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Living Kidney Donation: The Impact of Transplant Center Labor and Organization

By

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To my son, Malaki, you are by far the greatest joy of my life

and

To my parents, Rene White and the late Stanley Milstead

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CHAPTER I

INTRODUCTION

Statement of the Problem

Organ transplantation is a challenging field of healthcare because it requires third party involvement-either the living or deceased organ donor (Institute of Medicine, 2006). Although clearly a superior alternative to dialysis for eligible individuals, the ability to perform kidney transplant is limited by the number of organs available. Each year, the number of patients with end stage renal disease (ESRD) listed for kidney transplantation rises, whereas there have been minimal increases in the number of kidneys available. There are less than 17,000 donor kidneys available each year for the 100,000 individuals on the kidney transplant waiting list (Figure 1)(Scientific Registry of Transplant Recipients (SRTR), 2016). This growing organ shortage results in an average of 18 patient wait-list deaths every day simply because the organ the patients needed did not become available in time (Figure 2)(SRTR, 2016). Faced with the current critical shortage and the likelihood of even more pronounced supply-demand disparities, organ donation is becoming an increasingly significant public health issue.

Living donors are key to improving access to transplantation. First, there are a limited number of deceased donor kidneys available for transplant. Second, relative to deceased donor kidney transplantation, living donor kidney transplantation has superior graft and patient survival rates, lower acute rejection rates, fewer episodes of delayed graft function, avoids or reduces dialysis exposure, pre-empts rapidly deteriorating quality of life, and is more cost effective in the long-term (SRTR, 2016; Neri, 2009;

USRDS, 2013; Barnieh, 2011). Despite the advantages of this treatment, the number of live kidney donation has declined in the United States in recent years.

Decline of live kidney donation. Live donor kidney transplants represent far less than half of all transplants performed in most centers. In fact, the number of live kidney donor transplants has declined nationally from the previous year in all but 1 year (2009) for the past ten years (SRTR, 2016; Rodrigue, 2013; Reese, 2008). Rodrigue and colleagues recently described a 13% decline in the annual number of living kidney donors from 2004-2011. Even more striking is the fact that the number of live kidney donations performed in 2014 was at the lowest level since the year 2000 (Figure 3) (UNOS, 2014).

The decline in the United States differs from recent increases in living donation seen in other regions of the world including the United Kingdom, Mexico, Australia, Japan, and The Netherlands (Rodrigue, 2013; Horvat, 2009). The authors describe the decline in the United States as more pronounced among men, blacks, younger adults, siblings, and parents. They conclude that this decline is one that warrants action by transplant centers, the transplant community, and the state and national governments (Rodrigue, 2013).

Variations in living kidney donation rates. Further complicating the phenomenon is the wide geographic and programmatic variations in living donation in the United States (SRTR, 2016; Gore, 2009; Levey, 2011). To facilitate transplantation, the United States is divided into eleven geographic regions (Figure 4) (UNOS, 2015). The number of live kidney donation varies by region with Region 5 boasting the largest number of

live donor transplants (820) in 2014 and Region 6 the lowest number (180) (SRTR, 2016). This same disparity exists amongst the state and transplant center level as well (Figure 5). This is evidenced by the number of live kidney donor transplants in 2015, which ranged from zero living donor transplant in 2015 at the lowest performing centers to as many as 173 at the highest performing center (SRTR, 2016).

Purpose of the Study

The act of donation is widely supported by the public, religious organizations, medical profession, and transplant community. According to a 2012 national survey of organ donation attitudes and behaviors, 95% of the public supports organ donation (U.S. Department of Health and Human Services, 2012). There is evidence that as many as one in four people would be willing to donate if they knew that a family member, community member, or even a stranger were in need of an organ (Reese, 2008; National Kidney Foundation, 2000). Therefore, in an era of growing organ shortages, it is imperative to determine why there are not more live organ donors, what barriers exist to live donation, and what, if anything, can be done to overcome these barriers.

Healthcare system factors can pose barriers to living kidney donation. Transplant and living donor evaluations can be complex and inefficient making it difficult for many transplant candidates and potential donors to navigate (Saunders, 2000). One likely contributing factor is the lack of organizational resources devoted to living donor programs. Based on the available literature on donor conversion, between 80-90% of potential donors who contact the center fail to donate (McCurdie, 2005; Lapasia, 2011; Reeves-Daniel, 2009; Lunsford SL, 2006; Saunders, 2000; Norman, 2011; Moore, 2012).

This low conversion rate may be related to the significant and time-consuming workload common in most living donor programs. The type and quantity of staffing and resources devoted to living kidney donor programs may be significantly different, potentially impacting the volume of living donor transplants performed by those programs (SRTR, 2016; Levey, 2011; Rudow, 2011). Determining how, if at all, program size, staffing, and organization play a role is essential (Levey, 2011).

Significance of the Issue and Need for Study

There are limited data that describe nurse staffing in transplant centers and living donor programs. (See Chapter 2 regarding literature review used to support this synthesis) Reported are mostly general in nature and based on individual nurse staff reports. There is no available research that examines actual nurse staffing and none that relates its relationship with patient or nurse outcomes in transplant centers or living donor programs. There is clearly a lack of research defining the types and quantities of transplant center staff, living donor staff, multiple responsibilities of staff members, functions that require significant resource utilization, and the organization of living donor programs.

There is also a lack of data to describe how much staff time is spent on each specific job function or the quantity of resources that must be devoted to these various aspects such as care coordination, patient education, or administrative duties such as data entry or scheduling tests. Skill mix is an important component to evaluate, because there are undoubtedly time intensive tasks that could be performed by nonlicensed personnel. The extent to which these personnel are utilized in transplant programs is uncertain but is

likely variable. Extrinsic factors that impact nurse staffing needs, nurse and patient outcomes, and organization in these settings have yet to be determined. It is important to determine if lack of resources, both labor and nonlabor, impact patient and program outcomes such as the number of living donations. Research is needed to identify which key organizational factors that are amenable to change most influence nurse coordinator performance and donation outcomes (Needleman, 2007).

Transplant center labor. The literature is replete with references to the importance of nurses in transplantation. Transplant recipient and living donor coordinators are considered a vital member of the transplant team primarily responsible for patient care coordination or case management throughout all phases of transplantation or living donation. The Centers for Medicare & Medicaid Services (CMS) regulations and the United Network for Organ Sharing (UNOS) policy define personnel roles, including the transplant coordinator and living donor advocate role, required for a transplant center (CMS, 2007; OPTN/UNOS, 2014; Hauff, 2007). CMS mandates nursing participation in multidisciplinary planning and the designation of a clinical transplant coordinator with primary responsibility for coordinating clinical aspects of transplant care, including continuity of care for patients and living donors throughout transplantation and donation (CMS, 2007). Both CMS and UNOS state that the transplant coordinator should be a registered nurse or licensed clinician (CMS, 2007; OPTN/UNOS, 2014).

CMS and UNOS also have regulations regarding the care of live donors within the transplant center. The regulations state that programs must have personnel and resources devoted to the care of live donors, but the regulations do not indicate the types

and numbers of health care providers involved or how their time should be spent (CMS, 2007; OPTN/UNOS, 2014). Two large collaboratives of national and internal experts, Consensus Conference on Best Practices in Live Kidney Donation (2014) and European Union Working Group on Living Donation (2014) recently highlighted the importance of nurse staffing to living donation (LaPointe Rudow, 2015). Their recommendations include investing in appropriate staffing and devoting specific nurse coordinator time to the living donor program; however, the type or amount of nurse staffing is not specified. The groups recognized that program size and staffing likely play a role in the geographic and programmatic difference in living kidney donation (LaPointe Rudow, 2015; European Union Working Group on Living Donation, 2014). Therefore, it is necessary at this time to develop a better understanding of the state of living donor program staffing and to examine the extent of association between nurse labor and living kidney donation outcomes.

Further study on the relationship of organizational structures and processes with outcomes is needed to begin to understand the role that labor, hospital structures, resources, and processes play in living donation because labor and the need for labor can be influenced by these variables (Minnick, 2001; Minnick, 2007; Minnick, 1998; Minnick, 1994; Needleman, 2007). This dissertation has applied the *Minnick and Roberts Outcomes Production Model* as *a* conceptual framework described in Chapter 2.

Research Aims

Research Aim 1: Describe characteristics and roles of the living donor coordinator within U.S. solid organ transplant centers.

Research Aim 2: Describe the current capital inputs, organizational facets, labor inputs, and employment terms within living kidney donor programs in the U.S.

Research Aim 3: Describe the extent to which administratively mediated variables (capital inputs, organizational facets, labor inputs, and employment terms) in living donor programs are associated with rates of live kidney donor inquiries, evaluations, and transplants among transplant centers.

Living donors are key to improving access to transplantation due to the limited number of deceased donor kidneys available. However, there has been a decline in living donation over the past decade. Further complicating this phenomenon is the wide geographic and programmatic variation in living donation. There are many potential barriers to living kidney donation including healthcare system factors. Determining how program size, staffing, and organization play a role in live kidney donor outcomes is essential. The aim of this study was to describe the labor inputs, organization, and resources available within U.S. living donor programs and the associated impact on living donor outcomes. The next section outlines the theoretical framework used to suggest variables needed for a basis to describe living donor programs and the literature review related to labor, organization, and resources within living donor programs.

CHAPTER II

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Theoretical Framework: The Minnick and Roberts Outcomes Production Model

A health services framework, the Minnick and Roberts Outcomes Production Framework (Minnick, 2001) is a conceptual framework that can be used to determine the impact of organization and labor in living donor programs on rates of donation (Figure 6). Previous research by Minnick and colleagues focused on resource clusters within organizations that must be present to achieve better outcomes (Minnick, 2007; Minnick, 2007; Minnick, 1997; Minnick, 1995; Maxwell 2012). Studies guided by this model identified the extent of variation of inter- and intra- institutional labor, capital, and process inputs to determine if variations contributed to outcomes. The model contends that examination of clusters of variables provides a more versatile approach that may be preferred over individual variable approaches (Minnick, 2007; Maxwell, 2012).

An important strength of this model is that it distinguishes factors that are changeable and within the control of administrators from non-modifiable factors (Maxwell, 2012). The term administratively- mediated variables (AMVs) is the over-arching concept within the framework. The model implies that multiple factors and interrelationships within health care settings contribute to patient outcomes. Administratively mediated variables (AMVs) are modifiable factors shaped by decisions of leaders within organizations. The concept implies that these variables can be altered (mediated) through administrative decisions. An assumption is that alterations in work

conditions (capital inputs, organizational facets, labor inputs) contribute to changes in outcomes (Minnick, 2007; Maxwell, 2012).

Capital inputs, employment terms/scope, organizational facets, and labor inputs serve as secondary concepts within the model. The model contends that these secondary concepts impact employee behavior. It is the employee behavior that then influences the patient experience and therefore outcomes. Another important component of this model is the role of patient characteristics. Health care systems (i.e. transplant centers, living donor programs) often design programs/educational materials/services based on homogenous patient populations, while in fact, variations in patient characteristics (age, gender, race/ethnicity, socioeconomic status, education level, geographic location) may call for designs that are customized to patient types (Minnick, 1997; Maxwell, 2012). These patient characteristics along with patient experience are what influence outcomes.

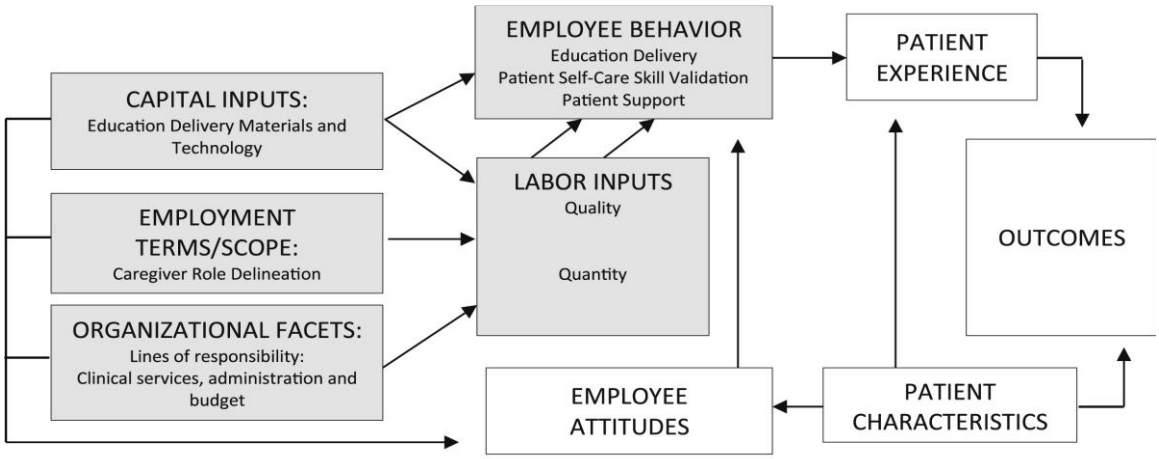


Figure 6. Conceptual Framework: Minnick & Roberts Outcomes Production Model

Table 1. Key Terms and Definitions

Key Terms/Concepts	**Definition**
Organizational facets	• Work environment, work traits, and work guides or organizational structures and procedures. • Structures include traits within an organization that affect worker autonomy (e.g., Magnet facility); and procedures include guidelines that influence the work environment (e.g., policies, standards of care). • Care delivery processes also include those that influence providers' ability to exercise their expertise and direct standardization of work (Minnick, 2007; Maxwell, 2012).
Capital inputs	• Tangible items that entail significant financial investments by organizations (e.g., transplant databases, electronic medical records, equipment).
Employment terms	• Temporal (time-related) and workload requirements of staffing (e.g., work hours per week, role requirements, how staff time is allocated to patient populations)
Labor Inputs	• Measures that reflect the quantity of providers or the quality (characteristics) of providers within settings. • Quantity includes factors such as number of RN FTEs, living donor advocates, or physicians devoted to the care of the living donor; and quality includes factors such as nurse certification, education, and level of experience. • Within the framework, a second assumption is that labor inputs mediate the effects of capital inputs, employment terms, and organizational factors, and influence employee behavior (Minnick, 2007; Maxwell, 2012).
Employee behavior	• Actions taken by employees for patients to increase quality of care, increase patient satisfaction, and improve outcomes.
Patient characteristics	• Represent baseline status at the outset of treatment and/or the status before onset of the problem that requires treatment. • Within any study, investigators must consider patient-related elements considered to be most relevant to the outcome(s) (Minnick,1997; Young, 1996).
Employee attitudes	• Reflect the internal disposition of employees.
Patient experience	• The objective and subjective life and healthcare experience of patients.

Critical Analysis of Relevant Literature

An inventory approach was used to identify administratively mediated variables that may potentially impact living kidney donation. This approach is based on the premise that many system factors, human factors, and interactions (clusters) contribute to healthcare outcomes (Longo, 2005; Minnick, 1997; Maxwell, 2012). Administratively mediated variables that may potentially impact living kidney donations were sought within the literature and an attempt was made to identify an inclusive list of the most salient variables. Criteria for variable inclusion included: 1) evidence from systematic reviews of literature, 2) evidence from other research studies, 3) published expert opinion, 4) recommendation or consensus documents, 5) national collaborate or best practices consensus conferences. An overview of selected AMVs categorized according to concept is displayed in Table 2.

Methodological approach to selected administratively mediated variables. The AMVs identified in Table 2 were described in the literature or by various transplant specific sources as important factors that may impact living kidney donation outcomes; however, few of these variables have actually been studied. For the purposes of this dissertation research, focus will be paid to labor inputs, specifically nurse coordinator quality and quantity, and their potential relationship to living donor outcomes.

Labor Literature Review and Results

Search Strategy. The following electronic databases were searched systematically: MEDLINE using PubMed CINAHL, Google Scholar and ProQuest. The search strategy to locate studies and gray literature related to staffing in living donor

programs included the following key search terms: live kidney, living donor, living donors, kidney, nephrectomy, kidney transplantation, transplant centers, living donor programs and health resources, health manpower, resource use, resource utilization, nurses/manpower, nurse utilization, nurse labor, nursing manpower, capital, length of stay/economics, organization, and administration.

The second search strategy was to screen reference lists from relevant primary and review articles for potentially useful studies. Inclusion criteria were English only, published, full-text primary research studies and gray literature. Aside from the above criteria there were no exclusion criteria including date restrictions. Due to the limited results obtained from the above search strategy the review was expanded to include: 1) published expert opinion, 2) recommendation or consensus documents, 3) national collaborate or best practices consensus conferences, and 4) government guidelines or public policy documents.

Living donor program specific staffing results. The literature review did not result in any published, full-text research studies regarding staffing or organization of living donor programs. The only results discovered were an unpublished, non-publicly available staffing survey of transplant centers and one single-center abstract. In fact only minimal evidence based or even descriptive research regarding staffing models, benchmarks, or organization was discovered for any area of transplantation. Published reports indicate a need for quantitative research that describes staffing in transplant centers. These reports make reference to the need to invest in adequate staffing, but there is lack of evidence-based research that describes what type and how much staffing is considered adequate (Pondrom, 2013; Hauff, 2007; Hoy, 2011)

Transplant center specific staffing results. A review of the literature yielded three studies that evaluated staffing in transplant centers, two examined nurse/advanced practice nurse staffing and one examined pharmacy staffing (Hoy, 2011; Stendahl, 2012; Staino, 2013). Due to limited results, the review was expanded to include research regarding staffing in ventricular assist device (VAD) programs. VAD programs are frequently incorporated into transplant centers and the job functions of VAD nurses in terms of care coordinator are very similar to transplant nurse coordinators. Two studies were found that examined staffing and organization of VAD programs (Widmar, 2014; Casida, 2011).

Designs and Methods. The researchers in four of the five studies employed a cross-sectional survey design. The aims of these studies were to examine staffing in or organization of transplant centers or VAD programs. This type of design seeks to describe a phenomenon for which there is limited previous research or data available. The studies were purely descriptive in nature and aimed to describe staffing in these previously unexplored areas.

The sample populations for four of the five studies were obtained from transplant specific transplant databases (UNOS database or SRTR registry) or databases/registries specific to VAD programs. One study was a convenience sample of participants at a national advanced practice conference (Hoy, 2011). Three of the four studies chose to survey the entire population of interest (nurses/APNs) and one surveyed only high volume centers. Surveying from the entire selected population reduces nonsampling error and is important in this setting due to the small sample size. Two of the studies used paper surveys, two provided the option of paper or electronic survey completion, and one

only allowed electronic survey completion. The response rates of studies ranged from 63-70%. Two of the five studies used reminders to increase response rates (Casida, 2011; Widmar, 2014). Only one of the five studies reported analysis of response bias by evaluating differences between respondents and nonrespondents (Widmar, 2014).

One disadvantage of this type of cross-sectional survey methodology was the lack of validation of participant reported staffing measures. Those who responded may not have complete knowledge of staffing levels, ratios, or workload. In addition, there is always the potential for nonresponse bias limiting external validity of the results. Nonresponse is a common problem in wide-scale surveys (Groves, 2009). Those who responded may be quite different from those who did not respond.

Measurement Tools. All five studies used investigator developed survey tools. Only two of the five studies discussed reliability or validity testing of the investigator developed survey tools (Casida, 2011; Widmar, 2014). The studies measured staffing by respondent self-report of number of persons who performed the role. Two of the five studies evaluated workload by self-respondent report of typical staff/patient ratios (Casida, 2011; Widmar, 2014). Two other studies evaluated workload by comparing staff ratios to average number of transplants performed at the center per year (Stendahl, 2012; Staino, 2013). However, with this method alone it is impossible to determine actual workload because staff mix, resources available to staff, and actual number of patients being managed (pre-transplant case load) are not measured.

Statistical Techniques. Three of the five studies used purely descriptive statistics using nominal data (counts and frequencies) to describe the study population but did not

examine relationships (Stendahl, 2012, Casida, 2011; Hoy, 2011). Bivariate analyses were used in the two studies that examined the relationships between two study variables (Staino, 2013; Widmar, 2014). Only one study adequately described the statistical techniques used in the study. This study by Widmar and colleagues used bivariate analysis to examine relationships between study variables and cluster analysis method to identify patterns of additional material and resource use, labor input, and quantity among VAD programs. The authors also described how they handled data that were not normally distributed. This was the only article that discussed how missing data were handled (Widmar, 2014).

There are no published full text research studies that look at organization, resources or labor within living donor programs. The literature reviewed identified only five studies that even described staffing models within transplant programs or related fields. All were descriptive studies. There is no available research that examines actual nurse staffing in transplant centers or living donor programs. In addition, there is no available research that describes a relationship or association of staffing, organization, or resources with patient or nurse outcomes in transplant centers or LD programs. Therefore, there is a need to describe labor inputs, organization, and resources available within U.S. living donor programs and the associated impact on living donor outcomes. Chapter III describes in detail the methodology for this dissertation research including instrument development, data collection procedures, and data analysis.

Research Aims: Definition of Terms

Table. 3.

Research Aim 1: Describe characteristics and roles of the living donor coordinator within U.S. solid organ transplant centers.				
Major Concepts	**Conceptual Definition(s)**	**Operational Definition(s)**	**Survey Questions**	**Analytic Considerations**
Characteristics of the living donor coordinator	• Characteristic: A feature or quality belonging to a person and serving to identify the person. • The living donor coordinator: the person who coordinates/facilitates/manages/assists the potential living donor throughout the donation process.	1. Job title 2. Gender 3. Race 4. Ethnicity 5. Years of experience a. Years in role b. Years at center 6. Professional license held 7. Certifications held 8. Education 9. Employment terms a. FT/PT	1. Item 6 2-8. Demographics 9. Item 3; Item 4; Item 5a; Item 5b; Item 13a	Target population is living donor coordinators Face validity and content validity confirmed by expert opinion, card sort, and cognitive interviewing. No further psychometric testing Administration: 1. Self-administration 2. 35 items, potential for response burden
Role of the living donor coordinator	• Role: a function or part performed in a particular operation, process, or situation.	1. Components/duties of the living donor coordinator role a. Job functions b. Dedicated to LD program 2. Span/trajectory of care delivery: a. Pre donation phase b. Hospitalization phase c. Post donation phase 3. Workload/patient load 4. Number of staff who perform the role	1a. Item 10 1b. Item 1; Item 5b 2. a,b,c. Item 10 3. Item 15; Item 16; 4. Item 2; Item 3; Item 4	
U.S. solid organ transplant	• Medical center or hospital that performs living donor solid organ	1. Transplant volumes: a. total transplants	1a,b,c,d. Data obtained via	

centers	transplants	b. deceased donor transplants c. living donor transplants d. number on the transplant waiting list 2. Living donor volumes a. Total LD inquiries b. Total LD evaluations	SRTR data request 2a-b. Item 16	

Research Aim 2: Describe the current capital inputs, organizational facets, labor inputs, and employment terms within living donor programs in the U.S.				
Major Concepts	**Conceptual Definition(s)**	**Operational Definition(s)**	**Survey Questions**	**Analytic Considerations**
Capital Inputs	• Tangible items that entail significant financial investments by organizations (e.g., transplant databases, electronic medical records).	1. Transplant electronic database system 2. Kidney Paired exchange software 3. Living donor initial screening software/website 4. Recipient Educational materials 5. Donor educational materials 6. Specialized educational programs/resources	1. Item 20 2. Item 20 3. Item 20 4. Item 24; Item 26 5. Item 23; Item 25; Item 26 6. Item 22; Item 25; Item 26;	Target population is living donor coordinators Face validity and content validity confirmed by expert opinion, card sort, and cognitive interviewing. No further psychometric testing Administration: 1. Self-administration 2. 35 items, potential for response burden
Organizational Facets	• Work environment, work traits, and work guides or organizational structures and procedures. • Structures include traits within an organization that affect worker autonomy (e.g., Magnet facility); and procedures include guidelines	1. Reporting Structure for staff members 2. Mission/philosophy 3. Strategic Plan 4. Private vs nonprofit 5. Academic Medical Center 6. COTH membership 7. Transplant center	1. Item 7, Item 8. Item 11 2. Item 14 3. Item 14 4-6. AHA Data	

	that influence the work environment (e.g., policies, standards of care). • Care delivery processes also include those that influence providers' ability to exercise their expertise and direct standardization of work	8. Organ Procurement and Transplantation Network (OPTN) region/geographic location/state 9. Program Processes/Protocols 10. Program Resources	7-8. Pre-code survey with center ID; SRTR data request 9. Item 17; Item 18; Item 19; Item 20; Item 21; Item 22; Item 23; Item 24 10. Item 20; Item 25; Item 26; Item 27; Item 28	
Labor Inputs	• Measures that reflect the quantity of providers or the quality (characteristics) of providers within settings. • Quantity includes factors such as number of RN FTEs, living donor advocates, or physicians devoted to the care of the living donor; and quality includes factors such as nurse certification, education, and level of experience.	1. Staff/Provider Training 2. Staff members within living donor program a. Roles b. Dedicated to living donor program (% effort) c. Physician Director/Champion	1. Item 9 2a. Item 11; Item 12, Item 13 2b. Item 5b; Item 12 2c. Item 11	
Employment Terms	• Temporal (time-related) and workload requirements of staff.	1. Workload/patient load	Item 15; Item 16;	

Research Aim 3: Describe the extent to which administratively mediated variables (capital inputs, organizational facets, labor inputs, and employment terms) in living donor programs are associated with rates of live kidney donor inquiries, evaluations, and transplants among transplant centers.				
Major Concepts	**Conceptual Definition(s)**	**Operational Definition(s)**	**Survey Questions**	**Analytic Considerations**
Rates of live donations	• Solid organ transplant volumes	1. Transplant volumes: a. total transplants b. deceased donor transplants c. living donor transplants d. number on the transplant waiting list 2. Living donor volumes a. Total LD inquiries b. Total LD evaluations 3. Number of living donor transplants in proportion to total number of transplant performed 4. Number of KPD performed	1. Data obtained via SRTR 2. Item 15; Item 16 3-4. Data obtained via SRTR data request	Target population is living donor coordinators Face validity and content validity confirmed by expert opinion, card sort, and cognitive interviewing. No further psychometric testing Administration: 1. Self-administration 2. 35 items, potential for response burden

CHAPTER III

METHODOLOGY

This chapter discusses the methodology for the two phases of research: I. instrument development and testing II. study methods.

Phase I: Preliminary Work

Instrument Development and Testing

There were no instruments to measure and describe the organizational structure or labor in living kidney donor programs. However, Widmar and colleagues developed a survey to describe how ventricular assist device programs are organized in the United States (Widmar, 2014). The survey instrument developed for this research to describe healthcare organizational structure and labor in living donor programs was modified from the Widmar survey. Preliminary work for the dissertation research included item development, conceptual card sort, and cognitive interviewing/debriefing based on the Dillman and Fink method for testing questions and questionnaires (Dillman 2014; Fink, 2013).

The PI developed the survey based upon the synthesis of the conceptual framework discussed in Chapter II (See Figure 6 and Table 1& 2.). The PI identified major concepts within the research aims through the synthesis of the previously described conceptual framework. Table 3 provides a listing of identified concepts, conceptual definitions, operational definitions, survey item intended to address each concept, and analytic considerations. The final survey consisted of 35-items describing components of living donor programs including organizational facets, capital inputs, and labor inputs. It also described characteristics and roles of the living

donor coordinator. The majority of question items in the survey required selected options resulting in nominal or ordinal-level data. There were a small proportion of question items such as program volumes and staffing numbers that resulted in continuous data.

Validity, Reliability, Credibility of Instrument

Several methods were used to ensure validity, reliability, and credibility of the instrument based on survey methodology experts (Dillman, 2014; Fink, 2013; Groves, 2009). The completed survey was reviewed to ensure accuracy of concepts and terminology before testing. Face validity, content validity, and reliability of the survey was assured through extensive literature review, by expert opinion of the dissertation committee, an independent card sort method, and cognitive interviewing with a convenience sample of five knowledgeable colleagues in the field. Based on these findings, the PI modified survey layout and wording. A well-designed, easy to use survey always contributes to reliability and validity (Fink, 2013)

The instrument developed for this research was based upon conceptual frameworks applied extensively in health services research, and applies concepts reflected in those frameworks. Credibility is enhanced by the use of survey question items developed and applied in previous healthcare workforce studies evaluating administratively mediated variables (Minnick, 2009; Widmar, 2014). Expert review and cognitive interviewing conducted after the conceptual card sort also enhanced credibility.

Phase II: National Study

Research Design and Assumptions

Research design. The research design for this study was cross-sectional and descriptive.

This research explored the influence of capital inputs, organizational facets, labor inputs, and employment terms on rates of live kidney donations among transplant centers. The methodology included the administration of a one-time survey to living donor coordinators. The survey included areas of the Minnick and Roberts model, specifically current capital inputs, organizational facets, labor inputs, and employment terms relative to living donor programs among all known living donor transplant centers in the United States. The PI selected living donor coordinators because this group has an in-depth knowledge of living donor care elements along the continuum of care. The survey results were linked to the American Hospital Association (AHA) and Scientific Registry of Transplant Recipients (SRTR) databases to collect data on center characteristics and outcome measures. This study used data from the Scientific Registry of Transplant Recipients (SRTR). The SRTR data system includes data on all donor, wait-listed candidates, and transplant recipients in the U.S. submitted by the members of the Organ Procurement and Transplantation Network (OPTN). The Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services provides oversight to the activities of the OPTN and SRTR contractors.

Research setting. The dissertation research sought to include all transplant centers (estimated n=255) that perform living donor transplants in the United States. The United Network for Organ Sharing (UNOS) is the private, non-profit organization that manages the nation's organ transplant system under contract with the federal government. Transplant centers in the United States belong to UNOS via membership. To identify potential research settings for study, a current listing of transplant centers that were approved to perform living donor kidney transplant in 2015 was obtained from UNOS.

Study Population. The PI's goal was to obtain data from all U.S. transplant centers that

were UNOS approved to perform living donor transplantation thus making this a universal study. To describe these transplant center organizations, the PI recruited living donor coordinators or coordinators who were responsible for the management of living donors within these organizations for survey completion. According to UNOS, there were approximately 255 transplant centers in the U.S. Two sequential methods for locating and identifying living donor coordinators or coordinators who were responsible for the management of living donors were conducted:

1. Data request to UNOS for a listing of all transplant centers in the U.S. approved to perform living donor kidney transplantation in the U.S. UNOS database contains a listing of transplant center contact information.

2. Phone contact of each transplant center to obtain living donor coordinator name and verify mailing address.

Study inclusion and exclusion. The criteria for study inclusion and exclusion for this dissertation research were:

a. The study population was all transplant centers within the U.S. that were approved to perform living donor kidney transplantation as obtained from UNOS data request. The final study sample included all transplant centers represented by living donor coordinators or coordinators responsible for the management of living donors who completed the paper or electronic survey.

b. The PI included all transplant centers in the study if the following criteria were met: (a) located within the United States and (b) approved to performed living donor transplantation by UNOS.

Methods for subject recruitment. The following methodology for subject recruitment and increasing response rates suggested by Dillman, Fink, and Fowler was incorporated into the following methods for subject recruitment.

Pre-Distribution Survey Announcement. Prior to distribution of the survey, the PI announced the survey in two ways: 1. via an announcement on two transplant related listserv: a. UNOS transplant coordinator listserv and b. UNOS transplant administrator's listserv 2. letter to the transplant administrator at each transplant center. Using this strategy increased the probability that the announcement would reach the target audience and be read. The announcements included the following information:

1. Study and its intent

2. When and where the survey will be mailed to participants.

3. The importance of knowledge development and participation in the research process.

4. The importance of describing the role of living donor coordinators and organizational components of living donor programs within transplant centers.

5. Notification that there is a $35 incentive for completing the survey.

6. A contact e-mail address that they may access for additional information.

7. A thank-you for their participation in the study process.

Survey Distribution. A paper copy of the survey was distributed via mail to each identified living donor coordinator at their listed contact address. Each survey included an identification code (1-255) that will allowed the PI to link each survey response with the transplant center code known only to the PI. The cover letter explained two options for return of the survey 1. Postal mail return via a pre stamped and addressed envelope or 2. Electronic submission via a hyperlink to the survey embedded within the paper survey. Study participants chose the method of completion most convenient for them thereby improving overall response rate (Minnick, 2010). The above procedure occurred over 3 cycles approximately two and a half weeks apart. Providing two methods of completion and 3 cycles served to increase survey recruitment. All messages sent by the PI had a disclaimer assuring that the PI would only report participant survey results as aggregate data to ensure confidentiality.

Incentives. To increase survey recruitment, a one-time thirty-five dollar gift card incentive was provided to all study participants who completed the survey. If the survey was completed electronically, the participant was directed to a link where he/she entered information for mail or electronic delivery of the thirty-five dollar gift card. If the survey was completed by paper, the participant was asked to complete a separate section (not attached to the paper survey) where he/she entered information for mail or electronic delivery of the thirty-five dollar gift card. The thirty-five dollar gift card was intended to compensate respondents for the time needed to complete the survey and increase response rates (Dillman, 2014). A social security number waiver was requested and granted from the IRB due to the small incentive amount. The waiver was needed to allow the incentive to be dispensed without requiring the social security number thus increasing confidentiality and survey respondent comfort.

Data Collection Procedures and Methods

Survey Administration. The procedures used in the dissertation research phase were implemented over the following timeline:

Month 1

1. The PI obtained Institutional Review Board (IRB) approval from Vanderbilt University Medical Center (VUMC) via an expedited application.

2. The PI was funded for dissertation research through the VUSN PhD Student Support Fund ($1,437.50) and CTSA/VICTR grant ($9,261.50). These funds were used for the costs associated with the research including incentives and survey printing, mailing, and postage.

3. The PI created the survey and study database within the Research Electronic Data Capture (REDCap) system. Vanderbilt University provides the REDCap survey system free for use to any student or employee of Vanderbilt University through grant support form the National Institute of Health (NIH) (1UL1 RR024975 from NCRR/NIH). Surveys developed for use in the REDCap system are encrypted and secure. The REDCap system is designed to protect healthcare information and any data input from a REDCap survey is stored on a database within a secure internet server at VUMC. Once data was stored within the REDCap database, the PI downloaded the data to a statistical software packages for data analysis. The PI ensured both the survey and generated database were functioning appropriately and corrected any problems prior to study utilization.

Months 2-5

1. The PI provided living donor coordinators or coordinators who were responsible for the management of living donors with two options for survey completion. The coordinator had the option to complete the survey process electronically or through paper survey. The PI provided recruitment for and dissemination of the survey via a postal mailed paper administration. The PI continued recruitment for a total of 3 cycles by standard mail (See Table 4).

Table 4. Recruitment and Data Collection Timeline.

Month	Week	Procedure
2-5	**1**	Posted announcement on transplant administrators and transplant coordinator Listserv and transplant administrators announcement of the survey
	2	Cycle 1: Standard mailing of survey
	3	
	4	Posted announcement on transplant administrators and transplant coordinator Listserv.
	5	Cycle 2: Standard mailing of survey
	6	
	7	Posted announcement on transplant administrators and transplant coordinator Listserv.
	8	Cycle 3: Standard mailing of survey
	9	
	10	
	11	Closed data collection

Recruitment Procedures

1. Listserv and e-mail Recruitment:

Prior to distribution of the survey, the PI announced the survey in two ways: 1. via an

announcement on two transplant related listserv: a. UNOS transplant coordinator listserv and b. UNOS transplant administrators listserv; 2. via letter to the transplant administrator at each transplant center. Using both strategies increased the probability that the announcement reached the target audience and was read. Both announcements included the following information: 1) study and its intent, 2) when and where the survey was to be mailed to participants, 3) the importance of knowledge development and participation in the research process, 4) the importance of describing the role of living donor coordinators and organizational components of living donor programs within transplant centers, 5) notification that there was a $35 incentive for completing the survey, 6) a contact e-mail address for additional information, 7) a thank-you for participation in the study process (Dillman, 2014).

Members/participants of the UNOS Internet Listserv receive bulletin board communications via a chosen email address selected when members initially register for access to the site. Electronic postings are delivered to the registered email account. Potential study participants were more likely to read the study invitation because it was posted through a familiar website where they discuss topics relative to their professional roles.

2. Standard Mail Recruitment—Initial Mailing:

a. The PI mailed a printed copy of the research study invitation and survey to each identified living donor coordinator at his/her listed contact address. The PI provided a postage-paid envelope with the PI's contact address in the mailing. The PI included an invitation to participate in the study attached to the first page of the survey mailing, which included information regarding 1) study and its intent, 2) the survey instrument, 3) the importance of knowledge development and participation in the research process, 4) the importance of

describing the role of living donor coordinators and organizational components of living donor programs within transplant centers, 5) information about data protection, 6) notification that there was a $35 incentive for completing the survey and directions for receipt of the incentive, 7) a contact e-mail address for additional information, 8) a web-address at the bottom of the page that when typed into a web-browser allowed the participants to take the survey electronically, and 9) a thank-you for their participation in the study process (Dillman, 2014).

b. The PI ensured that each paper-copy survey had an ID number placed in the upper right corner of the survey document in order to identify the transplant center described.

c. Completion and return of the paper copy of the survey implied consent for participation in the study. Individuals who opted to take the electronic version of the survey granted consent through the completion and submission of the electronic survey.

3. Second Listserv and e-mail Recruitment:

The PI posted a second announcement to the UNOS transplant coordinator listserv and transplant administrators listserv, thanking participants and reminding all living donor coordinators of the implications of the study.

4. Standard Mail Recruitment – Second Mailing:

The PI mailed a second printed copy of the research study invitation and survey to each identified living donor coordinator that had not yet participated in the study at his/her listed contact address. The PI provided a postage-paid envelope with the PI's contact address in the mailing. The PI included all information provided, as mentioned above, in the first standard mailing in the second mailing cycle.

5. Third Listserv and e-mail Recruitment:

The PI posted a third announcement to the UNOS transplant coordinator listserv and transplant administrators listserv, thanking participants and reminding all living donor coordinators of the implications of the study.

6. Standard Mail Recruitment – Third Mailing:

The PI mailed a second printed copy of the research study invitation and survey to each identified living donor coordinator that had not yet participated in the study at his/her listed contact address. The PI provided a postage-paid envelope with the PI's contact address in the mailing. The PI included all information provided, as mentioned above, in the first standard mailing in the third mailing cycle.

7. The PI closed data collection for the research study in approximately one month following the third cycle of recruitment. In return for participation in this research study and to increase survey recruitment, a one-time thirty-five dollar gift card incentive was provided to all study participants who completed the survey.

8. Data was automatically populated into the established database when the survey was completed electronically. The PI and research assistants entered data into the database for all completed surveys received via standard mail.

9. Background demographic information on transplant hospitals was obtained through the American Hospital Association (AHA) database and was added into the established study database (e.g., private versus nonprivate, academic medical center, COTH membership, etc.). Transplant and donor volumes were obtained through the SRTR database and were added into

the established study database (e.g. number of living and deceased donor transplants performed by center, number of transplant candidates on the waiting list, number of KPDs by center, etc).

Month 6-7:

1. The PI downloaded REDCap data into SPSS for analysis.
2. The PI analyzed data and evaluated results.

Month 8-9

1. The PI completed writing research study results.
2. The PI will ensure dissemination of research results through the dissertation defense and through submission of abstract presentation of aggregate results to the American Transplant Congress Annual Meeting NATCO Annual Meeting, the American Society for Transplant Surgeons Annual Meeting, or UNOS Transplant Management Forum for the following year after research is completed. The PI will format results into a manuscript suitable for publication, such as *American Journal of Transplantation, Clinical Transplantation, Transplantation, or Progress in Transplantation.*

Human Subjects Protection

First, the PI's dissertation committee reviewed and approved the dissertation research. Second, the research project was submitted to the Vanderbilt University Institutional Review Board (IRB) via expedited application and was approved prior to initiation of the research.

a. Potential risks. This dissertation research did not involve recording of patient protected health information (PHI) and did not alter the clinical care offered to potential or actual living donors or potential or actual transplant recipients. As this was a survey administered to

living donor coordinators, there was a risk of identification of individual healthcare professionals and their relation to specific healthcare organizations and locations.

b. Participant confidentiality. The methods for ensuring participant confidentiality are as follows:

1. Mail surveys were stored in a locked file cabinet at Vanderbilt University Medical Center accessible only to the PI and dissertation committee members.

2. Each survey was coded with a unique identifier that links it to the UNOS transplant center ID stored in an electronic database. Identifying information for transplant centers was used for further organizational and outcomes assessment via linkage with the SRTR (Scientific Registry of Transplant Recipients). Data was stored on a secure database server (REDcap) and only the PI and dissertation committee members had access to the database.

3. All messages sent by the PI had a disclaimer assuring that the PI would only report participant survey results as aggregate data to ensure confidentiality. We have not and will not share participation status of the LDC with the administrator at their center.

c. *Data Monitoring.* Study participant recruitment, provision of necessary measurement tools, data obtained from completed surveys, and accuracy of the data entry was reviewed. Any difficulties encountered during the study were discussed with the committee chair. There were no protocol deviations to report to the IRB.

The student's dissertation committee and the Vanderbilt University Institutional Review Board (IRB) reviewed the study protocol before beginning the study. The IRB will review the study protocol annually as required for renewal if needed. The PI and dissertation committee

will review the study protocol annually with protocol and study renewal if necessary.

Data Collection and Storage

1. The PI obtained research data from human subjects by electronic survey and from completed paper copy survey. The PI did not use any individual medical records or specimens in dissertation research.
2. The PI recorded data from human subjects including demographic information, open and closed-ended questions about living donor program processes and organizational structure, and the living donor coordinator role.
3. The PI generated created a random identifier maintained in the survey database with the survey data to create a linkage between survey responses and transplant center. The PI removed identifiers from any file downloaded for statistical analysis, and the PI will destroy all identifiers following entire study completion through deletion of electronic record or by shredding of completed paper copies of the survey. The PI reported data in aggregate only and will never attribute data to one hospital organization or living donor coordinator.
4. The PI collected data electronically as a response to an electronic survey, or by response to a mailed survey. The PI entered data into an electronic database.

Credibility, Rigor, Validity of Design and Methods

This research study sought to describe a phenomenon for which there was limited previous research or data available. The descriptive nature of the design was an important first step in exploring labor inputs and organization in a previously unstudied area. The advantage of this design was that there was potentially high external validity due to the representative nature

of the data. Surveying from the entire selected population reduced nonsampling error and was important in this setting due to the small sample size. Nonresponse is a common problem in wide-scale surveys (Groves, 2009). Techniques to increase response rates were incorporated into the design and methods of the study including: 1. Announcements and study reminders via listservs and transplant administrator letters 2. Three study mailings, 3. A statement ensuring confidentiality and reporting in aggregate, 4. Providing two methods for survey submission, and 5. Providing a study completion incentive (Dillman, 2014; Fink, 2013; Groves, 2009). An analysis of response bias was performed by evaluating differences between respondents and nonrespondents at the transplant center level.

Credibility was enhanced by the use of survey question items developed and applied in previous healthcare workforce studies evaluating administratively mediated variables (Minnick, 2009). Expert review and cognitive interviewing also enhanced credibility. Rigor was established through strict adherence to detailed study and recruitment procedures. Research assistants performed data entry and a second verification was performed by the PI thus minimizing coding variance (Groves, 2009).

Face validity, content validity, and reliability of the survey were assured through extensive literature review, by expert opinion of the dissertation committee, an independent card sort method, and cognitive interviewing with a convenience sample of five knowledgeable colleagues in the field (Fink, 2013). Linkage of survey responses to external databases including AHA and SRTR minimized the number of questions related to volumes and outcomes within the survey thus decreasing response burden. One of the disadvantages of a cross-sectional survey design is that it is impossible to infer causality. However, database linkage allowed the

researcher to explore if there were associations or relationships between survey responses and outcomes.

Data Analysis

The data analysis plan for the proposed research was designed to address the research aims of describing labor inputs and organizational facets within living kidney donor programs in the United States.

Data Entry. Surveys completed electronically were stored in a RedCap database. Surveys returned via mail were entered into the RedCap database. All mailed surveys were double entered to check for data entry errors. Data was verified for completion prior to statistical analysis. Data analysis was completed using the SPSS statistical software package (Statistical Package for the Social Sciences).

Missing data. To minimize the risks of missing data, the PI completed preliminary work consisting of cognitive interviewing and rewording of confusing items when designing the survey. The PI also informed survey participants of their confidentiality during the research process and that results would only be reported in aggregate. A complete review of response rates is included in the results section below.

Data Analysis. Many of the questions were descriptive in nature as little is known about living donor programs within the United States. Descriptive statistics were used to summarize responses to the questions regarding the characteristics and roles of the coordinator, capital inputs, organizational facets, labor inputs, and employment terms within U.S. living kidney donor programs. Frequency distributions were used to summarize nominal and ordinal data. Summaries of central tendency and variability as appropriate were used for continuous data.

However, given the highly skewed shape of most distributions, the majority of continuous variables were summarized using median and interquartile range (IQR). Comparisons of responders and nonresponders were tested using chi-square tests of independence (nominal, ordinal data) and Mann-Whitney tests (continuous data).

Multiple linear regressions were used to assess the association of each of the major components of aim three (capital inputs, organizational facets, labor inputs, and employment terms) with three outcome variables including number of live kidney donor initial inquires, evaluations, and transplants. Conceptual items that were most representative components of the model were included in each of the major categories of administratively mediated variables subsequently used in each regression analyses. Nominal/ordinal survey items were dummy coded to create meaningful contrasts. Transformations of continuous data were conducted as necessary to meet the assumptions of multiple linear regression. Continuous variables were transformed to ordinal categories and ordinal categories were collapsed as necessary.

Sample size and statistical power. Multivariate analyses were reasonable to use considering the response rate of 70% (sample size of 148). Given the sample size of 148, a minimal sample to variable ratio of 10:1 for arriving at stable estimates of regression weights allowed for the inclusion of a maximum of 10 measures with the five multiple regression analyses proposed (1 capital inputs, 3 organizational facets, and 1 labor inputs). Within each analysis, there was at least a sample of 115 or greater which was sufficient to detect an association (*beta* coefficient) as small as 0.27(80% statistical power, 2-tailed alpha = 0.05). Given that 10% shared variance (*beta* >=0.33) is generally accepted as meaningful, this sample was sufficient to detect meaningful effects.

The previous chapter described in detail the methodology for this dissertation research including instrument development, data collection procedures, and data analysis. A modified version of a tool developed by Widmar and colleagues to describe the organization of VAD programs was used as a basis for survey development. This dissertation research was a universal study that surveyed living donor coordinators within all U.S. living donor programs. Dillman, Fink, and Fowler recommendations were used to improve response rates. The survey results were linked to the AHA and SRTR databases to collect data on center characteristics and outcome measures. The following chapter provides the results of this dissertation research.

CHAPTER IV

FINDINGS

Following a discussion of sample characteristics, chapter IV provides the results of this study by each research aim.

Comparison of Living Donor Program Study Participants with the Universe

Study participants. There were a total of 240 U.S. living donor programs (Figure 7). Of those programs, twenty-five centers did not have stand alone living donor programs meaning that donors were evaluated either via contract or affiliation with another center. Four centers had closed or no longer performed kidney transplantation. Thus, 211 living donor programs were eligible to take part in this study. Those programs were invited to participate via survey distribution as described in Chapter III. Of those invited, responses were received from representatives of 148 programs for a response rate of 70%. Most (80%) of responders submitted a paper survey (n=119); 20% (n=29) of responders completed the electronic version.

Institutional characteristics of responders and non-responders. Characteristics of the 211 programs who were invited to participate, those who did not respond, and those who responded are summarized in Table 6. For those centers whose living donor programs included affiliations, we included volumes of all centers under the primary center in order to accurately reflect outcomes of the living door program of both the primary and affiliated centers. No statistically significant differences were observed between those who responded and those who did not in terms of program volumes, OPTN region, ownership, and membership in the Council of Teaching Hospitals (COTH) for the responding and non-responding centers ($p > .05$).

Of responding centers, the median number of total kidney transplants was 55 (IQR

33-100), total deceased donor transplants 39 (IQR 21-76), and living donor transplants 17 (IQR 6-30). The total median number of kidney transplant candidates on the waiting list was 425 (IQR 273-827). Seventy percent of responding centers were private not-for-profit ownership and 73% were teaching hospitals. OPTN region 2 had the highest number of responders with 24 centers (16%) and region 6 the lowest number with 7 (5%) (Table 6).

Table 6. Comparison of LDC Survey Responders and Non-Responders at the Transplant Center Level

Transplant Center Characteristics	**Responders n=148**	**Non responders n=63**	**National n=211**	**p-value**
Program Volumes n=211 (Median, IQR)				
Total Kidney Transplants	55 (33-100)	51 (22-121)	54 (29-112)	0.528
Total Deceased donor Transplants	39 (21-76)	40 (15-76)	39 (20-76)	0.486
Total Living Donor Transplants	17(6-30)	12 (5-47)	14 (5-34)	0.768
Total kidney transplant candidates on Waiting list	425 (273-827)	409 (192-942)	422 (233-866)	0.792
Ownership n=209 (n,%)				0.839
Private: Not-for-profit	102 (70%)	44 (70%)	146 (70%)	
Private: For-Profit	14 (10%)	4 (6%)	18 (9%)	
Government-Non-Federal	25 (17%)	13 (21%)	38 (18%)	
Government-Federal	5 (3%)	2 (3%)	7 (3%)	
Teaching Status (COTH) n=209 (n,%)				0.782
Teaching	107 (73%)	45 (71%)	152 (72%)	
Non-teaching	39 (27%)	18 (29%)	57 (27%)	
OPTN Regions n=211 (n, %)				0.541
Region 1	11 (7%)	2 (3%)	13 (6%)	
Region 2	24 (16%)	5 (8%)	29 (14%)	
Region 3	14 (10%)	7 (11%)	21 (10%)	
Region 4	18 (12%)	9 (14%)	27 (13%)	
Region 5	17 (12%)	11 (18%)	28 (13%)	
Region 6	7 (5%)	1 (2%)	8 (4%)	
Region 7	11 (7%)	8 (13%)	19 (9%)	
Region 8	11 (7%)	4 (6%)	15 (7%)	
Region 9	8 (5%)	6 (10%)	14 (7%)	
Region 10	12 (8%)	5 (8%)	17 (8%)	
Region 11	15 (10%)	5 (8%)	20 (10%)	
Total Region	148 (100%)	63 (100%)	211 (100%)	

Note. Characteristics were obtained from the latest SRTR Database (2015) and AHA Annual Survey Database (2013) available at the time of the study.

Findings Related to Research Aim One: Describe characteristics and roles of the living donor coordinator within U.S. solid organ transplant centers.

Characteristics of Living Donor Coordinators

As previously described, only one survey was completed per living donor program; however, to account for centers with more than one coordinator, demographic and role characteristics could be completed for up to two coordinators per center. Of the 148 centers with responses, 98 centers (66%) provided information on one coordinator and 50 centers (34%) provided information for two coordinators. Therefore, demographic and role characteristics were described for 198 coordinators (95% female, 87% white, 92% non Hispanic or Latino). Seventy-one percent of respondents reported having a BS/BA nursing degree and 17 % reported a master's level or higher degree. Of respondents, 99% reported having an RN (92%) or RN/NP (7%) license. Forty-four percent reported having a clinical transplant coordinator certification (CCTC) and 41% reported no certifications. The median number of years respondents were employed in their current position was 4.5 years (Interquartile range (IQR) 1-11). The median number of years respondents reported being a transplant coordinator regardless of employer was 7 years (IQR 3-14). Twenty-six percent of respondents reported being in their current position $\leq$ 1 year and 19% reported that they had been a transplant coordinator $\leq$ 1 year. Conversely, 25% of respondents reported $\geq$ 10 years of experience in their current position and 43% reported $\geq$ 10 years experience as a transplant coordinator.

Coordinator Labor Quantity

Summaries of the amount of labor supplied by coordinators to manage the living donor programs are displayed in Table 7. Of the 148 living donor programs with responders to the

survey, 74% (n=109) reported that the coordinator that manages potential living donors is dedicated to the living donor program and 26% (n=39) reported that the coordinator manages potential living donors and transplant candidates or other patient populations. The median number of coordinators who managed living donors at each center was 1 (IQR 1-2) with 66% (n=98) of center respondents reporting that only one coordinator managed living donors at the center. Twenty-two percent of centers reported more than one coordinator and 12% reported more than 2 coordinators managed living donors. The number of coordinator FTEs that performed the LDC role (Median 1, IQR 1-2) was similar to the number of actual individuals who performed the role with 15% (n=21) reporting less than 1 FTE, 54% (n=80) 1 FTE, 21% (n=30) more than 1 FTE, and 11% (n=16) more than 2 FTEs devoted to the living donor role (Table 7).

To assess how much time is devoted to the living donor coordinator role, survey respondents were asked to report the number of hours worked as a coordinator each week and the number of hours that were devoted specifically to the living donor coordinator role (Table 7). Of the 198 coordinators described in the sample, the median number of hours worked as a coordinator each week was 40 hours (IQR 40-45), and the median number of hours devoted to the living donor program was 40 hours (IQR 28-40). Eighty-seven percent of respondents reported working 40 or more hours per week and only 13% reported less than 40 hours per week as a coordinator. However, 19% of respondents reported devoting 20 or less hours per week to the living donor program, 18% reported 21-39 hours per week to the living donor program, and 63% reported devoting 40 or more hours per week to the living donor program (Table 7).

Table 7. Living Donor Coordinator Labor Quantity

LDC Labor Quantity	n (%)	Median (IQR)	LDC Labor Quantity	n (%)	Median (IQR)
Number of Coordinators (n=148) • 1 • >1 – 2 • More than 2	 98 (66%) 33 (22%) 17 (12%)	1 (1-2)	Number of FTEs (n=147) • Less than 1 • 1 • >1 – 2 • More than 2	 21 (15%) 80 (54%) 30 (21%) 16 (11%)	1(1-2)
Hours Worked as Coordinator Per Week (n=189) • 0-20 • 21-39 • 40 or more	 8 (4%) 17 (9%) 164 (87%)	40 (40-45)	Hours Devoted to LD Program Per Week (n=186) • 0-20 • 21-39 • 40 or more	 35 (19%) 34 (18%) 117 (63%)	40 (28-40)
Patient Management Structure (n=148) • Dedicated LDC • Manage LDs and other populations	 109 (74%) 39 (26%)				

Roles of Living Donor Coordinators

Living donor coordinator job titles. Approximately 53% (n=101) reported holding one role, 39% (n=75) reported holding two roles, and 8% (n=16) reported holding three or more roles. The roles and job titles held by the coordinators are summarized in Table 8. All of the respondents (n=192) reported performing the role of living kidney donor coordinator and 24% (n=47) also acted in the role of the pre-transplant candidate coordinator. Seven percent (n=14) of respondents performed the dual role of living donor advocate.

Table 8. Roles/job titles held by survey respondents

Types of Roles/Job Titles (n=192)	n (%)
Living kidney donor coordinator	192 (100%)
Pre-Transplant candidate/recipient coordinator	47 (24%)
Living liver donor coordinator	23 (12%)
Living donor advocate	14 (7%)
Other nurse/coordinator Role	13 (7%)
Administrator/manager	8 (4%)
Other	6 (3%)

Living donor coordinator role components/tasks. The role functions of the coordinators by phase (pre donation, inpatient, post donation, and other) and the frequency each were performed are summarized in Table 9. Frequently performed daily components occurred mostly in the pre-donation phase and included educating potential living donors (daily: n=94, 64%), initial donor screening/intake (daily: n=107, 73%), scheduling test/procedures (daily: n=85, 58%), reviewing tests/labs (daily: n=119, 81%), and communicating with patients/taking patient calls (daily: n=138, 93%). Another frequently performed function was triaging patient calls in the post donation phase (daily: n=86, 56%). Respondents indicated that there were certain functions that were almost never/never performed by them. These included education about financial assistance programs (almost never/never: n=59, 40%), submitting financial assistance applications (almost never/never: n=112, 76%), and performing living donor outreach activities (almost never/never: n=110, 74%).

Table 9. LDC Role Components/Functions (n=148)

Role Components	**Daily (%)**	**Weekly (%)**	**Monthly (%)**	**Almost Never/ Never (%)**	**Role Components**	**Daily (%)**	**Weekly (%)**	**Monthly (%)**	**Almost Never/ Never (%)**
Pre Donation Role Component					**Donation/Inpatient Functions**				
Take Patient Calls	93%	4%	2%	1%	Discharge Teaching	7%	50%	29%	14%
Review Tests/Labs	80%	13%	5%	1%	**Outpatient/Post Donation Functions**				
Initial Screening/Intake	73%	16%	7%	4%	Triage Patient Calls	58%	18%	17%	7%
Educate Potential LD	64%	28%	5%	3%	Clinic Nursing-Outpatient	19%	35%	19%	27%
Test/Procedure Scheduling	58%	25%	9%	8%	Donor Follow Up Tasks	19%	43%	25%	13%
Education Transplant Candidates about LD	28%	41%	14%	18%	**Other Functions**				
Coordinate Paired Exchange Program	26%	21%	20%	33%	Database Entry	44%	24%	17%	15%
Prepare Selection Committee Materials	22%	59%	17%	2%	Regulatory Requirements/Compliance	31%	35%	25%	10%
Clinic Nursing-Outpatient	16%	48%	16%	20%	Completion of UNOS Forms	8%	47%	26%	29%
Education about financial assistance	13%	30%	17%	40%	On Call Activities	8%	30%	31%	30%

programs									
Develop Educational Materials	2%	11%	60%	27%	Develop LD Policy/Procedures	2%	10%	59%	29%
LD Outreach activities	1%	4%	21%	74%	Research Activities	1%	5%	15%	79%
Submit Financial Assistance Applications	1%	5%	17%	76%	Other	4%	4%	2%	0%

Kidney paired donation coordination. One of the roles of living donor coordinator is to facilitate kidney-paired donation. As described in Table 9 the function of coordinating the paired exchange program was performed “almost never/never" by 33% (n=48) of coordinators and “monthly” by 20% (n=30) of coordinators. Of the 148 centers surveyed, 22% (n=33) of respondents indicated that coordinator time was dedicated solely to the kidney paired donation (KPD) program. Respondents were asked to indicate the FTEs or hours/week devoted to the KPD program. Twelve of the 33 indicated 0.75 FTE was median (IQR 0.5-1.0) and 16 of the 33 indicated that 5 hours/week was the median (IQR 1-14) devoted to the KPD program.

Findings Related to Research Aim Two: Describe the current labor inputs, organizational facets, capital inputs, and employment terms within living kidney donor programs in the U.S.

Living Donor Program Non-coordinator Labor Inputs

Table 10 provides a description of healthcare provider assignments in living donor programs. Respondents reported a multidisciplinary approach to the management of living donor patient care in which most providers were assigned exclusively to the care of LD patients or were assigned regularly to LD patients but also worked with other patient populations as well. The two providers most commonly not available to the living donor program were an outreach coordinator (55%) and a nurse practitioner (55%).

Table 10. Reported health care provider assignments in LD Programs (n=148)

Health Care Provider	1	2	3	4
Living Donor Coordinator	67%	32%	1%	0%
LD Advocate	58%	32%	10%	0%
Social Worker	21%	75%	4%	0%
Administrative/Clerical	20%	52%	20%	8%
LD Surgeon	6%	82%	11%	1%
Nephrologist	3%	85%	12%	0%
Nurse Practitioner	3%	26%	14%	55%
Dietician	2%	75%	20%	1%
Clinical Psychiatry	2%	45%	43%	10%
Data administrator/Manager	2%	60%	26%	12%
Financial Counselor	2%	66%	24%	8%
Transplant Administrator/Supervisor	1%	71%	25%	2%
Outreach coordinator	1%	20%	22%	55%
Pharmacist	0%	65%	34%	1%

1=Works with LD Program only; does not work with other populations
2=Same provider regularly assigned but also works with other kinds of patients
3=Not regularly assigned to the LD program, but is available as needed
4=Provider not currently available to LD program

Administrative/Clerical Labor Inputs. Survey respondents were asked to provide the number of administrative or clerical FTEs that supported the living donor program (Table 11). Of the 146 centers that responded, 16% (n=24) had no clerical FTEs and 26% (n=38) had less than one clerical FTE that supported the living donor program (Table 11). Twenty-five percent (n=36) of centers reported one clerical FTE and 33% (n=48) reported greater than one FTE that supported the living donor program. However, 77% (n=105) of all respondents (n=137) reported that FTEs are not dedicated solely to the living donor program.

Table 11. Administrative or clerical labor inputs that supported the LD Program

Administrative/Clerical Labor Inputs	**Total (n,%)**	Median (IQR)
Number of FTEs (n=146)		1 (0.25-2)
• 0	24 (16%)	-----
• >0-Less than 1	38 (26%)	-----
• 1	36 (25%)	-----
• >1-2	32 (22%)	-----
• Greater than 2	16(11%)	-----
Clerical FTEs dedicated to LD Program (n=137)		
• No	105 (77%)	-----
• Yes	32 (23%)	-----

Living Donor Program Organization and Structure

Survey participants were asked to respond to questions related to the organization and structure of the living kidney donor program (Table 12). Of the 148 center respondents, 36% (n=53) reported one physician and 45% (n=66) reported that more than one physician (medical & surgical physician) was considered the director/leader of the living donor program. Fifteen percent (n=22) reported that there was not a director/leader of the living donor program (Table 12). Center respondents were also asked to indicate the number and types of individuals to whom they report (Table 12). Twenty-nine percent of respondents (n=43) indicated reporting to one individual. More than 45% (n=68) of LD center respondents reported to three or more leaders. The list of individuals to whom the coordinator reports is described in Table 12. The transplant administrator (64%) is the most frequently cited individual to whom the LDC reports.

In order to determine if there was an organizational framework that guided the living donor program, respondents were asked to report if the program had a guiding mission statement, philosophy, or strategic plan. As shown in Table 12, $\geq$ 70% of living donor programs respondents had a mission statement, philosophy, and strategic plan either as a part of the transplant center or specific to the living donor program.

Table 12. Organization and structure of the living donor program n=148

Organization and Structure of LD Program	**n (%)**
Director/Leader of the LD Program	
More than One Physician (Medical & Surgical Director)	66 (45%)
One Physician	53 (36%)
Other non-physician	7 (5%)
None	22 (15%)
Number of Individuals to whom LDC Reports	
• 1	43 (29%)
• 2	37 (25%)
• 3 or more	68 (45%)
Type of Individual to whom LDC Reports	
• Transplant Administrator	94 (64%)

• Nursing Executive (Manager)	83 (56%)
• Physician Surgical Director	78 (53%)
• Physician Medical Director	77 (52%)
• Other	17 (12%)
• Chief Nursing Officer	8 (5%)
Written Organizational Components (n=144)	
• Mission Statement (yes)	103 (71%)
• Philosophy (yes)	102 (71%)
• Strategic Plan (yes)	101 (70%)

Living Donor Program Resources

In order to further describe organizational facets and capital inputs, respondents were asked about the availability of certain resources within the living donor program (Table 13). In regards to capital inputs, 78% of center respondents indicated that the program had a transplant specific database and 63% had kidney paired donation software or access to a registry. Center respondents were also asked to indicate if certain resources were offered to donors that may help to facilitate or support donors by removing barriers that may potentially discourage donation. Respondents indicated that 83% of centers paid for the cost of post donation labs and 75% centers paid for the cost of post donation office visits if insurance did not cover these costs (Table 13). Most centers (94%) offered the potential donor a medical opt out if the living donor decided not to donate (Table 13). Finally, 64% of center respondents reported that the transplant center covered the cost of post living donor complications if the recipients had only commercial insurance, which did not cover the cost of post donation complications (Table 14).

Table 13. LD Program Resources

Resources	n (%)
Medical Opt out if LDs decide not to donate n=146	137 (94%)
Transplant Specific Database n=143	112 (78%)
Center payment of post donation labs if insurance does not cover n=147	122 (83%)
Center payment of post donation visits if insurance does not cover n=147	115 (78%)

KPD Software or Registry n=147	92 (63%)
LD initial screening software/website n=147	50 (34%)

Table 14. How the cost of LD post donation complications are managed if the recipients had only commercial insurance n=148

Option	**n (%)**
Transplant Center covers the cost	95 (64%)
Commercial recipients must enroll in Medicare as a secondary payor	28 (19%)
Recipients and/or donors must sign a self pay waiver	4 (3%)
Donors must obtain an insurance policy (e.g. ACE American Ins) to cover potential complications	3 (2%)
Other	19 (13%)

Living Donor Program Protocols and Processes

Protocols and processes. Approximately one-fifth (22%; n=32) of respondents reported that the center required potential living donors to have personal health insurance and 28% (n=40) required potential donors to have a primary care physician (PCP) (Table 15). Seventy-five percent of respondents reported that the program offered or required preliminary testing prior to in-center evaluation. The median time to respond to an initial LD inquiry/contact was 1 day (IQR 1-2) with 19% (n=28) of programs responding in > 2 days (Table 15). The median number of days that the donor was required to be at the center for donor evaluation was 2 days (IQR 1.5-3) with 24% (n=33) completing in center evaluation in 1 day and 40% (n=56) of programs required the donor to be at the center for $\geq$ 3 days. Finally, the median number of days to complete an entire living donor evaluation (from initial contact to decision regarding candidacy) was reported to be 45 days (IQR 30-83) with 42% (n=59) of programs completing an entire donor evaluation in $\leq$ 30 days and 27% (n=38) requiring > 60 days to complete an entire donor evaluation.

Table 15. LD Program Protocols and Processes

Protocols/Requirements	n (%)	Median (IQR) days
Preliminary testing prior to in-center evaluation (BP readings, 24 hr urine) n=146	109 (75%)	
Potential LD to have a PCP n=145	40 (28%)	
Potential LD to have personal health insurance n=145	32 (22%)	
Processes		
Respond to initial LD inquiry/contact n=148		1 (1-2)
• 1 day or less	76 (51%)	
• >1 - 2 days	44 (30%)	
• > 2 days	28 (19%)	
Perform LD evaluation at the center (# days at center for eval) n=140		2 (1.5-3)
• 1 day	33 (24%)	
• 2 days	51 (36%)	
• 3 or more days	56 (40%)	
Complete an entire LD evaluation n=141		45 (30-83)
• ≤ 30 days	59 (42%)	
• 31-60 days	44 (31%)	
• > 60 days	38 (27%)	

Medical Criteria Protocols. To ascertain the center medical criteria for potential living donors, respondents were asked to indicate if the center had restrictions for controlled hypertension, body mass index (BMI), and age (Table 16). Eighty-one percent (n=119) of centers accepted donors with controlled hypertension. All center respondents reported a BMI restriction with the mean BMI restriction 34 ± 2.4 (min 30-max 40). Eighteen percent (n=27) of centers had a BMI restriction of ≤ 30 and 61% (n=90) reported a BMI restriction of ≥ 35. Less than half (43%; n=63) of center respondents reported an upper age limit with 46% (n=29) of these centers reporting an upper age limit of ≥ 70 years.

Table 16. LD Program Medical Criteria

Medical Criteria	Yes n (%)
Accept donors with controlled hypertension n=147	119 (81%)
BMI Restriction n=147	147 (100%)
• BMI ≤ 30	27 (18%)
• BMI 31-34	30 (20%)
• BMI ≥ 35	90 (61%)
Upper Age Limit n=147	63 (43%)
• 50-64	11 (17%)
• 65-69	23 (37%)
• ≥ 70	29 (46%)

Educational Components

Respondents were asked to report educational components and resources available within living donor programs. The median estimated education time per donor was 90 minutes (IQR 60-120) with 40% (n=56) of centers reporting ≤ 60 minutes per donor and 41% (n=58) of centers reporting ≥ 91 minutes per donor (Table 17). The median estimated education time per transplant candidate about living donation was 20 minutes (IQR 10-30) with 27% (n=38) of centers reporting ≤ 10 minutes per transplant candidate and 20% (n=28) reporting >30 minutes per transplant candidate. Respondents were also asked in what format education about living donation most often occurred (one on one in person, group session, or via phone). Respondents could select more than one method with 68% selecting more than one format to educate potential living donors and 53% selecting more than one format to educate transplant candidates. Coordinators responded that education of potential living donors occurred as follows: 92% one on one in person, 23% in a class/group, and 66% via phone. Education of transplant candidate about living donation occurred as follows: 66% one on one in person, 69% in a class/group, and 32% via phone.

Center respondents were asked to indicate the types of programs and resources that were offered by the living donor program (Table 17). Kidney paired donation was the most common program offered to living donors and transplant candidates with 75 % (n=114) of centers reporting this program. Fifty-eight percent (n=83) offered financial counseling programs and 56% (n=81) trained transplant candidates and their social network on how to identify and approach potential living donors. Living donor education at the dialysis units (34%) and to referring nephrologist (29%) were the least offered programs.

Table 17. Educational components within living donor programs

Educational Components	n (%)	Median (IQR)
Education time/Donor (mins) n=141		90 (60-120)
20-60	56 (40%)	
61-90	27 (19%)	
≥91	58 (41%)	
Education time/Tx Candidate (mins) n=141		20 (10-30)
0-10	38 (27%)	
11-20	47 (33%)	
21-30	28 (20%)	
>30	28 (20%)	
Educational Resources/Programs		
Kidney paired donation (n=146)	114 (78%)	
Financial Counseling (e.g. programs to remove financial hardship of donation) (n=144)	83 (58%)	
Train transplant candidates and/or others how to identify and approach potential LDs (n=145)	81 (56%)	
Pre donation peer support group or mentors for potential LD (n=143)	61 (43%)	
LD education at dialysis units (n=146)	49 (34%)	
LD education for referring nephrologists (n=145)	42 (29%)	

Survey respondents were also asked to indicate what materials/tools were used in the education of potential living donors and transplant candidates about living donation. These educational materials are described in Table 18. Written materials/brochures were the most commonly available educational tools for living donors (100%) and transplant candidates (99%). An online website and multilingual materials were also frequently used educational tools. Center respondents were also asked to indicate what types of living donor financial assistance programs were included as part of living donor education (Table 19). Eighty-nine percent (n=132) reported educating potential living donors about the National Living Donor Assistance Center (NLDAC) indicating widespread dissemination since its inception in 2007. Other less commonly included types of financial assistance programs included in education were fundraising (37%) and state tax deduction/credit (26%).

Table 18. Center reported educational materials/tools for used for potential living donors and transplant candidates

Educational Materials/Tools	**Potential Living Donors**	**Transplant Candidates**
	n (%)	**n (%)**
Written materials/brochures	147 (100%)	141 (99%)
Online Website	115 (80%)	101 (73%)
Multilingual Materials	112 (78%)	107 (78%)
DVD/Videotape	57 (40%)	55 (40%)
Social Networking (e.g. Facebook)	29 (21%)	31 (23%)
Podcasts/Web conferencing/YouTube Video	14 (10%)	13 (10%)
Other	11 (12%)	13 (16%)

Table 19. Financial assistance programs included in LD education n=148

Program	n(%)
NLDAC	132 (89%)
Fundraising	55 (37%)
State Tax Deduction/Credit	39 (26%)
American Transplant Foundation	39 (26%)
American Living Organ Donor Fund	29 (20%)
Other	22 (15%)
None	8 (5%)

Living Donor Conversion Rates/Donor Yield

Survey respondents were asked to provide the average annual number of potential living donor inquires/initial contacts and evaluations at the transplant center. The median number of potential LD inquires was 200 (IQR 87-385) with a minimum reported of 4 and maximum of 1820 (Table 20). The median number of living donor evaluations at the transplant center was 50 (IQR 28-120) with a minimum reported of 1 and a maximum of 400 (Table 20). Also shown is the median number of living donor transplants by survey respondents 16 (IQR 6-29) with a minimum of 1 and a maximum of 155. The conversion rate/donor yield from initial contact to living donor transplant is 8% and the conversion rate from evaluation to living donor transplant is 32%. Table 21 describes the percentage of centers by volume of living donor inquiries, evaluations, and living donor transplants.

Table 20. Program volumes of living donor inquires, evaluations and transplants

Program Volumes	Median (IRQ)	Min-Max
LD inquiries/initial Contacts n=130	200 (87-385)	4-1820
LD evaluations at the tx center n=131	50 (28-120)	1-400
LD Transplants n=147	16 (6-29)	0-155

Table 21. LD inquiries/initial contact, evaluations, and LD transplant volumes by centers

Volume Inquires (n=130)	Centers n (%)	Volume Evaluations (n=131)	Centers n (%)	Volume LD Transplants (n=147)	Centers n (%)
0-50	20 (15%)	0-25	30 (23%)	0-15	73 (50%)
51-100	26 (20%)	26-50	37 (28%)	16-30	39 (27%)
101-200	23 (18%)	51-100	29 (22%)	31-50	16 (11%)
201-500	37 (28%)	101-150	17 (13%)	51-75	8 (5%)
500-750	10 (8%)	151-200	10 (8%)	76-100	3 (2%)
>750	14 (11%)	>200	8 (6%)	>101	8 (5%)

Barriers/Actions

The qualitative reports of the most common barriers to increasing the number of live donor transplants in the programs, as well as the actions that could be taken to increase those numbers are summarized in Table 22. A total of 438 barriers were reported from the 148 respondents. The quality of the donor pool/health status of potential donors was identified as the most common barrier (26%). Lack of education and outreach regarding living donation (17%) and lack of staffing (14%) were also frequently reported barriers. The most commonly cited actions that could be taken to increase LD transplant numbers were outreach and education about living donation (26%), recipient education about living donation (19%), and dedicated staff/additional living donor staff (17%) (Table 22).

Table 22. Most common barriers (themes) and actions to increasing the number of LD transplant at this program

Barrier (n=438)	**N (%)**
Health status/Quality of donor pool	115 (26%)
Lack of education/outreach	73 (17%)
Lack of Staffing	61 (14%)

Programmatic processes/lack of non staffing resources	52 (12%)
Donor financial barriers	32 (7%)
Donor Fear/Concerns	28 (6%)
Recipient willingness to pursue LD	24 (6%)
Other	22 (5%)
Culture/lack of support of LD program	18 (4%)
Recipient/donor cultural barriers	13 (3%)
Action (n=149)	**N (%)**
Outreach and Education about LD	39 (26%)
Recipient Education about LD	28 (19%)
Dedicated Staff/Additional Staff	26 (17%)
Programmatic Protocol/Process Changes	15 (10%)
KPD/KPD Expansion	11 (7%)
Other	9 (6%)
Non staffing resources	8 (5%)
LD Champion/Advocate Program	7 (5%)
Financial incentives/removing disincentives	6 (4%)

Findings Related to Research Aim Three: Describe the extent to which administratively mediated variables (capital inputs, organizational facets, labor inputs, and employment terms) in living donor programs are associated with number of live kidney donor inquiries, evaluations, and transplants among transplant centers.

Using the theoretical model, variables hypothesized to be potentially significant to outcomes were divided into categories and subcategories of labor inputs, organizational facets, and capital inputs to determine associations with the outcome variables of numbers of live donor inquires, evaluations, and transplants.

Outcome: Number of Live Kidney Donor Inquires

Labor Inputs. Descriptive statistics for number of live kidney donor inquires and labor input variables included in the conceptual model are summarized in Tables 7, 10, 11, 20, and 21. As shown in Table 23, in the univariate analysis, with the exception of whether or not a center

had an outreach coordinator, each of the other variables were statistically significantly associated with number of live kidney donor inquires. In general, more LDC and administrative/clerical FTEs, having an LDC that managed only the living donor population, and having clerical/administrative support dedicated to the LD program were each associated with higher reported numbers of LD inquires to the center (p=0.003). After controlling for the effects of the other variables, the number of LDC FTEs and having a structure in which the coordinator manages only living donors remained statistically significant ($p \leq 0.001$) (see Table 23).

Table 23. Summaries of univariate and multivariate associations of labor inputs with live kidney donor initial inquires/contacts n=115

	Unadjusted			**Adjusted***		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
LDC FTEs (< 1)			0.70 (<0.001)			0.49 (<0.001)
1	0.27	0.008		0.10	0.341	
>1 - 2	0.70	<0.001		0.53	<0.001	
> 2	0.65	<0.001		0.43	<0.001	
Management (Dedicated LDC)			0.44 (<0.001)			0.07 (<0.001)
Managed/LDC Not Dedicated	-0.44	<0.001		-0.27	<0.001	
Admin/Clerical FTEs (0)			0.36 (0.002)			0.02 (0.207)
<1	0.03	0.830		0.02	0.818	
1	0.18	0.179		0.08	0.419	
> 1	0.41	0.003		0.15	0.153	
Admin/Clerical (Not Dedicated LD Program)			0.41 (<0.001)			0.01 (0.198)
Clerical Dedicated LD Program	0.41	<0.001		0.10	0.209	
Outreach coordinator (Not available)			0.15 (0.108)			0.01 (0.278)
Outreach coord. available	0.15	0.108		0.07	0.278	

- **Multiple R=0.77 (p=<0.001), Multiple R^2=0.59, Adjusted R^2=0.56**

Process Inputs. Descriptive statistics for number of live kidney donor inquires and process input variables included in the conceptual model are summarized in Tables 15, 20 and 21. Statistically significant univariate associations were observed for time it takes to complete an entire live donor evaluation with the centers that have an evaluation time > 60 days having a

higher number of reported living donor inquires per year (p=0.010, see Table 24). There was also an association observed for number of days at the center for evaluation with a decrease in number of living donor inquires as the number of required days at the center for evaluation increased (p<0.050). After controlling for the other process variables, elements of both variables remained statistically significantly associated with number of inquires. Relative to centers reporting a total evaluation time of < 30 days, centers reporting an evaluation time of > 60 days reported higher inquiry volumes (p=0.040). Centers reporting that donors generally needed to stay at least three days at the center for an evaluation, also tended to report less inquires than those centers reporting a one day evaluation (p=0.024, see Table 24).

Table 24. Summaries of univariate and multivariate associations of organizational facets-process inputs with live kidney donor initial inquires/contacts n=121

	Unadjusted			**Adjusted***		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
Time to complete entire LD eval (≤30 days)			0.25 (0.026)			0.06 (0.026)
31-60 days	0.19	0.063		0.18	0.077	
>60 days	0.26	0.010		0.21	0.040	
Days at center for eval (1 day)			0.25 (0.020)			0.04 (0.063)
2 days	-0.24	0.043		-0.19	0.116	
3 or more	-0.33	0.005		-0.28	0.024	
Days to respond to initial inquiry (≤1)			0.10 (0.585)			0.01 (0.702)
>1-2 days	0.08	0.404		0.07	0.437	
>2 days	0.08	0.410		-0.01	0.939	

*** Multiple R=0.33 (p-value=0.037), Multiple R^2=0.11, Adjusted R^2=0.06**

Organization/Structure. Descriptive statistics for number of live kidney donor inquires and organization/structure variables included in the conceptual model are summarized in Tables 6, 12, 20, and 21. As shown in Table 25, similar results were found for both the unadjusted and adjusted analyses. Centers with COTH teaching status and centers with a coordinator reporting to only one individual reported higher numbers of inquiries than did those centers without COTH

status and those centers with coordinators reporting to two individuals respectively ($p \leq 0.006$, see Table 25).

Table 25. Summaries of univariate and multivariate associations of organization facets-organization/structure of living donor program with live kidney donor initial inquires/contacts n=125

	Unadjusted			Adjusted*		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
Director of LD program (no)			0.08 (0.660)			0.01 (0.660)
Yes-MD	-0.02	0.816		0.03	0.778	
Yes-not a MD	0.07	0.482		0.03	0.787	
Hospital Ownership (government)			0.20 (0.077)			0.04 (0.092)
Not for Profit (non gov)	<0.01	0.996		0.13	0.176	
For Profit	-0.20	0.050		-0.09	0.400	
Strategic Plan (No)			0.12 (0.428)			0.02 (0.339)
Yes-specific to LD program	-0.06	0.572		-0.12	0.199	
Yes-as part of tx center	0.08	0.449		0.09	0.385	
COTH teaching status (Teaching)			0.34 (<0.001)			0.10 (<0.001)
Non-teaching	-0.34	<0.001		-0.33	<0.001	
Number of Individuals to whom LDC Reports (1)			0.26 (0.015)			0.07 (0.007)
2	-0.25	0.019		-0.28	0.006	
3 or more	0.02	0.852		-0.02	0.855	

*** Multiple R=0.48 (p-value=<0.001), Multiple R^2=0.23, Adjusted R^2=0.17**

Protocols. Descriptive statistics for number of live kidney donor inquires and program protocol variables included in the conceptual model are summarized in Tables 14, 15, 16, 20, and 21. As with the structure variables, consistent findings were observed for both the unadjusted and adjusted analyses. Centers accepting donors with controlled hypertension and centers covering the cost of post donation complications reported statistically significantly more living donor inquires than did the centers not accepting the controlled hypertension donors and centers not covering complications respectively ($p \leq 0.012$, see Table 26).

Table 26. Summaries of univariate and multivariate associations of organization facets-protocols of living donor program with live kidney donor initial inquires/contacts n=124

	Unadjusted			Adjusted*		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
BMI Criteria (≥ 35)			0.18 (0.129)			0.03 (0.129)
≤ 30	-0.02	0.799		0.01	0.924	
31-34	-0.18	0.045		-0.15	0.100	
Accept LDs with controlled HTN (no)			0.31 (<0.001)			0.08 (0.001)
Yes	0.31	<0.001		0.29	0.001	
Age Criteria (none)			0.11 (0.669)			0.01 (0.598)
50-64	-0.10	0.275		0.01	0.897	
65-69	-0.02	0.804		0.01	0.959	
≥70	0.03	0.713		0.16	0.086	
Potential LD to have health insurance (yes)			0.14 (0.110)			0.01 (0.366)
No	0.14	0.110		-0.03	0.748	
Potential LD to have PCP (yes)			0.14 (0.104)			0.01 (0.191)
No	0.14	0.104		0.13	0.179	
Center cover cost of post donation complications (no)			0.22 (0.014)			0.04 (0.012)
Yes	0.22	0.014		0.23	0.012	

- **Multiple R=0.43 (p-value=0.003), Multiple R^2=0.19, Adjusted R^2=0.13**

Educational programs/resources. Descriptive statistics for number of live kidney donor inquires and educational program/resource variables included in the conceptual model are summarized in Tables 17, 20, and 21. In the univariate analysis, programs participating in kidney paired donation and centers having a pre-donation living donor peer support/mentor program reported higher numbers of donor inquires than did centers not doing paired kidney donations and centers without a pre-donation peer support program respectively ($p \leq 0.011$, see Table 27). After controlling for all of the educational program/resource variables however, only the effect of participation in paired kidney donation remained statistically significant (~3% shared variance with number of inquires, $p<0.001$)(Table 27).

Table 27. Summaries of univariate and multivariate associations of educational programs/resources in living donor program with live kidney donor initial inquires/contacts n=116

Characteristic	Unadjusted			Adjusted*		
	beta	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
Tx Candidate Education Time (0-10 mins)			0.16 (0.408)			0.03 (0.408)
11-20 mins	-0.14	0.219		-0.17	0.099	
21-30 mins	-0.12	0.275		-0.08	0.452	
> 30 mins	0.02	0.863		-0.09	0.378	
Train Tx candidates how to identify/approach LDs (yes)			0.15 (0.110)			0.02 (0.121)
No	-0.15	0.110		-0.05	0.603	
Kidney Paired Donation (yes)			0.43 (<0.001)			0.16 (<0.001)
No	-0.43	<0.001		-0.40	<0.001	
LD Pre donation peer support/mentors (yes)			0.24 (0.011)			0.01 (0.204)
No	-0.24	0.011		-0.12	0.201	
LD education at dialysis units (yes)			0.03 (0.793)			≤0.01 (0.518)
No	-0.03	0.793		0.07	0.490	
LD education for referring nephrologists (yes)			0.15 (0.116)			≤0.01 (0.587)
No	-0.15	0.116		-0.11	0.341	
Financial counseling (yes)			0.07 (0.441)			0.02 (0.089)
No	0.07	0.441		0.14	0.120	
Donor Education Time (20-60 mins)			0.16 (0.226)			0.02 (0.233)
61-90 mins	-0.01	0.921		0.05	0.628	
≥ 91mins	0.16	0.129		0.17	0.091	

*** Multiple R=0.52 (p-value=<0.001), Multiple R^2=0.27, Adjusted R^2=0.19**

Outcome: Number of Live Kidney Donor Evaluations

Labor Inputs. Descriptive statistics for number of live kidney donor evaluations and labor input variables included in the conceptual model are summarized in Tables 7, 10, 11, 20, and 21. As shown in Table 28, in the univariate analyses, the presence of or more of each labor input variable was statistically significantly associated with a higher number of live kidney donor evaluations than not having the resource (e.g., dedicated LDC) or fewer resources (e.g., fewer LDC FTEs) (p<0.050). After controlling for the effects of the other variables, with the exception of having an outreach coordinator, those associations remained (p<0.050). Centers with dedicated LD coordinators and dedicated LD clerical/administrative staff reported higher

numbers of LD evaluations than did centers without ($p \leq 0.003$). In terms of FTEs, centers with more than one LDC FTE reported higher numbers of evaluations than did those centers with less than one FTE ($p \leq 0.004$). Centers with more than one administrative/clerical FTE, reported higher numbers of evaluations than did those with no such clerical/administrative FTEs (p=0.025, see Table 28).

Table 28. Summaries of univariate and multivariate associations of labor inputs with live kidney donor evaluations n=116

	Unadjusted			**Adjusted***		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
LDC FTEs (< 1)			0.62 (<0.001)			0.39 (<0.001)
1	0.31	0.005		0.09	0.397	
>1 - 2	0.65	<0.001		0.37	<0.001	
> 2	0.61	<0.001		0.28	0.004	
Management (Dedicated LDC)			0.48 (<0.001)			0.09 (<0.001)
Managed/LDC Not Dedicated	-0.48	<0.001		-0.30	<0.001	
Admin/Clerical FTEs (0)			0.39 (<0.001)			0.04 (0.025)
<1	0.07	0.602		0.09	0.346	
1	0.26	0.044		0.13	0.204	
> 1	0.47	<0.001		0.24	0.025	
Admin/Clerical (Not Dedicated LD Program)			0.51 (<0.001			0.04 (0.003)
Clerical Dedicated LD Program	0.51	<0.001		0.24	0.003	
Outreach coordinator (Not available)			0.18 (0.047)			0.014 (0.066)
Outreach coord. available	0.18	0.047		0.12	0.066	

*** Multiple R=0.76 (p=<0.001), Multiple R^2=0.57, Adjusted R^2=0.54**

Process Inputs. Descriptive statistics for number of live kidney donor evaluations and process input variables are summarized in Tables 15, 20 and 21. Summaries of the associations of the process input variables with the reported number of evaluations by the centers are summarized in Table 29. None of the unadjusted or adjusted associations were statistically significant (p>0.050).

Table 29. Summaries of univariate and multivariate associations of organizational facets-process inputs with live kidney donor evaluations n=122

Characteristic	Unadjusted			Adjusted*		
	beta	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
Time to complete entire LD eval (≤30 days)			0.13 (0.365)			0.02 (0.365)
31-60 days	0.12	0.255		0.11	0.296	
>60 days	0.13	0.207		0.10	0.326	
Days at center for eval (1 day)			0.16 (0.217)			0.02 (0.303)
2 days	-0.18	0.133		-0.15	0.234	
3 or more	-0.19	0.102		-0.16	0.195	
Days to respond to initial inquiry (≤1)			0.09 (0.593)			0.01 (0.757)
>1-2 days	0.08	0.423		0.07	0.461	
>2 days	0.08	0.402		0.03	0.752	

*** Multiple R=0.20 (p-value=0.552), Multiple R^2=0.04, Adjusted R^2=-0.01**

Organization/Structure. Descriptive statistics for number of live kidney donor evaluations and organizational/structural variables are summarized in Tables 6, 12, 20, and 21. As shown in Table 30, programs with COTH teaching status reported a higher number of living donor evaluations than did the programs without that status (adjusted p<0.002, ~7% shared variance with number of evaluations). In the univariate analysis, for profit centers reported fewer evaluations than did government-affiliated centers (p=0.037); however, after controlling for the other organizational structure variables, that association was no longer statistically significant (p=0.315)(Table 30).

Table 30. Summaries of univariate and multivariate associations of organization facets-organization/structure of living donor program with live kidney donor evaluations n=124

Characteristic	Unadjusted			Adjusted*		
	beta	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
Director of LD program (no)			0.17 (0.176)			0.03 (0.176)
Yes-MD	-0.02	0.869		0.01	0.918	
Yes-not a MD	0.16	0.113		0.11	0.265	
Hospital Ownership (government)			0.22 (0.044)			0.05 (0.061)
Not for Profit (non gov)	0.02	0.863		0.13	0.203	
For Profit	-0.22	0.037		-0.10	0.315	
Strategic Plan (No)			0.15 (0.252)			0.03 (0.207)
Yes-specific to LD program	0.02	0.830		-0.03	0.734	

Yes-as part of tx center	0.16	0.121		0.15	0.129	
COTH teaching status (Teaching)			0.31 (0.001)			0.07 (0.002)
Non-teaching	-0.31	0.001		-0.29	0.002	
Number of Individuals to whom LDC Reports (1)			0.17 (0.155)			0.04 (0.081)
2	-0.20	0.059		-0.22	0.030	
3 or more	-0.07	0.489		-0.08	0.482	

*** Multiple R=0.45 (p-value=0.002), Multiple R^2=0.20, Adjusted R^2=0.14**

Protocols. Descriptive statistics for number of live kidney donor evaluations and program protocol variables are summarized in Tables 14, 15, 16, 20, and 21. Consistent findings were observed for both the unadjusted and adjusted analyses. Centers accepting donors with controlled hypertension and centers covering the cost of post donation complications reported statistically significantly more living donor evaluations than did the centers not accepting the controlled hypertension donors and centers not covering complications respectively ($p \leq 0.008$, see Table 31).

Table 31. Summaries of univariate and multivariate associations of organization facets-protocols of living donor program with live kidney donor evaluations n=130

	Unadjusted			**Adjusted***		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
BMI Criteria (≥ 35)			0.12 (0.394)			0.02 (0.394)
≤ 30	-0.01	0.917		0.03	0.750	
31-34	-0.12	0.181		-0.06	0.477	
Accept LDs with controlled HTN (no)			0.34 (<0.001)			0.10 (<0.001)
Yes	0.34	<0.001		0.31	<0.001	
Age Criteria (none)			0.22 (0.107)			0.03 (0.256)
50-64	-0.19	0.034		-0.09	0.327	
65-69	-0.14	0.113		-0.12	0.164	
≥70	-0.04	0.632		0.07	0.427	
Potential LD to have health insurance (yes)			0.15 (0.085)			≤0.01 (0.431)
No	0.15	0.085		-0.04	0.654	
Potential LD to have PCP (yes)			0.15 (0.082)			0.01 (0.240)
No	0.15	0.082		0.11	0.233	
Center cover cost of post donation complications (no)			0.24 (0.006)			0.05 (0.008)
Yes	0.24	0.006		0.24	0.008	

*** Multiple R=0.46 (p-value=0.001), Multiple R^2=0.21, Adjusted R^2=0.15**

Educational programs/resources. Descriptive statistics for number of live kidney donor evaluations and educational programs/resources available from the centers are summarized in Tables 17, 20, and 21. Summaries of the unadjusted and adjusted results of the associations of the educational resources with the number of evaluations at the centers are shown in Table 32. Consistently observed from both sets of analysis was that increasing transplant candidate educational time was associated with decreasing numbers of evaluations completed (adjusted 7% variance shared, p=0.034). Furthermore, programs participating in paired kidney donation performed a higher number of evaluations than those programs not participating (adjusted 19% variance shared, p<0.001). While centers having a pre-donation peer support/mentor program and centers providing LD education to referring providers demonstrated statistically significantly higher numbers of evaluations than did centers not providing those services in the univariate analysis ($p \leq 0.014$), after controlling for the other educational resource variables those effects were no longer statistically significant (p>0.05, see Table 32).

Table 32. Summaries of univariate and multivariate associations of educational programs/resources in living donor program with live kidney donor evaluations n=116

	Unadjusted			**Adjusted***		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
Tx Candidate Education Time (0-10 mins)			0.27 (0.034)			0.07 (0.034)
11-20 mins	-0.25	0.023		-0.33	0.001	
21-30 mins	-0.28	0.010		-0.31	0.002	
> 30 mins	-0.09	0.422		-0.25	0.014	
Train Tx candidates how to identify/approach LDs (yes)			0.12 (0.192)			0.02 (0.176)
No	-0.12	0.192		≤0.01	0.981	
Kidney Paired Donation (yes)			0.45 (<0.001)			0.19 (<0.001)
No	-0.45	<0.001		-0.37	<0.001	
LD Pre donation peer support/mentors (yes)			0.25 (0.007)			0.01 (0.242)
No	-0.25	0.007		-0.09	0.317	
LD education at dialysis units (yes)			0.09 (0.327)			0.003 (0.533)
No	-0.09	0.327		≤0.01	0.985	
LD education for referring nephrologists (yes)			0.23 (0.014)			0.02 (0.129)

No	-0.23	0.014		-0.21	0.046	
Financial counseling (yes)			0.05 (0.597)			0.03 (0.047)
No	0.05	0.597		0.16	0.070	
Donor Education Time (20-60 mins)			0.19 (0.139)			0.03 (0.093)
61-90 mins	-0.13	0.200		-0.10	0.268	
≥ 91mins	0.09	0.393		0.12	0.185	

*** Multiple R=0.60 (p-value<0.001), Multiple R^2=0.36, Adjusted R^2=0.29**

Outcome: Number of Live Kidney Donor Transplants

Labor Inputs. Descriptive statistics for number of live kidney donor transplants and labor input variables included in the conceptual model are summarized in Tables 7, 10, 11, 20, and 21. In the univariate analysis, each of the five variables was statistically significantly associated with number of live kidney donor transplants (Table 33). In general, higher labor inputs were associated with centers reporting higher numbers of transplants. After controlling for the contributions of all of the variables, number of LDC FTEs, a LDC managing only the living donor population, and a structure in which clerical/administrative support was dedicated to the LD program remained statistically significant ($p \leq 0.001$). The number of administrative/clerical FTEs available to the living donor program and having an outreach coordinator were no longer statistically significantly associated with total number of transplants ($p > 0.05$, see Table 33).

Table 33. Summaries of univariate and multivariate associations of labor inputs with live kidney donor transplants n=132

	Unadjusted			**Adjusted***		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
LDC FTEs (< 1)			0.70 (<0.001)			0.49 (<0.001)
1	0.29	0.003		0.13	0.162	
>1 - 2	0.64	<0.001		0.44	<0.001	
> 2	0.71	<0.001		0.48	<0.001	
Management (Dedicated LDC)			0.43 (<0.001)			0.06 (<0.001)
Managed/LDC Not Dedicated	-0.43	<0.001		-0.22	0.001	
Admin/Clerical FTEs (0)			0.36 (0.001)			0.02 (0.131)

<1	0.13	0.285		0.09	0.303	
1	0.29	0.018		0.10	0.256	
> 1	0.47	<0.001		0.14	0.143	
Admin/Clerical (Not Dedicated LD Program)			0.51 (<0.001)			0.04 (0.001)
Clerical Dedicated LD Program	0.51	<0.001		0.23	0.001	
Outreach coordinator (Not available)			0.17 (0.048)			0.01 (0.152)
Outreach coord. available	0.17	0.048		0.08	0.152	

*** Multiple R=0.78(p < 0.001), Multiple R^2=0.61, Adjusted R^2=0.58**

Process Inputs. Descriptive statistics for number of live kidney donor transplants and process input variables are summarized in Tables 15, 20 and 21. In the univariate analysis, increasing number of days donor was required to be at the transplant center for evaluation was statistically significantly associated with fewer LD transplants performed by the center (p<0.05, see Table 34). The multivariate analysis that included all of the process input variables however was not statistically significant (R=0.28, p=0.095).

Table 34. Summaries of univariate and multivariate associations of organizational facets-process inputs with live kidney donor transplants n=135

	Unadjusted			**Adjusted***		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
Time to complete entire LD eval (≤30 days)			0.16 (0.192)			0.03 (0.192)
31-60 days	0.17	0.070		0.15	0.119	
>60 days	0.08	0.404		0.03	0.748	
Days at center for eval (1 day)			0.22 (0.034)			0.04 (0.054)
2 days	-0.26	0.016		-0.23	0.041	
3 or more	-0.25	0.024		-0.23	0.048	
Days to respond to initial inquiry (≤1)			0.13 (0.312)			0.01 (0.430)
>1-2 days	0.12	0.194		0.11	0.207	
>2 days	0.10	0.250		0.06	0.504	

*** Multiple R=0.28(p-value=0.095), Multiple R^2=0.08, Adjusted R^2=0.04**

Organization/Structure. Descriptive statistics for number of live kidney donor transplants and organizational/structural variables are summarized in Tables 6, 12, 20, and 21. Similar effects of COTH teaching status were observed for both the unadjusted and adjusted analyses

(see Table 35). Centers with COTH teaching status completed more LD transplants than those centers without teaching status (adjusted ~13% shared variance, p<0.001). While not statistically significant univariately, after controlling for the other organizational structure variables non-profit centers completed a higher number of transplants than did government-affiliated centers (adjusted ~5% shared variance, p<0.016) (Table 35).

Table 35. Summaries of univariate and multivariate associations of organization facets-organization/structure of living donor program with live kidney donor transplants n=141

	Unadjusted			Adjusted*		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
Director of LD program (no)			0.18 (0.107)			0.03 (0.107)
Yes-MD	-0.07	0.478		-0.03	0.761	
Yes-not a MD	0.14	0.135		0.09	0.319	
Hospital Ownership (government)			0.19 (0.073)			0.03 (0.106)
Not for Profit (non gov)	0.13	0.189		0.23	0.016	
For Profit	-0.10	0.314		0.03	0.762	
Strategic Plan (No)			0.04 (0.876)			0.003 (0.790)
Yes-specific to LD program	0.03	0.773		-0.03	0.742	
Yes-as part of tx center	0.05	0.609		0.04	0.665	
COTH teaching status (Teaching)			0.34 (<0.001)			0.11 (<0.001)
Non-teaching	-0.34	<0.001		-0.36	<0.001	
Number of Individuals to whom LDC Reports (1)			0.18 (0.116)			0.04 (0.058)
2	-0.20	0.045		-0.23	0.019	
3 or more	-0.06	0.529		-0.10	0.337	

*** Multiple R=0.46 (p-value < 0.001), Multiple R^2=0.21, Adjusted R^2=0.16**

Protocols. Descriptive statistics for number of live kidney donor transplants and protocol variables are summarized in Tables 14, 15, 16, 20, and 21. As shown in Table 36, the univariate analysis revealed that compared to centers with BMI criteria of ≥35, those with a criteria of 31-34 were doing fewer LD transplants (p=0.008). Centers that accepted donors with controlled hypertension performed more LD transplants than centers not accepting those donors (p=0.001). Furthermore, those centers that do not required donors to have personal health insurance

performed higher numbers of live donor transplants than those who do have such a requirement (p=0.014). The analysis that included all of the protocol variables in the model revealed similar findings with the exception that after controlling for the other variables, whether or not centers required donors to have personal health insurance was no longer statistically significant (p=0.356, see Table 36).

Table 36. Summaries of univariate and multivariate associations of organization facets-protocols of living donor program with live kidney donor transplants n=145

	Unadjusted			Adjusted*		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
BMI Criteria (≥ 35)			0.22 (0.028)			0.05 (0.028)
≤ 30	-0.02	0.829		<0.01	0.981	
31-34	-0.23	0.008		-0.20	0.023	
Accept LDs with controlled HTN (no)			0.27 (0.001)			0.05 (0.005)
Yes	0.27	0.001		0.20	0.021	
Age Criteria (none)			0.14 (0.406)			0.02 (0.475)
50-64	-0.12	0.151		-0.05	0.596	
65-69	-0.07	0.429		-0.05	0.545	
≥70	0.03	0.750		0.10	0.277	
Potential LD to have health insurance (yes)			0.20 (0.014)			0.02 (0.093)
No	0.20	0.014		0.09	0.356	
Potential LD to have PCP (yes)			0.12 (0.169)			≤0.01 (0.680)
No	0.12	0.169		0.04	0.691	
Center cover cost of post donation complications (no)			0.13 (0.107)			0.02 (0.123)
Yes	0.13	0.107		0.13	0.123	

*** Multiple R=0.39 (p-value < 0.007), Multiple R^2=0.15, Adjusted R^2=0.10**

Educational programs/resources. Descriptive statistics for number of live kidney donor transplants and the center's educational program/resource variables are summarized in Tables17, 20, and 21. As shown in Table 37, both the univariate and multivariate analyses indicated that centers participating in kidney-paired donation were performing more transplants than those that were not participating (p<0.001). After controlling for all of the other educational/resource variables, increasing time spent on transplant candidate education was associated with fewer

completed transplants (p<0.05). While in the univariate analysis having a pre-donation living donor peer support/mentor program and providing LD education to referring providers were associated with increased numbers of transplants compared to centers not offering those services respectively (p<0.05), after controlling for the other educational resource variables those effects were no longer statistically significant (P>0.05) (Table 37).

Table 37. Summaries of univariate and multivariate associations of educational programs/resources in living donor program with live kidney donor transplants n=129

	Unadjusted			**Adjusted***		
Characteristic	***beta***	***p*-value**	***R (p-value)***	***beta***	***p*-value**	***. R^2-Change (p-value)***
Tx Candidate Education Time (0-10 mins)			0.20 (0.183)			0.04 (0.183)
11-20 mins	-0.18	0.086		-0.24	0.010	
21-30 mins	-0.20	0.054		-0.20	0.028	
> 30 mins	-0.07	0.526		-0.21	0.023	
Train Tx candidates how to identify/approach LDs (yes)			0.02 (0.803)			≤0.01 (0.788)
No	-0.02	0.803		0.11	0.159	
Kidney Paired Donation (yes)			0.51(<0.001)			0.25(<0.001)
No	-0.51	<0.001		-0.47	<0.001	
LD Pre donation peer support/mentors (yes)			0.20 (0.025)			0.01 (0.194)
No	-0.20	0.025		-0.10	0.217	
LD education at dialysis units (yes)			0.10 (0.247)			0.01 (0.332)
No	-0.10	0.247		-0.05	0.622	
LD education for referring nephrologists (yes)			0.18 (0.039)			≤0.01 (0.481)
No	-0.18	0.039		-0.11	0.280	
Financial counseling (yes)			0.03 (0.724)			0.01 (0.144)
No	0.03	0.724		0.11	0.179	
Donor Education Time (20-60 mins)			0.22 (0.042)			0.04 (0.025)
61-90 mins	-0.20	0.041		-0.14	0.104	
≥ 91mins	0.05	0.619		0.12	0.169	

*** Multiple R=0.60 (p-value <0.001), Multiple R^2=0.36, Adjusted R^2=0.30**

Outcomes: Summary Tables

A summary of findings from the analysis of variables associated with the number of living donor outcomes (inquires, evaluations, transplants) are displayed in Tables 38-42.

Summaries of the associations of labor input variables with those outcomes are shown in Table 38. More than one LDC FTEs was associated with higher numbers of each of the outcomes, as was having a dedicated living donor coordinator. Having clerical staff dedicated to the program was associated with higher numbers of evaluations and transplants. Higher numbers of clerical/administrative FTEs was also associated with higher numbers of evaluations (see Table 38).

Table 38. Summary of Labor Input Associations

	Inquiries	**Evaluations**	**Transplants**
	eta^2	*eta*^{2}	*eta*^{2}
LDC FTEs			
1	.01	.01	.02
>1-2	**.28***	**.14***	**.19***
> 2	**.18***	**.08***	**.23***
Dedicated LDC Mngnt			
No	**-.07***	**-.09***	**-.05***
Admin/Clerical FTEs			
<1	<.01	.01	.01
1	.01	.02	.01
>1	.02	**.06***	.02
Dedicated Clerical			
Yes	.01	**.06***	**.05***
Outreach Coordinator			
Available	<.01	.01	.01

eta^2 (effect size interpreted as % shared variance), ***statistically significant adjusted model**

Process input variables were statistically significantly associated with only living donor inquires (see Table 39). Of those variables, centers that reported >60 day evaluation timeframe were associated with higher number of living donor inquires. Centers that reported $\geq$ 3 day transplant center evaluation were found to have fewer living donor inquires (Table 39).

Table 39. Summary of Process Input Associations

	Inquiries	**Evaluations**	**Transplants**
	eta^2	*eta*^{2}	*eta*^{2}
Time Complete Eval (<30 days)			
31-60	.03	.01	.02

>60	**.04***	.01	<.01
Time at Center (1 day)			
2	-.04	-.02	-.05
>=3	**-.08***	-.03	-.05
Respond Initial Inquiry (<=1 day)			
1-2	<.01	<.01	.01
>2	<.01	<.01	<.01

eta^2 (effect size interpreted as % shared variance), ***statistically significant adjusted model**

Organizational/structural input variables were found to be associated with each of three living donor outcomes (LD inquires, evaluations, and transplants) (see Table 40). Variables appearing to contribute the most to those associations were COTH teaching status and reporting structure of the LDC. Compared to centers without COTH status, those with COTH status reported more inquires, evaluations, and transplants. Relative to those centers with a LDC reporting to one person, those with an LDC reporting to more than one individual also reported having fewer living donor outcomes. The only other specific organization/structural input found to be associated with any of the outcomes was ownership. Non-profit centers performed more living donor transplants than did government-owned centers.

Table 40. Summary of Organizational/Structural Inputs Associations

	Inquiries	**Evaluations**	**Transplants**
	eta^2	*eta*^{2}	*eta*^{2}
LD program director (none)			
Yes, MD	<.01	<.01	<.01
Yes, non-MD	<.01	.01	.01
Ownership (govt)			
Non-profit	.02	.02	**.05***
Profit	-.01	-.01	<.01
Strategic plan (none)			
Yes, LD specific	-.01	<.01	<.01
Yes, part of transplant ctr	.01	.02	<.01
COTH teaching status			
No	**-.11***	**-.08***	**-.13***
# to whom LDC reports (1)			
2	**-.08***	**-.05***	**-.05***
>=3	<.01	-.01	-.01

eta^2 (effect size interpreted as % shared variance), ***statistically significant adjusted model**

As displayed in table 41, the set of protocol input variables were associated with all three living donor outcomes. Within the set, compared to centers that did not accept donors with controlled hypertension, centers that did reported higher numbers of LD inquires, evaluations, and transplants. In addition, centers that covered the cost of post donation complications had higher living donor inquires and evaluations than centers that did not cover the cost of complications. Finally, centers with BMI criteria of ≥35 performed more live donor transplants than centers with a BMI criteria of 31-34 (Table 41).

Table 41. Summary of Protocol Inputs Associations

	Inquiries	**Evaluations**	**Transplants**
	eta^2	*eta*^{2}	*eta*^{2}
BMI Criteria (>=35)			
<=30	<.01	<.01	<.01
31-34	-.02	<.01	**-.04***
Accept controlled HTN			
Yes	**.08***	**.10***	**.04***
Age criteria (none)			
50-64	<.01	-.01	<.01
65-69	<.01	-.01	<.01
>=70	.03	<.01	.01
Require health insurance			
No	<.01	<.01	.01
Have PCP			
No	.02	.01	<.01
Cover cost complications			
Yes	**.05***	**.06***	.02

eta^2 (effect size interpreted as % shared variance), ***statistically significant adjusted model**

Educational programs/resource input variables were also found to be associated with all three outcomes (LD inquires, evaluations, and transplants) (see Table 42). Within that set of variables, compared to centers that did not have a kidney paired donation program, those that did reported higher numbers of each outcome. Reported transplant candidate education time was found to be inversely associated with the centers' number of evaluations and transplants.

Increasing time spent on transplant candidate education was associated with fewer living donor evaluations and transplants. Furthermore, centers that reported education of referring nephrologist were observed to perform more living donor evaluations than those centers that did not report such education (Table 42).

Table 42. Summary of Educational Program/Resource Inputs Associations

	Inquiries	**Evaluations**	**Transplants**
	eta^2	eta^2	eta^2
Candidate educ time (0-10 min)			
11-20	-.03	**-.11***	**-.06***
21-30	-.01	**-.10***	**-.04***
>30	-.01	**-.06***	**-.04***
Train candidates identify LD			
No	<.01	<.01	01
Kidney paired donation			
No	**-.16***	**-.14***	**-.22***
Pre-donation peer support			
No	-.01	-.01	-.01
Education at dialysis units			
No	<.01	<.01	<.01
Education referring nephrologists			
No	-.01	**-.04***	-.01
Financial counseling			
No	.02	.03	.01
Donor education time (20-60 min)			
61-90	<.01	-.01	-.02
>=91	.03	.01	.01

eta^2 (effect size interpreted as % shared variance), ***statistically significant adjusted model**

Chapter IV describes in detail the results of the survey administered to living donor coordinators within U.S. living donor programs. The survey results were linked to the AHA and SRTR databases to describe center characteristics and volume measures. Descriptive statistics were used to summarize survey responses and multiple linear regressions were used to assess associations with outcome variables. The survey response rate was 70% (148 out of 211 centers). Demographic and role characteristics were described for 198 coordinators. A summary of findings from the analysis of variables associated with the number of living donor outcomes

(inquires, evaluations, transplants) were displayed in the summary tables shown above. The final chapter includes a discussion of study results, limitations, and implications of findings.

CHAPTER V

DISCUSSION

This dissertation research was the first national study that described the characteristics and organization of living donor coordinators and living donor programs. Chapter V includes a discussion and interpretation of study results by research aim including comparisons with previous research findings. Limitations of the research, implications, and recommendations for future research are provided.

Sample Characteristics

One strength of this research study is the external validity of the findings. First, the study was a universal study with a 70% transplant center level response rate. Second, there were no observed differences between respondents and nonrespondents by institutional characteristics. Thus, there is good reason to believe these results can be generalized to most U.S. transplant centers based on program volumes, ownership status, COTH membership, and OPTN regions. In regards to institutional characteristics, nationally, seventy percent of transplant programs were private, not-for-profit institutions and teaching hospitals. Although there were no differences observed in program volumes between respondents and non-respondents, national program volumes varied significantly among programs. This center level variability existed for volume of transplants (deceased and living) performed and also for candidate waitlist volumes, which could be a possible explanation for the significant variation in findings among centers. One of the main themes of the research findings is this significant variation in labor, organization, and resources among programs. This is contrary to more developed service delivery organizations/programs that tend to have less variation. It is important to determine if these

variations result in differences in outcomes.

Findings in Relation to Research Aim One

Research Aim 1: Describe characteristics and roles of the living donor coordinator within U.S. solid organ transplant centers.

Demographic characteristics of living donor coordinators. This is the first national study to describe the characteristics and roles of the living donor coordinator or any type of nurse within the specialty of transplantation. There is little variability in characteristics of the transplant coordinators themselves with greater than 87% of coordinators being white, non Hispanic or Latino, females. The living donor coordinator workforce is less diverse than the national population of U.S. nurses (75% White, 9.9% Black/African American, 4.8% Hispanic/Latino, and 9.1% male) (HRSA, 2013). It is unknown how diversifying the living donor coordinator workforce would impact living donation outcomes. However, compared to their white counterparts, minorities constitute a disproportionate number of candidates on the U.S. kidney transplant waiting list (36.4% White, 33.6% African American and 19.5% Hispanic/Latino), relative to the U.S. population or nursing labor workforce (SRTR, 2016) (U.S. Census Bureau, 2017).

In addition, minorities are also less likely to receive live donor kidney transplant or to become live kidney donors (SRTR, 2016; Ladin, 2009; Gore 2009). Healthcare system factors may contribute to barriers for racial/ethnic minorities including transplant center processes, care delivery, and educational delivery materials (Rodrigue 2015; Gordon, 2010; Purnell, 2012). Cultural or language differences may pose barriers to the provider-patient relationship or the ability to understand patients live donor kidney transplant preferences (Ladin 2009; Waterman

2016; Monson, 2015; Rodrigue 2015). Identifying and acknowledging the homogenous makeup of the transplant coordinator workforce, emphasizes the need to consider strategies to reduce or remove these barriers. Future research should explore what impact, if any, expanding the role of racial/ethnic minorities in the transplant nursing workforce or patient educators may have on live donor rates and outcomes. There is evidence from other studies to suggest that strategies to provide culturally-tailored LDKT education via healthcare system provided educators to minority patients including patient guides/navigators, provider guided discussions, and home educators may be effective in reducing racial/ethnic disparities in access to LDKT (Rodrigue, 2012; Sullivan, 2012; Boulware, 2013).

The role that healthcare provider cultural competency training may have on living donor process, outcomes, and the patient-provider relationship should also be explored. Understanding that it is unlikely that the composition of the living donor coordinator workforce will change in substantial ways, training these front-line providers to deliver culturally competent care and education is essential. Transplant candidate and donor education and educational materials should also be culturally competent and incorporate health literacy best practices (Gordon, 2010). Findings from this dissertation research indicate that only 78% of centers reported the availability of multilingual materials. With the prevalence of written materials (LD 100%; TC 99%) and online resources (LD 80%; TC 72%) as educational tools, it is important that these materials should provide accurate and culturally sensitive information incorporating health literacy best practices. Although it was outside the scope of this research to review actual educational materials, previous studies have shown that transplant center education and materials do not consistently incorporate these practices (Gordon, 2010; Moody, 2007).

LDC Education/Experience. Not surprisingly, ninety-nine percent of living donor

coordinators are registered nurses with only seven percent of LDCs also nurse practitioners. Living donor coordinators are a well-educated nursing workforce. Eighty-nine percent of living donor coordinators report at least a bachelor's level education with 17% reporting a masters or higher level degree. This is significantly higher than the overall US nursing workforce with 55% holding a BSN or higher degree with 11% reporting a masters or higher degree (HRSA, 2013). Some variability does exist in living donor coordinator experience. Approximately one-fifth of coordinators would be considered new to the transplant coordinator role and living donor coordinator role with less than one-year experience as a transplant coordinator or living donor coordinator. Conversely, 43% reported greater than 10 years experience as a transplant coordinator and 25% reported greater than 10 years as a living donor coordinator.

There is limited nursing research, none in transplant nursing research, that explores the relationship between nursing workforce characteristics and patient outcomes. One study identified from the acute care setting that established a relationship between nursing experience and patient outcomes (fall rates and hospital-acquired pressure ulcers (HAPU)). The authors found that having a higher percentage of experienced RNs on the unit was related both to lower fall rates and lower HAPU (Dunton, 2007). Similarly, a systematic review of the literature found evidence that the prevalence of baccalaureate-prepared RNs was related to lower hospital mortality rates and that higher rates of nurse turnover were related to higher rates of patient falls (Kane, 2007). Transplant nurse coordinators and living donor coordinators specifically provide specialized care to a complicated population in a complex healthcare setting. Although unknown, it is possible that education and experience of nurse providers in this setting is associated with patient outcomes. Future research should explore if transplant coordinator experience is associated with living donor outcomes.

Findings in Relation to Research Aims Two and Three

Research Aim 2: Describe the current capital inputs, organizational facets, labor inputs, and employment terms within living kidney donor programs in the U.S.

Research Aim 3: Describe the extent to which administratively mediated variables (capital inputs, organizational facets, labor inputs, and employment terms) in living donor programs are associated with rates of live kidney donor inquiries, evaluations, and transplants among transplant centers.

Living donor coordinator labor quantity. There are two findings to consider when evaluating living donor coordinator labor: patient management structure and quantity. Twenty-six percent of programs had coordinators who managed both living donors and other patient populations. More often the other patient population was transplant candidates. As shown in the linear regression models, the programs that had coordinators who managed living donors and other populations were found to have fewer living donor inquires, evaluations, and transplants than programs who had dedicated living donor coordinators. There are several potential hypotheses for this finding. First, this could be a surrogate for how much time and resources the center devotes to the living donor program. If a center is not willing to devote one person to the living donor program, then it is possible there is a lack of emphasis on living donation. Alternatively, it is possible that the program cannot support the overhead of that FTE. Conversely, it could simply be that coordinator(s) who manage multiple populations are overburdened and are unable to focus on living donors, expediently move patients through the process, or adequately educate patients about living donation. This is the first study conducted that explores the impact of living donor patient management structure and living donor

outcomes. Based on these findings, living donor programs should consider investing in a patient management structure that provides dedicated coordinators to the living donor program.

Thirty-two percent of centers reported more than one FTE performed the LDC role. As displayed in the linear regressions models, more than one LDC FTEs was associated with higher numbers of living donor inquiries, evaluations, and transplants. There is extensive research that supports the association between nurse staffing and patient outcomes in the acute care sector (Lankshear, 2005; Kane, 2007; Brennan, 2013). However, this is the first study to evaluate nurse labor in living donor programs and the first in the transplant literature to show an association between nurse labor and patient outcomes. Interestingly, 37% of respondents reported devoting less than 40 hours per week to the living donor program and 38% held at least one or more roles that were not related to the living donor program. Findings from this research highlight the importance of investing in dedicated coordinator staff resources in living donor programs. Requiring a LDC to perform non-living donor related roles or tasks is likely a barrier to performing more living donor transplants.

One limitation of this cross sectional research study is that it is impossible to determine the sequence of events in which labor and program volumes influenced one another. It is impossible to determine if labor quantity drove program volume or if program volume drove labor quantity. Although unknown, one likely explanation for variations in patient management structure and LDC FTEs is program size. Smaller volume programs are less likely to have a devoted LDC patient management structure or to have more than one LDC FTE. Future research will be conducted to determine the proportion of LDC FTEs to program volumes. This could potentially provide useful metrics for LDC staffing in relation to program volumes. Acute care settings have developed staffing and acuity models to help determine appropriate nurse/patient ratios.

Although clearly an important factor to living donor outcomes, appropriate metrics and benchmarks for living donor program staffing have yet to be developed.

Living donor program non-coordinator labor inputs. Respondents reported a multidisciplinary approach to the management of living donor patient care with most providers exclusively or regularly designated to the living donor program. It is not surprising to find LD programs staffed with a core team of multidisciplinary care providers because LD programs are integrated into their hospital's transplant program which are historically multidisciplinary teams (CMS, 2007, Widmar, 2014; Hoy, 2011; Stendahl, 2012; Staino, 2013; Moore 2015). This study investigated in depth the role of clerical/administrative support personnel available within living donor programs. Skill mix is an important component to evaluate in a transplant program because there are time intensive tasks that can be performed by nonlicensed personnel. For example, survey respondents indicated that he/she scheduled tests/procedures (58% daily; 25% weekly), prepared selection committee materials (22% daily; 59% weekly), performed database entry (44% daily; 24% weekly), and answered patient calls (93% daily; 4% weekly). These could all potentially be performed or at a minimum initiated and triaged by clerical personnel.

The extent to which these clerical personnel were utilized in living donor programs was highly variable. Forty-two percent of center respondents reported that less than one dedicated or nondedicated clerical FTE supported the living donor program. Furthermore, 77% of program respondents reported the center did not have clerical FTEs devoted to the living donor program. As displayed in the linear regressions models, similar to the LDC staffing model, having clerical staff dedicated to the program was associated with higher numbers of evaluations and transplants. Higher numbers of clerical/administrative FTEs was also associated with higher numbers of LD evaluations but did not remain statistically significant for LD transplants. This is

the first study in the transplant literature to evaluate support staff labor in transplant programs and to show an association between labor and patient outcomes. The same limitations apply in the evaluation of support staff labor as does with LDC labor. In this cross sectional research study, it is impossible to determine the sequence of events in which labor and program volumes impacted one another. In addition, this research study was not intended to fully describe the role of clerical/administrative staff as with the LDC role.

Organization Facets. Several LD coordinator reporting structures were provided by survey respondents. Seventy percent of survey respondents indicated that they reported to more than one individual. The most cited individual was a transplant administrator, nursing manager, or physician surgical/medical director. As displayed in the linear regressions models, centers with LDCs reporting to more than one individual also reported having fewer living donor inquires, evaluations and transplants. Perhaps a single reporting line is not possible due to the nature and complexity of LD patient care requirements and a multidisciplinary approach to care management is required. Widmar and colleagues' findings were similar when exploring the organization and structure of VAD programs (Widmar, 2014). However, there is always the concern that there may be confusion regarding performance expectations and priorities when more than one leader has input into a coordinator's role components.

Previous literature regarding best practices in living donor programs specifically highlights the importance of a dedicated LD physician champion (LaPointe Rudow, 2015; Melcher, 2013). Eighty-five percent of programs report a LD program director/leader. Although only 15% of survey respondents indicated that they do not have a program director/leader, this is a potentially important finding because this could be a possible surrogate for center commitment

to the live donor program. Living donor program are highly complex and need a champion to advocate for resources, lead, and emphasize the importance of living donation (LaPointe Rudow, 2015; Melcher, 2013).

LD Program Resources/Protocols. This study evaluated the availability of post donation resources within living donor programs that helped to facilitate or support donors by removing potential financial hardship and improving post donation follow up. Economic hardship and fear of impact of donation on employment have been cited as barriers to living donation (Tushla, 2015; Pradel, 2003; Boulware, 2002; Lunsford, 2007; Pradel, 2003; Gaston, 2006). The prevalence of economic hardship amongst living kidney donors is well recognized by members of the transplant field (Tushla, 2015; Gaston, 2006; Clarke, 2006; Jacobs, 2006; Barnieh, 2012; Cynowiec, 2009; Rodrigue, 2009; Sickand, 2009). In addition, in an effort to promote donor safety, the OPTN/UNOS mandates transplant centers submit post donation clinical and laboratory data on all living donors at 6 months, 1 year, and 2 years post donation (OPTN, 2014). However, the U.S. lacks a payment system for the provision of post donation healthcare. Consistent with our study findings, an article developed out of a recent LD consensus conference of transplant professions suggests that transplant center interpretation and practice varies on insurance coverage for postdonation follow up visits, postdonation laboratory testing, and treatment of complications following donation (Tushla, 2015). In a 2013 study of living donor follow-up practices in U.S. kidney donor programs, lack of program (54%) or donor (49%) reimbursement for follow-up costs was cited as a barrier to living donor follow-up (Waterman, 2013).

Findings from this dissertation research suggest that, if there is not sufficient insurance coverage, transplant centers and transplant providers are attempting to reduce economic hardship

and/or ensure post donation follow up by paying for the cost of post donation labs (83% of centers) and office visits (75% of centers). Two-thirds of transplant centers (64%) also cover the cost of post donation complications if the donor or recipient does not have insurance that pays for these medical costs. Although post donation hospitalizations are low, 11% at 3 years after donation, they still result in healthcare expenditures (Tushla, 2015; Schold, 2014).

Clearly, these practices are intended to ameliorate financial burden for the donors and/or ensure regulatory compliance with mandated post donation follow up; however, it is unknown what the financial impact of these practices are for transplant centers and living donors (Waterman, 2013; Tushla, 2015). However, as indicated by results in the linear regressions models, centers that covered the cost of post donation complications had higher living donor inquires and evaluations than centers that did not cover the cost of complications. Based on survey results, it is unknown whether, how, or when this information is provided to transplant candidates or potential donors; therefore, it is difficult to interpret the significance of this finding to living donor outcomes. A possible explanation could be that transplant candidates and living donors are less concerned about financial implications of donation in these centers. Another possible explanation is that centers that cover the cost of post donation complications are committed to the care and well being of living donors therefore creating a culture promoting living donation. Research is needed to fully explore the significance of these findings and determine their validity. Research is also needed to fully understand the financial impact to transplant centers and donors and further explore the role that insurance payers could and should play in offsetting these costs. Transplant programs would also benefit from uniform guidance in relation to billing options for post donation office visits, laboratory tests, and complications (Tushla, 2015).

Long term donor health and outcomes are clearly a concern of the transplant community and policy makers. Interestingly, however, three-fourths of centers do not require potential living donors to have personal health insurance (78%) or to have a primary care physician (72%). While likely well intentioned to prevent barriers to proceeding with live donor evaluation or delaying the evaluation process, these may ultimately result in barriers post donation to long term donor health and follow up practices or compliance. This is especially true in light of the fact that a significant proportion of transplant centers report that living donors are lost to follow up and less than half of centers (43%) met the OPTN/UNOS required 6 month, 1-year, and 2-year LDF thresholds for LKDs who donated in 2013 (Waterman, 2013; Mandelbrot, 2009; Henderson, 2017; Schold 2015). In one study, lack of insurance was found to be one of the donor risk factors for missing laboratory data (Schold, 2015). Future research is needed to better understand the role that predonation practices/protocols may play in long-term donor health and follow up practices or compliance.

Living Donor Program Processes. This is the first known national study to evaluate the timeline of the living kidney donor workup and evaluation process. These findings are significant in that they provide important and useful median baseline metrics for living donor programs in regards to phases of care. However, significant variation exists among programs for all three process timelines (respond to LD inquiry, days at the center for evaluation, complete an entire LD evaluation). In fact, the only process timeframe reported by greater than 50% of centers was the time it takes centers to respond to the initial LD inquiry (1 day or less-51%).

As revealed in the linear regressions models, process variables were statistically significantly associated with only living donor inquires. Of those variables, centers that reported >60 day evaluation timeframe were associated with higher number of living donor inquires.

There could be several possible explanations for this finding including centers that have shorter evaluation times would find a donor in a more expedited manner thus obviating the need for additional individuals to come forward to donate. With prolonged evaluation times, transplant candidates are left uncertain about the outcome; therefore, they may continue to recruit donors resulting in higher numbers of living donor inquiries. Centers that reported $\geq$ 3 day transplant center evaluation were also found to have fewer living donor inquires. The significance of this finding requires further exploration; however, one possible explanation is that transplant candidates consider this a burdensome process for their family members/social support network and opt not to recruit living donors. A limitation of these research findings is the inability to validate LDC reported data. It is unknown whether these were actual or estimated process timelines.

Living Donor Program Protocols. To ascertain the center medical criteria for potential living donors, respondents were asked to indicate if the center had restrictions for controlled hypertension, body mass index (BMI), and age. The last survey of transplant centers exploring the medical evaluation of living donors was conducted in 2007. Centers that report no upper age limit for potential donors (57%) remains similar to 2007 survey findings (59%). However, there does appear to be an increase in the number of centers with an upper age limit $\geq$70 in the 2017 survey findings (20%) in comparison to 2007 (9%) thus indicating less restrictive age criteria across transplant centers. Hypertension requirements have also become less stringent with 81% of centers accepting donors with controlled hypertension in 2017 as compared to only 53% in 2007. Although, there is data that suggests a risk association between BMI and ESRD, sixty-one percent of centers still report a BMI criteria of $\geq$ 35 (Hsu, 2006; Vivante 2012; Grams 2016).

As shown in the linear regressions models, compared to centers that did not accept donors

with controlled hypertension, centers that did reported higher numbers of LD inquires, evaluations, and transplants. In addition, centers with BMI criteria of ≥35 performed more live donor transplants than centers with a BMI criteria of 31-34. Expanding the use of medically complex donors has been well documented, and findings from this study are consistent with these trends and the intended goal of increasing living donor outcomes (inquires, evaluations, transplants) (Tangdhanakanond, 2015; Niemi, 2014). Clearly, less restrictive living donor medical criteria expands the pool of available organ donors. However, future research is needed to determine the long-term health of these types of kidney donors.

LD and Transplant Candidate Education. Significant variations exist among programs in regards to transplant candidate and potential living donor education time about living donation. Although multiple studies indicate that higher quality transplant education may improve access to transplant and living donation, no consensus exists on the most effective ways to educate patients (Skelton, 2015). Potential donors clearly received significantly more time learning about living donation (median education time per donor 90 minutes) compared to transplant candidates (median education time per transplant candidate 20 minutes). Potential living donor education was more commonly performed one on one in person as compared to transplant candidate education about living donation, which was more commonly performed in a class/group setting.

As shown in the linear regressions models, reported transplant candidate education time was found to be inversely associated with the centers' number of evaluations and transplants. Increasing time spent on transplant candidate education was associated with fewer living donor evaluations and transplants. The significance of these findings is unclear because this study did

not explore the specific education components addressed in transplant candidate education about living donation. Other studies have found that compared to standard, group, transplant center educational classes, alternate educational delivery programs were more effective in transplant candidate education (Rodrigue, 2008; Waterman, 2010; Boulware, 2013; Sullivan, 2012). One hypothesis is that educational content as opposed to education quantity is the key component. Research is needed to explore what impact educational content, delivery method, and quantity has on living donor outcomes.

Educational Resources/Programs. Significant variation also existed among living donor programs in regards to educational resources and programs offered to transplant candidates and living donors. Only 56% of centers indicated that transplant center staff trained transplant candidates or their social support network on how to identify and approach potential living donors. Previous studies have shown that these methods are effective in improving living donor outcomes (Garonzik-Wang, 2012; Kumar, 2016). However, the only education resource program that was found to be associated with live donor outcomes in the linear regression model was LD education for referring nephrologist. Centers that reported education of referring nephrologist (29%) were observed to perform more living donor evaluations than those centers that did not report such education. Research is needed to further explore what type of education these referring nephrologist receive and what role, if any, this plays in live donor outcomes.

Kidney Paired Donation. In this study, kidney paired donation was the most common program offered to living donors and transplant candidates. Historically, prior to kidney paired donation, ABO-incompatibility was a barrier to transplant. Even though KPD offers the best option for patients with incompatible live donors, there have been wide programmatic variations

regarding participation in KPD programs (Levey, 2011; Segev, 2008: Massie, 2013). This study found that seventy-five percent of centers reported offering a KPD program and 63% reported access to kidney paired donation software or registry. As displayed in linear regressions models, compared to centers that did not have a kidney paired donation program, those that did reported higher numbers of living donor inquiries, evaluations, and transplants. Research is needed to identify programmatic variations to participation in KPD and what the barriers are to execution.

Living Donor Metrics and Outcome Measures

The ability to measure program productivity by establishing program metrics and benchmarks is the first step toward being able to evaluate programs both individually and nationally. Perhaps more importantly, these metrics can help to identify points in the living donor process where there could be potential interventions to increase living donor conversions. Findings from this study help to clarify possible program methods that could be used as metric or benchmarks for living donor programs.

Living Donor Conversion Rates/Donor Yield. This is the first know national study that evaluates the conversion rate from initial contact to living donor transplant. This is consistent with previous, single center studies on donor conversion. These prior studies found that between 80-90% of potential donors who contact the center fail to donate (McCurdie, 2005; Lapasia, 2011; Reeves-Daniel, 2009; Lunsford SL, 2006; Saunders, 2000; Norman, 2011; Moore, 2012). These findings are important first steps toward identifying appropriate living donor conversion metrics. Organ procurement organizations routinely use these types of conversion metrics to evaluate performance of deceased donor organ consent. The ability to incorporate conversion

metrics into living donor programs would require centers to more completely and accurately capture living donor inquires/initial contacts and evaluations. Further investigation is needed to determine what role, if any, conversion metrics could play in establishing living donor program metrics.

Program size/volume metrics. As opposed to evaluating kidney transplant or living donor programs by total transplant volume, perhaps it is necessary to establish metrics around program size. This could better delineate program productivity in terms of program size. This is important because it is unreasonable to assume that a program with 200 kidney transplant waitlist candidates will perform the same number of deceased or living donor transplants as a program with 2000 waitlist candidates. The denominators are not the same; therefore they cannot be measured the same. The number of kidney transplant waitlist candidates is a factor that drives volumes; therefore, it is necessary to evaluate this factor when discussing center productivity. Nationally, the median number of total transplants is 54 (median-39 deceased donor, 14 living donor). The median number of kidney transplant candidates on the UNOS waiting list is 422 candidates. When performing a comparison of transplant productivity with waitlist volume, the national median percentage of total transplants is 12.7% (9% deceased donor, 3% living donor).

Another potential metric to evaluation transplant centers in regards to living donor productivity is the percentage of living donor transplant in relation to the total number of transplants performed. Nationally, the median total transplants performed are 54 with a median of 14 living donor transplants. When performing a comparison of transplant productivity in regards to living donor volume, the national median percentage of total transplants is 26%.

Future investigation is needed to determine how living donor program metrics can be established in regards to program size.

Study Limitations

In this study it was assumed that the LD coordinator was the best person to describe the organization, structure, and resources available within living donor programs. It was further assumed that responders provided best responses to survey items and responses were accurate. Findings represent practices as they are reported, and the accuracy of how well they reflect actual practice cannot be confirmed, a limitation of using a survey relying on self-reported information. It is also unknown if center patient volume and process timeframe data were actual or estimated. The study investigator assumed that respondents made reasonable effort to provide accurate data.

Another limitation of this cross sectional research study is that the design was not intended to determine causation. Specifically, as previously mentioned, the data does not measure the sequence of events in which study variables and program volumes impact one another. It is impossible to determine if particular variables drove program volume or if program volume drove specific variables.

Implications

Implications for Practice: Nursing. This research contributes to the current knowledge of transplant centers by describing labor inputs, organizational care structures, and resources used in living donor programs across all US transplant centers. My findings may be of interest to living donor coordinators who are responsible for the care and coordination of living donors. This study contributes to the knowledge of transplant nursing by describing the characteristics and nursing labor inputs in living donor programs. It is also the first known study in the

transplant literature that describes an association between nurse labor and living donor outcomes. This research identifies nurse patient management structures that are associated with improved living donor outcomes. For example, having more than one LDC FTEs was associated with higher numbers living donor inquires, evaluations, and transplants, as was having a dedicated living donor coordinator. This may help LDCs better understand how to organize and structure their workload. It may also help them determine how to best allocate their time in order to more efficiently and effectively care for potential living donors.

Implications for Practice: Administrators. Study findings may be of particular interest to administrators who are responsible for providing labor and organizational resources to living donor programs. This research identifies administratively mediated variables that are found to be associated with increased numbers of living donor transplants. For example, centers that accept donors with controlled hypertension and centers that have a kidney paired donation program reported higher numbers of LD inquires, evaluations, and transplants. This may help center directors and administrators evaluate which organizational programs should receive time and resources. Also, identification of national trends in care team structure and resources may encourage an internal evaluation of existing methods used in transplant programs. These findings may help to determine total labor input and role components of team members who provide care within living donor programs. For example, this study found that having LDC and clerical staff dedicated to the program was associated with higher numbers of evaluations and transplants. Study findings may encourage administrators to review current living donor staffing and structure. Finally, these findings may provide useful median baseline metrics for living donor programs in regards to phases of care and living donor processes such as time to complete a living donor evaluation.

Implications for Policy. This is the first know national study that evaluates the conversion rates from initial contact to living donor transplant. The overall national conversion rate/donor yield from initial contact to living donor transplant was 8% and the conversion rate from evaluation to living donor transplant was 32%. These findings may prove useful in providing baseline data for the establishment of living donor performance or outcome metrics.

Implications for Research. Survey response rate for this study was 70%. Transplant researchers may be able to draw useful strategies from the research design that could potentially increase response rates for future studies.

Recommendations/Plans for Future Research

Findings from this research study generated additional recommendations and plans for future research. Several recommendations for future studies are as follows:

- Explore opportunities to establish living donor program performance metrics
- Future research should be conducted to determine how staffing, staff characteristics, program resources, protocols, and processes impact performance metrics.
- Future research will explore opportunities to establish staffing or acuity metrics/tools.
- Further health services research is needed in other areas of transplantation (liver, heart, lung, OPOs).
- Future research should explore what impact, if any, expanding the role of racial/ethnic minorities in the transplant nursing workforce or patient educators may have on live donor outcomes.
- The role that healthcare provider cultural competency training may have on living donor process, outcomes, and the patient-provider relationship should be explored.

- Future research will explore if transplant coordinator experience is associated with living donor outcomes.
- Research is needed to fully understand the financial impact to transplant centers and donors and further explore the role that insurance payers could play in offsetting these costs.
- There is a need to better understand the role that predonation practices/protocols may play on long-term donor health and follow up practices or compliance.
- Future research is needed to determine the long-term health of medically complex donors.
- Further research is needed to explore what impact educational content, delivery method, and quantity has on living donor outcomes.
- Research is needed to further explore what type of education referring nephrologists receive and what role, if any, this plays in live donor outcomes.
- There is a need to identify programmatic variations to participation in KPD and what the barriers are to execution.
- Further explore why people come forward to be living donors and the reasons that donation does not occur.
- Future research with the current data will explore if there is an association of center waitlist volume with total number of living donor transplants performed.

Conclusions

In an era of growing organ shortages, living donation is a means to increase the supply of organs available for transplant. Despite the benefits and support for live donation, rates of

kidney donation have declined over the past decade. Determining what barriers exist to live donation and what, if anything, can be done to overcome these barriers is an important objective for the transplant community. Healthcare system factors can pose barriers to living kidney donation. This cross-sectional and descriptive research was the first national study to explore the influence of capital inputs, organizational facets, labor inputs, and employment terms on rates of live kidney donations among transplant centers.

There were several key findings from this study. Significant variability existed among living donor programs involving staffing, organization, resources, and outcomes. Therefore, an important finding of this study was to identify which factors within programs were associated with improved living donor outcomes. This is the first known study in the transplant literature that described an association between nurse labor and living donor outcomes. This research also identified patient management structures that were associated with improved living donor outcomes. These findings may help living donor programs better understand how to organize and structure resources including labor inputs to potentially improve live donor outcomes.

Appendices

Appendix A

Transplant Administrator Study Announcement

Dear Colleague,

This is to alert you to an upcoming (date) invitation to your living donor coordinator to participate in the first national study of how this service is organized and its effect on living donation. I respectfully request you support completion of the survey. The 15-20 minute survey seeks to understand the current staffing, organization, and resources available within living donor programs. There is a lack of data describing the role of living donor coordinators and the organizational components of living donor programs within transplant centers. The goal is two-fold: 1. identify how best to support potential and actual living donors to increase the volume of living donor transplants; 2. help to improve living donor coordinator work processes and to develop strategies to improve the role of the nurse coordinator.

The coordinator's identity, and that of your organization, will not be known to anyone except the study team. All data collected from this research will be secured and accessible only by the researchers. To protect your coordinator and your institution, your answers will only be reported in the aggregate, not at the individual level.

You will have access to data from the study available via the following website at the conclusion of the study _____. The study results will be made available as a presentation and submitted for publication in a peer-reviewed journal following completion of the research study and dissertation defense, estimated to be within a year.

Thank you in advance for your support of the research process.

If you have any questions, please contact me at deonna.moore@vanderbilt.edu, or my PhD advisor, Ann Minnick PhD, RN, FAAN, at Ann.Minnick@Vanderbilt.Edu.

Thank you for your time and consideration.

Sincerely,

Deonna Moore, PhD(c), MSN, ACNP-BC
Doctoral Candidate,
Vanderbilt University School of Nursing

Appendix B
Living Donor Coordinator Participant Study Invitation

Dear Colleague,

I am a kidney transplant nurse practitioner who is conducting research as part of the requirements for a PhD in Nursing Science degree at Vanderbilt University School of Nursing, Nashville, TN. As a coordinator, your participation in an approximately 15-20 minute national survey concerning the structure and processes of living kidney donor programs will influence outcomes and support for potential and actual living kidney donors. The results from this study will also help to improve living donor coordinator work processes and help us to develop strategies to improve the role of the nurse coordinator.

Your identity, and that of your organization, will not be known to anyone except the study team. All data collected from this research will be secured and accessible only by the researchers. To protect you and your institution, your answers will only be reported in the aggregate, not at the individual level.

The study results will be made available as a presentation and submitted for publication in a peer-reviewed journal following completion of the research study and dissertation defense, estimated to be within a year. If you respond, you will have access to data from the study available via the following website at the conclusion of the study _____.

As a thank you for completing and returning the survey, you are eligible for a **$35** Visa gift card. You will have the option to receive this either electronically or via mail once the investigator receives the survey. If there is more than one living donor coordinator at your institution, complete the survey jointing so that there is only one survey per institution. However, all the living donor coordinators who participate in survey completion are eligible for the $35 gift card.

If you have any questions, please contact me at deonna.moore@vanderbilt.edu, or my PhD advisor, Ann Minnick PhD, RN, FAAN, at Ann.Minnick@Vanderbilt.Edu.

Thank you for your time and consideration.

Sincerely,

Deonna Moore, PhD(c), MSN, ACNP-BC
Doctoral Candidate,
Vanderbilt University School of Nursing

If you have received this invitation by mail, you may also access the survey electronically by typing the following address into your web-browser:

ENTER WEB ADDRESS HERE

Appendix C

Living Donor Coordinator Survey

Instructions

Are you a transplant coordinator who has a primary role in care coordination and management of potential or actual living kidney donors?

- Yes—**Please go to Question 1 to begin the survey.**

- No—**Please give to coordinator who manages living kidney donors**

- No—**There is no living kidney donor program in my facility. Please return survey**

To Complete and Return the Survey:

- Use the provided postage-paid envelope for the paper survey and send, by DATE, to:

Deonna Moore

Insert Address

- For your convenience, you may also complete the survey online. Please type the following link into your web-browser to be directed to the survey:

INSERT LINK HERE

Thank you for your participation!

LIVING DONOR COORDINATOR SURVEY ID Code:____

Part 1: These items pertain to how living kidney donors are managed at this transplant center.

Key: LDC=living donor coordinator; LD=living donor

Complete only one survey per transplant center even if there is > 1 LDC.

1. Which of the following best reflects how the transplant coordinator(s) manage patients?

☐ Dedicated LDC(s) manage(s) only potential or actual living donor (LD) patients

☐ Coordinator(s) manage(s) LD patients and transplant candidates or other patients.

2. How many coordinator(s) manage LDs? _____ **[If >1, please complete only 1 survey per center]**

3. How many FTEs (full time equivalents) perform the LDC role? _____

(1.0 FTE = full-time worker e.g. 40 hour work week; 0.5 FTE= part-time worker e.g. 20 hour work week)

4. Is any LDC time dedicated solely to the kidney paired donation program (KPD)?

☐ Yes (if yes, how many FTE's _____ or hours per week_____ spent solely on KPD)
☐ No

5. LDC 1:

a. What is the average # of hours per week worked as a coordinator? _____hours

b. # of these hours per week devoted to the LD program _____hours; *If none enter 0*

If >1, LDC 2:

a. What is the average # of hours per week worked as a coordinator? _____hours

b. # of these hours per week devoted to the LD program _____hours; *If none enter 0*

6. Indicate **all** of the job titles held by:

LDC 1:

- O Living kidney donor coordinator
- O Living liver donor coordinator
- O Kidney recipient transplant coordinator
- O Liver recipient transplant coordinator
- O Kidney living donor advocate
- O Liver living donor advocate
- O Other (please specify)_____

If >1, LDC 2:

- O Living kidney donor coordinator
- O Living liver donor coordinator
- O Kidney recipient transplant coordinator
- O Liver recipient transplant coordinator
- O Kidney living donor advocate
- O Liver living donor advocate
- O Other (please specify)_____

7. Indicate the title(s) of all the people to whom the LDC(s) report(s)? *Check all that apply*

Report(s)=the person who is responsible for LDC performance including but not limited to hiring, evaluating, and terminating.

- O Physician Medical Director
- O Physician Surgical Director
- O Chief Nursing Officer
- O Other nursing executive (administrator)
- O Transplant Administrator
- O Other (Please List)_____

8. How many people (if any) reports to the LDC(s)? _____ (*If none enter 0)*

9. Is annual education about living donation offered to transplant center staff? ☐ Yes ☐ No

10. How often are the following functions performed by the LDC(s)? *Mark 1 box for each statement*

Function	Daily	Weekly	Monthly	Almost Never/Never
Pre Donation Functions				
Educate transplant candidates about living donation	☐	☐	☐	☐
Educate potential LDs	☐	☐	☐	☐
Develop LD educational materials	☐	☐	☐	☐
Educate about financial assistance programs	☐	☐	☐	☐
LD outreach activities (at dialysis units, community events)	☐	☐	☐	☐
Initial screening/intake	☐	☐	☐	☐
Testing and procedures scheduling	☐	☐	☐	☐
Submit financial assistance applications	☐	☐	☐	☐
Clinic nursing-Outpatient (e.g., vital signs, weight, med reconciliation)	☐	☐	☐	☐
Review tests and labs	☐	☐	☐	☐
Prepare selection committee materials	☐	☐	☐	☐
Coordinate paired exchange program	☐	☐	☐	☐
Take patient calls	☐	☐	☐	☐

Function	Daily	Weekly	Monthly	Almost Never/Never
Donation/Inpatient Hospitalization Functions				
Discharge teaching	☐	☐	☐	☐
Outpatient/Post Donation Functions				
Triage patient calls	☐	☐	☐	☐
Clinic nursing-Outpatient (e.g. vital signs, weight, med reconciliation)	☐	☐	☐	☐
Long Term LD Functions				
Contact donor for follow up data/ schedule follow up appts/ arrange collection of clinical/lab data	☐	☐	☐	☐
Other Functions				
Completion of UNOS forms	☐	☐	☐	☐
Ensure regulatory requirement compliance (ABO verification, UNOS/CMS policies)	☐	☐	☐	☐
Develop LD policy and procedures	☐	☐	☐	☐
Database entry	☐	☐	☐	☐
Research	☐	☐	☐	☐
On-call	☐	☐	☐	☐

Other: Please Specify_____

Part II: Living Donor Program Organization

11. Is there a named director (head) of the LD program?
    ☐ Yes, one MD ☐ Yes, not a MD (write professional credential)_____
    ☐ Yes, > one MD (e.g., medical director and surgical director) ☐ No, no one is currently named head of program

12. What are the following providers' assignments in the LD program? *Check only 1 for each caregiver*

Type of Assignment:

1=Works with LD program only; does not work with other populations
2=Same provider regularly assigned but also works the other kinds of patients
3=Not regularly assigned to the LD program, but is available as needed
4=Provider not currently available to LD program

Provider	1	2	3	4
LD Surgeon	☐	☐	☐	☐
Nephrologist	☐	☐	☐	☐
Nurse Practitioner	☐	☐	☐	☐
Pharmacist	☐	☐	☐	☐
Social Worker	☐	☐	☐	☐
LD Advocate	☐	☐	☐	☐
Clinical Psychiatry	☐	☐	☐	☐
Dietician	☐	☐	☐	☐
Living Donor Coordinator	☐	☐	☐	☐
Outreach Coordinator	☐	☐	☐	☐
Administrative/Clerical Staff	☐	☐	☐	☐
Transplant Administrator/Supervisor	☐	☐	☐	☐
Data administrator/manager	☐	☐	☐	☐
Financial counselor	☐	☐	☐	☐

13. How many **FTEs** (total) provide administrative or clerical support to the LD program?
    _____ *# FTEs* Are they dedicated solely to the LD program? ☐ Yes ☐ No

14. Does your LD Program have a written:

	Yes (specific to LD program)	Yes (included in transplant center statement)	No
•Mission	☐	☐	☐
•Philosophy	☐	☐	☐
•Strategic Plan	☐	☐	☐

Part III. Transplant Center Resources and Requirements

15. Does your transplant center accept LDs with controlled hypertension? ☐Yes ☐ No

16. What is the BMI restriction for LDs? _____BMI; *If none, check here* ☐

17. What is the age restriction for LDs? _____years*; If none, check here* ☐

18. Do the following resources and requirements exist within the LD program?

Resource	Yes	No	Requirements	Yes	No
•Transplant Specific Database	☐	☐	•Require preliminary testing prior to evaluation at the center (BP readings, 24 hr urine)	☐	☐
•KPD Software or Registry	☐	☐			
•LD Initial Screening Software/Website	☐	☐	• Require potential donor to have personal health insurance	☐	☐
•Center payment of post donation labs if insurance does not cover	☐	☐			
•Center payment of post donation visits if insura does not cover	☐	☐	•Require potential donor to have a PCP	☐	☐
•Medical Opt out if LDs decide not to donate	☐	☐			

19. How is the cost of **post donation complications** for recipients with only commercial insurance managed?

- ☐ The transplant center covers the cost
- ☐ Commercial recipients must enroll in Medicare as a secondary payor
- ☐ Recipients and/or donors must sign a "self pay waiver."
- ☐ Donors must obtain an insurance policy to cover any potential complications (e.g., ACE American Insurance Policy)
- ☐ Other (please specify) _____

20. Which of the following financial assistance programs is/are a part of the education for LDs?
Check all that apply

- O National Living Donor Assistance Center
- O State Tax Deduction/Credit
- O American Living Organ Donor Fund
- O None
- O Fundraising
- O American Transplant Foundation
- O Other (please specify_____

21. a. Is there an allotted amount of time for education of potential living donors?
☐ Yes (if yes, please specify total time: _____minutes) ☐ No

b. How is education of potential living donors performed?
☐ Individual (1 on 1) education in person ☐ Class or Group education ☐ Phone
Other (please specify): _____

22. a. Is there an allotted amount of time for the education of transplant candidate regarding specifically **living donation**? ☐Yes (if yes, please specify total time: _____mins) ☐ No

b. How is education of transplant candidates regarding specifically **living donation** performed?
☐ Individual (1 on 1) education in person ☐Group education ☐Phone
Other (please specify): _____

23. Does the LD program offer any of the following educational resources or programs?

Program/Resource	Yes	No	Program/Resource	Yes	No
•Train transplant candidates and/or others how to identify and approach potential LDs	☐	☐	•LD education for referring nephrologists	☐	☐
•Pre donation peer support group or mentors for potential LD	☐	☐	•Financial counseling (e.g. programs to remove financial hardship of donation)	☐	☐
•Kidney Paired Donation	☐	☐	•Other (please specify)_____	☐	☐
•LD education at dialysis units	☐	☐			

24. Indicate the resources used for the education of potential LDs and transplant candidates regarding living donation. *Check all that apply*

Resource	Potential Living Donors		Transplant Candidates	
	Used	Not Used	Used	Not Used
Written materials/brochures	☐	☐	☐	☐
DVD/Videotape	☐	☐	☐	☐
Online Website	☐	☐	☐	☐
Podcasts/Webconferencing/ YouTube Video	☐	☐	☐	☐
Social Networking (e.g. Facebook)	☐	☐	☐	☐
Multilingual Materials	☐	☐	☐	☐

Other (please specify)_____

Part IV. Workload/Patient Load

25. On average, how many days does it take:
a. to respond to an initial LD inquiry/contact? _____days
b. to perform a LD evaluation at the transplant center?_____days
c. to complete an entire LD evaluation (initial contact to decision regarding candidacy)? _____day

26. What is the average annual number of LD inquires/initial contacts? _____
27. What is the average annual number of LDs evaluated at the transplant center? _____

28. What are the most frequent barriers to living donation within this program?

a. _____

b. _____

c. _____

Part V: LDC Demographics

Answer the following questions for the coordinator(s) considered LDC's.

Indicate **all** of the degrees held by:

LDC 1:	If >1, LDC 2
O Diploma	O Diploma
O LPN	O LPN
O AD Nursing	O AD Nursing
O BS/BA Nursing	O BS/BA Nursing
O BS/BA other	O BS/BA other
O MS/MA Nursing	O MS/MA Nursing
O MS/MA other	O MS/MA other
O DNP	O DNP
O PhD Nursing	O PhD Nursing
O PhD Other	O PhD Other
O Other _____	O Other _____

Indicate the number of years LDC 1 has been employed:

a. In your current position at this institution_____years

b. As a transplant coordinator regardless of employer: _____years.

Indicate the number of years LDC 2 been employed:

a. In his/her current position at this institution_____years

b. As a transplant coordinator regardless of employer: _____years.

Indicate **all** of the licenses held by:

LDC 1:	If >1, LDC 2
O LPN	O LPN
O RN	O RN
O RN/NP	O RN/NP
O LCSW	O LCSW
O None	O None
O Other_____	O Other_____

Indicate **all** of the certifications earned by:

LDC 1:	If >1, LDC 2
O CCRN	O CCRN
O CCTC	O CCTC
O None	O None
O Other _____	O Other _____

Indicate gender for:

LDC 1:	If >1, LDC 2
☐ Female	☐ Female
☐ Male	☐ Male

Indicate ethnicity for:

LDC 1:	If >1, LDC 2
☐ Hispanic or Latino	☐Hispanic or Latino
☐ Non Hispanic or Latino	☐ Non Hispanic or Latino

Indicate race for:

LDC 1:	If >1, LDC 2
☐ American Indian/Alaskan	☐ American Indian/Alaskan
☐ Asian	☐ Asian
☐ Native Hawaiian or Other Pacific Islander	☐ Native Hawaiian or Other Pacific Islander
☐ Black or African American	☐ Black or African American
☐ White	☐ White
☐ More than One Race	☐ More than One Race
☐ Prefer Not to Report	☐ Prefer Not to Report

Tables

Table 2. Administratively Mediated Variables Potentially Impacting Living Donation

Variable (Type AMV)	*Transplant Specific Data Source*
Capital Inputs	
• Electronic health record/transplant electronic database systems • Transplant center/program design -Clinic space for appointments -Office space and location of program staff • Patient LD educational materials -Recipient LD educational materials -LD educational materials -Print materials -Electronic/Web materials -Materials in multiple languages -Culturally sensitive materials -Appropriate health literacy level materials • Screening systems/Electronic screening tool • Access to operating rooms • Histocompatibility lab support/location • Kidney paired donation matching software	• HRSA Transplant Center Growth and Management Collaborative: Best Practices Evaluation (2007) • European Union Working Group on Living Donation (2014) • LaPointe Rudow (2015) • Patzer et al. (2012) • Schweitzer et al. (1997) • Rodrigue et al. (2008) • Rodrigue et al. (2007) • Lockwood et al. (2013) • Curtis et al. (2009) • Waterman et al. (2010) • Neyhart et al. (2008) • Waterman et al. (2009) • Waterman et al. (2008) • Dageforde (2014) • Ephraim et al. (2012) • Wilson et al. (2012) • Ameling et al. (2012) • Gordon et al. (2010) • Gordon et al. (2012) • Freirer et al. (2010)
•	• Freeman et al. (2013) • Nasr et al. (2009) • Street et al. (1997) • Moore et al. (2013) • Kidney Paired Donation Consensus Conference (2012) • Melcher et al (2013) • Clark et al. (2010)
Employment Terms	
• Coordinator/Nurse Workload • Independent living donor advocate workload • Social worker workload • Nephrologist workload • Surgeon workload • Psychologist/Psychiatrist workload • Advanced practice nurse workload • Administrative/Clerical staff workload • Pharmacist workload	• Saunders et al. (2000) • Staino et al. (2013) • Casida et al. (2011) • Widmar et al. (2014) • Hoy et al. (2011) •
Organizational Facets	
• Living donor organizational culture (culture of support within the transplant center for living donation	• HRSA Transplant Center Growth and Management Collaborative: Best Practices Evaluation (2007)

and the living donor program) • Evidenced based living donor protocols for program processes and LD evaluation • Physician Director/Champion • Multidisciplinary LD selection committee • Recipient LD educational programs -Live Donor Champion -Home based education • Living Donor educational programs • LD centered care/focused services -Follow up programs -Lodging availability -Financial assistance/counseling regarding availability of programs (NLDAC, private, tax incentives) • Streamlined educational workup/evaluation • KPD/Desensitization Programs • LD QAPI Program • Organizational Leadership/structure • Nursing leadership • Organizational culture -Group participation -Flattened hierarchy • Professional development opportunities • Surgery Timing	• Consensus Conference on Best Practices in Live Kidney Donation (2014) • European Union Working Group on Living Donation (2014) • Rodrigue et al. (2008) • Rodrigue et al. (2007) • Weng et al. (2013) • Wilson et al. (2012) • Woodle et al. (2005) • Garonzik-Wang et al (2012) • OPTN/UNOS Guidance Document for living donor follow-up (2013) • Formica et al. (2012)—1 day workup • Kidney Paired Donation Consensus Conference (2012) • Melcher et al (2013)
Labor Inputs	
<u>Quantity</u>: • Multidisciplinary team • Dedicated LD Nurse/Coordinator • Nurse staffing • Social worker • Psychologist/Psychiatrist • Independent LD advocate • Nephrologist • Surgeon • Advanced practice nurse • Administrative/Clerical staff • Pharmacist • Home based educators <u>Quality</u>: • Nurse certification -Clinical transplant nurse certification (ABTC) -Clinical transplant coordinator certification (ABTC) • Professional Society membership -American Society of Transplant Surgeons - American Society of	• HRSA Transplant Center Growth and Management Collaborative: Best Practices Evaluation (2007) • Consensus Conference on Best Practices in Live Kidney Donation (2014) • European Union Working Group on Living Donation (2014) • CMS COP (2007) • OPTN/UNOS Transplant Policies (2014) • Boulware et al. (2012) • Rodrigue et al. (2008) • Rodrigue et al. (2007) • Sullivan et al. (2012) • Clay (2014) • Rudow (2011) • Pondrom (2013) • Hoy et al. (2011) • Hauff (2007) • Brennan et al. (2011) • McNatt (2008) • Owens et al (2010) • Clark et al. (2010)

Transplantation -NATCO -International Transplant Nurses Society • Education -ADN/BSN/APN percentage -Pharmacy solid organ transplant residency -Transplant Nephrology Fellowship (MD) -Transplant Surgery Fellowship (MD) -MSW/LSW • Experience	• Staino et al. (2013) • Casida et al. (2011) • Widmar et al. (2014)

Table 5. Dissertation Research Timeline

	Month	1-2	2-5	6-7	8-9
	Task				
Phase I	Identify Hospital Organizations	X			
	IRB Approval(s)	X			
	Database Development	X			
	Subject Recruitment		X		
	Data Collection		X		
	Statistical Analysis/Interpretation			X	
	Write-Up of Results/Defense				X

Figures

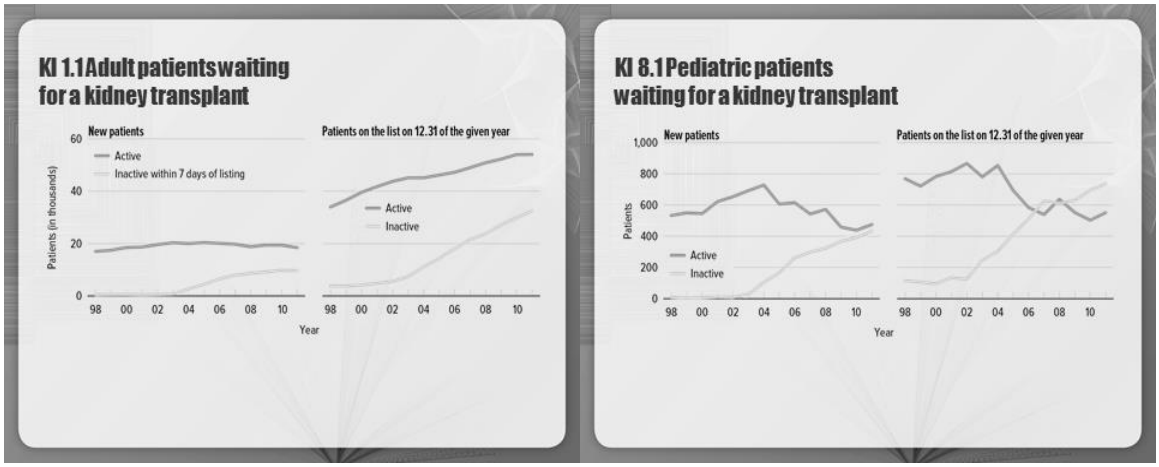
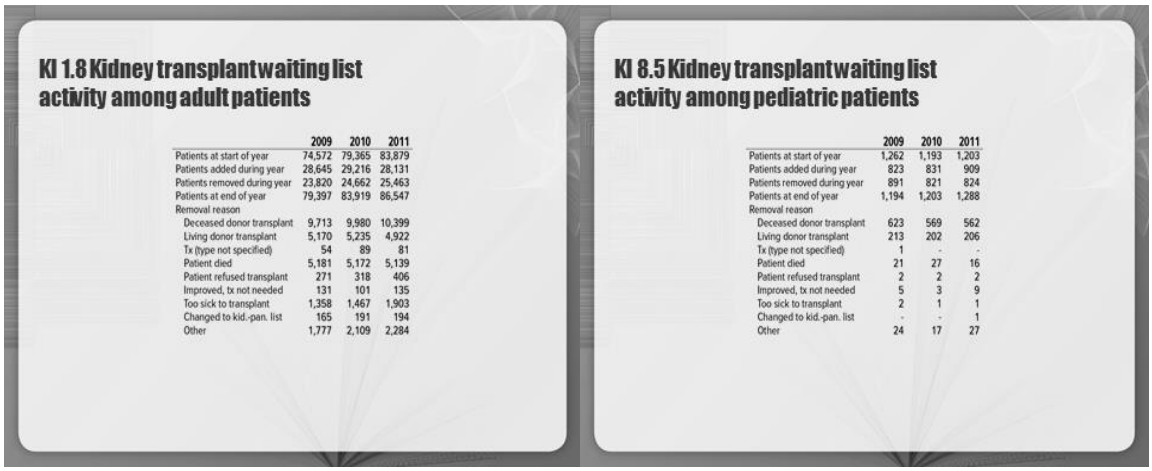


Figure 1. Adult and pediatric patients in U.S. waiting for a kidney transplant. (SRTR, 2014)



KI 1.8 Kidney transplant waiting list activity among adult patients

	2009	2010	2011
Patients at start of year	74,572	79,365	83,879
Patients added during year	28,645	29,216	28,131
Patients removed during year	23,820	24,662	25,463
Patients at end of year	79,397	83,919	86,547
Removal reason			
Deceased donor transplant	9,713	9,980	10,399
Living donor transplant	5,170	5,235	4,922
Tx (type not specified)	54	89	81
Patient died	5,181	5,172	5,139
Patient refused transplant	271	318	406
Improved, tx not needed	131	101	135
Too sick to transplant	1,358	1,467	1,903
Changed to kid.-pan. list	165	191	194
Other	1,777	2,109	2,284

KI 8.5 Kidney transplant waiting list activity among pediatric patients

	2009	2010	2011
Patients at start of year	1,262	1,193	1,203
Patients added during year	823	831	909
Patients removed during year	891	821	824
Patients at end of year	1,194	1,203	1,288
Removal reason			
Deceased donor transplant	623	569	562
Living donor transplant	213	202	206
Tx (type not specified)	1	-	-
Patient died	21	27	16
Patient refused transplant	2	2	2
Improved, tx not needed	5	3	9
Too sick to transplant	2	1	1
Changed to kid.-pan. list	-	-	1
Other	24	17	27

Figure 2. Kidney transplant waiting list activity among adult and pediatric patients (SRTR, 2014)

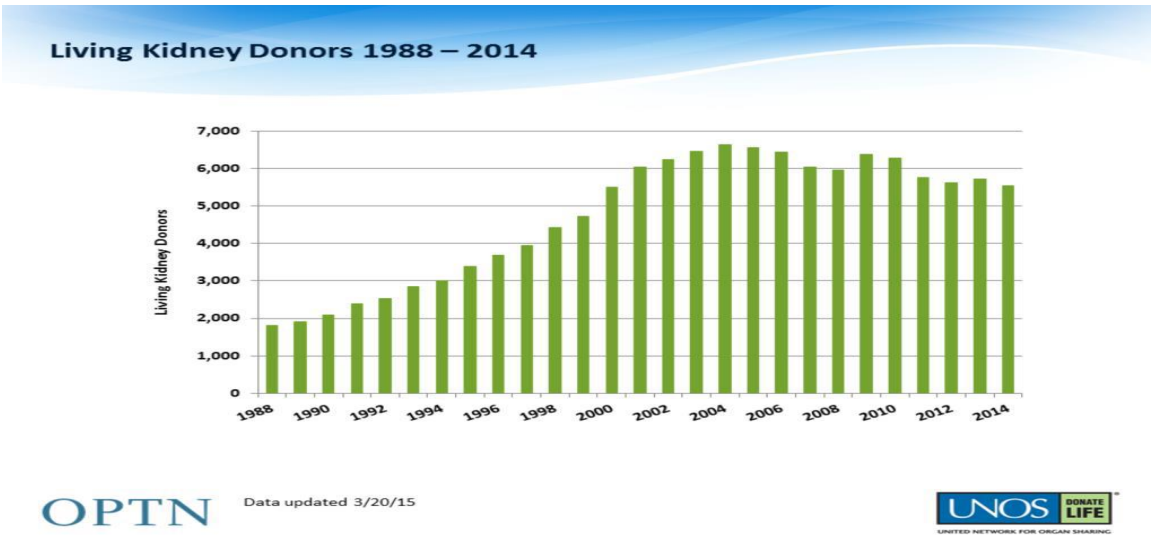


Figure 3. Living Kidney Donors 1988-2014 (UNOS, 2015)

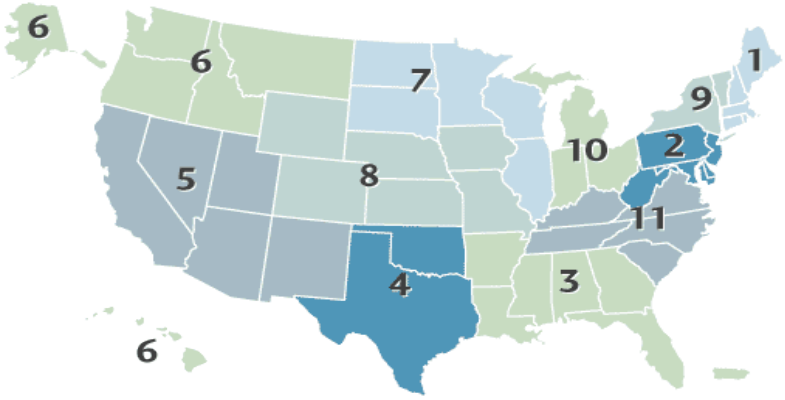


Figure 4. Organ Procurement and Transplantation Network Geographic Regions. (UNOS, 2015)

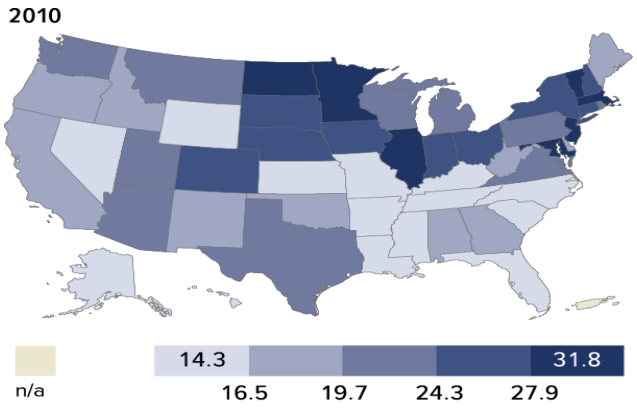


Figure 5. Living Kidney Donation Rates by State (per million population) (SRTR, 2014)

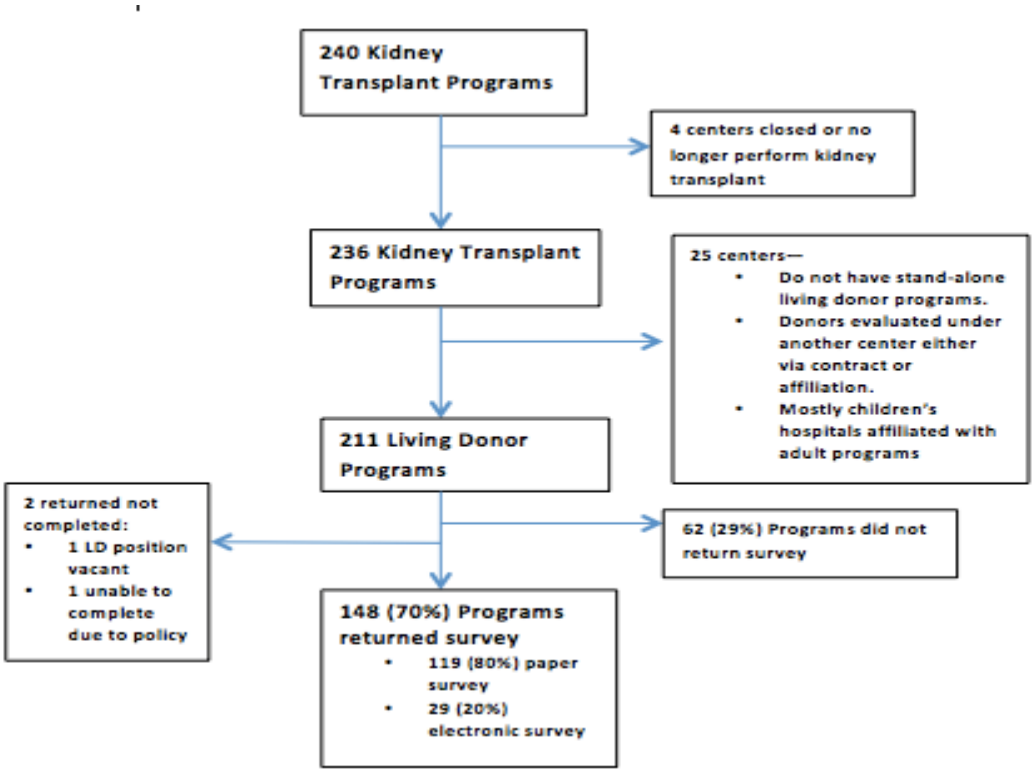


Figure 7. Flow diagram of living donor survey response rates

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