

ABSTRACT

THE EXPERIENCE OF LIVING WITH UNCERTAINTY: RECEIVING A SOLID ORGAN TRANSPLANT

By Tiffany A. Sasse

The journey from diagnosis that an organ has failed to transplant is extensive. However, the journey does not end there. The process of receiving an organ transplant is only the beginning of a new journey and time of uncertainty. There have been numerous studies looking at the issues related to adherence to an exhaustive immunosuppressive regimen, as well as the psychological and functional impact of individuals who have received an organ transplant. However, further examination of the experience of receiving an organ transplant, and the uncertainty associated with this experience, is needed to better understand the phenomenon and its impact upon the individual. The purpose of this study is to explore and describe the lived experience of persons who have received a solid organ transplant and the uncertainty associated with this experience.

Mishel's Theory of Uncertainty in Illness (1988, 1990) served as the framework for this study. A descriptive phenomenological design was utilized. A purposive sample of 10 participants, over age 18, who fulfilled the criteria for sample selection, were selected for this study. Data were collected through unstructured, audio-taped interviews that were transcribed verbatim. Data was then analyzed through Giorgi's (1985) phenomenological method. Results, implications, and conclusions were then based upon the data received.

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RECEIVING A SOLID ORGAN TRANSPLANT

by

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CHAPTER I

INTRODUCTION

The purpose of this study was to explore and describe the experience of persons who have received a solid organ transplant and the uncertainty associated with this experience. Close to 30,000 solid organ transplants are performed each year (Scientific Registry of Transplant Patients, n.d.). The United Network for Organ Sharing (n.d.) reports approximately 84,000 patients with end-stage organ disease are on the transplant list awaiting suitable organs to become available, with approximately 3,700 people being added to the list each month. Unfortunately, half of these people will die before the much needed organs become available. According to Kaserman (2007), in a 4-year time span, more than 6,000 potential transplant recipients died awaiting transplant.

Already in the last century, attempts were made to transplant human organs. These early transplants often did not succeed, due to a lack of understanding of blood type, tissue matching, and the importance of immunosuppression (Engle, 2001). The first successful human organ transplant in the U.S was performed in 1954, when a kidney was successfully transplanted using a living identical twin as the donor (Kaserman, 2007). Many advances in the number of successful transplants were made after the discoveries of immunosuppressive therapy. Because of improvements in organ preservation methods and immunosuppressive therapy, life expectancy after transplantation is estimated with a 1-year survival rate between 75% to 85% and a 5-year survival rate between 50% and 70%, depending on the organ transplanted (United Network for Organ Sharing, n.d.).

The screening process for individuals being considered for an organ transplant is extensive, with the biggest problem being the lack of organs available for transplant. Due to the shortage of organs, many candidates will wait for an organ. Each situation is unique, and waiting times can vary. Factors that determine who will receive an organ are based on the type of organ needed, participant age, donor age, blood type, geographic distance between the donor and recipient and the size of the donor organ in relation to the recipient. Heart transplant (HT) candidates are unique in that their physician will assign the person a code indicated the urgency of the needed transplant (Transplant Living, n.d.)

The procedure of an organ transplant consists of three operations. The first operation involves harvesting the organ from the donor. In the case of heart transplant, the donor must first be declared neurologically brain dead following stringent criteria. Common causes of neurologic brain death are head trauma, anoxic events, brain tumors, or cerebral vascular accidents (Rayburn, 2005). The donor's organs must be working well, which often involves use of medications and life support measures, such as a respirator. Once the organs are removed, they are kept on ice until transplantation. For a heart, the optimal time from donor to recipient is less than 6 hours. Kidney transplants often differ in that the donor is often a living donor.

The second operation involves removing the recipient's damaged organ, while the third surgery involves implanting the donor organ into the recipient. If there are no complications from surgery, the organ transplant patients are often able to leave the hospital within 1 to 2 weeks (Fishbein & Marks, 2007).

The initial surgical transplant is only the first step in the healing and recovery process. It is the time after transplant where the healing begins. The period following an

organ transplant may potentially test the uncertainty in one's life. Uncertainties may impact the person psychologically or functionally. Other uncertainties include compliance and adherence to the immunosuppressive medication regimen. If complications, such as infection or rejection, do arise, it may be several months or years before these complications appear. Within this period of time, there is also potential for other acute or chronic conditions.

After surgery, the organ transplant recipient will be monitored closely and have regular tests, including blood work, echocardiograms, electrocardiograms, and biopsies. There are many long-term adjustments that need to be made after transplant. One adjustment involves the medication regimen. Immunosuppressant or anti-rejection medications are given to decrease activity of the immune system and prevent the body from attacking the donor organ, thus reducing the incidence of rejection. Organ transplant recipients will often need to take these medications indefinitely. Although the immunosuppressants are effective, they are not without side effects. Immunosuppressants make the body more vulnerable to infection; they may worsen high blood pressure, high cholesterol, cancer, or diabetes (Babruth, 2004). Adherence to this regimen is often a struggle and has been reviewed extensively in the literature (Chisholm 2002; De Geest, Dobbles, Fluri, Pris, & Troosters, 2005; Wainright & Gould, 1997). Laederach-Hofmann and Bunzel (2000) found that one-fifth of all transplanted patients do not take their medication as prescribed. Reasons for noncompliance include side-effects, cost, and difficulty in taking the medications. Raiz, Kilty, Henry, and Ferguson (1999) found that 25% of their sample patients reported simply forgetting to take their medication occasionally.

There have also been many studies surrounding the psychological implications, including coping mechanisms and emotional response after organ transplant (Dew & DiMartini, 2005; Kaba, Thompson & Burnard, 2000; Kaba, Thompson, Burnard, Edwards & Theodosopoulou, 2005). Bunzel and Laederach-Hofmann (1999) assessed the physical and emotional factors in HT patients. Although they reported excellent physical performance 5 years post procedure, they had significant deterioration in their emotional well-being. According to Jones (2005), most organ recipients go through an initial phase of euphoria having survived the transplant surgery. Their emotions are then followed by bouts of fear, anxiety, and depression. The challenge often includes coping with the loss of their own organ, gaining acceptance of the donor organ, and guilt associated with the death of the donor. Psychological rejection of the organ is sometimes associated with a physical rejection of the donor organ (Kaba et al., 2005).

Another area of possible uncertainty is the functional impact upon the individual. Engle (2001) states, "The goal of performing organ transplant is to return the patient, as closely as possible, to normal functioning in terms of physical health, mental and emotional well-being and social functioning" (p. 533). Although overall functioning is greatly improved compared to pre-transplant, it may take some time before many recipients are able to return to work (Brann, Bennett, Keck & Hosenpud, 1998). Fisher, Lake, Reutzel, and Emery (1995) discovered marked improvements in all functional areas 5 years post transplant. Shiba et al. (2004) found better functional status 10 years post heart transplant, but a higher rate of hypertension, renal problems, graft coronary artery disease, and malignancy related to immunosuppressive therapy. O'Carroll, Turner, Flatley, McGregor and Hayes (2008) found significant recovery in many areas of

psychosocial functioning 1 year post liver transplant. However, much of the recovery was incomplete, with many of the patients not recovering to their pre-illness status.

Research has examined alterations in the psychological and functional impact, as well as, the difficulties adhering to the immunosuppressive medication regimen. Although studies have utilized qualitative approaches to understand the psychological and functional experience of organ transplant, there have not been any qualitative or quantitative studies that explored the experience of organ transplant and the uncertainties associated with this experience. The lack of research on the lived experience, and uncertainties associated, warrant further study.

Significance to Nursing

Patients with organ failure who have undergone a solid organ transplant have endured a long journey from diagnosis, surgery, and throughout postoperative process. This study will enable the Advanced Practice Nurse Practitioner (APNP) to gain a better understanding of the individual difficulties and needs, possibly suggesting new ways of caring for these individuals. This research will advance our knowledge of what organ transplant recipients face, their feelings, needs, and conflicts.

Due to the complications associated with immunosuppression, such as renal disease, high blood pressure, infections, and malignancy, the APNP in the primary care setting may be one of the providers to encounter a patient post solid organ transplant. Advanced practice nurse practitioners should possess knowledge of factors impacting the organ transplant experience and of treatments that may prevent some of the disabling issues. This knowledge will have the potential to promote functional and psychological restoration of the individual. The focus of nursing is to care for the

individual in a holistic manner or approach, taking into consideration the human response to the diagnosis and treatment. Therefore, the APNP is the ideal person to coordinate care for this individual, taking into account the application of theory, medical knowledge, and research. The APNP will then apply this knowledge and experience into the care and management of the patient living with an organ transplant.

Problem Statement

Further examination of the solid organ transplant experience is needed to better understand the phenomenon of uncertainty and its impact upon the individual.

Purpose of the Study

The purpose of the study was to explore and describe the experience of persons who have received a solid organ transplant and the uncertainty associated with this experience.

Research Question

What is the experience of individuals who have received a solid organ transplant? A related question includes: Describe the uncertainty associated with this process?

Definitions of Terms

Conceptual Definitions

Experience: Phenomenological inquiry to describe a phenomenon by the individuals who have experienced it to understand the meaning of the experience.

Solid Organ Transplant: A procedure in which a surgeon removes a diseased organ and replaces it with a donor organ. Solid organs include the heart, lung, kidneys, liver, or pancreas.

Individual: A person who has received a solid organ transplant (United Network of Organ Sharing, n.d.). People who had end-stage organ disease and failure with a limited life expectancy and given a new organ from a living or deceased donor.

Uncertainty: Cognitive state resulting from insufficient cues with which to form a cognitive schema, or meaning of a situation or event (Mishel, 1988).

Operational Definitions

Experience: The person's described or observed expression of their experience. In this study; whatever the person described or expressed as being part of their life since the organ transplant surgery.

Solid organ transplant: The surgical procedure involving removing the solid organ from the deceased donor and placing it into the recipient's body.

Individual: Any male or female, over age 18 years, living in Wisconsin, who has received a solid organ transplant (heart, lung, liver, kidney, or pancreas) from a living or deceased donor.

Uncertainty: What is unknown regarding the future and the meanings related to the event.

Assumptions

1. Subjects will be honest when responding to questions about their solid organ transplant experience.
2. All patients have a role in the management of their health.

3. The patient is the authority of his/her experiences.
4. Patients have perceptions and feelings regarding their experiences and uncertainties with receiving an organ transplant, and these experiences have meaning for the patient.
5. Regardless of the recovery stage, the subject will experience some uncertainty.
6. The participant may view the uncertainty as desirable, aversive, or neutral.
7. Patients are striving to adapt to their new organ.

Chapter Summary

It is well known that receiving a solid organ transplant impacts a person's life in many ways, including functionally, psychologically, and adhering to the immunosuppressive medication regimen. There were not any studies found that have looked at the lived-experience of receiving an organ transplant and the uncertainty that accompanies this journey.

Advanced practice nurse practitioners may encounter patients who have received a solid organ transplant in practice. The regimen of immunosuppressive therapy greatly impacts these patient's lives, placing them at greater risk for infection, diabetes, and hypertension. This study is undertaken to further examine the organ transplant experience and to better understand the phenomenon of uncertainty and its impact upon the individual.

In this chapter, the background of the study, problem statement, purpose of the study, research questions, definitions, and assumptions were outlined. The next chapter will include an overview of the theoretical framework and review of literature.

CHAPTER II

THEORETICAL FRAMEWORK AND REVIEW OF LITERATURE

The purpose of this study was to explore and describe the experience of persons who have received a solid organ transplant and the uncertainty associated with this experience. Mishel's Uncertainty in Illness Theory (1988, 1990) serves as the foundation for this study and is outlined in this chapter. The main concepts and their relationships will be identified and defined as well as the assumptions of this model. A literature review will include previous studies that have looked at the impact of receiving an organ transplant focusing on the psychological and functional impact along with issues related to adherence to the immunosuppressive medication regimen.

Theoretical Framework

The theoretical framework for this study is based upon Mishel's Uncertainty in Illness Theory (1988, 1990). Whether the illness is acute or chronic, uncertainty is a commonality with any illness experience. The journey of organ transplant is no different. From diagnosis that an organ has failed, followed by unsuccessful attempts to save the organ, and finally transplant, is a journey of considerable uncertainty. After transplant, a new journey of uncertainty awaits. The Uncertainty in Illness Model provides explanation of how patients process illness-related events and what those events mean to that person (Mishel, 1988). Adaptation is the desired end after coping with uncertainty (Mishel, 1988).

Mishel initially studied the concept of uncertainty in an attempt to explain the stresses that accompanied hospitalization. In an effort to better examine and understand the concept, she developed the Uncertainty in Illness Scale (Mishel, 1998). While the theory was initially developed as a construct, the model and instrument have since been the guiding force in numerous studies looking at cancer, cardiac diseases, and childhood illnesses (Kang, Daly & Kim, 2004; Mishel & Braden, 1998; Stewart & Mishel, 2000; Yu Ko & Degner, 2008). The theory of uncertainty has not been used to explore the experience of patients who have received an organ transplant. There is a need for nursing research to explore uncertainty associated with organ transplant to better understand the experience these patients endure and design supportive interventions.

Mishel reconceptualized the theory in 1990 to include chronic illness, along with the idea that uncertainty may not resolve but instead become a part of the individual's reality (Yu Ko & Degner, 2008). Mishel (1990) concludes the illness experience may cause uncertainty and be seen as a source of disequilibrium. This forces the individual to move from a state of equilibrium to a new and possibly more complex view of life with uncertainty being a part of life.

The earlier work of the theory based uncertainty upon three variables: stimuli frame, structure providers, and cognitive capacity (Mishel and Braden, 1998). The stimuli frame is described as the pattern of symptoms, event familiarity, and event congruency (McEwen & Wills, 2007). Structure providers are the tools that patients use to reduce uncertainty, such as social support, education, or credible authorities (e.g., APNP). Cognitive capacity is the third antecedent to uncertainty and is the information

processing capability (Wallace, 2005). The cognitive capacity allows the person to make sense of the situation and recognize uncertainty.

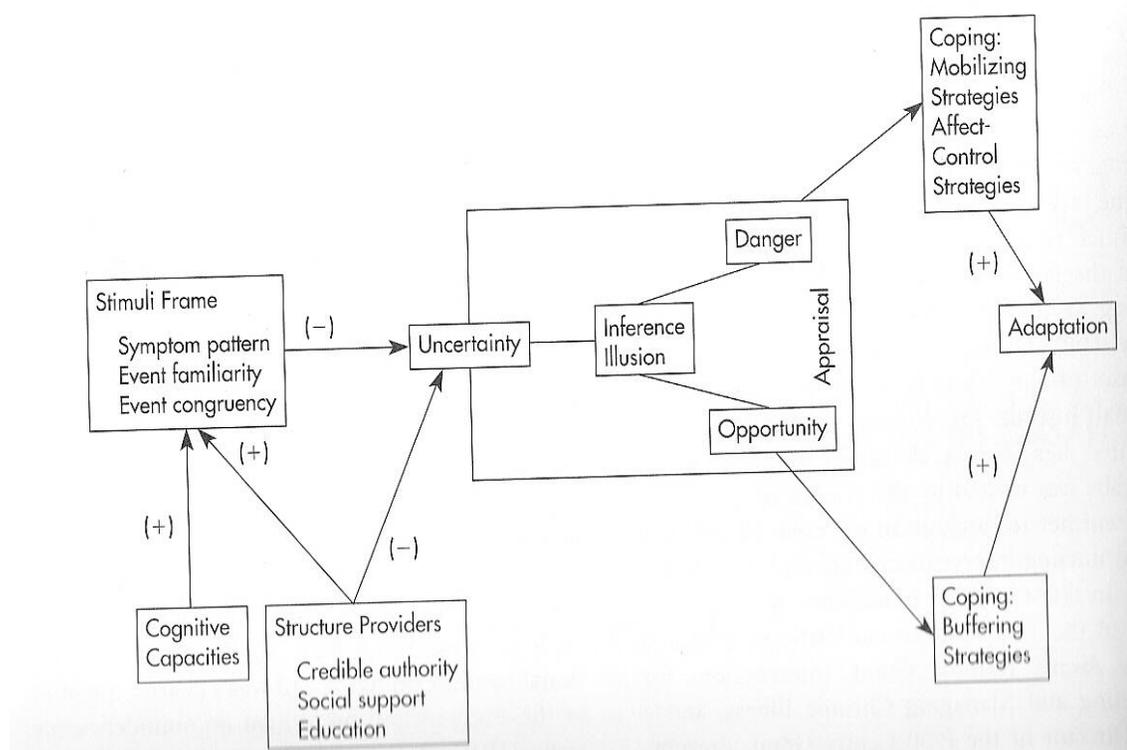


Figure 1. Model of Perceived Uncertainty in Illness (Mishel, 1988).

Several of the major assumptions of the theory include uncertainty as a cognitive state and uncertainty as a neutral experience (Mishel, 1988). Another assumption includes the idea that "(A)daptation represents the continuity of an individual's usual biopsychosocial behavior and is the desired outcome of coping efforts to either reduce uncertainty appraised as danger or maintain uncertainty appraised as opportunity"

(Tomey & Alligood, 2002, p. 565). The final assumption described by Tomey and Alligood states, "(T)he relationship between illness events, uncertainty, appraisal, coping, and adaptation are linear and unidirectional, moving from situations promoting uncertainty toward adaptation" (p.565). Mishel later challenged the last two assumptions due to the contradictory nature when applied to chronic illness. At this time, Mishel incorporated the chaos theory to replace linear stress with coping and adaption as the outcome portions of the model (Tomey & Alligood, 2002).

Case Study

Alice, a 38-year-old, married, mother of three, has recently received a heart transplant after years of suffering with dilated cardiomyopathy. Her cardiomyopathy stemmed from a heart attack at age 35 following the birth of her third child. Alice is 2-weeks post transplant and is preparing to be discharged from the hospital.

Wanda, the advanced practice nurse coordinating Alice's care (structure provider-credible authority), directs her care and interventions based on Alice's sources of uncertainty. Alice's sources of uncertainty include lack of information about treatment options and outcomes (event familiarity), unfamiliarity with treatment environment, and expectations for follow-up and immunosuppressive therapy. Another area of looming uncertainty is the thought of possible rejection and the impact of recovery upon her husband and children. Wanda addresses many of Alice's questions about what to expect (event congruence). Wanda also includes Alice's husband (structure provider-social support) in the conversation. Wanda encourages questions be asked to better facilitate understanding of the material. Wanda's support for Alice and her family

continues throughout the recovery process, and Wanda periodically assesses the sources of uncertainty for Alice and her family.

Two years after successful heart transplant, Alice returns for a follow-up appointment. Wanda asks Alice to reflect on her transplant experience. Alice describes the time of cardiomyopathy diagnosis, unsuccessful treatment, and finally transplant as times of enormous uncertainty. She is in awe of how much she has grown emotionally and spiritually. She has come to see this experience as a way of providing new meaning to her life. Alice now directs her energy on the important things in life, such as her husband, children, and friends. She now views each day as a gift.

Literature Review

The experience of receiving an organ transplant is a life changing experience. This section will explore what is in the literature regarding the psychological and functional impact, as well as adherence to an exhaustive medical regimen post transplant.

Psychological Impact

Attention to psychological well-being is an important area of concern after an organ transplant. These patients are challenged to cope with the loss of their own organ, as well as the acceptance of a donor organ. Another part of coping involves mourning the death of the donor. Kuhn et al. (1990) researched the psychiatric distress associated with heart transplant and concluded that psychiatric distress is typical during all stages of the heart transplant process.

Kaba et al. (2005) completed a study exploring the psychological problems experienced by heart transplant recipients using a qualitative, grounded theory

approach. This study revealed some of the psychological problems that may be experienced because of the constant concern about the donor's heart, guilt about the donor's death, and feelings of gratitude towards the donor's family. The findings from this study revealed four categories: (a) traumatic experience, (b) that's a small price to pay for being alive, (c) somebody else's heart inside me, and coping" (Kaba et al., p. 617).

In another qualitative study, Kaba et al. (2000) explored the coping strategies of heart transplant recipients. This study was done in an effort to assist cardiac nurses to aid in helping these patients. During the interviews, eight categories were revealed. A few of the themes revealed in this study include, acceptance/optimism, denial, and seeking social support. Kaba concluded the importance of understanding coping mechanisms and the effect such an understanding will have on the patient's recovery.

Goetzmann et al. (2008) investigated patients before heart, lung, liver, kidney, or bone marrow transplant and again at 6, 12, and 24 months to determine whether transplant patients fall into different groups of good or poor psychosocial outcomes. The results yielded two clusters of transplant patients. One cluster showed good psychosocial outcome, with improvement over a period of 2 years. The other group of patients reported a limited or poor outcome deteriorating after transplant. Overall, the results vary from patient to patient, with many recipients requiring psychosocial support.

Buldukoglu et al. (2005) carried out a phenomenological study to evaluate kidney transplant recipients' perceptions of their transplanted kidneys. Many themes evolved, indicating that in addition to the physiological care of the kidney patients, there is also a need for psychological care. Success of a kidney transplant not only is dependent upon the physical care, but the emotional support is equally important.

Evangelista, Doering, and Dracup (2003) explored the perceptions and meanings associated with end-stage heart failure and transplant surgery in women. The findings revealed an expression of fear and lack of control, as well as optimistic acceptance and a sense of self-fulfillment. Overall, a sense of meaning and purpose were strong motivating factors, as well as coping mechanisms, throughout the recovery process.

Adherence to Medication Regimen

The most favorable outcomes after any organ transplant can only be achieved if the patients are adhering to the medical regimen. This therapeutic regimen consists of taking immunosuppressive medication and monitoring for complications. Adherence also includes avoidance of illegal drugs or alcohol and attending checkups (DeGeest et al., (2005).

Sabate (2003), from the World Health Organization, summarized determinates of nonadherence into five categories: (a) socioeconomic-related factors; (b) healthcare systems/healthcare team-related factors; (c) therapy-related factors; (d) condition-related factors, and (e) patient-related factors.

Adherence or non-adherence to the therapeutic regimen is also being linked to the financial implications associated with these medications. Sisson, Tripp, Paris, Cooper, and Zuhdi (1994) looked at the link between nonadherence with the medication regimen and the financial implications. The average cost for these drugs in 1994 was \$1,000 per month. The findings revealed, most of the patients were able to purchase the necessary immunosuppressant drugs. Three of the 100 patients were non-adherent to the immunosuppressive regimen. Approximately 25% of the participants were non-

adherent to the other medications they deemed less essential, which was invariably linked to the financial restrictions of the medication cost.

Drent, Moons, De Geest, Kleibeuker, and Haagsma (2008) studied the relationship between symptom experience and medication non-compliance after liver transplant. Using a cross-sectional study, results showed that increased hair growth was the most common symptom experience in both sexes. However, symptom distress was more serious in women than men. The most distressing symptom reported by men was impotence, while women reported excessive and/or painful menstrual periods. Overall, there was no relationship between symptom experience and immunosuppressive non-compliance.

Orr, Orr, Willis, Holmes, and Britton (2007) used a qualitative approach to analyze patient perceptions of factors influencing adherence to medication following kidney transplant. Some of the themes that emerged from the study were: fear of kidney failure, loyalty to the renal team and donors, health beliefs, and forgetting. Participants stated some of the reasons for adherence were based upon avoidance of kidney failure, gratitude to the donor, and renal team. The study revealed non-adherence was largely due to forgetfulness.

DeGeest et al. (2005) reviewed current literature, looking at the prevalence, correlation, and consequences of nonadherence to the therapeutic regimen in heart, lung, and heart-lung transplantation. In an effort to effectively review the literature, the authors divided the research into determinates/correlates of nonadherence and the adherence-enhancing interventions. They found many studies have looked at the correlates of medication nonadherence, but few studies have looked at the determinants of smoking and diet nonadherence. Although it is well known that nonadherence is

linked to poor clinical outcome, the authors found scarce literature focusing on the preventative or adherence-enhancing interventions.

Functional Impact

Although heart transplant increases the survival for patients, they may still experience problems after transplant that affects their functional status. Jalowiec, Grady, and White-Williams (2007) compared the functional status of HT patients before transplantation and 1 year after to identify functional problems and variables that predicted worse function 1-year post-op. Using the Sickness Impact Profile, scores improved significantly from pre-transplant to post-transplant. Functional problems were still reported in areas such as work, eating, social interaction, recreation, and home management. Predictors of decreased functional status identified included increased stressors, neurologic problems, depression, female gender, and older age (Jalowiec et al., 2007).

Grady et al. (2005) conducted a study of 311 patients 5 to 6 years post transplant in an effort to describe the physical functional disability, identify differences in physical disability by demographic and other variables, and identify predictors of functional disability. The authors found the level of physical functional disability was low, with women experiencing more functional disability than men. They also found patients with comorbidities, such as diabetes and orthopedic problems, experienced more functional disability than those without comorbidities. The variance in disability was clarified by activities of daily living, symptoms, co morbidities, and psychological status.

Chapter Summary

Mishel's Uncertainty in Illness Theory (1988, 1990) served as the theoretical framework for this study. The earlier work of the theory is based upon three variables: stimuli frame, structure providers, and cognitive capacity. This model provides explanation to how patients process illness-related events and what those events mean to the person.

The review of literature looked at research concerning issues and themes related to receiving a solid organ transplant. Quality of life post-transplant, looking specifically at the functional and psychological status and adherence to the medical regimen, has been studied extensively. Further qualitative data is needed to better understand the lived experience of receiving a solid organ transplant. This data will assist the provider in understanding the phenomenon to provide holistic care.

CHAPTER III

METHODOLOGY

The purpose of this study was to explore the experience of those individuals who have received an organ transplant and the uncertainty associated with this experience. This chapter will discuss the research design including the population, sample, setting, data collection, analysis and limitations. Protection of the participants will also be addressed.

Research Design

A descriptive phenomenological approach was utilized for the purpose of exploring and describing the experience of receiving an organ transplant and the uncertainty associated with this experience. According to Speziale and Carpenter (2007), the goal of phenomenology is to describe a lived experience. This type of design was chosen because the human experience is a significant factor when caring for patients. There is a lack of knowledge regarding the experience of those who have undergone an organ transplant and the uncertainties associated with this experience.

Descriptive phenomenology involves the three steps of intuiting, analyzing, and describing (Speziale & Carpenter, 2007). Although described separately, all three steps are often occurring succinctly. The first step of intuiting requires the researcher to become immersed within the phenomenon of study. In this case, the researcher became immersed within the study of the organ transplant experience. The researcher became a tool for data collection, while listening intently to the descriptions of organ transplant from the individual. The second step of analyzing is when themes or

essences begin to emerge from the data. The final descriptive phase is when the researchers understand and attempt to define the phenomenon (Speziale & Carpenter, 2007).

Population, Sample, and Setting

The target population was defined as adults who have received an organ transplant and reside in the Midwest. A purposive sample of 10 individuals was selected. Criteria for selection included the following:

1. At least 18 years of age
2. Received a solid organ transplant (heart, lung, liver, kidney, or pancreas)
3. Able to read, write, speak, and understand English
4. Voluntary participation in the study
5. Agreement to be interviewed and audio-taped
6. Physically capable of tolerating a 45-minute to 1-hour interview session

The setting for the interviews either took place in the participant's home or a neutral environment agreed upon by the participant and researcher. Each participant was contacted by the researcher for scheduling of an interview time.

A purposive sample was used consisting, of individuals who have received an organ transplant. Many of the participants were gained through snowballing. The snowball technique uses one informant to find another (Speziale & Carpenter, 2007). The typical and atypical experience of organ transplant enriched the concept being studied. Morse (1989) identifies a good informant as one that is knowledgeable about the topic and is able to reflect and provide detailed data of the experience under study.

Data Collection Instrument

The researcher was the instrument for data collection and strived to ensure credibility, dependability, and overall trustworthiness of the data. After approval from the University of Wisconsin Oshkosh Human Subjects Committee (Appendix A), eligible participants located in the Midwest were contacted by the researcher, provided information about the study, and invited to participate in the study. They were informed of confidentiality, the right to withdraw from the study at any time, audio-taping and transcribing of the interview, data treatment, and telephone follow-up. The participants were also informed of the need to complete a brief demographic survey. Arrangement of individual interview time was negotiated between the researcher and each participant.

Data collection strategies to ensure credibility and dependability consisted of a brief demographic survey and interviews lasting 45 minutes to 1 hour. Unstructured, face-to-face interviews, with the use of open-ended questions, were utilized. All subjects were asked the questions, "Would you please tell me about your experience with receiving your organ transplant?" and "Describe the uncertainty you have experienced with the organ transplant?" Subjects were allowed to talk about their experience in an uninterrupted fashion.

The demographic information included information about the participant's age, race, education level, gender, marital status, range of income, and work history, including current status and previous occupation. A copy of this can be found in Appendix B.

Audio-recording of the interview was performed. In order to ensure confirmability, field notes were kept, with notations made immediately following the interview. These field notes were used to assist in obtaining the main themes or issues

that dominated the interview. These notes also included consideration of additional follow-up questions, and any observations, impressions, or other comments. The audio-tapes were then transcribed verbatim by a professional transcriptionist. The transcribed interviews were transferred to an external flash drive. One hard copy was made and secured in a locked storage box with the interview tapes and external flash drive.

In an effort to maintain trustworthiness and rigor of the study, the researcher attempted to bracket prior knowledge or biases prior and during the interview and throughout data collection and analysis. If the elements were unclear or misinterpreted, the researcher was then able to return to the analysis and revise the description. An audit trail was utilized to show the connectedness of the raw data to the interpreted meanings and themes.

Protection of Human Subjects

Following permission from the Human Subjects Committee of the University of Wisconsin Oshkosh, the data collection process began. Participants received a written and verbal explanation of the study, the purpose, and anticipated risks, which were expected to be minimal or none. A written consent was also obtained (Appendix C). The researcher's contact information was provided to the participant if they had any additional questions about the study.

Data Analysis Procedures

Giorgi's (1985) phenomenological approach to methodological interpretation was utilized for this study. Giorgi bases many of his works and methods from the French Existential Phenomenological Merleau Ponty's four principal characteristics: description, use of reduction, search for essence, and focus on intentionality (Giorgi).

Prior to following the steps of Giorgi's (1985) analysis, the researcher reads and rereads the transcripts to have a sense of the whole experience. From there, the researcher divides the content into meaning units. These units are divided based upon different terms, aspects, or attitudes expressed by the participants. The next step involves the transformation of the meaning units adding psychological insight. Giorgi states, "The intent of this method is to arrive at a general category by going through concrete expressions and not by abstraction or normalization which is selective according to criteria accepted" (p. 17). The final step involves synthesizing the units into statements about the experience and describing what the units have in common (Giorgi).

Limitations to the Study

1. Limited generalizability due to the small sample size.
2. Another possible limitation is that of researcher bias. According to Speziale and Carpenter (2007), bracketing (putting aside), personal thoughts, feelings, and perceptions occurs before the beginning of the study and are repeated throughout data collection and analysis. The researcher will keep a diary of personal thoughts and feelings to explicate personal bias.

Chapter Summary

In this study, a phenomenological approach was used to describe the lived experience of receiving a solid organ transplant and the uncertainty associated with this experience. This chapter discussed the population, sample, data collection, and analysis procedures of the study. A purposive sample of 10 participants was solicited to

participate in the study. Audio-taped, face-to-face interviews were conducted. The information from the interview was then transcribed verbatim by a professional transcriptionist. Additional field notes were made following the interviews. Data were analyzed according to Giorgi's (1985) methodological interpretation.

CHAPTER IV

RESULTS AND DISCUSSION

The purpose of this study was to explore and describe the experience of persons who have received a solid organ transplant and the uncertainty associated with this experience. Further examination of the solid organ transplant experience was performed to better understand the phenomenon of uncertainty and its impact upon the individual.

The results of the research study are presented and discussed in this chapter. Ten participants were interviewed, and the interviews were transcribed verbatim. Data were then examined for themes and meanings that led to a description of experience of receiving a solid organ transplant and the uncertainties associated with this experience. At the beginning of each interview, all subjects were asked the same open-ended questions: Please describe the experience of receiving an organ transplant. Participants were also asked: Please describe the uncertainties associated with this experience. All participants were asked at the end of the interview: What would be your recommendations to healthcare providers who are providing care to organ transplant recipients?

Demographic Data

Participants for the study were obtained through personal contacts and subsequent snowballing. Twelve eligible participants were contacted. Two of the participants were not interested in participating in the study. Ten participants were involved in the study. Eight participants were female, and two participants were male.

Ages ranged from 31 years to 70 years, with a mean age of 46.7 years. All participants were White. Two participants received heart transplants, and one participant received a lung transplant. Three of the participants received liver transplants, while three of the participants received kidney transplants. One of the participants received a kidney and pancreas transplant. Three of the participants were college educated; one is currently a college student, while the other six were high school educated. One of the participants is widowed, one is divorced, and the remaining eight participants are married.

Occupations of the participants included: self-employed business owner, secretary, dentist, certified nurses assistant, social worker, factory worker, and a student. Only six of the participants listed an income range. Three of the participants listed an income level greater than \$50,000 per year. Two of the participants listed an income of \$40,001 to \$50,000 per year. One participant listed an income between \$30,001 and \$40,000 per year. Another participant listed an income of \$10,001 to \$20,000 per year.

The Interview Process

The researcher telephoned each participant to discuss and ascertain interest in the study. With the initial telephone call or a through a subsequent telephone call to verify continued interest in the study, an interview was arranged with mutual agreement of location and time. Interviews lasted 45 minutes to 1 hour and were either performed in the participant's home or in a location mutually agreed upon by both the researcher and participant.

All interviews were audio-taped and transcribed verbatim by a professional transcriptionist. Participants were offered supportive comments and encouraged to contact the researcher if they desired additional support or information or elected to

decline further involvement in the study. Field notes were taken during and after the interview that included non-verbal behaviors and additional statements made by subjects after the interview were completed.

Results and Discussion

Data were collected through the use of a non-structured interview process. The responses were audio-taped and then transcribed verbatim. Data was analyzed using Giorgi's (1985) method of data analysis. Participants' descriptions of their experiences were reviewed thoroughly multiple times to obtain a sense of the data. The researcher attempted to bracket feelings, perceptions, and potential biases while analyzing the data. Significant statements and phrases were identified throughout the transcripts through highlighting and note taking.

Some common themes were revealed in the discussions by the participants. Three themes and nine subthemes were identified. Each will be discussed with direct quotes and narratives to depict the theme. These themes and subthemes were:

1. The Experience
 - a. Transplant Process
 - b. Transformation
 - c. Finding Comfort
 - d. Gratitude
2. Uncertainties
 - a. What if?
 - b. Betrayal
 - c. Medications

3. Advice for Providers
 - a. Listen
 - b. An Army of One

Theme 1: The Experience

Each participant was asked to describe their experience of receiving an organ transplant. Four subthemes identified were transplant process, transformation, finding comfort, and gratitude. The feelings and experience from pre-transplant to post-transplant had a dramatic variance. The transformation from being an incredibly sick individual to a healthy person, physically and emotionally, is a theme several participants discussed. Finding comfort through faith and family support was mentioned by virtually every participant. Whether the participants met their donor families or had the opportunity to say thank you, all participants discussed their gratitude for the donor and the donor's family in some way.

Transplant Process

The process of knowing one's organ has failed to actual transplant is an incredible journey. The journey does not end there. Several of the participants received a kidney transplant after being on dialysis for months or years prior to their transplant. These participants discussed how their lives were affected living on dialysis. Some talked about the lack of quality of life and how they viewed this experience as scary. Participant one stated,

I was on dialysis for 8 months, and they tell you -- we can call you anytime. So I would just go about my business and everything. Not really waiting for the call. You can't wait for it. And then they called me and said -- you have to be here within 12 hours. So, I mean, you feel panicked, you know. You have to call my

parents, and they drove me to Milwaukee and everything. It's scary because you have major surgery, you know.

Participant 3 had a similar view, stating, "Living on dialysis is no way to live. There is no quality of life receiving dialysis. Three days a week for 4 ½ years."

Participant 8 received a heart transplant and talks about her frustration while waiting.

It was, at times it wasn't so bad because you knew there may be an end in sight, and at times it was frustrating because you had to wait so long. I was actually in-patient waiting for 4 months before I received my transplant. It was frustrating because I saw patients go before me. I saw patients who passed away while they were waiting.

Similarly, Participant 9 was on a biventricular device that pumped blood through her body while waiting for her heart transplant. She describes this experience as scary and discusses her fears by saying,

I didn't ask questions. I didn't ask questions, and they didn't tell me. And you don't want to tell a sick person how dangerous the equipment is. I didn't find that out until afterwards. So, I didn't ask. I was very scared, and I don't know, personally when I get scared, I concentrate on staying alive in that condition.

Many of the participants felt as though they were given a second chance at life through the transplant. Participant 9 stated,

I would say within a week or two, I had my heart, and it was wonderful, absolutely wonderful, because I went from sleeping, I had to be propped up on a pillow, pillows because these huge tubes were stuck in my stomach. I couldn't lay on my back, my side, or my stomach or anything. I just remember waking up and

the anesthesiologist looked at me and said -- congratulations, you have a new heart.

Participant 2 had similar feelings and states, "It was a positive experience. I would do it again. I appreciate the opportunity I have been given." Participant 5 states, "I am now grateful for everyday that I am given." Participant 10 states,

I've had to grow up a lot faster (was a senior in high school when I was diagnosed with Leukemia). I see the world very differently. Both positive and negative experiences throughout treatments. I have come to a conclusion of what being thankful really means. Experienced a scope of living and dying...many times over. Realized what it means to fight for my life – a battle I'm still winning!

Transformation

With an organ transplant, the effects are both physical and emotional. There is a physical and emotional transformation that takes place. Participant 9 describes the physical transformation that takes place by stating, "I was half dead to normal. Totally healthy. A dead body to a healthy body." With the transformation of the physical body also comes a transformation of the psyche and a person's value system. Participant 4 describes the emotional transformation and states,

Changes the way you look at life, the way you see other people. Not that you were bad before hand, but I think anytime any person goes through, it doesn't have to be a transplant, any time a person goes through an illness, it changes your life. When you come out of it on the other end, you value things so different than ... just the way your life changes.

Participant 4 goes on to give an example of how her life has been transformed. Prior to her transplant, she used to laugh seeing pink flamingoes in people's yards, wondering why a person would put such a thing in their yard for everyone to see. After her transplant, some friends came to visit and brought her a gift of pink flamingoes as a joke, knowing her distaste for such décor. After her friends had left, she started to think about the pink flamingoes and was ashamed of herself for judging those people because those are the things that brought the owners joy. She states, "Anytime you can bring joy to somebody and make them smile, that's the most important thing in the world."

Finding Comfort

With any chronic illness or traumatic experience, a person must find some comfort within the circumstance at hand. Virtually all participants found comfort through their support systems or by their faith. Participant 5 supports this theme by saying, "Your life is your attitude. Your family is what it is all about." Her circumstances also brought her family a new found closeness, during and after her transplant process. All participants agreed they would not have been able to make it through their circumstances had it not been for their family. Participant 1 talks about her family and states,

They have been the best ever, because we've been dealing with this for so long, and my mom still takes me to my doctors, because I think, she wants to know what goes on and everything, too. It's just been pretty much a lifelong thing, and it's just accepted. I'm not, they don't look at me, like-oh, be careful with her, she's had a kidney transplant or anything like that.

Three of the participants had a strong faith in God, which helped them get through the transplant process. Participant 9 had an amazing story where she

remembers seeing angels surrounding her bed. She distinctly remembers there being hundreds of angels beside her bed and amidst the angels, there was a “head” angel that would direct the other angels. When this “head” angel would speak, the other angels would run very fast to do what the “head” angel told them to do. She remembers one angel holding her hand while another was wiping her forehead. Participant 9 goes on to say,

You know you're very sick. You don't ask questions because you're so scared. So you rely on Him. You ask Him to get you through, to help you through this ... and that's what I did. He helped me, and I concentrated on Him and I leaned on Him. He was with me the whole while ... the whole while I was at that place.

It is also important to note that Participant 9 lost her eyesight through some complications after her transplant. However, her faith is her foundation. She goes on to say,

I think I had to go through the hard part of life first, with my eyesight, and go through the angry stage and all that, all that junk, before I could come back to Christ ... in that place again, and I'm in that place again. Yeah, it's just, I don't know, that's how it goes, but without Him, I wouldn't have been here.

Although Participant 10 did not mention her faith, she had other ways of coping with the uncertainties associated with her transplant experience.

I love to dream. I have been called a “dreamer” in a condescending way. To me, I don't know how much time I have with my new lungs so I like to create a goal and work my way to reach it. I have always wanted to start a business ... and I did that (and still have it). I always wanted to go to college ... and I am doing that! I've wanted to see the ocean ... and I did that! I think of positive images,

healing images, happy images when someone or something has got me down. Music helps me get out of a negative frame of mind. I use aromatherapy, music/ambience, and stretching/massage for coping mechanisms. I also like to be crafty and artsy which helps in coping too.

Gratitude

Every participant in the study mentioned their gratitude for the gift they have been given. Some of the participants received their new organ from a cadaver and others from a family member or close friend. Regardless of the circumstances, all were gracious for this gift. Participant 3 received her kidney from her sister's best friend and raised the question, "How do you ever thank that person?" Participant 8 received her new heart from a young man who died from a gunshot wound. She talks about her experience meeting the donor family.

I was very nervous. It was ... Because you are meeting with total strangers that you've only communicated, at first, by letter, and it took me ... months to write that letter. How do you go about thanking somebody ... letting you live when they've lost ... a child. It was just, it was wonderful, and the fact that she welcomed me into her home with open arms and shared his story, and showed us pictures ... it's something that we'll never forget.

Participant 8 also went on to discuss how she has connected in a sense to her donor. For example, prior to her transplant, she did not like yogurt. One evening when she and her husband went to the grocery store, she found herself going directly to the dairy section and putting yogurt into their cart. Her husband questioned why she was buying yogurt when she had never liked it in the past. She later learned how much her donor loved yogurt. She also experienced a horrible nightmare one night. She dreamed

she was being chased and trying to run away from someone. This dream caused her to wake from a sound sleep, leaving her extremely frightened. After speaking with a nurse who was involved with the donation process and knew of the circumstances surrounding her donor's death, she told Participant 8 the story of how her donor had died. This participant felt it was the donor's way of telling her the story of his death and how it came to be.

Participant 4 also received her transplanted organ from a cadaver. Here is what she had to say about her gratitude:

(H)is family had difficulty making the decision to donate, and they had requested that we not be in contact, that's fine with me. It's all about the donor and their family, as far as I'm concerned ... say to me – do you know anything about the donor? And I tell them this; I know the most important things about my donor. And they go – what is that? And I'll say – I know that he was generous and that I know that he came from a loving family, don't need to know anything more than that.

Although Participant 1 has not written to her donor family, she thinks of it constantly, but is unable to find the words to adequately say thank you. When asked if she had had the opportunity to meet or contact the donor family, she responded by saying

No, I didn't and of course, you always have the option of writing them, and I always, all the time, it's been since 2002 and I always think about -- I should write them -- and I was going to do it right away, but, and I probably will someday still, but I just can't find words. I just really can't find the words, you know.

Theme 2: Uncertainties

With this incredible process come many uncertainties. The data revealed four subthemes under uncertainty which include: (a) What if? (b) betrayal, and (c) medications. The constant thoughts of rejection and illness are always looming overhead with the participants. Trusting one's body again after it became ill left a sense of betrayal with one of the participants. Although it was only one participant who verbalized this sense of betrayal, it was a significant statement. The current medication regimen can be costly, which is an incredible uncertainty in this unstable economy.

What if?

The question of "what if?" came up numerous times throughout the data collection. Participant 4 states, "It's wonderful, but there will always be that little nagging – what if this happens again? What if something goes wrong?"

For many of the participants any illness causes them to stop and ask the looming question of "what if?" A fever is not just a fever, and a cough is not just a cough for these people. Whenever a transplant recipient has these types of symptoms, the question of rejection is always looming around the corner. Participant four states,

Part of it is because of the immunosuppressive drugs, is that if you got just the flu; you know you'd be able to deal with it. It's that you're on these stupid drugs that are suppressing your immune system, so you don't have the ability for fight 'just the flu' and it can turn into something else. And that's what's so, that's what's so nerve-wracking

Participant 3 also tries not to think about the "what if's." She states she is not that type of person anymore. However, she does support the statement made by Participant 4. "Getting the flu isn't just the flu. Rejection symptoms are similar. You are

always wondering in the back of your mind ... am I rejecting the organ?" Participant 5 states, "There are so many other good things, I just don't let myself go there."

Participant 1 has children, which adds another dimension to the question of, "what if?" "Maybe like once in a great, great while I think, like I said with my kids – what if something would happen. I think more about them, you know. And it is depressing if you have to think about it, so I try not to."

Participant 8 also has these same concerns, as she describes her uncertainty prior to receiving her transplant. She constantly wondered when and if she was going to get her new heart. Along with the transplant came a whole new set of worries and fears.

Afterwards, you feel good, and now in the back of your mind, you're always thinking about – I'm running a little fever, am I getting sick, am I having rejection, you know, is it giving out? Or when the doctors do tests, because you're not quite sure what's going on, what's happening, unable to answer some of those questions.

Betrayal

There is also a sense of betrayal involved with the uncertainties of receiving a transplant. When interviewing Participant 4, she made a profound statement about learning to trust one's body again after an organ fails.

I think the greatest uncertainty is trust in yourself. I think it could be with any illness, also. It's that when you're healthy and you live for, maybe, 45 years with relatively few problems, and you don't ever think you really don't think very much about your body and how it's functioning and what's going on. And then, I was told I had a genetic liver disease called Primary Biliary Cirrhosis. Nothing that I could do to get it, stop, change it, period. You feel as if your body has betrayed

you. And I always tell people, it's kind of like this, is that if you think your body as your best friend and one day your best friend betrays you, you can be friends with that person again, but you never trust it completely.

Medications

The immunosuppressive medication regimen these participants have to take after transplant is exhaustive and causes an enormous amount of uncertainty. The uncertainties associated with the medication regimen revealed in this study include compliance, side effects, and cost. Participant 1 was quite young when she had her first kidney transplant. The stressors of being a teenager, compounded with other family issues, factored into her noncompliance.

I think one thing I'd like to add is people, like with transplants, they need to make sure they take their medicine everyday. Because I, when, before my second transplant, like my parents got a divorce, and a bunch of things were going on, and I just started to not care anymore, and so I didn't take my medicine for the longest time, and that, probably, was a huge reason why, you know. Even though, it was 14 years after, but still. That's one thing I totally regret is I shouldn't have gotten caught up in – poor me. I should've taken my medicine every single day. That was just a mess.

The cost of medication for these participants is another enormous factor when dealing with the medication regimen. The current economic climate just compounds this issue. Several of the participants had excellent insurance, several were eligible for Medicare and Medicaid, and one was enrolled in the renal program, which assisted in funding the medications and necessary testing. Participant 5 states,

Even with my husband's insurance, I mean, it's a lot of money monthly to get your blood drawn, get your meds, and everything else, and it's for the rest of your life, or until something else happens that we won't even talk about right now.

The side effects of the medications can also be reason for noncompliance.

Participant 6 states, "One time I was given new medication that was new on the market. The doctors were so excited about it. I ended up starting to reject the organ because of that medicine." Participant 7 also reiterates this issue.

The other thing is with medications, there're medications. It can lead to other complications, you know. The immunosuppressives can cause kidney damage; you know ... blood pressure medications ... all the side effects from those medications. Constantly going through someone's mind because you're taking one drug. Something that has to do with something else.

The side effects also had a tremendous effect on many of the participants. Participant 5 states,

Think the medicine the first time; I got all the things that a woman would hate to get. I got the hair growth, I got, I really had a really big change of weight from the lower to the upper part of your body. I had a big hump on the back of my neck for the first time.

Theme 3: Advice for Providers

The final question asked of the participants is what advice they would have for providers when dealing with patients who have received an organ transplant. The answers varied slightly, but an overall theme from many of the participants was to simply listen to the patient. Other participants felt alone in the transplant. This loneliness and lack of support left them feeling as though they were an army of one. Following a strict

diet and medication regimen is often difficult. Some of the participants wished their providers were more understanding with these lifestyle changes.

Listen

The subtheme of simply listening was reiterated by Participants 1, 2, 3, 5, 8 and 10. Participant 3 states,

Listen to the patient! We know more than they think we do. For example, I was just in the emergency department thinking I had the flu. I asked for my lab values results ... BUN, creatinine, AST, GGT, that stuff. That doctor, PA, or whatever he was, said we normally don't do that. He wasn't even going to draw those labs first of all, and then wasn't going to give me the results. As a transplant patient, I have to stay on top of my lab values.

Participant 8 also shared this same thought.

I mean, there's good things and there's bad things, because you as the person going in there have to watch your back and you have to ask questions. But, me as a person going in there, I haven't been to medical school, I don't knowAnd I just ... the doctors, they knew what they're doing, don't second guess them. Son, anything they could do? What are they; they're not going to listen to me. So, I don't have anything to say, you know.

Participant 10 states, "If I ask you to come in my room late at night, after my family has left, I would just like you to sit and listen to whatever it is I have to say. Help out if you can otherwise just listen. No advice."

An Army of One

Although there are now incredible resources available to the participants, many of the participants felt alone in this process. Participant four states,

But my experience with post-transplant patients, and I've talked to a lot of them, is that they're just so anxious, kind of like I was just talking, because, you know, you're just not sure of what's going to happen next. And it's not like somebody had their tonsils out, and you know 20,000 people who have had tonsils out. You know, it's hard to find other people that have gone through the same experience. So, you don't know who to talk to. And unless they're really brave and you get them going and they call the transplant center and they talk to their, and they talk to their transplant counselor about it, then they really do feel alone.

Participant 2 also talks about being an army of one and feeling alone in the process. Her advice to healthcare providers is this:

Be aware that it is very hard to be an army of one in your own household. The dialysis diet and even a kidney transplant diet are not easily followed. It's to give you more, to give support and find ways that we can stay on that. I think the idea of, and I realize that nobody can know everything, but be available to help them find the answers to questions they need. You know, there are a few things that I'm sure nurses, nurse practitioners, doctors, whatever, can find places to go and get answers, you know, much easier than lay people can.

Discussion of Results Relative to the Literature Review

The first theme identified in this study was the overall experience. The subthemes that were recognized included the transplant process, the transformation, and gratitude. Overall, there has been little research looking at experience of receiving an organ transplant and how it affects a recipient's life. Past studies have looked at the improvements in emotional functioning from the waiting list period to actual transplant

(Jones, Taylor, Downs, & Spratt, 1992; Mai, McKenzie, & Kostuk, 1990). There have also been studies that look at the functional outcomes after transplant (Reyes, et al., 2003). To date, there has been little research that has addressed how recipients perceive their transplant experiences, along with the uncertainties with this experience.

The actual transplant is not just a single event, but a process that will continue for the rest of the recipient's life (Kaba & Shanley, 1997). This was consistent with the first subtheme of the transplant process. The waiting period for transplant is often met with struggles over the fear of further physical deterioration, fear of dying, and the unpredictable timing of donor availability, which is supported in the literature, as well as throughout the data obtained in this study (Christopherson, 1987).

Several of the participants in the study discussed their quality of life prior to transplant. How the person finds comfort or copes with their quality of life pre-transplant may affect the quality of life post-transplant. The coping capacity and strategies, along with adaptability during the waiting period for a donor, may serve as predictors for quality of life post-transplant (Larsson et al., 1990). Finding comfort was a theme that resonated throughout data collection and analysis. Lindqvist, Carlsson and Sjoden (2004) looked at the coping strategies of patients post renal transplant. The aim of this particular study was to describe and compare different coping strategies in post renal transplant patients. This study found that evasive and fatalistic coping was associated with decreased efficiency in handling various aspects of the transplant experience and the uncertainties associated with this experience.

The subtheme of *Gratitude* identified in this study was also found in a study by Kaba et al. (2005). Kaba's 2005 study explored the psychological problems experienced by heart transplant patients in a qualitative study. This particular study revealed some of

the psychological problems that may be experienced because of the constant concern about the donor's heart, guilt about the donor's death, and feelings of gratitude towards the donor's family. In a similar study, Buldukoglu et al., (2005) studied the emotional attitudes kidney transplant recipients had towards their transplanted kidneys. The three themes that emerged from this study were savior, gratitude, and feelings of intense responsibility.

Uncertainties, the second theme identified in this study was evident in very few of the previous studies. Bjork and Naden (2008) conducted a qualitative study in Norway looking at the patient experiences while waiting for a liver transplant. The uncertainty related to life and death was a major issue in this study.

The subtheme of *Medications* was found throughout the literature. Several factors related to the uncertainties with medications that were revealed in this study were compliance, cost, and side effects. Sisson et al. (1994) looked at the link between nonadherence to the medication regimen and the financial costs. Drent et al., (2008) studied the relationship between symptom experience and medication non-compliance after liver transplant. Orr et al., (2007) used a qualitative approach to analyze patient perceptions of factors influencing adherence to the medication regimen following kidney transplantation.

The third theme of *Advice for Providers* was defined by this study's subthemes of *Listen* and *An Army of One*. Neither theme nor subthemes were found detailed in any other study reviewed.

Chapter Summary

Qualitative interviews conducted with 10 individuals who had received a solid organ transplant yielded three major themes and nine subthemes describing the essence of that experience. Receiving an organ transplant affects many facets of individuals' lives and, in turn, leaves many uncertainties. With review of the literature, some themes identified in this study were comparable to themes identified within other studies. Additionally, several themes identified in this study offered insight into the lived experience of receiving an organ transplant and the uncertainties associated with that experience.

CHAPTER V

SUMMARY, CONCLUSIONS, LIMITATIONS, AND RECOMMENDATIONS

The purpose of this study was to explore and describe the experience of persons who have received a solid organ transplant and the uncertainty associated with this experience. Further examination of the solid organ transplant experience was studied in an attempt to better understand the phenomenon of uncertainty, and its impact upon the individual. In this chapter, relation to the theoretical framework, along with a summary of the experience, will be provided. Limitations of the study will be discussed, and recommendations for nursing practice, education, and research will be made.

Relation to Theoretical Framework

The theoretical framework for this study was based upon Mishel's Uncertainty in Illness Theory (1988, 1990). Whether the illness is acute or chronic, uncertainty is a commonality with any illness experience. The journey of organ transplant is no different. From diagnosis that an organ has failed, followed by unsuccessful attempts to save the organ, and finally transplant, is a journey of considerable uncertainty. Adaptation is the desired end after coping with uncertainty.

Mishel (1990) concludes, the illness experience may cause uncertainty and be seen as a source of disequilibrium. This forces the individual to move from a state of equilibrium to a new and possibly complex view of life with uncertainty being a part of life. This is evidenced throughout the study with the theme of "What if?" Some participants would not allow themselves to think about the uncertainty of "what if?" Participant 5 states, "There are so many other good things, I just don't let myself go

there.” Whether the “what if” was illness, rejection, or medication, this uncertainty is a constant in the participant’s life.

The three variables in the earlier works of Mishel’s theory include stimuli frame, structure providers, and cognitive capacity (Mishel & Braden, 1998). The stimuli frame is the pattern of symptoms, event familiarity, and event congruency. The structure providers are the tools that patients use to reduce uncertainty, such as social support, education, or credible authorities. The cognitive capacity is the information processing capability and allows the person to make sense of the situation and recognize uncertainty.

The stimuli frame in this study was revealed in *Theme 1: The Experience*, but more specifically, in the subthemes of the *Transplant Process* and *Transformation*. The uncertainties in the transplant process are dealing with a failing organ, being put on a transplant list, and not knowing when an organ would become available. Participant 1 and Participant 3 recall their quality of life on dialysis being no way to live. Participant 9 also recalls her experience and uncertainties living on a biventricular device while awaiting her new heart. While waiting on the transplant list, the event congruency was the fight to stay alive. The physical and emotional transformation that occurred were also themes that supported the stimuli frame of the theory.

The structure providers in this study were the things that provided comfort to the participants to help deal with the uncertainties of the transplant process. Finding comfort amidst the chaos of the organ transplant process occurred through the participant’s faith and through familial support. Another structure provider that became evident in the study is that of gratitude. Being able to say thank you to the donor family became a source of comfort for the participants.

The cognitive capacity is what assists the person to make sense of the situation. For many in this study, this was accomplished through coping strategies or with the assistance of the healthcare providers.

Summary

The journey from diagnosis that an organ has failed to transplant is extensive; however, the journey does not end there. The process of receiving an organ transplant is only the beginning of a new journey and time of uncertainty. Close to 30,000 solid organ transplants are performed each year (Scientific Registry of Transplant Patients, n.d.). The United Network for Organ Sharing (n.d.) reports approximately 84,000 patients with end-stage organ disease are on the transplant list awaiting suitable organs to become available, with approximately 3,700 people being added to the list each month.

The screening process for individuals being considered for an organ transplant is quite comprehensive, with the biggest problem being lack of organs available for transplant. Each situation is unique, but the candidates will usually wait for an organ.

After the transplant surgery, the recipient will be monitored closely and have regular blood tests, echocardiograms, electrocardiograms, and biopsies. There are many long-term adjustments that need to be made after transplant, which include the medication regimen. Immunosuppressive therapy is usually taken indefinitely. These medications also have enormous side effects, which also make the body more vulnerable to infections. Adherence to this regimen is a struggle for many transplant recipients (Chisholm, 2002).

The theoretical framework used in this study was based upon Mishel's Uncertainty in Illness Theory (1988, 1990). Mishel initially studied the concept of uncertainty in an attempt to explain the stresses that accompanied hospitalization. In an effort to better examine and understand the concept, Mishel developed the Uncertainty in Illness Scale (Mishel, 1998). The earlier work of the theory based uncertainty upon three variables: stimuli frame, structure providers, and cognitive capacity (Mishel & Braden, 1998).

Review of the literature did not reveal any qualitative studies that provide insight into the experience of individuals who have received a solid organ transplant and the uncertainties associated with that experience. However, there have been numerous studies that have identified issues with quality of life post transplant. These studies have looked specifically at the functional and psychological impact of receiving a transplant, along with the issues of adhering to the medication regimen. Further qualitative data is needed to better understand the phenomenon of receiving a solid organ transplant and the uncertainties associated with this experience. The data will assist the providers in understanding the phenomenon and providing a more holistic approach when caring for patients who have received an organ transplant.

A descriptive phenomenological approach was utilized for this study. It is a method concerned with the discovery and with a purpose to explore, describe, and analyze particular phenomena. Phenomenology was chosen because human experience is significant to healthcare. Also, there is a lack of knowledge relative to the experience of receiving an organ transplant and exploring the uncertainties of this experience. The phenomenological method is well suited to nursing with its focus on the interrelated whole.

A purposeful sample of 10 participants meeting eligibility criteria was selected through personal contacts and snowballing. Audio-taped interviews were conducted asking the participants to respond to open-ended questions: (a) Describe your experience of receiving an organ transplant, (b) Describe the uncertainty associated with this experience, and (c) What advice do you have for healthcare providers?

The interviews were transcribed verbatim. Data were analyzed using Giorgi's (1985) method of data analysis. The questions produced a description of the experience of receiving an organ transplant, as well as descriptions of the uncertainties with this experience. Three major themes and nine subthemes were identified in this study.

The three major themes revealed in this study include *The Experience*, *Uncertainties*, and *Advice for Providers*. The subthemes under *The Experience* consist of *Transplant Process*, *Transformation*, *Finding Comfort*, and *Gratitude*. *What If?*, *Betrayal*, and *Medications* were subthemes that evolved under the theme of *Uncertainties*. Subthemes under *Advice for Providers* include *Listen* and *An Army of One*.

The transplant process is an incredible journey, starting from the time one learns their organ has failed until transplant. This journey continues even after the transplant surgery. Several of the participants lived on dialysis for months and years prior to their kidney transplant. Another participant lived via a biventricular device while awaiting a new heart. Regardless of the process, many of the participants expressed that the transplant process gave them a second chance at life and also expressed an enormous amount of gratitude.

The subtheme of *Transformation* is described as being on the verge of death prior to transplant and then being transformed into to a healthy individual post transplant.

The transformation was not just the physical transformation that takes place. There is also an emotional transformation, as well.

With any chronic illness or traumatic event, finding comfort within the situation or circumstance is an essential aspect to successful healing. Many of the participants of this study found comfort in their faith or through the support of their family.

The overwhelming feeling of gratitude was another subtheme that spoke loudly through data collection and analysis. Whether the participants chose to contact the donor family or not, they were eternally grateful for the gift they were given. Several of the participants described what it was like to meet the donor family and the feelings they had during this meeting. Other participants even described a connection they felt towards their donor.

Under the second theme, *Uncertainties* is the question of *What If?* This question is one that came up numerous times throughout data collection and analysis. The nagging thoughts of rejection, and what if the organ fails again, are reasons for this question. A simple cold to a healthy individual is not so simple to a person who has received an organ transplant. Often the symptoms of a cold are similar to that of rejection.

The subtheme of *Betrayal* includes learning to trust one's body again. One of the participants discussed this betrayal and compared the betrayal of her own body to that of a friend betraying you. When a friend betrays you, it takes time to learn to trust that friend again. The same is true of one's body when it betrays you. It takes time to learn to trust your body again, but that trust is never completely restored.

The medication regimen these participants must take after transplant is exhaustive and thus comprises another subtheme under *Uncertainties*. The

uncertainties associated with medications include the cost, adherence, and the side effects.

The final theme, *Advice for Providers*, included the subthemes of simply *Listening* and *An Army of One*. The subtheme of *Listening* was reiterated by several of the participants. The loneliness and lack of support are issues associated with the subtheme of being an *Army of One*

Conclusions

Findings of the study indicate the magnitude of change and struggle endured by the individuals who have received an organ transplant. The following are some conclusions:

1. The experience of receiving an organ transplant significantly affects the individual.
2. The experience of receiving an organ transplant is a time of tremendous uncertainty.
3. Healthcare professionals may assist the individual who has received an organ transplant by providing validation of their experience, listening, and strengthening the individual's resources.
4. Improved understanding of the experience of receiving an organ transplant and the uncertainties associated with this experience may potentiate optimal management of the medication regimen and quality of life for these individuals.

Limitations

Inexperience and lack of skill of the researcher in data collection and analysis with a phenomenological study may have resulted in errors in data collection and analysis (Speziale & Carpenter, 2007). Limitations may include failure in bracketing or recognizing and disclosing biases and perceptions on the topic prior to the start of the study. Other limitations may have been failure to achieve saturation or a failure to properly analyze the data while preserving the essence of the lived experience.

Implications

Implications for Nursing Practice

The results of this study indicated that healthcare providers are not adequately meeting the emotional needs of these patients. Knowledge of the experience of receiving an organ transplant and exploring the uncertainties that coincide with this phenomenon provide insight into the management needs that could assist in improving the health and quality of life for individuals who have received an organ transplant. This study has added to the knowledge base of nursing science, specifically related to the experience of patients who have received an organ transplant. While some of the findings of this study are similar to other studies that have looked at the organ transplant experience, the uncertainties of this experience add a new dimension to this study.

As the role of the nurse practitioner is expanding, nurse practitioners and other primary care providers will often be seeing these patients in the clinic setting. As medications improve and these patients are living longer, providers will need to have an understanding of what to expect with transplant recipients. Referral to support groups or

putting the transplant recipient in touch with others who have experienced a similar circumstance would fall under the scope of the provider.

Addressing the needs of the transplant patient and family necessitates a balanced holistic approach, recognizing that every individual is influenced by the common triad of body, mind, and spirit. Body, mind, and spiritual concerns are independent variables, which coexist to define the overall state of health of the individual. Illness or healing from any of the components affects the remaining two.

Healthcare providers also need to evaluate their own perceptions and knowledge about the transplant process and uncertainties with this experience. The patient is the expert of his or her own experience, and this must be embraced by the provider. Knowledge and acceptance of each person's experience is essential to developing a comprehensive and individualized plan of care.

Implications for Nursing Education

As the body of knowledge related to the transplant process increases through continued research, nursing education must reflect this knowledge. Consideration of the transplant process and the uncertainties associated with this experience is a multidimensional phenomenon with physiologic, psychological, sociocultural, developmental, and spiritual aspects.

Implications for Nursing Research

This study provides insight into the experience of receiving a solid organ transplant and the uncertainties associated with this experience. Further research could be done in exploration of the themes identified in the meaning of the experience of receiving an organ transplant in order to obtain a more complete understanding.

The transplant process is one that has a strong affect on the individual's support system. Research is also lacking in the area of the experience and uncertainties and it's affect on family members or other support structures. This would support further knowledge and understanding of the dynamics surrounding this experience.

Chapter Summary

In this chapter, the current study was summarized and limitations of the study identified. Based on the study findings, recommendations were made for nursing practice, education, and further research.

APPENDIX A

University of Wisconsin Oshkosh IRB



December 10, 2009

Ms. Tiffany Sasse
116 W. Marquette St.
Berlin, WI 54923

Dear Ms. Sasse:

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Participants (IRB), I am pleased to inform you that your application has been approved for the following research: The Lived Experience of Receiving a Solid Organ Transplant.

Your research has been categorized as NON-EXEMPT, which means it is subject to compliance with federal regulations and University policy regarding the use of human participants as described in the IRB application material. Your protocol is approved for a period of 12 months from the date of this letter. A new application must be submitted to continue this research beyond the period of approval. In addition, you must retain all records relating to this research for at least three years after the project's completion.

Please note that it is the principal investigator's responsibility to promptly report to the IRB Committee any changes in the research project, whether these changes occur prior to undertaking, or during the research. In addition, if harm or discomfort to anyone becomes apparent during the research, the principal investigator must contact the IRB Committee Chairperson. Harm or discomfort includes, but is not limited to, adverse reactions to psychology experiments, biologics, radioisotopes, labeled drugs, or to medical or other devices used. Please contact me if you have any questions (PH# 920/424-7172 or e-mail:rauscher@uwosh.edu).

Sincerely,

A handwritten signature in black ink, appearing to read "Frances Rauscher".

Dr. Frances Rauscher
IRB Chair

cc: Suzanne Marnocha
1700

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APPENDIX B
Demographic Questionnaire

Demographic Questionnaire

1. AGE: _____
2. GENDER: _____ Male _____ Female
3. RACE: _____
4. EDUCATION LEVEL: ___ Grade School ___ High School ___ College
5. MARITAL STATUS: ___ Married ___ Divorced ___ Widowed
 ___ Never Married ___ Partnered
6. INCOME: ___ Less than \$10,000/year
 ___ \$10,001-\$20,000/year

 ___ \$30,001-\$40,000/year

 ___ \$40,001-\$50,000/year

 ___ More than \$50,000/year
7. Describe your work history:
 - a. What is your current work status? _____
 - b. If not working, what was your previous occupation? _____

Thank you for your information and your time.

APPENDIX C
Informed Consent Form

Informed Consent Form
The Experience of Receiving an Organ Transplant

I, Tiffany Sasse, Masters in Nursing Science Candidate at the University of Wisconsin Oshkosh, am conducting a study to examine the experience of receiving a solid organ transplant. Your participation in the study would be appreciated to assist in increased knowledge to improve understanding and management of the multidimensional phenomenon of receiving an organ transplant. .

As part of this study, an audio-taped interview will be conducted concerning your experience of receiving a solid organ transplant. This interview is anticipated to be one to two hours in length. You may additionally be contacted by telephone for follow-up interview questions. The follow-up questions would develop during the course of interviews in the study in which additional or more detailed information is desired in order to clarify, confirm or describe recurrent themes or information. You will also be asked to fill out a demographic questionnaire.

It is strongly anticipated that the study will not present any medical or social risk to you other than the inconvenience of time require completing the interview(s) and any follow-up questions.

The information obtained will not have identifying evidence and will only be accessible by the researcher. It will be stored safely in a locked box. Information will not be released to your physician.

If you want to withdraw from the study at any time, you may do so without penalty.

I realize that I may not participate in this study if I am younger than 18 years of age or I cannot speak English.

Once the study is completed, results will be given to you. If you have questions in the meantime, you may contact:

Tiffany Sasse
116 W. Marquette St.
Berlin, WI 54923
Phone: 920-361-5190 or 920-539-5190
Email: sasset66@uwosh.edu

You may also contact:

Dr. Suzanne Marnocha
University of Wisconsin Oshkosh
College of Nursing
800 Algoma Blvd.
Oshkosh, WI, 54901-8660
Phone: (920) 424-1028 office
Email: marnocha@uwosh.edu

If you have concerns or questions about your treatment as a participant in the study, please call or write:

Chair, Institutional Review Board For Protection of Human Participants
C/O Grants office
UW Oshkosh
Oshkosh, WI 54901
(920)424-3215

Although the chairman may ask for your name, all complaints are kept confidential.

I have received an explanation of the study and agree to participate. I understand the participation in the study is strictly voluntary. I have been informed regarding audio-taping of the interview and follow-up questions and agree to this process.

Name of participant

Date

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