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## The Relationships Among Satisfaction With Social Support, Perceived Stress, and Coping on Quality of Life and Survival at 5 to 10 Years After Heart Transplantation

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THE RELATIONSHIPS AMONG SATISFACTION WITH SOCIAL SUPPORT,  
PERCEIVED STRESS, AND COPING  
ON QUALITY OF LIFE AND SURVIVAL AT  
5 TO 10 YEARS AFTER HEART TRANSPLANTATION

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A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham  
in partial fulfillment of the requirements for the degree of  
Doctor of Philosophy

BIRMINGHAM, ALABAMA

2009

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THE RELATIONSHIPS AMONG SATISFACTION WITH SOCIAL SUPPORT,  
PERCEIVED STRESS, AND COPING  
ON QUALITY OF LIFE AND SURVIVAL AT  
5 TO 10 YEARS AFTER HEART TRANSPLANTATION

CONNIE WHITE-WILLIAMS

SCHOOL OF NURSING

ABSTRACT

Introduction: Detailed information regarding satisfaction with social support and its relationship with quality of life (QOL) and survival 5 to 10 years (yrs) after heart transplantation (HT) is unknown. The purpose of this study was to examine the relationships among satisfaction with social support perceived stress, and coping with QOL and survival of patients (pts) who were 5 to 10 years post heart transplantation.

Methods: This study was a retrospective outcome analysis from data collected from two existing data sets: The HT QOL Study and the Cardiac Transplant Research Database (CTRD). Institutional Review Board approval was obtained. Data on 555 HT pts (78% male, 88% white, mean age=53.8yrs) at 4 U.S. sites using the following instruments: HT Social Support Index (lower score = better satisfaction), QOL Index, Jalowiec Coping Scale, HT Stressor Scale, and chart review were examined. Statistical analyses included descriptive analyses, correlational analyses, t-tests,

repeated measures, univariate and multiple regression, Kaplan-Meier survival actuarials, and Baron and Kenny's series of regression equations to test for mediation.

Results: Overall satisfaction with SS remained steady over time. There were sociodemographic differences in satisfaction with social support at 5 and 10 years after heart transplantation.. At 5 years, men reported more satisfaction with emotional social support than females. Older pts had more satisfaction with overall social support at 5 and 10 years after HT. Overall, emotional, and tangible social support was significantly correlated with QOL ( $p < .0001$ ) and found to be a predictor of QOL at 5 and 10 years after HT ( $p < .0001$ ). Multiple regression found overall social support to be a predictor of QOL at 5 years while satisfaction with emotional social support was a predictor at 10 years post heart transplantation. Satisfaction with social support was not predictive of survival. Satisfaction with emotional, tangible, and overall social support were found to be partial mediators between perceived stress and QOL.

Conclusions: Identification of demographic and psychosocial variables that are associated with satisfaction with social support at 5 to 10 years after heart transplantation will assist clinicians to target specific patients who may need additional social support resources.

Key words: Social support, Heart Transplantation, Quality of Life, Perceived Stress, Coping

## DEDICATION

This dissertation is dedicated to my parents, Clarence and Germaine White.

## ACKNOWLEDGMENTS

A work of this magnitude requires the effort of numerous people. I am truly indebted to the guidance and support of my dissertation committee, Dr. Karen Meneses, Dr. Linda Moneyham, Dr. Marguerite Kinney, Dr. Robert Bourge, and Dr. David Naftel, all of whom provided their own unique expertise to this project.

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## LIST OF ABBREVIATIONS

AHA	American Heart Association
HT	Heart Transplantation
ISHLT	International Society of Heart and Lung Transplantation
JCS	Jalowiec Coping Scale
Pts	Patients
QOL	Quality of Life
QLI	Quality of Life Index
WHO	World Health Organization

## CHAPTER 1

### INTRODUCTION

In 1964, Dr. James Hardy attempted the first heart transplant surgery in Jackson, Mississippi by transplanting a chimpanzee heart into a 68-year-old man. The patient died one hour after surgery due to the size discrepancy between the recipient and donor. Three years later in December of 1967, Dr. Christian Barnard performed the first successful human heart transplant in Capetown, South Africa. This patient survived 18 days before dying of pneumonia. During this early period, many transplant programs succumbed to closure because of higher than expected mortality rates. However, since the early days of heart transplantation, many landmark discoveries have produced the life-saving therapy it is today. With clinical advancements in the areas of organ procurement and allocation, immunosuppression, and long-term patient management, heart transplantation has become a viable treatment option for a select group of patients with end-stage heart disease. Dedicated researchers continue to examine conditions such as rejection of the transplanted heart, infection, coronary vasculopathy, and malignancies that plague long-term survival (Crespo-Leiro et al., 2008; Kirklin et al., 2006; Luckraz et al., 2003; Stork et al., 2006). As a result of this treatment option, issues surrounding the quality of life (QOL) of patients have emerged. Factors related to a variety of physical and psychosocial issues among patients who undergo transplantation have become increasingly important to study. The ideal outcome of cardiac transplantation is not only to prolong the life of the recipient, but also to enhance his or her QOL.

### **Purpose**

The purpose of this study is to examine the relationships among satisfaction with social support, perceived stress, and coping with QOL and survival of patients who are 5 to 10 years post heart transplantation. Specifically, this study examines the relationship between satisfaction with social support on QOL and survival over time, compares the predictability of the emotional and tangible social support on QOL and survival, and examines the relationships among social support, coping, perceived stress and QOL in long-term (5 to 10 yrs) survivors of heart transplantation.

### **Significance of the Problem**

The number of people with cardiovascular disease in the United States has continued to increase over the past two decades despite advancements in prevention and treatment options. The incidence and prevalence of heart failure has steadily increased with an estimated 5.3 million Americans having heart failure and 550,000 new cases diagnosed each year [American Heart Association (AHA), 2008]. The estimated direct and indirect cost of heart failure in the United States for 2008 was \$34.8 billion (AHA, 2008). Heart failure is the direct cause of 50,000 deaths per year and a contributing cause to an additional 250,000 deaths per year.

The significance of studying patients who have undergone heart transplantation has been identified by 3 major groups: National Institute of Nursing Research (NINR), the American Heart Association (AHA), and the International Society of Heart and Lung Transplantation (ISHLT). In 1998, the NINR convened a working group to discuss research opportunities in organ transplantation. Improving quality of life outcomes after



transplantation was one of its research priorities. The influence of social support, perceived stress, and coping and how these factors affect long-term outcomes was also considered a research priority. Sigmon and Grady (2001) stated,

Special topics in the field of transplantation research that have immediate application to studies of quality of life include signs and symptoms of chronic illness, biobehavioral risk factors for disease, functional disabilities, patient outcomes, adherence to treatment, care delivery, roles of family and caregivers, strategies of stress management, special needs of children and high-risk patients, health promotion and education, and long-term care (Sigmon & Grady, 2001, pg. 5).

These research initiatives were identified at a Spring Science Workgroup entitled “Quality of Life in Transplant Patients” in which this author participated. Additionally, the NINR’s Strategic Plan for 2006-2010 includes promoting health and preventing disease by examining strategies to improve QOL of persons with chronic illness.

The AHA also established priority research topics in its 2006-2010 Strategic Plan to include examining psychosocial factors and QOL in patients with cardiovascular disease (AHA, Research Initiatives, 2008). Research in the area of cardiac transplantation was also identified as an AHA research priority. Another organization with research priorities in transplantation is the ISHLT. This organization is dedicated to the advancement of the science and treatment of end-stage heart and lung diseases. In 2006, a report reviewing psychosocial outcomes after cardiothoracic transplantation from the Nursing and Social Sciences Council was published. Research priorities along with recommendations for future research included increasing longitudinal studies, examining psychosocial risk factors believed to be important to clinical outcomes, and studying outcomes of patients long-term (greater than five years) after transplantation (Cupples et al., 2006).

Patients who undergo heart transplantation are physically, psychologically, and socially affected by the consequences of therapy. While some researchers found that poor social support and inadequate coping strategies are associated with psychological distress and decreased survival (Dew et al., 2001; Dew et al., 2005; Farmer & Meyer, 1996), other researchers have found no relationship between social support and psychosocial outcomes (Westlake et al., 2002). Clear limitations of these studies include the use of cross-sectional designs with small sample sizes, not measuring QOL and survival as outcomes, and having short follow-up times (Artinian et al., 1995; Dew et al., 2001; Dew et al., 2005; Farmer & Meyer, 1996; Westlake et al., 2002; Wingate, 1995). Few studies address satisfaction with social support and its relationship with QOL and survival over time in long-term heart transplant patients, nor have any studies examined whether different types of social support (i.e., emotional and tangible) have an impact on QOL and survival in this population. Furthermore, there are no studies to date that examine the role of social support and coping as mediating the relationship between stress and QOL in the heart transplant survivor.

### **Specific Aims, Research Questions, and Hypotheses**

To address the gaps in the literature, the study aims, research questions, and hypotheses are:

**Aim 1:** To examine the relationships among perceived satisfaction with social support, QOL, and survival over time among survivors 5 to 10 years after heart transplantation.

**Research Question 1-1:** Does perceived satisfaction with social support change over time in long-term heart transplant survivors?

**Research Question 1-2:** Is perceived satisfaction with social support associated with QOL in long-term heart transplant survivors?

**Research Question 1-3:** Is perceived satisfaction with social support associated with survival in long-term heart transplant survivors?

**Research Question 1-4:** Are there sociodemographic differences in emotional, tangible, and overall social support in long-term heart transplant survivors?

**Hypothesis 1-1:** Married transplant survivors will report better perceived satisfaction with social support compared to unmarried survivors long-term after heart transplant.

**Hypothesis 1-2:** Women will report worse perceived satisfaction with social support compared to men in long-term heart transplant survivors.

**Hypothesis 1-3:** Older survivors ( $> 60$  years) will report better perceived satisfaction with social support compared to younger survivors ( $\leq 60$  years) long-term after heart transplant.

**Hypothesis 1-4:** There will be no relationship between race and perceived satisfaction with social support in long-term heart transplant survivors.

**Aim 2:** To examine the relationship between two types of social support (i.e., tangible and emotional), QOL in survivors 5 to 10 years after heart transplantation.

**Research Question 2-1:** Does satisfaction with emotional social support predict QOL in survivors 5 to 10 years after heart transplantation?

**Research Question 2-2:** Does satisfaction with tangible social support predict QOL in survivors 5 to 10 years after heart transplantation?

**Aim 3:** To examine the relationship among perceived satisfaction with social support,

emotional and tangible social support, perceived stress, coping and QOL at 5 years after heart transplantation.

**Research Question 3-1:** Does perceived satisfaction with emotional, tangible, or overall social support mediate the relationship of perceived stress and QOL at 5 years after heart transplantation?

**Research Question 3-2:** Does coping mediate the relationship of perceived stress and QOL at 5 years after heart transplantation?

### **Definition of Terms**

The definitions of the terms for this study are:

**Satisfaction with social support** is defined as the degree of perceived satisfaction with social support (i.e., emotional and tangible) by the patient which is provided by others (Bennett et al., 2001; Cohen & Syme, 1985; House, 1981). Social support is measured by the Heart Transplant Social Support Index.

**Quality of life** is defined as the effect of an illness and its consequent therapy upon a patient, as perceived by the patient's satisfaction with aspects of life that are important to them (Ferrans & Powers, 1994; Spiker & Revicki, 1996). Quality of life is measured by the Quality of Life Index.

**Perceived stress** is defined as the degree to which situations in one's life are viewed as stressful. Perceived stress is measured by the Heart Transplant Stressor Scale.

**Coping** is defined as the use of behaviors to manage stressful life events. Coping is measured by the Jalowiec Coping Scale.

Table 1 lists theoretical and operational definitions for each variable in this study.

The assumptions for this proposed study are:

1. Quality of life and satisfaction with social support can be measured by self-report.
2. Quality of life and satisfaction with social support are of value to the cardiac transplant patient.
3. Individuals with a heart transplant will experience stress and coping.

## CHAPTER 2

### REVIEW OF LITERATURE

The purpose of this chapter is to review the conceptual framework undergirding this study, and to review empirical evidence of the relationships among study variables. The first section presents the conceptual framework. The next section reviews literature on the following concepts and their relationships: social support, coping, perceived stress, quality of life, and survival, along with the current gaps in the literature. The last section summarizes the review of research literature.

#### **Conceptual Framework**

The combination of the works of James House (1981) and Lazarus and Folkman (1984) form a framework that provided the theoretical underpinning for examining satisfaction with social support, perceived stress, coping, QOL, and survival of patients with heart transplantation. The two frameworks provided the conceptualization of social support, and the stress and coping process which guided the development of important questions related to the context of the lives of individuals living with heart transplantation.

James House (1981) provides the framework for social support. House (1981) defines social support as an interpersonal transaction involving one or more of the following four functions: emotional concern (like, love, or empathy), tangible aid (goods and services), information (environment), or appraisal (information relevant to self-

evaluation). He proposes that social support is best approached by asking the question, who gives what, to whom, regarding what problem (House, 1981). In other words, House (1981) defines social support in terms of three major dimensions: the quantity of social relationships, the structure of social relationships, and the function of social relationships. Specifically, the quantity or number of relationships, such as marriage, friendships, or membership is referred to as social integration. The structure of a person's social relationships is defined as their social network. Lastly, the functional content of the relationships which involves the linkages of emotional concern, tangible aid, information, and appraisal is defined as social support (House & Kahn, 1985). House (1981) also purports that quality of social support, or in this case, satisfaction with social support, is important, but should not be confused with the availability of social support.

Lazarus and Folkman's (1984) well known theory of stress and coping is transactional and emphasizes an individual's appraisal and reappraisal of events. The major concepts in this theory are stress, coping, and appraisal. They define stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p.19). Perceived stress in this study will include physical, psychological, and sociodemographic variables that have an impact on QOL and survival outcomes. Coping is the process by which the "individual manages the demands of the person-environmental relationship that are appraised as stressful and the emotions they generate" (Lazarus & Folkman, 1984, p. 19). Cognitive appraisal is an "evaluative process that determines why and to what extent a particular transaction or series of

transactions between the person and environment is stressful” (Lazarus & Folkman, 1984, p. 19).

The major assumption of Lazarus and Folkman’s theory is that individuals along the course of life will experience stress, coping, and adaptation. Stress, coping, and adaptation are concepts that affect human beings in society. Appraisal is a process in which a person interprets their own situation. When encountering an event, an individual’s primary appraisal determines whether the event is benign or stressful. Benign events can lead to positive well-being, while stressful events can lead to harm or loss. Each appraisal is characterized by generating an emotional response. For example, harm or loss can be characterized by grief or sadness. Secondary appraisal is an individual’s evaluation of the resources available to deal with the grief or sadness.

The works of James House (1981) and Lazarus and Folkman's (1984) stress, appraisal, and coping framework undergirded this study of long-term heart transplant survivors. Lazarus and Folkman’s framework includes the personal and environmental variables as antecedent variables. In this study, personal variables include age, gender, race, and marital status. In addition, perceived stress reflects the situational stressors as perceived by the individual and may act as the antecedent variable. The heart transplant patient will cognitively appraise the situation. This appraisal of the situation may be perceived as benign or stressful. Satisfaction with overall, emotional, and tangible social support and coping are important variables that may mediate the relationship between perceived stress and QOL. Both satisfaction with social support and coping have been viewed in the literature as having either mediating effects (Cohen & Syme, 1985; Ellerton et al., 1997; House, 1981; Lazarus & Folkman, 1984; Lin, Dean, & Ensel, 1986;



Rockwell & Riegel, 2001; Stewart et al., 1997) or moderating effects on health outcomes (Cobb, 1976; Ellerton et al., 1997; Stewart et al., 1997).

Several studies have shown that perceived satisfaction with social support either has a direct or indirect effect on physical and mental health, thereby influencing coping and stress in chronic illness situations (Dew & Dimartini, 2005; Friedman & King, 1994; Paris & White-Williams, 2005). Although several studies (Ellerton et al., 1996; Friedman & King, 1994; Moneyham et al., 2005) have examined perceived satisfaction with social support, coping, and perceived stress in other chronic illness populations, there are no reported studies that have examined these relationships exclusively in the heart transplant population.

Figure 1 depicts how the works of James House and Lazarus and Folkman's stress and coping theory guided this study. For example, the long-term heart transplant survivor will appraise the situation. Perceived stress and sociodemographic variables were viewed as antecedent variables. Satisfaction with social support and coping were viewed as mediators which have a stress buffering effect on the outcome variables, QOL, and survival.

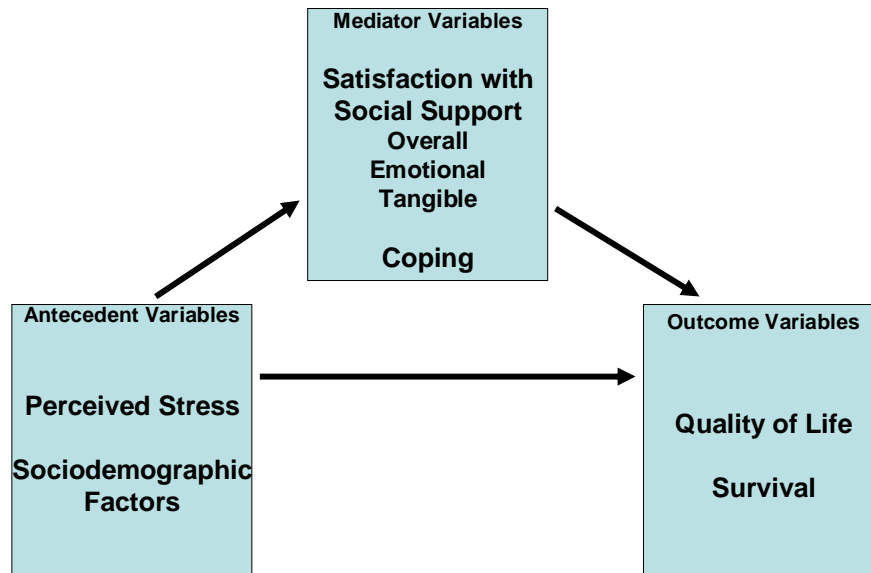


Figure 1: Conceptual Framework

In summary, the blending of the works of James House (1981) and Lazarus and Folkman (1984) formed the conceptual framework that provided the theoretical underpinning for examining satisfaction with social support, perceived stress, coping, QOL, and survival of patients with heart transplantation. The two frameworks provided the conceptualization of the process that each individual encounters as he or she appraises a life situation, which ultimately impacts QOL and survival.

### **Social Support**

Social support is a complex construct with broadly diverse definitions reported in the literature. Table 2 illustrates several of the definitions.

Table 2: Definitions of Social Support

Author	Definition
Cohen & Syme, 1985, p. 4	“the resources provided by other persons”
Shumaker & Brownell, 1984 p.13	“...an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient”
Berkman, 1984, p. 413	“the emotional, instrumental, and financial aid that is obtained from one’s social network”
Procidano & Heller, 1983	“the extent to which an individual believes that his/her needs for support, information, and feedback are fulfilled.”

Despite the variation of the definition of social support noted among researchers, researchers tend to agree that social support is a multidimensional concept that comprises common characteristics resulting in distinct types of social support. Social support involves the social network or sources who provide the support, the types of support provided such as emotional, tangible, informational, and one’s satisfaction with the support available and received (House, 1981; Thoits, 1982).

For this study, social support is defined as the degree of perceived satisfaction with social support which is provided by others (Bennett et al., 2001; House, 1981; Cohen & Syme, 1985). In other words, satisfaction with social support involves the appraisal in which an individual perceives his or her care as satisfactory, and that someone is available in times of need. Moreover, for this study, two types of social support, emotional and tangible, were examined. Tangible support involves the provision of material support such as financial assistance (Cohen et al., 1985; House, 1981).

Emotional support involves the provision of closeness, intimacy, and the ability to confide feelings to someone (Cohen et al., 1985; Cohen & Syme, 1985, House, 1981).

Several investigators found that prior to transplantation, it is important for the heart transplant candidate to identify the social support that will be available to the candidate before, during, and after surgery. They believe that the stressfulness and complexities of the medical regimen post transplantation demand some form of social support (Mehra et al., 2006; Rudis et al., 2000). It is posited that types of social support may play a role in health outcomes. Yet, conflicting results exist regarding which types of social support are important to health outcomes and QOL. Emotional social support has been found to be associated with better QOL outcomes while the importance of tangible support is less clear (Freidman & King, 1994; King et al., 1993). Our best evidence indicates that more important than the number of support persons available is the individual's satisfaction with the support that is available; however, support for this premise has not been reported in heart transplant patients. Researchers found that those patients with access to resources such as social support may be able to handle stressful situations and cope more effectively (House, 1980; Lazarus & Folkman, 1980; Thoits, 1982).

In the case of the heart transplant recipient, both emotional and tangible social support would appear to be important to QOL and survival; however, this has not been reported in the literature. Also not reported in the heart transplant literature is whether there is a relationship between sociodemographic variables and social support. Several studies reported contradictory findings regarding the relationships among age, gender, race, and marital status and outcomes in patients with chronic illness (Artinian et al.,

1995; Bennett et al., 2001; Brummet et al., 2001; Davidson et al., 1997; Emery et al., 2004).

Only three studies (Bohachick et al., 2002; Grady et al., 2007; Wang et al., 2006) were found to examine social support and heart transplantation. However, there are a plethora of studies examining social support in patients with other chronic illnesses in the literature. Studies on social support have examined patients with cancer (Coker et al., 2006; Melton, Northouse, & Weiss, 2006), arthritis (Blixen & Kippes, 1999), depression (Arthur, 2006; Krishana et al., 1998), psychiatric illness (Furukawa, Harai, Harai, Kitamura, & Takahashi, 1999), and human immunodeficiency virus (Gray, 1997; Moneyham, 2005; Sun, Zhang & Fu, 2007; Vyavaharkar et al., 2007), and patients with cardiovascular disease (Bennett et al., 2001; Case, Moss, Case, McDermott, & Eberly, 1992; Eaker, Pinsky, & Castelli, 1992; Frasure-Smith, et al., 2000; Friedman, 1997; Friedman & King, 1994; Hategan et al., 2008; Kaplan et al., 1988; Kristofferzon, Lofmark, & Carlsson, 2005; Luttik, Jaarsma, Veefer & Veldhuisen, 2006; O'Reilley & Thomas, 1989; Yates, 1995). Social support has also been described in the elderly, adolescent, and pediatric populations (Blazer, 1982; Ellerton, Stewart, Ritchie & Hirth, 1996; McReynolds & Rossen, 2004; Pakenham & Bursnall, 2006; Tak & McCubbin, 2002).

Since there were no studies examining the relationships among social support, perceived stress, and coping reported in the heart transplant literature, this review of literature examined the relationships among satisfaction with social support, perceived stress, coping, survival, and QOL in patients with chronic illnesses, concentrating on cardiovascular disease, heart failure, and patients with renal or other solid organ

transplantation. Specifically, this review examined the following: 1) social support, 2) emotional and tangible social support, and 3) changes in social support over time; 4) perceived stress; 5) coping; 6) sociodemographic variables such as age, gender, race, and marital status; 7) QOL; and 8) survival.

### ***Social Support in Heart Transplantation***

There are three studies in heart transplantation which have included social support as a measurement variable. Grady and colleagues (2007) found that satisfaction with emotional social support was a predictor of QOL in heart transplant patients who were 5 to 10 years post surgery.

In another study of heart transplant patients, Bohachick and colleagues (2002) studied heart transplant patients at discharge and six months after transplant. Using the Coping with Serious Illness Battery, they measured social support network, attachment/expressive support, understanding, advice and information seeking, and sense of control. The researchers found that satisfaction with life and sense of well-being improved significantly from discharge to six months post transplant (Bohachick et al., 2002). Patients who perceived better social support network helpfulness over time had better functioning and sense of well-being. Those who had stronger attachment/expressive support had less depression and anger and higher levels of optimism, well-being, satisfaction with life and personal functioning (2002).

Wang and colleagues (2006) examined self-care, hope, and social support in Taiwanese heart transplant candidates. Using the Self-Care Behavior Scale, Health Hope Index, and the Social Support Inventory, the authors found that social support was predictive of self-care behaviors and hope. Limitations of this study included lack of

randomization, small sample size, and purposive sampling. To date, there are no other studies reported in the literature specifically examining social support in long-term heart transplant patients.

### ***Emotional and Tangible Social Support***

According to House (1981), social support involves one or more of the following four functions: emotional support, tangible aid, information, or appraisal support. A few investigators established that emotional and tangible social support are the most important types of support for transplant life (Bohachick et al., 2002; Wang et al., 2006). Emotional social support is defined as love, care, and concern support given by a caregiver, family, friends, or other individuals (House, 1981). Tangible social support includes material assets such as financial resources, telephone calls, and transportation (House, 1981). It has been posited that satisfaction with tangible or emotional social support can positively or negatively influence health domains such as physical functioning, psychological functioning, and overall quality of life (Bennett et al., 2001; Cohen & Syme, 1985).

Numerous investigators have demonstrated that emotional social support has an impact on patient outcomes such as QOL (Bennett et al., 2001; Freidman & King, 1994; King et al., 1993). Fewer studies have examined the effects of tangible social support, and the results are more ambiguous than for emotional social support (Freidman & King, 1994; King et al., 1993). Emotional support appears to be more important than tangible support or size of social network; however, more research is needed to confirm this inference (Greenwood et al., 1996).

Two studies were found that compare types of social support in heart failure patients (Bennett et al., 2001; Friedman & King, 1994). Bennett and colleagues (2001) found men under 65 reported significantly lower emotional/informational support than men over 65 years of age. There were no differences in social support in between women and men in any age group.

Friedman and King (1994) examined the relationship between social support, symptom severity, and psychological well-being in 80 older women (age range 55 to 92 years, M=76) with heart failure who had a hospital admission within the last year. Using standard instruments to measure social support, symptomatology, and well-being, the descriptive examination of tangible, emotional, and informational support was assessed. Also assessed was the relationship between emotional and tangible support as a direct effect or mediating effect on psychological well-being. The authors found that subjects received tangible and emotional social support on a weekly basis, but few subjects received informational support. Emotional support was directly related to greater satisfaction with life and more positive affect, but tangible support was not significantly related to positive affect or life satisfaction.

In an examination of the relationships between social support and short and long term recovery in men with coronary artery disease, Yates (1995) adapted the Perceived Support Network Inventory instrument to study 73 men [age range 30-80 years, white (94%), married (88%)] one year after a cardiovascular event. The author found spouses provided more emotional support than health care providers; however, both spouses and health care providers provided informational support (Yates, 1995). Better health care provider support was found to be correlated with better recovery at one year. More



emotional and tangible support was associated with less depressive symptoms at one year after the cardiovascular event (Yates, 1995).

In a study investigating whether social support may play a protective role in reducing cardiovascular risk, Aggarwal and colleagues (2008) examined 501 patients enrolled in the National Heart, Lung, and Blood Institute Family Intervention Trial for Heart Health. Higher instrumental social support was positively associated with higher number of minutes of physical activity while higher emotional support was positively associated with number of days of physical activity, number of wine servings, and increased high-density lipoprotein cholesterol. Thus, the authors concluded social support may have a protective mechanism in reducing cardiovascular risk.

### ***Social Support Over Time***

Little is known about how social support changes over time, particularly within the context of chronic illness. While some studies reported a decline in social support over time (Friedman, 1997; Kristofferzon et al., 2003; Rankin, 2002), others have documented improvement (Burg et al., 2005). Bennett and colleagues (2001) found that some heart failure patients reported high social support at study onset with large decreases by 12 months, and others who reported low support at study onset experienced large increases in social support by 12 months. In her study of older women with heart failure, Friedman (1997) demonstrated continuity of emotional and tangible social support over time. In Burg and colleagues' (2005) study on perceived social support in myocardial infarction patients, all patients regardless of social support score or partner status had some improvement from baseline to 12 month follow-up.

## Perceived Stress

Perceived stress is defined as the degree to which situations in one's life are viewed as stressful. Many researchers have investigated the affect of psychological stress and its association with health and disease (Greenwood, Muir, Packham, & Madeley, 1996; Iso, Date, & Yamamoto, 2002). Researchers have shown psychological stress among heart transplant patients is not only determined by clinical health status, but it also could be influenced by personal and environment variables, self care behaviors, symptoms, and social support. Most reported studies examining stress have focused on symptom distress, stress related to medical regimen, depression, and anxiety (Dew et al., 1997; De Geest et al., 2001; Dobbels et al, 2000; Grady et al., 1998). For instance, several researchers revealed a link between social support, medication adherence, and health (DiMatteo et al., 2002; Dunbar-Jacob, 2001; Vyavaharkar et al., 2007). Vyavaharkar and colleagues (2007) studied relationships of social support, coping, and medication adherence in HIV-positive women with depression. The authors found that satisfaction with social support and coping focused on disease management were predictors of better patient outcomes, such as medication adherence. Sayers and colleagues (2008) examined the role of social support and self-care in 74 heart failure patients. Perceived social support was associated with better medication adherence and other self-care activities. The authors believed that emotional support may alleviate stress thereby having beneficial effects in chronic situations; however, longitudinal studies examining the role of social support, stress, and self-care are warranted.

In a study by Yu, Lee, Woo, and Thompson (2004) of heart failure patients, the authors found that high levels of psychological distress among the patients was associated

with poor emotional-informational support, poorer health perception, greater fatigue, and not living with family. Rosengren and colleagues (1991) found that emotional support provided protection to perceived stressful life events in middle-aged men. Men with more perceived stress had a higher death rate from cardiovascular disease. Lastly, Lache and colleagues (2007) studied social support and stress in 55 patients with an implanted cardioverter defibrillator. The authors concluded that patients with better perceived social support recovered more promptly from psychological stress.

### **Coping**

Coping is defined as the individual's behaviors, both cognitive and behavioral, to manage stressful life events (Jalowiec, 2003; Lazarus & Folkman, 1984). According to Lazarus & Folkman (1984), the two major functions of coping include management of emotional distress (emotion-focused coping) and management of problems causing the distress (problem-solving coping). The effectiveness of any coping strategy is determined by the match between the strategy and the situational need (Lazarus & Folkman, 1984). In addition, in her work, Jalowiec classifies coping strategies into types such as negative or positive. Specific types of coping responses can include confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant (Jalowiec, 2003).

Several researchers found that coping characteristics and social support can impact stressful life events (Cohen & Syme, 1985; Holohan et al., 1995; House, 1984; Taylor et al., 2007). Some studies found gender differences in coping styles (Holohan et al., 1995; Kristofferzon et al., 2005) while other studies focus on the conflicting results regarding whether coping modulates or mediates stress (Coker et al., 2006; Tak et al.,

2002). Few studies actually address the relationship between coping and social support, exclusively. Most often, studies examined relationships of several concepts. For instance, coping has been shown to predict early post-transplant QOL (Grady, Jalowiec & White-Williams, 1999), survival (Grady et al, 1999; Molassiotis et al., 1997), compliance (Harper et al., 1998), and disability (Myaskovsky et al, 2003).

Using the Jalowiec Coping Scale, SF-36 Health Survey, Social Support Questionnaire, and the Quality of Life Index, Kristofferzon and colleagues (2005) studied coping, social support, and QOL over one year in 74 women and 97 men who had experienced a myocardial infarction. Women and men differed in coping strategies with women using more evasive and supportive coping than men. Both men and women frequently used optimistic coping behaviors. No statistically significant differences were seen in social networks or support scales between men and women. Men reported lower emotional support than women did. The most supportive resources rated by both men and women were children, partners, and friends (Kristofferzon et al., 2005). Due to the relatively small sample size and the Cronbach alpha value of 0.67 for the Social Support Questionnaire, results of this study should be interpreted with caution.

In a population-based case-control study, Coker and colleagues (2006) studied stress, coping, and social support in 400 men with prostate cancer. Using the Global Perceived Stress Scale, the John Henryism Scale to measure high effort coping, and three items from Sarason's Social Support Instrument, the authors found that higher coping effort may be associated with prostate cancer risk. However, higher perceived stress or poorer social support was not associated with increased cancer risk.

Tung and Wei (2008) examined coping, anxiety, and QOL in 100 patients within 5 years of coronary bypass surgery (CABG). Using the Revised Ways of Coping Checklist, Short-form 36, State-Trait Anxiety Inventory and a demographic questionnaire, the authors found that better QOL was associated with less anxiety, more use of problem-oriented coping methods, and more role function responsibilities.

Lindqvist, Carlsson, & Sjoden (2004) examined coping strategies in patients with kidney transplantation with an age, gender, and civil-status matched general population. Using the JCS and a self-rated efficiency visual analog scale, 30 consecutive kidney transplant recipients and 30 matched general population participants completed the questionnaires and participated in an interview by the primary investigator. Kidney transplant patients used significantly more optimistic, self-reliant, supportive, and emotive coping behaviors than the general population. Study limitations include a non-random and small sample which could affect external validity of this study.

In a more recent study, perceived coping effectiveness was examined by Jalowiec, Grady, & White-Williams (2007) in 535 heart transplant candidates who were awaiting transplantation. The documented alpha reliability for the total effectiveness score was 0.92 and for each subscale ranged from 0.40 to 0.81. The authors found that perceived effectiveness of coping strategies in rank order were optimistic, confrontive, supportant, self-reliant, evasive, palliative, fatalistic, and emotive. Significant predictors of greater coping effectiveness were less use of emotive, evasive, and fatalistic coping behaviors; more perceived helpfulness of heart transplant team interventions; longer wait for transplant surgery; more use of optimistic coping; urgent transplant listing status, and

greater satisfaction with social support. A study limitation includes only examining one point in time during the waiting process.

Using a secondary data analysis, Taylor and colleagues (2007) studied social support, personal control, and psychological functioning in 242 heart failure patients. Social support was hypothesized to have a direct effect on depressive symptoms and anxiety and an indirect effect mediated by personal control. Social support reduced psychological distress through the patient's perceived control indicating an indirect effect. The authors reported that social support and personal control have important roles in psychological functioning of patients who are chronically ill. In addition, interventions designed to improve social support may reduce depressive symptoms and anxiety; thus allowing the heart failure population to cope more effectively with their chronic illness.

The roles of social support, coping, and depressive symptoms were examined by Holahan and colleagues (1995) in 325 patients with chronic cardiac illness, 71 patients with acute cardiac illness, and 219 healthy controls. Patients with chronic and acute cardiac illness reported more depressive symptoms. Women experienced more depressive symptoms than men. Men used more positive coping strategies than women while women had greater social networks than men. Moreover, the authors found that better social support and positive approach oriented coping strategies, such as directly dealing with the problem, predicted fewer symptoms of depression.

Lastly, in a study by Tak and McCubbin (2002), stress, perceived social support, and coping were explored in families who have a child with congenital heart disease. Although perceived social support was found to be a predictor of stress and coping, social support did not have a moderating or mediating effect on either stress or coping. Similar

contradicting reports have been found in studies examining social support and cardiovascular disease; however, no studies have examined the specific relationship of coping and social support in heart transplant patients.

### **Quality of Life**

Quality of life is recognized as a salient patient outcome. In 1948, the World Health Organization (WHO) defined health as not only the absence of disease and infirmity but also the presence of physical, mental, and social well-being [Constitution of the World Health Organization (WHO), 1952]. Over the next 25 years, little attention was focused on the patient's well-being or QOL as health care providers attempted to understand an illness's impact on a patient's life from the perspective of the patient. Then, in 1993, the WHO defined QOL as "the individual's perspective of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1997, pg. 1).

There are many definitions of QOL in the literature. Most definitions include statements referring to contentment, sense of well-being, health-related QOL, or satisfaction with life, many of which are used interchangeably in the literature. There is a consensus that QOL is a multidimensional concept composed of physical, psychological, social, spiritual, and somatic domains. For this study, QOL is defined as the effect of an illness and its consequent therapy upon a patient, as perceived by the patient's satisfaction with aspects of life important to them (Ferrans & Powers, 1994; Spiker & Revicki, 1996). QOL research has emerged as an increasingly important issue to study in patients after heart transplantation.

Previous research has demonstrated conflicting results regarding the relationship between social support and QOL in patients with cardiovascular disease. Several studies indicate that better social support is associated with better QOL outcomes (Rankin & Fukuoka, 2003; Wingate, 1995), yet other studies did not demonstrate this relationship (Bennett, et al., 2001; Heo, et al., 2007; Westlake et al., 2002).

A few studies examined social support as a predictor of QOL in heart failure patients. Bennett et al. (2001) conducted a longitudinal study examining social support in 227 patients with heart failure at hospitalization and at 12 months after hospitalization. Using the Social Support Survey and the Chronic Heart Failure Questionnaire, the researchers found that most patients perceived their social support as positive. Bennett and colleagues (2001) concluded that changes in social support was a significant predictor of health related QOL in heart failure patients; however, baseline social support was not.

In contrast, a study in 61 patients with mostly Class II and III heart failure recruited from an outpatient clinic by Westlake and colleagues (2002) studied health-related QOL using a six-minute walk test, the Medical Outcomes Study, and a chart review. Social support was a secondary outcome. The authors found patients reported a moderately high level of social support. Interestingly, there was no relationship between social support and health-related QOL (Westlake et al., 2002).

In a study comparing health related QOL between 90 older adults with heart failure and 116 healthy older adults, Heo and colleagues (2007) examined social support with the following criteria: marital status, having a confidante or not, living alone or not, and having a person who provides emotional support. In healthy older adults, social



support was associated with better health related QOL; however, in older adults with heart failure, better social support was associated with poorer health-related QOL.

Little is known regarding how social support impacts QOL in patients who have survived long-term after heart transplantation. However, QOL is an important outcome to study in patients with heart transplantation. Barr and colleagues (2003) examined 569 self-referred patients who were greater than five years post heart transplant that participated in the Transplant Learning Center program, and were on Cyclosporine-based immunosuppression. The authors found that being in a marital relationship was associated with increases in QOL over time.

One study by Grady and colleagues (2007) examined QOL in 555 patients longitudinally from 5 to 10 years after heart transplantation. They found that patients at 5 to 10 years reported high levels of satisfaction with life which remained stable over time. Predictors of better QOL at 5 to 10 years included: less depression, fewer negative emotions, more positive emotions, having less uncertainty, less fatigue, more satisfaction with emotional support, less family-related stress, being married, having less sleep problems, not working, more social interaction, using more positive coping mechanisms, more helpfulness in self-care interventions, not having an HMO insurance plan, and having less complications and dermatologic symptom distress, accounting for 71% of the variance (Grady et al., 2007).

### **Sociodemographic Factors: Age, Gender, Race, and Marital Status**

Several studies addressed gender, age, and racial differences in social support, and the impact of living arrangements (i.e., married, living with a companion, or living alone) on health outcomes and QOL.

#### ***Gender***

Gender-related studies revealed that women reported less perceived social support than men (Davidson et al., 1997; Emery et al., 2004; Gallicchio et al., 2007), significantly worse QOL (Bosworth et al., 2000; Emery et al., 2004; Gallicchio et al., 2007; Johnso et al., 1998), and poorer health outcomes (Artinian et al., 1995; Berkman & Syme, 1979). Contradictory findings were found in a few studies where there were no differences in perceived social support (Artinian et al., 1995; Bennett et al., 2001; Brummet et al., 2001), or QOL (Grady et al., 2007) between men and women. Also, men and women were found to cope differently (Kristofferson et al., 2005) with women using more optimistic coping strategies than men. Bosworth and colleagues (2000) found that women with coronary artery disease reported poorer health related QOL than men. While the authors did not report gender differences in social support, they did report that lack of social support was associated with significantly lower health-related QOL. Similarly, in their study on QOL in 410 cardiac patients, Emery and colleagues (2004) examined the relationships among QOL and appraisal, tangible, belonging, and esteem social support using the Short Form-36 and the Interpersonal Support Evaluation List—Short Form. There was a significant interaction of gender by belonging social support ( $p=0.009$ ), but not the other types of social support. On the other hand, neither Artinian and colleagues (1995) nor Bennett and colleagues (2001) found gender differences in social support.

### *Age*

Existing research examining age differences in social support is limited. Bennett and colleagues (2001) examined the interactions of gender by age in chronic heart failure patients. The authors found that men under the age of 65 perceived less social support as compared to men older than 65 years of age and women in either age group. These findings were found in the areas of total social support ( $F=5.04$ ,  $p=0.04$ ), emotional/informational support ( $F= 4.87$ ,  $p= 0.03$ ), and positive social interactions ( $F=4.43$ ,  $p= 0.04$ ).

In their study of healthy older adults and older adults with heart failure, Heo and colleagues (2007) found better social support was associated with poorer QOL in the healthy adults. This association was not seen in the heart failure patients. The authors found that age alone was not responsible for poorer QOL in either group.

### *Race*

Two studies compared racial differences in social support. Rankin (2002) examined social support in 76 women recovering from acute myocardial infarction, and found that social support did not differ between African American and Caucasian women. However, the types of support differed between the groups. African American women received more instrumental social support, while Caucasian women received more emotional social support. Bosworth and colleagues (2000) found that minority patients with poor social support had poorer general health, social functioning, and mental health.

### ***Marital Status***

Previous research on the association of living arrangements (married, living with a companion, living alone) as a measure of social support on outcomes in patients with cardiovascular disease have differing results. Several studies have shown strong relationships among being married or living with a partner and mortality and QOL (Barr et al., 2003; Bosworth et al., 2000; Case et al., 1992; Coyne et al., 2001; Grady et al., 2007) while others did not find this relationship (Luttik et al., 2006; O'Shea et al., 2002). Case and colleagues (1992) examined marital status in 1234 post myocardial infarction patients for 1 to 4 years. Living alone was an independent risk factor for mortality. Those living with more than two persons had better survival than those living with one person or alone. Bosworth and colleagues (2000) found that individuals living alone or not living with a companion had lower social functioning than those who were married. Conversely, Luttik and colleagues (2006) found that there was no difference in mortality between heart failure patients living alone or with a partner. Also, the authors found that univariately there was a difference in QOL between patients living alone or with a partner; however, multivariate analysis revealed that QOL was related to other factors such as age and gender. Two investigators found being married was associated with better QOL (Barr et al., 2003; Grady et al., 2007).

### **Survival**

Numerous studies have found the importance of social support as an independent risk factor of morbidity and mortality in cardiovascular disease (Case et al., 1992; Ikeda et al., 2008; Ruberman, Weinblatt, Goldberg & Chaudhary, 1994;

Williams et al., 1992) while other studies have shown social support to have no relationship with morbidity or survival (Frasure-Smith et al., 2000; Lett et al., 2007; O'Shea et al., 2002). It is postulated that the inconsistent findings may be related to the variations in definition and measurement of social support. Some studies use a social support measurement instrument (Bennett et al, 2001; Burg et al, 2005; Frasure-Smith et al., 2000), and others use a single measure such as marital status, having a significant other, or living alone, or not living alone (Coyne et al., 2001; Heo et al., 2007; O'Shea et al., 2002; Rohrbaugh, Shoham & Coyne, 2006). The definition and measurement of survival may also vary among studies, with most studies examining one-year mortality using Cox Proportional statistics (Mookadam et al., 2004).

Using partner status on the Enhancing Recovery in Coronary Heart Disease (ENRICHD) Social Support Instrument, and post-hoc analysis, Burg and colleagues (2005) investigated if low perceived social support in post myocardial infarction patients was associated with survival. Having a partner was an important factor in social support; however, change or improvement in social support was not associated with increased mortality.

Frasure-Smith and colleagues (2000) examined the role of social support, depression, and mortality in 877 patients within one year of myocardial infarction. Using the Beck Depression Inventory and the Perceived Social Support Scale, the authors found depression was a predictor of 1-year mortality, but social support was not. However, the authors also found that better perceived social support was related to improvement of depression symptoms. Moderate to high perceived social support was related to less depression-related cardiac mortality.

In contrast, several researchers have examined the relationship of social support and psychosocial stress on coronary heart disease. Researchers have found that lack of social support is a strong predictor in mortality (Berkman & Syme, 1979; House et al., 1988; Kaplan et al., 1988). Berkman and Syme (1979) examined 692 adults in the Amameda County Study. Four sources of social support were collected: marriage, friends and family, church membership, and group participation. Individuals with less social support and contacts had higher mortality with a relative risk of 2.3 for men and 2.8 for women. Case and colleagues (1992) found that living alone was an independent risk factor for predicting mortality. However, they also found that disrupted marriage was not a risk factor as long as cohabitation continued among the individuals.

Ikeda and colleagues (2008) examined the association between social support and risk of coronary heart disease and stroke. In this prospective study with 44,152 Japanese men and women aged 40 to 69 years, the authors found that low social support was associated with higher stroke mortality in men, but not in women. Men with lower social support were younger, non-smokers, and had a sedentary lifestyle, higher perceived stress, lower body mass index (BMI), and higher unemployment rate. Women with lower social support were younger, and had a more sedentary lifestyle, higher BMI, higher perceived stress, higher unemployment rate, and a higher ethanol intake. Social support was not associated with stroke incidence or coronary heart disease incidence or mortality.

### **Summary of the Review of Literature**

Only three studies examining social support were found in the heart transplant literature (Bohachick et al., 2002; Grady et al., 2007; Wang et al., 2006). The studies differed in sample, measurements used, and time frames studied. All of the studies examined social support in combination with other concepts. There were no studies found in the literature examining satisfaction with social support in long-term heart transplant survivors.

#### ***Social Support***

While some studies reported social support as the primary outcome (King et al., 1993; Yates, 1995), most studies discussed social support as a secondary finding or in combination with other findings in larger outcome studies such as QOL, spirituality, coping, self-care, medication adherence, or depression (Arthur, 2006; Bennett et al., 2001; Holahan et al., 1995; Kristofferzon et al., 2005; Vyavaharkar et al., 2007). Social support was examined in many ways including types of social support, perceived social support, or combined with another concept such as self-care. Social support was negatively correlated with self-care behaviors (Connelly, 1993) in one study, but positively correlated in another (Sayers et al., 2008). In addition, social support research was often pooled with related concepts such as caregiving, caregiver burden, social interaction or social networking (Dew et al., 1998; Hunt, 2003; Vrabec, 1997). Instruments used to measure social support varied from study to study with the most common instrument being the Social Support Survey which measured emotional, tangible, affectionate support, and social interaction (Sherbourne & Stewart, 1991). Some

studies used a single question such as living arrangements to measure social support (Heo et al, 2007; Luttik et al., 2006).

### ***Emotional and Tangible Social Support***

Emotional social support was found to positively impact health-related QOL (Bennett et al., 2001; Freidman & King, 1994), yet have a negative impact in others (Heo et al., 2007). In addition, emotional support was found to directly effect life satisfaction (King et al., 1993) while tangible social support was not associated with satisfaction in one's life. Little information was found regarding sociodemographic differences between emotional and tangible social support. One study found older men reported using more emotional support than younger men; however, there were no gender differences in either emotional or tangible support use (Bennett et al., 2001).

### ***Social Support Over Time***

Disparate findings were reported regarding changes in social support over time. Several researchers found improvement in social support over time (Bennett et al., 2001; Burg et al, 2005), and others have found a decline over time (Bennett et al., 2001; Friedman, 1997; Kristofferzon et al., 2003; Rankin, 2002). There were no studies found examining social support over time in heart transplant patients.

### ***Perceived Stress***

Most studies examined perceived stress along with another concept such as symptom distress, stress related to medical regimen, depression, or anxiety (Dew et al., 1997, De Geest et al., 2001, Dobbels et al., 2000, Grady et al., 1998). Researchers have found that patients with better perceived social support have less perceived stress (Lache et al., 2007; Rosengren et al., 1991; Sayers et al., 2008; Yu et al., 2007). There were no



studies found examining the relationship among perceived stress and social support in heart transplant patients.

### ***Coping***

Little information was found on the relationship between coping and social support. Researchers found that coping impacts stressful life events (Cohen & Syme, 1985; Holohan et al., 1995; House, 1984; Taylor et al., 2007). Some studies found gender differences in coping styles (Holohan et al., 1995; Kristofferzon et al., 2005) while other studies focused on the conflicting results of whether coping modulates or mediates stress (Coker et al., 2006; Tak et al., 2002). For instance, coping has been shown to predict early post-transplant QOL (Grady, Jalowiec, & White-Williams, 1999) and survival (Grady et al., 1999; Molassiotis et al., 1997). There were no studies reported in the literature examining the mediating effect of coping in long-term heart transplant patients.

### ***Quality of Life***

Conflicting results regarding the relationship between social support and QOL were reported in patients with cardiovascular disease. Several studies indicated that better social support was associated with better QOL outcomes (Rankin & Fukuoka, 2003; Grady et al., 2007; Wingate, 1995), yet other studies did not demonstrate this relationship (Bennett, et al., 2001; Heo, et al., 2007; Westlake et al., 2002). There were very few studies that examined QOL in long-term heart transplant survivors.

### ***Sociodemographic Factors***

Studies that addressed gender, age, racial, and marital status differences had varied findings. Women reported less perceived social support than men (Davidson et al., 1997; Emery et al., 2004; Gallicchio et al., 2007), significantly worse QOL (Bosworth et

al., 2000; Emery et al., 2004; Gallicchio et al., 2007), and poorer health outcomes (Artinian et al., 1995; Berkman & Syme, 1979). Contradictory findings were found in a few studies where there were no differences in perceived social support (Artinian et al., 1995; Bennett et al., 2001; Brummet et al., 2001), or QOL (Grady et al., 2007) between men and women. Men and women coped differently (Kristofferson et al., 2005) with women using more optimistic coping strategies than men. Three studies were found that addressed age and race differences. Younger men reported less perceived social support than older men and women (Bennett et al., 2001). Better social support was associated with poorer QOL in healthy older adults, but not in older adults with heart failure. No differences in social support were found between African American and Caucasian women (Rankin, 2002). No studies were found reporting age, gender, or race differences in social support in long-term heart transplant recipients. Some studies have found relationships among being married or living with a partner and mortality and QOL (Barr et al., 2003; Bosworth et al., 2000; Case et al., 1992; Coyne et al., 2001; Grady et al., 2007) while others did not find this relationship (Luttik et al., 2006; O'Shea et al., 2002). To date, there are no studies examining social support or living arrangement differences and the relationship to mortality or QOL in long-term heart transplant recipients.

### ***Survival***

There are contradictory findings regarding the role of social support and survival in chronic illness. Social support was found to be an independent risk factor of morbidity and mortality in cardiovascular disease (Case et al., 1992; Ikeda et al., 2008; Ruberman, Weinblatt, Goldberg & Chaudhary, 1994; Williams et al., 1992), while other studies found social support to have no relationship with morbidity or survival (Frasure-Smith et

al., 2000; Lett et al., 2007; O'Shea et al., 2002). To date, there have not been any studies documenting the association of social support and long-term survival of heart transplant patients.

In summary, these studies confirmed the importance of examining social support as a variable in QOL and survival in patients who have undergone heart transplantation. Current gaps in the social support literature included the numerous definitions of social support and the multiple instruments available to measure the different types of social support. Also seen in the literature were the contradictory findings regarding if social support changes over time. There were inconsistent findings regarding the relationships of social support and QOL, and social support and survival. In addition, there were varying reports regarding the importance of different types of social support and the ability to predict QOL and survival. Furthermore, inconsistencies existed among sociodemographic variables and their relationship with social support. Lastly, controversial findings remained regarding whether social support and coping have a mediating effect between perceived stress and QOL.

Therefore, this study examined satisfaction with social support over time from year 5 to year 10 after heart transplantation. Also, this study investigated the relationships among satisfaction of social support, perceived stress, and coping on QOL and survival. In addition, this study investigated which types of social support (emotional and tangible) predicted QOL and survival. Lastly, the relationship between satisfaction with social support, perceived stress, and coping was assessed to examine if satisfaction with social support or coping has a mediating relationship between stress and QOL.

## CHAPTER 3

### METHODOLOGY

This chapter describes the methodology of this study and includes the research design, protection of human subjects, data collection, instruments, data analysis, and study limitations. Appendix A illustrates important aspects from the parent study such as how the original sample was obtained, a description of the setting, and data management.

#### **Research Design**

This study was a retrospective outcome analysis of an original research question using data from two existing data sets. Data were collected as part of a larger parent study, the Heart Transplant QOL Outcomes Study (Grady et al., 2007; Grady et al., 2006; Rybarczyk et al., 2007; White-Williams et al., 2008). This study took place from July 1, 1999 to June 30, 2004 and used a longitudinal design to examine QOL outcomes in patients 5 to 10 years after heart transplantation. The second data set included data compiled from the Cardiac Transplant Research Database (CTRD) which is an event-driven database which collects information on transplant recipients such as donor data, immunosuppression, rejection episodes, infection, evidence of coronary vasculopathy or malignancy, and death (Crespo-Leiro et al., 2008; Kirklin et al., 2006; Luckraz et al., 2003; Stork et al., 2006). Study subjects were part of both databases. Each data set is housed in the Cardiovascular Transplant Research Department at the University of Alabama at Birmingham.

### ***Sample and Setting***

The sample consisted of data from 555 patients that underwent heart transplantation between July 1, 1990 and June 30, 1999, who participated in the Heart Transplant QOL Outcomes Study and the CTRD database. The four medical centers that participated in the parent study were: University of Alabama at Birmingham (UAB), Rush University, Cleveland Clinic Foundation, and University of California, Los Angeles (UCLA). The sample demographics have been reported elsewhere and remain the same for this study (Grady et al., 2007). The mean age of the sample was 54 years, 88% were Caucasian, and 78% were male. The mean years of education was 14, and most patients had private health insurance or Medicare.

### ***Protection of Human Subjects***

The Institutional Review Board (IRB) at the University of Alabama at Birmingham approved the analysis reported here on January 31, 2008 as an addendum to the original IRB application (Appendix B). The original expedited review was completed in 1999 and ongoing progress reports are submitted annually (Appendix C).

### **Data Collection**

Complete data from the Heart Transplant QOL Outcomes Study and the Cardiac Transplant Research Database were placed on a CD-rom disk for use by the investigator. The CD-rom disk contained identified data that were cleaned and checked. Data were also examined for outliers prior to the end of the parent study. The disk contained demographic, clinical, and psychosocial information along with the participant responses to 11 instruments at various time periods from 5 to 10 years post heart transplantation. A

protocol amendment granting permission (dated July 27, 2007) for the current investigator to obtain the CD-rom disk is contained in Appendix D.

### **Instruments**

Four instruments were used in this study: Heart Transplant Social Support Index (Grady, Jalowiec, Grusk, White-Williams, & Robinson, 1992), Jalowiec Coping Scale (Jalowiec, 1988), Quality of Life Index (Ferrans & Powers, 1985), and the Heart Transplant Stressor Scale (Grady et al., 1992).

#### ***Heart Transplant Social Support Index***

The Social Support Index (SSI) measures the structural aspects of the social support network, functional types of assistance received (emotional, tangible, and overall), and satisfaction (very satisfied, fairly satisfied, somewhat dissatisfied, very dissatisfied) with the support (Grady & Jalowiec, 1992). The tool has two parts. Part A assesses the number and composition of the interpersonal ties and satisfaction with amount of help the patient receives with each of 15 illness-related tasks such as personal care, taking medications, and travel to the doctor. Part B assesses the patient's perception of the quality of the relationship with spouse, and frequency of attendance at church, support groups, and social activities. Scoring of Part A of this instrument includes summarizing the main providers for each of the 15 tasks and calculating the number of support providers for each task. In addition, satisfaction with the support provided can have a numerical rating and a mean level of satisfaction with support and can be derived for all 15 tasks. Tasks are divided into tangible and emotional support. A lower score means more perceived satisfaction with support. Part B is mainly for descriptive

purposes. The theory undergirding the development of this instrument was Lazarus and Folkman's stress and coping framework. The SSI has psychometric support in the heart transplant literature (Grady et al., 1992; Jalowiec et al., 1997). Internal consistency reliability was supported: Cronbach's alpha for the overall tool was 0.84 and the subscales carried a 0.78 for tangible support and 0.69 for emotional support. Test-retest reliability for this instrument demonstrated significant ( $p < .0001$ ) correlations between study entry and three months after listing (Grady & Jalowiec, 1992). Concurrent validity was found from correlations of the number of supportive individuals and the use of supportant coping strategies ( $r = .33$ ,  $p < .0001$ ). An increased number of support persons was related to more supportant coping.

For this study sample ( $N = 555$ ), homogeneity reliability was assessed with Cronbach's alpha reliabilities. Cronbach's alpha for the overall tool was 0.75 and the subscales figured in at 0.95 for tangible support and 0.93 for emotional support.

### ***Jalowiec Coping Scale***

The Jalowiec Coping Scale (JCS) is a widely used instrument and examines the use and perceived effectiveness of 60 coping strategies. Patients rate the use of coping strategies on a 4-point Likert rating scale (0 = never used, 3 = often used) and the effectiveness of the strategies (0 = not helpful, 3 = very helpful). This instrument has eight subscales: confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant. These subscales are divided into positive and negative coping strategies. Patients are asked to rate their coping based on the stresses they are experiencing at the current time and may add and rate coping strategies not found on the instrument. Both a Use Score and an Effectiveness Score can be derived from the 1987

JCS. These scores can be obtained for each of the eight coping styles. Scores are summed for the individual items for each coping method. Also, scores for each of the eight coping styles can be expressed as either raw scores or individualized adjusted scores.

Individualized adjusted scores are the raw scores for a coping style that is adjusted for the number of coping methods used by each subject within the coping style. The possible range for raw scores for overall use and effectiveness are 0 to 180 and for subscales 0 to 39. The individualized adjusted scores for both use and effectiveness of coping strategies and for each subscale range from 0 to 3. Higher scores mean more use of the coping method and more effectiveness of the coping method.

The theory undergirding the development of the JCS was Lazarus and Folkman's stress and coping framework. The JCS has psychometric support published in the literature (Jalowiec, 2003; Kuo & Ma, 2000; Lindqvist, Carlesson, & Sjoden, 2004). Stability reliability was assessed by Grady, Jalowiec, and White-Williams (1999) by examining correlations between different time periods at retest intervals of 3, 6, 9, and 12 months in preoperative heart transplant candidates and postoperative heart transplant patients. The preoperative and postoperative times periods were analyzed separately because the stressors were different during those times. All coping strategies using subscales showed moderate stability reliability (.61, range = .56 to .69) and all effectiveness subscales showed low to moderate stability reliability (.52, range = .43 to .63). Content validity was supported by the comprehensive literature review, the number of items used, and the inclusion of cognitive and behavioral coping strategies. Construct validity was examined by conducting an empirical study examining the extent to which 25 expert nurse researchers agreed with the classification of the items on the JCS.



Concurrent and predictive validity were documented by Dr. Jalowiec using data from the 1987-1997 heart transplant study. She found that more frequent use of less desirable coping strategies was associated with poorer outcomes. She also found that greater effectiveness of the coping behavior was associated with better outcomes.

For this study sample (N = 555), homogeneity reliability was assessed with Cronbach's alpha reliabilities. Using SAS, the Cronbach's alpha for overall use of positive coping strategies was 0.86, and overall use of negative coping strategies was 0.87. The effectiveness of overall positive and negative coping strategies was 0.86 and 0.87, respectively. See Table 3 for Cronbach's alpha reliabilities for the subscales of the JCS. Table 4 depicts a comparison of Cronbach's alpha reliability scores for three studies.

Table 3

*Cronbach's Alpha Reliabilities of the Jalowiec Coping Scale*

<b>Coping use</b>	<b>5 year</b>	<b>Coping Effectiveness</b>	<b>5 year</b>
Positive use	.82	Positive effectiveness	.83
Negative use	.84	Negative effectiveness	.84
Confrontive use	.83	Confrontive effectiveness	.83
Emotive use	.85	Emotive effectiveness	.85
Evasive use	.84	Evasive effectiveness	.84
Palliative use	.83	Palliative effectiveness	.84
Optimistic use	.83	Optimistic effectiveness	.83
Supportant use	.84	Supportant effectiveness	.84
Fatalistic use	.85	Fatalistic effectiveness	.85
Self-reliant use	.83	Self-reliant effectiveness	.84

Table 4

*Comparison of Cronbach's Alpha Reliabilities Among Three Studies*

<b>Coping Style</b>	<b>Jalowiec Study (2003)</b>	<b>Grady Study (2001)</b>	<b>White-Williams Study (2008)</b>
Overall use	.93	.87	
Positive use			.86
Negative use			.87
Confrontive use	.81	.84	.86
Emotive use	.63	.86	.88
Evasive use	.78	.84	.87
Palliative use	.55	.84	.87
Optimistic use	.78	.86	.86
Supportant use	.63	.86	.87
Fatalistic use	.49	.86	.88
Self-reliant use	.70	.83	.86
Overall effectiveness	.94	.90	
Positive effectiveness			.86
Negative effectiveness			.87
Confrontive effectiveness	.79	.88	.86
Emotive effectiveness	.63	.89	.87
Evasive effectiveness	.82	.89	.87
Palliative effectiveness	.56	.88	.87
Optimistic effectiveness	.71	.89	.86
Supportant effectiveness	.56	.90	.87

***Quality of Life Index***

The Quality of Life Index (QLI), by Ferrans and Powers (1992) has 35 items to measure satisfaction with and importance of different areas of life such as health, health care, usefulness to others, happiness, worry, peace of mind, potential for long life, independence, relationships, appearance, leisure activities, and socio-economic status using a 6-point Likert scale. Part I which measures satisfaction (1 = very dissatisfied to 6 = very satisfied) and Part II which measures importance (1 = very unimportant to 6 = important) can produce a total and subscale scores. There are 4 subscales:

health/functioning, socioeconomic, psychological, and significant others. The theory undergirding this instrument is the Ferrans conceptual model of quality of life. This model was developed utilizing individual ideology which recognizes that QOL depends on the unique experiences of each individual (Ferrans, 1996). The scoring of the QLI is quite involved and a computer program is available for use from the authors. A description of the scoring can be seen in appendix A. Higher scores indicate better satisfaction or importance. This instrument has been widely used in the literature and has reported acceptable reliability and validity in various studies (Ferrans & Powers, 1993; Flemme et al., 2005; Haung, Ku, Liu, Ho, & Wei, 1994; Kristofferzon, Lofmark, & Carlsson, 2005; Nunes, Raymond, Nicholas, & Leuner, 1995). Internal consistency reliability for the total scale was supported with Cronbach alpha's ranging from .73 to .99 in 48 studies. Subscale reliabilities were reported in 24 studies: health functioning subscale (range = .70 to .94), psychological/spiritual subscale (range = .78 to .96), social and economic subscale (range = .71 to .92), and family subscale (range = .63 to .92) (Ferrans & Powers, 1992). Stability reliability was provided by test-retest correlations of .87 at a two-week retest time period and .81 at a one-month time period. Content validity was provided by an extensive literature review and a high content validity index. Construct validity was supported by strong correlations between the overall QLI score and a life satisfaction measure (Ferrans & Powers, 1992).

For this study sample (N = 555), homogeneity reliability was assessed with Cronbach's alpha reliabilities. Please see Table 5 for the Cronbach's alpha reliabilities of the total scale and subscales.

Table 5

*Cronbach's Alpha Reliabilities of the Quality of Life Index*

<b>Quality of Life Index</b>	
Overall QOL Index Satisfaction	.88
Health and Function Satisfaction	.86
Social and Economic Satisfaction	.89
Psychological/Spiritual Satisfaction	.89
Family Satisfaction	.90
Health and Function Importance	.90
Social and Economic Importance	.90
Psychological/Spiritual Importance	.90
Family Satisfaction Importance	.90

***Heart Transplant Stressor Scale***

The Heart Transplant Stressor Scale (HTSS) measures the perceived stressfulness of issues related to the transplant experience (81 questions) using a 4-point Likert scale (0 = not stressful, 3 = very stressful) (Grady & Jalowiec, 1992). Patients check yes or no if they have the stressor. If they check yes, patients rate the stressfulness of the stressor on a scale of 0 to 3 from not stressful to very stressful. The stressors are categorized into six subscales: physical, psychosocial, self-care, family, work/school/financial, and hospital/clinic. Scoring of this instrument involves summing the response ratings for all the items for the entire instrument or within each subscale and then dividing by the total score possible. The total score possible equals the total number of items in the total tool or subscale multiplied by 3. A percentage score can be calculated by multiplying the aforementioned score by 100. Higher total and subscale scores mean more perceived stressfulness. Similar to the JCS and Social Support Index, the theory undergirding the development of the HTSS was Lazarus and Folkman's stress and coping framework.

Cronbach's alpha coefficients for the total scale (0.95) and for the six subscales (0.78 to 0.90) support homogeneity reliability. Test-retest reliability was examined by correlating the stressor scores at the time of study entry and three months later. Stability reliability is supported for the total scale ( $r = .73$ ,  $p = .0001$ ) and each subscale ( $r = .51$  to  $.72$ ).

For this current study ( $N = 555$ ), homogeneity reliability was assessed with Cronbach's alpha reliabilities. Table 6 contains the Cronbach's alpha reliabilities of the total scale and subscales.

Table 6

*Cronbach's Alpha Reliabilities of the Heart Transplant Stressor Scale*

<b>Heart Transplant Stressor Scale</b>	
Overall Stressor	.95
Physical Stressor	.96
Psychological Stressor	.96
Hospital/Clinic	.96
Self Care	.96
Family	.96
Job/School/Financial	.96

***Clinical Data***

Clinical data, including number of co-morbidities, rejection episodes, and death, were accessed from two sources: the Cardiac Transplant Research Database and the chart review form.

### **Data Analysis**

The data for the current study was analyzed using descriptive, correlational, and inferential statistics. The SAS Software Version 13.1 (SAS Institute, Inc., Cary, NC) was used for data analysis. A p-value of less than 0.05 was considered statistically significant.

To address aim 1, to examine the relationships among perceived satisfaction with social support, QOL, and survival over time among survivors 5 to 10 years after heart transplantation, the following analyses were used:

- 1) Descriptive and inferential statistics including means, standard deviations, frequencies, percentages, and repeated measures to describe perceived satisfaction with social support plotted over time,
- 2) T-tests were used to test for differences in perceived satisfaction with social support over time by age, gender, marital status, and race,
- 3) Kaplan-Meier survival actuarials to examine the relationship of perceived satisfaction with social support and survival.

To address specific aim 2, to examine the relationship between two types of social support (tangible and emotional), QOL in survivors 5 to 10 years after heart transplantation, the following analyses were used:

- 1) Pearson's correlations to determine relationships between tangible and emotional social support and QOL,
- 2) T-tests were used to determine differences between tangible and emotional social support based on gender, age, marital status, and race (age for older and younger groups was determined at time of transplant),
- 3) Univariate and multiple regression equations were used to determine which

type of social support (tangible or emotional) is a significant predictor of QOL,

To address aim 3, to examine the relationship among perceived satisfaction with overall, emotional and tangible social support, perceived stress, coping, and QOL at 5 to 10 yrs after heart transplantation, the following analyses were utilized:

1) Pearson's correlation coefficients to examine relationships between perceived satisfaction with emotional, tangible, and overall social support and perceived stress and perceived satisfaction with emotional, tangible, and overall social support and coping,

2) Two separate series of regression equations, according to Baron and Kenny (1986), to examine if perceived satisfaction with emotional, tangible, and overall social support mediates the relationship between perceived stress and QOL, and if coping mediates the relationship between perceived stress and QOL.

To test for mediation of social support, the first step involved regressing the mediator (satisfaction with social support) and the independent variable (perceived stress). The second step in the test for mediation involved regressing the outcome variable (QOL) on the independent variable (perceived stress). The final step in the mediation involved regressing QOL on both the mediator (satisfaction with social support) and the independent variable (perceived stress).

To test for mediation of coping, the first step involved regressing the mediator (coping) and the independent variable (perceived stress). The second step in the test for mediation involved regressing the outcome variable (QOL) on the independent variable (perceived stress). The final step in the mediation involved regressing QOL on both the mediator (coping) and the independent variable (perceived stress).

### **Study Limitations**

The major limitation of this study was the study aims of the parent study did not include a detailed examination of social support. Since social support was not the primary research focus of the parent study, analysis was limited to the study instruments used. For instance, the Heart Transplant Social Support Index included emotional and tangible social support items, and had no instrumental or informational items which may have important relationships in heart transplantation. Lastly, the data set did not have an untreated control group for comparison because it would have been unethical not to treat a patient who was in need of a heart transplant surgery. Therefore, by examining only heart transplant patients who have already been transplanted, the study sample includes those patients who were already selected as having adequate social support by the transplant program.



Table 1

## Theoretical and Operational Definitions

<b>Variable</b>	<b>Measurement</b>	<b>Operational Definition</b>	<b>Theoretical Definition</b>
<b>Quality of Life</b>	Quality of Life Index (QLI)  (Ferrans & Powers, 1985)	The QLI has 35 items that measure satisfaction with and importance of various aspects of life including health, health care, usefulness to others, happiness, potential for a long life, job, physical/financial independence, marital/sexual relationships, relationships with family and friends, appearance, leisure activities, and goals in life. There are four subscales: health, psychological/spiritual, significant others, and socio-economic.	A multi-dimensional concept focusing on physical, psychosocial, and somatic domains.
<b>Social Support</b>	Social Support Index (SSI)  (Grady, Jalowiec, Grusk, White-Williams, & Robinson, 1992)	The SSI measures structural aspects of the support network, functional types of assistance received, and satisfaction with support. The tool has 2 parts: Part A assesses the number and composition of interpersonal ties and satisfaction for 15 illness-related tasks. Tangible, emotional, and informational support are assessed. Part B assesses the patient's perception of the quality of relationships and frequency of attendance at activities.	A multi-dimensional concept focusing on multiple dimensions: emotional, informational, and tangible interactions

<b>Emotional social support</b>	Social Support Index	See above	Other terms include esteem support, attachment support. Provision of discussion of feelings and concerns, approval, caring, and acceptance of person. Enhances self-esteem, reduces anxiety and depression, decreases stress, motivates coping
<b>Tangible social support</b>	Social Support Index	See above	Other terms include instructional support, practical support and material aid. Provision of money, household goods, transportation, assistance with care of the home, solves practical problems, allows time for rest, recovery, decreases stress, and facilitates coping
<b>Satisfaction with social support</b>	Social Support Index	See above	Patient's perception/satisfaction with social support received
<b>Stressor Scale</b>	Heart Transplant Stressor Scale  (Grady et al., 1992)	This 81-item tool measures areas of stress in 6 subscales: physical, hospital/clinic, self-care, family, work/financial, and psychological.	Stress may be related to quality of life and social support.
<b>Coping</b>	Jalowiec Coping Scale (JCS)  (Jalowiec, 1988)	The JCS is a tool widely used to measure the use and effectiveness of 60 coping strategies.	Type of coping use and effectiveness are important
<b>Demographic Variables:</b> age, gender, race, marital status, years of education, current employment	CTRD  Chart Review	Collected from chart review and patient demographic form	
<b>Physiological Variables:</b>	CTRD	Collected from chart review and patient	

Survival, NYHA class, number of hospital readmissions, number of co-existing illnesses, number of rejection episodes, number of infections, number of malignancies, coronary artery disease (CAD), treatment event of CAD, cardiopulmonary symptoms (yes/no), dermatology symptoms (yes/no), gastrointestinal symptoms (yes/no), sensory and neuromuscular symptoms (yes/no)

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## CHAPTER 4

### FINDINGS

This chapter presents a demographic and clinical description of the sample and results of the analysis. In the first section, the sample is described, including specific details describing the Heart Transplant Social Support Index and the frequencies of subject responses. The second section discusses the results related to satisfaction with social support, perceived stress, coping, QOL, and survival which are relevant to the specific aims, hypotheses, and research questions.

#### **Description of the Sample**

The clinical and demographic characteristics of the 555 patients in this sample have been published previously (Grady et al., 2007). A patient had to complete at least one questionnaire to be entered into the study. The number of patients in each time period can be seen in Table 7. The majority of the sample were men (78%), Caucasian (88%), with an average age of 54 years at the time of transplantation. In addition, the majority of subjects were married (79%), and 59% had a high school education or higher (mean years of education = 14). Ischemic cardiomyopathy (56%) and dilated cardiomyopathy (32%) accounted for most of the etiology of heart failure.

Table 7

*Number of Study Participants per Time Period*

Time Period	Frequency	Percent	Cumulative Frequency	Cumulative Percent
5.0	212	10.53	212	10.53
5.5	245	12.17	457	22.70
6	241	11.97	698	34.67
6.5	224	11.13	922	45.80
7.0	200	9.94	1122	55.74
7.5	185	9.19	1307	64.93
8.0	162	8.05	1469	72.98
8.5	154	7.65	1623	80.63
9.0	149	7.40	1772	88.03
9.5	131	6.51	1903	94.54
10.0	110	5.46	2013	100.00

By 5 to 10 years after heart transplantation, most patients were New York Heart Association (NYHA) Class I, which is defined as ordinary physical activity that does not cause undue fatigue, palpitations, dyspnea and/or angina. The most common co-morbidities were hypertension, hyperlipidemia, renal dysfunction, and cancer. Cumulative rates of rejection ( $2.2 \pm 2.0$ ) and infection ( $0.8 \pm 1.3$ ) were relatively low. Forty-two percent of patients developed coronary allograft vasculopathy.

### Heart Transplant Social Support Index and Subject Responses

The Heart Transplant SSI contains 15 questions with 2 subscales. There are 10 questions related to tangible social support and 5 questions on emotional social support. Subjects have the opportunity to check “no one helps me in this area even though I need help” and “I don’t need help in this area right now.” See Table 8 for an example of a question on the instrument. Individual satisfaction responses were coded and then converted to a 0 to 1 scale. Lower scores indicated better satisfaction.

Table 8

#### *Question 9 on Heart Transplant Social Support Index*

Check all those people who help you take your medications when you’re at home:

- spouse (or partner)
- family member (such as child, parent, brother, sister)
- relative (such as aunt, uncle, cousin, in-law)
- person from work or school
- spiritual advisor or person from church
- other transplant patients or their families
- friend or neighbor
- professional person (such as doctor, nurse, social worker, therapist)
- Paid helper
- no one helps me in this area even though I need help
- I don’t need help in this area right now

If you do get help in this area, how satisfied are you with the help?

- very satisfied
- fairly satisfied
- somewhat dissatisfied
- very dissatisfied

Individual subject response frequencies were overwhelmingly satisfactory at 5 years after heart transplantation (See Table 9). This trend continued into 10 years post heart transplantation (See Table 10).

Table 9

*Frequencies of Emotional Social Support Satisfaction at 5 and 10 Years post Heart**Transplantation*

	Q 6 Talk		Q 12 Confide		Q 13 Program		Q 14 Feel Good		Q 15 Encourage	
	N	%	N	%	N	%	N	%	N	%
Social Support: 5 Years										
Very Satisfied	114	77	123	81	101	93	130	85	134	88
Fairly Satisfied	26	17	25	16	6	6	20	13	16	10
Somewhat Dissatisfied	7	5	3	2	0	0	2	1	2	1
Very Dissatisfied	2	1	1	1	1	1	2	1	1	1
Total	149	100	152	100	108	100	154	100	153	100
<hr/>										
Social Support: 10 Years										
Very Satisfied	64	85	69	91	53	90	72	91	71	93
Fairly Satisfied	10	13	7	9	5	8	6	8	5	7
Somewhat Dissatisfied	1	1	0	0	1	2	1	1	0	0
Very Dissatisfied	0	0	0	0	0	0	0	0	0	0
Total	75	100	76	100	59	100	79	100	76	100

Table 10

*Frequencies of Tangible Social Support Satisfaction at 5 and 10 Years post Heart**Transplantation*

5 Years Question	Very Satisfied		Fairly Satisfied		Somewhat Dissatisfied		Very Dissatisfied	
	N	%	N	%	N	%	N	%
1	102	76	30	22	3	2	0	0
2	59	81	12	17	2	2	0	0
3	57	85	9	13	1	2	0	0
4	124	93	10	7	0	0	0	0
5	77	83	11	12	1	1	4	4
7	151	91	12	7	1	1	1	1
8	107	93	7	6	0	0	1	1

9	47	96	1	2	0	0	1	2
10	84	82	17	16	1	1	1	1
11	92	91	8	8	0	0	2	1

10 Years Question	Very Satisfied		Fairly Satisfied		Somewhat Dissatisfied		Very Dissatisfied	
	N	%	N	%	N	%	N	%
1	69	86	11	14	0	0	0	0
2	34	85	6	15	0	0	0	0
3	37	90	4	10	0	0	0	0
4	61	95	3	5	0	0	0	0
5	42	88	4	8	2	4	0	0
7	74	91	7	9	0	0	0	0
8	55	95	3	5	0	0	0	0
9	26	100	0	0	0	0	0	0
10	42	84	7	14	1	2	0	0
11	38	90	4	10	0	0	0	0

The number of subjects who selected “don’t need help in this area right now” in the emotional social support subscale ranged from 20 to 40% (See Figure 2). Those who selected that they did not need help with tangible social support ranged from 20 to 70% (See Figure 3). To better understand the data in this analysis, Table 11 depicts the study responses of two questions.



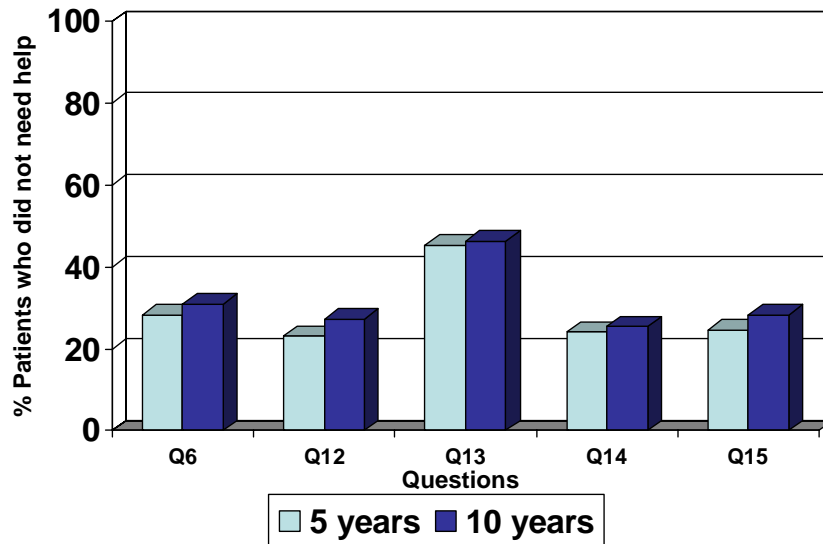


Figure 2. Subjects who do not need help with emotional social support.

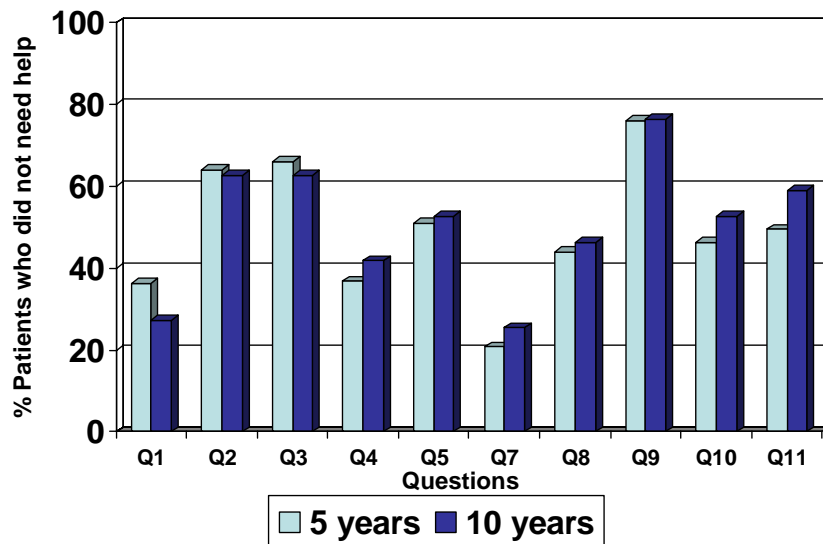


Figure 3. Subjects who do not need help with tangible social support.

Table 11

*Frequencies of Satisfaction with Social Support by Time Period: Questions 6 and 9*

Years Post HT	n	n Q6	Need help but no one helps	Don't need help	Have Help	V S	F S	S D	V D
5	212	212	2	60	149*	114	26	7	2
10	110	110	1	34	75	64	10	1	0
Years Post HT	n	n Q9	Need help but no one helps	Don't need help	Have Help	V S	F S	S D	V D
5	212	212	2	161	49	47	1	0	1
10	110	110	0	84	26	26	0	0	0

HT = Heart Transplantation

VS= Very Satisfied, FS = Fairly Satisfied, SD = Somewhat Dissatisfied, VD = Very Dissatisfied

n = number

Q6 = n who answered Question 6, Q9 = n who answered Question 9

\*1 missing

### **Results related to the Specific Aims, Research Questions, and Hypotheses**

The first study aim was to examine the relationships among perceived satisfaction with social support, QOL, and survival over time among survivors 5 to 10 years after heart transplantation.

#### ***Research Question 1-1***

Does perceived satisfaction with social support change over time in long-term heart transplant survivors? At 5 to 10 years after heart transplantation, results revealed that

heart transplant recipients were very satisfied with overall social support. Satisfaction with social support remained steady over time ( $p = 0.74$ ) (See Figure 4). Satisfaction with emotional social support ( $p = 0.53$ ) and tangible social support ( $p = 0.61$ ) also remained stable over time (See Figure 5). Subjects reported high satisfaction with both tangible and emotional social support.

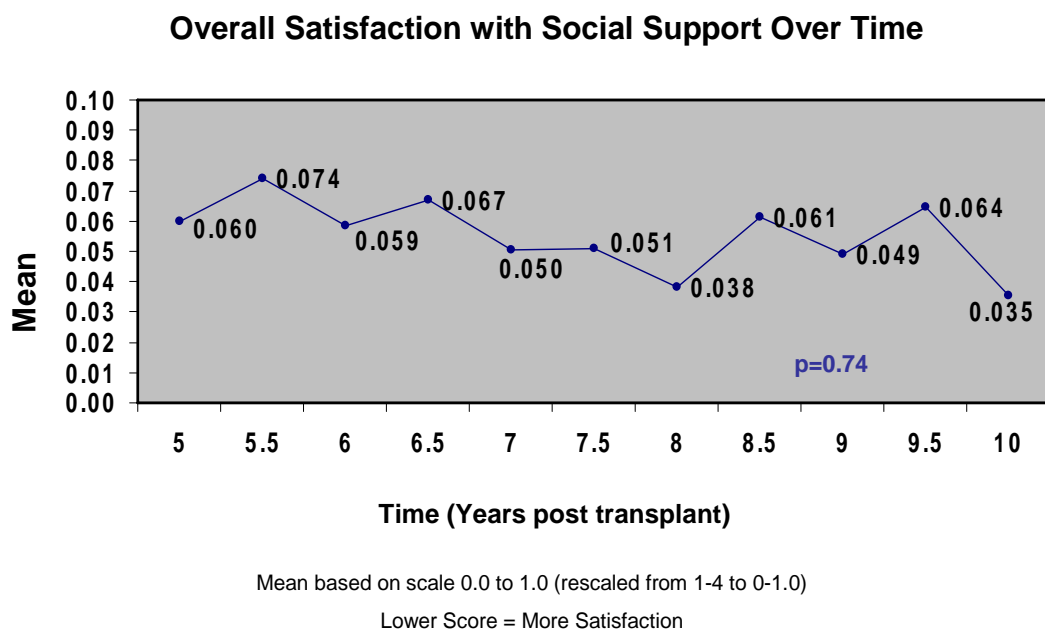


Figure 4. Satisfaction with Social Support Over Time

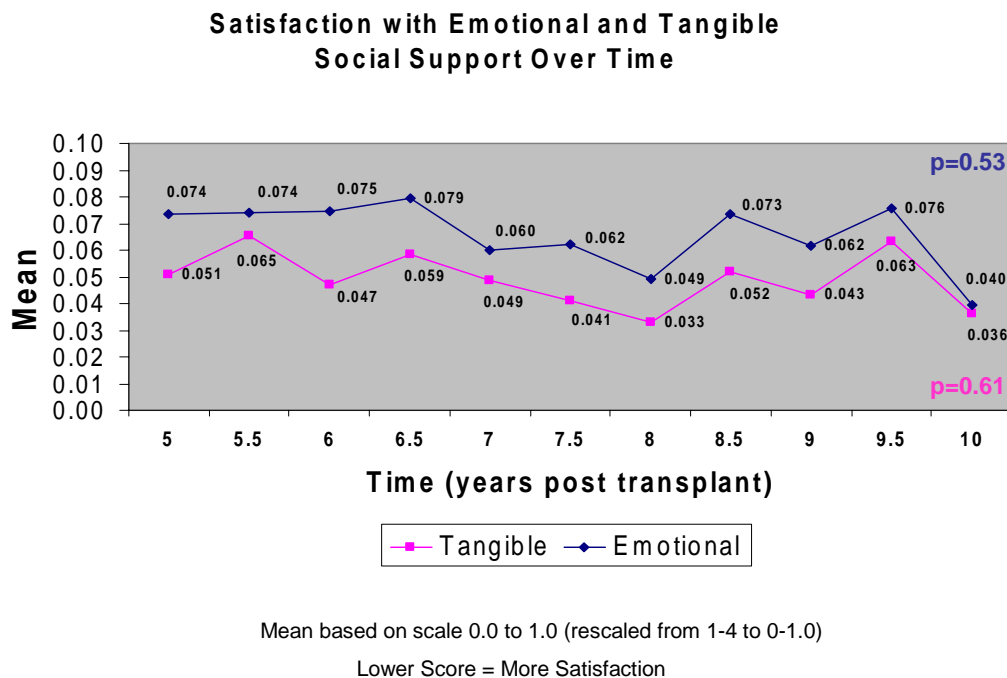


Figure 5. Satisfaction with Emotional and Tangible Social Support Over Time

The two areas in which subjects were most satisfied with emotional social support at 5 years were having someone help them with the transplant regimen and with encouragement. At 10 years post transplant, subjects were most satisfied with having someone for encouragement or someone to confide in (See Table 12). The areas in which patients were least satisfied with emotional social support at 5 and 10 years were someone to talk to about problems and someone to help with the transplant regimen (See Table 13).

Table 12

*Most Satisfaction with Emotional Social Support at 5 and 10 Years*

	n	M ± SD
<b>Most Satisfaction with Emotional Social Support at 5 Years</b>		
Help with Transplant Regimen	108	0.03 ± 0.12
Help with Encouragement	153	0.05 ± 0.15
<b>Most Satisfaction with Emotional Social Support at 10 Years</b>		
Help with Encouragement	76	0.02 ± 0.08
Someone to confide in	76	0.03 ± 0.10

(Based on Scale 0-1, Lower Score = More Satisfaction)

Table 13

*Least Satisfaction with Emotional Social Support at 5 and 10 Years*

	n	M ± SD
<b>Least Satisfaction with Emotional Social Support at 5 Years</b>		
Someone to talk to about problems	149	0.10 ± 0.21
Someone to confide in	152	0.07 ± 0.17
<b>Least Satisfaction with Emotional Social Support at 10 Years</b>		
Someone to talk to about problems	75	0.05 ± 0.13
Help with transplant regimen	59	0.04 ± 0.13

(Based on Scale 0-1, Lower Score = More Satisfaction)

The three areas in which patients were most satisfied with tangible social support at 5 and 10 years centered on help with transportation, medications, and running errands (See Table 14). At 5 and 10 years post heart transplantation, the areas of least satisfaction with tangible social support focused on help with finances and care of children and elders (See Table 15).

Table 14

*Most Satisfaction with Tangible Social Support at 5 and 10 Years*

	n	M ± SD
<b>More Satisfaction with Tangible Social Support at 5 Years</b>		
Help with Transportation	134	0.03 ± 0.09
Help with Medications	49	0.03 ± 0.15
Help with Running Errands	115	0.03 ± 0.12
<b>More Satisfaction with Tangible Social Support at 10 Years</b>		
Help with Transportation	64	0.02 ± 0.07
Help with Medications	26	0 ± 0
Help with Running Errands	58	0.02 ± 0.07

(Based on Scale 0-1, Lower Score = More Satisfaction)

Table 15

*Least Satisfaction with Tangible Social Support at 5 and 10 Years*

	n	M ± SD
<b>Least Satisfaction with Tangible Social Support at 5 Years</b>		
Help with Finances	93	0.09 ± 0.23
Help with Chores	75	0.09 ± 0.16
Help with Children/Elders Care	173	0.07 ± 0.16
<b>Least Satisfaction with Tangible Social Support at 10 Years</b>		
Help with Chores	80	0.05 ± 0.02
Help with Financial Advice	50	0.06 ± 0.15
Help with Finances	48	0.06 ± 0.16

(Based on Scale 0-1, Lower Score = More Satisfaction)

The changes in satisfaction with emotional social support from 5 to 10 years post heart transplant showed an improvement over time except for one question: help with the transplant regimen (See Figure 6). Changes in tangible social support from 5 to 10 years post transplant improved in all 10 areas (See Figure 7).

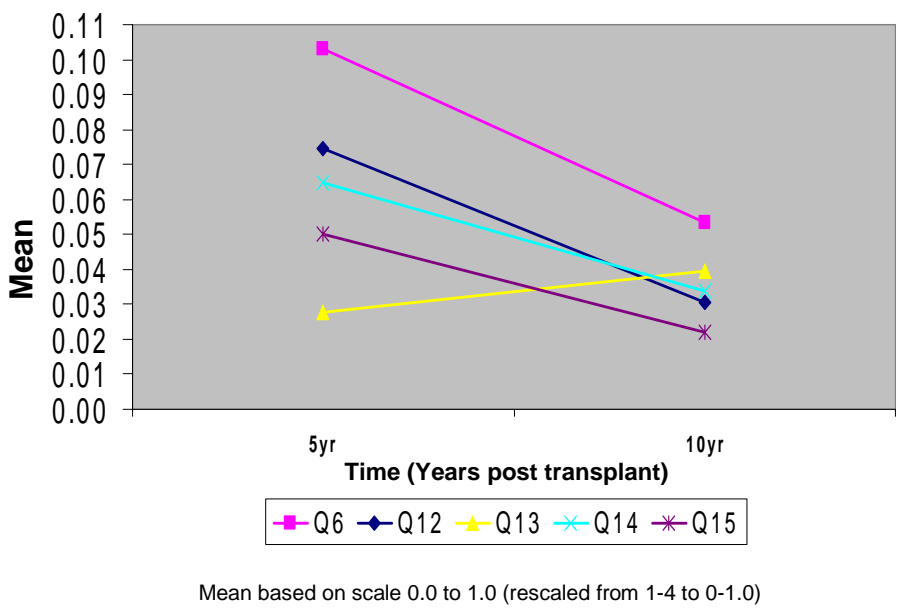


Figure 6. Change in Satisfaction with Emotional Social Support Over Time

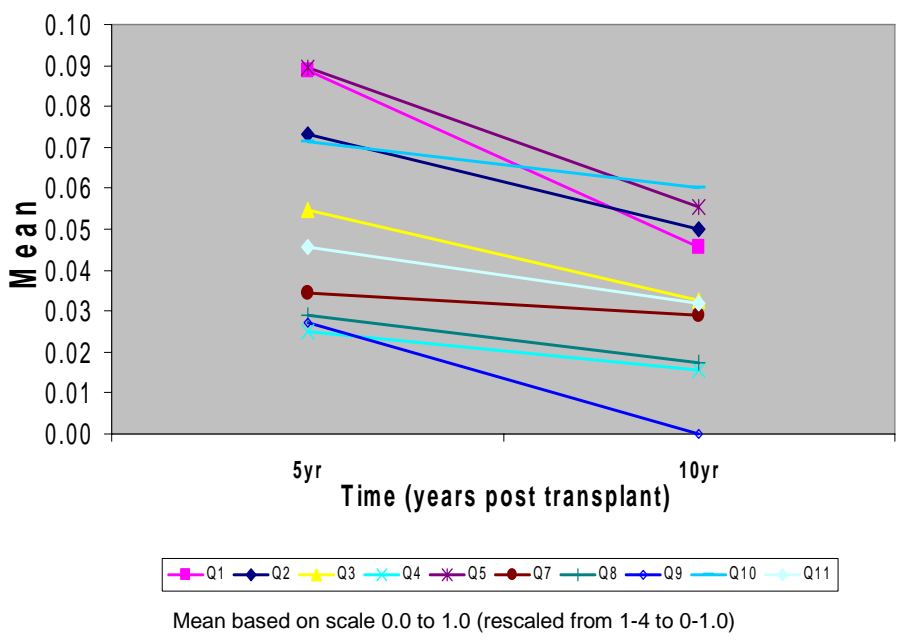


Figure 7. Change in Satisfaction with Tangible Social Support Over Time

### ***Research Question 1-2***

Is perceived satisfaction with social support associated with QOL in long-term heart transplant survivors? The results revealed that there was a significant negative relationship among satisfaction with emotional, tangible, and overall social support and QOL, indicating that more satisfaction with social support is associated with better QOL ( $r = -0.60, -0.50, \text{ and } -0.54$  respectively,  $p < .0001$ ; See Table 16). The negative relationship exists because of the scoring of the social support instrument (lower score = more satisfaction).

Table 16

*Correlations of Emotional, Tangible, and Overall Satisfaction with Social Support and QOL at 5 and 10 Years after Heart Transplantation*

	5 Years after HT			10 Years after HT		
	n	r	p-value	n	r	p-value
<b>Satisfaction with Social Support</b>						
Emotional	187	-0.42	<.0001	93	-0.60	<.0001
Tangible	191	-0.35	<.0001	99	-0.50	<.0001
Overall	200	-0.46	<.0001	105	-0.54	<.0001

### ***Research Question 1-3***

Is perceived satisfaction with social support associated with survival in long-term heart transplant survivors? Satisfaction with social support was not associated with survival of heart transplant recipients. Figure 8 depicts overall survival for the study sample. Twelve patients did not have a social support satisfaction response and were not



included in this analysis. Satisfaction with social support was stratified into 3 groups: very satisfied, medium satisfied, and low satisfied. This same group was then examined using survival actuarials and found to have no difference in survival ( $p = 0.24$ ) (See Figure 9).

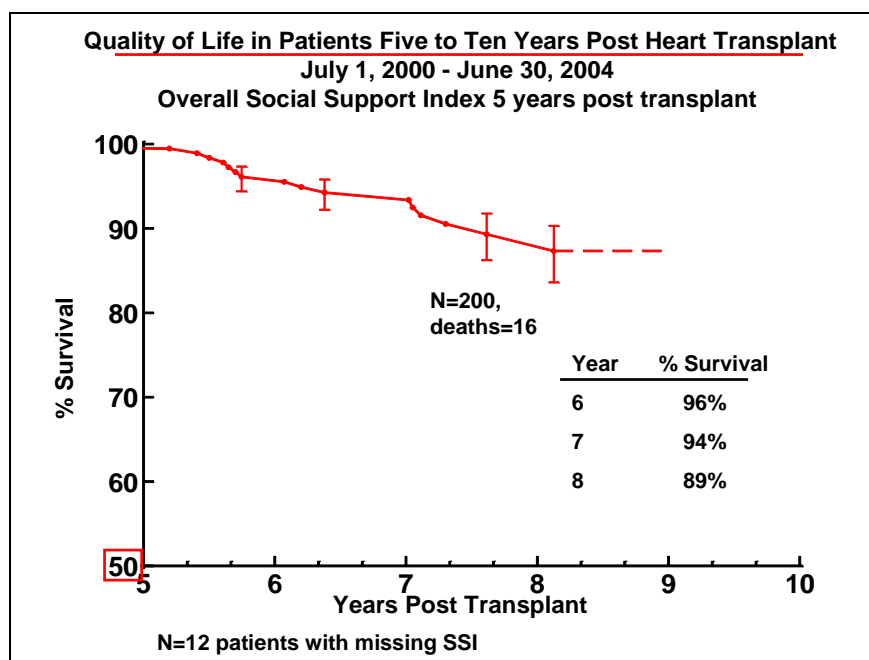


Figure 8. Overall Survival of Study Sample

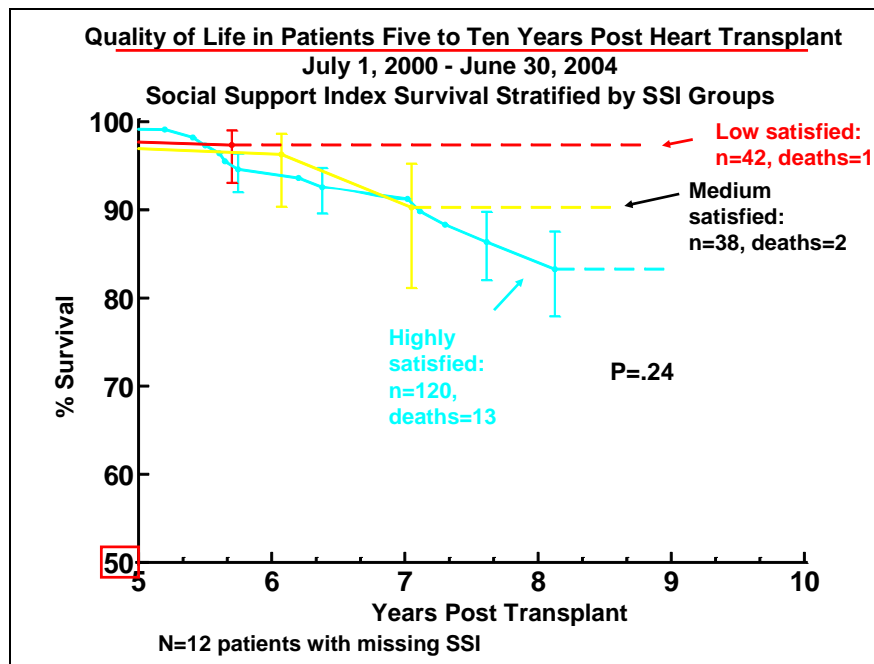


Figure 9. Satisfaction with Social Support and Survival

***Research Question 1-4:***

Are there sociodemographic differences in emotional, tangible, and overall social support in long-term heart transplant survivors?

***Hypothesis 1-1***

Married transplant survivors will report better perceived satisfaction with social support compared to unmarried survivors long-term after heart transplant. At 5 years after heart transplantation, there were no differences in satisfaction with social support between married and non-married patients (See Table 17). At 10 years post heart

transplant, there were significant differences in satisfaction with social support. Married heart transplant recipients were more satisfied with emotional, tangible, and overall social support than unmarried recipients (See Table 18).

Table 17

*Marital Status Differences in Satisfaction with Social Support at 5 Years after Heart Transplantation*

	Married		Not-Married		t	p
	n	M ± SD	n	M ± SD		
Satisfaction with Social Support						
Emotional	144	0.06 ± 0.14	42	0.12 ± 0.20	-1.72	0.09
Tangible	147	0.05 ± 0.10	43	0.07 ± 0.11	-1.36	0.18
Overall	154	0.05 ± 0.11	45	0.09 ± 0.12	-1.90	0.06

(Based on Scale 0-1, Lower Score = More Satisfaction)

Table 18

*Marital Status Differences in Satisfaction with Social Support at 10 Years after Heart Transplantation*

	Married		Not-Married		t	p
	n	M ± SD	n	M ± SD		
Satisfaction with Social Support						
Emotional	73	0.02 ± 0.07	20	0.10 ± 0.17	-2.03	0.05
Tangible	76	0.02 ± 0.06	23	0.09 ± 0.14	-2.17	0.04
Overall	82	0.02 ± 0.06	23	0.09 ± 0.14	-2.22	0.04

(Based on Scale 0-1, Lower Score = More Satisfaction)

***Hypothesis 1-2***

Women will report worse perceived satisfaction with social support compared to men in long-term heart transplant survivors. As seen in Table 19, men reported more satisfaction with emotional social support compared to women at 5 years after heart transplant. There were no differences in tangible or overall satisfaction with social support; however, there was a trend toward significance. There were no gender differences in satisfaction with social support at 10 years after heart transplantation (See Table 20).

Table 19

***Gender Differences in Satisfaction with Social Support at 5 Years after Heart Transplantation***

	Men		Women		t	p
	n	M ± SD	n	M ± SD		
Satisfaction with Social Support						
Emotional	148	0.06 ± 0.14	38	0.14 ± 0.20	2.29	0.03
Tangible	150	0.04 ± 0.09	40	0.09 ± 0.07	1.85	0.07
Overall	150	0.05 ± 0.10	40	0.10 ± 0.15	1.94	0.06

(Based on Scale 0-1, Lower Score = More Satisfaction)

Table 20

***Gender Differences in Satisfaction with Social Support at 10 Years after Heart Transplantation***

	Men		Women		t	p
	n	M ± SD	n	M ± SD		
Satisfaction with Social Support						
Emotional	72	0.03 ± 0.10	22	0.07 ± 0.12	1.23	0.23
Tangible	77	0.03 ± 0.08	23	0.05 ± 0.10	1.04	0.30
Overall	82	0.03 ± 0.08	21	0.07 ± 0.11	1.12	0.27

(Based on Scale 0-1, Lower Score = More Satisfaction)

***Hypothesis 1-3***

Older survivors (> 60 years) will report better perceived satisfaction with social support compared to younger survivors ( $\leq$  60 years) long-term after heart transplant. At 5 years post heart transplant, older recipients were more satisfied with overall and emotional social support, but there was no difference in satisfaction with tangible social support between older and younger recipients (See Table 21). As shown in Table 22, older heart transplant survivors were more satisfied with emotional, tangible, and overall social support than younger transplant survivors.

Table 21

*Age Differences in Satisfaction with Social Support at 5 Years after Heart Transplantation*

	Older (> 60 yrs)		Younger ( $\leq$ 60yrs)		t	p
	n	M $\pm$ SD	n	M $\pm$ SD		
Satisfaction with Social Support						
Emotional	71	0.04 $\pm$ 0.10	116	0.09 $\pm$ 0.17	2.42	0.02
Tangible	71	0.04 $\pm$ 0.08	120	0.06 $\pm$ 0.12	1.42	0.16
Overall	75	0.04 $\pm$ 0.08	125	0.07 $\pm$ 0.11	1.93	0.05

(Based on Scale 0-1, Lower Score = More Satisfaction)

Table 22

*Age Differences in Satisfaction with Social Support at 10 Years after Heart Transplantation*

	Older (> 60 yrs)		Younger ( $\leq$ 60yrs)		t	p
	n	M $\pm$ SD	n	M $\pm$ SD		
Satisfaction with Social Support						
Emotional	26	0.02 $\pm$ 0.10	67	0.08 $\pm$ 0.10	3.06	0.003
Tangible	25	0.03 $\pm$ 0.08	74	0.07 $\pm$ 0.10	2.43	0.02
Overall	28	0.01 $\pm$ 0.03	77	0.05 $\pm$ 0.10	2.96	0.004

(Based on Scale 0-1, Lower Score = More Satisfaction)

### ***Hypothesis 1-4***

There will be no relationship between race and perceived satisfaction with social support in long-term heart transplant survivors. Results supported this hypothesis; there were no differences in satisfaction with emotional, tangible, or overall social support among Caucasian and Non-Caucasian transplant recipients at 5 and 10 years (See Table 23).

Table 23

#### *Race Differences in Satisfaction with Social Support at 5 and 10 Years after Heart Transplantation*

	Caucasian		Non-Caucasian		t	p
	n	M ± SD	n	M ± SD		
<b>Satisfaction with Social Support at 5 Years</b>						
Emotional	172	0.07 ± 0.15	15	0.11 ± 0.13	-1.06	0.30
Tangible	176	0.05 ± 0.11	15	0.06 ± 0.09	-0.22	0.83
Overall	184	0.06 ± 0.11	16	0.07 ± 0.09	-0.35	0.73
<b>Satisfaction with Social Support at 10 Years</b>						
Emotional	80	0.03 ± 0.10	14	0.07 ± 0.13	-0.90	0.40
Tangible	85	0.03 ± 0.09	13	0.05 ± 0.08	-0.95	0.35
Overall	91	0.03 ± 0.09	14	0.06 ± 0.09	-1.00	0.34

(Based on Scale 0-1, Lower Score = More Satisfaction)

The second study aim was to examine the relationship between two types of social support (tangible and emotional) on QOL in recipients 5 to 10 years after heart transplantation. Univariate regression revealed overall, emotional, and tangible satisfaction with social support was predictive of QOL at 5 and 10 years post heart

transplantation. Multivariate regression found overall satisfaction with social support to be predictive of QOL at 5 years and satisfaction with emotional social support to be predictive at 10 years post heart transplantation.

***Research Question 2-1***

Will emotional social support predict QOL in survivors 5 to 10 years after heart transplantation? The first regression models examined satisfaction with social support univariately. At 5 years after heart transplantation, satisfaction with emotional social support was a predictor of better QOL and explained 17% of the variance ( $F=38.63$ ,  $p<.0001$ ). At 10 years after heart transplantation, satisfaction with emotional social support was also a predictor of better QOL, explaining 32% of the variance ( $F=43.60$ ,  $p<.0001$ ) (See Tables 24 and 25). There were no control variables or covariates in the model.

***Research Question 2-2***

Will tangible social support be predictive of QOL in survivors 5 to 10 years after heart transplantation? When examining satisfaction with tangible social support, tangible social support was a predictor of better QOL at 5 years after heart transplantation and explained 12% of the variance ( $F=25.60$ ,  $p<.0001$ ). In addition, satisfaction with tangible social support was a predictor of better QOL at 10 years after heart transplantation and explained 25% of the variance ( $F=32.10$ ,  $p<.0001$ ) (See Tables 24 and 25). There were no control variables or covariates in the model.

Table 24

*Regression Model at 5 Years post HT (n = 212)*

	$\beta$	SE	t	R <sup>2</sup>	p
Satisfaction with Social Support					
Emotional	-0.36	0.05	-6.22	0.17	<.0001
Tangible	-0.48	0.09	-5.06	0.12	<.0001
Overall	-0.60	0.08	-7.22	0.21	<.0001

Table 25

*Regression Model at 10 Years post HT (n = 110)*

	$\beta$	SE	t	R <sup>2</sup>	p
Satisfaction with Social Support					
Emotional	-0.84	0.12	-6.60	0.32	<.0001
Tangible	-0.85	0.15	-5.67	0.25	<.0001
Overall	-0.91	0.14	-6.45	0.29	<.0001

Variables entered into the multiple regression model included: 1) sociodemographic variable such as age, gender, race, marital status, and education; 2) clinical variables such as NYHA class, readmissions, rejection, infection, malignancy, coronary artery disease, co-morbidities (cardiac, pulmonary, dermatologic, neuromuscular, gastrointestinal, urinary, diabetes, orthopedic); and 3) psychosocial variables such as satisfaction with emotional, tangible, overall social support, overall stress, physical, psychosocial, self-care, family, work/school/financial, and hospital/clinic, overall positive coping, overall negative coping, confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant coping. There were no control variables or covariates in the model.

When emotional, tangible, and overall satisfaction with social support were



entered into the multiple regression model, overall satisfaction with social support was a significant predictor of QOL at 5 years post heart transplantation. Other predictors of QOL at 5 years were older age, fewer co-existing illnesses, fewer sensory-cognitive neuromuscular symptoms, more positive coping, less self reliant coping, less overall stress, and less financial stress, explaining 59% of the variance ( $F=31.82$ ,  $p<.0001$ ) (See Table 26). At 10 years post heart transplantation, emotional social support was a predictor of QOL. Additional predictors of better QOL at 10 years included being female, fewer cardiopulmonary symptoms, fewer dermatology symptoms, fewer sensory-cognitive neuromuscular symptoms, less negative coping, more supportant coping, and more self reliant coping explaining 66% of the variance ( $F=21.40$ ,  $p<.0001$ ) (See Table 27).

Table 26

*Multiple Regression Model at 5 years post HT (n=211)*

<b>Variable</b>	<b>B</b>	<b>SE</b>	<b>p</b>
Age (older)	.002	.000	.005
Co-existing illnesses (Fewer)	-.007	.002	.008
Sensory, cognitive, neuromuscular (Fewer)	-.223	.039	<.0001
Positive Coping (More)	.203	.066	.003
Self reliant Coping (Less)	-.123	.060	.042
Satisfaction with Overall Social Support (More)	-.388	.063	<.0001
Overall Stress (Less)	-.161	.068	.02
Job/School/Financial Stress (Less)	-.012	.004	.003

(These 8 variables explained 59% of the variance.)

Table 27

*Multiple Regression Model at 10 years post HT (n=110)*

<b>Variable</b>	<b>B</b>	<b>SE</b>	<b>p</b>
Female	-.063	.022	.005
Cardio-pulmonary symptoms (Fewer)	-.175	.056	.002
Dermatology symptoms (Fewer)	-.173	.043	.0001
Sensory, cognitive, neuromuscular (Fewer)	-.216	.074	.004
Overall Negative Coping (Less)	-.347	.085	<.0001
Supportant Coping (More)	.106	.045	.021
Self reliant Coping (More)	.153	.051	.003
Satisfaction with Emotional Social Support (More)	-.46	.108	<.0001

(These 8 variables explained 66% of the variance.)

The third study aim was to examine the relationship among perceived satisfaction with overall, emotional and tangible social support, perceived stress, coping, and QOL at 5 to 10 yrs after heart transplantation.

### ***Research Question 3-1***

Does perceived satisfaction with overall social support mediate the relationship of perceived stress and QOL at five years after heart transplantation? A series of regression equations was used to test the mediating effect of satisfaction with social support (Baron & Kenny, 1986). The first step involved regressing the mediator (satisfaction with social support) and the independent variable (perceived stress). There was a significant relationship when satisfaction with social support was regressed on perceived stress ( $\beta = 0.172, p < 0.0004$ ) indicating less satisfaction with social support is associated with more perceived stress. The second step in the test for mediation involved regressing the

outcome variable (QOL) on the independent variable (perceived stress). There was a significant inverse relationship indicating that subjects with better QOL experienced less perceived stress. Perceived stress explained 36% of the variance in QOL ( $r^2 = 0.36$ ,  $p < 0.0001$ ). The final step in the mediation involved regressing QOL on both the mediator (satisfaction with social support) and the independent variable (perceived stress). Together satisfaction with social support and perceived stress explained 46% of the variance in QOL ( $r^2 = 0.456$ ,  $p < 0.0001$ ). The effect of perceived stress was smaller in step three [ $\beta = -0.453$ ,  $p < 0.0001$ ] than in step two ( $\beta = -0.541$ ,  $p < 0.0001$ ); however, it remained significant, indicating that satisfaction with social support did partially mediate the effects of perceived stress on QOL (See Figure 10). There were no controls for other variables.

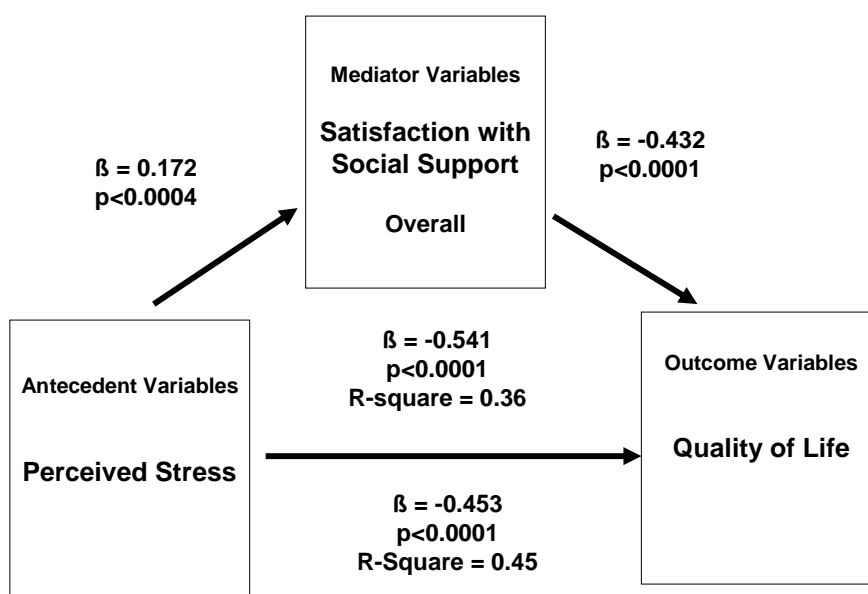


Figure 10. Mediation of Satisfaction with Social Support on Perceived Stress and QOL

In addition, both satisfaction with emotional and tangible social support also partially mediated the relationship between perceived stress and QOL (See Figures 11 and 12).

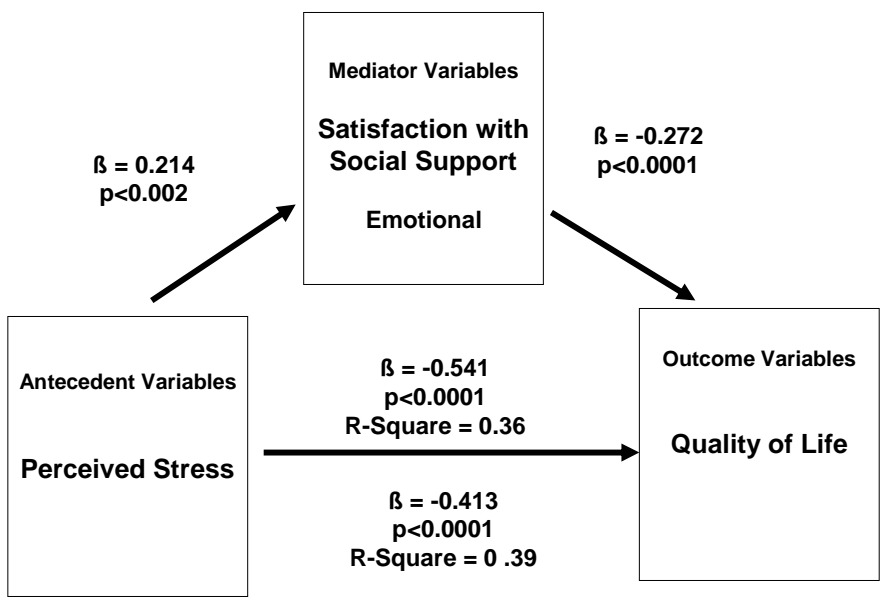


Figure 11. Mediation of Satisfaction with Emotional Social Support on Perceived Stress and QOL

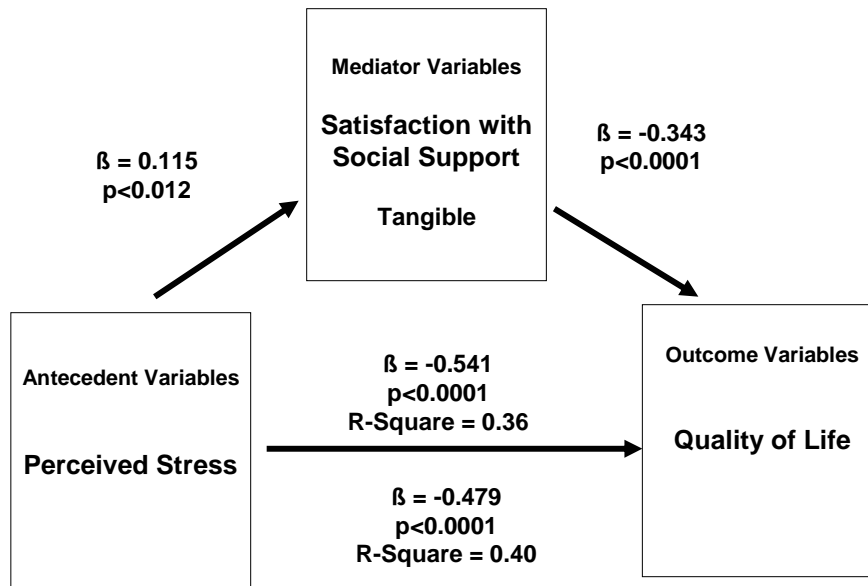


Figure 12. Mediation of Satisfaction with Tangible Social Support on Perceived Stress and QOL

### *Research Question 3-2*

Does coping mediate the relationship of perceived stress and QOL at five years after heart transplantation? Again, the series of regression equations was used to test the mediating effect of coping (Baron & Kenny, 1986). The first step involved regressing the mediator (coping) on the independent variable (perceived stress). There was an inverse significant relationship when coping was regressed on perceived stress ( $\beta = -0.264$ ,  $p = 0.0002$ ) indicating that those subjects who perceived more positive coping helpfulness had less perceived stress. The second step in the test for mediation involved regressing the outcome variable (QOL) on the independent variable (perceived stress). There was a significant inverse relationship indicating that subjects with better QOL experienced less perceived stress. Perceived stress explained 36% of the variance in QOL ( $r^2 = 0.36$ ,

$p < 0.0001$ ). The final step in the mediation involved regressing QOL on both the mediator (coping) and the independent variable (perceived stress). Together coping and perceived stress only explained 35% of the variance in QOL ( $r^2 = 0.354$ ,  $p < 0.0001$ ). Even though the effect of perceived stress ( $\beta = -0.432$ ,  $p < 0.0001$ ) was smaller in step three, the R-square was less; therefore it was concluded that coping did not mediate the effects of perceived stress on QOL (See Figure 13). There were no controls for other variables.

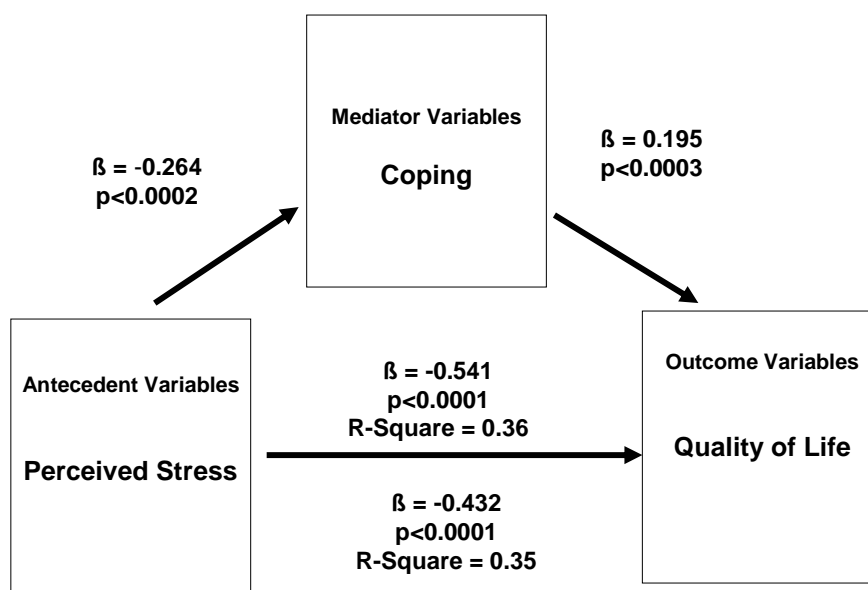


Figure 13. Mediation of Coping on Perceived Stress and QOL

### Summary of the Results

Satisfaction with social support was very high and stable over time. Transplant recipients reported more satisfaction with tangible social support compared to emotional social support; however, the result was not significantly different.

Men reported better satisfaction with emotional social support at five years post transplant; however, there were no differences between men and women in tangible and overall social support. No gender differences emerged at 10 years post heart transplantation. Married transplant recipients reported greater satisfaction with social support at 10 years, but this finding was not seen at 5 years post transplant. Except for tangible social support at 5 years, older transplant survivors had greater satisfaction with emotional, tangible, and overall social support than younger survivors at 5 and 10 years. No race differences were found in satisfaction with social support in either time period.

There were significant associations between satisfaction with social support and QOL. Satisfaction with emotional, tangible, and overall social support predicted QOL at both 5 and 10 years post transplant univariately. Multiple regression revealed satisfaction with overall social support was a significant predictor of QOL at 5 years post transplant. Satisfaction with emotional social support was a significant predictor at 10 years after heart transplantation. Using the Baron and Kenny (1986) regression equations, satisfaction with emotional, tangible, and overall social support partially mediated perceived stress and QOL; however, coping did not.

CHAPTER 5  
DISCUSSION, CONCLUSIONS, IMPLICATIONS,  
AND RECOMMENDATIONS

This chapter presents a discussion of the results of the study. Study conclusions, implications, and recommendations for future research are also presented.

**Discussion**

*Satisfaction with Social Support Over Time*

Satisfaction with social support was very high and stable over time in heart transplant recipients who were 5 to 10 years post surgery. This finding was similar to that reported by Burg and colleagues (2005); however most of the literature in other chronic disease populations reported a decline in social support over time (Friedman, 1997; Kristofferzon et al., 2003; Rankin, 2002). The high satisfaction with social support finding could be due to the fact that transplant candidates undergo a detailed social evaluation prior to transplantation. Potential transplant candidates with few social support resources would be considered high risk and may not be considered for transplantation. Friedman (1997) demonstrated continuity of emotional and tangible social support over time. Similar to Friedman, this study found that the type of satisfaction with emotional and tangible support remained stable over time. Recipients were more satisfied with the help they received with their transplant regimen at 5 years than at 10 years. At 10 years



post transplant, patients were least satisfied with financial help compared to at 5 years. This information tells us that resources that may be available at one point in time may not be available years later.

### ***Satisfaction with Emotional and Tangible Social Support***

Looking at satisfaction with emotional and tangible social support over time, transplant recipients reported greater satisfaction with tangible social support compared to emotional social support. Perhaps this is due to the fact one can assign a measurable limit to tangible types of social support, but emotional social support is always in continuous demand. With that said, emotional, tangible, and overall social support were all significantly correlated with QOL. Similar to Bennett and colleagues (2001), this study found men reported less satisfaction with emotional social support at 5 years post transplant. However, this was not found at 10 years. No differences were found in emotional, tangible, or overall satisfaction with social support between men and women at 10 years after heart transplant.

Even though Friedman (1997) found that only emotional social support was directly related to greater satisfaction with life and more positive affect, this study found both satisfaction with emotional support and tangible social support partially mediated perceived stress and QOL. This finding may be unique to transplant patients revealing the importance of both emotional and tangible social support in this patient population.

### ***Perceived Stress***

Similar to Lache and colleagues (2007), this study found that patients with better satisfaction with emotional, tangible, and overall social support had less perceived stress. This is an important finding because less perceived stress was a significant predictor of

better QOL. Satisfaction with social support partially mediated perceived stress and QOL.

### *Coping*

Although few studies in the literature addressed the relationship between coping and social support, conflicting results were found in deciphering whether coping modulates or mediates stress (Coker et al., 2006; Tak et al., 2002). This study found that patients using more positive coping behaviors had less perceived stress. Coping did not mediate the relationship between perceived stress and QOL.

### *Quality of Life*

There were significant associations between satisfaction with social support and QOL. Univariately, satisfaction with emotional, tangible, and overall social support predicted QOL at both 5 and 10 years post transplant. When other factors were entered into the regression equation, overall satisfaction with social support continued to be a significant predictor of QOL at 5 years post transplant. Other variables important to QOL at 5 years post transplant included older age, fewer symptoms, less stress, and better coping. At 10 years post transplant, satisfaction with emotional social support was a significant predictor of QOL. Other significant variables included being female, having fewer symptoms, and using certain types of coping. These results confirm the importance of satisfaction with social support, particularly emotional social support, in the daily lives of heart transplant recipients. Using the Baron and Kenny (1986) regression equations, satisfaction with overall, emotional, and tangible social support partially mediated the relationship between perceived stress and QOL; however, coping did not mediate the relationship between perceived stress and QOL.

### ***Sociodemographic Factors***

Several studies have shown strong relationships between being married or living with a partner and mortality and QOL (Barr et al., 2003; Bosworth et al., 2000; Case et al., 1992; Coyne et al., 2001; Grady et al., 2007) while others did not find this relationship (Luttik et al., 2006; O'Shea et al., 2002). This study revealed mixed results with married transplant recipients reporting more satisfaction with social support at 10 years, but not at 5 years post transplant. Possibly by 10 years post transplant, most couples are accustomed to transplant life which impacts their QOL in a positive way.

In this study, men reported better satisfaction with emotional social support at five years post transplant; however, there were no differences between men and women in tangible and overall social support. This finding was related to other studies which revealed that women reported less perceived social support than men (Davidson et al., 1997; Emery et al., 2004; Gallicchio et al., 2007). One explanation for this finding is that the heart transplant population, in general, has more men than women. Thus, more women assume the caregiving role and offer emotional social support than men during the transplant experience. Interestingly, there were no gender differences in satisfaction with social support at 10 years post transplantation. This finding is consistent with other studies (Artinian et al., 1995; Bennett et al., 2001; Brummet et al., 2001).

Except for tangible social support at 5 years, older transplant survivors had more satisfaction with emotional, tangible, and overall social support than younger survivors at 5 and 10 years. This finding may be due to the fact that older transplant recipients may have resolution with life and have opportunity to enjoy the support around them.

Limited information is available regarding racial differences in social support. Similar to Rankin (2005), this study found no race differences in satisfaction with social support at 5 or 10 years post transplant.

### ***Survival***

There are conflicting findings reported in the literature about the impact of social support on survival. This study found that satisfaction with social support did not have an impact on survival. In fact those with more satisfaction with social support had worse survival. However, there were very few recipients who were dissatisfied with their social support; thus, further research is warranted in the heart transplant population.

### **Conclusions**

The results of this study revealed the importance of examining satisfaction with social support in heart transplant recipients. Based on the findings of this study, the following inferences were identified:

1. Satisfaction with social support remains stable from 5 to 10 years post heart transplantation.
2. Satisfaction with emotional and tangible social support remains stable from 5 to 10 years post heart transplantation.
3. Transplant recipients are very satisfied with emotional, tangible, and overall social support from 5 to 10 years post heart transplantation.
4. Satisfaction with social support is significantly correlated with QOL.
5. Satisfaction with emotional, tangible, and overall social support univariately predicts QOL at 5 and 10 years post heart transplantation.

6. Multiple regression reveals overall satisfaction with social support was a significant predictor of QOL at 5 years post heart transplantation. Satisfaction with emotional social support is a significant predictor of QOL at 10 years post heart transplantation.
7. Satisfaction with social support does not have an impact on survival of heart transplant recipients.
8. Sociodemographic differences exist in satisfaction with social support.
9. Satisfaction with social support partially mediates the relationship between perceived stress and QOL.
10. Coping did not mediate the relationship between perceived stress and QOL.

## **Implications**

### ***Implications for Nursing Research***

Data generated from this study provided evidence that satisfaction with social support is an important factor in the QOL and survival of heart transplant recipients who are 5 to 10 years post surgery. Further investigation is needed to explore additional types of social support such as instructional and appraisal social support. In addition, the amount of social support available, along with satisfaction with the social support, should be examined. Also, the unique role of the heart transplant team and their function as a social support resource must be explored. A prospective study could accomplish these research goals. Further refinement of the Heart Transplant Social Support Index with

reliability and validity testing is also needed. Interventional studies are warranted to explore what type of intervention may best improve social support in specific areas.

### ***Implications for Nursing Education***

Findings from this study support the need for the education of nurses who care for heart transplant recipients. Nurses need to be educated on the psychosocial needs of patients who are long-term heart transplant survivors.

### ***Indications for Nursing Practice***

Results of this study have important implications for nursing practice. Thoughtful evaluation of the amount of social support, types of social support, and satisfaction with social support can impact patient outcomes such as QOL and survival. Indeed, important work lies ahead to further examine the impact of social support in the transplant population and to implement these findings into clinical practice.

## **Future Recommendations**

Further analysis of these data should include additional variables that have been collected previously such as depression, mood, and helpfulness of transplant team interventions. These variables may explain additional variance in the QOL of transplant recipients.

Prior to this study, the Heart Transplant Social Support Index had not been analyzed in such detail. Revision of this instrument to include other types of social support such as informational and appraisal is needed. Additional reliability and validity testing is also necessary.

Since this study was a secondary data analysis and social support was not the main focus in the primary study aims of the original study, a longitudinal prospective study aimed at examining social support in heart transplant recipients is warranted. This would provide more accurate information as the study aims would be designed to examine social support. Lastly, future studies should be conducted in other patient populations such as heart failure, or other organ transplant populations such as renal or liver transplantation.

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APPENDIX A

DESCRIPTION OF THE PARENT STUDY



## **Heart Transplant Quality of Life Outcomes Study**

### **Description of Parent Study**

The prospective longitudinal study took place between July 1999 and July 2004, and was funded by the National Institute of Nursing Research. The author of this paper was involved in all stages of the research process with responsibilities of co-investigator and site coordinator of the University of Alabama at Birmingham site. The principal investigator was Dr. Kathleen L. Grady from Rush University in Chicago.

### ***Sample***

All patients who underwent heart transplantation between July 1, 1990 and June 30, 1999 at four medical centers in the United States were recruited for the study. Every attempt to include all patients eligible for the study was made by the nurse researchers. Inclusion criteria for this study included age  $\geq 21$  years, able to read and write English, and having an orthotopic heart transplant surgery during the aforementioned time period. Exclusion criteria for this study were having a heterotopic heart transplant, having a multi-organ transplant (heart and kidney), being too ill to participate, children  $< 21$  years of age, and unable to read and write English. Any patient with a less than 12<sup>th</sup> grade education was required to complete and pass the Wide Range Achievement Test (WRAT) reading ability test. This test takes less than five minutes and was used to assess level of literacy.

There were 1,437 patient hearts transplanted during July 1, 1990 and June 30, 1999. Transplant recipients who were not part of the sample (n=553) for this report were

patients who either died prior to 4.5 years post transplant (n=386), or transferred care to another transplant center (n=167) leaving 884 patients between  $\geq 4.5$  and 10 years post heart transplantation who were eligible for recruitment. Therefore, of the 884 patients that comprised the study group for this analysis, 597 patients were consented. Patients not consented for this study (n = 287) were not enrolled due to the following reasons: did not meet inclusion criteria (n=53, 6%), could not be contacted (n=70, 8%), failed literacy test (n=15), did not speak English (n=35), had re-transplant or multi-organ transplant (n=3), self exclusion (n=127, 14%), and died before contact (n=37). Thus, of the 597 patients, 555 patients provided informed consent and completed one or more study questionnaires and comprised the sample for this study. The mean age of the sample at time of transplant (n=597) was  $53.6 \pm 10.1$ .

### ***Setting***

The setting for this study was four medical centers with active heart transplant programs in the United States: University of Alabama at Birmingham (UAB), Rush University, Cleveland Clinic Foundation, and University of California, Los Angeles (UCLA). Each of the sites receives referrals of patients with end-stage heart disease who are evaluated for transplant, listed on a national donor waiting list, and transplanted as donor hearts become available. UAB's referrals are mostly from Alabama and the surrounding southeastern states, referrals to Rush are mainly in the Chicago area, Cleveland Clinic captures patients in Ohio and the midwestern United States, and UCLA's referrals are from California and Nevada. All four centers are moderate-to large-volume transplant centers in different geographic locations: south, midwest, east, and west coast. Having four geographical areas assisted in achieving adequate sample size,

and racial and ethnic diversity. The average number of transplants performed at the four centers during the study time period ranged from 19 to 63 surgeries per year. Patients may be in the hospital, clinic, or at home when recruited to participate in the study.

### **Instruments in Parent Study**

For the overall study, participants completed 13 self-report instruments which were relevant to study aims. The patient-completed instruments included five established instruments developed by other researchers and eight instruments that were developed by the current research team for a previous heart transplant study. The study questionnaire contained all 13 instruments which were each a different color and randomly ordered for each time period to control for fatigue, sensitization, and response bias. The number of pages in the entire questionnaire was 60, and the time to complete the questionnaire was approximately one hour.

The Cardiac Transplant Research Database (CTRD) is an event-driven database which collects information on the recipients such as donor data, immunosuppression, rejection episodes, infection, evidence of coronary vasculopathy or malignancy, and death. These forms were collected independently of this current study and available for analyses. All four centers participate in CTRD which is housed at the University of Alabama at Birmingham. The chart review form was completed by the research staff and includes the following information: date of cardiac symptom onset, immunosuppression, complications, co-existing illnesses, test and procedure results, social habits, and hospital readmissions.

### **Data Collection Procedure**

This study utilizes data collected during years 2000 to 2004. Protection of human subjects was granted by the IRB at the University of Alabama at Birmingham in 1999 at the time of study commencement. The following describes the study recruitment process that was used during that time period. After the IRB approvals were obtained, the nurse researchers of the study at each site recruited patients who were  $\geq 4.5$  to 10 years post heart transplantation when patients came for clinic visits, laboratory testing, or were admitted to the hospital. The co-investigators and site coordinators explained the study to the potential patients, encouraged them to ask questions, and obtained written informed consent. Patients were given a copy of the questionnaire with a self-addressed, stamped envelope. Patients were instructed to return the questionnaire within two weeks. All subsequent questionnaires were mailed to the patients' home biannually, according to the patient's transplant date, two weeks before the due date. Questionnaires received from six weeks before to six weeks after the due date were accepted for study analysis. Patients who did not complete a questionnaire were not dropped from the study, but mailed another questionnaire at the next time period. Patients who chose not to participate in the study were asked to sign a consent allowing the researchers to gather the following data: date of heart transplant, name, gender, race, and reason for not participating in the study. Therefore, patients with missing data either due to not participating or other reasons (non-compliance, illness) can be compared to patients with data.

Retention of participants was a high priority for the research team. If a questionnaire was not returned, study participants were telephoned weekly for 3 weeks beginning 10 days after the questionnaire was due, and sent a letter if the questionnaire

was not returned within one month of its due date. Retention was also facilitated by the compensation of \$10 for each returned study questionnaire booklet. The study had a 70% retention rate.

The research team collected chart data every six months for all patients enrolled in the study using the chart review form. In addition, CTRD data was gathered independently from the study per CTRD protocol. Additionally, the research team collected an additional CTRD follow-up form (Form 8) at years 5.5, 6.5, 7.5, 8.5, and 9.5 since this was not part of CTRD protocol.

## **Data Management**

### ***Data checking and validation***

All completed booklets received from patients and chart review forms completed by co-investigators, site coordinators, and research assistants were examined for errors and omissions by site coordinators and mailed to the principal investigator who documented date of receipt, date of review, date of data corrections, date of coding, and date of data entry. The data was coded by research assistants at Rush. Coding manuals for all instruments, chart review forms, and CTRD have been developed. Using SAS software, data was entered and verified at the UAB site by the research staff. The entered data was verified by one research assistant verbally reading the raw data and another research assistant checking the entered data. After the entered data was screened and cleaned, the original study questionnaires and chart review forms were stored at an off-site secure storage site. The author continues to keep copied UAB study questionnaires and chart reviews in locked file cabinets in a locked storage room within University Hospital. After a period of seven years, the study questionnaires will be destroyed.

### **Data Quality**

Protocols for the study were developed and kept in an operations manual at each study site. Specific protocols included when to enter the patient into the study, distribution of study questionnaire to patients and monitoring of booklets for completeness, and collection of chart review data and CTRD data. A master list of the patients who entered into the study along with a master list of those who refused to participate was maintained.

A protocol monitoring log book was kept at each site to track the following: study entry date, date of heart transplant, patient name, and study identification. For each of the 11 potential time periods the following information was completed: date questionnaire was given or sent to patient, date of study questionnaire return, and date chart review form and CTRD forms were completed by nurse researchers. Per study protocol described earlier, several attempts were made to retrieve late questionnaires from patients. A non-completion questionnaire form was completed for any patient who did not return the questionnaire within the time period due dates. The reason why the booklet was not returned was recorded. A monthly tally of the number of booklets and chart reviews expected versus received was calculated for each site along with the number of patients who dropped from the study, died, or finished the study.

### ***Safety and integrity***

All study questionnaires, chart review forms, and CTRD data were identified with site and study numbers (ex. UAB 246) only to assure confidentiality. All study data was kept in locked file cabinets accessed only by study personnel.

### **Power Analysis**

This study is an outcome study examining relationships of outcomes with predictor variables among study variables. The power analysis was calculated from existing data on the patients at the four sites. A sample size of 800 patients combined with longitudinal follow-up was calculated, and it provided the study with sufficient power to detect meaningful effects.

### **Study Limitations**

The limitations of this study include not having random selection of subjects, not having an untreated control group for comparison, attrition due to respondent burden, morbidity, mortality, and the longitudinal design of the study.

Subjects will not be randomly selected; however, the researchers made every attempt to enter all patients who agreed to participate in the study. This enhanced the sample size, the representativeness, and diversity of the sample.

There is no untreated control group for comparison because it would be unethical not to treat a patient who is in need of a heart transplant surgery. Patients who have end stage heart failure and have not been listed for transplantation due to contraindications would not be an appropriate comparison group. This group of patients may have additional medical or psychological problems which would make this subset of patients an unlikely comparison group.

Given the longitudinal design and pool of patients, attrition was a concern over time. Attrition may be due to noncompliance, morbidity, or mortality.

APPENDIX B

DISSERTATION INSTITUTIONAL REVIEW BOARD APPROVAL





# Project Revision/Amendment Form



(PLEASE TYPE: In MS Word, highlight the shaded, underlined box and replace with your text; double-click checkboxes to check/uncheck.)

- Federal regulations require IRB approval before implementing proposed changes.
- Change means any change, in content or form, to the protocol, consent form, or any supportive materials (such as the Investigator's Brochure, questionnaires, surveys, advertisements, etc.).
- Complete this form and attach the changed research documents.

JAN 30 2008

Today's Date: 1/28/2008

## 1. Contact Information

Principal Investigator's Name: Connie White-Williams BlazerID: cwwilli E-mail: cwwilli@uabmc.edu  
 Contact Person's Name: Connie White-Williams BlazerID: cwwilli E-mail: cwwilli@uabmc.edu  
 Telephone: 975-8611 Fax: 975-9792  
 Campus Address: 760 THH

## 2. Protocol Identification

Protocol Title: Quality of Life Outcomes at 5 to 10 years after Heart Transplantation  
 IRB Protocol Number: X990707003

### Current Status of Project (check only one):

- Currently in Progress (Number of participants entered: \_\_\_\_\_)
- Study has not yet begun (No participants entered)
- Closed to participant enrollment (remains active)—  
 Number of participants on therapy/intervention: \_\_\_\_\_  
 Number of participants in long-term follow-up only: \_\_\_\_\_
- Closed to participant enrollment (data analysis only)—  
 Total number of participants enrolled: 555

APPROVED  
  
 MARILYN DOSS, M.A.  
 Vice Chair - IRB

1-31-08

### This submission changes the status of this study in the following manner (check all that apply):

- Protocol Revision
- Protocol Amendment
- Study Closed to participant entry
- Study Closure
- Other, (specify) \_\_\_\_\_
- Revised Consent Form
- Addendum (new) consent form
- Enrollment temporarily suspended by sponsor
- Change in protocol personnel

## 3. Reason for change

Briefly describe, and explain the reason for, the change. If normal, healthy controls are included, describe in detail how this change will affect those participants.

This study is secondary data analysis of the data collected from 1999 to 2004. IRB approval is required for all dissertation analysis. I will be examining the social support data which has not been studied previously. The title of my dissertation will be Social Support after Heart Transplantation. Include a copy of the protocol and any other documents affected by this change (e.g., consent form, questionnaire) with all the changes highlighted. There will be no changes.

## 4. Does this change revise or add a genetic or storage of samples component?

Yes XNo

If yes, please see the Guidebook to assist you in revising or preparing your submission, or call the IRB office at 934-3789.

## 5. Does the change affect subject participation (e.g. procedures, risks, costs, etc.)?

Yes XNo

## 6. Does the change affect the consent document(s)?

Yes XNo

If yes, briefly discuss the changes. \_\_\_\_\_

Include the revised consent document with the changes highlighted.

Will any participants need to be reconsented as a result of the changes?

Yes XNo

If yes, when will participants be reconsented? \_\_\_\_\_

Signature of Principal Investigator  
do1a6-1307



Date 1-29-08

APPENDIX C

HEART TRANSPLANT QUALITY OF LIFE  
INSTITUTIONAL REVIEW BOARD APPROVAL

### Protection of Human Subjects Assurance Identification/IRB Certification/Declaration of Exemption (Common Rule)

*Policy:* Research activities involving human subjects may not be conducted or supported by the Departments and Agencies adopting the Common Rule (56FR28003, June 18, 1991) unless the activities are exempt from or approved in accordance with the Common Rule. See section 101(b) of the Common Rule for exemptions. Institutions submitting applications or proposals for support must submit certification of appropriate Institutional Review Board (IRB) review and approval to the Department or Agency in accordance with the Common Rule. Institutions must have an assurance of compliance that applies to the research to be conducted and should submit certification of IRB review and approval with each application or proposal unless otherwise advised by the Department or Agency.

1. Request Type <input type="checkbox"/> ORIGINAL <input checked="" type="checkbox"/> CONTINUATION <input checked="" type="checkbox"/> EXEMPTION	2. Type of Mechanism <input type="checkbox"/> GRANT <input type="checkbox"/> CONTRACT <input type="checkbox"/> FELLOWSHIP <input type="checkbox"/> COOPERATIVE AGREEMENT <input type="checkbox"/> OTHER: _____	3. Name of Federal Department or Agency and, if known, Application or Proposal Identification No.
4. Title of Application or Activity Quality of Life Outcomes in Patients > 5 Years Post Transplant		5. Name of Principal Investigator, Program Director, Fellow, or Other WHITE-WILLIAMS, CONNIE L

6. Assurance Status of this Project (Respond to one of the following)

This Assurance, on file with Department of Health and Human Services, covers this activity:  
 Assurance Identification No. FWA00005960, the expiration date 10/26/2010 IRB Registration No. IRB00000726

This Assurance, on file with (agency/dept) \_\_\_\_\_, covers this activity.  
 Assurance No. \_\_\_\_\_, the expiration date \_\_\_\_\_ IRB Registration/Identification No. \_\_\_\_\_ (if applicable)

No assurance has been filed for this institution. This institution declares that it will provide an Assurance and Certification of IRB review and approval upon request.

Exemption Status: Human subjects are involved, but this activity qualifies for exemption under Section 101(b), paragraph \_\_\_\_\_.

7. Certification of IRB Review (Respond to one of the following IF you have an Assurance on file)

This activity has been reviewed and approved by the IRB in accordance with the Common Rule and any other governing regulations.  
 by:  Full IRB Review on (date of IRB meeting) \_\_\_\_\_ or  Expedited Review on (date) 6-3-08  
 If less than one year approval, provide expiration date \_\_\_\_\_

This activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by the Common Rule will be reviewed and approved before they are initiated and that appropriate further certification will be submitted.

8. Comments  
 Protocol subject to Annual continuing review.  
 HIPAA Waiver Approved?: No

Title X990707003  
 Quality of Life Outcomes in Patients > 5 Years Post Transplant

IRB Approval Issued: 6-3-08

9. The official signing below certifies that the information provided above is correct and that, as required, future reviews will be performed until study closure and certification will be provided.		10. Name and Address of Institution University of Alabama at Birmingham 701 20th Street South Birmingham, AL 35294	
11. Phone No. (with area code) (205) 934-3789	12. Fax No. (with area code) (205) 934-1301	15. Title Vice Chair, IRB	
13. Email: <u>smoore@uab.edu</u>	14. Name of Official Marilyn Doss, M.A.		
16. Signature		17. Date <u>6-3-08</u>	

APPENDIX D

PROTOCOL AMENDMENT PERMISSION

<b>IRB Review - Office Use Only</b> Northwestern University Institutional Review Board IRB #: 1603-001 APPROVED: 08/13/2007	<b>IRB Date Stamp - Office Use Only</b> <div style="text-align: center; font-size: 24pt; font-weight: bold;">RECEIVED</div> JUL 27 2007	<b>IRB Accession Number</b> 2007-187 <b>Office Use Only</b> IRB Project Number: <div style="text-align: center; font-size: 18pt; font-weight: bold;">1603-001</div>
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**OPRS**

**Northwestern University – Office for the Protection of Research Subjects  
REVISION SUBMISSION FORM**

Please check if this is in response to a pending issue  
 Name of IRB Staff who requested the change: \_\_\_\_\_

Please do not submit responses to pending issues on this form unless it has been requested by our office. Responses can be submitted electronically or in paper as a memo along with a cover memo to the person requesting the change.

For ease of submission, please submit your revisions electronically:

- Scan the documents (in PDF format), and e-mail them to [irb@northwestern.edu](mailto:irb@northwestern.edu)
- Use this format for the subject line of your message:  
 " Protocol Revision [IRB#]"

You can also send or bring them to the appropriate OPRS office:

- Biomedical: OPRS, Rubloff, 7<sup>th</sup> Floor, 750 N. Lake Shore Drive, Chicago, IL 60611
- Social/Behavioral: OPRS, Hogan, G100-6<sup>th</sup> Floor, 2205 Tech Drive, Evanston, IL 60208

**HANDWRITTEN FORMS WILL NOT BE ACCEPTED.**

<b>1. Submission Date:</b> 7/27/2007 <b>2. Principal Investigator Name:</b> Kathleen L. Grady, PhD, APN, FAAN Phone: (312) 695-4860      Fax: (312) 695-1903      E-Mail: <a href="mailto:kgrady@nmh.org">kgrady@nmh.org</a> <b>3. Submission Prepared By:</b> Kathleen L. Grady Phone: (312) 695-4860      Fax: (312) 695-1903      E-Mail: <a href="mailto:kgrady@nmh.org">kgrady@nmh.org</a> <b>4. Current Project Title:</b> Quality of Life Outcomes Greater than or Equal to 5 Years Post Heart Transplant [R01 NR05200]
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<b>5. Type of Protocol</b> <input checked="" type="checkbox"/> Biomedical <input type="checkbox"/> Social/Behavior Science
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<b>6. Revision Description:</b> This new revision was initiated by: <input checked="" type="checkbox"/> Investigator <input type="checkbox"/> Study Sponsor <b>Please check all applicable categories:</b> <input checked="" type="checkbox"/> Change in Authorized Research Personnel (please attach an updated personnel sheet found on our web-site) <input type="checkbox"/> Revised Consent/Consent and Authorization for Research Form (Please specify the type of submission) <input checked="" type="checkbox"/> Change in Protocol/Procedures (this includes inclusion/exclusion criteria, data collection, and recruitment)* <input checked="" type="checkbox"/> Protocol Amendment # 1 dated 7/27/07 <input type="checkbox"/> Revised Investigator's Brochure      Version Date: _____ Does this new IB represent any changes to risks listed in the current approved consent form? <input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> New/Revised Subject Recruitment Materials (Please specify if this is new or a revision of previously approved material in Section 7). Please check all applicable categories: <input type="checkbox"/> Newspaper/ Printed Periodical <input type="checkbox"/> Internet <sup>1</sup> <input type="checkbox"/> Brochure <input type="checkbox"/> Poster <input type="checkbox"/> TV/Radio <input type="checkbox"/> Letter to a potential participant <input type="checkbox"/> Scripts (for verbal contacts) <sup>2</sup> <input type="checkbox"/> Physician Letter <input type="checkbox"/> Videotapes (only script needed) <input type="checkbox"/> Other (Explain) _____
--

<sup>1</sup> Provide a copy of the printed version

<sup>2</sup> Submit scripts for all verbal contacts (including what may be verbally discussed with media over the telephone)

<input type="checkbox"/>	Change in total number of subjects to be consented or cases/persons/records to be studied
<input type="checkbox"/>	Change in Risks: Attach new version of consent    Version Date: _____
<input type="checkbox"/>	Change in Principal Investigator** New Principal Investigator's Signature: _____ Date: _____
<input type="checkbox"/>	Change in Title:* (Please indicate the new Protocol title in Section 7)
<input type="checkbox"/>	Change in study site(s)*
<input type="checkbox"/>	Change in HIPAA Compliance*
<input type="checkbox"/>	Change in funding source(s)*
<input type="checkbox"/>	Other:* Please specify: _____

**Note: Revisions that may affect your HIPAA forms are marked with a \*.**

**7. Description of Changes**

**Instructions:**

- Refer to the Revision Guidelines on the IRB website for additional information.
- Fill in the current status of each item to be revised in the left column below.
- Fill in the proposed revisions in the right column. Include the rationale for each revision. When the protocol has been revised, provide page numbers for each revision.
- **To enable a prompt and accurate review, all changes to the protocol, consents, HIPAA documents or recruitment materials must be highlighted. Revisions without highlighted changes will be returned to the investigator without review.**
- Version dates on all materials should be updated accordingly.
- If additional space is required, attach an additional sheet.

**Both Columns below must be completed.**

PRESENT SITUATION	REVISION REQUESTED
<p>Ed Wang, PhD, is not a current statistician / co-investigator on this research project.</p> <p>Data disks only reside at the University of Alabama, Birmingham, AL with the current data management team under the direction of the statistician, David Naftel, PhD.</p>	<p>I am adding Ed Wang, PhD, Center on Outcomes, Research, and Education (CORE) at Evanston Northwestern Healthcare (ENH) as a statistician to this research project. Dr. Naftel will also continue as a statistician for the project as well; but he will significantly decrease his time on the project which is why I have added Dr. Wang as a new member of this project.</p> <p>Dr. Wang, and current co-investigators Bruce Rybarczyk, PhD and Connie White-Williams, MSN, FNP, PhD(c) have disks containing all data. Dr. Rybarczyk, Ms. White-Williams, and I are the research project investigators who are actively submitting abstracts and writing manuscripts, and Dr. Wang will perform future data analyses for us. Drs. Wang, Rybarczyk and Ms. White-Williams have password protected computers. Dr. Wang has computer back-up capability as well. All disks will be returned to me for destruction upon completion of data analyses in the future.</p>

VA ACOS Research and Development Name and Signature (If applicable)

Date

Investigator's Name and Signature

Date

Please check all applicable sites listed below to be copied on this submission:

- AIDS
- CRO
- GCRC
- NCCR
- RJC
- NMH
- VA
- Other:

Submission Date: 7/27/07 PI Name: Kathleen L. Grady IRB Project Number: 1603-001

**Revision to Authorized Personnel**

List only additions and deletions of authorized personnel who will be involved in this research project.

Authorized project personnel includes all persons who will have a significant role in the conduct of the research, including all Principal Investigators and Co-Investigators, any individuals who are individually named on a grant or contract application, who are listed on a FDA form 1572 (for the conduct of the research at NU or an affiliate), who are named as contact persons in the informed consent documents or recruitment materials for research, who are obtaining informed consent to participate in research, or who are obtaining individually identifiable health information under an NU Business Associate Agreement.

NAME and DEPT	ROLE IN PROJECT	SPECIFIC EXPERIENCE WITH ROLE IN PROJECT	ROLE IN CONSENT PROCESS	Adding or Removing	Human Subjects Training Completion Date
Sample Person OB/GYN	Co-Investigator	Has 10+ years of experience in research in this field	Will be obtaining consent	<input checked="" type="checkbox"/> Add <input type="checkbox"/> Delete	Completion Date: 7/5/03
Edward Wang, PhD, Center on Outcomes, Research, and Education, Evanston Northwestern Healthcare	Co-investigator / statistician	Has 7-10 years of experience in research in this field	not applicable	<input checked="" type="checkbox"/> Add <input type="checkbox"/> Delete	Completion Date: 6/13/02
				<input type="checkbox"/> Add <input type="checkbox"/> Delete	Completion Date:
				<input type="checkbox"/> Add <input type="checkbox"/> Delete	Completion Date:
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