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# Perceived Barriers to the Pre-Transplant Evaluation: A Patient Perspective

Linda K. Buck

Grand Valley State University, buckli@gvsu.edu

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Perceived Barriers to the Pre-Transplant Evaluation: A Patient Perspective

Linda Kneffel Buck

A Dissertation Submitted to the Graduate Faculty of

GRAND VALLEY STATE UNIVERSITY

In

Partial Fulfillment of the Requirements

For the Degree of

Doctor of Nursing Practice

Kirkhof College of Nursing

August 2017

## **Dedication**

In memory of Wanda H. Kneffel

My mother and my first mentor

## **Acknowledgement**

The journey toward completion of this degree has been fraught with numerous challenges that at times seemed overwhelming. Enter the unwavering support of my family. To David, Jessica and Josh, Michael and Michelle (also my graphic designer), and Evangeline - I thank you from the bottom of my heart. You are the wind beneath my wings!

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Oh...and Peggy.

## Abstract

Patients who are afforded the opportunity for a kidney transplant tend to have better short and long-term outcomes, including improved physical health, quality of life, and long-term survival over those who are treated with prolonged dialysis (Landreneau, Lee, & Landreneau, 2010; Organ Procurement and Transplantation Network and Scientific Registry of Transplant Recipients (OPTN/SRTR), 2014; Wolfe et al., 1999). At the end of 2012, 402,514 people were being treated with hemodialysis while 40,605 were receiving peritoneal dialysis (USRDS, 2014). At this same time, only 92,885 people were listed on the OPTN national waitlist for kidney transplantation. The aim of this project was to identify barriers that might delay or halt progress toward waitlist placement in a midwestern hospital transplant program.

A patient-focused survey was sent to 346 end stage renal disease patients referred to a kidney transplant center for a pre-transplant work-up in 2014. The survey collected demographic and health literacy data as well as data focused on patient concerns and attitudes toward kidney transplantation. Eighty-eight patients (30% response rate) completed and returned the survey (50% male, 78% White, and a mean age of 62). Data were evaluated in aggregate with further evaluation of data based on race and sex. The question “how confident are you filling out medical forms” was statistically significant ( $p = .002$ ) for “sex” and “health literacy.” The greatest concerns were “length of time to wait for a kidney transplant” and issues inherent to “finding a living donor.” The survey prompt that “dialysis is not that bad” generated the most negative rating in the attitudes section of the survey.

Thirty-eight percent of respondents were identified as having limited health literacy (Short Literacy Survey [SLS] score 3-9). It is recommended that the SLS be added to initial patient screenings, with findings used to create an individualized care plan designed to assist

patients through the pre-transplant evaluation. All patient educational materials need to be evaluated for ease of reading and grade level. Patient education materials must also be created to address specific patient identified barriers (e.g. long wait time for a kidney transplant, finding a living donor, coping with long-term dialysis).

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## Key to Symbols

### Symbol

$\alpha$	Cronbach's index of internal consistency
$d$	Cohen's sample effect size
$M$	Sample mean
$Mdn$	Median
$N$	Total population or Sample
$n$	Limited number of the total sample
$p$	Probability
$SD$	Standard deviation
$\chi^2$	Chi square distribution

## Chapter 1

### INTRODUCTION

In the sixty years since the first successful solid organ transplant, thousands of people have experienced the benefits of this lifesaving procedure (Institute of Medicine [IOM], 2006). With the advent of improved immunosuppressant medications and refined surgical techniques, it is now possible to offer this treatment modality to those afflicted with end-stage disease of the heart, intestine, kidney, liver, lung, and pancreas (Corruble et al., 2010; IOM, 2006). There is a great need for these organs that grows larger every year; by far the greatest need is for transplantable kidneys (Organ Procurement and Transplant Network/Scientific Registry of Transplant Recipients [OPTN/SRTR], 2014).

#### **End Stage Renal Disease in the United States**

According to the 2014 Annual Data Report, compiled by the United States Renal Data System (USRDS), the United States ranked third globally for incidence of end stage renal disease (ESRD) in 2012 with 359 cases per million population. Of these cases, the diagnosis of ESRD is 50% more likely in Hispanics over non-Hispanics; African Americans are affected three times more often and Asians one and a half times more often than the White population (USRDS, 2014). The reported causes of ESRD are diabetes, hypertension, glomerulonephritis, and cystic kidney disease; however, after nearly a decade of steady growth, the incidence of ESRD in patients afflicted with these diseases has remained stable since 2010 (USRS, 2014).

The prevalence of ESRD has been increasing and was nearly 4% higher in 2012 than 2011, reflecting a 57.4% increase since 2000 (USRDS, 2014). This increase reflects the improvements in care for those afflicted with ESRD, as more ESRD patients are living with this chronic illness. Prevalence of ESRD is disproportionately higher in African Americans who are

four times as likely as Whites to be living with ESRD, two and a half times as likely as Asians, and twice as likely as Native Americans (USRDS, 2014).

### **Treatment Outcome Variance**

In spite of advances in treatment for ESRD, the long-term health outcomes for ESRD patients in the United States are not equal across the three primary interventions of hemodialysis, peritoneal dialysis and kidney transplantation. Patients who are afforded the opportunity for a kidney transplant tend to have better short and long-term outcomes, including improved physical health, quality of life, and long-term survival over those who are treated with prolonged dialysis (Landreneau, Lee, & Landreneau, 2010; OPTN/SRTR, 2014; Wolfe et al, 1999). Moreover, there is a direct correlation between the success of a kidney transplant and the time of ESRD diagnoses – the sooner the transplant takes place the better the outcomes (Mange, Joffe, & Feldman, 2001; Yuan, Bohen, & Abbott, 2012).

### **Quality of Life**

In a meta-analytic review comparing the interventions of hemodialysis and kidney transplantation, Landreneau et al. (2010) considered quality of life using the domains of general quality of life (functional impairment, internalization of illness, ability to perform daily activities, and sense of well-being), physical functioning (ease of mobility and level of fatigue), and psychosocial functioning (interpersonal relationships, ability to work, and psychological stability), as these domains were most often cited in the kidney transplant literature. Their review concluded that kidney transplant offered the opportunity for an improved life in the areas of general quality of life ( $d = 0.98$ ) and physical functioning ( $d = 0.769$ ). However, psychosocial functioning ( $d = 0.388$ ) was less conclusive in demonstrating an increase in quality of life (Landreneau, Lee, & Landreneau, 2010).

Looking at similar concepts, Purnell et al. (2013) concluded that kidney transplant provided improved physical functioning, increased participation in leisure activities, more individual independence, and a greater likelihood of employment over chronic dialysis patients. Tonelli et al. (2011) reached similar conclusions, particularly that kidney transplantation yielded the most significant short and long-term results in the areas of quality of life, and reduction in overall mortality and cardiovascular events, when compared to all forms of long term dialysis.

### **Treatment Costs: Transplant versus Dialysis**

The cost to care for ESRD has created a tremendous burden to the Medicare system, the primary insurer of nearly three quarters of all ESRD patients in the United States. Making up only 1% of the Medicare population, ESRD patients nonetheless are responsible for nearly 6% of total Medicare expenditures, accounting for \$28.6 billion in 2012, an increase of 3.2% over 2011 (USRDS, 2014). The estimated annual cost to care for an ESRD patient on dialysis is \$84,000, well below the estimated \$200,000 costs for a first-year kidney transplant recipient. However, following the first year, costs are estimated to drop to about \$27,000 to care for a post-transplant patient, while dialysis care will remain at the much higher rate (USRDS, 2014). Therefore, from a financial perspective kidney transplant presents a significant cost savings over the life of the recipient.

### **Transplant Waitlist**

At the end of 2012, 402,514 people were being treated with hemodialysis while 40,605 were receiving peritoneal dialysis (USRDS, 2014). At this same time, only 92,885 people were listed on the Organ Procurement and Transplant Network national waitlist for kidney transplantation (OPTN/SRTR, 2014). It is therefore important to understand what factors



contribute to a patient's decision to begin the process leading to placement on the kidney transplant waitlist and what barriers might stand in the way.

The journey toward transplantation begins with referral to a transplant center for evaluation – both physiological and psychological – and the many requirements of this process can feel overwhelming to the patients and their support system. For example, patients must complete routine cancer screenings, kidney transplant specific screenings (e.g. blood and urine testing), a social work assessment, a financial assessment, and various medical specialty consults (e.g. cardiology and general surgery) as indicated by their medical history. It is the hope for an increased quality of life and restoration of health that incite many people to begin the journey (Rainer, Thompson, & Lambros, 2010).

### **Project Aim**

As an integral part of a comprehensive program evaluation, an audit of ESRD patients referred in 2014 to a kidney transplant program affiliated with a large Midwestern health system was undertaken. The audit revealed that, of the 346 patients referred for pre-transplant evaluation, only 17% ( $n = 58$ ) had been added to the OPTN waitlist. Of the remaining referrals, 36% ( $n = 129$ ) were in “referral active” status, 38% ( $n = 131$ ) were classified as “referral inactive,” 6% ( $n = 20$ ) were in “referral hold” status, and 3% ( $n = 11$ ) died before the evaluation was completed. These data raise questions regarding the barriers patients may encounter as they consider kidney transplantation, which may delay or halt their progress toward waitlisting. The aim of this project is to begin to identify these barriers. In order to implement evidence based program changes and patient interventions, the patient's perspective must be understood.

## Chapter 2

### LITERATURE REVIEW

The aim of this project is to quantify perceived patient barriers which may interfere with completion of the required patient evaluation in the pre-transplant stage and to formulate a concise list of recommendations for future programming. As an integral piece of a kidney transplant program evaluation, a patient survey was conducted to enumerate perceived barriers in the ESRD patient population referred for evaluation to a large Midwestern health system's kidney transplant program. This work will provide direction to tailor evidence based interventions and patient support programming to meet patient identified needs. To provide a foundation for this inquiry, a review of pertinent literature was completed.

#### **Search Methods**

##### **Databases Accessed**

The Cumulative Index of Nursing and Allied Health Literature (CINAHL complete), PubMed, and Google Scholar were searched using the terms *kidney transplant AND barriers AND waitlist*. The search was then expanded to include *health literacy, access to kidney transplantation, end stage renal disease, and pre-transplant evaluation*. Articles were then hand searched for additional references.

##### **Inclusion and Exclusion Criteria**

Inclusion criteria were determined before the search process and included studies published in the English language, focused on patients greater than or equal to 18 years of age, and on patients diagnosed with ESRD. Inclusion was also limited to studies that provided details on outcome measurements and statistical results of data analysis. An exception was qualitative studies, which were included if details were provided regarding the qualitative data analysis.

Fourteen research based articles, all of which met the inclusion criteria, are included in this review.

### **Review of Identified Barriers**

There is much in the literature regarding the relatively low number of people with ESRD who are waitlisted for a kidney transplant. Yuan, Bohlen, and Abbott (2012) identified the most significant barrier to being waitlisted for kidney transplant as the pre-transplant evaluation process. Less than 15% of people with ESRD have received a transplant due to failure to complete the required screenings. It also has been noted that minorities and women more often struggle with the demands of the pre-transplant evaluation (Alexander & Sehgal, 1998; Sullivan et al., 2012; Weng, Joffe, Feldman, & Mange, 2005). Other barriers identified include concern of failing the required medical tests, fear of the transplant surgery, financial concerns regarding required post-transplant medications, and reduced health literacy (Grubbs, Gregorich, Perez-Stable, & Hsu, 2009; Kazley et al., 2014; Kazley, Simpson, Chavin, & Baliga, 2012).

#### **Failure to Complete the Pre-Transplant Evaluation**

The pre-transplant evaluation involves a comprehensive list of tests that each transplant candidate must complete. A psychosocial screening, chest x-ray, electrocardiogram, and numerous blood and urine tests (to include, but not limited to, blood chemistry, complete blood count, antibody serology, and human leukocyte antigen [HLA] typing) are examples of the required exams and are usually performed during the pre-transplant evaluation visit (Weng et al., 2005). In addition, transplant centers require all patients to complete routine annual preventive screenings such as a mammogram, a Papanicolaou screen or prostate exam, and, if applicable, a colonoscopy. Other biomedical tests (e.g. cardiac clearance, computerized tomography) may be

ordered based on an individual's physical exam, prior medical history, and the required surgical consult (Weng et al., 2005).

The purpose of this evaluation is to ensure that the limited number of kidneys available for transplant are placed into patients who are well positioned - physically, psychologically, and financially - for a successful outcome (Kazley, Hund, Simpson, Chavin, & Baliga, 2015). However, the burden of test completion, including the necessary time and expense, may cause patients to rethink the advantages of transplant and abort the evaluation process. Illustrating this phenomenon, Kazley et al. (2012), as a component of their larger study of barriers ESRD patients face when referred to a transplant center for evaluation, tracked the progress of all patients referred to their transplant center in 2010. Their focus on five stages of the evaluation process revealed the following: 1,428 patients were appropriately referred to the center, 846 attended a required education class, 508 participated in a physician evaluation, 428 completed all required testing and were reviewed by the transplant committee for listing, and finally, 339 patients were added to the wait list. These data demonstrates a 29.5% success rate.

**Single center study in a southern state.** Kazley et al. (2012) focused their study on patients referred for pre-transplant evaluation between December 2009 and June 2011. The study sample included 127 dialysis patients who were referred, but, for a variety of reasons, failed to complete the required screenings. For example, some did not attend transplant education, some began the required testing but failed to finish, and some self-selected out of the evaluation process by requesting that their file be closed. Patients who met the inclusion criteria were identified by the research team and approached by the nursing staff as they reported for care at the vascular access clinic. If willing, the patients then completed a survey as a part of the clinic visit. The study survey, developed by a group of researchers and practitioners, was pilot

tested before being used on the study subjects; however, no reliability or validity data were reported.

For the 83 patients (a 65% response rate) who completed the study survey, 59% were female and 79% were African American, ranging in age from 20 to 78 years. Descriptive analyses (frequencies, means, ranges and standard deviation) and chi-square were used to analyze the data. Barriers such as feeling that failure of the required medical testing was probable (18.1%), fear of the transplant surgery (15.7%), and not being able to afford post-transplant medications (14.5%) were most prominent and linked to patients dropping out of, or never beginning, the evaluation process. Recommendations from this study include the use of a patient navigator to assist patients through the maze of the pre-transplant evaluation process and the required follow-up testing, and a revision of pre-transplant education focusing on the areas of concern voiced by the study respondents.

Limitations of this study include it being conducted at a single transplant center which serves an entire southern state. It would be difficult to apply the study findings to more populated urban settings. Additionally, the researchers appeared to make some conclusions in areas not specifically assessed. For example, a conclusion that patient-perceived barriers may have been the result of miscommunication from providers, inaccurate information received from fellow ESRD patients or friends and relatives, or a lack of functional health literacy was offered; however none of these items were assessed in the survey employed in this study. Nonetheless, this study supports findings of other studies which also address the phenomenon of patient barriers to kidney transplantation.

**Evaluating attendance versus nonattendance for scheduled transplant evaluation.** In a cross-sectional study employing a convenience sample of 104 adult ESRD patients, Dageforde,

Box, Feurer and Cavanaugh (2015) sought to explore the differences between patients who attended an initial pre-transplant evaluation appointment and those who, although scheduled for an appointment, did not attend. The sample of patients were from a single transplant center, referred for evaluation between November 2012 and December 2013, and were matched for status of attendance: 52 who attended a pre-transplant evaluation and 52 who did not. The respondents were all English-speaking adult ESRD patients above 18 years of age, and were matched for race in order to explore elements other than race which might be associated with attendance. The total sample was 61% male, 41% white, with a median age of 52 years (no further descriptive information was provided). The aim of this study was to examine individual motivation and other factors which could influence a patient's decision to attend the initial pre-transplant evaluation. The study survey was administered via a structured telephone interview using Likert-style scaled questions and open-ended questions. The survey was created by the researchers, with the Brief Health Literacy Screen developed by Chew, Bradley, and Boyko (2004) embedded within it. No validity or reliability data were offered for the overall survey, although the Brief Health Literacy Screen has been independently validated by Chew et al. (2007).

The researchers compared characteristics such as socioeconomic and demographic data, health literacy, understanding of the pre-transplant evaluation, and general concerns about the transplant process. Using chi-square analysis, Fisher exact tests, *t* tests, and multivariate logistic regression, the differences between the group that attended the pre-transplant evaluation appointment and those that did not attend were examined. Findings indicated that patients who reported as scheduled to the pre-transplant evaluation appointment had a higher level of understanding of the pre-transplant evaluation and the transplant process over those who did not

attend the evaluation appointment ( $p \leq 0.005$ ). For those who did not attend, the significant findings were that they were more likely to have been evaluated at another transplant center ( $p = 0.029$ ) and on active dialysis ( $p = 0.008$ ). The attendee group demonstrated greater trepidation regarding the living donor process over those who did not attend ( $p = 0.038$ ); however, no further explanation is offered as to why this was so. There were no statistically significant differences found between groups for demographic data (i.e. age, race, gender, or education), income or insurance, miles from the transplant center, or length of wait time for the evaluation appointment.

The researchers also found that concerns regarding transplantation may factor into ESRD patients' capacity to participate in the pre-transplant evaluation process. These concerns may take the form of psychological issues, ability to comply with required post-transplant self-care (including financing the transplant and the costs of required lifelong medications), and past encounters with the medical community. Recommendations included raising awareness of patient concerns that may be preventing participation in the evaluation process and designing interventions to assist patients in verbalizing and working through these issues.

This study was conducted at a single center and the small sample was one of convenience, making generalities to another setting difficult. However, the survey the researchers created was comprehensive and included questions addressing not only transplant related barriers but also health literacy, thus making it an attractive tool for use in assessing patient perceived barriers in other transplant programs.

**Race versus insurance status as a barrier.** Schold et al. (2011) also sought to understand the barriers to evaluation faced by ESRD patients. Using a convenience sample of 3029 adult patients referred to a single transplant center, the sample of this study consisted of

adults, of which 70% were between 40 to 69 years of age, 56% were White, and 59% were male. Additionally, 53% had commercial health insurance at referral and 85% had no history of previous transplant. The aim of the study was threefold: to identify variables linked with advancement toward waitlisting; to highlight specific steps in the process where barriers were evident and to identify causes of these barriers; and to attempt to examine patient characteristics for previously unexplained relationships to other variables. Data were derived from a database internal to the transplant center.

Multivariate and nested logistic regression were used to analyze the data. For the model predicting likelihood of a pre-transplant evaluation from referral, adjusted odds ratios (AOR) and a 95% confidence interval (CI) were computed. The study found that ESRD patients age 30 to 39 (AOR = .90, 95% CI = 0.61 to 1.33) were more likely than those age 70 and over (AOR = 0.19, 95% CI = 0.13 to 0.29) to receive a pre-transplant evaluation. Besides older age, other findings indicated that a primary diagnosis of diabetes and/or hypertension, lower economic standing, and non-commercial insurance status were negatively associated with access to and completion of evaluation and wait-listing. Additionally, 56% of the referred patients completed a pre-transplant evaluation; 27% were placed on the kidney transplant wait list and 16% ultimately received a new kidney from a deceased or living donor. For patients not moving forward with the pre-transplant evaluation, documented reasons included medical issues (31%), patient refusal to participate (23%), insurance or other financial concerns (16%), and death before the evaluation could be completed (12%).

Interestingly, Schold et al. (2011) found that when covered by commercial insurance, there was no appreciable difference for African Americans compared to Whites (AOR = 0.93, 95% CI = 0.72 to 1.19) progressing to evaluation and wait list; however, when covered with



noncommercial insurance (i.e. Medicare or Medicaid), African Americans were less likely to be evaluated and wait listed when compared to Whites (AOR = 1.47, 95% CI = 1.07 to 2.01). In the final regression model, adjusting for median income, type of health insurance, and distance to the transplant center, this study found that African American status was no longer a significant barrier to evaluation and waitlisting. This is an important finding as the literature generally supports a long-standing claim that African Americans are disadvantaged when seeking kidney transplantation (Alexander & Sehgal, 1998). Schold et al. concluded that noncommercial insurance status may play a larger role than race or ethnicity when considering the participation rate for pre-transplant evaluation and eventual waitlisting, pointing toward financial burdens over race.

The study recommendations were to further explore the barriers lower socioeconomic ESRD patients face and what may be needed in terms of programming and support to successfully access transplant services. Moreover, factors such as the number of clinical comorbidities or contraindications to transplant, provider clinical reasoning, patient-provider relationships, and logistical variables (e. g. transportation needs, distance to the transplant center) also need to be considered when exploring barriers to the pre-transplant evaluation.

This single center study found a significant difference in insurance status as a way of explaining racial disparities in accessing transplant services, with lower socioeconomic standing adding to the racial imbalance. However, health literacy status and level of formal education might also play a role in this sample of ESRD patients' pursuit of transplantation – neither of which were addressed in this study. A major limitation was that the data were collected from an existing database and what was not contained within it (e.g. current employment status, current income, and a more complete listing of patient comorbidities) could not be analyzed. However,

the findings are a notable addition to the understanding of barriers ESRD patients face, and shed light on the importance of insurance status.

### **Psychological Concerns Regarding Transplantation**

There are several psychological barriers cited in the literature that may prevent forward movement in the evaluation process. A frequently cited concern, ranging from 18% to over 40% of respondents, involves a fear of not passing the required medical tests (Dageforde, Box et al., 2015; Kazley et al., 2012). This fear may be the culmination of self-doubt, accumulation of false, misguided information from well-meaning acquaintances, or misunderstood information from medical providers (Kazley et al., 2012). Fearful anxiety regarding the transplant surgery is another often cited emotion, noted as a barrier to evaluation in 40% to 50% of study respondents (Coorey, Paykin, Singleton-Driscoll, & Gaston, 2009; Dageforde, Box et al., 2015; Kazley et al., 2012).

**Psychological barriers: long term dialysis versus transplant recipients.** Coorey, Paykin, Singleton-Driscoll and Gaston (2009) conducted a study which aimed to compare the barriers and attitudes toward early or preemptive transplantation (transplantation before the onset of dialysis) between patients who had received a transplant over those who remained on long term dialysis. The researchers constructed a 28-question survey designed to elicit information on pre-transplant education, psychosocial issues, and financial concerns. Using the National Kidney Foundation's (NKF) database as the source for recruiting sample respondents, this study stands apart due to its national focus. Randomly selecting every tenth name on the list, 3,586 surveys were sent by either regular mail or email – in accordance with the NKF's recorded contact preference for each person. The 417 eligible surveys returned represented a response rate of 12.4%. Chi-square and independent group *t* tests were used to analyze the data. An option was

also available to input free text comments and 85% of study respondents did so, many providing insight into strongly held emotional concerns. For example, 56% of free text respondents detailed emotion-based barriers that contributed to a delay in pursuing a pre-transplant evaluation. Concerns that the transplant surgery, if successful at all, would fail to provide an increase in physical wellbeing or quality of life, as well as fear of the long-term effects of immunosuppressant therapy were noted. A general lack of understanding of the benefits of transplant, which may have alleviated some of these fears, was also noted prompting many respondents to indicate that if they had a more accurate understanding of the benefits of transplant, they would have actively engaged in the pre-transplant evaluation process much sooner. Finally, 60% of respondents who had not yet received a transplant believed that transplantation was an option of last resort, only to be considered after the failure of all other treatment modalities.

Although this study had a national focus, the sample was generated from patients who self-selected to join the National Kidney Foundation database and thus may not reflect the greater ESRD patient population. Additionally, the response rate of those surveyed was a low 12%. However, the study findings were able to shed some light on the fears and concerns of pursuing a kidney transplant. Whether based in rational or irrational beliefs, these concerns need to be addressed in order to assist moving patients forward armed with an accurate understanding of treatment options.

### **Financial Concerns**

Consideration of an ESRD patient's health insurance status is a required step in the pre-transplant evaluation process. Because a kidney transplant requires lifelong immunosuppressant therapy and medical follow-up, the ability of a patient to afford required long term care is

essential information. Patients without sufficient health insurance are less likely to be added to the transplant wait list than those who are deemed to have adequate resources (Laurentine & Bramstedt, 2010). In many cases, this restriction raises ethical dilemmas that need to be addressed.

**The ethics of transplant affordability.** Laurentine and Bramstedt (2010) performed a review of all cases ( $n = 218$ ) referred to the ethics committee of a large western medical center from 2007 to 2009. Their findings demonstrated that 27% of cases were related to transplantation and that of these cases, 40% concerned the inadequate “economic, financial, or insurance-related” resources of potential transplant recipients (Laurentine & Bramstedt, 2010, p.180). Of these cases, sixteen documented reduced transplant medical services due to inadequate finances or limits of health insurance. An additional two cases, involving patients who had received a kidney transplant, dealt with the individual’s inability to continually access required immunosuppressant medications. The harsh reality of these cases led these researchers to conclude that “one of the most difficult and essential roles of bioethicists is to balance the beneficent desire to help all patients with the economic pragmatism that allows ethical allocation of scarce and expensive technologies like transplantation” (Laurentine & Bramstedt, 2010, p.185). Therefore, health insurance status plays a large role in an ESRD patient’s ability to access transplantation services. Financial screening of each potential transplant recipient usually occurs before patients are allowed access to the pre-transplant evaluation.

A weakness of this single-center review is that it only involved cases sent to the ethics committee and may not represent all patients who sought services or who experienced restricted access to transplant services due to limited financial means. It also may not be generalized to other transplant centers due to the small number of cases reviewed.

**The financial concerns of patients.** A narrowly focused study by Ganji et al. (2014) considered the financial impact of kidney transplantation on recipients and their families. In light of the fact that most ESRD patients have Medicare as a primary insurer, these researchers noted that Medicare patients remain responsible for up to 20% of the costs of the transplant, a significant burden for those without supplemental coverage. Additionally, if not otherwise Medicare eligible (i.e. over age 65 or classified as disabled), Medicare coverage for ESRD patients will only extend 36 months after a successful kidney transplant.

Employing a structured qualitative methodology, these researchers conducted four small group interviews involving a total of 23 pre-transplant patients and family members, a majority of whom were at least 60 years of age. The overall sample was comprised of 13 African Americans and 10 non-African Americans. The sessions were conducted by trained moderators using a standard set of open-ended questions to stimulate discussion. Topics covered included the level of understanding of what insurers would cover over the transplant continuum and the amount of financial burden a patient might expect to assume. All sessions were audio recorded and transcribed verbatim. The transcriptions were then examined for themes and subthemes using inductive analysis.

In the beginning of the group interviews, patients and family members often remarked that they had a reasonable understanding of the financial intricacies of the transplant process; however as group discussions ensued, it became clear that many questions and misunderstandings remained. Findings indicated that patients and their families were confused regarding how to calculate what insurance would cover and what would remain their responsibility. Furthermore, patients noted that until services were rendered and bills received, it is virtually impossible to estimate what the financial liability might be. Patients were also

concerned about future insurability if they should receive a transplant and lose their Medicare coverage. This concern has been somewhat mitigated by the mandate of the Patient Protection and Affordable Care Act of 2010, 2015 (2016) which prohibits the use of “preexisting condition exclusions or other discrimination based on health status” (§2704).

Recommendations from this study include enhancement of financial education and support in pre-transplant visits. A comprehensive national health insurance policy, which encourages and supports kidney transplant recipients over time, was also recommended.

Through the focus group sessions, this study added a rich dialogue to the understanding of the financial barriers and concerns ESRD patients and their families encounter while trying to make the best decisions regarding short and long-term treatment options. It also highlighted where insurance reforms and patient education in the pre-transplant period need to focus. A limitation of the study was its small sample size and single-center focus.

**Personal income and transplant affordability.** Coorey et al. (2009) also included questions regarding financial concerns in their study. Not unexpectedly, over 79% of patients with incomes less than \$50,000, indicated concerns over escalating transplant related health care costs, while 62% were concerned with the costs of long-term medication therapy, and 40% were stressed over the general financial obligations for the transplant surgery. Furthermore, patients on long term dialysis had a median income of \$19,000 while the median income of those who had received kidney transplant was \$59,600 – quite a sizeable difference. Other studies also addressed financial worries and reported that between 14.5% and 60% of respondents struggled with being able to afford the transplantation surgery, the life-long immunosuppressant medications required post-operatively, or both (Dageforde, Box et al., 2015; Kazley et al., 2012).

## **Health Literacy**

Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000, p.vi). Additionally, the IOM (2004) advocates for increased attention to quality in health care, stating that patient “safety, patient-centered care, and equitable treatment” (p.12) can only be achieved if a patient understands the information providers are trying to impart. Those with limited health literacy may be hindered in the understanding of written health information, when speaking with health professionals, and negotiating the health care system in general (Grubbs et al., 2009). Moreover, low health literacy has been shown to correlate with diminished self-care capacity and compromised patient outcomes (Dageforde et al., 2014). This limited understanding may be interpreted as patient disinterest in the transplantation process on the part of the ESRD providers, leading to fewer referrals for evaluation (Grubbs et al., 2009).

**Health literacy status as a barrier to referral for pre-transplant evaluation.** In a study involving 62 hemodialysis patients receiving services at five dialysis centers in an urban area of a western state, Grubbs et al., (2009) found that low health literacy was associated with decreased referral for pre-transplant evaluation. The aim of the study was to assess health literacy as it related to being wait-listed for a kidney transplant. The study sample was 41% male and 72% African American, with a mean age of 52.4 years. A majority of respondents had Medicare and Medicaid insurance coverage. Each participant began by completing a self-administered Test of Functional Health Literacy in Adults, followed up by an interview using a standardized questionnaire. One investigator conducted all the interviews. Using Cox proportional hazard modeling this study found that approximately 32% of respondents had

insufficient health literacy with lower levels in patients 65 years and older. Insufficient health literacy was also associated with an annual income of less than \$30,000 and completion of formal education equal to or less than a high school diploma. Of the 62 study respondents, 75% received a referral to a transplant center for evaluation. Of the patients referred, the overall mean time from dialysis onset to referral was nearly 18 months. However, for those deemed to possess adequate health literacy, the mean time to referral dropped to 15.3 months while those with inadequate health literacy had a mean referral time of nearly 24 months.

Recommendations from this study are to create multimedia education sessions which could meet the needs of patients with various levels of health literacy. Another recommendation, which may be a challenge in the face of tight health care finances, is to allow ESRD patients who are in the evaluation stage to experience a short overnight stay in order to facilitate the completion of all required testing. This would alleviate the need for repeated trips to the health care facility for those who may find it a challenge. A limitation of this one-center study was the small sample size and the timing of the assessment, which took place after referral for evaluation, allowing for possible change in health literacy status related to the transplant process. However, findings of this study in examining health literacy specifically in the ESRD patient population provides an opportunity for transplant centers to review their own procedures for assessing the health literacy levels of their educational materials and presentations.

**Health literacy assessment tools.** In another study, Kazley, Hund, Simpson, Chavin, and Baliga (2015) hypothesized that higher health literacy would equate to increased access to the national kidney transplant wait list, and higher odds that a patient would receive a kidney transplant. The study sample consisted of 92 ESRD patients – 65% African American, 51% male, 42% married, and with a mean age of 53.52 years. Government sponsored health plans



(Medicare and/or Medicaid) were the primary source of health insurance and 25% of respondents were also covered by a private source of secondary insurance. Additionally, 58% of the sample obtained wait list status and 39% received a kidney transplant. A study coordinator met privately with each participant, administering three health literacy assessment tools: the Rapid Estimate of Adult Literacy of Medicine - Transplant (REALM-T), the Newest Vital Sign (NVS) assessment, and the Decision-Making Capacity Assessment Tool (DMCAT).

Descriptive analysis, univariate analysis, and multivariate logistic regression were used to examine the data. Multivariate analysis found a positive, significant correlation for each assessment tool and the likelihood of accessing the kidney transplant wait list. Odds ratios were as follows: REALM-T (1.044), NVS (1.672) and DMCAT (1.408). These findings support the hypothesis that health literacy impacts the likelihood of being added to the wait list for a kidney transplant. Interestingly, in all of the regression models, being married was found to be a positive and significant predictor of transplant wait list access, reinforcing the role support systems play in the transplant process.

Recommendations from this study included assessing transplant patients for health literacy status and tailoring education and supporting materials to the level appropriate for the patient. Also recommended was the use of patient navigators to assist patients along the transplant continuum of care. A weakness of this study was the assumption that being married was a predictable source of support. Without assessing the quality of the marriage, this seems to be an unsupported conclusion. Another weakness is the statement, made several times throughout the article, that health literacy influenced or predicted kidney transplant outcomes. This study did not address transplant outcomes, rather it assessed health literacy as a predictor of access to the transplant wait list – two very different concepts. Despite these limitations, this

study offers further understanding of the role health literacy plays in navigating the complex path toward kidney transplantation. It also offers evidence to support the consideration of any of the three most popular health literacy assessment tools for use with this population.

### **Summary**

The literature review findings validate that patients may experience system as well as self-imposed barriers when considering kidney transplantation. These barriers include fear of failing the required medical tests, fear of the transplant surgery, financial concerns, and reduced health literacy. To mitigate these barriers, these fears need to be acknowledged and systems should be designed to assist patients with the complex decision to either move forward with a kidney pre-transplant evaluation or to continue with long-term dialysis.

## Chapter 3

### CONCEPTUAL FRAMEWORK

The aim of this project is to identify perceived barriers that may interfere with completion of the required pre-transplant evaluation, the first step in the kidney transplant process. As an integral component of a kidney transplant program evaluation, a patient survey was conducted to identify perceived barriers in the ESRD patient population referred to a large Midwestern health system's kidney transplant program. This step is important in order to tailor evidence-based interventions and patient support programming to meet patient identified needs. The Theory of Planned Behavior (TPB) is the theoretical framework that was used as a basis for understanding how the transplant program can better support formation of a positive intention to proceed with the evaluation. Donabedian's Structure-Process-Outcome framework guided the program evaluation endeavor.

#### **The Theory of Planned Behavior**

Introduced in 1985, the TPB is a modification of the Theory of Reasoned Action (TRA), first described in 1975 by Ajzen and Fishbein. The TPB (Figure 1) expanded the original model to address situations that might be out of an individual's volitional control, a noted omission in the TRA (Ajzen, 1991). Grounded in social cognitive theory, the TPB considers the cognitive and non-cognitive processes involved in health-related decision making by acknowledging that deep seated beliefs may inform intention to act as much as rational thought (Montaño & Kasprzyk, 2008). These antecedent beliefs influence a person's attitude toward a particular health behavior and thus the intention to act. A positive intention to act is considered the most important predictor of behavioral action (Ajzen, 2015). The theory posits that perceived benefit of action versus inaction (behavioral belief), the opinion of others toward the behavior

(normative belief), and the facilitators or barriers that are perceived to be supporting or thwarting the decision to act (control belief), are most influential in formulating the intention to act (Ajzen, 1991).

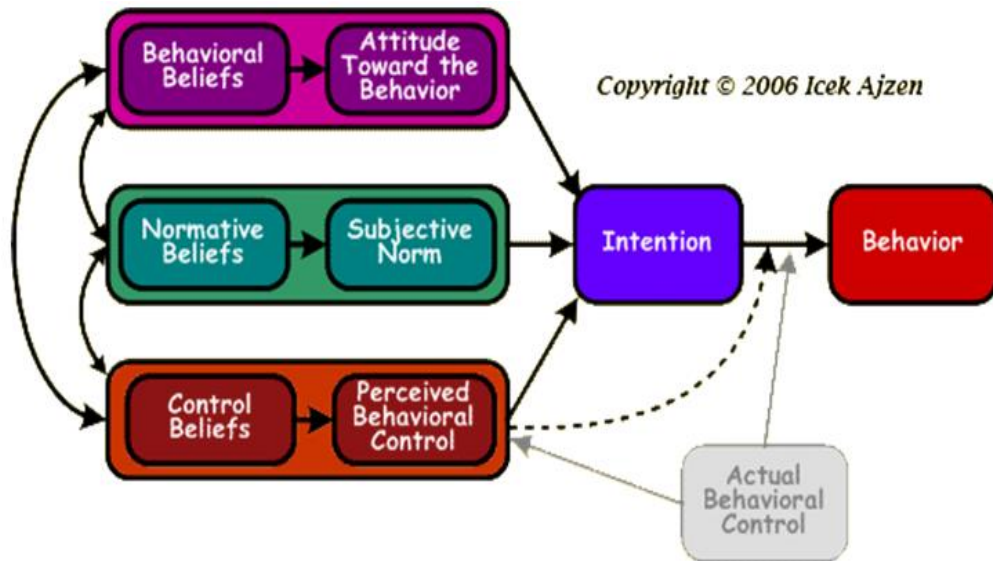


Figure 1. The Theory of Planned Behavior. Adapted from TPB Model by Icek Ajzen (<http://people.umass.edu/aizen/tpb.diag.html>). Copyright 2006 by Icek Ajzen. Used with permission (Appendix A).

### Behavioral Beliefs and Attitude Toward the Behavior

Behavioral beliefs are beliefs each person holds that contribute to the formation of an individualized, subjective view of the world (Ajzen, 1991). These beliefs are instrumental in the creation of attitudes toward targeted behaviors and expected results or outcomes if the behaviors are performed. Correspondingly, positive beliefs will more likely yield positive attitudes while negative beliefs will more likely yield negative attitudes (Montaño & Kasprzyk, 2008). Since these attitudes play a critical role in the formation of intention to act, it is important to understand the beliefs of ESRD patients toward kidney transplantation in order to develop support programming designed to address concerns and influence positive attitude formation.

## **Normative Beliefs and Subjective Norms**

Normative beliefs are influenced by the opinions and actions of those who are close to the person and whose opinions are held in high regard. Whether grounded in fact or myth, the opinion of these people matters greatly in the formation of subjective norms. Therefore, an endorsement in favor of the behavior may influence a favorable subjective norm while opposition more likely will influence the formation of a negative subjective norm (Montaño & Kasprzyk, 2008). It would then follow that an appraisal of the perceptions and opinions of those close to an ESRD patient should be considered to gauge how the subjective norm was formulated.

## **Control Beliefs and Perceived Behavioral Control**

Control beliefs are focused on the individual's volitional control of the selected behavior. Considerations include the number and strength of perceived facilitators and barriers surrounding the selected behavior and the perceived amount of control or influence a person may have to leverage a positive outcome (Ajzen, 1991). The TPB considers perception of control to be most important in forming a positive intention to act; however, the more consistent a perception is to reality the greater the actual chance of success (Ajzen, 1991; Montaño & Kasprzyk, 2008). This construct maintains a high level of independent influence in the formation of intention to act. For example, if both behavioral and normative beliefs are high but control over perceived barriers is low, a positive intention to act is less likely to result (Ajzen, 1991; Montaño & Kasprzyk, 2008). Conversely, if normative beliefs are low but perceived control is high a patient may be more likely to pursue the targeted behavior. This construct is important to consider in the ESRD population as the literature supports many perceived barriers to completion of the required pre-transplant evaluation. Discovery of the patient's level of perceived behavioral

control will assist in directing efforts to support the patient toward a successful pre-transplant evaluation experience.

### **Theory of Planned Behavior Application**

The model (Figure 1) demonstrates the interdependency of behavioral beliefs, normative beliefs, and perceived control on intention to perform a targeted behavior. Ajzen (2015) posits that efforts designed to influence behavior change may be targeted at a singular concept, or at all three at once, in order to influence intention to perform the targeted behavior. Though each are important, the survey efforts of this project were directed toward discovering the perceived barriers and facilitators, and therefore the perceived behavioral control, of the ESRD patient population referred for pre-transplant evaluation. The survey results assisted in providing data to support evidence-based interventions designed to move more patients toward kidney transplantation.

### **Donabedian's Structure-Process-Outcome Framework**

In 1966 Donabedian proposed the structure-process-outcome triad as a means of quantifying and evaluating quality in healthcare. At the time this framework was proposed, outcomes of care were the preferred focus of health care quality assessment. Donabedian proposed expanding this scope to include the structure of care as well as the processes in place to support the delivery of health care to patients (Donabedian, 1966). Admittedly structure and process are more difficult to assess, resulting in less quantifiable data; however, the advantage is a more realistic look at how services are delivered and received at the point of care (Donabedian, 1966). It is important to remember that neither structure, process, nor outcome are characteristics of quality. Rather, examining these concepts results in data that aid in the development of a comprehensive understanding of the complexities of delivering patient-focused

care. However, this understanding is only possible if there is a verifiable relationship between the three concepts, such that it is evident that structure plays a role in process thereby directly impacting outcome. Donabedian (2003) illustrated this relationship by placing a lower case “p” in the model (Figure 2) to underscore the “probability” of a relationship between the concepts. The strength of these relationships adds to the validity of the conclusions drawn regarding the quality of care delivered in a specific setting.



*Figure 2.* Donabedian Model. Adapted from “Selecting Approaches to Assessing Performance,” by A. Donabedian, 2003, *An Introduction to Quality Assurance in Health Care*, p.47. Copyright 2003 by the Oxford University Press. Inc. Used with permission (Appendix B).

## **Structure**

Structure refers to the context, or setting, where care is provided. Examples of structure include the physical space, the quality and quantity of material support such as supplies and equipment, dedicated human resources including the various professional and support staff, and the administrative support provided by the organization (Donabedian, 2003). Structure also refers to the general culture and accepted behaviors of the organization as a whole. The organization’s mission, vision, and values, and how these are manifested at the point of care can greatly impact the context of care delivery.

A comprehensive organizational assessment of the transplant program revealed that there are administrative structures in place to adequately support the patients and professional staff involved in providing care. The administration is organized in a standard vertical configuration where the transplant program manager is responsible for day-to-day operations and reports to the Clinical Services Director for Medical and Specialty Services. The Director reports to the Vice President for Clinical Services, who also serves as the Chief Nursing Officer. The culture of the

professional and support staff align with the mission and vision of the organization and the organization's faith-based values are reflected in the care provided. The physical space of the transplant program is generally adequate to meet current needs; however, with increased referrals and advances in post-transplant care, the program is expected to outgrow the current location in the near future.

The assessment further identified gaps in some structural areas, for example the need for dedicated clerical support. Using data generated in the evaluation process, budgetary requests to address the shortcomings were submitted and approved for fiscal year 2015-2016. In a time of considerable financial challenges, the approval of new positions (totaling 2.2 FTEs) is a testament to effectiveness of the evaluation process and the willingness of the organization to consider and respond to the data-driven request.

## **Process**

Process is meant to reflect the steps in the delivery of care at the patient-provider interface. Encompassing the continuum of care, from patient self-care to the highly technical care provided by professional and support staff, process includes all activities that impact the health of the patient (Donabedian, 2003). Donabedian (2003) also contends that understanding the patient-provider relationship is a critical component of process and is often overlooked by organizations. Here the relationship of structure to process is evident: if structure does not fully support process in a patient-centered design, the patient-provider relationship may suffer. Additionally, if the expressed needs of the patient population are not considered in the design of structure and process, then patient outcomes may also be affected.

A work flow analysis, undertaken as a part of the organizational assessment, demonstrated several areas of process weakness. For example, time from referral to the



transplant program to attendance at a patient education class was unreasonably long, taking an average of 82 days. In this case the identified process issue was that the person responsible for scheduling was a volunteer who worked one half day per week. Other identified process issues involve the time it takes to move the patient from the nephrologist assessment to the surgical consult (average of 51 days) and from the surgical consult to the Transplant Review Team (average of 81 days). These and other process issues have been targeted for rework, especially as staff are added to the transplant care team (e.g. full time administrative support staff). The overarching goal for the transplant team is to be able to streamline the pre-transplant evaluation experience for patients by reducing structure and process roadblocks.

### **Outcome**

Considered at a high level, outcome reflects changes that occur in patients as a result of care provided (Donabedian, 2003). Donabedian (2003) notes that these changes may occur on many levels and have the potential to be a positive or negative influence on health-related outcomes. Included are changes in the understanding of the medical condition on the part of patients or their support system, thereby impacting future care decisions; changes in patterns of personal behavior that may impact future health; changes in the level of satisfaction with the outcomes of care provided; and changes in overall health unrelated to the care received (Donabedian, 2003).

### **Application of the Structure-Process-Outcome Framework**

The outcome of interest is to increase the number of patients who complete the pre-transplant evaluation, allowing them to be considered for the transplant wait list. A comprehensive program evaluation is one way to identify structure and process issues that may prohibit a patient from achieving this outcome. However, the program evaluation had been one

sided, only considering structure and process issues identified internally by the transplant program staff. By affording ESRD patients the opportunity to identify perceived barriers to completing the pre-transplant evaluation, it was possible to begin to address both structure and process issues important to patients that impact this critical outcome.

### **Summary**

It has been determined that perceived barriers cause many patients to abandon the pursuit of a kidney transplant. This abandonment often manifests in a patient's failure to complete the required pre-transplant evaluation. The TPB offers a platform to begin to understand what influences a patient to form a positive intention to act. Once identified, structure and process changes, guided by Donabedian's model, can be implemented to support a patient's perceived behavioral control and formation of a positive intention to act on the pre-transplant evaluation.

A comprehensive program evaluation that results in changes to structure, process, and ultimately outcomes, will remain incomplete unless the patient's voice is heard. To provide outstanding patient-centered care, the needs of the patient must be considered and taken into account as program changes are considered, designed, and instituted. To reiterate, the aim of the project was to gather data regarding the perceived barriers patients face as they navigate the pre-transplant evaluation and to provide additional data to the organization as changes to the structure and process of the transplant program are considered.

## Chapter 4

### METHODS

This chapter describes the design, implementation, and evaluation plan for the scholarly project. The project utilizes a patient survey designed to elicit a better understanding of the barriers patients encounter on the path toward a kidney transplant. The work was undertaken in three phases. The design phase focused on gathering organizational data, selecting an appropriate patient survey, and securing authorization to use the identified tool. The implementation section details the steps taken to administer the survey, including the process for securing and storing the data. The evaluation phase provides details regarding how the data were analyzed, summarized, and disseminated.

#### **Design Phase**

##### **The Patient Population**

The design phase began with an audit of patients referred to the transplant program of a large Midwestern health system in calendar year 2014. In this time span, 346 patients were referred to the transplant program for evaluation of suitability for kidney transplant. This cohort of patients was 58% male ( $n = 201$ ), 60% White ( $n = 210$ ), 23% African American ( $n = 79$ ), 6% Hispanic ( $n = 20$ ), 1% American Indian ( $n = 4$ ), and 0.8% Asian ( $n = 3$ ). The remaining 9% ( $n = 31$ ) had no race recorded in the electronic health record. Ages ranged from 23 to 82 with a mean of 59 and a median of 61 (Table 1). In early 2015, only 2% ( $n = 6$ ) had received a transplant and another 7% ( $n = 25$ ) had progressed successfully to the transplant waitlist (Table 2).

In Table 2, “referral active” status reflects patients who are actively pursuing completion of the pre-transplant evaluation. Those in “referral hold” status are working through delays such

Table 1  
*Age Range of Referred Patients in Calendar Year 2014 (N = 346)*

Age Range	<i>n</i>	%
20 – 29	9	2%
30 – 39	19	5%
40 – 49	44	13%
50 – 59	84	24%
60 – 69	120	35%
70 – 79	64	19%
80 – 89	6	2%

Table 2  
*Status of Referred Patients in Calendar Year 2014 as of April 2015*

Status	<i>n</i>	%	Audited ( <i>n</i> = 107) ( <i>n</i> %)
Transplanted	6	2%	2 (2%)
Referral Active	173	50%	53 (50%)
Referral Hold	30	9%	10 (9%)
Referral Inactive	107	31%	33 (31%)
Waitlisted	25	7%	8 (8%)
Deceased	5	1%	1 (1%)

as health insurance issues or a referral to a medical specialty (e.g. cardiac clearance). Patients with “referral inactive” are, for a variety of reasons, currently not moving forward in the

evaluation process (e.g. excessive body mass index or repeated failure to complete required tests). Those who have completed all of the steps in the pre-transplant evaluation are in the “waitlisted” status, while those who have died before completing the evaluation are reflected in the “deceased” status.

To explore whether there was evidence of diminishing progression toward gaining access to the waitlist, similar to national trends, an audit of select patient records was undertaken. Approximately 30% of the patient population ( $n = 107$ ) were identified for inclusion in the audit based on a simple system of choosing every second or third patient from the spreadsheet for each of the categories (Table 2). Data from medical records were examined to understand the stages at which patients were lost to the pre-transplant evaluation process (Table 3). Attending a patient education class is the first step in the pre-transplant evaluation process. As illustrated in Table 3, 67% of audited patients completed this step. However, from this point, there is a steady decline of patients moving toward placement on the waitlist with only 19 (18%) making it to the final step (median days to listing = 169). To support patients through the evaluation process it is important to understand the barriers that may be preventing progression toward waitlist placement.

### **The Survey Tools**

The patient survey created by Dageforde, Box et al. (2015) to identify patient barriers to the pre-transplant evaluation was used in this project. The survey focuses on concerns of ESRD patients as described in the literature, specifically targeting patient understanding of the transplant process, perceived barriers, and health literacy (Appendix C). Permission to use the survey was granted from the corresponding researcher (Appendix D).

Table 3

*Estimate of Referred Patients Completing Each Step Based on Audited Sample (N = 107)*

Required Step Completed	<i>n</i>	%
Step 1: Attended Patient Education Class	72	67%
Step 2: Completed Personal History	66	62%
Step 3: Attended Transplant Center Evaluation Appointment	62	58%
Step 4: Attended Surgical Evaluation Appointment	50	47%
Step 5: File Reviewed at Transplant Review Team	23	22%
Step 6: Added to Waitlist	19	18%

*Note.* The progressive decline in respondents at each step reflects the fact that only those who participate in the prior steps can move forward to the next step.

Demographic data including age, gender, race, economic status, and level of education were also requested. The survey tool employs Likert-type responses, as well open-ended questions, where patients could expand on their most pressing concerns. The researchers did not report reliability statistics for the “concerns” or “attitudes” scales. The “concerns” scale of the survey consists of 12 items and uses a 3-point scale from “not at all concerned” to “very concerned.” The internal consistency of the concerns scale for this project is  $\alpha = .860$ . The “attitudes” scale of the survey consists of 7 items and uses a 4-point scale from “strongly disagree” to “strongly agree.” The internal consistency of the attitudes scale for this project is  $\alpha = .756$ . The composite survey’s internal consistency reliability for the 88 respondents in this study is acceptable ( $\alpha = .669$ ). The

survey was designed to be administered in a phone interview; however, for this project the survey was mailed to patients via the United States Postal Service (USPS).

**The literacy component of the survey.** Chew, Bradley, and Boyko (2004) created the Short Literacy Survey (SLS) for use in adult outpatient settings where more lengthy assessment tools proved to be time and resource intensive. The abbreviated SLS is based on a 16-item survey covering topics such as completing health related forms, maneuvering through the health care system, provider interactions, and understanding medication administration instructions (Baker et al., 1996). Chew et al. (2004) found that three of the 16 items were most valid in identifying patients with inadequate health literacy: “How often do you have someone help you read hospital materials?”; “How confident are you filling out medical forms by yourself?”; and “How often do you have problems learning about your medical condition because of difficulty understanding written information?” (Chew et al., 2004). The same three questions proved to be weaker in identifying marginal health literacy; however, they still outperformed other items in the survey. Further findings revealed that none of the questions performed better as a standalone item or in combination with the other two (Chew et al., 2004). Chew et al. (2004) also tested the three question SLS against the Short Test of Functional Health Literacy in Adults (S-TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM). Again, findings demonstrated a strong ability for the SLS to identify patients with inadequate health literacy over patients with marginal health literacy when compared to both the S-TOFHLA and the REALM instruments (Chew et al., 2007). The SLS is scored by assigning a numerical value to the three survey response choices (1-5) for a score range of 3-15. Each participant’s responses are then totaled and assigned either the adequate (10-15) health literacy category or the limited (3-9) health literacy category (Dageforde, Box et al., 2015).

Dageforde, Cavanaugh et al. (2015) further tested the SLS in an ESRD population (along with their healthy care givers) who were in the kidney transplant evaluation process. Findings revealed a high internal consistency reliability ( $\alpha = .794$ ) when considering all three questions. Internal consistency fell when any one of the questions was removed from the model ( $\alpha = .639$  to  $.656$ ). Dageforde, Cavanaugh et al. concluded that the written version of the SLS is reliable and valid for identifying limited health literacy in these populations.

Dageforde, Box et al. (2015) incorporated the SLS into their newly created survey for the purpose of assessing health literacy in patients involved in kidney transplant evaluation. The SLS consists of three items and a Likert-type response scale. The response scale for “How confident are you filling out medical forms by yourself?” included “extremely,” “quite a bit,” “somewhat,” “a little bit,” and “not at all.” The response scale for “How often do you have someone help you read hospital materials?”, and “How often do you have problems learning about your medical condition because of difficulty understanding written information?” included “all of the time,” “most of the time,” “some of the time,” “a little of the time,” and “none of the time.” For this project, an editing error occurred in formatting the survey. Instead of using the “extremely” to “not at all” scale for the first item (confident filling out forms), the scale of “all of the time” to “none of the time” was used for all three items. It is understood that the first item (confident filling out forms) is an emotion based question and the original responses (“extremely” to “not at all”) seek an emotion-based response; however, the “all of the time” to “none of the time” action-oriented response scale was sufficiently similar to overcome this error.

The composite survey (Appendix C) has a Flesch Reading Ease score of 69.3 and a Flesch-Kincaid Grade Level of 5.7 based on a US grade school level. Permission to use the



survey was granted from the corresponding researcher (Appendix D). Permission to use the SLS was also granted by the corresponding researcher (Appendix E).

### **Implementation Phase**

An application was submitted to the affiliated university's human research review committee as well as the health system's institutional review board. Expedited approval was granted by both institutions (Appendix F & G). Following approval, survey materials were sent to all living patients ( $n = 341$ ) referred to the transplant center for a pre-transplant evaluation in calendar year 2014 via the USPS. Patients known to be deceased were excluded from the survey ( $n = 5$ ). Patient postal information was accessed through the transplant center's electronic health record (EHR) and stored on a password protected spreadsheet on a password protected computer housed within the medical center. The survey sought only de-identifiable patient demographic information that is not traceable to any individual patient. The surveys were sent with a cover letter of introduction (Appendix H) and a stamped return envelope (Dillman, 1978). The letter has a Flesch Reading Ease score of 43.4 and a Flesch-Kincaid Grade Level score of 11.6. This mailing was followed one week later by a reminder post card (Appendix I) encouraging patient participation in the survey (Dillman, 1978). The post card has a Flesch Reading Ease score of 54.8 and a Flesch-Kincaid Grade Level score of 10.2. Completed surveys were handled only by the graduate nursing student spearheading the project and were stored in a secure area of the medical center.

### **Human Subject Protection**

The risk to human subjects was expected to be minimal as the surveys are anonymous and not traceable to any person. There was limited (e.g. phone call to indicate the death of a patient) to no direct contact between the survey respondents and the graduate student primary

investigator. There was no direct benefit to survey respondents. However, future ESRD patients are expected to benefit from program changes that may result from the data gathered for this project.

Completed survey hard copies, containing no protected health information, are stored in a locked, secure location within the affiliated university with access limited to the graduate student primary investigator and designated research staff. De-identified survey data were entered and stored on a password protected computer using Research Electronic Data Capture (REDCap) and Statistical Package for the Social Sciences (SPSS) software and on an encrypted flash drive. Both will be stored in a locked file in the graduate student project coordinator's office when not in use.

### **Evaluation Phase**

Study data were managed using REDCap tools hosted at the medical center. REDCap is a secure, web-based application designed to support data capture for research studies (Harris et al., 2009). IBM Statistical Package for the Social Science (SPSS) version 20.0 software was employed for data analysis. Descriptive and comparative statistics were used to identify barriers and concerns of the patient sample and subsamples. Findings will be disseminated through a presentation to the transplant team and medical center administrators along with recommendations for patient support programming.

### **Summary**

The purpose of the patient survey is to begin to understand the challenges and barriers ESRD patients face as they navigate the transplant evaluation process. Once identified, changes to existing patient support structures can be undertaken with an outcome of an increase in the number of patients gaining access to the transplant waitlist.

## Chapter 5

### RESULTS

Survey results are presented in two sections. The first is a general description of the survey respondents. The second section is the statistical data that summarizes the concerns, attitudes, and health literacy of the survey respondents that may contribute to barriers on the path to kidney transplant.

#### **Respondent Demographics**

Of the 341 surveys sent out, 41 were returned as undeliverable. Notification was received that eight patients were deceased with family not willing to participate in the survey. Ultimately 88 surveys were returned of the eligible 292 (30% response rate) and are included in the data analysis.

The survey respondent group had a 50% male/female split and ranged in age from 41 years to 82 years old (*Mdn* = 62 years). Within in this cohort, 54% were receiving hemodialysis, 12% were receiving peritoneal dialysis, and 34% were managing their ESRD without dialysis. A comparison of the survey respondents and the total study population (Table 4) reveals that the groups are congruent in many ways, but differ in race. Whites represent a greater percentage of survey respondents than African Americans compared to the study population. These data will be important to consider when trying to generalize the survey results to the study population.

#### **Data Analysis**

Data were first analyzed by examining the three separate categories of the survey – concerns, attitudes, and health literacy – including all survey respondents in the analysis. This analysis offers a high-level picture of the concerns, attitudes, and health literacy status of the whole group.

Table 4

*Comparison of Study Respondents and the Total Population*

Item	Respondents ( <i>n</i> = 88)		Population ( <i>n</i> = 292)	
	<i>n</i>	%	<i>n</i>	%
Age				
Range ( <i>Mdn</i> )	41 – 82 years (62)		23 – 82 (59)	
Sex				
Male	44	50%	169	58%
Female	44	50%	123	42%
Race				
White	69	78%	175	60%
African American	12	14%	67	23%
Hispanic	3	3%	18	6%
Other	0	0%	6	2%
Unknown	4	5%	26	9%
Marital Status				
Single	17	19%	Unknown	
Married	50	57%	Unknown	
Divorced	11	13%	Unknown	
Separated	0	0%	Unknown	
Widowed	7	8%	Unknown	
Unknown	3	3%	Unknown	
Education				
>High School Diploma	11	13%	Unknown	
High School Diploma	47	53%	Unknown	
Associate Degree	12	14%	Unknown	
Bachelor's Degree	10	11%	Unknown	
Graduate Degree	6	7%	Unknown	
Unknown	2	2%	Unknown	
Annual Income				
>\$20,000	25	28%	Unknown	
\$20,000 - \$39,000	24	27%	Unknown	
\$40,000 - \$59,000	12	14%	Unknown	
\$60,000 - \$79,000	11	12%	Unknown	
\$80,000 - \$99,000	5	6%	Unknown	
\$100,000 or >	5	6%	Unknown	
Unknown	6	7%	Unknown	
Health Insurance				
Medicare	76	87%	Unknown	
Medicaid	37	57%	Unknown	
Private Insurance	38	43%	Unknown	

## **Concerns**

The 12 items in this category (see Table 5) represent reasons why someone might find it difficult to participate in the pre-transplant evaluation. Survey respondents were asked to acknowledge how much of a “worry or concern” each statement was, considering their own circumstances (Table 5). The highest-ranking item, eliciting a “very concerned” response from 50% of survey respondents, involved the “length of time to wait for a kidney transplant.” The next most worrisome item, identified by 48% of respondents as “very concerned,” was “finding a living donor.” Forty-six percent of survey respondents indicated that both “affording medications” post-transplant and “knowing the next steps” in the transplant rated a “somewhat concerned” response. On the lower end of the response scale, the survey respondents ranked concerns regarding finding time for the evaluation, identifying support people, and the cost for travel to the transplant center as “not at all” a concern.

## **Attitudes**

The seven statements in the “attitudes” category represent thoughts and attitudes people have expressed about the pre-transplant evaluation process. Survey respondents were encouraged to indicate how strongly they agreed or disagreed with the statements (Table 6). Survey respondents agree with most attitude statements regarding the kidney transplant process, which suggest overall positive attitudes. Only the statement “dialysis is not that bad,” with 48% of survey respondents choosing “strongly disagree” or “disagree,” seems to be an outlier in this section of the survey.

## **Health Literacy**

The three items in this section of the survey were designed to gauge a patient’s ability to encounter a medical setting. Survey respondents were asked to identify the answer that best fits

Table 5

*Survey Results for Concerns Category Ranked from Highest to Lowest*

Item	Not at All		Somewhat		Very		Missing
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
The length of time to wait for a kidney transplant	8	9%	30	34%	44	50%	6
Finding a living donor	18	21%	24	27%	40	48%	6
Affording the medicines after the transplant	21	24%	40	46%	23	26%	4
Knowing the next steps to take	28	32%	40	46%	11	12%	9
Affording the costs for the visits and tests during the evaluation process	32	36%	38	43%	15	17%	3
Being medically healthy enough on the evaluation tests for transplant	30	34%	36	41%	17	19%	5
Fear of getting a transplant	32	36%	36	41%	16	18%	4
Affording the transplant operation	26	30%	34	39%	24	27%	4
Fitting the evaluation into my schedule	67	76%	13	15%	3	3%	5
Finding a support person to come with me	66	75%	10	11%	7	8%	5
Having transportation to the transplant center	61	69%	16	18%	7	8%	4
Having the money to get to the transplant center	49	56%	27	31%	8	9%	4

Table 6  
*Survey Results for Attitudes Category Ranked from Highest to Lowest*

Item	Strongly Disagree		Disagree		Agree		Strongly Agree		Missing
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
I know the next steps to take to have a kidney transplant	9	11%	10	13%	43	55%	15	19%	11
I am good at learning new things on my own	2	2%	12	14%	43	52%	25	30%	6
I know a lot about how a transplant would affect my life	5	6%	16	18%	41	47%	20	23%	6
I know a lot about how long a transplanted kidney might work for me	7	8%	22	25%	40	46%	13	15%	6
I feel that dialysis is not that bad	20	23%	22	25%	34	39%	2	2%	10
I know a lot about kidney transplant	7	8%	23	32%	34	39%	14	16%	5
I know that reason why a kidney transplant would be good for me	3	3%	4	5%	37	42%	38	43%	6

how they feel when dealing with medical information and forms, with scores ranging from three to 15 (Table 7). Overall, 62% ( $n = 49$ ) of respondents were found to have adequate health literacy (score of 10-15), while 38% ( $n = 30$ ) were found to have limited health literacy (score of 3-9). When examining individual items, the most telling result is that 67% of survey respondents have confidence filling out medical forms “all” or “most of the time,” with another 26% feeling confident only “some,” “little,” or “none of the time.” Another important finding is that 30% of

survey respondents admitted to having problems learning about their medical condition “some of the time” due to a lack of understanding written information. Finally, although 44% of survey respondents required no help in reading hospital materials, 40% of survey respondents identified needing help “all,” “most,” or “some of the time.”

Table 7

*Survey Results for Health Literacy Category*

Item	All		Most		Some		Little		None		Missing
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
How confident are you filling out forms?	24	27%	35	40%	8	9%	7	8%	8	9%	6
How often do you have problems learning about your medical condition because of difficulty understanding written information?	1	1%	5	6%	26	30%	21	24%	31	35%	4
How often do you have someone help you read hospital materials?	9	10%	12	14%	14	16%	9	10%	39	44%	5

An analysis of variance (ANOVA) using the health literacy scores showed that the effect of health literacy on transplant status, waitlist attainment, and dialysis status approached significance,  $F(2, 60) = 2.968, p = .059$ . For the ANOVA analysis, all survey respondents were separated into seven groups based on their reported treatment status. Four groups were deemed too small to analyze due to insufficient size. Ultimately three groups were compared using a subset of the 88 survey respondents ( $n = 63$ ). Group one ( $n = 18$ ) was composed of survey respondents who had a kidney transplant and were not on the waitlist nor on dialysis. Group two



( $n = 23$ ) was composed of respondents who had not received a kidney transplant, were on the transplant waitlist, and were receiving dialysis. Group three ( $n = 22$ ) was composed of respondents who had not yet received a transplant, were not on the waitlist, but were receiving dialysis. Post hoc analysis using the Tukey HSD test did not indicate significant differences between these groups; however, group three ( $M = 10.2273$ ,  $SD = 2.79$ ) was noted to be different enough to warrant future investigation (Table 8) about the impact of low health literacy scores on waitlisting.

Table 8

*Health Literacy Post-hoc Tukey Analysis – Group Means*

Group	<i>n</i>	<i>M</i>	<i>SD</i>
Group 1	18	12.0556	2.97978
Group 2	23	11.9565	2.53123
Group 3	22	10.2273	2.79339

**Qualitative Data**

Survey respondents were also given the opportunity to submit written comments about their experience and feelings regarding specific sections of the survey (concerns, attitudes, and health literacy) and the kidney transplant process overall. All comments were examined for common themes (e.g. Health Concerns; General Fears; Affording the Transplant, Medications, and After Care; Living Donor Concerns; Wait Time Concerns; and General Concerns and Comments) with select comments on a few of these themes presented in Table 9. The complete summary may be viewed in Appendix J. The comments provide a deeper understanding of the struggle patients face as they move through the kidney transplant evaluation process, particularly in relationship to finding a living donor.

Table 9

*Select Survey Respondent Written Comments by Themes*

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Health Concerns

- I have waited over two years and the average wait time is over 5 years. My health, other than kidneys, is very good, but I am nearly 74 years old and that can change as I wait.

Affording Transplant Medications and After Care

- My wife found on the internet a drug program for my antirejection meds (for reduced cost). It would have been nice to have been told about these programs by the transplant team/pharmacy.
- After I had my transplant [what] hit me at once was the overwhelming doctor appointments, all the driving to and from, the cost of motels, reliable transportation, [and] gas for the weekly visits - CRAZY! Seems like your local nephrology team could do them and send data or conference call weekly with blood work. Use Skype conferencing to call patient.

Living Donor Concerns

- Finding a living donor is difficult. Asking or soliciting people on Facebook or elsewhere is uncomfortable for me or my wife.
- Not knowing the next steps. Will not take a kidney from a living donor – they're going to need their own.
- Since the length of wait is high in Michigan for deceased donors – more concerned about getting a living donor. In addition, living donor kidney's last longer so more of a concern and goal to receive one.

General Concerns and Comments

- During the pre-transplant evaluation process it would be a good idea to see some of the after transplant patients - talk about their experiences.
  - I think most dialysis patients do not understand the full extent of their sickness because it is a slow process. Nor do I think most understand truly how their life will change so drastically post-transplant...but the overall improvement is amazing...I don't think most people think about the small things – increased warmth, decreased nausea, increased energy, decreased brain fog, increased concentration...the freedom you feel to live life again.
-

## **Data Analysis: Sex and Race**

The literature review provided evidence that women and African Americans with ESRD are often less likely to complete the pre-transplant evaluation than White males due to the barriers they encounter. The survey data were examined to discover if this held true for the respondents in this survey.

### **Sex**

Survey respondents were evenly split by sex, demonstrating a 50% participation by both males and females. Tables 10, 11, and 12 display data analysis for sex and “concerns,” “attitudes,” and “health literacy” respectively.

**Concerns.** The analysis for “sex” and “concerns” (Table 10) is consistent with the results of the overall survey respondents (Table 5). For both, the highest-ranking item was the concern over the wait time for an available kidney. Fifty percent of males and 57% of females identified this item as “very” concerning. Similarly, 46% of males and 51% of females ranked finding a living donor and affording post-transplant medications as the next most concerning items in this section of the survey. The items eliciting a “not at all” response were also congruent with the general population of survey respondents, including money to travel, scheduling the pre-transplant evaluation, and identifying support people. Kruskal-Wallis analysis did not identify any statistically significant difference in the comparison of ranks of “concerns” by sex.

**Attitudes.** Results for “sex” and “attitudes” (Table 11) also reflected results similar to the overall respondents in the survey (Table 6). One noted difference was that females were nearly evenly split on the item “dialysis is not that bad” with 24% indicating “strongly disagree,” 37% “disagree,” and 37% “agree” with the statement whereas 50% of males agreed with the statement.

Table 10

*Survey results for Concerns by Sex*

Item	Not at All		Somewhat		Very		Mean Rank
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Being medically healthy enough on the evaluation tests for transplant							
Male	15	37%	15	37%	10	25%	42.75
Female	15	35%	21	49%	7	16%	41.30
Fear of getting a transplant							
Male	16	39%	17	41%	8	20%	42.30
Female	16	37%	19	44%	8	19%	42.69
Affording the transplant operation							
Male	9	22%	19	46%	13	32%	46.11
Female	17	40%	15	35%	11	25%	39.06
Affording the medicines after the transplant							
Male	8	20%	23	58%	9	22%	42.49
Female	13	29%	17	39%	14	32%	42.51
Affording the costs for the visits and tests during the evaluation process							
Male	14	34%	23	56%	4	10%	42.13
Female	18	41%	15	34%	11	25%	43.81
The length of time to wait for a kidney transplant							
Male	4	10%	16	40%	20	50%	40.10
Female	4	9%	14	34%	24	57%	42.83
Finding a living donor							
Male	8	20%	14	34%	19	46%	41.23
Female	10	24%	10	24%	21	51%	41.77
Having the money to get to the transplant center							
Male	22	54%	15	36%	4	10%	44.32
Female	27	63%	12	28%	4	9%	40.77
Having transportation to the transplant center							
Male	32	78%	5	12%	4	10%	40.57
Female	29	67%	11	26%	3	7%	44.34
Finding a support person to come with me							
Male	31	75%	6	15%	4	10%	43.60
Female	35	83%	4	10%	3	7%	40.44
Fitting the evaluation into my schedule							
Male	30	75%	8	20%	2	5%	44.40
Female	37	86%	5	12%	1	2%	39.77
Knowing the next steps to take							
Male	14	39%	19	53%	3	8%	37.39
Female	14	32%	21	49%	8	19%	43.17

The items eliciting the most agreeable responses were also the same as the general survey respondents. Kruskal-Wallis analysis identified the item “I know a lot about how long a transplanted kidney might work for me” as approaching significance ( $\chi^2 = 3.708, p = .054$ ) in the analysis of rank order for “attitudes” by sex.

Table 11  
*Survey Results for Attitudes by Sex*

Item	Strongly Disagree		Disagree		Agree		Strongly Agree		Mean Rank
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
I feel that dialysis is not that bad									
Male	11	28%	8	20%	20	50%	1	2%	40.88
Female	9	24%	14	37%	14	37%	1	2%	38.05
I know the next steps to take to have a kidney transplant									
Male	4	11%	5	13%	24	63%	5	13%	37.54
Female	5	13%	5	13%	19	49%	10	25%	40.42
I know a lot about kidney transplant									
Male	3	7%	14	33%	16	38%	9	22%	43.85
Female	4	10%	14	34%	18	44%	5	12%	40.11
I know the reason why a kidney transplant would be good for me									
Male	0	0%	0	0%	23	55%	19	45%	42.96
Female	3	7%	4	10%	14	35%	19	48%	39.96
I know a lot about how long a transplanted kidney might work for me									
Male	1	2%	10	24%	23	55%	8	19%	46.08
Female	6	15%	12	30%	17	42%	5	13%	45.04
I know a lot about how a transplanted kidney would affect my life									
Male	1	2%	7	17%	22	52%	12	29%	44.06
Female	4	10%	9	22%	19	48%	8	20%	38.81
I am good at learning new things on my own									
Male	0	0%	5	12%	23	55%	14	33%	44.06
Female	2	5%	2	18%	20	50%	11	27%	38.81

**Health literacy.** The results for “sex” and “health literacy” (Table 12) also were generally consistent with the overall survey results (Table 7). Forty-two percent of males and 44% of females indicated that they felt confident filling out medical forms only “most of the time.” Surprisingly 42% of females indicated that they were confident “all of the time” while

males indicated being confident “all of the time” at 17%. The “problems learning” item reflected the most divergent responses with 44% of males stating that this was an issue “some of the time” and 51% of females stated that learning about their medical condition was an issue “none of the time.” Kruskal-Wallis analysis identified a statistically significant finding for “how confident are you filling out medical forms?” ( $\chi^2 = 9.966, p = .002$ ) for “health literacy” and sex.

Table 12  
*Survey Results for Health Literacy by Sex*

Item	All		Most		Some		Little		None		Mean Rank
	n	%	n	%	n	%	n	%	n	%	
How confident are you filling out medical forms?											
Male	7	17%	17	42%	5	12%	5	12%	7	17%	49.35
Female	17	42%	18	44%	3	7%	2	5%	1	2%	33.65
How often do you have problems learning about your medical condition because of difficulty understanding written information?											
Male	1	2%	2	5%	18	44%	11	27%	9	22%	36.28
Female	0	0%	3	7%	8	19%	10	23%	22	51%	47.33
How often do you have someone help you read hospital materials?											
Male	6	15%	7	17%	9	23%	4	10%	14	35%	35.46
Female	3	7%	5	12%	5	12%	5	12%	25	58%	49.21

## Race

Whites were predominant among survey respondents, representing 82% of returned surveys. The African American response rate accounted for 14% of total respondents.

Crosstabulation of survey results are presented in tables 13, 14, and 15.

**Concerns.** When analyzing the “concerns” data by race (Table 13), the items reflected overall survey respondents (Table 5) in terms of most to least important. The wait time for a transplant, finding a living donor, and affording post-transplant medications caused the most concern. However, unlike 51% of the Whites who were “somewhat concerned” regarding

Table 13

*Survey Results for Concerns by Race*

Item	Not at All		Somewhat		Very		Mean Rank
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Being medically healthy enough on the evaluation tests for transplant							
White	26	39%	28	42%	13	19%	38.63
African American	16	37%	19	44%	8	9%	44.82
Fear of getting a transplant							
White	26	39%	27	40%	14	21%	39.88
African American	5	46%	4	36%	2	18%	37.18
Affording the transplant operation							
White	23	34%	25	37%	19	29%	39.26
African American	3	27%	5	46%	3	27%	40.95
Affording the medicines after the transplant							
White	17	26%	33	51%	15	23%	38.88
African American	4	33%	4	33%	4	33%	39.67
Affording the costs for the visits and tests during the evaluation process							
White	27	41%	27	41%	12	18%	39.18
African American	4	33%	6	50%	2	17%	41.25
The length of time to wait for a kidney transplant							
White	6	9%	26	41%	32	50%	37.56
African American	1	8%	3	25%	8	67%	43.50
Finding a living donor							
White	17	26%	18	28%	30	46%	37.28
African American	1	9%	3	27%	7	64%	45.68
Having the money to get to the transplant center							
White	42	64%	19	29%	5	7%	38.08
African American	5	42%	5	42%	2	16%	47.29
Having transportation to the transplant center							
White	51	77%	11	17%	4	6%	38.29
African American	7	58%	3	25%	2	17%	46.17
Finding a support person to come with me							
White	53	81%	7	11%	5	8%	38.63
African American	9	75%	2	17%	1	8%	41.00
Fitting the evaluation into my schedule							
White	56	86%	6	9%	3	5%	37.92
African American	8	67%	4	33%	0	0%	44.83
Knowing the next steps to take							
White	24	38%	30	48%	9	14%	37.29
African American	4	36%	5	46%	2	18%	38.73

affording post-transplant medications, African Americans were evenly split across the three choices on this concern. Money to travel to the transplant center, transportation to the center, and identifying a support person were of lesser concern for both Whites and African Americans. Kruskal-Wallis analysis did not identify any statistically significant difference in the comparison of ranks of “concerns” by race.

**Attitudes.** The “race” and “attitudes” analysis (Table 14) was again generally reflective of the overall survey respondents’ responses, with similar mean ranking of items. One noted exception is the responses to the statement “I know a lot about kidney transplant.” Here 43% of White respondents agreed with the statement, while 50% of African American respondents disagreed. Kruskal-Wallis analysis identified the item “I know a lot about kidney transplant” as approaching significance ( $\chi^2 = 3.475, p = .062$ ) for “attitudes” and race.

**Health literacy.** The ranking of health literacy results by race (Table 15) was similar to the overall respondent responses (Table 7); however, within the items differences between White respondents and African American respondents was noted. For example, 73% of White respondents indicated that they were confident filling out medical forms “all” or “most of the time” compared to 64% of African American respondents. Conversely, for the item relating to “problems learning about medical conditions,” 62% of White respondents and 50% of African American respondents reported that this is an issue “little” or “none” of the time. Help reading hospital materials required the least assistance for both Whites and African Americans. Kruskal-Wallis analysis did not identify any statistically significant difference in the comparison of ranks of “health literacy” by race.



Table 14  
*Survey Results for Attitudes by Race*

Item	Strongly Disagree		Disagree		Agree		Strongly Agree		Mean Rank
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
I feel that dialysis is not that bad									
White	19	32%	16	27%	23	38%	2	3%	34.60
African American	0	0%	5	45%	6	55%	0	0%	43.64
I know a lot about kidney transplant									
White	5	8%	19	29%	28	43%	13	20%	40.93
African American	2	17%	6	50%	3	25%	1	8%	28.54
I know the reason why a kidney transplant would be good for me									
White	2	3%	1	2%	29	45%	32	50%	39.56
African American	1	8%	2	17%	4	33%	5	42%	32.83
I know a lot about how long a transplanted kidney might work for me									
White	4	6%	18	28%	32	50%	10	16%	39.19
African American	3	25%	2	17%	5	41%	2	17%	34.83
I know the next steps to take to have a kidney transplant									
White	6	10%	8	13%	33	55%	13	22%	37.20
African American	3	27%	2	18%	4	37%	2	18%	29.45
I know a lot about how a transplanted kidney would affect my life									
White	2	3%	14	22%	33	52%	15	23%	38.75
African American	3	25%	1	9%	4	33%	4	33%	37.17
I am good at learning new things on my own									
White	0	0%	10	16%	36	56%	18	28%	38.38
African American	2	17%	1	8%	4	33%	5	42%	39.17

### Summary

The aim of this project is to begin to understand the barriers ESRD patients encounter when referred to a transplant center for evaluation for a kidney transplant. These data reflect general survey respondent responses as well as comparison by sex and race. The respondents were evenly split by sex; however more Whites chose to participate in the survey than African Americans. This may affect generalizing the survey findings.

Table 15  
*Survey Results for Health Literacy by Race*

Item	All		Most		Some		Little		None		Mean Rank
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
How confident are you filling out medical forms?											
White	18	28%	29	45%	6	9%	4	6%	8	12%	38.72
African American	4	37%	3	27%	2	18%	2	18%	0	0%	37.23
How often do you have problems learning about your medical condition because of difficulty understanding written information?											
White	1	2%	3	4%	21	32%	17	26%	24	36%	38.38
African American	0	0%	2	17%	4	33%	3	25%	3	25%	42.73
How often do you have someone help you read hospital materials?											
White	7	11%	10	15%	11	16%	7	11%	31	47%	40.57
African American	3	7%	5	12%	5	12%	5	12%	25	58%	33.63

In the overall survey findings, the items of greatest concern were the “length of time to wait for a kidney transplant” and the issues inherent to “finding a living donor.” Other concerns which caused distress were “affording medications” post-transplant and “knowing the next steps” to take to move forward in the transplant process. Of least concern were “fitting the evaluation into my schedule,” the identification of a “support person to come with me,” having “transportation to the transplant center” and “having the money to get to the transplant center,” all of which fell into the “not at all” category of concern.

In general, the survey respondents agreed with most of the statements presented to gauge attitudes toward kidney transplantation. The statement most agreeable to the survey respondents was the statement “I know the next steps to take to have a kidney transplant.” This stands in contrast to the concerns category, where “knowing the next steps” was a mid-level concern and therefore deserves further investigation. It also stands in contrast to the drop off of patients at each step of the process. Other high-ranking statements in the attitudes section of the survey

were “I am good at learning new things” and “I know a lot about how a transplant would affect my life.” The statement that generated the greatest disagreement was “I feel that dialysis is not that bad” indicating a general dislike for the inconvenience dialysis brings to ESRD patients’ lives.

The item “I know a lot about how long a transplanted kidney might work for me” in the analysis of “sex” and “attitudes” approached significance, as did the item “I know a lot about kidney transplant” in the “race” and “attitudes” analysis. The item “How confident are you filling out medical forms” demonstrated a statistically significant finding in the “sex” and “health literacy” analysis. An ANOVA of health literacy and three survey respondent groups approached significance. Post-hoc Tukey HSD analysis, although not statistically significant, pointed toward a difference between groups. Group three (receiving dialysis, not on the waitlist, and not having received a kidney transplant) is different enough on health literacy to suggest that this group could be facing barriers not experienced by the other groups and warrants further investigation.

## Chapter 6

### DISCUSSION

The aim of this scholarly project was to examine barriers encountered by ESRD patients progressing toward placement on the kidney transplant waitlist with the goal of receiving a kidney transplant. A dual approach was used: an organizational assessment and a patient focused survey of concerns, attitudes, and health literacy.

The in-depth organizational assessment of a large Midwestern health system, and the transplant program it supports, revealed structure and process challenges faced by the staff. These challenges not only hampered the efficiency of the staff, but were thought to affect patient outcomes as well. Donabedian's structure-process-outcome framework guided this assessment at the point of care.

Ajzen's Theory of Planned Behavior (TPB) guided the work of the patient survey. The TPB posits that a patient's intention to perform an action is based on cognitive and non-cognitive beliefs and that a positive intention to act may be the most important predictor of action (Ajzen, 2015). Utilizing the opportunity to form a relationship with the ESRD patient, the transplant staff may be able to influence the formation of a positive intention. Through thoughtful interactions with the ESRD patient, the staff could shape attitudes toward kidney transplantation, model positive subjective norms, and influence perceived behavioral control – all key components of the TPB.

The patient focused survey examined concerns, attitudes, and health literacy status of ESRD patients referred for a pre-transplant evaluation. All responses were analyzed, with further analysis delving deeper into the data to examine the respondent responses based on sex and race. Through this analysis it may be possible to design patient interventions intended to

influence the patient's intention to complete the pre-transplant evaluation. Additionally, it has been suggested that females and African Americans are disadvantaged when accessing the transplant waitlist; it was important to understand if the local ESRD population follows this trend (Alexander & Sehgal, 1998; Schold et al., 2011; Sullivan et al., 2012; Weng, Joffe, Feldman, & Mange, 2005).

### **Organizational Issues**

A workflow analysis of the transplant unit revealed three areas of need. The first and most pressing need was that of an administrative support position to coordinate and perform the daily work of the unit. Under current processes, some of the clerical work was performed by the nursing staff, taking them away from other more essential nursing functions. Other tasks, such as scheduling patient visits, were performed by a part time volunteer. A position description was developed and a 1.0 FTE position was approved in the new budgetary cycle. Second, a review of patient referral patterns revealed the need for a patient outreach coordinator to encourage and coordinate patient referrals from community agencies (e.g. physician's offices and dialysis centers) to the transplant center. A position description for a 0.5 FTE position was submitted and approved by the budget committee. Finally, the need for dedicated pharmacist support for the ESRD and transplant population was identified and a 0.7 FTE pharmacist position was also approved. The approval of 2.2 FTE was outside the norm for the 2015-2016 budget cycle due in part to tight health care reimbursement models and was an unexpected outcome.

### **Survey Results**

#### **Concerns**

Overall, the respondents in this survey identified the wait time for a suitable kidney (Table 5) as the greatest concern over other concerns, such as fear of the surgery, affording the

transplant surgery, or finding a support person. This finding stands in contrast to other studies, which identified financial barriers (Dageforde, Box et al., 2015; Coorey et al., 2009), and fear of failing the required medical tests (Kazley, 2012) as higher-ranking concerns. Nonetheless, wait time is important as the evidence supports early transplantation – the earlier an ESRD patient receives a transplant the better the long-term outcomes (Schold et al., 2011; Coorey et al., 2009; Weng et al., 2005). The national median wait time for a deceased donor kidney transplant was 4.2 years in 2012 (OPTN/SRTR, 2014), adding to the validity of this concern. In 2015, the latest year for which national data are available, wait list time has slightly increased with nearly 50% of wait listed ESRD patients logging at least four years on dialysis; 16% at least five years; and 13% at least 11 years (OPTN/SRTR, 2016). Wait time is also related to the second greatest concern identified in this survey – that of finding a living donor. The identification of an acceptable living donor would greatly reduce the wait time for the ESRD patient. However, many survey respondents voiced discomfort in asking someone to consider donating a kidney, while others commented on the potential negative effects donation might have on a living donor, such as post-donation physical well-being (Appendix J). These concerns may be mitigated by an established relationship with the center that helps support the patient’s intentions to act and move forward in the process.

Financial barriers were also a concern although not ranked quite as high as in other studies (Corey et al., 2009; Dageforde, Box et al., 2015). Despite Medicare only supporting ESRD patients for three years following a kidney transplant (if transplant occurs before age 65) affording required medications after the transplant was only “somewhat” of a concern for 46% ( $n = 40$ ) of survey respondents. This finding may reflect the fact that 43% ( $n = 37$ ) of survey respondents were age 65 or older and therefore would receive Medicare support for transplant

related expenses for life. Additionally, 43% ( $n = 38$ ) of respondents reported having private insurance as either primary or secondary coverage, perhaps making affordability of post-transplant medications less of a concern.

**Sex and race.** Data analysis of the concerns category did not find significant differences in this survey for either sex or race. Neither females nor African Americans demonstrated a significant difference when compared to the overall findings in the concerns category. For both sex and race, findings reflect those of the overall respondent group in ranking wait time for a transplant as the most concerning. This would seem to indicate that both men and women, and all ethnic groups, shared similar concerns regarding the pre-transplant evaluation.

The respondent group was evenly split by sex – exactly half of the group was female – closely reflecting the overall survey population (42% female). For race, the respondent group was composed of 78% Whites ( $n = 69$ ) and 14% ( $n = 12$ ) African Americans. These percentages do not reflect the overall survey population, which was composed of 60% ( $n = 169$ ) White and 23% ( $n = 67$ ) African American. These ethnicity data need to be considered with caution because of the smaller proportion of African Americans who returned the survey. The low number of African American respondents may not accurately portray the concerns of the African American subgroup within the identified population.

### **Attitudes**

The survey respondents generally indicated agreement with the attitude statements such as knowing the next steps to take, knowing a lot about how a transplant would affect their lives, and how long a transplanted kidney might last. Nonetheless, the respondents in this study found dialysis more disagreeable than the respondents in the Dageforde, Box et al. (2015) study. Forty-one percent of the current respondents disagreed with the statement that dialysis was not that

bad, while 70% of the Dageforde, Box et al. respondents agreed that dialysis was not that bad. Although many of the respondents had not yet been waitlisted, this sense that dialysis is unpleasant may add impetus to achieving waitlist status. Considering the restraints dialysis places on an ESRD patient, such as dietary restrictions, dialysis schedules, and compromised quality of life, this current finding is understandable (Seah, Tan, Srinivas, Wu, & Griva, 2013). Since 54% of respondents were receiving hemodialysis in a dialysis center, the impact of dialysis on their quality of life is real. The respondents in this survey were apparently comfortable with their level of knowledge as described in the other items in the attitudes category of the survey.

**Sex and race.** For the most part, the analysis of sex and race yielded results similar to the overall respondents. However, the rank for dialysis being “not that bad” was mixed for females when compared to males. More males (50%) agreed with this statement, while females were more prone to rank dialysis with more displeasure (61% “disagreed” or “strongly disagreed”). The responses to the statement “I know a lot about how long a transplanted kidney might work for me” approached significance and should be considered further as it applies to sex. In this case, 45% ( $n = 18$ ) of females disagreed or strongly disagreed with the statement while only 26% ( $n = 11$ ) of males felt the same. There is not a clear explanation for this finding. It may be tied to level of formal education or economic status and bears further analysis in a larger sample.

### **Health Literacy**

Health literacy has been documented as playing an important role in successful patient outcomes (IOM, 2004; Ratzan & Parker, 2000). It has been posited that inadequate health literacy may act as an additional barrier to patients working through the pre-transplant evaluation process (Dageforde et al., 2014). In this survey, 62% ( $n = 49$ ) of respondents scored in the



adequate health literacy category and 38% ( $n = 30$ ) in the limited health literacy category. These findings are congruent with Dageforde et al. (2014), although adequacy of health literacy was not found to be associated with a patient's preference for dialysis over transplant by Grubbs, Gregorich, Perez-Stable, and Hsu (2009). For this survey, the ANOVA analysis for transplant status, waitlist attainment, and dialysis status approached significance. Post-hoc Tukey HSD analysis demonstrated that group three (no transplant, not on waitlist, receiving dialysis), although not statistically significant from the other two groups, had the lowest mean for health literacy and was different enough on post-hoc analysis to warrant further investigation ( $M = 10.2273$ ,  $SD = 2.79$ ). This important finding may be related to level of education, income, or other social determinant and bears further scrutiny.

**Sex and race.** The results for sex and race mirrored that of the overall survey respondents. However, in a Kruskal-Wallis analysis, the question "how confident are you filling out medical forms" was found to be statistically significant finding regarding sex and health literacy ( $p = .002$ ). The findings here go against the idea that females are at a disadvantage (Alexander & Sehgal, 1998; Sullivan et al., 2012; Weng, Joffe, Feldman, & Mange, 2005) since 86% ( $n = 35$ ) of female respondents indicated confidence "all" or "most" of the time compared to 59% ( $n = 24$ ) of males. This may be related to education or income and deserves further investigation. For the analysis of race and health literacy, no statistically significant findings were identified. This also goes against national trends in that in this survey, health literacy as it relates to race did not seem to be a barrier. However, this finding needs to be considered within the context of a low African American response. It may be that some ESRD patients with inadequate health literacy did not choose to respond to the mailed survey.

## **Strengths and Weaknesses**

One strength of this project is that it focused on an ESRD population from a Midwest state. Most studies referenced for this project focused on populations from the east coast or southern states of the United States. Another strength is the assessment of health literacy in the survey. Although well documented as a barrier to health services, too few studies have included health literacy status as a study variable. A weakness for this project is that the population was selected from a single transplant center and the results may not be applicable to other ESRD populations from another geographic area. Another weakness is the low participation of minority ESRD patients. Findings may not apply to all minority ESRD patients in this transplant center because of the low numbers of minority patients who chose to participate. Finally, a weakness could be found in the database where patient status was not consistently up-to-date. Status updates, such as noting a patient's death or transplant status, should also be noted. For example, the use of the United States Postal Service for survey delivery depended on the transplant database having current mailing addresses. Using the most current addresses on file, 12% ( $n = 41$ ) were returned as undeliverable. A process for updating patient information needs to be created and could be assigned to the newly hired administrative assistant.

## **Implications for Practice**

### **Health Literacy**

Thirty-eight percent of survey respondents were identified as having limited health literacy. It is recommended that the transplant staff add the SLS to initial assessment screening and data collection for each ESRD patient referred to the center. The SLS is easy to administer and score, and can be immediately used to address a patient's health literacy needs. This information would be useful in designing an individualized patient care plan and providing the

support each patient needs to successfully navigate the pre-transplant evaluation process. It is also recommended that the transplant team evaluate all patient education materials for ease of reading and grade level, adjusting as needed, to augment patient understanding and comprehension.

### **Clinical Practice**

The collection of email information would be useful as a means of contacting patients in a timely, cost efficient way. Whereas patients may change residences, changes in email addresses may occur less often. Not only can data be collected for analysis through electronic communication (e.g. surveys), information may be distributed in an electronic newsletter format, thereby keeping patients connected and involved. This may impact a patient's feelings of perceived control and ultimately contribute to a positive intention to complete the pre-transplant evaluation (Ajzen, 2015).

To address specific patient concerns, it is recommended that patient support materials be developed to address the highest-ranking concerns identified by the survey. For example, the identification of a living donor was identified as a high-ranking area of concern. Providing information on this topic could empower patients and guide their efforts to identify a willing and suitable living donor. Another initiative might be to invite a living donor and recipient pair to meet with ESRD patients and their families to discuss their experience and to provide guidance on how to request the living donation. Providing information on all avenues available to assist with post-transplant medication costs (e.g. drug company supported drug discount programs) is another service that could be provided. One frustrated survey respondent indicated that his wife, through independent online research, found a drug company discount program to reduce the cost of the required immunosuppressant medication. Providing this information during initial

appointments may help to alleviate anxiety regarding post-transplant medication affordability and management. After all changes are implemented it is recommended that the transplant staff consider ongoing evaluation by re-surveying referred ESRD patients every three to five years. These data would be useful for gauging the impact of program changes on patient concerns, and attitudes, and the progression of patients to waitlisting and transplantation.

### **Policy**

It is important that all staff be aware of policy recommendations and initiatives at all levels. There are many organizations (e.g. the United Network for Organ Sharing [UNOS]; the Scientific Registry of Organ Recipients [SRTR]; the Organ Procurement and Transplant Network [OPTN]; the Congress of the United States) that construct and enforce rules and regulations that directly affect the work of the front line transplant professionals. Becoming active and engaged with those in positions to affect changes in transplant legislation or policy is critical. Hearing from the professionals in the field makes a large impact when crafting, supporting, and voting on changes affecting transplant policy, process, and outcomes.

### **Implications for the Doctor of Nursing Practice Graduate**

The Doctor of Nursing Practice (DNP) degree was developed so that graduates would be skilled in evaluating evidence and applying it effectively at the point of care for real and lasting change at either the micro or macro systems level (Chism, 2016). This is also known as knowledge translation. The American Association of Colleges of Nursing (AACN), in developing the concept of the DNP, devised eight essentials of doctoral education for advanced nursing practice to guide curriculum development (AACN, 2016). It is incumbent that the DNP graduate be exposed to all eight essentials through course offerings and to interweave the

essentials in the completion of the DNP scholarly project. This project incorporated the DNP essentials as discussed below, using the writings of Chism (2016) as a guide.

### **Leadership, Collaboration, and Health Policy Advocate**

This project provided the opportunity for the student to demonstrate systems thinking and quality improvement for improved patient outcomes (DNP Essential II: “Organizational and Systems Leadership for Quality Improvement and Systems Thinking” [AACN, 2016]) through the evaluation of current organizational processes and use of a survey to elicit and understand barriers ESRD patients may face in completing the pre-transplant evaluation. This work also allowed the opportunity to collaborate with other providers (e.g. kidney specialists, transplant surgeons, and transplant financial experts) to quantify current structures, processes, and outcomes (Donabedian, 2003) and to identify the need to bring the patient’s point of view into the discussion (DNP Essential VI: “Interprofessional Collaboration for Improving Patient and Population Health Outcomes” [AACN, 2016]). Another critical piece of this project was the dissemination of the survey findings to appropriate staff and leadership at the transplant center and the medical center at large, which also supports Essential VI by improving the ESRD patient health outcomes and potentially influence administrative policy and procedural changes at the institutional level (DNP Essential V: “Healthcare Policy for Advocacy in Health Care” [AACN, 2016]).

### **Expert Clinician and Information Specialist**

Through the identification and use of an organizational assessment and an evidenced based survey, the student was able to evaluate the system of care and patient outcomes and to promote “equitable and patient centered care” (DNP Essential III: “Clinical Scholarship and Analytical Methods for Evidenced-Based Practice” [AACN, 2016]). In addition, the use of the

patient electronic health record and the use of SPSS and REDCap software provided the student with the opportunity to leverage data to better understand the needs of the ESRD population (DNP Essential IV: “Information Systems/Technology and Patient Care Technology for Improvement and Transformation of Health Care” [AACN, 2016]).

### **Translator of Research and Educator**

The DNP student was afforded the opportunity to review the literature surrounding the failure of ESRD patients to progress in the pre-transplant evaluation. This activity led to the identification of the evidence-based survey that was employed in this study. The ability to translate the knowledge and implement the study in a new setting with a new population of ESRD patients, while applying Donabedian’s Structure-Process-Outcome and Ajzen’s TPB, demonstrate the use of interdisciplinary theories to guide the work of this project (DNP Essential I: “Scientific Underpinnings for Practice” [AACN, 2016]). Additionally, the project allowed the DNP student to advocate for the improvement of ESRD patient health by highlighting the barriers that identified concerns, attitudes, and level of health literacy among the survey respondents (DNP Essential VII: “Clinical Prevention and Population Health for Improving the Nation’s Health” [AACN, 2016]). Through these processes the DNP student was able to enact the educator role through dissemination of the survey results with an eye toward changing nursing practice to enhance ESRD patient wait list attainment (DNP Essential VIII: “Advanced Nursing Practice” [AACN, 2016]).

### **Conclusion**

Individuals in the ESRD population face many challenges as they navigate treatment options and the unfolding of this distressing disease process. It is incumbent on support staff and providers of care to strive to understand the challenges and barriers these patients face. Both

cognitive and non-cognitive concerns and attitudes, as well as health literacy, can have an impact on patient choices when presented with care options. Although kidney transplant offers the best outcomes, many patients do not pursue this option – or may begin the journey only to drop out. Planned review of structures, processes, and outcomes of care are critical to patient success, as is hearing the patient’s voice in describing his or her personal experience coping with ESRD and the kidney transplant pre-transplant evaluation process. The relationship between the care staff and the ESRD patients, based on the TPB model, can be a useful tool to inspire a positive intent to act and move a patient toward completing the pre-transplant evaluation.

## Appendix A

### Permission to Use the Theory of Planned Behavior Model

Dear Ms. Buck,

The theory of planned behavior is in the public domain. No permission is needed to use the theory in research, to construct a TPB questionnaire, or to include an ORIGINAL drawing of the model in a thesis, dissertation, presentation, poster, article, or book. If you would like to reproduce a published drawing of the model, you need to get permission from the publisher who holds the copyright. You may use the drawing on my website (<http://people.umass.edu/aizen/tpb.diag.html>) for non-commercial purposes, including publication in a journal article, so long as you retain the copyright notice.

Best regards,  
Icek Ajzen  
Professor Emeritus  
University of Massachusetts - Amherst  
<http://www.people.umass.edu/aizen>

On 1/31/16, 12:41 PM, Linda Buck wrote:

Hello Dr. Ajzen,

I am a graduate nursing student nearing the completion of my Doctor of Nursing Practice degree with an emphasis in health systems leadership. I am using your Theory of Planned Behavior as a theoretical framework for my work with kidney transplant patients. In essence, I am attempting to identify and describe barriers patients encounter as they begin the journey of securing a place on the kidney transplant wait list. I will be mainly focusing on control beliefs and perceived behavioral control as it relates to a patient's intention to complete the required pre-transplant physical evaluation.

I will retain the copyright notice in both the visual presentation of my work and in the written form, as instructed on your website. The purpose of this communication is to inquire if there are further steps I need to take to be able to use a copy of your theoretical model in this way.

Thank you for considering my request and I look forward to hearing from you.

Best regards,

Linda K. Buck, MSN, RN  
Doctor of Nursing Practice Student  
Kirkhof College of Nursing  
Grand Valley State University  
Allendale, Michigan  
616-331-7160  
[buckli@gvsu.edu](mailto:buckli@gvsu.edu)



## Appendix B

### Permission to Use Donabedian's Structure-Process-Outcome Model

**From:** Academic Permissions <Academic.permissions@oup.com>  
**Sent:** Wednesday, March 23, 2016 7:52 AM  
**To:** Linda Buck  
**Subject:** RE: Academic Permissions Request Form

**Follow Up Flag:** Follow up  
**Flag Status:** Flagged

Yes that's fine.

**From:** Linda Buck [<mailto:buckli@gvsu.edu>]  
**Sent:** 22 March 2016 15:36  
**To:** Academic Permissions  
**Subject:** RE: Academic Permissions Request Form

Mr. Tom McKibbin,

Thank you for your permission to use Donabedian's model to assist in the understanding of the structure-process-outcome framework.  
Just to clarify – although my dissertation will not be published in an academic journal, it will be widely available to other students and scholars through the Grand Valley State University Library via ScholarWorks. ScholarWorks is a depository of thesis and dissertations that are searchable and accessible worldwide. I hope that this level of access will not affect your permission for me to use the model in my dissertation.

Best regards,  
Linda K. Buck, MSN, RN  
Senior Academic Advisor  
Kirkhof College of Nursing  
Grand Valley State University  
616-331-7160  
[buckli@gvsu.edu](mailto:buckli@gvsu.edu)

**From:** Academic Permissions [<mailto:Academic.permissions@oup.com>]  
**Sent:** Monday, March 21, 2016 5:01 AM  
**To:** Linda Buck <[buckli@gvsu.edu](mailto:buckli@gvsu.edu)>  
**Subject:** RE: Academic Permissions Request Form

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If at some future date your thesis/dissertation is published it will be necessary to re-clear this permission. **Please also note that if the material to be used is acknowledged to any other source, you will need to clear permission with the rights holder.**

Kind regards,  
Tom McKibbin  
Permissions Executive

-----Original Message-----

From: [no.reply@oup.com](mailto:no.reply@oup.com) [<mailto:no.reply@oup.com>]

Sent: 19 March 2016 14:55

To: Academic Permissions

Subject: Academic Permissions Request Form

URL: /academic/rights/permissions/request

a First name: Linda

b Last name: Buck

c Institution/Company: Grand Valley State University

d Address: Redacted from final copy

e Postcode: Redacted from final copy

f Country: USA

g Telephone number: Redacted from final copy

i Email: [buckli@gvsu.edu](mailto:buckli@gvsu.edu)

G Z TheirTitle: Perceived Barriers to the Pre-Transplant Evaluation: A Patient Perspective

H Z Author: Linda Buck

H Z Publisher: Grand Valley State University

I Z Covers: Paper

I Z PrintRunHard: 3

I Z pubDate: August 2016

J Z Territory: USA

K Z Language: English

K Z Notes: Final paper will also be available electronically via ScholarWorks depository of dissertations.

L Z Media1: text

M Z Author1: Avedis Donabedian

M Z editedby1: Rashid Bashshur

M Z Title1: An Introduction to Quality Assurance in Health Care

N Z Material1: p.47. Structure-Process-Outcome Model. Near the bottom of the page - a small graphic illustrating the relationships with probability relationships identified.

O Z ISBN1: 978-0-19-515809-0

O Z OUPpubDate1: 2003

M Z Title2:

M Z Title3:

W Z Additional: My project is a doctoral dissertation for the degree of Doctor of Nursing Practice - Health Systems Leadership.

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## Appendix C

### Survey

Please take a few minutes to fill out this research survey. Just check the box next to the answer that best describes you. A few questions ask you to write your own response.

If you do not know an answer or are uncomfortable with the question, you may leave it blank.

Your answers are private. You can help with this by not placing your name on the survey.

Thank you in advance for your help and participation in this research!

#### Dialysis Details

Have you received a kidney transplant?

Yes |  No

Are you on the transplant waitlist?

Yes |  No

Are you currently on dialysis?

Yes |  No

If so, what type of dialysis do you receive?

Hemodialysis in a center    Hemodialysis at home    Peritoneal dialysis

How long have you been on dialysis?

\_\_\_ Years   \_\_\_ Months

#### Concerns About Kidney Transplant

This is a list of some of the reasons that might make it hard for someone to come for a transplant evaluation. For each reason please indicate how much of a worry or concern it is for you.

Being medically healthy enough on the evaluation tests for transplant

Not at all concerned    Somewhat concerned    Very concerned

Fear of getting a transplant

Not at all concerned    Somewhat concerned    Very concerned

Affording the transplant operation

Not at all concerned    Somewhat concerned    Very concerned

## Concerns About Kidney Transplant, continued

---

Affording the medicines after the transplant

Not at all concerned    Somewhat concerned    Very concerned

---

Affording the costs for the visits and tests during the evaluation process

Not at all concerned    Somewhat concerned    Very concerned

---

The length of time to wait for a kidney transplant

Not at all concerned    Somewhat concerned    Very concerned

---

Finding a living donor

Not at all concerned    Somewhat concerned    Very concerned

---

Having the money to get to the transplant center

Not at all concerned    Somewhat concerned    Very concerned

---

Having transportation to the transplant center

Not at all concerned    Somewhat concerned    Very concerned

---

Finding a support person to come with me

Not at all concerned    Somewhat concerned    Very concerned

---

Fitting the evaluation into my schedule

Not at all concerned    Somewhat concerned    Very concerned

---

Knowing the next steps to take

Not at all concerned    Somewhat concerned    Very concerned

---

**Of those “very concerning” to you, please indicate which was the biggest trouble or was most concerning for you by circling it above. Please add any details around this concern in the space below.**

---

---

## Transplant Attitudes

Next are some thoughts that people have had about kidney transplantation and a choice of answers. Please indicate how strongly you agree or disagree with these statements.

---

I feel that dialysis is not that bad.

Strongly disagree  Disagree  Agree  Strongly agree

---

I know the next steps to take to have a kidney

transplant.  Strongly disagree  Disagree   
Agree  Strongly agree

---

I know a lot about kidney transplant.

Strongly disagree  Disagree  Agree  Strongly agree

---

I know the reason why a kidney transplant would be good for me.

Strongly disagree  Disagree  Agree  Strongly agree

---

I know a lot about how long a transplanted kidney might work for me.

Strongly disagree  Disagree  Agree  Strongly agree

---

I know a lot about how a transplanted kidney would affect my life

Strongly disagree  Disagree  Agree  Strongly agree

---

I am good at learning new things on my own.

Strongly disagree  Disagree  Agree  Strongly agree

---

## Health Literacy

Many people have trouble with the medical information they get at the doctor's office or hospital. Please select the answer that best fits how you feel.

---

How confident are you filling out medical forms?

All of the time  Most of the time  Some of the time  A little of the time  None of the time

---

How often do you have someone help you read hospital materials?

All of the time  Most of the time  Some of the time  A little of the time  None of the time

## Health Literacy, continued

---

How often do you have problems learning about your medical condition because of difficulty understanding written information?

- All of the time    Most of the time    Some of the time    A little of the time    None of the time

### Demographic Information

---

Please share a little bit about yourself.

Age

\_\_\_\_ Years

Sex

- Male |  Female

Race

- White    Black or African American    Other

Are you Hispanic or Latino?

- Yes |  No

What is the highest grade of school you completed?

What is the highest degree you achieved?

- High school diploma    Associate degree    Bachelor degree    Post-bachelor degree

- Other (please explain)

\_\_\_\_\_

What is your estimated annual household income?

- Less than \$20,000    \$20,000 - \$39,000    \$40,000 - \$59,000  
 \$60,000 - \$79,000    \$80,000 - \$99,000    \$100,000 or greater

What is your current health insurance status? **Please check all that apply**

- Medicare    Medicaid    Private insurance    None



## Demographic Information, continued

---

What is your marital status?

Single    Married    Divorced    Separated    Widowed

---

What is your height?

\_\_\_\_ Feet \_\_\_\_ Inches

---

What is your weight?

\_\_\_\_ Pounds

---

### Additional Feedback

Please share any other comments or information.

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### Thank You!

Thank you for completing this research survey. Please place the survey in the self-addressed, stamped envelope provided and return by mail to have your comments included.

## Appendix D

### Permission to Use Survey

**From:** Linda Buck  
**Sent:** Wednesday, March 25, 2015 11:47 AM  
**To:** Cavanaugh, Kerri  
**Subject:** RE: Understanding Patient Barriers to Kidney Transplant Evaluation

**Follow Up Flag:** Follow up  
**Flag Status:** Completed

Hello Kerri,

Thank you for sharing this information and I will most definitely cite your article as the source. I am very thankful that I found your publication in my search for information on this topic!

Sincerely,  
Linda K. Buck, MSN, RN  
Academic Advisor  
Kirkhof College of Nursing  
Grand Valley State University  
616-331-7160  
buckli@gvsu.edu

**From:** Cavanaugh, Kerri [<mailto:kerri.cavanaugh@Vanderbilt.Edu>]  
**Sent:** Friday, March 20, 2015 5:15 PM  
**To:** Linda Buck  
**Cc:** Dageforde, Leigh Anne  
**Subject:** RE: Understanding Patient Barriers to Kidney Transplant Evaluation

Dear Ms. Buck,  
Please find our attached survey related to your request. We hope that you might find this helpful in your research pursuits.

You are welcome to consider these items in your work, we ask only that you cite the published article as its source in any resulting reports or publications. Please note that the health literacy items are those described by Chew et al. [Refs 25,26].

Best regards,  
Kerri Cavanaugh

Kerri Cavanaugh, MD MHS  
Assistant Professor of Medicine  
Medical Director, Vanderbilt Dialysis Clinic-Campus  
Vanderbilt University Medical Center  
Division of Nephrology & Hypertension

Center for Health Services Research  
1161 21st Ave South  
S-3223 MCN  
Nashville, TN 37232-2372  
Phone: 615-936-7306  
Fax: 615-875-5626

**From:** Linda Buck [<mailto:buckli@gvsu.edu>]  
**Sent:** Sunday, March 15, 2015 6:21 PM  
**To:** Cavanaugh, Kerri  
**Subject:** Re: Understanding Patient Barriers to Kidney Transplant Evaluation

Hello Dr. Cavanaugh,

I am a graduate nursing student in my last year of a Doctor of Nursing Practice (DNP) degree with an emphasis on health systems leadership. My scholarly inquiry has taken the form of a program evaluation of a well-established renal transplant program in a Midwestern health system. To inform the program evaluation, I am interested in understanding the barriers prospective recipients in my setting encounter on the path toward being added to the transplant waitlist. A review of existing literature on this topic lead me to your 2015 article in the journal *Transplantation*.

My question surrounds the interview tool you and your fellow authors used. Is a copy available and might I use it in my work?

Thank you for your consideration of this request. I look forward to hearing from you in the near future.

Sincerely,

Linda K. Buck, MSN, RN  
Doctor of Nursing Practice Student  
Kirkhof College of Nursing  
Grand Valley State University  
616-331-5785  
[buckli@gvsu.edu](mailto:buckli@gvsu.edu)

## Appendix E

### Permission to Use the Short Literacy Survey

**From:** Lisa Chew <lchew@uw.edu>  
**Sent:** Thursday, February 25, 2016 3:25 PM  
**To:** Linda Buck  
**Subject:** RE: The Short Literacy Survey

Yes, feel free to use the survey.

Thanks,  
Lisa

The above email may contain patient identifiable or confidential information. Because email is not secure, please be aware of associated risks of email transmission. If you are a patient, communicating to a UW Medicine Provider via email implies your agreement to email communication; see <http://www.uwmedicine.org/Global/Compliance/EmailRisk.htm>

The information is intended for the individual named above. If you are not the intended recipient, any disclosure, copying, distribution or use of the contents of this information is prohibited. Please notify the sender by reply email, and then destroy all copies of the message and any attachments. See our Notice of Privacy Practices at [www.uwmedicine.org](http://www.uwmedicine.org).

**From:** Linda Buck [<mailto:buckli@gvsu.edu>]  
**Sent:** Thursday, February 25, 2016 11:39 AM  
**To:** [lchew@u.washington.edu](mailto:lchew@u.washington.edu)  
**Subject:** The Short Literacy Survey

Hello Dr. Chew,

I am a graduate nursing student in my last year of a Doctor of Nursing Practice (DNP) degree with an emphasis on health systems leadership. My scholarly inquiry has taken the form of a program evaluation of a well-established kidney transplant program in a Midwestern health system. To inform the program evaluation, I am interested in understanding the challenges and barriers prospective recipients in my setting encounter on the path toward being added to the transplant waitlist. A review of existing literature on this topic lead me to a 2015 article by Dageforde et al. in the journal *Transplantation* which incorporated the Short Literacy Survey into a broader survey on barriers and concerns patients face as they move toward being added to the wait list for a kidney transplant. The full article citation is:

Dageforde, L. A., Box, A., Feurer, I. D., & Cavanaugh, K. L. (2015). Understanding patient barriers to kidney transplant evaluation. *Transplantation*. Advance online publication. doi: 10.1097/TP.0000000000000543

I plan on using the survey designed by these researchers. Therefore I am writing to you to request permission to incorporate the Short Literacy Survey in my work.

Thank you for your consideration of this request. I look forward to hearing from you in the near future.

Linda K. Buck, MSN, RN  
Doctor of Nursing Practice Student  
Kirkhof College of Nursing  
Grand Valley State University  
Allendale, MI  
buckli@gvsu.edu

## Appendix F

### University IRBNet Approval Letter



DATE: August 29, 2016

TO: Linda Buck, MSN  
FROM: Grand Valley State University Human Research Review Committee  
STUDY TITLE: [943608-1] Perceived Barriers to the Pre-Transplant Evaluation: A Patient Perspective  
REFERENCE #: 17-014-H  
SUBMISSION TYPE: New Project

ACTION: APPROVED  
APPROVAL DATE: August 29, 2016  
APPROVAL EXPIRATION: August 29, 2018  
REVIEW TYPE: Expedited Review

Thank you for your submission of materials for this research study. The Human Research Review Committee has approved your research plan application as compliant with all applicable sections of the federal regulations, Michigan law, GVSU policies and HRRC procedures. All research must be conducted in accordance with this approved submission.

**Please insert the following sentence into your information/consent documents as appropriate. All project materials produced for participants or the public must contain this information.**

***This research protocol has been approved by the Human Research Review Committee at Grand Valley State University. File No. 17-014-H Expiration: August 29, 2018.***

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

**Note: One suggested change to informed consent (not affecting approval):**

***Suggestion from 1 reviewer: Modify language in IC: The PI is collecting height, weight, marital status, race, sex, age, ethnicity, length on dialysis, wait list status, type of dialysis, and whether they have received a kidney transplant. Comparison of these data with the dialysis center's data base could possibly be used to identify the respondent. Therefore, the statement in the recruiting letter should be "Please know that this survey will not be traced back to you."***

This approval is based on the HRRC determination that no greater than minimal risk is posed to research participants. This study has received expedited review, 45 CFR 46.110 category [7], based on the [Office of Human Research Protections 1998 Guidance on Expedited Review Categories](#).

Please note the following in order to comply with federal regulations and HRRC policy:

1. Any major change to previously approved materials must be approved by this office prior to initiation. Please use the *Change in Approved Protocol* form for this submission. This includes, but is not limited to, changes in key personnel, study location, participant selection process, etc. See *HRRC policy 1010, Modifications to approved protocols*.
2. All UNANTICIPATED PROBLEMS and SERIOUS ADVERSE EVENTS to participants or other parties affected by the research must be reported to this office within 7 days of the event occurrence, using the UP/SAE Report form. If the adverse event includes a fatality, hospitalization, or security breach of sensitive information immediately notify the Human Research Review Committee Chair, Dr. Steve Glass, (616)331-8563 **AND** Human Research Protections Administrator, Dr. Jeffrey Potteiger, Office of Graduate Studies (616)331-7207. See *HRRC policy 1020, Unanticipated problems and adverse events*.
3. All instances of non-compliance or complaints regarding this study must be reported to this office in a timely manner. There are no specific forms for this report type. See *HRRC policy 1030, Research non-compliance*.
4. All required research records must be securely retained in either paper or electronic format for a minimum of 3 years following the closure of the approved study. This includes original or digitized copies of signed consent documents. Research studies subject to the privacy protections under HIPAA are required to maintain selected research records for a period of at least 6 years after the close of the study.
5. **At least 60 days prior to current approval expiration**, please submit a Continuing Review form:
  - Protocols that are active and open for enrollment require both the Principal Investigator and Authorizing Official to electronically sign the Continuing Review submission in IRBNet.
  - Protocols that are active for data analysis or long term follow-up ONLY require the Principal Investigator's signature but do not need to be further authorized.
  - A copy of the informed consent/assent form currently in use in the study must accompany the submission unless the study has been closed to enrollment, and active only for data analysis, for more than 1 year.

If you have any questions, please contact the Research Protections Program at (616) 331-3197 or [rpp@gvsu.edu](mailto:rpp@gvsu.edu). The office observes all university holidays, and does not process applications during exam week or between academic terms. Please include your study title and reference number in all correspondence with our office.

Research Protections Program | 1 Campus Drive | 049 James H Zumberge Hall | Allendale, MI 49401  
Ph 616.331.3197 | [rpp@gvsu.edu](mailto:rpp@gvsu.edu) | [www.gvsu.edu/rpp](http://www.gvsu.edu/rpp)

## Appendix G

### Health System's Internal Review Board Approval Letter



MercyHealth.com  
Page 1 of 2

#### NOTICE OF IRB NEW EXPEDITED APPROVAL

To: Linda Buck, MSN, RN  
3564 Buckskin Rd.  
Kalamazoo, MI 49048

Re: IRB# 16-0705-1  
Perceived barriers to the pre-transplant evaluation: A patient perspective

Date: 08/03/2016

This is to inform you that the Mercy Health Regional Institutional Review Board (IRB) has approved the above research study by expedited review. This also includes approval for:

Waiver of Informed Consent  
Waiver of HIPAA Authorization  
Protocol 07-31-2016  
Recruitment Letter July 31, 2016  
Reminder Postcard July 21, 2016  
Survey Tool July 31, 2016  
Data Collection Spreadsheet (undated)

The approval period is from 08/03/2016 to 08/02/2017. Your study number is 16-0705-1. Please be sure to reference this number and/or your study title in any correspondence with the IRB.

Your responsibilities to the IRB do not end with this approval. You will be required to submit a continuing review report by the date indicated on the second page of this letter or, upon completion of the study, a notification of study closure form and a report of the study's findings. Failure to properly renew or close out your study may jeopardize future IRB approvals.

Continued approval is conditional upon your compliance with the following requirements:

- All protocol modifications to approved research must be submitted to the IRB and not be implemented until approved by the IRB except where necessary to eliminate apparent immediate risks to the study subjects.

Institutional Review Board - 200 Jefferson Ave. SE - Grand Rapids, MI 49503 - P: 616.685.6198

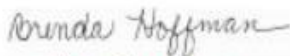


- Significant changes to the study site and significant deviations from the research protocol that may involve risks or affect the safety or welfare of subjects or others, or that may affect the integrity of the research must be promptly reported to the IRB.
- All forms of advertising (including but not limited to: television, radio, internet, flyers, brochures, posters) must be submitted to the IRB and must not be implemented until approved by the IRB.
- Unanticipated problems, adverse events and safety reports must be reported to the IRB if, in the opinion of the local investigator, the event is *unexpected, probably related* to the study article, **and** places subjects or others at *greater risk* than was previously known. (See IRB SOP# RR404 - <http://www.mercyhealth.com/irbsops>). EXCEPTION: If there is the *death* of a participant *at your site*, we request this information be submitted to the IRB.
- Please complete and submit reports to the IRB as follows:

Renewal of the study - complete and return the Continuing Review Report/Request for Renewal by 06/01/2017. The study cannot continue after 08/02/2017 until re-approved by the IRB.

Closure of the study - complete and return the Notification of Study Closure form.

Please call me if you have any questions about the terms of this approval.



Brenda Hoffman, CIM  
IRB Chairperson

Copy: File

Kristy Todd, DNP, FNP-BC, RN-BC

## Appendix H

### Survey Letter of Introduction



August 31, 2016

As a person who was referred to Mercy Health Saint Mary's Kidney Transplant Program, you know firsthand what a person encounters while considering the pre-transplant evaluation process. From this special point of view, you can assist health care professionals to better understand the barriers and obstacles people may face when considering this life-changing surgery. This is why I am seeking your input through participation in a research study. I am asking that you complete a short survey. It is my hope that through this better understanding, changes in the pre-transplant evaluation process to reduce barriers and better serve people can be made. The completion and return of the survey is your agreement to be a part of the research and allows for your answers to be used for the study purposes.

Participation in this research is voluntary; you do not have to participate. Returning the completed survey is all you have to do to be included in this study. Please know that this survey cannot be traced back to you. Your responses will be kept private and all results will be grouped together to protect your identity. Please do not add your name or other personal information to the survey. I will not know who participated and no protected health information will be included in the survey results.

I am a Doctor of Nursing Practice graduate student at Grand Valley State University (GVSU), doing my internship at Mercy Health Saint Mary's. I will be presenting the results of this study at GVSU as partial fulfillment of my graduate nursing program. Most importantly, the results of this study will be presented to the Kidney Transplant Team and Mercy Health Saint Mary's administration.

I would be happy to answer any questions you may have regarding this survey. Please feel free to contact me by email at [buckli@gvsu.edu](mailto:buckli@gvsu.edu) or by phone at 616-331-5785. Or you may contact my faculty advisor, Dr. Andrea Bostrom, at [bostroma@gvsu.edu](mailto:bostroma@gvsu.edu) or 616-331-7172. You may also contact Brenda Hoffman, IRB Chairperson at Mercy Health Saint Mary's at 616-685-5213 or Stephen Glass, HRRC Chairperson at Grand Valley State University at 616-331- 8563 if you have any questions about your rights as a research participant.

Thank you for your assistance in this important research.

Sincerely,

Linda K. Buck, MSN, RN  
Doctor of Nursing Practice Student  
Kirkhof College of Nursing  
Grand Valley State University

## Appendix I

### Survey Postcard Follow Up

August 31, 2016

Recently you received a research study survey seeking your thoughts on the barriers patients may face when thinking about a kidney transplant. You received the survey because you were referred to the Kidney Transplant Program at Mercy Health Saint Mary's.

If you have already completed and returned the survey please know that I am grateful for your time and thoughts on this important topic. If you have not yet completed it, I ask that you do so today. Because you have a unique perspective on this experience, your input is highly valuable and I would appreciate hearing from you.

If you did not receive the survey or it has been misplaced, please contact me, Linda Buck, MSN, RN, today for a replacement. I may be reached at [buckli@gvsu.edu](mailto:buckli@gvsu.edu) or at 616-331-5785.



## Appendix J

### Survey Respondent Written Comments Organized by Themes

#### Health Concerns

- I have waited over two years and the average wait time is over 5 years. My health, other than kidneys, is very good, but I am nearly 74 years old and that can change as I wait.
- I am concerned that there will be other complications with my health before I receive a transplant.

#### General Fears

- Scared about transplant. Have a lot of 'what if's'.
- I'm afraid I won't get a kidney.
- Knowing what comes after the transplant because I don't know but yes I'm very concerned. I want to know everything that comes with the transplant - good or bad. I know that with God I can handle it - all things are possible with God (Matthew 19:26).
- I have peripheral artery disease and some heart problems. Very poor circulation in legs. Many operations on both legs. Very weak. Don't think I would be eligible and don't want to waste a kidney. Scared of the operation - don't think I'd make it. Doing fine on dialysis. It gets me out of the house.
- I've been through the transplant evaluation a year or so ago. The experience was overwhelming. So much information in a short time. I myself am scared that it won't work and I'll be on dialysis anyway. I have all the faith in the medical aspect, I guess this is where I need to put my faith in God.

#### Affording the Transplant, Medications, and After Care

- After I had my transplant [what] hit me at once was the overwhelming doctor appointments, all the driving to and from, the cost of motels, reliable transportation, gas for the weekly visits - CRAZY! Seems like your local nephrology team could do them and send data or conference call weekly with blood work. Use Skype conferencing to call patient.
- Time waiting and the money to get to the transplant.
- Have fixed income. Left it up to God.
- All the tests are not possible on my budget.
- I cannot afford it out of pocket.
- I know that insurance will not cover the total cost of these expensive medications. With a limited income I'm not sure how I would pay for the remaining costs.
- It's hard to put a dollar amount on your life. I'm not spending the rest of my life worrying about a transplant. If I get one with God's help - great! If not, I plan on enjoying the time I have.
- I'm not sure if I am on the waitlist. Affording is my biggest concern. I'm poor.

- The drug cost if I get a kidney.
- Being on a fixed income I am very concerned with the cost of everything.
- I understand from my family doctor and the Mercy transplant team that a kidney transplant is very costly. I'm wondering if this is a factor (Medicare & Medicaid being my insurance provider) in the long - about 6 years - of the delay in my treatment. I have a living donor and have been given very little information on how to proceed.
- My wife found on the internet a drug program for my antirejection meds (for reduced cost). It would have been nice to have been told about these programs by the transplant team/pharmacy.

### **Living Donor Concerns**

- Finding a living donor is difficult. Asking or soliciting people on Facebook or elsewhere is uncomfortable for me or my wife.
- Not knowing how long it will take to get a transplant is concerning. Finding a living donor is difficult.
- Concerned about the physical hardship for a living donor.
- Not knowing the next steps. Will not take a kidney from a living donor - they're going to need their own.
- I have had three living donors who did not qualify.
- Because of age and health of most relatives makes them unlikely donors.
- I wish there was a list of live donors available for us. Even out of the country (Just a dream).

### **Wait Time Concerns**

- It has been a long time waiting. I don't drive.
- The time you have to wait to receive a kidney here in Michigan. Other states the wait time is 1 to 2 years. Michigan needs to check out how the other states do their waiting time.
- Since the length of wait is high in Michigan for deceased donors - more concerned about getting a living donor. In addition, living donor kidney's last longer so more of a concern and goal to receive one.
- I could not wait long due to my condition.
- If there was any way the wait for a transplant could be shortened that would be helpful. Issues of SPIRITUALITY and SEXUALITY need to be addressed.

### **General Concerns and Comments**

- Please keep in mind my answers are because: married with support, working full time with pre-approved insurance coverage and not on dialysis. Donated kidney (35 yrs ago - donors go to the top of the list) and no antibodies.
- I would think my age would be a deterrent.

- Ann Arbor transplant team said I needed to lose 20 pounds - no mention of getting off a certain med. Mercy transplant team said I must get off certain med - no mention of losing weight.
- Did not have any of these problems either before or after my transplant.
- Too old for transplant.
- Not sure if I am on the waitlist - I don't think so.
- First and only time I tried to have my name put on a transplant list I was told I was too old (69), so I gave up.
- I am not sure if I am on the waitlist or not. I am concerned that my age might be a problem. I hope not.
- I'm hoping to get a kidney before I have to be on dialysis.
- I work 3 days a week and have dialysis 3 days a week leaving me with 1 day a week to do housework and to relax. I miss my 'old self'.
- I had my first transplant when I was 20 years old. Living donor from my sister. Worked in education for 27 years. Taught PE and coached. Participated in the Transplant Games. Now my kidney of 40+ years is failing. I am back on dialysis and I HATE IT. My life has changed totally. I cannot wait to get another kidney and resume my 'normal' active lifestyle.
- First transplant 1980. Second in 2010. On dialysis for 1 year HATED every minute of it! Asked about a transplant as soon as I started dialysis knowing I would have a better chance at a longer life.
- I received a liver transplant in 2004. The anti-rejection drugs finished off my kidneys over 10 years. I know that the shock of deep surgery is a big shock to the system. But I got through it once and I can do it again.
- I think people should not be held back on account of weight. Some people are just big boned. You cannot help the way God made you!
- I have 19% of my heart remaining. I smoke. I am being discriminated against.
- My wife was my donor. It took her a couple of days to recover - it took me a couple of months. We continue on with life as before! We are grateful for the second chance at more years together.
- My greatest concern is my age. I know the transplant won't extend my life - just make the quality better.
- During the pre-transplant evaluation process it would be a good idea to see some of the after transplant patients - talk about their experiences.
- I think most dialysis patients do not understand the full extent of their sickness because it is a slow process. Nor do I think most understand truly how their life will change so drastically post-transplant. There are the logical things that occur that you as a patient think about. But the overall health improvement is amazing. Paired with being a productive worker and member of society. The gift you receive is priceless. You expect kidney function to return, But I don't think most people think about the small things - increased warmth, decreased nausea, increased energy, decreased brain fog, increased concentration, food appeal and variety opens up, increased sleeping, no dialysis. The

freedom you feel to live life again. The gratitude you have towards the team, the donor, and God!

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