



eCOMMONS

Loyola University Chicago
Loyola eCommons

Dissertations

Theses and Dissertations

2015

Easing My Burden: A Grounded Theory Study of Kidney Transplant Recipients' Experience with Their Transplant Coordinators

Gwen E. McNatt

Loyola University Chicago, gmcnatt@nm.org

Recommended Citation

McNatt, Gwen E., "Easing My Burden: A Grounded Theory Study of Kidney Transplant Recipients' Experience with Their Transplant Coordinators" (2015). *Dissertations*. Paper 1648.
http://ecommons.luc.edu/luc_diss/1648

This Dissertation is brought to you for free and open access by the Theses and Dissertations at Loyola eCommons. It has been accepted for inclusion in Dissertations by an authorized administrator of Loyola eCommons. For more information, please contact ecommons@luc.edu.



This work is licensed under a [Creative Commons Attribution-NonCommercial-No Derivative Works 3.0 License](https://creativecommons.org/licenses/by-nc-nd/3.0/).

Copyright © 2015 Gwen E. McNatt

LOYOLA UNIVERSITY CHICAGO

EASING MY BURDEN: A GROUNDED THEORY STUDY OF KIDNEY
TRANSPLANT RECIPIENTS' EXPERIENCE
WITH THEIR TRANSPLANT COORDINATORS

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN NURSING

BY

GWEN ELISE MCNATT

CHICAGO, ILLINOIS

AUGUST 2015

Copyright by Gwen Elise McNatt, 2015
All rights reserved.

ACKNOWLEDGEMENTS

First and foremost and with much gratitude, I acknowledge the support of my family in my pursuit of this work and of my entire demanding career. My husband, Chuck Enokian, has lovingly endured and kept the home fires burning during my long absences. He has tolerated my covering tables, floors and furniture with papers and books, and always encouraged me to keep moving towards the finish line. My children, Kenny and Nessa, who have had a mother in school for most of their childhood, have also been tolerant of my bringing laptops to school events to work on papers, coming home late, and even cooperated by leaving the house when “Mom needs to concentrate on her research.” Now that they are in college also, they have a new appreciation of what I have been doing all these years. My parents, Dolores and Ken McNatt, always encouraged their daughters to strive for excellence in everything they pursued. They both inspired and encouraged me to pursue this degree. I regret that my father cannot be here to see me finally complete this journey, but I am confident that he knows that I made it and knew all along that I would.

I gratefully acknowledge and thank the members of my dissertation committee who have each provided me with encouragement, guidance, and support. Dr. Fran Vlasses, my chair and advisor, has been my teacher, advisor, editor, counselor, advocate, and friend. I am also indebted to Dr. Lee Schmidt, who is one of those “once in a lifetime” teachers, for sparking my interest in qualitative research and for being

incredibly helpful by sharing with me his methodological wisdom. Dr. Shelia Haas has been generous in providing me resources as well as sharing with me her wealth of knowledge regarding healthcare policy. Dr. Nancy Hogan was a member of my proposal committee, her vast insight on the grounded theory methodology was invaluable. I was also fortunate to have attended Dr. Jessica Horowitz's "Dissertation Boot Camp" which put me back on track at a time when I was really struggling. I thank her for devoting so much time to this yearly event and for her support post Boot Camp. I also I would also like to acknowledge Dr. Ida Androwich, for initially encouraging me to pursue a doctoral degree and always making me feel as if I could do anything.

My fellow students at Loyola University have also been invaluable support to me on this journey. I would particularly like to thank Kristin Ramsey, Robert Fortney, Julie Cerese, Laura Rogers, Carol Sieck, and Barb Pudelek for their friendship, encouragement, and help.

I also owe a debt of gratitude to the many people with whom I have the honor to work. Michelle Janney, my chief nurse executive, has been steadfast in her support and encouragement of my pursuit of this degree as well as being one of the most influential people in my career. Michelle is an incredible role model and mentor with whom I am blessed to have had the opportunity to work. Similarly, I am grateful to Dennis Murphy, who was my manager and the chief operating officer of Northwestern Memorial Hospital. In showing interest and confidence in me and in my pursuit of this degree, Dennis helped to give me the confidence that I needed to persevere. Mike Abecassis, our chief surgeon also has been supportive of my career. My colleagues and friends, Corey King, Greg Ciaciura, Steve Nelson, Daniela Ladner, Luke Preczewski, Leigh Anne Mixon, and Nan

Burgess also tolerated and encouraged me along the way. Many, many thanks to my administrative assistant, Shannon Miller, who juggled my calendar, barricaded my office, and figured out how to work the recording device, all to allow me to work on this research. And finally thanks to Donna Woods, my colleague at the Northwestern Institute for Healthcare Studies, for her sage advice regarding the dissertation process. I am privileged to work at Northwestern.

I also acknowledge and thank the International Transplant Nurses Society for providing grant funding for this study.

Dedicated in loving memory to my father and personal hero, Ken McNatt, who never
stopped believing in me.

And in gratitude to my two mentors, Michelle Janney and Dennis Murphy.

How little the real sufferings of illness are known or understood. How little does any one in good health fancy him or even herself into the life of a sick person.

Florence Nightingale, *Notes on Nursing*

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	iii
LIST OF TABLES	x
LIST OF FIGURES	xi
ABSTRACT.....	xii
CHAPTER ONE: INTRODUCTION.....	1
Problem Statement	1
Background	3
Role Definition.....	8
Significance.....	10
Significance to Nursing.....	10
Significance to Patients.....	15
Purpose of the Study	17
Summary	18
CHAPTER TWO: LITERATURE REVIEW	20
Introduction.....	20
Definition and Practice of the Transplant Coordinator.....	20
History.....	23
Role Dimensions.....	24
Educational Preparation, Licensure, and Certification	31
Research Examining the Transplant Coordinator Role	38
Summary	49
CHAPTER THREE: METHODS	51
Purpose of the Study	51
Research Design and Methods.....	52
Participants.....	54
Sampling Strategies and Data Collection	55
Interview Techniques and Data Management Procedures.....	55
Data Analysis	57
Protection of the Participants	58
Summary	59
CHAPTER FOUR: RESULTS	60
Sample.....	60
Dimensions of Care Received by the Participants.....	63
Transplant Coordinator Transitions	63
The Theory.....	67
Core Category: Easing My Burden.....	68
Basic Social Psychological Problem: The Burden of ESRD	71

Trustworthiness of the Theory	92
Credibility	92
Transferability	92
Dependability and Confirmability	93
Assessing the Theory	94
Fit	94
Work	94
Relevance	95
Modifiability	95
Summary	95
CHAPTER FIVE: DISCUSSION.....	97
The Basic Social Psychological Problem: The Burden of ESRD.....	97
Easing My Burden.....	99
Peplau’s Theory of Interpersonal Relations.....	100
Trust	103
New Findings from this Study	110
Limitations of this Study.....	112
Implications for Public Policy	112
Implications for Nursing Practice	114
Implications for Nursing Education.....	115
Future Nursing Research.....	115
Summary	116
APPENDIX A: RECRUITMENT LETTER	118
APPENDIX B: INTERVIEW GUIDE	120
APPENDIX C: INSTITUTIONAL REVIEW BOARD APPROVAL.....	126
REFERENCE LIST	128
VITA.....	145

LIST OF TABLES

Table 1. Treatment Characteristics of Participants	62
Table 2. Demographic Characteristics of Participants	63

LIST OF FIGURES

Figure 1. Easing My Burden

68

ABSTRACT

Organ transplantation holds the promise of new life or better life for thousands of Americans every year. Transplantation involves a process that stretches over time beginning at referral, moving to transplantation and long term care. The transplant coordinator is considered an integral part of this care. Transplant coordinators are considered so important to the care of these patients that transplant centers are required to have at least one transplant coordinator by federal regulations.

The role of the transplant coordinator, however, is not well defined. Although many of the role dimensions attributed to transplant coordinators are consistent with nursing practice, the role has not been clearly identified as being exclusively within the domain of nursing. Research regarding the role is scarce, particularly research identifying the value of the role in promoting patient outcomes. Most glaringly absent are reports of the patients' experience with transplant coordinators and their expectations of the coordinator. This gap in knowledge effectively silences the voice of the patient in defining the role and limits the ability to define the role using a patient-centered approach.

Twelve kidney transplant recipients who received transplants at eight different transplant centers were interviewed. The participants were interviewed about their experiences and interactions with transplant coordinators. The data from these interviews were conceptualized as a Basic Social Process. Using classic grounded theory

methodology, the data from these interviews were analyzed. The resultant theory was Easing My Burden. The theory explains that, for the participants, end stage renal disease represented a Basic Social Psychological Problem. The Basic Social Process between the patient and the transplant coordinators, if successful, resulted in the development of a trusting relationship which in turn, eased the patient's psychological burden of end-stage renal failure.

Findings of this study offer previously unpublished insight into the relationship between transplant recipients and their transplant coordinators. The results are useful in public policy, nursing practice, and management as well as suggesting future research.

CHAPTER ONE

INTRODUCTION

Problem Statement

Kidney transplantation offers individuals with end stage kidney failure the option of extended life or improved quality of life (Wolfe, Merion, Roys, & Port, 2009). In 2013, there were over 100,000 individuals waiting for kidneys (United States Department of Health and Human Services, Division of Transplantation, 2015) and over 200,000 individuals living with functioning kidney allografts (Matas et al., 2015). Kidney transplantation is highly regulated under the federal government. Two branches of the Health and Human Services administration, Health Resources Services Administration (HRSA), Division of Transplantation and the Centers for Medicare and Medicare Services (CMS), regulate access to deceased donor organs, living donor transplantation, and reimbursement for transplantation. HRSA grants organ allocation control via sub-contract to the United Network for Organ Sharing (UNOS). Hospitals must be members in good standing of UNOS to be allocated deceased donor organs and to perform living donor organ transplant procedures. Member organizations must meet a variety of structure and process requirements delineated in its bylaws and policies (United States Department of Health and Human Services, Division of Transplantation, *n.d.*). Similarly, CMS certifies transplant centers to be eligible for reimbursement. The Conditions of Participation for Transplant Centers (U.S. Department of Health and Human Services,

(CMS), 2007) contain highly prescriptive requirements regarding structure, processes, and outcomes for certification. Both UNOS and CMS require that at least one clinical transplant coordinator be part of the transplant care team. The number of clinical transplant coordinators caring for patients is not known, however based on data from the United Network for Organ Sharing (UNOS) voluntary staffing survey, it is estimated that there are approximately 1,283 transplant coordinators working in American kidney transplant centers (J. Maghirang, personal communication, March 24, 2015). Although the role of the transplant coordinator is considered essential to the care of transplant candidates, recipients and live donors by the two major regulators of organ transplantation, neither of these regulators have provided clear definitions of transplant coordinator licensure, scope, or staffing levels. This lack of clarity is in stark opposition to the rigid education and experience requirements for medical and surgical directors in transplant centers. Similarly, professional organizations such as the North American Transplant Coordinators Organization (NATCO) and the International Transplant Nurses Society (ITNS) have failed to develop a cohesive definition of scope of practice, licensure or educational preparation (McNatt, 2008). Both CMS and UNOS requirements specify that the coordinator hold a clinical license but do not specify the profession. Furthermore, the only professional certifying organization (American Board of Transplant Certification, 2010) allows an individual to sit for the certification examination without holding any license.

Most transplant coordinators are registered nurses and much of what is described as the work of the transplant coordinator in the literature and regulations is consistent with

nursing practice (McNatt, 2008). Many of the reported dimensions of the role also correspond with the nursing domains of care coordination as identified by the American Nurses Association (2013).

The title of transplant coordinator represents what Abbott (1988) described as an unprotected name. This unprotected name poses a risk to patients and the profession in several ways. With no assurance of consistency in the professional status of the coordinator, the patient has no reference point from which to form expectations of the care to be received by the individual transplant coordinator. Additionally, if the role has no particular professional underpinnings, the actual care delivered by each transplant coordinator will likely vary. Furthermore, the professional status of the transplant coordinator assigned to a particular patient could be stratified based on the patient's payor or socioeconomic status. The unprotected name is also a risk to the profession of nursing. If nursing fails to claim jurisdiction to the role, subordinates or any other profession could claim jurisdiction of the name and the tasks attributed to the role. This risk makes this unprotected name an issue for all of nursing.

The failure to structure the role under nursing limits the ability to influence outcomes at a systems' level. However, a more prominent limitation to improving patient outcomes is the glaring absence of research on the patient's perspective on the care delivered by transplant coordinators.

Background

The role and scope of the transplant coordinator is inconsistently portrayed in the literature. The role is described as containing a wide range of tasks and functions. The

majority of tasks and functions delineated could be placed in one of two broad categories: providing direct patient care and coordinating patient care (McNatt, 2008). Although the majority of individuals in transplant coordinator roles are nurses, the role has not been identified as exclusively within the domain of nursing or any other profession (International Transplant Nurses Society, 2009; Vincent, Repper, & Peters, 2002). Certification does not require a license of any kind, but rather 12 months experience in vascularized organ transplant to qualify for the American Board for Transplant Certification (ABTC) certification (American Board for Transplant Certification, 2010).

Coordinating patient care was established as a national priority by the Institute of Medicine (2001; 2003a; 2003b) as well as the Agency for Healthcare Research and Quality (United States Department of Health and Human Service, 2013). In the non-transplant literature, care coordinators or the similar role of case managers, are described as predominantly, but not exclusively, registered nurses practicing in a variety of roles and practice arenas; in some cases blending coordination with other roles and in other instances, holding dedicated coordination roles (R. S. Brown, Peikes, Peterson, Schore, & Razafundrakoto, 2012; E. A. Coleman et al., 2004; Doty, Fryer, & Audet, 2012; Harbrecht, 2012; Institute of Medicine, 2003b; Jamison, Ross, Hornberger, & Morse, 1999; Lamb & Sofaer, 2008; Nutt & Hungerford, 2010; Peikes, Chen, Schore, & Brown, 2009; K. Robinson, 2010; U.S. Department of Health and Human Services, Healthcare Systems Bureau, Division of Transplantation, 2009).

The lack of a clear role definition leaves the title “transplant coordinator” vague and somewhat meaningless to the patient and others. The patient can have no confidence

that the person identified as a transplant coordinator is a registered nurse, a social worker, or an unlicensed staff member and therefore no confidence that the transplant coordinator has undergone the appropriate clinical education required for patient management.

The role of the transplant coordination evolved with the use of transplantation as a treatment for end-stage kidney disease in the 1960s. The appearance of this role and its evolution is consistent with many of the concepts delineated by Abbott (1988) in his essay describing the system of professions. Abbot described several phenomena in the workplace including professional regression, degradation, and workplace assimilation.

Transplant surgeons practicing in academic medical centers recognized that transplant patients required more care before and after surgery than did traditional surgical patients (Shafer, 2006; Vincent et al., 2002). One writer (Shafer) suggested that the transplant coordinator performed all the tasks that the surgeon did not want to perform; that all care exclusive of the surgery itself was the domain of the coordinator. The coordinators performed work that the surgeons chose to delegate. This work was described as including initial evaluation of patients, coordinating inpatient care, managing care in the post-transplant period, maintaining the recipient waiting list, and coordinating procurement and transplant events (Beaver et al., 1995; Haggerty & Harris, 1990; International Transplant Nurses Society, 2009; Shafer, 2006; Vincent et al., 2002). This delegation of tasks is consistent with Abbott's concept of professional regression. Abbott theorized that professionals tend to stratify internally, with those at the highest workplace status level practicing in the most purely professional environment or with less interaction with the public. Those in the profession who are able to practice purely using

the knowledge of the profession, with minimal outside influence achieve a higher workplace status than those in frontline service. Thus academic surgeons hold relatively high workplace status as their primary practice theater is the highly controlled operating room, practicing on an unconscious patient; a much more purely professional practice than that of the internist who regularly must interact with senescent patients in a less controlled environment. Given this perspective, it is not surprising that academic surgeons would delegate most of the frontline interactions to subordinates or physicians of lower workplace status as it is defined by Abbott. In the early days of transplantation, these tasks were performed solely by the coordinator. In latter times, physicians of relatively lower workplace status, in terms of Abbott's theory, such as nephrologists, have assumed some of this frontline work. This internal stratification has occurred at the nursing level at some transplant centers. Hoy and colleagues (Hoy, Alexander, Payne, & Zavala, 2011) described the nursing staffing mix at 21 transplant centers from across the country as reported by survey respondents. These respondents reported staff models composed of unlicensed staff, licensed practical nurses, registered nurses and advanced practice nurses. Without clear role boundaries, this stratification could continue to push more role functions to individuals without the appropriate professional preparation.

The work given to coordinators also illustrates another phenomenon that occurs in professions that Abbott (1988) labeled as degradation. In this process, professionals tend to delegate routine tasks and retain those that are not routine. In most cases, Abbott posited that this process often leads to a division of labor, as it did in the case of

transplant coordinators. The more routine tasks of the care of transplant candidates and recipients were delegated by the surgeons to the transplant coordinators.

The role developed differently at each transplant center based on the needs of the surgeon or institution, resulting in a role that is not consistent in regards to functions, educational, and vocational backgrounds, and compensation across centers (Vincent et al., 2002). This divergence of roles is the result of multiple instances of what Abbott (1988) described as workplace assimilation. In describing how professionals operate in the workplace, Abbott observed that the delegation of tasks in the workplace is often based on organizational needs and individual competencies, not on the formal professional roles or even job descriptions; professional boundaries are often blurred based on situation-specific needs. In the early transplant centers, there was more professional work, such as post acute hospitalization medical management, than the transplant surgeons could or chose to perform and thus this work was delegated to transplant coordinators, regardless of their actual licensure or qualifications. And, as Abbott described, tasks associated with a profession are assumed by individuals without formal disciplinary preparation, these individuals often develop expertise or a “craft version” (p.65) of that profession’s disciplinary knowledge. Abbott labeled this process of knowledge transfer “workplace assimilation” (p. 65). Thus, within the workplace, individual transplant coordinators negotiated roles that fit the needs of the institution and learned to fulfill these role expectations by on-the-job training. Abbott also recognized that workplace assimilation creates a tension between the public image of professions and the workplace realities. He observed that professionals attempt to mitigate this tension in

the public arena by either emphasizing the traditional professional boundaries to protect jurisdictional turf or by emphasizing the assimilation in an attempt to expand their boundaries. Abbott offered psychotherapy as an example of workplace assimilation. The public jurisdiction of psychotherapy was restructured when eligibility for third party payment was successfully moved from solely psychiatry (medicine) to include social workers and psychologists who had learned the art on-the-job. Early in development of the transplant coordinator role, nurses who became transplant coordinators developed a craft version of transplant medicine from physicians. Similarly, if nursing licensure is not required to be a transplant coordinator, workplace assimilation from nursing to other professions or unlicensed professionals may also be occurring. What nursing is risking by not claiming sole jurisdiction of the transplant coordinator role is that some other group may attempt to claim jurisdiction. Thus defining and claiming this role under nursing has significance for the entire profession as well as for patient care.

Role Definition

The scholarly approach to role definition is often accomplished by the job analysis or survey. The job analysis is a survey of individuals and in some cases, their supervisors, in a particular role or job that is used to elucidate job and role elements (Brannick & Levine, 2002). Traditionally, the job analysis survey is used to validate job-related competency examinations (Chornick & Yocom, 1995; Swindle, 2011). However the job analysis has also been used in nursing to describe nursing roles in specialties (Hackbarth, Haas, Kavanagh, & Vlasses, 1995; Ishihara et al., 2004; Salazar, Kemerer, Amann, & Fabrey, 2002). Although valuable, the job analysis provides only the perspective of those

delivering care, not that of the recipients of that care. The Clinical Transplant Coordinator certification examination is based on a job analysis (American Board for Transplant Certification, 2010). A true patient-centered care approach to defining the role demands the inclusion of the patient's perspective. Patient-centered care is also a recommendation of the Institute of Medicine (2001; 2003a; 2003b) and also a cornerstone of current health care reform (Patient Protection and Affordable Care Act, 2010; Thorpe & Ogden, 2010). Shaller (2007) pointed out that our current health care system was "not even close" (p. 5) to being truly patient-centered. Shaller also emphasized the need for systems and processes that support and nurture patient-centered care.

Donabedian (1992) and others (Davies & Ware, 1988; Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993) proposed that health care quality has two dimensions: the technical domain, primarily judged by the professionals, and the interpersonal domain, evaluated by the consumers. Donabedian also observed that the benefits of truly meeting patients' expectations extended beyond the patients' resultant satisfaction to favorable outcomes such as improved psychological well-being. He posited that patient satisfaction with the process of care also contributed to the care itself and subsequently, outcomes, as satisfaction motivated the patients to seek care and collaborate with care givers. This element of patient satisfaction seems particularly relevant given the longitudinal nature of transplantation care, the need for perpetual care and the necessity of adherence to medication regimens. Knowledge about the patients' experience and expectations of care received from transplant coordinators is an essential component of defining the role itself.

Patient centered care is care that respects the patients' needs and preferences

(Gerteis, 1993; Institute of Medicine, 2001). Dubois and colleagues (Dubois, D'Amour, Pomey, Girard, & Brault, 2013) conceptualized nursing care performance from a systems perspective using the works of both Donabedian (structure, process, and outcomes) and Parson's social action theory. The authors' emphasized that patient-centered care was a hallmark of nursing care, but that the quality of that care and ultimately the patient experience and outcomes of care was contingent on the structural aspects of the environment in which the nurse practices. The gap in knowledge of the patient experience, along with the lack of formal claim of transplant coordination under nursing, hinders the ability to design, maintain, and evaluate role competencies and work environments and care processes to effectively improve patient outcomes. These gaps also hinder the ability to effectively measure the performance and the value of the coordinator's contribution to patient outcomes.

Despite the importance of the patient's perspective, review of the literature revealed a paucity of knowledge concerning the patients' experience of care with transplant coordinators. This void in knowledge means that the voice of the over 200,000 individuals that are being cared for by transplant coordinators has not been heard. Research directed at filling this gap in scientific knowledge is needed as an essential component of clearly defining the role as well as developing measures of effectiveness.

Significance

Significance to Nursing

The current state of the transplant coordinator role is significant to nursing in two ways: lack of visibility of the value of the coordinators, who are primarily nurses, to

patient outcomes and the threat of unprotected name. There were very little data in the literature linking transplant coordinator work environment or practice to patient outcomes. This gap also relates to the unprotected name. If there is no evidence that transplant coordinators contribute to outcomes and the role is not claimed by nursing what barrier exists to put less qualified, less expensive personnel in the role? The significance of an unprotected name and the threat of others claiming jurisdiction is that the others claiming jurisdiction may not have the capacity to meet all of the needs of transplantation patients.

An example of an attempt of others to claim jurisdiction over the role is the effort by NATCO and ABTC to claim transplant coordination as a government-sanctioned profession by way of regulation. Jurisdictional claims between professions are sometimes attempted by organizations (Abbott, 1988). The creation of NATCO as the professional group for transplant coordinators outside of nursing and the subsequent development of non-nursing certification was an attempt to establish a new profession with its own jurisdiction. During the public comment period, prior to publication of the final Medicare Conditions of Participation for Transplant Centers (U.S. Department of Health and Human Services, (CMS), 2007), NATCO and the ABTC attempted to enclose their claim to the transplant coordinator role by proposing that ABTC certification be the required credential for the clinical transplant coordinator recognized in the Final Rule (Shafer, 2006). This proposal was contained in the public comment draft, but after public comment, it was removed in the Final Rule. This government regulatory decision, in effect, stopped these organizations from enclosing the transplant coordinator role within

their jurisdiction. Writing in the 1980's, Abbott (1988) pointed out that as the state , referring to the federal government, carries increasing stakeholder status in a profession, it will have more interest in resolving jurisdictional claims. He predicted that ultimately the state would become the chief negotiator in American health care. This prediction has become increasingly true in light of health care reform in general and specifically true in organ transplantation; where two government entities have created very prescriptive regulations around structure, processes, and outcomes.

An example of government-mandated boundary changes in nursing was found in the British nursing literature. Harmer (2010) described an identity crisis in British nurses due to jurisdictional boundary blurring as government health policy makers mandated both the expansion of nursing into traditional medical domains such as managing medications and the delegation of traditional nursing duties to non-nurses. The result of this more complex and varied role of nurses was described as providing the public with multiple images of nursing and was perceived as weakening nursing's brand (Maben & Griffiths, 2008). The preponderance of nursing role titles without underpinning licensure requirements was also discussed as a threat to nurses' public identity. The government-mandated rise of the health care assistant was explicitly discussed as possibly representing a claim into British nursing jurisdiction by one author (Waldie, 2010).

Although ABTC's bid to claim sole jurisdiction by regulatory settlement failed, the role of the transplant coordinator continues to not have a distinct "brand." Individuals with varied preparation and licensure practice under the role. Medicare's requirement for

a non-specific healthcare license could be considered thin protection against another profession, such as social work, attempting a claim.

To date, the majority of nursing's professional groups have failed to demand jurisdiction of the role; leaving it open to new attempts by others at claiming jurisdiction of the transplant coordinator role. In 2009, the American Nurses' Association recognized transplant nursing as a nursing specialty and published a scope and standards document (International Transplant Nurses Society, 2009). The document described several different transplant nurse coordinator roles, but the fact that not all coordinators are nurses was acknowledged without comment. The authors also named the ABTC transplant coordinator certification as a specialty certification that transplant nurses could pursue, without noting that this certification is not a nursing certification. Rather than attempting to enclose the role within the domain of professional nursing practice, it appears that workplace assimilation was accepted rather than challenged. However, recently, the International Society for Heart and Lung Transplantation (B. Coleman et al., 2015) published a consensus statement on adult cardiac and lung transplant nursing. The group recommended that transplant coordinators be registered nurses with a minimum of a baccalaureate degree in nursing and two years nursing experience. The consensus group also recommended that coordinators earn the Certified Clinical Transplant Coordinator credential without commenting that this certification is not a nursing certification. The current lack of clarity in the role that appears to have nursing dimensions but is not clearly claimed to be within nursing's jurisdiction, blurs the public image of nursing. Patients receiving care from transplant coordinators, even if they are certified, cannot be

assured that the individual holding this title is a nurse, an unlicensed staff member, or a physical therapist. Maintaining jurisdiction of a profession requires constant maintenance (Abbott, 1988). To achieve this end, the core, essential dimensions of the role need to be defined and those dimensions claimed to be either within or not within the domain of nursing practice. For example, care coordination is a prominent role dimension of the transplant coordinator (McNatt, 2008) many care coordination domains have been claimed under nursing by the American Nurses Association (2013). Given the emphasis on care coordination in the Patient Protection and Affordable Health Care Act (2010), maintaining nursing jurisdiction in the area of care coordination is an important for all American nursing. The American Academy of Ambulatory Care Nursing (Haas, Swan, & Haynes 2014) has developed and published a Care Coordination and Transition Management (CCTM) Core Curriculum, as well as Scope and Standards for CCTM and the Academy of Medical Surgical Nursing is developing a certification exam for CCTM (S. Haas, personal communication April 14, 2015).

However, the role of care coordinator, navigator, or transition coach is not clarified in non-transplant literature. Care coordination has been described as being performed by physicians (Doty et al., 2012; Harbrecht, 2012), advanced practice nurses (E. A. Coleman et al., 2004; Nutt & Hungerford, 2010; Palfrey et al., 2004; K.M. Robinson, 2010; Schram, 2012), registered nurses (R. S. Brown et al., 2012; Jamison et al., 1999; Lamb & Sofaer, 2008; Nutt & Hungerford, 2010; Peikes et al., 2009; Presler, 1998; K. Robinson, 2010; Sussman et al., 2011) and other individuals such as licensed practical nurses (Peikes et al., 2009), social workers (E. A. Coleman, 2003) or social

worker/RN teams (Betz & Redcay, 2005; Lindeke, Leonard, Presler, & Garwick, 2002; Stille & Antonelli, 2004) and non-licensed staff (Harbrecht, 2012). Nutt and Hungerford also described the difficulties caused by both the lack of clear role definition and title protection in the care coordinator role in Australia. Similarly with care navigators, Paskett and colleagues (Paskett, Harrop, & Wells, 2011) performed a literature review on the qualifications of navigators in cancer care and reported that most navigators were either nurses or lay/community health workers. The use of non-nurse navigators in transplantation has also been reported (Sullivan et al., 2012).

Significance to Patients

Ultimately, the patients hold the biggest “chit” in defining the role of the transplant coordinator. The inconsistency in the role definition, practice standards, licensure and educational preparation poses the biggest risk to patients. Unfortunately, there is very little in the literature describing the transplant patients’ experience with transplant coordinators or delineating specific biometric or patient-defined outcomes related to the care that they have received from transplant coordinators. The evolution of this role based on the needs of the surgeons and workplace assimilation was provider-centric, with the roles and tasks negotiated within and between the professionals themselves. Integral to the current health care reform movement is the concept of patient-centered care (Patient Protection and Affordable Care Act, 2010; Institute of Medicine, 2001; Institute of Medicine, 2003a; Institute of Medicine, 2003b; Thorpe & Ogden, 2010). Ultimately, the needs of the patients must be the key determinant in which

profession should gain jurisdiction over the transplant coordinator roles and in the structure of the work environment and care processes for transplant coordinators.

Another important element of health care reform is cost control (Patient Protection and Affordable Care Act, 2010). This tightening of resources may pose another risk to patients if a clear jurisdictional claim to role is not made. In cases of constraints of either resources or in the number of professionals themselves; jurisdiction may be established by client differentiation (Abbott, 2008). Abbott described the phenomenon of client differentiation as occurring when multiple professionals of different levels having overlapping jurisdictions differentiate themselves by the clients that they serve. The highest level or superordinates serve the higher status clients and subordinates serve the lower status clients. An example of this phenomenon can be found in counseling. Psychiatry, psychology, social work share overlapping jurisdictions in the service of counseling. Over time, a clear hierarchy has been established between the clients each profession serves, primarily stratified along socioeconomic lines, with welfare recipients receiving counseling from non-licensed staff and the highest socioeconomic groups receiving counseling from psychiatrists. Could stratification based on the patients' payor or socioeconomic statuses determine the professional status of the coordinator assigned to them if role jurisdiction is not clearly established? What prevents this from occurring now? There is evidence in the literature that patients with private insurance have better outcomes than those with Medicare or Medicaid (Kalil, Heim-Duthoy, & Kasiske, 1992). Evidence regarding both the technical/professional and the interpersonal components of the care delivered to transplant patients by transplant

coordinators must be established to ensure that every patient receives care from the best qualified professional, rather than on the basis of their ability to pay or their payor.

The lack of consistency in licensure, education, certification and practice standards also pose a risk to patient safety and quality. This risk exists as the practice of transplant coordinators has no consistent source of disciplinary knowledge, professional or regulatory oversight.

Purpose of the Study

The purpose of this study was to begin to fill the gap in the scientific knowledge about how kidney transplant recipients experience receiving care from individuals in the transplant coordinator role. The researcher's review of the literature (Chapter Two) revealed very little evidence of the patients' experience with transplant coordinators. Transplantation care is longitudinal, stretching out from referral to waiting on the list to transplantation or death and finally to the post-transplant phase to loss of organ function or death (W. Paris et al., 1995). This care has also been described as a process in which the patient and members of the health care team form a relationship (J. Brown, et al., 2006). This longitudinal, relationship-forming care process is consistent with Glaser's (1978) definition of a Basic Social Process. Care delivered by transplant coordinators has a beginning and an end and changes over time. Thus by conceptualizing the process of care received by the kidney transplant recipient as a Basic Social Process, the grounded theory method may be used to generate theory to explain the process (Glaser).

The research question for this study was: What is the patients' perception of the Basic Social Process between kidney transplant recipients and transplant coordinators?

The resultant theory could be used to inform practice, future research and policy development regarding the interpersonal component of the transplant coordinator role.

Summary

This chapter provided an overview of the clinical transplant coordinator role in American transplant centers. Two problems with the role were identified; lack of consistency in the role itself and lack of knowledge of the patients' experience and outcomes associated with transplant coordinators. The role is required in transplant centers, yet not claimed or assigned to a single profession, despite many of the role dimensions such as direct patient care and care coordination being consistent with nursing practice. The evolution of this role was explained using the theory regarding professional systems posited by Abbott (1988). Additionally, the threat of jurisdictional claim was described. The ambivalent status of the transplant coordinator role is ripe for claims by other professions or groups; one failed attempt at such a claim was described. A successful claim would have implications to all of nursing and for transplant patients. This threat also extends beyond transplantation as similar inconsistencies appear to exist in the important evolution of the roles of the care coordinator or care navigator. The inconsistencies in the role pose a threat to the overall quality of care.

Including the interpersonal or patient experience component of quality and patient-centered care when one is defining the role was also described. A review of the literature revealed a paucity of knowledge of the patients' experience with transplant coordinators. This knowledge gap needs to be addressed before a truly patient-centered transplant coordinator role can be defined. Examining the patients' perception of the

process of care as well as their needs and expectations of this care relationship is essential to determining how the role should be practiced, the structures necessary for optimal practice and to establishing the value of the role. Towards this end, the patient experience with transplant coordinators was conceptualized as Basic Social Process. Developing a substantive theory regarding this process was proposed to narrow this gap.

CHAPTER TWO

LITERATURE REVIEW

Introduction

A search of the health care and regulatory literature regarding the role of the transplant coordinator was undertaken to assess current knowledge and practice. The following databases were included: Academic Complete, CINAHL, ERIC, Medline, Health Source Nursing/Academic from 1985 to present and limited to peer reviewed texts. The search terms: “transplant coordinator,” “transplantation,” and “nursing” were used. The search revealed 165 articles, 75 were relevant to organ transplantation nursing or transplant coordinator practice. Additional sources were found using the references of these documents. Additionally the relevant CMS and UNOS regulatory documents as well as professional websites and publications from the ITNS, NATCO, and ABTC were reviewed. A second search using the same databases was performed using the search terms “patient experience,” “patient satisfaction,” “interviews,” and “transplantation.” A total of 104 articles were found, only two mentioned patients’ report on their experiences with transplant coordinators.

Definition and Practice of the Transplant Coordinator

The term transplant coordinator defines two subsets of roles; procurement coordinator and clinical coordinator (American Board for Transplant Certification, 2010; Vincent, et al., 2002). The role to be investigated in this study is the clinical

transplant coordinator role. Transplant coordinators have been called the “hub of the wheel that holds all the spokes together” in the transplant process (Shafer, 2006, p. 9), de facto managers of the transplant team (D. Paris et al., 1998), and “critical to all endeavors in transplantation” (Vincent et al., 2002, p. 212). Regulatory bodies such as the United Network for Organ Sharing (UNOS) define the transplant coordinator as “a designated member of the transplant team and will be assigned primary responsibility for coordinating clinical aspects of care” (United States Department of Health and Human Services, Division of Transplantation, *n.d.*, Appendix B, p. 10). The Centers for Medicare and Medicaid Services (CMS) (U.S. Department of Health and Human Services, CMS, 2007) defined the qualifications of the clinical transplant coordinator as a registered nurse or other licensed clinician with “experience and knowledge of transplantation and living donation issues” (p. 15236). Both UNOS and CMS require clinical transplant coordinators to be part of a transplantation multidisciplinary care team throughout all phases of care for candidates, recipients, and living donors. The disciplines mandated to be in the team are: medicine, social work, pharmacy, and nutrition. Financial counselors are also required by UNOS.

NATCO is the professional organization for transplant coordinators. On its website (North American Transplant Coordinators Organization, *n.d.*) the role of clinical transplant coordinator is described as an individual who manages the candidate evaluation process, monitors patients’ health statuses and adjusts waitlist status accordingly, and who manage care of recipients post-transplantation. In the ABTC (American Board for Transplant Certification, 2010) Clinical Transplant Coordinator examination content outline, which is based on a national job analysis, two major content

areas are delineated: evaluation and preparation for transplantation and post-transplant care. The pre-transplant job tasks include determining suitability for transplantation or donation; maintaining the organ wait list and preparation and education of transplant candidates and potential living donors. Post transplant job tasks described in the document included monitoring, evaluating and reporting, as appropriate, the postoperative organ function and complications of both donors and recipients; providing discharge instructions, coordinating post-hospitalization care and facilitating rehabilitation of patients.

The transplant coordinator role is also described in the scope and standards of transplant nursing document, co-published by the American Nurses Association and the International Transplant Nurses Society (International Transplant Nurses Society, 2009). The scope of recipient and living donor roles were described as assessment and management of a variety of processes including managing the recipients' health, educating patients and families, serving as patient advocates, and offering emotional support to patients and families. Other role expectations such as participation in research and serving as a consultant to other healthcare providers and the community are also cited.

To summarize, based on the professional practice of transplant coordinators described in the descriptions and definitions in the literature, the following definition is proposed: The transplant coordinator is an individual who provides and coordinates care for transplant candidates, recipients, potential and actual living donors, and their respective families throughout the transplant process; a process that extends from referral

to death or loss of organ function. As with other professional roles, practice may also include community service and research.

History

The evolution of the role began alongside the sub-specialty of organ transplantation in the 1960's (Shafer, 2006; Vincent et al., 2002). The role developed largely out of the need for the performance of a collection of varied non-surgical tasks prior to and after the transplant procedure (Shafer, 2006; Vincent et al., 2002). Shafer described one coordinator as stating that as the transplantation surgery was "the surgeons' domain, care of the recipients was largely the responsibility of the watchful transplant coordinator" (Shafer, 2006, p. 28). Vincent and colleagues (2002) suggested that the definition of the role had developed on a somewhat ad hoc, center-to-center basis and that this pattern of development had led to a lack of uniformity in role functions, educational and vocational backgrounds, and compensation. In other words, the transplant coordinator roles did not have an overarching framework, but evolved differently in each situation based on the both the skills and proclivities of the individual coordinator and the needs of the individual center. Whatever tasks or responsibilities that surgeon chose not to perform were absorbed by the transplant coordinator. Transplant surgeons looked for individuals who could multitask and utilize skills from several different professions such as medicine, nursing, and social work, to coordinate care (Shafer, 2006).

NATCO was formed in 1979 (Shafer, 2006). In 1986, NATCO developed standards of practice (no longer in use) and funded the development of The Board for Transplant Coordination (ABTC) to develop a certification process for transplant coordinators (Shafer, 2006). The ABTC became independent in 1988; it is now known as

the American Board for Transplant Certification and offers certification for transplant staff nurses, procurement coordinators, and clinical transplant coordinators. There are currently 1,250 certified clinical transplant coordinators (C. Miller, personal communication, February 23, 2015).

In 2009, the American Nurses Association recognized transplant nursing as a specialty and ITNS published the scope and standards of practice for transplantation nursing (International Transplant Nurses Society, 2009). The transplant coordinator is identified as a distinct role within the specialty. Three sub-roles are described: procurement nurse coordinator, living donor nurse coordinator, and recipient nurse coordinator. The scope of the latter two roles includes assessment and management of patient's health and response to interventions, consistent with professional nursing practice (ANA, 2010). Interestingly, the authors do not specify that the coordinator role is exclusively a nursing role. The authors concede that although most transplant coordinators are registered nurses, some are not and made no comment on this paradox: "Most transplant coordinators, wherever they practice around the world, are registered nurses, but they may be licensed as other healthcare providers, for instance paramedics" (p.10). This concession represents a missed opportunity to enclose the practice of the transplant coordinator within nursing. However, as stated in the introduction, the International Society of Heart and Lung Transplantation (B. Coleman et al., 2015) has recently recommended that heart and lung transplant coordinators be registered nurses.

Role Dimensions

Dimensions or characteristics of a role are described to more fully explicate the tasks, and the cognitive, affective, and behavioral activities of a particular role

(Hackbarth, Haas, Kavanagh, & Vlases, 1995). Similar activities and tasks are often categorized or grouped together to delineate scope, delegation to non-licensed staff, and necessary competencies (Acuna, Juristo, Moreno, & Mon, 2005; Hackbarth et al., 1995). Claiming professional jurisdiction of particular tasks is one of the ways that professions define themselves (Abbott, 1988). A variety of role dimensions for the clinical transplant coordinator are described in the peer reviewed and “gray” literature, including care manager, care coordinator, care provider, and educator.

Professional and regulatory literature role dimensions. In UNOS (United States Department of Health and Human Services, Division of Transplantation, *n.d.*) policy, the role is described as occurring in three phases. In the candidate phase, the coordinator role is described as assuring the performance of diagnostic studies, educating patients and families, assisting in living donor evaluation and selection, and monitoring patients’ status during evaluation and waiting periods. During the inpatient phase, the coordinator is described as facilitating staff, patient, and family education and serving as a communication conduit between the health care team and the patient and family and between the transplant team and the referring physicians. Discharge planning is also described as part of the role. In the recipient or post-transplant phase of care, transplant coordinator role expectations include monitoring of diagnostic studies, evaluating the recipients’ health status, coordinating comprehensive care and communicating concerns to transplant physicians.

The American Board for Transplant Certification (2010) offered a variety of role functions in its Candidate Handbook: planning, conducting, and evaluating educational activities for patients, families, health care professionals and the public; collecting and

evaluating data pertinent to potential organ donation and transplantation; assessing the suitability of and preparing the potential transplant recipient and live donor for solid organ transplantation or donation; applying recipient and deceased/live donor selection criteria at time of transplant; coordinating preoperative care for live donors and recipients; monitoring, evaluating, and reporting post-operative organ function; identifying complications in the post-transplant patient; providing discharge education to recipients and families; and coordinating post-transplant care.

Peer reviewed literature role dimensions. There were two studies in the peer reviewed literature that described transplant coordinator role functions. Beaver and colleagues (1995) studied liver transplant coordinators. The researchers used a questionnaire to explore educational preparation, program requirements, job responsibilities, motivation to become transplant coordinators, population served and quality assurance metrics used. Seventy-four coordinators from 46 centers responded to the questionnaire; the response rate was not reported. Job functions varied from direct patient care to research as well as public and staff education. Although 25% of respondents reported that their center had no formal quality assurance program or left the item blank, some coordinators also reported a variety of quality control or quality assurance tasks such as chart audits and attending or leading formal quality meetings.

Vincent and colleagues (2002) conducted a survey of 1661 transplant coordinators who were members of the NATCO in July 2000. The response rate was low (26%). The majority of these respondents were involved with kidney transplantation and reported responsibilities in both the pre-transplant and post-transplant phases of care. Functions reported included patient education, coordination of the evaluation of

candidates, coordination of complex care, receipt of organ offers, and facilitation of hospital admissions. Interestingly, nearly half of the respondents stated that the recipients' health care in the transplant clinic was primarily managed by a nurse, although very few respondents described themselves as holding advanced degrees or licensure, which is generally required to manage patient care. The dilemma of blurred boundaries between registered nursing practice, advanced practice nurses, and physicians was also described by the International Society for Heart and Lung Transplantation nursing consensus group (B. Coleman et al., 2015).

Haggerty and Harris (1990) described the transplant coordinator as educator, consultant, and researcher. Other dimensions mentioned in the literature included: financial counseling, (S.E. Ehlers, 2002; Beaver et al., 1995) and policy development (J. Bell, 2004; Shafer, 2006). Transplant coordinators are also described as monitoring both waitlist patients and recipients remotely (CMS, 2007; Kim, 2013; McBride, Kelley, Lonergan, & McCann, 1994;; Ohler & Daine, 2001; Zarifian & O'Rourke, 2006). This remote monitoring often extends to taking after-hour and weekend call. Although not well-described in the literature, this call may entail arranging taking organ offers and arranging admissions and/or triaging patient calls about symptoms. Call has been associated with burnout and turnover (B. Coleman et al., 2015; Kim, 2013). Transplant coordinators are also reported as directing the evaluation of and providing education and counseling to potential living donors (Kim, 2013; Lanza-Humphrey, 2014). Transplant coordinators caring for pediatric patients play the important role in facilitating these patients' transition to adult care (Lerret & Weiss, 2011; Lerret et al., 2014; Lerret et al., 2012).

The literature was also replete with references to the transplant coordinator as an educator; a dimension consistent with the transplant nursing standard mandating health teaching and promotion (International Transplant Nurses Society, 2009). Transplant coordinators were cited as essential in educating patients about a range of health-related issues including herbal supplements (Weeks et al., 2001), the use of over-the-counter medications (Ellingson, Wipke-Tevis, Messina, & Livesay, 1999), and the risks of raw shellfish (Tuttle, Kellerman, & Tauxe, 1994). Integrating ethics into practice was also identified as a role standard (International Transplant Nurses Society, 2009) and was described in the literature (Irwin, 1986; O'Rourke, Arnott, & Goldman, 2003).

Another dimension of the role includes participation in the candidate selection process. The vital role played by coordinators in determining candidates' eligibility for transplantation as part of interdisciplinary selection meetings (Corley et al., 1998; Kim, 2013; Neil & Corley, 2000); was also discussed in the literature.

Non-compliance with long-term treatment, particularly with medications, is a major cause of transplanted organ loss. Although several extensive reviews of non-compliance in transplant patients failed to mention nurses or coordinators (Achille, Ouellette, Fournier, Vachon, & Hébert, 2006; Kaul, Khurana, & Munoz, 2000; Wainwright & Gould, 1997), the role of transplant coordinators in preventing non-compliance is cited by several authors (Newton, 1999; Shallcross, 2002; Siegal & Greenstein, 1999).

Health promotion is also part of the standards of transplant nursing practice (International Transplant Nurses Society, 2009). Transplant coordinators were also cited as important in tobacco cessation programs (S.L. Ehlers et al., 2006) and in monitoring

recipients for relapse from tobacco or alcohol use. One group of researchers (Evon et al., 2005) studied these relapses and used transplant coordinators' report of tobacco use and alcohol abuse as the validation of the patients' self-report. The authors of this study also highlighted the importance of the relationship between the transplant coordinator and the patient:

Because of the close and trusting relationship that our coordinators have with the transplant recipients and their families, they are in a unique position to learn information about recipients' lifestyles during clinic visits. These visits provide the opportunity for patients and their families to discuss lifestyle and adherence issues encountered by the patient as he/she resumes life activities, and it is a good forum for family members to express their concerns if the patient is engaging in questionable (non-compliant) behaviors. (Evon, et al., p. 209)

These relationships are important as transplantation is a process, not an event (W. Paris et al., 1995). Cetingok, Hathaway, & Reed (1997) as well as Kim (2013) discussed that the transplant coordinator was often responsible for the recipient's care and the coordinator-patient relationship was key in the transplant process.

Care coordination role dimensions. As the name implies, coordination of care is a key dimension of the role. Clinical transplant coordinator participation in the interdisciplinary transplant team is mandated by CMS (U.S. Department of Health and Human Services, CMS, 2007) and is considered one of the practice standards of transplant nursing practice (International Transplant Nurses Society, 2009). This role was discussed by several authors in the literature (Ohler, 2007; Samela, Fennelly, Brosnan, & Robinson, 2005; Kim, 2013; Lanza-Humphrey, 2014; Zavala & Crandall, 2007). Coordination of the team or facilitating the entire process of the transplantation has also been described as an important component to the role (Kim, 2013, Shaefer & Williams,

1991). Neyhart, (2004) discussed the coordinator role as an “air traffic controller” (p. 337) in the transplant organ offer and procedure process.

Much of what is cited in the literature as part of the transplant coordinator role corresponds to the nursing domains of care coordination identified by the American Nurses Association (2013); specifically assessment, care planning, patient and family activation, engagement, and self-management, medication management, communication, care transitions, care management, and monitoring, follow up, and responding to change. The American Nurses Association (American Nurses Association, 2012) adopted the following definition of care coordination:

Care coordination is (a) a function that helps ensure that the patient’s needs and preferences are met over time with respect to health services and information sharing across people, functions, and sites; and (b) the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. (p.1)

Lamb and Sofaer (2008) defined care coordination as “actions initiated by nurses with patients, families and/or members of their health care team to manage and correct the sequence, timing and/or effectiveness of patient care from hospital admission to hospital discharge.” (para 9). This definition of care coordination as occurring in the acute hospital setting, similar to discharge planning was found frequently in the literature (Jamison et al., 1999;K. Robinson, 2010), although other authors described a more comprehensive role for the coordinator, a longitudinal role expanding across care settings (R. S. Brown et al., 2012; Chalmers & Coleman, 2006; Harbrecht, 2012; Nutt & Hungerford, 2010; Peikes et al., 2009; Schram, 2012; Sussman et al., 2011). This later definition is most similar to the transplant coordinator role.

In summary, a multitude of role dimensions for the transplant coordinator were discussed in the literature. The predominant dimensions described included care coordinator, team coordinator, expert care provider, educator, communicator, and health promoter. Other dimensions such as managing patients on the waitlist, discharge planning, patient advocacy, participation in research, and participating in quality assurance activities were also mentioned. These role dimensions are consistent with the ANA (2010) definition of nursing:

Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response and advocacy in the care of individuals, families, communities, and populations. (p. 3)

Additionally, the ANA standards of practice include: assessment, diagnosis, planning, outcomes identification, implementing (which includes care coordination and health education and promotion) and evaluation (ANA, 2010). These standards are also consistent with dimensions of transplant coordinator practice as described in the literature.

Educational Preparation, Licensure, and Certification

The educational preparation, professional licensure and certification of transplant coordinators as found in the literature and regulatory and professional literature was reviewed. No consensus was found.

Licensure. Both Beavers et al. (1995) and Vincent et al. (2002) found that transplant coordinators held varied professional licenses. In the Beaver et al. study of liver coordinators, 72 of the 74 respondents were registered nurses. Other backgrounds included physician assistant and licensed practical nurse. Vincent and colleagues found

that most respondents (81%) were nurses. These researchers also found a single physician, 1% of the respondents were physician assistants and the remainder of the respondents (18%) were unlicensed staff. In 2008, McNatt reviewed the literature and found a lack of consensus among the authors of the regulatory or professional literature regarding transplant coordinators' licensure.

Similarly, a nursing license is not required for an individual to be a care coordinator (R. S. Brown et al., 2012; Harbrecht, 2012; Lindeke et al., 2002; Peikes et al., 2009; Stille & Antonelli, 2004). In its white paper on care coordination, the American Nurses Association (2012), does not claim care coordination as the exclusive domain of nursing practice, but makes a strong case for nursing's role in care coordination: "For many patients, the registered nurse is the most appropriate care coordinator" (p. 2)

Educational preparation. As with licensure, education preparation of transplant coordinators was inconsistent. Researchers in the study of liver transplant coordinators (Beaver et al., 1995) reported that nearly half (46%) of the 72 registered nurses were prepared at the baccalaureate level, 30% at the master's level, the other respondents were prepared at the diploma or associate degree level or did not respond to the item. The authors of the 2002 survey of transplant coordinators (Vincent et al., 2002) also reported that half of all coordinators were prepared at the baccalaureate in nursing level and 18% of the coordinators had other nursing preparation such as associate degree, diploma, or nurse practitioner training. The authors did not specify if the nurse practitioner training was at the master's level and some respondents did not answer this question. In a single center study of compassion fatigue in kidney and liver transplant coordinators, the researcher reported 71% of the coordinators were prepared at the baccalaureate level,

14.3% held masters level degree and 14.3% were prepared at the associate degree level (Kim, 2013).

Discussion of licensure and educational preparation. Since a profession is undergirded by disciplinary knowledge (Flexner, 1915), professional licensure and requisite education should be considered together. McNatt (2008) discussed that the various role dimensions described in the literature were consistent with roles that required a broad range of education preparation and licensure. These requirements ranged from trained, unlicensed staff to master's prepared and licensed advanced practice nurses. This lack of consensus about license is also accurately reflected in the transplant nursing specialty scope and standards document: "Most transplant coordinators, wherever they practice around the world are registered nurses, but they may be licensed as other healthcare providers, for instance paramedics" (International Transplant Nurses Society, 2009, p. 10). This statement is oxymoronic to be written in a nursing specialty scope and standards of practice document. In ANA's Model of Professional Nursing Practice Regulation (Styles, Schumann, Bickford, White, 2008), the foundation of nursing practice that guides regulatory and institutional policy is the profession's own scope of practice and standards. Tacit acceptance of this incursion into what is identified as nursing practice by non-nurses represents failure to protect nursing's jurisdiction. If the practice is consistent with nursing's definition, scope and standards; the requisite licensure should be that of a registered nurse. As the preferred minimal educational level for professional nursing practice is the baccalaureate in nursing (ANA, 2010; Benner, Sutphen, Leonard & Day, 2008), this should be the minimal education requirement for transplant coordinators. This minimum level of educational preparation is the

recommendation of the International Society of Heart and Lung Transplantation for heart and lung transplant coordinators (B. Coleman et al., 2015).

Is baccalaureate preparation sufficient or are the dimensions of the role consistent with advanced nursing practice? Reviewing the literature suggested a range of disagreement. The scope and standards (International Transplant Nurses Society, 2009) do not clarify the boundaries between advanced practice transplant nurse and transplant coordinator. In the presentation of the individual role standards such as education, research etc., no distinction between the roles of advanced practice nurses and transplant coordinators is made. Neyhart (2004) discussed the evolution of the coordinator role from team coordinator in the transplant event coordination to being a specialist in pre-transplant and post-transplant care. She also pointed to the growing number of advanced practice nurses in these roles. The International Society of Heart and Lung Transplantation (B. Coleman et al., 2015) consensus group stated that although their current recommendation was that the baccalaureate in nursing be the minimum preparation for transplant coordinators, the increasing complexity of transplantation could make master's level preparation desirable.

Many of the role dimensions discussed in the literature and the published scope of practice point to a role that requires at least an expert registered nurse or what Calkin (1984) described as an expert-by-experience. Calkin's model illustrates the range of human responses, assumed to be in a normal distribution curve, to which a particular nurse could respond; with beginner (novice) nurse at one end of the curve and the advanced practice nurse at the other end. Benner (1984; 2004) also described the expert nurse in her model of skill acquisition in nursing in terms of experiential learning and the

characteristics of the nurse in each developmental stage. Expert nurse practice is an expectation in the collegiality standard for transplant coordinators explicated in the ITNS/ANA scope and standards document (2009). Calkin's model is more useful in understanding the practice of the transplant coordinator compared to staff nurses or advanced practice nurses. An expert nurse on the inpatient unit who takes the opportunity to move to a coordinator role may well move back towards the novice level until he or she has gained the experiential skills required in this new role. Benner's model is more useful in explaining how the coordinator becomes an expert.

Expert-by-experience nurses often struggle with blurred boundaries as their practice slips into the domains of advanced nursing practice or medicine. These blurred boundaries may be the result of workplace assimilation (Abbott, 1988). Nurses, physicians and other professionals negotiate their own roles within the workplace. Nurses may take on tasks within the traditional jurisdiction of medicine and develop a craft or on-the-job version of medicine. This experiential skill acquisition is also consistent with Benner's (1984; 2004) propositions. Certainly workplace assimilation and the development of craft versions of medicine and other professions was the experience of the early transplant coordinators who had responsibility for all of the care not delivered in the operating room (Shafer, 2006). In survey of transplant coordinators in New York state (Daskalakis & Sumrani, 1991), 94% of the respondents reported that they routinely wrote prescriptions, yet only 12% of them believed that they met eligibility requirements for prescriptive authority.

The International Council of Nurses (International Council of Nurses, *n.d*) defines an advanced practice nurse as:

A Nurse Practitioner/Advanced Practice Nurse is a registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context and/or country in which s/he is credentialed to practice. A Masters degree is recommended for entry level. (para 4)

The literature is replete with referencing coordinators as managing health; this concept of management is often described as an advanced practice nursing role. C. Morse (2001) described the advanced practice nursing role in the care of heart transplant patients as providing care throughout the transplant process in role very similar to that described for transplant coordinators in that the nurse was managing patients throughout the transplant process. Other authors (Eckhoff et al., 2000; McNatt & Easom, 2000) made similar observations about nurse practitioners practicing in a variety of organ transplant programs. Russell and Frieburghaus (2003) and Russell et al. (2006) described the role of the clinical nurse specialist in transplantation, emphasizing the role dimensions of educator and health promoter. Clearly, a useful role definition would differentiate between expert nurse and a nurse with advanced license and preparation. The blurring of boundaries between transplant coordinators and advanced practice nurses and the need for more explicit role differentiation was also cited by the International Society of Heart and Lung Transplantation nursing practice consensus group (B. Coleman et al., 2015).

Certification. Specialty nursing organizations recognize individual expertise through certification in the specialty (ANA, 2010). Beaver et al. (1995) found that 50% of respondents were certified transplant coordinators. The American Board for Transplant Certification (ABTC, 2010) offers certification for both procurement and clinical transplant coordinators. Neither certification requires any educational preparation or licensure of any kind; merely 12 months experience as a coordinator. In 2005, the CMS

released its first draft of the Conditions of Participation for Transplant Centers. NATCO and the ABTC successfully lobbied to have the ABTC certification included as a requirement for coordinators in this draft (Shafer, 2006), but due to opposition from the transplant community during the comment period, this requirement was not retained in the Final Rule (U.S. Department of Health and Human Services, CMS, 2007).

Commenters opposed to the inclusion of ABTC certification cited variety of rationale including doubts of the value of the certification, undue financial hardship on coordinators and transplant centers posed by certification and the fact that many transplant coordinators were nurses and held nursing certification.

Registered nurses in transplant staff nurse roles are eligible to sit for the Clinical Transplant Nurse certification examination after two years of nursing experience, 12 months of which is in transplantation. The authors of the scope and standards (International Transplant Nurses Society, 2009) described the Transplant Coordinator role as requiring “extensive experience in nursing and transplantation” (p. 10). For example, the consultation standard reads: “The transplant nurse coordinator or advanced practice registered nurse provides consultation to influence the plan of care, enhance the abilities of others, and effect changes” (p. 34). Consultation is reserved for graduate level prepared nurses in the ANA Standards (2010). One reading the ITNS standard six would find it reads that the transplant coordinator and advanced practice nurse: “evaluates the accuracy of the diagnosis and effectiveness of the interventions” (p.36) and the collegiality standard states that the transplant nurse coordinators should model “expert nurse practice” (p.41). It is not logical that the transplant coordinator, as described, would hold certification that would require no professional licensure and less experience than

the certified transplant staff nurse. Expertise in nursing practice is generally acquired with experience (ANA, 2010; Benner, 1984; 2004; Calkin, 1984). The authors of these standards for transplant coordinators implicitly and explicitly state that the transplant coordinator demonstrates expert nursing practice; therefore the transplant coordinator certification should both require a nursing license and transplant nursing experience. The certification paradox is that the staff nurse certification requires that the applicant have two years nursing experience but the transplant coordinator certification requires no clinical license of any kind and only 12 months experience. Interestingly, the International Society of Heart and Lung Transplantation consensus on nursing practice group (B. Coleman et al., 2015) recommended that transplant coordinators be registered nurses and that they earn the Clinical Transplant Coordinator certification, but failed to note that this certification is not a nursing certification.

In summary, there is no consensus among regulators or professional organizations on licensure, education, or certification for the transplant coordinator role. The current available certification does not require licensure of any kind. At least some, if not many of the dimensions of the role as well as the scope and standards suggest consistency with expert to advanced clinical nursing practice. Even with certification, the title “clinical transplant coordinator” holds no consistent meaning. These inconsistencies are a threat to quality in patient care. Clarity in defining the role and its profession including consistency in licensure, education, and certification is clearly needed.

Research Examining the Transplant Coordinator Role

An investigation into the literature on the transplant coordinator role yielded scarce results and was dominated by descriptive papers with little empirical data. In

particular, patient outcomes related to transplant coordinators or the patients' perspective of the care received by transplant coordinators was not found.

Patients' experience. There was a paucity of research regarding the patients' experience with transplant coordinators in the literature. The patients' experience with the interdisciplinary transplant team has been researched in some studies. These studies all examined care delivered by the entire team with physicians and staff nurses being the most frequently mentioned members of this team. Transplant coordinators were discussed by name in only two studies (J. Brown, Sorrell, & McClaren, 2006; J. Jones & Egan, 2000). The researchers in the first study reported that they used the transcendental phenomenological approach to study six patients waiting for liver transplantation. This study was weakened by the researchers' failure to properly apply the phenomenological methodology. The researchers' biases toward the phenomenon were evident throughout the paper, there was no mention of saturation in their sampling strategy, and the researchers failed to distill their findings into a single articulated concept (Paley, 1997). Nonetheless, the report provided rich raw documentation of the patients' descriptions of their experiences. The patients expressed the importance of developing trust in their transplant team and from that trust, developing hope. A perceived lack of attention from the transplant team eroded that trust and added to the waiting liver transplant candidates' despair. The researchers illustrated this observation by the following quote from one of the participants:

The consequence of a lack of positive care from the medical team was felt to contribute to depression, hopelessness, and worsening health: "I got to the point I believed I was not going to transplant-ever-and if I died it was going to be because of the transplant coordinator." (p. 127)

In their literature review, J. Brown and colleagues (2006) also support the claim that the transplant experience is a longitudinal process in which the patient forms a relationship with the coordinator and the transplant team. The researchers in the second study (J. Jones & Egan, 2000) explored the experiences of 20 liver transplant recipients. The researchers, social workers, reported that they used a phenomenological approach but also referenced Glaser and Strauss (1967) in the analysis section which is inconsistent with phenomenology. The results were presented as themes which are also not consistent with grounded theory, the methodology associated with Glaser and Strauss. Nonetheless, the researchers did report that the participants expressed that quality of care provided by the transplant coordinators was high, but believed that the coordinators were “overworked and overextended” (pg. 79).

Examining the literature regarding patients’ experience with interdisciplinary transplant teams provides some insight about transplant recipients’ experience of care. The findings suggest that elements of care important to the transplant patients included: trust in the health care team; (Bjørk & Nåden, 2008; J. Brown et al., 2006; del Barrio, Lacunza, Armendariz, Margall, & Asiain, 2004; Forsberg, Bäckman, & Möller, 2000; Lumby, 1997; Vermeulen, Bosma, Bij, Koëter, & TenVergert, 2005) warm, empathetic, and individualized care (J. Brown et al., 2006; del Barrio et al., 2004; Forsberg et al., 2000; Lumby, 1997; McCurdy et al., 2006); and some elements of self-control (J. Brown et al., 2006; Lumby, 1997; Wainwright, 1995).

Research about transplant coordinator practice. Researchers in several studies focused on the practice of transplant coordinators. In a descriptive qualitative study, Cetingok et al. (1997) studied the transplant coordinators’ perceptions of the

Chronic Illness and Recovery care models and the behaviors that the coordinators reported that were consistent with these models. Data were collected using focus group interviews. The researchers framed their study contrasting the Corbin and Strauss Chronic Illness model (1992) with the Dorsett Recovery (1991) model. The Chronic Illness model is used to describe human response to chronic illness as a multi-staged trajectory with interventions aimed at reaching stability. The Recovery model emphasizes assisting the patient in developing a new sense of wellness or normalcy. The researchers also viewed the care delivered by transplant coordinators as a social process as they underpinned their study with the theoretical framework of symbolic interactionism. Symbolic interactionism theory (Blumer, 1969) is based on the assumption that specific symbols have meanings for people and that these meanings are shared by groups and form the basis for social interaction. The researchers sought to discover the meaning that these models and the associated behaviors held for the coordinators. The researchers used purposive sampling to increase geographic and organ-specific diversity of the participants. A total of 10 participants in two focus groups were studied. No discussion of data saturation or other sample size determination was offered. The participants were given descriptions of both models and were asked a series of questions regarding the applicability of the models to their practice and their beliefs about the two models. The coordinators were then asked to describe behaviors and categorize them as consistent with one model or the other. The data were organized and analyzed according to the coordinators' determination.

The participants were reported as describing care delivered using the Chronic Illness model as fostering the patients' dependency on the transplant center and

coordinator. When asked to further characterize the Chronic Illness model's meaning to them, the participants reported that they associated this model with a lack of an interdisciplinary approach to care with each discipline working individually with the patient. The coordinators reported perceiving this model as describing care that kept the physicians and coordinators in control and not the patient. Interestingly, self-control over care was also found in the patient-related literature to be important to transplant recipients (J. Brown et al., 2006; Lumby, 1997; Wainwright, 1995).

The coordinators were reported to perceive that care consistent with the Recovery model as promoting the patients' independence and returning them to their community care providers. Coordinators also attributed behaviors consistent with a team or interdisciplinary approach as also consistent with the Recovery model. They labeled behaviors that allowed the patient to have control to be consistent with this model. The researchers reported that when asked about their own practice, the participants described using behaviors that had been categorized as being consistent with both models. Coordinators reported using behaviors consistent with either model based on the circumstances of the patient. For example, behaviors consistent with Chronic Illness model might be used in the pre-transplant phase when the patient needs to keep in close contact with the transplant center and the Recovery model behaviors would be used in the post-transplant phase as the patient prepares to return to the community for care.

W. Paris et al. (1995) studied communication styles and role expectations between transplant coordinators and transplant staff nurses. The researchers did not explicitly state a theoretical framework; however the underlying theory appeared to be, at least for the role expectation components, role theory (Hardy & Conway, 1988) as the

researchers were examining how individuals interpret, create and modify their own roles. The transplant coordinator role was described as evolving from a client-centered role to system-centered role, focused on coordination of care delivery. The researchers sent surveys to transplant coordinators at three southeastern transplant centers and to staff nurses at a single center. Twenty-five coordinators and 25 staff nurses responded, which represented a 77% return rate. The researchers used two tools: a health role expectation index (HREI) (Weiss & Davis, 1983) and the Kilman-Thomas Management of Difference Exercise (MODE). The authors of this study only reported a single reliability measure, test-retest scores for the HREI and MODE of only $r=.56$; $r=.64$, respectively. These scores are low and test-retest is not considered a good measure of reliability due to the tendency of respondents to remember and repeat previous responses (Nunnally & Bernstein, 1994). No validity metrics were reported for either instrument, another weakness of the study. Nonetheless, the researchers found that staff nurses expressed belief that their role was more important to patients' outcomes than were the roles of the physicians or of the patient themselves. Staff nurses communication styles were most commonly characterized as avoidance, accommodation, and compromise. Transplant coordinators described their belief that their role in patient care was similar to the physicians in importance in influencing patient outcomes; their communication styles suggested that they were significantly more assertive, willing to compromise, and less likely to defer to others than were the staff nurses. The researchers concluded that these findings suggested that because coordinators work very closely with physicians, they adopted a more collaborative communication approach than did staff nurses. In the discussion, the researchers also revealed that another part of this study examined

physicians' role expectations (W. Paris et al., 1995). Physicians reported viewing the transplant coordinator's role as more important in the transplant patients' care than their own. The researchers viewed these findings as supporting the contention that transplant coordinators were the "de facto managers of organ transplantation programs" (p. 121) and that physicians could have unrealistic expectations of coordinators; underscoring the need for coordinators to have adequate knowledge and skills. The geographical homogeneity of the sample and lack of reported validity metrics of the tool limit this study's usefulness.

Corley and colleagues (1998) stated that the first purpose of their study was to identify the lifestyle and psychosocial factors used by coordinators to select or exclude candidates from transplantation. The study was framed in the ethical principles of Beauchamp and Childress (1994). A 47-item tool (Criteria for Selection of Transplant Recipients or CSTR) was used in a survey tool mailed to NATCO members (n= 768). The tool was adapted from Olbrisch and Levenson's (1991) international survey of cardiac transplant candidate selection criteria. The coordinators were asked to rate each item from one to four with one representing "exclude from transplant" and four representing "include." The response rate was excellent at 73%. The tool's reliability evidence, measured by test-retest, was .85; a weak measure of reliability. Validity was reported solely as content validity using a panel of three subject matter experts. Content validity is largely a judgment about whether or not the scale items together adequately measure the domain of interest. However, other measures of validity such as criterion or construct are generally considered necessary to support an instrument's validity (Polit & Beck, 2004).

The results were subjected to factor analysis using an orthogonal rotation to reduce the data. A six-factor solution was chosen that explained 48% of the total variance: (a) current lifestyle/psychosocial including problems such as psychiatric problems, depression and non-compliance; (b) family/socioeconomic, including problems such as living alone or never being employed; (c) habits, such as smoking or excessive alcohol consumption; (d) recovering from psychological or psychiatric problems; (e) stigma, including issues such as HIV positive or in prison for a serious crime; and (f) cost, issues such as no insurance. The loading cut-off for the factors was .33; this is a low but acceptable cut-off value (Comery & Lee, 1992; Nunnally & Bernstein, 1994). Not surprisingly, given the low loadings, the Cronbach's alpha values measuring internal consistency were also somewhat low ranging from .68 to .77. DeVellis (2003) suggested a minimum of .7. The "current" factor explained 22% of the variance. The factor "stigma" had lowest mean scores 1.29, indicating that it was the factor that coordinators were most likely to be use when making a decision to exclude a patient from transplantation. The "cost" and "family/socioeconomic factors" had high means (3.34 and 3.09, respectively) meaning that these item were considered by participants as inclusion criteria for transplantation (3= probably include). The mean values of the "habits" and "recover" factors were reported as 2.51 and 2.60 respectively which would be associated with exclusion (2 = probably exclude). The researchers used an ANOVA followed by multiple comparisons using Scheffe's test to analyze the scoring of the factors by independent variables of coordinator characteristics such as age, experience, educational background, and type of organ program. Type of organ program (heart, liver, or kidney) was the most powerful predictor of low scores, with heart coordinators most likely to

give low scores, perhaps indicating the use of more stringent selection criteria for heart transplantation. There were other differences between organ programs as well. Coordinators with more kidney experience were more likely to assign lower scores to current and recover items than were liver coordinators. Liver coordinators were likely to attribute low scores to the stigma, habit, and family/socioeconomic factors. Gender was also a predictive variable but the authors cautioned that the numbers of males in the study was low. As the sample was 94% female, perhaps this variable should not have been entered into the model. Race of the transplant coordinator was also predictive with non-whites more likely than whites to give lower scores to patients with family/socioeconomic issues and those with recovery issues; although again 90% of the participants were white. The researchers suggested that the principle of distributive justice was illustrated by the most stringent criteria being applied to the scarcest resource (heart) and that coordinators demonstrated a strong use of justice and medical utility in determining eligibility for transplantation. The researchers also suggested that social utility, inclusion based on social worth was sometimes being used, in opposition to Beauchamp and Childress' (1994) tenet that health resource allocation be based solely on justice and medical utility. The generalizability of their findings regarding gender and race as predictive are weak due the homogeneity of these variables in the sample.

A secondary research question that was explored in this study was the participation of the transplant coordinators in the selection process. Participation was assessed with an 11-item tool designed by the investigators from interviews with coordinators. Each item represented a task or action that could possibly be performed by the coordinator as part of the selection process. No reliability or validity measurements

were presented. The researchers attempted to reduce the items but all loaded to a single factor with a loading factor of greater than .57. Cronbach's alpha was high at .92. These results suggest that the scale could be shortened by simply deleting some items (DeVellis, 2003). More than 90% of the respondents indicated that they always participated in the candidate selection process. Transplant coordinator participation in the selection process is now mandated by the Medicare Conditions of Participation (U.S. Department of Health and Human Services, CMS, 2007); indicating that this is an important competency.

Data from this study were also discussed by Neil and Corley (2000). The researchers performed further analysis on a single item ("open hostility to staff") in the CSRT related to explore transplant coordinator's response to hostile patients. The authors reported only face validity, a weak test of validity and test/retest reliability of .85. The researchers' hypothesis, based on personal experience, was that patients' hostility would produce negative reactions in coordinators. The mean score for this item was 2.1 with over 61% of the respondents rating this item as "exclude" or "probably exclude" supporting the researchers' hypothesis. Although the authors in this second paper did not mention Beauchamp and Childress (2001), excluding a patient from transplantation because of hostility towards caregivers could be considered as violating both the principles of justice and utility. The authors did suggest that coordinators' reaction to hostility negatively impacted the therapeutic relationship and that coordinators needed more education in ethical decision-making as well as skills in dealing with hostile patients. These studies had methodological weaknesses, but both describe the integral role of the transplant coordinator in the candidate selection process. Certainly participation in such a life-changing decision-making should require formal preparation

in patient assessment as well as ethics and be governed by professional practice standards. This participation may make the transplant coordinator a very powerful person to the patient. This patient perspective was expressed by the patient describing the wait for a liver transplant (J.Brown, et al., 2006) who essentially attributed to the coordinator the power of life (transplant) and death (no transplant).

Lerret and colleagues (2012) described pediatric and adult transplant coordinators' opinions about essential elements in the process of transitioning pediatric liver transplant recipients from pediatric to adult centers. The researchers used a 30-item questionnaire developed by content experts employed by a web-based electronic survey. The sample was drawn from multiple centers with excellent response rates (80% for the pediatric coordinators and 100% of the adult coordinators participated). The multi-center design as well as the excellent response rate heightens the generalizability and thus the usefulness of the results. However, the study is purely descriptive with no outcome data. The results are informative but represent expert opinion only. Both the pediatric and adult coordinators had similar opinions on what made the transition successful. The majority of the respondents stated that the process should be standardized and that coordination, communication, and information transfer between the adult and pediatric center was essential. No consensus was reached on the best age to initiate the process; respondents stated their belief that this decision should be individualized. Important discussion points for parents and children included preventative health care, selection of a new primary care provider, and the length of time for the transition. The researchers, recognizing the limitations of descriptive study, concluded that standardized evidence-based processes may improve the transition process.

Kim (2013) posited that the close relationship that transplant coordinators had with their patients as well as the number and diversity of role functions might put transplant coordinators at high risk for compassion fatigue and burnout. The study was exploratory and had the important limitation of using a single center from which to draw the small sample. Fourteen of fifteen kidney and liver transplant coordinators participated in the study. The researcher used the ProQOL (Stamm, 2010) tool to measure compassion fatigue. The author did not report reliability and validity of the tool but this is a widely used tool to measure compassion fatigue in caregivers. The results were compared between groups based on demographic characteristics such as age, tenure as a coordinator, and education level. The coordinators scored low to average on all the two negative sub-scales (burnout and secondary trauma stress) and average to high on the compassion satisfaction sub-scale (which is desirable) indicating that compassion fatigue was not likely a significant issue at the center. Interestingly, the only demographic variable that was statistically significant was education. Higher level of education was associated with lower scores on the burnout sub-scale; however the small numbers render these results of limited usefulness.

Summary

In summary, research regarding transplant coordinators was primarily descriptive in nature with methodological limitations; describing practice, behavior, and beliefs. Several gaps in the literature were identified. No research demonstrating the influence of transplant coordinators on patient outcomes was found. The most notable void in the literature was the absence of the voice of the patient. There was little data regarding the patients' experiences with or perspectives on the role. Such research is

needed to ensure that the transplant coordinator role is fulfilling the needs of the transplant patient. The following chapter describes the methodology of the study designed to add the patients' voice to the extant transplant coordinator literature. The aim of this study was to begin to fill the gap in the knowledge about the patients' experience with transplant coordinators.

CHAPTER THREE

METHODS

Grounded theory, a qualitative research approach was selected to gain new understanding of the patients' perspective on the Basic Social Process of the relationship between the kidney transplant recipient and the transplant coordinator. Researchers using the qualitative approach study social phenomena in a natural setting without preconceptions about the results (Marshall & Rossman, 2006). The qualitative method selected for this study was grounded theory as described by Glaser and Strauss (1967). Its theoretical roots lie in symbolic interactionism. Blumer (1969) posited in this theory that specific symbols hold meanings for people. The meanings attached to these symbols are shared by groups and form the basis for behavior and interaction with others (Carpenter, 2007); thus it is a social theory and an appropriate framework for the study of relationships.

Purpose of the Study

Although the literature revealed that most transplant coordinators are registered nurses (Beaver et al., 1995; International Transplant Nurses Society, 2009; Vincent et al., 2002) the role has not been claimed under nursing or any other profession. This lack of professional practice framework has made defining the role in terms of scope, licensure, certification and requisite education difficult. Furthermore there is very little in the literature about the patients' experience or the interpersonal nature of the role. This

interpersonal dimension of care has been identified as an important component of patient-centered, quality health care (Davies & Ware, 1988; Donabedian, 1992; Gerteis, 1993). Review of the literature revealed that a substantial gap exists in the extant knowledge of the patients' perspective of the care provided by transplant coordinators. The purpose of this study was to begin to fill this gap in the scientific knowledge by conceptualizing theory about the patients' perspective of his or her relationship with the transplant coordinator. This theory could be used to inform practice, future research and policy development regarding the transplant coordinator role. The research question for this study was: What is the patients' experience of the Basic Social Process between kidney transplant recipients and their transplant coordinators?

Research Design and Methods

In this study, the relationship between kidney transplant recipients and their transplant coordinators was examined from the patients' perspective to develop theory about this social process. The study utilized grounded theory qualitative design. The grounded theory method emphasizes conceptualizing phenomenon by systematic analysis of data found in the natural setting. Neither the theory nor the final design are preconceived but emerge as the researcher conceptualizes the phenomenon as data collection occurs (Glaser & Strauss, 1967; Glaser, 2001). The conceptualization is achieved by constant, systematic comparison of data. Similar data are sorted into categories and new data are compared with previous data. As the categories emerge, the researcher explores these categories in more depth by theoretical sampling (Charmaz, 2002; Glaser & Strauss, 1967; Glaser, 2001). Specific cases or examples of the category

are sought out to further saturate the properties of the category. Eventually, a single or core category emerges and the researcher narrows study to this category (Glaser, 2001).

Grounded theory methods have been characterized as either constructivist or objectivist (Charmaz, 2002). The objectivist method is a more positivist perspective; viewing qualitative data as objective facts and expecting that a single, knowable truth can be discovered from careful application of grounded theory methods. The constructivist grounded theory researcher believes that the data and its interpretation are constructed by the researcher and the participants. Charmaz (2002) stated the following assumptions in constructivist grounded theory:

(a) Multiple realities exist, (b) data reflect the researchers' and the research participants' mutual constructions and (c) the researcher, however incompletely, enters and is affected by participants' worlds. (p. 678)

In this study, the qualitative data were obtained from interviews with transplant recipients. This empirical, first-person experience is essential in developing theory that is most likely to reflect the experience of the patients. Using the constructivist approach, the researcher went beyond the content of the story that the participant told to the context of the interview to attempt to interpret what the participant wanted the researcher to understand.

The researcher constructed theory from these understandings about the patients' perspective of the social process between transplant coordinators and transplant patients. This theory could be utilized to better define a patient-centered transplant coordinator role.

Participants

The population for this study was initially adult kidney transplant recipients living in the Chicago area, however due to lack of participants, the recruitment moved to a national level. Inclusion/exclusion criteria included any recipient of a kidney transplant who was willing to participate. Patients who required renal replacement therapy from any type of disease were included. Participation was limited to English-speaking participants who were able to communicate verbally. To avoid potential coercion and promote candor, patients transplanted at the researcher's center or with previous care experience with the researcher were excluded from the study. Patients were interviewed to discover their experience with transplant coordinators. The recruitment strategy began with the use of area support groups. A large support group in the area with a mailing list of over 750 patients was solicited. The recruitment letter (see Appendix A) was distributed with the monthly newsletter and the researcher attended several monthly meetings to recruit participants. Several other internet kidney transplant support groups were also used to solicit participants. Membership in a support group was not an inclusion criterion for participation in the study and participants were not interviewed at the support group meetings.

Further recruitment was based on the snowball technique (Marshall & Rossman, 2006). Participants were asked to mention the study to other individuals (either from the support group or non-members) who had received kidney transplants. When these strategies failed to accrue enough participants to achieve theoretical saturation, the recruitment letters were distributed to transplant administrators at ten transplant centers (two in Chicago, three in Ohio, three in California, one in New York, one in Florida, and

one in North Carolina). The administrators agreed to distribute the letters to patients at their center. The administrators were selected by the researcher based on existent professional relationships and their willingness to distribute the recruitment letters. Six additional administrators in the Midwest and Florida distributed letters but yielded no participants.

Sampling Strategies and Data Collection

Sampling or interviewing began with the initial recruits and then became more purposeful with the use of theoretical sampling once the categories begin to emerge from the data. Theoretical saturation is described by Glaser (2001) as occurring when new data fail to provide new information about the core category. Sampling continued until theoretical saturation was achieved. Another technique that was employed was the use of multiple sequential interviews with the same participant. This technique is a form of theoretical sampling as the researcher goes back to the participant to explore a theoretical area in more depth (Charmaz, 2002). This technique was used twice. In one instance a participant who presented a very interesting negative experience that warranted further exploration was interviewed a second time. A second interview was also done with an early participant to use theoretical sampling to further explicate the extant categories that had emerged since the initial interview. The sequential interviews were compared to both participants' previous interviews and to the data as a whole.

Interview Techniques and Data Management Procedures

Based on both geography and participant preference, participants were primarily interviewed by telephone with one interview performed in person. The interviews were digitally recorded after obtaining verbal informed consent. The participant was advised

that the recorder would be turned off at his or her request at any time during the interview. The recordings were transcribed by a professional transcriber and verified word by word against the taped interviews by the researcher.

The interviews used the “grand tour” approach (H.J. Rubin & Rubin, 2005), encouraging participants to share rich data about their experiences. Using this strategy, the researcher used the initial questions from the interview guide (Appendix B), follow-up questions, and probing questions to clarify (Charmaz, 2006; H.J. Rubin & Rubin, 2005). After initial casual conversation to put the participant at ease, the interviewer began with a brief explanation of the purpose of the research and the participant’s role in the research. The participant was asked for demographic information about him or herself such as age, race, education, marital status, occupation and educational status and about the transplant experience such as: cause of renal failure, length of time waiting, and date of transplant. The participant was asked to describe his or her experience with transplant coordinators at each major phase of care (referral, waiting time, transplant event, and post transplant care). The first question was very open-ended: “Tell me about your experiences with transplant coordinators.” The researcher encouraged the participant to go deeper by using comparisons such as: “Does any particular experience or coordinator stand out as particularly good or helpful to you or bad and not helpful?” “Why was that?” “How has this relationship changed over time?” Probing questions were used to clarify and elicit more detail (H.J. Rubin & Rubin, 2005). As the data analysis proceeded and categories became evident, the follow up questions evolved to explore specific categories that emerged as important. Both the context of the interview, the researcher’s preconceptions, impressions, and feelings were recorded in real-time in field notes.

Data Analysis

Data analysis was performed using the constant comparison method. After each interview was transcribed and verified, the transcripts were uploaded into NVivo 10 software (QSR International Melbourne, Australia) and coded, initially using open coding (Glaser & Strauss, 1967). After the initial data collection interview, the data in each interview were compared to data obtained from previous interviews. This process was completed each time before proceeding to the next interview. As some codes began to appear frequently, these codes were conceptualized into categories and as categories began to emerge the coding, analysis, and comparison process changed from open to selective coding. These categories were constructed using the model functionality of NVivo and documented in the form of visual models. In selective or second level coding, categories were conceptualized from the open coding and subsequent coding used to illuminate the properties of these categories. As data collection became increasingly focused, the researcher narrowed the analysis to a single core category (Glaser, 2001). This core category, *Easing My Burden*, and its properties form the basis of the theory derived from the data. Except for the initial data, new data were always compared to the previous data for similarities and contrasts. Data not useful for the emergent theory were archived in a miscellaneous category. When no new data were found relevant to the category or categories of interest, saturation occurred and sampling and coding ended.

The strategy of theoretical memo writing was also employed. The researcher used the memos to record conceptualizations about the codes as she formed these into categories (Charmaz, 2002; Glaser 2001). These memos, which were recorded as visual models, reflected the researcher's analysis in moving from open coding to selective

(more focused) coding, and categories beginning to emerge. The memos formed the drafts of the theory, outlining properties of the categories and thoughts about future data collection (Charmaz, 2002). These memos were also useful as an audit trail, a step-by-step record of how the theory was conceptualized (Lincoln & Guba, 1982). The use of memos in an external audit will be described in the discussion of trustworthiness in the next chapter.

Protection of the Participants

The final proposal was approved by the researcher's Dissertation Committee and by the Loyola University Chicago Institutional Review Board (IRB). The Loyola IRB determined that a written informed consent form was not required. The consent process included informing the participant that they could choose to not answer any question and that at any time during the interview and at their request; the recorder would be turned off. Individual participant demographic information was secured separately from the other data. Interviews were digitally recorded and transcribed. As the transcription was outsourced, the transcriber signed a confidentiality agreement. All identifying information was removed from the transcription. The digital recordings were destroyed after verification against the transcripts. Paper data, including notes and memos were kept locked with access only to the researcher. Electronic forms of the data such as electronic copies of the transcripts, recordings and scanned memos were stored on password protected encrypted hardware. The collaborating auditor, Dr. Fran Vlasses, was approved by the IRB. Confidentiality was maintained by using numbers and not names on the documents and audiotapes. Pseudonyms have been used in this publication and will be in any future publication or presentation.

Summary

In this study, the researcher addressed the gap in the literature regarding transplant recipients' perception of the Basic Social Process between themselves and their transplant coordinators. A qualitative approach to the problem, grounded theory methodology, was used to gain insight and explicate theory about this process. Patients were recruited by a recruiting letter by support groups or letters distributed at their transplant centers. Volunteers who met eligibility requirements were interviewed by telephone or in person. The interviews were transcribed and then coded line by line, comparing the data with the data from the previous interviews. The coding moved from open to selective coding as categories began to emerge from the data. The interview questions were adapted to explore the codes and categories began to become evident. The researcher used theoretical memos to record her conceptualization of the categories and their properties and their relationship to each other. These memos became the drafts of the theory. When no new data relevant to the categories of the theory was found, the coding and sampling ceased and saturation occurred. The resultant patient-derived theory could be used to help more clearly define transplant coordinator role to deliver more patient-centered and effective care and is presented in the next chapter.

CHAPTER FOUR

RESULTS

The purpose of this chapter is to describe the findings of the study and the resultant theory explicating the Basic Social Process between kidney transplant recipients and their transplant coordinators. The core category, *Easing My Burden*, was conceptualized by the researcher using constant comparison of the qualitative data obtained from the participants. The core category represents the successful resolution of the participants' main concern or Basic Social Psychological Problem (Glaser, 1978): the burden of having end-stage renal failure and subsequent pursuit and attainment of a kidney transplant by trusting that the coordinator. The result of achieving this trusting relationship is *Easing My Burden*. All names used in this and subsequent chapters are pseudonyms.

Sample

Fourteen interviews were conducted with twelve different participants. The participants' were from nine different transplant centers from a wide geographic area: northeast (three participants at one center), southeast (one participant at one center), Midwest (six participants at five centers) and the west coast (two participants at two centers). Two participants agreed to two interviews. One of these participants was interviewed twice within a week to allow a more in depth exploration of her negative

experience with transplant coordinators. A second was an early participant in the study and was interviewed a second time, during the theoretical sampling phase, to explore and further explicate emerging theoretical concepts and tentative hypotheses such as patients “testing” the coordinator and the core category of “Easing My Burden.” The participants all had experienced end stage renal disease (ESRD) from a variety of causes; only one never underwent treatment by hemodialysis, and some had switched from hemodialysis treatment to peritoneal dialysis. The sample also represented a wide range of duration of end-stage renal disease treatment prior to transplant (zero –five years) and time since the index transplant at time of the interview ranged from less than a year to over ten years. Table 1 contains a summary of the treatment characteristics on the participants. The majority of the participants (67%) were white; 25% were black, with one participant claiming Hispanic ethnicity. Average age of the participants was 57 years; the age of the participants ranged from 42 to 71 years. The participants’ educational level and occupations were also diverse, although only three reported completing college. Table 2 contains a summary of the demographic data of the participants. All of the interviews, with the exception of one which was done face-to-face, were done via telephone and at a time convenient for the participant. All of the participants reported that their transplant coordinator was a registered nurse and one of the coordinators was an identified by a participant as an advanced practice nurse.

Table 1. Treatment Characteristics of Participants

Pseudonym	Length of ESRD treatment	Type of ESRD treatment	Time from Transplant at interview(s)
“John”	5 years	Living donor	Less than a year
“Sally”	4 years	Living donor	< year/ three years
“David”	1 year	Living donor	six years
“Melvin”	4 years	Living donor	four years
“Billy”	2 years	Deceased donor kidney/pancreas	more than 10 years
“Penny”	5 years	Deceased donor	Less than a year
“Marilyn”	2 years	Deceased donor	one year (both)
“Bob”	#2 - 13 months	Living donor	one year
“Kenneth”	2.5 years	Living donor	one year
“Harold”	5 years	Deceased donor	one year
“Darrel”	2 years	Living donor	four years
“Sonia”	none	Living donor	10 years

Table 2. Demographic Characteristics of Participants

Pseudonym	Race	Occupation	Married/ Children	Education
“John”	White	factory	Y/Y	high school
“Sally”	White	homemaker	Y/Y	high school
“David”	White	engineer	Y/Y	college
“Melvin”	White	production supervisor	Y/Y	high school (GED)
“Billy”	White	chef	Y/Y	vocational
“Penny”	Black	homemaker	Y/Y	high school
“Marilyn”	White	business analyst	Y/N	college
“Bob”	White	welder	recently divorced/Y	high school
“Kenneth”	Black	PE teacher	divorced/Y	masters
“Harold”	White	farm/ construction	Y/Y	high school
“Darrel”	Black	artist/author	Y/Y	art school
“Sonia”	Hispanic	research services coordinator	Y/Y	college

Dimensions of Care Received by the Participants

As the transplant coordinator role has not been claimed by nursing it is important to examine the dimensions of care received by transplant coordinators. The

dimensions of care were not part of the theory itself, it is worth noting that all of the patients received care from registered nurses functioning in the transplant coordinator role. These role functions were all coded as part of the data analysis. The participants reported receiving a variety of types of care from the nurse coordinators, primarily care coordination processes related to lab and diagnostic testing, facilitating the patient through the evaluation process, communicating with physicians and other care providers both on the transplant team and outside of the transplant team, facilitating the transfer of health care records both to and from other institutions, coordinating health care appointments, engaging the patient and family in self care activities such as taking medications properly, diet and exercise recommendations, medication management including changing medication dose based on lab results, proactive and anticipatory guidance regarding the expected treatment course and triaging physical symptoms. Some of the participants reported that the nurse coordinators also provided direct care such as wound care. All of the patients who received deceased donor kidneys reported that a coordinator called them in for the transplant. Kenneth described the care that he received in the pre-transplant phase:

[B]ut what I liked about her, she was very hands-on, and so far any needs that I've had, she has immediately taken care of them from medicine to rescheduling an appointment to something with dissatisfaction with maybe one of my doctors; she's been right on top of things. And I like it's been very convenient.

John talked about his coordinator post transplant:

She would take me in the room and tell me different things about what I should do, how I take my medicine, what each medicine is about. In fact, one time... I remember this. I went in one day and the chart; I was able to take a chart home with me and all my medicine because at that time I was taking like 26 pills or something like that.

Transplant Coordinator Transitions

All but one of the participants in this study had experiences with changing coordinators. Most commonly, the change occurred at the time of transplantation; switching from a pre-transplant coordinator to post-transplant coordinator but sometimes it occurred due to the coordinator leaving the institution or the role. One patient, Marilyn, switched centers to get a new coordinator. In some cases, the patient no longer had a coordinator but was followed by physician or clinic team. In some instances, particularly when the transition occurred when the current coordinator left the role, patients were not prepared or even notified of the change. David deduced that he had a new coordinator when he received a letter with his lab results:

They haven't told me who it is yet. I'm going to go in the summer for my annual checkup and a looksee [sic]. And then I'm going to ask at that time who my coordinator is. My last blood test was in April. I'm getting blood tests every two months, and all the letter said this time was your transplant team, there was no human listed there as a transplant coordinator.

Nonetheless, with the exception of Marilyn's experience at her first center which was related in the last chapter, no participant expressed concerns about loss of continuity during the transition, even when they were unaware of the change. As Kenneth said: "I got a different coordinator that also worked hand-in-hand with the previous one that I got, that I was with." Billy related that he cried when his coordinator told him she was leaving and then gave the new coordinator a difficult request:

Rose [second coordinator] took over, and she was almost like Ann [first coordinator] and I told her what I did with Ann and I asked her if she could be the same as Ann in other words... I asked, you know, 'Can I have your phone number? Can I call you at home if I have problems? And I was out ten years, I think, and I think I was more stable than I was with Ann I said I don't think I'm going to... 'I still mentally need your support. In other words, if I have a problem,

can I call you at home? Would you allow me to call you at home?’ And she says, ‘Billy, you do whatever it is you need to be comfortable’.

Billy’s response represents an extreme. The other participants simply began the process over again. Some patients reported that as time went on, they did not have as intense of a need for a coordinator or did not need one at all. Sonia explained that she stopped having a relationship with a coordinator after eight weeks post transplant and that she felt ready. John explained that he was “graduating” his care to a nephrology clinic without coordinators, demonstrating that he had some transition preparation:

It’s fine. I’m ready. I still know they’re down there. If I want to stop down there and bug them I will. I guess it’s like you start on the second floor and by the time you get to the fifth floor they don’t want to see them anymore.

His comments also contain another interesting element of the end of the relationship. For several of the kidney recipients, the relationship did not actually end when they were assigned to a new coordinator. Some maintained the relationship in some manner. Bob explained:

I mean I could still call Susie and she still would take care of things for me if I needed her to. Do you know what I mean? She’s that type of person you can rely on even though you’re not on her clinic floor no more, you know.

Sonia found another way to reconnect with her preferred coordinator from the pre-transplant treatment phase:

And then I also offered my services back to Amy because I was so happy with the way that my whole pre-transplant experience was, I told her that I would be willing to talk to any of her patients to help them to understand what they’re going through from a patient perspective and so she actually did buddy me up one time with a woman.

The lack of a structured transition, particularly when the change in coordinator was not expected, as in the case of the coordinator leaving the role, may indicate a lack of

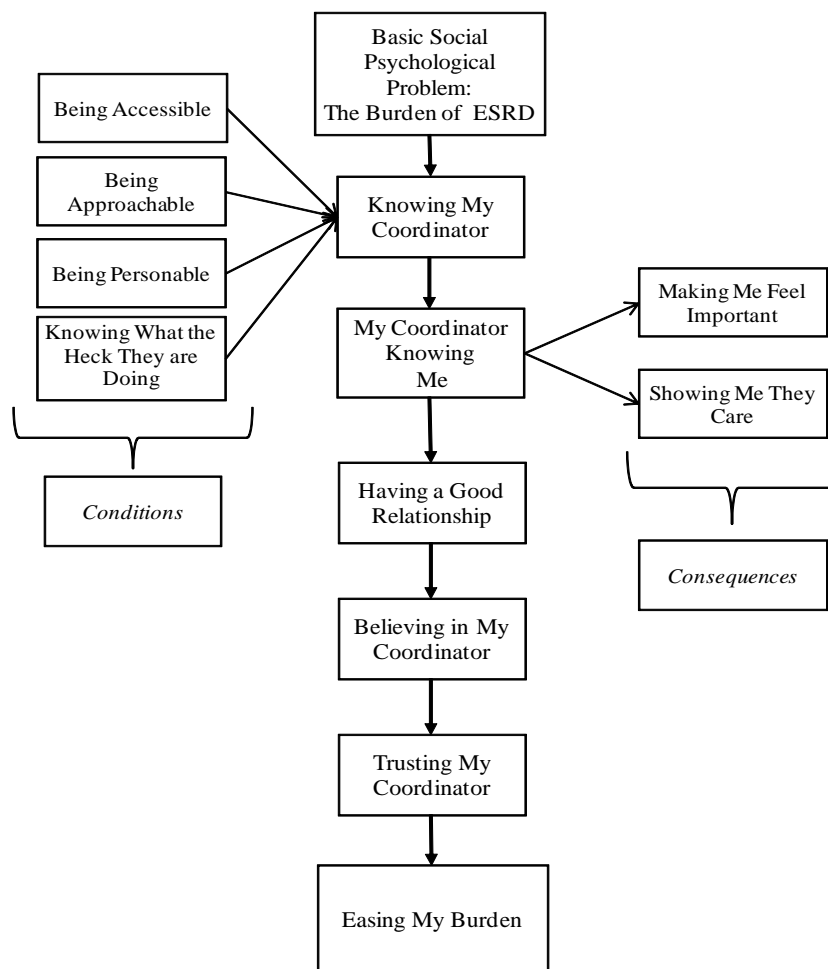
appreciation of the value of the coordinator-patient relationship by transplant centers or the coordinators themselves. The implications of this gap will be discussed later in the following chapter.

The Theory

The substantive theory that was conceptualized from the data is illustrated in Figure 1. The patients begin this process by presenting to the transplant center with the Basic Social Psychological Problem (Glaser, 1978) of *The Burden of ESRD*. The successful end point of this process is having this burden eased through the social process with the transplant coordinator. The transplant coordinator has the opportunity through this process to ease this burden for the patient, but only as each stage is successfully negotiated. These stages include: the category *Knowing my coordinator* which has four sub-categories representing the conditions that need to be met to successfully pass through this stage: *Being approachable*, *Being accessible*, *Being personable* and *Knowing what the heck they are doing*. The next stage is the category *My coordinator knowing me* has two sub-categories or consequences of the coordinator making the effort to know the patient: *Making me feel important* and *Showing me that they care*. If these two stages (*Knowing my coordinator* and *My coordinator knowing me*) are successfully resolved, the patient moves through the final stages: *Having a good relationship*, *Believing in my coordinator* and lastly *Trusting my coordinator*. The establishment of a trusting relationship led to the resolution of the informants' problem and subsequently to *Easing My Burden*. This process was repeated or cycled with each new coordinator and usually with each new patient situation or phase of care such as pre-transplant and post-

transplant or going to a new transplant center or the departure of the transplant coordinator with various degrees of success.

Figure 1. Easing My Burden



Core Category: Easing My Burden

In classic grounded theory, the core category crystallizes the substantive theory that describes the Basic Social Process being studied by identifying how the main concern of the participants is resolved (Glaser & Holton, 2007). Glaser (1978) listed the following criteria by which to judge a core category: centrality, frequency in the data, relating meaningfully and richly to other categories; clear theoretical implications as well

as carry throughout the entire analysis, high variability (or dependent on the other categories), yet also itself is a dimension of the problem. Easing My Burden describes both the problem and the successful resolution of the problem. This category is the consequence of the other categories or stages and is entirely dependent on these categories. All of the other codes and categories point to the need of the patient to find someone to help ease their psychological burden or problem of ESRD. Penny, a 64 year old Black homemaker described it this way “They helped me through it all. Without them caring, them keeping that upbeat, I don’t know; I wouldn’t have made it” Darrel expressed his feelings about his coordinator in this way: “Like I said, this is a new ballgame, but I don’t worry about things. There’s somebody there to, you know, reassure me”. Sonia, similar to other participants described her relationship with her coordinator as life saving:

Like anytime I called her or would leave her a message, she returned my call right away, so she just made me feel like a priority because and... she was basically the person that was, like I felt [she] was coordinating saving my life, I felt like... um, I really felt important to her. Like when she would call me, she knew my information. She was very familiar with my file and like spoke very familiarly about my file and things like that so um, that’s why. And she was very knowledgeable and ah, she was very professional

Sonia’s comment illustrated several categories and sub-categories encompassed in the core category: accessibility, making me feel important, coordinator knowing me, and knowing what the heck they are doing.

Another participant talked specifically about the burden of taking medications being relieved. “She went through and made that whole list to take that burden off me to sit there instead just trying to remember all this. I mean she made it easier for me.” He went on to talk about having his burden lifted in general:

Yep, now I can rely on my transplant coordinator. I can do a lot of things myself. I can turn around up there, ask them questions; they'll tell me what to do and how to do it, and I'm comfortable with that. You know, they help the patients out a lot. They put things together so it will make it easier for you at home. It's just great.

Patients also expressed a feeling of comfort or feeling good when their burden was eased.

Billy reported:

I would get down on myself. I was wondering why I had to take all these pills, and I would go how long do I have to take these pills for the rest of my life and why. She would always make me feel good after I got done talking.

He expanded about feeling comfortable:

But I would tell her what my symptoms were and she would have the answer for it and she would make me feel comfortable, and that was kind of like it. And she played a big role in the way I felt and the way I lived my life

Kenneth also talked about being made comfortable:

You know, even when I would be home and I'd be thinking of something and I'd call up to the hospital to talk to the coordinator, you know, even if she couldn't talk to me right then, she would call me that night before she'd go home or early the next morning and answer my questions. You know, that was a good thing. They made me feel comfortable that way.

If the Basic Social Process was not successful, meaning a trusting relationship was not formed, the participants described feeling alone in carrying the burden: Marilyn explained:

You know, I wouldn't call. Like I'm not talking about calling every day, every week, even every month. I'm talking about like every four to six months I would call, you know, kind of around the holiday. 'Hey, Happy Thanksgiving, Janie, just wanted to call and check in and say 'hi' and, you know, just let you know everything is going good;' and she'd be like, 'Why are you calling me?' I'm like, 'Just wanted to check in.' Just like that, you feel like you're just floating out there in space.

Basic Social Psychological Problem: The Burden of ESRD

The core category (Easing My Burden) describes the consequence if the patients resolved the Basic Social Psychological Problem. This problem begins with the initial diagnosis of ESRD and persists through the pre-transplant and post transplant phases of treatment. Although the purpose of this study was to understand and develop theory about the patients' experience with transplant coordinators and the Basic Social Process that occurs between patients and coordinators, an in-depth understanding of the Basic Social Psychological Problem of the Burden of ESRD was gleaned. This understanding provides important context and background of the patient who enters into this social process.

The Burden of ESRD: Diagnosis and dialysis treatment phase. Participants expressed that living with the diagnosis of ESRD was a mental, emotional, and physical burden. Participants expressed feelings of hopelessness, depression, and anxiety facing a lifetime of dialysis as well as life-style altering physical symptoms. The range of these experiences included those who did not like dialysis but continued their previous lifestyle without a great deal of change to those who described the burden as life-altering; causing physical, mental, and emotional misery. Darrel, a 61 year African American artist and author faced the sudden diagnosis of end stage renal disease at the age of 56:

Well, in the beginning you are told your kidneys have failed and at the time I was at County Hospital and things weren't really explained to me quite so clearly as the fact while your kidneys have failed, we all know why and being in somewhat shock over this, after I was in the ICU they took me to a room and they came to get me to go to dialysis. I'm like, 'well I just had a treatment.' 'Well, you have to have another treatment.' Well of course, two days later you are having another treatment, and I am like well, 'what's the deal with this?' 'Well, you will have to have this done every two days,' which is, if someone tells you, you have to have your blood drained out of you every other day, and the realization is well, for the

rest of your life, that is kind of hard to accept. Then I was left in a hall for probably, I think it was two hours after the procedure before someone came and got me and that was the first time that all of a sudden the whole thing hit me that I was seriously ill and was this how I was going to spend the rest of my life, and I actually cried. This was the first time I had broken down. I wanted to get out of there and as I said, the first time I cried was when I was in the hall. The second time was I was craving for fish because I am a fisherman, I love fish, and for some reason all of a sudden for dinner they brought me some kind of fish thing that was a patty of I don't know what, and it was so horrible that I broke down and again, I teared up. That is kind of my whole introduction to end stage renal disease. All right, and then it was okay, you can go home and for me adjusting to doing dialysis you know, I was sick afterwards, I was just in shock. I lost 20 pounds in nine days. When I got home I was so weak I could not walk up my stairs. We have a two story house. I had to crawl up the steps I was so weak. My legs were atrophied. I looked like I had paraplegic legs. I was just miserable.

Some participants such as Sonia, a Hispanic woman who was in early 20's at the time of her diagnosis expressed a particular dislike of dialysis itself: "Yeah, for some reason, the thought of my blood coming out of my body, going through a machine and coming back in freaked me out." Kenneth, a high school physical education teacher related dealing with both depression and anxiety.

I went through depression. I mean I never knew what depression was and I kind of took it for granted. People that had it, I was kind of like the guy, 'Oh, let's just go have a drink. You'll be okay.' But after going through it, I have a whole new appreciation for depression; and man, it could eat you up. And I started having anxiety attacks. You know, I actually had to go to the doctor. I had to get on some Prozac, some medicine. I was just unhappy combined with other things going in my life. You know, I had to bury two parents while I was on dialysis, and woo, it was rough, and I just felt; I just didn't feel like a good person. I just felt down. And I wore a game face because I teach; I go to work; I'm real happy outside the house, but I would come home and be miserable.

Marilyn, a business analyst in her forties described her time on dialysis: "Literally I felt like my life was gone." She went on to describe more of the emotional toll that dialysis took on her life and how no one was there to help her with this burden:

You know, those questions on those questionnaires that they make you fill out, I'm like well even if...So I fill those questionnaires out. That's a good example.

We're talking about, you know, the emotional burden. You fill out that dumb questionnaire every year or whatever it is about how you feel about being on dialysis, and I look at it and I go, okay, social worker, what in the hell are you going to do about any of these answers on here? There's nothing you can do. There's really nothing you can do because you're so busy with trying to get paperwork done for Medicare and insurance and all-which is completely important; you've got to pay for everything-but like my social worker had like four clinics and all...She was busy. She had too much; you know, too much to do. So yeah, emotionally it was just, it was a nightmare. It was just a nightmare. But on the outside nobody saw that because they saw me working every day and doing my treatments and staying together with everything, so I guess I must have been fine.

John, a middle aged retiree experienced less of a burden from ESRD:

So then I did hemo [dialysis] for about three months and hated it. And so then they told me about peritoneal, so I went and trained for that and switched over to PD [peritoneal dialysis], which for me was fantastic if you had to do dialysis. I did that for almost five years. And still had a pretty good life. We went to Myrtle Beach every year. We went to Colorado and we still were able to travel.

The Burden of ESRD: Nephrology care provider relationship. A common experience reported by the participants of this study was having negative experiences with ESRD care providers. Many of the participants expressed negative experiences with their nephrologists and other dialysis staff. Some patients like Darrel expressed his belief that the dialysis unit staff members were adversaries:

I mean when you are at some of these centers, they...I truly believe they don't think you will get transplanted. I don't think they even want...well; make an effort to give you information because one Dialysis Company, these companies are in business. It is their business and my plan was to get out of there, and their attitude is 'sure you will, sure you will.'

Many patients complained that they did not get sufficient information or education from dialysis providers, particularly about transplantation. Darrel talked about his initial ESRD experience:

Because again, you don't really know what is going on. This is all new to you. It is not really explained to you and your hope is well, this is just a temporary thing

because you don't know what the extent of, again, what chronic kidney failure or end stage renal disease means. So, well, okay, let's do this. I went to the [operating] theater and you are put into a twilight and for the whole ordeal for being sick and being in the hospital, which I never had a stay in the hospital [before], that was probably the most traumatic experience.

Sally was disheartened by the lack of attention that she received from her nephrologist and never being offered the transplant option:

Well, it made me feel that she's not a very good nephrologist because I should have been on the kidney transplant list like four years before I got on it. And then she always seemed, because when she would see me would be at the Center, she would come in on Tuesday's while I was doing my dialysis, and I mean, she'd just stop by my chair and talk for two or three minutes and then she was gone again. You know when I needed, and I had a problem, then I called the office, I talked to the secretary, not the secretary, talked to her nurse and I got a lot out of her that I didn't get from Dr. Brown.

David had a similar experience:

Yes, the least satisfactory part of my whole process was the nephrologist who followed me for years prior to the transplant. He followed me for probably ten years and I got very little information from him. He would just say get this blood test done, get this blood test done. And then finally one day he said in an appointment, he says, "It's time to start preparing you for dialysis." And looking back, he could have-in 10 years of appointments-he could have been more help. He was not a teacher, he was just a monitor-er [sic]. In looking back, I find that to be just unacceptable.

Sonia was frustrated by her care provider as well:

I walked into the doctor's appointment and I said that. I said okay, I've gone over it, I've accepted where I'm at, and I've found out some information and now I have an action plan and I want you to help me implement it. And then she was like, okay, hold on a second. And she was like, and then basically what she told me was I was sick, but I wasn't sick enough. So I was like, okay, I have end-stage renal failure but it's not end-stage enough to do anything about. So I have to just sit here and be sick? And, you know, that I really didn't understand. I had a really hard time with. And she was like, yeah, unfortunately we can't even get you on the transplant list, or do any type of testing or whatever until you have 10, I think it was 10% or less kidney function...I walked out of there just saying like this is so backwards. Like we're not being proactive. You know, I didn't understand at the time just like, I just didn't understand and so I was really frustrated with the

whole system. I was really frustrated that I had to just sit and be sick until I was sick enough to get help and so that kind of, that was kind of like a downer.

Other participants expressed that they had positive relationships with their ESRD providers. Kenneth reported a very positive experience with his ESRD providers that continued past the transplantation:

No, that was the wonderful part about it. I mean going all the way back to my first, my first initial nephrologist doctor that I got with University, although she hasn't had anything to do with me in about three or four years, she still checks up on me. You know, I can call her right now. My doctor when I was doing the hemo [hemodialysis]... not the hemo, PD [peritoneal dialysis], he came to see me when I got my transplant. You know, they run hand-in-hand, and I love that.

The Burden of ESRD: Seeking a transplant treatment phase. Participants sought to relieve the burden of ESRD by seeking a transplant. Participants expressed that their experience in seeking a transplant and in some cases, a living donor, as deepening the stress associated with ESRD, but offered the hope of escaping dialysis. A similar range of experiences emerged for this treatment phase with the attendant psychological drain being more or less tolerable. For some patients such as Harold, a retired farm and construction worker, there was not great deal of anxiety associated with seeking and waiting for a transplant.

I just waited my turn. That's all I can say. The anxiety was not yet there. The thing of it was, I was getting along good as I was doing. The dialysis I done three days a week, and the rest of the time was mine; and when this came along, everything looks up.

Kenneth responded to a question about considering seeking a transplant as a mental or emotional drain, he said "Both, mental and emotional. I went through depression... And the reason I say this, okay, for me again, I wanted to get a transplant. It was pretty hard".

He explained that part of this stress was the false alarms, getting calls for kidneys that don't end up in transplants.

And I guess I just thought it was just a simple thing and when that first match come up it would work, and it did, and I went through that a few times where I didn't get a kidney and I was like, 'Oh, my God!' It was just; it would just upset me. It was tearing me up.

Bob explained that while waiting for his second transplant he had similar experiences:

And at the time too, you know, they kept me. When I was coming to dialysis, they kept me working too, so I was working in the factory, coming to dialysis, you know, going home at night. You know, it was just a lot for me to consume. But like I say, when they would tell me I'm possibly going to get a kidney, I guess I just got my hopes up too much, and it would always frustrate me, you know, that I wasn't getting it.

Marilyn had similar comments about false alarms but also on the uncertainty of being on the waitlist. She described it this way:

Well, it was like you just. You know, people would ask me. They were like, 'Well, what's going on?' I'm like, 'I'm waiting.' You know, you just wait. You just wait and wait and wait and you don't know; you can't do anything. The way I feel about it, I lost two years of my life, gone, obliterated. I always say that. I lost two years of my 40s.

Sally was a 60 year old housewife when she confronted the need for a transplant. For her the burden manifested itself as tearful worry:

[I had] not as many tears after my transplant as I had before and that was just because I would get worried I know.

Researcher: What would you be worried about?

Sally: Different things at different times. Like that one is am I too old to have this kidney?

Darrel talked about the burden of waiting for transplant:

I am a pretty strong person I believe. I just knew it had to be done and it is inch by inch, step by step. Makes you want to get somewhere and get to your goal, you get it done, and that's why I said I think in some cases, I think some people just give up and that is why they can't do all that. [I] mean first off, you don't like hospitals anyway, and now you are going through all these tests. It is like a

colonoscopy; yes we all should get one in our 50's, yes. Do I really want to get one? No. Will I get one? Yes.

Researcher: You have to feel that the prize at the end is worth it.

Darrel: Right. But then the prize at the end is you are told that it is going to take you seven years to get a kidney. Then you are a little discouraged.

Bob also talked about waiting:

You know, I went to dialysis six, seven months and nothing was even happening. I wasn't hearing nothing. You know, nobody was saying anything. And at the time when I was married, my wife would call up there. Well, there's nothing going on, nothing happening yet. And I guess that was frustrating too.

Kenneth explained how he dealt with the burden of looking for a donor:

Family could not do it, and it came to a point I was going to do whatever I could within legal means, and social media was a big part of it. I wore a T-shirt around with a kidney on it that says, 'I need a kidney donor. Be my angel.' with my phone number. If anything it would bring up conversation.

David, a retired engineer, who approached ESRD as a project, also experienced anxiety while seeking a transplant.

And as it turned out, none of my blood relatives was suitable at that time, so by default I was placed on the deceased donor list. So, I had to be current. I was given a list of about seven tests that I had to be current on, EKG, a TB test, colonoscopy, and so forth. And some I was already current on, so I got the results to her and some not [current]. Now, that was March. By May, my wife offered a kidney to me. And at first I was a bit hesitant to accept a kidney, I didn't want to put her through the process, but as my kidneys continued to fail, her offer started to sound pretty good. So in the summer of 2006, I said, to ease the tension I said to Betty, my wife, I said, "Why don't we at least get tested, then we'll know. Maybe you're not....: Maybe we're not compatible, then we can stop agonizing over this.

The Burden of ESRD: Post transplant treatment phase. Once the patients were fortunate to enough to receive a transplant, they also retained the problem of ESRD, but in a different flavor; no longer on dialysis and seeking and waiting for a transplant they now had the problem of maintaining a new transplanted kidney. The psychological stress associated with having a kidney transplant was most intense immediately after transplant

procedure and varied in that intensity between patients. Patients expressed a desire to get back to a more normal life but being held back by fear and anxiety. As Darrel stated:

Because I have been to hell, I know what dialysis is like and you have gotten this gift that is just so wonderful and you just want to keep it, but you don't want to be afraid.

Sonia, ten years out from her transplant event still recalled these intense feelings of anxiety:

So I thought that I was, yeah, so I thought that I was in this super delicate position where anything I did was going to affect me negatively just because of that one experience of being readmitted, you know. So I think, compared to other patients, I might have been ultra sensitive to, or ultra scared. I don't know the word I should use, but just like super scared of the way that. I just thought that anything could damage me, you know? And so there were nights where I would just cry and cry and mom was like, 'what's wrong'? And I'm like, 'I just feel like something's going to go wrong'. Look, I already went to the hospital once and most of them don't go back to the hospital after transplant I don't think.

Kenneth referred to the post transplant period as "an emotional rollercoaster". David spoke about the uncertainty of the longevity of the transplant:

Because I can read the statistic charts just like anybody else can on the longevity. I know the 25% of the transplant recipients need another transplant and half-life of a living donor is probably about 15 years...so they don't last forever. But so you know this kind of stuff weighs on my mind.

Resolving the burden of ESRD for those who sought and received a kidney transplant began with the category or first stage of the Basic Social Process of the relationship between patient and coordinator: *Knowing my coordinator*.

Knowing my coordinator. The first category or stage of the process of Easing My Burden is Knowing my coordinator. Participants reported that it was very important to have a specific named coordinator assigned to them. It was important to participants that they had face-to-face contact with the coordinator or at least knew what the

coordinator looked like. The range in this category is: knowing the coordinator by face-to-face contact to not knowing who one's coordinator is at all. Most of the participants experienced and expressed acceptance of the model of having different coordinators pre-transplant and post-transplant. John explained it this way:

You know, I don't know how terribly busy their schedules are. I mean what I'm getting to is we got 600 people on the list here in Springfield [not actual name of city], but the only thing I was going to say is maybe if you could, they could, meet with you at least twice a year face-to-face would help, so you know who they are.

Sally commented: "It would be very bad if you had like your post coordinator, if you didn't have a certain individual. I mean, say they had the whole department and you had a different one calling you all the time". Marilyn related her experience of calling her first transplant center (she had listed at two centers) to tell them that she had been transplanted elsewhere

And it wasn't that I didn't like her. I just didn't have any contact with her, you know. It was like I have a coordinator, I guess. The one thing that really tweaked me was when I called the Transplant Center, because I thought it was what I should be doing, to say, 'Hey, guess what, Transplant Center, I got a kidney.' So I call up and I'm like, 'Hi, I'm calling for Janie,' and the person who answered the phone said, 'Yeah, she hasn't worked here in six months,' and I went, 'What?' So then I was like, well, what the heck? What if I really needed to talk to her? She's gone. I had no clue, none whatsoever. So I'm assuming I was given another coordinator, but I'm like that really unnerved me.

Marilyn further described the importance of knowing the coordinator when she described her new center's website:

Yeah, State Transplant Center [the second transplant center] had if you go to their web site, they have a list of all the coordinators and just a little picture and like two or three sentences about who they are, how long they've been doing this, that kind of thing. So I think even from then when a person, you know, my coordinator called and said, 'Hi, I'm Janie, I'm going to be your coordinator,' I can go to the web site and, oh, this is what you look like. I have a face to put to this name.

Glaser (1978) advocated the use of theoretical codes to explain how the substantive codes or categories relate to one another. Knowing my coordinator could be considered what Glaser (1978) referred to as a cutting point. Glaser used synonyms such as breaking point and critical juncture to describe these codes or categories. If the patient does not have a single named coordinator, a relationship cannot be formed and the process cannot go forward. Conditions or qualifiers explain that the sub-categories of knowing my coordinator are necessary to knowing the coordinator. Participants described four sub-categories as conditions to knowing my coordinator: *Being accessible*, *Being approachable*, *Being personable* and *Knowing what the heck they are doing*.

Condition: *Being accessible*. Accessibility was cited by the participants as a fundamental element in their relationship with coordinators. This was the first code to emerge from the data and remained constant throughout the theory generating process. Accessibility was generally by telephone, but email was also mentioned. The range of this sub-category was accessibility to the coordinator 24 hours a day; 365 days a year to coordinators who were not accessible at all. Most participants did not expect that their coordinator would be accessible 24 hours a day, 365 days a year, but did expect timely return of calls. Bob compared his experience with his latest transplant coordinator compared his first coordinator:

...and they got back to you. You know, keeping in touch with the patient when they call you and ask you stuff, I mean I think it's just a big thing. Because when you got those questions and they find out and get back to you and let you know stuff, I mean, it makes that patient feel better that someone's out there that you can rely on to get you those answers in the hospital. I hate playing phone tag with the hospital, and sometimes I used to call up there during my first kidney transplant and I'd call up there three times in one day and no one would answer, and even the next day they wouldn't answer, you know, and you have to call up there again and tell them why you called; but them were different coordinators

then and that was back how many years back in the '90s there. So it's changed today. I mean these two with Susan and Marge [pre and post coordinators], I mean, they're just, they're good.

David gave his calculated opinion comparing coordinators to nephrologists:

From a patient standpoint perhaps the coordinator is maybe a little more accessible. I think I get-this is an opinion-I think I had overall more face time by having a transplant coordinator than if I would have just had a nephrologist. I mean a transplant coordinator plus a nephrologist. I had more total face time than just with the nephrologist alone. And I think that's an important point.

Kenneth was just going back to work as a physical education teacher after his kidney transplant at the time of his interview:

Yes, I do like that ability to be able to contact somebody because I'm so busy and sometimes I only have a few minutes to make a call; and I understand I might not necessarily get a live voice, but it's just comfortable to know that they get the voice message and get back to me in a timely manner.

Bob explained the feelings he had when the coordinator was not accessible to him:

Nobody up at that hospital seems to care. Nobody calls me. Nobody talks to me about stuff. My wife has called up there a million times. No one responds back to us.

Kenneth related his experience with the transplant coordinator caring for his live donor:

I didn't feel that she was accessible enough, and it was several times where my donors were wondering stuff but they weren't contacting them, and it was kind of a mess for a while.

Condition: Being approachable. This sub-category is related to accessibility and was also a fundamental element to a successful experience with coordinators. The participants were satisfied when they perceived that the coordinator was willing to spend the time with the patient to listen and not hurry them, that they welcomed their questions.

John put it this way:

Like there might be six other people waiting to see her and the doctor, and because like clinic you usually see the pharmacy person and then there's a nurse

and a doctor and dietitian, so they are all in and out and stuff, and she just doesn't hurry no matter what, you know, if you've got questions or explain stuff.

Billy, a retired chef described the approachability of his coordinators: "You know, where you could tell them your problems; you can tell them any kind of issues you have and they were always there for you." Sally talked about her first coordinator telling her "If you need to know something, you call me and I will talk to you," and he says, 'none of your questions are dumb questions.'" John talked about his coordinator's approachability "She's, you know, call her any time if anything was wrong" At the other end of the range were the participants who described their coordinators as unapproachable and this inapproachability made having a relationship with the coordinator difficult if not impossible. Marilyn related inapproachability as part of the problem in her non-relationship with her first coordinator:

You know, you got a name and a phone number. Here's my coordinator. I call them. And, you know, you have to leave a message; and if it's not a specific question with a specific thing that they can do for you, they're just like, you know, basically 'don't bother me.'

Condition: Being personable. The participants described a desire for the coordinator to be personable or amiable. Unlike, accessibility or approachability, this sub-category was one that the patients were looking for, but it was not absolutely essential to a successful relationship. Nonetheless, most participants discussed how personable their coordinator was or was not. Sally stated it succinctly: "They got to be pleasant. I mean, because you're dealing with someone that is chronically ill." She also related that one of her coordinators was not personable: "The only complaint I had was with her is she wasn't as, I don't know if personable is the word I want to use, or friendly?" David, the engineer who approached kidney failure and transplantation as a

project compared his two coordinators in terms of being personable. His story describes the range of this sub-category; personable to cold. He described the relationship with his first coordinator:

It was very businesslike, it was very procedural, it was very medically oriented. She wasn't a shoulder to cry on. I only remember asking her one question that kind of bothered me a little bit. I said, I asked her, when she says you're compatible, I asked her how compatible are we? And she says, 'You're either compatible or you're not compatible and you are compatible.' I thought that was a little cold, but I thought she could have phrased it a little bit better. But other than that it was a very procedural, very businesslike. She was not a shoulder to cry on

In contrast was his description of his relationship with his second coordinator:

I thought it was very positive. Maria is a thirtyish, fortyish Hispanic woman... And I think she's very businesslike, but she has kind of a warm side to her. I never tried to cry on her shoulder or anything, but she was always helpful, very professional, always followed up, what else can I say about her? I liked calling her.

Condition: Knowing what the heck they are doing. Participants expected and in many cases, assumed, that the coordinator would be knowledgeable about transplant and ESRD. This category was rather one dimensional with all participants expressing the belief that their coordinators possessed the skills, knowledge and competence to care for them. Billy related: "Researcher: 'And then if you felt if you did call her she would know what to tell you?' Participant: 'Exactly, yes. She would have the right answer.'" This confidence occurred in two ways; context and testing. Context refers to the setting or ambience in which the process occurs and the meaning of that context to the participants (Glaser, 1978). Some participants expressed faith in the institution itself: "I just took for granted [that the] transplant center picked a coordinator for me and figured that was the best one for me" Sonia explained how she knew her coordinator was knowledgeable:

Like I would be able to ask her questions. I remember being able to ask her questions about like my diet and things like that, that she would say, ‘well, we can have you meet with a nutritionist?’ [And I would say] but I know that you know this and that, she would be able to answer it, but she’d always tell me we can set up an appointment with the nutritionist. But she would also know the answer, you know, but if I wanted more in-depth and to learn more, then that would mean that I would have to meet with the nutritionist. So things like that, I just felt that um [sic] and plus the fact that my best friend knew her and had worked with her for a long time also helped because she told me like that I had one of the best, that she was really good at her job so

Sonia’s comments illustrate both testing and context in that she relied on her best friends’ opinion. Sally described having confidence in nursing “Almost all RN’s know, if you mention a drug they’ll say, ‘Yeah, I know what that does and what it’s for.’ I think it’s good that they know stuff like that.” Sally also tested her coordinator’s knowledge and competency:

Researcher: Well, like, did you check out what she said, like she said something?

Participant: Yeah, I would always check with my general practitioner.

Researcher: So she tells you something; you check it out with somebody else?

Participant: Right, yeah, but I just haven't had any problems, you know, with her. I mean, what she was telling me then I would... Like if she told me before September, say I had to change my Prograf to a different dosage, I would change it and then I would do blood work and it would come out, so that gives me confidence in her that she knew what she was doing.

David also expressed confidence in his coordinator’s knowledge based on their role:

“They know an awful lot because Maria, for example, made a presentation at one of the living with transplantations and she gives handouts and stuff. So they know an awful lot.”

My coordinator knowing me. The next stage or category involves the patient being known to the coordinator. This category contains the concept of having the coordinator being familiar with the patient; knowing his or her history, background, etc. My coordinator knowing me also entailed the coordinator taking an interest in the patient, in other words knowing the patient because the coordinator cared about him or her as a

person. The range for this category was not knowing me to knowing me as a person including my personality. Sally talked about her first coordinator:

He just seemed I wasn't just a number to him. I mean when I would call down there, and I'm sure that the girls when I asked to speak to him they would say who was calling, but he knew exactly how to answer my question. I mean he knew, it seemed like he knew everything about me, like my whole life was right out there in front of him, which it might have been on a computer monitor, I have no idea.

Sally and others related that the coordinators knew their personalities and moods. For others it was somewhat less personal but important nonetheless: John related:

I don't know. I think especially right after surgery I would rather just have the same person so they know, like when you tell them about the swelling in your body and next time you go you don't have to tell somebody else.

Marilyn was also rather pragmatic:

And because it has been the same people for a few years now, I do think we feel a little bit of a relationship where the person calls and I know who they are and I'm not repeating myself over and over again about who I am and what's my deal.

The category my coordinator knowing me also has two sub-categories relating to the more intimate or personal feelings that the participants expressed that were a consequence (Glaser, 1978) of the coordinator knowing them. These are: *Making me feel important* and *Showing me they care*. Interestingly, there were very few negative instances of this stage if the patient and coordinator had moved successfully through knowing my coordinator; patients did not describe coordinators with whom they had already moved through that stage successfully as not taking the time to know them. Rather the variability was in the depth of that knowing; from simply being familiar with symptoms (knowing what's my deal) to a more personal knowledge.

Consequence: Making me feel important. Participants related that the coordinator made them feel important. As part of getting to know the patient, the

coordinator took the time to recognize the unique needs and concerns of the patient. The coordinator treated them a unique person whom they knew and cared about. This sub-category was dichotomous without gradations; participants either described being made to feel as if they were important to the coordinator or being made to feel that the coordinator did not consider them as unique or important. Sally talked about her first coordinator:

I still talk about him, how nice he was to me. Made you feel like a person, not a number. That's my big thing when you're in a hospital, you know you're bed A in room 320 and this way I was actually a person.

Kenneth related his experience: "She makes me feel that I'm important. I'm sure she has several other patients, but when she's dealing with me, she makes me feel like I'm number one."

Marilyn described her feelings of not being viewed as unique or important triggered by receiving a letter from her first coordinator about monthly blood samples. She had not moved through the knowing my coordinator stage with this coordinator either.

...especially once the transplant center sent me the letter that said they're no longer getting, taking my blood samples, that's when I started to kind of feel like, okay, I am now just a small cog in a giant machine

Sonia related that although her coordinator was accessible, knowledgeable and even somewhat personable, she did not believe that the coordinator knew her as a unique person with her own special needs:

I have to say, I mean she was very good about getting back to me I mean as soon as possible, but it definitely um just was; and when we did deal with one another, I felt a little more like one in a big crowd. Even though she knew me and she called, you know, we'd see each other in the hallway and she knew who I was and she'd say, 'Hi, 'Sonia',

things like that. But as far as like my particular situation, I just remember like I always felt the need to go over what I've already talked to her about just to make sure she knew I was the right patient that she was referring to.

Consequence: Showing me they care. This sub-category involves the patient having the perception that the coordinator cared about them. Participants expressed the appreciation of having the coordinator demonstrating care for them: Penny said: "I feel like they really care and they want to make sure that everything goes well with you. They don't want nothing to happen to you [sic]." Billy explained: "And you're not just a number to them but they care about you". John described his deep relationship with his nurse with whom he worked on Kidney Foundation committees "She's more of a friend than a nurse." Sonia compared her pre-transplant coordinator with whom she continued a friendship with her post-transplant coordinator with whom she had a much more shallow relationship.

So versus a nurse/patient type of relationship, it (the relationship with her first coordinator) felt much more personal and then, so in the post [coordinator relationship], that would have been nice because I kind of, um, would have felt like there was somebody I can call at any time to say I'm scared and I'm this and I'm that. But instead I was kind of like, 'Oh, I don't want to be one of those psycho patients calling all the time, so I'm not.'

Billy described how his coordinator showed him how she cared:

And she would always call me up no matter what because she knew that I wanted to know what was going on and she... We had a not like a husband and wife but we had like a really close relationship.

Having a good relationship. Once the patient has a known coordinator who is accessible, approachable, personable, and knowledgeable and believes that the coordinator knows and cares about them as a unique person with their own unique needs,

a relationship is formed between the coordinator and the patient. Participants described this relationship from non-existent to adequate to similar to a friendship or family relationship.

Marilyn related that she would have liked a relationship with her first coordinator, but did not have one and she went to another transplant center. Sonia stated that she did not have a relationship with her post coordinator because she was not personable and Sonia never believed that she knew her as a unique person (see quote in preceding paragraph): “she’s was very kind of by-the-book and a little more dry and so, that is just instantly like a turn-off to me.” Billy put it this way about his relationship with his first coordinator: “You know, it was like, it was just good. It was a great relationship.” It was such a good relationship that Billy did not want it to end, but eventually his coordinator moved on.

And then she left about two years after he [the surgeon] did, and it was a shock and I cried, and we hugged and kissed and all that kind of stuff. But when you have a relationship like that and your life is in their hands and they’ve done so much for you, it’s just hard. It was really difficult.

David contrasted his relationship with his two coordinators also illustrating the importance of being personable to a more positive patient-coordinator relationship. The relationship with his first coordinator:

I think it was adequate. I’m not a whiney, weepy person, so I wasn’t looking for somebody to feel sorry for me. I was mostly interested in the mechanics of it, what do we have to do next? And she was good at that. She was very businesslike, very impersonal about it.

This statement was in contrast to his second coordinator, Maria, whom he described as more warm and personable and described his relationship with Maria as “very positive.”

Bob, as did many participants described his relationship with his coordinator as similar to

a family relationship: “I mean, when I got the transplant. I mean she was like, almost like-how would I put it-like a mother or sister to you”. Billy had a similar description of his relationship: “It was just, you know it was like; I can’t say like a second wife. It was like a friendship or a sister brother relationship”

Believing in my coordinator. The next category in the process is *Believing in my coordinator*. Once patients have established a satisfactory relationship with their coordinator, they begin to have confidence or faith in the coordinator. Billy related how he believed in his coordinators:

They’re available for you when you need them and you have faith in them; you believe in them that your life is in their hands. If you have a problem, you can call them and you have no fear of well she can’t handle me or she doesn’t have time for me.

Billy’s remark also illustrates that the belief is conditional on being accessible and competent or “knowing what the heck they are doing” illustrating the dependence of the categories or variables on one another. Billy also made comments that illustrated the tie between believing in the coordinator and following the treatment plan: “And when I believe in them, I do what they tell me.” Harold was more succinct: “If she says something, I’ll believe it.” Sally had a similar comment about her first coordinator. When questioned if she ever doubted something that he told her, she replied: “Nope, I believed every word he told me.”

Trusting my coordinator. For kidney transplant recipients, having their burden eased required trusting someone to share it with them. Trusting means that the coordinator had proven themselves reliable in sharing the load of waiting for or caring for the kidney. This trust entailed having confidence in the reliability of the coordinator in

general. As Billy said: “To feel good you’ve got to trust somebody. Like I trust my wife with my life. I trust these coordinators with my life. I trust that whatever they tell me.”

This trust was strongly apparent in the process of the coordinator checking labs or other diagnostic tests. This checking is one way in which coordinators share this burden. Some participants discussed trusting the pre-transplant coordinators to monitor evaluation testing results. Checking labs after the transplant event was also described as an important part of the transplant coordinators’ role. After the transplant event, visits to the transplant center decrease to often once a year or less. But as the threat of rejection or complication is always present, a certain level of vigilance is required. This vigilance or monitoring is generally in the form of periodic laboratory blood testing. These labs are ordered very frequently initially and decrease to monthly or less over time. Patients with a successful relationship with their coordinator reported that they trusted the coordinator to check these blood and other test results, to know how to manage the results and to let them know if action was required. In many cases, the patient did not check their own results and trusted that the coordinator would call them if action was required but would not call if the results were acceptable and no action was required. In some cases, this trusting relationship was never formed or was breached by the coordinator’s failure to check or act upon the labs. Sally reported:

And then after January I’ll just do it once a month. And she told me, she said; ‘Now I will not be calling you after every one of your blood tests.’ Because I’d go for a blood test and then I’d sit here at home and think when are they going to call, when are they going to call? Well, she says, ‘I only call you if there’s a problem.’ So she has had to call me because they had to change my Prograf and they had to change my Coumadin a couple of times, warfarin is what I’m on, but they’ve had to change it before. So she warned me, she said, ‘Don’t sit and wait for a phone call because if your blood work is good I will not call you. But don’t you hesitate to call me if you have a question.’

Researcher: So what did you think about that, that she wasn't going to call you for every blood work?

Sally: It bothered my husband more than it bothered me, because he's one of these that has to know what your numbers are. And I figured if she thinks that my numbers are okay and I don't need to know, I'm satisfied with that.

Over time, it has become a way of life for Sally. She related that she now gets her blood drawn once a month and looks forward to not hearing from her coordinator:

Yeah, if there's anything wrong with my blood work, I mean, I can almost do my blood work at the lab, and before I'm home if they've tested it, she'll call me almost immediately. If there's something wrong. If I don't hear from her, then I know everything's okay, and I just love it when she doesn't call me.

Bob described both sides of the range of this category: not trusting the coordinator and trusting the coordinator enough to be comfortable with "no news is good news":

I mean, and that's the way it is. But if there's something that needs to be changed, I mean, they'll see it. That's even when I get my blood drawn in town and the blood work is sent up there, if there's something that needed to be changed, they will call me that day. If not, it will be early in the next morning I'll get a phone call saying change this or that.

Researcher: So you feel confident no news is good news?

Bob: Yeah, yeah.

Contrast that trust with his first experience:

No, I mean, you know, call me with my blood results and stuff. I mean before it just seemed like they would forget sometimes. I mean my first kidney transplant, I don't know how many times that they forgot to call me and tell me to change something in my meds, and I find out another week later that, 'Oh, you should have did this last week' or whatever, and it was like, 'What do you mean? No one frickin'[sic] called me or anything?'

But Bob had someone else to trust at that time, his wife who was a nurse. He had since become divorced but could trust his coordinator:

Bob: Well, at that time, you know, well, at the time, I mean, it wasn't that bad because my wife who I was married to was a nurse, and she knew a lot about the meds that I was on. You know, I was lucky she was around, but she used to call up there and get it situated somehow, but I was lucky to have somebody like that then but

Researcher: But now you can rely on your transplant coordinator?

Bob: Yep, now I can rely on my transplant coordinator. I can do a lot of things myself. I can turn around up there, ask them questions; they'll tell me what to do and how to do it, and I'm comfortable with that.

Bob and Sally have reached the point that their burden has been eased as they trust their coordinator to share it with them.

Trustworthiness of the Theory

The trustworthiness of qualitative research is measured by the four constructs for soundness in qualitative research as articulated by Lincoln and Guba (1982): credibility, transferability, dependability, and confirmability.

Credibility

The credibility of this theory is enhanced to the reader by the use of the participants' own words. Recording the interviews to produce word-for-word transcriptions supported establishing trustworthiness in the writing of the final report. The transcripts gave the researcher the ability to complete the portrayal of and establish the credibility of the theory by using the participants' own words. These quotes support the believability of each of the categories of the theory.

Transferability

Glaser (2001) asserted that grounded theory methodology is inherently transferable because the theory is conceptualized from the data. Transferability was also enhanced by the theoretical underpinning of the grounded theory methodology (Marshall & Rossman, 2006). Although the intent of this theory is to conceptualize the Basic Social Process between a kidney transplant candidate or recipient and their coordinator; the theory may also be useful in understanding the process between candidates and recipients

of other types of organ transplants or perhaps other patients with chronic illness and their caregivers. These patients also have somewhat similar Basic Social Psychological Problems in that they have the need for life-long illness care. Multiple informants and multiple interview sessions or triangulating data were also employed; these strategies have also been identified as strengthening generalizability (Marshall & Rossman, 2006). Transferability was also enhanced by the diversity of the sample. Participants lived in five states on both coasts and the Midwest, received transplants at nine different transplant centers. Age, race, gender and educational background were also heterogeneous.

Dependability and Confirmability

Dependability refers to the soundness of the research process and confirmability refers to the lack of bias (Lincoln & Guba, 1982). Dependability was enhanced by consistently applying the research methodology (Marshall & Rossman, 2006). The grounded theory methodology was consistently applied throughout the data collection process. Participants were interviewed sequentially, transcripts compared to previous transcripts and coded. The categories or concepts were continually refined as new data were reviewed, thus the accounting for changing conditions as Glaser (2001) suggested increased the dependability of the grounded theory methodology.

Confirmability or objectivity is demonstrated to some extent by the extensive use of the patients' own words as opposed to the researchers' words and opinion. The visual models used as theoretical memos form an audit trail for process of theory conceptualization as suggested by Lincoln and Guba (1982) as well as and co-authors (J. Morse, Barret, Mayan, Olson, & Spiers, 2002) as enhancing confirmability. The

researcher's coding was verified by members of her committee and the theoretical memos were also reviewed over the course of theory development.

Assessing the Theory

Glaser (1978) specified several criteria by which to judge grounded theory: fit, work, relevance, and modifiable. The theory of Easing My Burden meets these criteria.

Fit

The criterion of Fit is defined as the categories of the theory fit the data. The categories of this theory were conceptualized from codes that were derived directly from the data. The interviews were recorded, transcribed and coded line by line. These codes were then compared to the codes from previous transcripts. The participants own words were used as much as possible to name the codes. The codes were then used to fill out the properties of the categories. Thus, the conceptualization of the theory emerged from the data itself and naturally fits that data. This fit is also demonstrated by the use of the participants' own words to articulate the categories of the theory.

Work

To meet the criterion of work, the theory must explain the Basic Social Process studied (Glaser & Strauss, 1967), in other words, it must "work." The theory should "explain what happened, predict what will happen and interpret what is happening" (Glaser, 1978, p 4.) The theory of Easing My Burden works for this process as it interprets how a successful process solves the Basic Social Psychological Problem of the Burden of ESRD as well as describing what are the essential elements that make the process successful or work for the patient, thus allowing for prediction. This ability to both explain and predict renders the theory useful to both patients when choosing a

transplant center and for transplant coordinators and their managers in designing staffing and care models.

Relevance

A theory must not only fit the data and work to explain what is happening, it must also be relevant to what is or has happened (Glaser, 1978). The grounded theory methodology used to conceptualize the theory of Easing My Burden achieves relevancy to the action in question as it is conceptualized from the data, not deduced from other theories or preconceived ideas.

Modifiability

Modifiability refers to the ability of the theory to be “recast” (Glaser, 1978, p 5) as new data emerge. Using grounded theory methodology demands that the researcher not be testing hypothesis or preconceived theory, but conceptualizing theory based on constant comparison of data. This theory could be modified as new data emerge or for use in different settings such as patients with liver disease or cancer.

Summary

This chapter presented the findings of the study which were conceptualized from the data to generate the grounded theory: Easing my Burden. This theory explains and predicts the outcome of the Basic Social Process that occurs between a kidney transplant candidate or recipient and their transplant coordinator. A successful outcome or whether or not the Basic Social Psychological Problem of the Burden of ESRD is resolved is dependent on the concepts or categories of the theory being accomplished: knowing my coordinator, my coordinator knowing me, having a good relationship, believing in my coordinator, and trusting my coordinator. As a result of this process the patient’s burden

is eased. Hence the core category of the theory is Easing My Burden. The theory will be discussed in context of the extant literature and implications of this theory to nursing practice in the next chapter.

CHAPTER FIVE

DISCUSSION

In this chapter, the theory, *Easing My Burden*, will be discussed in context of extant theories and other findings in the literature. The unique findings that this study presents, most importantly the perspective of the kidney transplant recipient regarding the Basic Social Process between themselves and their transplant coordinators, will be discussed as well. The implication of the theory in public policy, nursing practice, education, and management will also be discussed as well as limitations of the study and directions for further study.

The Basic Social Psychological Problem: The Burden of ESRD

I recently went back to the dialysis unit. In one year, six dear friends there have died. Some people manage dialysis for 20 years, but the average life expectancy on dialysis is five to eight years. And as I now know, being on dialysis isn't really a life. It's not even half a life.

Nicolas Evans, author of the *Horse Whisperer*, recalling his life on dialysis prior to receiving a transplant (Evans, Hamilton, Bello-Villalba, & Bingham, 2012, p. 2). The diagnosis of end stage renal disease (ESRD) is a life-altering event for an individual that is associated with a decrease in quality of life (Cukor et al., 2008; Kimmel, Cohen, & Peterson, 2008; Rambod, Shabani, Shokrpour, Rafii, & Mohammadalliha, 2011; Watnick, 2009). The patient faces either life-long dependency on either a machine or medications or certain death. Even with treatment, their risk of death is estimated at between 5-500 fold greater than healthier peers (Watnick, 2009)

Patients experience changes in work and family role as well (Kimmel et al., 2008). The participants in this study reported feelings of both anxiety and depression. The prevalence of anxiety and/or depression in hemodialysis patients has been reported as high as 71% in a single center trial (Cukor et al., 2008). Other studies (Kimmel et al., 2008; Troidle et al., 2003) cite depression incidence at between 44-50%. A worldwide meta-analysis (Palmer et al., 2013) found that point prevalence of depression varied considerably between studies and was somewhat dependent on whether a tool or questionnaire (standardized) or professional interview (professional opinion/diagnosis) was used to diagnose. The investigators found the prevalence to be 39.3% in tool diagnosis and 22.8% in interview diagnosis in dialysis patients and 26% and 25.7%, respectively, in kidney transplant recipients. Several patients discussed high psychological distress related to waiting on the list. French researchers studied a longitudinal group of newly listed patients, measuring anxiety and depression during waiting and transplantation and they found that both symptoms progressively increased with waiting time and decreased at the time of transplantation (Corruble et al., 2010). Several patients also expressed that psychological stress decreased over time after transplantation. Their experience of decreasing depression and anxiety with time after transplantation has also been found in a Spanish study of kidney and liver transplant recipients studied at time of transplant and 12 months after transplant (Pérez-San-Gregorio, Fernández-Jiménez, Martín-Rodríguez, Pérez-Bernal, & Gómez Bravo, 2013). Overall, individuals with ESRD have higher prevalence of anxiety, depression and other negative psychological and cognitive symptoms compared to healthy controls (Kimmel et al., 2008; Pascazio et al., 2010; Troen et al., 2012). Although several authors discussed

the stress of treatment itself (Kimmel et al., 2008; Szeifert et al., 2010; Watnick, 2009), there were no studies discussing the impact of negative encounters with staff.

The researchers reporting on the Choices for Healthy Outcomes in Caring for ESRD (CHOICE) study (H.R. Rubin et al., 2004), a multicenter study on treatment choice conducted in the late 1990's, examined differences in patient satisfaction between hemodialysis and peritoneal dialysis patients. The study sample consisted of 1,041 patients in 81 clinics. Across modalities, the best ratings were given to the caring and concern of nurses and staff and lowest ratings were given to nephrologists for coordination with other physicians, availability, and accuracy of information given to the patients. Peritoneal dialysis patients were more likely to rate the nephrologists higher in accuracy of information given and these higher ratings were associated with higher satisfaction. Several patients in the Easing My Burden study expressed dissatisfaction with the information given to them by nephrologists.

Easing My Burden

The core category of this theory is Easing My Burden. This core category is both the consequence and the driving force of the patient who needs to find a solution to the Basic Social Psychological Problem of the Burden of ESRD. In the successful Basic Social Process between the patient and his or her transplant coordinator, a relationship is established. The establishment of this relationship was dependent on each of the categories being successfully resolved. The initial categories are: Knowing my coordinator, with condition sub-categories of: Being accessible, Being approachable, Being personable, and Knowing what the heck they are doing. These categories are followed by the category of My coordinator knowing me, with the consequence sub-

categories of: Making me feel important and Showing me they care. The process continues with the categories labeled: Having a good relationship, Believing in my coordinator, and finally with Trusting my coordinator (see Figure 1).

The patient-nurse relationship is a key element of nursing practice. The theory developed by this study is a practice-level theory as the scope is a single, specific phenomenon: the Basic Social Process between kidney transplant candidates and recipients and their transplant coordinators. The theory has some correspondence in its concepts to Peplau's (1952; 1988; 1991; 1992; 1997) middle-range theory of Interpersonal Relations. This theory includes the successive stages of Orientation, Work, and Termination or Resolution which describe the process of the relationship between and nurse and the patient.

Peplau's Theory of Interpersonal Relations

The Basic Social Process experienced by the patient and transplant coordinator represents the formation of a relationship between patient seeking and living with kidney transplantation. This concept of the importance of a relationship between a nurse and a patient is the foundation of the work of Hildegard Peplau (1952; 1988; 1991; 1992; 1997). Peplau stated that the nurse-patient relationship was the "central feature" (1992, pg 13) of nursing practice. The effectiveness of this relationship is measured by the patient's perception of the health-associated benefits of the relationship (Beeber, 2000). In her theory of Interpersonal Relations, Peplau hypothesized that the patient's anxiety regarding the change in health status caused him or her to seek care from the nurse. The anxiety concept has parallels to the initial category or the Basic Social Psychological Problem of the Burden of ESRD. Patients sought a relationship with the coordinator

because of the burden or anxiety caused by experiencing end stage kidney disease. The actual incidence of anxiety and depression in ESRD patients was discussed earlier in this chapter. Relieving fear and anxiety is also a cornerstone of patient centered care (Gerteis, et al., 1993).

In Peplau's theory, the relationship process is generically described as consisting of three phases: Orientation, Working, and Resolution (1997). Easing My Burden shares similar elements with the Orientation phase. This first phase begins with the nurse being a stranger and ends when the nurse-patient dyad is prepared to do "work." The nurse performs assessment but more importantly, establishes the environment of trust and respect. Specifically the patient comes to know the nurse and the nurse to know the patient (Beeber, 2000). However, the Easing My Burden theory, as a practice theory, describes, explains, and predicts this Basic Social Process as it occurs between patients and their transplant coordinators.

Knowing my coordinator is the first stage in the Easing My Burden theory. Knowing my coordinator has several sub-categories or conditions that are necessary for the stage to be successfully resolved. Time spent with patients, frequency of encounters, availability of the nurse were factors associated with increased positive relationships in the Orientation phase and were cited as facilitating successful resolution of this phase in several studies using Peplau's theory in the care of psychiatric patients (Forchuk et al., 2000; Forchuk et al., 1998; Forchuk, 1994; Stockmann, 2005). These findings are similar to the sub-category of Knowing my coordinator, the condition of Being accessible.

The stage of Knowing my coordinator also contained the conditions of: Being approachable, Being personable and Knowing what the heck they are doing. These stages

or phases have some similarity with the concepts attributed to Peplau, (1997) who theorized that the success of the nurse-client relationship was dependent on the nurse being present (approachable), perceived as being personable by the patient and on the nurse's overall interpersonal and intellectual competence. Researchers (Forchuk et al., 1998) explored successful transition from the Orientation phase to the Working phase and identified factors that facilitated this movement which represented the formation of a therapeutic relationship. Being approachable was one of the important factors as was being friendly and genuine which has similar features to the category Being personable.

Positive resolution of the Orientation phase was also associated with the patients' perception of the nurse as being interested in them, being caring, understanding and treating the client as a human being; these factors have correspondence with the sub-categories Making me feel important and Showing me they care which are sub-categories or consequences of the Knowing my coordinator stage. Patients moving to the Work phases also reported developing confidence in the nurses who were consistent between meetings in taking actions as promised and also expressed the development of trust. These factors correspond to the categories of Believing in my coordinator and Trusting my coordinator. The product of the Orientation phase in the Interpersonal Relationship theory is a decreasing of the client's anxiety gradient; the client is more able to participate in the Work phase which the nurse and patient enter together. This concept of the quality of the relationship decreasing the patients' anxiety about the health situation in which they find themselves has some similarity to concept that the process of forming a trusting relationship with the coordinator allows kidney transplant recipients to perceive that the coordinator is easing their burden, but again in Easing My Burden, the concept is

more narrowly applied to the relationship between kidney transplant recipients and their transplant coordinators.

The participants also experienced an end to their relationship with the coordinator. In Peplau's theory this corresponds with the Termination or Resolution phase. Part of the Resolution phase is that the nurse and client prepare for the end of the relationship (Peplau, 1952; Peplau, 1991). This preparatory or discharge process did not occur with every patient in this study. However with the exception of Billy, who remained very dependent on his coordinator after ten years, these patients expressed their readiness for the transition. Nonetheless, there was frequently an absence of a structured termination process when a coordinator left the institution and any kind of hand-off or transition process was not transparent to the patients.

Trust

The final phase of Easing My Burden is Trusting my coordinator. For the patients, the development of a trusting relationship was key to a successful process. Not surprisingly, the Easing My Burden theory bears similarities to theories describing and explaining the formation of trust between health care providers and patients. Individuals with end stage renal failure are faced with the inability to continue living without relying on others. Baier (1986) defined trust as the "reliance on others' competence and willingness to look after, rather than harm, things one cares about which are entrusted to their care" (p. 259). Participants in this study did not generally enter the relationship with the coordinator with blind trust but trust was developed as the phases in the process were successfully resolved.

The process begins with a need. The patients had a need to trust because of the problem of end stage renal disease. Hupcey, Penrod, Morse and Mitcham (2001) in their concept analysis of trust, named need as an antecedent to trust. A surprising element of the process for many of the kidney transplant recipients was that the burden or need was intensified by the lack of trust in their initial nephrology care givers. This initial loss of trust made them wary and cautious in trusting as they sought kidney transplantation. This phenomenon of loss of initial trust and the subsequent formation of new trusting relationships in patients with chronic illness was explained in a grounded theory study by Thorne and Robinson (1988). The informants in their study entered the relationship with the health care providers with illness symptoms and the expectation of cure; a somewhat blind or naïve trust that was shattered when the expected cure did not materialize. This loss of trust was labeled the Disenchantment phase and resulted in distress and negative feelings such as anger, suspicion and vulnerability. As the need for ongoing relationship with health care providers persisted, the need to decrease the distress or anxiety moved patients to the Resolution phase. In this phase, the patients were much more careful about establishing a trusting relationship; Thorne and Robinson described this process as forming a guarded alliance. The guarded alliance had four different configurations: Hero Worship; Resignation; Minimal involvement; and Team playing. Hero worship was defined as selecting one health professional as worthy of absolute trust, while distrusting health professionals in general. This kind of absolute trust was described by many of the kidney transplant recipients in this study who related their belief in their transplant coordinators: “[T]hey’re available for you when you need them and you have faith in them; you believe in them that your life is in their hands.”

Sloan (1999) explored the trust relationship in hemodialysis using the guarded alliance theory. The study was limited by sample size (four) all from a single unit. The informants described Hero worship alliances with a particular nurse or physician or in one case, the dialysis machine. Patients also described the other three configurations in their relationships with providers. Resignation is described as the patient withdrawing as he or she feels powerless. Anger, frustration, despair, and depression are common. Resignation was the alliance configuration utilized by the participant Marilyn as she described the relationship with her first transplant coordinator and eventually her decision to go to another center:

So I had very minimal contact with her because basically the way it was presented to me was we're going to put you on the list and you're going to sit here and you're going to sit and you're going to sit and you're going to sit; and only when it gets, you get somewhat close to the top are we going to even really contact you; and basically, don't bother us until that point. Don't call us and ask us where you are on the list. We can't tell you. We can't do this... Once you get put on the list, it's like we'll call you when we need you.

David's trust relationship with his first coordinator was consistent with minimal involvement. He developed his own body of knowledge in order to have minimal reliance on his coordinator. Minimal involvement was also the style of alliance described by Darrel with his dialysis unit staff whom he viewed as his adversaries:

I had friends that were tested [for transplant] and nothing worked out. It came to the point where being not happy at dialysis at Dialysis Company, I can say I was pretty angry... The anger is me and to turn that around, wait a minute. I mean when you are at some of these centers ... I truly believe they don't think you will get transplanted. I don't think they even want... well, [to] make an effort to give you information because one Dialysis Company, these companies are in business. It is their business and my plan was to get out of there, and their attitude is 'sure you will, sure you will'.

Minimal involvement was also the alliance that Marilyn had with her dialysis unit and nephrologist:

You know, I didn't rely on my nephrologist or my dialysis center or anything. And if you rely on other people to provide that [information about transplant] on their schedule, things can go really wrong really fast. You know, I've heard people who their labs aren't getting drawn because something goes wrong and they're expecting somebody else to be on top of it.

Team playing is the fourth configuration. In the team playing alliance, the patient negotiates mutually satisfying interpersonal relationships with selected professionals built on reciprocal trust (Thorne & Robinson, 1988). This fourth type of guarded alliance is most like the successful relationship described by many of the kidney recipients. The patients carefully determined the worthiness of the coordinator to earn their trust and ease their burden. Harold put it simply when questioned about his long term outlook with his transplant and his relationship with his coordinator and the rest of the transplant team: "I have confidence in myself. I know the difference between right and wrong, and they're going to help me along with it".

However another concept of Thorne and Robinson's work, the concept of reciprocal trust or the importance to the patient that the health care provider trusts them, was not present in the data. No patient expressed a need for the coordinator to trust him or her, perhaps because this trust is implicit in the relationship.

Receiving a kidney transplant requires lifelong adherence to a medical regimen; taking immunosuppressant medications and having regular diagnostic blood tests are the minimum expectations. Those patients who do not comply with these requirements often lose their transplanted organ or in some cases, their life. The multidisciplinary transplant selection committee makes the decision on whether or not to accept a patient for

transplantation based on medical criteria but also on an assessment of the patient's ability and likelihood to comply with the prescribed treatment plan. This assessment is required by the federal Medicare regulations (United States Department of Health and Human Services, Centers for Medicare and Medicaid Services, 2007). This decision to accept the patient for transplantation implicitly indicates that the selection committee trusts the patient to follow the prescribed regimen after transplantation. There is some evidence (Chisholm, 2002; De Geest et al., 2013; Dew et al., 2007; Johnstone, Walrath, Wohlwend, Jobe, & Thompson, 2004) in the literature that the patient and caregiver relationship is an important element of adherence in transplant and hemodialysis but none explicitly cite the concept of reciprocal trust.

The Easing My Burden theory bears some similarities to a grounded theory examining the Basic Social Process of the development of trust between nurses and hospitalized Hispanic patients (S. Jones, 2012). The researcher conducted face-to-face interviews with twenty-two patients of Mexican descent receiving care in a large urban medical center obstetric unit. The core category was *Making Me Feel Comfortable*. The Basic Social Process was initiated with *Having a need* and *Relying on a nurse*. This need led to an initial phase that was cyclical, repeated with each nursing shift, consisting of the categories *Taking care of me*, *Coming across to me*, *Connecting*. This cycle, if successful, was followed by the patient *Feeling confianza or trust* which lead to *Confiding in nurse* and *Taking away the negative*. The concept of comfortable was described as a state of being, not merely being physically comfortable. This core category has some correspondence to Easing My Burden; however it is much more narrowly focused. Patients felt comfortable with the nurse, so they would confide in the nurse which would

help take away the negative feelings. The core category of Easing My Burden encompasses a decreasing in the psychological stress of chronic illness by the development of a trusting, caring relationship. The process in the Jones study began in a similar fashion with the patients experiencing a Basic Social Psychological Problem (Having needs). The category of Coming across to me, which represents the initial impressions that the patient develops about the nurse, has some parallels to the Knowing my coordinator categories and its sub-categories of Being approachable and Being personable. The category of Taking care of me had a similar sub-category (Showing care) as the sub-category Showing me they care under the My coordinator knowing me category. Although a trusting relationship and relief of anxiety was central to both processes, the relationship between a transplant coordinator and a patient with ESRD spans a much longer time than a shift in the inpatient setting and would necessarily be less superficial in nature.

The development of trust as a dynamic process was also major finding of an extensive literature review of trust in nurse-patient relationships by researchers Dinç and Gastmans (2013). The authors discovered that patients had high levels of trust in their nurses. They further recognized trust as an essential element of the therapeutic relationship. They found certain pre-conditions that were essential to the formation of trust. These included: the availability and accessibility of the nurse, the patient feeling emotionally and physically safe, feeling at home and valued as an individual, feeling adequately informed, and respectful communication. The development of trust demanded technical competence as well as time and continuity of care to allow for a relationship to form. Some of these conditions that parallel categories and sub-categories in the Easing

My Burden: availability and accessibility (Being accessible and Being approachable), technical competence (Knowing what the heck they are doing), and feeling valued as an individual (Making me feel important). Developing a relationship also was identified as a precondition to trust as it is in the Easing My Burden theory. The researchers labeled this part of the process as *Getting to know each other* and it is a concept similar to the categories of Knowing my coordinator and My coordinator knowing me. Other preconditions cited in this study that were not in the Easing My Burden theory included characteristics of the nurses' approach to care such as being holistic, being in charge, anticipating and meeting expectations and needs and following through in a timely manner, feeling adequately informed and being the patient's advocate. Some of these preconditions could be subsumed under the Easing my Burden theory. For example, following up and being reliable were considered by the patients as part of accessibility. Meeting expectations and being informed were also part of accessibility. The patients expected that the coordinator would answer phone calls or return phone calls and provide information. These elements were all implicit to the relationship and secondary to the basic formation of the trusting relationship. To word it succinctly, the patients expressed that no relationship meant no care. The coordinator-patient relationship differs from the standard bedside or even clinic relationship in that so much of it is carried on remotely. This makes accessibility fundamental to the entire process.

The development of trust in the transplant team was cited as central to patients waiting for a liver transplant avoiding despair and maintaining hope (J. Brown, et al., 2006). As was discussed in the literature review chapter, this study was flawed methodologically but contains rich patient data:

The consequence of a lack of positive care from the medical team was felt to contribute to depression, hopelessness, and worsening health: “I got to the point I believed I was not going to transplant—ever—and if I died it was going to be because of the transplant coordinator.” (Brown et al., p. 127)

Believing my coordinator proceeds Trusting my coordinator in the model of Easing My Burden. Belief and trust are sometimes used as synonyms. Belief is defined as to “have a “firm conviction as to the goodness, efficacy, or ability of something” (Merriam-Webster, 2015) or in this case, someone. Trust, on the other hand, is defined as the “assured reliance” (Merriam-Webster, 2015) of the goodness or reliability of something or someone. The data gleaned from the kidney recipients in this study suggests that belief in the benevolence or good will of the nurse is an antecedent to trust as opposed to an element of trust itself as proposed by others such as L. Bell and Duffy (2009) or C. Robinson (2000). Trusting my coordinator developed over time and after the expectations that were set in Believing in my coordinator phase were met. For example, Sally believed in the good will of her coordinator but continued to test what the coordinator told her. Eventually, she reached a point that she trusted her enough to accept the “no news is good news” approach to having her labs checked. That trust allowed her to have a much more normal life with her psychological burden of ESRD eased.

New Findings from this Study

The most important contribution of this study is that it presents the voice of the kidney recipient. Although the Basic Social Process between nurses and patients has been studied and theorized about by other researchers, this study is unique in that it examines the relationship between transplant coordinators and kidney transplant patients and does so from the patients’ perspective. This phenomenon viewed from this perspective was not

found in the literature. The resultant theory likely validates what many transplant nurses intuitively know, that the patients want a trusting relationship with their coordinator. The study gives flesh and blood to the intense need of the patients to find some relief to the Basic Social Psychological Problem of the Burden of ESRD. This need begins when the patient makes the decision to seek transplantation and persists into the post transplantation phase. The requirements for that trusting relationship parallel in some ways Hildegard Peplau's (1952; 1988; 1991; 1992, 1997) middle-range theory on Interpersonal Relationships.

There is also the interesting finding of a lack of structured termination or resolution of the relationship for the participant transplant patients. The theory also posited that belief in a care provider's good will and competence is a distinct stage in the process of developing a trusting relationship and not synonymous with trust. The participants in the study believed in their coordinators and as their expectations continued to be met, they developed trust which leads to a state of less anxiety or easing of their burden.

This finding also highlights the fundamental nature of the interpersonal as well as the technical aspects of care coordination. Dubois and colleagues (2013) in their systematic review of nursing performance stated their findings that the holistic, patient-centered care delivered by nurses encompassed the technical, organizational and interpersonal dimensions of nursing and nursing systems. Key to care coordination is a continuity which requires a relationship between the coordinator and the patient.

An unexpected understanding was the common expression by the participants of feelings of dissatisfaction with their nephrologists and sometimes the dialysis staff. In

the context of studying the Basic Social Process between the coordinator and patient, this finding provided a rich context to the patient's psychosocial state as they entered into this process. David explained his dissatisfaction with his first nephrologist:

Yes, the least satisfactory part of my whole process was the nephrologist who followed me for years prior to the transplant. He followed me for probably 10 years and I got very little information from him. He would just say get this blood test done, get this blood test done. And then finally one day he said in an appointment, he says, "It's time to start preparing you for dialysis." And looking back, he could have, in 10 years of appointments; he could have been more help.

Limitations of this Study

The most obvious limitation of the study is selection bias or a threat to confirmability inherent in sampling from volunteers. The patients volunteered for the study either based on a support group solicitation, personal recommendation from another study participant or from a recruiting letter given to them at their transplant center. It could be hypothesized that patients who were happy with their care would be more likely to be willing to participate. However, one participant was able to articulate a very negative experience and many others described less than satisfactory experiences. Transferability was somewhat hindered by excluding participants who could not speak English and most had at least a high school education. Also all the patients had transplant coordinators who were nurses. Transferability is also limited by the sample consisting of only kidney transplant patients.

Implications for Public Policy

As discussed in chapters one and two, despite rigorous regulation of organ transplant processes and outcomes by several government agencies, and the existence of several professional transplant organizations related to transplant coordination, there are

no regulatory or professional requirements for a transplant coordinator to be a registered nurse. The role as portrayed by peer reviewed, regulatory, and professional literature, as well as the patients in this study is consistent with nursing practice and specifically with the nursing domains of care coordination (American Nurses Association, 2013). In this study, all of the coordinators were identified by the patients as nurses. And with that identification, the patients assumed certain competencies such knowledge about laboratory results and medications. The participants relied on both the interpersonal skills and the competence of the coordinator to carry out complex care such as monitoring medication levels and critical laboratory results. In some instances, the patients trusted the coordinator to be doing this important work without their direct involvement.

The American Nurses' Association (2012) White Paper on the Value of Nursing Care Coordination states "Different care settings, patients' needs and the availability of resources may influence the selection of a care coordinator. For most patients, the registered nurse is the most appropriate care coordinator." Looman and colleagues (2013) proposed that the complexity and intensity of the patients' need for coordination dictated the level of care provider required. Similarly, Gilbert et al., (2010), looking at care navigation in oncology, made similar observations based on the individual's need for clinical expertise and support as dictating the level of caregiver. Given the complexity both medically and psychosocially of transplant candidates and recipients, an expert nurse is the most qualified individual for the coordinator role. This conclusion that the complexity of the patients and their care necessitated that their care coordination be performed by a registered nurse was similarly made by the International Society of Heart and Lung Transplantation consensus group (Coleman et al., 2015). The group further

observed that in some instances an advanced practice nurse may be the more appropriate care coordinator. This study demonstrated the kidney transplant coordinators' need to trust coordinators to competently manage complex care. This need would suggest that the public and professional policy, regulations, and licensure regulations designed to protect organ transplant candidates, recipients, and donors should require that the coordinator be a registered nurse.

Implications for Nursing Practice

The theory provides transplant coordinators with a blueprint for providing the best care. Dubois and colleagues (2013) emphasized the need for nursing systems to be designed to promote optimal nursing performance. Staffing levels for both nursing and support staff must be sufficient to allow the nurse the time and opportunity to develop a trusting relationship with his or her patient. The model of practice should be structured to allow a single nurse to follow a single patient longitudinally, to be accessible to the patient, whether in person, phone, or even email, to learn about the patient and his or her needs and allow the patient to know the nurse. Nurse managers and administrators should ensure that the nurse has both a depth of knowledge regarding transplantation and transplant patients but also the requisite interpersonal skills to develop a relationship.

The participants expressed acceptance of the need, over time and treatment phases, to developing relationships with a new coordinators, however the lack of a structured termination or transition at most of the centers, reflects a lack of respect or value of the relationship on the part of the coordinator and/or institution. When there is a need for the patients to change transplant coordinators, nurses and their managers should

structure transition or discharge interventions to prepare the patient for the change and ensure adequate hand-off the next coordinator.

Implications for Nursing Education

The findings of this study point to the foundational need for nursing care to be delivered in the context of an interpersonal relationship between the nurse and the patient. This is not a new finding, but in the highly technical and complex healthcare environment in which nurses practice, the interpersonal must not be lost. The education of nurses must always include interpersonal skills that allow the nurse to form a therapeutic relationship with the patient; whether it is over a shift or many years.

Future Nursing Research

The paucity of research on the transplant coordinator and transplant patient relationship itself calls for more investigation. The perspective of patients with other types of organ transplants should be explored. Studying patients who had failed transplants could add depth the understanding of the contribution of the relationship on patient outcomes. Is there a difference in the nurse-patient relationships in recipients who experienced a loss of their transplanted organ compared to those who enjoyed long term success? The impact that a successful relationship between a transplant patient and nurse coordinator should be measured in terms of patient outcomes. Staffing models that support the concepts in *Easing My Burden* should be evaluated using metrics such as patient satisfaction, patient reports of unmet needs, readmission rates, unnecessary emergency department visits, treatment adherence, and clinical outcomes such as patient and graft survival; all measures cited by the ANA White Paper on Care Coordination (2012) as improved by nurse care coordination. Additional measures could include

overall costs and length of stay. These measures also would help establish the value of the contribution of the coordinator to patient outcomes. Investigation using similar measurements could also be used to test staffing models utilizing non-nurse coordinators.

Dubois et al. (2013) also pointed to the importance of nursing systems that promote nurses' professional satisfaction in influencing patient outcomes. What are the experiences of the transplant coordinator in this relationship? How can the nurse establish boundaries and balance between over-involvement and maintaining too much emotional distance and not being personable or approachable enough to nurture the relationship? The nurses' perspective of this Basic Social Process also bears investigation. Kim (2013) offered a very limited glimpse into the potential for caregiver fatigue and burnout in transplant coordinators which should be pursued further.

Although perhaps not in the domain of nursing research, the unexpected findings about the negative perceptions of the patients about their nephrology caregivers should also be explored. Are the perceptions of these caregivers clouded by the initial loss of trust stimulated by the lack of cure as theorized by Thorne and Robinson (1988) or are there substantive differences in practice that negatively impact the patient experience as suggested by the findings of the CHOICE study (H.R. Rubin et al., 2004)?

Summary

This study of the Basic Social Process between transplant coordinators and kidney transplant recipients resulted in the grounded theory *Easing My Burden*. The theory explains that ESRD represents a Basic Social Psychological Problem that the patients are attempting to resolve, at least in part, by developing a trusting relationship

with the transplant coordinator. This theory can be used to inform public policy, nursing practice, education, and management and future research.

APPENDIX A
RECRUITMENT LETTER

INTERESTED IN HELPING US LEARN MORE ABOUT YOUR TRANSPLANT
EXPERIENCE?

Dear Kidney Transplant Patient,

I am a graduate student at Loyola University Chicago. I am conducting a study about kidney transplant patients. I want to find about their experience with transplant coordinators. I hope that this study will help kidney transplant patients receive better care.

If you are a kidney transplant recipient, I would like to invite you to be part of this exciting project. Because I work at Northwestern Memorial Hospital and this could pose a conflict of interest, I can't ask patients who were transplanted at Northwestern to be part of this study.

If you decide to take part, you will be asked to be interviewed. The interviews can be at a time and place that is convenient for you. We could also do them over the phone. I expect that the interview will take about one hour.

I will audiotape the interviews and then they will be typed out by me or a typist. All information that could identify you, such as your name and where you had your transplant will be removed from the typed document. All information will be kept locked up. No one outside this study will know what you personally said in the interview. The nursing teachers at Loyola that are helping me with the study may also see the typed documents.

I will write a paper about this study and may present my findings to other health care professionals. No information that could identify you will be used in any paper or presentation.

You do not have to take part in this study. It won't affect any care that you have at Loyola or any place else. You can decide to stop participating at any time, even after you have had your interview with me.

If you would like to be part of this important research project or have any questions, you may do so by calling me, Gwen McNatt at 312-695-1705 or emailing me at gwenstudy@att.net.

Thanks for thinking about being part of this important study!

Gwen McNatt, MS, RN, PhD (c) CNN, FNP-BC
Principle Investigator

Doctoral Candidate
Niehoff School of Nursing
Loyola University Chicago

APPENDIX B
INTERVIEW GUIDE

Introduction:

Before the recording is started, the researcher introduces herself as a student and long time nurse in transplantation and a manager of transplant coordinators. The purpose of the study, to learn more about the patients' experience with transplant coordinators, is explained to the participant. Describing the purpose is followed by the informed consent elements: confidentiality, voluntary participation, and the option to stop participation or stop recording at any time. The possibility of contact for a second interview will also be discussed. Prior to the recording beginning, the researcher will obtain demographic information: name, age, marital status, work background, date and type of kidney transplant.

Initial Questions:

1. Tell me about your kidney failure. What caused it? When was it diagnosed? Were you ever on dialysis? When were you first referred to a transplant center?
2. Think back about when you were referred to the transplant center. When did you first have contact with a transplant coordinator? Can you remember what it was like and what you felt about it?
3. Had you ever heard about transplant coordinators before that time? (If response is yes) Tell me about what you heard about them.
4. Did anyone explain to you what the coordinator's role with you was?
5. What did you know about your coordinator's training or education? Was your transplant coordinator a nurse? (ask this about every different coordinator discussed)

Intermediate Questions:

6. Did you have one transplant coordinator or more than one? How did that work for you? Would you have preferred a different model?
7. Tell me about your ongoing experiences with the transplant coordinator(s). What worked for you? What would you have liked a little differently? Are there particular incidents or experiences that stand out to you as particularly helpful or bad? Was there anything that you really did not like or just did not help you? Would you have done anything differently?
8. (referring to the previous response) Tell me a little more about that. What were your feelings about that?
9. Think about your time on the waiting list. How long did you wait for your transplant? What was that time like for you? Who was the most helpful to you during that time?
10. What was your relationship with your transplant coordinator during that time? Did that work for you? Is there a particular incident that stands out as particularly helpful or bad? Is there something that you would have liked to be different? Was there anything that you did not like or just did not help you?
11. (referring the previous response) Tell me a little more about that? What were your feelings about that?
12. Think about when you were called in for the transplant. Tell me about that experience. When you first received that call – what went through your mind?
13. Who called you?

14. (if not the coordinator) Did you hear from your coordinator? (Yes) Was it the same coordinator or a different one? Tell me about that. What were your feelings about that contact? Did you feel ready to go in for your transplant? (No contact) move to question 16.
15. (if the coordinator called) Was this the same coordinator or a different one? Tell me about the call. What were your feelings about the call and the transplant coordinator? Did you feel ready to go in for your transplant?
16. If you could have it another way, how would you change the call?
17. Think back to when you were in the hospital for your transplant. Who was on your transplant team? Was there a coordinator?
18. (Yes) Was this the same coordinator or a different one? What did you feel about that? What was the coordinator's role in your care? How did that work for you? Does any incident stand out as particularly helpful or bad? Would you have liked something different? Did you feel ready to go home when you were discharged?
19. (referring to previous response) Tell me more about that. What were your feelings about that?
20. (No) Tell me about your care team in the hospital. How did that work for you? Would you have liked something different? What worked well for you? Did you feel ready to go home when you were discharged?
21. Think about your care since you left the hospital. Who is your main care provider for your transplant? Has this been the same system or has it changed over time?

22. Describe these care processes. What about the system or model works for you?
What does not work so well? What would you like differently?
23. Do you have a coordinator now? Note: for patients who have been transplanted for more than a year, these questions will likely have to be structured to discuss the immediate discharge period and long term care as they may be modeled differently.
24. (Yes) Is this the same coordinator or a different one? How do you feel about that? What is the coordinator's role in your care? Does that work for you or would you have like something different? What is working well for you?
25. (referring to previous response) Tell me more about that. What are your feelings about that?
26. Tell me about your relationship with your transplant coordinator(s). Have the relationships changed over time? Are you satisfied with this relationship?
27. (referring to the above response) Tell me more about that.
28. Are there any other events that come to mind when you think about your relationship with transplant coordinators? Can you describe each one to me?
29. Have your feelings about transplant coordinators changed over time? Have your needs changed over time?
30. How do you think your relationship with transplant coordinators has helped or hurt your ability to handle the transplant experience?

Closing Questions

31. As I mentioned before, I manage transplant coordinators. Think about what your ideal transplant coordinator would be like. When I am hiring someone what advice would you give me? What should I be looking for? What kind of personal characteristics? What kind of training should they have?
32. What would you tell someone else who needed a kidney transplant about transplant coordinators?
33. What do you really want me to know about your experience with transplant coordinators?
34. Is there anything that you believe I missed asking you about?
35. Is there anything that you would like to ask me?

APPENDIX C
INSTITUTIONAL REVIEW BOARD APPROVAL

Institutional Review Board LU# 202345.txt
 Institutional Review Board: LU# 20234502/20/2010

NOTICE OF FULL APPROVAL OF A RESEARCH PROJECT

Investigator Vlases, Frances
 LU Number 202345
 Title Kidney Transplant Recipients' Experience with Transplant
 Coordinators

Date of Initial Review 11/13/2009
 Type of Review Expedited
 Action of Initial Review Full Approval

IRB Findings 1. The study is of minimal risk and qualifies for expedited review 45CFR46.110, b-1, HHS Secretary Category # 6 and #7).

1. No substantive issues identified.
2. No personal data / PHI will be collected during the course of the interviews.
3. The requirement for written consent is waived.
4. The recruitment letter is approved for use.

Informed Consent Document required? YES

of Participants 20
 Participants Compensated? NO

IRB Number 202345111309
 Date of Approval 11/13/2009
 Frequency of Review Annual
 Date of First Review 11/13/2010

Conditions of Approval 1. You must obtain verbal consent to conduct and tape record the participant interview.

YOU HAVE FULL APPROVAL AND YOUR PROJECT MAY BEGIN.

The following is for your information and will help you meet local and federal IRB requirements.

1. You must use the final IRB-approved version of the Consent Document. Spelling and grammatical changes may be made as necessary, but any other changes require prior review and approval.
2. You are required to maintain complete records of this project. Any changes in the protocol and the Consent Document must receive prior IRB approval. Use the online Research Portal's Project Amendment form to report changes. A change to the protocol necessary for the immediate safety and welfare of a research participant may be implemented prior to IRB review and approval.

REFERENCE LIST

- Abbott, A. (1988). *The systems of professions*. Chicago: University of Chicago Press.
- Achille, M. A., Ouellette, A., Fournier, S., Vachon, M., & Hébert, M. (2006). Impact of stress, distress and feelings of indebtedness on adherence to immunosuppressants following kidney transplantation. *Clinical Transplantation*, 20(3), 301-306. doi:10.1111/j.1399-0012.2005.00478.x.
- Acuna, S. T., Juristo, N., Moreno, A. M., & Mon, A. (2005). *Role dimensions*. In *a software process model handbook for incorporating people's capabilities* (pp. 167-181). New York: Springer.
- American Board for Transplant Certification. (2010). Candidates' handbook: Clinical transplant coordinators. Retrieved from <http://www.natco1.org/Professional-Development/files/ABTC%20handbook%20Dec%202010.pdf>
- American Nurses Association. (2012). *The value of nursing care coordination. A white paper of the American Nurses Association*. Retrieved from <http://www.nursingworld.org/carecoordinationwhitepaper>
- American Nurses Association. (2013). *Framework for measuring nurses contribution to care coordination*. Silver Springs, MD: American Nurses Association.
- Baier, A. (1986). Trust and anti-trust. *Ethics*, 96(2), 231-260. Retrieved from <http://www.jstor.org/flagship.luc.edu/stable/2381376>
- Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics* (5th ed.). Oxford, UK: Oxford University Press.
- Beauchamp, T. L., & Childress, J. F. (1994). *Principles of biomedical ethics* (4th ed.). Oxford, UK: Oxford University Press.
- Beaver, S., Gaustad, K., Crotty, P., Dahlke, L., Pearson, L., & Richards, T. (1995). The clinical liver transplant coordinator: Commonalities and variations. *Journal of Transplant Coordination*, 5(2), 55-58.

- Beeber, L. S. (2000). Hildahood: Taking the interpersonal theory of nursing to the neighborhood. *Journal of the American Psychiatric Nurses Association*, 6(2), 49-55. doi:10.1067/mpn.2000.105895
- Belief. (2015). In *Merriam Webster's online dictionary*. Retrieved from <http://www.merriam-webster.com>
- Bell, J. (2004). Clinical consult. Development of an ABO verification policy for solid organ transplants. *Nephrology Nursing Journal*, 31, 218-220. Retrieved from <http://www.prolibraries.com/anna/>
- Bell, L., & Duffy, A. (2009). A concept analysis of nurse--patient trust. *British Journal of Nursing*, 18(1), 46-51. <http://www.magonlinelibrary.com/loi/bjon>
- Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing practice*. Menlo Park, CA: Addison-Wesley.
- Benner, P. (2004). Using the Dreyfus model of skill acquisition to describe and interpret skill acquisition and clinical judgment in nursing practice and education. *Bulletin of Science, Technology & Society*, 24(3), 188-199. doi:10.1177/0270467604265061
- Benner, P., Sutphen, M., Leonard-Kahn, V., & Day, L. (2008). Formation and everyday ethical comportment. *American Journal of Critical Care*, 17(5), 473-476. Retrieved from <http://ajcc.aacnjournals.org/>
- Betz, C. L., & Redcay, G. (2005). Dimensions of the transition service coordinator role. *Journal for Specialists in Pediatric Nursing*, 10(2), 49-59. doi: 10.1111/j.1744-6155.2005.00010.x
- Bjørk, I. T., & Nåden, D. (2008). Patients' experiences of waiting for a liver transplantation. *Nursing Inquiry*, 15(4), 289-298. doi:10.1111/j.1440-1800.2008.00418.x
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice Hall.
- Brannick, M. T., & Levine, E. L. (2002). *Job analysis*. Thousand Oaks, CA: Sage Publications.
- Brown, J., Sorrell, J. H., & McClaren, J. C., J.W. (2006). Waiting for a liver transplant. *Qualitative Health Research*, 16(1), 119-136. doi: 10.1177/1049732305284011

- Brown, R. S., Peikes, D., Peterson, G., Schore, J., & Razafundrakoto, C. M. (2012). Six features of Medicare coordinated care demonstration programs that cut hospital admissions of high-risk patients. *Health Affairs, 31*(6), 1156-1166. doi:10.1377/hlthaff.2012.0393
- Calkin, J. D. (1984). A model for advanced nursing practice. *Journal of Nursing Administration, 14*(1), 24-30. doi:10.1097/00005110-198401000-00009
- Carpenter, D. R. (2007). Grounded theory as method. In H. Speziale, & D. R. Carpenter (Eds.), *Qualitative research in nursing* (4th ed., pp. 133-152). Philadelphia: Lippincott Williams & Wilkins.
- Cetingok, M., Hathaway, D., & Reed, L. (1997). Perceptual and behavioral manifestations of the chronic illness and recovery models among clinical transplant coordinators. *Journal of Transplant Coordination, 7*(3), 116-122.
- Chalmers, S. A., & Coleman, E. A. (2006). Transitional care in later life: Improve the move. *Generations, 30*(3), 86-89. Retrieved from http://generations.metapress.com/content/120835/?sortorder=asc&p_o=31
- Charmaz, K. (2006). *Constructing grounded theory*. Los Angeles: Sage.
- Charmaz, K. (2002). Qualitative interviewing and grounded theory analysis. In J. Gubrium, & J. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 675-694). Thousand Oaks, CA: Sage.
- Chisholm, M. A. (2002). Enhancing transplant patients' adherence to medication therapy. *Clinical Transplantation, 16*(1), 30-38. doi:10.1034/j.1399-0012.2002.00104.x
- Chornick, N. L., & Yocom, C. J. (1995). NCLEX job analysis study: Questionnaire development. *Journal of Nursing Education, 34*(3), 101-105.
- Coleman, B., Blumenthal, N., Currey, J., Dobbels, F., Velleca, A., Grady, K. L., . . . White-Williams, C. (2015). Adult cardiothoracic transplant nursing: An ISHLT consensus document on the current adult nursing practice in heart and lung transplantation. *Journal of Heart & Lung Transplantation, 34*(2), 139-148. doi:10.1016/j.healun.2014.11.017
- Coleman, E. A. (2003). Falling through the cracks: Challenges and opportunities for improving transitional care for persons with continuous complex care needs. *Journal of the American Geriatrics Society, 51*(4), 549-555. doi:10.1046/j.1532-5415.2003.51185.x

- Coleman, E. A., Smith, J. D., Frank, J. C., Min, S., Parry, C., & Kramer, A. M. (2004). Preparing patients and caregivers to participate in care delivered across settings: The care transitions intervention. *Journal of the American Geriatrics Society*, 52(11), 1817-1825. doi:10.1111/j.1532-5415.2004.52504.x
- Comery, A. L., & Lee, H. B. (1992). *A first course in factor analysis* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Corbin, J. M., & Strauss, A. (1992). A nursing model for chronic illness management based on the trajectory framework. In P. Woog (Ed.), *The chronic illness trajectory framework: The Corbin and Strauss nursing model* (pp. 9-28). New York: Springer.
- Corley, M. C., Westerberg, N., Elswick, R. K., Connel, D., Neil, J. A., Sneed, G., & Witcher, V. (1998). Rationing organs using psychosocial and lifestyle criteria. *Research in Nursing & Health*, 21, 327-337. doi:10.1002/(SICI)1098-240X(199808)21:4%3C327::AID-NUR5%3E3.0.CO;2-H
- Corruble, E., Durrbach, A., Charpentier, B., Lang, P., Amidi, S., Dezamis, A., . . . Falissard, B. (2010). Progressive increase of anxiety and depression in patients waiting for a kidney transplantation. *Behavioral Medicine*, 36(1), 32-36. doi:10.1080/08964280903521339
- Cukor, D., Coplan, J., Brown, C., Friedman, S., Newville, H., Safier, M., . . . Kimmel, P. L. (2008). Anxiety disorders in adults treated by hemodialysis: A single-center study. *American Journal of Kidney Diseases*, 52(1), 128-136. doi:10.1053/j.ajkd.2008.02.300
- Daskalakis, R., & Sumrani, N. (1991). Prescriptive privileges for transplant coordinators. *Journal of Transplant Coordination*, 1(3), 124-126.
- Davies, A. P., & Ware, J. E. (1988). Involving consumers in quality of care assessment. *Health Affairs, Spring*, 33-48. doi:10.1377/hlthaff.7.1.33
- De Geest, S., Burkhalter, H., Berben, L., Bogert, L., Jane, Denhaerynck, K., Glass, T., R., . . . Schmidt-Trucksäss, A. (2013). The Swiss transplant cohort study's framework for assessing lifelong psychosocial factors in solid-organ transplants. *Progress in Transplantation*, 23(3), 235-246. doi: 10.7182/pit2013250
- del Barrio, M., Lacunza, M.M., Armendariz, A. C., Margall, M. A., & Asiain, M. C. (2004). Liver transplant patients: Their experience in the intensive care unit. A phenomenological study. *Journal of Clinical Nursing*, 13(8), 967-976. doi:10.1111/j.1365-2702.2004.01002.x

- DeVellis, R. F. (2003). *Scale development: Theory and applications* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Dew, A., DiMartini, A., Dabbs, A., Myakovsky, M., Steel, J. U., M., Switzer, G., . . . Greenhouse, J. (2007). Rates and risk factors for nonadherence to medical regimen after solid organ transplantation. *Transplantation*, *83*, 858-873. doi: 10.1097/01.tp.0000258599.65257.a6
- Dinç, L., & Gastmans, C. (2013). Trust in nurse–patient relationships: A literature review. *Nursing Ethics*, *20*(5), 501-516. doi:10.1177/0969733012468463
- Donabedian, A. (1992). The Lichfield lecture. quality assurance in health care: Consumers' role. *Quality in Health Care*, *1*(4), 247-251. doi:10.1136/qshc.1.4.247
- Dorsett, D. S. (1991). The trajectory of cancer recovery. *Scholarly Inquiry for Nursing Practice*, *5*(3), 175-184.
- Doty, M. M., Fryer, A., & Audet, A. (2012). The role of care coordinators in improving care coordination: The patient's perspective. *Archives of Internal Medicine*, *172*(7), 587-588. doi:10.1001/archinternmed.2012.212
- Dubois, C., D'Amour, D., Pomey, M., Girard, F., & Brault, I. (2013). Conceptualizing performance of nursing care as a prerequisite for better measurement: A systematic and interpretive review. *BMC Nursing*, *12*(1), 7. Retrieved from <http://www.biomedcentral.com/1472-6955/12/7>
- Eckhoff, D. E., McGuire, B. M., Young, C., Sellers, M. T., Contreras, J. L., Frenette, L. R., . . . Bynon, J. S. (2000). Liver transplantation in the era of cost constraints. *Southern Medical Journal*, *93*(4), 392-396. doi:10.1097/00007611-200004000-00008
- Ehlers, S. E. (2002). Financial aspects of organ transplantation. *Nephrology Nursing Journal*, *29*, 285-291. Retrieved from <http://www.prolibraries.com/anna/>
- Ehlers, S. L., Rodrigue, J. R., Patton, P. R., Lloyd-Turner, J., Kaplan, B., & Howard, R. J. (2006). Treating tobacco use and dependence in kidney transplant recipients: Development and implementation of a program. *Progress in Transplantation*, *16*(1), 33-37.
- Ellingson, T., Wipke-Tevis, D., Messina, C., & Livesay, T. (1999). The use of over-the-counter medications by transplant recipients: A guideline. *Journal of Transplant Coordination*, *9*(1), 17-24.

- Evon, D. M., Burker, E. J., Sedway, J. A., Cicale, R., Davis, K., & Egan, T. (2005). Tobacco and alcohol use in lung transplant candidates and recipients. *Clinical Transplantation*, 19(2), 207-214. doi:10.1111/j.1399-0012.2005.00320.x
- Flexner, A. (1915). Is social work a profession? Proceedings of the National Conference of Charities and Corrections at the Forty-Second Annual Meeting, Chicago. Retrieved from Research on Social Work Practice, <http://rsw.sagepub.com.flagship.luc.edu/cgi/reprint/11/2/152>.
- Forchuk, C. (1994). The orientation phase of the nurse-client relationship: Testing Peplau's theory. *Journal of Advanced Nursing*, 20(3), 532-537. doi:10.1111/1365-2648.ep8542060
- Forchuk, C., Westwell, J., Martin, M., Bamber-Azzopardi, W., Kosterewa-Tolman, D., & Hux, M. (1998). Factors influencing movement of chronic psychiatric patients from orientation to the working phase of the nurse-client relationship on an inpatient unit. *Perspectives in Psychiatric Care*, 34(1), 36-43. doi: 10.1111/j.1744-6163.1998.tb00998.x
- Forchuk, C., Westwell, J., Martin, M., Bamber-Azzopardi, W., Kosterewa-Tolman, D., & Hux, M. (2000). The developing nurse-client relationship: Nurses' perspectives. *Journal of the American Psychiatric Nurses Association*, 6(1), 3-10. doi: 10.1177/10783903000060010
- Forsberg, A., Bäckman, L., & Möller, A. (2000). Experiencing liver transplantation: A phenomenological approach. *Journal of Advanced Nursing*, 32(2), 327-334. doi:10.1046/j.1365-2648.2000.01480.x
- Gerteis, M. (1993). What patients really want. *Health Management Quarterly*, 15(3), 2-6.
- Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. (Eds.). (1993). *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*. San Francisco: Jossey Bass.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Somerset, NJ: Aldine.
- Glaser, B. G. (2001). *The grounded theory perspective: Conceptualization contrasted with description*. Mill Valley: CA: Sociology Press.
- Glaser, B. G., & Holton, J. (2007). Remodeling grounded theory. *Historical Social Research / Historische Sozialforschung*. (supplement (19)), Grounded Theory Reader, 47-68. <http://www.jstor.org.flagship.luc.edu/stable/40981068>

- Haas, S., Swan, B. A., Haynes, T. S., & American Academy of Ambulatory Care Nursing. (2014). *Care coordination and transition management: Core curriculum*. Pitman, NJ: A.J. Jannetti.
- Hackbarth, D. P., Haas, S. A., Kavanagh, J. A., & Vlasses, F. (1995). Dimensions of the staff nurse role in ambulatory care: Part I - methodology and analysis of data on current staff nurse practice. *Nursing Economic\$, 13*(2), 89-98. Retrieved from <http://www.nursingconomics.net/cgi-bin/WebObjects/NECJournal.woa>
- Haggerty, L., & Harris, G. (1990). Extended role of the nurses. In K. Sigardson-Poor, & L. Haggerty (Eds.), *Nursing care of the transplant recipient* (1st ed., pp. 389-392). Philadelphia, PA: WB Saunders.
- Hardy, M. E., & Conway, M. E. (1988). *Role theory perspectives for health professionals*. Appleton & Lange.
- Harmer, V. (2010). Are nurses blurring their identity by extending or delegating roles? *British Journal of Nursing (BJN), 19*(5), 295-299. doi:10.12968/bjon.2010.19.5.47062
- Harbrecht, M. (2012). New to the scene. Care coordinators play starring roles. *MGMA Connexion / Medical Group Management Association, 12*(3), 34-37. Retrieved from <http://www.mgma.com/practice-resources/articles/mgma-connexion/mgma-connection-magazine-members>
- Hoy, H., Alexander, S., Payne, J., & Zavala, E. (2011). The role of advanced practice nurses in transplant center staffing. *Progress in Transplantation, 21*(4), 294-298. Retrieved from <http://natco.metapress.com/content/122510/>
- Hupcey, J. E., Penrod, J., Morse, J. M., & Mitcham, C. (2001). An exploration and advancement of the concept of trust. *Journal of Advanced Nursing, 36*(2), 282-293. doi: 10.1046/j.1365-2648.2001.01970.x
- Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st Century*. Washington, D.C.: National Academies Press.
- Institute of Medicine. (2003a). *Health professions education: A bridge to quality*. Washington, DC: author.
- Institute of Medicine. (2003b). Priority areas for national action: Transforming health care quality. Retrieved from <http://www.iom.edu/Reports/2003/Priority-Areas-for-National-Action-Transforming-Health-Care-Quality.aspx>

- International Council of Nurses (ICN). Fact sheet on nurse practitioners/advanced practice nurses: Definition and characteristics. Retrieved from http://www.icn.ch/images/stories/documents/publications/fact_sheets/1b_FS-NP_APN.pdf
- International Transplant Nurses Society. (2009). *Transplant nursing: Scope and standards of practice*. Silver Springs, MD: American Nurses Association.
- Irwin, B. C. (1986). Ethical problems in organ procurement and transplantation. *ANNA Journal*, 13, 305-310.
- Ishihara, I., Yoshimine, T., Horikawa, J., Majima, Y., Kawamoto, R., & Salazar, M. K. (2004). Defining the roles and functions of occupational health nurses in Japan: Results of job analysis. *AAOHN Journal*, 52(6), 230-241.
- Jamison, M., Ross, V. M., Hornberger, C. A., & Morse, V. L. (1999). Implementation of the care coordinator role: A grounded theory approach. *Journal of Professional Nursing*, 15(6), 356-363. doi:10.1016/S8755-7223(99)80066-0
- Johnstone, S., Walrath, L. L., Wohlwend, V., Jobe, L. D., & Thompson, C. (2004). Overcoming early learning barriers in hemodialysis patients: The use of screening and educational reinforcement to improve treatment outcomes. *Advances in Chronic Kidney Disease*, 11(2), 210-216. doi: 10.1053/j.arrt.2004.01.002
- Jones, J. B., & Egan, M. (2000a). The transplant experience of liver recipients: Ethical issues and practice implications. *Social Work in Health Care*, 31(2), 65-88. doi:10.1300/J010v31n02_06
- Jones, S., M. (2012). *The development of trust in the nurse-patient relationship with hospitalized Mexican American patients (Doctoral dissertation)*. Retrieved from Proquest Dissertations and Theses database (UMI No. 2012257839).
- Kalil, R. S., Heim-Duthoy, K., & Kasiske, B. L. (1992). Patients with a low income have reduced renal allograft survival. *American Journal of Kidney Diseases: The Official Journal of the National Kidney Foundation*, 20(1), 63-69. doi: 10.1016/S0272-6386(12)80318-0
- Kaul, V., Khurana, S., & Munoz, S. (2000). Management of medication noncompliance in solid-organ transplant recipients. *BioDrugs*, 13(5), 313-326. Retrieved from <http://link.springer.com/journal/40259>
- Kennedy, E. T. (2008). Implementing ethically-sound research on online health-related support groups. *Internet Journal of Allied Health Sciences & Practice*, 6(4), 1-7. Retrieved from <http://ijahsp.nova.edu>

- Kim, S. (2013). Compassion fatigue in liver and kidney transplant nurse coordinators: A descriptive research study. *Progress in Transplantation*, 23(4), 329-335. doi:10.7182/pit2013811
- Kimmel, P. L., Cohen, S. D., & Peterson, R. A. (2008). Depression in patients with chronic renal disease: Where are we going? *Journal of Renal Nutrition*, 18(1), 99-103. doi: 10.1053/j.jrn.2007.10.020
- Lamb, G., & Sofaer, S. (2008). Measuring the work nurses do in coordinating care. Retrieved from <http://rwjf.org/en/about-rwjf/newsroom/newsroom-content/2008/03/measuring-the-work-nurses-do-in-coordinating-care.html>
- Lanza-Humphrey, J. (2014). Chronicles of a living kidney donor. *Nephrology Nursing Journal*, 41(6), 611-623. Retrieved from <http://www.prolibraries.com/anna/>
- Lerret, S. M., & Weiss, M. E. (2011). How ready are they? parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant. *Pediatric Transplantation*, 15(6), 606-616. doi:10.1111/j.1399-3046.2011.01536.x
- Lerret, S. M., Weiss, M. E., Stendahl, G., Chapman, S., Neighbors, K., Amsden, K., . . . Alonso, E. M. (2014). Transition from hospital to home following pediatric solid organ transplant: Qualitative findings of parent experience. *Pediatric Transplantation*, 18(5), 527-537. doi:10.1111/petr.12269
- Lerret, S., Marie, Menendez, J., Weckwerth, J., Lokar, J., Mitchell, J., & Alonso, E., M. (2012). Essential components of transition to adult transplant services: The transplant coordinators' perspective. *Progress in Transplantation*, 22(3), 252-258. doi:10.7182/pit2012110
- Lincoln, Y., & Guba, E. (1982). Establishing dependability and confirmability in naturalistic inquiry through an audit. Paper presented at the 66th Annual Meeting of the American Educational Research Association, New York, NY.
- Lindeke, L. L., Leonard, B. J., Presler, B., & Garwick, A. (2002). Family-centered care coordination for children with special needs across multiple settings. *Journal of Pediatric Healthcare*, 16(6), 290-297. doi: 10.1067/mpg.2002.121917
- Lumby, J. (1997). Liver transplantation: The death/life paradox. *International Journal of Nursing Practice*, 3(4), 231-238. doi: 10.1111/j.1440-172X.1997.tb00107.x
- Maben, J., Griffiths, P. (2008). *Nursing in society: Starting the debate*. London: National Nursing Research Unit, King's College. Retrieved from www.researchgate.net/...Maben/.../00b4952ea310136512000000.pdf

- Matas, A. J., Smith, J. M., Skeans, M. A., Thompson, B., Gustafson, S. K., Stewart, D. E., . . . Kasiske, B. L. (2015). OPTN/SRTR 2013 annual data report: Kidney. *American Journal of Transplantation, 15*(S2), 1-34. doi:10.1111/ajt.13195
- Marshall, C., & Rossman, G. (2006). *Designing qualitative research* (4th ed.). Thousand Oaks, CA: Sage Publications.
- McBride, L. H., Kelley, C., Lonergan, J., & McCann, B. (1994). The role of homecare in promoting compliance and positive patient outcomes. *Journal of Transplant Coordination, 4*(2), 107-111.
- McCurdy, C., DiCenso, A., Boblin, S., Ludwin, D., Bryant-Lukosius, D., & Bosompra, K. (2006). There to here: Young adult patients' perceptions of the process of transition from pediatric to adult transplant care. *Progress in Transplantation, 16*, 309-316. Retrieved from <http://natco.metapress.com/content/122510/>
- McNatt, G. E. (2008). Nursing and transplant coordination: A call for clarity. *Progress in Transplantation, 18*, 208-215. Retrieved from <http://natco.metapress.com/content/122510/>
- McNatt, G. E., & Easom, A. (2000). The role of the advanced practice nurse in the care of organ transplant recipients. *Advances in Renal Replacement Therapy, 7*(2), 172-176.
- Morse, C. J. (2001). Advance practice nursing in heart transplantation. *Progress in Cardiovascular Nursing, 16*(1), 21-24. doi: 10.1111/j.0889-7204.2001.00799.x
- Morse, J., Barret, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1*(2), 13-22.
- Neil, J. A., & Corley, M. C. (2000). Hostility toward caregivers as a selection criterion for transplantation. *Progress in Transplantation, 10*(3), 177-181. Retrieved from <http://natco.metapress.com/content/122510/>
- Newton, S. E. (1999). Promoting adherence to transplant medication regimens: A review of behavioral analysis. *Journal of Transplant Coordination, 9*(1), 13-16.
- Neyhart, C. (2004). Practice issues in nephrology nursing: Focus on issues from ANNA's special interest groups. Current issues in transplant nursing. *Nephrology Nursing Journal, 31*, 337. Retrieved from <http://www.prolibraries.com/anna/>
- North American Transplant Coordinators Organization, n.d. About NATCO. Retrieved from http://natco1.org/about_natco/index.htm

- Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory* (3rd ed.). New York: McGraw-Hill.
- Nutt, M., & Hungerford, C. (2010). Nurse care coordinators: Definitions and scope of practice. *Contemporary Nurse, 36*(1-2), 71-81. doi: 10.5172/conu.2010.36.1-2.071
- Ohler, L. (2007). The road to quality healthcare and safety in solid-organ transplantation. *Progress in Transplantation, 17*(1), 6-7. Retrieved from <http://natco.metapress.com/content/122510/>
- Ohler, L., & Daine, G. (2001). Risk management issues in transplantation. *Progress in Transplantation, 11*(1), 9-11. Retrieved from <http://natco.metapress.com/content/122510/>
- Olbrisch, M. E., & Levenson, J. (1991). Psychosocial evaluation of cardiac transplant candidates: An international survey of process, criteria, and outcomes. *Journal of Heart and Lung Transplantation, 10*, 948-955. Retrieved from <http://www.jhltonline.org/issues>
- O'Rourke, M., Arnott, L., & Goldman, J. S. (2003). Living liver donors: A coordinator's perspective. *Progress in Transplantation, 13*(2), 82-87. Retrieved from <http://natco.metapress.com/content/122510/>
- Paley, J. (1997). Husserl, phenomenology, and nursing. *Journal of Advanced Nursing, 26*, 187-193. doi: 10.1046/j.1365-2648.1997.1997026187.x
- Palfrey, J. S., Sofis, L. A., Davidson, E. J., Liu, J., Freeman, L., & Ganz, M. L. (2004). The pediatric alliance for coordinated care: Evaluation of a medical home model. *Pediatrics, 113*(5), 1507-1516. Retrieved from <http://pediatrics.aappublications.org/>
- Palmer, S., Vecchio, M., Craig, J. C., Tonelli, M., Johnson, D. W., Nicolucci, A., . . . Strippoli, G. F. M. (2013). Prevalence of depression in chronic kidney disease: Systematic review and meta-analysis of observational studies. *Kidney International, 84*(1), 179-191. doi:10.1038/ki.2013.77
- Paris, D., Smith, C., Carlson, J., Aussi, W., Bak, K., Emmett, C., et al. (1998). A comparison of role expectations and communication styles between transplant coordinators and transplant staff nurses. *Journal of Transplant Coordination, 8*(2), 119-124.
- Paris, W., Cooper, D., Samara, S., Carpenter, W., Crockett, S., Calhoun-Wilson, G., et al. (1995). A comparison of organ transplant patient and professional staff attitudes. *International Journal of Rehabilitation & Health, 1*(3), 167-178.

- Pascazio, L., Nardone, I. B., Clarici, A., Enzmann, G., Grignetti, M., Panzetta, G. O., & Vecchiet, C. (2010). Anxiety, depression and emotional profile in renal transplant recipients and healthy subjects: A comparative study. *Transplantation Proceedings*, 42(9), 3586-3590. doi:10.1016/j.transproceed.2010.08.056
- Paskett, E. D., Harrop, J. P., & Wells, K. J. (2011). Patient navigation: An update on the state of the science. *CA: A Cancer Journal for Clinicians*, 61(4), 237-249. doi:10.3322/caac.20111
- Patient Protection and Affordable Care Act, 42 USC § 18001 (2010).
- Peikes, D., Chen, A., Schore, J., & Brown, R. (2009). Effects of care coordination on hospitalization, quality of care, and health care expenditures among Medicare beneficiaries. *JAMA: Journal of the American Medical Association*, 301(6), 603-618. doi: 10.1001/jama.2009.126
- Peplau, H. E. (1952). *Interpersonal relations in nursing*. New York: G.P. Putnam.
- Peplau, H. E. (1988). The art and science of nursing: Similarities, differences, and relations. *Nursing Science Quarterly*, 1(1), 8-15. doi:10.1177/089431848800100105
- Peplau, H. E. (1991). *Interpersonal relations in nursing: A conceptual framework of reference for psychodynamic nursing*. New York: Springer.
- Peplau, H. E. (1992). Interpersonal relations: A theoretical framework for application in nursing practice. *Nursing Science Quarterly*, 5(1), 13-18. doi:10.1177/089431849200500106
- Peplau, H. E. (1997). Peplau's theory of interpersonal relations. *Nursing Science Quarterly*, 10(4), 162-167. doi:10.1177/089431849701000407
- Pérez-San-Gregorio, M. A., Fernández-Jiménez, E., Martín-Rodríguez, A., Pérez-Bernal, J., & Gómez Bravo, M. A. (2013). Evolution of anxious-depressive symptomatology in liver and kidney transplant recipients: Hospitalization and 12-month post-transplantation phases. *Transplantation Proceedings*, 45(10), 3656-3658. doi:10.1016/j.transproceed.2013.10.029
- Polit, D. F., & Beck, C. (2008). *Nursing research: Generating and assessing evidence for nursing practice* (8th ed.). Philadelphia: Lippincott, Williams and Wilkins.
- Presler, B. (1998). Care coordination for children with special health care needs. *Orthopedic Nursing*, 17(2 (supplement)), 45-51.

- Rambod, M., Shabani, M., Shokrpour, N., Rafii, F., & Mohammadalliha, J. (2011). Quality of life of hemodialysis and renal transplantation patients. *Health Care Manager, 30*(1), 23-28. doi:10.1097/HCM.0b013e3182078ab6
- Robinson, C. A. (2000). Response to "establishing and maintaining trust during acute care hospitalizations". *Scholarly Inquiry for Nursing Practice, 14*(3), 243-248.
- Robinson, K. M. (2010). Care coordination: A priority for health reform. *Policy, Politics & Nursing Practice, 11*(4), 266-274. doi:10.1177/1527154410396572
- Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Rubin, H. R., Fink, N. E., Plantinga, L. C., Sadler, J. H., Kliger, A. S., & Powe, N. R. (2004). Patient ratings of dialysis care with peritoneal dialysis vs hemodialysis. *JAMA: Journal of the American Medical Association, 291*(6), 697-703. doi:10.1001/jama.291.6.740
- Russell, C. L., Conn, V. S., Ashbaugh, C., Madsen, R., Hayes, K., & Ross, G. (2006). Medication adherence patterns in adult renal transplant recipients. *Research in Nursing & Health, 29*(6), 521-532. doi: 10.1002/nur.20149
- Russell, C. L., & Freiburghaus, M. (2003). Heart transplant patient teaching documentation. *Clinical Nurse Specialist, 17*(5), 249-257. doi:10.1097/00002800-200309000-00009
- Salazar, M. K., Kemerer, S., Amann, M. C., & Fabrey, L. J. (2002). Defining the roles and functions of occupational and environmental health nurses: Results of a national job analysis. *AAOHN Journal, 50*(1), 16-25.
- Samela, K., Fennelly, E., Brosnan, M., & Robinson, J. (2005). Interdisciplinary approach to the management of intestinal transplant recipients: Evaluation, discharge, and lifetime management. *Progress in Transplantation, 15*(1), 54-59. Retrieved from <http://natco.metapress.com/content/122510/>
- Schram, A. P. (2012). The patient-centered medical home: Transforming primary care. *Nurse Practitioner, 37*(4), 33-39. doi:10.1097/01.NPR.0000412893.04686.1e
- Shaefer, M., & Williams, L. (1991). Nursing implications of immunosuppression in transplantation. *Nursing Clinics of North America, 26*(2), 291-314.
- Shafer, T. (2006). The history of the transplant coordinator. In D. L. Rudow, L. Ohler & T. Shafer (Eds.), *A clinician guide to donation and transplantation* (1st ed., pp. 7-321). Lenexa, KS: Applied Measurement Professionals.

- Shallcross, J. (2002). Nursing management of patients for greater renal transplant success. *Professional Nurse, 17*, 725-728.
- Shaller, D. Patient-centered care: What does it take? Retrieved from The Commonwealth Fund. <http://www.commonwealthfund.org/publications/fund-reports/2007/oct/patient-centered-care--what-does-it-take>
- Siegal, B., & Greenstein, S. (1999). Compliance and noncompliance in kidney transplant patients: Cues for transplant coordinators. *Journal of Transplant Coordination, 9*(2), 104-108.
- Sloan, R. S. (1999). Guarded alliance relationships between hemodialysis patients and their health care providers. *ANNA Journal, 26*(5), 503-505.
- Stamm, B. H. (2010). *The concise ProQOL manual*, (2nd ed.). Pocatello, ID: ProQOL.org.
- Stille, C., & Antonelli, R. (2004). Coordination of care for children with special health care needs. *Current Opinion in Pediatrics, 16*, 700-705. doi: 10.1097/01.mop.0000144442.68016.92
- Stockmann, C. (2005). A literature review of the progress of the psychiatric nurse-patient relationship as described by Peplau. *Issues in Mental Health Nursing, 26*(9), 911-919. 10.1080/01612840500248197
- Styles, M. M., Schumann, M. J., Bickford, C., & White, K. M. (2008). *Specialization and credentialing in nursing revisited: Understanding the issues, advancing the profession*. Silver Spring, Maryland: American Nurses Association.
- Sullivan, C., Leon, J. B., Sayre, S. S., Marbury, M., Ivers, M., Pencak, J. A., . . . Sehgal, A. R. (2012). Impact of navigators on completion of steps in the kidney transplant process: A randomized, controlled trial. *Clinical Journal of the American Society of Nephrology, 7*(10), 1639-1645. doi:10.2215/CJN.11731111
- Sussman, J., Howel, D., Bainbridge, D., Brazil, K., Pyette, N., Abassi, S., & Whelan, T. (2011). The impact of specialized oncology nursing on patient supportive outcomes. *Journal of Psychosocial Oncology, 29*(3), 286-307. doi:10.1080/07347332.2011.563342
- Swindle, M. (2011). Job analysis survey: The foundation from which nursing knowledge and skill levels are validated. *Journal of Wound, Ostomy & Continence Nursing, 38*(2), 191. doi: 10.1097/WON.0b013e31820af261

- Szeifert, L., Molnar, M. Z., Ambrus, C., Koczy, A. B., Kovacs, A. Z., Vamos, E. P., . . . Novak, M. (2010). Symptoms of depression in kidney transplant recipients: A cross-sectional study. *American Journal of Kidney Diseases*, 55(1), 132-140. doi:10.1053/j.ajkd.2009.09.022
- Thorne, S. E., & Robinson, C. A. (1988). Reciprocal trust in health care relationships. *Journal of Advanced Nursing*, 13(6), 782-789. doi:10.1111/j.1365-2648.1988.tb00570.x
- Thorpe, K. E., & Ogden, L. L. (2010). The foundation that health reform lays for improved payment, care coordination, and prevention. *Health Affairs*, 29(6), 1183-1187. doi:10.1377/hlthaff.2010.0415
- Troen, A. M., Scott, T. M., D'Anci, K., Moorthy, D., Dobson, B., Rogers, G., . . . Rosenberg, I. H. (2012). Cognitive dysfunction and depression in adult kidney transplant recipients: Baseline findings from the FAVORIT ancillary cognitive trial (FACT). *Journal of Renal Nutrition*, 22(2), 268-276.e3. doi: 10.1053/j.jrn.2011.07.009
- Troidle, L., Watnick, S., Wuerth, D. B., Gorban-Brennan, N., Kliger, A. S., & Finkelstein, F. O. (2003). Depression and its association with peritonitis in long-term peritoneal dialysis patients. *American Journal of Kidney Diseases*, 42(2), 350-354. doi: 10.1016/S0272-6386(03)00661-9
- Trust. (2015). In *Merriam Webster's online dictionary*. Retrieved from <http://www.merriam-webster.com>
- Tuttle, J., Kellerman, S., & Tauxe, R. V. (1994). The risks of raw shellfish: What every transplant patient should know. *Journal of Transplant Coordination*, 4(1), 60-63.
- United States Department of Health and Human Services, Centers for Medicare and Medicaid Services. (2007). 42 CFR parts 405, 482, 488, and 498 *Medicare program; hospital conditions of participation: Requirements for approval and re-approval of transplant centers to perform organ transplants; Final rule*. Retrieved from <http://www.cms.hhs.gov/CertificationandCompliance/downloads/Transplantfinal.pdf>
- United States Department of Health and Human Services, Healthcare Systems Bureau, Division of Transplantation. (2009). *2009 annual report of the U.S. organ procurement and transplantation network and the scientific registry of transplant recipients: Transplant data 1999-2008*. Rockville, MD: Author. Retrieved from <http://optn.transplant.hrsa.gov/ar2009/default.htm>

- United States Department of Health and Human Services, Healthcare Systems Bureau, Division of Transplantation. (2015). *Data reports*. Retrieved from <http://optn.transplant.hrsa.gov/converge/latestData/rptData.asp>
- United States Department of Health and Human Service. (2013). *2013 annual report to congress: National strategy for quality improvement in health care*. Retrieved from <http://www.ahrq.gov/workingforquality/nqs/nqs2013annlrpt.pdf>.
- Vermeulen, K. M., Bosma, O. H., Bij, W. v. d., Koëter, G. H., & TenVergert, E. M. (2005). Stress, psychological distress, and coping in patients on the waiting list for lung transplantation: An exploratory study. *Transplant International*, *18*(8), 954-959. doi:10.1111/j.1432-2277.2005.00169.x
- Vincent, M. C., Repper, S. M., & Peters, T. G. (2002). Education, pay, and job status: A national survey of transplant coordinators. *Progress in Transplantation*, *12*(3), 212-216.
- Wainwright, S. P. (1995). The transformational experience of liver transplantation. *Journal of Advanced Nursing*, *22*(6), 1068-1076. doi:10.1111/j.1365-2648.1995.tb03107.x .
- Wainwright, S. P., & Gould, D. (1997). Non-adherence with medications in organ transplant patients: A literature review. *Journal of Advanced Nursing*, *26*(5), 968-977. doi:10.1046/j.1365-2648.1997.00451.x
- Waldie, J. (2010). Healthcare assistant role development: A literature review. *Journal of Advanced Perioperative Care*, *4*(2), 61-72. Retrieved from http://www.afpp.org.uk/books-journals/journal_archive
- Watnick, S. (2009). Quality of life and depression in CKD: Improving hope and health. *American Journal of Kidney Diseases*, *54*(3), 399-402. doi:10.1053/j.ajkd.2009.06.009
- Weeks, S. M., Barone, G. W., Gurley, B. J., Ketel, B. L., Lightfoot, M. L., & Ezz, S. R. (2001). St John's wort: A hidden risk for transplant patients. *Progress in Transplantation*, *11*(2), 116-120. Retrieved from <http://natco.metapress.com/content/122510/>
- Weiss, S. J., & Davis, H. P. (1983). The health role expectation index: A measure of alignment, disparity, and change. *Journal of Behavioral Medicine*, *6*, 63-76. doi:10.1007/BF00845277

Zarifian, A., & O'Rourke, M. (2006). Managing the kidney waiting list. *Progress in Transplantation*, 16(3), 242-246. Retrieved from <http://natco.metapress.com/content/122510/>

Zavala, E. Y., & Crandall, B. (2007). The practice of transplant administration. *Progress in Transplantation*, 17(2), 81. Retrieved from <http://natco.metapress.com/content/122510/>

VITA

Gwen Elise McNatt earned her baccalaureate degree in nursing at the University of Iowa in Iowa City, Iowa. She began her nursing career as a staff nurse on a transplant unit in Chicago and then worked as a transplant coordinator at several different Chicago transplant centers. She later completed a master's degree in nursing at the University of Illinois at Chicago. Her thesis research, funded by a grant by the American Nephrology Nurses Association, examined the phenomenon of kidney transplant recipients return to work after transplantation.

Dr. McNatt is a board-certified family nurse practitioner and a certified nephrology nurse. After working as a transplant nurse practitioner, she became the manager and then director of the Kovler Organ Transplantation Center at Northwestern Memorial Hospital in Chicago. She also maintains a clinical practice focusing on long term care of living kidney donors. She has been a co-investigator in several funded research projects pertaining to the educational and informed consent processes in transplant patients. She has authored or co-authored several articles and textbook chapters in the sub-specialty of organ transplantation. She is active in several transplant professional organizations.

Her focus during her doctoral studies at Loyola University has been on the transplant coordinator. Her passion is for transplant recipients and the care that they receive. To that end, she has focused on the role of the transplant coordinator and to

codifying the role in policy, regulation, and professional literature and certification.

Given the current emphasis on care coordination in healthcare; she believes this work will have significant influence on nursing as a whole.