

ABSTRACT

Janet B. Pelletier. APPRAISAL OF UNCERTAINTY WHILE WAITING FOR A KIDNEY TRANSPLANT (Under the direction of Dr. Martha Alligood). College of Nursing, November 2012.

This study tested a middle range nursing theory to better understand the experience of uncertainty in deceased-donor kidney transplant candidates with a goal of identifying ways to improve the care of persons by nurses as they await kidney transplant. From Mishel's Reconceptualized Uncertainty in Illness Theory a middle range theory was developed that proposes that deceased-donor kidney transplant candidates show growth through uncertainty as Mishel describes, waiting time for a transplant is related to the level of uncertainty, and growth through uncertainty is related to both waiting time and level of uncertainty in deceased-donor kidney transplant candidates. A descriptive survey research design was used to address two research questions: Do deceased-donor kidney transplant candidates experience growth through uncertainty as Mishel's Reconceptualized Uncertainty in Illness Theory proposes? What are the relationships among waiting time, level of uncertainty, and growth through uncertainty for deceased-donor kidney transplant candidates?

The study sample was adults who: volunteered to participate, were English speaking and were actively waiting for a deceased-donor kidney transplant. A convenience sample of 134 deceased-donor kidney transplant candidates was recruited through dialysis clinics, an electronic message posted on a National Kidney Foundation message board, and a mailing to deceased-donor transplant candidates registered with a transplant center. A strength of the study was the sample size and the sub-sample of 103 African American persons.

Mishel's Uncertainty in Illness Scale-Community version was used to measure uncertainty and the Growth through Uncertainty Scale quantified growth through uncertainty.

The relationships among waiting time, level of uncertainty and growth through uncertainty were analyzed using Pearson correlation coefficients. The independent-groups t-test was used to compare those waiting above and below the national median time to transplant.

Of the proposed relationships, a significant positive relationship between waiting time and growth through uncertainty was found. The findings provide further description of the uncertainty experienced by transplant candidates who are waiting for a deceased-donor kidney. The present study also supports the concept of growth through uncertainty when sustained uncertainty is present, contributing to the development of Mishel's Reconceptualized Uncertainty in Illness Theory.

APPRAISAL OF UNCERTAINTY WHILE WAITING FOR A KIDNEY TRANSPLANT

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the College of Nursing
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by
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DEDICATION

This dissertation is dedicated to Vincent, who waits, and to Phil, whose wait was too long.

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CHAPTER I: STATEMENT OF THE PROBLEM

Waiting is both a stationary and a dynamic phenomenon (Irvin, 2001), an act that entails being inactive. Although waiting implies anticipation or expectation, the timeframe is often indeterminate and unknown. While all patients may be waiting, the wait for an organ transplant might be considered an extreme form of waiting (Brown, Sorrell, McClaren, & Creswell, 2006). The wait for a transplant may be prolonged and the outcome is unpredictable.

Due to the shortage of organs, there are over 114,000 people awaiting organ transplant (United States Department of Health and Human Services, Health Resources and Services Administration, Organ Procurement and Transplantation Network, 2012) with the average wait for an organ increasing as the demand intensifies. Waiting for a transplant is not an orderly process. There is not a first-come first-served list. Rather, the selection of the candidate for transplant involves consideration of numerous factors besides the availability of an organ. The waiting period can be demanding, stressful, and life threatening, but also means the chance for a better physical, mental, and social quality of life (Franke et al., 2000). Being listed for a transplant brings its own stressors and an uncertain trajectory (McDermott, Hardy, & McCurry, 2010). Transplant candidates are vulnerable to both isolation and depression (Brown et al., 2006). Since the waiting time is indeterminate, the stress experienced by both the patient and family during the waiting period may increase and cannot be eliminated (Irvin, 2001).

With lengthening waiting times for organs and an ever increasing number of people on the waiting list for organ transplants, more understanding of the experience of waiting for a transplant is needed. While there is research examining physiological issues in organ transplant, research on the experience and perceptions of individuals who are waiting for a transplant is lacking. Although, a majority of nurses may not have a direct role in the pre-transplant or transplant process, many nurses have indirect experience with organ transplants. Individuals

awaiting transplant have concomitant health conditions that are usually addressed by nurses in settings other than a transplant center. More understanding of the concerns and needs of this population is needed to help guide nursing interactions with transplant candidates and improve their care.

The pre-transplant period is a liminal time, an uncertain and ambiguous time (Molzahn, Bruce, & Shields, 2008). Brown et al. (2006) describe the pre-transplant time as a paradox. Transplant candidates plan for the future and prepare for death during the unpredictable wait for a transplant. Escalating health problems may hasten a transplant or make a candidate ineligible for transplant. As the waiting time increases, the risk of dying while waiting for a transplant increases (Zhang, Kumar, Ramcharan, & Reisin, 2004). Being sicker creates a greater medical need for a transplant, but may also prevent a transplant from occurring or affect survival following transplant.

Different responses to waiting for a transplant have been observed in previous studies for different pre-transplant waiting times (Brown et al., 2006; Jonsen, Athlin, & Suhr, 2000; Weems & Patterson, 1989). Boredom, frustration and discouragement were noted by liver transplant candidates as waiting time increased (Brown et al., 2006). Changes in coping strategies were needed when the waiting period became longer than anticipated (Weems & Patterson, 1989). Waiting for a transplant allows time to prepare for and focus on the potential positive outcomes of a transplant, however, when the wait is considered too long, waiting may be viewed negatively (Jonsen et al., 2000). In a study of patients awaiting heart transplantation, Evangelista et al. (2005) found quality of life changed over time. Quality of life improved with increasing length of waiting time up until two years. However, if the patients had not undergone transplantation after two years, quality of life declined.

Qualitative studies have identified uncertainty as a key characteristic of the experience of waiting for a transplant (Baker & McWilliam, 2003; Brown et al., 2006; Liddle & Innes, 2005; Weems & Patterson, 1989). Mishel (1990) defines uncertainty as the inability to determine the meaning of illness-related events and/or to accurately predict outcomes due to the lack of sufficient cues. McCormick (2002) proposed that uncertainty is present when one does not know how long it will be until the unpredictability of the situation is resolved. Pervasive uncertainty is present in the pre-transplant period and is a major concern for individuals awaiting transplant (Weems & Patterson, 1989). Interacting with the transplant team, not knowing when or if an organ will become available, and not being able to influence the outcome are sources of uncertainty for transplant candidates.

Uncertainty is a significant source of stress in chronic illness (Anema, Johnson, Zeller, Fogg, & Zetterlund, 2009) and is viewed as a major feature of the illness experience (Babrow, Kasch, & Ford, 1998). Uncertainty can be regarded as a natural component of an illness situation, prevalent when unpredictability is ongoing (McCormick, 2002). Waiting for a transplant may involve prolonged, continual uncertainty associated with the unpredictable and indeterminate wait for the transplant. With transplants, what the future holds is uncertain (Mishel & Murdaugh, 1987). Transplant candidates have no influence over when or if they will receive a transplant, which affects their experience of uncertainty (Penrod, 2001).

Individuals assign meaning to uncertainty and determine if it is viewed as positive or negative (Neville, 2003). The appraisal of uncertainty may be different at different times during an illness (Brashers et al., 2003). Various factors influence the appraisal of uncertainty as a threat or an opportunity. Bailey and Nielsen (1993) found that when the level of uncertainty is higher, uncertainty is more likely appraised as a danger or threat. They suggested that living longer with

uncertainty may be associated with a positive appraisal of uncertainty, but the length of time since a diagnosis may also not be associated with how uncertainty is viewed. Some individuals with chronic illness may tend to view continued uncertainty as positive if the alternative is confirmation of the downward trajectory of an illness (Mishel, 1990). If, as these findings suggest, the appraisal of uncertainty is individual and dynamic, then uncertainty may change throughout the wait for a transplant.

Mishel (1990) proposed that reconstruction and reframing occur in response to the uncertainty of chronic illness. She suggested that uncertainty, even if prolonged, can be accepted and integrated into one's life and leads to a new view of life (Mishel, 1990). Others have suggested that living through uncertainty may evoke personal growth (Penrod, 2007). If, or how transplant candidates integrate the uncertainty of waiting for a transplant into a new view of life is not known. With lengthening waiting times for organs and an ever increasing number of people waiting for organ transplants, more understanding of the experience of waiting for a transplant is needed. While uncertainty is described in qualitative research for transplant candidates, further description of the experience of uncertainty in those waiting for a transplant provides both greater insight into the needs of transplant candidates and additional understanding of the experience of uncertainty in illness.

The majority of people waiting for organ transplant, over 98,000, are awaiting a kidney transplant (United States Department of Health and Human Services, Health Resources and Services Administration, Organ Procurement and Transplantation Network, 2012). Most adults waiting for a kidney transplant have end-stage renal disease (ESRD) with kidney function that is so low that dialysis or kidney transplantation is required. Risk factors for ESRD include age

> 60 years, African American ethnicity, low socioeconomic status, diabetes, hypertension, autoimmune disorders and systemic infection. Diabetes and hypertension are responsible for the majority of ESRD (Yee, 2008). Renal transplantation offers a greater chance of survival for individuals with progressive renal disease (Yee, 2008).

An increasing number of people are being diagnosed with ESRD; however, the percentage of dialysis patients who receive a transplant within three years of registering on the transplant wait list has declined (Wolfe, 2005). There are two types of kidney transplants. In one type, the kidney is from a living donor, and in the other type, the kidney is from a deceased donor. The focus of this study is on individuals awaiting deceased-donor kidney transplants. The average wait for a donor kidney depends on geographic region, blood type, tissue type and the presence of antibodies. More than half of the transplant candidates have been waiting over two years for a transplant and approximately 12 % of the transplant candidates have been waiting for transplant for more than five years (United States Department of Health and Human Services, Health Resources and Services Administration, Organ Procurement and Transplantation Network, 2012).

Both physical and psychosocial challenges confront individuals during the wait for a transplant (Hutchinson, 2005). As waiting time increases, transplant candidates are becoming sicker and the chances of survival following transplant may be lessened (Neuberger & James, 1999). A longer time on dialysis is linked to less positive outcomes for persons receiving renal transplants (Meier-Kriesche & Kaplan, 2002). Transplant candidates may become concerned about how deteriorating health will complicate their prospective transplant.

Differences in waiting times and complications exist for heart, renal, liver and lung transplant candidates (Kurz & Cavanaugh, 2001). The experience of uncertainty within each of

these groups may have similarities, but there may be differences that influence the responses of the transplant candidate to stressors during the pre-transplant period. Stoeckle (1993) found that adults awaiting kidney transplant had a low to moderate level of uncertainty during the pre-transplant period. Moderate levels of uncertainty were also found in another study of individuals awaiting deceased donor kidney transplant (Russell & Brown, 2002). No other research specifically focused on uncertainty in individuals awaiting kidney transplants was found in the literature.

Theoretical Framework

Mishel's (1990) Reconceptualized Uncertainty in Illness Theory provided the framework for this study. The theory was developed to accommodate responses to uncertainty over time in people with chronic conditions (Bailey & Stewart, 2010). Mishel (1981) originally developed the Uncertainty in Illness Theory to investigate the role of uncertainty in the experience of stress associated with various acute illnesses. Mishel (1999) maintained that uncertainty in chronic illness might involve more areas of life than uncertainty in acute illness. Mishel's reconceptualization expanded her original theory to focus on integration of uncertainty into one's life when living with continual uncertainty rather than the focus of the earlier theory on reducing uncertainty (Mishel, 1999).

The antecedents to uncertainty in both the original and the reconceptualized theory are cognitive capacity, stimuli frame and structure providers (Bailey & Stewart, 2010). Figure 1 depicts the antecedents of uncertainty according to Mishel. Cognitive capacity refers to the ability of a person to process information (Wallace, 2005). The stimuli frame includes symptom pattern, which encompasses characteristics about the number, frequency, intensity and duration of symptoms (Mishel & Braden, 1988). Event familiarity, which develops over time, is also part

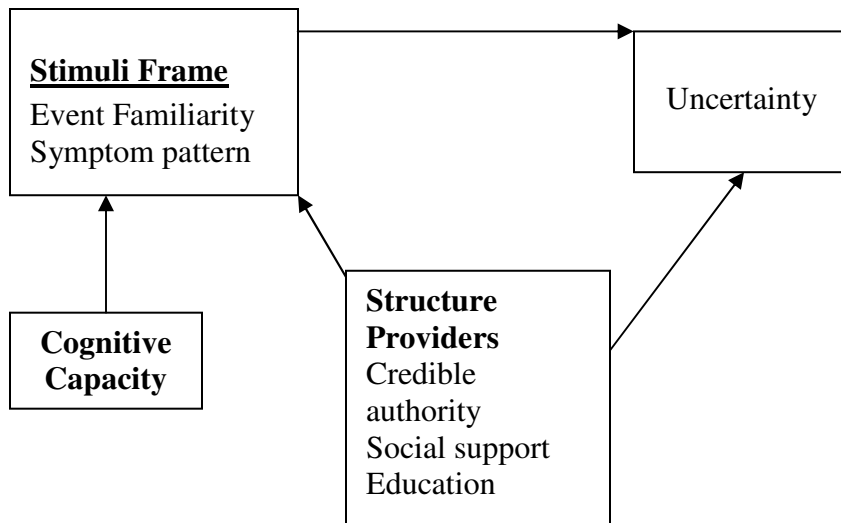


Figure 1. Antecedents of uncertainty based on Mishel's uncertainty in illness theory.

Note. (Adapted from Mishel & Braden, 1988; Wallace, 2005).

of the stimuli frame. Unfamiliarity with an event or situation is more likely to be associated with greater uncertainty (Mishel & Braden, 1988). According to Mishel, structure providers include education, social support and credible authority (Bailey & Stewart, 2010; Mishel & Braden, 1988). The latter refers to confidence in health care providers. Education directly impacts uncertainty by influencing how information can be assimilated (Mishel & Braden, 1988). Uncertainty is also influenced by social support; the individuals interpretation of uncertain illness related events is affirmed or rejected by supportive others (Mishel & Braden, 1988).

In research based on Mishel's theory, nurses, as structure providers, have a significant role in helping a chronically ill individual view uncertainty as an opportunity (Bailey, Mishel, Belyea, Stewart, & Mohler, 2004; Bailey & Stewart, 2010). According to Mishel's theory, structure providers directly influence uncertainty by assisting the patient to determine the familiarity of events and the pattern of their symptoms (Mishel & Braden, 1988). Affirmation of views about a situation by structure providers who provide social support reduces uncertainty about illness and treatment (Mishel & Braden, 1988). Mishel (1990) emphasizes that structure providers, specifically social support figures, are influential in helping the patient acquire a probabilistic view of uncertainty.

Mishel revised her original theory after noting the response to uncertainty evolving from disorganization to a new life view in patients with chronic illness (Bailey & Stewart, 2010; Mishel, 1999). A proposition within this theory is that a new state may evolve when a person has to live with enduring uncertainty. Mishel's reconceptualized model of the evolving nature of the experience of uncertainty is shown in Figure 2. Mishel reasoned that in long-term uncertainty, an individual might begin to more positively evaluate uncertainty as the uncertainty is incorporated into

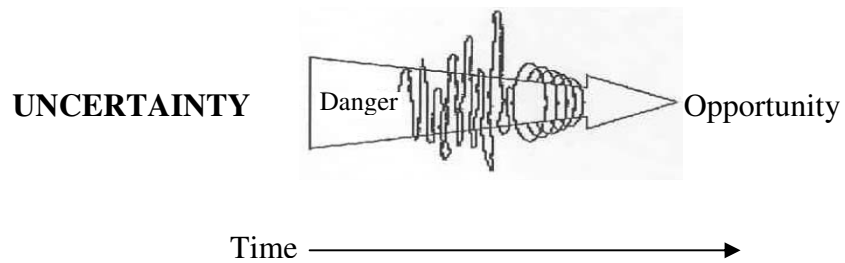


Figure 2. Mishel's reconceptualized model of uncertainty in chronic illness.

Note. The evolving nature of the experience of uncertainty according to Mishel's Reconceptualized Uncertainty in Illness Theory with reorganization and repatterning leading to a new view of life. [Printed with electronic permission of Dr. Donald Bailey Jr., September 30, 2010 (see Appendix B)].

a person's life and is accepted as normal (Mishel, 1999). Life experience, physiologic status and social resources influence the new orientation to uncertainty (Mishel, 1990). In the Reconceptualized Uncertainty in Illness Theory the concepts of self-organization and probabilistic thinking are added (Mishel & Clayton, 2008). Mishel and Clayton (2008) describe self-organization as the new sense of order that results from integrating and accepting continuous uncertainty and it is through probabilistic thinking that the expectation of certainty and predictability is abandoned. In the Reconceptualized Uncertainty in Illness Theory, enduring uncertainty that is initially viewed as danger is reappraised over time and through repatterning and reorganization a new view of life can emerge (Mishel & Clayton, 2008).

When waiting for an organ transplant, what the future holds is uncertain. Mishel's reconceptualized theory supports the premise that perspectives of uncertainty evolve and change over time in kidney transplant candidates. Uncertainty is the force leading to a new perspective on life (Mishel, 1999). Mishel's reconceptualized theory provides a framework for the appraisal of uncertainty in individuals experiencing continual uncertainty and for considering the outcome of sustained uncertainty, including the opportunity for growth through uncertainty. The Reconceptualized Uncertainty in Illness Theory proposes the appraisal of uncertainty changes over time when an individual experiences the prolonged uncertainty associated with chronic illness. Based on Mishel's Reconceptualized Uncertainty in Illness Theory:

- If persons experience prolonged uncertainty in chronic illness, their appraisal of uncertainty evolves and changes over time (Mishel, 1990).
- If appraisal of uncertainty evolves and changes, when persons experience prolonged uncertainty in chronic illness, growth through uncertainty can occur and a new view of life may develop (Mishel, 1990).

Since qualitative studies have identified uncertainty as a theme when waiting for a transplant (Baker & McWilliam, 2003; Brown et al., 2006; Liddle & Innes, 2005; Mishel & Murdaugh, 1987; Pelletier-Hibbert & Sohi, 2001; Weems & Patterson, 1989), the following was proposed:

1. Transplant candidates experience growth through uncertainty.
2. There are relationships among waiting time, level of uncertainty, and growth through uncertainty in transplant candidates.

A middle range theory of the relationship among waiting time, level of uncertainty, and growth through uncertainty was proposed and tested in this study. It was proposed that:

1. Deceased-donor kidney transplant candidates show growth through uncertainty as Mishel describes.
2. The level of uncertainty is related to waiting time in deceased-donor kidney transplant candidates.
3. Growth through uncertainty is related to both the waiting time and the level of uncertainty experienced by deceased-donor kidney transplant candidates.

The proposed relationships are depicted in Figure 3.

Therefore, the use of Mishel's Reconceptualized Uncertainty in Illness Theory as a framework for research about the experience of uncertainty during the wait for a deceased-donor kidney transplant, guides the description of the uncertainty as well as possible growth through uncertainty for kidney transplant candidates. This description of the experience of uncertainty in kidney transplant candidates increases the understanding of the experience of waiting for an organ transplant which leads to improved nursing care for this population.

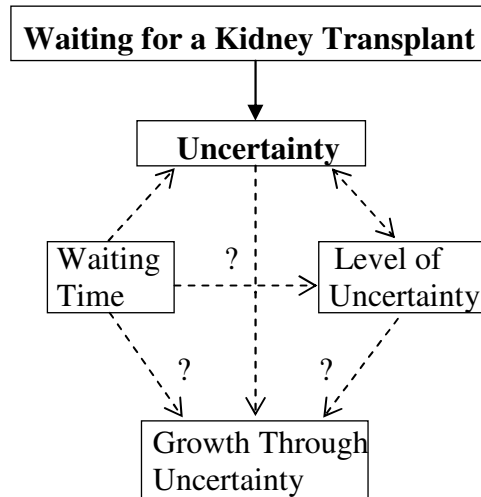


Figure 3. Middle range theory of the experience of uncertainty while waiting for a kidney transplant.

Note. Visual model of the proposed relationships among waiting time, level of uncertainty, and growth through uncertainty in the middle-range theory developed by the researcher and tested in the current study.

Purpose

Since limited research has explored the pre-transplant period and qualitative studies have identified uncertainty as a hallmark of the experience of waiting for an organ transplant, the purpose of this study was to test a middle range theory proposing that deceased-donor kidney transplant candidates show growth through uncertainty as described by Mishel (1990). The middle range theory further proposed that waiting time for a transplant is related to the level of uncertainty in deceased-donor kidney transplant candidates and growth through uncertainty is related to both waiting time and level of uncertainty. The relationships among waiting time, level of uncertainty and growth through uncertainty were proposed and explored to provide further understanding of the experience of uncertainty in deceased-donor kidney transplant candidates.

Research Questions

1. Do deceased-donor kidney transplant candidates experience growth through uncertainty as Mishel's Reconceptualized Uncertainty in Illness Theory proposes?
2. What are the relationships among waiting time, level of uncertainty and growth through uncertainty in deceased-donor kidney transplant candidates?

Definition of Terms for this Study

End-Stage Renal Disease (ESRD): According to the National Kidney Foundation Kidney Disease Outcome Quality Initiative [KDOQI] (2012), ESRD occurs when there are signs and symptoms of kidney failure that necessitate the initiation of treatment by renal replacement therapy (dialysis or transplant) in order to sustain life.

Growth through Uncertainty: Based on Mishel's (1990) Reconceptualized Uncertainty in Illness Theory, when uncertainty is integrated into one's life, a new view of life can evolve, which is measured by Growth Through Uncertainty Scale (GTUS) (Bailey et al., 2004).

Dialysis: Dialysis replaces some of the functions of the kidney when the kidney is no longer working or in ESRD. There are two are two types of dialysis, hemodialysis and peritoneal dialysis. In end stage kidney failure the need for dialysis is permanent or a transplant is needed (KDOQI, 2012).

Pre-transplant Period: The period of time beginning from being placed on the wait list for a kidney transplant until a transplant is received.

Transplant Candidate: An adult, age 18 or over, who is listed for a deceased-donor kidney transplant [officially registered with the United Network for Organ Sharing (UNOS)] and is active on the waiting list.

Uncertainty: A component of illness, defined as the “the inability to determine the meaning of illness-related events, occurring when the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately because sufficient cues are lacking” (Mishel, 1990, p. 256).

Level of uncertainty: The total score that the transplant candidate receives on the Mishel Uncertainty in Illness Scale-Community version (Mishel, 1997).

Waiting time: The amount of time, in months, the transplant candidate has been listed for a transplant.

Limitations

This study included individuals waiting for a deceased-donor kidney transplants in a specific region of the United States and is representative of the region. The findings may not be applicable to kidney transplant candidates in other regions nor to candidates for other types of organ transplants.

Delimitations

A delimitation in this study was the convenience sample. Only individuals who were English speaking were included in the study. Most of the sample of adult deceased-donor kidney transplant candidates was from a single transplant center in the southeastern United States. The majority of the sample was accessed by a mailing coordinated by the transplant center. Participants volunteered to participate in this study. Although all participants were actively waiting for a deceased-donor kidney transplant, participants were not specifically selected based on waiting time for this preliminary test of the middle range theory. Transplant candidates who had been waiting longer for a kidney are less represented in the sample.

Significance of the Study

This study is significant in several ways. The experience of uncertainty during the pre-transplant period, which is a theme in previous qualitative studies, was explored in this study. While uncertainty is described in qualitative research for transplant candidates, and has been measured in transplant candidates in a limited number of studies in the literature, the experience of uncertainty while waiting for a transplant needs additional description and definition. This study was designed to contribute to the understanding of the nature of uncertainty during the pre-transplant period. Transplant candidates are a vulnerable population (Brown et al., 2006) with longer waits for donor organs prolonging the uncertainty of the pre-transplant period. With more people needing organ transplants and the increasing waiting time for organs, further description of the experience of waiting for a transplant may help identify patient needs and guide research to develop nursing interventions. Using Mishel's Reconceptualized Uncertainty in Illness Theory (Mishel, 1990), the level of uncertainty experienced by deceased-donor kidney transplant candidates was described. Mishel's Reconceptualized Uncertainty in Illness Theory addresses

prolonged uncertainty in chronic illness. This study was designed to further describe the nature of uncertainty in the deceased-donor kidney transplant candidate and to determine if the appraisal of the continual uncertainty associated with the wait for a transplant and the outcomes of uncertainty for deceased-donor kidney transplant candidates are explained by Mishel's theory.

The results of this research expand nursing knowledge through contributing to further understanding of the experience of uncertainty while waiting for a transplant and the development of the theory of uncertainty in illness. Within Mishel's Uncertainty in Illness Theory, nurses are structure providers, credible authorities who can influence a patient's appraisal of uncertainty. Through supportive communication, nurses can develop the capacity of transplant candidates to view uncertainty as an opportunity (Santacroce, Asmus, Kadan-Lottick, & Grey, 2010). More knowledge of the uncertainty experienced by the transplant candidate supports improved, more comprehensive nursing care for this population. Understanding uncertainty increases understanding of patient responses to illness and is important for changing responses to unavoidable uncertainty (Kang, 2009). The study provides a basis for further study related to nursing care of transplant candidates as they navigate the pre-transplant period.

Summary

The wait for an organ transplant is an uncertain time. Physical and psychosocial challenges confront transplant candidates. Waiting times are increasing as more people wait for a limited number of organs. Greater understanding of the experience of waiting for a transplant is needed to help guide nursing care for transplant candidates.

Mishel's Reconceptualized Uncertainty in Illness Theory provided the theoretical framework for this study. Mishel's theory proposes that in long term uncertainty, an individual may more positively evaluate uncertainty and incorporate uncertainty into a new view of life,

which Mishel describes as growth. From Mishel's theory a middle range nursing theory was proposed and tested in this study to further describe the experience of uncertainty for deceased-donor kidney transplant candidates and describe the relationship among growth through uncertainty, waiting time, and level of uncertainty for these transplant candidates.

CHAPTER II: REVIEW OF THE LITERATURE

Mishel (1990) has proposed that growth through uncertainty can occur when prolonged uncertainty is experienced in chronic illness. The purpose of this study was to test a middle range theory that proposes that deceased-donor kidney transplant candidates show growth through uncertainty as described by Mishel (1990). The middle range theory tested in this study further proposes that waiting time for a transplant is related to the level of uncertainty in deceased-donor kidney transplant candidates and growth through uncertainty is related to both waiting time and the level of uncertainty. The relationships among waiting time, level of uncertainty and growth through uncertainty were explored.

The first section of this review of the literature focuses on research related to the experience of waiting for a transplant. The next section discusses research addressing the experience of uncertainty in individuals with chronic illness. This discussion of the literature on uncertainty focuses on research based on Mishel's theory of uncertainty in illness that explores sustained uncertainty, concluding with a discussion of research that has used Mishel's measure of Growth through Uncertainty in Illness.

Waiting for a Transplant

When an individual needs an organ transplant, there is a wait involved. The description of the health status of the transplant candidate by Brown et al. (2006) provides insight into the experience of waiting for a transplant. The transplant candidate is "neither healthy nor ill, just 'pre-transplant'" (Brown et al., 2006, p. 132). The future is the goal. Brown et al. completed a phenomenological study to explore the meaning that people with liver failure ascribe to the experience of waiting for a transplant. The participants in the study had been waiting for a transplant between 4 months and 8 years. Changes in response to waiting were noted as waiting

time increased. When first listed for transplant, the participants described experiencing a feeling of relief and gratitude at being placed on the list. As waiting time increased, discouragement, frustration and boredom was described. There was both a fear that the transplant would never occur as well as fear of the impending surgery.

Brown et al. (2006) described a difference in the experience of time for the transplant candidate. For the transplant candidates in their study, time had a different meaning with times experienced as “until transplant...and after transplant” (Brown et al., 2006, p. 130). While waiting for a transplant, a diagnosis is known, treatment of underlying conditions continues, but the timing and occurrence of the transplant is uncertain. Transformation was one of the themes that emerged in the study. Since being listed for a transplant, participants described a new self emerging, but there was also resistance to the possible changes related to waiting for a transplant. Participants developed coping strategies to deal with the uncertainty, the waiting and the differences in how they experienced time. The authors note that all the participants in the study were white and suggest that different cultural beliefs about time and illness may lead to different results. The results of their study suggest that further description of the relationship between waiting time and the response to waiting, including the experience of uncertainty, will provide more understanding of the challenges of the pre-transplant period.

A participant in a qualitative study of lung transplant candidates by Macdonald (2006) described the pre-transplant period as, “I’m not really living, I’m just getting by” (p. 570). Macdonald examined the lived experience of patients with cystic fibrosis and their carers as they coped with chronic illness while waiting for a lung transplant. Semi-structured interviews were completed with eight patients and five carers. The theme that emerged for the transplant waiting period was “life in limbo” (Macdonald, 2006). The experience of transplantation was

characterized by uncertainty (Macdonald, 2006). Limitations of this study included the small sample size, which made it difficult to achieve data saturation (Macdonald, 2006), inclusion of post-transplant candidates in the study, which brought a retrospective slant to the description of the pre-transplant period, and data from transplant candidates and carers were combined. The present study included only individuals who are waiting for a transplant and specifically describes the experience of uncertainty during this phase of the experience of transplantation.

The overarching pattern in a qualitative study exploring the experiences of patients with ESRD who were having hemodialysis was “Waiting for a kidney transplant” (Moran, Scott, & Darbyshire, 2011). The study was conducted in the Republic of Ireland with 16 participants. The participants described “living in hope” of a transplant (Moran et al., 2011). Participants seemed to interpret the average waiting time for a transplant as the actual time they would wait and over time the hope turned to uncertainty if the transplant did not occur by an expected date (Moran et al., 2011). The experience of “life on hold” was also described by participants in this study with life centered on waiting for a transplant, which, according to the authors, suggests an inability to project forward into possibilities in the future. The authors propose that the participants are “enduring,” which implies focusing on the present and blocking out the past and the future. Their findings supported exploring the relationship between uncertainty and waiting time for a transplant in the current study and determining whether or not individuals experience growth through uncertainty when they are “enduring” life on hold.

Transplant candidates may experience feelings of uncertainty about whether or not a transplant would improve their quality of life (Weems & Patterson, 1989). Weems and Patterson (1989) explored the experience of waiting for a transplant through interviews with 14 hospitalized patients ten days after they had received a kidney transplant. For these participants,

uncertainty pervaded the waiting period. One transplant candidate likened the experience of waiting to “walking in the dark” (Weems & Patterson, 1989). The transplant candidate makes a choice of continuing to wait or just going on with life as it is now. The uncertainty was related to when they might receive a kidney and, later in the waiting period, wondering if they would ever receive a transplant. Ways of coping and sustaining hope varied among transplant candidates and individuals modified their coping strategies as they faced ongoing uncertainty. This was a retrospective study exploring the experience of waiting for a transplant after the participants had a kidney transplant rather than during the pre-transplant period was proposed in this study. Further exploration of the experiences of transplant candidates while waiting for a transplant can provide a more comprehensive understanding of the pre-transplant time.

Quality of life during the pre-transplant period is also described in the literature. In a study of quality of life in patients referred for heart transplant, Evangelista et al. (2005) found an improvement in physical health and depression scores over time, which was attributed to patients adjusting to the knowledge that they needed a heart transplant and finding ways to cope with their condition. However, when comparing patients who had not undergone transplantation at two years to the patients who had received a transplant and those who were determined to be too well for transplant, the transplant candidates were more depressed and had worse physical and mental health (Evangelista et al., 2005). The study was limited by the small sample size with only 13 subjects in the pre-transplant group at the time of the two-year follow-up, but results of this study suggest that waiting time may affect perceptions while waiting for a transplant. Corruble et al. (2010) found that patients who were waiting for a kidney transplant showed an increase in anxiety and depression from the time they were added to the waiting list and when they were assessed two years later. The 390 patients in this study were assessed for anxiety and

depression at the time of inclusion on the waiting list for a kidney transplant, and 12 months and 24 months later, unless they had a transplant, and three months after transplantation (Corruble et al., 2010). The authors suggest that transplant candidates may progressively lose hope and experience an increasing fear of not receiving a transplant.

Molzahn et al. (2008) maintained the experience of living between the promise of prolonged life and the threat of death is not well understood. The authors used narrative inquiry of secondary data, consisting of 100 different narratives, in a study exploring the liminal experiences of people with ESRD. Transplantation was viewed as a “ticket to freedom” and the chance to lead a normal life. For a few people, dialysis was just a necessary in-between phase with the goal of a transplant, while others described a less restrictive attitude toward dialysis coexisting with the possibility of transplant. The authors suggested further exploration of whether comfort in liminal space is affected by how one deals with uncertainty. The responses of transplant candidates to possibly prolonged liminal experiences are influenced by their appraisal of and response to uncertainty. Their study lends strong support for the present study, which is focused on the nature of uncertainty in a liminal period. Further understanding of the experience of uncertainty while waiting for a transplant can lead to knowledge that nurses and other health care providers need to improve their capacity to comfort transplant candidates during this liminal time.

Uncertainty has been found to vary considerably from pre-transplant to post-transplant among patients and their partners in an exploratory study of the process of adjustment to kidney transplantation (Starzomski & Hilton, 2000). The level of uncertainty was one of the measures used to compare adjustment to kidney transplantation with and without a period of dialysis. Uncertainty was described as moderate to low with a significant decrease in uncertainty post-

transplant. Consistent areas of uncertainty were the patient's ability to function and concern about the stability of the patient's condition. Starzomski and Hilton (2000) recommended further research to account for changes that may occur while waiting for a transplant. This present study addresses that recommendation.

There have been a limited number of qualitative studies that describe the experiences of family members and support persons during the pre-transplant period, which offer a broader view of the experience of waiting for a transplant (Mishel & Murdaugh, 1987; Myaskovsky et al., 2004; Pelletier-Hibbert & Sohi, 2001; Saxe-Braithwaite & Chapman, 1992). This family and support person literature was reviewed but is not discussed further here since it is beyond the purpose of the present study.

Uncertainty about the future and waiting for a donor organ were identified as two of the ten worst stressors for heart transplant candidates (Jalowiec, Grady, & White-Williams, 1994). The worst stressor was finding out that they needed a transplant. The majority of the population in this study of 175 heart transplant candidates had been told about the need for a heart transplant within the three months prior to the study. The authors suggested that the wait for a compatible organ might rank higher as a stressor with longer waiting times. Cupples, Nolan, Augustine and Kynoch (1998) also found that waiting for a donor heart was a consistent stressor but not one of the biggest stressors for heart transplant candidates. Stressors were measured at three, six, nine and twelve months after being listed for transplant. Stressors fluctuated throughout this time period. These authors recommended description of stressors beyond a one-year waiting period since waiting times for transplants are increasing.

How transplant candidates manage uncertainty affects their quality of life (Scott, Martin, Stone, & Brashers, 2011). Most of the participants in a qualitative study of individuals who had

received or were waiting for a kidney, liver, heart, or pancreas described significant uncertainty related to their illness, identity and relationships (Scott et al., 2011). The authors of the study examined the role of social support in uncertainty management for transplant patients. The study included eight pre-transplant participants who had been waiting between 2 and 36 months for an organ. The results of the study found that the participants interact with others with a goal of managing uncertainty and while social support may facilitate uncertainty management, at other times social support may interfere with uncertainty management. Scott et al. (2011) suggest that uncertainty experiences likely differ by organ type and support for uncertainty management may differ before and after transplantation. The present study focused on the uncertainty during the time before transplant for deceased-donor kidney transplant candidates providing a more specific description of uncertainty during the wait for a transplant.

The qualitative studies that have described the experience of waiting for a transplant for the transplant candidate provide insight about what it means to wait for a transplant. Some studies described different experiences associated with different waiting times. While there is limited research in the literature that focuses on the pre-transplant period and the wait for a transplant, uncertainty emerges as a common theme in the studies. The wait for an organ is one of the stressors identified in the research for heart transplant candidates. The pre-transplant period has been described as a time of pervasive uncertainty with the unpredictability of when or if an organ will become available for transplant as one of the primary sources of uncertainty. The research also suggests that differences in length of waiting time are associated with differences in the experience of waiting for a transplant and response to waiting for a transplant. This literature is supportive of the need for this study to describe the experience of uncertainty and explore the

relationship between waiting time and the experience of uncertainty during the pre-transplant period.

Uncertainty in Chronic Illness

Mishel's (1990) Reconceptualized Uncertainty in Illness Theory, which addresses the experience of sustained uncertainty, may provide information about the prolonged uncertainty of the pre-transplant period. She has found that uncertainty in individuals with chronic conditions fluctuates over time (Mishel, 1990). Mishel (1990) maintains that aside from physiological status, factors influencing an individual's orientation to uncertainty include life experiences, social support and health care providers. Studies on the experience of sustained uncertainty in transplant candidates are limited; therefore this section of the literature review focuses primarily on research on sustained uncertainty in chronic illness that uses Mishel's theory.

One qualitative study applied Mishel's theory of uncertainty in illness. Martin, Stone, Scott and Brashers (2010) identified forms of uncertainty across the "transplantation trajectory." Eight of the participants were pre-transplant and were waiting for a heart, kidney or liver transplant with waiting times ranging from 2 to 36 months. Overlapping medical, personal and social forms of uncertainty were identified for these participants. Participants reported experiencing medical uncertainty related to insufficient information about diagnosis, making decisions about transplantation, concerns about not getting a transplant and uncertainty related to unclear information about medical procedures such as dialysis (Martin et al., 2010). Personal uncertainty pre-transplant was about the meaning of life, role changes, and unclear financial consequences related to transplant costs. Questioning from others about the transplant process and unclear relational implications were social forms of uncertainty in the pre-transplant period. The causes of uncertainty pre-transplant identified in the study go beyond medical issues, which

lend support to Mishel's theory of uncertainty in illness (Martin et al., 2010). Further research to identify how transplant patients evaluate and manage uncertainty was recommended and the current study addresses that recommendation.

Uncertainty is present among cancer survivors because of the risk of relapse and the possibility of late effects of treatment regimens (Santacroce & Lee, 2006). Uncertainty has been negatively correlated with quality of life in breast cancer survivors (Sammarco, 2003).

Sammarco (2003) investigated the relationship among perceived social support, uncertainty and quality of life in 103 breast cancer survivors who were older than 50 years. Uncertainty was measured using Mishel's Uncertainty in Illness Scale-Community form. The experience of uncertainty was positively correlated with age and was also higher in women who had other diseases that were associated with a decreased quality of life. The time since diagnosis of breast cancer ranged from one to 24 years. The relationship of length of time since diagnosis and uncertainty was not specifically reported.

The experience of long-term uncertainty in cancer patients was also the focus of research by Bailey, Wallace and Mishel (2007). Mishel's Reconceptualized Uncertainty in Illness Theory was the organizing framework for analysis in a qualitative descriptive study of men undergoing watchful waiting for prostate cancer. Watchful waiting was defined by the authors as surveillance followed by treatment if the cancer progresses and causes bothersome symptoms. The men lived with uncertainty about whether their disease would remain stable or progress (Bailey et al., 2007). A defining characteristic of the uncertainty experienced by the participants was that there were few symptoms that they could monitor to give them information about the progression of their disease. Their health care providers could not predict how the cancer might progress. The men in the study had been living with prostate cancer for four to twelve months.

The decision of watchful waiting rather than treatment caused persistent worry, stress and uncertainty for some of the men. Others viewed watchful waiting as an opportunity to use a variety of activities, such as work or self-care strategies, to manage their uncertainty. Although the results of this study are not generalizable, there may be similarities to the experience of waiting for a transplant. Transplant candidates must also respond to the unpredictable progression of their disease while they wait for a transplant.

In another study involving watchful waiting, Bailey et al. (2009) examined the experience of uncertainty for patients with chronic hepatitis C (CHC). The cross-sectional study used the Mishel Uncertainty in Illness Scale (MUIS) to explore the relationship between illness uncertainty and fatigue, pain, depressive symptoms, co-morbidity and quality of life. Up to 50% of patients with CHC are not actively undergoing treatment. Instead they are undergoing a “watchful waiting” protocol which can be “observation, expectant management, active monitoring or deferred treatment” (Bailey et al., 2009, p. 138).” Results indicated that ambiguity or unclear bodily cues about the state of one’s illness (Bailey et al., 2009), is a key construct of the uncertainty experienced by patients with CHC who are managing their disease with their healthcare provider through watching and monitoring their condition (Bailey et al., 2009). Similarly, transplant candidates are waiting, but qualitative research suggests that not knowing when or if a transplant would occur and not knowing the outcome of a transplant are the primary sources of uncertainty for transplant candidates. Bailey et al. maintained that identifying the constructs of uncertainty is essential to understanding the experience of patients and for developing interventions for uncertainty management that can be targeted to specific patient populations. Further description of the uncertainty experienced by transplant candidates is needed before interventions can be developed to help transplant candidates manage uncertainty.

Bailey and Nielsen (1993) examined whether appraisal of uncertainty could be predicted by the length of illness and degree of uncertainty in women with rheumatoid arthritis. There is no cure for rheumatoid arthritis and women are unable to predict the course or progression of their disease (Bailey & Nielsen, 1993). The number of years since diagnosis for the subjects ranged from one to 42 years with a mean length of illness of 17 years. The length of illness was not associated with the degree of uncertainty as measured by the Mishel Uncertainty in Illness Scale, but women who perceived more uncertainty related to their disease, appraised the uncertainty as more of a danger (Bailey & Nielsen, 1993). The authors suggested that the large range of length of illness in the small sample might limit discerning relationships between length of illness and uncertainty. Research specifically describing the relationship between how long uncertainty had been experienced pre-transplant and level of uncertainty in transplant candidates was not identified in the literature.

Two studies were found in the literature that measured uncertainty in the kidney transplant candidates. Stoeckle (1993) examined health-related hardiness, uncertainty, power and environment in 23 adults waiting for a kidney transplant. Uncertainty was measured using the Mishel Uncertainty in Illness Scale (MUIS) and she reported that the participants had low to moderate uncertainty. Relationships among the variables examined by Stoeckle included a negative correlation ($r = -.67$) between health related hardiness and uncertainty. Difficult environmental factors described by the participants, based on the Stoeckle Environmental Influence Checklist developed by the author, were related to length of time waiting for a transplant. A limitation of the study was the small sample size. The author recommended further study of the relationship among the variables, including the relationship between uncertainty and the length of time on the transplant waiting list. The results of this present study expand on

Stoeckle's results, providing additional information on the level of uncertainty experienced by deceased-donor kidney transplant candidates and the relationship between uncertainty and waiting time.

The second study measuring uncertainty in kidney transplant candidates was a randomized controlled study by Russell and Brown (2002) examining the effects of a nursing intervention to provide information and social support to individuals awaiting deceased-donor kidney transplantation. Hope and uncertainty, measured by the MUIS, were evaluated at the beginning of the study and six months later. The nursing intervention consisted of monthly phone calls and mailings once a month for six months. One group received the intervention and the other did not. No change in hope or uncertainty was found in the treatment group or control group. A limitation was that no information was given related to the length of time the participants had been waiting for a transplant and the study only looked at a six month time period. Understanding the pre-transplant experience can be expanded by further description and measurement of the experience of uncertainty and the relationship between uncertainty and waiting time for a transplant.

The research described in this section examined uncertainty in individuals who were faced with sustained uncertainty. The majority of the people who are waiting for a transplant have had a long-standing chronic illness and, similar to individuals with cancer or individuals with CHC or rheumatoid arthritis, may appraise and reappraise uncertainty over time and, according to Mishel, may integrate the uncertainty into a new view of life. The experiences of individuals with chronic illness provide greater understanding of the experience of sustained uncertainty. However, the experience of sustained uncertainty may be different for the transplant candidate as the hoped-for transplant may lead to greater well-being. Additional research is

needed to determine if the experience of uncertainty while waiting for a transplant is similar to or different from the uncertainty experienced by individuals with chronic illness. This study is designed to address that need.

Growth through Uncertainty

Based on Mishel's Reconceptualized Uncertainty in Illness theory, individuals who experience chronic uncertainty can perceive the uncertainty positively and develop a new view of life or growth through uncertainty (Bailey et al., 2004). This section of literature reviews research that measures growth through uncertainty as described by Mishel (1990). Growth through uncertainty occurs when continual uncertainty is integrated into a person's life and the uncertainty is used to reorganize their life views (Mishel, 1990). Few studies were found in the published literature that explored growth through uncertainty.

Bailey et al. (2004) explored the effects of a watchful waiting intervention on mood state, quality of life, cognitive reframing and growth through uncertainty in men with prostate cancer. The subjects were men who were being monitored rather than treated with surgery or radiation (watchful waiting) and had been followed for one to 124 months. A telephone intervention was designed to help the men reframe the way they viewed their illness and the uncertainty associated with their illness. Subjects were randomly assigned to a control group or to an experimental group that received the intervention. The Growth through Uncertainty Scale (GTUS) was administered at the time of enrollment in the study and ten weeks later or about five weeks after the telephone intervention was completed. A significant difference in total scores on the GTUS was not found, but there was a significant difference on the new view of life subscale. Men who received the intervention had a more positive perception of their future (Bailey et al., 2004).

More symptoms, higher level of education, greater religious participation, younger age and cognitive reframing were associated with higher levels of personal growth in breast cancer survivors who were 5-9 years since diagnosis (Porter et al., 2006). A negative cognitive state, which consisted in part of uncertainty, was associated with less personal growth. Gil et al., (2006) used the GTUS in an evaluation of the long-term effects of uncertainty management interventions for breast cancer survivors. Women in the intervention group reported stable levels of personal growth while women in the control group reported a decline in growth over time. Personal growth during the wait for a transplant has not been measured.

The relationship of living with continual uncertainty and growth through uncertainty was explored in a study of 301 Taiwanese parents of children with cancer (Lin, Yeh, & Mishel, 2010). Based on examination of a conceptual model, the results of the study demonstrated that parental uncertainty had no significant direct effect on growth through uncertainty. Coping mediated the effect of parental uncertainty on growth through uncertainty with lower uncertainty associated with more coping which was associated with more growth through uncertainty. The results of this study are specific to Taiwanese parents of children with cancer, suggesting the experience may be different with different illnesses and there may be cultural differences in the experience of growth through uncertainty. It is not known if the effect of uncertainty on growth through uncertainty is the same as deceased-donor kidney transplant candidates and supports exploration of the relationship between level of uncertainty and growth through uncertainty in the current study.

The appraisal of uncertainty as opportunity in cancer survivors emphasizes the positive aspects of the situation. Although, Mishel's Reconceptualized Uncertainty in Illness theory proposes that continual uncertainty can be integrated into a person's life with reorganizing and

reframing leading to a new view of life (Mishel, 1990), no research was identified in the literature describing this experience in the pre-transplant population. Similar to men choosing a watchful waiting approach to treatment of prostate cancer or long term breast cancer survivors, transplant candidates may confront ongoing uncertainty if the wait for an organ is prolonged. Uncertainty may be different or be appraised differently at different points in time during the pre-transplant period. Further description of how the appraisal of uncertainty changes over time and whether growth through uncertainty occurs in the transplant candidate is needed for better understanding of the experience and to help guide the development and timing of nursing interventions.

Summary

This review of the literature has discussed the research focused on the experience of waiting for a transplant, uncertainty in chronic illness based on Mishel's theory of uncertainty in illness, and research that has measured growth through uncertainty in illness. Uncertainty is described in the qualitative research as a predominant characteristic of the pre-transplant experience. The unpredictability of when or if an organ would become available was a primary source of uncertainty. The qualitative research on the experience of waiting for a transplant also suggests that there are changes in the response to waiting for a transplant as the wait becomes longer.

Few quantitative studies have specifically looked at the experience of uncertainty while waiting for a transplant. Researchers have suggested that with longer waits for donor organs, studies should examine the experience of waiting for a transplant over longer time periods. The experience of continual uncertainty and appraisal of uncertainty has been studied in cancer survivors. Results suggested that an individual could begin to appraise uncertainty positively

leading to a new view of life. Further study is needed to describe the nature of uncertainty while waiting for a transplant, including the level of uncertainty during the pre-transplant period, changes in uncertainty in relation to waiting time, and the transplant candidate's appraisal of uncertainty.

Uncertainty is a theme in qualitative studies describing the experience of waiting for a transplant. Literature on chronic illnesses describes the nature of prolonged uncertainty, but it is not known if the experience of uncertainty is the same for individuals who are waiting for an organ transplant. This study was designed to address the need for further research by exploring growth through uncertainty and by describing the relationship among waiting time, level of uncertainty and growth through uncertainty in the deceased-donor kidney transplant candidate.

CHAPTER III: METHODOLOGY

The purpose of this study was to test a middle range theory that proposes that kidney transplant candidates show growth through uncertainty as described by Mishel (1990). The middle range theory further proposes that waiting time for a kidney transplant is related to the level of uncertainty in deceased-donor kidney transplant candidates and growth through uncertainty is related to both waiting time and level of uncertainty. The relationships among waiting time, level of uncertainty, and growth through uncertainty were explored to provide further understanding of the experience of uncertainty in kidney transplant candidates. This chapter describes the research design, the sample selection and the survey instruments used in this study. A description of the procedures for data collection and data analysis is given and measures for protection of human subjects are described.

Research Design

This study used a level II correlational descriptive survey research design (Wood & Ross-Kerr, 2006). Wood and Ross-Kerr (2006) specify that when a problem has a conceptual or theoretical base, a descriptive survey design is used to describe the relationship among variables based on correlational analysis. The theoretical base for this study is Mishel's Reconceptualized Uncertainty in Illness Theory which suggests that continual uncertainty may result in personal growth as noted in chapters I and II. Growth through uncertainty has been demonstrated in chronic illness. However, the outcome of growth through uncertainty has not been tested in kidney transplant candidates. The middle range theory tested in this study proposes that: Candidates for deceased-donor kidney transplants show growth through uncertainty as described by Mishel, waiting time is related to the level of uncertainty in kidney transplant candidates, and growth through uncertainty is related to both the waiting time and the level of uncertainty

experienced by the kidney transplant candidate. Therefore this correlational study was designed to address the following research questions:

1. Do candidates for deceased-donor kidney transplants experience growth through uncertainty as defined by Mishel?
2. What are the relationships among waiting time, level of uncertainty and growth through uncertainty for deceased-donor transplant candidates?

Descriptive statistics, specifically frequencies and percentages, were used to analyze demographic data. The theoretically proposed relationships among waiting time, level of uncertainty, and growth through uncertainty were analyzed using correlation analysis. There was a wide range of waiting times for a transplant among participants in this study. Jalowiec et al. (1994), in their study of patients waiting for a heart transplant, used median waiting time to divide their sample into two groups to examine the effect of the transplant wait on perception of stressors because of a wide range of waiting times in the sample. In order to complete further analysis of the relationship between waiting time and level of uncertainty, and growth through uncertainty in the current study, the sample was divided into two groups based on national data for median waiting time to kidney transplant. Participants in one group had less than or equal to the median time to transplant and the other group consisted of the participants with a waiting time longer than the median time to transplant. The independent-groups t-test was used to compare waiting time groups in the study.

Sample

The study sample was drawn from adults, 18 years old or older, who were actively awaiting a deceased-donor kidney transplant in the southeastern United States. A convenience sample of the population was recruited through dialysis clinics, an electronic message posted on

a National Kidney Foundation message board, and a mailing to deceased-donor transplant candidates registered with a transplant center. Participation in the study was voluntary and participants had to be able to speak and read English.

A minimum of 45 transplant candidates from this population was needed to test the middle range theory proposed in this study. One hundred thirty-six transplant candidates volunteered to participate in the study. One participant was going to receive a living donor transplant and was therefore excluded from the sample. Participants either returned the survey to the researcher by mail or contacted the researcher by phone to complete the survey. Demographic information was collected from the participants. The data collected included, age, gender, number of years of education, marital status, race/ethnicity, type of dialysis and the length of time a participant had been waiting for a kidney transplant. A copy of the demographic form is provided in Appendix B. The demographic characteristics of the participants are presented in Tables 1 and 2.

Participants ranged in age from 25 to 73 with a mean age of 54.6 years. More participants were male (56%). Eighty of the participants were married. Fifty-two of the participants were high school graduates. Most of the participants were receiving hemodialysis (73.1%) with only 10 participants not on dialysis. The mean waiting time for a transplant for participants in this study was just over three years.

The majority of the participants were African American (76.9%). Nationally, African Americans comprised 36.8 % of the kidney transplant candidates in 2009 while white transplant candidates were 38.7 % of the total number of transplant candidates (United States Department of Health and Human Services, Health Resources and Services Administration, Organ

Table 1

Age, Waiting Time, and Years of Education of Participants

	Range	<i>M</i>	<i>SD</i>
Age	25-73 years	54.6	9.96
Waiting time for a transplant	3-180 months	37.95	28.19
Years of Education	7-22 years	12.99	2.36

Note. (n=134).

Table 2

Type of Dialysis, Gender, Race, and Marital Status of Participants

	n	%
Dialysis		
Hemodialysis	98	73.1
Peritoneal dialysis	26	19.4
None	10	7.5
Gender		
Male	75	56
Female	59	44
Race		
African American/Black	103	76.9
White	25	18.7
Other	4	3.0
Marital Status		
Married	80	59.7
Divorced	13	9.7
Widowed	9	6.7
Single	28	20.9
Living with a Partner	4	3.0

Note. (n = 134).

Procurement and Transplantation Network, 2012). However, the sample is representative of the region that the participants are from. The sample in this study was primarily from a single transplant center that has predominantly African Americans (76%) waiting for a transplant (United States Department of Health and Human Services, Health Resources and Services Administration, Organ Procurement and Transplantation Network, 2012) in a state where 22% of the population is African American (U.S. Department of Commerce United States Census Bureau, 2011).

The rate of deceased-donor kidney transplants is lower among African Americans than whites and reflects a longer time on the transplant wait list for African Americans (Hall, Choi, Xu, O'Hare, & Chertow, 2011). Given the larger number of African American participants in this sample and the racial ethnic differences in kidney transplantation, the data for the subset of African American participants was analyzed separately. The demographic characteristics of the subset of African American participants are presented in Tables 3 and 4.

The African American participants ranged in age from 27-72 years. Over half were married and more than a fourth of the participants in this subset were single. The mean number of years of education was 12.60; more than half of the African American participants completed high school or had attended college. The mean waiting time for a transplant for the African American participants was almost three and one-half years.

Nationally, the median waiting time for a kidney transplant is 1297 days or approximately 43 months (United States Department of Health and Human Services, Health Resources and Services Administration, Organ Procurement and Transplantation Network, 2012). The national median time to transplant for African Americans is 1968 days or approximately 66 months, and the national median time to transplant for Whites is 952 days or

Table 3

Age, Waiting Time, and Years of Education of African American Participants

	Range	<i>M</i>	<i>SD</i>
Age	27-72 years	53.47	9.62
Waiting time for a transplant	6-180 months	41.87	29.34
Years of Education	7-17 years	12.60	1.94

Note. (n = 103).

Table 4

Type of Dialysis, Gender, and Marital Status of African American Participants

	n	%
Dialysis		
Hemodialysis	78	75.7
Peritoneal dialysis	21	20.2
None	4	3.9
Gender		
Male	59	57.3
Female	44	42.7
Marital Status		
Married	59	57.3
Divorced	10	9.7
Widowed	5	4.9
Single	26	25.2
Living with a Partner	3	2.9

Note. (n = 103).

about 32 months. The independent-groups t-test was conducted to compare the relationship among waiting time, level of uncertainty, and growth through uncertainty in the two waiting time groups.

Instruments

Two instruments were used in this study. Mishel developed the instruments that were used to measure both uncertainty and growth through uncertainty and gave permission to use these instruments in this study (see Appendix B). Each instrument is described separately below.

Mishel Uncertainty in Illness Scale-Community Version

The Mishel Uncertainty in Illness Scale-Community version (MUIS-C) (see Appendix D) is a modification of the Mishel Uncertainty in Illness Scale (MUIS) (Mishel, 1981). The original scale was designed to measure uncertainty in ill, hospitalized adults. Mishel developed the MUIS based on a model of uncertainty in illness and after completing an exploratory study to compile statements from interviews with hospitalized patients that were perceived to reflect uncertainty (Mishel, 1981). Studies were conducted to establish validity of the scale (Mishel, 1981).

The MUIS-C was developed for individuals who were residing in the community and were not hospitalized. The MUIS and the MUIS-C have been widely used in research with a variety of chronic illness populations (Mishel, 1997). Stoeckle (1993) and Russell and Brown (2002) used the MUIS to measure uncertainty in kidney transplant candidates.

The MUIS-C has 23 items. The items are scored on a five-point Likert-type scale to indicate the respondent's level of agreement with the statements. The responses on the scale are scored with 5 = strongly agree, 4 = agree, 3 = undecided, 2 = disagree, and 1 = strongly disagree. A total scale score is obtained with a higher score indicating higher levels of uncertainty. Scores can range from 23 to 115. Negatively worded items are reversed before coding. "I am unsure if

my illness is getting better or worse” and “I have a lot of questions without answers” are examples of items on the MUIS-C. Reliabilities for the MUIS-C, based on normative data from twenty studies, are in the moderate to high range ($\alpha = .74-.92$) (Mishel, 1997). More recent studies (Bailey et al., 2009; Kazer, Bailey, Sanda, Colberg, & Kelly, 2011) have used the MUIS-C for men experiencing chronic uncertainty associated with active surveillance for prostate cancer. Bailey et al. (2009) had a reliability of $\alpha = 0.9$ for the MUIS-C and Kazer et al. (2011) had a Cronbach alpha of 0.88. In the present study, the Cronbach alpha coefficient for the MUIS-C was 0.87, suggesting strong reliability of the scale for individuals waiting for a deceased-donor kidney transplant.

Growth Through Uncertainty Scale

The Growth Through Uncertainty Scale (GTUS) (see Appendix E) measures positive psychological changes and the change in life view (Bailey et al., 2004; Lin et al., 2010). Mishel and Fleury developed the scale based on Mishel’s Reconceptualization of Uncertainty in Illness Theory (as cited in Bailey et al., 2004; Lin et al., 2010). The scale has 39 items that are scored on a 6-point Likert-type scale. Respondents may choose strongly agree, moderately agree, agree, undecided, disagree or strongly disagree. Examples of items are: “I have a new perspective on life,” and “I greet each day with more joy.” A total score is obtained with the possible scores ranging from 39 to 234 (Bailey et al., 2004; Lin et al., 2010). Higher scores indicate more psychological growth through uncertainty and changes in life view. Negatively worded items were reversed before coding. Mast (1998) and Porter et al. (2006) used the GTUS in research with breast cancer survivors with alpha coefficients for the scale of 0.94 and 0.95 respectively. In a study of men with prostate cancer (Bailey et al., 2004), the alpha coefficient for the GTUS was 0.94. Cronbach alpha for the GTUS in the present study was 0.95, which indicates that the scale

is reliable for the sample. Construct validity has been established for the GTUS (Bailey et al. 2004; Lin et al., 2010; Porter et al., 2006). The construct validity of the instrument is supported by findings of a negative correlation of the GTUS with the Profile of Mood States Scale, which measures mood and psychological distress (Mast, 1998).

Procedure

Permission to conduct the study was obtained from the East Carolina University and Medical Center Institutional Review Board (UMCIRB). Modifications of the procedure to recruit participants were necessary and the UMCIRB gave permission for each change. The UMCIRB study approval letters are in Appendix A. Participation in the study was voluntary. Choosing to participate or not participate in the study did not affect the transplant candidate's access to care. Individuals were advised to direct questions regarding their health care to their health care providers. The instruments contained no information that personally identified the subject. The surveys were coded numerically and the identity of the participants was not associated with their responses. Individuals who wished to receive ten dollars for participating in the study either provided their name and mailing address by phone or completed a card with the information and returned it with the survey to the researcher. The data was maintained in a locked location by the researcher. Contact information was kept separately from the completed surveys.

Initially, fliers describing the research were posted in ten kidney dialysis centers and two clinics for kidney transplant candidates after obtaining permission verbally or by electronic mail from the facility. The clinics were located in both smaller, more rural communities and larger urban areas. The flier (see Appendix F) informed the transplant candidates that they may contact the researcher at a toll free number to volunteer to participate in the study and indicated that

participants receive ten dollars for completing the study. Business cards with the toll free number were attached to the flier for interested individuals to take for the contact information.

When transplant candidates called the researcher to participate in the study, the researcher read a script (see Appendix G) describing the research to them. In the script, confidentiality was assured and the transplant candidates were informed that they may ask questions or choose to stop at any time. Verbal consent to participate in the study and to proceed with the questions was obtained from the transplant candidates. After verbal consent was obtained, the researcher asked the transplant candidates questions to complete the demographic form, including age to verify that the participants were over eighteen, and then completed the MUIS-C and GTUS with them. Eight participants responded to the fliers.

In order to recruit more participants, UMCIRB permission was obtained to post a message on a message board on the National Kidney Foundation website. The message contained the same information that was given on the flier. Two individuals responded to the message and volunteered to participate in the study. The same procedure to obtain verbal consent by phone and complete the demographic form, MUIS-C and GTUS was used for these two participants.

Finally, the UMCIRB gave approval for yet another way to access the population that required expanding the methodology to a mailed survey method. The researcher contacted a transplant center in the southeastern United States, who agreed to mail a packet to adult patients who were active on the center's waiting list for a deceased-donor kidney. The packet contained: a letter from the transplant center, a letter from the researcher, the demographic form, the MUIS-C, the GTUS, a stamped return envelope, a business card with information on how to contact the researcher, and a card for the name and address of the participant. The researcher prepared the

packets for mailing, including all postage. The staff at the transplant center identified potential participants, prepared address labels for 237 adult patients who were waiting for a deceased donor kidney transplant, and mailed the packets. The researcher did not have any knowledge of the names of patients or their contact information. The letter from the transplant center included in the mailing supported the study and assured patients of the confidentiality of their contact information (see Appendix H). An explanation of the nature of the study and instructions on how to complete and return the survey to the researcher was in the letter from the researcher (see Appendix I). Participants were given the option of completing a self-administered survey and returning the completed survey to the researcher by mail or calling the researcher at the toll free number to complete the survey by phone. The instructions indicated that participants would receive ten dollars for completing the survey. A stamped envelope addressed to the researcher was provided to return the survey. Verbal consent to participate in the study was obtained from individuals who completed the survey by phone. Consent was implied if an individual returned the completed survey to the researcher by mail. Two reminder postcards (see Appendix J) provided by the researcher were sent to all 237 patients by the transplant center approximately 2 weeks and 4 weeks after the initial mailing. Fourteen participants chose to complete the survey by phone. A majority, 82%, returned the survey to the researcher by mail, making the self-administered mailed survey the most effective method for data collection for the study population. The use of the mailed survey significantly increased the number of participants in the study and expanded the strength of the analysis of the results.

Participants were informed that they may contact the researcher at the toll free telephone number and may contact the researcher's faculty advisor with any questions regarding the research. A letter expressing appreciation for participating in the study, which included contact

information for the researcher and the faculty advisor, was sent to the participants along with the ten dollars (see Appendix K). Upon completion of the study, the data of each subject's response to each item on the MUIS-C will be submitted to the author of the scale, Merle Mishel, as she requested for use of her instrument. The data will be used to add to a normative database for clinical populations. No other use will be made of the data submitted to Dr. Mishel. The participants of this study will remain anonymous.

Summary

This chapter provided information on the methodology used for testing the middle range theory proposed in this study, including the research design, which encompassed the methods used for analysis of data. A description of the demographic characteristics of the sample and the African American subset of the sample was given. Procedures for data collection, recruitment of participants, and measures for protection of human subjects were explained and the instruments that were used in this study were described.

CHAPTER IV: FINDINGS

The purpose of this study was to test a middle range theory that proposes that waiting time for a transplant is related to the level of uncertainty in deceased-donor kidney transplant candidates and growth through uncertainty is related to both waiting time and level of uncertainty. The relationships among waiting time, level of uncertainty, and growth through uncertainty were explored to provide further understanding of the experience of uncertainty in kidney transplant candidates. The research questions were:

1. Do deceased-donor kidney transplant candidates experience growth through uncertainty as defined by Mishel?
2. What are the relationships among waiting time, level of uncertainty and growth through uncertainty for deceased-donor kidney transplant candidates?

Figure 3, given in Chapter I, depicts the middle range theory which was developed, proposed and tested by the researcher in this study based on Mishel's Reconceptualized Uncertainty in Illness theory. The middle range theory proposes that:

1. Deceased-donor kidney transplant candidates show growth through uncertainty as Mishel describes.
2. The level of uncertainty is related to waiting time in deceased-donor kidney transplant candidates.
3. Growth through uncertainty is related to both the waiting time and the level of uncertainty experienced by the deceased-donor kidney transplant candidate.

Data Analysis

The analyses that were completed using IBM SPSS statistical software (version 19) included descriptive statistics. Frequencies, percentages, ranges, means and standard deviations

were used to describe the sample and the performance on the MUIS-C and the GTUS. The relationships among waiting time, level of uncertainty and growth through uncertainty were analyzed using Pearson correlation coefficients. One participant did not complete multiple items on the GTUS and was excluded from the data analysis. The independent-groups t-test was used to determine if individuals who had been waiting for a kidney transplant longer, based on the national median time to transplant, differed in level of uncertainty and growth through uncertainty when compared to those who had been waiting less than or equal to the median time to transplant. A serendipitous finding was the large number of volunteers and the high percentage of African Americans in the sample. Since racial ethnic differences in kidney transplantation have been described in the literature (Hall et al., 2011) and over 78% of the participants in this study were African Americans, the relationships among waiting time, level of uncertainty and growth through uncertainty were analyzed for the African American and White subsets in the sample. Among the sample, two participants did not indicate their race and four of the participants were from a racial group other than White or African American.

Growth through Uncertainty

The first research question was: Do kidney transplant candidates experience growth through uncertainty as Mishel's Reconceptualized Uncertainty in Illness theory proposes? Mishel (1990) maintains that prolonged uncertainty can be accepted and integrated into one's life and leads to a new view of life or growth through uncertainty. The GTUS provides a measure of growth through uncertainty. Scores on the GTUS can range from 39-234 with higher scores indicating greater growth through uncertainty. The results for the participants in this study ranged from 67-223. The mean score for the participants was 154.6 with a standard deviation of 29.3. In previous studies of individuals living with continual illness-related uncertainty,

including breast cancer survivors, parents of children with cancer, and men with prostate cancer, the mean GTUS score ranged from 137.40 to 166.00 (see Table 5). The mean GTUS score of 154.6 in this study falls within the range of mean scores of previous studies with other patient populations. Therefore, the answer to the first research question is: Yes, kidney transplant candidates waiting for a deceased-donor transplant do experience growth through uncertainty as Mishel describes in her Reconceptualized Uncertainty in Illness Theory.

Similar to the experience of uncertainty with chronic health conditions, the continual uncertainty of waiting for a kidney transplant can lead to a new view of life.

Relationship among Waiting Time, Level of Uncertainty and Growth through Uncertainty

The second research question was: What are the relationships among waiting time, level of uncertainty and growth through uncertainty for deceased donor kidney transplant candidates? Participants in this study had transplant waiting times ranging from 3-180 months with a mean waiting time of 37.8 months. The level of uncertainty measured by the MUIS-C ranged from 27-89 with higher scores indicating greater uncertainty. The scores on the measure of growth through uncertainty, the GTUS, ranged from 39-234. Table 6 summarizes these results.

Pearson correlation coefficients were used to determine the relationships among waiting time, level of uncertainty, and growth through uncertainty. These relationships were analyzed for the total sample, and the African American and White subsets of the sample. These correlation coefficients are reported in Table 7.

Table 5

Growth Through Uncertainty Scale (GTUS) Scores in the Literature

Study	<i>n</i>	<i>M</i>
Bailey et al. (2004)	49 men with prostate cancer	137.40 (pre-intervention) 152.10 (post-intervention)
Lin et al. (2010)	301 parents of children with cancer	156.63
Mast (1998)	109 survivors of breast cancer	166.00
Current study	134 deceased-donor kidney transplant candidates	154.6

Table 6

Mean, Standard Deviation, Potential Ranges and Obtained Ranges

Measure	<i>n</i>	<i>M</i>	<i>SD</i>	Potential Range	Obtained Range
Growth through uncertainty	134	154.6	28.16	39-234	83-226
Waiting Time	134	37.95	28.19	N/A	3-180 months
Level of uncertainty	134	55.85	12.97	23-115	27-89

Table 7

Intercorrelations of MUIS-C, GTUS, and Waiting Time for Total Group (n = 134), African

Americans (n = 103,) and Whites (n = 25)

	Total		African American		White	
	GTUS	Wait Time	GTUS	Wait Time	GTUS	Wait Time
MUIS-C	-.06	-.02	-.06	.03	-.12	-.41*
GTUS	--	.27**	--	.24*	--	.18
Wait Time		--		--		--

Note. * $p < .05$, ** $p < .01$.

A positive relationship was found between waiting time and growth through uncertainty for the total population ($r = .27, p < .01$). Although the strength of this positive relationship is classified as low (Munro, 2005), the significance indicates a stable relationship. Other proposed relationships between waiting time and level of uncertainty, or between growth through uncertainty and level of uncertainty were not significant for the total population. A similar relationship between waiting time and growth through uncertainty was found in the African American subset ($r = .24, p < .05$), but no significant relationship between waiting time and growth through uncertainty was found in the White subset. Waiting time was inversely related to level of uncertainty for Whites ($r = .41, p < .05$).

Division into waiting time categories. In order to address the wide range of waiting times for the participants in this study, the sample was divided into two groups, those who had been waiting less than or equal to the national median waiting time to transplant of 1297 days (United States Department of Health and Human Services, Health Resources and Services Administration, Organ Procurement and Transplantation Network, 2012) and those who had been waiting longer than or equal to the national median waiting time. The median time to transplant is from the point of view of a transplant candidate who has just been registered on the waiting list for a kidney. Differences in level of uncertainty and growth through uncertainty between the two waiting time groups were examined using the Independent-groups t-test. The test results, listed in Table 8, indicated a significant difference in the GTUS scores between those who had been waiting longer and those who had been waiting less time ($p < .001$). No statistically significant difference in MUIS-C was found between the categories of waiting time for the total sample.

Table 8

Independent-groups T-Test for Uncertainty and Growth Through Uncertainty by Waiting

Time Category

	Total Sample				African American				White			
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>p</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>p</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>p</i>
<u>GTUS</u>												
$\leq MD$	86	151.8	25.0		89	159.4	26.5		18	142.83	26.0	
$> MD$	48	170.9	29.5	.000	14	172.9	31.7	.090	7	150.14	38.4	.566
<u>MUISC</u>												
$\leq MD$	86	56.0	11.4		89	55.9	12.4		18	57.22	12.9	
$> MD$	48	55.2	15.5	.73	14	57.7	14.2	.743	7	48.00	7.9	.138

African American subset. Differences in level of uncertainty and growth through uncertainty between the two waiting time categories were examined separately for the large (n = 103) sample of African Americans in the study. The national median waiting time for a kidney transplant for African Americans of 1968 days is longer than the median time to transplant for total population of kidney transplant candidates on the wait list for a deceased-donor kidney (United States Department of Health and Human Services, Health Resources and Services Administration, Organ Procurement and Transplantation Network, 2012). Eighty-nine African American participants had been waiting less than or equal to the national median waiting time to kidney transplant for African Americans and 14 had been waiting longer than the national median time to transplant for African Americans.

An Independent-groups t-test was used to compare growth through uncertainty (GTUS) and level of uncertainty (MUIS-C) in the two waiting time groups. There are very different means for the GTUS in these two groups. The mean for the GTUS for the group with wait times at or above the median time to transplant for African Americans was 172.93, while the group that had been waiting for less than the median time to transplant had a mean of 159.42. However, the sample sizes in the two waiting time groups were widely different (n = 14 and n = 89), leaving the researcher to wonder if more participants had been waiting longer than the median time to transplant, would the results have reached statistical significance? When level of uncertainty was compared for transplant candidates who had been waiting less the median time to transplant and transplant candidates who had been longer than 1968 days, no significant difference was found.

White subset. The median time to transplant for White transplant candidates is 952 days (United States Department of Health and Human Services, Health Resources and Services Administration, Organ Procurement and Transplantation Network, 2012). When the white subset

of participants is considered, no statistically significant relationship between waiting time category and level of uncertainty or between waiting time category and growth through uncertainty was found for the white participants, although there is a difference in the means for the MUIS-C and the GTUS. The total number of White participants was small and the sample size was also disparate in this subset with 18 White participants waiting less than the median time to transplant and seven in the group that had been waiting at or above the median time to transplant.

Middle Range Theory

A middle range theory of the relationship among waiting time, level of uncertainty, and growth through uncertainty was proposed and tested in this study. It was proposed that:

1. Deceased-donor kidney transplant candidates show growth through uncertainty as Mishel describes.
2. The level of uncertainty is related to waiting time in deceased-donor kidney transplant candidates.
3. Growth through uncertainty is related to both the waiting time and the level of uncertainty experienced by the deceased-donor kidney transplant candidate.

The first proposition in the middle range theory is supported by the results. The sample of kidney transplant candidates in this study demonstrated growth through uncertainty based on the results of Mishel's GTUS. Scores on the GTUS quantify growth through uncertainty with higher scores indicating greater growth through uncertainty. The mean score for the sample was 158.66 out of a maximum of 234. The mean score in this study was within the range of means of other studies using the GTUS (Bailey et al., 2004; Lin et al., 2010; Mast, 1998).

The second proposition in the middle range theory proposed in the study was not supported by the results when considering the total sample. There was no relationship between level of uncertainty, which was the score on the MUIS-C, and waiting time. However, when considering the White subset, an inverse relationship was found between waiting time and level of uncertainty, with longer waiting times associated with lower scores on the MUIS-C. The final proposition in the theory stating that growth through uncertainty was related to both waiting time and level of uncertainty was partially supported. No relationship between level of uncertainty and growth through uncertainty was found. However, there was a significant positive relationship ($r = .265$, $p = .002$) between waiting time and growth through uncertainty in the sample indicating that a longer waiting time for a transplant was associated with greater growth through uncertainty (see Figure 4).

The findings in this study supported two important propositions in the theory:

- The sample of deceased-donor kidney transplant candidates demonstrated growth through uncertainty,
- There was a significant positive relationship between waiting time and growth through uncertainty in deceased-donor kidney transplant candidates (see Figure 4).

In addition, among White participants, there was a significant relationship between waiting time and level of uncertainty, although, no relationship between waiting time and level of uncertainty was found for the total study population. Therefore, support of the proposed relationships was mixed.

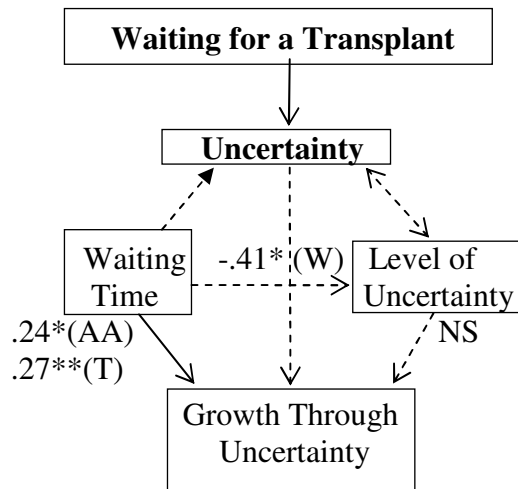


Figure 4. Correlations for the relationships proposed in the middle range theory of the experience of uncertainty while waiting for a kidney transplant.

Note. Description of the correlation among growth through uncertainty, waiting time, and level of uncertainty proposed in the middle range theory. T = total study population. W = White subset of study population. AA = African American subset of the study population. NS = Not statistically significant. $*p < .05$, $**p < .01$.

Summary

This chapter describes the analysis of data for this study. Descriptive statistics were provided for each scale used in the study and for waiting time. The correlation coefficient for waiting time, level of uncertainty, and growth through uncertainty was determined to describe the relationships among them. The independent-groups t-test was used to compare those whose waiting times were longer than the national kidney transplant median waiting time to transplant with those whose waiting times were less than or equal to the national median time to transplant. Results indicated that deceased-donor transplant candidates experience growth through uncertainty as described by Mishel and there was a positive relationship between waiting time and growth through uncertainty. The African American subset was analyzed separately and waiting time was also associated with growth through uncertainty in this subset. These results support an important proposition in the middle range theory proposed in this study.

CHAPTER V: DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

Qualitative studies have identified the experience of uncertainty as a key feature of the pre-transplant period (Baker & McWilliam, 2003; Brown et al., 2006; Liddle & Innes, 2005; Weems & Patterson, 1989) which can be prolonged. According to Mishel's Reconceptualized Uncertainty in Illness Theory, continued uncertainty associated with chronic illness can lead to growth through uncertainty and a new view of life (Mishel, 1990). The purpose of this study was to further describe the experience of uncertainty during the wait for a transplant, which will help identify patient needs and contribute to the development of nursing interventions to improve the nursing care of this growing population. A middle range theory was tested that proposes that deceased-donor kidney transplant candidates show growth through uncertainty as described by Mishel (1990). Since nurses are structure providers within this theoretical framework, they can help transplant candidates appraise illness-related uncertainty as opportunity rather than danger. The relationships among waiting time, level of uncertainty, and growth through uncertainty were explored to provide further understanding of the experience of uncertainty in deceased-donor kidney transplant candidates. A descriptive survey research design was used to address the following research questions:

1. Do deceased donor kidney transplant candidates experience growth through uncertainty as defined by Mishel?
2. What are the relationships among waiting time, level of uncertainty and growth through uncertainty for deceased donor kidney transplant candidates?

The discussion of the findings, conclusions, and recommendations are presented in this chapter.

Discussion

The purpose of this study was to describe the experience of uncertainty in deceased-donor kidney transplant candidates through testing of a middle range theory that proposes that:

1. Deceased-donor kidney transplant candidates show growth through uncertainty as Mishel (1990) describes.
2. The level of uncertainty is related to waiting time in deceased-donor kidney transplant candidates.
3. Growth through uncertainty is related to both the waiting time and the level of uncertainty experienced by the deceased-donor kidney transplant candidate.

Personal growth in response to living with sustained uncertainty has been proposed in the literature (Mishel, 1990; Penrod, 2007). As noted in the first proposition of the middle range theory, Mishel has described growth through uncertainty in chronic illness, and the GTUS was developed to quantify growth through uncertainty. Although growth through uncertainty has been described for chronic conditions such as in men with prostate cancer (Bailey et al., 2004) and in breast cancer survivors (Mast 1998; Porter et al., 2006), the question of whether or not deceased-donor kidney transplant candidates appraise uncertainty as an opportunity and develop a new view of life that no longer includes an expectation of predictability had not been addressed. The questioning of the experience of growth through uncertainty in transplant candidates stemmed from descriptions of the pre-transplant period in the literature as being a time when “life was on hold” (Moran et al., 2011) or likened to “walking in the dark” (Weems & Patterson, 1989), but also could be a time of transformation (Brown et al., 2006). Was the appraisal of uncertainty while enduring this wait and hoping for a transplant to lead to greater well-being different than the appraisal of uncertainty in chronic illness, when uncertainty may be preferred to confirmation that one’s condition is worsening? When tested in this study, deceased-donor kidney transplant candidates did experience growth through uncertainty, indicating that they respond to the ongoing uncertainty during the wait for a transplant by integrating

uncertainty into their life and creating a new view of life, which Mishel labeled growth.

Although the mean for the GTUS in this study fell within the range of means for previous studies using the GTUS (Bailey et al., 2004; Lin et al., 2010; Mast, 1998), the scores for the GTUS in this study ranged from 83-226, indicating that some deceased-donor kidney transplant candidates experienced more growth through uncertainty than others.

The second proposition proposes that deceased-donor kidney transplant candidates have different levels of uncertainty associated with different waiting times for a transplant. Brashers et al. (2003) suggest that appraisal of illness-related uncertainty may vary over time. Findings in qualitative research have suggested: The stressors and the experience of uncertainty change during the wait for a transplant (Brown et al., 2006; Corruble et al., 2010; Evangelista et al., 2005; Moran et al., 2011; Weems & Patterson, 1989); there are different responses to different pre-transplant waiting times (Brown et al., 2006; Moran et al., 2011; Weems & Patterson, 1989) and there is a need for further description of uncertainty pre-transplant, especially in relation to waiting time (Brown et al., 2006; Cupples et al., 1998; Martin et al., 2010; Stoeckle, 1993). The present study measured uncertainty in deceased-donor kidney transplant candidates and explored the relationship between waiting time and level of uncertainty. Overall, the level of uncertainty reported by deceased-donor kidney transplant candidates in the present study did not vary based on waiting time. However, when the subset of White transplant candidates was considered, uncertainty decreased as the waiting time increased. The mean waiting time for the White participants of 25 months was less than the mean waiting time of almost 38 months for the total sample in the study, raising the question of whether, initially, uncertainty decreases as waiting time increases, but, at some point, as waiting time increases, the level of uncertainty experienced by kidney transplant candidates becomes more

variable. Lasker, Sogolow, Olenik, Sass, and Weinrieb (2010) found that uncertainty in women waiting for a liver transplant was related to fatigue, depression, fear/anxiety, and satisfaction with Information while on the waiting list. Other factors may have a greater correlation with level of uncertainty in deceased-donor kidney transplant candidates than waiting time.

The third relationship proposed in the middle range theory in this study was that growth through uncertainty is related to waiting time and to level of uncertainty in deceased-donor kidney transplant candidates. Bailey and Nielson (1993) found higher levels of uncertainty may lead to appraisal of uncertainty as a threat rather than an opportunity. The proposed relationship suggests that transplant candidates who are more uncertain do not experience the same amount of growth through uncertainty as those who are less uncertain. No significant relationship between the level of uncertainty for deceased-donor kidney transplant candidates and growth through uncertainty was found in this study. Similarly, Lin et al. found that parental uncertainty did not have a significant direct effect on growth through uncertainty in Taiwanese parents of children with cancer. Perhaps level of uncertainty needs to be considered in combination with other factors when examining the relationship of uncertainty to growth through uncertainty in transplant candidates. Lin et al. (2010) found that coping mediated the effect of parental uncertainty on growth through uncertainty. In their study of breast cancer survivors, Porter et al. (2006) constructed a variable labeled “negative cognitive state” consisting of uncertainty, troublesome thoughts, and catastrophizing, which was a significant predictor of personal growth.

The relationship between waiting time and growth through uncertainty was also explored in this study. Living longer with uncertainty may be associated with how uncertainty is appraised (Bailey & Nielsen, 1993; Mishel, 1990). This study demonstrated that a longer waiting time is

related to greater growth through uncertainty in deceased-donor kidney transplant candidates, which supported an important proposition in the middle range theory proposed in this study. While various factors can influence the appraisal of uncertainty, the relationship between waiting time and growth through uncertainty in this study builds support for Mishel's Reconceptualized Uncertainty in Illness Theory which proposes that continued uncertainty, such as waiting for a transplant, may lead to a new view of life (Mishel, 1990).

Uncertainty has been identified as a pervasive characteristic of the wait for a transplant in qualitative studies (Baker & McWilliam, 2003; Brown et al., 2006; Liddle & Innes, 2005; Weems & Patterson, 1989). The description of uncertainty and growth through uncertainty for deceased-donor kidney transplant candidates in this study builds on the qualitative studies that have focused on the experience of waiting for a transplant. The study adds to the description of uncertainty pre-transplant through quantitatively describing the relationship between uncertainty and waiting time and the experience of growth through uncertainty in deceased-donor kidney transplant candidates. Studies that focus on the pre-transplant period are limited in the literature. The results of this study expand what is known about the experience of waiting for a transplant.

A descriptive survey research design was used to explore the relationships among waiting time, level of uncertainty, and growth through uncertainty in this study. The modifications in methodology that were necessary to implement this study may provide some insight into reaching the population of kidney transplant candidates in the community. Each change in strategy to recruit participants required UMIRB approval. Initially, recruitment of participants was a struggle. Fliers posted at dialysis clinics and messages on a National Kidney Foundation Message Board recruited less than a tenth of the overall number of participants. Ultimately, a mailed survey was the most effective means to reach the deceased-donor kidney transplant

candidates. Over 50% of the transplant candidates actively waiting for a deceased-donor kidney at a transplant center responded when the survey was mailed to them. Mailing the survey through the transplant center may have added to the credibility of the study.

The majority of the transplant candidates at the transplant center that mailed the survey are African American and most of the participants in the study are African American. Patients with ESRD who are African American are less likely to be on the wait list for a kidney transplant, although the African American population has a higher incidence of ESRD (Hall et al., 2011). African Americans comprise approximately 14% of the population in the United States (U.S. Department of Commerce, United States Census Bureau), but about 37% of kidney transplant candidates are African American [Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR)]. Once on the wait list for a kidney transplant, African Americans wait longer for a transplant. The description of growth through uncertainty and the relationships among waiting time, level of uncertainty and growth through uncertainty for the large subset of African Americans in this study provides additional information on the experience uncertainty while waiting for a transplant in this more vulnerable population.

The instruments (MUIS-C and GTUS) were reliable for the sample in this study. The MUIS-C has been more extensively used in research measuring uncertainty in various populations (Mishel, 1997). The GTUS has been used in few studies, but the growth through uncertainty found in the study sample falls within the range of means of other studies using the GTUS. However, further research may consider questions that are uniquely crafted for the pre-transplant period.

The methodology of this study has both strengths and limitations. The sample size contributed to the strength of the analysis in this study. These findings are specific to the deceased-donor kidney transplant candidates in the study and are not generalizable to other types of organ transplants.

Mishel's Reconceptualized Uncertainty in Illness Theory was the framework for this study. From Mishel's theory a middle range theory was proposed and tested. A key proposition of the middle range theory was that deceased-donor kidney transplant candidates experience growth through uncertainty as Mishel describes. This proposition was supported which allowed for testing the proposed relationship among growth through uncertainty, waiting time and level of uncertainty.

Conclusions

Waiting for a transplant implies uncertainty; the unknown of when or if an organ will become available. Transplant candidates appraise and respond to uncertainty in the liminal space between the promise of a transplant and the threat of death which affects their well-being during the wait for a transplant (Brown et al., 2006; Molzahn et al., 2008). The description of uncertainty experienced by deceased-donor kidney transplant candidates in this study builds on qualitative research that identified uncertainty as a theme of the pre-transplant period. Previous studies on the experience of waiting for a transplant noted differences related to waiting time (Brown et al., 2006; Cupples et al., 1998; Evangelista et al., 2005; Martin et al., 2010; Stoeckle, 1993). This study specifically focused on waiting time, describing the relationship among waiting time, level of uncertainty and growth through uncertainty.

Mishel (1990) contends that continued illness-related uncertainty can lead to growth through uncertainty. The findings of this study support Mishel's Reconceptualized Uncertainty in

Illness Theory that a new view of life can evolve when sustained uncertainty is experienced. For the deceased-donor kidney transplant candidates in this study, greater growth through uncertainty was associated with longer waiting time. Therefore, the present study contributes to the development of the theory of uncertainty in illness through describing the growth through uncertainty experienced by deceased-donor kidney transplant candidates and the relationship between waiting time for a transplant and growth through uncertainty. Studies based on Mishel's Reconceptualized Uncertainty in Illness Theory have considered growth through uncertainty in chronic conditions such as prostate cancer, childhood cancer, and breast cancer (Bailey et al., 2004; Lin et al., 2010; Mast, 1998). There was no prior research in the literature on the measurement of growth through uncertainty in kidney transplant candidates and limited research on the experience of uncertainty pre-transplant in Nursing and other health care literature. The present study extends understanding of sustained uncertainty in illness.

Nurses and other health care providers, who are conceptualized as structure providers in Mishel's Reconceptualized Uncertainty in Illness Theory (Bailey & Stewart, 2010; Mishel, 1990; Mishel & Clayton, 2008), may influence the appraisal of uncertainty by transplant candidates. Appraising the uncertainty associated with waiting for a transplant as an opportunity rather than a threat may improve the well-being of the transplant candidate. Expanding the care of transplant candidates to include consideration of how they appraise uncertainty associated with the unpredictable wait for a transplant may encourage the development of interventions to help transplant candidates incorporate the uncertainty into a new view of life.

Recommendations

The findings of this study suggest several areas for further research:

- Are there factors other than waiting time associated with growth through uncertainty in transplant candidates?
- How can the role of structure providers within the theoretical framework, including nurses, be expanded to support transplant candidates?
- Since the uncertainty related to when or if a transplant will occur cannot be eliminated, how can transplant candidates be supported while they are waiting for a transplant?
- What nursing interventions might be developed for helping transplant candidates to incorporate sustained uncertainty into a new view of life?

Some qualitative studies have considered the experience of waiting for a transplant for family members and support persons (Mishel & Murdaugh, 1987; Pelletier-Hibbert & Sohi, 2001; Saxe-Braithwaite & Chapman, 1992; Starzomski & Hilton, 2000). Mishel's Reconceptualized Uncertainty in Illness Theory proposes that support persons influence appraisal of uncertainty (Bailey & Stewart, 2010; Mishel, 1990; Mishel & Clayton, 2008). Further study is needed on how caregivers or support persons may influence the experience of uncertainty and growth through uncertainty pre-transplant. Nurses and other health care providers can then consider interventions that include consideration of support persons. Essentially, ongoing research needs to add to the understanding of the experience of waiting for a transplant and lead to changes in care that will provide more support to those who wait.

In this study, growth through uncertainty was positively related to waiting time for transplant candidates. Research to look more specifically at waiting time and differences in the appraisal of uncertainty may help tailor nursing interventions that will provide greater support to transplant candidates. A study sample that has a more equal distribution of waiting times and

includes more transplant candidates who have been waiting longer than the median time to transplant would provide more specific information related to waiting time. A longitudinal study would allow for assessing how a transplant candidate appraises uncertainty over time. The instruments used in this study have been used to measure uncertainty and growth through uncertainty with individuals with a variety of chronic health conditions. Development of tools specific to transplant candidates may be a means to assess the experiences of transplant candidates during the wait and may be designed to help identify the support that a transplant candidate may want from health care providers.

Comments were not solicited from participants, but, when comments were volunteered by a participant they were noted. The comments were anecdotal related to their experience or were in response to a particular item on the GTUS or MUIS-C. Fewer than 10% of the participants commented, but the comments may provide some insight into areas for further research. Some of the comments volunteered by participants (see Appendix L) relate to maintaining hope during the wait for a transplant. Transplant candidates may wonder if they will ever be called to receive a transplant and getting through each day may mean continuing to hope that the call will come. Some participants described praying and trusting in God to help them during the wait for a transplant. These comments suggest that spirituality and the ability to remain hopeful may affect how uncertainty is appraised. One participant suggested that more communication with the transplant center and more knowledge of successful transplants may help preserve hope. Previous studies have considered hope, coping or spiritual well-being in relation to the experience of uncertainty (Anema et al., 2009; Lin et al., 2010; Weems & Patterson, 1989). Future studies of the experience of waiting for a transplant should consider what influences how a transplant candidate responds to the uncertainty including:

- What coping strategies do transplant candidates use during the wait for a transplant? Do coping mechanisms change as waiting time increases? How are coping strategies related to the experience of uncertainty and growth through uncertainty?
- What is the relationship among spirituality, waiting time, uncertainty, and growth through uncertainty?
- What interactions with nurses and other health care providers facilitate hope and coping during the wait for a transplant?

The large African American subset in this study reflects the higher number of African Americans who are waiting for a kidney transplant. Although, not the purpose of this study, based on the suggestion by Brown et al. (2006) that different cultural beliefs about time and illness may lead to different experiences of time pre-transplant, the unique experiences of this population during the wait for a transplant need further description.

- How is the experience of African American deceased-donor kidney transplant candidates different?
- Are different types of intervention needed to support African Americans as they wait for a transplant and/or is support needed at different times?

Exploring the relationship between demographic factors, such as age, education, and marital status, and uncertainty and growth through uncertainty may also increase understanding of the experience of uncertainty while waiting for a transplant.

Summary

This chapter discusses the findings of this study, the conclusions drawn from this study, and recommendations for further study. The findings of this study extend nursing knowledge through providing further understanding of the appraisal of uncertainty in deceased-

donor transplant candidates. An important proposition of the middle-range theory proposed in this study was supported by the findings, which builds support for Mishel's Reconceptualized Uncertainty in Illness Theory. The results also provide direction for future research focused on describing other factors that influence growth through uncertainty in transplant candidates and the development of nursing interventions that facilitate the integration of uncertainty into a new life view and offer support during the wait for a transplant.

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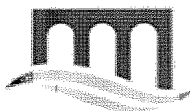
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APPENDIX A: UNIVERSITY MEDICAL CENTER INSTITUTIONAL REVIEW

BOARD LETTERS OF APPROVAL



EAST CAROLINA UNIVERSITY

University & Medical Center Institutional Review Board Office
1L-09 Brody Medical Sciences Building • 600 Moye Boulevard • Greenville, NC 27834
Office 252-744-2914 • Fax 252-744-2284 • www.ecu.edu/irb

TO: Janet Pelletier, 5410 Trade Winds Rd., New Bern, NC 28560

FROM: UMCIRB *JK*

DATE: November 19, 2010

RE: Expedited Category Research Study

TITLE: "Appraisal of Uncertainty While Waiting for a Kidney Transplant"

UMCIRB #10-0661

This research study has undergone review and approval using expedited review on 11.17.10. This research study is eligible for review under an expedited category number 7. The Chairperson (or designee) deemed this **unfunded** study **no more than minimal risk** requiring a continuing review in **12 months**. Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The investigator must adhere to all reporting requirements for this study.

The above referenced research study has been given approval for the period of **11.17.10 to 11.16.11**. The approval includes the following items:

- Internal Processing Form (dated 10.28.10)
- Telephone Script
- COI Disclosure Form (dated 11.15.10)
- Request for Waiver or Alteration of Informed Consent
- Survey
- Research Proposal
- Advertisement

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

The UMCIRB applies 45 CFR 46, Subparts A-D, to all research reviewed by the UMCIRB regardless of the funding source. 21 CFR 50 and 21 CFR 56 are applied to all research studies under the Food and Drug Administration regulation. The UMCIRB follows applicable International Conference on Harmonisation Good Clinical Practice guidelines.

*****IMPORTANT INFORMATION*****

Continuing Review/Closure Obligation

As a investigator you are required to submit a continuing review/closure form to the UMCIRB office in order to have your study renewed or closed before the date of expiration as noted on your approval letter. This information is required to outline the research activities since it was last approved. You must submit this research form even if you there has been no activity, no participant s enrolled, or you do not wish to continue the activity any longer. The regulations do not permit any research activity outside of the IRB approval period. Additionally, the regulations do not permit the UMCIRB to provide a retrospective approval during a period of lapse. Research studies that are allowed to be expired will be reported to the Vice Chancellor for Research and Graduate Studies, along with relevant other administration within the institution. The continuing review/closure form is located on our website at www.ecu.edu/irb under forms and documents. The meeting dates and submission deadlines are also posted on our web site under meeting information. Please contact the UMCIRB office at 252-744-2914 if you have any questions regarding your role or requirements with continuing review.
<http://www.hhs.gov/ohrp/humansubjects/guidance/contrev0107.htm>

Required Approval for Any Changes to the IRB Approved Research

As a research investigator you are required to obtain IRB approval prior to making any changes in your research study. Changes may not be initiated without IRB review and approval, except when necessary to eliminate an immediate apparent hazard to the participant. In the case when changes must be immediately undertaken to prevent a hazard to the participant and there was no opportunity to obtain prior IRB approval, the IRB must be informed of the change as soon as possible via a protocol deviation form.
<http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm#46.103>

Reporting of Unanticipated Problems to Participants or Others

As a research investigator you are required to report unanticipated problems to participants or others involving your research as soon as possible. Serious adverse events as defined by the FDA regulations may be a subset of unanticipated problems. The reporting times as specified within the research protocol, applicable regulations and policies should be followed.
<http://www.hhs.gov/ohrp/policy/AdvEvtGuid.htm>



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Notification of Amendment Approval

From: Biomedical IRB

To: [Janet Pelletier](#)

CC: [Martha Alligood](#)

Date: 11/28/2011

Re: [Ame1 UMCIRB 10-0661](#)

[UMCIRB 10-0661](#)

[IMPORTED] Appraisal of Uncertainty While Waiting for a Kidney Transplant

Your Amendment has been reviewed and approved using expedited review for the period of 11/23/2011 to 11/22/2012 . It was the determination of the UMCIRB Chairperson (or designee) that this revision does not impact the overall risk/benefit ratio of the study and is appropriate for the population and procedures proposed.

Please note that any further changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. A continuing or final review must be submitted to the UMCIRB prior to the date of study expiration. The investigator must adhere to all reporting requirements for this study.

The approval includes the following items:

Name	Description	Modified	Version
Mailing information.docx History	Additional Items	11/11/2011 3:36 PM	0.01
Reminder Postcard content.docx History	Recruitment Documents/Scripts	11/11/2011 3:06 PM	0.01
Survey Consent Letter for mailing.doc History	Recruitment Documents/Scripts	11/11/2011 3:05 PM	0.01
UHS Transplant Services letter.docx History	Recruitment Documents/Scripts	11/11/2011 3:04 PM	0.01

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
 IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418 IRB00004973

East Carolina U IRB #4 (Behavioral/SS Summer) IORG0000418



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Notification of Continuing Review Approval: Expedited

From: Biomedical IRB
 To: [Janet Pelletier](#)
 CC: [Martha Alligood](#)
 Date: 11/7/2012
[CR00000615](#)
 Re: [UMCIRB 10-0661](#)
 [IMPORTED] Appraisal of Uncertainty While Waiting for a Kidney Transplant

The continuing review of your expedited study was approved. Approval of the study and any consent form(s) is for the period of 11/7/2012 to 11/6/2013. This research study is eligible for review under expedited category #7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

The approval includes the following items:

Name	Description	Modified	Version
demographics.doc History	Surveys and Questionnaires	11/1/2011 5:37 PM	0.01
flier submitted.docx History	Recruitment Documents/Scripts	11/1/2011 5:34 PM	0.01
Growth Through Uncertainty Scale.doc History	Surveys and Questionnaires	11/1/2011 5:39 PM	0.01
letter for participants.docx History	Information Sheet	11/1/2011 6:16 PM	0.01

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Notification of Amendment Approval

From: Biomedical IRB
To: [Janet Pelletier](#)
CC: [Martha Alligood](#)
Date: 11/7/2012
Re: [Ame2_ UMCIRB 10-0661](#)
[UMCIRB 10-0661](#)
[IMPORTED] Appraisal of Uncertainty While Waiting for a Kidney Transplant

Your Amendment has been reviewed and approved using expedited review for the period of 11/7/2012 to 11/6/2013 . It was the determination of the UMCIRB Chairperson (or designee) that this revision does not impact the overall risk/benefit ratio of the study and is appropriate for the population and procedures proposed.

Please note that any further changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. A continuing or final review must be submitted to the UMCIRB prior to the date of study expiration. The investigator must adhere to all reporting requirements for this study.

The approval includes the following items:

Sample size increased to from 100 to 150.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418 IRB00004973

APPENDIX B: PERMISSIONS

FW: Mishel 's Model

ZZZ_Pelletier, Janet Bottomley [JBP1024@ecu.edu]

Sent: Thursday, September 30, 2010 8:08 AM

To: Pelletier, Janet Bottomley

Attachments: Figure 2.doc (22 KB) ; Janet Figure.doc (35 KB) ; reconceptualized figure.doc (95 KB)

From: Chip Bailey [cbaile061@mc.duke.edu]

Sent: Sunday, October 21, 2007 9:07 AM

To: Pelletier, Janet Bottomley

Subject: Re: Mishel 's Model

Janet, I didn't have these in a manuscript, just models I have worked with over the years. Use any of this that is helpful (or not). Sounds as if you are moving forward! Great news! Keep me posted. Chip, I didn't get to the program last Thursday night.

Chip Bailey, PhD, RN
Assistant Professor
Senior Fellow, Center for the Study of Aging and Human Development
John A. Hartford Foundation Fellow - 2003-2005
Duke University School of Nursing - Office 3005
DUMC 5322
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Phone: 919-681-3003
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"Pelletier, Janet Bottomley" <JBP1024@ECU.EDU>

10/20/2007 11:38 PM

To: <cbaile061@mc.duke.edu>

cc:

Subject: Mishel 's Model

Hi-

Did I understand you to say that one of your articles had a model that depicted the antecedents from the original model with the reconceptualized model? If so, which article was it? Unfortunately, with moving some of my articles were put in different places and I am still sorting them out.

Janet

[https://sn2prd0102.outlook.com/owa/?ec=Item&it=IPM Note&ic=RgAAAD7A8FiD63k...](https://sn2prd0102.outlook.com/owa/?ec=Item&it=IPM+Note&ic=RgAAAD7A8FiD63k...) 10/6/2012

FW: Dr. Mishel's Manual and Scale

Z77_Pelletier, Janet Bottomley [jBP1024@ecu.edu]

Sent: Thursday, September 30, 2010 7:45 AM

To: Pelletier, Janet Bottomley

Attachments: New PDF made 2-25-2009.pdf (4 MB) ; Community Form.doc (35 KB) ; 20100108083514677.pdf (48 KB)

From: sandy staley [sstaley@email.unc.edu]

Sent: Friday, January 08, 2010 8:44 AM

To: Pelletier, Janet Bottomley

Subject: Dr. Mishel's Manual and Scale

Thank you for your request for Dr. Mishel's MUTS-C and manual. Please find them attached to this email along with a signed copy of your request form. If I can be of further assistance, please feel free to contact me.

Sandy Staley
Project Support Technician
UNC School of Nursing
3300 Carrington Hall, CB 7460
Chapel Hill, NC 27599-7460

FW: Dr. Mishel's Scale

Alligood, Martha [ALLIGOODMAR@ecu.edu]

Sent: Wednesday, November 14, 2012 9:18 AM

To: Pelletier, Janet Bottomley

Importance: High

Attachments: Growth Through Uncertainty~1.doc (69 KB)

Martha Raile Alligood, PhD, RN, ANEF
Professor
East Carolina University College of Nursing
Health Sciences Building, #3146
Greenville, NC 27858-4323
(252) 744-6416 Office
(252) 744-6388 FAX
alligoodmar@ecu.edu

Hope is hearing the harmony of the future; faith is dancing to it today.

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

From: Martha R. Alligood [mailto:alligoodmar@suddenlink.net]

Sent: Tuesday, December 01, 2009 6:00 PM

To: Alligood, Martha

Subject: Fw: Dr. Mishel's Scale

Martha Raile Alligood, RN, PhD, ANEF

122 Providence Place

Chocowinity, NC 27817

(252) 946-5120 Home phone

(252) 975-5130 Home FAX

alligoodmar@suddenlink.net

"Theory without practice is empty and practice without theory is blind"
(Cross, 1981)

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

From: "sandy staley" <sstaley@gmail.unc.edu>

To: <alligoodmar@suddenlink.net>

Sent: Monday, November 23, 2009 7:17 AM

Subject: Dr. Mishel's Scale

- > Please find attached a copy of Dr. Mishel's Growth Through Uncertainty
- > Scale. If I can be of further assistance, please don't hesitate to
- > contact me.
- >
- > --
- > Sandy Staley
- > Project Support Technician
- > UNC School of Nursing
- > 3300 Carrington Hall, CB 7460
- > Chapel Hill, NC 27599-7460
- >
- >

<https://sm2prd0102.outlook.com/owa/?ae=Item&tr=IPM.Note&id=RgAAAAD7A8EiD63k...> 11/14/2012

APPENDIX C: DEMOGRAPHIC FORM

IF YOU WANT TO MAIL THE SURVEY, PLEASE COMPLETE ALL PAGES OF THE SURVEY AND MAIL IN THE STAMPED ENVELOPE THAT IS ENCLOSED. FILL IN THE CARD WITH YOUR NAME AND ADDRESS AND PLACE IT IN THE ENVELOPE WITH THE SURVEY SO THAT YOU CAN RECEIVE \$10.00 TO THANK YOU FOR YOUR PARTICIPATION. OR, YOU CAN JUST CALL THE TOLL FREE NUMBER, 1-877-719-9910, TO COMPLETE THE SURVEY BY PHONE.

In order to analyze the information that you are providing, some information about your personal background is needed.

1. How long have you been on the wait list for a kidney transplant?

_____years _____months

2. Type of dialysis:

Hemodialysis

Peritoneal

None

3. How old are you? _____

(age in years)

4. Gender: Male Female

5. Race/Ethnicity: (Please check one)

African American

Asian/Pacific Islander

Hispanic/Latino

White

Other _____

(please specify)

6. Marital status: Married Divorced Widowed Single Living with partner

7. Number of years of education: _____

**APPENDIX D: MISHEL UNCERTAINTY IN ILLNESS SCALE
(Community) SAMPLE
Do not administer.**

INSTRUCTIONS:

Please read each statement. Take your time and think about what each statement says. Then place a “X” under the column that most closely measures how you are feeling TODAY. If you agree with a statement, then you would mark under either “Strongly Agree” or “Agree”. If you disagree with a statement, then mark under either “Strongly Disagree” or “Disagree”. If you are undecided about how you feel, then mark under “Undecided” for that statement. Please respond to every statement.

1. I am unsure if my illness is getting better or worse.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

2. The doctors say things to me that could have many meanings.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

3. It is difficult to know if the treatments or medications I am getting are helping.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

4. Because of the unpredictability of my illness, I cannot plan for the future.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

5. The seriousness of my illness has been determined.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

(http://nursing.unc.edu/ccm/groups/public/@nursing/documents/content/ccm3_032880.pdf)

APPENDIX E: GROWTH THROUGH UNCERTAINTY SCALE SAMPLE

I am interested in learning how your view of life has changed as a result of living with the uncertainty of waiting for a transplant. The statements below describe feelings people sometimes have in the period following an illness. **For each item, circle the response that best describes your feelings TODAY. Please make sure that you answer every item.** There are no right or wrong answers.

My life has new meaning.		6	5	4	3	2	1
		Strongly Agree	Moderately Agree	Agree	Undecided	Disagree	Strongly Disagree
D1	My situation has opened new possibilities for me.	Strongly Agree	Moderately Agree	Agree	Undecided	Disagree	Strongly Disagree
D2	I greet each day with more joy.	Strongly Agree	Moderately Agree	Agree	Undecided	Disagree	Strongly Disagree
D3	I fear the unexpected more now.	Strongly Agree	Moderately Agree	Agree	Undecided	Disagree	Strongly Disagree
D4	My dreams are clearer to me now.	Strongly Agree	Moderately Agree	Agree	Undecided	Disagree	Strongly Disagree
D5	I focus more now on what is important in life.	Strongly Agree	Moderately Agree	Agree	Undecided	Disagree	Strongly Disagree

APPENDIX F: STUDY FLIER



Are you waiting for a kidney transplant?

Share your experience. Receive a \$10 gift card.

Call toll free: 1-877-719-9910
Janet Pelletier, RN, FNP-BC (PHD Candidate)
East Carolina University College of Nursing

I'm a nurse studying to learn more about the waiting period for kidney transplants. Just one phone call and less than 30 minutes of your time will help this study improve care for transplant candidates. Your responses are strictly confidential.

Participation in this study is **NOT** associated with your health care at this center.

TAKE ONE

APPENDIX G: TELEPHONE SCRIPT

Telephone Script

Thank you for calling about my research study. I am a nurse and a doctoral student at East Carolina University. I will be talking with you to learn more about your experiences while waiting for a transplant.

I will be asking you a series of questions.

It will take about 30 minutes.

I will read a sentence to you and you will answer by telling me if you agree or disagree.

There are no right or wrong answers since this is about how you feel.

Your answers will be confidential and will be kept in a locked file

Your name is not used and you will not be personally identified.

I will ask for your mailing address only for sending you \$10.00 to thank you for participating. I will not be keeping this information.

You can ask questions about the study and you may stop at any time.

You may contact me at this toll free number and I will send you information on how to contact my advisor at East Carolina University in case you have questions about the research.

Do you have any questions about what I am asking you to do?

Do you have any questions about the confidentiality of the information you are giving me?

Do you have any other questions?

If you are ready, I would like to start with the first question.

APPENDIX H: LETTER FROM TRANSPLANT CENTER

We are sending you this letter on behalf of Janet Pelletier, RN, FNP-BC, a doctoral candidate in nursing at East Carolina University. She is conducting a study of people who are waiting for a kidney transplant. Your name or contact information has not been given out. We are giving you the opportunity to participate in her study. The survey takes about 20 minutes to complete by phone or you can mail the survey. Your responses are confidential and are not associated with your care at the transplant clinic. She will send you ten dollars in appreciation of your participation.

We understand that the wait for a transplant can be trying. This study is designed to provide information to improve care for transplant candidates. We hope you will agree to participate by calling 1-877-719-9910 or by completing the survey provided with this letter.

Sincerely,

Transplant Coordinator

APPENDIX I: LETTER TO PARTICIPANTS FROM RESEARCHER

Dear Participant,

I am a doctoral candidate at East Carolina University in the College of Nursing. I am asking you to take part in my research study entitled, "Appraisal of Uncertainty While Waiting for a Kidney Transplant."

The purpose of this study is to learn more about uncertainty while waiting for an organ transplant. By doing this research, I hope to increase understanding of the experience of waiting for a transplant to help identify patient needs and guide research to improve nursing care of transplant candidates. Your participation is voluntary.

You are being invited to take part in this study through the transplant clinic because you are waiting for a kidney transplant. The amount of time it will take you to complete this study is about 20-30 minutes. You are being asked to complete a survey by phone or by mail, which will involve answering multiple choice questions about how you are feeling.

Because this research is overseen by the ECU Institutional Review Board, some of its members or staff may need to review my research data. However, the information you provide will not be linked to you in any way. I will ask for your mailing address to send you the \$10.00 in appreciation of your participation, but your name will not be associated with your responses on the survey.

If you have questions about your rights as someone taking part in research, you may call the UMCIRB Office at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this study, you may call the Director of UMCIRB Office, at 252-744-1971.

You do not have to take part in this study, and you can stop at any time. If you are willing to participate, call me toll free at **1-877-719-9910**. Please leave a message with how and when I may contact you if I am unable to take your call. If you prefer to complete the survey by mail, it is enclosed.

Thank you for taking the time to participate in my study.

Sincerely,

Janet Pelletier, Principal Investigator

APPENDIX J: REMINDER POSTCARDS



It's not too late to complete the survey you received in the mail. You can mail it back to Janet Pelletier, the nurse and doctoral candidate, who is conducting the study. Or, you can complete it by phone. Just call the toll free number, 1-877-719-9910. She will send you \$10 for participating in the study. If you have already completed the survey, thank you for your time.

www.natap1.com



Thank you, if you have already completed the survey that was sent to you on behalf of Janet Pelletier, a doctoral candidate in Nursing at ECU. If you have not completed the survey, please return it by mail or call Janet Pelletier toll free at 1-877-719-0910.

www.ecu.edu/~jpe1011

**APPENDIX K: LETTER TO PARTICIPANTS FOLLOWING PARTICIPATION
IN THE STUDY**

Janet Pelletier, PhDc, RN, FNP-BC
Doctoral Candidate
East Carolina University College of Nursing
P.O. Box 707
Bridgeton, North Carolina 28519

Thank you very much for participating in my research study and sharing your experiences about waiting for a kidney transplant! Ten dollars is enclosed with this letter in appreciation of your participation. If you have any questions about the study or would like to receive a summary of study results, you may contact me by mail or at my toll free telephone number. The number is 1-877-719-9910 and my e-mail address is: pelletierj04@students.ecu.edu. You may also contact my faculty advisor: Martha Raile Alligood, PhD, RN, ANEF, Professor, East Carolina University College of Nursing, Health Sciences Building, Greenville, NC 27858-4323. Her telephone number is 252-744-6416.

Questions related to your care or waiting for a transplant, should be directed to your health care provider or transplant coordinator.

Thank you again for taking the time to participate in the study. You are greatly appreciated and I wish you well.

Sincerely,

Janet Pelletier, PhDc, RN, FNP-BC

APPENDIX L: PARTICIPANT COMMENTS

These questions are really more for people who were recently listed;"

"I was never upset at little things- I don't worry." (Waiting 4 years).

"Some of the questions I don't know how to ask." (Waiting 5 years, 11 months).

"I know it's getting worse;" "Everything changes;" When you are sick, you always have to challenge yourself more." (Waiting 2 years).

"My wife just died two months ago so that affects how I answer some of the questions;" "My (sibling) will not donate a kidney." (Waiting 3 years).

"I have "dialysis head" and feel loopy some of the time." (Waiting 11 months).

"I have lots of trust in God;" "It will happen if it is meant for me;" "It would break my heart to do worse after the transplant than I have been doing day by day for the past 15 years, but it could make my life better;" "I have never let it pull me down-I try to stay active-I have a lot of buddies." (Waiting 15 years).

"I can get out and do what I want and when;" "Sitting back and dwelling on things is the last thing I am gonna do- it makes things look bad;" "I'm better off than I would be without a chance for a transplant;" "I'm not changing-things have a way of working out-a lot of things are worse- I've got to make the best of the situation." (Waiting 8 months)

"I'm trying to be positive;" "I'm not afraid, but I do think about the outcome;" "It's a second chance-I'm doing good on dialysis, but I don't want to be on it all my life;" "I take one day at a time," "Even though I have this situation, I have the same values," "My outlook is more positive since waiting for a transplant-a chance to be off dialysis." (Waiting 3 years, 1 month)

"I'm glad to still be living;" "Everything has changed in my life, I have to eat right and do right;" "I don't have no choice (but to go with the flow);" "It has changed my life;" "I have to have joy in my heart;" "I know I have to go to dialysis so I don't mind doing it;" "It's for my health so I don't mind being told what to do;" "I love to travel and I can't travel-you have to pay for dialysis when you travel;" "Sometimes (I am more afraid of how I will end up)- I try to keep positive that things will get better-that I will get a kidney." (Waiting 2 years 3 months)

"I know I'm getting worse." (Waiting one year).

"I was doing better a year ago;" "The medications and dialysis are helping;" (Described having more problems during dialysis)-"I am not sure I will make it through dialysis;" "If I get a kidney, my future is clearer;" "It gives you hope-It will be a little better when you get a kidney;" "Thinking that I might get a call helps me get through the day," "I can be active the morning after dialysis- I get full of fluid and don't want to be around other people-I'm weak on the day I

have dialysis;" "My appearance has changed-I get short of breath from the fluid;" "I'm able to spend less time with others;" "I am hoping for the best;" "I try not to worry;" "Praying helps;" "You have to work with the time you feel good;" "My hopes are the same;" "I still expect a kidney-that's what keeps me going." (Waiting 2 years).

"They never talk about transplants at the dialysis clinic;" "There needs to be more communication from the transplant clinic;" "If you hear about successes, you have more hope-at least there's hope;" "People need to be more comfortable talking about transplants;" "There needs to be more education in the black community about what it (a transplant) is- If there were more education in the community, people would be more receptive to organ donation;" "Patients on dialysis need to have a means of communication (with the transplant clinic)" (Waiting 3 years)

"Dialysis is a different way of life that few could even imagine. Filled with some very sick people, the dialysis centers are filled with the sights, sounds and smell of death and dying alongside those who are trying to keep their world from unraveling. My personal philosophy has been to make the best of a very grim and sobering reality of ESRD. The worst part of wait time for transplants is what I refer to as "donor apathy." In my personal situation, I have campaigned for donors locally and statewide; however, my impression is that donors will choose to donate if they have strong personal feelings or if they are hit squarely in the face with a relative or close friend who needs a kidney. In my personal situation, I was initially excited about the possibility of a donor. In time, the excitement would end. I actually became conditioned to life with dialysis---or not.

During this time, I became somewhat frustrated at not having an idea of my relative standing or if I would ever be called. In the meantime, I delivered two eulogies and attended several funerals while simultaneously doing everything I could to be compliant and stay as healthy as I could. The wait became so iffy in my view that I had actually dismissed the possibility of a real donation. Fortunately, I was incorrect in my view when I received a call this week. Hopefully, there will be more." (Submitted in writing and mailed to the researcher by a participant)