# CHAPTER I

### INTRODUCTION

Renal transplantation is the surgical placement and vascular integration of a human kidney from a living or cadaveric donor into a patient who has end stage renal disease (ESRD). It is considered the only treatment that restores reasonably normal kidney function and health (Wallace, 1998). Although renal transplantation brings many benefits to patients, it is potentially associated with a number of drawbacks, which include constant risk of rejection, the need to comply with a complex medication regimen capable of producing pronounced side effects, and the need for ongoing medical supervision. These drawbacks are also stressors for patients (Fallon, Gould, & Wainwright, 1997), with some of the most important being fear of kidney transplant rejection, worries about the risk of infection, compliance with the medication regimen, repeated hospitalizations, and changes in body appearance (Fallon et al., 1997; Kong & Molassiotis, 1999). Thus, renal transplant patients experience stress and uncertainty, which influence their health-related quality of life (HRQOL). Coping, defined as cognitive and behavioral efforts to manage stressors (Lazarus and Folkman, 1984), is considered an important predictor of HROOL of renal transplant patients (White et al., 1990). Problem-focused coping and religious coping were positively correlated to HRQOL in renal transplant patients (Christensen et al., 2000, 2002; Frazier, Davis-Ali, & Dahl, 1995; Tix & Frazier, 1998), while emotion-focused coping (evasive, emotive, and fatalistic coping) was less effective in adjustment of renal transplant patients (Lindqvist,

Carlsson, & Sjödén, 2004). However, factors affecting coping were not well documented in the literature on renal transplant studies. According to Lazarus and Folkman's (1984) model of stress and coping, appraisal is a cognitive mediator affecting coping. Selfefficacy and social support were found to influence patients' appraisals of their situations and then their coping behaviors in various chronic illnesses (Hagger & Orbell, 2003; Manne & Zautra, 1989; Merluzzi & Martinez-Sanchez, 1997; Ptacek et al., 2002; Shaw, 1999). It is necessary for nurses to understand the coping strategies patients use and factors influence coping, then develop interventions to help patients use effective coping strategies to reduce stress related to renal transplantation. It is expected that these strategies would help renal transplant patients improve their HRQOL. Thus, the proposed study is designed to investigate the relationships among cognitive appraisal of health, perceived self-efficacy, perceived social support, coping, and HRQOL in renal transplant patients.

Renal transplantation is considered the first-choice method of renal replacement therapy for ESRD patients who have no physical or psychological contraindications (Jacobs & Luciani, 1992). When successful, a transplant helps restore the recipient to a healthier daily life. If a transplant is unsuccessful, the patient can return to dialysis or have a second transplant (Wallace, 1998). There are more than 500,000 renal transplant patients in the world (Ji, 2002). In 2002, the incidence of renal transplant in the US was 51.22 per 1 million population, with a 3:2 ratio between men and women (Annual Report, 2003). Each year since 1993 in the United States, more than 10,000 kidney transplants have been performed on patients with ESRD (Wallace, 1998).

With advanced medical techniques and immunosuppressive medications, patient survival rates also have improved. According to the Annual Report of the Organ Procurement and Transplantation Network (2003), the one year patient/graft survival rate in the US was 94.0%/88.4%, the three year patient/graft survival rate was 88.4%/78.5%, and the five year patient/graft survival rate was 79.9%/63.3%. However, renal transplantation is not risk-free. The risks of transplantation include rejection, infection, cardiovascular problems, increased incidence of malignancies such as lymphomas and skin cancers, hypertension, and steroid-induced complications (Harasyko, 1989). Among them, rejection is the main complication that causes graft failure. The majority of irreversible rejection episodes occur within the first three to six months after transplantation (McCarley & Lewis, 1996). To prevent and control graft rejection, immunosuppressive therapy is used after transplantation. Immunosuppressive medications have many side effects, with infection being the most common complication. Leukopenia, high blood pressure, facial and body changes, increased appetite, hair growth, bone pain, muscular weakness, depression, anxiety, irritability, sexual dysfunction, and personality changes are common side effects (Duborsky & Penn, 1980; Matas, 2002). These side effects not only impact patients' health and functioning but also their psychological response.

The high cost of the operation and the life-long immunosuppressive medications present a significant economic challenge for renal transplant patients and their families as well as for society. The intensive follow-up regimen influences renal transplant patients' daily and social activities and employment and, in turn, increases their economic burden (Molzahn, Northcott, & Dossetor, 1997). Hauser and colleagues (1991) also suggested

that repeated hospitalizations of transplant patients and intensive follow-up in the first year post-transplant severely disturb normal family life and usually cause their children anxiety and loneliness.

In summary, renal transplantation may negatively impact a patient's physical, psychological, socioeconomic, and family status. Renal transplant patients live with chronic illness even after transplantation has been performed successfully (Fallon et al., 1997). They worry about rejection and have distress related to side effects of medications, economic burden, family relationships, and social functioning; all of these problems influence their HRQOL.

Renal transplantation is a chronic condition that involves the total human environment for supportive care and self-care. It not only affects the patients but also the family and society. The long-term nature of post-transplant healthcare often creates the need for ongoing family support and thus presents an additional potential burden (Lewis et al. 1990). Additionally, the relatively high cost of the surgery and life-long immunosuppressive medications bring economic consequences for patients' families as well as society. The intensive follow-up regimen may impact daily and social activities and employment, which in turn may exacerbate the economic burden (Molzahn, Northcott, & Dossetor, 1997). Thus, helping renal transplant patients effectively cope with the negative impact of transplantation and increasing opportunities for employment are important issues for both healthcare professionals and society.

Increasing quality and years of healthy life is one of the two major goals of Healthy People 2010 (U.S. Department of Health and Human Services, 2000). Additionally, chronic illness is one of the 28 focus areas identified by Healthy People

2010. Clearly, renal transplantation is a problem of significant interest to U.S. society. Improvement of the HRQOL of renal transplant patients is consistent with the goals of Healthy People 2010.

Because advanced technology and therapies have produced longer survival after renal transplantation, HRQOL of renal transplant patients has become an increasingly important healthcare issue. Health-related quality of life is considered a primary endpoint in healthcare (Pais-Ribeiro, 2004). Survival, HRQOL, and cost-effectiveness are the main parameters to evaluate ESRD treatment (Gritsch, 1996). Studies have shown that renal transplant patients face many new challenges after transplantation (Fallon et al., 1997; Frey, 1990; White et al., 1990). They experience some physical, psychological, socioeconomic, and family problems, which influence their HRQOL. To achieve the goal of Healthy People 2010 and enhance clinical outcomes, it is important for healthcare professionals to help these patients cope with the impact of renal transplantation. Healthcare professionals need to develop interventions to educate renal transplant patients to use effective coping strategies to better manage the side effects of immunosuppressive medications and increase their socialization and their ability to maintain employment. Thus, their general state of health and well-being will be improved.

Nursing, as a discipline, encompasses "the diagnosis and the treatment of human responses to actual or potential health problems" (American Nurses' Association [ANA], 1995, p. 6). "Attention to the full range of human experiences and responses to health and illness without restriction to a problem-focused orientation" (ANA, 1995, p. 6) is included as one of the four essential features of contemporary nursing practice. The

holistic perspective of nursing addresses both physiological and psychological concerns of patients. From this standpoint, understanding the experience of renal transplant patients, identifying their response to transplantation, and helping them effectively cope with its impacts are within the realm of nursing. McHaffie (1992) stated that helping patients develop successful coping strategies is an essential element of nursing, and how well a person copes is central in determining his or her well-being. Nurses have a unique role and must take professional responsibility for assisting patients and their families learn to cope with events effectively and to achieve an optimum HRQOL.

Thousands of patients with ESRD have received renal transplantation. Renal transplant recipients experience a variety of factors that negatively impact their HRQOL in comparison to the healthy population and other clinical populations. One important focus of nursing is to promote well-being of both healthy and ill people (ANA, 1995). Thus, how to improve these patients' HRQOL is a phenomenon of specific interest for nephrology nurses. In doing so, nephrology nurses must be able to educate renal transplant patients about self-care skills, including recognizing the signs and symptoms associated with impending rejection and preventing infection. They must also be able to develop evidence-based protocols for follow-up care. Most importantly, they must be able to help patients develop the skills to cope with the stresses experienced after renal transplantation. It is important to understand coping and HROOL in renal transplant patients. With increased understanding of these phenomena, nephrology nurses may develop effective interventions to help renal transplant patients use adaptive coping strategies to improve their HRQOL. Additionally, the body of nursing knowledge on coping and HRQOL in renal transplant patients will be enhanced.

Renal transplant patients live with a chronic illness once transplantation has been performed successfully. They face many new challenges and experience stress, which require them to cope with ongoing stressors. Cognitive appraisal, personal (e.g., selfefficacy), and situational (e.g., social support) variables are identified in the literature as predictors of coping and HRQOL in individuals with chronic illness, such as cancer, multiple sclerosis, and rheumatoid arthritis. However, these variables were not examined in renal transplant patients. The purpose of this study was to investigate the relationships among cognitive appraisal of health, perceived self-efficacy, perceived social support, coping, and HRQOL in renal transplant patients. Because there is a lack of conceptual model in renal transplant studies, a modified model derived from Lazarus and Folkman's (1984) Model of Stress and Coping was proposed and tested in patients following renal transplantation. In addition, the effects of clinical factors (e.g., duration of dialysis, history of hospitalizations, time post-transplantation, side effects of immunosuppressive medications, and donor type) that are ignored in most psychosocial renal studies were considered in this study. Information from this study may help nurses develop nursing interventions that facilitate effective coping strategies and improve HRQOL of renal transplant patients.

### CHAPTER II

# **REVIEW OF LITERATURE**

The purpose of this review was to examine the conceptual and empirical literature relevant to the study of coping and HRQOL in renal transplant patients. This review of literature was organized into four major sections: a review of the conceptual and methodological approaches to HRQOL in renal transplant patients; a review of the conceptual and methodological approaches to coping in renal transplant patients; a synthesis of the conceptual and methodological knowledge of coping and HRQOL in renal transplant patients; a methodological approaches to coping in renal transplant patients; a synthesis of the conceptual and methodological knowledge of coping and HRQOL in renal transplant patients; and a proposed conceptual framework.

Health-related Quality of Life in Renal Transplant Patients

#### History of the Concept of Health-related Quality of Life

The term quality of life (QOL) was first mentioned in 1920 (Pigou, 1920) and was widely acknowledged in the 1960s. Since the World Health Organization (WHO) defined health as being not only the absence of disease and infirmity but also the presence of physical, mental, and social well-being (WHO, 1948), QOL issues have become more prevalent in healthcare research and practice. Although it has become an important health outcome, there is no standard definition of QOL.

In the 1960s and the 1970s, QOL was usually defined globally and incorporated ideas of satisfaction/dissatisfaction and happiness/unhappiness (Farquhar, 1995). Quality

of life was defined by Abrams (1973) as the degree of satisfaction or dissatisfaction felt by people with various aspects of their lives and by Andrew (1974) as the extent to which pleasure and satisfaction characterized human existence. These are all examples of global definitions. Because of the generality of this kind of definition, it tells us little about the components of QOL or how the concept should be operationalized.

In the 1980s and the 1990s, definitions of QOL often were broken down into a series of dimensions and this trend continues today. George and Bearon (1980) defined QOL in terms of four underlying dimensions. Two objective dimensions are general health and functional status, and socioeconomic status; two subjective dimensions that reflect the personal judgment of the individual are life satisfaction and related measures, and self-esteem and related measures. Another example is Clark and Bowling's (1989) definition which stated that QOL was not only functional ability, level of activity, mental state, and longevity but also included the concepts of privacy, freedom, and respect for the individual, freedom of choice, emotional well-being, and maintenance of dignity. Dimensional definitions are useful for empirical work and easier to operationalize. Some researchers have combined the global and dimensional definitions of QOL. For example, Ferrans and Power (1985) defined QOL as a person's perception or sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him or her. This model includes four domains: health and functioning, psychological / spiritual, socioeconomic, and family.

The terms "quality of life" and "health-related quality of life" are often used interchangeably in healthcare research, although QOL is a much broader concept, including many more domains of life than HRQOL. Health-related quality of life

concerns the impact of disease and treatment on the lives of patients and is the subjective assessment of the impact of disease and treatment across the physical, psychological, social, and somatic domains of functioning and well-being (Revicki et al., 2000). Similarly, Cella (1995) defined HRQOL as the extent to which one's usual or expected physical, emotional, and social well-being are affected by a medical condition or its treatment. Testa and Simonson (1996) stated that HRQOL refers to the physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person's experiences, beliefs, expectations, and perceptions, and can be measured in two dimensions, which are objective assessments of functioning and health status and more subjective perceptions of health. There seems to be agreement among researchers that HRQOL takes into account levels of physical, mental, social, and role functioning, and includes abilities, relationships, perceptions, values, satisfaction, and well being (Bergner, 1989; Patrick & Erickson, 1993; Testa & Simonson, 1996; Ware & Sherbourne, 1992).

There are several major differences between QOL and HRQOL. Quality of life represents a broad range of human experiences including many domains, such as community, education, family life, friendships, health, housing, marriage, nation, neighborhood, self, standard of living, and work (Campbell, Converse, & Rodgers, 1976). Quality of life is used in sociology, economy, political science, and psychology. HRQOL focuses on health and is often used in the healthcare field. In healthcare research, HRQOL describes what the person has experienced as the result of medical care. It assesses the differences between what the person expected from the treatment and what the reality was.

Conceptual Approaches to Health-related Quality of Life of Renal Transplant Patients

HROOL was not clearly defined in renal transplantation studies during the 1980s. The researchers implied that QOL was life satisfaction and well-being (Bremer et al., 1989; Bremer & McCauley, 1986; Evans, Hart, & Manninen, 1984). Bremer and colleagues (1989) described objective QOL as life condition and resources (e.g., income, education, activities, employment), and subjective QOL as the cognitive evaluation of objective conditions and emotional responses to those conditions. From the 1990s, HROOL was well recognized as a multidimensional concept including physical, psychological, and social domains in most renal transplantation studies. For example, QOL was defined as patients' subjective appraisal of their physical, psychological, and social functioning (Moons et al., 2002). Each of the domains comprises diverse components. The physical domain includes functional capacity and work capacity; the psychological domain includes life satisfaction, well-being, self-esteem, anxiety, and depression; and the social domain concerns labor rehabilitation, pastimes, and familial and social interaction. Hathaway and colleagues (1998) defined QOL as a multidimensional construct including physical, psychosocial, functional, and self esteem dimensions.

Conceptual frameworks for HRQOL were not well documented. Only a few researchers mentioned QOL frameworks in their studies. Herrman's (1997) definition of QOL, which refers to quality of life as a person's perception of his/her position in life within the culture and value systems and in relation to individual goals, expectations, values, and concerns, was used as a framework in some studies (Franke et al., 2000; Kong & Molassiotis, 1999). Ortuzar (2001) proposed that evaluation of QOL of the

transplant patient should include "his or her self-determination, control, and responsibility over his or her own life" (p. 1915) along with the level of functional capabilities of the person. Ortuzar also mentioned that the psychosocial dimension is fundamental in understanding QOL of renal transplant patients. Geest and Moons (2000) indicated that a transplant patient's subjective appraisal of side-effects of immunosuppressive regimens should be included in the QOL framework. Hathaway and colleagues (2003) provide the QOL framework for the Patient Outcomes Registry for Transplant Effects on Life (PORTEL). The framework is composed of five interrelated domains, which are health factors, social factors, major health events, major life events, and quality of life and related factors. The first four domains interact with one another and together influence quality of life in terms of its physical and psychological components.

Definition of HRQOL in renal transplant patients evolved from a global concept as life satisfaction and well-being to a multidimensional, subjective construct including physical, psychological, and social domains. HRQOL is considered to relate to individual goals, expectations, values, and concerns. For renal transplant patients, subjective appraisal of side effects of immunosuppressive regimens and functional capacities should be included in the evaluation of HRQOL. The psychosocial dimension is fundamental in renal transplant patients' HRQOL due to fears of transplant rejection, emotional stress caused by the chronic character of the illness, difficulties of employment, and the loss of social opportunities.

# <u>Methodological Approaches to Health-related Quality of Life of Renal Transplant</u> <u>Patients</u>

With advanced immunosuppressive therapy, patients' survival rates have increased and HRQOL has become an increasingly important parameter for evaluating the outcome of renal transplantation. HRQOL of renal transplant patients has been extensively studied in recent decades. Fifty-four studies on HRQOL in renal transplant patients were reviewed for this paper. These studies were conducted in 14 countries, with the majority of the studies conducted in the US (41%). One study included US, European, and Australian sites. Study designs, samples, measurements of HRQOL, factors influencing HRQOL, and strengths and limitations of these studies are discussed in this section.

Designs and samples for the studies. A majority of the 54 studies (55.6%) used cross-sectional designs in which respondents were assessed once after transplant. Some researchers included comparison or control groups within the study design. Among the comparison studies, most researchers compared the transplant patients with dialysis patients, and some researchers examined the effects of immunosuppressive medications. A growing number of recent studies have used a stronger prospective design and longitudinal investigations (5 prospective, 9 longitudinal studies) in which respondents were assessed both before and after transplantation. In the longitudinal studies, respondents were assessed periodically, usually for the first 1-2 years after transplant, but sometimes for much longer periods. There were two test-retest design studies to assess an instrument and two qualitative studies to explore the experiences of renal transplant patients. Sample sizes varied widely across these studies, from small samples of 10 to very large samples of more than 700 renal transplant patients.

Measurements of health-related quality of life used in the studies. Quality of life is a very complex concept that has not been well defined. As a result, a great number of measurement instruments have been developed. It is well recognized in the literature that evaluation of QOL of renal transplant patients should include multiple dimensions that are both objective and subjective. Generic and specific instruments were used to measure QOL of renal transplant patients. Generic instruments assess health concepts that represent basic human values and are relevant to everyone's health status and well-being. Generic instruments permit comparison across different populations and different treatments. In contrast, specific instruments focus on problems associated with specific diseases, groups of patients, or areas of function. Specific instruments may be more sensitive to changes in disease or treatment-related factors. There is a trend to use both generic and specific instruments in recent studies. In the 1980s, generic instruments such as the Structure of Psychological Well-being including Positive and Negative Affect Scales and the Affect Balance Scale (Bradburn, 1969); the Quality of American Life consisting of Life Satisfaction, the Index of General Affect and the Index of Well-being (Campbell, Converse, & Rodgers, 1976); and objective measurements such as the Karnofsky Index and the Comorbid Index were used most often (Bremer et al., 1989; Bremer & McCauley, 1986; Evans, Hart, & Manninen, 1984; Johnson, McCauley, & Copley, 1982). These measurements were consistent with the global definition of QOL. In the early 1990s, as QOL was accepted as a multidimensional construct, some researchers developed questionnaires to measure physical, emotional, and social wellbeing, vocational rehabilitation, leisure time activities, family relations, and sexual adjustment (Gorlen et al., 1993; Koch & Muthny, 1990; Simmons & Abress, 1990).

Hathaway and colleagues (1990) developed a transplant interview guide to evaluate posttransplant QOL expectations. In the late 1990s, generic instruments, such as the Sickness Impact Profile (SIP), the Medical Outcomes Study 36-item short form (SF-36<sup>®</sup>), and Brief Symptom Inventory (BSI), were most frequently used in the studies. Some diseasespecific instruments also were developed such as Ferrans and Powers' (1985) Quality of Life Index (QLI)-Transplant Version, Kidney Transplant Questionnaire (Laupacis et al., 1993), and End-Stage Renal Disease Symptom Checklist-Transplantation Module (Franke et al., 1999). The SF-36 was widely used across the world after it was developed by Ware and Sherbourne (1992). Findings have shown that the SF-36 is a proper method to evaluate HRQOL in renal transplant patients (Feurer et al., 2004; Manu et al., 2001), and it has been used in many studies with the renal transplant population. Jacobs and colleagues (1998) conducted a study to determine whether the self-administered Kidney Transplant Questionnaire (KTQ) performs similarly to the interview and demonstrated that the self-administered KTQ exhibited high internal consistency and validity, and the intra-scale correlations between interview and self-administration also were high.

Health-related quality of life of renal transplant patients and factors influencing it. The terms QOL and HRQOL were used interchangeably in these studies. There is consensus in the literature that renal transplant patients with functional grafts had a better QOL than patients treated with various dialysis techniques (Bremer et al., 1989; Cameron et al., 2000; Franke et al., 2000; Fujisawa et al., 2000; Jofre et al., 1998; Koch & Muthny, 1990; Laupacis et al., 1996; Mingardi et al., 1998; Muthny & Koch, 1991; Rebollo et al., 2000; Russell et al., 1992; Simmons & Abress, 1990). Patients' QOL improved after transplantation (Fisher et al., 1998; Jofre et al., 1998; Luk,, 2004; Ponton et al., 2001),

comparable to the general population in some dimensions (i.e., physical, psychological, daily activities, and the global index of QOL) (Bremer et al., 1989; Franke et al., 2000). However, in France and Japan, renal transplant patients reported lower physical and general health than the general population (Karam et al., 2003; Tsuji-Hayashi et al., 1999).

QOL of renal transplant patients with different immunosuppressive regimens also has been examined (Moons et al., 2002; Oberbauer et al., 2003; Reimer et al., 2002; Shield et al., 1997; Simmons & Abress, 1990). Patients treated with sirolimus alone demonstrated better QOL in fatigue, appearance, and vitality dimensions than patients with the treatment combination of sirolimus and cyclosporine A (Oberbauer et al., 2003). Reimer and colleagues (2002) reported patients with tacrolimus-based therapy had significantly better SF-36 physical component summary scores and better scores on the subscales regarding physical functioning and general health as well as overall diseasespecific QOL than patients with cyclosporine-microemulsion based therapy. However, some researchers reported that the increases in HRQOL scores were similar for the two groups (tacrolimus-based vs cyclosporine-microemulsion based), favoring tacrolimusbased therapy in only Physical Appearance scale (Sheld et al., 1997). Patients with steroid-free regimens demonstrated better social, role-emotional functioning, mental health, and lower symptom occurrence and distress levels compared with patients taking steroids (Moons et al., 2002).

The source of the transplanted organ also influences the QOL of renal transplant patients. The incidence of physical HRQOL impairment was greater in recipients of transplants from cadaveric donors than in recipients of transplants from living donors

(Griva et al., 2002). The recipients of cadaveric organs demonstrated less overall improvement at year one than recipients of organs from living donors (Kizilisik et al., 2003). Patients receiving a kidney transplant from a living donor with a highly supportive family environment exhibited a reduction in depression, increased mobility, and increased social functioning (Christensen et al., 2002). Evans and colleagues (1984) reported no significant differences in either objective or subjective QOL assessment between recipients of cadaveric organs and living-related organs in their study with randomly selected renal transplant patients.

Demographic variables and medical conditions that influence the QOL of renal transplant patients have been investigated. Female renal transplant patients had a poorer QOL and demonstrated less improvement after transplantation (Franke, 2003; Jofre et al., 1998; Johnson et al., 1998; Mingardi et al., 1998; Muthny & Koch, 1991; Rebollo et al., 2000). Matas and colleagues (2002) reported that male renal transplant patients had lower QOL on the Life Satisfaction Index and the Transplant Care Index than female renal transplant patients. This inconsistency with other studies may be related to the focus of these instruments on self-care and personal relationships.

The effect of age on QOL is controversial. In some studies, younger renal transplant patients had better QOL than elderly patients (Franke et al., 2000; Jofre et al., 1998; Muthny & Koch, 1991). However, Humar and colleagues (2003) reported that the overall benefit on QOL was similar for both a younger and older group, and the older group scored higher with regard to social functioning and mental health. Rebollo et al. (2001) indicated that elderly renal transplant patients had higher scores than younger patients in the physical function, bodily pain, general health, social function, role

emotional, and mental health subscales of the SF-36. However, the sample size of elderly renal transplant patients was smaller than younger patients (28 vs 213) in this study. Another reason for these controversial findings may be related to the studies being conducted in different countries (Spain, Germany, and US).

Indo-Asian renal transplant patients had a significantly lower QOL than Caucasian European patients in physical health, mental health, kidney disease-targeted issues, patient satisfaction, and social deprivation (Bakewell, Higgins, & Edmunds, 2001). Johnson et al. (1998) reported African-American renal transplant patients achieved less improvement than Caucasian-Americans in affective dimensions, such as self-image and emotional behavior, as well as functional measures. Some studies indicated education was positively related to the QOL of renal transplant patients (Matas et al., 2002; Pinson et al., 2000; Rebollo et al., 2000).

Comorbidity was inversely related to QOL (Bremer et al., 1989; Hricik et al., 2001; Jofre et al., 1998; Rebollo et al., 2000). Diabetes had negative effects on QOL (Baiardi et al., 2002; Kizilisik et al., 2003; Matas et al., 2002; Pinson et al., 2000). Serum creatinine concentration was associated with scores on the general health, vitality, and social function subscales of the SF-36 (Ichikawa et al., 2000; Tsuji-Hayashi et al., 1999). Rejection and the number of hospitalizations also negatively affected the QOL of renal transplant patients (Hathaway et al., 1998; Shield et al., 1997; Simmons & Abress, 1990). Adverse effects of immunosuppression were common in renal transplant patients. The main adverse effects were unusual hair growth, gingival hyperplasia, easy bruising, slow healing, weight gain, hypertension, sexual dysfunction, bone pain, muscular weakness, and headaches, and these side effects had negative effects on QOL (Hricik et al., 2001;

Ichikawa et al., 2000; Matas et al., 2002; Witzke et al., 1997). It seems that immunosuppressive therapy has adverse effects and these adverse effects, along with comorbidities, and rejection have negative impacts on QOL of renal transplant patients.

Time after transplantation also may influence QOL of renal transplant patients. Two cross-sectional design studies compared QOL of patients at different stages posttransplant. A study conducted in Italy demonstrated there was a significant improvement in the QOL between the pre-transplant and the immediate post-transplant (first 6 months) patients, but the QOL progressively worsened during the third year post-transplant period, and then settled back to levels similar to those recorded immediately after transplant (Ponton et al., 2001). Another study conducted in Japan compared QOL among shortterm (<5 year), middle-term (5-10 years), and long-term (>10 years) post-transplant patients and indicated that the middle-term group had the highest SF-36 scores and the long-term group had the lowest scores (Ichikawa et al., 2000). Studies on QOL of longterm (>10 years) post-transplant patients showed that the majority of these patients reported a good QOL and were almost fully rehabilitated in the second and third decade after their transplant (Gorlen et al., 1993; Pisani et al., 1997).

There are several longitudinal studies on the evolution of QOL of renal transplant patients over time, and some findings are inconsistent. Some studies indicated patients' overall functional performance improved after transplantation at 3 months, 6 months, and 1 year, after which it stabilized at year 2 (Kizilisik et al., 2003; Pinson et al., 2000). Matas et al. (2002) assessed 598 renal transplant patients every three months and observed no significant improvement in Life Satisfaction Index scores and a small significant improvement in Transplant Care Index scores over time. Laupacis et al. (1996)

reported renal transplant globally improved patients' QOL compared to pre-transplant, with these improvements stabilizing throughout the two years of follow-up. In general, renal transplant patients seem to have stable QOL after one year post-transplant.

There is one study on stress and QOL (Fallon, Gould, & Wainwright, 1997), and there are two studies on stress, coping, and QOL (Kong & Molassiotis, 1999; White et al., 1990) in the reviewed articles. The major stressors identified in these studies were fear of rejection, compliance with a complex medication regimen, side-effects of medications, uncertainty about the future, fear of infection, repeated hospitalizations, social adjustment, and the cost factor. Findings also indicated patients between one and five years posttransplant experienced the most stress and less changes in QOL scores than the patients within six weeks and five or more than five years post-transplant (Fallon, Gould, & Wainwright, 1997). White et al. (1990) investigated stress, coping, and QOL in 55 adult kidney transplant recipients within the first 6 months and found that total stress was negatively related to QOL, and total coping was positively related to QOL after transplant. Some studies also reported that psychological problems had a negative impact on the QOL of renal transplant patients (Franke et al., 2003; Hricik et al., 2001).

<u>Summary</u>. The QOL of renal transplant patients was a well documented benefit related to transplantation. Different factors have been associated with the HRQOL perceived by patients, such as patient factors (i.e., age, gender, education, psychological distress) and clinical factors (i.e., comorbidities, adverse medication effects, time since transplant, treatment type, donor type). However, there are some limitations in the literature. There is a lack of homogeneity of the groups of patients compared and poor conceptualization of QOL in most studies. In many studies, the case-mix adjustment has

not been considered to correct such variables as age, comorbidities, and socioeconomic factors. The majority of the studies were cross-sectional designs and some studies had small sample sizes. A quality of life framework was not mentioned in the majority of the studies. Many studies were conducted with wide differences in cultural patterns, durations of follow up, and instruments, all of which made it difficult to compare studies. Self-administered questionnaire bias was not mentioned. Most studies were done in transplant centers where the researchers worked; therefore, the patients' loyalty to the medical team may have made patients answer the questions in positive ways. There were no intervention studies and the usefulness of the findings in actual practice was not addressed. Personal and psychosocial factors influencing QOL also were not well documented. Some studies showed that there were differences in QOL expectations between patients and health care professionals (Hathaway, Strong, & Ganza, 1990; Hauser et al., 1991). Patients' perceptions of transplantation and coping strategies used to cope with the situation need further investigation. In future studies, psychological factors such as stress, appraisal, and coping in renal transplant patients and their associations with HRQOL need to be explored.

#### Coping in Renal Transplant Patients

### History of Coping

In the 1960s, the concept of coping began to be formally used along with the interest in stress. Some researchers labeled certain "adaptive" defense mechanisms "coping" activities, and their work was within the tradition of defense mechanism

research (Parker & Endler, 1996). This traditional approach to coping emerged from two different literatures: animal experimentation and psychoanalytic ego psychology. Within the animal model, coping is frequently defined as acts that control aversive environmental conditions, thereby lowering psychophysiological disturbance. The emphasis is largely on avoidance and escape behavior. In the psychoanalytic ego psychology model, coping is defined as realistic, flexible thoughts and acts that solve problems and thereby reduce stress (Lazarus & Folkman, 1984). While carefully addressing the limitations and defects of the traditional approach that emphasized coping as a style or trait, Lazarus and Folkman (1984) defined coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). This approach views coping as an ongoing dynamic process and is concerned with what the person actually thinks or does in a specific context, as well as changes in these thoughts and actions across encounters. Lazarus (1993) further conceptualized coping as a purposeful response that attempts to change the person-environment realities behind negative emotions and attempts to change either what is attended to or how it is appraised. This definition was derived from a cognitive-motivational-relational theory of emotion, which emphasizes the process of appraisal and relational meaning. Coping is considered to be a goal-directed process in which the individual orients thoughts and behaviors toward the goals of resolving the source of stress and managing emotional reactions to stress (Lazarus, 1993).

# Theory of Coping

Lazarus and Folkman's (1984) Stress and Coping Model is the best known and most widely used model in coping research. The basic assumption of the model is that individuals who are confronted with a stressor evaluate this stressor and that this evaluation determines their emotional or behavioral reactions. This evaluation is called cognitive appraisal, which is defined as "the process of categorizing an encounter, and its various facets, with respect to its significance for well-being" (Lazarus & Folkman, 1984, p. 31). Cognitive appraisal can be classified as primary appraisal and secondary appraisal. Primary appraisal refers to a set of cognitions regarding the impact or significance of the stressful encounter (e.g., it is a threat, challenge, or harm/loss to his or her well-being), whereas secondary appraisal refers to a set of cognitions concerning one's resources or options for dealing with the encounter. Coping is defined as any effort to manage external or internal demands that are appraised as negative or challenging. External demands refer to the encounter itself, while internal demands refer to the emotional reactions to the encounter. Problem-focused and emotion-focused coping are the two major functions of coping. Problem-focused coping involves activities that aim to change the elements of the stressful situation. In contrast, emotion-focused coping involves activities that modify one's emotional reactions resulting from the stressful situation and make life bearable by avoiding situations that can be overwhelming if confronted directly (Lazarus & Folkman, 1984).

The consequences of coping may be effective or ineffective for managing psychological, social, and physiological stressors. Most people use various forms of coping in a stressful situation; however, problem-focused coping predominates when

people feel that something constructive can be done, and emotion-focused coping predominates when people believe the stressful situation cannot be changed (Lazarus, 1990). Problem-focused coping is viewed as a more effective strategy in Western societies (Lazarus, 1993). Unsuccessful coping appears to be more associated with emotion-focused coping, such as avoidant strategies, wishful thinking, and self-blame (Folkman et al., 1986). Some findings indicate that emotion-focused coping strategies seem to be more adaptive in the short run, whereas problem-focused coping may be more adaptive in the long run (Suls & Fletcher, 1985).

In Lazarus and Folkman's (1984) model of stress and coping, appraisal and coping were considered as processes, and relationships among stress, appraisal, and coping were stated clearly. The model particularly emphasized appraisal as the cognitive mediator affecting coping. This model is suitable to study chronic illness conditions. However, there are some limitations to this original stress and coping model. Although Lazarus and Folkman (1984) emphasized the person-situation transactions, the situation dimension is poorly represented in this model. The model also neglected interactions with the context, such as the importance of social support on coping, and also overlooked the effects of the individual as a whole person who has a particular goal or motivation, situational intentions, belief systems and a life pattern of plans, and social connections on the meaning of an event. A few researchers have addressed some of the limitations through incorporating other models into this stress and coping model (Schwarzer, 1998; Shaw, 1999).

# Self-efficacy

Schwarzer (1998) gave an overview of personal and social coping resources from a social-cognitive perspective. Schwarzer highlighted perceived self-efficacy as a personal coping resource for managing a stressful situation. Bandura (1995) defined selfefficacy as "the belief in one's capabilities to organize and execute the course of action required to manage prospective situations" (p. 2). Self-efficacy gives one a sense of control over the environment. Efficacy expectancy is the belief that a person can and has the intention to complete a specific behavior required to produce a desired outcome, and outcome expectancy is the estimate that a given behavior will lead to the outcome (Bandura, 1977). Efficacy expectancies reflect the belief of being able to master challenging demands by means of adaptive action and an optimistic view of one's capacity to deal with stress. Self-efficacy makes a difference in how people feel, think, and act. This resource plays an important role in determining how a person copes. Selfefficacy also can affect a person's motivation to act. High self-efficacy individuals probably choose to perform more challenging tasks, set higher goals, and stick to them. They tend to select a challenging setting, explore their environment, or create new situations. Macdonald et al. (1998) also suggested that greater perceived self-efficacy predicted increased frequency of the use of problem-focused coping, and high selfefficacy individuals appeared to be more likely to cope with day-to-day stressors. Selfefficacy as a personal coping resource affects appraisal, which affects motivation and then coping behaviors.

There are three levels of measurement of self-efficacy in the literature. According to Bandura (1977), self-efficacy is specific to behaviors and the situations, and is most

appropriately measured at a very specific level. A number of scales were developed to assess self-efficacy for specific health behaviors (e.g., healthy eating behavior, Schwarzer, 1993) and showed considerable power in predicting the specific behaviors within a particular context. Some researchers argued that more general measures are better suited for predicting more general patterns of behaviors and a lot of highly general measures of self-efficacy were developed (Smith et al., 1991; Wallston, 1989). These general measures have demonstrated strong relationships to broad adaptive outcomes (Smith, Wallston, & Smith, 1995). After considering few measures assessing efficacy/competence beliefs at a more intermediate, domain-specific level, Smith and colleagues (1995) designed the Perceived Health Competence Scale (PHCS) to assess efficacy/competence beliefs concerning one's health at this intermediate level of domain-specificity. This scale would be appropriate in this study for investigating renal transplant patients' beliefs of capability to perform healthy behaviors to cope with their health conditions, especially for the early period renal transplant patients who have little experience and have not yet developed more specific expectancies.

#### Social Support

Social support generally is viewed as a generic construct including social networks and social interactions (Schreurs & Ridder, 1997). Cohen and Syme (1985) defined social support as the processes by which interpersonal relationships protect individuals against the deleterious effects of stress and promote psychological well-being. Weiss (1974) described social support as a composite concept including (1) a sense of belonging; (2) a provision for intimacy or attachment; (3) an opportunity for nurturing

behavior; (4) the availability of assistance in the form of informational, emotional, and instrumental help; and (5) a reassurance of individual worth and role accomplishments. The mechanisms through which social support influences coping and psychological wellbeing were explored by researchers. There are two theoretical models of social support. The direct effects model proposes that social support has beneficial effects irrespective of whether the persons are under stress or not; there is a direct link between social support and health outcomes. This model derives from a statistical main effect of social support (Cohen & Wills, 1985). The stress-buffering model suggests that social support protects persons against the deleterious effects of stress at times of crisis. It derives from a statistical interaction effect, that is, there should be a positive correlation between social support and health outcomes for persons facing high stress, but no correlation between them for persons with little or no stress (Cohen & Wills, 1985). The key to stressbuffering is the perception that others will provide resources when they are needed and the beliefs about its availability are more important for health and adjustment than whether or not one actually receives support (Cohen, Gottlieb, & Underwood, 2001). In the buffering model, social support is connected with coping. Schreurs and Ridder (1997) suggested four ways to link coping and social support in the context of chronic disease: (1) seeking social support as a form of coping, (2) social support as a coping resource, (3) social support as dependent on coping, and (4) coping by a social system.

In this study, social support may be perceived as a coping resource. Integrated into the Lazarus and Folkman's (1984) Stress and Coping Model, social support is a resource that affects appraisals of stressors. With more resources available, perceptions of the amount of control one has or the level of one's self-efficacy with regard to coping

may increase. In turn, these beliefs may influence whether a given event is appraised as stressful and what course of coping is pursued (Ptacek et al., 2002). In addition to influencing coping by altering appraisals, social support resources may also directly affect specific coping efforts. Higher levels of perceived support may facilitate the use of generally more adaptive coping strategies and inhibit the use of generally less adaptive strategies.

### Conceptual Approaches to Coping in Renal Transplant Patients

Coping has not been clearly defined in renal transplant studies. Lazarus and Folkman's (1980, 1984) definition of coping was used in two studies (Kong & Molassiotis, 1999; White et al., 1990). Coping referred to the person's constantly changing cognitive and behavioral efforts made to manage specific external and internal demands that were appraised as taxing or exceeding the resources of the person. It involves on-going appraisal and reappraisal of the dynamic person-environment relationship.

Appraisals related to spiritual beliefs also can be incorporated into Lazarus and Folkman's (1984) Stress and Coping Model. Religious coping was defined by Tix and Frazier (1998) as the use of cognitive or behavioral techniques, in the face of stressful life events, that arise out of one's religion or spirituality. Spirituality is considered as a resource that affects secondary appraisals and would foster improved coping with healthrelated post-transplant adverse events (Martin & Sachse, 2002). Spirituality was defined by Reed (1987) as an awareness of one's inner self and a sense of connection to a higher being, nature, others, or to some purpose greater than oneself. It is multidimensional,

existential in meaning and composition, and fundamental to the well-being of chronically ill individuals (O'Neill & Kenny, 1998).

Most renal transplant studies did not present/utilize a conceptual framework of coping. Some researchers mentioned Lazarus and Folkman's (1984) Stress and Coping Model, but they did not apply the model to their studies. Some researchers focused on only one aspect of coping. Coping as a style or process was not clearly stated. Factors influencing coping were not mentioned.

### Methodological Approaches to Coping in Renal Transplant Patients

Eleven articles that focused on stress, coping, and adjustment were reviewed. Across the 11 studies, eight were conducted in the US, and the other three were done in China, UK, and Sweden. Designs, samples, stressors, measurements of coping, coping strategies, and associations among stress, coping, and HRQOL in renal transplant patients are discussed in this section.

Designs and samples. Most studies (82%) utilized a cross-sectional design. Only two studies used a prospective design in which participants were assessed twice. Some researchers included comparison groups to compare the transplant patients at different stages after transplantation. All the studies applied convenience sampling methods to recruit participants. The sample size varied from 28 to 297 participants, with the majority of studies including less than 100 renal transplant patients.

<u>Stressors experienced by renal transplant patients.</u> According to Lazarus and Folkman's (1984) Stress and Coping Model, stressors precipitate appraisals which then trigger coping behaviors. Stressors experienced by renal transplant patients were

investigated in some of the reviewed studies. Frey (1990) explored stressors in renal transplant recipients at six weeks after transplant. The Kidney Transplant Recipient Stress Scale (KTRSS) (Hayward et al., 1989) was used to determine stressors. Findings demonstrated that the most salient stressor was the possibility of repeated hospitalizations. The next four in order were possibility of rejection, cost of medications, uncertainty about the future, and side effects of medications. The least stressful stressor was changes in friends. The next four least-stressful items included admission process, loss of contact with dialysis patients, changes in spiritual activities, and unfamiliar surroundings. The stressors of most concern were similar to those in other studies. Sutton and Murphy (1989) reported the stressors of renal transplant patients less than four years posttransplant. The five highest stressors were cost, fear of rejection, weight gain, uncertainty concerning the future, and limitation of physical activities. Fear of not being accepted by friends and family, feeling that the kidney transplant is not part of one's body, and reversal in family roles with the children were the lowest. White et al. (1990) found that health-related items (concern about the success of transplant, risk of infections, side effects) were the most stressful for patients in the first six months after renal transplant; work-related items were least stressful. Fisher et al. (1998) interviewed 5 patients who had undergone their first transplant within the previous four months and found that risk of rejection and possibility of repeated hospitalization were of greatest concern to their patients.

In London, Fallon, Gould, and Wainwright (1997) conducted a study on stress of renal transplant patients using the modified KTRSS. The most important stressors were identified as fear of rejection, worries about risk of infection, worries prior to clinic visits,

repeated hospitalizations, and changes in body appearance. Cost was not considered an important stressor in this sample, which may be related to the health insurance policy in England. Another study was conducted in China by Kong and Molassiotis (1999). These researchers used an open-ended question inquiring about stressors or concerns experienced by renal transplant patients. The main stressors/concerns were fear of rejection, compliance with a complex regimen, side-effects of medications, uncertainty about the future, fear of infection, social adjustment, and the cost factor.

Frazier, Davis-Ali, and Dahl (1995) compared the stress experienced by kidney transplant patients and their spouses. Patients experienced significantly more overall stress than spouses. Patients reported significantly more stress than spouses on side effects and interpersonal relationships; spouses reported significantly more stress on patients' future health. The stressors' rank for patients was (1) financial issues; (2) fears regarding future health and medication side effects; (3) interpersonal relationships and medical regimen; and (4) complying with the medical regimen. For spouses, the rank was (1) financial issues and concerns regarding the patient's future health; (2) medication side effects; (3) interpersonal relationships; and (4) following the medical regimen.

The most salient stressors identified in these studies were similar, which are cost, fear of rejection, side effects of medications, uncertainty about the future, compliance with a complex regimen, and repeated hospitalizations. Most of the studies examined newly transplanted patients; thus it is not surprising to get consistent findings. Only two studies explored stress at different stages following transplant and indicated that patients 1 to 5 years post-transplant experienced the most stress (Fallon et al., 1997; Sutton & Murphy, 1989). The limitations of these studies were small sample sizes and cross-

sectional designs. Larger sample sizes including different stages of post-transplant patients are needed to compare the stressors experienced by renal transplant patients. Longitudinal design studies also are needed, so that the changes in stressors over time will be captured.

Coping strategies used by renal transplant patients. Coping consists of the cognitive and behavioral efforts to manage specific demands appraised as stressful (Lazarus & Folkman, 1984). Some researchers investigated coping strategies used by renal transplant patients to cope with transplantation. Lindqvist, Carlsson, and Sjödén (2004) conducted a study to compare use and perceived effectiveness of different coping strategies in people with kidney transplants (n=30) and an individually matched sample of the general Swedish population(n=30). The Jalowiec Coping Scale (Jalowiec, 1991) was used to measure coping strategies. Results showed that renal transplant patients used significantly more optimistic, supportive, self-reliant and less emotive coping than the general population. Renal transplant patients regarded self-reliant and confrontive coping as more effective and emotive coping as less effective than the general population. Evasive, emotive, and fatalistic coping were associated with low perceived efficiency in handling various aspects of conditions. Strong positive correlations in renal transplant patients were found between use and effectiveness ratings for most coping strategies. Similarly, Sutton and Murphy (1989) identified that patients used more problem-oriented coping (e.g., try to look at the problem objectively, maintain some control over the situation) than affective-oriented coping (e.g., take drugs, drink alcohol, blame someone else). Prayer also was found as one of the most used coping methods. Sutton and Murphy further compared the coping methods between patients 0-23 months post-

transplant and patients 24-48 months post-transplant. There were no significant differences on the mean total coping scores, but the two groups differed on affectiveoriented coping scores with the 24-48 months group scoring higher. Kong and Molassiotis conducted a study on 101 Chinese renal transplant patients (with 23 within one year and 78 more than one year post-transplant) in Hong Kong using the Chinese Coping Scale to assess coping. Findings suggested Chinese renal transplant patients used more internal locus of coping than external locus of coping, and there were no significant differences between patients within one year and patients more than one year posttransplant for overall coping score and all coping subscale scores. White, Ketefian, Starr, and Voepel-Lewis (1990) assessed coping strategies used by adult kidney transplant recipients in the first six months after transplant. The coping section of the Kidney Transplant Questionnaire (Ketefian & Starr, 1987) was used to measure coping and found that the highest scoring coping strategies were on the distancing/ detachment and selfcontrol/ accepting responsibility subscale (positive attitudes), while the escape/wishful thinking subscale scores were the lowest. Religious coping also was identified as a popular coping strategy in dealing with transplant-related stress (Tix & Frazier, 1998). Martin and Sachse (2002) indicated that female renal transplant patients reported high levels of spiritual perspective.

Renal transplant patients seem to use more optimistic, supportive, self-reliant and less emotive coping than the general population. Generally, renal transplant patients used more problem-oriented coping than affective-oriented coping; however, renal transplant patients within two to four years post-transplant used more affective-oriented coping than patients within two years post-transplant. Distancing/detachment and self-

control/accepting were used most, while escape/wishful thinking were used least in patients within the first six months after renal transplant. Religious coping was also frequently used in dealing with transplant-related stress. Cultural differences in coping were found, which indicated that Chinese renal transplant patients used less emotional discharge. They used more internal locus of coping than external locus of coping. Different labels of coping strategies and different instruments measuring coping presumably with varying levels of psychometric validation were used in these studies, making it difficult to compare and reach conclusions across studies. Some researchers did not mention the conceptual framework for their studies; thus, we cannot evaluate if they measured what they wanted to measure well.

Associations of stress, coping, and health-related quality of life. The relationships among stress, coping, and HRQOL also were explored in some of the studies. White et al. (1990) examined stress, coping, and QOL in adult kidney transplant recipients within the first six months and found that total stress was positively correlated with total coping. Both total stress and total coping were important predictors of QOL after transplant. Stress was negatively related to QOL; in contrast, coping was positively related to QOL. However, Sutton and Murphy (1989) found that total stressor scores were not significantly correlated with total coping scores or total problem-oriented coping scores; total stressor scores were only significantly correlated with total affective-oriented coping scores. This inconsistent finding may be related to the different instruments used to measure stress and coping and patients' time post-transplant differing in the two studies.

Christensen et al. (2000) conducted a prospective study to examine the effect of patient coping preferences on change in depression following renal transplantation. Sixty

patients were assessed using the Krantz Health Opinion Survey (KHOS) (Krantz, Baum, & Wideman, 1980) and the Beck Depression Inventory (BDI) (Beck et al., 1961) while on the waiting list and reassessed approximately 12 months later. Among the 33 patients receiving transplant during the follow-up period, those with a high preference for health-related information showed a substantial reduction in depression, and patients with a low preference for information exhibited a slight increase in depression. Among the 27 patients not receiving transplant, preference for information had no effect on depression. Patient differences in preference for behavioral involvement had no significant effect on depression.

The effects of religious coping on adjustment were investigated in renal transplant patients and significant others by Tix and Frazier (1998). Results suggested that there was an overall positive relationship between religious coping and psychological adjustment. Religious coping at three months was related to greater life satisfaction at three and 12 months for patients and significant others and to less distress at three months for significant others. Religious coping was associated with less distress and more life satisfaction for Protestant significant others than for Catholic significant others. For all samples, cognitive restructuring, social support, and perceived control, whether considered independently or together, did not account for the significant effects of religious coping. It seemed that religious coping was positively correlated to life satisfaction for both renal transplant patients and significant others. Religious coping benefited Protestant significant others more than Catholic significant others in relation to psychological adjustment. Martin and Sachse (2002) also discussed that female

transplant patients with higher levels of spiritual perspective had higher levels of spiritual religious well-being and existential well-being.

Frazier, Davis-Ali, and Dahl (1995) investigated stressors, social support, and adjustment in kidney transplant patients and their spouses. Patient and spouse adjustment was assessed using standardized measures – the Dyadic Adjustment Scale (DAS) (Spanier, 1976) and the Beck Depression Inventory (BDI) (Beck et al., 1961). Patients reported receiving significantly more helpful behaviors, which involved concern and support, than unhelpful behaviors, which involved criticism, over-concern, and advice giving, from their spouses. Patients who received more helpful support were more satisfied with their marriages and were less depressed; those who received more unhelpful support were more depressed than patients who received less unhelpful support. The strongest predictor of patients' marital satisfaction was the amount of helpful support they received from their spouses and the second was stress level, while the strongest predictor of patients' depression was their total amount of stress. Patients who were experiencing higher stress benefited more from the support they received from their spouses. For spouses, total stress was negatively correlated with marital satisfaction and positively correlated with depression. Spouses who were more stressed offered less helpful and more unhelpful support than spouses who were less stressed. Helpful support from a spouse has a positive correlation with adjustment, and family support may have the same function.

Christensen et al. (2002) examined the effect of family environment and donor source on patient HRQOL following renal transplantation. The Family Relationships Index from the Family Environment Scale (FES) (Moos & Moos, 1986) was used as a
measure of family support. The Beck Depression Inventory (BDI) (Beck et al., 1961) and the Sickness Impact Profile (SIP) (Bergner et al., 1981) were used to assess patient emotional distress and HRQOL respectively. FES scores were initially lower in the cadaveric-donor group, but increased significantly after transplant, while FES scores were initially higher in the living-donor group and remained unchanged after transplant. BDI scores and Scores on the SIP Recreational Functioning Scale decreased significantly from pre-transplant to post-transplant in both groups. Post-transplant depression levels were nearly identical for both groups. The interaction of donor source and family environment was a significant predictor of change in depression and HRQOL. Patients who received a kidney from a living donor and who also reported a more supportive family environment exhibited a reduction in depression, improved mobility, and improved social functioning from pre-transplantation to post-transplantation. In contrast, those living-donor recipients with less family support exhibited slightly increased depression and diminished mobility and social functioning after transplantation. Among patients receiving a cadaveric renal graft, those with high versus low levels of family support showed similar reductions in depression and modest improvements in HRQOL.

In summary, total stress was negatively related to HRQOL in renal transplant patients. Total stressor scores were positively correlated to total affective-oriented coping scores. High preference for health-related information was related to reduction in depression among renal transplant patients. Overall, religious coping was related to greater life satisfaction for patients and less distress for significant others. Patients with more helpful support were more satisfied with their marriages and were less depressed.

A more supportive family environment predicted improved mobility and improved social functioning post-transplantation among living-donor recipients.

Summary of these coping studies. Findings showed that renal transplant patients experience stress after transplantation. Fear of rejection, side effects of medications, uncertainty about the future, cost, and the possibility of repeated hospitalizations are the main stressors. Renal transplant patients tend to use optimistic, self-reliant, self-control, supportive seeking, problem-solving, and religious coping strategies to deal with transplant-related stress, whereas escape/wishful thinking, evasive, emotive, fatalistic coping and affective-oriented coping were used less frequently. It also is suggested that renal transplant patients regard problem-oriented coping as more effective than emotive coping. Some studies found that stress was negatively related to HRQOL in renal transplant patients. Total stressor scores were positively correlated to total affective-oriented coping, information seeking, helpful support, and family support were positively correlated with HRQOL in renal transplant patients, while evasive, emotive, and fatalistic coping were associated with low perceived efficiency in handling various aspects of illness.

The relationships among stress, coping, and HRQOL in renal transplant patients are not well documented. Some studies described the stress, coping and QOL of renal transplant patients, but they did not link them together. Most studies focused on only one aspect of coping and correlated it only to psychological adjustment. In some prospective studies, coping strategies were measured at one time point; thus, the changes in coping cannot be identified. Different labels of coping strategies and different instruments measuring coping were used, and patients at different stages post-transplant were

assessed in these studies, thus making it difficult to compare and reach conclusions across studies. Appraisals of transplantation in renal transplant patients were not mentioned in these studies. Factors influencing coping in renal transplant patients were not addressed either. Instruments used to measure QOL/ well-being were not satisfactory. Quality of life is a multidimensional concept, but some researchers measured it using one question. Inadequate sample size in some studies and cross-sectional design are other limitations. Most studies investigated only renal transplant patients less than one year after transplantation.

## Synthesis of Conceptual and Methodological Knowledge of Coping and Health-related Quality of Life in Renal Transplant Patients

### Strengths and Weaknesses of Conceptual Approaches

Several researchers presented definitions of HRQOL in renal transplant patients. There was agreement that HRQOL is a multidimensional, subjective construct including physical, psychological, and social domains. HRQOL also was related to individual goals, expectations, values, and concerns by some researchers. The psychosocial dimension was considered fundamental to renal transplant patients' HRQOL. Some researchers pointed out that renal transplant patients' subjective appraisals of side effects of immunosuppressive regimens and functional capacities should be included in evaluating HRQOL. However, there was no elaborated conceptual framework of HRQOL in renal transplant patients. Only one framework on HRQOL in transplant patients was provided by Hathaway and colleagues (2003). This framework needs further evaluation with renal transplant patients. Based on the literature, HRQOL in renal transplant patients may be the perceptions of the impacts of renal transplantation on their functioning and wellbeing, which includes physical, psychological, and social domains.

A few researchers used Lazarus and Folkman's (1984) definition of coping and mentioned Lazarus and Folkman's (1984) Stress and Coping Model in their studies. However, this model was not well applied in these coping studies. Appraisal as a key component in Lazarus and Folkman's model was not addressed in these coping studies. Factors influencing appraisal and coping were not mentioned either. Some researchers defined religious coping and spirituality, but they did not incorporate them into a framework. Coping in renal transplant patients was not well defined and there is no framework to link coping and HRQOL in renal transplant patients in these studies.

A framework, which incorporated Lazarus and Folkman's Stress and Coping Model and Social Cognitive Theory on self-efficacy, and social support, may be useful to renal transplant studies. Applying this framework, the cognitive appraisal of renal transplantation would influence patients' coping behaviors, and then affect their HRQOL. Self-efficacy as a personal coping resource may affect renal transplant patients' appraisal of their conditions, and then their coping behaviors. As coping resources, social support may precede the coping process through influencing appraisals and coping efforts. Social support may enable renal transplant patients to use effective coping strategies by helping them understand the situation faced and reducing emotional stress, helping them have a positive appraisal of their health condition, and increasing their motivation to perform positive health behaviors; thus improving their HRQOL.

#### Strengths and Weaknesses of Methodological Approaches

The HRQOL of renal transplant patients was well documented and demonstrated that renal transplant patients had better HRQOL than before transplantation. Clinical factors such as comorbidities, adverse effects, time since transplant, treatment type, and donor type have been investigated and shown to be correlated to patients' HRQOL. However, there is a lack of homogeneity of the groups of patients compared in most QOL studies. A variety of questionnaires were used, and studies were conducted with major differences in cultural patterns and durations of follow up. It was not mentioned if the researchers used power analyses to determine the sample sizes in the reviewed studies. Personal and psychosocial factors influencing QOL also were not well documented in these QOL studies.

It is well recognized that renal transplant patients experience stress after transplantation. The stressors of most concern have been identified, which are cost, fear of rejection, side effects of medications, uncertainty about the future, compliance with a complex regimen, and repeated hospitalizations. Renal transplant patients tend to use optimistic, supportive, self-reliant coping, religious coping, and problem-oriented coping to cope with the stressors. Affective-oriented coping, escape/wishful thinking, and emotive coping are used less frequently. It also is suggested that renal transplant patients regard problem-oriented coping as more effective than emotive coping. Some studies indicated that stress was negatively related and coping was positively related to HRQOL after transplantation. Overall, religious coping, information seeking, helpful support, and family support were positively correlated with psychological adjustment in renal transplant patients.

Most coping studies used small sample sizes, assessed renal transplant patients at different stages post-transplant, used different instruments to measure coping and HRQOL, and focused on only one aspect of coping (e.g., religious coping). All of these differences/factors made it difficult to compare and integrate the results across studies. Obviously, studies on coping and HRQOL of renal transplant patients focus more on the effects of coping on psychological well-being. There is a need for systematic examination of the relationships among stress, coping, and HRQOL in a study with a larger sample size. Factors influencing coping in renal transplant patients were not addressed in these studies. There also is no well-developed instrument designed to measure coping in this specific population.

### Gaps in the Literature

Research on coping in renal transplant patients is in its initial stage, although HRQOL of renal transplant patients has been maturing. A theoretical framework for studying coping and HRQOL in renal transplant patients has not been well developed. Some coping studies mentioned Lazarus and Folkman's (1984) Stress and Coping Model. However, they did not apply or strictly follow this model. Appraisal and coping processes are the central concepts in this model. No researchers assessed appraisals of renal transplant patients in their studies. Personal and situational factors that influence the appraisal processes were not addressed in these studies. Appraisal is the cognitive mediator that affects coping in stressful situations. If we do not know how patients appraise their situation, it is difficult for us to interpret why patients use different coping strategies. Coping as a process is also context specific. Reviewed studies used different

instruments to measure coping, and they did not mention if the instruments were modified to be specific to renal transplantation. Specific measurement of coping in renal transplant patients needs to be developed. Additionally, coping is multidimensional and multifunctional, and people use different coping strategies to deal with a stressful encounter. In the overall coping process, coping strategies are interdependent and work together; thus, studies focused only on one aspect of coping were incomplete.

Most studies only linked coping to psychological adjustment, such as depression. Effects of coping on behavioral, physiological, or objective health-related outcomes were not well addressed. Some studies examined the relationship between coping and QOL; however, QOL was not defined and the instrument used to measure QOL did not capture the multidimensional characteristics of QOL. Intervention studies related to helping renal transplant patients cope effectively with stressful situations were not found in the reviewed literature.

Most studies used convenience sampling methods with small sample sizes. Some studies included renal transplant patients at only one stage post-transplant (e.g., six weeks, six months); thus, these studies cannot compare coping strategies and HRQOL at different stages post-transplant.

#### Proposed Conceptual Framework

Theoretical and methodological limitations in the studies of coping and HRQOL in renal transplant patients were identified in the reviewed literature. Efforts are made to address some of these limitations in this study. Considering the lack of a specific theoretical framework for studying coping and HRQOL in renal transplant patients, a particular conceptual model was proposed. Based on the findings of the literature, Lazarus and Folkman's (1984) Stress and Coping Model integrated with Social Cognitive Theory on self-efficacy, and literature on social support and HRQOL served as the theoretical basis for this proposed model (Figure 1).



Figure 1: Proposed Model of Coping and HRQOL in Renal Transplant Patients (Modified from Lazarus and Folkman's (1984) Stress and Coping Model)

In this proposed model, coping is defined as a process and the way in which individuals apply their coping options depends on the cognitive appraisal of renal transplantation. Personal variables, also called "personal coping resources" (e.g., perceived self-efficacy), and situational variables (e.g., perceived social support) affect patients' cognitive appraisal, and their coping behaviors. An individual's coping is constantly changing in response to external demands and subjective appraisals. Effectiveness of coping depends on the fit between coping strategies and the situation. Choices of coping strategies are related to HRQOL of renal transplant patients. Healthrelated quality of life is defined as the subjective assessment of the impact of renal transplant across the physical, psychological, and social domains of functioning and wellbeing.

According to the literature, renal transplant patients live with chronic conditions, face many new challenges, and experience continuing stresses. They have the risk of kidney rejection, must take immunosuppressive medications with side effects and high cost, need ongoing follow-up and repeated hospitalization, and are uncertain about the future. Patients' cognitive appraisal of these conditions would affect their coping behaviors. Renal transplant patients' perceived self-efficacy gives them a sense of control over their conditions, thus influencing their appraisals. Patients who have or perceive a high level of self-efficacy may believe they can control the situation and may not appraise transplantation as extremely stressful. In addition, a sense of one's own ability motivates one to act and to choose and perform more challenging tasks; therefore, perceived self-efficacy also affects the coping strategies patients use. Patients who have a high level of self-efficacy may use more problem-focused coping strategies.

Renal transplant patients do not live in a vacuum, and environmental variables have effects on their coping. Social support is one of the most significant factors. Studies in cancer patients suggested that perceived social support not only enhances specific coping efforts directly but also influences the appraisal processes (Komproe et al., 1997; Ptacek et al., 2002). In the early post-transplant period, renal transplant patients need to obtain information on self-care, medications, and follow-up regimens, and need to attend hospital clinics. They cannot go to work and/or shoulder the responsibility for a family. They need support from medical professionals, family, and friends. Social support offers resources, referrals to professional services, encouragement to seek assistance, provision of information and problem-solving techniques. Patients who perceive high levels of social support may tend to use adaptive coping strategies and may have better HRQOL.

### **Research Questions**

The purposes of this study were to examine relationships among measures of coping and HRQOL in renal transplant patients, and to identify factors influencing the coping process. Based on the knowledge derived from the reviewed literature on coping and HRQOL, a conceptual model was proposed and the following research questions were addressed in this study.

#### **Research Questions**

1. Does the hypothesized model fit the data following renal transplantation?

2. What are the effects of clinical factors (donor type, history of transplantation related hospitalizations, side effects of immunosuppressive medications, duration of dialysis, and time post-transplantation) on perceived self-efficacy, perceived social support, cognitive appraisal of health, coping, and HRQOL following renal transplantation?

### Hypotheses

1. Perceived self-efficacy has both direct and indirect effects on coping, and exerts a direct effect on cognitive appraisal of health.

2. Perceived social support exerts both direct and indirect effects on coping, and a direct effect on cognitive appraisal of health.

3. Cognitive appraisal of health has a direct effect on coping strategies.

4. Coping strategies have a direct effect on HRQOL.

5. Clinical factors related to renal transplantation have direct effects on cognitive appraisal of health.

### Definition of Terms

<u>Cognitive appraisal of health.</u> Cognitive appraisal of health was defined as the process by which an individual evaluates or judges a potential health problem for meaning and significance to their well-being, and is composed of both primary and secondary dimensions (Lazarus & Folkman, 1984).

<u>Coping.</u> Coping was defined as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding personal resources (Lazarus & Folkman, 1984).

<u>Perceived Self-efficacy</u>. Perceived self-efficacy was defined as the belief that one is capable to organize and execute a course of action to attain what is desired (Wallston, 2001).

<u>Perceived Social Support.</u> Perceived social support was defined as the belief in the availability of support including attachment/intimacy, social integration, nurturance, reassurance of worth, and assistance (Weiss, 1974).

<u>Health-related Quality of Life (HRQOL).</u> Health-related quality of life was defined as the subjective assessment of the impact of disease and treatment across the physical, psychological, social domains of functioning and well-being (Revicki et al., 2000).

### CHAPTER III

### METHODOLOGY

The purpose of this chapter is to describe the methodology used in this study of coping and HRQOL of renal transplant patients. Study design, description of research setting, sample and sampling plan, data collection methods, and data analysis procedures are presented.

### Study Design

A descriptive, correlational, cross-sectional design with a sample that includes patients at two distinct periods post-transplant (early [less than 1year] and later [1 to 3 years post transplant]) was used in this study to examine coping and HRQOL in renal transplant patients and to test the proposed model. In this study, cognitive appraisal of health, perceived self-efficacy, perceived social support, coping strategies, and HRQOL were measured using self-report instruments. Demographic and clinical factors also were included.

### **Research Setting**

This study was conducted at a major transplant center located in the Southeastern Unites Sates. The center draws patients from Middle Tennessee, Southern Kentucky, and Northern Alabama.

### Sample and Sampling Plan

### Sample Characteristics

The target population of this study was adult renal transplant recipients. The accessible population was renal transplant recipients who are managed at the Vanderbilt Transplant Center. Participants who met the following inclusion criteria were invited to participate in the study: (1) at least 18 years of age; (2) had received a renal transplant on only one occasion; (3) with a functioning kidney graft (defined as not needing dialysis support) at the time of enrollment; (4) had a clinic appointment that is at one of the following periods: less than 1 year post-transplant, and 1 to 3 years post-transplant at the time of enrollment; (5) able to read and understand English.

Potential participants were excluded if they had received more than one renal transplant; if they had received another organ or tissue transplant (e.g., liver, pancreas, and stem cell); if they presented with a failed graft (requiring dialysis support) at the time of enrollment; if they were unable to read English; or if they declined to participate. Previous transplant experience may influence how patients perceive their illness, appraise their conditions, and then the selection of their coping strategies. Patients with a failed kidney graft may return to dialysis, and they have different situations and experience different stresses. Participants with these conditions were excluded to avoid potential confounds. Participants who did not read English could not be included because of the study's reliance on English language-based survey instruments and the unavailability and expense of translation services.

### Sample Size

Convenience sampling was used to recruit participants. A multiple regressionbased approach model was used to conduct the power analysis in order to determine the number of observations required to achieve either an incremental or cumulative squared multiple correlation coefficient ( $\mathbb{R}^2$ ) within a target range assuming a given number of predictor variables. On the basis of previous studies conducted in this transplant center, a moderate effect (cumulative  $\mathbb{R}^2 = 0.14$ -0.17) would be expected, and the target sample size was identified accordingly. One hundred and sixty participants were included in this study with 141 participants who had complete data being included in the multivariate models. With a maximum of 10 variables in any regression model, cumulative  $\mathbb{R}^2 = 0.15$ (moderate effect), alpha set at 0.05 (two tailed), and sample size of 140, the power of this study was 0.94 (Borenstein et al., 1997).

#### <u>Recruitment</u>

The principal investigator and data manager queried the Patient Analysis and Tracking System (PATS) database weekly to identify eligible patients, and provided appropriate survey packets to the renal transplant clinic staff. Eligible patients were given a survey packet at the time of check-in to the clinic and were asked to return it before leaving. As described in the IRB-approved cover letter, patients were not obligated to complete survey packets. A knowledgeable clinic staff member (e.g., transplant nurse coordinator) was available to answer questions that patients may have had about the surveys or the research program.

### Data Collection Methods

### Instruments

Each of the key constructs in the proposed model was measured using self-report instruments. In the following section, a description of each of the instruments used to measure cognitive appraisal of health, perceived social support, perceived self-efficacy, coping strategies, and HRQOL is provided. Instruments were selected on the basis of their applicability for self-report, published reliability and validity, and limited response burden. Demographic characteristics and clinical factors related to renal transplant are also described.

The Cognitive Appraisal of Health Scale (CAHS) (Appendix A). The CAHS (Kessler, 1998) is a self-report instrument developed to measure primary and secondary appraisals associated with potentially stressful health-related events. It is derived from Lazarus and Folkman's Stress and Coping Model. The CAHS contains 28 items with four separate scales measuring the primary appraisal dimensions of threat (5 items), challenge (6 items), harm/loss (8 items), benign/irrelevant (4 items), and 5 items measuring the secondary appraisal dimensions of coping options and resources. Four out of the five items measuring secondary appraisal were developed by Folkman et al. (1986); one was added by Kessler (1998). All items are scored on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores indicate more agreement with the appraisal item or scale. The CAHS was tested with a breast cancer sample and demonstrated sound reliability and validity. The internal consistency of each of the primary appraisal scales was greater than 0.70 (threat 0.85, challenge 0.72,

benign/irrelevant 0.78, and harm/loss 0.88) (Kessler, 1998). The psychometric evaluation also was investigated with prostate cancer patients (Ahmad, 2005). The 13-item three-factor model of CAHS was supported. The Cronbach's alphas for the three-factor were 0.79 for harm/loss appraisal, 0.74 for threat appraisal, 0.70 for challenge, and 0.70 for the total scale (Ahmad, 2005).

The CAHS with 28 items (Kessler, 1998) was used in this study. Preliminary factor analysis was conducted and a weighted single composite scale score was used as a predictor in the path analyses and as a criterion measure in analysis of variance-based models.

Personal Resource Questionnaire (PRQ 2000) (Appendix B). The PRQ2000 (Weinert, 2000) has been revised from the PRQ85 (Weinert, 1987) and the Personal Resource Questionnaire (Brandt & Weinert, 1981) to measure perceived level of social support. It is a self-administered instrument composed of 15 items on a 7-point Likert scale. The conceptual framework is based on Weiss's (1969, 1974) model of relational functions. The item responses range from 1 (strongly disagree) to 7 (strongly agree). Scores of the 15 items are summed to calculate the total score, which ranges from 15 to 105, with higher scores indicating higher levels of perceived social support. The internal consistency reliability ranged from 0.87 to 0.93 in various samples with chronic illness, such as multiple sclerosis, cancer, and cardiac disease (Weinert, 2003). Preliminary construct validity estimates are similar to those found for the PRQ82 and PRQ85 (Weinert, 2003).

<u>Perceived Health Competence Scale (PHCS) (Appendix C).</u> The PHCS (Smith et al., 1995) is a valid and reliable measure of perceived self-efficacy relevant to one's

health in general. It measures the degree to which one feels competent to effectively manage one's health outcomes. The PHCS is an eight-item scale that asks the subjects about their level of agreement with phrases such as, "I handle myself well with respect to my health," and "Typically, my plans for my health don't work out well." Level of agreement is measured with a Likert response scale with possible responses ranging from "Strongly disagree" (1) to "Strongly agree" (5). Negatively-valenced items are reverse scored before summing across all eight items. The psychometric properties of the instrument are supported by data from five studies of both healthy and chronically ill adult subjects (Smith et al., 1995). The internal consistency of the scale ranged from 0.82 to 0.90. Stability estimates varied from 0.82 over a one-week interval for healthy undergraduates, to 0.60 over approximately 2.5 years among persons with arthritis (Smith et al., 1995). The PHCS also demonstrated sound predictive validity and convergent validity within these samples (Smith et al., 1995).

Brief COPE (Appendix D). The Brief COPE (Carver, 1997) is the abbreviated version of the COPE inventory (Carver, Scheier, & Weintraub, 1989). The Brief COPE consists of 14 scales with 2 items each, assessing different coping dimensions: 1) active coping, 2) planning, 3) using instrumental support, 4) using emotional support, 5) venting, 6) behavioral disengagement, 7) self-distraction, 8) self-blame, 9) positive reframing, 10) humor, 11) denial, 12) acceptance, 13) religion, and 14) substance use. Ratings are made on a four-point Likert scale: 1=I did not do this at all, to 4=I did this a lot. This inventory is built from acknowledged theoretical models (Lazarus & Folkman' Stress and Coping Model, 1984; Behavioral Self-regulation Model, Carver & Scheier, 1981, 1990). It can be used to assess trait coping (the usual way people cope with stress in everyday life) and

state coping (the particular way people cope with a specific stressful situation). As the COPE inventory, the Brief COPE is a measure used for many health-relevant studies: drugs addiction, aging, breast cancer, depression, AIDS. The internal consistency alpha ranged from 0.50 to 0.90 for the 14 scales. All exceeded 0.60 except for Venting, Denial, and Acceptance (Carver, 1997). The state version of this inventory will be used. The directions for this inventory will be modified to fit the renal transplant condition. The substance use subscale will not be used in this study because it does not fit the clinical situation of this population. Renal transplant patients take many medications and the questions in the substance use subscale may be very confusing. Preliminary factor analysis was performed to determine the composition of the second-order factors of this inventory. Two distinct second-order factors (engagement coping and disengagement coping strategies) were identified and individuals' weighted scores on these second-order factors were used in the path analyses and as criterion measures in analysis of variance-based models.

<u>Medical Outcomes Study 36-item Short Form Health Survey (SF-36<sup>®</sup>) (Appendix</u> <u>E)</u>. The SF-36<sup>®</sup> is one of the most widely used and validated instruments for the measurement of generic, self-reported HRQOL. Eight subscales, physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role emotional (RE), and mental health (MH), are generated as unitweighted sums of specific item scores. After standardizing these scales to z-scores based on means and standard deviations for the general US population, aggregate physical and mental component summary scales (the PCS and MCS, respectively) are computed by summing across the eight differentially weighted scales. In the final step, each

component score is transformed to a normalized T-score having a mean of 50 and standard deviation of 10. Higher scores represent better quality of life. Cronbach's alpha coefficient of this measurement ranged from .65 to .94, and the test-retest correlation coefficients was .65 to .97 in other populations (Ware, 1997). The SF-36<sup>®</sup> has been frequently used in kidney transplant population studies. Cronbach's alpha coefficients were 0.76 for PCS and 0.80 for MCS in a previous study at the Vanderbilt Transplant Center (Feurer et al., 2004).

Demographic and Clinical Data (Appendix G). Demographic characteristics and related clinical information were collected through the Patient Analysis and Tracking System (PATS) and clinical databases. It included gender, age, race, level of education, marital status, original cause of ESRD, type of dialysis, duration of dialysis before transplant, donor type, relationship of living donor, time post-transplant, current immunosuppressive medications, history of rejection episodes (grade and date of diagnosis), and number of transplant-related hospitalizations. Additionally, data specific to the side effects experienced related to the immunosuppressive medications were assessed using a symptom checklist developed by the investigator, clinical experts, and the committee (Appendix F). It includes a list of 12 symptoms of side effects of immunosuppressive medications. Participants were asked to indicate if they were currently experiencing the symptoms, and if yes, how bothersome each symptom was (0= No symptoms, 1 = Yes, but bothers me not at all, 2 = bothers me slightly, 3 = bothers me moderately, 4 = bothers me quite a bit, to 5 = bothers me extremely). Preliminary factor analysis was performed and a one-component solution was derived. A single composite score was used in subsequent analyses.

### Procedures

After the study was approved by the IRB, subject recruitment began. The principal investigator prepared survey instruments. Only packet identification codes appeared on the surveys, which contained no personally identifying information. The clinic setting used for the study regularly collects information from patients at specific monitoring points (e.g., 3 months, 6 months, and annually post transplant). The questionnaires for this study were embedded in the survey packets distributed to patients willing to complete the forms. All pages comprising a packet of surveys were pre-printed so that a large volume of packets was able to be prepared in advance. Survey packets and a cover letter with description of the project, response confidentiality, the consent procedure, and contact information were packaged in unsealed envelopes.

The principal investigator and Transplant Center QOL data manager queried the PATS database weekly and prepared appropriate survey packets and delivered them to the clinical staff for distribution. Packets were distributed at the time of check in and patients were invited to participate, as explained in a cover letter. As explained in the cover letter, patients are not required to participate and may consent to participate by completing and returning the surveys. Knowledgeable clinic staff (e.g., transplant nurse coordinator) was present at the clinic to answer patients' questions.

Completed survey packets were stored in secured cabinets. The principal investigator double-entered the survey data into a password protected, Excel-based data set that was backed up on the secure Transplant Center data storage "drive". Information linking the packet and patient identifiers, and dates of distribution and

return, was maintained in a log that was kept in a secure location by the principal investigator and electronically by the data managers as a separate PATS data set.

### Human Subjects' Protection

Study participation was open to both women and men of all ethnic or racial groups. No one was excluded based upon gender, race, or ethnicity. There were no anticipated potential risks to participants involved in this study. Participants may have been inconvenienced by the time required for questionnaire completion, and the impact of response burden was assessed during the initial phase of data collection. The nature of the research was explained in an IRB-approved cover letter to potential participants, along with the fact that data are confidential, participation is voluntary, and that choosing not to participate would not influence clinical care. Protection against possible breaches of confidentiality derived from several factors: 1) survey data did not contain any personally identifying information; 2) surveys packets had pre-printed packet identification codes; 3) surveys were returned in sealed envelopes; 4) a separate data set linking patient identifiers to survey packet identifiers was maintained; 5) all data managers and persons who analyzed the data have approved access to necessary records and routinely work with and protect the confidentiality of sensitive medical records; 6) all computers and confidential data bases were password protected. Individual participants may not have benefited from participation. However, an improved understanding of coping and HRQOL following renal transplantation has the potential to benefit renal transplant patients and their families through its impact on post-transplant clinical care.

Adherence to study protocol was verified by the PI and any deviations or reasons for drop out were documented and discussed with the dissertation chair. The PI and the biostatistician met, at a minimum, every other week to discuss the progress of recruitment and any issues regarding safety to the participants. The PI also periodically checked the documentation to assess for any unanticipated problems. There were no unanticipated and/or serious events that needed to be reported to the IRB per IRB requirements.

#### Data Analysis Procedures

Statistical analyses were performed using the SPSS-PC (v14.0) and AMOS (v6.0) statistical packages. Prior to data analysis, each variable was examined using frequency distributions and visual representations, such as histograms or boxplots, to identify any outliers, missing values, coding errors. Distribution characteristics including tests of Normality also were examined. If any unusual or missing values were identified, the raw data were reexamined to rectify any data collection or entry errors. After cleaning and verifying the raw data, complete data were available on 141 participants for the path analyses and 143 participants for the ANOVA models. Because there were few missing values ( $\leq 12\%$ ), the path analyses and analysis of variance-based models were conducted using observations having complete data. Other analyses were performed using data from participants who had complete data on the particular variable of interest. Distribution of the data was explored. Some subscales of Brief COPE were identified as not being normally distributed, and the weighted second-order factor scores were used for analyses. Following data cleaning, descriptive statistics (e.g., percentages, means, standard deviations) were used to describe the sample. An indexed table was used to display the demographic characteristics of the sample. Descriptive statistics were also used to

summarize the study variables. Internal consistency reliability of the major instruments such as CAHS, Brief COPE, PRQ2000, PHCS, and HRQOL were examined. Second-order factor analysis was conducted on the four CAHS subscales and the 13 Brief COPE scales for the purpose of discerning the factor structure of these instruments and deriving weighted composite scores (for each of these instruments) for application in the subsequent path analyses and analysis of variance-based models. Multiple regression-based path analysis, multivariate analysis of covariance (MANCOVA), and multivariate analysis of variance (MANOVA) were used to analyze the data to answer research questions.

Research question 1. Does the hypothesized model fit the data following renal transplantation?

For this question, a series of nested path analyses were used to test the initial, alternative, and hypothesized models. Procedures for performing path analysis are described in the following section.

#### Preparation for the Path Analysis

The zero-order correlations among model variables were examined. Dichotomous variables such as donor type (living vs cadaveric) were dummy coded before analysis. History of transplant-related hospitalizations was categorized as no hospitalization and having hospitalizations following transplantation. Duration of dialysis before transplantation also was categorized as less and equal 6 months and more than 6 months. Variables in the correlation matrix are listed below.

**Renal transplantation related variables**: History of transplant-related hospitalizations, side effects of immunosuppressive medications, donor type, duration of dialysis, and time post-transplant.

#### **Perceived self-efficacy**

#### **Perceived social support**

Cognitive appraisal of health: One second-order factor-CAHS composite.

**Coping strategies**: Two second-order factors-engagement coping strategies and disengagement coping strategies.

**HRQOL**: Physical component summary and mental component summary.

Initial model. An initial model which posits the largest number of direct and indirect effects was developed (Figure 2). In this model, there are five exogenous, renal transplantation-related variables (history of transplant-related hospitalizations, side effects of immunosuppressive medications, donor type, duration of dialysis, and time post-transplant) and six endogenous variables: HRQOL (PCS or MCS), which is completely endogenous and is therefore affected by all exogenous (transplant-related) variables and all other endogenous variables (perceived self-efficacy, perceived social support, cognitive appraisal of health, and engagement and disengagement coping strategies); engagement and disengagement coping strategies, which are affected by the exogenous variables and by perceived self-efficacy, perceived social support, and cognitive appraisal of health; cognitive appraisal of health, which is affected by the exogenous variables and by perceived self-efficacy, and perceived social support; perceived social support, which is affected by the exogenous variables; and perceived self-efficacy, which is affected by the exogenous, renal transplantation-related variables. In this model, perceived self-efficacy, perceived social support, cognitive appraisal of health, and coping strategies exert direct and indirect effects on all subsequent endogenous variables. The only two effects that are not posited in this model are any

direct relationship between perceived self-efficacy and perceived social support, and between engagement and disengagement coping strategies. The set of multiple regression equations that collectively represent the initial model are listed below.

$$(1a) D_{PCS}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7 + b_8X_8 + b_9X_9 + b_{10}X_{10}$$

$$(1b) D_{MCS}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7 + b_8X_8 + b_9X_9 + b_{10}X_{10}$$

$$(2) D_{CSE}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7 + b_8X_8$$

$$(3) D_{CSD}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7 + b_8X_8$$

$$(4) D_{CAHC}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7$$

$$(5) D_{PSE}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5$$

$$(6) D_{PSS}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5$$



Figure 2: Initial Model

<u>Alternative model</u>. An alternative model was posited to test whether perceived self-efficacy and perceived social support are exogenous or mediating variables (Figure 3).



Figure 3: Alternative Model

In this model, renal transplantation-related variables, perceived self-efficacy, and perceived social support are modeled as correlated exogenous variables. Four endogenous variables, cognitive appraisal of health, engagement and disengagement coping strategies, and HRQOL (PCS or MCS) remain. The following set of multiple regression equations are needed to represent the alternative model. The goodness of fit of the alternative model (in relation to its fully saturated counterpart) was tested using the chi-square statistic and the goodness-of-fit index.

 $(1a) D_{PCS}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7 + b_8X_8 + b_9X_9 + b_{10}X_{10}$   $(1b) D_{MCS}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7 + b_8X_8 + b_9X_9 + b_{10}X_{10}$   $(2) D_{CSE}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7 + b_8X_8$   $(3) D_{CSD}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7 + b_8X_8$   $(4) D_{CAHC}=a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7$ 

Hypothesized model. A hypothesized model was constructed. It was hypothesized that perceived self-efficacy has both direct and indirect effects on coping strategies and direct effects on cognitive appraisal of health; perceived social support has both direct and indirect effects on coping strategies and direct effects on cognitive appraisal of health; cognitive appraisal of health has direct effects on coping strategies; coping strategies have direct effects on HRQOL; and renal transplantation-related variables have direct effects on cognitive appraisal of health. Figure 4 shows the hypothesized model. There are four endogenous variables: the fully endogenous variable, HRQOL (PCS or MCS); engagement and disengagement coping strategies, which are modeled as mediating the effects of the transplantation-related variables, cognitive appraisal of health, perceived self-efficacy, and perceived social support on HRQOL; and cognitive appraisal of health, which is modeled as mediating the effects of all the exogenous variables on subsequent endogenous variables. Thus, the set of multiple regression equations needed to represent the hypothesized model are:



The goodness of fit of the hypothesized model also was tested in relation to the

alternative model using the chi-square test and the goodness-of-fit index.



Figure 4: Hypothesized Model

### <u>Analysis</u>

A series of nested path analyses were performed to test the initial, alternative, and hypothesized models. Path coefficients were derived as linear regression coefficients. Standardized coefficients ( $\beta$ ) were reported because they allow comparison of the absolute (either positive or negative valence) relative magnitude of one path with that of other paths in the model. Total effects including the direct effects (simple paths) and indirect effects (compound paths) were calculated.

Research question 2. What are the effects of clinical factors (donor type, history of transplantation-related hospitalizations, duration of dialysis, side effects of immunosuppressive medications, and time post-transplant) on the psychosocial variables and HRQOL?

Multivariate Analysis of Covariance (MANCOVA) was used to address the effects of donor type (living vs cadaveric), history of transplantation related hospitalizations (yes vs none), duration of dialysis ( $\leq 6$  months and >6 months), side effects of immunosuppressive medications (score  $\leq 17$  and score >17) on cognitive appraisal of health, perceived self-efficacy, perceived social support, coping strategies, and HRQOL with the time post-transplant as a covariate. A separate Multivariate Analysis of Variance (MANOVA) was used to test the effect of time post-transplant (less than 1 year and 1 to 3 years post-transplant) on these psychosocial variables.

### CHAPTER IV

### RESULTS

This chapter presents the results of the data analyses used to examine the research questions posed in this dissertation research study. Six principal sections are provided. In section one, a description of the sample is given including frequencies, percentages, means, standard deviations, and minimum and maximum scores. Section two presents the descriptive statistics for each instrument including the instrument's internal consistency reliability, means, standard deviation, minimum and maximum scores, skewness and kurtosis. In section three, the bivariate relationships between observed variables in the proposed model are presented. Section four addresses the findings for the path analysis for the test of the hypothesized relationships in the model for coping and HRQOL. Section five presents the results of data analyses for the second research question asked in the study. Section six briefly summarizes the chapter.

### Description of the Sample

A total of 160 renal transplant patients with 55 in the early post-transplant period (less than 1 year) and 105 in the later period (1 to 3 years) participated in this study. Demographic data including age, gender, marital status, race, and level of education were collected (see Table 1, 2). The convenience sample (N=160) in this study ranged in age from 18 to 75 years (M=47.7, SD=13.2). The sample consisted of 86 males (53.8%) and 74 females (46.3%). Approximately 70.6% (n=113) of participants were

married, while the remaining participants were single (n=31, 19.4%), widowed (n=4, 2.5%), separated (n=3, 1.9%), or divorced (n=9, 5.6%). The majority of participants were Caucasian (n=124, 77.5%), with the remaining participants identified as African American (n=33, 20.6%) or Asian (n=3, 1.9%). Regarding the level of education, the majority of participants had high school education (n=93, 58.1%), 21.3% (n=34) of participants attended college, 15% (n=24) of participants had an associate/bachelor's degree, and 3.1% (n=5) of participants had a graduate degree.

Variable	Early Group (n=55)	Later Group (n=105)	Total Sample (N=160)	
	Frequency (%)	Frequency (%)	Frequency (%)	p**
Gender				.416
Male	32 (58.2)	54 (51.4)	86 (53.8)	
Female	23 (41.8)	51 (48.6)	74 (46.3)	
Age (years) *	46.4 (14.3)	48.4 (12.6)	47.7 (13.1)	.357
Marital Status				.718
Married	37 (67.3)	76 (72.4)	113 (70.6)	
Single	11 (20.0)	20 (19.0)	31 (19.4)	
Widowed	1 (1.8)	3 (2.9)	4 (2.5)	
Separated/ Divorced	6 (10.9)	6 (5.7)	12 (7.5)	
Race				.856
African-American	10(18.2)	23 (21.9)	33 (20.6)	
Asian	1 (1.8)	2(1.9)	3 (1.9)	
Caucasian	44 (80.0)	80 (76.2)	124 (77.5)	
Education Level				514
Less than high school	2 (3 6)	2 (1 9)	4 (2,5)	.011
High school	$\frac{2}{28}(50.9)$	65 (61.9)	93 (58 1)	
Attended college	13 (23.6)	21(200)	34(213)	
Associated/bachelor	9 (16 4)	15(143)	24(150)	
degree	~ ()	()	- ()	
Graduate degree	3 (5.5)	2 (1.9)	5 (3.1)	

Table 1. S	Summary c	of Particip	oant Demo	graphic Data

\* Data reported are the Mean (SD)

\*\* Type I error probability level for the chi-square or t-test of differences between groups

Using chi-squared tests of proportions, with alpha of <.05, no differences were found between the early period post-transplant and later period post-transplant groups on gender, marital status, race, and education level. An independent sample *t* test demonstrated that there was no difference in age between the two groups.

Clinical data including original cause of ESRD, type of dialysis, duration of dialysis before transplant, donor type, relationship of living donor, time post-transplant, current immunosuppressive medications, history of rejection episodes, and number of transplant-related hospitalizations, were recorded because they are important variables for the renal transplant population (see Table 2). The major causes of ESRD in this sample were hypertension (n=41, 25.6%) and diabetes (n=27, 16.9%), followed by adult polycystic kidney disease (n=16, 10.0%), and IgA nephropathy (n=14, 8.7%). In terms of type of dialysis, 61.3% (n=98) of participants had hemodialysis and 24.3% (n=39) had peritoneal dialysis. Approximately 14% of participants received no dialysis before transplantation. The duration of dialysis before transplantation ranged from 0 to 275 months (M=23.7, SD=32.0), with 70% (n=112) of participants having dialysis more than six months. More than half of the participants received a living donor graft (n=95, 59.4%) with 37.5% of them biologically-related and 21.9% not biologically-related such as spouse or friends, while the remaining participants received cadaveric donor graft (n=65, 40.6%). Regarding current immunosuppressive medications, the majority of participants (n=103, 64.4%) were taking steroids (prednisone), mycophenolate mofetil (Cellcept), and tacrolimus (Prograf); 19.4% (n=31) were prescribed prednisone, Cellcept, and sirolimus (Rapamune); 6.8% (n=11) reported taking prednisone, Cellcept, and Neoral; and 4.4% (n=7) received the prednisone avoidance protocol (taking Cellcept and

Prograf, or Cellcept and Rapamune). Approximately 90% (n=144) of the study participants had no graft rejection episodes, while 8.8% (n=14) of participants had one rejection episode and only two (1.2%) participants had two rejection episodes. Because few participants had rejection episodes in this study, history of rejection was not included in the regression models and MANOVA analyses. The majority of the study participants had no transplant-related hospitalizations (n=95, 59.4%), with the remaining participants hospitalized once (n=41, 25.6%) or more than once (n=24, 15.0%). The length of time since transplantation was also recorded and ranged from 3 to 43 months (M=18.8, SD=12.8).

The differences in the clinical data between the early and later period posttransplant groups also were tested. Results from chi-squared tests indicated that there were no significant differences in original cause of ESRD, type of dialysis before transplantation, duration of dialysis ( $\leq 6$  months/> 6 months), donor type (living/ cadaveric), immunosuppressive medications, rejection episodes, and grade of rejection between the two groups. However, there was a statistically significant difference in history of transplant-related hospitalizations (yes/no) between the two groups (p = .013). The result indicated that more participants in the early group had no history of transplantrelated hospitalizations than participants in the later group. The difference between the two groups on months of dialysis therapy before transplantation was examined using independent t test and no difference was found between the early and later period posttransplant groups.

Variable	Early Group (n=55)	Later Group (n=105)	Total Sample (N=160)	
	Frequency (%)	Frequency (%)	Frequency (%)	p**
Original Cause of ESPD				502
Hypertension	11(200)	30 (28.6)	41 (25.6)	.393
Diabetes	11(20.0) 12(23.6)	15(143)	$\frac{41}{25.0}$	
Adult polycystic kidney disease	7(127)	9 (8 6)	16(10.0)	
IgA nephropathy	5 (9 1)	9 (8 6)	14 (8 7)	
FSGs	4(73)	6 (5.8)	10(62)	
Others	16 (40.0)	36 (34.3)	52 (32.6)	
				272
Type of Dialysis	20 (52 7)		00((1,2))	.272
Hemodialysis	29 (52.7)	69 (65.7)	98 (61.3)	
Peritoneal dialysis	16 (29.1)	23 (21.9)	39 (24.3)	
No dialysis	10 (18.2)	13 (12.4)	23 (14.4)	
Duration of Dialysis (month) *	21.6 (23.7)	24.8 (35.6)	23.7 (32.0)	.554
$\leq 6$ months	14 (25.4)	34 (32.4)	48 (30.0)	.364
> 6 months	41 (74.6)	71 (67.6)	112 (70.0)	
Donor Type				115
Cadaveric donor	27 (49 1)	38 (36 2)	65 (40.6)	.115
Living donor	28 (50.9)	67 (63.8)	95 (59.4)	
Biological related	16(291)	44 (41 9)	60 (37 5)	
Unbiological related	12 (21.8)	23 (21.9)	35 (21.9)	
<b>T T T T</b>				107
Immunosuppressive medications	22((0,0))	70(((7))	102((4,4))	.105
Prednisone, Cellcept, Tacronmus	33 (00.0) 15 (27.2)	/0 (00./)	103(04.4)	
Prednisone, Cellcept, Shohihus	13(27.3) 1(1.8)	10(13.2) 10(0.5)	51(19.4) 11(6.8)	
Prednisone avoidance	1(1.0) 1(7.3)	10(9.3)	7(4.4)	
Others	2 (3.6)	6 (5.7)	8 (5.0)	
	()		- ()	
Rejection Episodes				.587
None	50 (90.9)	94 (89.5)	144 (90.0)	
One episode	5 (9.1)	9 (8.6)	14 (8.8)	
Two episodes	0 (0.0)	2 (1.9)	2 (1.2)	
Grade of Rejection				.919
Mild	3 (5.4)	7 (6.8)	10 (6.3)	
Moderate	2 (3.6)	3 (2.9)	5 (3.1)	
Severe	0 (0.0)	1 (1.0)	1 (0.6)	
Transplant-related Hospitalizations				013
None	40 (72 7)	55 (52 4)	95 (59 4)	.015
One time	8 (14 5)	33(314)	41 (25.6)	
Two to five times	7 (12.8)	14 (13 3)	21 (13 2)	
Six times or above	0 (0.0)	3 (2.9)	3 (1.8)	
Months Sings Transplantation*	A 5 (0 A)	262(0.0)	100(170)	000
months since transplantation*	4.3 (2.4)	20.3 (9.0)	10.0 (12.8)	.000

# Table 2. Summary of Participant Clinical Data

\* Data reported are the Mean (SD) \*\* Type I error probability level for the chi-square or t-test of differences between groups
## Description of Instruments

### Instrument Reliability

All the main instruments for the research study were tested for internal consistency reliability using Cronbach's alpha (see Table 3). Reliability coefficients for most scales approached or exceeded 0.70 except the benign/irrelevant ( $\alpha$ =.53) subscale of CAHS, and some of the subscales of Brief COPE such as self-distraction (.45), active coping (.50), behavioral disengagement (.59), positive reframing (.63), and self-blame (.66). It is important to note that each of the subscales of Brief COPE has only two items.

#### Descriptive Statistics of the Instruments

Descriptive statistics from the Cognitive Appraisal of Health Scale (CAHS), Brief COPE, Perceived Health Competence Scale (PHCS), Personal Resource Questionnaire (PRQ), Medical Outcomes Study 36-item Short Form Health Survey (SF-36<sup>®</sup>), and the Symptom Checklist are summarized in Table 4.

<u>CAHS.</u> Cognitive appraisal of health was measured using CAHS. Only the primary appraisal subscales which include threat, challenge, harm/loss, and benign/irrelevant were analyzed in this study. Higher scores indicate more agreement with the subscales. Scores on the four subscales can range from 5 to 25 for the Threat scale, 6 to 30 for the Challenge scale, 8 to 40 for the Harm/Loss scale, and 4 to 20 for the Benign/Irrelevant scale. In this study, participant scores ranged from 5 to 23 (M=12.02, SD=3.83) for the Threat scale, 6 to 30 (M=22.84, SD=4.13) for the Challenge scale, 8 to 38 (M=19.75, SD=7.09) for the Harm/Loss scale, and 4 to 18 (M=10.58, SD=2.95) for the Benign/Irrelevant scale.

Instrument	Cronbach's Alpha
SE-36	
PCS	78
MCS	.81
D. CONT	
Brief COPE	
Self-distraction	.45
Active coping	.50
Denial	.72
Use of emotional support	.72
Use of instrumental support	.71
Behavioral disengagement	.59
Venting	.72
Positive reframing	.63
Planning	.68
Humor	.88
Acceptance	.70
Religion	.86
Self-blame	.66
PHCS (Perceived Health Competence Scale)	.82
PRQ (Personal Resource Questionnaire)	.93
CAHS (Cognitive Appraisal of Health Scale)	
Threat	.73
Challenge	76
Harm/loss	89
Benign/irrelevant	.53
Symptom Survey	.79

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Instruments	Mean (SD)	Range (possible range)	Skewness	Kurtosis
CAUS				
CARD Throat	12 02 (2.82)	5 22 (5 25)	27	11
Challenge	12.02(5.65)	5-25 (5-25) 6 20 (6 20)	.57	11
	22.04 (4.13)	0-30 (0-30) 8 28 (8 40)	05	1.42
Harm/IOSS	19.75 (7.09)	8-38 (8-40)	.28	/3
Benign/Irrelevant	10.58 (2.95)	4-18 (4-20)	.17	30
Primary appraisal Component	0.00 (1.00)	-2.06-2.94	.27	04
Brief COPE				
Self-distraction	4.88 (1.82)	2-8 (2-8)	02	90
Active coping	5.61 (1.70)	2-8(2-8)	28	61
Denial	2.39 (1.03)	2-8(2-8)	3.06	9.97
Use of emotional support	5 43 (1 94)	2-8 (2-8)	- 27	- 99
Use of instrumental support	4 10 (1.82)	2-8(2-8)	55	- 66
Behavioral disengagement	2.57(1.19)	2-8(2-8)	2.43	6.18
Venting	3 81 (1 74)	2-8(2-8)	79	- 08
Positive reframing	5.01(1.71) 5.47(1.91)	2-8(2-8)	- 12	-1.16
Planning	4 69 (1 91)	2-8(2-8)	16	-1.03
Humor	3 67 (2.02)	2-8(2-8)	90	- 53
Acceptance	6 70 (1 70)	2-8(2-8)	-1.26	71
Religion	5 96 (2.14)	2-8(2-8)	- 64	- 98
Self-blame	3 10 (1 50)	2-8 (2-8)	1 45	1 64
	5.10 (1.50)	20(20)	1.10	1.01
Engagement Coping	0.00 (1.00)	-2.68-2.21	37	-3.68
Disengagement Coping	0.00(1.00)	-1.47-4.27	1.53	3.03
PHCS	30.23 (5.69)	17-40 (8-40)	06	72
PRQ	87.16 (13.76)	30-105 (15-105)	-1.23	2.42
Symptom Checklist	17.08 (9.32)	0-46 (0-60)	.48	10
SE 26				
DCS	12 16 (11 06)	18 62 (0 100)	22	1.04
ICS MCS	42.40 (11.00) 50.04 (11.16)	12 66 (0 100)	23	-1.04
MCS Individual Scalas	30.04 (11.10)	13-00 (0-100)	95	.29
Dhyrical Eurotion	60 14 (27 20)	0,100 (0,100)	17	00
Physical Function	08.14(27.38)	0-100(0-100)	47	88
Role Physical	55.00 (42.05) (0. (2. (2(.40)	0-100 (0-100)	22	-1.08
Boully Pain Concred Health	09.03 (20.40) 50.50 (21.07)	0-100(0-100) 5 100(0 100)	39	55
General Health	39.39 (21.97) 76 56 (26.19)	5-100(0-100) 12 100(0 100)	33	02
Social Functioning	/0.30 (20.18) 72.28 (40.00)	13-100(0-100)	/3	//
Kole Emotional	/3.38 (40.00)	0-100(0-100)	-1.02	/3
Iviental Health	/3.99 (18.96)	12-100(0-100)	68	0/
vitality	54.84 (22.37)	0-100 (0-100)	10	/8

# Table 4. Descriptive Statistics of Instruments (Total Sample)

Instruments	Mean (SD)	Range (possible range)	Skewness	Kurtosis
CALLS				
CAHS	11.54(2.07)	5 22 (5 25)	50	07
Challongo	11.34(3.97) 24.02(4.21)	5-22 (5-23) 6 20 (6 20)	.30	.07
Harm/loss	24.02(4.51) 10.34(6.54)	8 33 (8 40)	-1.61	J.40 96
Renign/irrelevent	19.34(0.34) 10.74(2.77)	6 18 (4 20)	.10	90
Demgn/melevant	10.74 (2.77)	0-18 (4-20)	.78	.20
Primary appraisal Component	-0.15 (0.94)	-2.06-2.08	.25	.01
Brief COPE				
Self-distraction	5.19 (1.80)	2-8 (2-8)	32	79
Active coping	6.21 (1.57)	2-8 (2-8)	63	32
Denial	2.25 (0.83)	2-6 (2-8)	3.49	11.56
Use of emotional support	5.94 (1.83)	2-8 (2-8)	52	75
Use of instrumental support	4.38 (1.92)	2-8 (2-8)	.37	80
Behavioral disengagement	2.43 (0.91)	2-5 (2-8)	1.88	2.11
Venting	3.85 (1.88)	2-8 (2-8)	.73	53
Positive reframing	5.81 (1.86)	2-8 (2-8)	24	-1.22
Planning	5.12 (2.06)	2-8 (2-8)	12	-1.15
Humor	3.73 (2.06)	2-8 (2-8)	.92	43
Acceptance	6.85 (1.67)	2-8 (2-8)	-1.68	2.37
Religion	5.98 (2.06)	2-8 (2-8)	67	87
Self-blame	3.00 (1.23)	2-6 (2-8)	.89	66
Engagement Coping	0.29 (1.00)	-2.56-2.21	53	.17
Disengagement Coping	-0.09 (0.79)	-1.32-2.18	.87	.71
PHCS	32.02 (5.13)	19-40 (8-40)	48	42
PRQ	90.33 (10.63)	67-105 (15-105)	33	75
Symptom Checklist	17.06 (9.07)	2-42 (0-60)	.30	03
SF-36				
PCS	43.29 (10.53)	20-63 (0-100)	38	80
MCS	50.94 (10.21)	21-63 (0-100)	-1.01	.60
Individual Scales				
Physical Function	71.94 (25.36)	11-100 (0-100)	69	44
Role Physical	55.00 (43.41)	0-100 (0-100)	19	-1.76
Bodily Pain	71.04 (24.66)	22-100 (0-100)	23	-1.26
General Health	63.04 (20.41)	20-100 (0-100)	38	67
Social Functioning	76.36 (25.87)	25-100 (0-100)	58	-1.03
Role Emotional	77.58 (37.44)	0-100 (0-100)	-1.34	.14
Mental Health	75.96 (18.28)	32-100 (0-100)	53	59
Vitality	57.78 (21.03)	10-100 (0-100)	22	56

# Table 5. Descriptive Statistics of Instruments (Early Group)

CAHS	
Thread $17.76(7.75)$ $5.77(5.75)$ $22$ $13$	
Infeat $12.20(5.75)$ $5-25(5-25)$ $.55$ $11$ Challange $22.24(2.02)$ $11.20(6.20)$ $29$ $12$	
$\begin{array}{c} \text{Chantenge} \\ \text{Leave} \\ \text{Leave} \\ \text{Leave} \\ \begin{array}{c} 22.24 \\ (5.92) \\ 11-50 \\ (0-50) \\58 \\ .15 \\ .$	
Harm/Ioss $19.94(7.39)$ $8-38(8-40)$ $.51$ 70	
Benign/irrelevant $10.49(3.06)$ $4-1/(4-20)$ $04$ $56$	1
Primary appraisal Component         0.08 (1.02)         -2.02-2.94         .25        06	,
Brief COPE	
Self-distraction 4.73 (1.81) 2-8 (2-8) .138	
Active coping $5.30(1.68)$ $2-8(2-8)$ $-12$ $-50$	)
Denial $2.47(1.11)$ $2-8(2-8)$ $2.88$ $8.94$	ļ.
Use of emotional support $5.17(1.96)$ $2-8(2-8)$ $-14$ $-10$	3
Use of instrumental support $3.95(1.77)$ $2.8(2.8)$ $64$ $-54$	1
Behavioral disengagement $2.65(1.31)$ $2.8(2.8)$ $2.38$ $5.6$	1
Venting $3.78(1.67)$ $2.8(2.8)$ $84$ $27$	r
Positive reframing $5.79(1.07)$ $2.8(2.8)$ $-05$ $-11$	4
Planning $4.48(1.81)$ $2.8(2.8)$ $26$ - 90	, )
Humor $3.64(2.01)$ $2.8(2.8)$ $90$ $-5^{4}$	
$\begin{array}{cccc} \Delta ccentance & 6.63 (1.72) & 2.8 (2.8) & -1.09 & 16 \end{array}$	
Recipitation $5.05(1.72)$ $2.8(2.8)$ $-63$ $-1.0$	2
Kengton $5.75(2.16)$ $2-6(2-6)$ $-1.05$ $-1.05$ Salf blama $3.16(1.60)$ $2.8(2.8)$ $1.56$ $1.9$	<u>~</u>
Sen-blaine 5.10 (1.00) 2-0 (2-8) 1.50 1.00	)
Engagement Coping -0.15 (0.97) -2.68-1.753856	)
Disengagement Coping $0.04(1.09)$ -1.47-4.27 1.57 3.0	<b>5</b>
PHCS 29.31 (5.77) 17-40 (8-40) .1757	/
PRQ         85.58 (14.87)         30-105 (15-105)         -1.25         2.12	2
Symptom Checklist         17.10 (9.49)         0-46 (0-60)         .56        10	1
SF-36	
PCS 42.46 (11.06) 18-63 (0-100)16 -1.1	2
MCS 50.04 (11.16) 13-66 (0-100) - 88 16	
Individual Scales	
Physical Function 66 13 (28 30) 0-100 (0-100) - 36 - 10	3
Role Physical $56.01(42.45)$ $0.100(0.100)$ $-24$ $-16$	6
Bodily Pain $68.87 (27.36)$ $0.100 (0.100)$ $-44$ $-8'$	)
General Health $57.73(22.64)$ $5-100(0-100)$ $-27$ $-60$	
Social Functioning $76.67(26.46)$ 13-100(0-100) - 81 - 60	
Role Emotional $71.15(41.30)$ $0.100(0.100)$ $80$	2
Montal Health $72.93(19.32)$ $12_100(0-100)$ $-74$ $11$	-
Vitality $53.30(22.99)$ $0-100(0-100)$ $-03$ $-84$	Ļ

# Table 6. Descriptive Statistics of Instruments (Later Group)

These results indicated that participants in this study had a high degree of agreement with the challenge appraisal of their health and a moderate degree of agreement with the threat, harm/loss, and benign/irrelevant appraisal of their health.

In order to enhance the power of the statistical analyses by reducing the covariate set, factor analysis on the four primary appraisal subscales of CAHS was performed to identify the second-order factors to be used in the analyses for this study. A one-component solution (63.49% of total variance) was derived and interpreted as the primary appraisal of health. The component matrix was as follows: Threat (0.85), Challenge (-0.72), Harm/Loss (0.85), and Benign/Irrelevant (-0.76). A weighted single component score (M=0, SD=1) was used with a higher score indicating negative primary appraisal of health (e.g., threat, harm, or loss).

Brief COPE. Coping strategies used by participants were assessed by Brief COPE. There are 13 subscales with 2 items in each scale. Scores on each of the subscales can range from 2 to 8. Higher scores on the subscale indicate more use of the coping strategies represented by the subscale. In this study, actual scores on the 13 subscales ranged from 2 to 8. Results show that participants in this study used active coping, emotional support, positive reframing, acceptance, and religion coping moderately or a lot. Denial, behavioral disengagement, and self blame are used a little or not at all by the participants.

Second-order factor analysis also was conducted on the 13 subscales of Brief COPE to improve the power of the statistical analyses by reducing the covariate set. Some of the subscales had lower reliabilities, some subscales had higher skewness, and there were too many variables in the path models. A two-component solution (46.83%)

was derived based on the scree plot, the percentage of variance extracted, and item loadings. Component 1 (31.94% variance) includes acceptance, active coping, use of emotional support, use of instrumental support, planning, positive reframing, religion, and self-distraction. Component 2 (14.89%) includes behavioral disengagement, denial, humor, self-blame, and venting. The two-component solution was interpreted as engagement coping (component 1) and disengagement coping (component 2). The weighted component scores (M=0, SD=1) were used in this study. Higher scores in the first weighted component indicated more use of engagement coping strategies, while higher scores in the second weighted component indicated more use of disengagement coping strategies.

<u>PHCS</u>. The Perceived Health Competence Scale (PHCS) was used to assess perceived self-efficacy on health of participants in this study. After reverse scoring the negatively valenced items, all scores on eight items are summed. Total scores on PHCS can range from 8 to 40. Higher scores indicate a higher degree of perceived self-efficacy. Participant scores in this study ranged from 17 to 40 (M=30.23, SD=5.69). These data suggest that study participants had a high degree of perceived self-efficacy with respect to their health.

<u>PRQ</u>. Perceived social support was measured using the Personal Resource Questionnaire (PRQ). Scores on the PRQ can range from 15 to 105. High scores indicate a high level of perceived social support. Actual scores in this study ranged from 30 to 105 (M=87.16, SD=13.76). These results indicate participants in this study perceived high levels of social support. <u>SF-36</u>. Self-reported HRQOL was measured by SF-36 in this study. SF-36 has eight scales with scores ranging from 0 to 100 for each of them. The physical component summary scale (PCS) and the mental component summary scale (MCS) are derived from transforming and summing across the eight standardized weighted subscales. Scores on the PCS and the MCS can range from 0 to 100 and are normed to the general US population with a mean of 50 and standard deviation of 10. Higher scores represent better HRQOL. In this study, participant scores on the PCS ranged from 18 to 63 (M=42.46, SD=11.06), while scores on the MCS ranges from 13 to 66 (M=50.04, SD=11.16). These data suggest that participants in this study had a lower physical HRQOL and a normal mental HRQOL in comparison to the general US population.

Symptom Checklist. The Symptom Checklist was developed by the researcher and her dissertation committee to measure the side-effects of immunosuppressive medications. Principal component analysis with varimax rotation was used to evaluate the latent dimensionality of the 12 item symptom checklist. A one-component solution (31.43%) was derived on the basis of the scree plot, percentage of variance extracted, salient item loading, and solution clarity. Total scores are obtained by summing the 12 item scores and can range from 0 to 60. High scores indicate that the individuals were experiencing more bothersome symptoms. The Cronbach's alpha of this symptom checklist was .79 in this study. Participant scores in this study ranged from 0 to 46 (M=17.08, SD=9.32). Based on these results, participants experienced mildly bothersome side-effects of immunosuppressive medications. The median score on the symptom checklist was 17. The median split was used to create the subgroups rather than the mean score because two equal size groups could be obtained. Using the scores on the symptom

checklist, participants in this study were categorized into two groups, scores  $\leq 17$  group (*n*=71) and scores >17 group (*n*=70). This classification was used to test the effect of medication side-effects on the psychosocial variables in this study.

Table 5 and Table 6 show the descriptive statistics for each of the instruments by group (the early group and the later group). The differences between the psychosocial variables were examined using MANOVA in the research question 2. The results are described later in this chapter.

### Correlational Analysis Between Observed Variables

The zero-order correlations for observed variables in the models for the total group of subjects are presented in Table 7. There was a significant positive relationship between negative primary appraisal of health and disengagement coping (r=.42, p<.01). The more the participants appraised their health condition as a threat, harm/loss, the more they used disengagement coping. There were significant negative correlations between negative primary appraisal and PCS (r=-.45, p<.01) and between negative primary appraisal and PCS (r=-.45, p<.01) and between negative primary appraisal and PCS (r=-.45, p<.01) and between negative primary appraisal and PCS (r=-.45, p<.01) and between negative primary appraisal and PCS (r=-.45, p<.01) and between negative primary appraisal and PCS (r=-.45, p<.01) and between negative primary appraisal and PCS (r=-.45, p<.01) and between negative primary appraisal and PCS (r=-.45, p<.01) and between negative primary appraisal and PCS (r=-.45, p<.01) and between negative primary appraisal and PCS (r=-.54, p<.01). These results indicated that the more the participants appraised their health condition negatively (higher scores), the worse their physical and mental HRQOL (lower scores).

There was a significant negative relationship between perceived self-efficacy and negative primary appraisal (r=-.62, p<.01). The lower the degree of perceived self-efficacy of the participants, the more negatively they appraised their health condition. Perceived self-efficacy also was negatively related to disengagement coping (r=-.39, p<.01). The higher the degree of perceived self-efficacy, the less disengagement coping

was used. Perceived self-efficacy also had significant correlations with PCS (r=.41, p<.01) and MCS (r=.44, p<.01). These data suggested that participants with a higher degree of perceived self-efficacy had better physical and mental HRQOL.

The correlation analysis showed that perceived social support had a significant negative relationship with negative primary appraisal (r=.35, p<.01). The higher the level of perceived social support, the less the participants appraised their health condition as a threat or harm/loss. There was a statistically significant positive relationship between perceived social support and engagement coping (r=.21, p<.05) and a significant negative relationship between perceived social support and disengagement coping (r=-.18, p < .05). These results indicated that participants in this study who reported higher levels of perceived social support tended to use more engagement coping and less disengagement coping. Perceived social support was also moderately correlated to perceived self-efficacy (r=.34, p<.01). This result suggested that participants with a higher level of perceived social support reported a higher degree of perceived selfefficacy. Perceived social support had a significant negative relationship with time posttransplant (r=-.14, p<.05). This result indicated that the longer the time post-transplant, the lower the degree of perceived social support participants reported. This correlation analysis also demonstrated that perceived social support was significantly related to PCS (r=.21, p<.05) and MCS (r=.27, p<.01). The higher the level of social support perceived by participants, the better HRQOL they reported.

There was a significant negative relationship between disengagement coping and MCS (r=-.45, p<.05); a significant negative relationship between disengagement coping and PCS (r=-.18, p<.05). These results indicated that participants who used more

disengagement coping reported worse physical and mental HRQOL. Correlation analysis demonstrated that engagement coping had no statistically significant relationships with either PCS or MCS (all p>.05).

Side-effect symptoms related to immunosuppressive medications had a significant positive relationship with negative primary appraisal (r=.44, p<.01). The more bothersome the symptoms reported by participants, the more they appraised their health condition negatively. There was also a significant positive correlation between the degree of bothersome medication side-effects and disengagement coping (r=.40, p<.01). This result indicated that participants who reported more bothersome symptoms used more disengagement coping. Correlation analysis demonstrated that the level of bothersome symptoms was inversely related to perceived self-efficacy (r=-.47, p<.01), PCS (r=-.32, p<.05), and MCS (r=-.46, p<.01). These results suggested that participants with more bothersome symptoms reported a lower degree of perceived self-efficacy, worse physical and worse mental HRQOL.

History of transplant-related hospitalizations had a significant positive relationship with negative primary appraisal (r=.17, p<.05). This result indicated that participants who reported having transplant-related hospitalizations appraised their health condition negatively. History of transplant-related hospitalizations was also negatively related to perceived social support (r=.18, p<.05) and physical HRQOL (r=.18, p<.05). These results suggested that participants with a history of transplant-related hospitalizations reported a lower degree of perceived social support and lower physical HRQOL.

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46**	15	21*	.39**	60 <sup>.</sup>							
55**	12	46**	.43**	.27**	.13						
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There was a significant negative correlation between duration of dialysis before transplantation and physical HRQOL (r=-.18, p<.05). This result suggested that participants who received dialysis more than 6 months reported a lower physical HRQOL.

Relationships between time post-transplantation and other variables also were assessed. Correlation analysis demonstrated that time post-transplantation had significant negative associations with engagement coping (r=-.28, p<.01) and perceived self-efficacy (r=-.22, p<.01). These results indicated that the longer the time post-transplantation, the less engagement coping was used by the participants and they reported a lower degree of perceived self-efficacy.

Correlational analyses between the observed variables in the model also were performed for the early period post-transplant group (Table 8) and later group (Table 9). Results indicated that perceived self-efficacy was significantly related to perceived social support, physical and mental HRQOL, while perceived self-efficacy had a significant inverse relationship with negative primary appraisal of health and side effects of immunosuppressive medications in both groups. There were significant positive relationships between perceived social support and physical and mental HRQOL, and significant negative relationships between perceived social support and negative primary appraisal of health, side effects of immunosuppressive medications, and history of transplant-related hospitalizations in the early group. However, perceived social support was not significantly related to physical HRQOL, side effects of immunosuppressive medications, and history of transplant-related hospitalizations in the later group. Perceived social support had a significant negative relationship with duration of dialysis before transplantation in the later group. Negative primary appraisal of health was

significantly related to disengagement coping and side effects of immunosuppressive medications, and negatively related to physical and mental HRQOL in both groups. There was a significant negative relationship between disengagement coping and mental HROOL in both groups. Disengagement coping was not significantly related to physical HRQOL in the early group, but there was a significant negative relationship to physical HRQOL in the later group. Side effects of immunosuppressive medications had a significant positive relationship with disengagement coping and negative relationships with physical and mental HRQOL in both groups, while side effects of immunosuppressive medications was also positively related to engagement coping in the later group. History of transplant-related hospitalizations was negatively related to physical HRQOL in the later group and no significant relationship was found in the early group. Donor type had a negative relationship with mental HRQOL in the early group and a negative relationship with side effects of immunosuppressive medications in the later group. There were no significant relationships found between duration of dialysis, time post-transplant and other variables in the early group. However, duration of dialysis had a significant negative correlation to perceived social support and physical HRQOL; time post-transplant was positively related to donor type in the later group.

#### Path Analysis of Proposed Models

A series of nested path analyses were used to test the initial, alternative, and hypothesized models using the AMOS program. Participants with complete data on all measures were included (N=141) to perform all the multiple regression analyses. To test the model fit, the following indices were used in the analysis: the chi-square fit statistic ( $\chi^2$ ), relative chi-square (ratio of chi-square to degree of freedom,  $\chi^2/df$ ), the goodness of fit index (GFI), and the comparative fit index (CFI). These indices were chosen because they are commonly reported in the literature and Bollen (1989) suggested that assessing model fit should be based on multiple goodness-of-fit indices. The chi-square fit statistic ( $\chi^2$ ) assesses the discrepancy between the observed data and a restricted structure resulting from the model under consideration. A high chi-square value leads to the rejection of the null hypothesis of model fit. A limitation of the chi-square fit statistic is that it is greatly influenced by sample size and violations of multivariate normality (Jöreskog & Sörbom, 1988). The relative chi-square is calculated by dividing the chi-square value by the degrees of freedom. The relative chi-square should be less than three if the fit between the data and model is to be considered good (Bollen, 1989). This index is an indication of how well the model under scrutiny matches an alternative model (Jöreskog & Sörbom, 1988). The GFI directly assesses the extent to which the model reproduces the data, and it indicates the relative amount of the observed variances and covariance that are associated with the model. The CFI assesses the extent to which the model reproduces the data as compared to a baseline model in which all variables are uncorrelated. Values of 0.9 or above for the GFI and CFI usually suggest good model fit (Bollen, 1989).

### Initial Model

Analyses of the initial models predicting PCS and MCS were performed first. Results showed the initial model predicting PCS did not fit the data well in relation to its fully saturated counterpart. The  $\chi^2$  statistic was significant (13.20, *p*= 0.001) with 2 degrees of freedom (df). The  $\chi^2$ /df was 6.60. The goodness of fit index (GFI) was 0.98.

The comparative fit index (CFI) was 0.83. Similarly, the saturated model predicting MCS also did not fit the data with  $\chi^2$  (13.20, df =2, p= 0.001),  $\chi^2$ /df (6.60), GFI (0.98), and CFI (0.83).

## Alternative Model

In the alternative models predicting PCS and MCS, paths from transplantationrelated variables to perceived self-efficacy and perceived social support were removed and perceived self-efficacy and perceived social support were added to the correlated exogenous variable set. Model fit analyses demonstrated that the alternative model predicting PCS fit the data well. The  $\chi^2$  statistic was not significant (0.00, p=0.995) with 1 degree of freedom. The  $\chi^2$ /df was 0.00. Both the GFI and the CFI were 1.00. Results of the alternative model predicting MCS mirrored the results for PCS, and fit the data well. Path coefficients are summarized in Table 10. Path coefficients are bolded if the p-value was  $\leq 0.1$ .

Nested path analyses were performed for the alternative model predicting PCS. A series of nested models were set up by constraining some paths by setting the selected path coefficients to equal zero. Alternative model 1 had no constrained paths; alternative model 2 constrained the paths with p-values greater than 0.1; alternative model 3 constrained the paths with p-values greater than 0.05; and alternative model 4 constrained the paths with p-values greater than or equal to 0.05 (see Table 10).

	Unstandardized	S.E.	Standardized	Р
Self-efficacy on CAHS	083	.014	477	.000
Hospitalization on CAHS <sup>c</sup>	.263	.131	.128	.046
Social support on CAHS	012	.005	162	.017
Symptom on CAHS	.024	.008	.214	.003
Duration of dialysis on CAHS <sup>a,b,c</sup>	018	.136	009	.892
Time post-transplant on CAHS <sup>b,c</sup>	.000	.000	117	.078
Donor type on CAHS <sup>a,b,c</sup>	.124	.136	.060	.364
Self-efficacy on Engagement Coping <sup>a,b,c</sup>	.023	.020	.127	.253
Self-efficacy on Disengagement coping <sup>a,b,c</sup>	018	.018	103	.316
Hospitalization on Engagement Coping <sup>a,b,c</sup>	.036	.173	.017	.837
Hospitalization on Disengagement Coping <sup>a,b,c</sup>	.112	.154	.055	.469
Social support on Disengagement Coping <sup>a,b,c</sup>	003	.006	045	.580
Symptom on Engagement Coping <sup>a,b,c</sup>	.016	.011	.137	.144
Symptom on Disengagement Coping	.030	.009	.273	.002
Donor type on Engagement Coping <sup>a,b,c</sup>	.018	.178	.009	.918
Donor type on Disengagement Copinga,b.c	.230	.158	.113	.145
Duration of dialysis on Engagement Coping <sup>a,b,c</sup>	073	.177	034	.680
Time post-transplant on Engagement Coping	001	.000	239	.005
Time post-transplant on Disengagement Coping <sup>a,b,c</sup>	.000	.000	005	.948
Social support on Engagement Coping	.013	.006	.182	.038
CAHS on Engagement Coping <sup>a,b,c</sup>	.119	.110	.117	.278
CAHS on Disengagement Coping	.200	.098	.203	.041
Duration dialysis on Disengagement Coping <sup>a,b,c</sup>	.025	.158	.012	.875
Self-efficacy on PCS <sup>b,c</sup>	.371	.194	.192	.056
CAHS on PCS	-2.854	1.083	259	.008
Hospitalization on PCS <sup>a,b,c</sup>	-2.515	1.680	111	.134
Symptom on PCS <sup>a,b,c</sup>	172	.107	141	.109
Donor type on PCS <sup>a,b,c</sup>	.474	1.729	.021	.784
Duration of dialysis on PCS <sup>b,c</sup>	-3.058	1.717	130	.075
Time post-transplant on PCS <sup>a,b,c</sup>	002	.002	067	.391
Social support on PCS <sup>a,b,c</sup>	.037	.063	.047	.559
Disengagement Coping on PCS <sup>a,b,c</sup>	1.052	.917	.094	.252
Engagement Coping on PCS	-1.853	.817	172	.023
Self-efficacy on MCS <sup>a,b,c</sup>	.014	.180	.007	.939
CAHS on MCS	-3.519	1.004	318	.000
Hospitalization on MCS <sup>a,b,c</sup>	1.846	1.556	.081	.236
Symptom on MCS	277	.099	225	.005
Donor type on MCS <sup>a,b,c</sup>	-1.642	1.602	072	.305
Duration of dialysis on MCS <sup>a,b,c</sup>	304	1.591	013	.848
Time post-transplant on MCS <sup>a,b,c</sup>	001	.002	030	.679
Social support on MCS <sup>a,b,c</sup>	.094	.058	.119	.106
Disengagement Coping on MCS	-2.260	.850	201	.008
Engagement Coping on MCS <sup>a,b,c</sup>	052	.757	005	.945

Table 10. Path Coefficients in the Alternative Model Predicting PCS and MCS

a: path constrained in alternative model 2 b: path constrained in alternative model 3 c: path constrained in alternative model 4

Model fit analyses demonstrated that alternative model 1 and the other three alternative models fit the data. Fit indices for models 1 to 4 were as follows: 1)  $\chi^2 = 0.00$ ,  $\chi^2$ /df =0.00, p=0.995; 2)  $\chi^2 = 16.42$ ,  $\chi^2$ /df =0.78, p=0.746; 3)  $\chi^2 = 27.40$ ,  $\chi^2$ /df =1.14, p=0.286; and 4)  $\chi^2 = 32.58$ ,  $\chi^2$ /df =1.30, p=0.142. Results of model comparisons indicated alternative models 2, 3, and 4 were not significantly different from alternative model 1 if it was assumed that alternative model 1 was correct (all p>.1). However, alternative models 3 and 4 were significantly different from alternative model 2 if it was assumed that alternative model 2 was correct (all p<.05). Alternative model 2 was derived as an empirical model predicting PCS based on the nested path analyses (see Figure 5). Path coefficients in the empirical model predicting PCS are summarized in Table 11.

For the alternative model predicting MCS, the same analytic steps were performed. Model fit analyses showed all four models predicting MCS fit the data well. There were no significant differences between model 2 ( $\chi^2$ =15.12,  $\chi^2$ /df=0.69, p=0.857), model 3 ( $\chi^2$ =17.26,  $\chi^2$ /df=0.75, p=0.797), and model 4 ( $\chi^2$ =19.93,  $\chi^2$ /df=0.83, p=0.701). Results of model comparisons demonstrated that alternative models 2, 3, and 4 predicting MCS were not significantly different from alternative model 1 for MCS if it was assumed that alternative model 1 for MCS was correct (all p >.6). Alternative models 3 and 4 for MCS were not significantly different from alternative model 2 for MCS if it was assumed that alternative model 2 for MCS was correct (all p>.05). Alternative model 4 for MCS was not significantly different from alternative model 3 for MCS if it was assumed that alternative model 3 for MCS was correct (p=.102). Alternative model 2 was derived as an empirical model predicting MCS based on the nested path analyses (see Figure 6). Path coefficients in the empirical model predicting MCS are summarized in Table 12.







Label	Unstandardized	S.E.	Standardized	Р
Self-efficacy on CAHS	087	.014	503	.000
Hospitalization on CAHS	.281	.134	.137	.036
Social support on CAHS	011	.005	157	.021
Symptom on CAHS	.020	.008	.182	.014
Time post-transplant on CAHS	.000	.000	099	.131
Time post-transplant on Engagement Coping	001	.000	265	.001
Social support on Engagement Coping	.013	.006	.181	.029
Symptom on Disengagement Coping	.032	.009	.297	.000
CAHS on Disengagement Coping	.277	.082	.288	.000
Duration of Dialysis on PCS	-3.325	1.704	147	.051
Self-efficacy on PCS	.496	.182	.265	.006
CAHS on PCS	-2.977	1.058	277	.005
Engagement Coping on PCS	-1.413	.811	133	.081

Table 11. Path Coefficients in Empirical Model predicting PCS

Unstandardized	S.E.	Standardized	Р
089	.013	509	.000
.261	.133	.128	.049
011	.005	157	.022
.020	.008	.176	.016
.000	.000	100	.125
001	.000	257	.002
.012	.006	.173	.039
.031	.009	.284	.000
.281	.082	.290	.000
281	.096	234	.003
-3.907	.858	361	.000
-2.092	.881	187	.018
	Unstandardized 089 .261 011 .020 .000 001 .012 .031 .281 281 281 281 292	Unstandardized         S.E.          089         .013           .261         .133          011         .005           .020         .008           .000         .000          001         .000           .012         .006           .031         .009           .281         .082          281         .096           -3.907         .858           -2.092         .881	Unstandardized         S.E.         Standardized          089         .013        509           .261         .133         .128          011         .005        157           .020         .008         .176           .000         .000        100          001         .000        257           .012         .006         .173           .031         .009         .284           .281         .082         .290          281         .096        234           -3.907         .858        361           -2.092         .881        187

Table 12. Path Coefficients of Empirical Model predicting MCS

#### Hypothesized Model

Model fit analyses demonstrated that the hypothesized model predicting PCS did not suitably fit the data. The  $\chi^2$  statistic was significant (51.59, *p*=0.000) with 19 degrees of freedom. The  $\chi^2$ /df ratio was 2.72. The GFI was 0.93 and the CFI was 0.50. Path analyses for the alternative model for PCS indicated the path from CAHS to PCS ( $\beta$ =-.26, *p*=.008) and the path from perceived self-efficacy to PCS ( $\beta$ =.19, *p*=.056) represented significant effects. A modified hypothesized model predicting PCS was derived by adding paths from CAHS to PCS and from perceived self-efficacy to PCS (see Figure 7).

Model fit analyses demonstrated that the modified hypothesized model for PCS fit the data well. The  $\chi^2$  statistic was not significant (27.02, *p*=0.058) with 17 degrees of freedom. The  $\chi^2$ /df ratio was 1.59. The GFI was 0.97 and the CFI was 0.85. The model comparisons were performed on the alternative model for PCS, the modified hypothesized model for PCS, and the hypothesized model for PCS. Results indicated that the modified hypothesized model and the hypothesized model for PCS were significantly different from the alternative model for PCS (all *p*<.05) if it was assumed that the alternative model was correct. The hypothesized model for PCS was significantly different from the modified model for PCS if it was assumed that the modified model for PCS was correct (*p* <.05).

For the hypothesized model predicting MCS, results of model fit analyses indicated that it did not suitably fit the data. The  $\chi^2$  statistic was significant (50.24, p=0.000) with 19 degrees of freedom. The  $\chi^2$ /df ratio was 2.64. The GFI was 0.94 and the CFI was 0.52. A modified hypothesized model predicting MCS was developed (see Figure 8). Paths from CAHS to MCS and from symptom to MCS, which were significant in the path analyses for the alternative model for MCS ( $\beta$ =-.32, p=.000, and  $\beta$ =-.23, p=.005, respectively) were added in the modified hypothesized model predicting MCS. Results of model fit analyses indicated that the modified hypothesized model for MCS fit the data well. The  $\chi^2$  statistic was not significant (23.51, *p*=0.133) with 17 degrees of freedom. The  $\chi^2$ /df ratio was 1.38. The GFI was 0.97 and the CFI was 0.90. Model comparisons also were performed on the alternative model for MCS, the modified hypothesized model for MCS, and the hypothesized model for MCS. Results suggested that the modified hypothesized model for MCS was not significantly different (*p*=.101) and the hypothesized model for MCS were significantly different (*p* <.05) from the alternative model for MCS if it was assumed that the alternative model for MCS was correct. The hypothesized model for MCS was significantly different from the modified hypothesized model for MCS if it was assumed that the modified model for MCS was correct (*p* <.05).

Path coefficients in the modified hypothesized models for PCS and MCS are summarized in Table 13 and Table 14. Standardized total effects including direct and indirect effects for the endogenous variables were also calculated (see Table 15, Table 16). Results indicated that perceived self-efficacy had the largest total effects on negative primary appraisal of health (-.45), disengagement coping (-.36), and physical HRQOL (.39), while negative primary appraisal of health had the largest total effects on engagement coping (.21) in the modified hypothesized model predicting PCS. In the modified hypothesized model predicting MCS, perceived self-efficacy had the largest total effects on negative primary appraisal of health (-.46) and disengagement coping (-.36), while negative primary appraisal of health had the largest total effects on engagement coping (.21) and mental HRQOL (-.43).









Label	Unstandardized	S.E.	Standardized	Р
Hospitalization on CAHS	.294	.135	.140	.029
Social support on CAHS	012	.005	172	.012
Symptom on CAHS	.030	.009	.254	.001
Duration of dialysis on CAHS	.003	.142	.001	.983
Time post-transplant on CAHS	.000	.000	124	.074
Donor type on CAHS	.148	.139	.070	.288
Self-efficacy on CAHS	078	.014	448	.000
Social support on Disengagement Coping	.000	.006	.004	.966
Social support on Engagement Coping	.016	.006	.239	.012
CAHS on Engagement Coping	.200	.108	.210	.064
CAHS on Disengagement Coping	.287	.097	.308	.003
Self-efficacy on Engagement Coping	.027	.019	.163	.150
Self-efficacy on Disengagement coping	036	.017	222	.032
CAHS on PCS	-3.632	1.074	344	.000
Engagement Coping on PCS	-1.763	.857	160	.040
Disengagement Coping on PCS	1.402	.987	.124	.156
Self-efficacy on PCS	.530	.186	.287	.004

Table 13. Path Coefficients in the Modified Hypothesized Model Predicting PCS

Table 14. Path Coefficients in the Modified Hypothesized Model Predicting MCS

	Unstandardized	S.E.	Standardized	Р
Self-efficacy on CAHS	080	.014	456	.000
Hospitalization on CAHS	.263	.134	.127	.050
Social support on CAHS	013	.005	173	.012
Symptom on CAHS	.029	.009	.244	.002
Duration of dialysis on CAHS	020	.136	009	.883
Time post-transplant on CAHS	.000	.000	129	.062
Donor type on CAHS	.162	.141	.077	.251
Social support on Disengagement Coping	.000	.006	007	.933
Social support on Engagement Coping	.017	.007	.240	.012
CAHS on Engagement Coping	.202	.109	.212	.064
CAHS on Disengagement Coping	.285	.097	.307	.003
Self-efficacy on Engagement Coping	.028	.019	.164	.147
Self-efficacy on Disengagement Coping	036	.017	219	.035
Disengagement Coping on MCS	-2.314	.913	201	.011
Engagement Coping on MCS	.186	.794	.017	.815
symptom on MCS	265	.101	212	.009
CAHS on MCS	-3.992	.943	373	.000

	Primary appraisal			Engag. coping			Diseng. coping			PCS		
	D	ID	Т	D	ID	Т	D	ID	Т	D	ID	Т
Self-efficacy	45	.00	45	.16	09	.07	22	14	36	.29	.10	.39
Donor type	.07	.00	.07	.00	.02	.02	.00	.02	.02	.00	02	02
Time post	12	.00	12	.00	03	03	.00	04	04	.00	.04	.04
Dialysis	.00	.00	.00	.00	.00	.00	.00	.00	.00	.00	.00	.00
Symptom	.25	.00	.25	.00	.05	.05	.00	.08	.08	.00	09	09
Social support	17	.00	17	.24	04	.20	.00	05	05	.00	.02	.02
Hospitalization	.14	.00	.14	.00	.03	.03	.00	.04	.04	.00	05	05
Primary appraisal	.00	.00	.00	.21	.00	.21	.31	.00	.31	34	.00	34
Engag. coping	.00	.00	.00	.00	.00	.00	.00	.00	.00	16	.00	16
Diseng. coping	.00	.00	.00	.00	.00	.00	.00	.00	.00	.12	.00	.12

Table 15. Direct, Indirect, and Total Effects in the Modified Hypothesized Model Predicting PCS

D-Direct effect, ID-Indirect effect, T-Total effect Engag.-Engagement Diseng.-Disengagement

Table 16. Direct, Indirect,	and Total Effects in the M	Modified Hypothesized Model
Predicting MCS		

	Primary appraisal		Engag. coping		Diseng. coping			MCS				
	D	ID	Т	D	ID	Т	D	ID	Т	D	ID	Т
Self-efficacy	46	.00	46	.16	09	.07	22	14	36	.00	.24	.24
Donor type	.08	.00	.08	.00	.02	.02	.00	.02	.02	.00	03	03
Time post	13	.00	13	.00	03	03	.00	04	04	.00	.06	.06
Dialysis	01	.00	01	.00	.00	.00	.00	.00	.00	.00	.00	.00
Symptom	.24	.00	.24	.00	.05	.05	.00	.08	.08	21	11	32
Social support	17	.00	17	.24	04	.20	01	05	06	.00	.08	.08
Hospitalization	.13	.00	.13	.00	.03	.03	.00	.04	.04	.00	06	06
Primary appraisal	.00	.00	.00	.21	.00	.21	.31	.00	.31	37	06	43
Engag. coping	.00	.00	.00	.00	.00	.00	.00	.00	.00	.02	.00	.02
Diseng. coping	.00	.00	.00	.00	.00	.00	.00	.00	.00	20	.00	20
Diseng. coping	.00	.00	.00	.00	.00	.00	.00	.00	.00	.12	.00	.12

D-Direct effect, D-Indirect effect, T-Total effect Engag.-Engagement Diseng.-Disengagement

Hypothesis 1. Perceived self-efficacy has both direct and indirect effects on coping, and exerts a direct effect on cognitive appraisal of health. This hypothesis was partially supported. Perceived self-efficacy was a significant predictor of negative primary appraisal of health in both modified hypothesized models for PCS and MCS ( $\beta$ = -.45, *p*=.000, and  $\beta$ = -.46, *p*=.000, respectively). Individuals with low degrees of perceived self-efficacy were predicted to appraise their health conditions negatively (as threat or harm/loss). Perceived self-efficacy had both a direct effect ( $\beta$ = -.22, *p*<.05 in both modified models) and an indirect effect (both  $\beta$ = -.14) through primary appraisal of health on disengagement coping. Participants who reported low degrees of perceived self-efficacy were predicted to use more disengagement coping. Perceived self-efficacy was not a significant predictor of engagement coping in both modified hypothesized models for PCS and MCS (both *p*>.1).

Hypothesis 2. Perceived social support exerts both direct and indirect effects on coping, and a direct effect on cognitive appraisal of health. This hypothesis was partially supported. Perceived social support had a direct effect on negative primary appraisal of health (both  $\beta$ = -.17, p<.05) in the modified hypothesized models for PCS and MCS. Participants with low degrees of perceived social support were predicted to appraise their health as a threat or harm/loss. Perceived social support had a significant direct effect on engagement coping (both  $\beta$ = .24, p=.012) and no significant indirect effects on engagement coping (both  $\beta$ >.05) in both modified hypothesized models. Perceived social support had no significant direct effect (both p>.90), but had an indirect effect on disengagement coping through negative primary appraisal of health (both  $\beta$  = -.05) in both modified hypothesized models. Thus, participants with a high degree of perceived

social support were predicted to use more engagement coping and less disengagement coping by appraising their health positively (as a challenge or benign/irrelevant).

Hypothesis 3. Cognitive appraisal of health has a direct effect on coping strategies. This hypothesis was partially supported. Negative primary appraisal of health had a direct effect on disengagement coping (both  $\beta$ = .31, p= .003) in the two modified hypothesized models. Participants who appraised their health negatively (as a threat or harm/loss) were predicted to use more disengagement coping strategies. Negative primary appraisal of health was not a significant predictor of engagement coping in either modified hypothesized models (both p> .05).

Hypothesis 4. Coping strategies have a direct effect on HRQOL. This hypothesis was partially supported. In the modified hypothesized model predicting PCS, engagement coping was a significant predictor of physical HRQOL ( $\beta$ = -.16, p= .040), while disengagement coping was not a significant predictor of physical HRQOL (p= .156). The results indicated that participants who used more engagement coping were predicted to report a lower physical HRQOL. In the modified hypothesized model predicting MCS, disengagement coping was a significant predictor of mental HRQOL ( $\beta$ = -.20, p= .011), while engagement coping was not a significant predictor of mental HRQOL (p= .815). The results suggested that the more the disengagement coping used, the lower the mental HRQOL of the participants.

<u>Hypothesis 5. Clinical factors related to renal transplantation have direct effects on</u> <u>the cognitive appraisal of health</u>. This hypothesis was partially supported. History of transplant related hospitalizations ( $\beta$ = .14, p=.029 and  $\beta$ = .13, p=.050, respectively) and side-effects of immunosuppressive medications ( $\beta$ = .25, p= .001 and  $\beta$ = .24, p=.002,

respectively) had direct effects on primary cognitive appraisal of health, while donor type, duration of dialysis before transplantation, and time post-transplant were not significant predictors for the primary appraisal of health (all p>.05) in both modified hypothesized models. Participants who had history of transplant-related hospitalizations and experiencing more bothersome symptoms of medication side effects were predicted to appraise their health negatively (as a threat or harm/loss).

Multivariate Analysis of Variance on Research Question Two

Research question 2. What are the effects of clinical factors (donor type, history of transplant-related hospitalizations, side effects of immunosuppressive medications, duration of dialysis, and time post-transplantation) on perceived self-efficacy, perceived social support, cognitive appraisal of health, coping, and HRQOL following renal transplantation?

The effects of clinical factors such as donor type (living vs cadaveric), duration of dialysis before transplantation (≤6 months, >6 months), history of transplant related hospitalizations (yes vs no), and symptom of side-effects of immunosuppressive medications (scores≤17, vs scores>17) on the psychosocial variables (e.g., perceived self-efficacy, perceived social support, cognitive appraisal of health [negative primary appraisal component], coping strategies [engagement coping, disengagement coping], and HRQOL [PCS, MCS]) were evaluated using Multivariate Analysis of Covariance (MANCOVA) with the time post-transplant as the covariate. The effect of time post-transplant on the criterion measures needed to be controlled because, as expected, correlational analysis showed that time post-transplant had significant relationships with some of the

psychosocial variables such as engagement coping and perceived self-efficacy. Levene's test of equality of error variances was performed first and was supported for all of the dependent variables (all p > .05). Initial multivariate analyses demonstrated statistically significant omnibus main effects for medication side effects on the psychosocial variables (p < .01). There were no omnibus main effects for donor type, duration of dialysis before transplantation, and history of hospitalizations on these psychosocial variables (all p > .05). Table 6 summarizes the tests of the main effects for clinical factors on all the psychosocial variables. Participants with high scores (>17) on symptom checklist reported high scores on CAHC, which indicated they appraised their health condition negatively (p=.00). Participants with high scores (>17) on the symptom checklist used more disengagement coping (p=.00) and they had a lower degree of perceived self-efficacy, physical and mental HROOL (all p=.00).

	Multivariate	riate Univariate Tests (p)							
	Test (p)	CAHC	CSE	CSD	PSE	PSS	PCS	MCS	
Intercept	.000								
Symptom ( $\leq 17, >17$ )	.000	.000	.069	.000	.000	.714	.000	.000	
Donor type (living,				~~ <b>-</b>					
cadaver)	.329	.212	.736	.087	.089	.322	.765	.156	
Duration of dialysis ( $\leq 6M$ ,	224	072	564	420	026	264	025	277	
>6M)	.324	.273	.364	.438	.036	.264	.025	.377	
History of nospitalizations $(\mathbf{V}/\mathbf{N})$	211	072	084	325	805	074	078	018	
(1/1)	.211	.072	.904	.323	.895	.074	.078	.910	
Covariate (time post)	.012								
CAHC - Cognitive Appraisa	posite	CSE	- Coping	Strategie	es-Engag	ement co	ping		
CSD-Coping Strategies-Dise	ng	PSE -Perceived Self-efficacy							

Table 17. MANCOVA of Clinical Factors on Psychosocial Variables Controlling for Time Post-transplant (*N*=143)

MCS-Mental Component Summary (HRQOL)

PSS - Perceived Social Support

PCS - Physical Component Summary (HRQOL)

The main effects of time post-transplant on the psychosocial variables were also assessed using multivariate analysis of variance (MANOVA) (see Table 7). The length of time post-transplant was categorized as the early period (less than 1 year) and later period (1 to 3 years). Results indicated that there were statistically significant main effects of time post-transplant on the psychosocial variables (p=.027). Results demonstrated that participants in the early period post-transplant used more engagement coping strategies than participants in the later period (p=.005). Participants in the later period posttransplant also reported a lower degree of perceived self-efficacy and perceived social support than those in the early period (p=.004, p=.040, respectively). There were no main effects of time post-transplant on primary appraisal, disengagement coping, PCS, and MCS (all p>.05).

	Early Group M (SD)	Later Group M (SD)	F ratio (df=1)	р
Primary appraisal	14 (.89)	.07 (1.05)	1.45	.231
Engagement coping	.32 (1.04)	19 (.98)	8.23	.005
Disengagement coping	11 (.79)	.02 (1.10)	.49	.484
Perceived self-efficacy	32.32 (5.10)	29.39 (5.84)	8.65	.004
Perceived social support	90.32 (10.90)	85.19 (15.19)	4.28	.040
Physical component summary	43.73 (10.71)	42.33 (11.34)	.49	.485
Mental component summary	51.07 (9.72)	49.69 (11.81)	.48	.489

Table 18. Effects of Time Post-transplant Group on Psychosocial Variables (N=143)

#### Summary of Results

One hundred and sixty adult renal transplant patients participated in this study. Most of them were married and Caucasian. Hypertension and diabetes were the major causes of ESRD for the participants. The majority of the participants in this study had hemodialysis before transplantation, with an average duration of two years. More than half of the participants received a living donor graft and took prednisone, Cellcept, and Prograf for immunosuppressive therapy. Few participants experienced an episode (or episodes) of rejection following transplantation. The majority of the participants had no transplantrelated hospitalizations. The average length of time post-transplant was one and a half years.

Participants in this study indicated that they appraised their health as a challenge rather than a threat. They reported greater use of active coping, emotional support, positive reframing, acceptance, and religion coping strategies and less use of denial, behavioral disengagement, and self-blame coping strategies. Participants viewed themselves as capable of managing their health and perceived that social support was available to them. They experienced few symptoms of side-effects of immunosuppressive medications and if experienced, these symptoms bothered them only slightly. Participants had a lower physical HRQOL than the U.S. general population and a mental HRQOL that was equivalent to the general U.S. population as assessed by SF-36 scores.

Bivariate correlational analyses showed that negative primary appraisal had a moderate positive relationship with disengagement coping. Participants who endorsed health primary appraisals as threat or harm/loss reported more use of disengagement coping and they also reported lower physical and mental HRQOL. Participants with a high

degree perceived self-efficacy and perceived social support appraised their health as a challenge or benign/irrelevant. Participants with a high degree of perceived self-efficacy reported a high degree of perceived social support, used less disengagement coping, and reported higher physical and mental HRQOL. Participants with a high degree of perceived social support also used less disengagement coping, and reported high physical and mental HRQOL. Participants with a high degree of perceived social support also used less disengagement coping, and reported high physical and mental HRQOL. Participants who reported numerous bothersome symptoms on the checklist appraised their health as a threat or harm/loss, used more disengagement coping, had lower degrees of perceived self-efficacy, and reported lower physical and mental HRQOL. Participants with longer time post-transplant used less engagement coping and reported lower degrees of perceived self-efficacy.

Model fit analyses indicated that the alternative models predicting PCS and MCS fit the data well, while the initial and hypothesized models for PCS and MCS did not fit the data well. The modified hypothesized models predicting PCS and MCS were derived by adding in the paths from perceived self-efficacy to PCS and from primary appraisal of health to PCS in the hypothesized model for PCS and by adding in the paths from medication side effects to MCS and from primary appraisal of health to MCS in the hypothesized model for MCS. Both modified hypothesized models fit the data well. Path analyses demonstrated that perceived self-efficacy had a significant direct effect on negative primary appraisal of health and physical HRQOL, and had both a direct effect and an indirect effect through primary appraisal on disengagement coping. Perceived social support had significant direct effects on negative primary appraisal of health and engagement coping, while perceived social support had an indirect effect on
related hospitalizations and side effects of immunosuppressive medications were found to have direct effects on primary cognitive appraisal of health. Side effects of immunosuppressive medications had a direct effect on mental HRQOL. Results also indicated that negative primary appraisal of health had a significant direct effect on disengagement coping, physical and mental HRQOL. Regarding the effects of coping strategies on HRQOL, the findings suggest that engagement coping had a significant direct effect on physical HRQOL, while disengagement coping had a significant direct effect on mental HRQOL

The effects of clinical factors on psychosocial variables were evaluated. There were no significant effects of donor type, duration of dialysis before transplantation, or history of transplant-related hospitalizations on the psychosocial variables after controlling for time post-transplant. There were significant effects of symptoms and time post-transplant on these psychosocial variables. Participants with high scores (>17) on symptom checklist appraised their health as threat or harm/loss, used more disengagement coping, had lower perceived self-efficacy, physical and mental HRQOL than participants with low scores (<17) on the symptom checklist. Participants less than one year post-transplant used more engagement coping, reported higher degrees of perceived self-efficacy and perceived social support than participants in the later period post-transplant.

## CHAPTER V

### DISCUSSION

The relationships among clinical factors, perceived self-efficacy, perceived social support, cognitive appraisal of health, coping, and HRQOL following renal transplantation were tested in this study with 160 renal transplant patients. This chapter presents a discussion of the study results in five principal sections: (a) sample characteristics, (b) interpretation of instruments, (c) interpretation of bivariate correlation analysis, (d) interpretation of the findings related to research questions, (e) study strengths and limitations, (f) recommendations for future research, and (g) conclusions and implications for nursing practice.

### Sample Characteristics

The characteristics of the sample in this dissertation research study were similar to those of previous studies reported in the literature and, for the most part, reflected the characteristics of renal transplant patients in the U.S. reported by the Organ Procurement and Transplantation Network (OPTN; Annual report 2004). Of the 160 participants, 77.5% were Caucasian and 20.6% were African-American. This percentage is consistent with the annual report (2004), which documented 79.4% of recipients of living donor kidneys were Caucasian and 15.0% were African-American, while 63.0% of recipients of cadaveric donor kidneys were Caucasian and 29.6% were African-American. Sehgal (2000) also reported African-American patients were less likely to have access to transplantation compared with Caucasian patients. The majority of the participants (70.6%) were married, compared to 66.3% in Franke et al's (2003) study. Participants were well-educated, and 39.3% had a college or postgraduate degree. The mean age of this sample was 47.7 years old, which mirrored the 47.7 years mean age in Rowenberger et al.'s (2005) study. The mean age also is similar to previous studies in this transplant center (Kizilisik et al., 2003; Pinson et al., 2000). Approximately 54% of the participants were male and 46% were female. This gender distribution was slightly different from the 3:2 ratio between male and female renal transplant patients reported by OPTN (Annual Report, 2004). The percentage of females was higher compared to previous studies (Hathaway et al., 1998; Kizilsik et al., 2003; Rosenberger et al., 2005). The first two leading causes of ESRD for the participants were hypertension (25.6%) and diabetes (16.9%), which also reflected the common causes of ESRD as reported by OPTN (Annual Report, 2004). The majority (61.3%) of the participants in this study received hemodialysis therapy before transplantation and the mean dialysis time was 2 years. These findings are similar with Rosenberger et al.'s (2005) and Hathaway et al.'s (1998) studies. More than half of the participants received a living donor graft (59.4%). This percentage is consistent with the trend reported by OPTN (Annual report, 2004). The medications used for immunosuppressive therapy in this study were similar to those reported in the annual report (2004), which were prednisone (91.4%), tacrolimus (69.1%), Cellcept (82.3%), and sirolimus (21.2%). To enhance the homogeneity of this study, only participants who were short-term post-transplant were included. The mean time post-transplant was 18.8 months. Only 10% of participants had one or two rejection episodes following transplantation, and the majority (59.4%) of the participants had no transplant-related hospitalizations. Few studies in the literature

documented the data on rejection and hospitalizations. Thus, it is difficult to compare these data with data from other studies.

There were no statistical significant differences on most of the demographic and clinical data except the history of transplant-related hospitalizations between the early and later period post-transplant groups. In the later period post-transplant groups, there were more participants who had a history of transplant-related hospitalizations. One possible explanation may be that the longer the time post-transplant, the greater the risk of having rejection, infection, and side effects of medications, with a greater incidence of hospitalization.

# Interpretation of Instruments

#### The Cognitive Appraisal of Health

The Cognitive Appraisal of Health (CAHS) (Kessler, 1998) was used to measure the participants' appraisal of health in this study. Internal consistency reliabilities of the subscales of threat, challenge, and harm/loss were appropriate and similar with Kessler's (1998) study. However, the internal consistency reliability of the benign/irrelevant subscale was not acceptable (0.53) and lower than the reliability reported in Kessler's (1998) study on breast cancer patients (0.78). The items in the benign/irrelevant subscale, such as "I have nothing to lose because of this health condition;" "I don't think much about this health condition;" and "This health condition doesn't affect my life;" seemed unsuitable to renal transplant patients' health condition and seemed to measure different

interpretations of the health condition (e.g., no loss, not thinking, not affecting life). The subscale needs to be refined and examined in other studies of renal transplant patients.

Participants scored relatively higher on the challenge subscale compared to other subscales, so they indicated greater agreement with the challenge appraisal. There were no previous studies assessing the cognitive appraisal of health in renal transplant patients, so we cannot compare this finding with other studies. One possible explanation for this finding may be that renal transplantation is considered the first-choice method of renal replacement therapy for ESRD patients that helps restore the patients to a healthier daily life (Jacobs & Luciani, 1992; Wallace, 1998). In addition, patients perceive transplantation as a gift of life; therefore, participants appraise their health positively.

A one-component solution which explained 63.49% of total variance was derived from the second-order factor analysis on the four subscales. This solution was consistent with the theoretical bases of the CAHS that designated the four subscales measuring the primary appraisal dimensions of cognitive appraisal (Kessler, 1998). Because the challenge and benign/irrelevant subscales were negatively related to the component, while threat and harm/loss subscales were positively related to the component, a higher weighted score on the component suggested a negative primary appraisal of health.

### Brief COPE

The Brief COPE (Carver, 1997) was used to measure coping strategies used by the participants. The internal consistency reliabilities of some subscales, such as self-distraction, active coping, behavioral disengagement, were low (Cronbach's alpha less than 0.6) and the reliabilities of other subscale were appropriate. This alpha was different from

Carver's reliability data in studies on breast cancer, depression, and AIDS. It was reported the Cronbach's alpha of the subscales of denial, venting, and acceptance were less than 0.6, while the Cronbach's alpha of other subscales exceeded 0.6 (Carver, 1997). The inconsistency may be related to the different population studied. The lower internal consistency reliabilities also may be explained by only two items in each subscale. This is the first study using the Brief COPE to measure coping in renal transplant patients. The reliability of this scale needs to be further examined in this population.

Participants in this study reported they used more active coping, emotional support, positive reframing, acceptance, and religious coping, with relatively less use of denial, behavioral disengagement, and self-blame coping. This finding was consistent with data from previous studies on coping in renal transplant patients (Lindqvist, Carlsson, & Sjödén, 2004; Sutton & Murphy, 1989; Tix & Frazier, 1998). Lindqvist, Carlsson, and Sjödén (2004) reported renal transplant patients used significantly more optimistic, supportive, and self-reliant coping strategies, and less emotive coping in their study. Sutton and Murphy (1989) also suggested that patients used more problem-oriented coping (e.g., try to look at the problem objectively, maintain some control over the situation) than affective-oriented coping (e.g., take drugs, drink alcohol, blame someone else). Religious coping also was identified as a popular coping strategy in dealing with transplant-related stress (Sutton & Murphy, 1989; Tix & Frazier, 1998). The names of coping strategies in these studies were different because different coping measurements were used. However, the patterns of coping strategies used more often and used less were similar because renal transplant patients used more positive, active coping strategies and used less passive coping strategies.

Second-order factor analysis suggested there were two components for the 13 subscales of Brief COPE, which were interpreted as engagement coping and disengagement coping. The two-component solution was different from Lazarus and Folkman's (1984) problem-focused and emotion-focused coping dimensions. Engagement coping for this study included some problem-focused coping (e.g., planning, active coping, and use of instrumental support) and some positive emotion-focused coping (e.g., acceptance, use of emotional support), while disengagement coping included behavioral disengagement and some negative emotion-focused coping (e.g., denial, self-blame). This two-component solution was consistent with Compas et al.'s (2001) conceptualization of coping, which indicated that engagement coping includes responses that are oriented either toward the source of stress or toward one's emotions or thoughts; disengagement coping refers to responses that are oriented away from the stressor or one's emotions or thoughts. This study was the first study using second order factors of Brief COPE in renal transplant patients. The reliability and validity need to be further evaluated.

# Perceived Health Competence Scale (PHCS)

Perceived self-efficacy related to health was measured using the PHCS. The internal consistency reliability of this scale was adequate and similar with reliabilities reported in other studies on healthy and chronic illness subjects (Smith et al., 1995). The PHCS was not used in previous renal transplant studies. The findings of this study suggested that participants had a high degree of perceived self-efficacy related to health. Participants in this study all had a functional kidney graft. The literature indicated that transplant patients reported better health compared to pre-transplant patients. All of these

factors may influence their perceived self-efficacy, and they reported high self-efficacy scores on this scale.

### Personal Resource Questionnaire (PRQ 2000)

The Personal Resource Questionnaire (PRQ 2000) was used to assess the perceived social support of the participants. This questionnaire was used widely with patients with other chronic illnesses, but had not been used in renal transplant patients before. The internal consistency reliability of this questionnaire was high and within the range of the Chronbach's alpha values reported by Weinert (2003). Participants reported high levels of perceived social support in this study. This finding was consistent with Frazier, Davis-Ali, and Dahl's (1995) study which indicated renal transplant patients received more helpful social support and Christensen et al.'s (2002) study which suggested both cadaveric-donor and living-donor renal transplant patients reported higher family support after transplantation. This finding was also consistent with the fact that patients with high social support have a greater chance of being selected for transplantation therapy.

# Medical Outcomes Study 36-item Short Form Health Survey (SF-36<sup>®</sup>)

Self-reported HRQOL was measured using the SF-36<sup>®</sup>. This scale has been used extensively in renal transplant patients. The internal consistency reliability for the PCS and MCS were adequate and similar with reliabilities in a previous study (Feurer et al., 2004). Participants in this study reported lower physical HRQOL compared with the general U.S. population, especially role physical and general health subscales. This was consistent with the studies conducted by Karam et al. (2003) and Tsuji-Hayashi et al. (1999) which indicated renal transplant patients reported lower physical and general health than the general population. The findings were inconsistent with Baiardi et al.'s (2002) study which suggested renal transplant patients reported a slightly higher physical HRQOL. The inconsistency may be related to the fact that Baiardi et al.'s study was conducted in Italy with a small sample size of 34 renal transplant patients. Participants in this study reported similar mental HRQOL to the general U.S. population. This finding was consistent with previous studies (Karam et al., 2003; Rebollo et al., 2000). However, Humar et al. (2003) reported older renal transplant recipients had better mental HRQOL than national norms.

# Symptom Checklist

The symptom checklist was developed for this dissertation research to measure the side effects of immunosuppressive medications. The internal consistency reliability of the symptom checklist was adequate. Factor analysis suggested a one-component solution which indicated it measures one construct. As a group, participants scored low on the checklist, which indicated that they experienced mildly bothersome side effects of immunosuppressive medications. This finding was consistent with Rosenberger et al.'s (2005) study which suggested renal transplant patients reported low stress from adverse effects of immunosuppressive medication. The symptom checklist was newly developed and the symptoms were related to the currently used immunosuppressive protocol (prednisone, Cellcept, tacrolimus/sirolimus). The reliability and validity needs further examination.

### Interpretation of Bivariate Correlation Analysis

Bivariate correlation analysis was performed between observed variables in the models. Relationships between transplant-related factors, personal and social resources, appraisal of health, coping, and HRQOL were identified and explained below.

#### Transplant-related Variables and Psychosocial Variables

Side effects of immunosuppressive medications were positively related to negative primary appraisal of health. This finding was expected. Participants experiencing more bothersome symptoms of medication side effects would be more likely to appraise their health as harm/loss. Experiencing more bothersome symptoms was associated with lower degrees of perceived self-efficacy and greater use of disengagement coping strategies. Participants with more bothersome side effects of medication may believe they cannot control their health, reported lower degrees of perceived self-efficacy and used more behavioral disengagement coping, denial, or self-blame coping strategies. More bothersome symptoms of side effects of medications were related to worse physical and mental HRQOL. This finding was consistent with the findings of previous studies which indicated that higher levels of symptom distress are associated with lower perceived overall quality of life (Geest & Moons, 2000; Hricik et al., 2001; Matas et al., 2002).

A history of transplant-related hospitalizations was positively correlated to negative primary appraisal of health. Participants having hospitalizations appraised their health as threat or harm/loss. This finding was expected. Results also suggested participants with a history of hospitalizations reported lower degrees of perceived social support. Hospitalized patients need more social support, and the available social support may not meet their

needs. Thus, they reported lower degrees of perceived social support. History of transplant-related hospitalizations was negatively related to physical HRQOL. This finding was reasonable. Hospitalized participants were patients who had transplant-related complications such as rejection, infection, and these complications affect patients' physical health. Therefore, they reported lower physical HRQOL.

Duration of dialysis before transplantation was identified as having a negative relationship with physical HRQOL. This finding was consistent with Kizilisik et al.'s (2003) study which indicated renal transplant patients who received dialysis therapy for six months or more before transplant demonstrated lower physical HRQOL. Participants receiving more than six months of dialysis before transplant were positively correlated with episodes of transplant-related hospitalization. Participants with longer term dialysis had more complications and worse health and were more likely to be hospitalized.

Time post-transplant was correlated to perceived self-efficacy. Participants with a longer time post-transplant reported lower degrees of perceived self-efficacy. Although transplant patients had better health outcomes than before, they still live with a chronic health condition and need ongoing supervision and life-long immunosuppressive therapy. These factors may influence their perceived self-efficacy. Results also suggested that the longer the time post-transplant, the less the participants used engagement coping. This finding was inconsistent with previous studies which suggested there were no differences in frequency of problem-oriented coping between early and later period post-transplant patients (Kong & Molassiotis, 1999; Sutton & Murphy, 1989). The time post-transplant also was related to a history of transplant-related hospitalizations. The longer the time of post-transplant, the more chances to have rejection, infection, and side effects of

medication, with greater chances of hospitalization. Living donor transplantation was also related to longer time post-transplant. This finding was consistent with the findings of Evans et al. (1984), who suggested renal transplant patients with living donor grafts had higher survival rates and higher graft retention rates. The type of donor transplantation (living or cadaveric) was not correlated to other variables in this study. This finding was unexpected and needs further examination.

### Correlations between Psychosocial Variables

Negative primary appraisal of health was positively correlated to disengagement coping and negatively correlated to both physical and mental HRQOL. This was consistent with previous theoretical works that suggested negative appraisals trigger emotional coping and disengagement behavior (Lazarus & Folkman, 1984; Schwarzer, 1998). Participants who appraised their health negatively used more disengagement coping. The relationship between primary appraisal and HRQOL was not examined in previous renal transplant studies. Participants who appraised their health as threat or harm/loss may have worse health status and reported lower HRQOL.

Perceived self-efficacy was highly negatively correlated to negative primary appraisal of health. Participants with high degrees of perceived self-efficacy appraised their health less negatively. This finding supports previous theoretical works (Lazarus & Folkman, 1984; Schwarzer, 1998; Shaw, 1999), which suggested perceived self-efficacy as personal coping resource influences the primary appraisal in the coping process. Perceived self-efficacy also was negatively related to disengagement coping. Participants with high degrees of perceived self-efficacy believed they could control their health, so they would

not choose the disengagement coping strategies (e.g. denial, self-blame). Perceived selfefficacy positively related to both physical and mental HRQOL. This finding was consistent with previous theoretical and empirical studies that indicated that perceived selfefficacy had a positive correlation with quality of life (Bandura, 2002; Cunningham, Lockwood, & Cunningham, 1991; Han et al., 2005).

Perceived social support was negatively related to negative primary appraisal, positively correlated to engagement coping, and negatively correlated to disengagement coping. Perceived social support as a coping resource influences an individual's primary appraisal and coping strategies (Lazarus & Folkman, 1984; Schreurs & Ridder, 1997). Participants with the perception or belief that others are available to provide emotional, informational, and material resources in times of need may appraise their health less negatively and tend to use more engagement coping strategies (e.g., active coping, planning, use of emotional and instrumental support). Perceived social support had a positive relationship with both physical and mental HROOL. This finding was consistent with findings from previous studies which suggested high degrees of perceived social support were associated with better health outcomes (Cohen & Wills, 1985; Frazier, Davis-Ali, & Dahl, 1995). Results also indicated that perceived social support was positively correlated to perceived self-efficacy. This finding was reasonable. Participants with high levels of perceived social support may perceive that they have a greater ability to control their situation and reported higher degrees of perceived self-efficacy.

Disengagement coping was negatively related to both physical and mental HRQOL. This finding was consistent with findings from previous studies which suggested that disengagement forms of coping, such as denial, self-blame, behavioral disengagement were

related to poorer health outcomes (Folkman & Moskowitz, 2004). There were no significant correlations between engagement coping and physical/mental HRQOL in this study. This finding was unexpected and inconsistent with previous studies which indicated that engagement coping (e.g., planning, use of informational support, active coping) was related to better health outcomes (Christensen et al., 2000; Lindqvist, Carlsson, & Sjödén, 2004; Tix & Frazier, 1998). The specific relationship between coping and health outcomes are probably affected by diverse personal and situational factors and need to be further examined in complex model analysis.

### Interpretation of Research Questions

<u>Research Question 1.</u> Does the hypothesized model fit the data following renal transplantation?

Model fit analyses demonstrated that the initial models for PCS and MCS did not fit the data well. Both the chi-squares were significant, which suggests that the models should be rejected. The relative chi-squares were more than three and the CFI were less than 0.90, which also suggested they were not a good fit with the data. For the initial models, the important direct relationship between perceived self-efficacy and perceived social support was missing, so it is reasonable that the initial models for PCS and MCS were not a good fit for the data.

Perceived self-efficacy and perceived social support were considered as personal and social resources for coping in this study. They were considered contextual factors as the transplant-related variables were (e.g., history of hospitalizations, side-effect of immunosuppressive medications, and donor type), which influence the coping process.

The paths from transplant-related variables to perceived self-efficacy and perceived social support were removed in the alternative models for PCS and MCS. Perceived self-efficacy and perceived social support were examined as exogenous variables. Results indicated that the alternative models for PCS and MCS fit the data well. However, there were a lot of non-significant paths in the alternative models. An empirical model predicting PCS excluding paths with a p value more than 0.1 was derived and nested path analyses suggested it fit the data well, and not statistically significant different from the alternative model predicting PCS. Based on the nested path analyses, an empirical model predicting MCS excluding paths with a p value more than 0.1 was derived. Analyses indicated that the model fit the data well and was not significantly different from the alternative model predicting MCS. The empirical models predicting PCS and MCS were developed using only statistical criteria as indicators that may maximize a statistical fit to the data, while ignoring the theoretical implications. An acceptable model should consider both the theoretical and statistical soundness.

The researcher developed the hypothesized models for PCS and MCS based on Lazarus and Folkman's (1984) Stress and Coping Model. Unfortunately, the hypothesized models did not fit the data well. Compared to the alternative model for PCS, the significant paths from perceived self-efficacy to PCS and from primary appraisal of health to PCS were absent in the hypothesized model predicting PCS. A modified hypothesized model predicting PCS was derived by adding the paths from perceived self-efficacy to PCS and from the primary appraisal of health to PCS in the hypothesized model predicting PCS. The model analyses indicated that the modified hypothesized model predicting PCS fit the data better than the hypothesized model

predicting PCS. Similarly, by adding the significant paths from the primary appraisal of health to MCS and from medication side effects symptoms to MCS in the hypothesized model predicting MCS, a modified hypothesized model predicting MCS was derived. Analyses also suggested the model fit the data better than the hypothesized model predicting MCS.

The modified hypothesized models predicting PCS and MCS were acceptable because the models were developed by considering both the theoretical and statistical meanings, and the models demonstrated good solutions and an adequate fit for the data. The models suggested that HROOL of renal transplant patients is the outcome of a complex interplay between the transplant-related factors, personal and social resources (perceived self-efficacy and perceived social support), cognitive appraisal of health, and coping strategies. In the modified hypothesized models predicting PCS and MCS, history of transplant-related hospitalization and medication side effects symptoms had a significant direct positive effect on negative primary appraisal of health. Cognitive appraisal refers to the evaluative process that reflects the person's subjective interpretation of an event (Lazarus & Folkman, 1984). Experiencing hospitalizations and bothersome medication side effects symptoms would actually promote negative appraisals of health. Perceived self-efficacy and perceived social support demonstrated significant direct negative effects on negative primary appraisal of health. This finding was consistent with previous theoretical works (Lazarus & Folkman, 1984; Schwarzer, 1998; Shaw, 1999), which suggested perceived self-efficacy and perceived social support as resources that influence the primary appraisal in the coping process. Participants with

high degrees of perceived self-efficacy and perceived social support appraised their health less negatively.

For the coping variables in the modified hypothesized models, results indicated that negative primary appraisal of health had a significant positive direct effect on disengagement coping; perceived self-efficacy had a significant negative direct effect on disengagement coping; while perceived social support had a significant positive effect on engagement coping. The findings were consistent with previous theoretical and empirical works and are discussed in the following section on hypotheses.

Negative primary appraisal of health was found to have significant negative direct effects on both physical and mental HRQOL. Cognitive appraisal was studied extensively as an integrative part of the coping process and was not directly linked to health outcomes in previous theoretical and empirical works. However, some studies on other chronic illness suggested that lower threat and higher controllability appraisals were associated with better psychosocial adjustment and health status (Pakenham & Rinaldis, 2001). It is reasonable that participants who appraised their health negatively (as threat, harm/loss) reported lower HRQOL. Perceived self-efficacy demonstrated a significant positive direct effect on physical HRQOL. This finding was consistent with the literature. The theory on self-efficacy suggests that it can have main effects on quality of life, as well as a moderate effect on distress in the relationship to health (Bandura, 2002). Some empirical literature on chronic illness also indicated that perceived self-efficacy had a positive correlation with quality of life (Cunningham, Lockwood, & Cunningham, 1991; Han et al., 2005). Participants with high degrees of perceived self-efficacy may think they have control over their health and abilities to do daily activities, so they reported higher physical HRQOL.

Results also suggested that engagement coping had a significant negative effect on physical HRQOL and disengagement coping had a significant negative effect on mental HRQOL. The negative relationship between engagement coping and physical HRQOL was unexpected and the effects of coping on HRQOL were discussed in the section on hypothesis 5. Another interesting finding was that medication side effects symptoms had a significant negative direct effect on mental HRQOL. This finding was consistent with previous studies that suggested that adverse effects of immunosuppressive medication had negative effects on life satisfaction and perceived overall quality of life (Geest & Moons, 2000; Hricik et al., 2001; Matas et al., 2002). Participants experiencing more bothersome medication side effects symptoms may feel distress, lack of ability to perform work or other activities, and disturbed relationships with family and friends, and therefore they reported lower mental HRQOL.

Side effects of immunosuppressive medications, primary appraisal of health, perceived self-efficacy, and perceived social support were significant predictors for coping or HRQOL of the studied participants. Perceived self-efficacy had the largest total effect on primary appraisal of health, followed by side effects of medication. Perceived social support and primary appraisal had a nearly equivalent total effect on engagement coping. Perceived self-efficacy had the largest total effects on disengagement coping and physical HRQOL, followed by primary appraisal of health. For mental HRQOL, primary appraisal of health had the largest total effects, followed by side effects of medication and perceived self-efficacy. Few studies on renal transplant patients have examined the relationships among these variables. However, as previously discussed, perceived self-efficacy, perceived social support, and cognitive appraisal were significant predictors for health

outcomes in patients with other chronic illnesses. These findings suggest that increasing the degrees of perceived self-efficacy, perceived social support, altering the negative appraisal of health, and decreasing the effects of the side effects of immunosuppressive medication are important nursing interventions that can improve the HRQOL of renal transplant patients.

Five hypotheses were derived from the hypothesized models. The following section focuses on the discussion of these hypotheses.

Hypothesis 1. As predicted, perceived self-efficacy had a significant direct effect on negative primary appraisal of health. Participants with low degrees of perceived selfefficacy were predicted to appraise their health conditions negatively (as threat or harm/loss). According to Bandura (1995), perceived self-efficacy is the belief of what one can do and this cognition mirrors a sense of control over the environment. Selfefficacy makes a difference in how people feel and think. A low degree of perceived self-efficacy is associated with depression, anxiety, helplessness, and pessimistic thoughts (Schwarzer, 1998). Thus, individuals with low degrees of perceived selfefficacy tend to appraise their health negatively. Perceived self-efficacy had both direct effects and indirect effects through primary appraisal of health on disengagement coping. This finding was consistent with theoretical literature (Schwarzer, 1998; Shaw, 1999). Perceived self-efficacy as a personal coping resource affects primary appraisal and the coping strategies selected by individuals. Participants with low degrees of perceived selfefficacy might lack the motivation to act and invest less effort into changing the situation. They used more disengagement coping such as behavioral disengagement or denial.

Hypothesis 2. Perceived social support had a direct negative effect on negative primary appraisal of health. Participants with less perceived social support were predicted to appraise their health as threat or harm/loss. This finding was consistent with Lazarus and Folkman's (1984) Stress and Coping Theory. According to Lazarus and Folkman (1984), social support influences and informs primary and secondary appraisals through a proactive response that minimizes stressful events before they become major stressors. The perceptions of social support could potentially buffer the negative emotional impact of stress appraisals through positive appraisals of the situation, or by buffering against high levels of stress through the provision of material coping resources. Thus, individuals with high levels of perceived social support appraised their health less negatively.

Perceived social support had a significant positive direct effect on engagement coping. This finding was consistent with theoretical works that suggested social support plays a buffering role in stressful situations. Perceived social support has been studied extensively as a coping resource and identified as having linkages with problem-focused coping (Lazarus & Folkman, 1984; Schreurs & Ridder, 1997). The perception or belief that others are available to provide emotional, informational, and material resources in times of need influences what course of coping is pursued (Ptacek et al., 2002). Individuals with high levels of perceived social support tended to use more engagement coping strategies (e.g., active coping, planning, use of emotional and instrumental support). Findings from this study suggested perceived social support had no significant direct effect on disengagement coping. This finding was unexpected and inconsistent with previous theoretical works that suggested a negative association between perceived

social support and emotion-focused coping (e.g., denial and self-blame). However, perceived social support had an indirect effect on disengagement coping through negative primary appraisal of health. This finding indicated participants with high degrees of perceived social support used less disengagement coping by appraising their health positively. This finding was consistent with Lazarus and Folkman's (1984) Stress and Coping Theory, which suggested that perceptions of social support affect coping through their impact on appraisals of stressful situations.

Few empirical studies on renal transplant patients investigated the relationships among perceived social support, appraisal, and coping. Some studies examined the relationship between social support and psychological outcomes, which demonstrated that social support or family support was negatively related to depression in renal transplant patients (Christensen et al., 2002; Frazier, Davis-Ali, & Dahl, 1995). In this study, perceived social support was not found to be a significant predictor for both physical and mental HRQOL. This inconsistency may be due to differences in the outcome constructs measured. The relationship between perceived social support and HRQOL needs further exploration.

Hypothesis 3. Negative primary appraisals of health had a direct effect on disengagement coping and no direct effect on engagement coping. Participants who appraised their health negatively (as threat or harm/loss) were predicted to use more disengagement coping strategies. This finding was consistent with Lazarus and Folkman's (1984) Stress and Coping Theory. According to Lazarus and Folkman (1984), primary appraisal refers to a set of cognitions regarding the impact or significance of the stressful encounter. In primary appraisals, a situation is perceived as being a challenge,

threat, harm/loss, or benign/irrelevant (Kessler, 1998; Schwarzer, 1998). With negative appraisals, such as harm/loss, the person surrenders, overwhelmed by feelings of helplessness and uncontrollability, which triggers disengagement coping strategies (e.g., behavioral disengagement, denial, self-blame, and venting). In addition, with negative appraisals, the person is less likely to try engagement coping such as planning, active coping, and use of instrumental support to change the stressful situation.

Hypothesis 4. Engagement coping had a significant negative direct effect on physical HROOL. The result indicated that participants who used more engagement coping were predicted to report a lower physical HROOL. This finding was interesting and inconsistent with some research studies. Engagement coping (e.g., planning, active coping, use of instrumental support, religion coping) was correlated with better health outcomes in previous studies (Christensen et al., 2000; Lindqvist, Carlsson, & Sjödén, 2004; Tix & Frazier, 1998). However, Folkman and Moskowitz (2004) suggested that some kinds of coping (e.g., seeking of instrumental support, problem-focused forms of coping) are sometimes associated with negative outcomes, sometimes with positive ones, and sometimes with neither, depending on characteristics of the appraised stressful encounter. Theoretically, people who choose coping strategies that fit the appraised controllability of a task will have better outcomes than people who do not (Folkman & Moskowitz, 2004). For the participants, they may appraise the transplant-related stressors such as side effects of medication and risk of rejection as uncontrollable, so engagement coping strategies may not fit the context, resulting in negative outcomes. Another explanation may be that this study was a cross-sectional design and cannot determine any causal relationship. Participants reporting lower physical HRQOL had

limited daily activities and poor energy and needed more support, so they used more engagement coping strategies such as use of instrumental support. Results also indicated that disengagement coping had a negative direct effect on mental HRQOL. The more disengagement coping was used, the lower the mental HRQOL of the participants. This finding was consistent with previous theoretical and empirical studies which indicated that certain kinds of coping strategies such as denial and behavioral disengagement are consistently associated with poor mental health outcomes (Folkman & Moskowitz, 2004).

Hypothesis 5. History of transplant-related hospitalizations and side effects of immunosuppressive medications had direct effects on primary cognitive appraisal of health, while donor type, duration of dialysis before transplantation, and time posttransplant were not significant predictors for primary appraisal of health. Participants who had a history of transplant-related hospitalizations and reported more bothersome medication side effects symptoms were predicted to appraise their health negatively (as threat or harm/loss). No previous studies investigated the relationship between transplant-related variables and cognitive appraisal of health. One plausible explanation for this finding may be that hospitalizations and side effects of medications were the most stressful events after transplantation for the participants. These events disrupt their normal daily lives and bring distress to them. Thus, participants appraised their health negatively. The finding that donor type, duration of dialysis before transplantation, and time post-transplant had no significant direct effects on primary appraisal of health was unexpected. It was reported that donor source, length of dialysis therapy prior to transplantation, and time post-transplant affected the physical HRQOL of renal transplant patients (Griva et al., 2002; Kizilisik et al., 2003). The participants in this study were

short-term post-transplant. They all (living or cadaveric donor transplantation) had a functional kidney graft and they did not need dialysis. Therefore donor type and history of dialysis before transplantation may not influence their appraisals of health. The relationship between donor type, duration of dialysis before transplantation, time post-transplant, and cognitive appraisals needs to be further examined in long-term post-transplant patients.

<u>Research Question 2</u>. What are the effects of clinical factors (donor type, history of transplant-related hospitalizations, side effects of immunosuppressive medications, duration of dialysis, and time post-transplantation) on perceived self-efficacy, perceived social support, cognitive appraisal of health, coping, and HRQOL following renal transplantation?

Donor type (living vs. cadaveric) had no main effects on perceived self-efficacy, perceived social support, cognitive appraisal of health, coping, and HRQOL following renal transplantation. There were few studies in the literature addressing the effects of donor type on perceived self-efficacy, perceived social support, cognitive appraisal of health and coping in renal transplant patients. Some previous studies examined the effects of donor type on the HRQOL of renal transplant patients. The finding of this study was consistent with AasebØ et al. (2005) and Evans et al. (1984) who reported there were no significant differences in HRQOL of recipients based on living vs. cadaveric donor kidney transplantation. However, Griva et al. (2002) reported that the incidence of physical HRQOL impairment was greater in cadaveric donor transplant recipients than living donor transplant recipients. One possible explanation for this conflicting finding in Griva et al's study may be the large difference in the sample sizes of the living donor and cadaveric

donor transplantation groups (76 vs. 271) in Griva's study. It was unexpected that donor type had no main effects on perceived social support. It was expected that living donor recipients might feel they had closer social network ties and perceived a higher level of social support than cadaveric donor recipients. Griva et al. (2002) revealed that living donor kidney recipients expressed stronger feelings of guilt in relation to the donor, which may counteract the positive effect of closer social network ties. Another possible explanation for the lack of significant main effects may be that participants in this study reported high levels of perceived social support with a mean of 87 (range 15 to 105) regardless of the donor type.

There were no differences in perceived self-efficacy, perceived social support, cognitive appraisal of health, coping, and HRQOL following renal transplantation between patients who had a history of transplant-related hospitalizations and those who had no history of transplant-related hospitalizations. There were few studies with which we can compare this finding. One possible explanation may be that the majority of the participants had no transplant-related hospitalizations and most of the participants who had a history of hospitalization were only hospitalized once. The finding of the effect of hospitalization on HRQOL was consistent with Fujisawa et al. (2000) who reported there was no significant difference in HRQOL when comparing renal transplant patients who had a period of hospitalization with those with no history of hospitalization. However, results from the study of Hathaway et al. (1998) indicated the number of hospital days in the first 6 months predicted the quality of life of kidney transplant patients at 12 months. This finding suggested that perhaps the duration of hospitalization was more important than whether or

not there were any transplant-related hospitalizations. The effect of the duration of transplant-related hospitalizations on the psychosocial variables merits further exploration.

Results of the MANCOVA demonstrated that side effects of immunosuppressive medications had significant main effects on the psychosocial variables. Univarate tests revealed that participants with high scores (>17) on the symptom checklist appraised their health condition more negatively; used more disengagement coping; had lower perceived self-efficacy; and had lower physical and mental HRQOL than participants with low scores  $(\leq 17)$ . There were no significant differences in perceived social support and engagement coping between the high and low scoring groups. Side effects of immunosuppressive medications were considered the main stressor by renal transplant patients in many studies (Fallon, Gould, & Wainwright, 1997; Frazier, Davis-Ali, & Dahl, 1995; Frey, 1990; Kong & Molassiotis, 1999; Sutton & Murphy, 1989; White et al., 1990). Participants with bothersome symptoms of medication side effects may feel more stressed and then may appraise their health negatively. High stress and threat appraisal were positively correlated to disengagement coping (Folkman, 1984; Sutton & Murphy, 1989). Thus participants with high scores on the symptom checklist used more disengagement coping. With more bothersome symptoms, participants may believe that they cannot manage their situation, and these beliefs may cause lower perceived self-efficacy. Some previous studies demonstrated that adverse effects of immunosuppressive medication were quite common and headaches had the strongest negative effect on life satisfaction (Hricik et al., 2001; Matas et al., 2002). Geest and Moons (2000) also indicated that higher levels of symptom distress were associated with lower perceived overall quality of life. The findings from

these earlier studies supported the findings of the current study that indicated participants with more bothersome symptoms of side effects reported lower HRQOL.

There were no significant main effects of duration of dialysis before transplantation  $(\leq 6 \text{ months vs.} > 6 \text{ months})$  on perceived self-efficacy, perceived social support, cognitive appraisal of health, coping, or HRQOL following renal transplantation. The effects of duration of dialysis on perceived self-efficacy, perceived social support, cognitive appraisal of health, and coping of renal transplant patients were not documented in the literature. Participants in this study with a functional graft were able to quit dialysis following transplantation. They felt better than before and the experiences of dialysis before transplantation may not influence the current subjective assessment of psychosocial variables. However, patients with a longer history of dialysis had more complications compared to those with less dialysis, which may influence their HRQOL. Kizilisik et al. (2003) found that patients receiving dialysis therapy for six months or more demonstrated lower post-transplant physical component scores on the SF-36 than patients who were transplanted preemptively. In this study, although multivariate analysis indicated there were no significant main effects, the univariate test noted that participants who had more than six months of dialysis before transplantation reported lower physical HRQOL than those who had equal to or less than six months of dialysis.

Time post-transplant had significant main effects on engagement coping, perceived self-efficacy, and perceived social support, while it had no statistically significant main effects on primary cognitive appraisal, disengagement coping, physical or mental HRQOL. Participants in the early period post-transplant (less than 1 year) used more engagement coping strategies than participants in the later period (1 to 3 years) and there were no

differences in using disengagement coping strategies between the two groups. These findings differed from those reported by Kong and Molassiotis (1999), who found no statistically significant differences in overall coping and all coping subscale scores between patients within one year post-transplant and patients more than one year post-transplant. This inconsistency may be due to the small sample size (23 in the early period vs. 78 in the later period) in Kong and Molassiotis's study. Another possible explanation may be that Kong and Molassiotis examined the coping strategies in Chinese renal transplant patients and used a different coping scale. Participants in the early period post-transplant face many new challenges such as learning new self-care skills, intensive follow-up appointments, and a need for informational and instrumental support. Thus, they use more engagement coping (e.g., use of instrumental support, planning). Participants in the later period post-transplant reported lower degrees of perceived self-efficacy and perceived social support. Few previous studies examined the effects of time post-transplant on these two variables in renal transplant patients. Participants in the later period post-transplant still live with a chronic illness condition, face the high risk of chronic rejection, and need ongoing supervision. All of these factors may influence their perceived self-efficacy. Participants in the later period post-transplant had less need for social support compared to immediate post-transplant patients. Their relatives and friends may think they have adapted to this situation and not continue to provide support. Thus, they reported lower degrees of perceived social support.

Cognitive primary appraisal of renal transplant patients has not been documented in the literature. Effects of time on HRQOL were examined in some previous studies and different patterns of changes in HRQOL were found. A study conducted by Ponton et al.

(2001) demonstrated there was a significant improvement in HRQOL between pretransplant and immediate post-transplant (first 6 months) patients, but the HRQOL progressively worsened during the period of 7 to 36 months, and then settled back to levels similar to those recorded immediately after transplant. Pinson et al. (2000) reported renal transplant patients made small gains in physical performance and no changes in HRQOL after transplantation, and then remained stable within the two years post-transplant. Findings from the current study were consistent with Pinson et al.'s study which suggested there were no statistically significant differences in HRQOL between the early period (less than 1 year) and later period (1 to 3 years) groups.

### Strengths and Limitations of the Study

### Study Strengths

The major distinction of the study is that it is the first research study to test a theoretical model of coping and HRQOL in renal transplant patients with a large sample size. By incorporating personal and situational factors into the model, this study attempted to identify how contextual factors influence the coping process and HRQOL in renal transplant patients. This dissertation study attempted to synthesize a more expansive and functional portrait of a person's experience in coping with transplantation. Another distinction of this study is that data were collected during the early post-transplant period (less than 1 year) and at a later period (1 to 3 years following transplantation), which captured the different relationships among the variables at two stages post-transplant and provided opportunities for comparison between the two groups.

In this study, both objective and subjective, self-reported data were collected from all subjects, which enhances the study's validity. The effects of clinical factors such as duration of dialysis, donor type, history of transplantation related hospitalizations, and side effects of immunosuppressive medications on coping and HRQOL were assessed, which provide the objective data for the study. Psychosocial variables were measured using instruments with established validity and reliability that had been validated in patients with chronic illnesses, which enhances the construct validity of this study. A relatively large sample size was obtained providing adequate power for the statistical analyses. Path analysis and multivariate statistical methods were used to analyze the data.

## Study Limitations

There were several limitations in this study, including factors that potentially impact external validity, construct validity, and internal validity. External validity is concerned with the generalizability of the findings to other samples. Study participants were recruited from a single transplant center that was affiliated with an academic health science center. The geographic location of the transplant center may introduce potential bias that could limit the generalizability of the findings to other populations of renal transplantation. Another factor potentially influencing the external validity of this study is the convenience sampling method used in this study. The convenience sample potentially limited representation of the broader characteristics of the general renal transplant population. Participants in this study were more educated than the general population; had a higher percentage of females compared to the gender distribution of general renal transplant population; and were short term post-transplant. Therefore, the findings from this study would only potentially apply to a renal transplant population with similar characteristics.

Construct validity refers to the extent to which instruments used in the study actually measure the constructs of interest. The symptom checklist was developed for this dissertation study and was untested in other samples. Using an untested symptom checklist may potentially impact the construct validity of the study, although it showed adequate internal consistency reliability in this study. The reliability and validity of the checklist need to be further evaluated.

Use of the composite cognitive appraisal of health (CAHS) and Brief COPE scores in data analysis may be another limitation in terms of exploring the influences of these constructs in depth. By using the composite scores, we cannot identify the potential key roles of the subscales represented in the CAHS and Brief COPE. Thus, it is difficult to determine whether a given outcome can be attributed to certain kinds of appraisals (e.g. threat, harm/loss, challenge, and benigh/irrelevant) or particular coping strategies (e.g. active coping, positive reframing, use of instrumental support). In addition, most measures are selfadministered questionnaires that may be influenced by fluctuations in respondent attention, motivation, comprehension, and response biases such as social desirability (Lispsey, 1990), which can potentially cause measurement error.

Finally, use of a descriptive, correlational, cross-sectional design limits the ability to make causal conclusions about the variables studied. This cross-sectional, one-time data collection method also was unable to verify the temporal sequence of variables. This factor is particularly salient in relation to the findings regarding cognitive appraisal of health, coping, and HRQOL. Because participants were not studied prospectively over time, it is not clear if the negative appraisal of health predicted worse HRQOL or worse HRQOL led to a negative appraisal of health. Similarly, for the relationship between engagement coping and physical HRQOL, it is difficult to interpret whether greater use of engagement coping

predicted worse physical HRQOL or worse physical HRQOL promoted greater use of engagement coping.

#### **Recommendations for Future Research**

With respect to study strengths, limitations, and findings, the following strategies are recommended for future research. First, research samples need to be recruited from other geographic regions and minority populations in an attempt to study these relationships in more diverse samples.

Second, longitudinal and experimental designs are needed to address the issue of causality. In addition, the longitudinal study could start at the evaluation of transplantation stage, enabling changes in the coping process from pre-transplant to post-transplant to be captured. For the study design, another recommendation would be to blend quantitative and qualitative methodologies. Qualitative research may help identify, clarify, or confirm key constructs and themes that portray perceptions and experiences about coping with renal transplantation.

Third, the model tested in this study can be modified by including gender, race, and education level and removing some non-significant clinical data (e.g., donor type, duration of dialysis) in future studies. Literature suggested gender, race, and education level are important factors that influence HRQOL.

Fourth, the symptom checklist needs further examination in other organ transplant patients (e.g., liver, heart, lung transplant). Since symptoms of immunosuppressive medication side effects are important predictors for coping and HRQOL, the checklist can be used to examine whether similar effects occurs in other organ transplant patients, and its reliability and validity can be tested in these populations.

Finally, replication studies are recommended. The process of theory validation requires systematic replication and cross-validation to increase confidence in the generalizability of findings. The theory validation process involves considering whether the model varies across groups. The model of coping and HRQOL was tested in a sample consisting of both kidney transplant patients at an early period (less than 1 year) and later period (1 to 3 years) post-transplant. Further studies could examine whether the model fits the data in a sample including only patients at immediate post-transplant (less than 6 months) or at long-term post-transplant (more than 3 years). The model also could be tested with different organ transplant patients (e.g., liver, heart, and lung transplant patients). Analysis of data across groups and model comparison over time would provide a more in-depth understanding of the model of coping and HRQOL.

# Conclusions and Implications for Nursing Practice

There has been relatively little empirical research on testing models of coping and HRQOL in renal transplant patients. This study examined the relationships between transplant-related clinical variables (history of transplant-related hospitalizations, side-effect of immunosuppressive medications, donor type, duration of dialysis before transplant, and time post-transplant), perceived self-efficacy, perceived social support, cognitive appraisal of health, coping, and HRQOL in a model of coping and HRQOL. This model was developed based upon the theoretical model of Lazarus and Folkman's (1984) stress and coping, and statistical fit. Findings suggested the modified hypothesis models predicting PCS and MCS fit the data well. Findings demonstrated that history of transplant-related hospitalizations, side effects of immunosuppressive medications, perceived self-

efficacy, and perceived social support are significant predictors for negative primary appraisal of health. Perceived self-efficacy and negative primary appraisal are significant predictors for disengagement coping, while perceived social support is a significant predictor for engagement coping. Perceived self-efficacy, negative primary appraisal of health, and engagement coping are significant predictors for physical HRQOL. Side effects of immunosuppressive medications, negative primary appraisal of health, and disengagement coping are significant predictors for mental HRQOL. Findings also indicated that there were no significant effects of donor type, duration of dialysis before transplantation, or history of transplant-related hospitalizations on the psychosocial variables after controlling for time post-transplant. Participants with high scores (>17) on the symptom checklist appraised their health negatively, used more disengagement coping, had lower degrees of perceived self-efficacy, and reported lower physical and mental HRQOL than participants with low scores (<17) on the symptom checklist. Participants less than one year post-transplant used more engagement coping, and reported higher degrees of perceived self-efficacy and perceived social support than participants in the later period post-transplant. These findings have important theoretical and practical implications for nursing.

This study provides preliminary evidence to support the modified hypothesis model on coping and HRQOL in renal transplant patients. The testing of the model of coping and HRQOL advances theoretical knowledge of the concepts of coping and HRQOL. This model also can provide a conceptual framework for future studies in the area of coping and HRQOL. Findings from this study not only provide empirical support for important established relationships related to coping and HRQOL, but also provide some new

findings, such as primary appraisal of health having direct effects on both physical and mental HRQOL. This model can guide nursing practice by providing a framework that incorporates various individual and situational variables relevant to nurses working with transplant patients. The model may contribute to the development of effective intervention strategies to help patients cope with their transplantation and improve their HRQOL.

Findings suggested that perceived self-efficacy had the largest effects on negative primary appraisal of health, disengagement coping, and physical HRQOL. This finding indicated that perceived self-efficacy plays an important role in the model. Renal transplant nurses need to consider developing interventions to enhance perceived selfefficacy in patients. If self-efficacy can be enhanced, patients may appraise their health less negatively, use less disengagement coping, and report higher physical HRQOL. Symptoms of immunosuppressive medications were also identified as significant predictors for negative primary appraisal of health and mental HRQOL. This finding provides empirical support recommending the development of new medication with fewer side effects, using a protocol with optimal benefit for patients, and actively treating with the symptoms of medication side effects. Renal transplant nurses also need to develop interventions to alleviate bothersome symptoms and educate patients about coping with the side effects of medications. Primary appraisal of health served as a mediator and plays a key role in the model of coping and HRQOL. In addition to physical impairment influencing HRQOL, the model suggested that the subjective appraisal of health probably affects how people cope and assess their HRQOL. Therefore, renal transplant nurses need to understand the perceptions of their patients and help them alter their negative appraisals of their health.

Health-related quality of life of renal transplant patients is the outcome of a complex interplay between clinical factors, personal and social resources, cognitive appraisal of health, and coping strategies. Holistic and dynamic interventions including physical and psychosocial components are needed to help renal transplant patients cope with transplantation and improve their HRQOL.
APPENDIX A

# COGNITIVE APPRAISAL OF HEALTH SCALE (CAHS)

Below are several statements that describe ways people think about their health condition. Please read each item and circle one number that best describes how much you agree or disagree with the statement according to what is happening to you right now. The answers range from strongly agree (5) to strongly disagree (1). Please be sure to answer all statements. There are no right or wrong answers.

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
	e				U
1. I can control what will happen to	1	2	3	4	5
me					
2. This health condition won't get me	1	2	3	4	5
down					
3. I have not been able to do what I want to do	1	2	3	4	5
because of this health condition					
4. The health condition is frightening to	1	2	3	4	5
me					
5. This health condition isn't stressful to	1	2	3	4	5
me					
6. Things will only get worse because of this health	1	2	3	4	5
condition					
7. This health condition will not go	1	2	3	4	5
well					
8. This health condition has damaged my	1	2	3	4	5
life					
9. I have lost interest in the things around	1	2	3	4	5
me					
10. I have had to give up a great deal because of this	1	2	3	4	5
health condition					
11. I can beat this health condition despite the	1	2	3	4	5
difficulties					
12. This health condition is one that I can change or	1	2	3	4	5
do something about					
13. I have a sense of loss over the things I can no	1	2	3	4	5
longer do					
14. I feel I can handle this health	1	2	3	4	5
condition					
15. I have nothing to lose because of this health	1	2	3	4	5
condition					
16. During this health condition, I have to hold	1	2	3	4	5
myself back from doing what I want to do					
17. I have a lot to lose because of this health	1	2	3	4	5
condition					
18. I worry about what will happen to	1	2	3	4	5
me					
19. Relationships with my family and friends have	1	2	3	4	5
suffered					
20. There is nothing I need to do for this health	1	2	3	4	5
condition					

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
21. I have been harmed in some way by this health condition	1	2	3	4	5
22. I need to know more before I can do anything about this health condition	1	2	3	4	5
23. I don't think much about this health condition.	1	2	3	4	5
24. This health condition has caused me to learn more about myself	1	2	3	4	5
25. I have been hurt by this health condition	1	2	3	4	5
26. There is a lot I can do to overcome this health condition.	1	2	3	4	5
27. I have to accept this health condition.	1	2	3	4	5
28. This health condition doesn't affect my life	1	2	3	4	5

APPENDIX B

PERSONAL RESOURCE QUESTIONNAIRE (PRQ2000)

## PERSONAL RESOURCE QUESTIONNAIRE (PRQ2000)

Below are some statements with which some people agree and others disagree. Please read each statement and **CIRCLE** the response most appropriate for you. There is no right or wrong answer.

	1 S	TRO	NGI	LY D	ISA	GRE	E
	2 I	DISA	GRE	E			
	3 S	SOME	EWH	AT I	DISA	GRI	EE
	4 N	VEUT	'RAI				
	5 S	SOME	EWH	AT A	AGR	EE	
	6 A	AGRE	ΕE				
	7 S	TRO	NGI	JY A	GRF	ΕE	
Q-1. There is someone I feel close to who makes me	1	2	3	4	5	6	7
feel secure							
Q-2. I belong to a group in which I feel	1	2	3	4	5	6	7
important							
Q-3. People let me know that I do well at my work	1	2	3	4	5	6	7
(job, homemaking)							
Q-4. I have enough contact with the person who	1	2	3	4	5	6	7
makes me feel special							
Q-5. I spend time with others who have the same	1	2	3	4	5	6	7
interests that I do							
Q-6. Others let me know that they enjoy working	1	2	3	4	5	6	7
with me (job, committees, projects)							
Q-7. There are people who are available if I need	1	2	3	4	5	6	7
help over an extended period of time							
Q-8. Among my group of friends we do favors for	1	2	3	4	5	6	7
each other							
Q-9. I have the opportunity to encourage other to	1	2	3	4	5	6	7
develop their interests and skills							
Q-10. I have relatives or friends that will help me out	1	2	3	4	5	6	7
even if I can't pay them back							
Q-11. When I am upset, there is someone I can be	1	2	3	4	5	6	7
with who lets me be myself							
Q-12. I know that others appreciate me as a	1	2	3	4	5	6	7
person							
Q-13. There is someone who loves and cares about	1	2	3	4	5	6	7
me							
Q-14. I have people to share social events and fun	1	2	3	4	5	6	7
activities with							
Q-15. I have a sense of being needed by another	1	2	3	4	5	6	7
person							

APPENDIX C

## PERCEIVED HEALTH COMPETENCE SCALE (PHCS)

### Perceived Health Competence Scale (PHCS)

This is a questionnaire designed to determine the way in which different people view certain important issues related to their health. Each item is a belief statement, with which you may agree or disagree. Next to each statement is a scale that ranges from strongly disagree (1) to strongly agree (5). Respond to each of the following items by putting a mark through one box next to each statement, using the response choices listed below. Please try to respond to each item separately without thinking about the other items. Choose your answers thoughtfully and make your answers as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU-not what you think most people would say or do.

	Strong	ly ee	Strongly Agree		
	1	2	3	4	5
1. It is difficult for me to find effective solutions for health problems that come	1	2	3	4	5
my way					
2. I find efforts to change things that I don't like about my health are	1	2	3	4	5
3. I handle myself well with respect to my health	1	2	3	4	5
4. I am able to do things for my health as well as most other people	1	2	3	4	5
5. I succeed in the projects I undertake to improve my health	1	2	3	4	5
6. Typically, my plans for my health don't work out well	1	2	3	4	5
7 No matter have hand I tree may health					
doesn't turn out the way I would like	1	2	3	4	5
8 I'm generally able to accomplish my					
goals with respect to my health		2	3	4	5

APPENDIX D

BRIEF COPE

#### Brief COPE

These items deal with ways you've been coping with the stress in your life since you received your kidney transplant. There are many ways to try to deal with stress. These items ask what you've been doing to cope with the stresses related to your kidney transplant. Each item says something about a particular way of coping. Please describe the extent you've been doing what the item says <u>over the past 4 weeks</u>. How much or how frequently. Use these response choices. Make your answers as true FOR YOU as you can.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off	1	2	3	4
things.				
2. I've been concentrating my efforts on doing something about	1	2	3	4
the situation I'm in.				
3. I've been saying to myself "this health condition isn't real".	1	2	3	4
4. I've been getting emotional support from others.	1	2	3	4
5. I've been giving up trying to deal with this health condition.	1	2	3	4
6. I've been taking action to try to make the situation better.	1	2	3	4
7. I've been refusing to believe that this health condition has happened.	1	2	3	4
8. I've been saying things to let my unpleasant feelings escape.	1	2	3	4
9. I've been getting help and advice from other people.	1	2	3	4
10. I've been trying to see this health condition in a different light, to make it seem more positive.	1	2	3	4
11. I've been criticizing myself.	1	2	3	4
12. I've been trying to come up with a strategy about what to do.	1	2	3	4

## Continuation of Brief COPE

- 1 = I haven't been doing this at all
  2 = I've been doing this a little bit
  3 = I've been doing this a medium amount
  4 = I've been doing this a lot

13. I've been getting comfort and understanding from someone.	1	2	3	4
14. I've been giving up the attempt to cope.	1	2	3	4
15. I've been looking for something good in what is happening.	1	2	3	4
16. I've been making jokes about this health condition.	1	2	3	4
17. I've been doing something to think about this health condition less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
18. I've been accepting the reality of the fact that this health condition has happened.	1	2	3	4
19. I've been expressing my negative feelings.	1	2	3	4
20. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
21. I've been trying to get advice or help from other people about what to do.	1	2	3	4
22. I've been learning to live with this health condition.	1	2	3	4
23. I've been thinking hard about what steps to take.	1	2	3	4
24. I've been blaming myself for things that happened.	1	2	3	4
25. I've been praying or meditating.	1	2	3	4
26. I've been making fun of the situation.	1	2	3	4

## APPENDIX E

# HEALTH STATUS SURVEY (SF-36®)

# Health Status Survey (SF-36®)

This survey asks for your views about your health. Answer each question by marking a circle with the best answer you can give. *Thank you*.

1. In general, would you say your health is:	Excellent	Very goo	d Goo	d Fa	air	Poor
(Mark only one circle).	0	0	0	С	)	0
The following items are al might do during a typical <u>health now limit you</u> in th so, How much?	oout activitie day. Does <u>vc</u> ese activities	es you <u>our</u> \$? If	Yes, Limited a lot	Yes, Limited a little	l L	No, Not Jimited at all
2. <u>Vigorous activities</u> , such heavy objects, participating sports	as running, li in strenuous	ifting	0	0		0
3. <u>Moderate activities</u> , such pushing a vacuum cleaner, a shanning	as moving a bowling or	table,	0	0		0
4. Lifting or carrying groceries			0	0		0
5. Climbing <u>several</u> flights of stairs	of		0	0		0
6. Climbing <u>one</u> flight of stairs			0	0		0
7. Bending, kneeling, or stooping			0	0		0
8. Walking <u>more than a</u> mile			0	0		0
9. Walking <u>several</u>			0	0		0
10. Walking <u>one</u> block			0	0		0
11. Bathing or dressing yourself			0	0		0
During the <u>past 4 weeks</u> , h problems with your work result of your physical hea	nave you had or other reg <u>alth</u> ?	l any of the ular daily	e following activities	g <u>as a</u>	Yes	No
12. Cut down on the amoun activities	t of time you	spent on o	ther work		0	0
13. Accomplished less than like	you would				0	0
14. Were limited in the kind	l of work or o	other			0	0
15. Had difficulty performinit took extra effort)	ng work or ot	ther activiti	es (for exa	ample,	0	0
During the past 4 weeks, h	nave you had	l any of the	e following	g	Yes	No

<u>result of any emotional problems</u> (such as feeling depressed or								
anxious)?	anxious)?							
16. Cut down the <u>amount of time</u> you spent on work or other								
activities								
17. <u>Accomplished less</u> than you would O								
like								
18. Didn't do work or other activities as <u>carefully</u> as								
usual								
19 During the <u>past 4 weeks</u> , to w	hat	Not at	Slightl	Moder	Quite	Extre		
extent has your physical health o	r	all	У	ately	a bit	mely		
emotional problems interfered w	ith							
your normal social								
activities with family, friends,	activities with family, friends,							
neighbors or		0	0	0	0	0		
groups?								
20. How much <u>bodily</u> pain	None	Very	Mild	Moder	Severe	Very		
have you had during the <u>past 4</u>	_	Mild		ate		Sever		
weeks?	0	0	0	0	0	0		
					- ·	_		
21. During the <u>past 4 weeks</u> , how	v much	Not at	A little	Moder	Quite	Extre		
did <u>pain</u> interfere with your norn	nal	all	bıt	ately	a bit	mely		
work								
(including both outside the home	e and	$\sim$	$\sim$	$\sim$	$\sim$	$\sim$		
housework)?		0	0	0	0	0		

problems with your work or other regular daily activities as a

The following questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

comes closest to the way you	nave be	ch itenng	•			
	All of	Most	A good	Some	A little	None
How much time during the	the	of the	bit of	of the	of the	of the
past 4 weeks:	time	time	the	time	time	time
			time			
22. Did you feel full of	0	0	0	0	0	0
pep?						
23. Have you been a very	0	0	0	0	0	0
nervous						
person?						
24. Have you felt so down	0	0	0	0	0	0
in the dumps that nothing						
could cheer you						
up?						
25. Have you felt calm and	0	0	0	0	0	0
peaceful?						

26. Did you have a lot of energy?	0	0	0	0	0	0
27. Have you felt downhearted and	0	0	0	0	0	0
28. Did you feel worn (out?	0	0	0	0	0	0
29. Have you been a happy person?	0	0	0	0	0	0
30. Did you feel	0	0	0	0	0	0
31. During the past 4 weeks, how		All of	Most	Some	A little	None
much of the time has your physica	al	the	of the	of the	of the	of the
health or emotional problems		time	time	time	time	time
interfered with your social activity	es	$\sim$	0	0		0
(like visiting with irlends, relative)	s,	0	0	0	0	0
How TRUE or FALSE is each of t	the	Definit	Mostly	Don't	Mostly	Definite
following statements for you?	the	Demin	truc		false	ly folco
following statements for you.		elv	irne	KNOW	laise	
		ely true	true	KNOW	laise	ly laise
32. I seem to get sick a little easier	r	ely true	crue	know		
32. I seem to get sick a little easier than other	r	ely true	O	O	O	O
<ul><li>32. I seem to get sick a little easier than other people</li><li>33. I am as healthy as anybody I know</li></ul>	r 	ely true	0 0	©	O O	O O
<ul> <li>32. I seem to get sick a little easier than other people</li> <li>33. I am as healthy as anybody I know</li> <li>34. I expect my health to get</li> </ul>	r 	ely true	0 0		0 0	
<ul> <li>32. I seem to get sick a little easier than other people</li> <li>33. I am as healthy as anybody I know</li> <li>34. I expect my health to get worse</li> </ul>	r 	ely true O	0 0 0		0 0	0 0 0
<ul> <li>32. I seem to get sick a little easier than other people</li> <li>33. I am as healthy as anybody I know</li> <li>34. I expect my health to get worse</li> <li>35. My health is</li> </ul>	r 	ely true O O O	0 0 0		0 0 0	0 0 0 0
<ul> <li>32. I seem to get sick a little easier than other people</li> <li>33. I am as healthy as anybody I know</li> <li>34. I expect my health to get worse</li> <li>35. My health is excellent</li> </ul>	r 	ely true O O	0 0 0		0 0 0	0 0 0 0
<ul> <li>32. I seem to get sick a little easier than other people</li> <li>33. I am as healthy as anybody I know</li> <li>34. I expect my health to get worse</li> <li>35. My health is excellent</li> <li>36. Compared to <u>one year ago</u>, how</li> </ul>	r 	ely true O O O Much	C C Some	know	O O O Some	O O O Much
<ul> <li>32. I seem to get sick a little easier than other people</li> <li>33. I am as healthy as anybody I know</li> <li>34. I expect my health to get worse</li> <li>35. My health is excellent</li> <li>36. Compared to one year ago, how would you rate your health in generation of the second second</li></ul>	r  w eral	ely true	Some what better	<ul> <li>Know</li> <li>O</li> <li>O</li> <li>O</li> <li>About the same</li> </ul>	Some what worse	O O O Much worse

APPENDIX F

SYMPTOM CHECKLIST

## Symptom Checklist

We are interested in learning about symptoms that you currently have that may be related to your kidney transplant. If you are currently experiencing any of the following symptoms, please check the appropriate box for that symptom.

	No	Ves				
	1.0		I have	this and it bo	thers me	
	I don't have this	Not at all	Slightly	Moderately	Quiet a bit	Extremely
1. excess hair growth						
2. hair loss						
3. headache						
4. hand tremors						
5. overgrowth of gum tissue						
6. diarrhea/GI distress						
7. acne						
8. difficulty sleeping						
9. high blood sugar						
10. high blood pressure						
11. weight gain						
12. tiredness						

APPENDIX G

DEMOGRAPHIC AND CLINICAL DATA FORM

1.	Male,Female	
2.	Date of birth(dd/mm/yy)	
3.	Ethnicity/Race	
	White	Black or African American
	Hispanic/Latino	Asian
	American Indian/Alaskan Native	
	Native Hawaiian or other Pacific Is	lander
4.	Education Level	
	None	Grade school (0-8)
	High school (9-12)	Attended college/Technical school
	Associate/Bachelor degree	Post-college Graduate degree
	Unknown	
5.	Marital Status	
	Single	Married
	Divorced	Separated
	Life partner	Unknown
6.	Cause of ESRD	
	Diabetic nephropathy	Hypertension
	Glomerulonephritis	Cystic kidney disease
	Other, Specify	_
7.	Type of Dialysis	
	No dialysis	Hemodialysis
	Peritoneal dialysis	Unknown type
8.	Date first dialyzed(dd/mm	/yy)
9.	Significant Complication of Dialysis	
	Cardiovascular disease	Anemia
	Renal osteodystrophy	Uremic neuropathy
	Amyloidosis	Dialysis access failure
	Other, Specify	
10.	Donor Type	
	Cadaveric	
	Living	
	Biological, blood related (parent,	child, identical twin, full sibling, half
	sibling, other relative)	
	Non-biological (spouse, life partne	er, friend, other)
11.	Current Anti Rejection Medications	
	Prednisone	Cyclosporine A/Neoral
	Mycophenolate Mofetil(Cellcept)	Tacrolimus(Prograf)
	Sirolimus (rapamune)	Other, Specify
12.	Dates of biopsy-proven rejection episo	de
	Grades of rejection	
13.	Dates of tx-related hospitalizations	
14.	Graft function	
	Fuctioning,	

# Demographic and Clinical Data Form

Serum Creatinine	mg/dl
Creatinine clearance	ml
Failed	
15. Date of transplanted	(dd/mm/yy)

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