Author: **Tackmann, Alexis, M.**

Title: ***How the Kidney Transplant Process Effects Kidney Recipients' Families***

The accompanying research report is submitted to the **University of Wisconsin-Stout**, **Graduate School** in partial completion of the requirements for the

Graduate Degree/ Major: **MS Family Studies and Human Development**

Research Adviser: **Kevin Doll, Ph.D.**

Submission Term/Year: **Spring, 2013**

Number of Pages: 24

Style Manual Used: American Psychological Association, 6th edition

☒ **I understand that this research report must be officially approved by the Graduate School and that an electronic copy of the approved version will be made available through the University Library website**
☒ **I attest that the research report is my original work (that any copyrightable materials have been used with the permission of the original authors), and as such, it is automatically protected by the laws, rules, and regulations of the U.S. Copyright Office.**
☒ **My research adviser has approved the content and quality of this paper.**

STUDENT:

NAME Alexis Tackmann **DATE: 5/1/13**

ADVISER: (Committee Chair if MS Plan A or EdS Thesis or Field Project/Problem):

NAME Kevin Doll **DATE: 5/7/13**

This section for MS Plan A Thesis or EdS Thesis/Field Project papers only
Committee members (other than your adviser who is listed in the section above)

1. **CMTE MEMBER'S NAME:** **DATE:**

2. **CMTE MEMBER'S NAME:** **DATE:**

3. **CMTE MEMBER'S NAME:** **DATE:**

This section to be completed by the Graduate School
This final research report has been approved by the Graduate School.

Director, Office of Graduate Studies: **DATE:**

Tackmann, Alexis M. ***How the Kidney Transplant Process Effects Kidney Recipients' Families***

Abstract

This literature review examines how the kidney transplant process effects kidney recipients' families. Kidney transplant have been performed for approximately 60 years, and this process highlights a variety of family dynamics including parent and child relationships, sibling relationships, the feeling of indebtedness after transplant, the complexity of family, and the family members' decision to donate a kidney.

Professionals should keep in mind that families are affected by the kidney transplant process. Communication throughout the kidney process is encouraged for families. Additional research on families is needed on this topic, especially within the various types of kidney transplant procedures including living donor, deceased donor, and paired living donation exchange.

Table of Contents

Chapter I: Introduction

Per the United States Renal Data System, there were 17,778 kidney transplants performed in the United States in 2010, which means an equal number of families were affected by the transplant process (U. S. Renal Data System, 2012). Examining the effect kidney transplant has on families is significant because the process of transplant has many psychosocial components for the patient (the kidney recipient) and the patient's family. To add another layer to the effect kidney transplant has on family, a patient's family member may have been the kidney donor so one family is often dealing with two people having surgeries at the same time. This topic is also significant because the patient's family is often the primary support system, outside of medical staff, throughout the transplant process.

The theory that best relates to the topic of family stress associated with kidney transplant is Family Stress Theory (ABC-X model). In this situation, the stressor (A) would be the transplant process. The strengths and resources for the family (B) may be the healthcare team. Other strengths and resources could be financial or emotional support from friends and extended family. Perception of the process (C) may be determined by how much education the family has received about the transplant, how long the patient has had kidney failure, or how long the patient has been on the waiting list for a kidney transplant. The crisis (X) is the situation that could erupt at any time during the transplant process. The Family Stress Theory best applies to this topic because the "protective" factors of this theory (B and C) can shape the severity of the crisis (X), or prevent the crisis from even occurring (Hobfoll & Spielberger, 1992).

The first kidney transplant was performed nearly 60 years ago. With the passage of Medicare legislation in the 1970s to include coverage for renal replacement therapy such as dialysis and transplant, individuals with kidney failure can explore treatment options (Danovitch,

2010). The kidney transplant process has significantly evolved since that first transplant. There have been many medical advances such as medications and surgical techniques that improve kidney transplant outcomes for both donors and recipients (Danovitch, 2010). Along with medical advances there have been social advances including advocacy for donors and recipients to prevent exploitation.

Families and transplant have been studied for approximately 35 years, with the first edition of the book, *Gift of Life: The Effect of Organ Transplantation on Individual, Family, and Societal Dynamics*, being published in 1977, with the updated edition being published in 1987. Family, stress, and illness in various combinations can be found throughout the literature. Families of individuals with other illnesses such as breast cancer, and heart failure with transplant have been examined (Grunfeld, et al., 2004; Nolan, et al., 1992; Sirri, Magelli, & Grandi, 2011). The social supports and quality of life in dialysis patients has been researched (Rambod & Rafii, 2010), as well as the role of marital status on kidney transplant outcomes (Naiman et al., 2007), and the effect family environment has on kidney recipients' quality of life post-transplant (Christensen, Raichle, Ehlers, & Bertolatus, 2002). The psychosocial influence of the transplant process on recipients has also been studied (Engle, 2001; Fisher, 2006). Family and the various stages of kidney failure have been explored in the literature, including the effects of renal failure on patient's siblings (Batte, Watson, & Amess, 2006), and the patients' parents and caregivers (Friedman, 2006; Tsai, Liu, Tsai, & Chou, 2006). Quality of life in dialysis patients as perceived by their spouses has also been researched (Ferri & Pruchno 2009).

Purpose of Study

The purpose of this thesis is to address the following questions:

- How does the kidney transplant process effect kidney recipients' families?
- Are the needs of the families of kidney transplant recipients being met throughout the kidney transplant process?

Definition of Terms

- **Kidney**. An essential organ of the body. Most individuals are born with two kidneys, however an individual only needs one kidney to survive. The kidneys have many jobs including filtering the blood and excreting waste, regulating blood pressure, and balancing electrolytes.
- **Kidney failure**. The gradual process in which the kidneys stop working. This may be caused by diabetes, hypertension, and/or an inherited or congenital condition, among other medical conditions. There are five stages of kidney failure. During the last stage, an individual must choose a treatment modality (such as dialysis or transplant) to continue survival.
- **Dialysis**. A treatment option for kidney failure, in which the dialysis machine functions as an artificial kidney.
- **Kidney transplant**. Another treatment option for kidney failure. The process of surgically removing one kidney from a healthy individual and surgically implanting it into an individual with kidney failure.
- **Donor**. The person who has expressed desire to give one of their kidneys to another individual with kidney failure.

- **Living transplant**. The process where the donated kidney is retrieved from a living, healthy individual. The living donor may or may not be biologically related to the recipient. If the living donor is not biologically related to the recipient, there is often an emotional relation such as a spouse or friend.
- **Deceased-donor transplant**. The process where the donated kidney is retrieved from an individual who has expired from brain or cardiac death.
- **Recipient**. The person with kidney failure who receives a kidney from the donor.

Methodology

The sampling technique for this literature review was purposive sampling. Articles included in this literature review were found in scholarly, peer-reviewed journals published between 2000 and 2012 that have quantitative, qualitative, or quantitative and qualitative data collection. Other literature views were also included in the sample. Articles were identified via searches on EbscoHost university and hospital library databases. Searches included the following keywords: kidney transplant, marriage, family, and stress. Article titles and abstracts were reviewed and pertinent articles were retrieved. Once articles were retrieved, references were reviewed so a snowball strategy of retrieving additional articles could be completed. After pulling references from the initial articles, it was decided to include articles published before 2000 for historical merit. Articles referring to family stress associated with the decision to donate a loved one's organs after brain or cardiac death were excluded as this topic poses a series of ethical dilemmas and decisions that will not be explored in this particular literature review.

Assumptions and Limitations

It is assumed that this sampling technique selected articles that best represent family stress associated with kidney transplant. One limitation in this sampling technique is that personal and professional author bias excluded particular articles. Another limitation is that including previous literature reviews may not fully explore family stress with kidney transplant. A total of eight articles are included in this literature review.

Chapter II: Literature Review

Five primary themes emerged from the eight articles included in this literature review. These themes include parent and child relationships, sibling relationships, the feeling of indebtedness after transplant, complexity of family, and family members' decision to donate a kidney.

Parent and Child Relationships

The parent and child relationship throughout the transplant process is unique, especially if the parent is the donor and the child is the recipient. Two articles included in this literature highlight this relationship. The study by Karrfelt, Berg, & Lindblad (2000) focuses primarily on the parental perspective of the kidney transplant process. The investigators of this study gathered information via semi-structured interviews with eighteen parents of children with end-stage renal disease. This study found that parents—both donors and non-donors—experienced stress throughout their child's transplant process. This stress stemmed from medical changes in their child, fears of surgery and possibly death of a child, as well as financial stress related to quitting or losing a job to care for the ill child. This study also highlights that the child's illness influenced the parent's view of life including organization of life priorities. Several parents in this study changed their work hours or quit their job completely to care for their ill child. Other parents found themselves isolated from friends and relatives who had healthy children because parents of healthy children did not fully understand their family's circumstances, or that people—in general—were "complaining about nothing" compared to their own family's situation.

The idea of parental control vs. closeness with the ill child is reviewed in the article by Karrfelt et al., (2000) as well as the article by Franklin and Crombie (2003). Both studies found

that control and closeness are a matter of perception; parents expressed increased closeness with their child after transplant while children reported that there was much more parental intrusion on their lifestyle after kidney transplant, especially if the parent was the organ donor.

Sibling Relationships

The relationship among siblings is also unique. Biological siblings may genetically be the best potential match for kidney donation, which may pressure a person into the role of a kidney donor for an ill sibling. Jacobs, Johnson, Anderson, Gilligham, & Matas (1998) found that individuals reported more pressure to donate if they were a sibling, however these donors reported an improved relationship with their sibling after donation. This study was the follow-up to an initial study that reviewed the incidence and type of kidney donor perioperative complications. The authors followed up the same kidney donors (N=524) to determine any differences between quality of life and psychosocial functioning in donors with and without post-operative complications. Franklin and Crombie (2003) also found that siblings reported closer relationships with their ill siblings after kidney transplant. Both studies concluded that, overall, sibling donors had a positive experience with the transplant process.

Feeling of Indebtedness After Transplant

Two studies included in this literature review discussed that kidney recipients experience the feeling of indebtedness to their donor after transplant. This is an interesting phenomenon because as previously stated most donors and recipients report having a stronger or more positive relationship after kidney transplant. It does not appear that this phenomenon only exists in certain family relationships; transplant patients who received a kidney from a parent or sibling report feeling indebted to their donor (Franklin & Crombie, 2003). Whether or not the donor is aware of the indebtedness the kidney recipient is feeling varies. Franklin and Crombie (2003)

report one instance where the kidney recipient states, “we were equals before and then suddenly I owed her something.” This same recipient also reported, “It think that people think if someone gives you a kidney that you are totally indebted to the person for the rest of your life. I never saw that coming.”

Other donors report not knowing that the kidney recipient is harboring these feelings (Crombie & Franklin, 2006). One donor reported that after her sister—who received her kidney in the transplant—spoke with her about her feelings of indebtedness that she “didn’t give it to her so that she would feel obligated. What would be the point of that?”

Complexity of Family

Families come in all shapes and sizes, and the kidney transplant process highlights the variety of relationships within a family. Franklin and Crombie (2003) eloquently summarized the complexity of relationships involved with living related kidney donation:

> Unlike donation from a decreased person to an anonymous recipient, particular attention is focused on the mutual identities of the donor and the recipient involved in the light of their shared kin status, and also concerns about rights, duties, obligations, and expectations, as well as respective roles and statuses. Such considerations and concerns are not just chronologically time bound or merely a preliminary to the point at which a decision is made to donate or to receive an organ. They have implications and ramifications for recipients and their kin for many years to come, irrespective of whether a decision is made to donate or not.

Kidney donors and recipients may have different experiences of the same event. Burroughs, Waterman, & Hong (2003) found that the kidney donors’ primary concerns were that

their recipients would die without a transplant, the surgery would be painful, and they may have long-term health problems after kidney donation. It is important to note that the majority of the donors and recipients in this study were immediate family members. This study provided a questionnaire to 174 kidney donors plus their recipients and a third party (who was neither the kidney donor nor recipient) from 41 transplant hospitals to evaluate the different perspectives and experiences associated with the kidney transplant process. Recipients underestimated all three of the donor's concerns about the transplant process. Regarding the donors' decision-making process, recipients underestimated the amount of time the donors needed to decide to be a donor. Kidney recipients also underestimated the extent that their donors considered backing out of the transplant process (Burroughs et al., 2003).

The idea of the family of birth vs. the family of marriage is brought into the spotlight during the kidney transplant process. The study by Franklin and Crombie (2003) found that partners of recipients were supportive of kidney donation, however one husband reported he felt jealous that his wife's brother (the donor) could help in a way that he could not, meaning the patients brother could improve or save his wife's life and he could not. This same study also found that partners of donors were generally supportive of their spouses' decision to donate a kidney, however there were some partners that were not as supportive. One partner felt that his wife should not become a donor out of loyalty to their marriage and children, citing specific concerns about potential medical complications for his wife as well as the hypothetic situation where one of their children would a kidney in the future and his wife could no longer be a donor. Another partner did not want his wife to donate a kidney to her ill brother because he did not like the brother. The authors noted that this couple ultimately separated after donation with the donor

having no regrets about the experience because she preferred her brother to her husband to begin with (Franklin & Crombie, 2003).

The idea of family of birth vs. family of marriage is also apparent in a study conducted by Taylor and McMullen (2008). This study interviewed eleven husbands of kidney donors three months after the transplant. Each of the husbands reported that their wives made the decision to donate independently, and that their discussion about donation was more informative than permission seeking. Husbands in this study also reported that the decision-making process involved the siblings of the individual with kidney failure rather than spouses (Taylor & McMullen, 2008).

Family Members' Decision to Donate a Kidney

All eight of the studies included in this literature review discussed the decision-making process involved with kidney donation. Conrad and Murray (1999) state that organ donation is the ultimate form of gift giving. There are many factors that influence a family-member's decision to donate. These include whether or not the recipient would do the same for the donor if roles were reversed (Crombie & Franklin, 2006), donation as a form of reconciliation for outcasts in the family (Conrad & Murray, 1999), and potential consequences within the family if they chose not to donate a kidney (Franklin & Crombie, 2003).

Many potential kidney donors feel pressure to donate, and this pressure stems from a variety of sources: general moral pressure to save a life (Crombie & Franklin, 2006), coercion from other family members (Conrad & Murray, 1999), and pressure if a deceased donor kidney transplant is not available (Conrad & Murray, 1999). Siblings and offspring also report feeling more pressure to donate a kidney than other family members (Jacobs et al., 1998). Parents donating a kidney to a child have the most altruistic experience as they chose to donate out of

love (Franklin & Crombie 2003), and that parents do not regret their decision to donate a kidney to their ill child (Karrfelt et al., 2000).

Kidney donation can be a group process (Burroughs et al., 2003), however it appears that spouses of donors have little influence on the final decision to donate (Conrad & Murray, 1999; Franklin & Crombie, 2003; Neuhaus, Wartmann, Weber, Landolt, Laube, & Kemper, 2005; Taylor & McMullen, 2008).

Despite the variety of factors that could influence the decision to become a kidney donor, the majority of donors does not have any regrets about deciding to become a kidney donor (Franklin & Crombie, 2003), and would go through this process again (Burroughs et al., 2003).

Chapter III: Summary, Critical Analysis, and Recommendations

Summary

The kidney transplant process does affect kidney recipients' families. The process highlights various relationships within the family, including parent/child and sibling relationships. These relationships are especially in the spotlight if a parent or sibling is the kidney donor. A family member's decision to donate is multi-layered with many influences, and the decision to donate has both positive and negative consequences. Each family is different and the kidney transplant process verifies that families are complex units.

Per the review of literature, it is difficult to determine if the needs of the families of kidney transplant recipients are being met throughout the kidney transplant process. Studies included in this literature review demonstrate that families experience stress and that the different types of stress were unexpected, however families would ultimately repeat the transplant process over again.

Critical Analysis

Studies included in this literature review were all written in English, however the studies were conducted in countries all over the world. When evaluating research from other countries it is important to consider the specific country's overall quality of life, general health and wellness, as well as healthcare access, coverage, and payor source. All three of these aspects can significantly impact a patient and their family's perspective on illness. For example, the country of Switzerland provides universal health insurance for its residents while the United States has a blend of public and private health insurance options. The pros and cons to each type of coverage may also be influenced by a family's financial situation as well as their political leanings. It is important to note that in order for the kidney transplant process to be available for patients, that

specific country must have access to the appropriate medical technology for the kidney transplant to be successful. This would eliminate certain countries from being included in kidney transplant studies.

Most of the articles included in this literature review focused on living kidney donation. This may be because many of the families included in the studies were also the kidney donor. While living kidney donation accounts for almost half of the kidney transplants in the United States (Danovich, 2010), families of individuals who have received a kidney from a deceased donor should be not ignored. The deceased donor kidney transplant process poses additional stressors for families. Attitudes and concerns surrounding the decision to become an organ donor or to donate a family member's organs after brain or cardiac death have been studied (DuBois & Anderson, 2006; Fahrenwald & Stabnow, 2005; Verble & Worth, 2000), however there is a need for studies on how the decreased donor kidney transplant process effects families of patients on the kidney waiting list. Speculated stressors for families may include inability for a family member to donate, length of time the patient is on the kidney waiting list, or patient death while waiting for a kidney transplant (Beard, Jackson, & Kaserman, 2008; Beard, Jackson, Kaserman, & Kim, 2012; Gillespie et al., 2011; Sanner, Lagging, & Tibell, 2011). Another type of kidney transplant that was not discussed in the studies included this literature review is paired living donation exchange. This is a relatively new transplant option for individuals with kidney failure (Danovich, 2010), which may also have a unique impact on families (Waterman et al, 2006).

The five themes found throughout the literature included in this review are intertwining, which adds another layer of intricacy. For example, a family member's decision to donate is likely related to the relationship that the individual has with the patient, which demonstrates the

complexity of family. The reverse of this is also true in that family dynamics can influence a person's decision to become a kidney donor. For example, if a sibling of a person with kidney failure is considered the "black sheep" of the family is there double the pressure to donate because the sibling is 1. the genetic ideal match and 2. would also be a redemption opportunity for that sibling? Another example of intertwining themes surrounding the complexity of family is the irony of the feelings of indebtedness after kidney transplant, however most families would choose to go through he kidney transplant process again if they. The article by Franklin & Crombie (2003) decided to report the individual studies conducted by each author together because, "the authors believe that the psychological, social, and cultural aspects of live donation are closely intertwined. Therefore, joint results provide validity and depth and, in addition, provide a great insight and understanding into these complex aspects of this area of transplantation."

Many of the articles in this literature review used qualitative data in the study design. Because of this design the number of subjects included in the studies is very small (Karrfelt, et al., 2000; Neuhaus et al., 2005; Taylor & McMullen, 2008), and is a limiting factor. A positive aspect of using qualitative date is that the study authors were able to use direct quotes from participants rather than relying on a digit on a number scale, which may be more meaningful.

Of the articles included in this literature review many cited older references (Burroughs et al., 2003; Conrad & Murray, 1999; Crombie & Franklin, 2006; Franklin & Crombie, 2003; Jacobs et al., 1998), had a small number of subjects, cited the authors' previous work—both published and unpublished—(Burroughs, et al., 2003; Conrad & Murray, 1999; Crombie & Franklin, 2006; Taylor & McMullen, 2008), or a combination of the three. Some of the articles in this literature review had an extensive reference list, however there was one article where the

findings continuously cited one or two books rather than individual studies (Conrad & Murray, 1999). Several of the studies also cited anecdotal events from the author's experience (Conrad & Murray, 1999; Crombie & Franklin, 2006), which leads to incredibly biased results. Upon closer examination of two articles included in this literature review, the authors used the same interviews in two different papers (Crombie & Franklin, 2006; Franklin & Crombie, 2003).

Recommendations

Professionals within the transplant community need to remember that the kidney transplant process effects families. There should continue to be advocacy for families, especially if one of the family members is selected to be the kidney donor. Also, there should be continuous assessment of family dynamics before transplant, at time of surgery and hospitalization, as well as for several months—if not years—after kidney transplant. Appropriate referrals, including but not limited to physicians, pharmacists, social work, patient representatives, psychology, and spiritual care, should also be available throughout the kidney transplant process. This multidisciplinary approach has been recommended for trauma-response teams (Mendenhall, 2006; Mendenhall & Berge, 2010), and would beneficial for patients and families within the kidney transplant process.

For patients and families on the spectrum of kidney disease and transplant, open communication should be encouraged throughout he kidney transplant process. This dialogue should include assumptions and expectations about the transplant, as well as any potential symbolism that the kidney holds for both the kidney donor and recipient.

Additional research is needed especially as the general population ages and chronic disease, such as kidney failure, becomes more common. With the kidney transplant waiting list becoming longer and longer (Danovich, 2010), families involved with the decreased donor and

paired living donor exchange transplant process should be studied so they are adequately supported. In the spirit of advocacy, potential donors within a family who elect not to donate should also be studied to determine relationship consequences between the individual and the family. How families are impacted by the paired living donation exchange should also be studied. With any future research, every attempt should be taken to reach a high number of subjects, as well as to include other transplant centers in research design.

References

Batte, S., Watson, A. R., & Amess, K. (2006). The effects of chronic renal failure on siblings. *Pediatric Nephrology, 21*, 246-250.

Beard, T. R., Jackson, J. D., & Kaserman, D. L. (2008, Winter). The failure of U. S. organ procurement policy. *Regulation*, 22-30.

Beard, T. R., Jackson, J. D., Kaserman, D., & Kim, H. (2012). A time-series analysis of the U. S. kidney transplantation and the waiting list: donor substitution effects. *Empirical Economics, 42,* 261-277.

Burroughs, T. E., Waterman, A. D., & Hong, B. A. (2003). One organ donation, three perspectives: experiences of donors, recipients, and third parties with living kidney donation. *Progress in Transplantation, 13*(2), 142-150.

Christensen, A. J., Raichle, K., Ehlers, S. L, & Bertolatus, J. A. (2002). Effect of family environment and donor source on patient quality of life following renal transplantation. *Health Psychology, 21*(5), 468-476.

Conrad, N. E., & Murray, L. R. (1999). The psychosocial meanings of living related kidney organ donation: recipient and donor perspectives—literature review. *American Nephrology Nurses Association Journal, 26*(5), 485-490.

Crombie, A. K., & Franklin, P. M. (2006). Family issues implicit in living donation. *Mortality, 11*(2), 196-210.

Danovitch, G. M. (Ed.). (2010). *Handbook of kidney transplantation* (5th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

DuBois, J. M., & Anderson, E. E. (2006). Attitudes toward death criteria and organ donation among healthcare personnel and the general public. *Progress in Transplantation, 16*(1), 65-73.

Engle, D. (2001). Psychosocial aspects of the organ transplant experience: what has been established and what we need for the future. *Journal of Clinical Psychology, 57*(4), 521 549.

Fahrenwald, N. L., & Stabnow, W. (2005). Sociocultural perspective on organ and tissue donation among reservation-dwelling American Indian adults. *Ethnicity and Health, 10*(4), 341-354.

Ferri, C. V., & Purchno, R. A. (2009). Quality of life in end-stage renal disease patients: differences in patient and spouse perceptions. *Aging & Mental Health, 13*(5), 706-714.

Fisher, M. S. (2006). Psychosocial evaluation interview protocol for pretransplant kidney recipients. *Health & Social Work, 31*(2), 137-144.

Fox, R. C., & Swazey, J. P. (1992). *Spare parts: Organ replacement in American society*. New York, NY: Oxford University Press, Inc.

Franklin, P. M., & Crombie, A. K. (2003). Live related renal transplantation: Psychological, social, and cultural issues. *Transplantation, 76*(8), 1247-1252.

Friedman, A. L. (2006). The broader burden of end-stage renal disease on children and their families. *Kidney International, 70*, 1893-1894.

Gillespie, A., Hammer, H., Lee, J., Nnewihe, C., Gordon, J., & Silva, P. (2011). Lack of listing status awareness: results of a single-center survey of hemodialysis patients. *American Journal of Transplantation, 11,* 1522-1526.

Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C., …Glossop, R. (2004). Family caregiver burden: results of a longitudinal study of breast cancer patients and their principle caregivers. *Canadian Medical Association Journal, 170*(12), 1795-1801.

Hobfoll, S. E., & Spielberger, C. D. (1992). Family stress: integrating theory and measurement. *Journal of Family Psychology, 6*(2), 99-112.

Jacobs, C., Johnson, E., Anderson, K., Gillingham, K., & Matas, A. (1998). Kidney transplants from living donors: how donation affects family dynamics. *Advances in Renal Replacement Therapy, 5*(2), 89-97.

Karrfelt, H. M. E., Berg, U. B., & Lindblad, F. I. E. (2000). Renal transplantation in children: psychological and donation-related aspects from the parental perspective. *Pediatric Transplantation, 4*, 305-312.

Mendenhall, T. J. (2006). Trauma-response teams: inherent challenges and practical strategies in interdisciplinary fieldwork. *Families, Systems, & Health, 24*(3), 357-363.

Mendenhall, T. J., & Berge, J. M. (2010). Family therapists in trauma-response teams: bringing systems thinking into interdisciplinary fieldwork. *Journal of Family Therapy, 32*, 43-57.

Naiman, N., Baird, B. C., Isaacs, R. B., Koford, J. K., Habib, A. N., Wang, B., …Goldfarb Rumyantzev, A. S. (2007). Role of pre-transplant marital status in renal transplant outcome. *Clinical Transplant, 21*, 38-46.

Neuhaus, T. J., Wartmann, M., Weber, M., Landolt, M. A., Laube, G. F., & Kemper, M. J. (2005). Psychosocial impact of living-related kidney transplantation on donors and partners. *Pediatric Nephrology, 20*, 205-209.

Nolan, M. T., Cupples, S. A., Brown, M-M., Pierce, L., Lepley, D., & Ohler, L. (1992). Perceived stress and coping strategies among families of cardiac transplant candidates during the organ waiting period. *Heart & Lung, 21*(6), 540-547.

Rambod, M., & Rafil, F. (2010). Perceived social support and quality of life in Iranian hemodialysis patients. *Journal of Nursing Scholarship, 42*(3), 242-249.

Sanner, M. A., Lagging, E., & Tibell, A. (2011). The kidney recipient's path to transplantation: a comparison between living and deceased kidney donor recipients in Stockholm, Sweden. *Nephrology Dialysis Transplantation, 26*, 1053-1057.

Simmons, R. G., Marine, S. K., & Simmons, R. L. (1987). *Gift of life: The effect of organ transplantation on individual, family, and societal dynamics.* New Brunswick, NJ: Transaction Publishers.

Sirri, L. Magelli, C., & Grandi, S. (2011). Predictors of perceived social support in long-term survivors of cardiac transplant: the role of psychological distress, quality of life, demographic characteristics, and clinical course. *Psychology and Health, 26*(1), 77-94.

Taylor, L. A., & McMullen, P. (2008). Living kidney organ donation: experiences of spousal support of donors. *Journal of Clinical Nursing, 17*(2), 232-241.

Tsai, T. C., Liu, S. I., Tsai, J. D., & Chou, L. H. (2006). Psychosocial effects on caregivers for children on chronic peritoneal dialysis. *Kidney International, 70*, 1983-1987.

U. S. Renal Data System, USRDS 2012 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2012.

Verble, M., & Worth, J. (2000). Overcoming families' fears and concerns in the donation discussion. *Progress in Transplantation, 10*(3), 155-160.

Waterman, A. D., Schenk, E. A., Barrett, A. C., Waterman, B. M., Rodrigue, J. R., Woodle, E. S., ...Schnitzler, M. (2006). Incompatible kidney donor candidates' willingness to participate in donor-exchange and non-directed donation. *American Journal of Transplantation, 6*, 1631-1638.