups	.094	1	.094	.075	.785
	Within Groups	169.191	135	1.253		
	Total	169.285	136			
Q_4_t44	Between Groups	.000	1	.000	.000	.992
	Within Groups	147.752	135	1.094		
	Total	147.752	136			
Q_5_t45	Between Groups	.293	1	.293	.289	.592
	Within Groups	136.787	135	1.013		
	Total	137.080	136			
Q_6_t46	Between Groups	.264	1	.264	.237	.628
	Within Groups	150.918	135	1.118		
	Total	151.182	136			
Q_7_t47	Between Groups	1.105	1	1.105	.940	.334
	Within Groups	158.574	135	1.175		
	Total	159.679	136			
Q_8_t48	Between Groups	.053	1	.053	.044	.835
	Within Groups	163.829	134	1.223		
	Total	163.882	135			
Q_9_t49	Between Groups	.617	1	.617	.691	.407
	Within Groups	120.507	135	.893		
	Total	121.124	136			
Q_10_t50	Between Groups	.007	1	.007	.006	.938
	Within Groups	153.774	135	1.139		
	Total	153.781	136			
Q_11_t51	Between Groups	1.697	1	1.697	1.598	.208
	Within Groups	143.368	135	1.062		
	Total	145.066	136			
Q_12_t52	Between Groups	.233	1	.233	.230	.632

		Sum of Squares	Df	Mean Square	F	Sig.
	Within Groups	134.700	133	1.013		
	Total	134.933	134			
Q_13_t53	Between Groups	.026	1	.026	.036	.850
	Within Groups	95.500	133	.718		
	Total	95.526	134			
Q_14_t54	Between Groups	.092	1	.092	.163	.687
	Within Groups	74.505	132	.564		
	Total	74.597	133			
Q_15_t55	Between Groups	.331	1	.331	.317	.574
	Within Groups	138.662	133	1.043		
	Total	138.993	134			
Q_16_t56	Between Groups	.010	1	.010	.013	.908
	Within Groups	101.394	134	.757		
	Total	101.404	135			
Q_17_t57	Between Groups	.331	1	.331	.386	.536
	Within Groups	113.995	133	.857		
	Total	114.326	134			

In terms of the respondent's sex, there was no statistical significance in mean scores on the Medical Mistrust Scale questions between the different sex groups.

Table 73. Results of MMS Question Means by Sex.

Question 1	$F_{(1, 134)}=1.059$, p=.305
Question 2	$F_{(1, 135)}=.526$, p=.470
Question 3	$F_{(1, 135)}=.075$, p=.785
Question 4	$F_{(1, 135)}=.000$, p=.992
Question 5	$F_{(1, 135)}=.289$, p=.592
Question 6	$F_{(1, 135)}=.237$, p=.628
Question 7	$F_{(1, 135)}=.940$, p=.334
Question 8	$F_{(1, 134)}=.044$, p=.835
Question 9	$F_{(1, 135)}=.691$, p=.407
Question 10	$F_{(1, 135)}=.006$,p=.938
Question 11	$F_{(1, 133)}=1.598$, p=.208
Question 12	$F_{(1, 133)}=.230$, p=.632
Question 13	$F_{(1, 133)}=.036$,p=.850
Question 14	$F_{(1, 132)}=.163$, p=.687
Question 15	$F_{(1, 133)}=.314$, p=.574
Question 16	$F_{(1, 134)}=.013$, p=.908
Question 17	$F_{(1, 133)}=.286$, p=.536

Race

Next the ANOVA was run to look at differences in total mean scores on the Medical Mistrust Scale across the respondent's race groups.

Table 74. ANOVA-Descriptives MMS by Respondent's Race.

	N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Asian	6	2.8917	.18872	.07705	2.6936	3.0897	2.65	3.18
Black	14	2.9814	.20983	.05608	2.8603	3.1026	2.59	3.29
Hispanic	4	3.0725	.25656	.12828	2.6642	3.4808	2.82	3.41
Mixed	6	2.7833	.10783	.04402	2.6702	2.8965	2.65	2.94
White	105	2.7703	.28016	.02734	2.7161	2.8245	1.89	3.35
Total	135	2.8071	.27407	.02359	2.7605	2.8538	1.89	3.41

Table 75. ANOVA-MMS Score and Respondent's Race.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	.896	4	.224	3.175	.016
Within Groups	9.169	130	.071		
Total	10.065	134			

In terms of the respondent's race, there was a statistically significant difference in the total mean score on the Medical Mistrust Scale between the different race groups. Participants who identified as White (2.77), had the lowest mean score on the Medical Mistrust Scale. Hispanic participants had the highest average score (3.07) with black participants having the second highest average score (2.98)

Table 76. MMS and Race

Total Mean Score	$F_{(4, 130)}=3.175$, p=.016

Then the ANOVA was run to look at differences in mean scores on each question on the Medical Mistrust Scale across the respondent's race groups.

146

Table 77. ANOVA-Descriptives Individual MMS Mean Scores by Race

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Minimum	Maximum
Q_1_t41	Asian	6	2.83	.983	.401	1.80	3.87	2	4
	Black	14	2.64	1.151	.308	1.98	3.31	1	4
	Hispanic	5	3.60	1.342	.600	1.93	5.27	2	5
	Mixed	6	2.67	1.033	.422	1.58	3.75	1	4
	White	104	2.76	1.195	.117	2.53	2.99	1	5
	Total	135	2.78	1.176	.101	2.58	2.98	1	5
Q_2_t42	Asian	6	3.17	.983	.401	2.13	4.20	2	4
	Black	14	3.29	1.204	.322	2.59	3.98	1	5
	Hispanic	5	3.80	1.304	.583	2.18	5.42	2	5
	Mixed	6	3.17	.983	.401	2.13	4.20	2	4
	White	105	2.78	1.185	.116	2.55	3.01	1	5
	Total	136	2.90	1.186	.102	2.70	3.11	1	5
Q_3_t43	Asian	6	3.17	1.169	.477	1.94	4.39	1	4
	Black	14	2.29	1.139	.304	1.63	2.94	1	4
	Hispanic	5	2.00	1.000	.447	.76	3.24	1	3
	Mixed	6	3.50	1.225	.500	2.21	4.79	2	5
	White	105	2.57	1.091	.106	2.36	2.78	1	5
	Total	136	2.59	1.119	.096	2.40	2.78	1	5
Q_4_t44	Asian	6	2.83	1.329	.543	1.44	4.23	1	5
	Black	14	3.14	.770	.206	2.70	3.59	2	4
	Hispanic	5	3.20	.837	.374	2.16	4.24	2	4
	Mixed	6	2.50	1.049	.428	1.40	3.60	1	4
	White	105	2.53	1.057	.103	2.33	2.74	1	5
	Total	136	2.63	1.046	.090	2.46	2.81	1	5
Q_5_t45	Asian	6	3.50	.837	.342	2.62	4.38	3	5
	Black	14	3.71	.825	.221	3.24	4.19	2	5
	Hispanic	5	4.00	1.000	.447	2.76	5.24	3	5
	Mixed	6	2.83	1.329	.543	1.44	4.23	1	4
	White	105	3.02	.980	.096	2.83	3.21	1	5
	Total	136	3.14	1.005	.086	2.97	3.31	1	5
Q_6_t46	Asian	6	3.50	1.049	.428	2.40	4.60	2	5
	Black	14	4.00	.784	.210	3.55	4.45	3	5
	Hispanic	5	3.00	1.225	.548	1.48	4.52	1	4

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Minimum	Maximum
	Mixed	6	2.50	.548	.224	1.93	3.07	2	3
	White	105	2.41	.948	.092	2.23	2.59	1	5
	Total	136	2.65	1.058	.091	2.47	2.83	1	5
Q_7_t47	Asian	6	3.17	.753	.307	2.38	3.96	2	4
	Black	14	3.14	1.292	.345	2.40	3.89	1	5
	Hispanic	5	2.80	1.095	.490	1.44	4.16	1	4
	Mixed	6	3.50	1.049	.428	2.40	4.60	2	5
	White	105	3.20	1.087	.106	2.99	3.41	1	5
	Total	136	3.19	1.085	.093	3.01	3.38	1	5
Q_8_t48	Asian	6	3.67	.516	.211	3.12	4.21	3	4
	Black	13	3.31	.855	.237	2.79	3.82	2	5
	Hispanic	5	3.80	.837	.374	2.76	4.84	3	5
	Mixed	6	3.17	.753	.307	2.38	3.96	2	4
	White	105	2.91	1.161	.113	2.69	3.14	1	5
	Total	135	3.03	1.106	.095	2.84	3.22	1	5
Q_9_t49	Asian	6	3.00	.000	.000	3.00	3.00	3	3
	Black	14	3.43	.756	.202	2.99	3.87	2	5
	Hispanic	5	3.00	.707	.316	2.12	3.88	2	4
	Mixed	6	3.67	.516	.211	3.12	4.21	3	4
	White	105	3.30	1.018	.099	3.10	3.49	1	5
	Total	136	3.30	.945	.081	3.14	3.46	1	5
Q_10_t50	Asian	6	2.83	.983	.401	1.80	3.87	2	4
	Black	14	3.29	1.204	.322	2.59	3.98	1	5
	Hispanic	5	3.40	.548	.245	2.72	4.08	3	4
	Mixed	6	2.33	1.033	.422	1.25	3.42	1	4
	White	105	2.78	1.056	.103	2.58	2.99	1	5
	Total	136	2.84	1.063	.091	2.66	3.02	1	5
Q_11_t51	Asian	6	2.83	1.329	.543	1.44	4.23	1	5
	Black	14	3.07	.917	.245	2.54	3.60	1	4
	Hispanic	5	3.00	.707	.316	2.12	3.88	2	4
	Mixed	6	2.83	1.169	.477	1.61	4.06	2	5
	White	105	2.75	1.045	.102	2.55	2.95	1	5
	Total	136	2.80	1.032	.088	2.63	2.98	1	5
Q_12_t52	Asian	6	2.50	.837	.342	1.62	3.38	2	4
	Black	13	1.92	.641	.178	1.54	2.31	1	3

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Minimum	Maximum
	Hispanic	4	2.00	.816	.408	.70	3.30	1	3
	Mixed	6	3.00	1.265	.516	1.67	4.33	1	4
	White	105	2.81	1.001	.098	2.62	3.00	1	5
	Total	134	2.69	1.005	.087	2.52	2.87	1	5
Q_13_t53	Asian	6	2.50	.548	.224	1.93	3.07	2	3
	Black	13	2.85	.899	.249	2.30	3.39	1	4
	Hispanic	4	3.25	.957	.479	1.73	4.77	2	4
	Mixed	6	1.67	.516	.211	1.12	2.21	1	2
	White	105	2.53	.833	.081	2.37	2.69	1	5
	Total	134	2.54	.846	.073	2.40	2.69	1	5
Q_14_t54	Asian	6	2.67	.516	.211	2.12	3.21	2	3
	Black	13	2.69	.630	.175	2.31	3.07	2	4
	Hispanic	4	3.00	.816	.408	1.70	4.30	2	4
	Mixed	6	1.83	.408	.167	1.40	2.26	1	2
	White	104	2.59	.771	.076	2.44	2.74	1	5
	Total	133	2.58	.751	.065	2.45	2.71	1	5
Q_15_t55	Asian	6	2.50	.548	.224	1.93	3.07	2	3
	Black	14	2.64	.745	.199	2.21	3.07	2	4
	Hispanic	4	2.50	.577	.289	1.58	3.42	2	3
	Mixed	6	3.50	1.517	.619	1.91	5.09	1	5
	White	105	3.08	1.035	.101	2.88	3.28	1	5
	Total	135	3.01	1.018	.088	2.83	3.18	1	5
Q_16_t56	Asian	6	2.50	.837	.342	1.62	3.38	2	4
	Black	14	2.14	.663	.177	1.76	2.53	1	3
	Hispanic	4	2.00	.816	.408	.70	3.30	1	3
	Mixed	6	2.83	.983	.401	1.80	3.87	2	4
	White	105	2.79	.863	.084	2.62	2.96	1	5
	Total	135	2.69	.868	.075	2.54	2.84	1	5
Q_17_t57	Asian	6	2.00	1.095	.447	.85	3.15	1	4
	Black	13	3.00	.707	.196	2.57	3.43	2	4
	Hispanic	4	2.75	.957	.479	1.23	4.27	2	4
	Mixed	6	1.83	.408	.167	1.40	2.26	1	2
	White	105	2.30	.929	.091	2.12	2.48	1	5
	Total	134	2.34	.927	.080	2.18	2.50	1	5

Table 78. ANOVA-Individual MMS Question Mean Scores by Race.

		Sum of Squares	Df	Mean Square	F	Sig.
Q_1_t41	Between Groups	3.762	4	.940	.673	.612
	Within Groups	181.571	130	1.397		
	Total	185.333	134			
Q_2_t42	Between Groups	8.472	4	2.118	1.530	.197
	Within Groups	181.286	131	1.384		
	Total	189.757	135			
Q_3_t43	Between Groups	10.036	4	2.509	2.068	.089
	Within Groups	158.905	131	1.213		
	Total	168.941	135			
Q_4_t44	Between Groups	6.637	4	1.659	1.542	.194
	Within Groups	140.981	131	1.076		
	Total	147.618	135			
Q_5_t45	Between Groups	11.193	4	2.798	2.929	.023
	Within Groups	125.152	131	.955		
	Total	136.346	135			
Q_6_t46	Between Groups	36.668	4	9.167	10.498	.000
	Within Groups	114.390	131	.873		
	Total	151.059	135			
Q_7_t47	Between Groups	1.382	4	.345	.287	.886
	Within Groups	157.648	131	1.203		
	Total	159.029	135			
Q_8_t48	Between Groups	7.917	4	1.979	1.650	.166
	Within Groups	155.964	130	1.200		
	Total	163.881	134			
Q_9_t49	Between Groups	2.030	4	.508	.561	.692
	Within Groups	118.610	131	.905		
	Total	120.640	135			
Q_10_t50	Between Groups	6.255	4	1.564	1.401	.237
	Within Groups	146.186	131	1.116		
	Total	152.441	135			
Q_11_t51	Between Groups	1.483	4	.371	.342	.849
	Within Groups	142.157	131	1.085		
	Total	143.640	135			
Q_12_t52	Between Groups	11.842	4	2.960	3.115	.017

		Sum of Squares	Df	Mean Square	F	Sig.
	Within Groups	122.614	129	.950		
	Total	134.455	133			
Q_13_t53	Between Groups	7.822	4	1.956	2.886	.025
	Within Groups	87.409	129	.678		
	Total	95.231	133			
Q_14_t54	Between Groups	4.264	4	1.066	1.945	.107
	Within Groups	70.157	128	.548		
	Total	74.421	132			
Q_15_t55	Between Groups	6.388	4	1.597	1.566	.187
	Within Groups	132.605	130	1.020		
	Total	138.993	134			
Q_16_t56	Between Groups	7.495	4	1.874	2.607	.039
	Within Groups	93.438	130	.719		
	Total	100.933	134			
Q_17_t57	Between Groups	8.778	4	2.195	2.685	.034
	Within Groups	105.431	129	.817		
	Total	114.209	133			

In terms of the respondent's race, there were six questions on the scale that statistically significant differences in mean scores on the Medical Mistrust Scale due to respondent's race (Q 5, 6, 12, 13, 16 and 17). For question 5, the statement was: *When healthcare organizations make mistakes they usually cover them up.* For the fifth question, the Hispanic respondents had the highest mean (4.00) whereas the respondents who identified as mixed (2.83). For the sixth question, the statement: *Healthcare organizations have done harmful experiments on patients without their knowledge,* the black respondents had the highest mean (4.00). The statement for question 12 is*: I typically get a second opinion when I am told something about my health.* For this, the group with the highest mean was the mixed group (3.00) and the lowest group was the black respondents (1.92). The statement: *I trust that healthcare organizations check their staff's*

credentials to make sure they are hiring the best people showed Hispanics with the highest mean (3.25) and the respondents who identified as mixed had the lowest mean (1.67).

The next statement that had a statistical significance was: *mistakes are common in the healthcare organization,* respondents who identified as mixed had the highest mean (2.83) and Hispanic respondents have the lowest mean (2.00). Lastly, for the statement: *I trust that healthcare organizations keep up with the latest medical information* black respondents had the highest mean (3.00) and respondents who identified as mixed had the lowest mean (1.83).

Table 79. Results of MMS Question Means by Race.

Question 1	$F(4, 130)=.673$, p$=.612$
Question 2	$F(4, 131)=1.530$, p$=.197$
Question 3	$F(4, 131)=2.068$, p$=.089$
Question 4	$F(4, 131)=1.542$, p$=.194$
Question 5	$F(4, 131)=2.929$, p$=.023$
Question 6	$F(4, 131)=10.498$, p$=.000$
Question 7	$F(4, 131)=.287$, p$=.886$
Question 8	$F(4, 130)=1.650$, p$=.166$
Question 9	$F(4, 131)=.561$, p$=.692$
Question 10	$F(4, 131)=1.401$, p$=.237$
Question 11	$F(4, 131)=.342$, p$=.849$
Question 12	$F(4, 129)=3.115$, p$=.017$
Question 13	$F(4, 129)=2.886$, p$=.025$
Question 14	$F(4, 128)=1.945$, p$=.107$
Question 15	$F(4, 130)=1.566$, p$=.187$
Question 16	$F(4, 130)=2.607$, p$=.039$
Question 17	$F(4, 129)=2.685$, p$=.034$

Income Level

Next the ANOVA was run to look at differences in total mean scores on the Medical

Mistrust Scale across the respondent's income level groups.

Table 80. ANOVA-Descriptives MMS by Income Level.

	N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Less than $15,000	14	2.9186	.22532	.06022	2.7885	3.0487	2.59	3.41
$15,000-$24,999	11	2.8027	.31538	.09509	2.5909	3.0146	2.24	3.24
$25,000-$34,999	12	2.8183	.24591	.07099	2.6621	2.9746	2.41	3.18
$35,000-$44,999	12	2.8192	.28247	.08154	2.6397	2.9986	2.29	3.19
$45,000-$54,999	10	2.6270	.29124	.09210	2.4187	2.8353	2.06	3.00
$55,000-$64,999	7	2.6214	.38563	.14576	2.2648	2.9781	1.94	3.15
$65,000-$74,999	14	2.9193	.26143	.06987	2.7683	3.0702	2.53	3.35
$75,000-$84,999	12	2.8633	.36423	.10514	2.6319	3.0948	1.89	3.24
$85,000-$94,999	6	2.7650	.23856	.09739	2.5146	3.0154	2.41	3.06
> $95,000	34	2.7800	.20629	.03538	2.7080	2.8520	2.29	3.18
Total	132	2.8053	.27466	.02391	2.7580	2.8526	1.89	3.41

Table 81. ANOVA-MMS Score and Respondent's Income Level.

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	.992	9	.110	1.513	.151
Within Groups	8.890	122	.073		
Total	9.882	131			

In terms of the respondent's income, there was no statistically significant difference in

the total mean score on the Medical Mistrust Scale between the different income groups.

Table 82. MMS and Income

Total Mean Score	F(9, 122)=1.513, p=.151

153

The ANOVA was then run to look at differences in mean scores on each question on the

Medical Mistrust Scale across the respondent's income groups.

Table 83. ANOVA-Descriptives Individual MMS Mean Scores by Income Level

| | | N | Mean | SD | Std. Error | 95% Confidence Interval for Mean | | Min | Max |
						Lower Bound	Upper Bound		
Q_1_t4 1	$15,000-$24,999	11	2.36	1.206	.364	1.55	3.17	1	5
	$25,000-$34,999	12	2.50	1.087	.314	1.81	3.19	1	4
	$35,000-$44,999	12	2.92	.900	.260	2.34	3.49	1	4
	$45,000-$54,999	10	2.50	1.509	.477	1.42	3.58	1	5
	$55,000-$64,999	7	2.00	1.155	.436	.93	3.07	1	4
	$65,000-$74,999	14	2.93	.997	.267	2.35	3.50	1	4
	$75,000-$84,999	12	3.33	1.073	.310	2.65	4.02	1	5
	$85,000-$94,999	6	3.33	1.033	.422	2.25	4.42	2	5
	Greater than $95,000	34	2.74	1.136	.195	2.34	3.13	1	5
	Less than $15,000	14	2.93	1.141	.305	2.27	3.59	1	5
	Total	132	2.77	1.138	.099	2.57	2.96	1	5
Q_2_t4 2	$15,000-$24,999	11	2.45	1.368	.413	1.54	3.37	1	4
	$25,000-$34,999	12	2.58	1.240	.358	1.80	3.37	1	4
	$35,000-$44,999	12	3.00	1.044	.302	2.34	3.66	1	4
	$45,000-$54,999	10	2.90	1.729	.547	1.66	4.14	1	5
	$55,000-$64,999	7	2.29	.951	.360	1.41	3.17	1	3
	$65,000-$74,999	14	3.07	.997	.267	2.50	3.65	2	5
	$75,000-$84,999	12	3.42	1.165	.336	2.68	4.16	1	5
	$85,000-$94,999	6	2.50	1.378	.563	1.05	3.95	1	4
	Greater than $95,000	35	2.80	1.132	.191	2.41	3.19	1	5
	Less than $15,000	14	3.50	.650	.174	3.12	3.88	3	5
	Total	133	2.89	1.176	.102	2.69	3.10	1	5
Q_3_t4 3	$15,000-$24,999	11	2.73	1.191	.359	1.93	3.53	1	4
	$25,000-$34,999	12	3.17	1.030	.297	2.51	3.82	2	5
	$35,000-$44,999	12	3.08	.900	.260	2.51	3.66	2	4
	$45,000-$54,999	10	2.20	1.398	.442	1.20	3.20	1	4
	$55,000-$64,999	7	3.29	1.254	.474	2.13	4.45	1	5
	$65,000-$74,999	14	2.64	1.082	.289	2.02	3.27	1	4
	$75,000-$84,999	12	2.08	1.165	.336	1.34	2.82	1	4
	$85,000-$94,999	6	2.50	1.049	.428	1.40	3.60	1	4

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Min	Max
	Greater than $95,000	35	2.23	1.031	.174	1.87	2.58	1	4
	Less than $15,000	14	2.79	.699	.187	2.38	3.19	2	4
	Total	133	2.59	1.102	.096	2.40	2.78	1	5
Q_4_t4 4	$15,000-$24,999	11	2.36	1.120	.338	1.61	3.12	1	4
	$25,000-$34,999	12	2.33	.985	.284	1.71	2.96	1	4
	$35,000-$44,999	12	2.50	.905	.261	1.93	3.07	1	4
	$45,000-$54,999	10	2.10	1.197	.379	1.24	2.96	1	5
	$55,000-$64,999	7	2.00	.816	.309	1.24	2.76	1	3
	$65,000-$74,999	14	3.07	.917	.245	2.54	3.60	2	4
	$75,000-$84,999	12	3.00	.953	.275	2.39	3.61	1	5
	$85,000-$94,999	6	2.67	1.033	.422	1.58	3.75	1	4
	Greater than $95,000	35	2.71	1.152	.195	2.32	3.11	1	5
	Less than $15,000	14	3.00	.877	.234	2.49	3.51	1	4
	Total	133	2.64	1.047	.091	2.46	2.82	1	5
Q_5_t4 5	$15,000-$24,999	11	2.82	1.401	.423	1.88	3.76	1	5
	$25,000-$34,999	12	2.67	.888	.256	2.10	3.23	1	4
	$35,000-$44,999	12	3.00	.739	.213	2.53	3.47	2	4
	$45,000-$54,999	10	2.40	1.075	.340	1.63	3.17	1	4
	$55,000-$64,999	7	3.14	1.069	.404	2.15	4.13	1	4
	$65,000-$74,999	14	3.21	.975	.261	2.65	3.78	2	5
	$75,000-$84,999	12	3.50	1.000	.289	2.86	4.14	2	5
	$85,000-$94,999	6	3.33	.816	.333	2.48	4.19	2	4
	Greater than $95,000	35	3.31	.963	.163	2.98	3.65	1	5
	Less than $15,000	14	3.57	.646	.173	3.20	3.94	2	4
	Total	133	3.14	.993	.086	2.97	3.31	1	5
Q_6_t4 6	$15,000-$24,999	11	2.55	1.368	.413	1.63	3.46	1	5
	$25,000-$34,999	12	2.33	.888	.256	1.77	2.90	1	4
	$35,000-$44,999	12	2.92	.900	.260	2.34	3.49	2	5
	$45,000-$54,999	10	2.10	1.101	.348	1.31	2.89	1	4
	$55,000-$64,999	7	2.71	1.380	.522	1.44	3.99	1	5
	$65,000-$74,999	14	2.79	.802	.214	2.32	3.25	1	4
	$75,000-$84,999	12	2.75	1.138	.329	2.03	3.47	1	5
	$85,000-$94,999	6	2.17	.983	.401	1.13	3.20	1	3
	Greater than $95,000	35	2.71	1.126	.190	2.33	3.10	1	5
	Less than $15,000	14	2.86	.949	.254	2.31	3.41	1	4
	Total	133	2.64	1.061	.092	2.46	2.82	1	5

155

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Min	Max
Q_7_t4 7	$15,000-$24,999	11	3.18	1.250	.377	2.34	4.02	1	5
	$25,000-$34,999	12	3.50	1.000	.289	2.86	4.14	1	5
	$35,000-$44,999	12	3.33	1.303	.376	2.51	4.16	1	5
	$45,000-$54,999	10	3.10	1.197	.379	2.24	3.96	1	5
	$55,000-$64,999	7	2.86	.900	.340	2.03	3.69	2	4
	$65,000-$74,999	14	3.43	.938	.251	2.89	3.97	1	4
	$75,000-$84,999	12	3.08	1.379	.398	2.21	3.96	1	5
	$85,000-$94,999	6	3.67	1.211	.494	2.40	4.94	2	5
	Greater than $95,000	35	3.06	1.083	.183	2.69	3.43	1	5
	Less than $15,000	14	3.29	.611	.163	2.93	3.64	2	4
	Total	133	3.22	1.075	.093	3.03	3.40	1	5
Q_8_t4 8	$15,000-$24,999	11	2.73	1.348	.407	1.82	3.63	1	5
	$25,000-$34,999	12	2.83	1.030	.297	2.18	3.49	1	4
	$35,000-$44,999	11	2.55	1.214	.366	1.73	3.36	1	4
	$45,000-$54,999	10	2.50	1.080	.342	1.73	3.27	1	4
	$55,000-$64,999	7	2.71	.951	.360	1.83	3.59	1	4
	$65,000-$74,999	14	3.21	1.051	.281	2.61	3.82	2	5
	$75,000-$84,999	12	3.42	1.379	.398	2.54	4.29	1	5
	$85,000-$94,999	6	3.17	1.472	.601	1.62	4.71	1	5
	Greater than $95,000	35	3.09	.951	.161	2.76	3.41	1	5
	Less than $15,000	14	3.50	.941	.251	2.96	4.04	2	5
	Total	132	3.02	1.112	.097	2.82	3.21	1	5
Q_9_t4 9	$15,000-$24,999	11	3.27	1.104	.333	2.53	4.01	1	5
	$25,000-$34,999	12	3.67	.778	.225	3.17	4.16	2	5
	$35,000-$44,999	12	3.50	.798	.230	2.99	4.01	2	4
	$45,000-$54,999	10	3.60	1.174	.371	2.76	4.44	2	5
	$55,000-$64,999	7	4.00	.577	.218	3.47	4.53	3	5
	$65,000-$74,999	14	3.07	.829	.221	2.59	3.55	2	4
	$75,000-$84,999	12	3.17	1.267	.366	2.36	3.97	1	5
	$85,000-$94,999	6	3.50	1.225	.500	2.21	4.79	2	5
	Greater than $95,000	35	3.20	.901	.152	2.89	3.51	1	5
	Less than $15,000	14	2.93	.616	.165	2.57	3.28	2	4
	Total	133	3.32	.940	.082	3.15	3.48	1	5
Q_10_t 50	$15,000-$24,999	11	2.45	1.440	.434	1.49	3.42	1	5
	$25,000-$34,999	12	2.58	.996	.288	1.95	3.22	1	4
	$35,000-$44,999	12	2.33	.888	.256	1.77	2.90	1	4

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Min	Max
	$45,000-$54,999	10	2.80	1.033	.327	2.06	3.54	1	5
	$55,000-$64,999	7	2.43	1.272	.481	1.25	3.61	1	5
	$65,000-$74,999	14	3.14	1.099	.294	2.51	3.78	1	5
	$75,000-$84,999	12	3.08	1.379	.398	2.21	3.96	1	5
	$85,000-$94,999	6	3.67	.816	.333	2.81	4.52	2	4
	Greater than $95,000	35	2.97	.891	.151	2.67	3.28	1	4
	Less than $15,000	14	2.79	.975	.261	2.22	3.35	1	4
	Total	133	2.83	1.074	.093	2.65	3.02	1	5
Q_11_t 51	$15,000-$24,999	11	2.73	1.104	.333	1.99	3.47	1	5
	$25,000-$34,999	12	2.75	1.138	.329	2.03	3.47	1	5
	$35,000-$44,999	12	2.58	.996	.288	1.95	3.22	1	4
	$45,000-$54,999	10	2.70	.949	.300	2.02	3.38	1	4
	$55,000-$64,999	7	2.57	1.397	.528	1.28	3.86	1	4
	$65,000-$74,999	14	2.86	.949	.254	2.31	3.41	1	4
	$75,000-$84,999	12	3.00	1.206	.348	2.23	3.77	1	5
	$85,000-$94,999	6	3.17	.753	.307	2.38	3.96	2	4
	Greater than $95,000	35	2.86	.974	.165	2.52	3.19	1	5
	Less than $15,000	14	2.79	1.188	.318	2.10	3.47	1	5
	Total	133	2.80	1.033	.090	2.63	2.98	1	5
Q_12_t 52	$15,000-$24,999	11	3.00	1.414	.426	2.05	3.95	1	5
	$25,000-$34,999	12	3.42	.793	.229	2.91	3.92	2	5
	$35,000-$44,999	12	2.67	.985	.284	2.04	3.29	2	4
	$45,000-$54,999	10	2.50	.707	.224	1.99	3.01	1	3
	$55,000-$64,999	6	2.50	.548	.224	1.93	3.07	2	3
	$65,000-$74,999	14	2.93	1.141	.305	2.27	3.59	1	4
	$75,000-$84,999	12	2.42	.900	.260	1.84	2.99	1	4
	$85,000-$94,999	6	1.83	.983	.401	.80	2.87	1	3
	Greater than $95,000	34	2.65	.981	.168	2.30	2.99	1	5
	Less than $15,000	14	2.43	.938	.251	1.89	2.97	1	4
	Total	131	2.68	1.010	.088	2.50	2.85	1	5
Q_13_t 53	$15,000-$24,999	11	2.64	1.120	.338	1.88	3.39	1	5
	$25,000-$34,999	12	2.42	.793	.229	1.91	2.92	1	3
	$35,000-$44,999	12	2.58	.996	.288	1.95	3.22	1	4
	$45,000-$54,999	10	2.60	.699	.221	2.10	3.10	2	4
	$55,000-$64,999	6	2.17	.753	.307	1.38	2.96	1	3
	$65,000-$74,999	14	2.64	1.082	.289	2.02	3.27	1	5

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Min	Max
	$75,000-$84,999	12	2.42	.669	.193	1.99	2.84	1	3
	$85,000-$94,999	6	2.33	1.033	.422	1.25	3.42	1	3
	Greater than $95,000	34	2.56	.660	.113	2.33	2.79	2	4
	Less than $15,000	14	2.71	.994	.266	2.14	3.29	1	5
	Total	131	2.54	.844	.074	2.40	2.69	1	5
Q_14_t 54	$15,000-$24,999	11	2.64	1.027	.310	1.95	3.33	1	5
	$25,000-$34,999	12	2.25	.866	.250	1.70	2.80	1	4
	$35,000-$44,999	12	2.25	.622	.179	1.86	2.64	2	4
	$45,000-$54,999	10	2.50	.972	.307	1.80	3.20	1	4
	$55,000-$64,999	5	2.40	.548	.245	1.72	3.08	2	3
	$65,000-$74,999	14	2.71	.825	.221	2.24	3.19	1	4
	$75,000-$84,999	12	2.67	.651	.188	2.25	3.08	2	4
	$85,000-$94,999	6	2.67	.516	.211	2.12	3.21	2	3
	Greater than $95,000	34	2.65	.597	.102	2.44	2.86	2	4
	Less than $15,000	14	2.71	.726	.194	2.29	3.13	2	4
	Total	130	2.57	.736	.065	2.44	2.70	1	5
Q_15_t 55	$15,000-$24,999	11	3.55	1.368	.413	2.63	4.46	1	5
	$25,000-$34,999	12	3.42	1.084	.313	2.73	4.11	2	5
	$35,000-$44,999	12	3.25	.866	.250	2.70	3.80	2	4
	$45,000-$54,999	10	3.30	1.252	.396	2.40	4.20	1	5
	$55,000-$64,999	7	2.71	.756	.286	2.02	3.41	2	4
	$65,000-$74,999	14	2.86	.949	.254	2.31	3.41	2	5
	$75,000-$84,999	11	2.91	.701	.211	2.44	3.38	2	4
	$85,000-$94,999	6	2.00	.894	.365	1.06	2.94	1	3
	Greater than $95,000	34	2.94	.983	.169	2.60	3.28	1	5
	Less than $15,000	14	2.93	.829	.221	2.45	3.41	2	4
	Total	131	3.02	1.011	.088	2.85	3.20	1	5
Q_16_t 56	$15,000-$24,999	11	3.55	.934	.282	2.92	4.17	2	5
	$25,000-$34,999	12	2.83	.835	.241	2.30	3.36	2	4
	$35,000-$44,999	12	3.00	.739	.213	2.53	3.47	2	4
	$45,000-$54,999	10	2.80	1.033	.327	2.06	3.54	1	4
	$55,000-$64,999	7	2.43	.976	.369	1.53	3.33	1	4
	$65,000-$74,999	14	2.79	.893	.239	2.27	3.30	1	4
	$75,000-$84,999	12	2.58	.669	.193	2.16	3.01	2	4
	$85,000-$94,999	6	2.17	.753	.307	1.38	2.96	1	3
	Greater than $95,000	34	2.50	.826	.142	2.21	2.79	1	4

158

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Min	Max
	Less than $15,000	14	2.43	.514	.137	2.13	2.73	2	3
	Total	132	2.70	.856	.074	2.55	2.84	1	5
Q_17_t	$15,000-$24,999	11	2.64	1.286	.388	1.77	3.50	1	5
57	$25,000-$34,999	12	2.67	.985	.284	2.04	3.29	1	4
	$35,000-$44,999	12	2.42	.900	.260	1.84	2.99	2	5
	$45,000-$54,999	10	2.10	.876	.277	1.47	2.73	1	4
	$55,000-$64,999	6	1.83	.753	.307	1.04	2.62	1	3
	$65,000-$74,999	14	2.29	.914	.244	1.76	2.81	1	4
	$75,000-$84,999	12	2.08	.900	.260	1.51	2.66	1	4
	$85,000-$94,999	6	2.33	1.366	.558	.90	3.77	1	4
	Greater than $95,000	34	2.29	.719	.123	2.04	2.54	1	4
	Less than $15,000	14	2.50	1.019	.272	1.91	3.09	1	4
	Total	131	2.34	.925	.081	2.18	2.50	1	5

Table 84. ANOVA-Individual MMS Question Mean Scores by Income Level.

		Sum of Squares	Df	Mean Square	F	Sig.
Q_1_t41	Between Groups	14.283	9	1.587	1.246	.274
	Within Groups	155.437	122	1.274		
	Total	169.720	131			
Q_2_t42	Between Groups	16.109	9	1.790	1.323	.232
	Within Groups	166.418	123	1.353		
	Total	182.526	132			
Q_3_t43	Between Groups	20.302	9	2.256	1.983	.047
	Within Groups	139.953	123	1.138		
	Total	160.256	132			
Q_4_t44	Between Groups	14.160	9	1.573	1.483	.162
	Within Groups	130.517	123	1.061		
	Total	144.677	132			
Q_5_t45	Between Groups	15.064	9	1.674	1.787	.077
	Within Groups	115.222	123	.937		
	Total	130.286	132			
Q_6_t46	Between Groups	7.740	9	.860	.751	.662
	Within Groups	140.937	123	1.146		
	Total	148.677	132			
Q_7_t47	Between Groups	5.195	9	.577	.481	.885

		Sum of Squares	Df	Mean Square	F	Sig.
	Within Groups	147.482	123	1.199		
	Total	152.677	132			
Q_8_t48	Between Groups	13.115	9	1.457	1.194	.305
	Within Groups	148.854	122	1.220		
	Total	161.970	131			
Q_9_t49	Between Groups	9.865	9	1.096	1.261	.265
	Within Groups	106.872	123	.869		
	Total	116.737	132			
Q_10_t50	Between Groups	13.443	9	1.494	1.323	.232
	Within Groups	138.918	123	1.129		
	Total	152.361	132			
Q_11_t51	Between Groups	2.564	9	.285	.253	.985
	Within Groups	138.353	123	1.125		
	Total	140.917	132			
Q_12_t52	Between Groups	15.079	9	1.675	1.726	.090
	Within Groups	117.455	121	.971		
	Total	132.534	130			
Q_13_t53	Between Groups	2.203	9	.245	.328	.964
	Within Groups	90.316	121	.746		
	Total	92.519	130			
Q_14_t54	Between Groups	3.652	9	.406	.735	.676
	Within Groups	66.224	120	.552		
	Total	69.877	129			
Q_15_t55	Between Groups	14.074	9	1.564	1.592	.125
	Within Groups	118.857	121	.982		
	Total	132.931	130			
Q_16_t56	Between Groups	14.135	9	1.571	2.344	.018
	Within Groups	81.744	122	.670		
	Total	95.879	131			
Q_17_t57	Between Groups	5.693	9	.633	.725	.685
	Within Groups	105.528	121	.872		
	Total	111.221	130			

In terms of the respondent's income level, there were statistically significant differences in mean scores on question 3: *I trust that health care organizations will tell me if a mistake is made about my treatment*. For this question, the respondents with the highest mean (3.29) were in the $55,000 to $64,999 category. There was also statistical significance for question 16: *Mistakes are common in healthcare organization* on the Medical Mistrust Scale due to respondent's income. For this question, the lowest income level $15,000 to $24,999 had the highest mean (3.55) and the second highest income level $85,000 to $94,999 had the lowest mean (2.17).

Table 85. Results of MMS Question Means by Income Level.

Question 1	$F(9, 122)=1.246$, p=.274
Question 2	$F(9, 123)=1.323$, p=.232
Question 3	$F(9, 123)=1.983$, p=.047
Question 4	$F(9, 123)=1.483$, p=.162
Question 5	$F(9, 123)=1.787$, p=.077
Question 6	$F(9, 123)=.751$, p=.662
Question 7	$F(9, 123)=.481$, p=.885
Question 8	$F(9, 122)=1.194$, p=.305
Question 9	$F(9, 123)=1.261$, p=.265
Question 10	$F(9, 123)=1.323$, p=.232
Question 11	$F(9, 123)=.253$, p=.985
Question 12	$F(9, 121)=1.726$, p=.090
Question 13	$F(9, 121)=.328$, p=.964
Question 14	$F(9, 120)=.735$, p=.676
Question 15	$F(9, 121)=1.592$, p=.125
Question 16	$F(9, 122)=2.344$, p=.018
Question 17	$F(9, 121)=.725$, p=.685

Education

Next the ANOVA was run to look at differences in total mean scores on the Medical

Mistrust Scale across the respondent's education level.

Table 86. ANOVA-Descriptives MMS by Education Level.

	N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
High School	42	2.8231	.26770	.04131	2.7397	2.9065	1.89	3.35
Some College	34	2.8144	.23833	.04087	2.7313	2.8976	2.35	3.24
College	27	2.7381	.33842	.06513	2.6043	2.8720	1.94	3.41
graduate or professional degree	32	2.8456	.25239	.04462	2.7546	2.9366	2.29	3.29
Total	135	2.8093	.27254	.02346	2.7629	2.8557	1.89	3.41

Table 87. ANOVA-MMS Score and Respondent's Education Level.

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	.188	3	.063	.840	.474
Within Groups	9.765	131	.075		
Total	9.953	134			

In terms of the respondent's education, there was no statistically significant difference in

the total mean score on the Medical Mistrust Scale between the different education levels.

Table 88. MMS and Education Level

Total Mean Score	$F(3, 131)=.840, p=.474$

Next the ANOVA was run to look at differences in mean scores on each question on the

Medical Mistrust Scale across the respondent's education level.

Table 89. ANOVA-Descriptives MMS Questions by Education Level.

		N	Mean	SD	SE	Lower Bound	Upper Bound	Min	Max
Q_1_t41	College	42	2.90	1.055	.163	2.58	3.23	1	5
	Grad/profess. degree	34	3.09	1.240	.213	2.66	3.52	1	5
	high school	27	2.22	1.155	.222	1.77	2.68	1	5
	some college	32	2.78	1.128	.199	2.37	3.19	1	5
	Total	135	2.79	1.168	.101	2.59	2.98	1	5
Q_2_t42	College	42	2.93	1.197	.185	2.56	3.30	1	5
	Grad/profess. degree	34	3.03	1.114	.191	2.64	3.42	1	5
	high school	27	2.52	1.252	.241	2.02	3.01	1	5
	some college	33	3.12	1.111	.193	2.73	3.52	1	5
	Total	136	2.92	1.174	.101	2.72	3.12	1	5
Q_3_t43	College	42	2.69	1.093	.169	2.35	3.03	1	4
	Grad/profess. degree	34	2.32	1.121	.192	1.93	2.71	1	5
	high school	27	2.63	1.149	.221	2.18	3.08	1	4
	some college	33	2.64	1.113	.194	2.24	3.03	1	5
	Total	136	2.57	1.113	.095	2.38	2.76	1	5
Q_4_t44	College	42	2.69	.975	.150	2.39	2.99	1	5
	Grad/profess. degree	34	2.74	.931	.160	2.41	3.06	1	5
	high school	27	2.52	1.189	.229	2.05	2.99	1	5
	some college	33	2.61	1.116	.194	2.21	3.00	1	5
	Total	136	2.65	1.037	.089	2.47	2.82	1	5
Q_5_t45	College	42	3.10	1.100	.170	2.75	3.44	1	5
	Grad/profess. degree	34	3.32	1.007	.173	2.97	3.67	1	5
	high school	27	2.81	1.001	.193	2.42	3.21	1	5
	some college	33	3.33	.816	.142	3.04	3.62	2	5
	Total	136	3.15	1.003	.086	2.98	3.32	1	5
Q_6_t46	College	42	2.74	1.106	.171	2.39	3.08	1	5
	Grad/profess. degree	34	2.71	1.219	.209	2.28	3.13	1	5
	high school	27	2.59	.931	.179	2.22	2.96	1	4
	some college	33	2.58	.902	.157	2.26	2.90	1	4
	Total	136	2.66	1.049	.090	2.48	2.84	1	5
Q_7_t47	College	42	3.33	1.074	.166	3.00	3.67	1	5
	Grad/profess. degree	34	2.76	1.130	.194	2.37	3.16	1	5
	high school	27	3.56	.974	.187	3.17	3.94	1	5

		N	Mean	SD	SE	Lower Bound	Upper Bound	Min	Max
	some college	33	3.15	1.034	.180	2.78	3.52	1	5
	Total	136	3.19	1.085	.093	3.01	3.38	1	5
Q_8_t48	College	41	3.02	1.107	.173	2.68	3.37	1	5
	Grad/profess. degree	34	3.12	1.094	.188	2.74	3.50	1	5
	high school	27	2.81	1.178	.227	2.35	3.28	1	5
	some college	33	3.15	1.064	.185	2.77	3.53	1	5
	Total	135	3.04	1.102	.095	2.85	3.22	1	5
Q_9_t49	College	42	3.29	.944	.146	2.99	3.58	1	5
	Grad/profess. degree	34	3.29	.906	.155	2.98	3.61	1	5
	high school	27	3.56	.934	.180	3.19	3.92	1	5
	some college	33	3.12	.992	.173	2.77	3.47	1	5
	Total	136	3.30	.945	.081	3.14	3.46	1	5
Q_10_t50	College	42	2.95	1.058	.163	2.62	3.28	1	5
	Grad/profess. degree	34	2.97	1.087	.186	2.59	3.35	1	5
	high school	27	2.56	1.050	.202	2.14	2.97	1	4
	some college	33	2.85	1.064	.185	2.47	3.23	1	5
	Total	136	2.85	1.065	.091	2.67	3.03	1	5
Q_11_t51	College	42	2.88	.968	.149	2.58	3.18	1	5
	Grad/profess. degree	34	3.06	1.043	.179	2.69	3.42	1	5
	high school	27	2.48	1.014	.195	2.08	2.88	1	5
	some college	33	2.76	1.091	.190	2.37	3.14	1	5
	Total	136	2.82	1.034	.089	2.64	2.99	1	5
Q_12_t52	College	42	2.86	1.002	.155	2.54	3.17	1	4
	Grad/profess. degree	33	2.30	.847	.147	2.00	2.60	1	4
	high school	27	2.78	1.050	.202	2.36	3.19	1	5
	some college	32	2.75	1.047	.185	2.37	3.13	1	5
	Total	134	2.68	1.001	.086	2.51	2.85	1	5
Q_13_t53	College	42	2.33	.816	.126	2.08	2.59	1	5
	Grad/profess. degree	33	2.67	.736	.128	2.41	2.93	1	4
	high school	27	2.63	.884	.170	2.28	2.98	1	5
	some college	32	2.63	.942	.166	2.29	2.96	1	5
	Total	134	2.54	.846	.073	2.40	2.69	1	5
Q_14_t54	College	42	2.48	.707	.109	2.26	2.70	1	4
	Grad/profess. degree	32	2.78	.659	.117	2.54	3.02	2	4
	high school	27	2.59	.844	.162	2.26	2.93	1	5

		N	Mean	SD	SE	Lower Bound	Upper Bound	Min	Max
	some college	32	2.53	.803	.142	2.24	2.82	1	4
	Total	133	2.59	.750	.065	2.46	2.72	1	5
Q_15_t55	College	42	2.98	.897	.138	2.70	3.26	1	5
	Grad/profess. degree	33	2.88	1.023	.178	2.52	3.24	1	5
	high school	27	3.04	1.091	.210	2.61	3.47	1	5
	some college	32	3.13	1.129	.200	2.72	3.53	1	5
	Total	134	3.00	1.019	.088	2.83	3.17	1	5
Q_16_t56	College	42	2.69	.680	.105	2.48	2.90	2	4
	Grad/profess. degree	34	2.38	.985	.169	2.04	2.73	1	4
	high school	27	2.78	.934	.180	2.41	3.15	1	5
	some college	32	2.88	.833	.147	2.57	3.18	1	4
	Total	135	2.67	.862	.074	2.53	2.82	1	5
Q_17_t57	College	42	2.14	.872	.134	1.87	2.41	1	4
	Grad/profess. degree	33	2.45	.905	.157	2.13	2.78	1	4
	high school	27	2.48	1.014	.195	2.08	2.88	1	5
	some college	32	2.38	.942	.166	2.04	2.71	1	5
	Total	134	2.34	.927	.080	2.18	2.50	1	5

Table 90. ANOVA-Individual MMS Question Mean Scores by Education Level.

Q_1_t41	Between Groups	15.444	4	3.861	2.967	.022
	Within Groups	170.490	131	1.301		
	Total	185.934	135			
Q_2_t42	Between Groups	9.754	4	2.439	1.788	.135
	Within Groups	180.012	132	1.364		
	Total	189.766	136			
Q_3_t43	Between Groups	4.935	4	1.234	.991	.415
	Within Groups	164.350	132	1.245		
	Total	169.285	136			
Q_4_t44	Between Groups	3.538	4	.885	.810	.521
	Within Groups	144.213	132	1.093		
	Total	147.752	136			
Q_5_t45	Between Groups	6.613	4	1.653	1.673	.160
	Within Groups	130.468	132	.988		

	Total	137.080	136			
Q_6_t46	Between Groups	3.425	4	.856	.765	.550
	Within Groups	147.757	132	1.119		
	Total	151.182	136			
Q_7_t47	Between Groups	11.319	4	2.830	2.518	.044
	Within Groups	148.360	132	1.124		
	Total	159.679	136			
Q_8_t48	Between Groups	3.061	4	.765	.623	.647
	Within Groups	160.822	131	1.228		
	Total	163.882	135			
Q_9_t49	Between Groups	3.312	4	.828	.928	.450
	Within Groups	117.812	132	.893		
	Total	121.124	136			
Q_10_t50	Between Groups	3.997	4	.999	.881	.478
	Within Groups	149.784	132	1.135		
	Total	153.781	136			
Q_11_t51	Between Groups	5.977	4	1.494	1.418	.231
	Within Groups	139.088	132	1.054		
	Total	145.066	136			
Q_12_t52	Between Groups	8.154	4	2.039	2.090	.086
	Within Groups	126.779	130	.975		
	Total	134.933	134			
Q_13_t53	Between Groups	3.063	4	.766	1.077	.371
	Within Groups	92.463	130	.711		
	Total	95.526	134			
Q_14_t54	Between Groups	2.165	4	.541	.964	.430
	Within Groups	72.432	129	.561		
	Total	74.597	133			
Q_15_t55	Between Groups	2.038	4	.510	.484	.748
	Within Groups	136.954	130	1.053		
	Total	138.993	134			
Q_16_t56	Between Groups	6.232	4	1.558	2.145	.079
	Within Groups	95.172	131	.727		
	Total	101.404	135			
Q_17_t57	Between Groups	2.761	4	.690	.804	.525
	Within Groups	111.565	130	.858		
	Total	114.326	134			

In terms of the respondent's education, there were statistically significant differences in mean scores on questions 1 (*you better be cautious when dealing with healthcare organizations*) and 7 (*The patient's medical needs come before other considerations at healthcare organizations*) of the Medical Mistrust Scale due to respondent's education. For question 1, respondents with a graduate/professional degree had the highest mean (3.09) and repondents with a high school diploma had the lowest mean (2.22). Interestingly enough, it was the opposite results for question 7. The respondents with the graduate/professional degree had the lowest mean (2.76) whereas respondents with a high school diploma had the highest mean (3.56).

Table 91. Results of MMS Question Means by Education Level.

Question 1	$F_{(4, 131)}=2.967$, p=.022
Question 2	$F_{(4, 132)}=1.788$, p=.135
Question 3	$F_{(4, 132)}=.991$, p=.415
Question 4	$F_{(4, 132)}=.810$, p=.521
Question 5	$F_{(4, 132)}=1.673$, p=.160
Question 6	$F_{(4, 132)}=.765$, p=.550
Question 7	$F_{(4, 132)}=2.518$, p=.044
Question 8	$F_{(4, 131)}=.623$, p=.647
Question 9	$F_{(4, 132)}=.928$, p=.450
Question 10	$F_{(4, 132)}=.881$, p=.478
Question 11	$F_{(4, 132)}=1.418$ p=.231
Question 12	$F_{(4, 130)}=2.090$, p=.086
Question 13	$F_{(4, 130)}=1.077$, p=.371
Question 14	$F_{(4, 129)}=.964$, p=.430
Question 15	$F_{(4, 130)}=.484$, p=.748
Question 16	$F_{(4, 131)}=2.145$, p=.079
Question 17	$F_{(4, 130)}=.804$, p=.525

Research Question 5: Are reported kidney transplant wait times (pre and post) associated with the recipients' predisposing characteristics (age, race, sex, educational achievement), enabling resources (insurance type, transplant center type, transplant center location and income level) or with their perceived discrimination or mistrust?

ANOVA-Comparing age and reported wait times both pre listing (time from diagnosis to getting waitlisted) and post listing (time from getting wait listed to receiving transplant)

Table 92. ANOVA-Descriptives Wait times by Age.

		N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
Pretime	21-35	24	10.25	24.168	4.933	.04	20.46	0	120
	35-44	27	16.26	17.995	3.463	9.14	23.38	0	72
	45-54	29	20.79	29.190	5.420	9.69	31.90	0	120
	55-64	37	22.43	53.794	8.844	4.50	40.37	0	324
	65 or ol	17	22.41	39.770	9.646	1.96	42.86	0	168
	Total	134	18.65	36.578	3.160	12.40	24.90	0	324
Posttime	21-35	24	28.92	28.556	5.829	16.86	40.97	0	100
	35-44	27	23.52	29.977	5.769	11.66	35.38	0	144
	45-54	29	28.86	43.966	8.164	12.14	45.59	0	168
	55-64	36	24.22	27.786	4.631	14.82	33.62	0	120
	65 or ol	14	32.00	45.037	12.037	6.00	58.00	0	168
	Total	130	26.82	34.188	2.998	20.88	32.75	0	168

Table 93. ANOVA-Wait times by Age.

		Sum of Squares	df	Mean Square	F	Sig.
Pretime	Between Groups	2750.872	4	687.718	.506	.731
	Within Groups	175193.643	129	1358.090		
	Total	177944.515	133			
Posttime	Between Groups	1139.325	4	284.831	.238	.916
	Within Groups	149634.245	125	1197.074		
	Total	150773.569	129			

In terms of the respondent's age, there were no statistically significant differences noted in pre or post-wait times. However, as you can see from Table 75, even though the participant's age group did not seem to have a significant effect on pre-wait times, the mean wait time does increase over the age groups. For instance, participants in the youngest age group reported waiting less on average than any other group. The youngest age group (21-34) reported waiting 6 months less than the next age group (35-44), 10 months less than the 45 to 54-year-old group

and 12 months less than the 55 to 64-year-old group. The data showed a positive relationship

between pre-wait times and the participants' age group. Important to note is that in the post-wait

time category did not show this wait time increase over age groups. In fact, the group with the

shortest reported wait time was the oldest age group of participants 65 years or older.

ANOVA-Comparing race and reported wait times both pre listing (time from diagnosis to getting waitlisted) and post listing (time from getting wait listed to receiving transplant)

Table 94. ANOVA-Descriptives Wait times by Race.

		N	Mean	SD	Std. Error	Lower Bound	Upper Bound	Minimum	Maximum
Pretime	Asian	6	15.83	17.577	7.176	-2.61	34.28	3	50
	Black	14	34.21	45.831	12.249	7.75	60.68	1	168
	Hispanic	5	15.00	15.000	6.708	-3.62	33.62	0	36
	Mixed	6	10.83	10.998	4.490	-.71	22.38	0	24
	White	102	17.38	37.694	3.732	9.98	24.79	0	324
	Total	133	18.70	36.711	3.183	12.40	25.00	0	324
Posttime	Asian	6	30.50	17.615	7.191	12.01	48.99	5	48
	Black	13	37.31	59.027	16.371	1.64	72.98	1	168
	Hispanic	5	26.60	19.995	8.942	1.77	51.43	12	60
	Mixed	6	14.83	12.336	5.036	1.89	27.78	0	28
	White	99	26.18	32.280	3.244	19.74	32.62	0	168
	Total	129	26.99	34.261	3.017	21.02	32.96	0	168

Table 95. ANOVA-Wait times by Race.

		Sum of Squares	df	Mean Square	F	Sig.
Pretime	Between Groups	4035.858	4	1008.964	.743	.565
	Within Groups	173864.112	128	1358.313		
	Total	177899.970	132			
Posttime	Between Groups	2409.962	4	602.491	.505	.732
	Within Groups	147839.030	124	1192.250		
	Total	150248.992	128			

In terms of the respondent's race, there were no statistically significant differences in pre or post-wait times. However, of note, during both the pre-wait time and the post-wait times, black patients reported waiting longer in both time frames. During the pre-wait times, black patients reported waiting an average of 16.8 months longer than white patients and close to 2 years longer than patients that identified as mixed race. During post-wait times, black patients reported waiting an average of 11.13 months longer than white patients.

ANOVA-Comparing respondent's sex and reported wait times both pre listing (time from diagnosis to getting waitlisted) and post listing (time from getting wait listed to receiving transplant)

Table 96. ANOVA-Descriptives Wait times by Sex.

		N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
Pretime	Male	30	16.27	18.903	3.451	9.21	23.32	0	93
	Female	104	19.34	40.310	3.953	11.50	27.18	0	324
	Total	134	18.65	36.578	3.160	12.40	24.90	0	324
Posttime	Male	30	19.20	21.246	3.879	11.27	27.13	0	72
	Female	100	29.10	36.985	3.698	21.76	36.44	0	168
	Total	130	26.82	34.188	2.998	20.88	32.75	0	168

Table 97. ANOVA-Wait times by Sex.

		Sum of Squares	df	Mean Square	F	Sig.
Pretime	Between Groups	219.427	1	219.427	.163	.687
	Within Groups	177725.088	132	1346.402		
	Total	177944.515	133			
Posttime	Between Groups	2261.769	1	2261.769	1.949	.165
	Within Groups	148511.800	128	1160.248		
	Total	150773.569	129			

In terms of the respondent's sex, there were no statistically significant differences in pre or post-wait times. However, of note, during the pre-wait time women reported waiting an average of 3 months longer than men. This gap becomes even larger during the post-wait time where women reported waiting an average of almost 10 months longer than men.

ANOVA-Comparing respondent's education level and reported wait times both pre listing (time from diagnosis to getting waitlisted) and post listing (time from getting wait listed to receiving transplant)

Table 98. ANOVA-Descriptives Wait times by Education Level.

		N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
Pretime	High School	42	13.43	17.801	2.747	7.88	18.98	0	78
	Some College	33	17.61	30.508	5.311	6.79	28.42	0	168
	College	27	26.41	64.380	12.390	.94	51.88	0	324
	Grad/profess. degree	31	20.29	28.560	5.130	9.81	30.77	0	120
	Total	133	18.70	36.711	3.183	12.40	25.00	0	324
Posttime	High School	42	18.76	21.769	3.359	11.98	25.55	0	84
	Some College	31	33.52	44.997	8.082	17.01	50.02	1	168
	College	25	33.32	42.998	8.600	15.57	51.07	0	168
	Grad/profess. degree	31	26.52	26.162	4.699	16.92	36.11	0	100
	Total	129	26.99	34.261	3.017	21.02	32.96	0	168

Table 99. ANOVA-Wait times by Education Level.

		Sum of Squares	df	Mean Square	F	Sig.
Pretime	Between Groups	2888.900	3	962.967	.710	.548
	Within Groups	175011.070	129	1356.675		
	Total	177899.970	132			
Posttime	Between Groups	5172.449	3	1724.150	1.486	.222
	Within Groups	145076.543	125	1160.612		
	Total	150248.992	128			

In terms of the respondent's educational level, there were no statistically significant differences in pre or post-wait times. Interestingly enough, it was identified in both the pre and post-wait times that patients with a college degree reported longer average wait times. During the pre-wait times, patients with a college degree reported waiting about a year longer than patients with a high school diploma. During post-wait times, patients with a college degree reported waiting, on average, about 15 months longer than those with a high school diploma.

ANOVA-Comparing respondent's income level and reported wait times both pre listing (time from diagnosis to getting waitlisted) and post listing (time from getting wait listed to receiving transplant).

Table 100. ANOVA-Descriptives Wait times by Income Level.

		N	Mean	SD	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
Pretime	< $15,000	10	13.40	10.157	3.212	6.13	20.67	3	36
	$15,000-$24,999	12	26.00	46.093	13.306	-3.29	55.29	0	168
	$25,000-$34,999	12	18.08	32.670	9.431	-2.67	38.84	3	120
	$35,000-$44,999	10	14.00	14.832	4.690	3.39	24.61	1	36
	$45,000-$54,999	7	56.86	118.921	44.948	-53.13	166.84	0	324
	$55,000-$64,999	14	26.71	31.099	8.312	8.76	44.67	0	93
	$65,000-$74,999	12	18.67	19.764	5.705	6.11	31.22	1	72
	$75,000-$84,999	6	28.50	31.760	12.966	-4.83	61.83	0	78
	$85,000-$94,999	35	5.97	5.623	.950	4.04	7.90	0	24
	> $95,000	13	21.38	32.528	9.022	1.73	41.04	3	120
	Total	131	18.76	36.913	3.225	12.38	25.14	0	324
Posttime	<$15,000	11	47.73	57.226	17.254	9.28	86.17	1	168
	$15,000-$24,999	12	28.75	47.826	13.806	-1.64	59.14	0	168
	$25,000-$34,999	12	32.08	49.074	14.166	.90	63.26	0	168
	$35,000-$44,999	8	17.00	16.767	5.928	2.98	31.02	2	54
	$45,000-$54,999	4	14.50	16.683	8.342	-12.05	41.05	0	38
	$55,000-$64,999	14	20.86	25.237	6.745	6.29	35.43	0	78
	$65,000-$74,999	12	14.17	17.246	4.978	3.21	25.12	1	54
	$75,000-$84,999	6	26.50	15.424	6.297	10.31	42.69	12	45
	$85,000-$94,999	34	23.29	30.440	5.220	12.67	33.92	0	120
	> $95,000	13	38.92	27.140	7.527	22.52	55.32	1	100
	Total	126	26.73	34.718	3.093	20.61	32.85	0	168

Table 101. ANOVA-Wait times by Income Level.

		Sum of Squares	df	Mean Square	F	Sig.
Pretime	Between Groups	18576.937	9	2064.104	1.575	.130
	Within Groups	158557.246	121	1310.390		
	Total	177134.183	130			
Posttime	Between Groups	11309.614	9	1256.624	1.046	.408
	Within Groups	139359.211	116	1201.373		
	Total	150668.825	125			

In terms of the respondent's income level, there were no statistically significant differences in pre or post-wait times.

ANOVA-Comparing Transplant Center Locations and reported wait times both pre listing (time from diagnosis to getting waitlisted) and post listing (time from getting wait listed to receiving transplant)

All assumption testing was completed and once all of the assumptions were addressed, the ANOVA was run for each location category. The responses for each location category were run by the respondent's reported pre and post-wait times and the results are shown in the table and graphs below.

Table 102. ANOVA-Descriptives Wait times by Transplant Center Location

		N	Mean	SD	SE	Lower Bound	Upper Bound	Min	Max
Pretime	Rural	9	15.89	22.217	7.406	-1.19	32.97	0	72
	Urban	93	19.22	28.619	2.968	13.32	25.11	0	168
	Suburban	25	21.28	63.584	12.717	-4.97	47.53	0	324
	Other	5	6.00	4.583	2.049	.31	11.69	1	13
	Total	132	18.88	36.808	3.204	12.54	25.22	0	324
Posttime	Rural	8	21.38	18.392	6.503	6.00	36.75	1	54
	Urban	92	29.96	38.029	3.965	22.08	37.83	0	168
	Suburban	23	15.39	18.923	3.946	7.21	23.57	0	60
	Other	5	34.80	31.862	14.249	-4.76	74.36	0	72
	Total	128	26.99	34.409	3.041	20.97	33.01	0	168

175

Table 103. ANOVA-Wait times by Transplant Center Location.

		Sum of Squares	df	Mean Square	F	Sig.
Pretime	Between Groups	1064.433	3	354.811	.257	.856
	Within Groups	176413.628	128	1378.231		
	Total	177478.061	131			
Posttime	Between Groups	4461.013	3	1487.004	1.264	.290
	Within Groups	145907.979	124	1176.677		
	Total	150368.992	127			

In terms of the transplant center location type, there were no statistically significant differences in pre or post-wait times.

ANOVA-Comparing Transplant Center Type and reported wait times both pre listing (time from diagnosis to getting waitlisted) and post listing (time from getting wait listed to receiving transplant)

All assumption testing was completed and once all of the assumptions had been addressed, the ANOVA was run for each transplant center category. The responses on the type of transplant center were run by the pre and post-wait times and the results are shown in the table and graphs below.

Table 104. ANOVA-Wait times by Transplant Center Type.

		Sum of Squares	df	Mean Square	F	Sig.
Pretime	Between Groups	6223.702	3	2074.567	1.561	.202
	Within Groups	171474.072	129	1329.256		
	Total	177697.774	132			
Posttime	Between Groups	200.127	3	66.709	.056	.983
	Within Groups	150136.803	125	1201.094		
	Total	150336.930	128			

In terms of the type of transplant center, there were no statistically significant differences in pre and post wait times between the transplant center types.

T-Tests with the Medical Mistrust Scale

In order to run t-tests on the pre and post wait times reported by the respondents, the wait times were broken up into two categories: more than two years and two years or less. The first three assumptions of the t-test: continuous variable, independent variable is categorical with two groups and there is independence of observations have already been discussed and met.

 Assumption #4

This assumption states that there should be no significant outliers. To test this, box plots were run to identify any outliers and to determine if these outliers are affecting the data set. The box plots for each category for each question are located in the Appendix.

The data was reviewed to ensure it was entered properly and it was noted that the answers to these questions due vary quite a bit amongst respondents, but the data was entered correctly. It was decided that the outliers will remain in the data set and the t-tests will be run with and without them to determine if they effect the analysis significantly or not.

Assumption #5

This assumption is regarding the dependent variable being approximately normally distributed (Laerd Statistics, 2019). To test for the normal distribution, the Shapiro-Wilk test of normality was completed. The results of this test for each variable is displayed in the Appendix.

There are some questions where the scores were normally distributed. The other areas do not indicate normal distribution, however the data will be run due to the "robust" nature of a t-test. "The assumption of normality is necessary for statistical significance testing using an independent-samples t-test. However, the independent-samples t-test is considered "robust" to

violations of normality. This means that some violation of this assumption can be tolerated and the test will still provide valid results" (Laerd Statistics, 2019, p.7)

<u>Assumption #6</u>

The t-test assumes homogeneity of variances and this assumption was tested using Levene's test of equality of variances to see if the variances between the groups for the dependent variable are equal (Laerd Statistics, 2019). The tables below show the results of this test.

<u>Pre-wait times</u>

There was homogeneity of variances, as assessed by Levene's test for equality of variances (p>.05) for all the questions on the scale as shown in the table below except for questions 3 (p=.011) and question 7 (p=.045).

Table 105. Pre-wait Time Levene's Test.

		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Q_1	Equal variances assumed	.134	.715	.266	131	.790	.034	.129	-.221	.290
	Equal variances not assumed			.253	28.622	.802	.034	.136	-.243	.312
Q_2	Equal variances assumed	.450	.504	-1.758	131	.081	-.359	.204	-.763	.045
	Equal variances not assumed			-1.658	28.419	.108	-.359	.217	-.803	.084
Q_3	Equal variances assumed	6.656	.011	-1.455	131	.148	-.314	.216	-.741	.113
	Equal variances not assumed			-1.236	26.345	.227	-.314	.254	-.836	.208
Q_4	Equal variances assumed	.318	.574	-.392	129	.696	-.061	.155	-.367	.246
	Equal variances not assumed			-.356	26.071	.725	-.061	.170	-.411	.290
Q_5	Equal variances assumed	.703	.403	.487	131	.627	.079	.162	-.242	.400
	Equal variances not assumed			.493	30.277	.626	.079	.160	-.248	.407
Q_6	Equal variances assumed	.375	.541	-.433	131	.666	-.066	.152	-.367	.235
	Equal variances not assumed			-.401	28.019	.691	-.066	.164	-.402	.271
Q_7	Equal variances assumed	4.104	.045	-1.261	131	.209	-.307	.244	-.789	.175
	Equal variances not assumed			-1.100	26.810	.281	-.307	.279	-.880	.266

T-test Results for Pre-Wait Times

The table below shows the results of the pre-wait time t-test. The results are displayed for each question on The Discrimination in Medical Settings Scale.

Table 106. Pre-Wait Time T-Test Results by Question on the DMS.

Question 1	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the pre-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .034$, $SE = 0.129$, $t(131) = .266$, $p = .790$
Question 2	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the shorter wait time groups $M = -.359$, $SE = 0.204$, $t(131) = -1.758$, $p = .081$
Question 3	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the shorter wait time groups $M = -.314$, $SE = 0.216$, $t(131) = -1.455$, $p = .148$
Question 4	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the shorter wait time groups $M = -.061$, $SE = .155$, $t(129) = -.392$, $p = .696$
Question 5	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the pre-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .079$, $SE = 0.162$, $t(131) = .487$, $p = .627$
Question 6	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the shorter wait time groups $M = -.066$, $SE = 0.152$, $t(131) = -.433$, $p = .666$
Question 7	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the shorter wait time groups $M = -.307$, $SE = 0.244$, $t(131) = -1.261$, $p = .209$

Post Wait Times

There was homogeneity of variances, as assessed by Levene's test for equality of variances (p>.05) for all the questions on the scale as shown in the table below except for questions 1 (p=.042), question 2 (p=.015) and question 5 (p=.015).

Table 107. Post-wait Time Levene's Test.

		F	Sig.	T	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Q_1	Equal variances assumed	4.239	.042	1.024	128	.308	.104	.102	-.097	.305
	Equal variances not assumed			1.099	116.015	.274	.104	.095	-.083	.292
Q_2	Equal variances assumed	6.022	.015	1.754	128	.082	.280	.159	-.036	.595
	Equal variances not assumed			1.848	110.961	.067	.280	.151	-.020	.580
Q_3	Equal variances assumed	1.312	.254	.829	128	.409	.143	.172	-.198	.484
	Equal variances not assumed			.844	100.743	.401	.143	.169	-.193	.478
Q_4	Equal variances assumed	1.122	.291	.646	126	.520	.078	.121	-.161	.317
	Equal variances not assumed			.653	96.440	.515	.078	.119	-.159	.315
Q_5	Equal variances assumed	6.101	.015	1.333	128	.185	.170	.127	-.082	.422
	Equal variances not assumed			1.437	117.217	.153	.170	.118	-.064	.404
Q_6	Equal variances assumed	1.266	.263	.643	128	.521	.079	.123	-.165	.323
	Equal variances not assumed			.661	103.516	.510	.079	.120	-.159	.317
Q_7	Equal variances assumed	.009	.925	1.291	128	.199	.250	.193	-.133	.632
	Equal variances not assumed			1.259	88.547	.211	.250	.198	-.145	.644

T-test Results for Post-Wait Times

The table below shows the results of the post-wait time t-test. The results are displayed for each question on The Discrimination in Medical Settings Scale.

Table 108. Post-Wait Time T-Test Results by Question on the DMS.

Question 1	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .104$, $SE = 0.102$, $t(128) = 1.024$, $p = .308$
Question 2	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .280$, $SE = 0.159$, $t(128) = 1.754$, $p = .082$
Question 3	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .143$, $SE = 0.172$, $t(128) = .829$, $p = .172$
Question 4	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .078$, $SE = 0.121$, $t(126) = .646$, $p = .520$
Question 5	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .170$, $SE = 0.127$, $t(128) = 1.333$, $p = .185$
Question 6	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .079$, $SE = 0.123$, $t(128) = .643$, $p = .123$
Question 7	There was not a statistically significant difference in scores on the Discrimination in Medical Settings Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .250$, $SE = 0.193$, $t(128) = 1.291$, $p = .199$

T-Tests of Pre and Post Wait Times with Mean Scores on the Medical Mistrust Scale

In order to run t-tests on the pre and post wait times reported by the respondents, the wait times were broken up into two categories: more than two years and two years or less. The first three assumptions of the t-test: continuous variable, independent variable is categorical with two groups and there is independence of observations have already been discussed and met.

Assumption #4

This assumption states that there should be no significant outliers. To test this, box plots were run to identify any outliers and to determine if these outliers are effecting the data set. The box plots for each category for each question are located in the Appendix.

When analyzing the box plots, some outliers were noted for pre and post times on specific questions on the Medical Mistrust Scale. The table below provides a list of the outliers for each wait time category.

Table 109. Medical Mistrust Scale Outliers.

	2 years or less	**More than 2 years**
Pre-time	4, 6, 9, 11, 13, 14, 16,17	7, 15
Post-time	3, 6, 7, 9, 12, 13, 17	4, 5, 6, 9, 11, 13, 14, 16, 17

This was assessed by inspection of the boxplot for values greater than 1.5 box-lengths from the edge of the box (Laerd Statistics, 2019). The data was reviewed to ensure it was entered properly and it was noted that the answers to these questions due vary quite a bit amongst respondents but the data was entered correctly. It was decided that the outliers will remain in the data set and the t-tests will be run with and without them to determine if they effect the analysis significantly or not.

This assumption is regarding the dependent variable being approximately normally distributed (Laerd Statistics, 2019). To test for the normal distribution, the Shapiro-Wilk test of normality was completed. The results of this test for each variable is displayed in the Appendix.

There are some questions where the scores were normally distributed. The other areas do not indicate normal distribution, however the data will be run due to the "robust" nature of a t-test. "The assumption of normality is necessary for statistical significance testing using an independent-samples t-test. However, the independent-samples t-test is considered "robust" to violations of normality. This means that some violation of this assumption can be tolerated and the test will still provide valid results" (Laerd Statistics, 2019, p.7)

Assumption #6

The t-test assumes homogeneity of variances and this assumption was tested using Levene's test of equality of variances to see if the variances between the groups for the dependent variable are equal (Laerd Statistics, 2019). The tables below show the results of this test.

Pre-wait times

There was homogeneity of variances, as assessed by Levene's test for equality of variances ($p>.05$) for all the questions on the scale as shown in the table below.

Table 110. MMS Pre-wait Time Levene's Test.

		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Q_1_t41	Equal variances assumed	.145	.704	-.058	131	.954	-.016	.274	-.558	.526
	Equal variances not assumed			-.059	30.345	.953	-.016	.270	-.567	.535
Q_2_t42	Equal variances assumed	2.913	.090	-.091	132	.928	-.025	.278	-.575	.524
	Equal variances not assumed			-.080	27.082	.937	-.025	.313	-.668	.617
Q_3_t43	Equal variances assumed	.001	.982	-.388	132	.699	-.101	.262	-.619	.416
	Equal variances not assumed			-.386	29.695	.702	-.101	.263	-.639	.436
Q_4_t44	Equal variances assumed	.207	.650	-.083	132	.934	-.020	.243	-.501	.461
	Equal variances not assumed			-.090	32.055	.929	-.020	.227	-.482	.441
Q_5_t45	Equal variances assumed	.802	.372	-.788	132	.432	-.183	.233	-.644	.277
	Equal variances not assumed			-.911	35.044	.368	-.183	.201	-.592	.225
Q_6_t46	Equal variances assumed	.973	.326	-1.077	132	.284	-.265	.247	-.753	.222
	Equal variances not assumed			-1.134	31.411	.265	-.265	.234	-.743	.212
Q_7_t47	Equal variances assumed	.661	.418	-.086	132	.931	-.022	.254	-.524	.480
	Equal variances not assumed			-.091	31.371	.928	-.022	.241	-.513	.470
Q_8_t48	Equal variances assumed	.010	.921	-.386	131	.700	-.100	.259	-.611	.412
	Equal variances not assumed			-.386	29.908	.702	-.100	.259	-.628	.429

		F	Sig.	t	df	Sig.	Mean Diff.	SE Diff.	Lower	Upper
Q_9_t49	Equal variances assumed	.660	.418	-.651	132	.516	-.142	.218	-.574	.289
	Equal variances not assumed			-.611	28.259	.546	-.142	.232	-.618	.334
Q_10_t50	Equal variances assumed	1.463	.229	-.350	132	.727	-.088	.250	-.583	.408
	Equal variances not assumed			-.305	26.736	.763	-.088	.288	-.678	.503
Q_11_t51	Equal variances assumed	.575	.450	-1.381	132	.170	-.332	.240	-.808	.144
	Equal variances not assumed			-1.448	31.260	.158	-.332	.229	-.800	.136
Q_12_t52	Equal variances assumed	2.080	.152	.756	130	.451	.179	.237	-.289	.647
	Equal variances not assumed			.884	33.223	.383	.179	.202	-.233	.591
Q_13_t53	Equal variances assumed	.829	.364	-2.140	130	.034	-.427	.200	-.822	-.032
	Equal variances not assumed			-2.296	30.068	.029	-.427	.186	-.807	-.047
Q_14_t54	Equal variances assumed	.801	.372	-1.003	129	.318	-.178	.177	-.529	.173
	Equal variances not assumed			-.903	25.927	.375	-.178	.197	-.583	.227
Q_15_t55	Equal variances assumed	.024	.876	1.131	130	.260	.264	.233	-.198	.725
	Equal variances not assumed			1.168	30.989	.252	.264	.226	-.197	.724
Q_16_t56	Equal variances assumed	.739	.391	1.130	131	.260	.230	.203	-.172	.632
	Equal variances not assumed			1.040	27.888	.307	.230	.221	-.223	.682
Q_17_t57	Equal variances assumed	5.527	.020	-1.282	130	.202	-.283	.221	-.720	.154
	Equal variances not assumed			-1.094	24.967	.284	-.283	.259	-.816	.250

T-test Results for Pre-Wait Times

The table below shows the results of the pre-wait time t-test. The results are displayed

for each question on The Medical Mistrust Scale.

Table 111. Pre-Wait Time T-Test Results by Question on the MMS.

Question 1	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.016$, $SE = 0.274$, $t(131) = -.058$, $p = .954$
Question 2	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.025$, $SE = 0.278$, $t(132) = -.091$, $p = .928$
Question 3	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.101$, $SE = 0.262$, $t(132) = -.0388$, $p = .699$
Question 4	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.020$, $SE = 0.243$, $t(132) = -.083$, $p = .934$
Question 5	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.183$, $SE = 0.233$, $t(132) = -.788$, $p = .432$
Question 6	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.265$, $SE = 0.247$, $t(132) = -1.077$, $p = .284$
Question 7	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.022$, $SE = 0.254$, $t(132) = -.086$, $p = .931$
Question 8	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.100$, $SE = 0.259$, $t(131) = -.386$, $p = .259$

Question 9	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.142$, $SE = 0.218$, $t(132) = -.651$, $p = .516$
Question 10	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.088$, $SE = 0.250$, $t(132) = -.350$, $p = .727$
Question 11	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.332$, $SE = 0.240$, $t(132) = -1.381$, $p = .170$
Question 12	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = -.179$, $SE = 0.237$, $t(130) = .756$, $p = .451$
Question 13	There was a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.427$, $SE = 0.200$, $t(130) = -2.140$, $p = .034$
Question 14	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.178$, $SE = 0.177$, $t(129) = -1.003$, $p = .318$
Question 15	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .264$, $SE = 0.233$, $t(130) = 1.131$, $p = .260$
Question 16	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .230$, $SE = 0.203$, $t(131) = 1.130$, $p = .260$
Question 17	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the pre-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.283$, $SE = 0.221$, $t(130) = -1.282$, $p = .202$

There was homogeneity of variances, as assessed by Levene's test for equality of variances (p>.05) for all the questions on the scale as shown in the table below

Table 112. Post-Wait Time Levene Test for MMS.

		F	Sig.	T	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Q_1	Equal variances assumed	.091	.764	-.823	127	.412	-.178	.216	-.606	.250
	Equal variances not assumed			-.825	93.660	.411	-.178	.216	-.607	.250
Q_2	Equal variances assumed	.011	.917	-.359	128	.720	-.078	.217	-.507	.351
	Equal variances not assumed			-.361	96.637	.719	-.078	.216	-.507	.351
Q_3	Equal variances assumed	.058	.810	-1.03	128	.305	-.208	.202	-.608	.191
	Equal variances not assumed			-1.02	93.933	.308	-.208	.203	-.611	.195
Q_4	Equal variances assumed	.544	.462	1.541	128	.126	.291	.189	-.083	.664
	Equal variances not assumed			1.595	105.711	.114	.291	.182	-.071	.653
Q_5	Equal variances assumed	.112	.739	-1.18	128	.237	-.214	.180	-.569	.142
	Equal variances not assumed			-1.20	99.690	.231	-.214	.177	-.565	.138
Q_6	Equal variances assumed	1.310	.254	-.220	128	.826	-.042	.192	-.422	.337
	Equal variances not assumed			-.227	104.163	.821	-.042	.186	-.412	.327
Q_7	Equal variances assumed	.203	.653	.513	128	.609	.101	.198	-.290	.492
	Equal variances not assumed			.506	91.848	.614	.101	.200	-.296	.499
Q_8	Equal variances assumed	.155	.695	-.461	127	.646	-.091	.198	-.482	.300
	Equal variances not assumed			-.458	94.128	.648	-.091	.199	-.486	.304
Q_9	Equal variances assumed	.307	.580	.073	128	.942	.013	.171	-.326	.351
	Equal variances not assumed			.074	97.224	.941	.013	.170	-.325	.350
Q_10	Equal variances assumed	.180	.672	1.482	128	.141	.286	.193	-.096	.667
	Equal variances not assumed			1.492	97.484	.139	.286	.192	-.094	.666
Q_11	Equal variances assumed	.725	.396	.250	128	.803	.047	.188	-.325	.419
	Equal variances not assumed			.239	83.463	.812	.047	.197	-.344	.438
Q_12	Equal variances assumed	.001	.981	-.764	126	.446	-.142	.186	-.509	.226
	Equal variances not assumed			-.757	93.548	.451	-.142	.187	-.514	.230
Q_13	Equal variances assumed	.120	.729	-.573	126	.568	-.090	.156	-.399	.220
	Equal variances not assumed			-.581	100.250	.563	-.090	.154	-.396	.216
Q_14	Equal variances assumed	3.633	.059	.041	126	.967	.006	.140	-.271	.282

	F	Sig.	t	df	Sig.	Mean Diff.	SE Diff.	Lower	Upper
Equal variances not assumed			.039	78.724	.969	.006	.149	-.291	.303
Q_15 Equal variances assumed	.028	.867	-.248	126	.805	-.046	.185	-.413	.321
Equal variances not assumed			-.246	93.759	.806	-.046	.187	-.417	.325
Q_16 Equal variances assumed	.005	.944	-.467	127	.641	-.074	.158	-.387	.239
Equal variances not assumed			-.460	91.543	.647	-.074	.161	-.393	.245
Q_17 Equal variances assumed	2.368	.126	-.751	126	.454	-.126	.168	-.458	.206
Equal variances not assumed			-.723	85.535	.472	-.126	.174	-.472	.220

T-test Results for Post-Wait Times

The table below shows the results of the post-wait time t-test. The results are displayed

for each question on The Medical Mistrust Scale.

Table 113. Post-Wait Time T-Test Results by Question on the MMS.

Question 1	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.178$, $SE = 0.216$, $t(127)$ $= -.823$, $p = .412$
Question 2	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.078$, $SE = 0.217$, $t(128)$ $= -.359$, $p = .720$
Question 3	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.208$, $SE = 0.202$, $t(128)$ $= -1.031$, $p = .305$
Question 4	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups $M = .291$, $SE = 0.189$, $t(128)$ $= 1.541$, $p = .126$
Question 5	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.214$, $SE = 0.180$, $t(128)$ $= -1.187$, $p = .237$

Question 6	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups M = -0.42, SE = 0.192, t(128) = -.220, p = .826
Question 7	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups M = .101, SE = 0.198, t(128) = .513 p = .609
Question 8	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups M = -.091, SE = 0.198, t(127) = -.461, p = .646
Question 9	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups M = .013, SE = 0.171, t(128) = .073, p = .942.
Question 10	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups M = -.286, SE = 0.193, t(128) = 1.482, p = .141
Question 11	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups M = -.047, SE = 0.188, t(128) = -.250, p = .803
Question 12	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups M = -.142, SE = 0.186, t(128) = .764, p = .446
Question 13	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups M = -.090, SE = 0.156, t(126) = -.573, p = .568
Question 14	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the shorter wait time groups scoring higher than the longer wait time groups M = .006, SE = 0.140, t(126) = .041, p = .967
Question 15	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups M =-.046, SE = 0.185, t(126) = -.248, p = .805

Question 16	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.074$, $SE = 0.158$, $t(127) = -.467$, $p = .641$
Question 17	There was not a statistically significant difference in scores on the Medical Mistrust Scale between the post-wait time groups, with the longer wait time groups scoring higher than the lower wait time groups $M = -.126$, $SE = 0.168$, $t(126) = -.751$, $p = .454$

Qualitative Analysis

In order to get a more nuanced dive into the research questions, ten in-depth interviews were conducted by phone with kidney transplant recipients. The researcher compiled a list of the respondents who provided their contact information and volunteered for an interview on the survey. As previously discussed, the sample for this study consisted of primarily white participants (77%). The original list of participants who agreed to be contacted for an interview consisted of 75 transplant recipients. Two of these participants were excluded as they had not fully completed the survey. Similar to the total sample, the interview sample was primarily white as well. Out of the 73 interview respondents remaining, seven identified as Black (9.6%), one identified as Middle Eastern (1.4%), five were Asian (6.8%) and three were Hispanic (4.1%) and the remaining 57 (78%) identified as White.

Based on the literature review and the theories chosen for this research, Fundamental Cause Theory and Critical Race Theory, the researcher attempted to contact all minority participants (16) who agreed to be called for an interview. Unfortunately, there were some participants who also had to be excluded from the interviews due to the inability to get into contact with them. One Black participant and one Hispanic participant did not provide a phone

number but rather only an email address which, when emailed came up as invalid therefore these participants could not be interviewed. One participant who identified as southeast Asian only provided an email and did not respond to the email to set up an interview. The last reason for exclusion was simply that multiple contact attempts were made and messages were left for the participants but no return phone call was received (one Asian participant and two black participants).

Therefore, the ten interviews were conducted with one Middle Eastern participant, three Asian participants, two Hispanic participants and four Black participants. As previously stated, these interviews were audio recorded, transcribed verbatim and coded by a team of two doctoral students. The content analysis began using open coding. Two coders began by independently reviewing the first two interview transcripts. The two coders went through the two interviews thoroughly identifying and noting all categories that emerged from each interview question. Once both interviews were reviewed, the two coders met and compared categories.

Any category that differed between the coders was discussed and a conclusion on which category to use was made. Subcategories were also identified within some of the categories. For example, under the category of discrimination, there were subcategories of no discrimination, subtle discrimination, ageism, and multifactorial discrimination. During the open coding stage, coders used relevant quotations from the interviews to add evidence of the category assigned. The researcher worked through the interviews until saturation of the themes was reached (Strauss & Corbin, 1990). As all of the interviews were being analyzed, fewer new categories emerged which indicated saturation. Below is the codebook which provides all of the identified codes, definitions and direct quotes from the interviews to depict each code. This information provides an in depth look into each interviewee's experience.

Code Book

Code	Definition	Evidence from the interviews
Communication	This includes any issues with regards to communication between the transplant center and patient.	*I have not really gotten any update if I am on the list or not but that is something I am working on *It is still challenging because again I do not know what is going on, they are not really up to date with telling me information about me being on the list *Sure um I was placed on the waiting list and I waited 7 years, I never got a single phone call, nothing *The lack of communication with the transplant center, always getting mixed up about which test I got, which test I need to get, which test I don't need to take and with the lack of communication and getting everything mixed up, the test I took expired so I had to go back and retake some of the tests *probably knowing what is going on, you know letting me know what is going on because I would like to know you know *they do not tell me anything * I think at the transplant center um they really rushed through the information like um when I got there for my consult I feel like they rushed.

		I mean she explained how the waitlist worked but you really have to kind of be proactive and do your own research because I just feel like they are so busy I feel like sometimes they rush through it
		*Communication made it all difficult because with the transplant center, you cannot just pop up there without an appointment so of course I was never going to drive an hour away to not be seen because I didn't have an appointment you know. So it was definitely hard with the lack of communication and then you know I didn't know that anyone could apply at any transplant center.
		*I still have no idea what I am doing, you know I still need help asking how to do I get on the list and how do I do this and how do I do that. And you know it is not new to me but it is challenging
Center Wait Times	This includes any information respondents provided about wait times in the transplant center.	*um I did Northwestern and their waittime is 5 to 10 years
		*Wisconsin's wait time is shorter and their waittime is 3 to 5 years
		*so the waittimes in Chicago are insane they are five to seven years I think. Um and then he said, and what I heard from different centers in Wisconsin I think on average is about two to

		three years but obviously it is just a different population, being from Chicago or New York or anything like that. And similarly in Iowa the waittimes were about 1 to 3 years.
Previous transplant	This includes information regarding participants who have received previous kidney transplants	*I received my kidney back in 2014 and it lasted me 4 ½ years *December will be 6 years, 2013 I got mine. I had 2 kidney transplants * They wanted to make sure that I was completely well, in the mental capacity to have another transplant, so the second transplant was in September 2017 so I was on dialysis for like 13 months.
Multi-listing	This includes any information regarding participants who listed on more than one transplant list at a time.	*I was on Madison's Waiting List and Freider's Waiting List and over here in Illinois I was on Northwestern's waiting List. I said I am going to list on all the transplant lists. I will go to Tampa General, I went to Gainesville, and I went to Miami, listed on all three *1st transplant I was on Michigan and Minnesota because my main doctors were at the Mayo Clinic in Minnesota and that is where I actually ended up having my transplant. 2nd transplant but I was waiting longer than that I was listed in two states, I was listed in Michigan and Ohio. And I actually got the call

		in Ohio three times however I was the backup each time so I never got, never got the opportunity to get the kidney then.
Personal wait times	Information about how long each participant was either on the wait list for or how long it took to get on the waitlist	*I was on the waiting list for about 3 ½ years and they actually added that time I was on dialysis they added that to the waiting points
		*I was placed on the waiting list and I waited 7 years. I was actually diagnosed 15 years before I received the transplant
		*I was part of the paired exchange so my husband donated on my behalf and we did the swap so I was on there maybe a year, maybe a year and ten months, a year and nine months.
		*My whole process from when I was diagnosed, I never even went on dialysis, but from the time I was diagnosed to the time I received my transplant was less than a year
		*I was on the list for 14 years Were you on dialysis that whole time? That whole time.
		*I was on dialysis for a little over a year. Just listed at the one center
		*Oh my goodness, it took a good couple of months, close to three months (to get on the wait list) cuz where I live. I had to travel an hour away to get the tests done

		*I was on dialysis for a little over 3 years, when I found a donor, from the time I found the donor to the time of the transplant it was about 5 months.
		*So the first one well I started, well mine is a little bit different because I was not in America when I was having kidney issues. So when I came to America I was waiting for dialysis and already I think after a couple of years I go on the list and then I waited for about 4 to 5 years before I got called for the transplant
		You waited how long for the second one?
		4 years because in 2007 I got the transplant *Yeah so the first one was 7 years ago in 2012 and I was on dialysis for 14 months and I was on the waiting list for shorter than that because I had gotten listed after I started dialysis
		*2nd time I knew prior to that that I was in kidney failure because I actually got listed, I got listed before I had dialysis this time around. So I was listed in February of 2016, I had a family friend had gotten tested and he was a match so we went ahead once we found out he was a match in I want to say July, we scheduled it for September
Compliance	Any information provided regarding compliance with medication, appointments, and medical regimen.	*I was a terrible patient to be honest and the reason I needed another transplant was because I was not compliant. With the medications, with follow ups, with taking care of it, with everything. I drank, i was just stupid then and this time. And actually while I was waitlisted, I was put on hold due to non-compliance as well

| Paired Exchange | Information participants' provided on group studies and paired exchange programs. | *I was the last person to receive a kidney out of the 4 families that were donating

*okay so there are four families and the first family donates to the second family, um the second family has a family member that can donate to the third family member that is waiting and the third family member donates their kidney to me so that they can get bumped up the list faster to receive a kidney

*Um I do not think (the experience was easy) because I was lucky actually because I waited only 3 ½ years and I actually received my kidney from a complete stranger through a group study

* I had a couple of people who would donate but I would never have thought that their kidney would have to be some sort of swap system

*They were like hey we are going to put you in a group study and you will get the call when we have a family that is going to donate a kidney to you. And that is when they called me and they were like, well fingers crossed you will get this kidney but if like the first, second or third family doesn't want to donate, then you will not have a kidney. Because if the first family member decided to not donate to the second family in need, then I wouldn't receive one |

Lack of Support	This includes information regarding when support was not available to the participant.	*when I first started on the list, yes I did (have support), now not so much, now it is just me dealing with it
		*I am dealing with it on my own, so I mean it is nothing new to me but it would be nice to have someone there you know
		*I thought maybe my family would be more involved, it was kind of, the family support was not what I thought it would be. Because there were some people who were against my husband donating and all the drama of that you, some people on my side they were just apprehensive about the whole thing.
		*Yeah you know that's true, that is true, this process opened my eyes to a lot. The people I thought would come through were the ones who disappeared.
Support System	Support from family	*my mom was by my side the first time I went through all of this, she was my rock and it was difficult for her, you know it was very emotional
		*My husband is always dependable but I was actually more worried about him donating um versus some of my other family members but it just worked out that he donated.
		*Family and friends
		*My family has been always around. Like in Minnesota when we moved it was just me and my sister I, my parents used to come back and forth from Dubai to here. You know because my dad

		had a business in Dubai so I used to live with my cousins in Minnesota, I have a few cousins. *Family support has always been there for me so I have never any issues about that *Family and friends *My wife would have to be the one I would say was my main support.
	Support from friends	*I also had a friend, a friend of 30 years and mother or my godson who offered to donate and she flew all the way from Virginia to have her testing done. but that didn't work out. But that was very heartwarming to have her do that *I have my best friend who would like to donate her kidney to me *Yeah so I have my best friend *Um honestly a lot of the people we were friends with came through, We have a lot of friends *A lot of friends and friends of friends helped us more than our own family
	Support from online support groups	*the people in the support groups on Facebook, they been through it, they really helped too, they answered questions sometimes better than the doctors (laughter). Yeah I think that was my best resource.

		*Like you know my husband he donated and he had his own separate group and he was able to ask them a bunch of questions and you know that I couldn't answer or that the doctor couldn't answer really or like truthfully I would say
		*the people I least expected were so sweet to us, so loving to us and it was just amazing
	Support from the healthcare team	*I had a nurse who drove up all the way from Miami it was on a Saturday or whenever she could to come give me the IVIG medicaition
		*The nurses were actually very helpful.
		*I really um I really liked my pretransplant nurse coordinator um she just like every time she called me and told me about the possibility of the kidney maybe there being a kidney for me, it was like one of my family members was calling me. She was just as excited as my mom was. * I really had some awesome people on my medical team that were just like super helpful and always there to answer questions and whatnot.
		*Yes definitely so I would say the nurse coordinator for sure
		*Also the transplant RN, Brittany, I remember her name because she went above and beyond and she did not need to. Post transplant I was not feeling well and I could not keep any food down. She saw me in the office and gave me some of

		her own soup that she was planning on having for lunch. She waited with me to make sure I was able to keep the soup down before having me leave the office.
Discrimination	Responses that indicate no discrimination	*there was no overt discrimination that I can think of

*No, no not at all
*No only for being a bad patient but it was warranted (laughter) |
| | Responses that indicate little, very subtle discrimination | Well I started the process when I was about 58 and as I got closer and closer to 65, I kept making sure my team knew I was still working. And I worked up until the day before my transplant and I had a sense, and they may be totally in my head, but I had a sense that since I was still contributing to society, I was working and paying taxes, and this may have given me a slight edge over somebody who didn't do those things or who couldn't work. Well that could be all in my head

*Um yes and no, I would say that a lot of times they dismiss your concerns and that just urks me, like if you have a concern, they just dismiss it or they compare you to the whole group.

So that would be my only thing and I think sometimes too since I am a nurse, sometimes they I do not know, sometimes they get irritated if you have a lot of questions and I think this just gets passed over |

| | Statements about being treated differently due to insurance or income | *Right you could start that process (early). The doctors are funny about who they tell, if you got good insurance, then they will let you know and if you have VA or if you are a veteran or if you are a business person, someone with a lot of money, they are going to let you know, you cant avoid a transplant and they start doing the tests. So as soon as you get close, you get on the list, you can get a transplant and avoid dialysis. *But there are people that they say oh well, you have to be on Medicaid or Medicare for at least a year or year and a half before you can do anything. Well who is in charge and who is the one decided which people get on the list, not get on the list, you know insurance company, the doctors you know and it is not fair. *Now they are saying you got to have at least 3,500 in the bank and you got to show it. You gotta show it. And that is crazy and you know the thing about it is they tell you that you gonna have to be able to afford these drugs, well you know some people are, some people don't but you know it is just crazy. For them to make you say you need to have this money in the back |
| | Ageism Statements where participants felt discriminated by age | *Well no not really but I felt like because I was so young they just were like "oh you just got to make sure you take your meds" and they just kept |

		constantly repeating themselves, "take your meds", take your meds"
		*I will remember this, you do not have to tell me everytime, all the time, you know so that I felt like because I was young they were like oh gotta do this, you gotta do that, and I was like okay I will. You don't have to worry I will take my meds on time you don't have to remind me and I was doing good
		*Yeah, Yeah and I just feel like because I am young, they don't want to tell me some things and I get upset so I start snapping on them and they get all upset but I wouldn't be snapping on them if they would just tell me what is going on
	Multifactorial discrimination Statements indicating discrimination across many factors	*Those kidneys are going to waste and there are people who need um but you cant get um because your transplant center is already discriminating against you because maybe you are an African American, you have Medicare, you cant afford your 20% and plus you need to have your 3-5,000 dollars in the bank. Then you gotta go fundraise
Changes to Make Waitlist Process Easier	No changes	*No no I personally did not run into any issues at all so no.
	Response regarding better education as a change to the waitlist process	*With the waitlist I would say more research I guess because I realize now there are different regions um that have different wait times and maybe I could have went to a different state where

		I have family, you know. I think they just don't really talk about that very much like if you live in a certain region. Cause I guess on the East Coast the times might be long and maybe if you do have finances or family in another state, I think they should talk more to that and maybe you could go somewhere else and get listed faster besides just going to another hospital in your region, you could go outside of your region
	Responses regarding changes needed when a patient gets a call for a transplant	*I was offered a kidney three times, one was a cadaver um it wasn't a complete match, um I went all the way up to Madison they took my blood, I spent the whole night there and the next morning they were like, I am sorry it is not a 100% match, so I was crushed you know, heartbroken *the second time, a few months later, they called me up and was like um we have a kidney for you and at the time I had a common cold and I told them I was sick and they were like oh well then we cant give you this kidney if you are sick because we need you to be 100% healthy so I was kind of bummed out about that and then the third call was the group study call.
	Reponses related to financial issues in the process.	Well like I said before, if I had the right insurance, we would not have had to raise any of the money.

Post-Transplant	Information regarding side effects post-transplant	*Oh yeah because now I have diarrhea from one of the meds, I have lower back pain which is another side effect of one of the meds, and I am so tired, even more tired than I was before
	Information about feelings post-transplant	*Absolutely. In fact, my health is worse than before transplant. * So yeah transplant did not improve my life, it worsened it. * what I have done is I have exchanged length of life for quality of life. *I didn't feel badly. The only symptom I had was that towards the end I was feeling more tired. *Transplant is not and easy thing you know because you have to take so many pills and stuff like that
Obstacles	Information about obstacles endured in the waitlist process.	Just the travel. You know people that live in rural areas like that could be an issue but for me, it was not since for both transplants I had them near my home, even Toledo was only about an hour away so had I got a call and had to be there in under 2 hours, I could have done it. * when I got ready to get onto the transplant list, they said you know you gotta lose weight and all of that sort of thing and I said ok no problem *It was me and my medical issues that caused obstacles

		*Well we were notified that I was placed as inactive on the list because with my insurance, there was concern that I could not afford the medications if I did get a transplant. Well first of all, I had Medicare insurance and I thought I also had Medicaid but there was some kind of issue where the Medicaid was terminated. I called and spoke with many people at Medicaid but there was no quick fix for the problem so we had to fundraise and we were told we needed $5000 in the account to get back to active status
Advice for New Patients	Information respondents provided as advice for new kidney patients	*Do it as soon as possible, because you never know if they get you on or not and then you are sitting there wasting your time doing treatment and that is just like am I on the list for a kidney because that would be great and if not what can we do
		*I would just recommend that people try one or more transplant centers because when I went to the second one, they were more thorough than the first place that I went to so I think that helped hearing the information again from a different transplant center.
		*Yeah, yeah I feel really bad about the people who cannot get on the list because I have heard a lot of people who say they financially they cannot do it or they do not feel they have the support to

do it. You know because they find dialysis is too hard

*I would try to get on (the list) even if you have reservations with it, whether it be financial or support, because I know at the dialysis center there were a couple of people who choose not to get on the transplant list and from the ones that I do talk to they said it was because of their age, or maybe they did not have enough support or you need all this financial money to get on the list, um I think you should get on just in case and not be so reserved about it but I think that comes with education too

*Oh yeah copies of everything. And multiple lists. Yeah I am always telling people to get on many lists, I tell them about the new centers in Largo, there is one in Orlando, you got Shands, you got Tampa General and I think they just opened a new one in Ft. Myers.

*Do your yearly tests, your heart stress tests, etc. The communication breaks down. Are you doing your physicals, for a woman you have to do your breast tests, your pap smears, they don't care if you have had a hysterectomy or not, they still want you to do it every year

*Right and then another thing that people don't know is that if you are at a 3.5 creatinine, or

		predialysis, CKD, you should automatically start going onto the transplant list.
		*Definitely do your research and do not limit to just one hopefully you have a good support team but definitely do your research, there are a lot of things out there that they will not tell you.
		*Um yeah follow all the rules, do everything they tell you. I mean it is a process, be patient. There is a lot that they need but there is a reason for everything that the doctors and the medical staff need so I would just say be patient and do whatever you need to do to get onto that waitlist
	Information on the importance of maintaining a positive outlook.	*there are a lot of people that are reading and they are so depressed about dialysis and stuff like that. If they are going to be that way you know it is going to be hard for them so it is better to just be positive
		*from age 16 I was on dialysis and I been through all that so I mean people need to be positive, stop being depressed about it if you not getting a transplant you know, hopefully some day your day will come
		*It is just a state of your mind, you know, that is how I look at it you know ok I have many other medical conditions, you know, but things could be worse you know

Ways to Improve the Waitlist Process	Wait times Statements identifying shorter wait times as the way to improve the process	*Um yeah wishing the waiting time is less instead of years because there is a lot of people who need organs, you know, there are people dying every day waiting *Finding a way to shorten waittimes would obviously be ideal. This would help in so many ways.
	Quality of Life Statements identifying ways to improve quality of life as a way to make wait listing more bearable.	*being on the machine 3 days out the week for 3 ½ hours it is tough, its draining, it is exhausting and you know people just want to live their life as normal as they can but we cant because we are on a machine *I can tell a difference, my heart was so weak before the transplant, I mean like even now, I still get short of breath but it is so much better than when I was in dialysis and before it was hard to even walk a little bit. *Right, it gives you back some quality of life It is a different way, definitely not the same life, there are side effects which I feel they do not discuss that either I think of transplant. You might think it is a cure all but it is definitely a new life, you will not go exactly back to your old life but I think they not prepare me for that, just knowing that your life is still changing, you will

		not be completely back to where you were, but just know it is going to be a new life.
		*Yeah, I think this was kind of heart breaking for me in the beginning, I was like oh, this was not what I expected. I wanted to be back to my old self.
	Communication/Education Statements identifying ways to improve communication and education as a way to improve the wait list process	*Communication most definitely and a more fair and equal system. Also more education like I try my best to educate in my group and in the community but many people do not know what is out there.
		*They just need to be better with the communication because I probably would have been on the waitlist a lot sooner if the communication was there to where the tests didn't expire
		*I did not even know that some of my tests had expired until my kidney transplant date was set so basically like 4 days before my transplant I am running around and trying to get my tests done rather than just waiting for my transplant.
		* Also education and information could be improved. The communication could be improved as well
	Outlook	*So so I mean it is emotional and it is tiring but I take it day by day and I have to be positive through life

| | Statements identifying ways to improve patient's outlook as a way to improve wait listing. | *So I mean, I do not take life for granted so I have to live life positive and just gotta believe that there is going to be good out there eventually, hopefully

 *Yeah and then when I go to dialysis I see the grumpy old people and they are like "I need this" "I need that" and I am just like why cant you just be thankful that you are still here

 *And they both told me, you just wait, the minute you wake up from your transplant you are going to feel 100% better, it is such a wonderful feeling, all of a sudden you feel healthy again |

The categories for the codebook were originally organized by the interview question they coincided with but once the categories were reviewed, it was noted that there were categories that overlapped. The categories were reorganized and categories that were the same were combined together. For example, a common theme amongst the interview questions was issues with communication. Many interviewees mentioned how difficult the lack of communication was for their waitlist process across many of the questions asked. The categories are discussed in detail below.

Communication

Many interviewees expressed how they would not even know what tests they needed, if they needed to complete anything else, and some even stated that they were not sure if they were

on the list at all. One participant stated "It is still challenging because again I do not know what is going on, they are not really up to date with telling me information about me being on the list", while another stated "I have not really gotten any update if I am on the list or not but that is something I am working on". Another interviewee who has been trying to get onto the list stated, "I still have no idea what I am doing, you know I still need help asking how to do I get on the list and how do I do this and how do I do that. And you know it is not new to me but it is challenging". One interviewee even shared that "Sure um I was placed on the waiting list and I waited 7 years, I never got a single phone call, nothing". Interviewees expressed communication as being an area of concern and an area they hope will improve in the future.

Center Wait Times

Interviewees discussed variations in wait times across centers which caused some interviewees to list at centers further from their home due to the wait time being less. "So the waittimes in Chicago are insane they are five to seven years I think. Um and then he said, and what I heard from different centers in Wisconsin I think on average is about two to three years but obviously it is just a different population, being from Chicago or New York or anything like that. And similarly in Iowa the wait times were about 1 to 3 years." One interviewee stated that "Wisconsin's wait time is shorter and their waittime is 3 to 5 years". Due to wait time differences and other differences across transplant centers, some transplant recipients waitlisted at multiple centers rather than just one in hopes of bettering their chances of receiving a transplant.

Multi-listing

Some transplant recipients were able to list in multiple transplant centers. One

interviewee shared "I was on Madison's Waiting List and Freider's Waiting List and over here in

Illinois I was on Northwestern's waiting List. I said I am going to list on all the transplant lists. I

will go to Tampa General, I went to Gainesville, and I went to Miami, listed on all three".

Another interviewee had to be waitlisted on two separate occasions and shared that their "1st

transplant I was on Michigan and Minnesota because my main doctors were at the Mayo

Clinic in Minnesota and that is where I actually ended up having my transplant. 2nd transplant

but I was waiting longer than that I was listed in two states, I was listed in Michigan and Ohio.

And I actually got the call in Ohio three times however I was the backup each time so I never

got, never got the opportunity to get the kidney then." Other interviewees also shared that they

had to navigate the transplant process more than once due to kidney failure.

Previous Transplant

As discussed from the literature, a kidney transplant may not last long enough for the

recipient therefore these patients will find themselves back on dialysis and working to get back

onto the waitlist. One interviewee shared about how long their transplant lasted "I received my

kidney back in 2014 and it lasted me 4 ½ years" whereas another interviewee shared "December

will be 6 years, 2013 I got mine. I had 2 kidney transplants". Participants shared how long their

personal wait times were as well. "Yeah so the first one was 7 years ago in 2012

and I was on dialysis for 14 months and I was on the waiting list for shorter than that because I

had gotten listed after I started dialysis. Second time I knew prior to that that I was in kidney

failure because I actually got listed, I got listed before I had dialysis this time around. So I was listed in February of 2016, I had a family friend had gotten tested and he was a match so we went ahead once we found out he was a match in I want to say July, we scheduled it for September".

Personal Wait Times

The variations in waittimes just amongst the ten interviewees was eye opening. One person shared "I was on the waiting list for about 3 ½ years and they actually added that time I was on dialysis they added that to the waiting points". Another interviewee shared she had many medical issues throughout the process and she stated "I was on the list for 14 years" and she shared that she was indeed on dialysis that entire time. Another patient shared that she was aware of her kidney disease early on and stated "I was placed on the waiting list and I waited 7 years. I was actually diagnosed 15 years before I received the transplant". Others had shorter wait times and shared "I was on dialysis for a little over a year. Just listed at the one center" and "My whole process from when I was diagnosed, I never even went on dialysis, but from the time I was diagnosed to the time I received my transplant was less than a year". One interview had a unique story as "the first one well I started, well mine is a little bit different because I was not in America when I was having kidney issues. So when I came to America I was waiting for dialysis and already I think after a couple of years I go on the list and then I waited for about 4 to 5 years before I got called for the transplant. With the second transplant he waited "4 years because in 2007 I got the transplant". Some patients shared their experience receiving a kidney through the shared exchange program which was developed to encourage more live donation and in turn hopefully less wait time.

216

Paired Exchange

The paired exchanged program is designed to help patients in need of a transplant that have someone who is willing to donate their kidney to them but may not necessarily be compatible for them. This program "gives the candidate another option. In kidney paired donation, living donor kidneys are swapped so each recipient receives a compatible transplant" (UNOS, 2019, para 1). One interviewee explains their experience with this program. "Okay so there are four families and the first family donates to the second family, um the second family has a family member that can donate to the third family member that is waiting and the third family member donates their kidney to me so that they can get bumped up the list faster to receive a kidney". One patient explained how they felt lucky for this program, " Um I do not think (the experience was easy) because I was lucky actually because I waited only 3 ½ years and I actually received my kidney from a complete stranger through a group study". Having support during this difficult process was identified as important by many interviewees.

Some respondents expressed how difficult it was when they would get a call that a kidney was available and they would get all the way to the hospital to find out that it wasn't a match for them. "I was offered a kidney three times, one was a cadaver um it wasn't a complete match, um I went all the way up to Madison they took my blood, I spent the whole night there and the next morning they were like, I am sorry it is not a 100% match, so I was crushed you know, heartbroken". Another interviewee experienced similar difficulties in the paired exchange program, "the second time, a few months later, they called me up and was like um we have a kidney for you and at the time I had a common cold and I told them I was sick and they were like

oh well then we cant give you this kidney if you are sick because we need you to be 100% healthy so I was kind of bummed out about that and then the third call was the group study call".

Social Support

Many interviewees identified their family as an important part of their support system. "My family has been always around. Like in Minnesota when we moved it was just me and my sister I, my parents used to come back and forth from Dubai to here. You know because my dad had a business in Dubai so I used to live with my cousins in Minnesota, I have a few cousins". One interviewed stated that "my mom was by my side the first time I went through all of this, she was my rock and it was difficult for her, you know it was very emotional". "Family support has always been there for me so I have never any issues about that".

Many interviewees also discussed having their friends as part of their support team. "I also had a friend, a friend of 30 years and mother or my godson who offered to donate and she flew all the way from Virginia to have her testing done. but that didn't work out. But that was very heartwarming to have her do that". Some even stated that they found friends to be more supportive than their own family. "A lot of friends and friends of friends helped us more than our own family". "Um honestly a lot of the people we were friends with came through, We have a lot of friends".

Online support groups were also mentioned as providing a networking of transplant recipients who provide information from their own experiences that has been helpful. " the people in the support groups on Facebook, they been through it, they really helped too, they answered questions sometimes better than the doctors (laughter). Yeah I think that was my best

resource." One interviewee even expressed how she felt supported from and online support group and her husband, who donated to her, was also able to find support from a separate online support group. "Like you know my husband he donated and he had his own separate group and he was able to ask them a bunch of questions and you know that I couldn't answer or that the doctor couldn't answer really or like truthfully I would say".

The last subcategory of support is that of support from the healthcare team. Nurses were mentioned often as an important component to the support network. "I had a nurse who drove up all the way from Miami it was on a Saturday or whenever she could to come give me the IVIG medication". "I really um I really liked my pretransplant nurse coordinator um she just like every time she called me and told me about the possibility of the kidney maybe there being a kidney for me, it was like one of my family members was calling me. She was just as excited as my mom was". "Also the transplant RN, Brittany, I remember her name because she went above and beyond and she did not need to. Post transplant I was not feeling well and I could not keep any food down. She saw me in the office and gave me some of her own soup that she was planning on having for lunch. She waited with me to make sure I was able to keep the soup down before having me leave the office."

Discrimination

When asked if the recipient felt discriminated against in any aspect of the waitlist process, some interviewees stated they felt little or no discrimination, "there was no overt discrimination that I can think of". Some shared discrimination based on insurance or income level. "The doctors are funny about who they tell, if you got good insurance, then they will let

you know and if you have VA or if you are a veteran or if you are a business person, someone with a lot of money, they are going to let you know, you can't avoid a transplant and they start doing the tests". "Now they are saying you got to have at least 3,500 in the bank and you got to show it. You gotta show it. And that is crazy and you know the thing about it is they tell you that you gonna have to be able to afford these drugs, well you know some people are, some people don't but you know it is just crazy. For them to make you say you need to have this money in the back". Some interviewees expressed discrimination due to their young age, "I will remember this, you do not have to tell me every time, all the time, you know so that I felt like because I was young they were like oh gotta do this, you gotta do that, and I was like okay I will. You don't have to worry I will take my meds on time you don't have to remind me and I was doing good". "Yeah, Yeah and I just feel like because I am young, they don't want to tell me some things and I get upset so I start snapping on them and they get all upset but I wouldn't be snapping on them if they would just tell me what is going on".

Much like the discussion of discrimination based on insurance and income level, one interviewee discussed her frustration with multi-factorial discrimination. "Those kidneys are going to waste and there are people who need um but you cant get um because your transplant center is already discriminating against you because maybe you are an African American, you have Medicare, you can't afford your 20% and plus you need to have your 3-5,000 dollars in the bank. Then you gotta go fundraise".

When asked about ways to improve the waitlist process and to ways to make it easier for recipients, interviewees identified better education, better communication, better response system, shorter wait times, improve quality of life, help improve patient outlook, and better system not based on access to insurance. One interviewee stated that they felt that financial areas need to be improved, "if I had the right insurance, we would not have had to raise any of the money."

Better Education and Communication

An interviewee expressed how she felt she could have been better educated on the ability to waitlist at different and multiple locations. "I guess on the East Coast the times might be long and maybe if you do have finances or family in another state, I think they should talk more to that and maybe you could go somewhere else and get listed faster besides just going to another hospital in your region, you could go outside of your region". Many interviewees shared the same concern regarding communication issues within the centers. "Communication most definitely and a more fair and equal system. Also more education like I try my best to educate in my group and in the community but many people do not know what is out there." One interviewee explained that "They just need to be better with the communication because I probably would have been on the waitlist a lot sooner if the communication was there to where the tests didn't expire". Another shared a similar feeling stating" I did not even know that some of my tests had expired until my kidney transplant date was set so basically like 4 days before

my transplant I am running around and trying to get my tests done rather than just waiting for my transplant".

Shorter Wait Times

Many interviewees stated that they wished wait times were shorter. "Yeah wishing the waiting time is less instead of years because there is a lot of people who need organs, you know, there are people dying every day waiting". One interviewee stated that "finding a way to shorten waittimes would obviously be ideal. This would help in so many ways."

Quality of Life/Maintaining a Positive Outlook

While trying to get onto the wait list and even once on the wait list, awaiting a kidney, patients are typically enduring dialysis treatments to stay alive. Some expressed how " being on the machine 3 days out the week for 3 ½ hours it is tough, its draining, it is exhausting and you know people just want to live their life as normal as they can but we cant because we are on a machine". One interviewee even expressed how quality of life post-transplant was still not what they expected. "It gives you back some quality of life. It is a different way, definitely not the same life, there are side effects which I feel they do not discuss that either I think of transplant. You might think it is a cure all but it is definitely a new life, you will not go exactly back to your old life but I think they not prepare me for that, just knowing that your life is still changing, you will not be completely back to where you were, but just know it is going to be a new life." "I can tell a difference, my heart was so weak before the transplant, I mean like even now, I still get

short of breath but it is so much better than when I was in dialysis and before it was hard to even walk a little bit."

One interviewee in particular focused a great deal on people keeping a positive outlook as a way to cope and make it through the hardships. "So I mean it is emotional and it is tiring but I take it day by day and I have to be positive through life." "I mean, I do not take life for granted so I have to live life positive and just gotta believe that there is going to be good out there eventually, hopefully". Another stated "there are a lot of people that are reading and they are so depressed about dialysis and stuff like that. If they are going to be that way you know it is going to be hard for them so it is better to just be positive". One interviewee expressed frustration with other people's outlooks in his dialysis center, "Yeah and then when I go to dialysis I see the grumpy old people and they are like "I need this, I need that" and I am just like why can't you just be thankful that you are still here". One interviewee provided advice about this, " from age 16, I was on dialysis and I been through all that so I mean people need to be positive, stop being depressed about it if you not getting a transplant you know, hopefully some day your day will come"

Obstacles

When asked about obstacles, interviewees expressed "just the travel. You know people that live in rural areas like that could be an issue but for me, it was not since for both transplants I had them near my home, even Toledo was only about an hour away so had I got a call and had to be there in under 2 hours, I could have done it." Another recipient stated that " when I got ready to get onto the transplant list, they said you know you gotta lose weight and all of that sort

223

of thing and I said ok no problem". Another discussed how insurance was an obstacle for them, "well we were notified that I was placed as inactive on the list because with my insurance, there was concern that I could not afford the medications if I did get a transplant. Well first of all, I had Medicare insurance and I thought I also had Medicaid but there was some kind of issue where the Medicaid was terminated. I called and spoke with many people at Medicaid but there was no quick fix for the problem so we had to fundraise and we were told we needed $5000 in the account to get back to active status". Based on their experience, interviewees were also asked to provide advice they would give to new patients going through the transplant experience.

Advice

One bit of advice given was to "do it as soon as possible, because you never know if they get you on or not and then you are sitting there wasting your time doing treatment and that is just like am I on the list for a kidney because that would be great and if not what can we do". Another interviewee discussed multi-listing, "I would just recommend that people try one or more transplant centers because when I went to the second one, they were more thorough than the first place that I went to so I think that helped hearing the information again from a different transplant center." One interviewee shared that they " would try to get on (the list) even if you have reservations with it, whether it be financial or support, because I know at the dialysis center there were a couple of people who choose not to get on the transplant list and from the ones that I do talk to they said it was because of their age, or maybe they did not have enough support or you need all this financial money to get on the list, um I think you should get on just in case and not be so reserved about it but I think that comes with education too".

Another interviewee had advice for new patients regarding how to advocate for themselves throughout the evaluation process. "Oh yeah copies of everything. And multiple lists. Yeah I am always telling people to get on many lists, I tell them about the new centers in Largo, there is one in Orlando, you got Shands, you got Tampa General and I think they just opened a new one in Ft. Myers." As far as the evaluation testing, an interviewee advised to "do your yearly tests, your heart stress tests, etc. The communication breaks down. Are you doing your physicals, for a woman you have to do your breast tests, your pap smears, they don't care if you have had a hysterectomy or not, they still want you to do it every year". Per the interviews, new patients should "follow all the rules, do everything they tell you. I mean it is a process, be patient. There is a lot that they need but there is a reason for everything that the doctors and the medical staff need so I would just say be patient and do whatever you need to do to get onto that waitlist". Lastly the advice given was to encourage new patients to do their research, "follow all the rules, do everything they tell you. I mean it is a process, be patient. There is a lot that they need but there is a reason for everything that the doctors and the medical staff need so I would just say be patient and do whatever you need to do to get onto that waitlist".

Post-Transplant Education

Lastly, interviewees discussed how they felt more information could have been provided about what to expect post-transplant. Some recipients stated they expected to feel great post-transplant but some expressed the difficulties of not being educated on some of the side effects of the medication. One interviewee stated that they wish they had known because "now I have diarrhea from one of the meds, I have lower back pain which is another side effect of one of the

meds, and I am so tired, even more tired than I was before". Some people even expressed that they felt worse post-transplant. "So yeah transplant did not improve my life, it worsened it." "Absolutely. In fact, my health is worse than before transplant". Lastly an interviewee provided advice about the difficulties post-transplant, "Transplant is not an easy thing you know because you have to take so many pills and stuff like that".

The information provided from the interviews provides insight into each individual's experience which is an important piece of understanding the patient's wait list experience. More qualitative research in this field can add valuable information to the literature.

Results of Hypothesis Testing

H1a-Respondents will report that they perceive their race/ethnicity as important in the process of getting waitlisted.

The majority of the survey respondents indicated that they strongly disagreed that their race or ethnicity had a negative effect on their waitlist experience. Out of the total number of respondents, 62% stated they strongly disagreed that their race had a negative effect on their waitlist process and 61.3% stated the same for their ethnicity. Only one respondent reported that they strongly agreed that their race had a negative effect on their wait list experience.

H1b- Respondents will report that they perceive their age as important in the process of getting waitlisted.

More than half of the survey respondents indicated that they strongly disagreed that their age had a negative effect on their waitlist experience. Out of the total number of respondents,

56.2% stated they strongly disagreed that their age had a negative effect on their waitlist process. Only two strongly agreed that their age had a negative effect on their wait list experience.

H1c- Respondents will report that they perceive their sex as important in the process of getting waitlisted.

Many of the survey respondents indicated that they strongly disagreed that their sex had a negative effect on their waitlist experience. Out of the total number of respondents, 63.5% stated they strongly disagreed that their sex had a negative effect on their waitlist process. There were no respondents that agreed or strongly agreed that sex had a negative effect.

H1d- Respondents will report that they perceive their education level as important in the process of getting waitlisted.

Some survey respondents indicated that they strongly disagreed that if they had a better education, the waitlist process would have been easier for them. Out of the total number of respondents, 51.8% stated they strongly disagreed that if they had a better education, the waitlist process would have been easier. Only one respondent strongly agreed that if they had a better education, the wait list process would have been easier for them.

H2a- Respondents will report that they perceive their income/employment as important in the process of getting waitlisted.

Almost half of the survey respondents indicated that they strongly disagreed that if they had a better paying job, the waitlist process would have been easier for them. Out of the total number of respondents, 48.2% stated they strongly disagreed that if they had a better paying job, the waitlist process would have been easier. Only six respondents (4.4%) strongly agreed that having a better paying job would have helped.

227

H2b- Respondents will report that they perceive their health insurance type as important in the process of getting waitlisted.

More than half of the survey respondents indicated that they strongly disagreed that if they had better insurance, the waitlist process would have been easier for them. Out of the total number of respondents, 51.8% stated they strongly disagreed that if they had a better health insurance, the waitlist process would have been easier. Only three respondents (2.2%) strongly agreed that having better insurance would have helped.

H2c- Respondents will report that they perceive their support system as important in the process of getting waitlisted.

Less than half of the survey respondents indicated that they strongly disagreed that if they had better social support, the waitlist process would have been easier for them. Out of the total number of respondents, 45.3% stated they strongly disagreed that if they had a better support system, the waitlist process would have been easier. Only five respondents (3.6%) strongly agreed that having a better support system would have helped. Based on these results, the hypothesis was rejected.

H3a-Higher mean scores on the Discrimination in Medical Settings will be found

   in respondents in the older age groups

In terms of the respondent's age, there were no statistically significant differences in total mean scores on the Discrimination in Medical Settings Scale or on the individual question means due to respondent's age.

H3b- Higher mean scores on the Discrimination in Medical Settings will be found

   in respondents in non-white racial groups

228

In terms of the respondent's race, there were no statistically significant differences in total mean scores on the Discrimination in Medical Settings Scale or on the individual question means due to respondent's race.

H3c- Higher mean scores on the Discrimination in Medical Settings will be found

      in female respondents

In terms of the respondent's sex, there were no statistically significant differences in total mean scores on the Discrimination in Medical Settings Scale or on the individual question means due to respondent's sex.

H3d- Higher mean scores on the Discrimination in Medical Settings will be found

      in respondents with lower educational achievement

In terms of the respondent's education level, there was no significant difference when looking at the total mean scores on the scale. However, as previously discussed there were three questions that showed statistically significant differences in mean scores (Q1, 3, and 7) on this scale due to respondent's education level.

H3e- Higher mean scores on the Discrimination in Medical Settings will be found

      in respondents in the lower income groups.

In terms of the respondent's income level, there were no statistically significant differences in total mean scores on the Discrimination in Medical Settings Scale or on the individual question means due to respondent's income level.

H3f-Higher mean scores on the Discrimination in Medical Settings will be found in

      respondents with non-private insurance.

In terms of the respondent's insurance type, there was no statistically significant difference in the total mean score on the Discrimination in Medical Settings Scale. However, as

previously discussed there were three questions that showed statistically significant differences in mean scores (Q1, 3, and 4) on this scale due to respondent's insurance type.

H3g- Higher mean scores on the Discrimination in Medical Settings will be found in respondents in rural transplant centers

In terms of transplant center location, there was no statistical significance in the total mean score on the Discrimination in Medical Settings Scale and this was also true when analyzing each individual question on the scale.

H4a-Higher mean scores on the Medical Mistrust Scale will be found in respondents in the older age groups

In terms of the respondent's age, there was no statistical significance when analyzing total mean scores on the Medical Mistrust Scale. However, there was one question on the scale that had a statistically significant difference in mean score on the Medical Mistrust Scale due to respondent's age (Q 2).

H4b- Higher mean scores on the Medical Mistrust Scale will be found respondents in non-white racial groups

In terms of the respondent's race, there was no statistical significance when analyzing total mean scores on the Medical Mistrust Scale. However, as previously discussed there were six questions on the scale that had statistically significant differences in mean scores on the Medical Mistrust Scale due to respondent's race (Q 5, 6, 12, 13, 16 and 17).

H4c- Higher mean scores on the Medical Mistrust Scale will be found in female respondents

In terms of the respondent's sex, there were no statistically significant differences in total mean scores or on the individual question means on the Medical Mistrust Scale between the different sex groups.

H4d- Higher mean scores on the Medical Mistrust Scale will be found in respondents with

lower educational achievement

In terms of the respondent's educational level, there was no statistical significance when analyzing total mean scores on the Medical Mistrust Scale. However, as previously discussed there were two questions on the scale that had statistically significant differences in mean scores on the Medical Mistrust Scale due to respondent's educational level (Q1 and 7).

H4e- Higher mean scores on the Medical Mistrust Scale will be found in respondents in the lower income groups.

In terms of the respondent's income level, there was no statistical significance when analyzing total mean scores on the Medical Mistrust Scale. However, as previously discussed there were two questions on the scale that had statistically significant differences in mean scores on the Medical Mistrust Scale due to respondent's income (Q3 and 16).

H4f-Higher mean scores on the Medical Mistrust Scale will be found in respondents with non-private insurance.

In terms of the respondent's insurance type, there were no statistically significant differences in total mean scores or on the individual question means on the Medical Mistrust Scale between the respondent's insurance.

H4g-Higher mean scores on the Medical Mistrust Scale will be found in respondents in rural transplant centers.

In terms of the transplant center location, there were no statistically significant differences in total mean scores or on the individual question means on the Medical Mistrust Scale between the different center locations.

H4h-Higher mean scores on the Medical Mistrust Scale will be found in respondents in private transplant centers.

In terms of the type of transplant center, there was no statistical significance when analyzing total mean scores on the Medical Mistrust Scale. However, there was one question on the scale that did have statistically significant differences in mean scores (Q15).

H5a-Longer reported wait times will be found in respondents in the older age groups

In terms of the respondent's age, there was no statistical significance in reported pre or post wait times.

H5b- Longer reported wait times will be found in respondents in non-white racial groups

In terms of the respondent's race, there was no statistical significance in reported pre or post wait times.

H5c- Longer reported wait times will be found in female respondents

In terms of the respondent's sex, there was no statistical significance in reported pre or post wait times.

H5d- Longer reported wait times will be found in respondents with lower educational achievement

In terms of the respondent's educational level, there was no statistical significance in reported pre or post wait times.

H5e- Longer reported wait times will be found in respondents in the lower income groups.

In terms of the respondent's income level, there was no statistical significance in reported pre or post wait times.

H5f- Longer reported wait times will be found in respondents with higher scores on the MMS scale.

There were no statistically significant differences in scores on the Medical Mistrust Scale and wait times except on question 13. For this question there was a statistically significant difference between the score on the Medical Mistrust Scale and the pre-wait time group

CHAPTER FIVE: DISCUSSION

This study looked into the inequalities in the transplant wait list process through the experiences of the transplant patients. This final chapter discusses the implications of the results of this study. The key findings from the data is discussed below and is related to information already found in the literature. The data collected could add to future research and provides a unique perspective from each transplant recipient's wait list experience.   Additionally, limitations of this study will be discussed.

Key Findings

Theoretical Findings-Anderson Model

As previously stated, The Anderson Model was used to organize the examination of factors that impact the likelihood of a patient getting onto a transplant waitlist. This model coincides with fundamental cause theory regarding resources operating at the individual and organizational levels that result in variance in health care utilization, or in this case, access to the transplant waitlist. The Anderson Model suggests that predisposing characteristics, enabling resources and patient's needs play a role in the patient's ability to access healthcare resources or in this case, access the transplant waitlist.

The predisposing characteristics (or causes) included the demographics (age, sex, race), social structure (ethnicity, education, employment) and health beliefs (patient education). The model also includes enabling resources (social support, insurance type, income level, location). Additionally, this model takes into account the patient's need (patient perception

including discrimination and medical mistrust) for medical services which Anderson (1995) divides amongst perceived health need versus evaluated needs for health services. The patient's predisposing characteristics as well as their enabling resources can play an integral part in identifying the patient's access to getting onto the transplant list.

This study surveyed a sample 137 kidney transplant patients from transplant support groups (in person and online groups) in the United States to explore factors within the transplant wait list process. The table below displays the average wait time (pre meaning wait time from diagnosis to getting onto the list and post meaning wait time from getting waitlisted to getting a transplant) as well as the mean scores on both the Discrimination in Medical Settings and the Medical Mistrust Scale across the respondents' predisposing characteristics and enabling resources.

Table 114. Summary of All Variables Across Wait Times and DMS/MMS Scores.

Variables	Respondents n=137	Average Wait Time		Average Scores	
		Pre (months)	Post (months)	DMS Mean Score	MMS Mean Score
Race					
Asian	6	15.83	30.50	1.1917	2.8917
Black	14	34.21	37.31	1.7043	2.9814
Hispanic	5	15.00	26.60	1.6000	3.0725
Mixed	6	10.83	14.83	1.5000	2.7833
White	105	17.38	26.18	1.4080	2.7703
Sig.		.565	.732	.392	.016
Sex					
Male	31	16.27	19.20	1.5863	2.8357
Female	106	19.34	29.10	1.3948	2.7986
Sig.		.687	.165	.137	.513
Age					
21-35	24	10.25	28.92	1.5772	2.8720
35-44	27	16.26	23.52	1.4659	2.7656
45-54	30	20.79	28.86	1.3913	2.8662

55-64	39	22.43	24.22	1.3979	2.7776
65 or older	17	22.41	32.00	1.3481	2.7400
Sig.		.737	.916	.747	.304
Income					
less than $15,000	14	13.40	47.73	1.3782	2.8027
$15,000-$24,999	13	26.00	28.75	1.5708	2.8183
$25,000-$34,999	12	18.08	32.08	1.1317	2.8192
$35,000-$44,999	12	14.00	17.00	1.8140	2.6270
$45,000-$54,999	9	56.86	14.50	1.3083	2.6214
$55,000-$64,999	6	26.71	20.86	1.8071	2.9193
$65,000-$74,999	14	18.67	14.17	1.3917	2.8633
$75,000-$84,999	12	28.50	26.50	1.2850	2.7650
$85,000-$94,999	6	13.40	23.29	1.3637	2.7800
> $95,000	35	26.00	38.92	1.3464	2.9186
Sig.		.130	.408	.140	.151
Education					
High school	28	26.41	33.32	1.0848	2.7381
Some college	34	20.29	26.52	1.4367	2.8456
College	41	13.43	18.76	1.6157	2.8231
Grad/professional	33	17.61	33.52	1.5115	2.8144
Sig.		.548	.222	.005	.474
Insurance					
Medicaid	26	22.04	37.56	1.3084	2.7972
Medicare	23	38.33	33.84	1.5132	2.8070
Other	6	10.71	13.67	1.6114	2.7583
Private	40	9.68	25.05	1.2898	2.8498
Private+	42	16.61	20.50	1.5922	2.7766
Sig.				.146	
Center Location					
Rural	9	15.89	21.38	1.3822	2.8167
Urban	96	19.22	29.96	1.4436	2.8259
Suburban	25	21.28	15.39	1.4292	2.7400
Other	5	6.00	34.80	1.3120	2.7640
Sig.		.856	.290	.964	.562
Center Type					
University	83	13.79	26.44	1.4770	2.7947

Private hospital	36	24.11	26.73	1.3671	2.8249
Other	8	25.88	28.63	1.1062	2.8325
Unsure	9	36.44	31.11	1.6833	2.8300
Sig.		.202	.983	.219	.932

Predisposing Characteristics

Age

There are many studies in the literature that address the issues surrounding the patient's age and treatment when it comes to kidney transplantation. In a study by Salter, et al. (2014) they found that older adults reported that medical professionals had discussions with them about the option of transplant much less than the younger population. Even when looking at the time from first meeting a nephrologist and beginning dialysis, older adults were more likely to have never had a discussion with a medical professional at that point (Salter, et al., 2014). When these discussions did take place, older participants felt their discussions were less encouraging than younger patients (Salter, et al., 2014).

The results from our study in terms of pre wait times (time from diagnosis to waitlisting) showed that respondents from age 55-64 took an average of 22.43 months to get onto the waitlist and the respondents aged 65 and older took on average 22.41 months. On the other hand, respondents ages 21-35 took an average of only 10.25 months and those between the ages of 35-44 reported an average of 16.26 months to get onto the waitlist.

"Many transplant teams are still reluctant to include elderly patients on the waitlist for kidney transplant as objective selection criteria for transplantation in this population are poorly defined" (Hernandez, et al., 2018, p.257). According to Hernandez, et al. (2018), due to donor

236

shortage, patients over the age of 65 are placed on the waitlist less frequently than younger patients. They also state that once listed, they are still less likely to receive a transplant. The respondents in this study aged 21-35 reported waiting on average 28.92 months to get onto the list and respondents between the ages of 35-44 reported waiting an average of 23.52 months. The respondents in the older age group of 65 years and older reported waiting an average of 32 months and those between the ages of 55 and 64 waiting on average 24.22 months. Of note, this study only included kidney transplant patients and therefore cannot account for those who have never made it to the transplant wait list.

<center>

Sex

</center>

As stated previously, the sample for this study consisted of 137 respondents, 77.4% (106 respondents) of which identified themselves as female and 22.6% (31 respondents) identified as male. In terms of their sex, participants were provided with the statement: *I feel that my sex had a negative effect on my waitlist experience.* More than half of the respondents (56.2%) stated effect on their waitlist experience.

The literature noted that during the pre-transplant stage, "women were more likely to be reported as unsuitable due to age, medically unfit and declined" (Kucirka, et al., 2012, p. 351). Women were also less likely than men to have discussions about the option of kidney transplant with medical professionals (Salter, et al., 2014). Even though research shows that women have higher incidences of chronic kidney disease, they are still less likely to being dialysis or receive a transplant than men (Antlanger, et al., 2019). In the pre wait time of our study, women reported

<center>237</center>

waiting an average of 19 months to be waitlisted as compared to the 16 months reported by the males.

With post wait time, Schaubel, et al. (2000) explained that men in the US are more likely than women to receive a transplant. In our study, women reported waiting an average of 29 months for a transplant whereas the male respondents reported an average of 19 months. Schaubel, et al. (2000) found that women are transplanted less often and they stated that "women are either actively or unintentionally discriminated against, perhaps due to the overestimation of medical risks" (p. 2353). Again, this study is not able to capture information from anyone who did not either get a transplant or those who never made it on the list at all.

Race

In terms of race, participants were provided with the statement: *I feel that my race had a negative effect on my waitlist experience* and 86 respondents (62.8%) stated that they strongly disagree that their race had a negative effect on their waitlist experience. Whereas one person reported that they strongly agreed with this statement (.7%) and five reported they agreed (3.6%). These results were similar when the respondents were asked the same question regarding their ethnicity.

The literature identifies many areas throughout the transplant process in which minorities patients are treated differently than white patients. Even though transplantation increases quality of life and has shown to be the best treatment for kidney disease, many studies show that black and Hispanic patients have had decreased access to both living and deceased donor transplant (Rhee, et al., 2014). Preemptive transplantation is considered even more optimal for patients

238

with ESRD (OPTN Minority Affairs Committee, 2015). Similar racial disparities were present

for preemptive referral as well.

In the initial steps of wait listing, minority patients tend to have a lower rate of referral to

a transplant center despite their desire for transplant (Higgins & Fishman, 2006). "The lower

rate of referral for kidney transplant among blacks is also thought to be due in part to lack of

education and information about the risks and benefits" (Harding, et al., 2017, p. 167). The

black respondents in this study reported the longest average wait time in both categories with an

average of 34.21 months (pre). and 37.31 months (post). White respondents reported an average

wait time of 17.38 months (pre) and 26.18 months (post). The findings in this study were

consistent with the literature where Williams and Delmonico (2016) noted that blacks and other

minority groups are disadvantaged in kidney transplantation. Goldfarb-Rumyantzev, et al.

(2012) also identified that racial disparities are evident when comparing blacks and whites in

access to kidney transplantation.

Education

Participants were then provided with the statement: *I feel that if I had a better education,*

the waitlist process would have been easier and 71 respondents (51.8%) stated that they strongly

disagree that their educational level needed to be better to make the waitlist experience easier.

Whereas, similar to race and ethnicity, one person reported that they strongly agreed (.7%) with

this statement and five reported they agreed (3.6%).

The respondents with a high school education reported waiting the longest during the pre

waitlist stage. They weighted an average of 26.42 months. Respondents who reported only

some college education were the next longest reporting an average of 20.29 months. This is

consistent with the study by Greer, et al. (2011) which showed that physicians were less likely to

have discussions in kidney disease office visits with patient some college education. Patzer, et al.

(2012) identified that patient education may be another factor that may account for some of the

disparities evident in the wait list process.

On the contrary when looking at the post wait list stage, the high school education group

reported similar wait times as the graduate or professional degree group. The high school

education group reported an average of 33.32 months whereas the graduate/professional group

reported an average of 33.52 months. This finding differed from what was found by Schaeffner,

Mehta and Winkelmayer (2008) as they found that college graduates were three times more

likely to be waitlisted or transplanted. Goldfarb-Rumyantzev, et al. (2012) found that disparities

may be lessened if the patient has a higher education level. Their study pointed out that racial

disparities due exist within kidney transplantation but found that this may be alleviated for

patients with higher eduation (Goldfarb-Rumyantzey, et al., 2012).

Enabling Resources

__Insurance Type__

In terms of health insurance, participants were provided with the statement: *I feel that if I*

had a better health insurance, the waitlist process would have been easier. Out of the 137

respondents, 71 respondents (51.8 %) stated that they strongly disagree that with a better

insurance the waitlist experience would have been easier. Whereas three people reported that they strongly agreed with this statement (2.2%) and six reported they agreed (4.4%).

In a recent study by King, et al. (2019) which evaluated the newer Kidney Allocation System, they noted that patients who received transplants preemptively (which has been shown to be the ideal for patient's to accrue wait time while on dialysis) were more likely to have private insurance. Also to note, they found that patients who had Medicaid insurance were even less likely to receive a transplant preemptively (King, et al., 2019). Harhay, et al. (2018) uncovered that during the Medicaid expansion under the Affordable Care Act there was an increase in preemptive listing for patients due to now having access to insurance coverage. Of this group, they found that the Medicaid expansion provided insurance coverage to the minority groups who had been shown to already have longer wait times and difficulty accessing the transplant list (Harhay, et al., 2018). This is particularly important when discussing the kidney transplant wait list as the months while a patient is on dialysis can be counted towards their wait times and having insurance coverage provides the patient with this access.

Income Level

In terms of income, participants were provided with the statement: *I feel that if I had a better paying job making more money, the waitlist process would have been easier*. Out of the 137 respondents, 67 respondents (48.9%) stated that they strongly disagree that with a better paying job the waitlist experience would have been easier. Whereas six people reported that they strongly agreed with this statement (4.4%) and seven reported they agreed (5.1%).

In our study, the highest income level (greater than $95,000/year) reported wait times of 26 months to get onto the list and an average of 38.92 months once on the list to get a transplant. In the lowest income bracket from our study (<$15,000/year) the average reported wait time to get onto the list was only 13.4 months and once on the list, they reported an average wait time of 47.73 months to transplantation. Looking into disparities by income level or socioeconomic status is particularly difficult due to the fact that many barriers arise for patients in the low income bracket and it may make it difficult to determine if income is the only contributing factor (Zhang, Gerdtham, Rydell, & Jarl, 2018).

The discussion of a patient's income level can be particularly important when talking about post-transplant care necessary for transplant survival. Simmerling (2007) discussed and provided an estimate of the high cost of post-transplant immunosuppressant medications which are important for the life of the transplant. This article goes further to explain that these high cost medications may deter a medically suitable transplant recipient from ever getting onto the list. This may be due to the patient's choice or the decision of the transplant team (Simmerling, 2007). Not only does a patient's income level affect wait listing but it also becomes a factor after a patient receives a transplant. If a patient has received a transplant and for whatever reason is unable to pay for the medications, the organ could fail and then the patient would find themselves back on dialysis (Simmerling, 2007).

While the cost of the medications is important, Hod and Goldfar-Rumyantzev (2014) state that the inability to afford care may not be the only factor in explaining the association between income and the outcomes of transplantation. They discussed a study in the UK which has universal healthcare therefore the immunosuppressive medications were covered and they

found that low income was still a significant factor in survival of the transplant (Hod, & Goldfar-Rumyantzev, 2014).

Transplant Center Location

Survey respondents were then asked which type of area the center was located. A large portion of the respondents (70.1%) stated that they received their transplant in a transplant center located in an urban area. Twenty-five respondents (18.2%) stated their center was located in a suburban area and nine respondents (6.6%) stated their center was in a rural location.

Axelrod, et al. (2008) identified that patients in rural areas experienced lower rate of waitlisting and lower rates of transplantation. In our study respondents living in rural areas did report less average wait times both pre waitlist (15.89 months) and post listing (21.38 months waiting to get a transplant). Whereas patients in urban areas reported an average of 19.22 months to get onto the list and 29.96 months to get a transplant. However, overall there were no statistically significant differences in pre and post wait times between the transplant center types. Axelrod, et al. (2008) had similar results where significantly longer wait times were not found in kidney transplantation. Tonelli, et al. (2009) also yielded similar results where "remote or rural residence was not associated with increased time to kidney transplantation among people treated for ESRD in the United States" (p. 1681).

Transplant Center Type

Regarding the type of transplant center setting that patients received their transplant, 83

respondents (60.6%) identified their center as a University or University Affiliated Center. Thirty-six respondents (26.3%) identified their center as a Private Hospital Transplant Center. Hall, et al. (2012) found racial disparities in all transplant centers in the US when referring to living donor kidney transplant.

Ramos, et al. (1995) identified that university-based centers as well as larger centers were more willing to accept higher risk patients. For our study in terms of the transplant center location type, there were no statistically significant differences in pre or post-wait times. The differences in transplant center criteria and structure can impact which patient's ability to get waitlisted, leaving some patient's never hearing about transplant as an option.

Theoretical Findings-Fundamental Cause Theory

As previously stated, Fundamental Cause Theory seeks to identify why, even with advances in medicine and improvements in population health, some patients still tend to benefit more than others based on their demographics and socioeconomic status. The first feature of this theory was addressed in the literature review and states that these causes, such as low SES and lack of education, can be utilized when discussing different diseases. The second feature of this theory is that socioeconomic status can affect the outcome of the disease with multiple risk factors. The sample for this study was unique in that 25.5% of the sample reported an income of greater than $95,000 and the group in this higher income bracket did not report the shortest wait times.

As previously discussed, looking into disparities solely by income level or socioeconomic status is particularly difficult due to the fact that many barriers arise for patients in the low

income bracket and it may make it difficult to determine if income is the only contributing factor (Zhang, Gerdtham, Rydell, & Jarl, 2018). For instance, insurance type is a factor that may be impacted by income level along with the coverage provided by the insurance plan. The interviews from transplant recipients provided insight into personal experiences in which patients identified how socioeconomic status and insurance type played a role in their experiences. One patient felt that doctors were more likely to get patients educated and started on the pre transplant testing if "you got good insurance, then then will let you know, or if you are a veteran or if you are a business person, someone with a lot of money" (personal communication, 2019). One patient also discussed how they had to raise money to get onto the transplant list as their insurance was not good enough. Another patient explained how "we were notified that I was placed as inactive on the list because with my insurance, there was concern that I could not afford the medications if I did get a transplant" (personal communication, 2019). A lot can be learned from patient experiences and these patients were able to discuss the factors that could come along with income levels that may also play a part in access to the transplant list.

This leads into the third feature of this theory which involves access to resources that can be utilized to either avoid risk or to lessen the consequences of the disease (Phelan, Link, & Theranifar, 2010). The key resources include knowledge, money, power, prestige, and beneficial social connections (Phelan, Link, & Theranifar, 2010). While discussing these resources, the discussion of minority status is necessary as well. One of the limitations to the study that was identified was that the sample was not diverse with 77% of the sample identifying as female and 77% of the sample identifying as White. With that said, female patients reported longer wait times than the male patients. Black patients also reported, on average, longer wait times than all other races.

To recap, Ford, Collins, and Airhihenbuwa (2010) discuss the four features of CRT they have identified, which include: race consciousness, contemporary orientation, centering the margins rather than in the mainstream and praxis. Race consciousness is important as it provides an understanding as to a person's awareness and understanding of racism in their own life and how it affects them (Ford, Collins, & Airhihenbuwa, 2010). The Discrimination in Medical Settings Scale and Medical Mistrust Scales were used to gain an idea of whether the transplant recipients in the sample had felt discriminated against in the transplant process and also to address the third feature of this theory of the "outsiders within" concerns. As previously discussed, Cuevas and O'Brien (2017) identified that the patient's racial identity was an important component of the patient's experience in terms of receiving equitable health care. The sample for this study was primarily white and the scores on both scales did not show significance but the patients in the minority groups did report longer wait times.

Discussing race at the system level or contemporary orientation is the second feature of CRT. Wait times at transplant centers and differences in transplant criteria are just some examples of system level issues. While interviewing transplant recipients, some explained how they wish they had better insurance or better means of proving they could afford the post transplant medications as they felt that they were at a disadvantage. Some mentioned the need for them to fundraise to provide money to prove they could afford the medications. Some also expressed their wish to have the ability to financially afford transportation to many centers as multilisting provided more opportunity for those who were able to. Also similar to findings by Cuevas, O'Brien, and Saha (2017) who explained that "although African Americans perceive

discrimination in health care settings, experience higher levels of medical mistrust compared with European Americans, and experience poorer communication with health care providers" (p. 987). One of the most common and consistent issues identified in the interviews was that communication within the transplant center were lacking. Many identified wanting more transplant education and information needed.

The final feature of CRT is praxis which has to do with using the information to guide the research by focusing on the information provided by those within the marginalized communities (Ford, Collins, & Airhihenbuwa, 2010). One goal of this study was to gain insight and information from patient experiences in particular those in marginalized groups. Future research could be the key into being better able to control access to the transplant list especially to those in marginalized communities in need.

Medical Mistrust

Medical mistrust has been shown to lead to many issues within the healthcare system including the underutilization of services which can be particularly troublesome for someone with kidney disease. Harmoda, et al. (2017) found that "perceived medical racism, medical mistrust, and medical discrimination persist in the African American transplant patient population" (para 4).

Medical Mistrust can impact a patient's willingness to get the care and services they need and this is especially important when discussing End Stage Renal Disease. Harding et al. (2017) identified mistrust of clinicians and mistrust from the healthcare team as a reason for the racial disparities evident in kidney transplant wait listing. As previously stated, LaVeist (n.d.) explains

that trust is evident in many areas such as doctor/patient relationships, trust in the pharmaceutical companies, trust in competence of the health care team, and trust in the education received and appropriate decision making in regard to the diagnosis.

The mean scores on the Medical Mistrust Scale were run by each category and those categories that showed significance are shown below in the table. The patient's scores did not show any significant differences based on the patient's sex.

Table 115. Significance of MMS Mean Scores Across Demographics.

Medical Mistrust Statement	Significant by:
1.You better be cautious when dealing with healthcare organizations	Education level
2. Patients have sometimes been deceived or mislead by healthcare organizations	Age
3. I trust that healthcare organizations will tell me if a mistake is made about my treatment	Income Level
4. Healthcare organizations often want to know more about your business than they need to know.	
5. When healthcare organizations make mistakes they usually cover it up	Race
6. Healthcare organizations have sometimes done harmful experiments on patients without their knowledge	Race
7. The patient's medical needs come before other considerations at healthcare organizations	Education level
8. Healthcare organizations are more concerned about making money than taking care of people	
9. Healthcare organizations put the patient's health first	
10. Healthcare organizations don't always keep your information totally private	
11. Patients should always follow the advice given to them at healthcare organizations	
12. I typically get a second opinion when I am told something about my health	Race

13. I trust that healthcare organizations check their staff's credentials to make sure they are hiring the best people	Race Pre-wait time
14. They know what they are doing at healthcare organizations	
15. Sometimes I wonder if healthcare organizations really know what they are doing	
16. Mistakes are common in healthcare organization	Race, Income Level
17. I trust that healthcare organizations keep up with the latest medical information	Race

Discrimination in Medical Settings Scale

"Evidence indicates that cultural factors including medical mistrust, perceived racism and discrimination, religious beliefs, and family influence, play a key role in decision making about medical interventions and that these issues are critical to understanding disparities in kidney transplantation" (Muaskovsky, et al., 2012, p. 423). Shaubel et al. (2000) discussed that women are discriminated against in the transplant world and this may be due to overestimation of the medical risks in transplant for women. They noted that physician bias may only be one factor as to why women are less likely than men to receive a transplant (Shaubel, et al., 2000).

Shavers, et al. (2012) found that "74% of African Americans, 69% of other non-Whites, and 30% of Whites report personally experiencing general race-based discrimination" (p. 953). Harmoda, et al. (2017) found that of the patients who reported being treated unfairly while receiving medical care, 78% reported race/ethnicity as the main reason for the discrimination.

In our study there was no statistical significance in mean scores on the Discrimination in Medical Setting Scale when discussing race, age, sex, or income. This is inconsistent with the literature. The patient's education level and Insurance type showed significance on only the questions shown in the table below.

Table 116. Significance of DMS Mean Scores Across Demographics.

Discrimination in Medical Settings Statement	Significant by:
1. I had a doctor or nurse act as though they were afraid of me	Education Level, Insurance Type
2. I had a doctor or nurse act as though they thought I was not smart	
3. I had a doctor or nurse act as if he or she was better than me	Education Level, Insurance Type
4. I felt I was treated with less courtesy than other people	
5. I felt I received poorer services than other people	
6. I felt as though I was treated with less respect than other people	
7. I felt like a doctor or nurse was not listening to what I was saying	Education Level

Limitations to the Study

When discussing the results of the study, the limitations must also be identified. While the survey was distributed to online support groups across the United States, the intention was to have a diverse sample size. However, it turned out that the respondent group was not as diverse as originally planned which could account for some of the results that were obtained. For example, the sample was 77% female. This could be that the sample was taken from online support groups. Studies have shown that females are more likely to join and participate in support groups than men (Mo, Malik, & Coulson, 2008).

Also, to note was that 77% of the sample was white. This could have had an effect on the results as discrimination in medical settings was "most common for Blacks…. minorities were more likely to report worse treatment compared to Whites" (Benjamins, & Whitman, 2014, p. 403). Prior research provides evidence that whites are less likely to report discrimination

compared to other racial groups (Shavers, et al., 2012). Other "evidence suggests that perceived racial discrimination further varies with SES" (Stepanikova, & Oates, 2017, p. 953).

Stepanikova and Oates (2017) found that subjects with a lack of health insurance, lower income, lower education levels and financial barriers to healthcare showed increased perceptions of racial discrimination. Out of our sample, 49% reported an income over $65,000/year, with 26% of the total sample reporting an income level greater than $95,000. In terms of insurance, 55% of the total sample reported having either private insurance or private and Medicare insurance.

Another limitation is that the survey requires the respondents to self-report about their experiences. Self-reported data collection can have a limitation in that the respondent's answers on the survey are taken at face value as there is no way to verify the answers provided (Sacred Heart University, n.d.). Sacred Heart University (n.d.) identifies the potential sources of bias as: selective memory, telescoping, attribution and the possibility of exaggeration when discussing self-reported data. Selective memory and telescoping refer to what Althubaiti (2016) referred to as recall bias.

Selective memory was identified as "remembering or not remembering experiences or events that occurred at some point in the past" (Sacred Heart University, n.d., para 15). Similar is the concept of telescoping where respondents recall events that they think happened at one time but actually happened at a different time. This survey asked respondents to answer each question as truthfully and accurately as they could recall. Also the survey did not include a way to differentiate if the respondents received a living or deceased donor which would have added more information to the study as this can affect wait time and there are many studies that look into disparities amongst living vs. deceased donor kidney access.

Future Research

The purpose of this study was to bring more information and awareness on this topic and to add to the literature that exists to help continue to work on improvements. The persistent challenges of bridging healthcare disparities for African Americans in need of a kidney remains an issue today at the national level (Harding, et al., 2017). It is evident that there are issues with patients gaining access to the kidney transplant list even when transplant has been shown to be the best option for the patient. There are many studies that identify areas in need of improvement, but this is no easy task. There are many authors that discuss possible solutions or possible answers to alleviate some of the areas of inequalities.

Williams and Delmonico (2016) note that the solutions to the disparities is quite complex and they offer three areas in need of improvement. The three areas they discuss start from when the patient is first diagnosed as some are already facing barriers to care and some never even receive a referral or are never made aware in the first place. Secondly is to focus on the issue with equal distribution of the kidneys as there are not enough for all the patients that need them. Lastly they identify that the outcomes after the transplant need to be addressed to ensure the patients also have equal access here as well (Williams & Delmonio, 2016).

Hod and Goldfarb-Rumyantzey (2014) focused on making improvements at the post transplant level in terms of access to insurance as this is a time when the patient will need to be able to have access to the necessary medications to keep the transplant alive. This is also an area where disparities exist as some patients may be discriminated against due to not having enough

income or good enough insurance to cover the necessary medications. They focused on improving the Medicare coverage for these medications to every transplant recipient by lengthening the amount of time the patient is able to keep their Medicare benefits post transplant. As is currently stands, the Medicare immunosuppressive benefits cover a patient for 3 years post transplant and Hod and Goldfarb-Rumyantzey suggest extended this as lifetime coverage.

In the area of transplant center improvements, there have been websites and online tools created such as the one from the Scientific Registry of Transplant Recipients (n.d.) which lists the transplant centers and provides detailed information about each center. The information includes the distance of the center from the patient (once a city inputed), number of deceased donor transplants in a year, number of living transplant donors in a year, survival rating on the waitlist, and survival outcomes (Scientific Registry of Transplant Recipients, n.d.). This can help educate patients but again if the distance is too much, not all patients can actually get to the center. In terms of geographical disparities in access to kidney transplants in the US, Ata, Skaro and Tayur (2016) suggest an operational solution including using affordable jet services (OrganJet) to transport patients on the waitlist to their kidney so that these patients may place themselves on multiple lists to try to shorten their time on the list and improve their quality of life.

An executive order recently signed by the president is focusing on five new payment models to motivate doctors to provide information to patient's earlier and focus on limiting some of the lack of consistency within organizations. This order also focuses on raising awareness and patient education and discusses the benefits of home dialysis for increasing quality of life (Berstein & Kindy, 2019). These issues were also discussed by Patzer (2012) who explained that

dialysis centers have no incentive or financial motivation to refer patients for transplant or to spend time educating them on it.

Awareness is also the key to improvement. Purnell, et al. (2017) provide information on the barriers towards transplant as patient's attitudes and beliefs, health care provider knowledge as well as their attitudes and beliefs and population awareness and attitudes. Williams and Delmonico (2015) discuss how the newer system where patients can begin to accrue wait time while on dialysis is an excellent start but patients and health care providers need to know about these options so that they are able to benefit from them. They go further to state that public health initiatives need to take place to better educate patients especially in the communities of color (Williams & Delmonico, 2015).

Research such as this study and taking time to speak with transplant recipients as well as those on the waitlist can give an insider's view as to their experiences to be better able to identify areas of strength and areas in need. It is also important to continue to do research on the patients who have been diagnosed but have not begun dialysis or have not wait listed as we need to ensure that these patients are all aware of their options regardless of race, sex, age, or socioeconomic status.

APPENDIX A: IRB APPROVAL LETTER

University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Determination of Exempt Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Melanie Bergeron**

Date: **December 04, 2018**

Dear Researcher:

On 12/04/2018, the IRB reviewed the following modification as human participant research that is exempt from regulation:

Type of Review:	Exempt Determination
Modification Type:	Minor change to protocol: addition of audio-recording of phone interviews
Project Title:	Disparities within the Kidney Transplant Waitlist Process
Investigator:	Melanie Bergeron
IRB Number:	SBE-18-13798
Funding Agency:	
Grant Title:	
Research ID:	N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

This letter is signed by:

Signature applied by Racine Jacques on 12/04/2018 08:36:28 AM EST

Designated Reviewer

APPENDIX B: INTERVIEW ONE

Introduction

Hello this is Melanie and I want to thank you and tell you how much I appreciate you taking the time out for the interview.

You are welcome

How are you doing

Well I am okay but I am back on dialysis

I heard you say you are back on dialysis

Yeah unfortunately, and today was pretty hectic considering the fact that they put us on late.

Oh I am sorry to hear about this.

And then they stuck me wrong and the needle was sitting on the wall and the machine kept beeping

Oh you are kidding

Yes so I got out of there pretty late

How many hours do you have to be on it for?

3 hours and 15 minutes

Oh goodness

How many times a week are you going

3 days

That takes a lot out of you so I am sure you are exhausted today

Oh yeah plus I work a part time job too.

Wow that takes a lot of strength to be out doing all of that

Yeah (laughter)

I work at a doggie daycare so I work with dogs all day

Oh well that is rewarding though , I think

No it is not boring at all

No I said rewarding, it must be rewarding to be able to hang out with them

Yes it beats dealing with people

(Laughter) Yeah they cant talk back to you right (laughter)

Yeah

That's excellent, Well I wont hold up too much of your time as I am sure you would like to get some dinner and get some rest at this point, you know

Yeah

Um I just have like 8 open ended questions to kind of go along with the survey just to kind of get people's view of, you know with surveys you can never really get a full idea of what people want to say if you are only able to answer multiple choice questions so um I just want to kind of get your ideas on waitlist stuff, I have like 8 questions that you can answer as long or as short as you want or some of your answers might be like no (laughter). Um just to kind of get your feel if you had a few minutes

Ok sure

Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

Well I am actually dealing with that right now um

OK you are back on

Well I hope so, I have not really gotten any update if I am on the list or not but that is something I am working on and before I went to um I did Northwestern and their waittime is 5 to 10 years.

Oh my goodness

And so I went up to Wisconsin because Wisconsin's wait time is shorter and their waittime is 3 to 5 years so I was on Madison's Waiting List and Freider's Waiting List and overhere in Illonois I was on Northwestern's waiting list. And that is all most recent, or was this previously

This was previously, now I am waiting to see which list I am on.

Oh my goodness, and how long ago were you on the waitlist before

Um I received my kidney back in 2014 and it lasted me 4 ½ years

Um hm

Um so I was on the waiting list for about 3 ½ years and they actually added that time I was on dialysis they added that to the waiting points

Ok so how long have you been on dialysis this time

Um I want to say about 2 months now

Ok

Yeah

Do you feel like it is any easier getting on the waitlist this time versus last time or kind of even though you know how to do it, it is still quite a challenge

It is still challenging because again I do not know what is going on, they are not really up to date with telling me information about me being on the list

OK

It is like when I ask, nobody knows

That is terrible, you don't have like a point of contact right I am assuming then right?

Yeah no I talk to my nephrologist and he just lets me know

Please describe some of the obstacles you experienced when trying to get waitlisted

Um I just, probably knowing what is going on, you know letting me know what is going on because I would like to know you know and they do not tell me anything and I am sitting her like okay I am so young, I am not like 80 something years old where I have lived my life and people take care of me and that is not the case

Umhm

I am 28 years old,

Goodness you are very young

Yes my kidneys failed when I was 20

Wow

Yeah so you can imagine I had a lot of growing up to do

Absolutely and that waitlist process is a hard one to navigate especially when you are young

Yeah I had no idea, I still have no idea what I am doing, you know I still need help asking how to do I get on the list and how do I do this and how do I do that. And you know it is not new to me but it is challenging

Absolutely and I am sure part of that is that your health is important and it is scary too

Yeah absolutely yeah, I have been in and out of the hospital a lot where the hospital knows me as soon as I walk in

Awe (laughter)

Please describe any areas of the waitlist process that you found to be easy to navigate

Um I do not think so because I was lucky actually because I waited only 3 ½ years and I actually received my

kidney from a complete stranger through a group study

Interesting

Yeah they, actually I was the last person to receive a kidney out of the 4 families that were donating

And this was a live donation for you?

It was yes

That is amazing

Yeah I think, I think that a lot more hospitals should do more group studies

And what does the group study entail

Um , okay so there are four families and the first family donates to the second family, um the second family has a

family member that can donate to the third family member that is waiting and the third family member donates their

kidney to me so that they can get bumped up the list faster to receive a kidney

Wow

Yes

And how did you get chosen for that study

Oh I do not know, they just called me and asked if I would like to be in a group study and I was like sure

You were like, sign me up (laughter)

Please discuss any people in particular that were helpful during the transplant waitlist process

Um when I first started on the list, yes I did, now not so much, now it is just me dealing with it

Ok

So I mean it is nothing new to me but it would be nice to have someone there you know

Absolutely

Yeah I am dealing with it on my own

And that is a lot being 28, on dialysis and to be working

Yeah watching my fluids and what I eat, you know I have no kids but I have a dog I take care of and he is the world

to me and that is basically my child (laughter). And even dealing with renal failure like I do not even know if I want

children at this point. Dealing with all of this

I understand.

Do you feel there are any people in particular that were helpful during this process either this time or last time?

Um my mom was by my side the first time I went through all of this, she was my rock and it was difficult for her, you know it was very emotional

Um hm

Um but now I am older and I have been through it I guess and it is like she is on her own and doing her own thing and I am doing my own thing and um I have my best friend who would like to donate her kidney to me

Oh wow

I just want to see if we are a match, you know we have to be 100% compliance with the kidney, and tissue and all the antibodies and all that

Yeah and that is a big process too

Yeah so I have my best friend

That is tough

Yeah

Please discuss any times where you felt discriminated against for any reason during the waitlist process

No, well no not really but I felt like because I was so young they just were like "oh you just got to make sure you take your meds" and they just kept constantly repeating themselves, "take your meds", take your meds"

Ok

And I am like, I understand, again I am not like 80 something years old where I forget easily you know

Um

I will remember this, you do not have to tell me everytime, all the time, you know so that I felt like because I was young they were like like oh gotta do this, you gotta do that, and I was like okay I will. You don't have to worry I will take my meds on time you don't have to remind me and I was doing good, I was taking my pills on time when I received my kidney. Um I did doctors appointments and went to those y0ou kknow

Ok

So you know yeah I took care of this kidney the best I could it was just giving me a rollercoaster ride and it wasn't agreeing with me

Oh

Yeah, so

Describe anything about yourself or your personal situation that, if you had the ability to change it, would have made the transplant list process easier

Yep anything that will get a kidney sure um well I was offered a kidney three times

Wow

Yeah one was a cadaver um it wasn't a complete match, um I went all the way up to Madison they took my blood, I spent the whole night there and the next morning they were like, I am sorry it is not a 100% match, so I was crushed you know, heartbroken

I cant imagine

And then the second time, a few months later, they called me up and was like um we have a kidney for you and at the time I had a common cold and I told them I was sick and they were like oh well then we cant give you this kidney if you are sick because we need you to be 100% healthy so I was kind of bummed out about that and then the third call was the group study call. They were like hey we are going to put you in a group study and you will get the call when we have a family that is going to donate a kidney to you

Um hm

And that is when they called me and they were like, well fingers crossed you will get this kidney but if like the first, second or third family doesn't want to donate, then you will not have a kidney. Because if the first family member decided to not donate to the second family in need, then I wouldn't receive one.

I understand, that must have been stressful for you

Yeah it is like a chain reaction

So how long were you on the waitlist before you got into the group study, was that the 3 ½ years

Yes it was, they put that waiting time towards um when I was doing dialysis, they put that waiting time towards my kidney

And how long did it take you to get onto the list the first time

Um (uffff) it was so long, I want to say probably a month

Is there any advice you would give to other patients trying to get onto the transplant waitlist

Do it as soon as possible (laughter) Um because you never know if they get you on or not and then you are sitting

there wasting your time doing treatment and htat is just like am I on the list for a kidney because that would be great

and if not what can we do, like

Have you ever been taken off the list

Um I was taken off when I received my kidney

Ok so that was the only time

Yes other than that , I was on the list until I received it but I have heard people have been taken off the list because

of their situation whether it is taking drugs or they are not compliant, or you know it is just different circumstances

but I have been good (laughter)

Ok, that is important

Yeah

 Please discuss any areas that you feel could have been improved in order to make waitlisting easier for you?

Um yeah wishing the waiting time is less instead of years because there is a lot of people who need organs, you

know, there are people dying every day waiting and being on the machine 3 days out the week for 3 ½ hours it is

tough, its draining, it is exhausting and you know people just want to live their life as normal as they can but we cant

because we are on a machine

Absolutely

So so I mean it is emotional and it is tiring but I take it day by day and I have to be positive through life because I

actually flat lined I died three times, like they had to bring me back. Like the first time I was rushed to the

emergency room because of my kidneys, they failed, and they had no idea and I was being rushed to the ER and I

was in the ambulance I flat lined and they had to resuscitate me to bring me back.

Oh my goodness'

So I mean, I do not take life for granted so I have to live life positive and just gotta believe that there is going to be

good out there eventually, hopefully

Absolutely, well you have a good outlook on it despite all of the struggles you have had with it, you know

Yeah and then when I go to dialysis I see the grumpy old people and they are like "I need this" "I need that" and I am just like why cant you just be thankful that you are still here, you do not have to be so rude. But I do not say that to them I just think it (Laughter)

Yes you just keep it in your thought bubble

Yeah I just think I hope I am not that grumpy when I get old. (laugter) And I hope to be off dialysis by then as well. I hope to receive a kidney that cause they told me that this kidney was supposed to last me my whole life but that didn't work out

Oh no

So I mean four years is pretty long for a kidney but not as long as what they had told me

Right and not getting the correct information seems to be a theme that you are having you know

Yeah, Yeah and I just feel like because I am young, they don't want to tell me some things and I get upset so I start snapping on them and they get all upset but I wouldn't be snapping on them if they wouldl just tell me what is going on

Um hm how long did it take when you found out you had kidney disease for them to mention transplant, or did you already know that transplant was an option early on or did they take a while to mention it to you

Um no they told me um they told me that I could receive a kidney or a transplant um but I had no idea that my kidneys had failed at all like it took me getting rushed to the hospital to realize trhat they were completely dead

Oh my

Yeah so

That is so scary

It is, I wasn't breathing right, I was hyperventilating and I was just weak and wanted to sleep all day. Ugh, pale, it was bad

Um hm. I totally appreciate you sharing your story with me, I know it is hard when I am sure you just want to go to sleep probably (laughter). Cause I know how draining dialysis can be as my husband had been on dialysis for quite some time so I can understand the struggle with that because it is so draining

Yeah and a lot of people do not understand that, and I try to explain but they are just like all you do is sit in a chair for three hours. But they do not understand that the blood is filtering throughout my whole body.

Yes it takes a big strain on your body

Right like today was bad, they got me in late, they stuck me wrong they infiltrated my graft and the way the needle was sitting, the machine kept beeping and every time the machine would beep, it stops so the more it stops, the longer I am there

Right

And I am just like sometimes I get anxiety and I am just like I need to get off of this machine so I have to look into being prescribed something while being on the machine because there are days when I can sleep through it and there are days when I am just like get me off

Oh I can imagine

Yeah and the needles are not friendly either

No they do not look friendly that is for sure (laughter)

Yeah no not at at all

Well I really hope things get better for you, I hope you get on that list and I hope you get the information about getting on the list soon.

Thank you me too

And I hope all goes well for you and I hope you will be feeling better and will be running around in no time, you know

Yeah so do I

Continue taking it one day at a time like you do you know and the support groups, I know you are on the online ones but any other ones you find, finding the support I am sure will help too you know

Oh yeah I like reading people's stories or people that have questions I like putting my input in and so

You have a good story to share and to help other people

Yeah thank you

Your welcome

APPENDIX C: INTERVIEW TWO

Introduction

Hello

Hi is this Lenora

Yes this is she

Hello Lenora, this is Melanie I am the one who was emailing you a couple of times regarding the interview

It is okay, I know we were just going back and forth

I know and I tried to call your house number and it was not working

Oh sorry about that, just letting you know that I am currently at TJ Maxx but you can still ask me the questions

I know you have received a kidney and I was wondering how it is going

It is great, today is actually my year anniversary

Today is your anniversary, congratulations, that is a lot to be celebrated as I know how hard it can be

Yeah, yeah, it is a long process and I can see how some people give up

Yes, How are you feeling now

Um well I have had my ups and downs with medication but I thank God they got it right now finally

Oh

It has been like three months, and I have been having to see the doctor like every 1 to 2 weeks but now we can

spread it out now

Good that makes all the difference when you are feeling better

Yes, it really does

A lot of my questions relate to the transplant waitlist as this is the focus of my paper, I find it amazing how there is

not a lot of information about how difficult the process is, so my questions pertain to your waitlist experience if that

is okay?

Yes of course, go ahead, shoot away

 Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

As far as the waitlist process, I was very proactive in the process and so was my nephrologist. My local

nephrologist had been working with me because this was like my ___ flare up of lupus nephritis, I have had it since I

was 12. I guess after I had my daughter, she (nephrologist) began talking about it because I had a structural valve

268

after after having her and then I had another flare and my _____ went down to like the 30s. so she started talking to me then about being prepared when don't know how long your natural kidneys are going to last so keep that in the back of your mind. So you know I thought maybe around that time I still had a lot of time but um I guess it was like 3 summers ago I had another lupus flare up and I had no idea, I had no symptoms like I normally had with my lupus like the pain in my hands and my feet and like having a lot of froth in my urine. I just didn't recognize any symptoms. The only thing I noticed was my blood pressure kept going up so I went to the ER and that it when I found out it was the lupus again but this time it totally wiped out the rest of my kidney function.

Oh wow

So I was at like a 10 and I spoke with my nephrologist so she came and she told me, I was kinda shocked because you know I thought I had more time but at that time I had to start dialysis and she just kept mentioning make sure we got to get you on the list because you are young and pretty healthy, it's just your kidneys aren't working. So since then you know I worked on getting my testing done, as far as you know getting the echo, bloodwork, making sure I was compliant with dialysis and I scheduled my own consult for transplant. I had no idea where you know she gave me an idea of where to go but basically I am a nurse by trade so I was very proactive and was like let me hurry and try to get this done. She gave me the list of what kinds of tests I needed to you know get the consult going. She knows me, I am not going to wait so I just started doing everything on my own, pulling my own records that was needed, you know from my lupus doctor, my heart doctor you know to let them know that my lupus is okay. I had everything so when I went to the consult, I had all my paperwork, all my tests done.

Wow that is excellent, that means you had a great nephrologist to even mention it so early to you and to give you all the information

Yes, yeah, she is really good that way. I think for most people, they don't really even talk about it until you are close to that stage and you know I think earlier would be a benefit. You know because once that thing happens, people need to know what kind of tests they need to get on a transplant list and what kind of support they need or whatever. So that way when they go to the consult, they are not wasting their time getting the testing done

Absolutely because that is key, how long did you wait on the waitlist for?

Um I was part of the paired exchange so my husband donated on my behalf and we did the swap so I was on there maybe a year, maybe a year and ten months, a year and nine months.

That is a wonderful husband you have

Yeah, yeah he is. It is a stiff conversation that I am willing to ask someone to donate and you know we put it out there but you know there are a lot of people who were _____ and I did not want to push them to get tested, I just kind of let people, you know get tested for me, I mean on their free will, I did not want people to feel pushed into it, you know?

Absolutely

But my husband is always dependable but I was actually more worried about him donating um versus some of my other family members but it just worked out that he donated.

Oh that is wonderful

Please describe some of the obstacles you experienced when trying to get waitlisted

Um no I think at the transplant center um they really rushed through the information like um when I got there for my consult I feel like they rushed, I had a new, I guess, new NP that was doing the training so it was just like she was rushing through it, she never, she just started working for transplant so I just did not think it was that informative to be honest. I mean she explained how the waitlist worked but you really have to kind of be proactive and do your own research because I just feel like they are so busy I feel like sometimes they rush through it and I would just recommend too that people try one or more transplant centers because when I went to the second one, they were more thorough than the first place that I went to so I think that helped hearing the information again from a different transplant center.

And it is good that you knew you could go to more than one, you know?

Yeah that is true too, people do not know that they can.

Right, absolutely

Please describe any areas of the waitlist process that you found to be easy to navigate

Not really as I said I just tried to be proactive.

Please discuss any people in particular that were helpful during the transplant waitlist process

Um honestly a lot of the people we were friends with came through, I thought maybe my family would be more involved, it was kind of, the family support was not what I thought it would be. Because there were some people

who were against my husband donating and all the drama of that you, some people on my side they were just apprehensive about the whole thing. We have a lot of friends, we did one of those, I forget one of those website things.

Like a GoFundMe?

No not a GoFundMe, its like so people can help by signing up for services for you.

Oh ok

Cause like we needed people to drive us, because neither one of us could drive. I needed a babysitter because this was happening in the summertime. Um and I had a dog so somebody had to walk the dog so it was just so we used like, I forget what it is called, Care something. They could sign up to bring you meals, like helping do services for you and like that helped a lot

Absolutely

A lot of friends and friends of friends helped us more than our own family

Oh, sorry to hear that, it is good to know who your friends are during your times of need.

Yeah you know that's true, that is true, this process opened my eyes to a lot. The people I thought would come through were the ones who disappeared. And the people I least expected were so sweet to us, so loving to us and it was just amazing

That is wonderful, I am glad you found some good people, it is good you found others to help provide some support because without that, it would make it that much more difficult.]

Yeah, it was stressing us a little bit until somebody brought that website to my attention and I was like, you know what, I am just going to put it on Facebook and if people want to sign up to help us that is the easiest way you know people don't know what they can do, or how they can help and that was the easiest way to do it.

That sounds awesome. That would be helpful for other people in this situation to know about too you know

Yeah I put it a couple of times on the support groups on Facebook. That is another thing, the people in the support groups on Facebook, they been through it, they really helped too, they answered questions sometimes better than the doctors (laughter). Because they know that

I noticed that a lot of people respond on those support groups if someone posts a question

Yeah I think that was my best resource if I could say you know besides me researching and talking to my own doctor, like, that was like second to none. Like you know my husband donated and he had his own separate group and he was able to ask them a bunch of questions and you know that I couldn't answer or that the doctor couldn't answer really or like truthfully I would say. (laughter)

People who have been through it can tell you the nitty gritty (laughter)

Exactly, exactly

Please discuss any times where you felt discriminated against for any reason during the waitlist process

Um yes and no, I would say that a lot of times they dismiss your concerns and that just urks me, like if you have a concern, they just dismiss it or they compare you to the whole group. And you know if you have kidney disease, you have been in the health system for a long time and you understand your body and medicines might work and which don't. you know even down to how you take your pills, like just simply, sometimes they are not susceptible to hearing your concerns like they have a protocol and they just don't want to stray from that, I mean even the time you take your pills or you know what I mean, or times you get your labs done. Just to make it easier for you as an individual.

Absolutely

So that would be my only thing and I think sometimes too since I am a nurse, sometimes they I do not know, sometimes they get irritated if you have a lot of questions. So I think because you just know a little bit more, so you might be asking more about the mismatch and how does that work and what is the percentage of outcomes with this and that or with this type of medication vs. other medication and I think this just gets passed over

Describe anything about yourself or your personal situation that, if you had the ability to change it, would have made the transplant list process easier

With the waitlist I would say more research I guess because I realize now there are different regions um that have different wait times and maybe I could have went to a different state where I have family, you know. I think they just don't really talk about that very much like if you live in a certain region. Cause I guess on the East Coast the times might be long and maybe if you do have finances or family in another state, I think they should talk more to that and maybe you could go somewhere else and get listed faster besides just going to another hospital in your region, you could go outside of your region, you know what I mean?

Is there any advice you would give to other patients trying to get onto the transplant waitlist

I would try to get on even if you have reservations with it, whether it be financial or support, because I know at the dialysis center there were a couple of people who choose not to get on the transplant list and from the ones that I do talk to they said it was because of their age, or maybe they did not have enough support or you need all this financial money to get on the list, um I think you should get on just in case and not be so reserved about it but I think that comes with education too

Absolutely

Please discuss any areas that you feel could have been improved in order to make waitlisting easier for you?

Yeah, yeah I feel really bad about the people who cannot get on the list because I have heard a lot of people who say they financially they cannot do it or they do not feel they have the support to do it

Well and hopefully putting something a little more standard in place so people know what resources are available to them you know

Yeah

You know because they find dialysis is too hard

I can tell a difference, my heart was so weak before the transplant, I mean like even now, I still get short of breath but it is so much better than when I was in dialysis and before it was hard to even walk a little bit.

Right, it gives you back some quality of life

It is a different way, definitely not the same life, there are side effects which I feel they do not discuss that either I think of transplant. You might think it is a cure all but it is definitely a new life, you will not go exactly back to your old life but I think they not prepare me for that, just knowing that your life is still changing, you will not be completely back to where you were, but just know it is going to be a new life.

Absolutlely

Yeah, I think this was kind of heart breaking for me in the beginning, I was like oh, this was not what I expected.

Yeah

I wanted to be back to my old self.

I just want to thank you for allowing me to interview you and hear your story, I learn a ton from every person that I speak to and yours was no different, I learned a ton from you and I really appreciate that

APPENDIX D: INTERVIEW THREE

Introduction

Do you mind if I record our interview since I am driving and this way I can transcribe this accurately. I will delete it once I transcribe it.
Yes absolutely

SO I just have questions mainly regarding, my research project for the PhD program that I am in is a lot to do with the waitlist and how difficult it is for people, how long some people have to wait on it versus others and just kind of learning what, there are a lot of statistics out there but I wanted to hear from the people themselves what it was like for you and what your experience was like cause I feel like you get a better understanding of the problem that way, you know?

 Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

YEAH so for me, things moved entirely fast

Oh wonderful

It is not typically what you hear I imagine

NO

Um my whole process from when I was diagnosed, I never even went on dialysis, but from the time I was diagnosed to the time I received my transplant was less than a year

Oh my goodness, that is excellent

Isn't that insane?

And you never had to go on dialysis?

I didn't, no, so I was diagnosed I guess, it was three years ago, so I guess it was in the beginning of 2016.

Ok

Like very early January, um and we tried a bunch of things to try to improve my GFR but that was not working so by like March, and they were saying we need to start, actually it was probably even in January when they were saying it was pretty bad, we are hoping to correct it but you should probably start looking into getting on the transplant lists. You know that process takes a while so I think by the time I actually got onto the transplant list, it was maybe April May timeframe. I got on 3 different lists and I know not everyone can do that and but I got onto the one that would be closest to me so that would be Chicago. Um I think I did UIC which is the University of Illinois Chicago. Um and actually, the UNOS President, at least at the time, was one of the surgeons there and so I met with her which was kind of cool

Oh that is awesome

Yeah and you know my doctor, had um recommended, just based on where we are in the mid-west, he said well why don't you try to get on the Wisconsin list, it is not that far. Um a couple of hours away and also get on the Iowa list, University of Iowa and the University of Wisconsin. And they are both drivable and the decision to try those was based on how the system works with the geography borders and he is like, so often the waittimes are you know, so the waittimes in Chicago are insane they are five to seven years I think, at least that is what I heard but I obviously didn't experience it. Um and then he said, and what I heard from different centers in Wisconsin I think on average is about two to three years but obviously it is just a different population, being from Chicago or New York or anything like that. And similarly in Iowa the waittimes were about 1 to 3 years. Um so I got on those lists and I even turned down one in either June or July from Iowa as it was a bit of a high risk one.

Ok

Intervenous drug use so, based on my age and other health factors, and the fact that I would need a transplant but wasn't on dialysis um they scored me pretty highly and they sort of said, well the advice at Iowa, or really all the centers was that because of all these benefits of your otherwise healthy body, you should really be waiting for the cream of the crop in terms of the quality of kidney you got

Ok

And I mean I am still early in the process so it seemed fine to wait, I am sure I would think differently about whether I would have accepted a high risk one if I was a couple years into the wait

Um huh

Um and another thing kind of pushed me up in terms of priority on the list um I would get a kidney quicker than expected no matter where I was because I had a really high antibody level so my PRA score was really high. Um I think it can happen often in women, I hadn't had any blood transfusions but I guess if you had children, there is a chance that your blood and their blood kind of mixes and because it increases your antibodies. Um and it sounds like mine was 99 and because of that I got a lot of extra points or however it works, a lot of extra priority on the transplant list and that was a new thing. I think by the time I actually got the transplant, even now, I don't think there is much data out there on people with very high antibodies and how well kidneys do and how long the grafts last. Because from what I understood, before they did not prioritize these people and then people like me, were very low on the list because there was always the thought that well we can give her a kidney but because she's got so many antibodies, or like because they think the chance of rejection is higher so why waste a kidney on someone like that

That is a sad thought.

Yes it is a very sad thought but things changed when it was about my time to get my transplant. I think within a year or two of that, they started refocusing I think they had redefined the regional borders and um they kind of thought that people like me should not be deprioritized but rather be pushed to the top of the list. Um because you have the ability to really miss close matches you know. So you know whereas I am not saying anybody but whereas how you match is obviously important but um because of the antibodies, it was already known that nobody in my family or my husband's family could donate to me so that would always, I had a couple of people who would donate but I would never have thought that their kidney would have to be some sort of swap system

Yeah like a paired exchange

Yeah, and so um because of the antibodies they were like well these people should be at the top of the list because any kidney that comes in that is a match for that person, they should get it over someone who might be 4th or 5th on the list but don't have that antibody issue. Because the likelihood of me finding a match is just slimmer than for other people

More difficult I can see

Yeah um so the other factor that made mine go quite quickly, my doctor, my nephrologist had actually talked about this a little bit, the reason the waitimes are shorter in Iowa or Wisconsin a lot of rural areas.

What kind of side effects are you dealing with?

Its kind of well you know I mean obviously you are susceptible to a little bit more and um your immune system is not what it used to be. I get a lot of hand tremors, tons of hand tremors I mean to the point where my fine motor skills are absent, they are terrible, I cant open packaging. I have little kids so just think about how much packaging there is to deal with in my life (laughter)

Yes I can understand

Yeah so it is kind of annoying um I get a lot of foot cramps, these weird foot cramps that I heard can be very common as well.

Yeah foot cramps especially when my husband was on dialysis that was the toughest, cramping was insane

Yeah you are right about that, it is. What else is there? There is another main one (side effect) but I cannot remember what it was (laughter)

Too much to remember

Yeah I do get tingling you know in different spots of my body

Oh my that is difficult

It just comes and goes, yeah but it is not life impacting at all, it is just weird things, totally weird things.

Yeah I can understand and I am sure you thought once you got the transplant you would be good

Yeah exactly right

APPENDIX E: INTERVIEW FOUR

Introduction

Hey how are you

Good and I am glad we are finally able to connect and I apologize for keep missing you

You are fine and I was trying to get the time zone situation correct when I called you

Oh I get it, I have a cousin who lives in Florida and he is forever calling me at midnight and I am like stop doing that

That is exactly what I was trying to avoid.

Well and the last time he did that, I was like hey you are a cross country truck driver, you should know better

(laughter)

Right there is no excuse at that point (laughter)

Absolutely.

So how are you doing, are you doing okay

I am well thank you and good for you for pushing forward with the program and finishing you thesis and doing all

that good stuff as it is not easy

It is not easy and will hopefully be done soon (laughter).

So I have a list of about eight questions to ask as I am trying to learn about each person and their personal

experiences as I am getting great information from each person. So if you have some time I could get started.

Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

Sure um I was placed on the waiting list and I waited 7 years, I never got a single phone call, nothing and then at

that point my GFR was down to 7 and my husband stepped up and said I want to donate my kidney.

No way

So I said oh alright so I was fortunate enough to never go on dialysis and always thought well some day I would get

to the top of the list.

Never on dialysis?

Nope um um. Yep that was a relief.

Absolutely because 7 years is a long time to wait.

Yes yeah, well I did a lot of things in between to try to slow the progression of my disease. I was actually diagnosed

15 years before I received the transplant

Wow

And so when they told me I had chronic kidney disease, I did a lot of alternative sorts of things. I checked with my team, I went to the doctor, I did all my labs, I did all the things I was supposed to do. But I kept saying, okay I would like to try to do this and they just shrugged and said, oh well there is no research on that. I said fine but there was nothing contraindicated and so I ended up doing acupuncture and tapping EFT and I consulted a couple of nutritionists to discuss things because nephrologists had specificially told me that diet does not make any difference (laughter) so I reached out to dieticians to see who could help me. And just a lot of things like that, prayer, medication, hands on healing, all those sorts of things, whatever it was unfortunately I did not do a single subject design on myself so I cant tell you what worked.

Right, right (laughter) it is very difficult to know what worked right?

I know because I just did it all at once, I did not do it in a clean, scientific way, I just wanted to be better, I did not necessarily want to change the world of research.

Right and to avoid dialysis for that long is wonderful

Yes, uh huh

And your husband was a perfect match?

He is a type O so he is a universal donor

Oh wonderful

Yep so he matched, he would have matched anybody because you know now they do not look for a blood type match that much anymore.

Right, right it is more about all the other testing and all of that

Yeah

Please describe some of the obstacles you experienced when trying to get waitlisted

Nope uh I remember my nephrologist looking at me and saying you are very compliant patient and I came home and told my family and I remember laughing as I did not think I was doing anything right. I began to realize how important that word compliance was. What he was saying was, you make all your appointments, take what we prescribe and do all sorts of things and you are showing you are responsible enough to get a kidney and I just remember thinking he thinks I am going to do what he says (laughter).

As long as you are listed as compliant that is all that matters right?

Yep (laughter) Hey here I am not knowing the deep meaning of that word in the transplant community

Please describe any areas of the waitlist process that you found to be easy to navigate

I know you said there were no barriers for you but how did you know you needed to get on to the list, was it mainly driven by your nephrologist?

That is the good thing my nephrologist did he said you need to go and talk to the transplant team. And so I had my first eval when I was not at 20% yet but they ran all of the tests and so as soon as my GFR because we were doing labs, was at 20%, they said okay so here we go

So they did it really early for you so that is wonderful

They did and I have to praise the nephrologist for that because he screwed up some stuff but he was absolutely right on about that one.

Please discuss any people in particular that were helpful during the transplant waitlist process

Besides the nephrologist and obviously your husband as you had previously mentioned?

I also had a friend, a friend of 30 years and mother or my godson who offered to donate and she flew all the way from Virginia to have her testing done.

No way

Yep but that didn't work out. But that was very heartwarming to have her do that

Absolutely. Just the thought and the gift all in of itself is wonderful.

Yes absolutely, I have a good friend

And how is your kidney now, how long have you had it

My transplant was April 14th 2016 and it has been working fine since um my last creatinine was .88 and GFR of 60 and above on my lab reports. I am sure I could go figure it out with the National Kidney Foundation and their calculator (laughter)

Please discuss any times where you felt discriminated against for any reason during the waitlist process

Well this is very subtle

OK

Well I started the process when I was about 58 and as I got closer and closer to 65, I kept making sure my team knew I was still working

OK

And I worked up until the day before my transplant and I had a sense, and they may be totally in my head, but I had a sense that since I was still contributing to society, I was working and paying taxes and I was a girl scout leader, and this may have given me a slight edge over somebody who didn't do those things or who couldn't work. Well that could be all in my head

Right right, I think about those things too

I know but there was no overt discrimination that I can think of

Ok

Describe anything about yourself or your personal situation that, if you had the ability to change it, would have made the transplant list process easier

Um no because I didn't really mind waiting, I didn't feel badly. The only symptom I had was that towards the end I was feeling more tired.

Ok

But I have talked to people and I have read things and I know there are some really you know really life affecting symptoms that you can get, metal taste in your mouth, swollen legs and all of those sorts of things and you cant function and a friend of mine talked to me about being on dialysis and saying that he couldn't think and I, I didn't have any of those

Oh that is wonderful. Do you have any side effects now from the medications or anything?

Absolutely. In fact my health is worse than before transplant.

No way

Oh yeah because now I have diarrhea from one of the meds, I have lower back pain which is another side effect of one of the meds, and I am so tired, even more tired than I was before and what I have done is I have exchanged length of life for quality of life.

Wow

So yeah transplant did not improve my life, it worsened it.

Oh I am so sorry to hear that and I feel that many people just think that when you get a transplant, you are going to be healed and feel amazing.

Hey I gotta tell you I thought I did my homework, I talked to two people, one was a friend, one was somebody that the National Kidney Foundation paired me up with as a mentor, like a peer mentor

Um hum

And they both told me, you just wait, the minute you wake up from your transplant you are going to feel 100% better, it is such a wonderful feeling, all of a sudden you feel healthy again well what I didn't realize was that both of them had been on dialysis.

I was actually going to say it could have been because they had been on dialysis.

APPENDIX F: INTERVIEW FIVE

Introduction

Hello Janice this is Melanie, how are you

Oh pretty good hello Miss Melanie, how are you doing?

Good, good how are you doing?

I am doing pretty good, yeah pretty good

How have you been feeling

Pretty good, I just came back from an amputee bowling group

Interesting

Yeah it is run by one of my friends who is a kidney patient and she got a transplant and all of that you know kind of goes together because the diabetes, high blood pressure, amputation, it is kind of like one big group of people

Absolutely, that is wonderful that you all get together for a bowling league

Yeah it was for the students who make prostetic legs and stuff who were graduating so the teacher took them out with the amputees and everybody just started celebrating

Oh that is amazing

Yeah what they do, is like they take like my friend Cheryl, she is an amputee, and what she does is she goes and lets them practice on her you know making a prosthetic leg because what that does is gets them used to training on how to do it

Right

So they need amputees to practice on so they can become good at it

Wow that is amazing and she also had kidney disease too?

Yeah yes she did, she had a kidney transplant, yes yes she does

Oh man and you as well?

Yes yes both of us kidney transplants. She had a lot of similar problems as I did and I kind of you know helped her through it and she helps me a lot with the support group

Wow that is wonderful

Yes

You and her attend a face to face support group?

Awesome, I did not know that, I know you were the point of contact for that group but that is wonderful

Yes I started the All Kidney Support Group as a means to bring more awareness because every year since 2009 I started doing World Kidney day and educated people on kidney disease when diabetes and blood pressure issues are two of the number one causes and you know I would get speakers and doctors to come in and yhou know talk to people and different things you know and from there then I moved on and created the support group and then I decided to become a 5013C and you know a non-profit and we just keep growing and growing

Wow you are an amazing advocate

Yes yes I just thank God for all of this and the contacts I make because you know it is amazing how you just meet people. You know in the dialysis center the other day we were doing a live feed and a lady came to the door and it was like, she was just standing there and nobody was in the lobby but me and she was just standing there and I was like doesn't she know she can just ring the buzzer so I just kind of like looked at her and then I said let me just open the door for her.

Oh that is sweet

Yes and I just opened the door and she asked if I worked there and I said no and she said I know you, I know you do the group. And I was like, you do? She said yes and she said she had made some blankets for kidney patients. She said that her dad was a kidney patient and he would always get cold so she made these blankets to give out to the kidney people. And she said I got about 10 blanket and I was like Oh my God, Oh my God.

That is so wonderful

Yeah and she said and you can have all of them. And I said I will make sure the center gets one and I told her I run a support group and I let her know that not only this center but every center that I go to will get one of these blankets. Somebody at that center gets a blanket

Awww you are amazing

It is not me (laughter) there was nobody around, just me. It was like divine timing

Right it was meant to be.

It was meant to be and so you know I gave some of the people, you know and then when I gave a lady the blanket a lady came in in a wheelchair and she was from a nursing home and I said you are going to be the first person I gave

one to. And I gave her a blanket and the way she looked at me, her eyes was, it was just like, you know how when you give a baby a candy or something like that

Yeah

She said, I could feel with her eyes, they were just so thankful.

Oh that is so rewarding

Yeah and she was like you are giving me this? This is such a beautiful, you are giving me this? You giving me this? And I am like yes you deserve it.

That is amazing

Yes that was just, that was just something, and those eyes, oh

How rewarding this was, you can change a life just from a blanket

I know because she gets so cold, and she said that most of the people from the nursing home don't have no blanket.

Oh you are kidding, that is so sad.

Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

December will be 6 years

Wow that is great

Yeah 2013 I got mine

How long were you on the list for?

I was on the list for 14 years

Oh my goodness

14 years

Were you on dialysis that whole time?

That whole time. I did in center, I did peritoneal dialysis, I went back to in center, and I was like oh my God, in center was like oh I couldn't take it. And then my sister saw something on the news about this machine called the next stage machine and she gave me the article from the newspaper and I called every name on that list who to get an idea. I told them I need to know about the machine, I need to know about what it is, what it is called, how can I get it, what is goig on with it and they were like you know well we don't know, we don't know what the focus it. You know I did not give up until I got that machine

287

You know you do not seem like somebody who would

So they finally got me in and they said that in Florida the closest place was Orlando so I told my doctor about it and I told my doctor about it and I am like look I am fittin to move to Orlando because I want to do this dialysis treatment and I called Orlando and Orlando was like there are so many weeks of training. I was like okay that is fine I will do it because I got to drive there everyday and so then I found out that it is in North Clearwater they have it. Ok me and my friend went to Clearwater because if they have it, then that is where I got to go.

You made sure you went there and got it

Nope what happened was my doctor did not want to leave me. Like my nephrologist because I would have to sign off from him being my nephrologist. And he said Janice something is going down the um the line here. He said there is a maching that will be given out by Davita. He said if you give me a year they were thinking about doing the Next Stage, he said if you give me a year, you will be one of the patients on the new machine and I told him well you need to be the first one to try it. (laughter)This was a test trial for them, I had already talked to a nurse and got her all excited about it. So she would be the nurse and I already had everything in place, you know by talking about it. And I was in business school at the time, working on my MBA and I said look I said you would be the first doctor with this ne hemo and look at all the patients you could have. I said you would be the first doctor and he decided to do it (laughter

Oh that is wonderful how long ago was that, how long ago were you on the home dialysis

I was on there for about 6 years so I was on 3 years on peritoneal, 3 or 4 no 6 years on home hemo, And then the rest of the 4 year years was on in center

Oh wow

Yes so that is about 14 years.

That is a long time to be waiting

Yes a long time

Please describe some of the obstacles you experienced when trying to get waitlisted

Yes so I knew with all of the things that I went through I said you know I gotta be able to give back to the community and then with my transplant in 2003 when I got ready to get onto the transplant list, they said you know

you gotta lose weight and all of that sort of thing and I said ok no problem, I said I am going to list on all the

transplant lists. I will go to Tampa General, I went to Gainesville, and I went to Miami

You listed on all three

Yes yep

Where did you reside, where is your home located

I am in St. Petersburg, FL

And which list did you finally get your transplant from?

Miami

Wow

Yep at Jackson Memorial Hospital. I had to drive back and forth to Miami to you know get on the list, you know

you have to do all the appointments

Yes all the appointments

Yep you have to be at all the appointments and I tell people you have to be at your yearly check, I tell people you

know they would lose my check, the doctors would lose my check I sadi to them get a copy of everything, every test

you take, get a copy, keep a copy so whatever transplant center you go to, when they say the doctor did not send in

your echo or your ekg, I got it.

Laughter, you got it

Yep and when you go in with your notebook when you go for your transplant, you make sure you know because

there is lack of communication. You know in Miami Jackson, they speak mostly um Spanish, Cuban and I you

know they would lose stuff, they couldn't find stuff,

Oh man

Uhh it was really something.

Allo fthat on top of trying to get healthy and getting what you need

Yes and in 2013 they said I had calcium in my milk ducts in my left breast so I said well me and my doctor talked

and I said well I want to stay on the transplant list I said so go and remove my left breast.

Wowo

So I talked them into removing it but in the process of removing it, the doctor left a capillary open in my chest

No way

Yeah and I started bleeding so I bled and bled and bled and bled and so it was a little small capillary and he kept saying they gave me heparin and the doctor didn't want to see me. So I kept getting bigger and bigger and I am like why is my arm getting big and everything and I remember laying in the hospital bed like I feel something dripping down the side of my body and the nurse was like no Ms Sterling, we have nothing, but it was the blood it was the capillary it was small and between my skin and my tissue so I could still feel it

Oh so you could feel it inside like it was dripping

Yes like it was dripping because I had got over 25 to 30 transfusions and plasma

Please discuss any people in particular that were helpful during the transplant waitlist process

And then my nephrologist, that was my third year on the transplant list and my nephrologist say you took your breast off to help you but I am telling you, it is keeping you from staying on the transplant list. Because I kept getting blood, kept getting blood, now he kept me alive but I kept getting blood and it will go up and then drop and up and drop

Oh my goodness

I was in the hospital for over a week or so and they started looking at me in the bed and they started I started looking at the machine and my blood just kept dripping and dripping and dripping. The little JP drain would just fill up with blood, fill up with blood and so I was just sent back to the ICU room and the doctor said look and my nephrologist said we should call the administration of the hospital because something is wrong and they are not owning up to it. So I called and told the doctor that if you do not come see me, I am going to file charges. I called the hospital and I had to say that and then the doctor came in and said what is going on Ms. Sterling, I need to be giving you all this heparin, I have a very busy schedule. Whats going on? I said look I am not afraid of you, I said look get over here. The lord has told me you need to fix this problem so get over here and pray, you only a man so come and lets pray so you know what to do

And I said give me your hand so we can pray and I prayed with him and I tell you you talk about a humble man, he said Ms. Sterling I am fittin to clear my schedule right now and we are going to go in and see what is going on

Oh man

So when he went in, I went into surgery, that is when they had them small little cell phones. Well I stuck a cell phone under my thigh so it was right with me because I was so scared they wasn't going to do right I wanted to be able to call my family right away

Oh my goodness

So when I was in surgery, because I had so much blood and fluid in me, they couldn't hardly get the IV in. and they kept sticking me and trying to get me stuck and all of this so in the process of when they finished the surgery, the phone rung and when I woke up. (laughter)

And so the doctor looked at me and said Ms. Starling, where is that phone. I said oh don't worry it is just my sister, she is calling me. (laughter)

You had to tell them the phone is under my leg

(Laughter) yep I know right, and so they were like we are almost done here. He had brought in like 5 other people to make sure he got the surgery correct.

Oh my goodness

And it was that he had left a little capillary there and it was now fixed but the damage had been done because I had all of the antibodies and I had already had all the transfusions. Yep so that is why I had to wait so long, going to Miami, going to Shands, going to Tampa General.

Ugh

Please discuss any times where you felt discriminated against for any reason during the waitlist process

Tampa General said I was overweight I was too fat. So I wrote them a letter telling them that I am not too fat, I said you are discriminating against my fat (laughter). Iwas so upset and they said they would bring me in and look at me and they did. They said you know you are right, you are not normal fat, you do not have a lot of fat around your belly you right but you still have to lose the weight (laughter)

How much did they say you had to lose

Well I was like 230, 240 so they wanted me to get down to 190, 195

Oh my goodness

So I went ahead and had the lap band surgery

Oh ok

So I went ahead and had that done and then I lost you know the weight and I was able to get the transplant, it made the transplant go even better.

I am glad the transplant is going well for you

It is, it has its ups and downs you know

Yes

And I continued to educate myself by going to conferences and I learned about IVIG to help lower antibodies and I spoke with the doctor about it at Jackson Memorial and at that time, it had not yet been approved by the FDA but once it was, I had a nurse who drove up all the way from Miami it was on a Saturday or whenever she could to come give me the IVIG medicaition

Wow how amazing

Yeah so I did that for almost 2 years and once they kept giving me the medicine, this was back in 2013, this was when my antibodies was low enough and I could get a kidney transplant

Wow

Now I have had one they tried to change my medicine so I went into rejection so I had to do diaphoresis

Oh my goodness

And so last year, they did the same thing and so now there is the BK virus but for me I have the BK but is in my bloodstream and not in my kidney and so with the BK they say it is something you have to look out for, because the rejection level cause I am taking the antirejection medications. This is why I had to have the kidney biopsy. I had like 4 to 5, almost 4 or 5 kidney biopsies where they tested my kidney to see if the BK is in the kidney but the BK is not in the kidney

So now in between figuring out what is the dosage of anti rejection I have to take since I do not have the BK virus all the way up to the thousands. They don't want me to get up to 5000 or something. So I still do labs once a week and they still check me for the BK virus to see what is going on with my labs

That is a lot of work to get labs every single week too

Oh no not each week, I meant once a month, yeah every week girl I would be like "whoo"

Laughter

Yeah and I am anemic, anemic, that is another problem I have

Oh

I have my hemoglobin has always been off which was another sign of my kidney disease. That is one of the other things I have had to deal with but you know I am still here and I am still happy

And you are still advocating which is amazing

Yes I am advocating that is right you know other people they don't have it easy. Just like I went to a conference last week and we have a meeting once a month and you know I met a woman who stated they had built a dialysis center um close to my group and I am thinking about inviting her into the group to a meeting here you know which could be great for some of these people

Oh that is wonderful

So um yeah she said that she knows a person that is homeless on dialysis. I couldn't believe being homeless and on dialysis.

Wow and unfortunately if you get sick, you may not be able to avoid that sometimes

Right, you right. She said she has many people on dialysis that are homeless

This may be a population that not many people think about

Right, right, she said she is trying to help them because most have diabetes and dialysis people that are diabetic and they are not able to control it, plus being homeless and just does help you know

Is there any advice you would give to other patients trying to get onto the transplant waitlist

I know you already said to make copies of everything which I think is great advice

Oh yeah copies of everything. And multiple lists

Multiple listing is something not many people know about and that is why you educating everyone is a great

Yeah I am always telling people to get on many lists, I tell them about the new centers in Largo, there is one in Orlando, you got Shands, you got Tampa General and I think they just opened a new one in Ft. Myers.

Oh wow

Then there is Miami but the thing about Miami is the language there. You got to be patient enough to deal with the language barrier and the paperwork and the people, that is with any transplant center is the paperwork and the moving around of the paperwork. Not finding it, they say they got it, oh the fax was down, the fax was broke that day. That is one thing that people don't know. One man thought since he went to talk to Tampa General, that bam

293

he was on the list. It was like, well are you doing your yearly tests, your heart stress tests, etc. The communication breaks down. Are you doing your physicials, for a woman you have to do your breast tests, your pap smears, they don't care if you have had a hysterectomy or not, they still want you to do it every year

These are all things that if you don't get the right education from your nephrologist or your center, you are left in the dark

Right and then another thing that people don't know is that if you are at a 3.5 creatinine, or predialysis, CKD, you should automatically start going onto the transplant list.

You are right and that is where some people get missed. They can absolutely start the process early

Right you could start that process, I have had people, who ask this and I don't want to say this but the doctors are funny about this. The doctors are funny about who they tell, if you got good insurance, then they will let you know and if you have VA or if you are a veteran or if you are a business person, someone with a lot of money, they are going to let you know, you cant avoid a transplant and they start doing the tests. So as soon as you get close, you get on the list, you can get a transplant and avoid dialysis. But there are people that they say oh well, you have to be on Medicaid or Medicare for at least a year or year and a half before you can do anything. Well who is in charge and who is the one decided which people get on the list, not get on the list, you know insurance company, the doctors you know and it is not fair.

  Now they are saying you got to have at least 3,500 in the bank and you got to show it. You gotta show it. And that is crazy and you know the thing about it is they tell you that you gonna have to be able to afford these drugs, well you know some people are, some people don't but you know it is just crazy. For them to make you say you need to have this money in the back

Right, before you can get on the list

Before you can do something that can change your life. Now I tell you, that is stress enough to make you to get a heart attack. You know, they just telling you to go on dialysis and you know there is no hope because you don't have that kind of money. And then you have to get up and go to work, so I can understand why some people just don't want to be bothered.

And they don't try to get onto the list your right

Yep they don't try to get on. That is something else I learned from the workshop, there is something called Lord I cant remember the name but some kind of kidney where like if you are like 60 years old instead of getting a kidney from someone that is 30 or 25, they give you a kidney from someone that is like 40. So they are disregarding those kidneys or they are just tossing kidneys from like people incarcerated because they are probably thinking that they don't want a kidney from someone who is incarcerated becaasu they might this or that, you know

Yeah

Those kidneys are going to waste and there are people who need um but you cant get um because your transplant center is already discriminating against you because maybe you are an African American, you have Medicare, you cant afford your 20% and plus you need to have your 3-5,000 dollars in the bank. Then you gotta go fundraise

People are afraid to donate because they are afraid they are going to kill me off, put me on ice (laughter)

That is why it is good that you are educating people

You are right

Please discuss any areas that you feel could have been improved in order to make waitlisting easier for you?

Communication most definitely and a more fair and equal system. Also more education like I try my best to educate in my group and in the community but many people do not know what is out there.

APPENDIX G: INTERVIEW SIX

Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

Yes First I was put on dialysis and my doctor told me about the waitlist process and all the tests I would need to do in order to be put on the waitlist.

Ok how long were you on dialysis before they mentioned the waitlist

I was on dialysis for a little over a year

How long did it take for you to get all your stuff in to get onto the waitlist

Oh my goodness, it took a good couple of months, close to three months cuz where I live I had to travel an hour away to get the tests done

Oh that is hard

Yeah

Did you list at more than one center?

Just listed at the one center

How long did it take for you?

I was on dialysis for a little over 3 years, when I found a donor, from the time I found the donor to the time of the transplant it was about 5 months.

Ok so total like 3 ½ years?

Yeah

So did you find your own donor or was it a deceased donor

She is a living donor and she is 6 years younger than me. Um I found my donor through the news because I posted on craigslist.

Oh wow

So that is how I found my donor through craigslist and a lot of people found me on the news and they contacted me and the transplant began

That is wonderful to find people that are willing to give you their kidney

Yes definitely'

I know you said that getting onto the list took you a long time Please describe some of the obstacles you experienced when trying to get waitlisted

The lack of communication with the transplant center, always getting mixed up about which test I got, which test I need to get, which test I don't need to take and with the lack of communication and getting everything mixed up, the test I took expired so I had to go back and retake some of the tests

Oh man

Please describe any areas of the waitlist process that you founds to be easy to navigate

Communication made it all difficult because with the transplant center, you cannot just pop up there with out an appointment so of course I was never going to drive an hour away to not be seen because I didn't have an appointment you know. So it was definitely hard with the lack of communication and then you know I didn't know that anyone could apply at any transplant center.

Which one did you end up receiving your transplant at, which state are you in

I am in Florida and I got my transplant in Miami at Jackson Memorial

Please discuss any people in particular that were helpful during the transplant waitlist process

Family and friends, and there was this one lady who was like the nursing coordinator or something, I cannot remember her title but she was basically my transplant coordinator or whatever, and she was very good. When she came on board and started dealing with me, I did not have any more problems from that point on. She was awesome both before the transplant and even after the transplant.

That is good to have that follow up and one person you know you can talk to

Yes

Please discuss any times where you felt discriminated against for any reason during the waitlist process

Well when my daughter went through the testing and then they found out we were on the news trying to get a kidney. They denied us the psychological evaluation they denied it so they denied the transplant stating that she answered the questions too fast and they believed I was paying her to donate.

Oh my so how did you get through that

My mom made a phone call and went off on them, and I do not know what she said but it helped

Is there any advice you would give to other patients trying to get onto the transplant waitlist

Definitely do your research and do not limit to just one hopefully you have a good support team but definitely do your research, there are a lot of things out there that they will not tell you.

Ok

Please discuss any areas that you feel could have been improved in order to make waitlisting easier for you?

They just need to be better with the communication because I probably would have been on the waitlist a lot sooner if the communication was there to where the tests didn't expire

Ok understandable

Because I did not even know that some of my tests had expired until my kidney transplant date was set so basically like 4 days before my transplant I am running around and trying to get my tests done rather than just waiting for my transplant.

Oh man, were you ever removed from the list at all

No

Oh that is good

Well my doctor told me because I was young, I was about 24 or 25 because I was very young and I was on dialysis for a long amount of time already, that we would need to hurry up and try to get a new kidney because when you are on dialysis for a certain amount of time, it can start causing heart problems. So we knew one way or another we had to get this transplant.

How long have you had it for

7 ½ years

Wonderful

APPENDIX H: INTERVIEW SEVEN

Hello sir

Hello

So basically what I am trying to do is kind of get everyone's story about their waitlist process so first I just want to ask

Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

Oh ok I had 2 kidney transplants

Ok

So the first one well I started, well mine is a little bit different because I was not in America when I was having kidney issues

Ok

So like when I came to America uh like in like 2000, sorry 1991, and uh I was waiting for dialysis and already I think after a couple of years I go on the list and then I waited for about 4 to 5 years before I got called for the transplant

Oh ok, so you started dialysis in the other country?

Yes

Which country did you come from

Well I come from West Africa

Ok

But I lived in Dubai

Ok wow

Yes

So you started dialysis over there first?

Well over there they were telling me that transplant was not an option for me because I have some other issues but then when I came over here, things just turned around and they were like yeah you can get a transplant. Whatever you know

Well that must have been good to hear

Oh yeah you know and then so like after I went through the workup and everything, I went to the doctors and I got

everything tested and then I got on the list. That took, sorry that one was a long time so I don't really remember

but…

Yeah

But it was just maybe around 6 months, maybe less or more

Ok

And how long did that kidney last for

It lasted for, I would say, it lasted for about 7 years

Ok

And then you went back on dialysis and started over

Yeah then I got on the dialysis and then I moved ok well at that time I had moved to Minnesota. Like from the

middle east I came to Minnesota and that is where I was living. And then I had moved to over to Florida and then I

think in 2004 I started having problems with that kidney. I think actually about 2003 I started having issues, 2004 I

got back on dialysis and with that short time, I got put back on

And you waited how long for the second one?

That is what I am trying to remember, because I got in 2004 (counting) yeah 4 years because in 2007 I got the

transplant

Oh an so far so good?

Yes so far so good

Oh that wonderful, because that is longer than your first one

Oh yes, oh yes

And how are you feeling

Oh yeah feeling good

So I know your first transplant was in Minnesota and your second one was here in Florida

Yes, yes

Ok did you list on multiple centers?

No just one in each state

Please describe some of the obstacles you experienced when trying to get waitlisted

I do not really recall anything

Not anything ok, ok

Please discuss any people in particular that were helpful during the transplant waitlist process

Oh my nephrologist and everyone to me to do this, this, this, have to get this thing done. Ok, done next this. My family has been always around. Like in Minnesota when we moved it was just me and my sister I, my parents used to come back and forth from Dubai to here. You know because my dad had a business in Dubai so

Ok

I used to live with my cousins in Minnesota, I have a few cousins. Family support has always been there for me so I have never any issues about that

Well that is wonderful because I know it is hard to make a move from another country especially for medical care

Yeah

Please discuss any times where you felt discriminated against for any reason during the waitlist process

No, no not at all

Well that is wonderful

Is there any advice you would give to other patients trying to get onto the transplant waitlist

Differently? I mean ok, just to come off of the subject where was the survey located

On the online support group

Oh yes okay, I do not know if you have been reading it much but there are a lot of people that are reading and they are so depressed about dialysis and stuff like that. If they are going to be that way you know it is going to be hard for them so it is better to just be positive you know

Yep from age 16 I was on dialysis and I been through all that so I mean people need to be positive, stop being depressed about it if you not getting a transplant you know, hopefully some day your day will come

Absolutely

Transplant is not and easy thing you know because you have to take so many pills and stuff like that

Yeah

It is just a state of your mind, you know, that is how I look at it you know ok I have many other medical conditions, you know, but things could be worse you know

That is a good outlook on life

Yeah so, yeah that is about it

I appreciate your story as yours is very unique

Well see over there at that time, it was not an option for me because transplant was still new where over here they I think it had already started.

Oh yes

Thank you

Ok no more questions

No sir I just hope all goes well for you and you continue to feel good.

APPENDIX I: INTERVIEW EIGHT

I have about 8 questions to ask you as I am doing my research on people's waitlist experiences and instead of just getting numbers, I like to hear people's personal stories just so we can get a better idea of what people had to go through

Ok cool no problem

First of all how are you feeling

I am doing good thank you, very well

Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

Um yeah definitely so the first time I was uh, well lets see, I had two transplants so do you want me to give you the times for both of them?

Sure if you remember them as I don't know how long ago they were

Yeah so the first one was 7 years ago in 2012 and I was on dialysis for 14 months and I was on the waiting list for shorter than that because I had gotten listed after I started dialysis

Ok

Because I had no clue I was in kidney failure and by the time I was in kidney failure I had to start dialysis. By the time I found out I was in kidney failure I had to start dialysis and we had no idea what the process was at that point so I was on dialysis for 14 months and my mom was my donor and that time I had a living donor um so I want to say my waitlist time from the time I found out I was um probably only a year from the time I found out, I am sorry from the time I was listed to the time I received my transplant

Ok

Um so we tested a few other people in between before my mom, um my brothers had to be tested for the disease that I had so to rule that out. They don't have the disease I have so they were able but um they were not matches. So my brother was tested, my dad was tested, and then a friend was tested and none of them were compatible and mom was tested and she was compatible however she had an iron deficiency so before we could go through with it, she had to go through a few months of iron infusion and have constant good numbers with her iron before she could donate.

So then my transplant was in May of 2012

How long did that kidney last for you

Uh well it lasted until July of 2016

306

Ok so you got 4 years out of it, and then did you have to go back on dialysis after that?

I did I had to go back on dialysis in July of 2016

Wow

Um I knew prior to that that I was in kidney failure because um I actually got listed, I got listed before I had dialysis this time around.'

Ok

So I was listed in February of 2016

Is that because you knew or did someone tell you to get listed

Um yeah my doctor knew I was going to be in failure, well I was in failure but I did not need to immediately start um dialysis because I was doing okay but they knew it was coming. I was a terrible patient to be honest and the reason I needed another transplant was because I was not compliant

Ok with the mediciations?

With the medications, with follow ups, with taking caer of it, with everything. I drank, i was just stupid then and this time, well by the time I had my transplant I was 22

Ok

So between the ages of 22 and 26 or 27 you know I am not looking to be a patient, I am looking to have fun and I quickly learned quickly meaning that 4 years, that that was not clearly not going to work for me. And that was not going to work for me, so I obviously get another chance and they said like you know you cant do this and you cant do that. Yeah I got the warnings from everybody in the transplant center. And actually while I was waitlisted, I was put on hold um due to non-compliance as well, cause they were not just going to say hey you can have another kidney, they wanted to make sure that I was completely well, in the mental capacity to have another transplant, so the second transplant was in September 2017 so I was on dialysis for like 13 months.

Wow

Um but I was waiting longer than that I was listed in two states, I was listed in Michigan and Ohio. And I actually got the call in Ohio three times however I was the backup each time so I never got, never got the opportunity to get the kidney then. Again I did not get a deceased donor this time, I had a family friend had gotten tested um and he

was a match so we went ahead once we found out he was a match in I want to say July, we scheduled it for

September and everythgin has been good so far

That is wonderful, it is still pretty new so hopefully it goes for a very long time

For sure, I am doing it all right this time.

When you waitlisted the first time were you on multiple lists then too or just one

Um I was on Michigan and Minnesota because my main doctors were at the Mayo Clinic in Minnesota and that is where I actually ended up having my transplant.

Ok

Please describe some of the obstacles you experienced when trying to get waitlisted

Um I wouldn't say so no, not anything that had to do with the waitlist itself but with me and my medical issues that caused obstacles but the actual waitlist process no

Please discuss any people in particular that were helpful during the transplant waitlist process

The nurses were actually very helpful. In the Toledo one and the Michigan one I went to both, um I have gone through the training for this four times now so um both introductory classes, adb the nutrition classes and the medication classes and all that were run by nurses for the most part and everybody really in the process was super helpful. I really um I really liked my pretransplant nurse coordinator um she just like everytime she called me and told me about the possibility of the kidney maybe there being a kidney for me, it was like one of my family members was calling me. She was just as excited as my mom was.

Oh

Yes so I really had some awesome people on my medical team that were just like super helpful and always there to answer questions and whatnot.

Oh that is excellent and it helps to make things less stressful.

Yes definitely so I would say the nurse coordinator for sure.

Ok

Please discuss any times where you felt discriminated against for any reason during the waitlist process

No only for being a bad patient but it was warranted right (laughter)

Ok fair enough

Describe anything about yourself or your personal situation that, if you had the ability to change it, would have made the transplant list process easier

Um lets see if I can think of anything. Yeah no nothing off the top of my head. Just the travel. You know people that live in rural areas like that could be an issue but for me, it was not since for both transplants I had them near my home, even Toledo was only about an hour away so had I got a call and had to be there in under 2 hours, I could have done it.

Is there any advice you would give to other patients trying to get onto the transplant waitlist

Um yeah follow all the rules, do everything they tell you. I mean it is a process, be patient. There is a lot that they need but there is a reason for everything that the doctors and the medical staff need so I would just say be patient and do whatever you need to do to get onto that waitlist.

Ok great advice

Yep yeah

Please discuss any areas that you feel could have been improved in order to make waitlisting easier for you?

No no I personally did not run into any issues at all so no.

Ok well I appreciate everything and I appreciate you taking the time to tell me your story.

Absolutely thank you

Thank you so much

Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

The waitlist process was something I had never even thought about but the steps did take longer than I anticipated.

However after hearing other people's experiences, I realize that my wait time was not nearly as bad as others.

How long did it take you to get on the list

Um, well once my wife and I figured out how to even get onto a list, it took about a year or so

Oh wow, and how long until you received a transplant?

I waited about 2 ½ years and was on dialysis the entire time.

Please describe some of the obstacles you experienced when trying to get waitlisted

Some obstacles we faced were definitely financial and insurance issues

Oh really, how so?

Well we were notified that I was placed as inactive on the list because with my insurance, there was concern that I could not afford the medications if I did get a transplant.

Oh my, so what did you do

Well first of all, I had Medicare insurance and I thought I also had Medicaid but there was some kind of issue where the Medicaid was terminated. I called and spoke with many people at Medicaid but there was no quick fix for the problem so we had to fundraise and we were told we needed $5000 in the account to get back to active status

Wow so how did you fix this?

Well thanks to social media, we were able to raise the money in a reasonable timeframe and I was so lucky for this.

That is amazing

Yes but I wondered if other people have had the same experience as me and would they be able to get the money quick enough.

Please describe any areas of the waitlist process that you found to be easy to navigate

Once I actually received some type of guidance and information, I was able to navigate they process but I literally had no idea when we started.

Please discuss any people in particular that were helpful during the transplant waitlist process

My wife would have to be the one I would say was my main support. I had a heart attack as well and required surgery. This was a lot for all of us.

I cannot even imagine

Also the transplant RN, Brittany, I remember her name because she went above and beyond and she did not need to. Post transplant I was not feeling well and I could not keep any food down. She saw me in the office and gave me some of her own soup that she was planning on having for lunch. She waited with me to make sure I was able to keep the soup down before having me leave the office. I will be forever grateful for that and I will not forget it.

That is such a beautiful memory

Yes we definitely need more people like that in the world. If only all the transplant team could be that nice.

Please discuss any times where you felt discriminated against for any reason during the waitlist process

I never felt discriminated against in the process. I am actually not even sure I paid attention to this as I was so overwhelmed with trying to figure out the process.

Ok I understand this must have been very overwhelming for you

You have no idea

Describe anything about yourself or your personal situation that, if you had the ability to change it, would have made the transplant list process easier

Well like I said before, if I had the right insurance, we would not have had to raise any of the money.

Totally understand

I also wish I had better education about the whole process from the beginning. There could hav been more information provided so I did not feel so lost.

That must have been so difficult for you.

It was but thank God I have my transplant now

Congratulations for that

Is there any advice you would give to other patients trying to get onto the transplant waitlist

I would say to educate yourself, do your research and look at all centers.

What do you mean?

I did not know anything about multilisting but I do wish I had because some centers have different wait times and different criteria for transplant.

I agree that education is key to success

Got that right (laughter)

Please discuss any areas that you feel could have been improved in order to make waitlisting easier for you?

One of the main ways to improve the process is finding a way to shorten waittimes would obviously be ideal. This would help in so many ways.

Totally agree, I wish there were enough for everyone so they did not have to pick who gets a transplant

Yes it would be nice if there were more available

Also education and information could be improved. The communication could be improved as well.

There have been many people who have said the same thing

Well I really appreciate your time and I hope you have been feeling well.

Yes actually, I have been feeling great thank you for asking. I hope to read your paper when this is all completed.

Absolutely and have a great day

APPENDIX J: INTERVIEW NINE

Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

The waitlist process was something I had never even thought about but the steps did take longer than I anticipated. However after hearing other people's experiences, I realize that my wait time was not nearly as bad as others.

How long did it take you to get on the list

Once my wife and I figured out how to even get onto a list, it took about a year or so

Oh wow, and how long until you received a transplant?

I waited about 2 ½ years and was on dialysis the entire time.

Please describe some of the obstacles you experienced when trying to get waitlisted

Some obstacles we faced were definitely financial and insurance issues

Oh really, how so?

Well we were notified that I was placed as inactive on the list because with my insurance, there was concern that I could not afford the medications if I did get a transplant.

Oh my, so what did you do

Well first of all, I had Medicare insurance and I thought I also had Medicaid but there was some kind of issue where the Medicaid was terminated. I called and spoke with many people at Medicaid but there was no quick fix for the problem so we had to fundraise and we were told we needed $5000 in the account to get back to active status

Wow so how did you fix this?

Well thanks to social media, we were able to raise the money in a reasonable timeframe and I was so lucky for this.

That is amazing

Yes but I wondered if other people have had the same experience as me and would they be able to get the money quick enough.

Please describe any areas of the waitlist process that you found to be easy to navigate

Once I actually received some type of guidance and information, I was able to navigate they process but I literally had no idea when we started.

Please discuss any people in particular that were helpful during the transplant waitlist process

My wife would have to be the one I would say was my main support. I had a heart attack as well and required surgery. This was a lot for all of us.

I cannot even imagine

Also the transplant RN, Brittany, I remember her name because she went above and beyond and she did not need to. Post transplant I was not feeling well and I could not keep any food down. She saw me in the office and gave me some of her own soup that she was planning on having for lunch. She waited with me to make sure I was able to keep the soup down before having me leave the office. I will be forever grateful for that and I will not forget it.

That is such a beautiful memory

Yes we definitely need more people like that in the world. If only all the transplant team could be that nice.

Please discuss any times where you felt discriminated against for any reason during the waitlist process

I never felt discriminated against in the process. I am actually not even sure I paid attention to this as I was so overwhelmed with trying to figure out the process.

Ok I understand this must have been very overwhelming for you

You have no idea

Describe anything about yourself or your personal situation that, if you had the ability to change it, would have made the transplant list process easier

Well like I said before, if I had the right insurance, we would not have had to raise any of the money.

Totally understand

I also wish I had better education about the whole process from the beginning. There could hav been more information provided so I did not feel so lost.

That must have been so difficult for you.

It was but thank God I have my transplant now

Congratulations for that

Is there any advice you would give to other patients trying to get onto the transplant waitlist

I would say to educate yourself, do your research and look at all centers.

What do you mean?

I did not know anything about multilisting but I do wish I had because some centers have different wait times and different criteria for transplant.

I agree that education is key to success

Got that right (laughter)

Please discuss any areas that you feel could have been improved in order to make waitlisting easier for you?

One of the main ways to improve the process is finding a way to shorten waittimes would obviously be ideal. This would help in so many ways.

Totally agree, I wish there were enough for everyone so they did not have to pick who gets a transplant

Yes it would be nice if there were more available

Also education and information could be improved. The communication could be improved as well.

There have been many people who have said the same thing.

Well I really appreciate your time and I hope you have been feeling well.

Yes actually, I have been feeling great thank you for asking. I hope to read your paper when this is all completed.

Absolutely and have a great day

You do the same.

APPENDIX K: INTERVIEW TEN

Good afternoon and I want to first thank you for taking time out of your day to speak with me

You are welcome, I really don't mind sharing my story as I know how hard this process can be

Totally agree. How have you been doing?

Well, to tell you the truth, I have been feeling great. I am able to work which is nice but it sure does make me tired.

I can understand that, do you take some time for yourself to get some rest?

I try but you know, you gotta keep up the household so there is sometimes not much time for napping.

Please discuss the steps of the transplant waitlist process and approximately how long each step took for you

Please describe some of the obstacles you experienced when trying to get waitlisted

Please describe any areas of the waitlist process that you found to be easy to navigate

Please discuss any people in particular that were helpful during the transplant waitlist process

Please discuss any times where you felt discriminated against for any reason during the waitlist process

Describe anything about yourself or your personal situation that, if you had the ability to change it, would have made the transplant list process easier

Is there any advice you would give to other patients trying to get onto the transplant waitlist

Please discuss any areas that you feel could have been improved in order to make waitlisting easier for you?

REFERENCES

Althubaiti, A. (2016). Information bias in health research: definition, pitfalls, and adjustment methods. *Journal of Multidisciplinary Healthcare*, *9*, 211-217.

American Kidney Fund (2016). *Kidney Failure/ESRD*. Retreived from http://www.kidneyfund.org/kidney-disease/kidney failure/?gclid=CjwKEAiAkajDBRCRq8Czmdj-yFgSJADikZgg9nnQMeZQhCuFPj8arHA7IOF3Ntt8c5pGvV4BxnY9IRoCMtfw_wcB#symptoms

American Kidney Fund (2015). Kidney Disease Statistics. Retrieved from http://www.kidneyfund.org/assets/pdf/kidney-disease-statistics.pdf

Americans, H., & Americans, N. (2015). CKD in disadvantaged populations. *Kidney International*, *87*, 251-253.

Antlanger, M., Noordzij, M., van de Luijtgaarden, M., Carrero, J. J., Palsson, R., Finne, P., ... & Traynor, J. P. (2019). Sex differences in kidney replacement therapy initiation and maintenance. *Clinical Journal of the American Society of Nephrology*, *14*(11), 1616-1625.

Axelrod, D. A., Lentine, K. L., Xiao, H., Bubolz, T., Goodman, D., Freeman, R., ... & Schnitzler, M. A. (2014). Accountability for end-stage organ care: Implications of geographic variation in access to kidney transplantation. *Surgery*, *155*(5), 734-742.

Avery, N. (2014). *Understanding the role of a renal social worker*. Retrieved from https://www.aakp.org/education/resourcelibrary/dialysis-resources/item/understanding-the-role-of-a-renal-social-worker.html

Ayanian, J. Z., Cleary, P. D., Keogh, J. H., Noonan, S. J., David-Kasdan, J. A., & Epstein, A. M.

    (2004). Physicians' beliefs about racial differences in referral for renal transplantation.

    American journal of kidney diseases, *43*(2), 350-357.

Bayat, S., Macher, M. A., Couchoud, C., Bayer, F., Lassalle, M., Villar, E., ... & Kessler, M.

    (2015). Individual and Regional Factors of Access to the Renal Transplant Waiting List

    in France in a Cohort of Dialyzed Patients. *American Journal of Transplantation*, *15*(4),

    1050-1060.

Beard, T. R., Jackson, J. D., Kaserman, D., & Kim, H. (2012). A time-series analysis of the US

    kidney transplantation and the waiting list: donor substitution effects. *Empirical*

    Economics, *42*(1), 261-277.

Benjamins, M. R., & Whitman, S. (2014). Relationships between discrimination in health care

    and health care outcomes among four race/ethnic groups. *Journal of Behavioral*

    Medicine, *37*(3), 402-413.

Bird, S. T., & Bogart, L. M. (2001). Perceived race-based and socioeconomic status (SES)-based

    discrimination in interactions with health care providers. *Ethnicity & Disease*, *11*(3), 554-

    563.

Browne, T. (2006). Nephrology social work: History in the making. *Journal of Nephrology*

    Social Work, *25*, 11-29.

Calestani, M., Tonkin-Crine, S., Pruthi, R., Leydon, G., Ravanan, R., Bradley, J. A., ... & Cairns,

    J. (2014). Patient attitudes towards kidney transplant listing: qualitative findings from the

    ATTOM study. *Nephrology Dialysis Transplantation*, *29*(11), 2144-2150.

Cangro, C. (2014). Psychosocial Issues in Renal Transplantation. In *Kidney Transplantation* (pp.

    173-181). Springer New York.

Cantekin, I., Kavurmacı, M., & Tan, M. (2016). An analysis of caregiver burden of patients with hemodialysis and peritoneal dialysis. *Hemodialysis International*, *20*(1), 94-97.

Cash, J.C., & Glass, C.A. (2010). Stages of CKD. *Family Practice Guidelines*, 254.

Cass, A., Cunningham, J., Snelling, P., & Ayanian, J. Z. (2003). Late referral to a nephrologist reduces access to renal transplantation. *American Journal of Kidney Diseases*, *42*(5), 1043-1049.

Chertow, G. M., Levin, N. W., Beck, G. J., Daugirdas, J. T., Eggers, P. W., Kliger, A. S., ... & Greene, T. (2015). Long-Term Effects of Frequent In–Center Hemodialysis. *Journal of the American Society of Nephrology*, ASN-2015040426.

Cloyes, K.G., & Rivera, A. (2015). *Proceedings from 68th Annual Scientific Meeting*. Lake Buena Vista, FL.

Daniels, N. (2001). Justice, health, and healthcare. *American Journal of Bioethics*, *1*(2), 2-16.

Danovich, G. M. (2009). Handbook of Kidney Transplantation (5th Edition). Lippincott Williams & Wilkins.

Davis, A. E., Mehrotra, S., Friedewald, J. J., Daskin, M. S., Skaro, A. I., Abecassis, M. M., & Ladner, D. P. (2014a). Improving geographic equity in kidney transplantation using alternative kidney sharing and optimization modeling. *Medical Decision Making*,

Davis, A. E., Mehrotra, S., McElroy, L. M., Friedewald, J. J., Skaro, A. I., Lapin, B., ... & Ladner, D. P. (2014b). The extent and predictors of waiting time geographic disparity in kidney transplantation in the United States. *Transplantation*, *97*(10), 1049-1057.

Davita (2016). Stages of Kidney Disease. Retrieved from https://www.davita.com/kidney-disease/overview/stages-of-kidney-disease/stage-1-of-chronic-kidney-disease/e/4745

Emory Healthcare (2016). Dialysis Treatment Options. Retrieved from

http://www.emoryhealthcare.org/dialysis/treatments.html

Friedewald, J. J., Samana, C. J., Kasiske, B. L., Israni, A. K., Stewart, D., Cherikh, W., & Formica, R. N. (2013). The kidney allocation system. *Surgical Clinics of North America*, *93*(6), 1395-1406.

Garcia, G. G., Harden, P., & Chapman, J. (2012). The global role of kidney transplantation. *Nephron Clinical Practice*, *120*(2), c101-c106.

Garcia-Garcia, G., Jha, V., & World Kidney Day Steering Committee. (2015). CKD in disadvantaged populations. *American journal of nephrology*, *41*(2), 116-120.

Gaylin, D. S., Held, P. J., Port, F. K., Hunsicker, L. G., Wolfe, R. A., Kahan, B. D., ... & Agodoa, L. Y. (1993). The impact of comorbid and sociodemographic factors on access to renal transplantation. *Jama*, *269*(5), 603-608.

Ghai, S., Das, K., Sharma, P., & Kohli, H. S. (2015). Burden on Caregivers of ESRD Patients on Dialysis Waiting for Kidney Transplantation in a Tertiary Care Hospital. *Journal of Nursing Science & Practice*, *4*(3), 22-29.

Gill, J. S., Hendren, E., Dong, J., Johnston, O., & Gill, J. (2014). Differential association of body mass index with access to kidney transplantation in men and women. *Clinical Journal of the American Society of Nephrology*, *9*(5), 951-959.

Gill, J. S., & Tonelli, M. (2012). Penny wise, pound foolish? Coverage limits on immunosuppression after kidney transplantation. *New England Journal of Medicine*, *366*(7), 586-589.

Goldfarb-Rumyantzev, A. S., Sandhu, G. S., Baird, B., Barenbaum, A., Yoon, J. H., Dimitri, N., & Shihab, F. (2012). Effect of education on racial disparities in access to kidney transplantation. *Clinical Transplantation*, *26*(1), 74-81.

Grams, M. E., Massie, A. B., Schold, J. D., Chen, B. P., & Segev, D. L. (2013). Trends in the inactive kidney transplant waitlist and implications for candidate survival. *American Journal of Transplantation*, *13*(4), 1012-1018.

Greer, R. C., Cooper, L. A., Crews, D. C., Powe, N. R., & Boulware, L. E. (2011). Quality of patient-physician discussions about CKD in primary care: a cross-sectional study. *American Journal of Kidney Diseases*, *57*(4), 583-591.Gutmann, A. (1983). For and against equal access to health care. In *In Search of Equity* (p. 43-67). Springer US.

Hall, E. C., James, N. T., Wang, J. M. G., Berger, J. C., Montgomery, R. A., Dagher, N. N., ... & Segev, D. L. (2012). Center-level factors and racial disparities in living donor kidney transplantation. *American Journal of Kidney Diseases*, *59*(6), 849-857.

Hamm, L. L., Hostetter, T. H., Shaffer, R. N., & ASN Accountable Care Organization Task Force. (2013). Considering an integrated nephrology care delivery model: six principles for quality. *Clinical Journal of the American Society of Nephrology*, *8*(4), 682-686.

Hammond, W. P. (2010). Psychosocial correlates of medical mistrust among African American men. *American Journal of Community Psychology*, *45*(1-2), 87–106. http://doi.org/10.1007/s10464-009-9280-6

Harding, K., Mersha, T. B., Pham, P. T., Waterman, A. D., Webb, F. J., Vassalotti, J. A., & Nicholas, S. B. (2017). Health disparities in kidney transplantation for African Americans. *American Journal of Nephrology*, *46*(2), 165-175.

Harhay, M. N., McKenna, R. M., Boyle, S. M., Ranganna, K., Mizrahi, L. L., Guy, S., ... &

Harhay, M. O. (2018). Association between Medicaid expansion under the Affordable

Care Act and preemptive listings for kidney transplantation. *Clinical Journal of the*

American Society of Nephrology, *13*(7), 1069-1078.

Hamoda, R., Lipford, K., McPherson, L., Gander, J., & Patzer, R. (2017). Medical mistrust,

perceived racism, and experiences of medical discrimination among transplant patients.

American Journal Transplant. 2017;17 (suppl 3).

Hausmann, L. R. M., Jeong, K., Bost, J. E., & Ibrahim, S. A. (2008). Perceived discrimination in

health care and health atatus in a racially diverse sample. *Medical Care*, *46*(9), 905–914.

Http://doi.org/10.1097/MLR.0b013e3181792562

Held, P. J., Pauly, M. V., Bovbjerg, R. R., Newmann, J., & Salvatierra, O. (1988). Access to

kidney transplantation: has the United States eliminated income and racial differences?.

Archives of Internal Medicine, *148*(12), 2594-2600.

Hernández, D., Alonso-Titos, J., Armas-Padrón, A. M., Ruiz-Esteban, P., Cabello, M., López,

V., ... & Gutiérrez, E. (2018). Mortality in elderly waiting-list patients versus age-

matched kidney transplant recipients: where is the risk?. *Kidney and Blood Pressure*

Research, *43*(1), 256-275.

Higgins, R. S. D., & Fishman, J. A. (2006). Disparities in solid organ transplantation for ethnic

minorities: facts and solutions. *American Journal of Transplantation*, *6*(11), 2556-2562.

Hod, T., & Goldfarb-Rumyantzev, A. S. (2014). The role of disparities and socioeconomic

factors in access to kidney transplantation and its outcome. *Renal Failure*, *36*(8), 1193-

1199.

Hricik, D. E. (2008). Kidney Transplantation. Washington: Remedica Publishing Ltd.

Israni, A. K., Salkowski, N., Gustafson, S., Snyder, J. J., Friedewald, J. J., Formica, R. N., ... &

Samana, C. J. (2014). New national allocation policy for deceased donor kidneys in the United States and possible effect on patient outcomes. *J Am Soc Nephrol*, *25*(8), 1842-8.

Johnson, S. R. (2014). Home dialysis grows despite cost and logistical hurdles. Retrieved from http://www.modernhealthcare.com/article/20141011/MAGAZINE/310119932

Kazley, A., Jordan, J., Simpson, K., Chavin, K., Rodrigue, J., & Baliga, P. (2014). Development and testing of a disease-specific health literacy measure in kidney transplant patients. *Progress in Transplantation*, *24*(3), 263-270.

Killian, M. (2013, January). Adherence Assessment During Transplant Social Work Services in Pediatric Heart and Lung Organ Transplantation. In *Society for Social Work and Research 17th Annual Conference: Social Work for a Just Society: Making Visible the Stakes and Stakeholders*. Sswr.

Kressin, N. R., Raymond, K. L., & Manze, M. (2008). Perceptions of race/ethnicity-based discrimination: A review of measures and evaluation of their usefulness for the health care setting. *Journal of Health Care for the Poor and Underserved*, *19*(3), 697.

Kucirka, L. M., Grams, M. E., Balhara, K. S., Jaar, B. G., & Segev, D. L. (2012). Disparities in provision of transplant information affect access to kidney transplantation. *American Journal of Transplantation*, *12*(2), 351-357.

Kutner, N. G., Johansen, K. L., Zhang, R., Huang, Y., & Amaral, S. (2012). Perspectives on the New Kidney Disease Education Benefit: Early Awareness, Race and Kidney Transplant Access in a USRDS Study. *American Journal of Transplantation*, *12*(4), 1017-1023.

LaVeist, T.A. (n.d.). *Measuring Trust in Healthcare: Medical Mistrust Index 2.1*. Retrieved from https://www.jhsph.edu/research/centers-and-institutes/johns-hopkins-center-for-health-disparities-solutions/Projects/MMT.html

LaVeist, T. A., Nickerson, K. J., & Bowie, J. V. (2000). Attitudes about racism, medical mistrust, and satisfaction with care among African American and white cardiac patients. *Medical Care Research and Review*, *57*(1_suppl), 146-161.

Lee, D. K., Chertow, G. M., & Zenios, S. A. (2010). Reexploring differences among for-profit and nonprofit dialysis providers. *Health Services Research*, *45*(3), 633-646.

Lee, D. K., & Zenios, S. A. (2012). An evidence-based incentive system for Medicare's end-stage renal disease program. *Management Science*, *58*(6), 1092-1105.

Leppke, S., Leighton, T., Zaun, D., Chen, S. C., Skeans, M., Israni, A. K., ... & Kasiske, B. L. (2013). Scientific Registry of Transplant Recipients: Collecting, analyzing, and reporting data on transplantation in the United States. *Transplantation Reviews*, *27*(2), 50-56.

Lewis, R. M., Sankar, A., & Pittman, J. (2014). Disparities in access to kidney transplantation between donor service areas in Texas. *American Journal of Transplantation*, *14*(10), 2303-2309.

Link, B. G., & Phelan, J. (1995). Social conditions as fundamental causes of disease. *Journal of Health and Social Behavior*, *35,* 80-94.

Lopez-Cervallos, D. & Harvey, S. M. (2016). Proceedings from APHA Annual Meeting and Expo. Denver, CO.

Mackelaite, L., Gaweda, A. E., Muhs, E., & Ouseph, R. (2014). Impact of Patient Awareness on Access to Transplantation in End Stage Renal Disease. *World Journal of Nephrology and Urology*, *3*(2), 67-71.

Madhavan, P., Jairath, S., Sukumaran, N., Sagar, A., Molmenti, E., Natarajan, B., ... & Bhaskaran, M. (2014). Kidney Transplant Access in the Southeast: Middle View. *American Journal of Transplantation*, *14*(11), 2669-2670.

Maggiore, U., Oberbauer, R., Pascual, J., Viklicky, O., Dudley, C., Budde, K., ... & ERA-EDTA-DESCARTES Working Group. (2014). Strategies to increase the donor pool and access to kidney transplantation: an international perspective. *Nephrology Dialysis Transplantation*, gfu212.Europe-

Matas, A. J., Smith, J. M., Skeans, M. A., Thompson, B., Gustafson, S. K., Schnitzler, M. A., ... & Israni, A. K. (2014). OPTN/SRTR 2012 annual data report: kidney. *American Journal of Transplantation*, *14*(S1), 11-44.

Mayo Clinic (2016). *Peritoneal Dialysis*. Retrieved from http://www.mayoclinic.org/tests-procedures/peritoneal-dialysis/home/ovc-20202856

Miller, A. (2015). The Job Requirements for a Transplant Social Worker. Retrieved from http://work.chron.com/job-requirements-transplant-social-worker-16696.html

Mo, P. K., Malik, S. H., & Coulson, N. S. (2009). Gender differences in computer-mediated communication: a systematic literature review of online health-related support groups. *Patient Education and Counseling*, *75*(1), 16-24.

Muringai, T., Noble, H., McGowan, A., & Chamney, M. (2008). Dialysis access and the impact on body image: role of the nephrology nurse. *British Journal of Nursing*, *17*(6), 362-366.

Murtagh, F. E., Addington-Hall, J., & Higginson, I. J. (2007). The prevalence of symptoms in end-stage renal disease: a systematic review. *Advances in Chronic Kidney Disease*, *14*(1), 82-99.

Myaskovsky, L., Doebler, D. A., Posluszny, D. M., Dew, M. A., Unruh, M., Fried, L. F., ... & Shapiro, R. (2012). Perceived discrimination predicts longer time to be accepted for kidney transplant. *Transplantation*, *93*(4), 423.

Nakayama, M., Ishida, M., Ogihara, M., Hanaoka, K., Tamura, M., Kanai, H., & Marshall, M.

R. (2015). Social functioning and socioeconomic changes after introduction of regular dialysis treatment and impact of dialysis modality: A multi-centre survey of Japanese patients. *Nephrology*, *20*(8), 523-530.

National Kidney Foundation (2016a). Acute Kidney Injury. Retrieved from https://www.kidney.org/atoz/content/AcuteKidneyInjury

National Kidney Foundation (2016b). Understanding Lab Values. Retrieved from https://www.kidney.org/kidneydisease/understandinglabvalues

National Kidney Foundation (2016c). Glomerular Filtration Rate. Retrieved from https://www.kidney.org/atoz/content/gfr

Nephrology and News Issues (2014). The role of the social worker on the transplant team. Retrieved from http://www.nephrologynews.com/the-role-of-the-social-worker-on-the-transplant-team/

Nissenson, A. R. (2013). Improving outcomes for ESRD patients: Shifting the quality paradigm. *Clinical Journal of the American Society of Nephrology*, CJN-05980613.

OPTN (2016). *Regions*. Retrieved from https://optn.transplant.hrsa.gov/members/regions/

Öyekçin, D. G., Gülpek, D., Sahin, E. M., & Mete, L. (2012). Depression, anxiety, body image, sexual functioning, and dyadic adjustment associated with dialysis type in chronic renal failure. *The International Journal of Psychiatry in Medicine*, *43*(3), 227-241.

Pagels, A. A., Söderkvist, B. K., Medin, C., Hylander, B., & Heiwe, S. (2012). Health-related quality of life in different stages of chronic kidney disease and at initiation of dialysis treatment. *Health and Quality of Life Outcomes*, *10*(1), 1-14.

Palomino, J. (2015). Georgia's dialysis crisis: Living, and dying, on a mechanical kidney. *Al Jazeera America*.

Partridge, K. A., & Robertson, N. (2011). Body-image disturbance in adult dialysis patients. *Disability and rehabilitation*, *33*(6), 504-510.

Patzer, R. E., Amaral, S., Wasse, H., Volkova, N., Kleinbaum, D., & McClellan, W. M. (2009). Neighborhood poverty and racial disparities in kidney transplant waitlisting. *Journal of the American Society of Nephrology*, *20*(6), 1333-1340.

Patzer, R. E., Gander, J., Sauls, L., Amamoo, M. A., Krisher, J., Mulloy, L. L., ... & Pastan, S. O. (2014). Southeastern Kidney Transplant Coalition: The RaDIANT community study protocol: Community-based participatory research for reducing disparities in access to kidney transplantation. *BMC Nephrol*, *15*(1), 171.

Patzer, R. E., & McClellan, W. M. (2012). Influence of race, ethnicity and socioeconomic status on kidney disease. *Nature Reviews Nephrology*, *8*(9), 533-541.

Patzer, R. E., & Pastan, S. O. (2014). Kidney transplant access in the Southeast: view from the bottom. *American Journal of Transplantation*, *14*(7), 1499-1505.

Patzer, R. E., Perryman, J. P., Pastan, S., Amaral, S., Gazmararian, J. A., Klein, M., ... & McClellan, W. M. (2012). Impact of a patient education program on disparities in kidney transplant evaluation. *Clinical Journal of the American Society of Nephrology*, *7*(4), 648-655.

Patzer, R. E., Perryman, J. P., Schrager, J. D., Pastan, S., Amaral, S., Gazmararian, J. A., ... & McClellan, W. M. (2012). The role of race and poverty on steps to kidney transplantation in the southeastern United States. *American Journal of Transplantation*, *12*(2), 358-368.

Patzer, R. E., Plantinga, L., Krisher, J., & Pastan, S. O. (2014). Dialysis facility and network factors associated with low kidney transplantation rates among United States dialysis facilities. *American Journal of Transplantation*, *14*(7), 1562-1572.

Patzer, R. E., Plantinga, L. C., Paul, S., Gander, J., Krisher, J., Sauls, L., ... & Pastan, S. O. (2015). Variation in dialysis facility referral for kidney transplantation among patients with end-stage renal disease in Georgia. *JAMA*, *314*(6), 582-594.

Peek, M. E., Nunez-Smith, M., Drum, M., & Lewis, T. T. (2011). Adapting the everyday discrimination scale to medical settings: reliability and validity testing in a sample of African American patients. *Ethnicity & Disease*, *21*(4), 502.

Phelan, J. C., Link, B. G., & Tehranifar, P. (2010). Social conditions as fundamental causes of health inequalities theory, evidence, and policy implications. *Journal of Health and Social Behavior*, *51*, S28-S40.

Pondrom, S. (2012). The AJT Report News and issues that affect organ and tissue transplantation. *American Journal of Transplantation*, *12*(2), 269-270.

Purnell, T. S., Hall, Y. N., & Boulware, L. E. (2012). Understanding and overcoming barriers to living kidney donation among racial and ethnic minorities in the United States. *Advances in chronic kidney disease*, *19*(4), 244-251.

Pussell, B. A., Bendorf, A., & Kerridge, I. H. (2012). Access to the kidney transplant waiting list: a time for reflection. *Internal medicine journal*, *42*(4), 360-363

Ramos, E.L., Kasiske, B.L., Alexander, S.R., et al. (1995). The evaluation of candidates for renal transplantation. The current practice of U.S. transplant centers. *Transplantation*, *57*(4):490-497.

Rawls, J. (2009). *A theory of justice*. Harvard University Press.

Reed, A., Chapman, W. C., Knechtle, S., Chavin, K., Gilroy, R., & Klintmalm, G. B. (2015).

Equalizing MELD scores over broad geographies is not the most efficacious way to allocate a scarce resource in a value-based environment. *Annals of surgery*, *262*(2), 220-223.

Rhodes, R., Battin, M. & Silvers, A. (2012). *Medicine and social justice: essays on the distribution of health care*. Oxford University Press.

Rivera, A., Agarwal, C., Walzer, N., Donato, D., & Wright, L. (2016). Proceedings from WPATH: World Professional Association for Transgender Health. Amsterdam.

Robinson, D. H., Perryman, J. P., Thompson, N. J., Powell, C. L., & Arriola, K. R. J. (2015). Exploring Donotion-related Knowledge Attitudes, Beliefs and Distrust Among African Americans. *Journal of the National Medical Association*, *107*(3), 42-50.

Rubin, M. F., & Weir, M. R. (2015). Access to Kidney Transplantation: Is There a Potential Conflict of Interest. *American Journal of Nephrology*, *41*(6), 502-503.

Sacred Heart University (n.d.). *Organizing Academic Research Papers: Limitations of the Study.* Retrieved from https://library.sacredheart.edu/c.php?g=29803&p=185934

Salter, M. L., Kumar, K., Law, A. H., Gupta, N., Marks, K., Balhara, K., ... & Segev, D. L. (2015). Perceptions about hemodialysis and transplantation among African American adults with end-stage renal disease: inferences from focus groups. *BMC nephrology*, *16*(1), 49.

Salter, M. L., McAdams-Demarco, M. A., Law, A., Kamil, R. J., Meoni, L. A., Jaar, B. G., ... & Segev, D. L. (2014). Age and sex disparities in discussions about kidney transplantation in adults undergoing dialysis. *Journal of the American Geriatrics Society*, *62*(5), 843-849.

Saunders, M. R., Lee, H., Maene, C., Schuble, T., & Cagney, K. A. (2014). Proximity does not

equal access: Racial disparities in access to high quality dialysis facilities. *Journal of Racial and Ethnic Health Disparities*, *1*(4), 291-299.

Schaefer, D. R., & Dillman, D. A. (1998). Development of a standard e-mail methodology: Results of an experiment. *Public Opinion Quarterly*, 378-397.

Schaubel, D. E., Stewart, D. E., Morrison, H. I., Zimmerman, D. L., Cameron, J. I., Jeffery, J. J., & Fenton, S. S. (2000). Sex inequality in kidney transplantation rates. *Archives of Internal Medicine*, *160*(15), 2349-2354.

Schiller, B. (2015). The Medical Director and Quality Requirements in the Dialysis Facility. *Clinical Journal of the American Society of Nephrology*, *10*(3), 493-499.

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*, *6*(7), 1760-1767.

Shavers VL, Fagan P, Jones D, et al. (2012). The state of research on racial/ethnic discrimination in the receipt of health care. *American Journal of Public Health, 102*(5), 953–966.

Srinivas, T. R. (2014). Kidney Transplant Access in the Southeastern United States: The Need for a Top-Down Transformation. *American Journal of Transplantation*, *14*(7), 1506-1511.

Steel, J. L., Dunlavy, A., Friday, M., Kingsley, K., Brower, D., Unruh, M., ... & McCloskey, C. (2013). The development of practice guidelines for independent living donor advocates. *Clinical Transplantation*, *27*(2), 178-184.

Stepanikova, I., & Oates, G. R. (2017). Perceived discrimination and privilege in health care: The role of socioeconomic status and race. *American Journal of Preventive Medicine*, *52*(1), S86-S94.

The Renal Association (2013). CKD Stages. Retrieved from http://www.renal.org/information-resources/the-uk-eckd-guide/ckd-stages#sthash.mlxol4lL.Xd7FaW4s.dpbs

Tonelli, M., Klarenbach, S., Rose, C., Wiebe, N., & Gill, J. (2009). Access to kidney transplantation among remote-and rural-dwelling patients with kidney failure in the United States. *JAMA*, *301*(16), 1681-1690.

Tong, A., Hanson, C. S., Chapman, J. R., Halleck, F., Budde, K., Papachristou, C., & Craig, J. C. (2014). The Preferences and Perspectives of Nephrologists on Patients' Access to Kidney Transplantation: A Systematic Review. *Transplantation*, *98*(7), 682-691.

Tso, P. L. (2014). Access to renal transplantation for the elderly in the face of new allocation policy: A review of contemporary perspectives on "older" issues. *Transplantation Reviews*, *28*(1), 6-14.

Uchino, B. N. (2009).Understanding the links between social support and physical health a life-span perspective with emphasis on the separability of perceived and received support. *Perspectives on Psychological Science, 4*(3), 236-255.

United States Renal System (2016). *ADR Reference Tables*. Retrieved from https://www.usrds.org/reference.aspx

UNOS (2019). Kidney Paired Donation. Retrieved from https://unos.org/transplant/kidney-paireddonation/?gclid=EAIaIQobChMIsOLm_LR6AIVgp6zCh1hDAd0EAAYAyAAEgIhM_D_BwE

UPMC (2016). Kidney Transplant Process. Retrieved from http://www.upmc.com/Services/transplant/PublishingImages/kidney/transplant-process.png

Wachterman, M. W., McCarthy, E. P., Marcantonio, E. R., & Ersek, M. (2015, March). Mistrust,

Misperceptions, and Miscommunication: A Qualitative Study of Preferences About Kidney Transplantation Among African Americans. In *Transplantation proceedings* (Vol. 47, No. 2, pp. 240-246). Elsevier.

Walker, R. C., Howard, K., Tong, A., Palmer, S. C., Marshall, M. R., & Morton, R. L. (2016). The economic considerations of patients and caregivers in choice of dialysis modality. *Hemodialysis International, 20,* 634-642.

Williams, W. W., & Delmonico, F. L. (2016). The end of racial disparities in kidney transplantation? Not so fast!.

Wong, G., Howard, K., Chapman, J. R., Chadban, S., Cross, N., Tong, A., ... & Craig, J. C. (2012). Comparative survival and economic benefits of deceased donor kidney transplantation and dialysis in people with varying ages and co-morbidities. *PLoS One*, *7*(1), e29591.

Wyld, M., Morton, R. L., Hayen, A., Howard, K., & Webster, A. C. (2012). A systematic review and meta-analysis of utility-based quality of life in chronic kidney disease treatments. *PLoS Med*, *9*(9), e1001307.

Zhang, Y., Gerdtham, U. G., Rydell, H., & Jarl, J. (2018). Socioeconomic inequalities in the kidney transplantation process: a registry-based study in Sweden. *Transplantation Direct*, *4*(2).

Zhang, Y., Thamer, M., Kshirsagar, O., Cotter, D. J., & Schlesinger, M. J. (2014). Dialysis chains and placement on the waiting list for a cadaveric kidney transplant. *Transplantation*, *98*(5), 543-551.